

**Delineating Disease: a system for investigating
Fibrodysplasia Ossificans Progressiva**

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ABSTRACT

This thesis explores a particular method of drawing which I describe as delineation. This is seen here to be a phenomenological activity. Its application within the setting of a rare congenital disease called Fibrodysplasia Ossificans Progressiva (FOP) suggests delineation as a viable method of revealing new insight and understanding of this phenomenon in a way that aims to dignify and remains respectful of the subject.

The use of the term delineation in this investigation originates from its use by the 19th Century pathologist Sir Robert Carswell. It has been developed here to mean a drawing system that is realistic and based in observation. Unlike a scientific model, the activity of delineation is presented from the first person point of view and focuses on relationships that develop between delineator and object; and delineation and viewer. The emphasis is on coming to understand a phenomenon through the activity of drawing it.

In this thesis I show delineation as a way to record experiences continuously throughout the duration of an encounter, with focus on unique visual experiences as opposed to generic archetypes. Relevant detail is emphasized without additional embellishment or alteration of information, offering clarity to the understanding of the delineator and the viewer.

Collaborative workshops with medical illustrators and archaeologists were undertaken to understand differences and correlations between related practices. Evaluation included engagement with clinical experts, patients and a variety of informed individuals to establish an understanding of value in and consequences of the practice of delineation. A portable compendium of 66 delineations was created consisting of museum samples, living patients and the bodies of two donors undergoing processes of preparation for display. This has provided useful additional insight into FOP and has added evidence to support clinical studies concerning areas of ossification in a form that can be easily accessed and added to by future researchers. This inquiry shows that the activity of delineation has brought new knowledge to FOP by revealing detail of each specific phenomenon while preserving dignity and respectfulness.

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GLOSSARY

<i>Ankylosis</i>	when a joint has become fused and causes immobility. This can be caused by disease, injury, or surgical procedure.
<i>Ectopic</i>	the term for bone that grows outside the usual site of growth. Bone formed in the site of pathology.
<i>Heterotopic</i>	tissue in an abnormal location. Bone formed in secondary areas of site of pathology.
<i>Histology</i>	is the microscopic study of tissue.
<i>Histopathologist</i>	studies disease and makes diagnosis from the evidence found in the histology sample.
<i>Maceration</i>	a process of defleshing and removing all internal organs of a cadaver as part of the process of preparation.
<i>Metamorphosis</i>	change of structure or shape.
<i>Microtome</i>	instrument used to cut biological specimens into transparent thin sections for microscopic examination.
<i>Myofascial planes</i>	the areas involving the fascia surrounding and associated with the muscle tissue.
<i>Myositis Ossificans Progressiva</i>	condition where calcifications occur at the site of injured muscle. It is not progressive or hereditary. A general term used to describe FOP but is incorrect.
<i>Ossification</i>	conversion of tissue into bone.
<i>Preparator</i>	a person who prepares scientific specimens or museum displays.
<i>Prosection</i>	is the dissection of a cadaver by a professional in order to demonstrate for students anatomic structure. These are often preserved and re-used.

INTRODUCTION

In this research I have investigated the potential for drawing to be used as a form of delineation, providing a method of inquiry in pathology. I have developed the research through a series of practical exercises in which I employ and explore a variety of delineation techniques in collaboration with clinicians and other experts.

This research examines the use of delineation as a system for investigating disease. It proposes that delineation in the context of this inquiry is a phenomenological process that can record and present visual experiences as visual knowledge. The research has been pursued through encounters with Fibrodysplasia Ossificans Progressiva (FOP) a rare congenital disease that turns connective tissue to bone.

This inquiry joins up several areas: drawing, anatomy and pathology, practices of pathology and theory of phenomenology. In this thesis I intend to draw together these and develop a methodology for delineation in pathology. Methodology and theory are discussed throughout the thesis.

The interpretation of the term delineation as applied to the setting of this investigation, began with Sir Robert Carswell's use of the word in the 19th century. This research has since developed understanding of this to include the role of experiencing the object being observed and to emphasize the importance of the actual process of making a drawing as a method of presenting information and conveying visual knowledge. The concept of this system is grounded in the act of drawing that which is observed directly without codifying or generalizing the data.

Through the activity of delineation, an object and our experience of an object are simultaneously presented. We encounter an object's information and properties such as the size, shape, colour and weight. Each time the object is viewed, the encounter is unique as it changes. These differences include colour and light caused by different times of day; angle and viewpoints; surroundings; circumstances, and specifically in this study, progression as the process of maceration has continued. Each of these is so different, like seeing a new object each time. It is frequently something

seen in the periphery or background that becomes the focus of an encounter, events which can not be predicted but are part of the fugitive collection of ongoing unique experiences that allow the presentation of visual experience to contain fuller information than one based on photography or textual description alone.

I have investigated historical examples and explored the use of delineation within other visual fields and its use in educational theory as part of the rationale for its precise use within this inquiry. The research question is positioned within a particular philosophical framework and my interpretation of phenomenology has been constructed from differing aspects of this branch of philosophy. I have looked at caricature as an example of an alternative solution to delineation as a phenomenological process. The caricatures I have chosen to discuss are relevant to this project as they also make use of drawing to investigate disease and portray experiences with these encounters.

I have included an overview of the history of pathology and medical illustration in order to place the subject of my research in context and help clarify the word disease. A drawing workshop was held because there are some correlations between the appearance of my work and that of medical illustrators. As medical illustrators are trained artists who frequently depict human anatomy, it is necessary to compare our work through discussion and a practical workshop. A drawing workshop was conducted with archaeologists as they also depict similar subject matter and draw directly from objects but are not artists and have far less experience in drawing. Evidence of similarities and differences in subject, application and intentionality resulting from these workshops has been documented in Chapter 7.

Definition of FOP

The setting of this inquiry is the disease Fibrodysplasia Ossificans Progressiva (FOP) and definitions and historical examples are discussed. This is a very rare and under-researched area of study. The main data comes from a series of projects. These include delineations from living sufferers, from historical skeletal specimens and the largest project, which depicts the process of maceration and preparation of two donors.

FOP is a congenital disease affecting only one in two million people. The disease demonstrates the devastation caused when a gene triggers the over - production of bone growth. Progressive heterotopic¹ ossification occurs in the connective tissue both spontaneously and through trauma. These are known as 'flare ups' and result in the growth of a secondary skeleton. The extra bone forms spurs and then finally bridges by meshing with another part of the body effectively 'locking' limbs. This is known as ankylosis.²

Both diagnostic investigation and treatment involve tissue trauma of some type, often biopsy, which greatly exacerbates the condition. The only visible clue to diagnosing a child with FOP is that usually the patient has malformed great toes. However, this is not always the case. Sufferers usually die from respiratory failure due to thoracic cage restriction, or starvation caused by jaw ankylosis. Currently there is no treatment and no cure. There is, however, a greater breadth to the disease than previously accepted and reports of 'milder' cases, patients who developed extra bone much later in childhood than is usual. There is even a case of an octogenarian patient who still had the ability to walk (Jannoff, Tabas & Shore, 1995).

I was drawn to FOP in the first place because its effects on subjects are so extreme and arresting. However, for this study it is more relevant that few have studied the disease and a new inquiry was likely to reveal further insights if the method I propose is relevant. This has turned out to be the case. All the data collected in this research is original and has not been recorded in this way previously. This inquiry has allowed me to produce the first drawings of FOP since 1897 and the first detailed drawings of processes of maceration, chronicling the preparation of the bodies of two FOP donors.

¹ Het.ero.to.pia (-to'pe-ah) displacement or misplacement of parts; the presence of a tissue in an abnormal location. Heterotop'ic, adj. (Dorland's Pocket Medical Dictionary, 2004, p. 406).

² An.ky.lo.sis (ang'ki-lo'sis) pl. *ankylo'ses*. [Gr.] immobility and consolidation of a joint due to disease, injury, or surgical procedure. Ankylot'ic, adj. artificial a., arthrodesis. Bony a., union of the bones of a joint by proliferation of bone cells, resulting in complete immobility; true a., (Dorland's Pocket Medical Dictionary, 2004, p. 49).

The main claims made within this study as to why delineation is the most appropriate way of presenting FOP are argued throughout this thesis. They are that knowledge is gained through the activity of making a delineation and that delineation offers further information and presents visual experience to the viewer.

Unlike previous experiences with anatomy, in pathology I find each encounter is new and can only be experienced and understood as unique and specific rather than in broad, general terms. Based in observation, delineation appears to be rooted in empiricism. Observation seems to be equated with objectivity and the two terms are somehow interchangeable. The former cannot exist without being shaped within terms of the latter. However, this research argues that delineation is a descriptive form of interpretation that offers useful information.

Through delineation, the investigator not only records data, but also understands and expresses observed phenomena. This approach creates a situation in which the presence of the delineator is explicit and a vital part of the process of interpretation. I have applied delineation as a research tool that is different from other scientific methods used. These would normally include examining generic examples and seeking explanation through the investigation of causal relationships and comparisons only. Delineation makes use of a specific system rather than generic models. It is less concerned with purely causal events and uses intentional reasoning and understanding of the subject within a phenomenological framework.

Phenomenological framework

Defining delineation as a phenomenological activity allows interaction with the subject rather than the empirical recording of data alone. Participation through a phenomenological methodology is central to understanding the use of delineation. The philosopher Michael Crotty says phenomenology,

*'requires us to engage with phenomena in our world
and make sense of them directly and immediately'*
(Crotty, 1998, p. 79).

By using delineation as a method for presenting encounters and my experience of phenomena, I have been able to develop a phenomenological approach and present my experiences precisely and quickly. Pathology is an excellent subject in which to explore this as the visual experiences are unexpected, particularly in a disease as diverse and dramatic in appearance as FOP.

As this research is an investigation into the application of a drawing system, I have not made an in depth survey of painting. I have only examined this art practice where the subject matter has made it relevant.

The purpose of this study is to gather and examine information presented through delineation as this system is the most appropriate way to immediately and directly present specific events rather than generic. The emphasis in this inquiry is firmly on delineation as process and type of visual experience rather than as end product. This thesis does not claim to be medical research and is positioned within the field of drawing research.

Defining roles

Many people have contributed to this project and it is important to set out their roles. Martyn Cooke is Head of the Conservation Unit at the Museums and Collections of the Royal College of Surgeons of England. Throughout this project he took on the role of medical preparator. This term is used to indicate a highly skilled person who prepares scientific specimens or museum displays. This was essential to me as I was able to draw on his expertise and observe his work while developing my approach to delineation.

James Triffitt, Professor of Bone Metabolism at the Botnar Research Centre, part of the Institute of Musculoskeletal Sciences, at the Nuffield Department of Orthopaedic Surgery, University of Oxford and Professor Paul Wordsworth, Consultant Rheumatologist at the Nuffield Department of Orthopaedic Surgery, University of Oxford were essential to this project. James Triffitt is a leading researcher in the field of FOP and Paul Wordsworth treats FOP sufferers and is an expert in the subject of ankylosing spondylitis, another bone fusing disease. They arranged for me to draw the donors and discussed the condition and its symptoms. They

offered frequent advice and suggestions and participated in a final discussion to evaluate the delineations. This is examined in Chapter 7.

The medical illustrators who participated in the workshop are training for a professional Masters qualification from the Medical Artists' Association (MAA). Three are students who all have professional experience. A tutor who also drew in the workshop is Joanna Cameron, BA (Hons), MMAA, RMIP, PGCE. Joanna is currently the Director of Education for the Medical Artists' Education Trust. The former course director, Philip Wilson, FMAA, RMIP joined in the discussion.

The archaeologists who participated in a workshop are MA students from University College London, studying different specializations in archaeology. They have a wide variety of professional fieldwork experience between them.

FOP sufferers contributed a great deal to this investigation. Professor Triffitt spoke to patients on my behalf and those who wanted to participate contacted me themselves. The two people with the largest roles to play in this investigation were the donors whose families agreed I could make drawings of them.

Summary of aims of inquiry

In this research I have developed a substantial body of data, particularly visual data, relevant to both medical researchers and lay people. By doing so I have demonstrated and evaluated an approach that is novel, generalisable and able to reveal both information and insight.

Delineation presents the visual experience of each unique encounter with phenomena in a manner that is understandable and familiar to a wide audience. Its advantage is the ability to offer an insight into FOP for sufferers, medical professionals and to those who have an interest but either find direct encounters with disease or illness difficult or would never have the opportunity to experience them in reality.

I have situated delineation, in the terms of this research, as a phenomenological method, apart from both fine art and medical

illustration. As well as a means of recording, delineation provides a method of understanding and conveying understanding, which supports the development of new knowledge and insight in pathology.

Plan of thesis

- Chapter 1. Delineation is defined in historical terms. Delineation is explored in other fields. This includes an examination of drawing in architecture and archaeology and educational theories. The interpretation of delineation is developed.
- Chapter 2. Delineation is set within a philosophical framework where definitions of phenomenology are outlined. The interpretation of phenomenology is pursued and a history of medical illustration given as way of comparison.
- Chapter 3. A survey of the history of anatomy and pathology is briefly described and the history of medical illustration is outlined. Images made using caricature are discussed.
- Chapter 4. Projects undertaken in this research are described beginning with an explanation of the importance of histology.
- Chapter 5. Examples of historical images of FOP and two documentaries are described.
- Chapter 6. A detailed analysis of the delineations made for this research is given. This descriptive analysis places the delineations into categories and examines which have been more successful than others.
- Chapter 7. Medical experts, patients and informed members of the public, give evaluations and responses to the delineations. Drawing workshop events with medical illustrators and archaeologists are used to examine the way other practitioners use drawing.
- Conclusion. Evidence is shown to support the contribution of delineation as developed in this research.

CHAPTER ONE

Delineation: definitions and rationale

In this chapter I begin by briefly explaining some techniques used in medical imaging and the different aims of delineation. Early clinical studies of skin diseases are outlined and place the contribution made by Sir Robert Carswell into historical context. The relevance of Carswell's use of the term delineation and his achievements are set out. The aspect of dignity is raised and two of Carswell's works are described as examples.

Delineation is defined from a variety of sources. Its imaginative use in architecture, its recording capabilities in archaeology and issues of the use of symbols and codes are examined. Perception-delineation, a theory that is placed in the field of education and psychology is discussed. The advantages of photography and other forms of imaging are brought to light and I argue why delineation is of value and can offer different information from that shown in a photograph. Examples are given of problems associated with visualizing overcomplicated information.

The specificity of delineation is explained and evidence shown of how understanding is developed through the activity of drawing. Examples as evidence are drawn from Leonardo da Vinci, Max Brödel, the architect Brian W. Edwards and theories from Kenneth Bittel and Philip Rawson. The interpretations of delineation as developed in this research are summarized.

Introduction

Images in science today, particularly in medicine are often made using techniques like CT scanning, nuclear imaging, MRI and X-ray. Their purpose is diagnostic and training is needed to extrapolate the information they contain. It takes a great deal of time to learn to how to interpret the data shown in medical imaging. Medical illustration provides additional information to this and might take the form of a diagram, graph, schematic or a realistically observed picture. It could make use of computer design or photography as well as more traditional techniques. It can be imaginative or symbolic and is usually made up of a composite of views or stages of development. The purpose of an illustration is to

embellish and clarify the concepts and procedures taking place and offer images that are likely to be more representational and easier to interpret than the technical imaging methods.

These clinical processes are essential for diagnosis but I am exploring whether there is a different approach that would offer insight into disease. I will argue that the combination of observational skills and traditional rendering of a subject studied over a period of time presents visual encounters as immediately and directly as possible, something that cannot be done by the other methods. Delineation presents the relationships developed and an understanding of how knowledge has been accumulated. It provides another valid form of presenting and communicating information.

The French dermatologist Jean-Louis Alibert, (1766-1837) introduced observation-based classification of cutaneous (skin related) diseases. He believed it was vital for the vast array of examples of skin disease to be illustrated accurately in detail. In 1800 he was appointed director of the Hôpital Saint-Louis in Paris. He personally financed the publications of illustrations, culminating in the *Clinique de l'Hôpital Saint-Louis* (1832-1834). To create the images, he employed two painters, Moreau and Valvile and an engraver called Salvatore Tresca. Alibert's insistence on depicting exactly what was visibly revealed was a break with the ideal notion encouraged at this time where the generalized example would usually be held up as the model that visually explained a theory, an approach comparable with that of medical illustrators today. The aim was both diagnostic and to give the viewer an idea of what Alibert had actually seen. They were clinical studies. However, he could only oversee the portrayal of the experience, although he supervised the artists closely. By contrast, Sir Robert Carswell (1793-1857) had the ability, as both artist and doctor, to convey directly the visual experience of illness he encountered.

Carswell's delineations

'You should see these Delineations...that you may appreciate their value not as art, but as instruments of medical science by means of which more precise, more accurate and more perfect information may be acquired and communicated respecting the various and numerous organic changes to which the human body is subject'
(Carswell, 1831).

The 19th Century Scottish pathologist, Sir Robert Carswell, used the term delineation to describe the drawings he made of patients in the poor hospitals of France. His use of the word has great bearing on the meaning and application of delineation within this research.

Carswell began his career as an artist and his gift for drawing was stimulus for his entering the medical profession at the age of twenty-five. His drawing skills played an important role in his contribution to the field of pathology. Unlike predecessors from the medical profession, Carswell made all his own drawings.

Carswell's use of drawing as a tool for science is not unprecedented. During the Renaissance Andreas Vesalius, professor of surgery at Padua, made use of drawings he commissioned from the artist Stephen Calcar as a way of explaining anatomy as demonstrated in *De Human: Corporis Fabrica* published in 1543. However Carswell's belief that his delineations could communicate knowledge of disease was quite new. Anatomy was the focus of the first wave of medical science starting with Vesalius and his contemporaries. Pathology was the second wave and Alibert and Carswell were part of the vanguard. Drawing was established as an art form but its application to pathology was new. Carswell felt his delineations were not just helpful but essential to the understanding of disease.

'Convinced as I am, that lectures in Pathologies and anatomy could neither be understood nor appreciated without coloured delineations'
(Carswell, 1830).

In 1822 he went to France '*where the supply of [pathological] material was unrivalled*' (Hollman, 1995, p. 566), and by 1826 had made 1,200 delineations. He became an M.D. that year, and only two years later in 1828 at the age of thirty-five, was made the first Professor of Pathological Anatomy at University College London. He returned to the teaching hospitals in Paris where he had the opportunity to portray a wide variety of diseases suffered by the many poor patients who could not afford to be treated at home. He returned to Britain in 1831 with over 1,000 pictures after three years spent delineating these patients. They were some of the last clinical drawings made before the widespread use of the microscope.

Carswell's atlas, published, in 1838 was the culmination of sixteen years of work spent depicting patients in the hospitals for the poor in France. He drew the patients as he found them and rendered every subject in detail portraying each person's unique experience of pain and suffering. In some cases his delineations were the first ever depictions made of specific diseases. He was the first to visually describe a dissection of a chronic aorta, produced probably one of the earliest portrayals of a myocardial infarct and drew a rare view of an example of Ehlers-Danlos syndrome. He created the earliest renderings of the pathology of multiple sclerosis and most famously made the first colour pictures of Hodgkin's disease. But he also revealed the character and experience of those suffering from the ailments. He portrayed sorrow, humiliation and strength in many of the patients he drew and his delineations reflected their experiences and his responses to his own personal encounters with both the patients and their illnesses.

Carswell's definition is the basis of my interpretation of the activity of delineation in my research and is crucial as a point of departure for this investigation. He was an artist and a pathologist rather than an anatomist and drew unique and individual portrayals of diseases he encountered instead of building composite or generic examples of diseases. I have also observed within his images an aspect which supports the hypothesis that delineation is a phenomenological activity and appropriate methodology with which to present encounters as visual experience. This is the element of dignity.

I argue that one dignifies a subject by the attention one pays to it. To take in every part of something, every detail, every idiosyncrasy and afford it both the dignity of seeing it and then presenting every nuance of this through delineation, is all part of the matter of respectfulness. Rather than generalize these events, each patient was treated as unique. Carswell used delineation to describe specific details and personal attributes of each sufferer, and communicate the visual experience of these encounters.

His depiction of 1829 of a female patient in the Hôpital Saint-Louis, Paris, portrays a woman afflicted with a skin disease, *Variola disersta and psoriasis* (smallpox). It is an example of an image that uses delineation to convey the visual experience of her illness and Carswell's encounter with her. She is a large lady and is shown wearing a cloth on her head. Her earring is a pretty disc of aqua blue on white and gold. Her entire face, neck and legs are covered in pustular sores. Her encrusted eyelids hood her downward looking eyes. His visual experience offers knowledge of his encounter with her as a living being, a whole person, not just a disease. Through this visual experience we gain insight. We are dignifying her through the action of acknowledging her presence rather than turning away and ignoring her. It is human nature to turn away from disease, illness and difference. Carswell instead draws us into his experience of the disease, focusing on her differences and delineating each element of her condition. His inclusion and scrupulous attention to detail of the woman's earring in his delineation exemplifies this.

Another image shows a cancer sufferer. It is a study of a man and is entitled *Subcutaneous Cancer* (Fig.1). There is use of intricate cross-hatching over light watercolour washes. The man's eyebrows are knitted together and his unflinching stare reveals an expression of absolute despair and anguish. Carswell has delineated in minute detail all the clusters and lumps and growths. One, slightly larger, is in the middle of the man's chest and looks almost like a sea anemone. The largest and most colourful has eaten away at his left breast. The greenish yellow hue that tints his entire sickly body is juxtaposed violently by the blood red flecks which describe the inside corners of his haunted eyes and contrast sharply with the whites of his eyeballs. The simple white sheet wrapped loosely around his hips affords him modesty and gives him some dignity.

With his left arm outstretched, he is reminiscent of paintings of Jesus as the 'man of sorrows'. His ravaged body has the flayed and disfigured appearance of the Christ figure in Grünewald's Isenheim altarpiece, a painting I will refer to again in the thesis.

Fig.1 Subcutaneous Cancer (Carswell, 1829).

In this harrowing depiction of one man's suffering and the disease from which he endures, Carswell has presented his encounter, through the process of delineation. These are very powerful images that both present the disease to us and give us an understanding of the experience of that encounter.

Delineation is both the subject of this research and the methodological tool used to present visual experience and my understanding begins with Carswell's definition of the term. In his letters and book he continuously described his depictions not as illustrations or art but as delineations and his usage indicates the key characteristics of this research.

My delineations are made on a similar scale to Carswell's; they are the size of a large format book. They are intimate, large enough to contain a high level of detail, but small enough to have a sense of being personal and precious. They can be held. At first I did not recognize the

significance of working exclusively in an A3 sketchbook, it was simply a matter of convenience. I had worked on large-scale drawings previously and predominately used charcoal. It was only later in the project I realized that working in a book rather than on individual pieces of paper was part of the experience and reflects the tradition of books of anatomy and is similar even to Carswell's treatise on Pathology.

There is a sense that each delineation takes a certain amount of time to make. It is not a 'snapshot,' like a photographic image. Therefore there is a devotion to the actual surface, which is intrinsic to the process of making the image, revealing where it has been touched, smudged, rubbed, scraped and inscribed upon. The delineator's presence is felt through the marks and impressions made by a hand and incidental marks that are all part of its making would not appear in any photomechanical or digital process. There is a compulsion I have as delineator, in the activity itself of laying down marks, to remove, re-draw, to create and bring about some sense of understanding of a subject through the activity of seeing it through drawing it and knowing it through the experience of delineation. Leonardo da Vinci is a good example of someone who used drawing not just to record, but also as a way of gathering evidence and to think through ideas and theories. By looking and portraying the muscles in a human arm, he came to understand the mechanism of how they operated.

My inquiry examines a subject from the field of medicine but is based in art practice. It aims to present further understanding and visual knowledge of a medical condition and the way the activity of drawing offers insight through processes of close observation and continuous drawing.

I argue that using delineation as a drawing system for recording the visual experience of a phenomenon is a valid and useful method of presenting information. In Chapter 7 further support to this claim is provided from evidence produced during a workshop with archaeologists who found they were beginning to understand the specimen far more as they spent more time engaged in the process of drawing it.

In some formal definitions of the term, for example Webster's Dictionary, delineation is defined as something material representing objects. Most

often, the term is found in geography, architecture, archaeology and anthropology to describe the processes of topography, mapping, planning, and outlining used in these disciplines.

In some fields, for example architecture and archaeology, delineation has been described as a method of rendering with the aim of representing something. In this research delineation is intended to *present* experiences of observing objects rather than *represent* them. These practices may include use of symbols, which stand in for something else, or allegory can be used as a way to describe a subject using suggestive resemblances in place of the object being depicted. Also codes might be used whereby a set of rules is in place to guide how an image is made. All these are valuable methods however representation is not the main aim of delineation as developed in this thesis.

In the system of delineation I develop in this thesis, the data of both the object and experiences of the object have been delineated as immediately and precisely as possible. Individual and subjective, they are intended to be direct in rendering the visual experiences as they happen. The objective was not to use notations and symbols for representation. My main preoccupation has been to present the data with delineation as my tool.

Delineation in other fields

Initial searches on delineation in other fields located architecture and archaeology as two rich sources. As part of the investigation I examined a variety of standard textbooks used in these professional communities. These describe technical rules and methods that must be followed. Certain materials and media are most frequently used and the lists of tools needed for the purpose are specific and comprehensive. I will begin with an examination of delineation in architecture.

Architects use both hand made and Computer-aided design (CAD) drawing in architecture. There are advantages to both. Osuma A. Wakita, Professor of Architecture at Los Angeles Harbor College, and architect Richard M. Linde list advantages of using manual drafting skills in their

book *The Professional Practice of Architectural working drawings* (3rd ed.):

- '1. Eye-hand coordination is developed*
 - 2. Viewers get to look at the drawing as it will appear to the construction workers in the field*
 - 3. Drawing is done at the scale that will be printed*
 - 4. Hard copies allow you to look at all the drawings in a set one at a time, even during development*
 - 5. Line quality can be varied, depending on need and intent of the drawing*
 - 6. Metes and bounds (a method of describing land) can be varied, exactly as the civil engineer labels them in the site plan*
 - 7. Hand drawing allows the drafter to think through the drawing process and assesses his or her own skills to match the task*
 - 8. Hand drafting enhances other skills needed in the office, such as model making, creating presentation drawings, and even the process of design or translating design*
 - 9. Hand drafting allows assessment of personal human skills, rather than those of machines*
 - 10. Hand drafting promotes a better understanding of how to incorporate the computer into the production drawing'*
- (Wakita & Linde, 2003, p. 25).

They also point out advantages to drawing with CAD. Drawing with a computer allows you to draw at 1:1 scale as the drawings are made in a virtual space so can be any size you like. They can be enlarged or reduced immediately and can reveal all the different layers needed to make a plan, clearly and simultaneously. For example the floor plan can be shown at the same time as a layer showing the walls, the layer depicting appliances, the layer with doors and window, and the ceiling plan.

Terry L. Patterson, architect and author of *Architect's studio handbook* uses a collection of plans and schematics from architects firms that have already constructed the buildings as examples for both professionals and students. He comments that working drawings are only as good as the

architect who made them. Ralph L. Leibing a senior architect points out in his book *Architectural Working Drawings* (4th ed.) not only how vital drawing is to the process, but that working drawings are part of the contract documents and are therefore legally binding.

These textbooks also set out examples of drawing conventions. In *Working Drawing Handbook A Guide for Architects and Builders* (2nd ed.) by the architect Robert C McHugh, clear guidelines are given and step-by-step ordering of process that it is necessary to adhere to. Schematics are intended to communicate clearly, be economical and sketched lightly in pencil. Each sheet should be designed within a certain layout produced in a specific order. Keys, codes and symbols are used to represent or stand in for the things as yet not created (Fig. 2). Every delineation, elevation, plan, schematic has a purpose. This might be cost, function or construction. Each element like foundation or floor plan or framing plan etc. is produced separately for clarity. Generic examples of features of architectural spaces depicted in these manuals make use of tracing and overlaying composites and have been created using pens, pencils and photographs. There are models and styles for every aspect from elevations to how to draw generic people with which to populate the architectural rendering, and methods for illustrating generic trees. Images of people portrayed are not specific; they are delineated merely as a device for establishing scale.













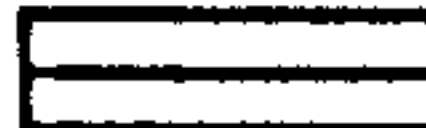

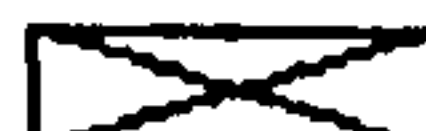

ARCHITECTURAL SYMBOLS	
	EARTH
	BRICK
	CONCRETE
	CONCRETE BLOCK
	GYP SUM BOARD
	GYP SUM SHEATHING
	INSULATION - BLANKET OR BATT
	INSULATION - RIGID
	GRAVEL OR CRUSHED ROCK
	METAL
	PLYWOOD
	CERAMIC TILE
	WATER PROOFING
	WOOD BLOCKING
	WOOD BLOCKING CONTINUOUS
	WOOD FINISHED

Fig. 2 Conventions used to depict building material (Burnett, 2008).

Some architects describe themselves as Delineators but this term is not regularly used. It is applied to a specific type of rendering made at a particular point in the process of making architectural delineations for a client. It describes when architects render an accurate portrait of the 'building-to-be'. Its purpose is to be an exact delineation that communicates the visual experience of something that has yet to exist. Ernest E. Burden author of many architecture resource books describes delineation in his book *Architectural Delineation (3rd ed.)* as being like, 'an anticipated photograph of the complete project' (Burden, 1992, p. 42). So rather than depict what is being experienced now, architectural delineation is used to project the experience of a finished thing, which will be completed in the future.

The illustration procedure in architecture makes use of various practices and methods. Certain key stages have to be achieved and particular processes used to get to them. There are different renderings that use tracing, selection and composites and systems of plotting, planning and mapping. It is at the final stage of delineation, where the architectural illustrators take previously made accurate maps and plans and interpret them with a view to creating stunning vistas.

In the field of architecture drawing is an important part of the creative process and delineation is a visualization process used to depict future possibilities. This is distinct from the use of delineation in archaeology where it is used as a recording process to present unique objects. It is more concerned with capturing the physical, closer to the purpose of delineation in this research, and I will explore the use of drawing in this field in two ways, first looking at techniques here and later through discussion and workshops in which archaeologists and medical illustrators participated.

Author and academic Barbara Ann Kipfer discusses the importance of drawing in her book *The Archaeologist's Fieldwork Companion*. In it she explains that archaeological drawing will often begin in the field. Frequently a site map will be drawn as well as photographed. This is for several reasons, for example, features drawn to scale can be reduced later and drawing techniques like hatching can be applied to help differentiate

between features. All drawings are logged and artefacts must be measured exactly and drawn in profile in outline only. She emphasises how important the role of drawing is.

'Without the careful drawing and mapping of artifacts, features, stratification etc., a site would be meaningless. Accurate drawing and mapping influences the way a site will be studied and presented in publications. Photographs of the site and excavated artifacts are supplemented by scale drawings, which can emphasize relevant details in ways not generally possible in photographs...These drawings can offer more detail'

(Kipfer, 2007, p. 243).

As well as drawing in the field, it is crucial that all artefacts are recorded accurately. In *Drawing Archaeological Finds A Handbook*, a publication from the Institute of Archaeology at University College London, a successful illustration is defined as being one that combines understanding of the object and its components with an, *'ability to make an accurate and aesthetic rendering of its character'* (Griffiths & Jenner, 1990, p. 1). The justification for drawing these objects in the first place is argued.

'Why illustrate them [archaeological finds] at all? Why not just write about them? It is always better to have a picture of an object in front of you than any number of sentences explaining it, as no amount of words could be expected to sum up all the characteristics and components of an artefact in sufficient detail for the mind to reconstruct the object in its entirety'

(Griffiths & Jenner, p. 1).

As in the fields of medical illustration and architecture, archaeology has developed recommended methods for depictions of artefacts, and standardized techniques and conventions. Unlike these, archaeology demands a record made from observation, in situ if possible and is concerned with presenting a unique object rather than a generic one.

Visually documenting archaeological objects became a vital part of the process of recording findings when General Pitt-Rivers, the 19th century

archaeologist, had carefully delineated recordings made of every object discovered and published these findings. This methodical approach declined in the 1970's when images were only made by tracing around the actual objects. Pitt-Rivers and Carswell both saw the value of using drawing to precisely render the details of unique objects and it is this sustained method of recording and attention to detail that the activity of delineation developed in my research refers to.

Standardized processes for portraying an assortment of objects have developed to allow reliable comparisons, from facets of flint items to different elevations of a piece of pottery, and a range of ways to render various types of decoration, and regulations regarding the expected orientation. There are also methods for how to reconstruct an image of the whole piece by drawing the fragment in situ. Conventions are visually understood, for example, cross-hatching on areas of flint, indicate abrasion from use rather than portrayal of a shadow, or that a combination of line and irregularly spaced stippling will represent an uneven surface on a stone artefact.

The instructions for making archaeological illustrations are similar to those in medical illustration. For example a scale of 1:1 is used where possible. An object should always be depicted as if it has been lit from the left even if this is imagined light, a scale is always used and importantly, an object ought to be orientated so it is portrayed the right way up. There are rules regarding the hardness of pencil to be used, from 3H to HB, recommended width of pen nib, 0.2 to 0.6 and the type of paper and card to draw on. Instruments like 'French curves', callipers and dividers are employed to carry out these imposed technical regulations. The technique of hatching which is used to show marks or shading, should be done with a machine or using the following 'simple' instructions,

'First, draw horizontal and vertical axis lines above and to the left of the section or area to be hatched. The drawing most probably has horizontal and vertical axis already. Next, mark a point at the same distance along each axis from the crossing-point 'a'. The distance doesn't matter as long as it is exactly the same in each case. A line drawn between these two points is at 45° to the axes. Finally, mark

two lines of points at the spacing chosen for the hatching, at 90° to the diagonal line. This can be done by eye (with practice) or accurately, by drawing a line from 'a' to cut the diagonal in the centre (measure from each axis) at 'b'. Measuring to either side of this line will give two parallel lines ('c' and 'd') along which the spaced points can be marked. Finally, draw lines between these points and the section has 45° hatching'

(Griffiths & Jenner, p. 9).

This description demonstrates the difference between my use of the term delineation as a phenomenological methodology with which to present a visual experience of an object as precisely and immediately as possible, and that of other fields that use lines as code/symbol which are used to suggest shape or shading to give a general idea of the object being depicted. An example of another convention is a description of how pots should be drawn (Fig. 3).

'All ceramic vessels are drawn in profile and then split into two halves down the centre of the body of the pot. The right hand side normally shows any external detail and the left only internal detail. This rule holds true for Europe and a number of other countries'

(Griffiths & Jenner, p. 56).

Fig. 3 Pot illustration (Yankowski, n.d.).

With these uses of illustration, plans are rendered, a series of sketches are often made and then final composites. They are idealized, generic images that make use of symbolic rules of representation. This is a very different system from the way I have delineated disease.

The use of drawing in both the areas of medical illustration and archaeology will be discussed further in detail in Chapter 7.

Another use of the term delineation arises in theory developed by June King McFee, Professor Emeritus of Art Education at the University of Oregon. Her research pursues cultural understanding through art. She developed her theory of perception-delineation by studying differences in children's reactions to visual phenomena. From the results methods were developed for teaching art according to each individual child's needs. The theory based in psychology and children's education is used to describe the practice observed. According to McFee, learning is a behavioral adjustment. Art activity is seen to be central to educational experience and she focuses on the effects of home life and culture on productivity. Her research shows why a child's drawing may be constructed as a composite made up of previous experiences.

'A person may delineate a specific person's portrait or, to express a more universal idea, a composite face that expresses his experience with a class of people (such as children, adolescents, peasants) made up of many past perceptions'

(McFee, 1961, p. 42).

Perception-delineation provides a model of how to teach art to children taking into consideration many cultural and psychological factors. This is very different from the development of delineation as a phenomenological activity that presents detail and specificity of visual experience of an observed object.

Photography and other technical imaging

Alongside these pre-existing forms of delineation it is important to consider the role of technical imaging in medicine since it is natural to assume that the wide variety of imaging techniques available can supplant

traditional manual processes. I encountered such views quite frequently in discussions with clinicians, technicians and fellow researchers.

A camera is an excellent tool that can capture detailed information quickly and in full colour. The visual information is presented to us as a photograph, which may be studied, by a clinician or other researcher. The colour and composition can easily be added to or changed digitally if needed. It is a quick and efficient way to create an image that can be reproduced in large quantities in various formats. A photograph is able to show a subject, but cannot claim to present knowledge and visual understanding of an encounter in the same way as the action of drawing it can.

It could be said that the machine-made image is better, more accurate, objective and reliable than the hand-made for capturing scientific data. Dominic Lopes, Professor of Philosophy at the University of British Columbia said

'Data capture must be reliable and objective; machines have both virtues; draftsman have neither'
(Lopes, 2005, p. 6).

He goes on to use examples of botanical and anatomical drawings that depict idealized versions and how particular features stand in for a type, i.e., *'drawing represents type'* (Lopes, p. 5). This is the ideal in the sense of a type, a pure case that is generalized and stands in to represent and be an example of something that does not actually exist in reality. It is useful as a model to show what might be possible or what is adequate. Therefore it would appear to be more accurate to draw the specific object, being observed first hand, at that moment in time.

Max Brödel, the founder of modern medical illustration, saw the necessity to,

'originate a different type of picture, one that shows far more than any photograph can ever do'
(Brödel, 1993, p. 113).

A camera does not 'see' light in the same way the human eye does. We do not perceive the greenish hue of fluorescent light that is automatically captured when photographed with some processes. Our depth of field and peripheral vision constantly shift to give a rich view but in photography these remain fixed. Our eyes and head move more than we realize when observing a scene. This visual data is far richer and more diverse than the visual information that can be captured from a statically positioned camera or even from manipulation of several images to form a composite. Cropping in photography occurs initially when looking at an object through the viewfinder and often later when the image is printed or uploaded. This visual editing offers a subjective record and, especially in the case of medical photography, can deliver information but not necessarily understanding. Most importantly, a camera can only record instantaneous events rather than the actual data experienced over a period of time.

Modern technological advances in imaging have brought about a wonderful range of ways to produce medical images. What Carswell did and delineation developed in this research seeks to achieve, is include an element of empathy through being in the presence of the object being observed. Medical imaging lacks the guiding hand of the observer and the system does not give room to be interfered with. The gadgetry and mechanisms which intervene and displacement caused through their projection via screens and monitors, robs us of the sense of physical activity and presence of a maker. In the same way there is a sense of an act of drawing, there is also a specific act of delineating.

Delineation is a system that makes use of a great variety of techniques and tools and utilizes methods employed in drawing and applies them specifically with the intention of presenting an encounter with phenomena. Delineation is an act of engagement.

Scientific illustration and design

Other than using technical imaging to record an object, there are different ways and means to collect and show scientific information. Graphic designers and illustrators make graphs, diagrams, and images with the aim of visually interpreting other people's research by telling other people's

stories. At the MIT (Massachusetts Institute of Technology), Image and Meaning Conference held in the Getty Centre 23rd – 26th June 2005, discussion focused on different methods used and effects these have on understanding of information. An example highlighted by Melissa Franklin Professor of Physics at Harvard is the familiar image of a ball in a net used as a way of explaining Einstein's theory of relativity in time and space. She felt it is a very potent image, but it is in fact misleading.

The relevance of any data is dependent on the quality of visual information if it is to offer greater understanding and lead to explanation. However, too much data does not necessarily offer more information and therefore knowledge of a subject. In fact the opposite can happen. In his book *Visual Explanations Images and Quantities Evidence and Narrative* Edward R. Tufte, Professor Emeritus of Statistics, Information Design, Interface Design and Political Economy at Yale University, gives an example of how displaying the less important data can lead to catastrophic events. By leaving out vital evidence about the significance of temperature variation and making the images overcomplicated, the rocket engineers failed to convince NASA not to launch Space Shuttle Challenger on 28th January 1986. Seventy-three seconds after launch, it blew up. They had the right reasons, but had inadequately displayed the data, leading to momentous consequences (Tufte, 1997).

In this investigation I argue that images made using only two dimensions sometimes offer clearer information than three-dimensional data. In two separate events, clinicians have 'explained' something to me by drawing over an original image. This 2D line offered clearer understanding of the subject being discussed.

Alf Linney, Professor of Medical Physics and leader of the Medical Imaging and Graphics Group at University College London, has pioneered use of virtual reality to provide functional images that create the effect of 'X-ray vision' during surgical procedures. In a meeting with him on 30th June 2004 he explained some imaging methods particularly the process of helical CT scanning (Computerised (Axial) Tomography scan). This is an imaging procedure where pictures are taken from all around the body using an X-ray beam that rotates in a spiral shape. This gives a continuous

picture, with no possible gaps between the 'slices' of the scan. A computer programme is used to put the 'slices' together to make a whole image. He expressed his view that 3D is the clearest medium for visualizing the internal workings of the human body. However, a member of the team then went on to describe how one surgeon she works with always prefers to look at X-ray film rather than computer generated scans. He then holds the X-ray against a generic model, made by the department, and draws over it to show how it should look.

The tools and processes used in visualizing scientific data are often sophisticated and highly specialized. Too much technology and not enough good application can result in the production of inferior images, something which happens all too frequently with the amount of data tools and plug-ins freely available on the web allowing us to be inundated with mass produced bad visualizations. Conversely, oversimplification or alternatively over complication of data driven by a desire for aesthetically pleasing images may unwittingly communicate incorrect information. Form over content may actually misinform. The importance of recording data precisely is sometimes overlooked in the great desire to find and communicate results. Actual data collection and description of functionality is a crucial part of research and precise visual realization is vital. The visualizing process used to collect and then disseminate information has a direct affect on that raw data.

By contrast, drawing on paper with a pencil or other hand tool, objects directly being viewed, can record, analyse and offer new knowledge of them, inexpensively, through its application. Delineation as a system for recording involves coming to know the subject through the process of delineating it and understanding how it functions through that activity.

I have examined the role of photography and other technical imaging and described other uses of the term delineation. I will now move on to describe some of the characteristics of delineation within this research.

Interpretation of delineation

This research proposes a strategy for delineation that involves communication, memory and problem solving, simultaneously as the

emerging question continues to develop. Each mark made is determined by the previous mark. Understanding of the visual experience is developed and fed back into the process of continuing to make marks. This furthers the emerging understanding of the encounter. Insight of the encounter is embodied in the process and situated in a particular time and place. It is fugitive in that it continues cumulatively through the actions of translating, experiencing, presenting, analysing, evaluating, redefining, etc. This reflects the transient nature of looking and time spent in the activity of making which defines delineation as being an appropriate tool with which to research a subject.

Delineation here is seen as a phenomenological activity. The activity involves the process of depicting minute detail with the aim of describing and explaining the item or experience it is epitomizing. Whilst it can map and outline the object, it should characterize the specificity of it, almost tracing the actuality of the thing. It should be lifelike in appearance and is used to portray the experience of encounters with a disease and is not just about documentation but participation.

For the purpose of this research I argue that delineating phenomena by its nature is concerned with specific encounters rather than generic archetypes and reflects the immediate responses and relationships formed within each encounter in a way that is particular to the act of drawing. The delineator inscribes each fugitive experience, cumulatively, in such drawings as they proceed. What is produced is a vehicle for these visual experiences to be presented to others whose own background allows them to develop new insights and interpretation of the original phenomena. By comparison with McFee's theories, this is not the same as rendering a composite from remembered experiences beyond the present encounter. It is a way of directly communicating each experience of each encounter with the phenomenon as instantaneously and as closely as possible.

The process of delineation offers a system for collecting and presenting visual data in ways that seek to avoid the problems discussed. Whilst delineation in other fields is an umbrella term for a form of representation and recording, I am using it specifically to mean a form of recording and presenting which captures the experience of observation of an object. I

have already explained that representation makes use of symbols to stand in for the object, something not done in the system of delineation described here. The term recording does not describe the whole of this activity since it does not capture the experience of observation of an object. Use of the word in this investigation implies a wider understanding intended to go beyond the field of inquiry and practice and possibly into medicine and other science fields.

In many ways, delineation is a contradiction. Its objective is to present the encounter with a real three dimensional phenomenon but it does this only in two dimensions. It uses lines where there are none in the real world. It does not use colour when the world is not monochromatic and makes explicit its own process, making no attempt to hide the activities involved in its emerging creation, so remains as being a delineation. The delineations make clear the presence of an encounter and the object being experienced. They do not claim to *be* the object and neither are they mere representation. Objects are experienced by the delineator first hand and rendered directly by the delineator. Delineation aims to present the experience of the encounter with the phenomenon.

Martin Heidegger put forward the notion that we come to know the world through our tools and understand our tools through their use. A pencil can be seen as a tool for marking, laden with intention in the hand of the maker holding it. This is distinct from its application as a tool for knowing and experiencing our encounters with things in the world. It becomes much more through how it is used, making it a vehicle for these visual experiences. Unique in that no two drawings can ever be exactly identical, the delineations created with this tool, present the experiences of each spontaneous moment. The idiosyncrasy of delineating is that it is not always a physically robust record of information. Graphite can easily smudge, be accidentally rubbed out or altered and paper is delicate and prone to deterioration.

In the act of delineating there is a sense of a hand holding the instrument used to make the line forming a relationship directly with the delineator, the tool and the observed object. There is no sense of a programme, a software package, and mechanical eye or a third party being part of the

visual process. The activity of delineating is part of its process. Within this research I interpret delineation as denoting a method of scrutinizing the object in such a way that the qualities of the data being revealed within it are understood and visually explained. It is presented as closely as possible to the experience of seeing the object.

Support for claims

In this thesis, I claim that through the activity of drawing an object, you come to understand it. By this I mean that by drawing something, the delineator comes to have knowledge of the object. I also claim that delineation allows a viewer to gain a comparable understanding, relevant to his or her own knowledge and experience. These claims must be substantiated and I will examine evidence from several sources to support them. I will use examples of the way drawing is used by Leonardo da Vinci, Max Brödel and Brian W. Edwards Professor of Architecture, University of Huddersfield. The work of two theorists, Kenneth Biettel and Philip Rawson who have examined the activity of drawing will be cited as further evidence.

In an article *Leonardo da Vinci as a paradigm to modern clinical research*, Francis Wells, Consultant Cardio-thoracic Surgeon at Papworth Hospital and Associate lecturer at University of Cambridge, and Thereza Wells, Co-ordinator of the Leonardo Laboratory for the Universal Leonardo Project at University of the Arts London, examine the aspect of understanding through drawing in the work of Leonardo da Vinci. They discuss the importance of his drawings for their scientific worth rather than their beauty. They focus on the fact that Leonardo has the

'ability to investigate a vast range of subjects by meticulous observation...produced anatomical and physiological revelations, elements of which remain relevant now'

(Wells & Crowe, 2004, p. 929).

Beyond wishing to merely represent the body, Leonardo's aim was to have knowledge of how it works.

Wells and Crowe recognize the significance of the capability of his drawings to both reveal understanding Leonardo has gained and to convey knowledge to others. The knowledge Leonardo gains through observational drawing is supported by the accuracy of his writing which

accompanies the images in his notebooks. In this extract from *Codex Atlanticus Volume II*, p. 107 from *The Notebooks of Leonardo da Vinci*, edited by J. P. Richter, Leonardo describes how his drawing can offer understanding of both structure and function of anatomy.

'And you who say it would be better to watch an anatomist at work than to see these drawings, you would be right, if it were possible to observe all the things which are demonstrated in such drawings in a single figure, in which you, with all your knowledge of more than some few veins, to obtain a true and perfect knowledge of which I have dissected more than ten human bodies...this I repeated twice, to learn the difference'

(Wells & Crowe, p. 936).

This adds support to the claim in this research that drawing cumulative experiences allows the delineator to gain further knowledge of the object through the continuous activity of drawing. In Leonardo's opinion, words describe things in a confused and convoluted manner while a drawing will sum up all that is needed. Leonardo also felt strongly that drawing is able to convey information. For him, drawing becomes a means of explanation. This is also the intention of delineation.

Leonardo's use of cross sectioning and drawing sections as if transparent, are techniques he uses when continuing his exploration of a theory. I do not use these and delineations in my investigation are made in situ and aim to be as accurate and precise a presentation of the object and my experience of that object as possible.

Another example of the way the activity of drawing offers insight can be found in an article written in 1941 in the *Journal of American Medical Art* by the medical illustrator Max Brödel who describes how his mentor, the gynaecologist Howard A. Kelly used drawing.

'Dr. Kelly had the remarkable gift of explaining with sketches. In a few but simple graphic lines he could show all the new ideas in connection with his operative work...He made it clear that the conception of a picture is

the all important thing, not the plastic elaboration, the realism or technical finish'

(Schultheiss & Jonas, 1999, p. 114).

As I have argued previously, the process of drawing dignifies the object being drawn. The architect Brian W. Edwards also claims that his own work,

'seeks to revive analytical drawing as means of understanding form and construction'

(Edwards, 1994, p. 3).

The sketch can be used as a learning tool rather than mere representation. He goes on to point out that by spending a large amount of time drawing an object, dignifies it.

'To have sat for an hour and drawn an old panelled door is to create a respect for the object ...[of its] qualities or beauty...the sketch rather than the instantly obtained photograph is means to this awareness'

(Edwards, p. 7).

Kenneth R. Beittel, artist and tutor at Pennsylvania State University, sees drawing as being imbued with an experience of an object and that we comprehend the drawing process through tacit knowing as our understanding of drawing comes from knowing the tools of drawing through using them. We have all held a pencil or pen or other mark making tool and used them to draw so we comprehend the drawing process through tacit knowing.

Each object in this inquiry is experienced on several levels simultaneously. As an observer, an object is seen as a phenomenon that needs to be explained, before, during and after delineation. It is understood as a series of shapes in a physical space, a specimen, a fragment, a terrible disease and a visual conundrum.

'The phenomena ...are merely more subjective, in that they are shaped by the drawing process and the drawing series as much as they shape these'

(Beittel, 1972, p. 133).

Both Biettel and McFee's theories are based in psychology and education. They reject the phenomenological aspect that is the framework for delineation as developed here. Biettel's emphasis is on how we experience art rather than how we experience a phenomenon and present it and McFee focuses on studying the ways children present phenomenon with a view to gauging their educational needs.

Philip Rawson has written extensively on drawing and in his book *Drawing* outlines the foundations of drawing practice. He claims,

'drawing's basic ingredients are strokes or marks that have a symbolic relationship with experience, not...reality. And relationships between marks, which embody the main meaning of a drawing, can only be read into the marks by the spectator, so as to create their own mode of truth'
(Rawson, 1987, p. 1).

His theory that drawing is a form of explanation and understanding takes into account the cumulative nature of looking and drawing as we look and supports Leonardo's views on continuous drawing and experience.

'[A drawing] is also an image of our own subjective experience of what it means to exist, an image taken not just at one moment but gathered together from long stretches of time into a sum which is outside any individual time'
(Rawson, p. 9).

Biettel and Rawson are important in their analysis of how the process of drawing furthers understanding. However they both focus on understanding of the drawing rather than the understanding of the object and experience of the object which is the foci of this inquiry.

I argue that the series of 66 delineations (see Chapter 6) I made over 3 years did not lead to technically better rendered drawings, but to delineations that present the visual experiences of the objects encountered. They are evidence of the information being better understood by the delineator and this being presented with greater clarity to the viewer. In

the activity of drawing both the problems that arise and the process of them being solved are presented on the page. The emerging knowledge is made explicit.

Conclusion

This investigation seeks to bring back the notion of restoring something lost by the emphasis of use of technology, that may be taking attention away from the process of gathering raw data, analyzing, interpreting it and communicating findings through observation and drawing visual information.

Architecture and archaeology have rules in place. Drawing also can be seen as reliable because the activity of delineation has a system in position. By system I mean that in this research, the process of delineation is specific, structured and complex rather than a model that is a simplified version of something and used as a defining example. The delineator focuses on the specificity of an object, rendering relevant features clearly and precisely. The process of delineation is intended to be reliable as the standardizing of drawing allows comparisons between drawings to take place.

I have given examples of how delineating is used in other fields, as a way of precisely rendering a found object, and as a way of conveying conceptual information about facts which are not yet actual as in architectural renderings. The process of delineation developed in this inquiry records visual experience of phenomena and presents the development of insight gained by the delineator through continuity of this activity. The delineations are beyond mere record. The aim is to record and present '*fugitive subjective experience*' (Rawson, p. 316).

The definition of delineation as described in this study originates from Carswell's use of the term to indicate an image that is essential for clearly communicating precise and accurate information within his field of pathology. Having also adopted its description as being specific, detailed and directly tracing a lifelike portrayal of an object, the interpretation of delineation used within this research, has been developed further.

Understanding delineation as a phenomenological activity that can present visual experiences of encounters with phenomena is central to its concept.

Delineation in this inquiry is defined as being a descriptive form of subjective explanation of objects, experiences of them and a means of understanding them. It also has the ability to 'dignify' objects in a way other methods do not achieve.

As an activity, this thesis claims the action of delineating is an appropriate tool for investigating, presenting, and offering insight into the disease FOP.

CHAPTER TWO

Delineation: a phenomenological activity

In this chapter I will set out the case for delineation as a process for engaging as directly as possible with an object's phenomenal reality through the process of drawing it. I begin with a description of my first encounters with anatomy and pathology, paying attention to the physical and emotional experiences involved, and differences between the two disciplines.

My rationale for placing this research within the philosophical framework of phenomenology is explained and I claim delineation as developed in this research is a phenomenological activity and the information in this chapter supports this proposition. I give definitions of phenomenology focusing on the interpretations of Husserl, Heidegger, Merleau-Ponty and Sartre. These are summarized and problems are identified. An argument about truth in images is discussed and an example from a histology experiment is used as evidence. An interpretation of phenomenology is given.

Introduction- personal experiences of anatomy and pathology

My first experience of anatomy was in 1992. As an undergraduate at Norwich School of Art, I gained permission to draw in the dissection room in Norfolk and Norwich Hospital. Until then I had spent most of my time drawing from the life model and had developed a fascination with the human form and its workings. Armed with my sketchbook and charcoal I went into the dissection room.

The first thing I encountered was the smell. It was overwhelming. The pungent, putrid, cloying stench clawed up my nose and gripped the back of my throat, as if something was coating every part of the olfactory organ. It had a physical presence. Small and unstructured, the room had a section with potted specimens, mainly shoulders, knees and hands, one freshly fixed cadaver called 'Matilda', a teaching skeleton and a room with a large tank. The tank was filled with various body parts: legs, feet, arms, a spine and several heads.

Any potted specimens were to be returned to the shelves at the end of each day. Latex gloves were supplied, but sometimes ran out, and I was told to help myself to anything from the tank except the backbone. I would lean into the tank, grab something lurking in the liquid and place it on a metal tray and put it in the middle of a table.

Matilda (a name given to her by the students, not her real name) was on a trolley and covered by a white sheet. She was my greatest concern as I had never seen a dead person and there was a real one, under that sheet. Once I removed the cover and saw her, any anxieties went. She was fascinating, beautiful and sad.

There was a skeleton in the cupboard and one morning, I discovered students had put his head on back to front. I found this displacement more troubling than any experience I had in the dissecting room, as it was an act of human intervention that had disturbed and profoundly altered the nature of the ubiquitous skeleton.

The two most significant experiences I had whilst working there involved a leg and a head. I had seen a leg in the tank that I wanted to draw. To reach into the very deep tank, I had to stand on tiptoe and lean right in. The smell of formaldehyde was extremely overwhelming, and made my eyes water. I grasped the leg with both hands and started to lift it. Only then did I fully realize the heaviness of a whole, male leg, as the weight of it nearly pulled me into the tank. The sense of touch, smell and the consequences of its size and weight made it a significant experience that encapsulated many senses simultaneously.

I had decided to draw a head because it is the hardest thing to see as a fragment of the whole body. It is your face by which you are usually recognised and our heads are the part of us with which we are most familiar.

I called him Hedley. I find it easier to work if I have some sort of relationship with the object or person I am drawing. I often spend a long time with the subject, getting to know them, and sometimes personalizing them. I saw a lot of character in that isolated, bodiless head. The top of his

head had been removed, as had his brain and I spent time observing and drawing him from several positions. The physical weight and shape of the head proved a problem making it difficult to position him exactly where I wanted him and sometimes I would have to prop something under his neck to obtain the angle I required. This became such an everyday issue that when the most annoying impediment to my drawing happened, I thought nothing of it. His face fell off. Instinctively I tried to stick it back. I kept pressing the face back onto the muscle underneath, but slowly and gracefully it would unfurl and drop off. Finally I used a tiny amount of chewing gum to secure it long enough to complete my drawing. It seemed an appropriate response, just a natural and practical solution to allow me to complete my work. I also felt saddened by the thought of the indignity of Hedley's face falling off and wanted to stick it back on for him.

This and other experiences in the dissecting room were my introduction to the realities of experiencing anatomy.

In 1999 I began studying the collection at the Wellcome Museums of Anatomy and Pathology at the Royal College of Surgeons of England (RCSEng). There are many differences between a dissection room and a medical museum. There are no whole cadavers in these museums, all the specimens are potted, everything is neatly ordered into categories and above all there is no smell.

The specimens are all at various stages of dissection as they are intended to benefit the studies of medical students. One of the first drawings I made was of a girl's head. It was a very different experience to my previous encounter with Hedley, as this head was in a Perspex case. She was untouchable. The dissection was beautifully done and reveals subtleties of gross anatomy, facial muscles, and nerves etc. What drew me to her was the fact that she was so obviously young, and has the appearance of being in good health. From a certain angle, she looks almost alive and it is clear how pretty she was. The casing itself became an issue and rather than struggle to ignore it, I made a point of incorporating its presence into my work. This is when I realized how vital the element of the field of display was. I found myself contemplating the specimens that appeared to be contemplating their own reflections. I explored the effects of liquid

refracting light and the distortions that occurred. It then became fundamental to my work and the effects of the glass/Perspex, the light bouncing across, the reflections and the refractions, became integral to my visual experience of the prosections.

All humans have hearts, lungs, bowels, tendons and arteries. When seen anatomically, these derivative specimens are peoples' organs, the same as those we all have. They could and do, belong to anyone. Pathological specimens are each unique to the person who suffered from the diseases that caused them. Each person's experience of a disease is unique. One person's experience is likely to be different from another's. The specimens have a sense of belonging to a specific person, as they show the pathology that had an actual affect on a person. We tend to become aware of our bodies' systems and constituent parts when they are made noticeable to us through pain or disorder.

In 2001 I studied Anatomy for Artists at University College London (UCL). In the Dissection Room (DR), I once again experienced working with cadavers but on a much larger scale than in Norfolk and Norwich Hospital. Here were rows of bodies known as cadavers, placed in an orderly fashion throughout the enormous room that also had a large number of potted specimens as well as a collection of limbs and prosections ready for dissection and examination. A prosection involves the dissection of a body by a professional for the purpose of demonstrating specific techniques and anatomic structure. Once again the smell featured as a powerful component to the whole experience of the encounter. Work in the DR was linked directly to the lecture programme, so I would learn about the upper limb in the morning and work with arms in the DR in the afternoon. As in Norwich, I was able to lift and hold the sections, getting a sense of their texture, weight, presence and flexibility or lack of it. I pulled tendons, making the muscles extend and flex, to examine the mechanics of the arm. I compared skulls and heads between species and ages and watched the medical students carrying out their dissections.

By pulling on the muscles and tendons in the arm, I was learning by doing. This can be described as a kinaesthetic approach. It is a direct way to engage with the matter I was exploring. In some ways this very direct

engagement prefigures more subtle questions about experiential knowledge and understanding brought about through the activity of drawing. It is a direct form of learning where my experience of the action informs my insight of the object and how it functions. The industrial designer Henry Dreyfuss believed that basic knowledge is gained through trying to work out how things work and through the activity of making things. For him first hand experience is essential. First hand experience is crucial to the system of delineation as described in this thesis. Learning by looking, drawing, re-looking, thinking about how and where the marks should go to convey the experience of the phenomenon. Understanding more with each viewing, and corresponding to this new insight by readjusting the marks on the page to communicate this newly found knowledge, are vital components to the system of delineation in this research.

One of the most significant experiences I had during the course at UCL occurred whilst watching a medical student. He had completed sawing the top of a cadaver's head and lifted out the brain to examine the cranium. No longer needing the brain for his purpose of study, the student dropped the organ into a container which had the appearance of a rubbish bin. This action made me feel uncomfortable as it seemed as though the organ that maintains the body's functions, that is responsible for thought and which makes us aware of our own existence, was just thrown away.

I was allowed to draw more or less what I wanted and worked with whole cadavers as well as dissections and potted specimens. The work I produced at UCL was important as it was during this time I began developing my drawing methods and I extended my experience and understanding of anatomy.

Returning to work with the collections housed at the RCSI. I was struck once again by how different an environment a medical museum is to a morgue or a dissection room. The lack of smell and the focus of display completely changed the experience.

One of the first pathological specimens I drew was a melanoma leg. This was a different experience from drawing an example of a healthy leg. This

was a diseased fragment of a human who had suffered from the affects of an illness and I began to understand some of the differences between anatomy and pathology. I spent many days studying the leg. It had attracted me because in my opinion it seemed to convey the pain and suffering felt by the patient. The huge blisters and scabs that covered the skin reminded me of Grünewald's *Isenheim Altarpiece* (1513-1515). I have compared this painting previously with one of Carswell's delineations and will discuss it further later in the thesis (Chap. 3, p. 73). The other important factor that was highly influential to me was that the specimen was accompanied by a detailed history. There was a story that connected me to the leg and the person to whom it belonged. I became fascinated with it and found it both horrific and saw the beauty of the cancerous tumours.

I began to focus almost exclusively on pathology. Pathological specimens are sections that have been removed and are seen as displaced from the body. There is a sense of dislocation and often they have been removed from necessity. They are fragmented, fractured sections of the body. Whilst anatomical specimens begin as a dissection of a whole body and are often presented as separate sections, they are seen in terms of how they relate to the whole body.

The other aspect that makes pathology so different from anatomy is microscopy. Many images of pathology shown in the museum display not just the tissue sample, but also photographs of the histology slides taken and images from electron microscopy. The histological procedure involves taking a tissue sample and cutting a very small section of it, dyeing it with chemicals to make it clearer and viewing it under the microscope to find out what may be causing symptoms of an illness. These images are indispensable in giving further insight into a section and are another level of the experience of pathology. While the actual specimens themselves seem so isolated, for me there is a sense of fullness, of wholeness about them due to the supporting knowledge surrounding them that extends from the textual history and microscopic images through which we are further informed. The processes of histology is an important part of pathology and significant in supporting my rationale for the histology drawing case study that is described in detail in Chapter 4.

Beyond the look of a thing is its form. In this research understanding the experience of an object is conveyed through presenting understanding of its form. This is done by recording experiences with it through knowledge of methods employed in its creation, for example, the histological process and the phenomenological activity of delineating itself. At this stage it is important to describe the rationale for the use of phenomenology as the methodological framework in this research and set out my understanding of phenomenology in this context.

Rationale for phenomenological framework

At the start of this project I worked under the assumption that I would be employing a scientific approach to the research i.e., I would find the data, observe the data objectively, I would describe it, compare it with other data and analyze my findings.

Using a descriptive model based on recipes to structure my research, I began listing every tool I used and described my method of executing each drawing. I formed criteria for choosing which object to study and made detailed descriptions of how these drawings were made. This model allowed me to list materials and actions but did not offer information about why and how I was looking at these objects, what I was experiencing or what insights I was discovering. It had become a useful exercise but no more and I realized it did not provide the framework I required and served no further purpose in this inquiry.

The research as it stood may have offered some understanding of what the effects of FOP look like and include a unique collection of visual examples of this disease. It would not have fulfilled the overarching aims of this research; of coming to know the disease through encounters and processes used to render these experiences and offer insight into the impact of this disease on the people who have FOP.

Rather than just collect examples of FOP for comparison as a scientific method would require, the emphasis of this inquiry shifted from being objective to subjective; to research that aimed to present experience of uniqueness of encounters with FOP and aimed to find a way of presenting

these encounters to others in a dignified, respectful and informative way. This caused a shift from the scientific 3rd person to the subjective, descriptive form of observation of the 1st person that is based on experience and not just observation. I sought a methodology that would take into account the significance of the experiences of the activity of delineating, the experience of the laboratory environment as well as the experience of the object. The research altered to focus on what the delineator had understood from the experiences of the object rather than the resemblance of what has been observed. Importantly, the framework had to present understanding of the object and not just require me to render it as a complex object.

I found in this inquiry that a scientific model did not take into account the development of dialogues between delineator and object or delineation and viewer. Issues of smell, gore and the relationships that developed became significant to each unique encounter and integral to the notion of dignity and respectfulness. Rather than continue to force the research to fit within a scientific framework, I looked for a model that offered a philosophical standpoint sympathetic to my requirements and allowed me to make sense of these experiences when applied to a practical visual activity.

There is a strong connection between phenomenology and art theory. The activity of delineation in the context of this thesis, claims to allow the delineator to come to understand the encounters with the world around them through the action of drawing. The act of looking and simultaneously using a pencil to inscribe the interpretation of that experience as immediately as possible; the dialogues developed between delineator and object and delineation and audience are all aspects linked to phenomenology. This 1st person experiencing of the world seemed to offer a richer and more appropriate framework with which to develop the research.

Definitions of phenomenology

While not undertaking an inquiry into phenomenology, it is necessary here to build up an understanding of its development and practicalities and define an interpretation appropriate to this research.

Phenomenology is a descriptive approach from the first person, to the study of phenomena, appearances and events and our experiences of them. Phenomena are often seen as being the things we observe. The philosopher David Smith explains at the heart of phenomenology,

'is how we observe and reason and seek to explain phenomena we encounter in the world'.

He describes it as,

'that lived character of experience that allows a first-person perspective on the object of study, namely, experience, and that perspective is characteristic of the methodology of phenomenology'

(Smith, 2003).

In this inquiry, I propose delineation to be a system that can present the experience of visual encounters and is a phenomenological activity.

Every encounter with a phenomenon is unique and every presentation of that visual experience is distinctive from the next. I interpret phenomenology in the context of this inquiry as being the way visual experience is presented through a drawing system. It describes the activity of delineating and the process used to make the delineation. As we are not just mind but also body, as we are living in this world, physical understanding can be seen to be connected to the mind's experience through a physical activity which describes the experience, i.e., delineation.

Delineation is a phenomenological activity that is rooted in observational realism and accuracy. The act of delineating itself occurs and progresses throughout time and is made up of collections of many unique moments brought together through the continuing process of rendering an image. Through this activity the aim is to come to know something through experiencing it and to use delineation as a system with which to experience it. The phenomenon encountered is presented both as real and as visual experience.

Husserl, Sartre, Merleau-Ponty and Heidegger are four key philosophers from the first half of the 20th Century responsible for the conception and development of differing definitions of phenomenology (Fig. 4). Husserl and Merleau-Ponty saw it as pure description or ‘lived through’ description. This is a way of describing experience as we find it. It is interpretive and is dependent upon the notion of our experience ‘of’ an object. Husserl described it as purely about the experience independent of the object whereas Merleau-Ponty believed it to be experienced through the body. Sartre explained it in terms of the human condition and Heidegger’s definition was reliant upon interpreting it by relating it to other things within its context i.e., social or linguistic.

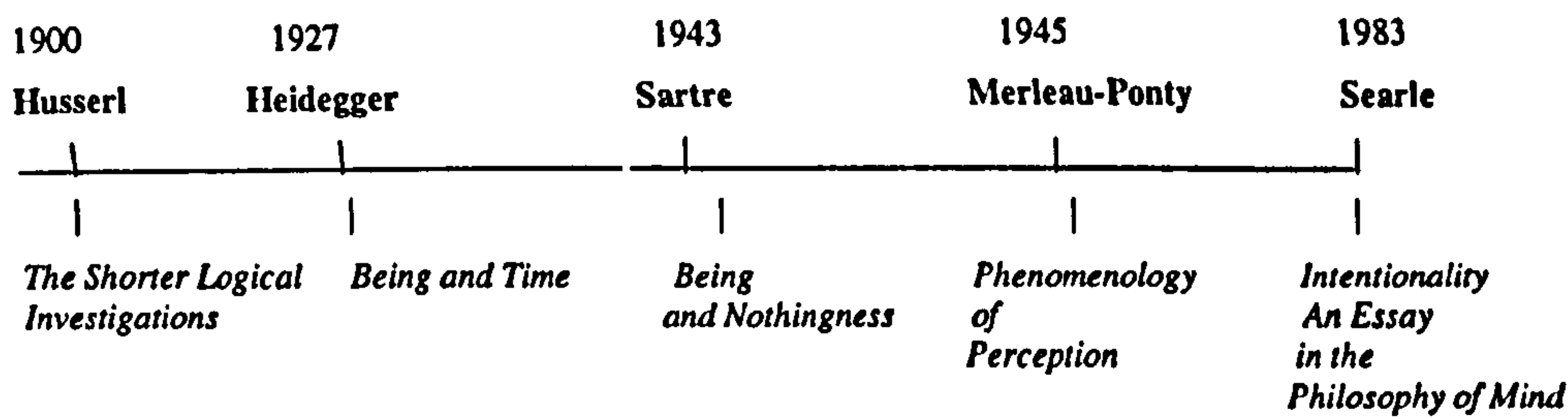


Fig. 4 Timeline of key phenomenological philosophers.

Husserl

‘Every epistemological investigation that we carry out must have its pure foundations in phenomenology’
(Husserl, 2001, p. 97).

Edmund Husserl inaugurated the movement of phenomenology and sought to set out a science of pure consciousness. He first devised a method of reduction as a way of isolating the essential features of phenomena. These are things as they appear in our experience, or the way we experience the things we encounter. Our experience is directed towards or intends, things through particular concepts like thought, ideas and image, as distinct from the things they mean. This included the range of experience, from perception, imagination, and memory to embodied action and social activity.

Professor of Philosophy Dermot Moran describes the way Husserl conceived this as a model whereby we might be able to detach ourselves from conventional opinion by dislocating or excluding ourselves from our normal positing of the world and discounting our affirmation of existence of something. He saw reduction as a means of accessing a new realm. By suspending judgement and avoiding assumptions and central to his concept, Husserl felt we could begin to know what it means to perceive something. In reality, total reduction is not possible, but this description comes close to capturing the experience of the activity of delineation.

Some things can be conceived of and experienced as whole and others only in parts. These can be objects, for example body parts, as opposed to the body whole. Other phenomena cannot be experienced as a whole but only in parts, i.e., stages of preparation, processes and anything else experienced in sections over a sustained period of time,

'pieces of pieces of a whole are themselves pieces of the whole'

(Husserl, p. 179).

The aggregate of these individual parts makes another kind of experience, a total and full experience and this one is, I would suggest, the general essence of the interpretation of the experience described by Husserl.

Husserl saw the experience as being made up of a collection of experiences.

'By the real phenomenological content of an act we mean the sum total of its concrete or abstract parts, in other words, the sum total of the partial experiences that really constitute it'

(Husserl, p. 229).

Husserl's phenomenology is attributed to different forms of experience as we experience them. Characterizing experiences of seeing, hearing and feeling etc. embodied within actions of walking and talking etc using phenomenological analysis featuring ways,

'we ourselves would experience that form of conscious activity. And the leading property of our familiar types of experience is their intentionality, their being a consciousness of or about something experienced or presented or engaged in a certain way. How I see or conceptualize or understand the object I am dealing with defines the meaning of that object on my current experience. Thus, phenomenology features a study of meaning in a wide sense that includes more than what is expressed in language'

(Smith, 2003).

This could also be a description of delineation as a phenomenological activity.

Husserl's logic involved 'intentionality' that is the directedness of experience toward things in the world. 'I' indicates the nature of the experience and the intentionality proceeds from the subject. We *experience* conscious experiences, live through and participate in them being experienced rather than just observe them. We are aware of the experiences.

An intentional object is there to be noticed and is not always experienced just by looking at it because it is there to be looked at. Each time the object is observed, from a different side or angle for example, it *'yields a new 'content of consciousness'* (Husserl, p. 221).

In his interpretation, there is no reference at all to the causality; only phenomenological description and he denied reality of the world beyond the reality of the experience. For him only the descriptive content of the isolated experience was crucial and that,

'What things are causally connected with such an experience, what psychological consequences may follow from it, all this does not concern us. Such things concern the psychology of abstraction, not its phenomenology...What is of interest to epistemology, must be shown up exclusively in the content of the meaning-

experiences and the fulfilment-experiences themselves'

(Husserl, pp. 148-9).

Husserl claimed that experiences of phenomena could not be presented by depicting them at all because the representations would only show the *object as object*. He referred to this as '*The erroneous image-theory*' (Husserl, p. 239). This is because he saw the image made as trying to stand in for consciousness. He reasoned that as a representation cannot be anything other than a representation and the object cannot be a representation of itself, the depiction has failed to go beyond the conscious experience.

For Husserl, phenomenological experience was epistemological. He describes it as transcendental phenomenology concerned with essences and not realism. By his definition the object could not be experienced in any way and this 'living through' was connected to the subject of experience alone, not reality. He believed the experience could somehow be completely disconnected from the object and set apart as a new and unknown event. This form of total reduction is not possible, as we cannot come to un-know something.

The Philosopher John R. Searle offers us an approach which integrates objects with experiences in contradiction to Husserl's ideas of pure essences. He sees Intentionality as directedness that is not the same as consciousness. We *have* a visual experience

Of the object

But don't *see* the visual experience (Searle, 1983, p. 38).

He claims these experiences have intentionality as the experience is directed *at* or *of* the object. He sees three components to visual perception working here; the perceiver, the visual experience and the scene perceived. But he also points out that the object perceived causes that visual experience. There is a relationship between them and it is both intentional and causal.

This contrasts with the ideas developed by Roger Scruton Research Professor at the Institute for the Psychological Sciences in Arlington, Virginia who defines an intentional action as one that is subjective e.g. a

painting can exist even if the subject of that painting does not. A causal action is caused by existence of an object. It is automatically formed without creative intervention from a person. It is real (Scruton, 1989). However, in this research it can be seen that delineation is both intentional and causal.

Delineation in this inquiry is a phenomenological methodology used to investigate the specific rather than the general. As a feature of the system involves the accurate portrayal of observed phenomena, it is therefore concerned with the causal as well as intentional effects and meaning of visual experience.

Heidegger

'Intentionality designates a relation of the subject to the object'
(Heidegger, 1982, p. 62).

Martin Heidegger, saw that a depiction made, shaped of that experience meant,

'that both concepts are understood by reference to the process of shaping, forming, producing. The order and connection of these two concepts is established by the performance of the process of forming and shaping and the necessary precedence in that process of the look of what is to be formed'
(Heidegger, p. 107).

For Heidegger, phenomenology was ontological rather than epistemological and he asserted clearly *'that being is the proper and sole theme of philosophy'* rather than knowledge (Heidegger, p. 11). Unlike the generalized essences of Husserl, Heidegger looked to the specifics of the understanding of being.

In *Being and Time* 1927, Heidegger argued that we should interpret our activities by looking at our contextual relations to things in the world around us.

'By contrast, Heidegger held that our more basic ways of relating to things are in practical activities like hammering, where the phenomenological reveals our situation in a context of equipment and in being-with-others'
(Smith, 2003).

So Heidegger's focus on what something *is* may seem to be more in line with the subject of the experience I am describing. Applying delineation as a methodology with which to understand these encounters would be more in keeping with Heidegger's concept of experiencing what something is through tools and the process of doing. However, by focusing solely on the tool or instrument he neglects to consider the body and its relevance in the process.

Merleau-Ponty

'We need to reawaken our experience of the world as it appears to us in so far as we are in the world through our body, and in so far as we perceive the world with our body'
(Merleau-Ponty, 1992, p. 206).

Maurice Merleau-Ponty wrote *Phenomenology of Perception* in 1945 and unlike Husserl and Heidegger incorporated experimental psychology. He analyzed reported experiences of amputees who felt phantom limbs. These were very real experiences for the patients. He focused on the 'body image', our experience of our own body and its significance to our activities. The body in this instance can be seen as me, engaged in action with things that I perceive.

Unlike Heidegger, Merleau-Ponty extended his phenomenological philosophy to include understanding of the world by taking into account the body holding the tool, not just the tool.

'The blind man's stick has ceased to be an object for him, and is no longer perceived as for itself; its point has become an area of sensitivity, extending the scope and active radius of touch, and providing a parallel to sight'
(Merleau-Ponty, 1992, p. 143).

This description has similarities with a pencil in the artist's hand acting as a tool for delineation, yet also an extension of their body experiencing the medium of drawing. Through it the perception of the observed world is presented directly for others to see. Where the pencil touches the paper's surface, the object being observed is visually understood. We understand it through its functionality and the world becomes understood through the tool and the tool understood through its use and application.

The nearest we can come to phenomenological reduction, is to view something in a new way. Whilst the total reduction of Husserl can be seen to be impossible, Merleau-Ponty saw phenomenology as a way to unite subjectivism and objectivism. This 'standing back' allowed the world to be viewed more clearly. Merleau-Ponty could not see how human beings could separate themselves from the world but did feel we might somehow return to the pre-conceptual experience of the child and re-discover the world this way.

Rather than *essences* as described by Husserl, he analysed *qualities* of an object like its smell, appearance, colour and texture. He understood that different surroundings, time of day and progression produced changes that could be so different as to make it seem like seeing a new object and encountering a whole new experience. For example he described looking at a landscape upside down and being unable to recognize anything familiar (Merleau-Ponty, p. 46). He felt it was impossible to forget experience which was always felt through the body as '*The body is the vehicle of being in the world*' (Merleau-Ponty, p. 82). This new view, offered a new experience of the object in question.

Sartre

Like Husserl and Heidegger, Jean-Paul Sartre's phenomenology was dependent on the assumption of intentionality, i.e. all consciousness is consciousness *of* something. His approach questions some of the assumptions in this research.

Initially Sartre saw phenomenology as Husserl did, as a science, but he rejected the idea of reduction. Sartre came to see it as a form of existential anthropology focusing on the human condition within the context of a

world of social and political struggle. Unlike Heidegger's 'Being' he offered 'modes of being'. These were neglected areas of reflection like anxiety and vertigo that allowed the experiencing of existence itself. Sartre felt life had meaning by living it.

Vital to his interpretation was considering existence in terms of freedom of choice from conventional rules and he used his talent in creative writing to be as descriptive as possible when he wrote *Being and Nothingness* in 1943. In his opinion there was no such thing as human nature, man just is; so no one chooses to be anti-social or cruel, it is just how we are in the context of society and circumstance. He also formulated the theory that rather than phenomenology being dependent on perception as Husserl had stated, the imagined was more significant. Imaginary, descriptive consciousness and what is *probable* rather than what *is* were more important than what has been perceived. This was central and reliant on Sartre's theory that freedom offers choice thereby allowing things to be experienced, as they are *not*. What we *think* an object will feel like makes an object *as* present as it actually existing in reality.

Sartre claimed that image could *never* be a source of knowledge and we cannot learn from it. Imagination also offers no knowledge and a drawing only presents an object to us as absent. Descartes, a philosopher whose theories influenced Sartre, saw drawings as being nothing more than a collection of lines and squiggles. Instead of presenting the object Sartre saw it in terms of lines and shapes that you *imagine* look like a recognizable object.

Arguably he failed to consider that these lines and marks *are* translated and tacitly understood simultaneously as being both what we know to mean by 'drawing' and are part of how a drawing functions.

Sartre agreed with Husserl that a phenomenon could not be depicted as a visual representation. He dismissed pictorial images as merely relational outcomes of the imagined object. Sartre saw, '*An image is nothing else than a relationship*' (Moran, 2004, p. 381).

Sartre was correct to recognize this relationship but I suggest it has great relevance that he has not acknowledged. Any occasion when time is spent describing an object whether in words or by the action of drawing, equates to the formation of a relationship. As Searle mentioned previously (Chap. 2, p. 47), there is a bond between the object caused by an observer, the object, the visual experience caused by the object and the perceiver. This research demonstrates how this connection continues as the visual experience is presented firstly to the delineator perceiving the object and then later to an audience via the process of delineation.

Delineation presents visual experience concurrently with evidence of the process of its own making. The drawing acts as a way of presenting visual experience and leads us back to the object itself and the particular fugitive collection of moments in which it was experienced. Understanding brought about by the action of drawing and the relationship between object and delineator, and between delineation and observer is formed by this phenomenological activity.

Where Sartre saw states of being like nausea or anxiety as ways of having immediate access to a phenomenon and to describe it without intermediary, I see delineation as providing a direct, immediate relationship that presents the visual experience of a phenomenon.

Summary of interpretations of phenomenology

Husserl saw phenomenology as a way to describe a pure experience. Using reduction as a way to have a pure unmediated first encounter he sought to explain the experience as isolated from the object. His interpretation was only interested in the meaning of the content of the experience and essence as a generality and did not acknowledge the object as really existing. It centred on the intentional as things experienced were 'lived through'. He felt images could not replace the experience as they used representation. His definition of phenomenology was epistemological and intended to further knowledge.

Heidegger's definition of phenomenology focused on the ontological question of being, understanding what it *is* instead of what it *means*. Rather than the generality of Husserl's description, Heidegger focused on

specificity. He saw phenomenological reduction as impossible and a negative methodology. Like Sartre his version was existential as it was concerned with phenomenological description of man's place in the world. He highlighted different possibilities of understanding and claimed an experience of a phenomenon could be experienced through the tools of its making.

Merleau-Ponty saw the body as the vehicle through which we experience being in the world. His phenomenology made use of psychological analysis and consisted of experience being understood via a continuous synthesis of immediate moments (Merleau-Ponty, p. 70). He examined the particularities of an object's qualities as being the properties that made up the experience. He argued that art, rather than attempting to produce a representation of the world, provided evidence of the connection between body and world and consciousness and object. He saw the image as able to *present* rather than *represent* the experience.

Sartre's descriptive explanation of phenomenology was a form of existential anthropology that was dependent upon the notion of being free from every day constraints and relied upon the imagination as consciousness broken free. Influenced by the ontological stance taken by Heidegger, he saw modes of being as a way of accessing phenomena.

Phenomenology describes experience from a first-person position unlike the third person approach of scientific research. John Searle has criticized some versions of phenomenology where the actual material object has become lost and only replaced by 'private sense data'. He also criticised its failure to,

'realize that the material object can only be the object of visual perception because the perception has an Intentional content, and the vehicle of the Intentional content is a visual experience'

(Searle, p. 61).

This is something denied by Husserl. Searle has defended certain other properties of phenomenological inquiry, and the vital awareness it brings

to the role of experiences. His belief that scientific data that excludes subjective data is incomplete is a justification for this inquiry.

'The characteristic philosophical mistake in the case of visual experience has been to suppose that the predicates which specify the conditions of satisfaction of the visual experience are literally true of the experience itself'
(Searle, p. 43).

A delineation that presents the experience cannot, of course replace or exactly copy or *be* the experience, but it can offer a way of understanding the encounter. It is important to note that a delineation need not be perceived in the terms set out by Husserl, Sartre etc. but as a form of deliberate phenomenological communication.

Interpretation of truth

The first person position taken by phenomenology leads some to be unsure of its value and use in research as it is a subjective and descriptive form of interpretation based on experience and not just observation. The worth of data that has been gathered and analyzed using these methods rather than more objective, quantitative methods may be thought of as less useful. Embedded within the public consciousness is the idea that science is equated with truth. We believe something because we are told it has been scientifically proven. Science has outcomes, results are provided as proof in the form of visible evidence, facts that must be true because they are scientific.

To illustrate this, Lewis Wolpert, Professor of Biology as Applied to Medicine at University College London claims that science is based in reality, is always objective and is either right or wrong and never open to interpretation. He appears to deny that scientists have any imagination or ideas and he refutes medical predication, suppositions and sheer calculated guesses that have produced theories that have led to the most exciting scientific discoveries. He also dismisses the possibility of interpretation and any form of subjectivity in the medical sciences (Wolpert, 2002).

In a conversation on 28th May 2004 with Steve Gschmeissner, then at the EM unit at Cancer Research UK, he explained how most decisions he makes are based on his experience of judging at which point aesthetics meet visual information. Whilst the Scanning Electron Micrographs (SEMs) he makes have a vital role in making scientific facts visible, he is aware that he consciously chooses the most aesthetically pleasing images as examples of medical evidence. He also pointed out the important fact that the colours used in electron microscopy are false. They are created in Photoshop. Even the original real tissue samples are stained using chemicals, which are relevant diagnostically but alter in hue and intensity dependent on individual histopathologist's taste.

As further evidence to support this argument, in an article from a health care journal, the *Bandolier Journal*, this precise issue is tackled. A test is described whereby, 8 leading pathologists were given 37 tissue slides to examine. One thought 21 were cases of malignant melanoma and 16 were benign while another thought of the same 37 slides, only 10 were malignant and 26 benign. In 11 cases one pathologist identified a case as malignant while the other identified the same case as benign. These discrepancies of opinion between experts observing identical medical information reveals a major problem called Inter-observer variability. In other words, the data from the material presented to them, is open to interpretation. All these variables lead one to wonder whether any raw data is pure and to what extent it has been subjected to the aesthetic controls of someone. In medicine, how information is gathered and which procedures are used are of vital importance to the patient ("Pathology as Art Appreciation", 1997).

However, my inquiry indicates that investigating an issue in a medical field from the perspective of a non medical discipline, can produce observations and interpretations that are both valid and useful and arguably may avoid some of the pitfalls described above. This development of delineation as a system takes account of reliability and replicability whilst acknowledging the subjective nature of first hand experience. Like other methods, it has a foundation in observation. Where it differs is in its concern with offering a unique and specific system with which to present understanding of encounters and make sense of them

directly and spontaneously, therefore making it interpretive, rather than the generalizing method preferred in science that aims to offer explanation. Merleau-Ponty and Heidegger both believed science created models that it then manipulated, '*science makes everything appear as an object in general*' (Moran, p. 400).

'Nothing is more difficult than to know precisely what we see'

(Merleau-Ponty, p. 58).

It is human nature to try to interpret and understand the encounters we have with the world around us. Delineating visual experiences of phenomena is an attempt to achieve this.

There are different experiences of phenomena, psychological, emotional, imaginary etc. This research focuses on *visual* experiences, of seeing the object with the intention of delineating it, of coming to understand it through the process of delineation and present knowledge of it to those who see the delineation. In this inquiry the act of delineating can be seen to form connections in the space between the object and the subject where each encounter is experienced both through the process of making and by the conscious experience of each unique event as it occurs through time. When looking with the purpose of drawing, a different experience is achieved and this phenomenological activity is mediated through the physical act of delineating. This is a non-verbal alternative to articulating the experience. The connection with experience is an affirmation of the actual presence of, or acknowledgement of the phenomenon in visual terms. Whilst a phenomenological analysis of an experience can be discussed as a theory, this investigation aims to show that the act of delineation can make this analysis actual. As the encounter with a phenomenon is experienced as a relationship, delineation demonstrates how the experience of a relationship occurs.

A delineation presents the object and visual experience of the object simultaneously, and this visual experience does not remain static, it is not a snapshot. There is an ongoing interchange between the world and ourselves. A delineation is made over a period of time and encompasses each of these experiences of looking, and each of us has a different

experience of looking, unique to ourselves. This in itself will change over a course of time. It becomes your visual memory of that encounter, memory manifested. Even something familiar, when scrutinized by looking at it intensely with the purpose of rendering it, becomes re-seen, almost newly seen and is differently understood.

By its nature, any encounter with a phenomenon is a singular experience and unique in that instance. It is also part of a continuous series of unique, fugitive encounters that roll together as one accrued encounter experienced over a period of time; like each individual static frame of a film reel where every moment is captured and each image is unique. Placed together, twenty-four of these frames, each one slightly different from the next, become perceived as a second of movement.

Husserl presupposed that an image made would be of one singular experience with an object, in the same way a sentence once spoken, once heard, once experienced then becomes a past event. In his opinion the depiction,

'can throw no light on the essence of the representative relation to the object, to the original, which is external to itself'

(Husserl, p. 239).

When delineating, the time factor has to be taken into account, both the extension of the actual time encountering the event, and as a part of the ongoing moments spent experiencing the phenomena. Therefore every part of each encounter is unique but also as an ongoing experience in the process of making, it includes the imagined, and remembered phenomena. This thesis challenges Husserl's position that 'Mere' presentation was an act of 'Mere' imagination. I propose that these collections of experiences should not be overlooked because the immediacy of a current experience becomes combined with other previous encounters with the same object.

Delineation as phenomenological activity

The *activity* of making is crucial within this inquiry. The experience of the object becomes a part of the experience of depicting that encounter and therefore part of the whole experience. The significance of process in this

context is one that has been largely overlooked. It goes beyond acknowledging the object's presence and becomes part of the experience of 'living it'. The process of looking connects the thing experienced and the person experiencing. A delineation is overt in laying bare the experience of its own making as marks are inscribed, removed and smudged. There are fingerprints and grooves on the page, scratch marks, layers of line and various weights of mark. The transparency of its making allows it to be tacitly recognized as drawing.

Whilst resemblance between object and drawing is not a phenomenological analysis of the experience I would argue that delineation is a phenomenological activity that does fulfil that role. When looking at pathological specimens, there are a number of things being observed: pain, deformity, bone, connective tissue, or swirls, twists and curlicues. I have visual experiences of an object both as fragmented and as a whole. I also experience objects as new and unknown things whilst simultaneously comparing them with something more familiar. As I can only present these encounters from the delimited confines of experiencing the world from inside my body, I can only present these continuous and fugitive visual experiences subjectively. During the activity of portraying these encounters, I become conscious of other qualities I perceive within the objects and the visual experiences I have of them. I experience the process, marks, smudges, scribbles and indentations on the pages. I experience the smell of the wood and graphite from my pencil, the pencil shavings, putty from my rubber and the wood pulp from the paper. These are cumulative experiences.

Delineation in this thesis is a system with which to interrogate the world around us in an intense and sustained manner. There is no prior knowledge of how this relationship will be, even if there is prior knowledge of the object to be experienced. Information and experience, accrued through the duration of this adds to the whole experience.

As Husserl asserted previously, delineation cannot stand in for consciousness. Whilst each experience is particular to that moment, it is not unrelated to any other. They are not isolated encounters and though each is different, the former informs the proceeding. In my opinion

Husserl was right in realizing the connectedness of experiences. These fugitive encounters are interlinked. In the sense of representing meaning the use of symbol, allegory or allusion to portray an object, I have not attempted to try and *represent* the visual experience, an objective that caused Husserl to refute the possibility of image making having any bearing upon furthering understanding of experience. Instead, as Merleau-Ponty suggested, I have used delineation as a way to *present* the visual experience and the object encountered.

Delineation presents the relationship between observer and thing observed and is intentional as the experience is directed at or of an object yet is causal as it exists and is a real and factual presentation of real experiences that are brought about by the existence of actual objects, directly observed. Heidegger's notion of experiencing through looking, and the process of looking for the purpose of drawing is one which goes beyond everyday seeing and is specific to the action of delineating. The act of drawing brings understanding of an object and the relationship between the delineator and the image is presented through the activity of making.

Conclusion

In this thesis I have defined delineation as a phenomenological activity that can both present the object and the action of rendering the visual experience. The activity is dependent on the presence of an object and knowledge is presented both through the process of coming to know something by drawing it and in the way this knowledge has been shown.

Experience is made up of a series of cumulative unique fugitive moments interconnected through time and this is demonstrated in the activity used to present the visual experience of encountering the phenomenon. An object and the visual experience of a phenomenon come to be understood through the experience of looking with the intention of delineating. The resulting marks made by the tools remain visible and acknowledge the presence of the delineator.

Having defined the framework for delineation I will now describe pathology and demonstrate other examples of visualizing disease in the next chapter.

CHAPTER THREE

Historical survey of pathology and medical illustration

The setting of this thesis is the disease Fibrodysplasia Ossificans Progressiva (FOP). As this work draws on knowledge of disease, anatomy and pathology, this chapter will start with an overview of these areas, including the history of pathology and anatomy.

Within this the specific role of microscopy and histology are explained as they play a significant part in the research. Alternative methods of depicting disease such as the use of caricature by Gillray and Cruikshank and painting by Géricault and Grünewald are discussed.

My delineation work has some relationship with medical illustration but it is important to clarify the differences so this chapter examines medical illustration including Leonardo da Vinci’s methods, the significance of Max Brödel and rivalry between collaborators. The chapter concludes that delineation is different from medical illustration because it does not make use of composites and is focused on specificity.

Introduction

The earliest developments in medical science were focused on anatomy, with pathology succeeding it, coming to the fore in the 18th Century (Fig. 5).

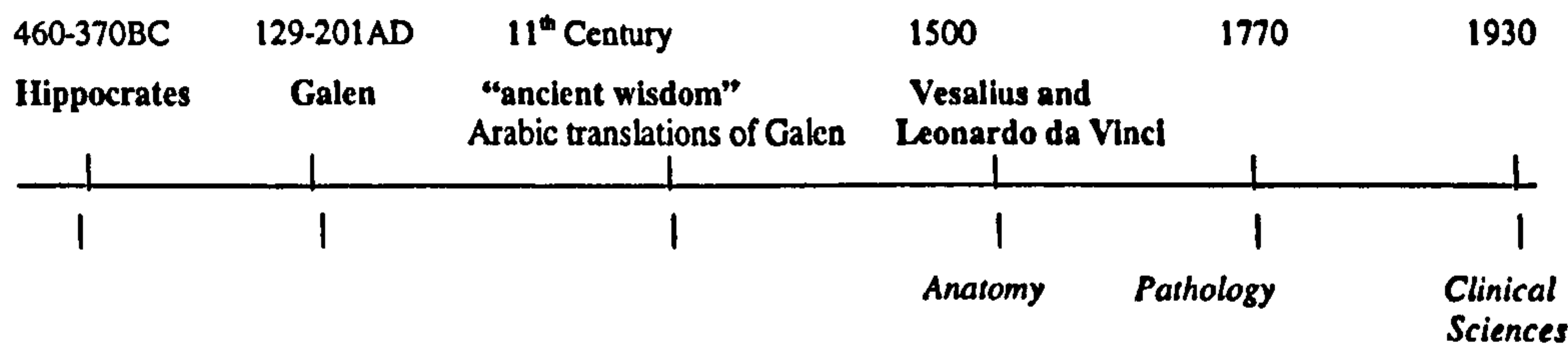


Fig.5 Key names in history of medicine.

Anatomy is related to structure and physiology relates to function. Dissections are performed in specific rooms, i.e. the DR or *Dissection Room*. Actual instruments needed to perform the task are specialist but few. Anatomy is seen with the unaided eye and does not require technology to reveal it. It is primarily interested in seeing how the body

works and naming these systems. It is represented by the image of the ideal body, a perfect example.

Imhotep was the founder of Egyptian medicine around 2600 B.C. The doctors and physicians of ancient Egypt had some understanding of anatomy and were aware of the importance of the rate of heartbeat in relation to a patient's health. Hippocrates, a Greek physician (460-370BC) is hailed as being the father of medicine. He realized the importance of observation of symptoms as the way to establish diagnosis. This became what we know today as clinical observation. He believed that all diseases stemmed from natural causes rather than from supernatural ones. Over a period of about 600 years, medicine developed as a "scientific" art. Claudius Galen (129-201AD) was also Greek and revived Hippocrates theories when he went to work in Rome. He predominantly dissected animals and due to his methods of working, insisted animals and humans shared the same anatomical make up. His work was greatly respected in the Middle East as well as in Greece and Rome and his writings were translated into Arabic.

During the Middle Ages Galen's writings were accepted as "ancient wisdom" and his findings were not altered or improved upon. Human dissection was considered unacceptable and unnecessary as Galen's observations were still viewed as being the canon of knowledge regarding anatomy. In the 9th Century monks established the first European medical school in Salerno, in southern Italy. By the 11th Century scholars there began translating Arabic medical texts into Greek and Latin. They reintroduced the theories of Hippocrates and Galen via Islamic scholarship.

Pope Boniface VIII issued the Bull De Sepulturis issued in 1300, which effectively outlawed dissection. Colleges were permitted to dissect one body a year, but in fact many more dissections were performed surreptitiously and the first recorded dissection was conducted by Mondino de' Luzzi (1275-1326) at Bologna in 1315. Rather than learn from it, he used it to instead perpetuate the teachings of Galen, including all his inaccuracies.

Artists were among the first to practice the discipline and it could be said that dissection developed from art. Donatello (Donato di Niccolò di Betto Bardi (1386-1466) was the first to begin a scientific study of the body but Leonardo da Vinci (1452-1519) is the most well documented artist associated with anatomy and dissection. He used drawing not just to record, but also as a way of gathering evidence, and thinking through his ideas and theories.

'Yet, it remains one of the most astonishing phenomena in the history of medicine that not until 1538 was an anatomical object as accessible as the bones of the human body drawn "correctly"- that is, from nature- in medical literature, although medical illustration had long been technically capable of doing this. What is more, there is no better proof for the theory that naturalistic medical illustration – medical illustration in the sense of scientific documentation – was not needed before 1500, than the total non existence of naturalistic skeleton figures even at the end of the 15th century. The causes lie in medical history and not in the history of graphic art. Like its sister sciences of geography and botany, medicine long relied on a traditional body of illustrations, which perpetuated as a kind of secret doctrine for several centuries after the style of secular illustrations had turned in new directions' (Herrlinger, 1970, p. 42-43).

In 1502, Gabriele Zerbi (1445-1505) was the first artist/anatomist to write a modern thesis on human anatomy. In his book *Liber Anatomicae Corporis Humani et Singulorum Memborum Illius*, organs are collected into systems for the first time forming the foundation of modern medicine.

Andreas Vesalius was appointed professor of surgery at Padua in 1537. While visiting Bologna in 1541, he discovered that Galen's research was not based on human anatomy but informed by the dissection of animals, primarily Barbary Apes. Despite some opposition, Vesalius went on to correct this oversight. He helped to advance understanding of structure through dissection and, like Leonardo da Vinci, also employed a scientific

method with which to study the body. His work helped to dispel misunderstanding of human anatomy and therefore improved diagnosis.

He published *De Human: Corporis Fabrica* in 1543 in which the artist Stephen Calcar, a pupil of Titians, expressed Vesalius' knowledge and findings through drawings. Both he and Leonardo da Vinci made significant discoveries that have contributed to the accurate knowledge of human anatomy.

By the 18th Century medicine had become a respected science but surgery was not established in the same way and was regarded as a craft. It was surgeons who performed anatomical dissections. René Croissant de Garengot (1688-1759) codified specialized hand movements and finger applications in 1720s. He taught students how to use their hands based on his own actual experiences. He distinguished medicine from surgery. The art historian Barbara M. Stafford describes how the divide

'between the "practical" visual and the "theoretical" textual became, during the course of the eighteenth century, an untraversable abyss' (Stafford, 1991, p. 53).

The developments made in anatomy are also those that are vital to the field of pathology. These are, the evolution of preservation techniques and methods of preparation and fixation.

Anatomy remains historically rooted in its ancient traditions and has tended to develop mainly in artistic and creative terms, as there is no need to improve or radically change the way in which dissections are performed. It is in the field of pathology, which is driven by ongoing technological advancements and development in medical imaging, that new discoveries are made and progress occurs, and continues to do so.

It was not until Günther von Hagens perfected a technique to preserve bodies or body parts by replacing water and fat with a type of plastic, called plastination in the 1990s that methods of preservation and fixing radically altered. While van Hagens' own work was extremely populist and commercial and is regarded with suspicion by some scientists, his

technical methods have proved useful to the development of medical museum display and the preservation techniques of prosection.

Definitions of pathology

Anatomy developed from *dissection*, which is a way of investigating how the body works, and of mapping and naming organs and systems. Its purpose is to understand what these do and how they relate to each other. *Autopsy* emerged from anatomy and depended on the knowledge that had been developed by anatomists over 300 years. Its purpose is diagnostic. Dr. William Crawford, a pathologist from the University of Southern California School of Dentistry explains that pathology is the study of disease. *Path* means disease and *ology* means the study of. Disease literally means lack of ease, i.e. the study of abnormal structures (Crawford, 2004). Pathology has so many stages to its process; it cannot be performed in one specified location and employs the use of many pieces of equipment, tools and chemicals to make it visible. The process of autopsy studies the body to ask why something has changed. Disease *pathologizes* the anatomized body.

Clinical pathologist William Derek Foster writes that,

'The primary object of the clinical pathologist's work is to assist the clinician in diagnosis, during the patient's life if possible, but if not, retrospectively, after death'

(Foster, 1961, p. xi).

An account of another clear definition of pathology is described in a paper given in 1981 by Dr. Edward Mormon, a medical historian. He said that:

'Pathologists are doctors who do seek opportunities to perform autopsies, but are equally anxious to examine tumours, or blood samples, and to search for microscopic pathogens. Their workplace has to be converted from a morgue and museum into a laboratory which communicates directly with the ward or operating room'

(Letts & Jacques, 1981, para, 29).

Initially pathology was known as morbid anatomy. The earliest autopsies recorded were not ascribed to doctors seeking knowledge, but lawyers

seeking justice. When a nobleman died in suspicious circumstances in 1302, a court ordered an autopsy to discover the cause of death.

Florentine physician Antonio Benivieni (1443-1502) was a contemporary of Leonardo da Vinci. He performed what can be seen as the first ever autopsy where anatomic dissection was used to determine a cause of death for medical purpose. Autopsy has developed as a direct consequence of the discoveries made through the practice of dissection in the field of anatomy. He also brought about the first protocols for medical ethics, seeking out permission and ensuring accurate recordings in his book *The Hidden Causes of Disease* published in 1507. He could be seen as the first pathologist but the term pathology was not introduced until the Renaissance when the French physician Jean Fernel (1497-1558) divided medicine into three parts, Physiology, Pathology and Therapeutics. As their study was taken from information formulated from the dissection of human cadavers, they were known as anatomic pathologists, or morbid anatomists. Morbid anatomy is the oldest branch of pathology.

Like Andreas Vesalius, Giovanni Battista Morgagni (1682-1771) taught anatomy at the University of Padua and compiled clinical observations in a series of case studies. He formed the principle used today of correlating the patient's symptoms with the findings of the autopsy. These he published in *De Sedibus et Causis Morborum per anatoman indagatis* in 1761.

Development of depicting and presenting specimens progressed when in 1775 Felice Fontana (1730-1805) produced incredibly life like multi layered wax anatomical figures for display at Florence's Museum of Physics and Natural History, to great acclaim.

John Hunter (1728-1793) became one of the most influential surgeons and organized a museum of anatomical and pathological specimens in 1791, The Hunterian. His nephew, Matthew Baillie (1761-1823) based his handbook of anatomic pathology, *The Morbid Anatomy of Some of the Most Important Parts of the Human Body*, on these specimens.

By the late 1770's, pathology was finally established as a scientific discipline. French anatomist Marie Francois Xavier Bichat (1771-1802) revolutionised the study of pathology in two ways, by using visual observation assisted by a hand lens he was the first scientist studying disease to classify, subdivide and develop the idea of tissues rather than organs as units of function and disease. He also greatly aided those working in the field by furthering the development of tissue fixation.

The pathologist Rudolf Virchow (1821-1905) made very detailed descriptions of dissections, but lost the sense of relationships between systems through the separation and removal of organs at an early stage of the process. The importance of descriptive pathology in overcoming this problem was made clear by Carl Rokitansky, Bohemian physician and pathologist (1804-1876) who performed over 20,000 autopsies throughout his career. He examined organs in situ and made detailed notes. The process of removing organs en bloc prior to dissection, developed by German pathologist Friedrich Albert von Zenker, also allowed a more holistic view (Foster, 1961).

Development of pathology has been affected by three key elements: the development of dissection of the human body, the use of the microscope and the introduction of chemistry and biochemistry.

The next major development was the introduction of the microscope and histological techniques providing the most important tool for modern pathology leading to new methods of examining organs. Hans and Zacharias Janssen probably developed the first microscope between 1590 and 1610. Further developments were made by Robert Hooke (1635-1703) and Antony van Leeuwenhoek (1632-1723) which meant that for the first time, more information could be revealed in tissue samples than were visible to the unaided eye. This led to pathology becoming a discipline in its own right, no longer beholden to the confines of the field of anatomy and dissection.

Hooke published his illustrations depicting the capabilities of his compound lens microscope in *Micrographia* in 1667 and Leeuwenhoek used his simple single lens microscope to become the first person to see

bacteria, spermatozoa, protozoa and blood corpuscles in 1673. By 1692, however, Hooke said that the microscope had little more serious use.

It was not until 1829 when Joseph Jackson Lister made improvements by combining lenses, that its huge importance was realised. By 1835 Guy's Hospital had a Microscopy Department. The instrument was in general use by all pathologists and it was mainly used to make the distinction between malignant and benign tumours. This field of pathology was referred to as morbid histology.

But it was Rudolf Virchow the 'father of pathology' (1821-1905) who really showed the extent of the capabilities of the microscope through his application of it as an essential tool with which to study disease. One of the impacts of Virchow's use of the microscope was that it led him to describe the cell as basic to all normal and abnormal biological functions. He summed this up in the statement "Omnis cellula e cellulae." He compiled his detailed observations of the conditions he was now able to identify in his book *Cellularpathologie* published in 1858. The knowledge he gathered from information about disease revealed at the microscopic level led to the development of biopsy procedures. Along with advancements to the microscope, which were made mainly through improvements made to lenses and with the addition of a staging table, other developments were ensured.

Clinical microscopy deals with bodily fluids and excretions of the living patient rather than tissue from biopsy or post mortem. It developed directly as a result of the advancements made in microscopes and is concerned with the study of blood, urine, sputum, skin, vomit, faeces and tumours. From the light microscope has come the electron microscope and with it the ability to see disease at a molecular level.

Histology

What the microscope did was magnify what was seen. The development and use of histological techniques and staining, allowed for the interpretation of this information.

Robert Hooke like other scientists of the time, examined sections of tissue by slicing them with a razor into very thin slithers. Around the 1840s histopathologists, the doctors who examine biopsies and larger pieces of tissue to aid in the diagnosis, realized they needed to harden the slices so used preservatives used in museum specimens. Tissue samples must first be chemically preserved and then embedded in a supporting material to allow them to be sliced very thinly. There are two ways of suspending a tissue sample so it can be sliced into sections. One is through freezing and the other by embedding it in wax.

The first person to successfully freeze a tissue sample was Pieter de Riemer (1760-1831) and in 1869, Edwin Klebs introduced the first method of paraffin embedding. Wax embedding was perfected in the early 20th Century. Microtomes were invented around 1770 though many still sliced samples by hand. By the 1880s however, freezing Microtomes became very popular. A Microtome works in a similar way as a bacon slicer and allows very thin, almost transparent sections of tissue to be sliced with a very sharp blade. I will explain the processes and equipment used in histology in more detail in Chapter 4 where I discuss a project which involves drawing histology.

The preservation, preparation and fixation of specimens are vital stages in histology. The next stage is staining. It is the process of staining tissue samples that is crucial to the way pathology is revealed and interpreted.

'The discovery that sections of organs could be stained by a variety of dyes and that the various tissues and structures of which the organ was composed did not take up all the dyes in the same way revolutionized histological technique'
(Foster, 1961, p. 19).

In 1847 the anatomist J. Gerlach Mainz discovered the secret to staining by accident. It was common practice at the time to inject the vascular system. Mainz noticed the carmine in the gelatine he used leaked out and stained the nuclei of cells around it. By 1865 Haematoxylin was established as a dye and Eosin in 1876 as a routine technique used as standard today (Edwards & Edwards, 1959).

Most significant in histological staining was German scientist Paul Ehrlich who in 1878 wrote in his paper, on the theory and practice of histological staining in which he tried to show,

*'the relationship between chemical structure and affinity
for tissues'*

(Foster, 1961, p. 21).

I have demonstrated the importance of the microscope and techniques used in histology to the development of pathology. Now I will describe where, how and for whom pathological specimens are revealed.

Depictions of anatomy and pathology

There are great differences in the way depictions are used in anatomy and pathology. In images of anatomized bodies, figures are seen as 'alive', walking around in landscapes, or as being aware of their situations whilst revealing the muscle tissue under their skin. They are imaginative. Books often incorporated visual techniques such as flaps, pullouts and overlays as ways of adding visual explanation. The layers of artwork reflected the layers of tissue and muscle. Drawing methods and techniques incorporated include cross-section, topographical relations, rotating views, transparency, exploded views, and views as if flattened out like a map of the world. By contrast the artist and tutor in drawing at Ruskin College, University of Oxford, Sarah Simblet describes how,

*'Pathological specimens are normally presented as dead
and disconnected from the whole body. They are either
preserved or illustrated plainly, as part of a catalogue of
abnormality, disease, atrophy and malfunction...So, it is the
anatomical figure who is most free to carry on living'*
(Simblet, 1999, p. 54).

The method of dissection has an influence on the anatomical observations that can be made and recorded which in turn affects methods of dissection and so on. Tools with which to dissect the human body have changed little and observation still begins with the naked eye. Unlike anatomy, the discipline of pathology has progressed rapidly in line with the development of more advanced instruments and advances made in medical imaging and the evolution of chemicals used in histology.

Traditionally, anatomical knowledge is experienced by both investigators and learners in the dissection room. In contrast, diagnostic knowledge arising from pathology is not only experienced at first hand, but also, and significantly, through a variety of media, for example through lenses, photography and imaging techniques. Unlike anatomy, diagnoses while still depending on observation and experience, rely heavily on interpretation as demonstrated by problems of inter-observer variability (Chap. 2, p. 55).

Historically, both anatomical and pathological specimens were displayed in cabinets of curiosity, which evolved into medical museums. These came into existence thanks to developments made in the fields of fixation of tissue, including use of resin and injecting preserving fluids, methods of preparation, and the technique of making anatomical wax models out of which grew the art of plastination (Edwards & Edwards, 1959). Unlike the field of anatomy, there were very few depictions of pathology. The exception to this is in the area of teratology where the display of and depiction of monstrous births and birth defects was one of the most popularly investigated aspects of pathology.

The whole subject of display in both pathology and anatomy is directly related to progress made in the development of preservation techniques and methods of preparation and fixation. The question of where they are displayed is bound up with issues of intention, the implications of the context of the textbook and the gallery wall.

The influence artists have had on the nomenclature, classification and taxonomy of the body cannot be overemphasized but the original purpose of anatomy drawing was in its value as a mnemonic device. Within this context of providing instruction and knowledge, it is common for images to be simplified and abstract but I believe delineation can also be a valuable system for investigating medical phenomena.

Images of experience of disease

As a phenomenological activity, specifically applied to the subject of medicine, there are other successful solutions to presenting the phenomenon of disease besides delineation. In the 18th Century, during the age of Enlightenment, several illustrators came to public attention because of their depictions of the desire of this time, to further science, especially understanding of disease.

English artists James Gillray and George Cruikshank illustrated the experiences of disease using caricature. Through a combination of immediate observation, general perspective and allegory, they demonstrated the dehumanizing process of illness. Their work was brought together as part of *Ars medica*: a collection of medical prints by great artists of the past shown at The Philadelphia Museum of Art in 1955. In the Catalogue compiled by Carl Zigrosser, he describes their work as,

'presenting what might be called clinical reports by artists. They may not be scientific or professional in the medical sense, but they do manage to convey the "feel" of a malady from the victim's point of view. Added to these are several compositions somewhat further afield, more in the nature of fanciful personifications or pasquinades of medical import' (Zigrosser, 1955. p. i).

James Gillray was born in 1756. His depiction *The Gout* of 1799 shows a rendering of a swollen foot upon which a sharp taloned, miniature devil is feasting. Its fiery claws dig deep into the flesh as it gnaws mercilessly at the inflamed limb. The claws of the beast hook through and pull up the painful flesh and the pitiless points have pierced the skin, forcing their way through and out the other side. The demon has cruel teeth that bite and chew at the foot whilst the creature remains grinning. This really must be what gout feels like.

George Cruikshank was born in 1792. His 'pictorial allusions' went even further. *The Headache*, drawn in 1819, shows five little devils that have set about a pale, sickly looking man with great ferocity. Swinging axes and spears, one has already embedded an axe into the top of the poor man's skull whilst another turns a giant corkscrew until it begins to

emerge out of the other side of his head. This man has apparently collapsed in his seat and appears to have buckled from the pain being inflicted upon him. It is an image of such violence, it could be a representation of a migraine rather than a mere headache as the title suggests. It is an intense realization of a common but painful condition.

His depiction *The Colic* in 1835 portrays a woman whose pain is illustrated as being like a rope tied around her waist and pulled so tightly by evil and demonic beings as to physically contort her strictured form and cause her features to twist into a screaming face of agony. This horrific scene takes place in the domesticity of her own home. She is shown seated on her sofa, surrounded by resplendent and luxurious carpet and curtains. The understanding of pain has been accurately translated through the use of caricature, but the pictorial strategies do not make use of empirical observation alone and instead the experience has been presented as a visual encounter, using allegory and imagination.

*'The caricaturist has thus managed to bridge the gulf,
described by Diderot, separating the suffering "I see" from
the suffering "I feel"'*

(Stafford, 1991, p. 195).

It is a very successful approach that is very different from the objectives of delineation.

As part of this investigation, I found a selection of relevant examples of visual models used to portray illness and disease. Caricature has been shown to be an excellent model used in illustration. Another successful way of depicting the experience of disease is through painting.

Théodore Géricault's radically empirical portraits of the insane, painted between 1821 and 1824, were commissioned by Dr. Etienne-Jean Georget (1785-1828).

*'They captured, in a coldly diagnostic way, the fleeting
expressions of a nervous condition difficult to describe
verbally'*

(Stafford, 1991, p. 436).

Here, the use of paint presents the unique experience of each encounter with specific individuals and the manifestation of the affects of their mental illness using clinical observation. As patients could not always be present at medical lectures, students were instead shown these paintings in their place. They were intended to be as informative as if the actual sufferer were there and were regarded as being as beneficial as a visual teaching aid as first hand observation of a patient.

Informative and successful in their presentation of the phenomena of the sufferers' unique experiences, these images were made using paint and were not always completed in situ, but in Géricault's studio. Unlike delineation, the process of their creation is not as important as the final outcome. They are not direct presentations of experience as they continued to completion after the original source of observed datum, the patient, was removed.

Matthius Grünewald (1475-1528) painted the Isenheim Altarpiece between 1513-1515. I have compared both Carswell's delineation of a subcutaneous cancer (Fig. 1, p. 13) and the first delineation I made of a pathological specimen, which also is an example of cancer, (Chap. 2, p. 40) to this painting. It is a powerful image of pain that bears a very close resemblance to both images.

The painting was made specifically for the Hospital chapel of St Anthony's Monastery in Isenheim in Alsace. Using great observational skills, it is a depiction of Jesus, crucified on the cross, and is shocking and repellent. Rigor mortis has just set in, his injuries are recorded in detail and the weight of his body has pulled his arms almost out of their sockets. He is shown at night, a nocturnal crucifixion, which is very unusual.

Patients were brought before the painting so they could be shown and come to realize that Christ understood their suffering as he had suffered also. Even the fabric of his loincloth appears to be made from the same material as that used to make the linen bandages of the patients contemplating his gruesome portrayal. The most common ailment for patients in the hospital was ignis sacer poisoning. This was caused by eating cereal that had been affected by a fungus. The dreadful results of

this condition caused limbs to decay, which then led to the need for their amputation. The marks Christ has on his body mirror those of the disease.

The Isenheim Altarpiece has a purpose beyond the depiction of the crucifixion. The painting communicates the experience of suffering to those who are also suffering. It acts as the visual experience of a shared phenomenon. Its aims, unlike those of this project, are to teach religious and moral instruction.

Both these paintings, and the examples of caricature are very successful methods of presenting experiences of disease. They make use of symbols and imagination. However, they are not based on the visual experience of the observed phenomenon. The aim of delineation as a methodology is to record visual experience and present it as visual knowledge.

Other than in the form of caricature, during the age of Enlightenment, it was rare for disease to be the subject of art. This was because during the 18th Century it was expected that an artist would remove himself from the horrifying visions of deformity and malady that surrounded him in his pursuit of beauty. It was his duty. To create a statue of a beautiful woman meant using many women as models to create the ideal from the best parts of each woman and discard the rest. This describes the schism between illustration and delineation, which can also be seen in terms of the generic and the specific. At the same time, however, there was a profound desire to gain insight and know intimately both the visible and invisible body. Strategies for imaging the unseen were developed and society became increasingly visually dependent rather than text based.

I have examined architectural and archaeological drawing models in Chapter 1 and have shown in this chapter examples of paintings and caricatures that portray visual experiences of disease. I will now investigate the foremost group involved in depicting scientific data, the medical illustrators.

Medical illustration

'Medical artists may be distinguished from other illustrators by their ability to offer illustrative and practical skills combined with a comprehensive knowledge of medicine and science'

(Medical Artists' Association of Great Britain website).

'The aim of the medical illustrator is to reveal the truth and make it apprehensible through visual media, with the fidelity of the scientist and the imagination of the artist'

(The Association of Medical Illustrators, code of ethics, pp. 40-44).

Whilst studying anatomy, I found I began to simplify marks I made and started to develop a form of visual shorthand as I became more knowledgeable about what the body's systems should look like. Subconsciously, my drawings described the generic, i.e., I drew generalized characteristics of things, and composites of the many examples I had viewed. I only later realized that this is a standard method for medical illustrators to adopt in their practice.

Unlike the specificity of precise and accurate rendering which defines delineation, to illustrate something is to give comparison or example, to elucidate or decorate a story or textual information using a picture or diagram to make a subject more pleasing or easier to understand.³ An illustration may be in the form of a drawing, but also can be a photograph, graphic visual or diagram that accompanies and complements a printed, spoken or electronic text. It is an example, a demonstration and can be produced by both traditional and new media.

Medical illustration is produced for print and projection media, and some 3D models. Its purpose is to clarify the biomedical concepts and procedures but not necessarily the understanding of object itself. It is vital for making visual the nomenclature of anatomy and physiology or to

³ The Free Dictionary states, it comes from 16c and means 'to enlighten (the mind):' 'to beautify' or 'to throw light or distinction on someone': from Latin *illustrare*, *illustratum* to light up.

depict surgical procedures and uses images as example rather than as precise portrayal. It can make imaginative use of symbols or composites to represent the object being depicted and is often used as a decorative accompaniment to text which might embellish or beautify. It does not have to be lifelike or accurate. An illustration does not have to be a drawing.

In the 15th Century, Leonardo da Vinci founded the philosophical and methodological system for what has become known as medical illustration. This incorporated the requirement of understanding what something is, and its underlying properties and *why* something is. He also developed a compositive method of working from multiple views of the same image. By combining the observed phenomenon and using the compositive method as reasoned fact, Da Vinci was able to produce drawings that were evidence of visual understanding.

*'Drawing therefore became a means of explanation for him,
as well as representation of the structure under
investigation'*

(Wells, 2004, p. 36).

His importance to the field of anatomy and to medical illustration is undeniable and his understanding of physiology was gained through the experience of his artistic renderings.

From his earliest anatomical drawings in the 1490s he was rigorous and systematic, wanting to consider each feature from three aspects. He developed the technique of under shading to make the object stand out more clearly. He would try and see several examples of the same structures and produce a synthesis of his observations depicting the typical version and introduced technical methods still employed in medical illustration today. These include illustrating systems from the inside out, that is from bone, to muscle, layer upon layer until the final layer of skin is illustrated. He was the first to produce cross sectional drawings and he used transparent figures where internal organs seem to be projected on the surface of the figure depicted.

Frequently a representation, a depiction, a visual record when it is of or about anything scientific or medical is referred to as an *illustration*. Dr.

Dirk Schultheiss and Dr. Udo Jones from The Department of Urology, at the Hanover Medical, describe how Max Brödel, the founder of modern medical illustration himself chose to specialize in being a medical *illustrator* rather than be a 'general' *artist* (Schultheiss, 1999). So it would appear that the world of fine art and medicine and medical illustration are inextricably linked but at some points they converge and then separate.

In 1911, Max Brödel became the head of the first 'Department of Art as Applied to Medicine' in the world, at the Johns Hopkins Medical School, USA. In his career he founded new artistic techniques and made significant contributions to medical science.

'It is necessary to originate a different type of picture, one that shows far more than any photograph can ever do. The artist must fully comprehend the subject matter from every standpoint: anatomical, topographical, histological, pathological, medical and surgical. From this accumulated knowledge grows a mental picture, from which he crystallizes the plan of the future picture'

(Brödel, 1993, p. 113).

In addition to Max Brödel's categories of accumulated knowledge required for the purpose of medical illustrators of anatomical, topographical, histological, pathological, medical and surgical, I would add phenomenological.

The addition of this category establishes where the emphasis and intention of my research differs from that of medical illustration. I believe this inclusion can offer an even deeper understanding of the subject as it takes into account the effects of the experience of the object; the delineator's encounter and communicates this to a viewer. Brödel's belief was that,

'The planning of the picture, therefore, is the all important thing, not the execution'

(Brödel, 1993, p. 113).

This seems to represent the point where *fine artist* and *illustrator* part company. What he has described in the first part of his statement is visual thinking something I believe is shared between the two disciplines at some

points but then becomes separate through notions of intentionality and modes of display.

In her record of the Medical Artists Association of Great Britain, medical illustrator Patricia Archer outlined the history of this relatively new profession. According to her investigation, key to the work of a medical illustrator is the collaboration between anatomist or surgeon and artist. Famous partnerships include Vesalius and Calcar, Hunter, Smellie and Jenty, and their collaboration with Riemsdyk on their obstetrical atlases, Henry Tonks (1862-1937) with Sir Harold Gillies (1882- 1960), and Erich Lepier (1900-1974) with Eduard Pernkopf (1888-1955). However, even the greatest had problems, for in spite of close co-operation with their artists and their work, Vesalius,

*'complained vehemently of the large sums of money he had to pay in order to induce 'skilled artists' to do the art work... the artists are more interested in doing paintings of Venus and the Graces as opposed to drawing foul, decayed and smelling bodies'*⁴

(Archer, p.87).

Riemsdyk also complained sadly about a lack of appreciation.

Throughout her thesis, Archer describes illustration as addition to thought. The main purpose of medical illustration is to show events, mainly surgical procedures. If a disease is shown, it has been created as a composite of many different examples, *The example* of what a disease should look like which is distinctive to a visual description of each experience of a disease and the specificity of that encounter, which is the aim of my research.

Photography can record the facts exactly as they are observed, but an illustrator can select and interpret the observed facts, in order to provide illustrations which are more meaningful than those which are directly seen, so making a difficult procedure easier to understand and clearer to follow in practice. Yet the belief in drawing as a reliable tool with which to collect data was refuted.

⁴ From Ball J. M. *Andreas Vesalius: The Reformer of Anatomy*, St Louis Medical Science Press, 1910 p. 26

The art historian Philip Prodger points out that,

'Scientists increasingly came to equate photography with accuracy in representation'

(Prodger, 1998, p. 3).⁵

An illustrator can be far more selective than the 'all seeing eye' of the camera and can edit out the extraneous information of surroundings and focus on drawing the object being observed. As the science illustrator and author Phyllis Wood writes,

'while the camera establishes and documents the existence of a subject, the illustrator illuminates its essence'

(Wood, 1994, p. 9).

However, unlike the specificity of delineation as a methodology within this research, an illustrator would summarize, idealize, simplify and reconstruct.

It is interesting that in the case of forensic illustration, composites, which by their very nature cannot be completely accurate, can be used as items of evidence in court. Karen T. Taylor, forensic artist and instructor at the FBI Academy explains how they become pieces of factual evidence. Making a composite is a device used for most illustration and is defined in forensic art as,

'hand drawn, composed of component parts which have been put together'

(Taylor, 2001, p. 517).

It is also not unknown for artists in this area of science illustration to be asked to redo their own illustrations, and even to redo the work of others if new information or witnesses contribute to a case at a later stage.

⁵ *'Scientists began to consider photography as a practical alternative to traditional forms of illustration. Unlike drawings, which are clearly subject to the limitations of the artists who produce them, photographs were thought to afford a relatively objective means of recording empirical events...scientists increasingly came to equate photography with accuracy in representation'* (Prodger, 1998, p. 3).

Conclusion

There is an act of drawing and also of delineating. These are part of the process. There is no specific act of illustrating, as the outcome of the image is dependent on the choice of material, process and technique deployed in it's planning. There is no rule regarding realism in design or colour as long as the information is clearly displayed and within the context of this research. In making an illustration, an artist might draw five, ten or even more sketches of the same thing and then make a composite of all these. This end result is an illustration of the perfect example of the subject, a generic example. This is not the aim of my delineations and calling them illustrations is an inappropriate description of the work as it suggests the generic when I am investigating the specificity of FOP.

CHAPTER FOUR

Delineating disease: initial encounters and specific projects

The previous chapters have discussed the relevant practices and principles of pathology, different forms of delineation and the methods of illustration and imaging used in medicine. They have also introduced the concept of delineation as a phenomenological process. In this chapter I will move on to describing the material of this particular research including my own experiences of FOP and the different exploratory delineation projects I have undertaken to develop my understanding and technique of delineation.

The first part of this chapter deals with the delineation of histology samples viewed through a microscope. I undertook this work partly because histology is an important aspect of pathology, and because it raised the question of how far the delineator needs to engage in the full practical process of a pathology inquiry. In this case I describe both the delineation work itself and the preparatory processes used to create the histology slides.

Although this was a useful and revealing exercise, the main material of the research will be found in the second part of this chapter in which I progress through a series of six projects including drawings of historical specimens, living sufferers and the process of preparing the bodies of two donors for display as medical specimens.

Introduction

During this research I have delineated a wide range of encounters with FOP from the whole living patient, to encounters with visual experiences of microscopic phenomena. Part of my inquiry has involved observing dissections, drawing from cadavers and potted specimens, and participating in some surgical skills workshops. I have also observed procedures for de-fleshing, maceration, preparation and display. These I have documented through photography, text and delineation. As the process of histology has become part of my experience of disease I felt it

necessitated investigation and designed a drawing project as the basis for my first case study.

I provided an example of how, through learning and applying dissection techniques, Leonardo da Vinci gained knowledge of the workings of the human body (Chap. 1, p. 29). Further support for this experiential method of learning is supplied where I refer to the industrial designer Henry Dreyfuss. His principle was to gain knowledge through learning how things work and by participating in the process of making things (Chap. 2, p. 39). For him first hand experience is essential. Max Brödel also understood how important it was to learn about diagnostic and surgical methods for the benefit of his own work.

'He [Brödel] soon realized that working...was of no use without a profound understanding of anatomy and medical techniques'

(Schultheiss and Jonas, 1999, p. 114).

As this investigation developed it became apparent that like Brödel, and Dreyfuss I also needed to gain experience and an understanding of the methods and techniques used in diagnostic processes and in preparation of pathology specimens.

The way a medical specimen looks is dependent on the methods used to present it. Objects are perceived via processes used, for example they are seen through lenses or on screens and undergo transformation in the preparatory processes of histology. In histology a small piece of tissue is removed, put through various stages of preparation then stained with colour to allow the tissue to be observed clearly when placed under a microscope. Histology is still a commonly used method for making diagnosis in many diseases. The preparation of tissue is part of the visual experience encountered. It is therefore relevant to begin with a drawing project that explores the effects of histology on the delineator's experience of pathology.

This preliminary project was subsequently influential in informing my engagement with the process of maceration later in this chapter.

Histological preparation of tissue

Histology remains a crucial process of diagnosis and very little has changed in fixation and histology techniques in the last 100 years. After removing a section of tissue, for example part of a mole or a tumour, it is frozen or fixed and embedded in wax after which a very thin slice is cut, the wax is removed and the tissue is placed on a slide. This sample is then stained so it can be seen clearly. Often particular stains are used which only appear if certain cells are present. To learn the process of preparation and histological staining, I worked with Martyn Cooke at the RCSEng. We used animal tissue, not human.

We began by taking a small amount of tissue and fixing this using formaldehyde to kill off and prevent putrefication by organisms of self-digestion. This is also essential for health and safety reasons as infections can spread very quickly from untreated decomposing bodies. Any mineral tissue is removed by decalcification using a well-fixed acid. This aims to keep the tissue safe from damage in future preparations.

The next step is called embedding. This is the stage that can cause distortion and damage. A cassette, which is a small rectangular case about an inch and a half in size with tiny holes placed at regular intervals and a hinged lid, is labelled before a tissue sample is placed in it (Fig. 6). The sample is placed upright in the cassette to allow it to be cut transversely. Warm wax is poured in. When that has started cooling, more is added, allowing the excess to pour through the holes and ensuring the tissue is completely covered in wax.



Fig .6 Wax pouring onto tissue in cassette.

The cooled wax forms a solid block with the tissue suspended within it. This is placed on ice for about five minutes to aid cutting. The sides of the block are cut away with a knife. Then it is trimmed with a Microtome until the tissue sample is seen clearly (Fig. 7).

Fig. 7 Diagram of a Microtome (Mallery, 2007).

A Microtome is a machine that is turned by hand to cut very thin slices with a sharp blade. It acts like a bacon slicer and the thickness is measured in microns (1 micron = .001mm). The slices we made are four microns thick. A smooth action is needed to turn the knife blade. Breathing gently on the section whilst turning the handle, just as the block is going past the knife blade, allows the rectangular sections of wax to stay together and permits air to get under the fine ribbon of wax that forms. This also prevents the ribbon from piling up. A paintbrush is used to keep cleaning wax off the blade. If there is any difficulty, the block is put back on ice and then slicing the section is attempted again.

The delicate ribbons of wax are floated on the surface of the hot water in a water bath. These thin sections are dragged across the water to split the ribbons. A rectangular glass slide is then put in at an angle and the section is gently pressed onto it, below the middle to leave room for a label. The slide with the section now attached, is carefully removed from the water again at a slight angle. Information is scratched onto the label with a diamond pen or in pencil if frosted (Fig.8).

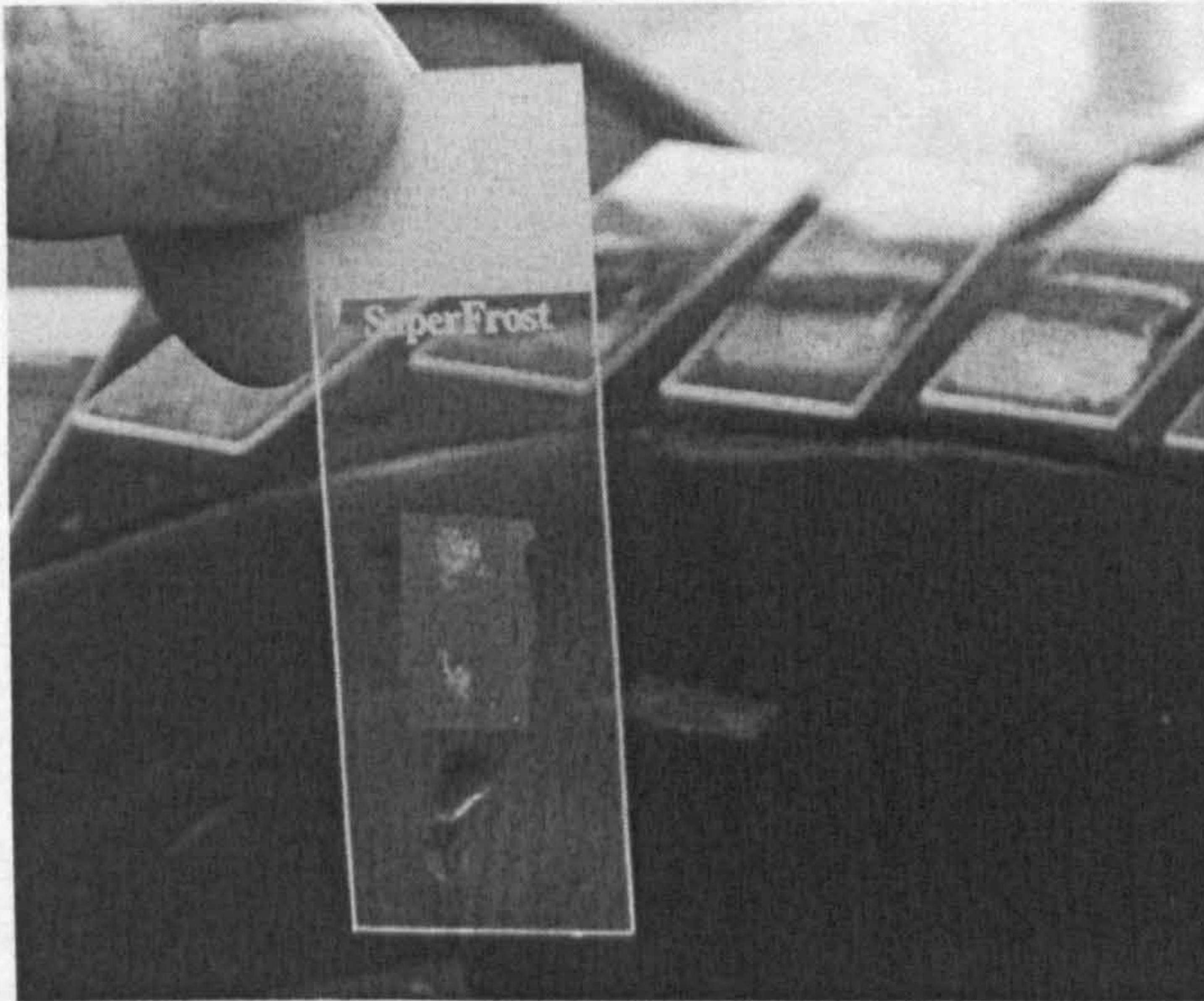


Fig. 8 Slide with tissue on it.

To ensure the slice adheres properly in a uniform way, it is put on an incubator/drying rack. This also helps to ease out any creases. It is then necessary to de-wax the slides as wax is only the vehicle and needs to be removed so the tissue can be stained. De-waxing is done using Xylene or Histoclear. The slides are left in a mix with alcohol for at least five minutes. They are then dipped into trays in sequence with each one getting increasingly less solvent from, 95% to 75% water.

The choice of which chemicals are used to stain is dependent on tissue type, for example, muscle stains red, collagen stains pale pink and elastic fibres do not stain well. The molecular size of the stain relates directly to the size of the molecules in the tissue.

When staining it is best to use a *coplin* jar large enough for up to five slides (Fig.9). Haematoxylin and Eosin staining or H&E as it is known, is a commonly used basic stain. It is red but stains nuclei blue. The tissue is put in a jar and stained with Haematoxylin for ten minutes then put in a jar

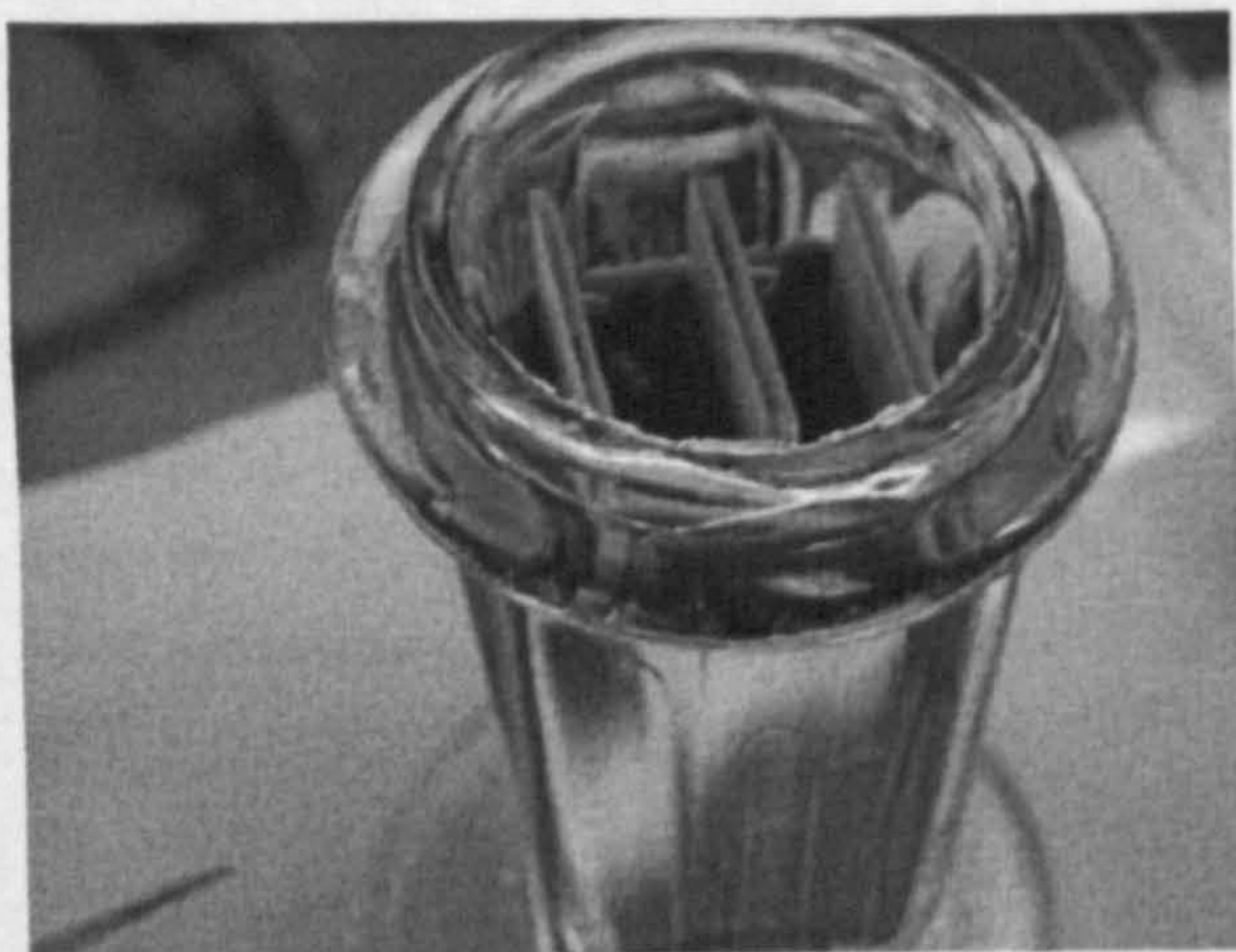


Fig. 9 Histology staining in Coplin jar.

of acid alcohol. This is called a differentiator and acts by breaking down any bond with other parts because the dye is attached to the nuclei but not everything else. The slide is literally dunked in it after washing, and then washed again, then dunked again, then washed again. The slide is then counterstained with Eosin which is a very messy red dye that stains everything except the blue nuclei.

After staining, the tissues are dehydrated by being dipped in a sequence of trays each one containing increasingly strong solutions of Xylene. Finally a clear plastic layer is adhered on top of the tissue sample to cover and protect the now fixed and stained tissue. Once finished, histology slides are viewed under a microscope.

Microscope drawing – mapping histology

A project in delineating histology was designed to explore the question of how to present the visual experience of encounters with prepared and stained tissue. The process involved using a microscope to make visible detail that is invisible to the naked eye and included equipment (Zeichenokular lens) that allows phenomena to be delineated whilst remaining in visual contact continuously with the mediated view of the specimen.

This drawing experiment took place in the Centre for Drawing, a research space at Wimbledon College of Art from 5th – 12th April 2005. The section of tissue I chose to delineate was H&E stained heart tissue. I

viewed it using a brass Leitz Mikroskop made in 1920 (Fig. 10). The object being observed, i.e. the tissue was seen indirectly as the visual experience was mediated via the use of lenses.

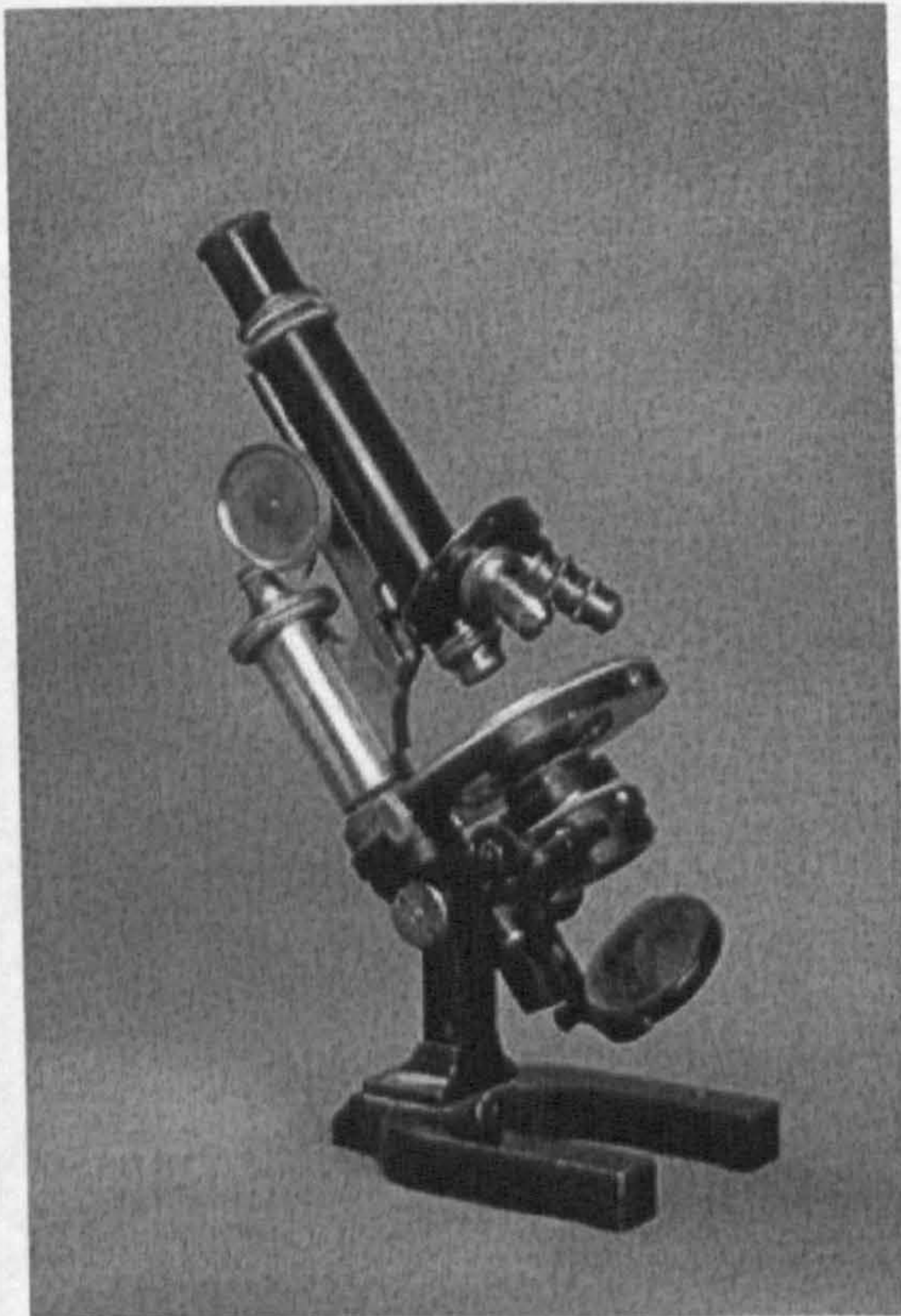


Fig. 10 Leitz Brass Microscope.

The experience of looking down a microscope and drawing what I saw was difficult, time consuming and enlightening. Several experienced clinicians encountered in this research reported finding their student experience of drawing with microscopes both taxing and rewarding. Students learning histology still have to make drawings as part of their taught programme. The activity of drawing tissue in this way forces a student to spend longer intensely observing what is being seen down the microscope than if they were looking at a photomicrograph of the slide.

I began by adjusting the microscope until I saw a clear image of the histology slide in the viewfinder. Then I exchanged the eyepiece for a projecting lens attachment called a Zeichenokular. It is a miniature camera lucida that is about 10cm in length and fits into a special ring which slots down the tube of the microscope usually reserved for the viewing eyepiece (Fig. 11).

Fig. 11 Zeichenokular lens (Mappes, 2002).

The object and paper being drawn upon appear simultaneously only when looking down the eyepiece, through the lens. When you take your eye away from the microscope and just look directly at the paper, all you see is the blank paper and any drawn marks that have been made. It is a great deal harder to see down the eyepiece with the Zeichenokular lens. The image is viewed within a circular shape and seems to shift about a lot if there is even fractional head or eye movement. The Zeichenokular made the image appear at an angle so I had to tilt the paper slightly to compensate for this discrepancy making it even more awkward to draw.

The whole process produced a very strange experience. When I looked down the eyepiece through the Zeichenokular lens, I saw the image of the tissue slide, the page on which I was drawing, my hand and my pencil simultaneously, one superimposed over the other. By moving my head slightly the image of the slide became fainter. It is at that point I was able to put the pencil on the corresponding place where I could see both my hand and the image of the tissue on the page. I was then able to 'trace' it. If I moved my eye away from the eyepiece completely to look directly at the page, the image disappeared. It was only visible whilst looking down the lens (Figs. 12, 13 and 14).

Fig. 12 The camera lucida a. (Mappes, 2002). *Fig.13* The camera lucida b. (Mappes, 2002).

Fig. 14 The projected image and hand holding a pencil (Mappes, 2002).

I had to keep relaxing my eyes and try not to focus on the object only otherwise the image of my hand holding the pencil would vanish and I lost my place. I needed to refocus my eyes frequently. It is like trying to trace air. The closest comparison I can make is with a surgical skills workshop I had attended. We learned to use mechanical 'grippers' to pick up Smarties from one pot and place them in another, but instead of looking at them directly, we had to watch what we were doing via a monitor. This is to teach surgeons how to perform keyhole surgery where you observe everything you are doing on a screen so you can see and access areas that are too small to see directly.

The sensation I had viewing an image through the Zeichenokular was a feeling of disembodiment as if I were not fully in control of my own actions. It is similar to the difficulties one has drawing an object whilst looking in a mirror and only seeing the reflected activity and the reversed drawing. Usually, you look at the surface on which you make a drawing, but in this case, I was forced to remain in a fixed position and stare down the microscope, whilst drawing. The view I had of the drawing I made and the object I was observing, were only seen simultaneously when looking down the microscope. The visual experience was mediated through the lens of the Zeichenokular.

It is very uncomfortable leaning over and looking down the lens for long periods of time. I needed to shut my right eye and hold my head so the lashes of my left eye rested just on the top the Zeichenokular lens. I saw a circular image of the tissue (Fig. 15). It did not fill the whole eyepiece as I had expected, and was much fainter. By turning the Zeichenokular one way or another, I could see the image of the object at the side of the microscope, like a ghost image. I could see the paper, my hand and the pencil I held. I moved the pencil tip directly following the shapes of the tissue I saw. I saw the image of my semi transparent hand and traced the contours and shapes of the magnified, semi-transparent tissue that appeared to hover above and below the image of my hand.

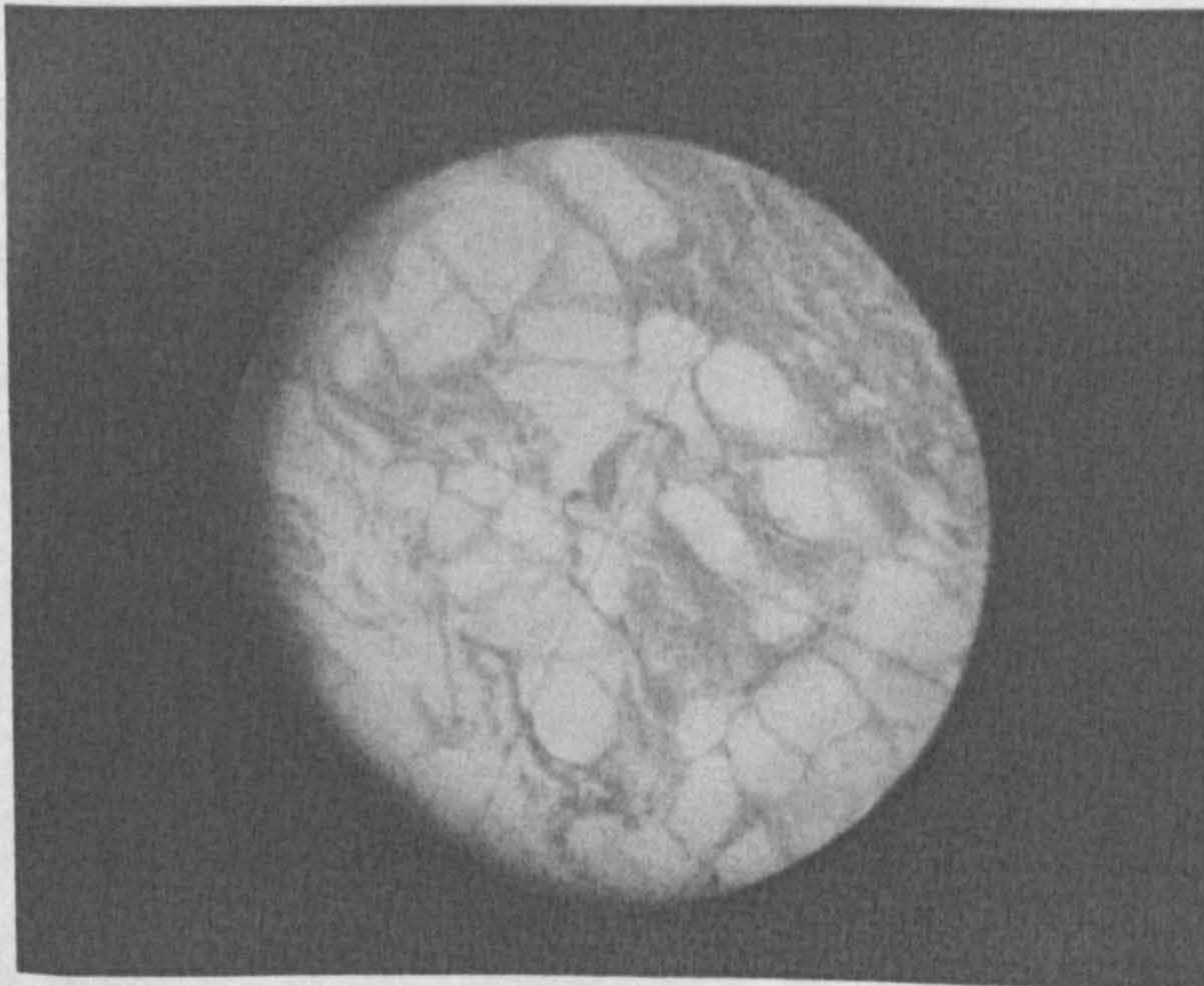


Fig. 15 Photomicrograph of tissue.

When looking at a histology slide under a microscope, only a tiny fragment of tissue can be seen at a time. Each tiny point of the object viewed down the microscope is like a minute, circular, vignette, a fraction of a fragment. When looking down the eyepiece, I drew the visual information that filled the viewing circle. It was only when the slide was moved, even incrementally, that the next 'scene' was revealed. These were minute, fugitive moments of the whole visual experience; collections of ongoing encounters. Each section unfolded like a map. Delineating this map became a method that was informed by the process of how the object was seen; in minute, fragmented pieces, like an animation storyboard, or the unfolding and flattening out of a map. My visual experience of the phenomenon occurred in fragmented sections

I worked on A4 pieces of paper. I rarely work on such a small scale. The circular images were not very big and could only be experienced bit-by-bit, fragment-by-fragment. I struggled, constantly readjusting the focus and the projection aperture to coincide with the ever-changing light in the studio and my own physical discomfort from hours of looking down the microscope, staring and focusing (Fig. 16).

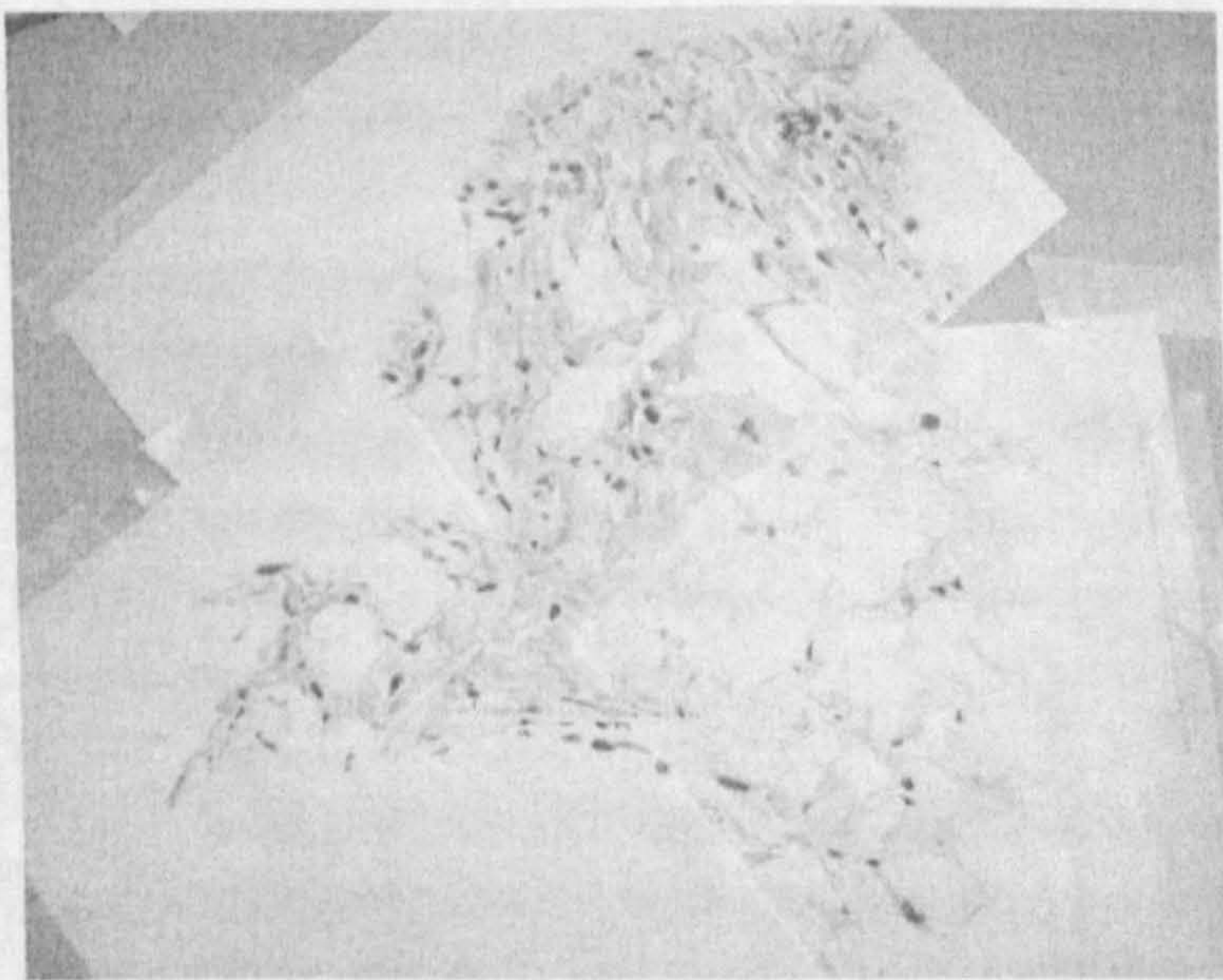


Fig. 16 Mapping Histology 1.

I continued 'mapping' the object I viewed via the Zeichenokular lens. I then moved the histology slide incrementally to reposition it and visually record the next vignette. Simultaneously I added another sheet of A4 paper to draw on, placing it however was required to correspond with the view I

had of the next section of the tissue. I attempted to match up this view with the previously drawn fragment (Fig. 17).

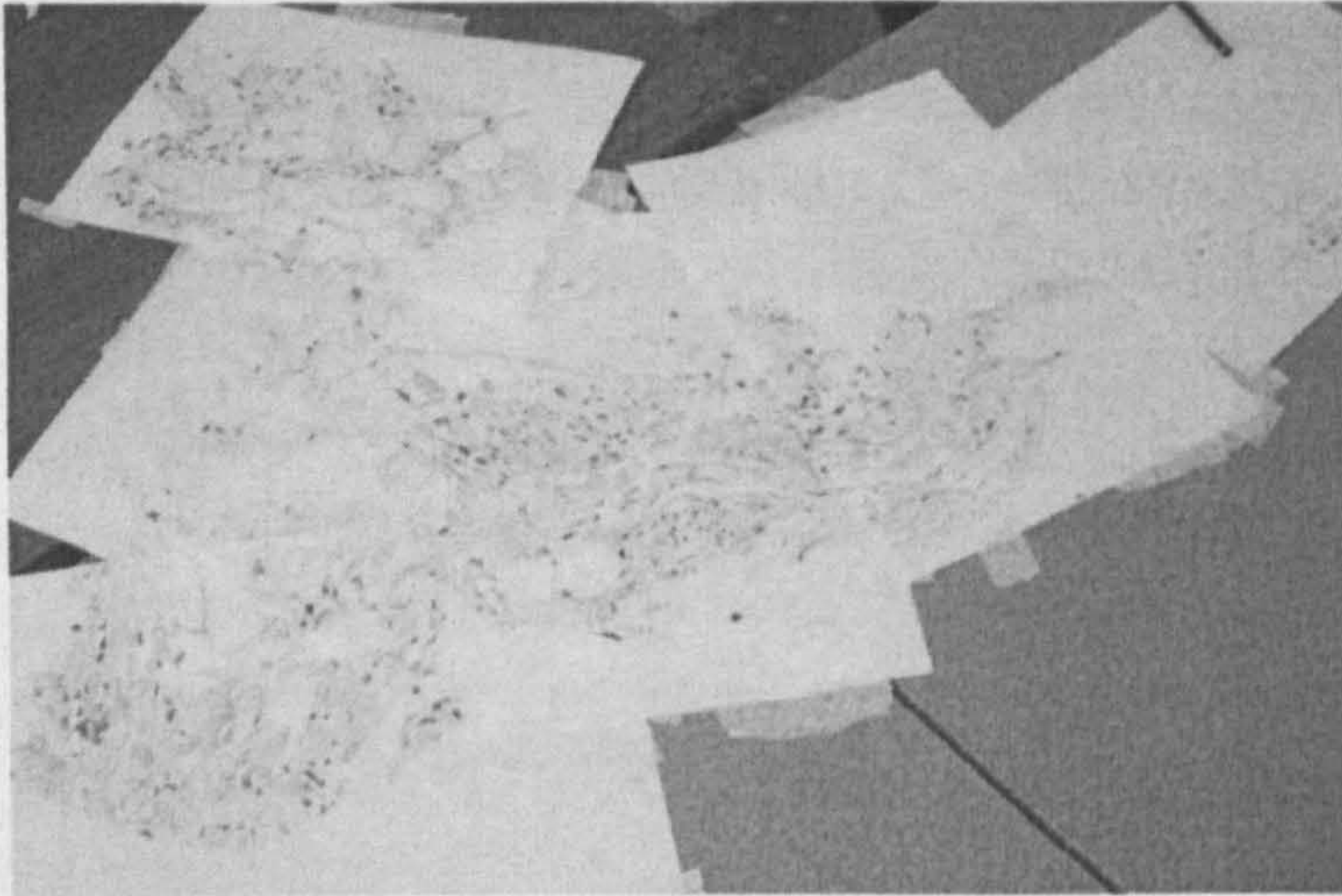


Fig. 17 Mapping Histology 2.

The visual experience is presented as scraps of paper, stuck here and there, linked together; growing and spreading like a kind of visual virus. The pieces of paper turn in whichever direction is needed at the time, up, down and sideways. Placed all together there is no clear sense of 'right way up'. They present my visual experience of the histology slide. The encounter is presented as a series of real time encounters, made visible, magnified, flattened, and projected out like a map.

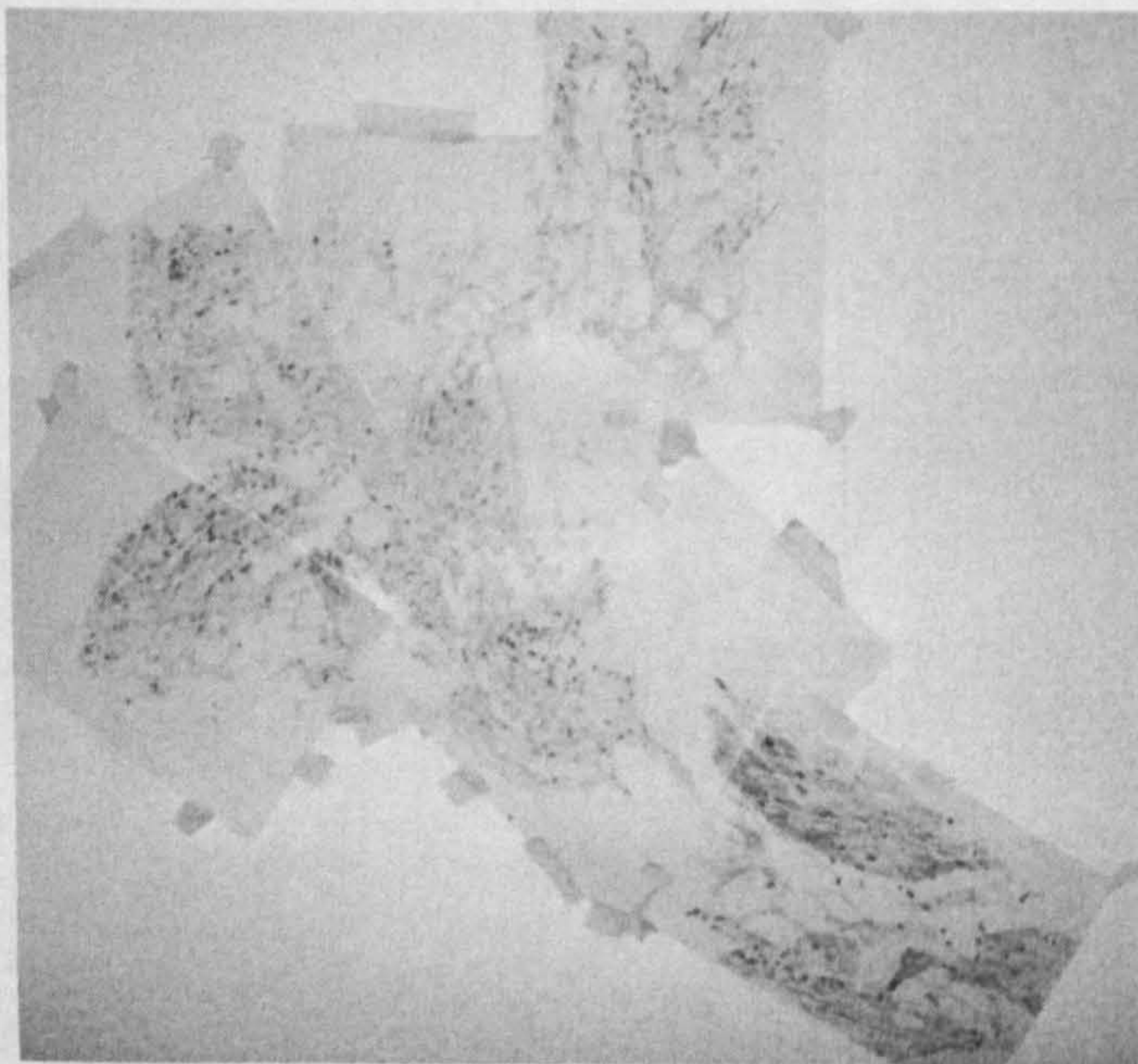


Fig. 18 Mapping Histology 3.

The delineation presents the fugitive collection of experiences of each visual experience as it was encountered. These are mapped out as one continuous ongoing encounter. Looking down a microscope and drawing is exhausting and extremely difficult. I realize how easy it is to be seduced by beautiful shapes and patterns. There are flares and reflections that obscure the image and distortions and shadows which are erroneous information but are included as part of the experience.

The delineations made became a system of mapping the mediated experience of the heart tissue. Each area viewed through the microscope has been drawn. By moving the paper and the histology slide in conjunction with each other, the next part of the tissue was drawn on paper attached to the piece already completed, growing as tissue grows (Fig. 18).

Drawing the tissue in this way produced more than a factual record; it incorporates the experience of the fugitive collection of events, the materials, the equipment, and the tissue. The delineation reflects the process of the creation of the specimen, the mediated experience of the phenomenon, and conveys these visual experiences. My experiences and the process of how I came to understand the heart tissue is recorded and presented through delineation. When shown to Martyn Cooke, he not only recognized the tissue, but the stain used despite the image being monochromatic. He had not seen a histology image that recorded and presented tissue in this way. It offered further insight into my experience encountering the phenomenon.

This drawing project produced interesting results that raised questions about issues of mediation and dequantification, a term that describes a lack of clear orientation and scale (Tufte, 1997). The method of adding paper as the drawing progressed corresponded with the activity of looking and recording collections of experiences.

In this project it became plain that delineation can be used with microscopic material but the mediation of the lens gives a different focus from direct observation of actual material. The work of delineating images viewed whilst looking down a microscope was found to be difficult and demanding and anecdotal reports from clinicians and students encountered

indicate that even experienced users of microscopes have continuing difficulty.

This would be an appropriate topic for a more substantial inquiry but it was not pursued here since the material of FOP provided an ideal opportunity to explore delineation with direct observation of phenomena.

The next section gives a detailed account of my development of delineation as a system to present the experiences of FOP. This took place over a series of projects engaging with historical specimens, patients with FOP and the main project, the maceration and preparation of two donors. A detailed analysis of the delineations is described in Chapter 6.

I end this chapter by concluding that delineating the processes used to prepare the donors is integral to my overall experience of FOP and that greater understanding has been gained through the activity of delineation.

Experiencing FOP: introduction

Initially the subject area of my investigation was much wider and looked at approaches of depicting pathology and the processes used to reveal disease. On finding an example of a leg prosection with Fibrodysplasia Ossificans Progressiva, I sought further information about this disease. Martyn Cooke was about to begin preparation of two FOP sufferers who had donated their bodies to the RCSEng. They had been patients of Professor Triffitt and Professor Wordsworth at the Nuffield Orthopaedic Unit, University of Oxford and now their remains came under the jurisdiction of the RCSEng. Professor Triffitt and Martyn contacted the families of the donors and gained consent for me to be involved in studying the process of their maceration and preparation for display at the medical museum.

In this inquiry, each encounter is treated as being distinct from the next. Delineation as developed throughout this series of projects, aims to present visual experiences without being influenced by pre conceptions. I argue that it is difficult to predict what an experience will be like or how the delineator will respond to each encounter. The effect FOP has on the body is so extraordinary that it cannot allow for generalization. Nothing looks as it should and nothing can be taken for granted. Delineation as

described in this research, develops a drawing activity that is responsive and flexible to the unique and unusual character of encountering this phenomenon.

While sitting in front of patients, specimens and the remains of the donors it became evident there was a need to develop a system for drawing that allowed me to unravel the overwhelming confusing visual information before me that was beyond my experience or comprehension and would present the visual experience of the encounters. Many examples of FOP experienced in this research have not previously been depicted.

First experiences of delineating FOP

Leg Myositis Ossificans: Wellcome Museum of Anatomy and Pathology collection number S107.4, was the first FOP specimen I drew (Delineation 1, p. 129). The leg had been taken from a dissection and no information is known about the donor. This was the first opportunity I had to closely examine the structures of ossification in a specimen. I had spent a long time doing background research on FOP. This involved reading many articles from medical journals across a wide spectrum of medical fields. I also read newspaper articles and found information from the IFOPA (International FOP Association) website. This was my first encounter with a real example of the disease.

I find the bridges and spurs to be breathtaking, especially as the bones have been cleaned and are shimmering and gleaming white. The tiny intricate spurs at the end of the ossified tissue are like delicate flecks, sudden sharp inflections. There is a sculptural quality to the facets and planes that have twisted and grown, fusing joint to joint, one part of the skeleton hermetically fused with another. I can see a great visual similarity between these shapes and the gnarled twists and curves of fresh root ginger.

After making two delineations of this specimen I then went on to delineate the first whole skeleton of FOP I had seen (Delineation 3, p. 133).

Due to the rarity of the disease there are very few skeletons available. In this research I have drawn three. The first complete skeleton I drew was

that of Mr. Jeffs. His skeleton has been displayed at the Hunterian Museum at the Royal College of Surgeons of England since the 1930s. He was rarely noticed as he was displayed facing forwards and the effects of FOP occur most noticeable on the back. In 2003 Mr. Jeffs was placed with his back facing towards us allowing his secondary skeleton to be clearly seen. He is one of the oldest skeletons of an FOP sufferer. He was 39 years old when he died. His remains were dug up and the surgeon George Hawkins kept the skeleton in his collection. When Hawkins died in 1783 John Hunter bought Mr. Jeffs' remains for 85 guineas.

I was struck by the horror and beauty of what FOP really looked like. The secondary skeleton looks remarkable. It has encased, engulfed and bridged great swathes of space between joints. I was so conscious of this having been someone, a person, who slowly and catastrophically turned to stone. His condition has a pitiful appearance but its effects look beautiful. The encounter raises questions of how and why this could happen to a body.

My visual experience of Mr. Jeffs was so powerful because he was a human being, a man, who had lived with this terrifying disease. To endure physical metamorphosis of tissue on such an extreme level is beyond my experience. As my experience of him is as a whole skeleton, it necessitated placing the whole image on the page to try and encapsulate my encounter.

The secondary skeleton is extremely complicated. It has grown mainly out from the right clavicle and shoulder blade, around the right arm, curls across the back, and dips down around the spine, back around the left shoulder and then down to a complex bony network across the sacrum. Another main area of heterotopic bone starts at the right hip and curves dramatically back out and then down to bridge with the right femur. The already intricate normal skeleton has connected and is encased by the heterotopic bone, but remains visually separate.

I wanted to gain further experience and knowledge of FOP. Other FOP skeletons include Harry Eastlack's who is on display at the Mutter Museum in Philadelphia ("The Skeleton of Harry Eastlack", IFOPA website) and another skeleton from 1886 is on display in the Anatomy

Museum of the Adelaide Medical School (Allen, 1998). The long distances involved made it difficult to justify visiting. I undertook an email search contacting academics in archaeology, anthropology and in medical museums. Professor Don Ortner from the Smithsonian Institution suggested the Naturhistorisches Museum in Basel where I found two further FOP skeletons.

The two skeletons are part of the Galler Collection, a little-known historic Swiss bone collection consisting of approximately 600 mostly dry-bone specimens of many major bone diseases dating from the late 19th and early 20th Centuries. There are many rarely documented conditions represented in the collection which includes two female middle-aged skeletons of donors who had suffered from FOP. The collection is located in the department of Physical Anthropology at the Naturhistorisches Museum in Basel, Switzerland. The collection is not on public display and is for research purpose only. Dr. Gerhard Hotz, head of the department of Physical Anthropology gave me permission to study the two skeletons in storage at the museum. I spent four days in the museum from 20th – 24th February 2006.

On my arrival Dr. Hotz took the two skeletons out of their cabinets and put them in the middle of the room and left me to work. The very loud noise from the air conditioning unit was distracting and I was freezing. I had to work wearing several layers of jumpers. As with my encounter with Mr. Jeffs, I felt the phenomenon to be unfamiliar and unique. I took photographs of the skeletons but these recorded not only the objects but also the extraneous information surrounding them, all in equal detail. The surroundings interfered with the information I was trying to extract from the image.

I began work delineating the first specimen numbered in the museum collection as **NMB 5695 Galler 190** (Delineation 14, p 137). This first drawing took two days. I chose to draw her skeleton at a similar scale to the second, close up delineation of Mr. Jeffs (Delineation 4, p. 135), from the neck down to the knees, and viewed from the back. The effects of FOP are most clearly seen in this area. Her lower left arm is missing.

My aim is to use delineation as an activity to record and present my experiences of the phenomenon. The consequences of the symptoms of FOP on her body were as unfamiliar as Mr. Jeffs' had been. The bridges, and spurs of the heterotopic bone in this sufferer are unique to her. Every example of FOP differs from one sufferer to another, and no two skeletons are identical. The growths around her neck are prolific but small and delicate as are the spurs down the back of her right arm. The heterotopic bone that has grown around her ribs flows up to the right scapula and bone growth on the left forms a large 'V' shape and then travels in a twisted pattern down her spine. The extra bone that has grown from her left femur extends out a great distance before bridging at the back of her knee.

Integral to the visual experience is the way in which she has been displayed. From a white metal pole that rises up vertically from a circular floor base, she has been suspended by very crude and harsh looking clamps, which curve from the central columns to grip her by both femurs. A 'V' shaped metal bracket, bolted to the top of the pole that ends by her sacrum also holds her in position. The visual effect is of her being imprisoned and encased by bone whilst being confined and held by metal.

I then delineated the same specimen from the front (Delineation 15, p. 139). Expecting the view from the back to have been the most dramatic and clinically useful due to the nature of the path of progression of the disease, I was surprised to discover the visual experience encountered when viewed from the front was even more shocking. A spur had grown from her lower jaw and bridges with the top of her sternum, effectively locking her jaw to her chest. Her mouth has been fixed permanently partially open and her head is completely immobilized. It is horrific.

The second skeleton (Delineation 16, p. 141) is numbered in the museum collection as NMB 5695 Galler 191. The feet, head and lower arms of this female skeleton are missing. The twist of her vertebrae is spectacular. Her tiny, compressed ribs, are kinked and bowed. I could almost feel her crushed lungs, constantly battling to fill with enough air. There is a twisting contusion of network of bone, entwined in and out around the vertebrae, between the ribs, linking them together with bony fingers. In some places her ribs are anchored to her pelvis. The devastation caused by

the disease is so severe that her legs are locked and cross over each other. The bridging all down her left leg looks beautiful and has the appearance of twisting ginger root. The delicate, bony spurs that have become entwined and turn have caught the two leg bones and dragged them together.

I then drew a detail from her left leg (Delineation 17, p. 143). This gnarled, twisted heterotopic bone is the most contorted and convoluted I had seen so far. It juts out at a hideous distance from the femur and is attached to her hip and then runs down the back of her thigh. Shards of bone like tiny daggers protrude from every separate twist and end in needle sharp points. They are like branching twigs and look heartbreakingly painful.

I made another delineation of this second skeleton, NMB 5695 Galler 191, viewed from the front this time (Delineation 18, p. 145). The severity of her disability is dramatic. Her right leg has been permanently forced over and completely crosses in front of her left leg. The mass of spurred heterotopic bone extends from the base of her pelvis right down to the backs of her knees. Although the effects of FOP on this skeleton are the most severe and visually complicated I have seen, I managed to produce three drawings in two days, the fastest I had done yet.

The specimens I have described are all historical examples of full or nearly complete skeletons. I will now discuss encounters with people living with FOP. Professor Triffitt and Professor Wordsworth gave my details to patients under their care and suggested that those who were interested in contributing to this investigation should contact me themselves. Six people contacted me. Eventually I met three and drew two.

FOP patient participation

It has been vital to this research to include delineations of FOP sufferers as well as their personal descriptions of their experiences of FOP. By using delineation as a way of presenting the visual experiences of FOP rather than photography, more time was spent with patients and they felt more

comfortable being drawn than being photographed. To preserve anonymity I only refer to them by a letter.

On my initial visit to Oxford on 4th October 2005 to visit Professor Wordsworth and Professor Triffitt, I had my first meeting with someone suffering from FOP. She was the subject of a television documentary being filmed that day and I will describe that documentary *The Girl Whose Muscles Are Turning to Bone*, in Chapter 5. L is a seven-year-old girl and we spent the afternoon together. Her mother endorses any promotion of awareness of such a rare disorder but preferred that I did not show her daughter my previous delineations. I will discuss the significance of this in Chapter 6. Later in the inquiry, we all agreed it was not necessary to draw L. I had been anxious about meeting L and my greatest fear was appearing to be condescending in any way. Her head juts forward slightly and her arms are rigid and fixed. They are raised and held slightly forwards as if she is about to hug someone. She demonstrated how capable she was of movement by running around a lot.

I met P on 19th October 2005. He is twenty-nine years old and had been diagnosed with FOP when he was twelve years old. We spent a couple of hours talking and getting to feel comfortable with each other. P's exuberance and conversation about his extremely active social life helped dispel any misconceptions I might have had.

In our conversation that day he told me that when he was born, staff noticed he had deformed big toes. When offered corrective surgery, thankfully his mother declined. His great toes are smaller than would be found in someone not suffering from this condition and turn inwards. He had been a junior champion swimmer. During a competition when he was eleven years old, his father noticed a swelling on his back. He went to the GP who then referred him to a chiropractor which led to an inappropriate course of treatment for his condition. Later he was admitted to Brighton Hospital. He describes his father crying out when he heard P's back 'snap'. He thought they had broken his son's back.

P told me he had a series of X-rays and scans. Then, when the swellings appeared on his shoulders, he was sent to Warwick Hospital. Under

general anaesthetic, he had biopsies taken, one from each shoulder. When he awoke his father called him his 'little angel' as he had white bandages binding the bloody stumps left on each shoulder after the surgery. He looked as though his wings had been amputated.

Thankfully, before he was subjected to any further damaging invasive procedures, P recalls a student saying 'stop - I think he has FOP!' This student only recognized the condition, because they had studied under Professor Roger Smith, Professor Paul Wordsworth's mentor at the University of Oxford. P then came under the care of Professor Jim Triffitt.

P believes the condition began when he went abseiling and banged his back on a rock whilst away with the school for a swimming competition. It did not break the skin, but soon, the tell tale FOP swelling appeared. He describes that 'tingle' as being absolutely distinctive and knowing immediately that this is the start of another flare-up.

He describes what a flare-up feels like.

'Imagine you are swimming and you get the worst cramp ever, really bad worse than you've ever had. Well, then imagine that your muscle inside is burning, red hot, all the way along it from the point of swelling right along to the other point on the wrist. And then it feels like it has teeth and it's trying to eat its way out from inside, through your skin. For two weeks solid. Day and night. And you think you'll go fucking mad 'cos you can't sleep or anything. That's what a flare up feels like'
(P, 19th October, 2005).

This is P's description of how it feels when connective tissue turns to bone and then fuses. It is an incredibly powerful description. This is what it feels like to ossify. How it feels to P. He told me he often controls the pain through sheer will power, whereby he feels the ache and the process of ossification in the flare-up, but tunes out the agony. Although P uses a walking stick he is very active. He is unable to put his hands to his face and told me whenever he smokes he sticks a cigarette on the prongs of a fork attached to a stick and holds that.

My experience of working with 'living' subjects is limited to years I have spent life drawing. Drawing a model in the life room or studio is a very different experience from going into the home of a stranger, especially the home of one who suffers from such a rare and horrific disease. I asked the people with FOP who participated in this project to choose when and how I drew them. P has a special armchair that has been designed to tilt so he remains supported in an almost completely upright position, as he is unable to bend. His walking stick is longer than a usual one. He wore shorts, a sleeveless t-shirt and had gelled his hair.

While drawing I could see clearly that he has a broadened neck that is rigid from fusion and extra bone is visible beneath the skin of his shins. After completing my first drawing (Delineation 5, p. 147), I drew more detailed images of his hand, concentrating on the thumbs which whilst not deformed do appear to be shorter than usual (Delineation 6, p. 149).

He allowed me to draw his feet (Delineation 7, p. 151). As he cannot bend, I had to remove his socks for him. This was a very intimate moment as I was removing clothing from a man I had only just met and he in return was in a vulnerable position, relying on me and entrusting me with this very personal task. We discussed his feet, issues of balance and how vital a chiropodist is. After I drew them, I put his socks back on for him. His toes are deformed, particularly the big toe on his left foot, which curves back inwards.

On 29th October 2005 I met K. She is fifty-one years old and lives with her seventy-seven year old mother. K was born with severely deformed hands and feet. This was the extent of her disability as an infant. The first sign of FOP appeared when K was six and a half years old and swelling become visible from her ears down to her shoulders. She was diagnosed with FOP at seven years old.

K told me that on the morning of her fifteenth birthday, she was walking to the bus stop when she was hit by a motorbike which drove off and left her with severe hip and leg injuries. This accident changed her life. She told me her father had just deserted the family that morning. After being

given pills to help a flare- up she became sick and dizzy and fell. She had to stop her studies, and was made to stop taking all vitamin D. This misconception at the time seemed logical as bone growth is linked with vitamin D. K told me she was a great believer in massage, yoga and swimming and that keeping active was the reason she was so mobile.

When I met her she was wearing a blonde wig with a hair slide and a scarf. Her extended walking stick resembles a shepherd's crook (Delineation 8, p. 153). K took a long time to feel comfortable with me drawing her and wanted to spend a long time talking. Sitting in an alcove she remained in shadow seated on a high pile of pillows on a stool. Her fingers are all incredibly deformed and the frozen features of her face stayed rigid throughout our conversation, like a mask. She wears specially made large shoes which help her to keep her balance when she is mobile.

In July 2006 K fell and broke her leg. She was in hospital and had asked if I would like to visit. I asked if she wanted me to draw her and she said yes (Delineation 34, p. 155). I went to visit her on 25th July 2006. It was an incredibly hot and humid day and the hospital had no air conditioning, only electric fans. K was in a separate side room. She was propped up on lots of pillows, her bed tilted to almost sitting position and she wore her blonde wig with a pretty blue slide.

She has accepted the news that her broken leg means she will no longer be mobile far more stoically than I could ever imagine being if I were in the same position. After her lunch I sat and drew her while talking about skin care and saunas. She held her severely shortened and deformed fingers together as if in prayer and looked far more vulnerable to me, lying on the hospital bed, her head sinking into the pillows as we chatted. The fall has aged her and her frozen face seems more rigid than previously. She will be unable to return home and can no longer walk.

Many medical journal articles include clinical photographs of sufferers and descriptions of observed physiological changes that have taken place in the patients. Examples of these will be discussed in Chapter 5. However, I argue that to gain further understanding of FOP, the

contribution made by the sufferers is necessary. Their first hand accounts describing what FOP is like in their own words are crucial.

I worked from November 2005 until May 2008, on the main project: the process of delineating two patients who donated their bodies to the RCSEng. During these two and a half years I also photographed the processes involved and kept a notebook. I will now give an account of the encounters with the donors and the processes used in their preparation. A detailed analysis of the delineations made will be described in Chapter 6.

Account of main project

Both donors are female and I will refer to them by the museum numbers given to them to preserve anonymity. The donor known here by her museum number 7646 is a fifty-year old female. She had developed torticollis following an episode of 'myositis' at the age of two years. Torticollis is a muscle spasm in the neck that causes the head to twist to one side. She was able to swim and ice skate in her teenage years. Subsequently she became progressively disabled but worked as a secretary into her forties.

The donor known here by her museum number 8149 had survived until she was seventy-seven. She suffered her first episode of ossification at the age of six years, when she fell from a gate. She was completely disabled for the last twenty-five years of her life. She had been diagnosed with FOP at nine years old. At twenty she decided to be set prone not seated. Her brother would place her on a board, put down the car seat, push her in and swivel her so she was propped up enough to see out of the window. She could not speak clearly towards the end of her life. Her teeth were removed to make room for food to go in. Her brother described her as always happy.

On the 8th November 2005, once permission had been gained, I started working alongside Martyn Cooke, photographing and drawing progressive removal of tissue, treatment of bones and all the methods and processes involved in preparation of a large-scale specimen. We agreed to coordinate our working times so Martyn only worked when I was also there. Our sessions together were usually once a fortnight but on many occasions they were more frequent and a couple of times there were longer

gaps between sessions due to technical problems. The following is a description, taken from accounts in my notebooks, of processes and experiences of my main project in this research.

I felt overwhelmed by my first encounters with the donors. 7646 had a lot of flesh still around the thoracic area and shoulders and her lower jaw had fallen off. 8149 still had her feet intact and the deformity in the great toe on her right foot revealed the abnormality usual in FOP. Her left toes were severely deformed and she appeared to have only her large toe and two strangely angled smaller toes remaining.

Due to lack of articulation and the need to avoid destroying the ectopic bone protruding from the main skeleton, the bodies could not be separated into small, easy to manage sections as is the usual method. Martyn concentrated on getting 8149 ready for display. He began working on her left arm. The tissue had become soft after being left to simmer in a tank of water and the use of more Antiformin gel. Her skin was pale and flaccid, like a drowning victim and her fingers were only attached by the loose skin. Once these fell off they were labelled and kept for safety in a plastic bag.

Small sections were treated separately. A section would be placed in a jar and Antiformin applied with a brush to reduce the tissue down into a more gelatinous consistency. Then sodium perborate powder, another bleaching agent, was sprinkled liberally over the section and then slightly cooled. Boiled water was then poured over the specimen. When effervescence occurs the oxygen bubbles produced strip flesh and detach tissue and allows it to float to the surface. The crystallized residue comes off easily. Brushing on Antiformin softened tissue but the sodium carbonate and hydroxide in it will eventually destroy bone so care has to be taken over the amount of application. The tissue became gelatinous and after about ten minutes, Martyn would return to scraping the tissue away with a curved scalpel. It was a very smelly process.

Unlike a normal skeleton that would have been broken into smaller neat sections with holes drilled at each end of the cut bones so that the fat from inside the bones could be removed easily, there are no appropriate points

at which to split and divide up 8149 easily. She had naturally separated into some sections but from the head down to her pelvis, she remained in one fused section. There was difficulty separating her in the normal way because of the nature of her ankylosis. The main section is from her head all the way down to her pelvis and includes the left femur and left humerus. The top of her cranium had been separated, as had the whole of her right leg, lower left leg, lower left arm, whole right arm and patellae.

Many practical problems kept arising. Most reoccurring problems were concerned with the simmering tank. The original plan had been to remove tissue by placing the bodies into a tank of hot simmering water. This is a gentle and safe way to remove tissue but can take a long time. However, the fuse kept blowing, water would not reach a high enough temperature and often we were reduced pouring boiling water from a kettle which was awkward and messy. Another problem was the overuse of Antiformin or sodium perborate, which can actually damage the bone so we had to be careful how much, was used. On the other hand, Martyn also had to be careful not to cause too much damage with the scalpel blade either. It is very messy work. All human waste was collected in special containers to be disposed of appropriately and ethically in a cremation ceremony, at a later date.

Preparation is a time consuming, intricate and laborious progress. Equipment became so slippery that several times a session, the scalpel would fly from Martyn's hand because his gloves were so greasy from fat. The gelatinous consistency of the tissue meant it attached itself to the blade which became gunged up. The process is quite dangerous, extremely fiddly and tedious. Tissue samples were also taken from a tumour found on the pelvis of 7646. This was prepared, stained and examined. The processes used have already been explained and the resulting delineations will be discussed in Chapter 6.

Throughout the two and a half years spent working on this main project, smell has been an intrinsic part of the whole experience. Though it is not visible, it is an aspect that has continuously dominated the project with its presence and is inextricable from the experience. The olfactory encounter has been as much part of the phenomenon as the ocular. The smell is

something like a combination of un-emptied rubbish bins left out in the heat, rotting flesh, vomit, ammonia and other caustic chemicals. Its intensity throughout this project varied between constant background ambient smell, to becoming eye watering and almost unbearable in its intensity. There were moments when the smell, this miasma even induced gagging.

Two of the worst experiences of smell were results of Martyn's decision to try using enzymes Pancreatin and Papain to see if they worked any better than the techniques previously described. The human body contains natural enzymes that break down meat in the stomach. We tried Pancreatin first. This is a mixture of several digestive enzymes produced in the pancreas. To one bucket of 100 ml saline we added 20 grams of Pancreatin and 10g sodium sulphide.

It stank. The smell of intestinal juice and rotting food as it breaks down decaying meat is absolutely horrible even in the fume cupboard in the preparation room. The stench became so unbearable we agreed to stop and return to scraping, and digging. Then Martyn tried using Papain. This is an enzyme used to break down meat fibres and is a component found in powdered meat tenderizer. It is an enzyme that breaks down more naturally but a lot is needed and it has to stay on for a long time to produce natural tissue putrefaction. This helped to loosen tissue but was taking too long so we tried using Pancreatin again. However, we found the smell to be overwhelming and went back to using Antiformin, which is more damaging. As it removed more tissue, fingers and toes began to fall off. These were bagged and labelled.

At times during the project, Martyn needed to wear two pairs of gloves at the same time to protect him from the scalpel blade. On occasions the process needed great effort, for example, 8149's right leg became very glutinous and flesh had to be scooped under to push it away and then wrenched off with forceps and sliced with a scalpel. In another incident cartilage found at the knee was very tough and Martyn struggled sawing and cutting. Scalpel blades continued to break while he scraped muscle, tissue and fascia. Everything got greasy and clogged up with fat and I kept

getting very tired and dizzy as the extractor fan was sucking all the air out of the room. It helped a little but the smell was always there.

It was difficult scraping flesh and tissue from normal skeletal bone because it is textured and rough so connective tissue is able to stick to it. But flesh and tissue just *fell off* heterotopic bone easily as, unlike normal bone, it has an incredibly smooth surface. The main project was completed when all tissue had been removed. Separated toes and fingers have been set aside and identified. Once de-greased, a simple process to complete removal of any remaining fat from bones, preparation is finished.

This project was an intense, long-term collaboration between Martyn and myself. The work involved was recorded in my notebook and documented using photography.

Conclusion

In this chapter I have examined the importance of both recording my experience and my understanding of the object through the activity of drawing. Part of this involved the process of learning about the tools and techniques and participating in the use of these methods. Further justification for this experiential approach can be seen in the work of Henry Dreyfuss who said,

'I have washed clothes, cooked, driven a tractor, run a Diesel locomotive, spread manure, vacuumed rugs, and ridden in an armoured tank. I have operated a sewing machine, a telephone switchboard, a corn picker, a lift truck, a turret lathe, and a linotype machine...We ride in submarines and jet planes. All this in the name of research'

(Dreyfuss, 1955, p. 64).

In the following chapter I will present a detailed analysis of my delineations and other images to support the claims made in this inquiry.

CHAPTER FIVE

History of visual evidence of FOP

In Chapter 4 I gave an account of my experiences of delineating histology and FOP. To set this practical work against its broader context this chapter will examine other approaches to the pathology and experience of FOP. These include photographs of patients taken from medical journals, an examination of historical drawings of 'Living Skeletons' and description of two documentaries about FOP sufferers.

This is followed by an analysis of my delineations in Chapter 6. I looked for significant groupings and considered the different purposes and contexts of the delineations, the development of the process over the project and the value and effectiveness of the different groups.

Introduction

The pathologists Charles F. Geschickter and I. H. Masreitz wrote,

'Although many cases of MOP [Chap. 5, p. 116] have been collected in literature, only 2 were found in the series of 25 cases of muscle ossification. This form, which was first described by Guy Patin in 1692, usually begins in childhood and has a predilection for the muscles of the spine. As the name implies, it is progressive and eventually involves the muscles of the entire skeletal system'

(Geschickter & Masreitz, 1938, pp. 661-674).

In fact Geschickter and Masreitz, were incorrect in their date as Patin gave this description in a letter dated 1648 based on a description by his unnamed correspondent, Patin's text translates as follows:

'As to the observation that you made on the woman who became as hard as wood, it is a very rare example. I definitely do not remember having seen or read of anything similar, except for the child that petrified inside its mother's womb about which Mr. D Aliboux, Mr. Rousset and Mr. Bauhin wrote, and which is usually called Lithiodium Senonense. It is a good example of diseases of the kind that [Jean] Fernel studied: if this hardness could

be treated, I believe it would require frequent purges and mercury salves, and waters from Alsie and Flavigny, commonly called Sainte Reine'
(Patin, 1688, p. 33).⁶

This has been recognised as the first description of a case of FOP. Others include; John Freke's account from 1736,

'As the Ramifications of Coral do, they make, as it were, a fixed bony Pair of Bodice'
(Peltier, 1998, p. 6).

And that of Reverend William Henry in 1759 who described a young man of whom,

'A great part of his body is, within the space of two years, ossified; and the ossification is continually seizing more of the muscles'
(Medical Museum, 1763, p. 38).

Reports of FOP can be found in medical journals, in many different specialist areas of medicine, including: rheumatology, orthopaedics, paediatrics and medical imaging. When viewed externally, FOP has been shown in a similar way for decades. Photographs show patients in their underclothes and they are made anonymous by using a 'black box' effect to disguise their eyes, or are positioned so their faces are completely excluded from the composition. Sometimes cropped, fragmented images of feet or hands are represented. Imaging techniques like, CT scans, X-rays or bone Scintigraphy which is a form of bone scanning that shows where active bone formation is occurring, etc. are used to reveal internal structures (Trikha, Kumar, Khan & Rastogi, 2005). Two examples of

⁶ The original letter is in the British Library, the translation above was provided for me by Laura Keshav. The original text is : *'Pour ce qui est de cette obsevation que vous avez faite de cette femme qui est devenuë dure comme du bois, c'est un exemple fort rare. Je ne me souviens point d'avoir vû ni lû rien de pareil, si ce n'est de cet enfant qui se pétrifia dans le ventre de sa mere à Sens, duquel ont écrit Mr. D' Aliboux, Mr. Rousset, & Mr. Bauhin, & qui s'apelle ordinairement Lithipædium Senonense. C'est un bel exemple pour maladies de la matière de Fernel : si cette dureté étoit capabl de remedes, je croirois qu'il feroit befoin de purgations fréquentes & de la salivation procurée par le Mercure, & les eaux d'Alfie & de Flavigny, appellées vulgairement de Sainte Reine. Je suis, &c. De Paris, le 27. Août 1648'*

images of infants from 1899 and 1914 are notable as the child or infant photographed is shown held in position and someone other than the patient is visible.

In an early photograph of an FOP sufferer, the case of a six-year-old boy is described in the *Lancet* in April 1899 (Crawford & Lockwood, 1899). His illness was first noticed as stiffness in the shoulder after a fall when he was two and a half years old. He has been photographed from the back. This is because the effects of FOP are most visible around the shoulders, spine and hips. He is shown hunched and naked, held on a woman's lap. As an observer unable to ignore my feelings I found him vulnerable. There is something about his being 'held' which troubled me. It is not clear if the hands belong to his mother or a nurse and the image of them grasping him emphasises the horror of the onset of constriction.

By comparison, an article in *The American Journal of Bone and Joint Surgery* by FOP expert Dr. Fred Kaplan contains two images of a four-year-old girl (Kaplan et al., 1993). One photograph has been taken from the back and one from the left side view. The characteristic bony ridges are apparent on her back but she has been allowed both anonymity and rather more dignity than the little boy discussed in the previous example as she is wearing underclothes and the photograph has been cropped so her face is not revealed. She appears to be standing and supporting herself alone, which gives a greater sense of willingness to be examined than the little boy discussed above. Both children have the characteristic shortened neck and their heads are jutting forwards.

Physicians Frederick Parkes Weber and Alwyne Compton describe a seven and a half month old baby in a case study in the *British Journal of Children's Diseases* (Weber & Compton, 1914). In the accompanying photographs the baby is shown with her legs grasped firmly by the knees to allow a photograph to be taken of her feet while she is in a standing position (Fig. 19). In the following photograph, she is being held in a seated position with her legs extended straight out in front. Hands grip her feet, turning them to the required angle. In the second, another pair of hands appears to be holding her in a seated position. To me, these hands seem to intrude disturbingly and restrict the patient in a way that gives the

impression of being constraining and uncomfortable rather than supportive. Compton, co-author of the article, also drew all the microscope drawings. Until the development of photomicrography, this was the only way to reveal what was viewed under the microscope. The article is also rare in its use of drawing to visually describe the specific sites of swellings using simple outlines and dotted lines drawn over diagrams of torsos to show the areas discussed. The drawings visually explain the areas in question incredibly clearly.

Fig.19 Child's feet (Weber & Compton, 1914, p. 498).

In contrast, in *Genetic Transmission of FOP*, another article written in the American Journal of Bone and Joint Surgery, the feet of a baby and a toddler have been photographed from above so there is no visual 'interference' from grasping hands. Even the photograph of a nodule on the baby's back has been taken when he is lying face down. He remains anonymous and appears to be comfortable. Again, the print has been cropped to allow anonymity (Kaplan, et al., 1993, p. 1219).

Images of adults tend to show the side and/or back view. Patients are usually anonymous and shown wearing underclothes. In another example in the same article, *Genetic Transmission of FOP*, a twenty six year old male is depicted in full view. The accompanying text describes him as,

'showing a thin body habitus and fixed deformity of the neck, chest, back, left elbow, pelvis and right ankle'
(Kaplan, 1993, pp. 1214-1220).

He is presented from both front and back views and the photographs have not been cropped but instead carefully composed in what appears to be a

studio setting (Fig. 20). This helps to give a fuller picture of how the patient has been affected by the symptoms rather than just depicting evidence of the symptoms themselves. A 'black rectangle' has been pasted over his eyes in the photograph and he is wearing dark shorts.

His unusual stance has been lit so he casts a dramatic shadow. He has been illuminated from two sources and the pictorial space he inhabits is clearly defined by allowing the division between the floor and the wall behind him, to be shown.

Fig. 20 Male patient (Kaplan et al., 1993, 1215).

There are similarities between the image of the patient in Kaplan's article and with the photograph of Albert Schwartz, a patient of Professor Rudolph Virchow, the 'father of pathology'. This photograph is dated August 1896 (Fig. 21). Schwartz was aged thirty-one when his picture was taken and he earned a living showing himself to medical schools for money. He has been photographed naked and from the back view. Half his body has become engulfed by the surrounding darkness. The strong light on the other side acts as sharp contrast and picks out in heightened detail the bony ridges that form the landscape of his back. His face remains

hidden as it is turned away from us. His head has the characteristic forward tilt and he appears to merge into the murky surroundings.

Fig. 21 Albert Schwartz. (1896). From the Wellcome Library.

The use of sharp contrasting light and shade and the strong composition of the pose make this an extremely dramatic portrayal of an FOP patient and there is a strong visual correlation between this photograph Fig. 20. Both focus on the visual drama of FOP and concentrate on the effects of strong lighting.

Other than from medical journals I have found a source of images of people exhibited in circuses known as 'Living Skeletons'. Some of these in fact suffered from forms of muscular atrophy and lack of skeletal development. Others had FOP. Two of these 'Living Skeletons', Jonathan Richardson Bass and Claude Ambroise Seurat are significant to this research as drawings were made of both of them.

Claude Ambroise Seurat is relevant because in 1826 he was the subject of drawings by two very important artists, Goya and Cruikshank.

FOP drawings – “living skeletons”

In the 18th and 19th Centuries, Spanish artist Francisco de Goya conveyed through his drawings, not just what a disease looked like, but also its context. His images go some way to displaying the experience of what it might be like to have a condition, how it affects, transforms and is part of that person. His sketchbooks present several examples of his encounters with disease. His drawing of a beggar afflicted with elephantiasis is an effective interpretation of the man's condition. In another image, a man suffering from obesity has not been mocked or caricatured in his drawing, but depicted clearly and concisely (Gassier, 1973). The lines emphasize the fact the sufferer is unable to stand while at the same time capture the personality of the man. How the condition affects the man is revealed rather than just what the condition looks like. He is depicted as an individual and his experience of obesity is expressed as unique to him through Goya's sympathetic lines.

Claude Ambroise Seurat, was a completely emaciated man dubbed the “Living Skeleton” who frequently exhibited himself at circuses in the tradition of freak shows. Born in France on 10th April 1797, he seemed healthy but by ten years old was feeble and revealing his skeletal form. He was reputed to have a very weak and shrill voice (Gould and Pyle, 1897, p 364).

Goya's drawing of Claude Ambroise Seurat is a remarkable example of an FOP sufferer.⁷ He portrayed Seurat, standing alone, supported by a walking stick (Fig. 22). Seurat's thin legs and arms are devoid of muscle and he appears to be isolated and vulnerable. His neck and left arm reveal evidence of ankylosis and there seem to be deformities in his hands as drawn both by Goya and Cruikshank. Unfortunately neither made images of his feet.

⁷ 'H.45 [460] p. 616 *Claudio Ambrosio Surat / Llambado el Esquelete viviente/ en Bordeaux ano 1826* (Bc) (Claudio Ambrosio Surat known as the living skeleton in Bordeaux the year 1826) – 1826-28-Bc-No. (Bc)-Paper: horizontal chain lines – (26 mm) – Hist.: Javier Goya; F.de Madrazo; Saragossa, B. Montanes; Madrid, A. de eruete; Berlin, Gerstenberg (after 1907) – Destroyed (1945) in Berlin, formerly Gerstenberg coll. – GW 1806' (Gassier, 1973, p. 643).

Fig. 22 Goya's Claude Ambroise Seurat, 1826 (Gassier, 1973).

In an article in the British Medical Journal, clinicians Richard H. R. Park and Maureen P. Park suggest the description of the scapula to be the same as Sprengel's disease; described by Otto Sprengel in 1892 and the deformity of the neck to be Klippel-Feil syndrome discovered in 1913 (Park & Park, 1991). This diagnosis was later disputed when surgeon Geoffrey Hooper suggested in his article that Seurat might have suffered from MOP (Hooper, 1992). Myositis Ossificans Progressiva was the term previously used for FOP. It is still sometimes used, but rarely. MOP is usually caused by impact and bony deposits form in deep muscle tissue. Hooper made a diagnosis from evidence revealed in a drawing.⁸

⁸ The affect of analysing visual evidence revealed through drawing also occurred when Mr. F. C. Wells, a thoracic surgeon, found that a drawing made by Leonardo da Vinci of the heart, actually made him successfully alter his technical approach to a surgical procedure (Da Vinci clue for heart surgeon, 2005).

The English illustrator George Cruikshank made drawings of Seurat entitled, *'Living Skeleton (The) An Account of that Most Extraordinary Phenomenon called the Living Skeleton, Claude Seurat, now Exhibiting at the Chinese Saloon, Pall Mall, etc'* in William Hone's *Every day book* Vol. I. (Hone, 1826). Evidence found in these drawings shows major skeletal abnormalities, including deformities of the scapula and a short, broad neck. Seurat's arms appear to be fixed in a slightly raised position (Figs 23 and 24).

Fig. 23 & Fig.24 Cruikshank's Claude Ambroise Seurat (Hone, 1826).

Despite neither artist drawing his feet, there is a description that

'The feet are well formed; a trifling overlapping of the toes is probably accidental'

(Hone, 1826, p. 35).

This 'accidental' malformation of the toes is further evidence that Seurat had FOP.

Jonathan Richardson Bass was born in 1830. He was known as the 'Ossified Man' and the 'Stone Man'. Although he suffered in childhood from severe bouts of rheumatism, a flare up did not occur until he was seventeen years old. The similarities in description with patient P are apparent. According to writer and journalist B. M. Stickney,

'It started in 1848 with a morning of stiffness of the joints that Jonathan Bass easily shook off and then finally hit on July 22 when he was strolling down the High Street in Lockport and "suddenly the ball of his right foot felt as though some sharp instrument was penetrating it to the bone." He took off his boot, yet failed to find the peg or nail that could have caused the pain. He limped home and the pain turned to a burning sensation.

He couldn't even stand up the next day and the pain spread to his knees. He was treated again for rheumatism. He was seen by a number of physicians, but, what became defined as Bass's already unknown "malady" continued until fall 1848 when he could finally only walk with a cane or crutches'

(Stickney, chap. 2, para. 2).

By 1857 his jaw was ankylosed and his teeth were knocked out to allow him to eat. Fearing he was a burden to those caring for him decided to earn some money.

He was first exhibited as "*Living Wonder of the Age, the Ossified or Bone Man*" in 1887. Unlike other ossified people, Bass was shown in an upright position, strapped to a board. A photograph taken nine years before the photograph of Albert Schwartz is the earliest photographic depiction I have located of someone with FOP. He is shown lying down in a coffin-like bed he had specially built. He appears to be completely immobile and the severe deformity of his toes is clearly depicted. The evidence is strong that Bass had FOP.

Anonymous illustrations depict Bass from the front and the side (Gould & Pyle, 1897, p. 787). Despite being very small drawings the deformities of his big toes are clear (Fig. 25). The tiny illustrations are minutely detailed and cross-hatched in ink.

Fig.25 Jonathan Bass illustration
(Gould & Pyle, 1897, p. 787).

Fig.26 Woodcut of Bass 1882 (Anderson, 2008).

A woodcut print of Bass appeared in The Davenport (Iowa) Daily Leader in January 10th 1892. Bass is show in an upright position with a clamp supporting him around his thorax (Fig. 26).

The inclusion of his toes in the drawings makes it easier to diagnose Bass than Seurat. However, the evidence is strong enough to lead me to the conclusion that Seurat also had FOP. The film historian Miguel Abad Vila provides further support for this view in a recent article. In it he examines the medical conditions of actors in the cult film 'Freaks' and he states that some of the 'living skeletons',

'are probably affected by an extremely rare disease called Fibrodysplasia Ossificans Progressiva (Myositis Ossificans Progressiva), a group in which we highlight the classic Claude Ambroise Seurat. He exhibited himself as a phenomenon in the fairs of Europe at the beginning of the 19th Century'

(Abad Vila, 2008, p. 58).

The drawings by Goya and Cruikshank appear to be the earliest depictions, but the drawings of Bass are the first to clearly portray the deformed large toes that are still the initial way to diagnose the disease. My investigations conclude that hand drawn images made directly of FOP sufferers have not been made since the depictions of Bass which were made one hundred and eleven years ago.

Other than through drawing, filmmaking has also been used as a way of offering information about FOP. Two documentaries have been made that attempt to both explain the condition and give patients' perspectives to the public. I will describe them briefly.

The Skeleton Key

In 1999, the BBC transmitted the documentary *The Skeleton Key*. This is a clear, moving, and passionate explanation of FOP made in the United States. In the opening scene, a young man is shown walking in the snow. He is completely stiff and rigid, walking with a long stick associated with sufferers. His progress is so slow another man helps him by picking him up and moving him.

In the documentary, Dr. Fred Kaplan, who is an expert on FOP, describes the disease.

'We have a condition where normal skeletal muscle that moves our joints turns into bone. This is unheard of'
(Sage, 1999).

In the documentary, flare-ups are described as lasting one to four weeks and being red, tender and painful. Once the swelling subsides, newly formed bone floats in the muscle tissue. It then grows and becomes permanent. Descriptions are heartfelt, personal and moving. One of the most important contributions to understanding the progression of FOP is illustrated in the case of Harry.

In 1973 just before his fortieth birthday, Harry whose skeleton is on display in The Mutter Museum in Philadelphia, died. The legacy he has left is the only photographic documentation of the development of the disease from the age of four through to his death. The documentary

explains that photographs of Harry depict him with his head slightly tilted forward and familiar widened shortened neck and sloped shoulders when young. Later photographs reveal a massive tilt in his head and the progression of fusion in his left leg forcing it to be bent back and his right leg which became permanently raised and bent at the knee. His torso curves and bends down to the right, and his head became bowed lower and lower with each passing year.

This was the first documentary made which depicts and makes people aware of this condition. To me, the portrayal of twisted and rigid figures as they continue with every day life in their locked positions is dramatic and moving.

The Girl Whose Muscles Are Turning to Bone

This documentary about FOP made in 2005 by Zig Zag productions for Channel 5 was part of the *Extraordinary People* series and featured seven-year old Luciana Wulkan.

The narrator describes her as having,

'a very rare genetic disorder that causes her muscles and tendons to turn into bone. As she grows older, the condition will lock her limbs, gradually freezing her body into a living statue'

(Quinn, 2005).

As well as deformed toes, a clear indicator that all was not well was the rigidity of her upper body. Rather than being floppy as babies should be, Luciana was stiff and held her head up from an extremely early age. This was because the vertebrae had already fused.

We are told that her first lump developed on her back a few months after she fell down the stairs when she was two years old. This trauma triggered new bone growth. In the documentary her frustration is displayed when she is unable to scratch her own head.

The emphasis in the documentary is on the problems her mother has bringing up a disabled child and the journey of learning more about the

disease while protecting her daughter from the information at the same time. Both documentaries give an insight into the personal experiences of a small group of FOP sufferers and their carers.

Conclusion

So far I have examined images of people with FOP depicted within a clinical context and discussed drawings made of FOP sufferers within the context of circus exhibition and performance.

The photographs of patients described in the first part of this chapter show the general picture of how FOP is presented and its context. They demonstrate problems of dignity and lack of empathy. We experience and remember the photograph rather than its subject. The nature of FOP seems to disrupt the professional consistency that we would expect to see in medical photographs. Possibly the need to capture extreme deformity has led to exaggerated use of lighting etc. and the images seem to focus more on drama.

In this research I have only found four significant sources of drawings of FOP. The two of Seurat are clearly by artists observing unusual phenomena. The drawings are revealing of the artists' experience of the sufferer and it is significant that clinicians have used these drawings to make diagnoses of FOP. Both artists who depicted Bass are unnamed and the illustrations are more ambiguous in that one might have been produced either for medical or popular purposes and the other was made specifically as an illustration for a newspaper. All are depictions of people with FOP presented in the context of them as performers who are exhibiting themselves as 'living skeletons.'

In this chapter I have provided a context in the form of other practices of representation of FOP none of which relate closely to delineation in this research, or other related practices such as Carswell's. In the next chapter I will examine actual material produced in this research.

CHAPTER SIX

The delineations

In Chapter 5 I examined historical examples of depictions of FOP. This chapter examines in detail all but 11 of the 66 delineations produced in this research. Through the descriptions I have developed a scheme of categories indicating different purposes of the drawings as well as their place in the development of the method.

It has been possible to assess the relative success of delineations against their aims and to map the development of the technique through the whole process. Arguably the delineations themselves provide the main evidence of process that has developed and the main aim of this chapter is to provide a framework within which that can be understood.

Introduction to analysis of delineations

During the series of projects that formed the setting for this research I made 66 delineations. All are shown in this thesis as each one forms part of the collection of fugitive experiences of my encounters with the phenomenon. Seen in the context of a system for recording and presenting experiences of FOP, the criteria I am using are specific to this project and do not draw on the critical methods used in fine art. All the delineations have been included here regardless of personal preference, issues of taste, aesthetic quality and originality.

The context of designing an exhibition formed a model for this analysis in a broadly similar way to the use of a theoretical exhibition as a model for the development of designer Graham Whiteley's practice based thesis (Rust & Wilson, 2001). This was an approach employed by Whitely to make creative work central to the thesis. Where contribution to research takes forms other than traditional forms of writing, the emphasis is on the way visual material is communicated. Needing to find an approach to presenting this visual research clearly and to best effect, Whitley looked to the example used by many fine art researchers who have an exhibition of their practice. This was not a practical option for his thesis but he worked on the assumption he was going to have a 'theoretical' exhibition. Bringing together all his drawings gave him a holistic overview of his research and allowed him to develop a model that focused on how the drawings were placed in the thesis and how the text accompanied them. This model is similar to the way I chose work for the museum display as well as how I assembled the delineations within the thesis. It is an appropriate model because my experience, training and methods of working are largely based on the practice of both creating and organizing material for publication and exhibition. Therefore this process provided a very familiar medium and set of critical tools for addressing this visual analysis task.

Original drawings are bound into sketchbooks and their size (A3) means that the whole set would cover a very large physical area if unbound and spread out. I therefore prepared a set of smaller sized (A4) low resolution photocopies to act as place holders for the originals, with which I was very familiar, and allow the whole set of material to be viewed and manipulated as a complete body of work similarly to the development of narratives in Graham Whiteley's research,

'all the events, decisions and connections of the past three years were laid out in view and instantly, concurrently accessible'

(Rust & Wilson, 2001, p. 5).

I spread all the photocopies around on the floor in chronological order. I began to move them and re-order the sequence and realized groups were forming. For example, two groups that formed naturally were the delineations from the Hunterian and Basel skeletons that make up the historical category and the delineations of people with FOP that form the patients' category.

The process of considering what was to be conveyed to the museum visitor provided a starting point for identifying the main categories and the more finely grained subsets emerged from the process of manipulating and ordering groups in the various workspaces where I was able to engage with the whole set of material, for example when working on scanning the images for reproduction.

The selection process continued in the Hunterian Museum in preparation for the exhibition held from 16th September – 23rd December 2008. There were several constraints to consider; the gallery space, the expectations of the curator, expectations of the public, ethical concerns and the order in which the delineations were placed.

The space allowed for 30 of the 66 delineations to be displayed without seeming overcrowded. I made the initial selection alone and then Simon Chaplin, the Director of the Museum Collections and Martyn Cooke took part in a final editing process. I had decided that delineations that were almost duplicates of others or that presented the same thing several times would be excluded. So were any from what came to be the process of preparation category because it was felt these delineations were too gratuitous and beyond the expectations of the public. Other delineations seen to be unsuitable to display included any in which the donor's facial features are too recognizable.

The sequencing of the delineations became an issue, for example, Simon Chaplin pointed out that by placing the delineations of living sufferers after the historical drawings and before the main project drawings, gave the impression that these were drawings of the donors whose bodies were then prepared for display. We chose to put the patient's delineations at the end of the sequence to avoid this confusion.

Categories of delineations

66 delineations were made between August 2005 and May 2008. They have been placed into 6 main categories; *Historical delineations, Delineations of patients, Process and preparation delineations, Workshop delineations, Main project delineations* and *Problematic delineations*. This section starts with a brief description of each category and then goes on to more detailed, descriptive analysis.

Historical delineations

There are 9 of these delineations. Delineations 1 and 2 are of a lower limb kept in the Wellcome Museum of Anatomy and Pathology. Delineations 3 and 4 are of Mr. Jeffs which is in the Hunterian Museum. 14-18 are of specimens at the Naturhistorisches Museum in Basel.

Delineations of patients

There are 5 delineations of patients, 3 of P and 2 of K. The contribution the patients have made to this project is invaluable. Their perspectives on the disease and descriptions from first hand experience of FOP has helped give a fuller understanding of encounters with this condition.

Process of preparation delineations

These 9 delineations focus more on the experiences of encountering preparation techniques. Some, Delineations 21, 26, 36 and 59, capture the events by presenting the sometimes strange or unintentionally gruesome arrangement of body parts that occur when placed, often arbitrarily on the workspace during maceration.

Workshop delineations

These are the 5 drawings I made with other groups. Delineation 46 was made with the medical illustrators and Delineations 63-66 were made with

the archaeologists. I will describe the drawings made by those who took part in these drawing workshops in Chapter 7.

Main project delineations

These consist of 22 key delineations that present my understanding of the object and my experience of the object, through the phenomenological activity of drawing. The experiences of the phenomenon are presented with the intention of communicating further insight to the viewer. The drawings in this category are Delineations 25, 29, 32, 33, 37, 40, 41, 42, 43, 44, 45, 47, 48, 49, 50, 54, 55, 56, 57, 58, 61, and 62.

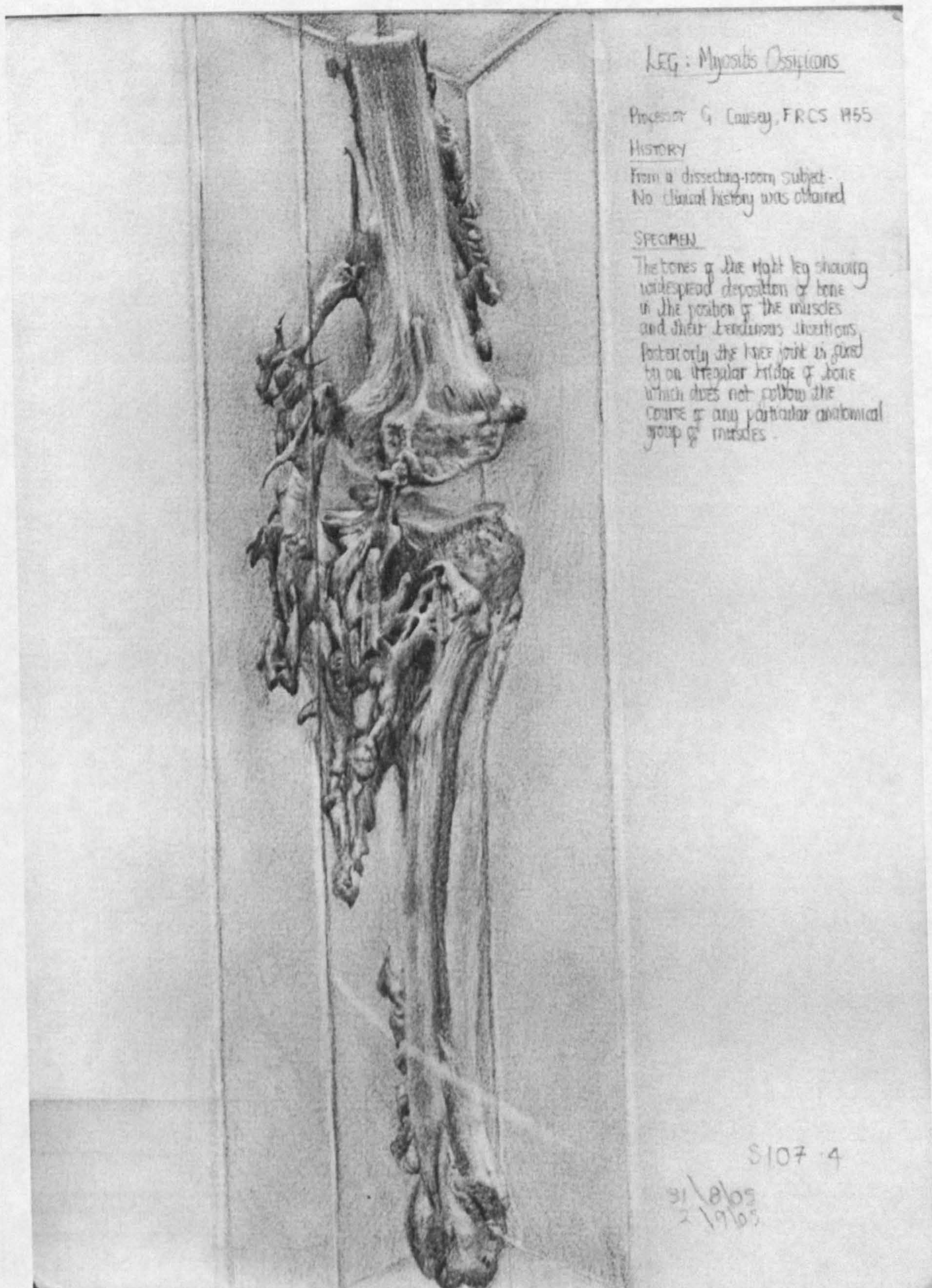
That accounts for 50 of the 66 delineations. The remaining 16 include some that were repetitious or did not advance the work in any recognizable way. 5 of these demonstrate significant problems and will be discussed in those terms in the *Problematic delineations* category. The remaining delineations have been omitted from the discussion here but are included in the thesis.

Each analysis starts with a short description of each delineation which points back to the full descriptions of the projects in Chapter 4.

Historical delineations

Delineation 1 (p. 129) is a pencil drawing of a lower limb prosection suspended in a Perspex jar and was made in September 2005. In previous drawings made during my first experiences in the museum described in Chapter 2, I had incorporated the jars in which specimens are contained, including the highlights and reflections I observed, as these were part of the encounters. I used a very soft pencil and my fingers to smudge.

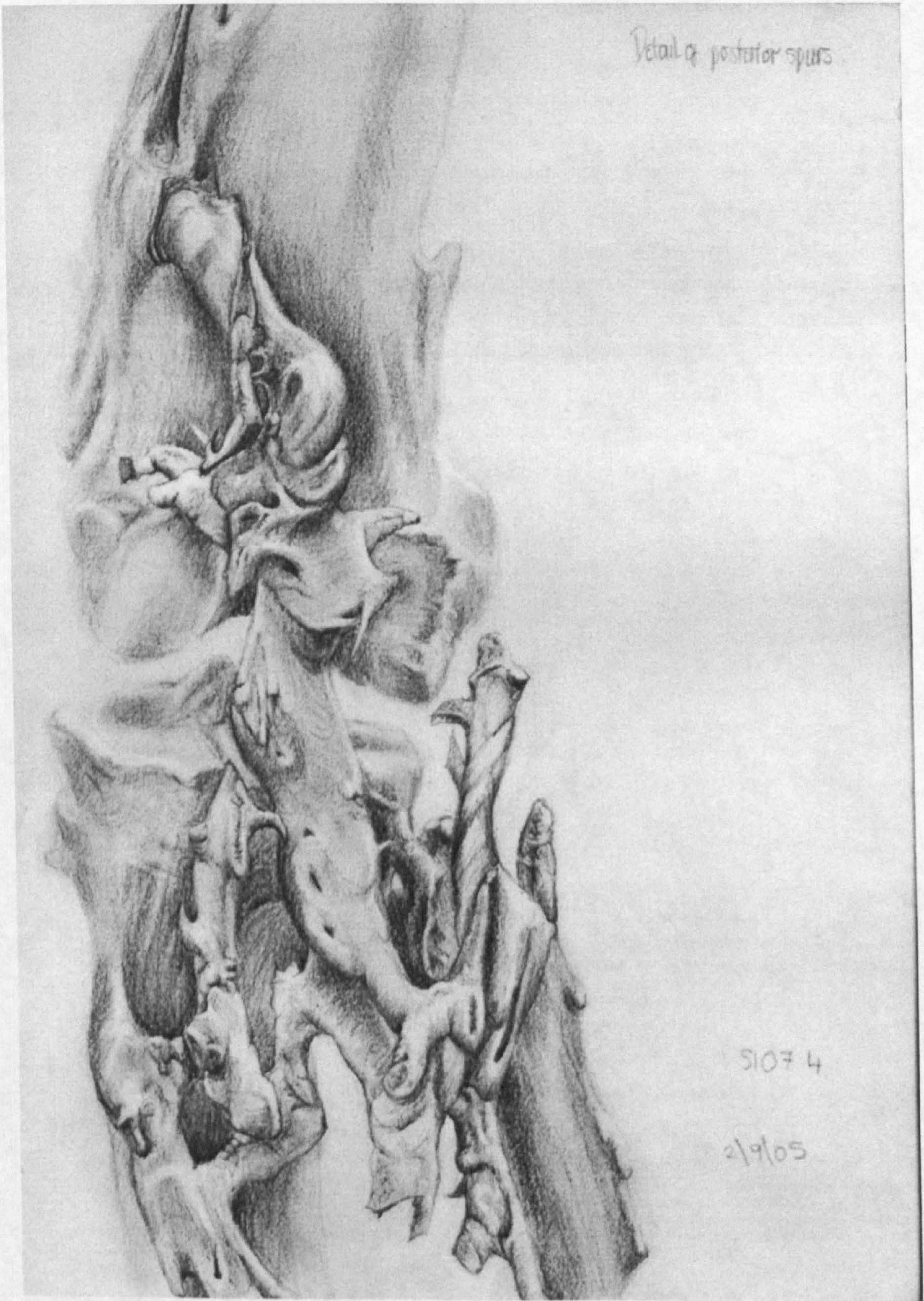
Faced with my first experience with an FOP specimen, I fell back onto this proven formula and drew in a way that was comfortable and familiar to me.



Delineation 1. Leg Specimen In Museum S107.4 (31/8-2/9/05).

In Delineation 2 (p. 131) I drew the same prosection again, this time at a different scale. This scale change meant I had to regard the page in a different way. What I was observing was contained within a specimen jar, but no longer contained by the edges of the page, which was an entirely new departure for my work. This close up also allowed me to focus further on the spurring and bridging which I found extremely hard to comprehend being outside any previous experience of anatomy. There is a great deal of shading and the marks remain soft. The image fills the entire page. The composition is complete and contained within the rectangle of paper but attempts to go beyond it, losing the confines of the jar that has become superfluous to the information experienced. It was like nothing else I had ever drawn. Because the visual encounter with spurring of heterotopic bone was so exceptional I had to re-draw many times to re-see it and attempt to understand this phenomenon.

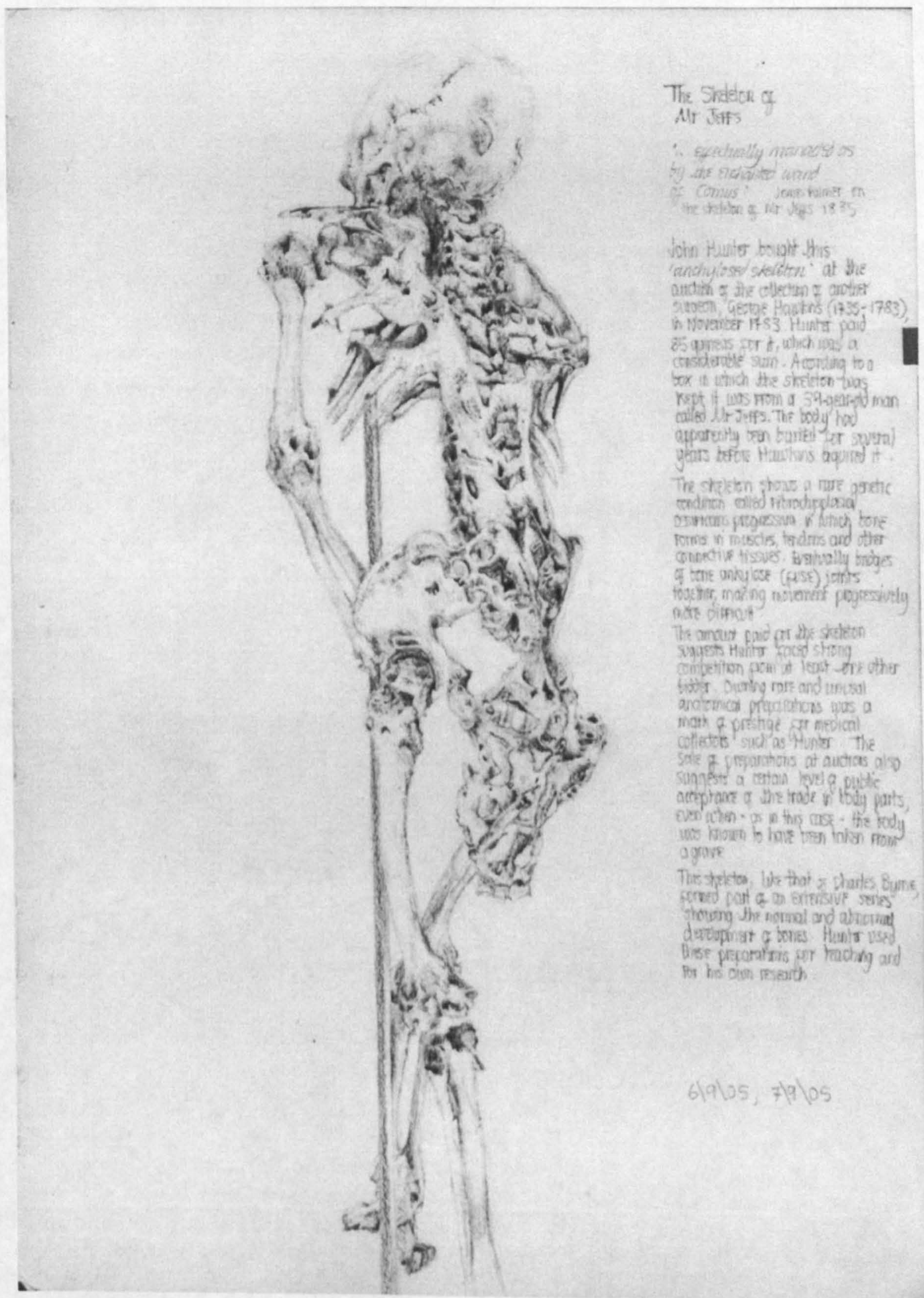
Both these delineations go some way to offering a description of the complexity of some of the effects of FOP. In my opinion they are less clear than later developed delineations within this inquiry as they emphasize shadow and form and demonstrate drawing ability rather than understanding of the phenomenon.



Delineation 2. Leg Specimen In Museum Close Up (2/9/05).

The first drawing of Mr. Jeffs, Delineation 3 (p.133) presents the secondary skeleton of heterotopic bone clearly and precisely in the detail of the delineation. As it was unfamiliar, nothing is assumed. The drawing records a specific encounter with a unique phenomenon, where extra bone is interwoven across the main skeleton and nothing appears as it should. Close observation of detail was vital and re-drawing was an essential part of recording my experience of Mr. Jeffs.

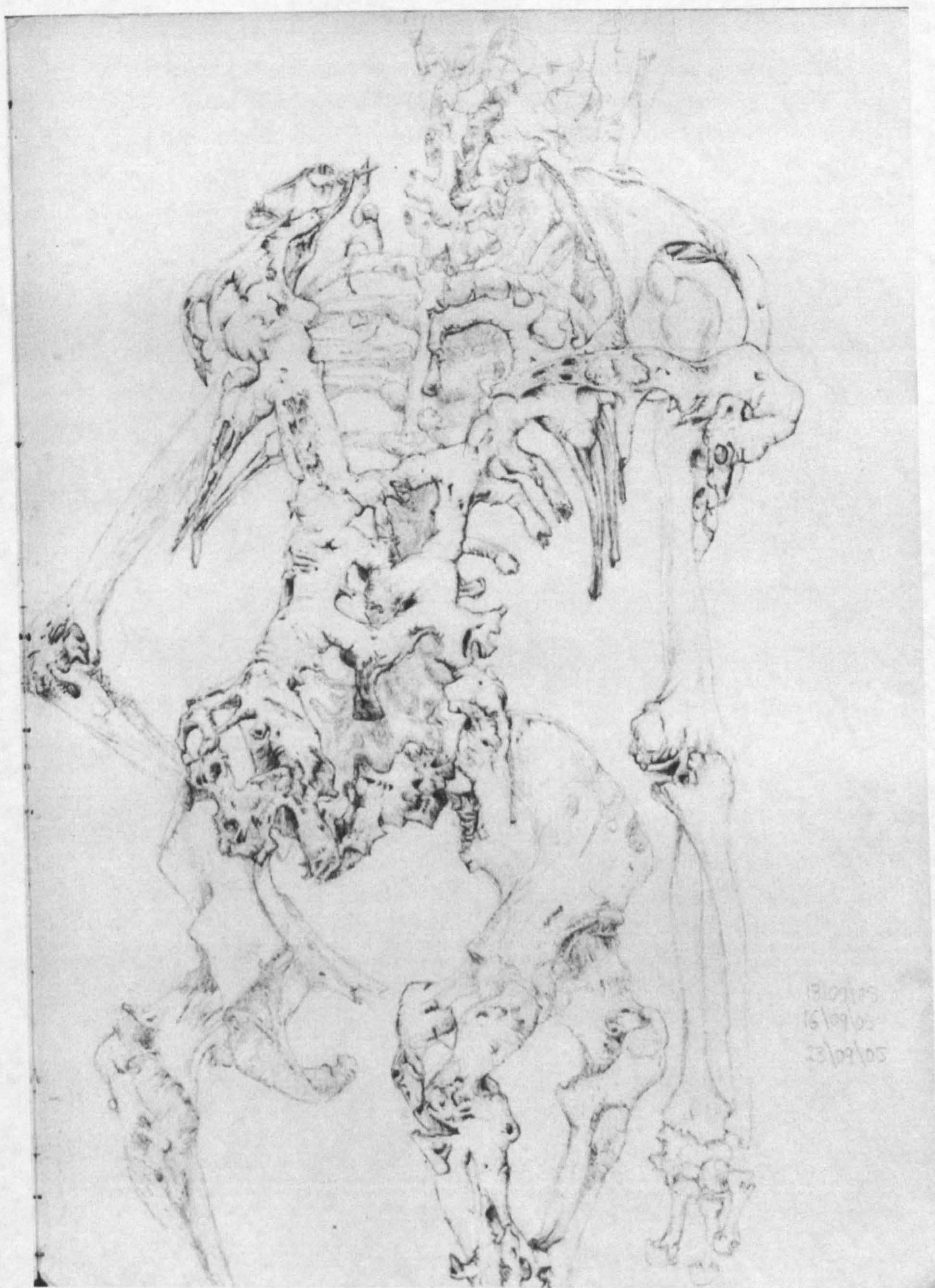
Trying to fit a whole skeleton onto an A3 page meant working at a much smaller scale than I am used to and I was unable to achieve the level of detail I required. It was my first encounter with FOP on a human scale, not just with a fragment.



Delineation 3. Mr. Jeffs (6/9-7/8/05).

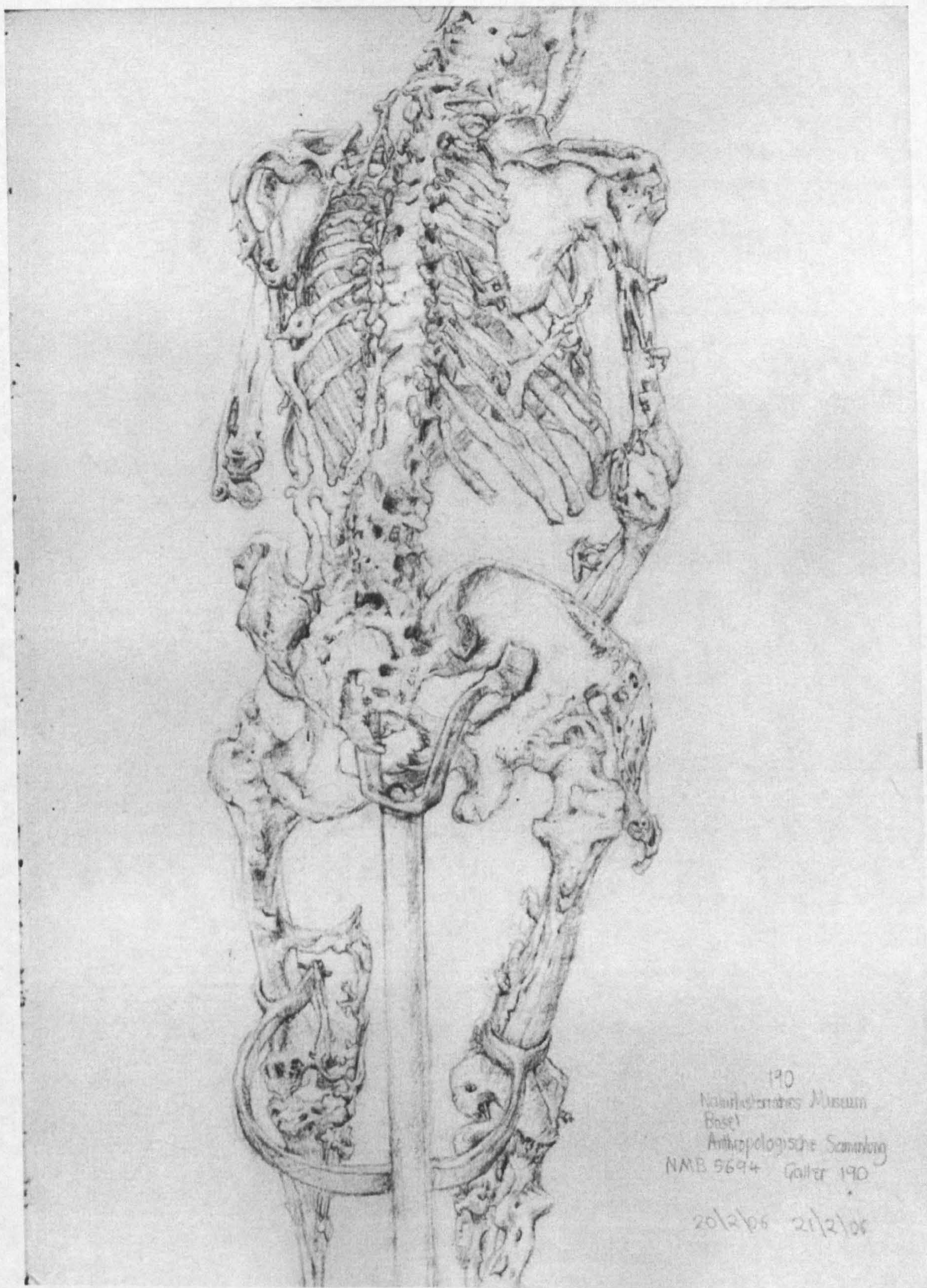
While drawing Mr. Jeffs in more detail in Delineation 4 (p.135) I concentrated on delineating him from the neck down to his thighs where the effects of FOP can be seen most prominently. The system of delineation as used in this inquiry, began to develop. Marks became more decisive and defined, discriminating between relevant and secondary information, reflecting my growing understanding. This was confirmed in the observations of both clinicians and non-experts discussed in Chapter 7.

Delineation 4 signals the point at which I started to understand the effects of FOP on the body and I began to develop delineation as a specific methodology to understand and present the visual experience encountered. I began drawing the secondary skeleton using a much darker, heavier line. This developed as a natural system, allowing information to be clearer without actually altering the data or making a composite. By picking out the relevant detail and changing emphasis on weight of line, I began to present my understanding of the visual experience of the phenomenon encountered. This delineation demonstrates how the action of drawing is able to isolate relevant visual data through the insight gained by the process of drawing. This approach was sustained and developed through most of the subsequent delineations and some of the problems recorded below arose where I departed from it.



Delineation 4. Mr. Jeffs 2 Close Up (13/09-23/09/05).

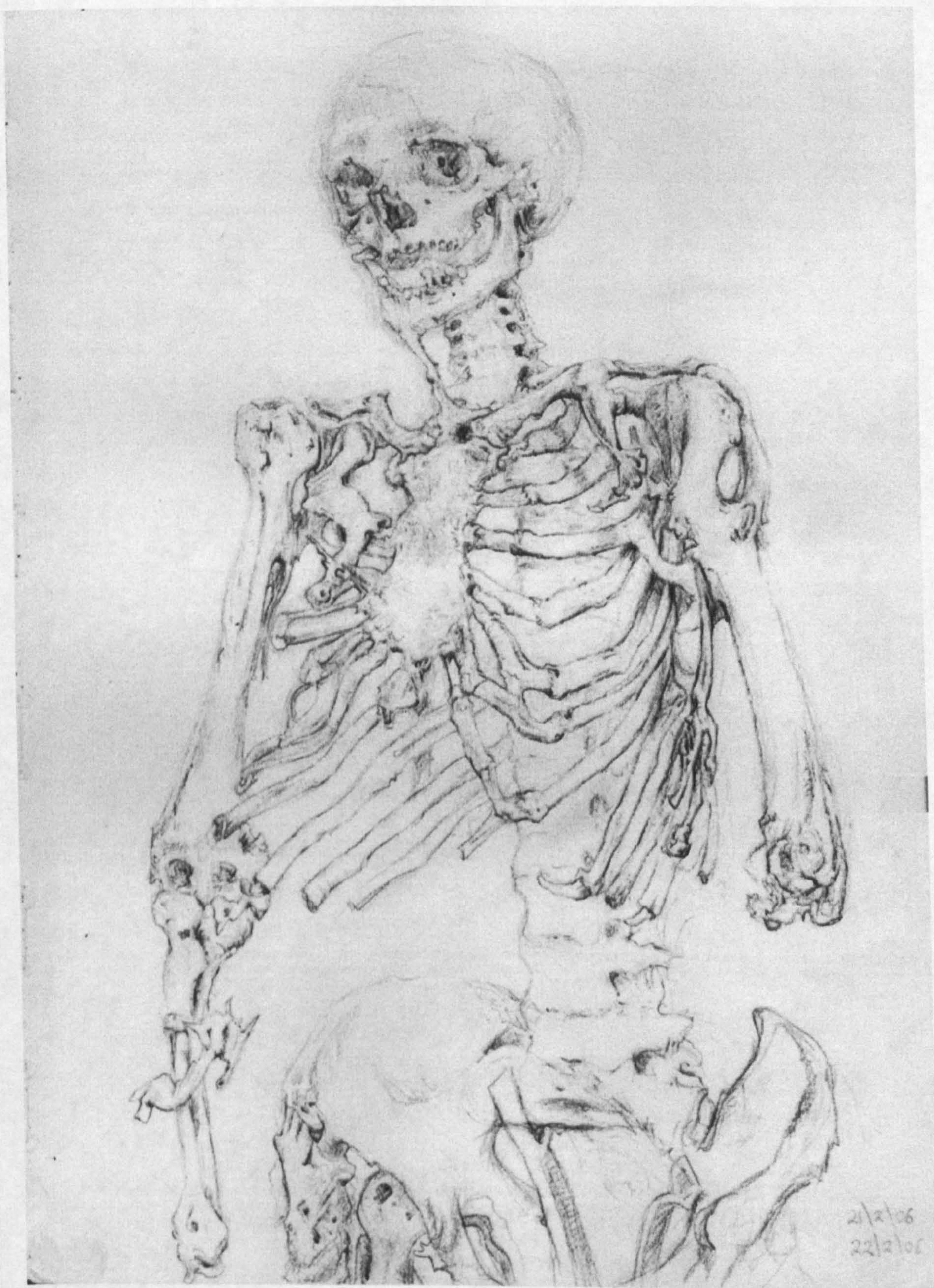
The two skeletons from the collection at the Naturhistorisches Museum in Basel form part of this category. The visual experiences I had of NMB 5695 Galler 190 in Delineations 14 and 15 are presented by the amount of marks made, rubbed out and re-drawn. In Delineation 14 (p. 137) the detail of spurring in the left scapula and the journey taken by the heterotopic bone that has travelled down her spine are drawn clearly. The lines used to delineate the stand and clamps supporting the skeleton are similarly strong but more crude, corresponding with the experience of the crudeness of the object and its purpose. All marks made remain; presenting the number of times I looked and could not understand the fugitive experiences of the phenomena.



Delineation 14. 1st Basel 190 Back View (20/2-21/2/06).

This evidence of difficulty is particularly seen in Delineation 15 (p. 139). This presents a new and very unfamiliar experience resulting in the numerous marks that appear around the skull. They are a record of the frequency I observed and had to re-adjust lines to more precisely convey the complexity and detail of the ossification that had occurred. It was difficult to comprehend the effect because it dealt with the most exceptional aspects of FOP specific to this skeleton.

At this point in the process of intensive observation and drawing, my understanding can be seen to have developed as each mark was made, corrected, reviewed and re-drawn.



Delineation 15. 2nd Basel 190 Front View (21/2-22/2/06).

NMB 5695 Galler 191 has been drawn from the side view in Delineation 16 (p. 141) and I found her skeleton to be one of the most difficult subjects I had ever drawn. The extraordinarily complex detail of the intricate spurring required careful observation and a clear and delicate line to give insight into the experience. Darker lines are used to convey the mass of extra bone engulfing the compressed ribcage that has been more lightly handled to give visual juxtaposition.

Myositis Ossificans Progressiva

Pathologisches Institut Zürich 191

48 J. Wbl. S. 2406/68

Preparator J. Bängli

Naturhistorisches Museum Basel

Anthropologische Sammlung

NMB - 6695 Geller 191



Delineation 16. Basel 191 Side View (22/2-23/2/06).

This delicate, convoluted detail is seen in the close up of spurring presented in Delineation 17 (p. 143). Focusing on this fragment and ignoring other visual data, created a particular experience for me as the observer. This is presented in the delineation. My understanding of the elaborate and complicated shapes formed by the spurring bone is recorded and conveyed to the viewer.



Delineation 17. Basel 191 Close Up, Bridging (23/2/06).

Delineation 18 (p.145) is the last of the Historical category. This time when drawing NMB 5695 Galler 191, I have delineated her from the front viewpoint. Each time I looked, I saw the skeleton anew: by applying intense scrutiny, and by drawing as immediately and directly as possible, new dialogues developed between object and delineator. The movement of marks made in this delineation reveal the beginning of my insight. This can be evidenced by the visual differences presented between skeletal bone and heterotopic bone. The way in which the mass of spurring bone has ankylosed to form intricate bridges locking the pelvis and the legs has been recorded clearly.

There is intensity in the quality of line developed in the delineations of both these skeletons. As noted in Chapter 4, I was working in uncomfortable conditions under the pressure of time and I suggest that the delineations communicate my urgency to place the marks as precisely and immediately as I could whilst in the process of observing closely the phenomenon and my experience of the object. This time factor was very present in the main project where I needed to work at a pace that corresponded with Martyn's preparation work.

These delineations present the progress of my understanding of each unique experience and demonstrate visual information about a range of historical examples of FOP that have not previously been presented through the use of a drawing system. Some of these examples have only been seen by a small number of experts and most have never been depicted. By bringing together all this visual information from historical specimens, this work has created a unique body of material relating to FOP. Through the delineation process further insight is presented of the range of effects FOP has on the body.



Delineation 18. Basel 191 Front View (23/2/06).

Delineations of patients

In these delineations, as well as the action of drawing the different physical nature of the whole living body, a relationship forms between the delineator and the subject. Given the nature of the subjects' experiences, these encounters are extremely challenging.

In Delineation 5 (p. 147) a drawing of P, problems were encountered with placing a whole figure on the page in a similar way to that described in the analysis of Delineation 2 (p. 131). There is a different feel to the lines used in this delineation; they are looser and more free flowing responding to the different forms of the living body encountered. By using a lighter line, the delineation intimates the visual evidence of what lies beneath his skin and its implied horror. P is shown holding his specialized long walking stick.



Delineation 5. P. (19/10/05).

Delineation 6 (p. 149) records P's right hand. There is indication of deformity but no features that are exceptional compared to some of the other delineations. However, it was felt the activity of drawing every aspect of FOP was an appropriate method as details thought to be irrelevant by the delineator may be significant when the whole anatomical picture is reviewed by experts. As reported in Chapter 7, clinicians were very eager to have the fullest possible picture of this perplexing disease.



Delineation 6. **P's** Hand (19/10/05).

The drawing of P's bare feet, Delineation 7 (p. 151) uses lines that give a record of the experience of this intimate encounter. The delineation reveals his lower legs and feet. The deformities in his big toes are plainly visible. This is significant diagnostically as the malformation of the big toe is still the first indication that a person has FOP. The lines of the delineation retain a softness which is appropriate to recording living flesh. Lighter lines reveal further deformities and the hard, thick toenails are drawn with a heavier, thicker line. The delineation could be seen to have a sense of isolation and vulnerability in the depiction of lower legs.



Delineation 7. **P's** Feet (19/10/05).

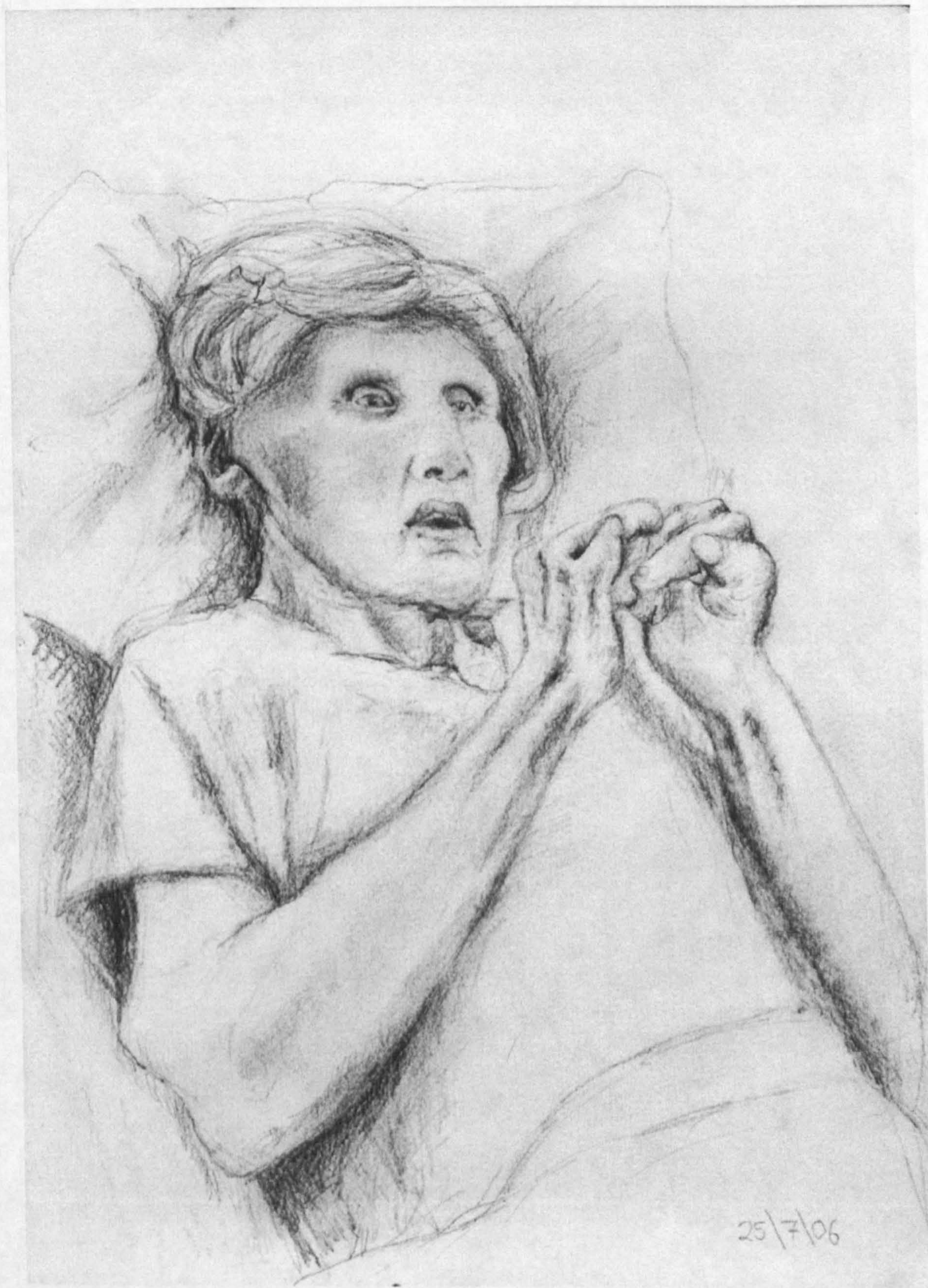
In Delineation 8 (p. 153) it is evident from the composition that there is greater focus on the surroundings than in delineations of P. K chose to place herself in a position that made the experience of the delineator include her habitat. There is heavy use of shading in the area behind her back and the inclusion of shelves next to her. The details of her features reveal the taut skin and sunken eyes that seem to be symptomatic of the effects of FOP. The same problems arise concerning issues of placing a whole figure on the page as discussed previously. K is also shown holding her specialized long walking stick.



Delineation 8. K. (29/10/05).

The drawing of K produced nine months later records a different experience. At her request, I drew K lying in her hospital bed in Delineation 34 (p. 155). The lines are more sensitive and smudging is used to create shadows. Her sunken features and deformed fingers are recorded more precisely and in greater detail.

What the delineations do tell us is about the way the patients chose to be recorded and how they wanted to be seen. This is their contribution, their story overlapping with mine, bringing together the aspects of empathy and dignity found in Carswell's delineations. I found the experiences of drawing them were both positive and negative. There were issues with the limited time. To walk into the home of a stranger with a progressive congenital disease and expect to be able to just draw them instantly is not achievable. A relationship has to be allowed to develop and I did not begin to draw them until they felt comfortable with me being there. Another problem for me was their clothing. I had gained an understanding of the effects of FOP from looking at specimens and bones. Clothing obscures the effects of this disease but I did not expect the patients to remove their clothes for a complete stranger so I could draw them. The clothes were drawn as part of the encounter with them.



Delineation 34. **K** in Hospital (25/7/06).

I will now discuss the delineations from the main project. These have been categorized in three parts: *Process of preparation delineations*, *Main project delineations* and *Problematic delineations*. I will begin with the delineations in the process category.

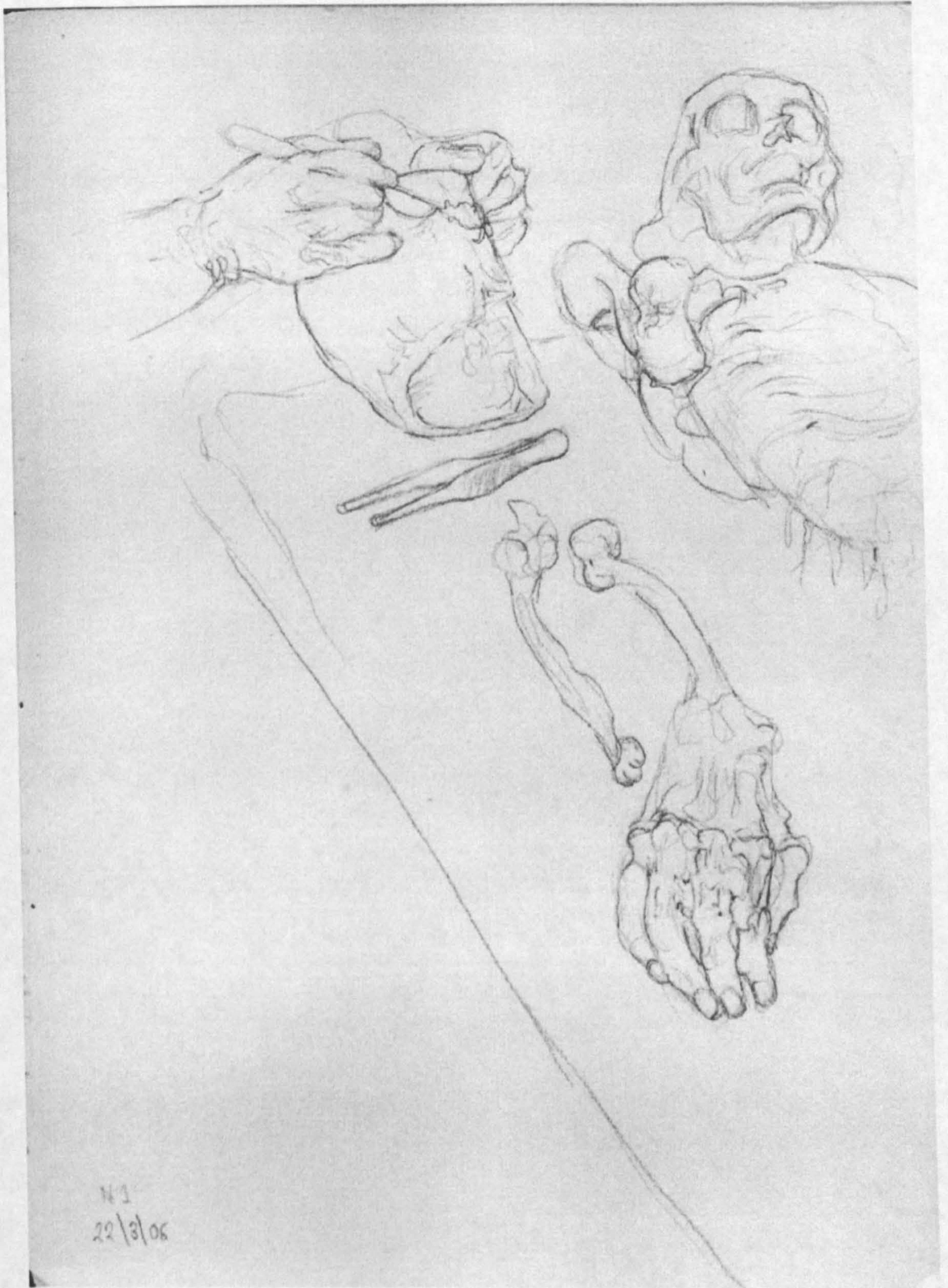
Process of preparation delineations

The preparation process was integral to the collection of experiences. It was therefore valid to present these encounters with the phenomenon of experiencing the methods of preparation. These delineations reveal further understanding of what is involved in the process of macerating a body and present the encounters as precisely and directly as possible.

Within this category are; delineations that include Martyn Cooke's hands, delineations that show other effects of preparation work in the lab and 2 'maps'.

Delineations 23, 35 and 52 all show Martyn's hands. As they are similar I will discuss these delineations together. They attempt to present my experiences of encountering the activity of Martyn working on the preparation of the donors, as each action occurred. In them, he is shown engaged in a different activity. In Delineation 23 (p. 157) he is shown holding the top of the donor's skull in his left hand whilst using a scalpel to remove tissue with his right hand. His gloves were thick making his movements awkward. Tweezers are lying on the table, waiting to be used.

These delineations were not drawn from photographs but were made rapidly and completed in situ. Whilst Martyn limited his movements where possible, he did not cease his activity or pose for the drawings.



Delineation 23. 8149 Process, Martyn's Hands and Scalpel (22/3/06).

Delineation 35 (p. 159) depicts him working on a different part of the body and holding both the tweezers and a scalpel in his hands.

Martyn's hands appear to be disembodied in all three delineations because there was no time to make detailed drawings of his entire figure. The focus is on my experience of his actions and it seemed to be unnecessary to draw more than his hands. Anything more would be superfluous. In Delineation 35, there are no detailed marks or lines to portray the donor and the drawing of the skeleton seems to have become secondary to the lines used to present the techniques of maceration.



Delineation 35. 8149 Process, Hands, Scalpel and Tweezers (2/8/06).

Martyn is depicted holding a brush to work Antiformin into other areas of the body in Delineation 52 (p. 161). The lines used to portray the donor's torso are light and fast. There is little detail but enough to present the object as recognizable. Emphasis is on Martyn's hands and the movement of the brush he holds. These lines are weightier and bolder.

The marks in all three delineations are quicker and looser than previous delineations described. It is evident from the nature of the lines they were made at a much faster rate than other drawings. The speed at which the activities took place is conveyed. The phenomenological activity of drawing, and the experience of the activity of preparation are presented simultaneously. This communicates to the viewer simultaneous fugitive experiences encountered by the delineator of both action and object.

The delineations remain unambiguous as they only present clear relevant data of the activities experienced. These delineations were made in situ as each activity took place and present knowledge gained of the process and further information about the phenomenon being experienced. The action recorded was fast paced and there was no time to rub any lines out. Evidence of insight gained during the activity of drawing, is supported by the number of loose, light, marks clearly seen on the page. More definite lines reveal the points at which I came to understand the experiences being encountered. They reveal the activity of delineating and delineate the activity of the lab.

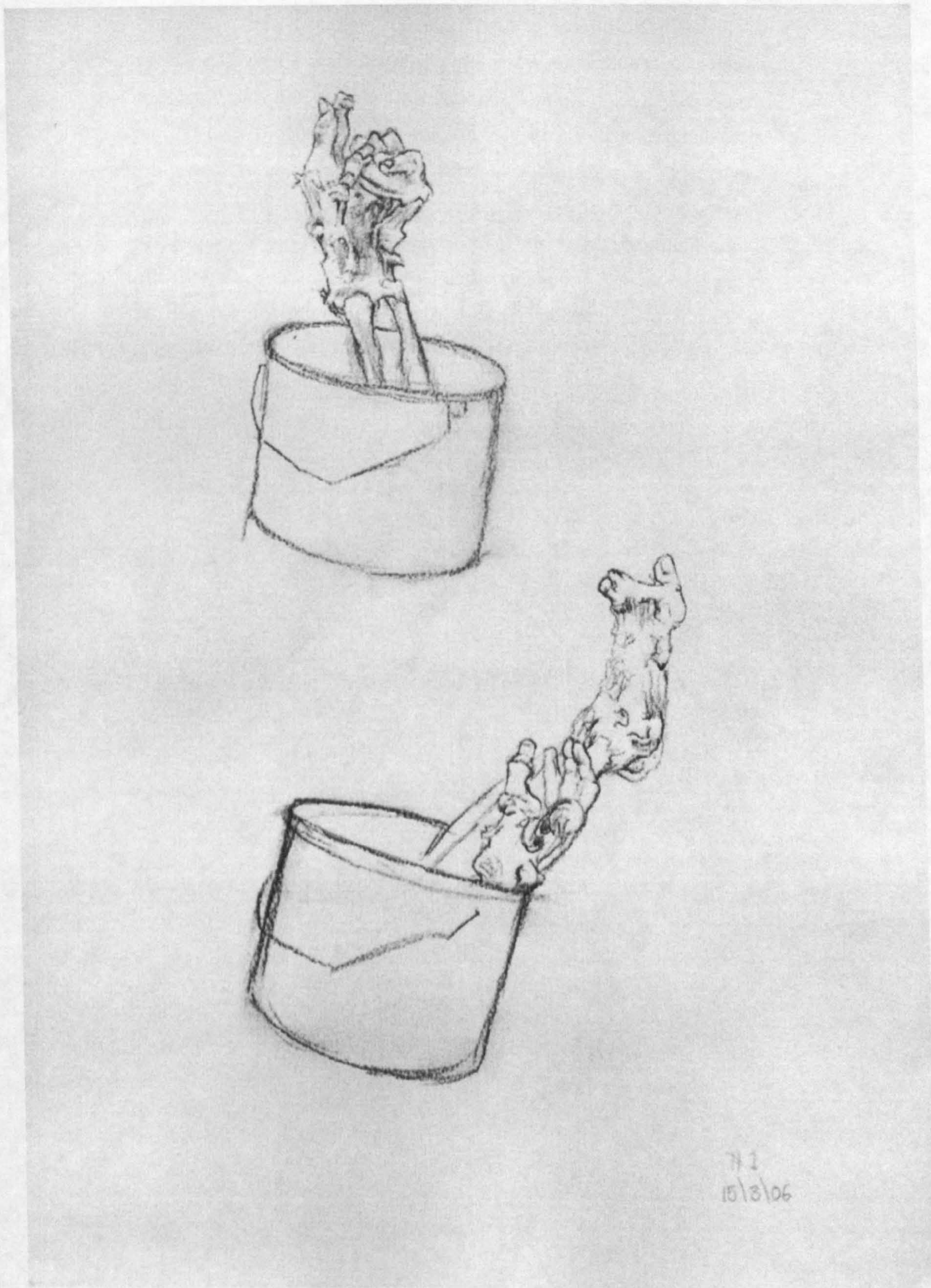
None of the above delineations were included in the exhibition at the museum. Both Simon Chaplin and Martyn Cooke felt that they contained information beyond the scope of both the donors' wishes and the expectations of the public. The consensus was that delineations revealing information about activities that occurred in the lab were too overt.



Delineation 52. 8149 Process, Martyn's Hands and Brush (11/9/07).

Delineations 21, 26, 36 and 59 are part of this category too but record different experiences in the lab and the unfamiliarity of this environment.

These 4 delineations present how unintentionally macabre scenes were formed as a consequence of the *modus operandi* of preparation work in the lab. In Delineation 21 (p. 163) an arm and a leg are shown in buckets. This would seem to be lacking in dignity and an unconventional view of the process. However, it is a precise and immediate presentation of the encounter with these two parts as they were being treated with Antiformin. The delineation is made using quick, bold, charcoal lines that do not have great detail but convey the bizarreness of the scenario. Initially I found it difficult to communicate the encounter as it is outside the scope of my usual experience.



Delineation 21. 8149 Hand and Foot in Buckets (15/3/06).

Delineation 26 (p. 165) is different as this presents a particular moment when I noticed the strangeness of the composition in front of me. An arm had been placed in a plastic, rectangular container. The hand, which still had skin and nails on it, was hanging over the edge of this box and appeared to be reaching for the brush and tweezers lying in front of it. It seemed as though the hand was going to grasp the instruments used in preparation and participate in the process itself. In the delineation, the tools, the box and surrounding visual information are only lightly sketched in. Emphasis is on the detail of the hand itself and the skin and nails that remain attached.



Delineation 26. 8149 Left Hand Overhanging Box (28/3/06).

Delineations 36 and 59 have similarities with each other as they show the arrangement of body parts as a consequence of the procedures. Once more there is a sense of an encounter with a 'dismembered' body in Delineation 36 (p. 167) as a leg is recorded alongside the main head and trunk of the body. This displaced limb would appear to be gratuitous here but it presents my experience of the every day occurrences in an environment that is unfamiliar. Bold, dark lines are used to record the torso, leg and tweezers. It is evident in the delineation that the foot has been moved and re-drawn and the area around the skull has lines that display my progress of understanding the encounter. Detail of the remaining tissue has been drawn precisely and the confusion of encountering body parts that are in unexpected positions is recorded in this and Delineation 59 (p. 169). The arrangement of these parts is particular to the moment they were experienced by the delineator.

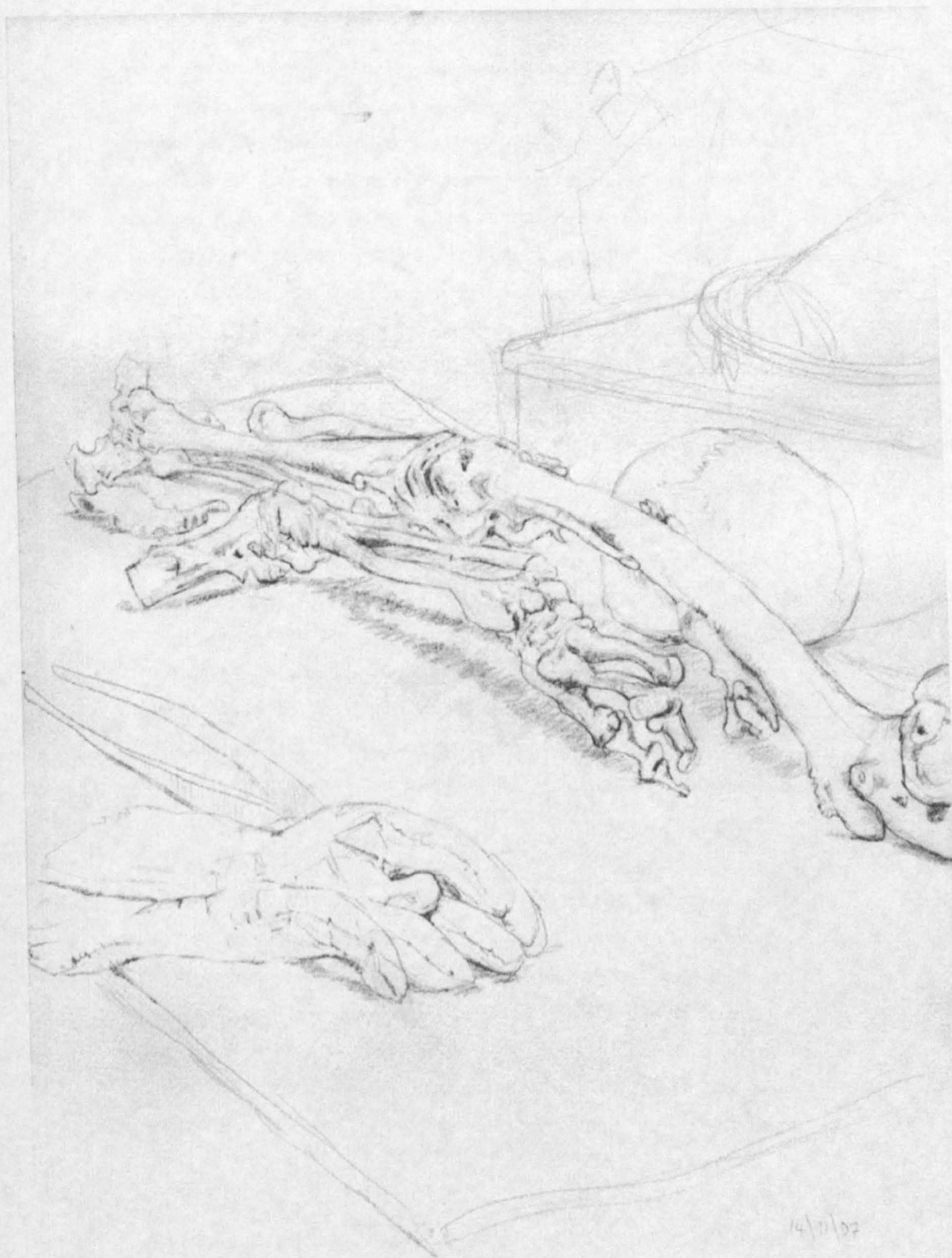


Delineation 36. 8149 Process, Torso, Leg and Tweezers (2/8/06).

Delineation 59 (p. 169) was made over a year after Delineation 36 (p. 167). The lines have a sharpness and confidence that support the claim I had come to have further insight into these experiences through the process of drawing them. The fragmented arrangements of parts are once again unprecedented. It is like nothing encountered before. In the delineation an arm is portrayed sitting parallel with a leg and next to it is the top of the skull. Their preparation has been completed and placed beside them are Martyn's gloves and tweezers. Their presence suggests the task of maceration has finished and gloves and tools have been downed. There is far less evidence of rubbing out and the bolder lines have been placed clearly. The box next to the bones is only lightly drawn.

These 4 delineations present the strangeness encountered in my experiences in an unfamiliar environment. They demonstrate the activity of delineating macabre and unusual scenarios that form part of the experiences of the lab environment. Unexpected situations arose where limbs and objects were placed inadvertently side-by-side. They do not intend to be gory but are perhaps perceived as such because they lack the appearance of Martyn's hands or any other sign of the activity that would justify their presence. These delineations were not included in the exhibition at the Hunterian and were seen to be particularly gratuitous when later evaluated in Chapter 7.

Included as a subsection in this category are the 2 'maps', Delineations 22 and 28. These were also excluded from the exhibition for the same reasons. They offer visual information regarding experience of the whole bodies and the logistical problems encountered with preparation due to their lack of articulation.

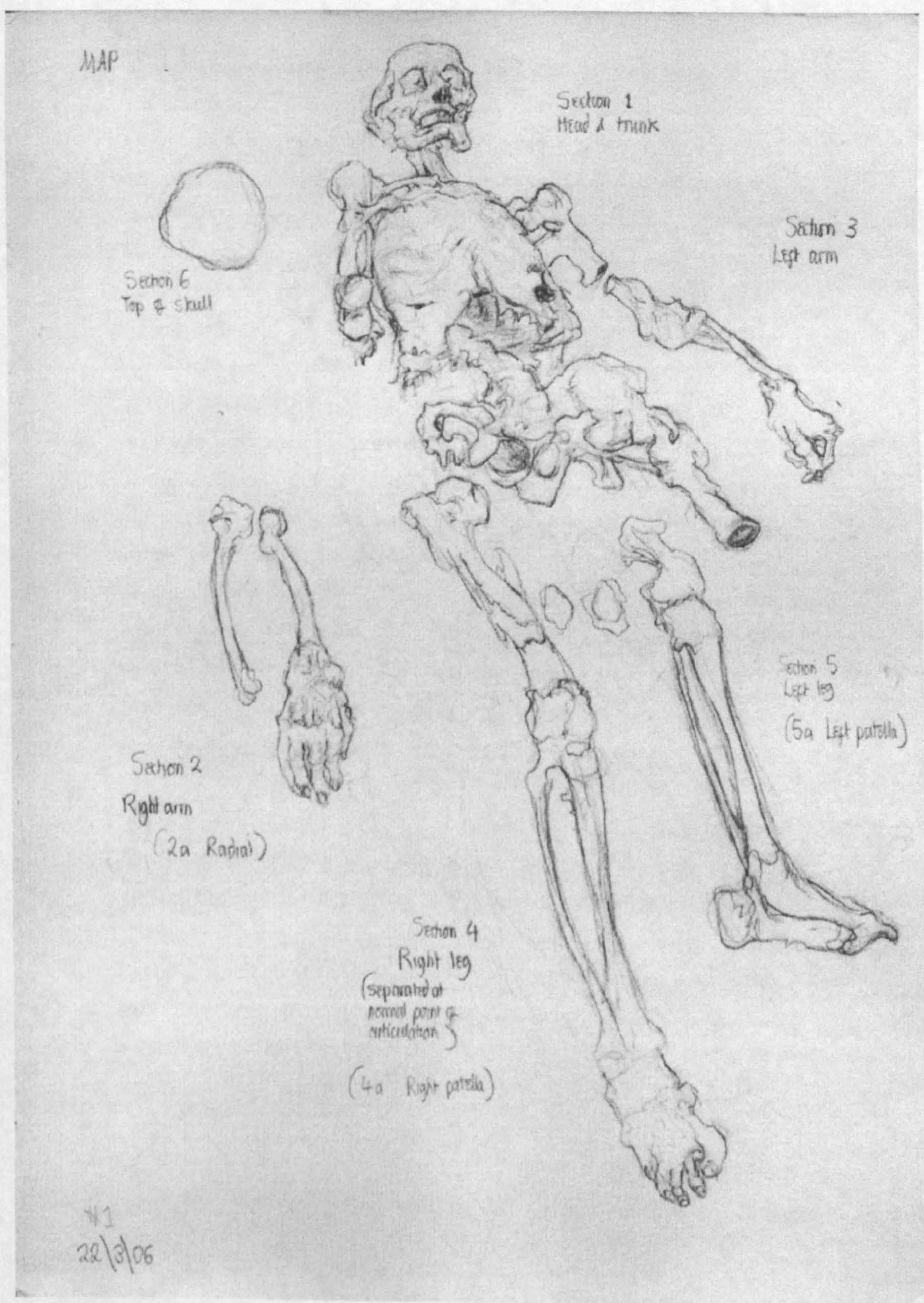


Delineation 59. 8149 Process, Leg, Arm and Glove (14/11/07).

Both delineations are the only examples of drawings of the whole donor yet are very different from the delineations in the historical category. This is because I experienced and drew the skeletons of Mr. Jeffs and the two skeletons in Basel, when they were upright. In Delineations 22 and 28 the donors' bodies were lying prone being viewed from above. To achieve this, I had to climb up and stand on the table. This sense of looking down on the scene before me allowed me to experience the donors as 'maps'. The sensation of looking down is also similar to making the histology drawings that unfolded like maps as described in Chapter 3, though on a different scale. The delineations also both offer the experience of seeing the 'plan of work'. By this, I mean they present the sections that were being worked on together, in the context of the whole specimen. Due to the nature of ankylosing caused by FOP, it was impossible to separate the bodies in the usual way for preparation. They each became separated at locations in the body where the FOP allowed. Placed in sections, they were drawn as components that formed one skeleton. However, the experience of seeing them all together but placed apart, was felt by some to be gruesome. Martyn also saw them as being maps. For him, they gave an overview of the journey of preparation and helped him to plan how to proceed from that point. He photocopied and laminated the maps for reference.

The placement of the overall form of the trunk of each donor on the centre of the page was difficult. This is demonstrated by the amount of lines that have been clearly made, rubbed out, moved and re-drawn and then rubbed out again. Placing a whole figure on an A3 page had proved difficult previously, as in the example of Mr. Jeffs. Beyond this the experience of seeing a whole person not just as separated components as I had seen in the museum or during the main preparation project, but *as fragmented* was a new experience.

Delineation 22 (p. 171) is of donor 8149. This 'map' shows her in 6 main parts.

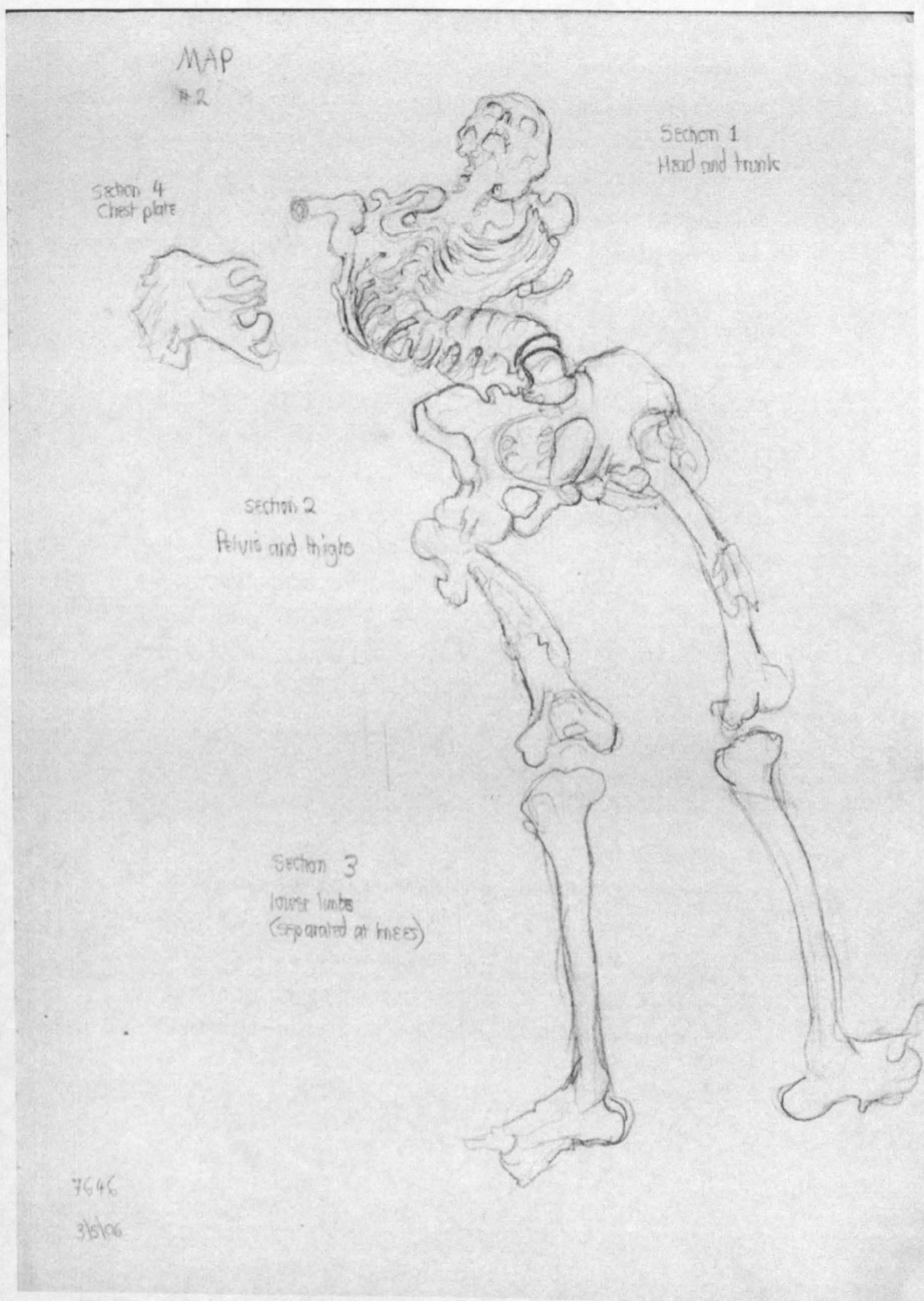


Delineation 22. 8149 Map No. 1 (22/3/06).

Her head and torso are labelled as section 1. The chest area is shown to have a great deal of tissue remaining and fusion is evident around her shoulders down to her hips. Spurring bone has ankylosed between her pelvis and her left femur. Sections 2 and 3 show the ulna and radius of both arms and the hands have still have almost all the flesh attached. Sections 4 and 5 display the legs. The right leg has ossification that has caused the femur to fuse with the tibia and fibula. Both feet are attached and very little flesh has been removed from them. The top of her skull is labelled as section 6 and both patellae are also separate.

The lines on the paper that have been removed have left a visible trace of where the specimen was initially shown to lie on the page. To allow a clear overview when drawing this phenomenon, I had to stand at an awkward angle, which accounts for the drawing of the donor being arranged diagonally across the page. The relationships of body parts and their disconnectedness from each other, is recorded. The re-drawn lines present the attempts to understand the encounter. Unlike other delineations there are no points of focus but the same overall weight of line and level of detail.

The next 'map', Delineation 28 (p. 173) of 7646 has the same diagonal composition viewed from above. She is in 4 main parts. The head and trunk are labelled as Section 1. She has been separated above the pelvis due to the pathologist's procedures, not because of ankylosis. Section 2 includes her pelvis and both femurs, Section 3 includes both legs and feet and Section 4 is her chest plate which has a great deal of tissue still attached.



Delineation 28. 7646 Map No. 2 (3/5/06).

Both delineations were made quickly as it was difficult to maintain the position I was in for long. They present an experience of the donor as 'dismembered' because the separated body parts are shown in proximity to the trunk of each donor. However, the emphasis of the delineation is to focus on the useful potential of delineation as information. They appear to be gruesome images because they reveal the physical, violent intervention used to separate the sections yet are intended to convey the sense of mapping and planning that formed an integral part of the method of preparation.

All the delineations discussed within this category present several aspects of my encounters with the phenomenon. They present my experience of being in an unfamiliar environment, and participating and observing in activities outside the safety of my every day experience. Beyond communicating my developing understanding of the object and my experiences of the phenomenon, they convey my experience of the actions used to bring this about. The relationships developing between the delineator and the objects being viewed have been revealed through the type of marks made and how they have been made. They present insights into my experiences of the activity of preparation, and my experiences of the progressively macerated bodies.

Workshop delineations

As part of this inquiry I involved specialists trained in the fields of medical illustration and archaeology. They participated in drawing workshops. The accounts and outcomes of these are described in chapter 7. This includes detailed descriptions of the drawings they made. I will now examine the delineations I made during these drawing workshops.

During the event with the medical illustrators I made one drawing, Delineation 46 (p. 175).



Delineation 46. 7646 Back of Torso With Medical Illustrators (18/4/07).

Drawing with the medical illustrators gave me the opportunity to experience the specimen from a new position and a chance to see the skeleton in a different context. Until then, I had only experienced viewing both donors in the preparation room. The torso of donor 7646 was brought into the Wellcome Museum of Anatomy and Pathology for this event and placed on a much lower table than I was used to seeing her on. This allowed me to view her from a new perspective and therefore offered a fresh encounter with the object.

Despite problems caused by general interruptions that occurred during the workshop, the delineation provides useful insight into these visual experiences. The heterotopic bone can be seen clearly and where it has extended from the scapula is particularly evident.

In a conversation with Philip Wilson senior tutor and ex president of the Medical Artists Association, he commented on the lack of what he described as 'underpinning' in my delineation.

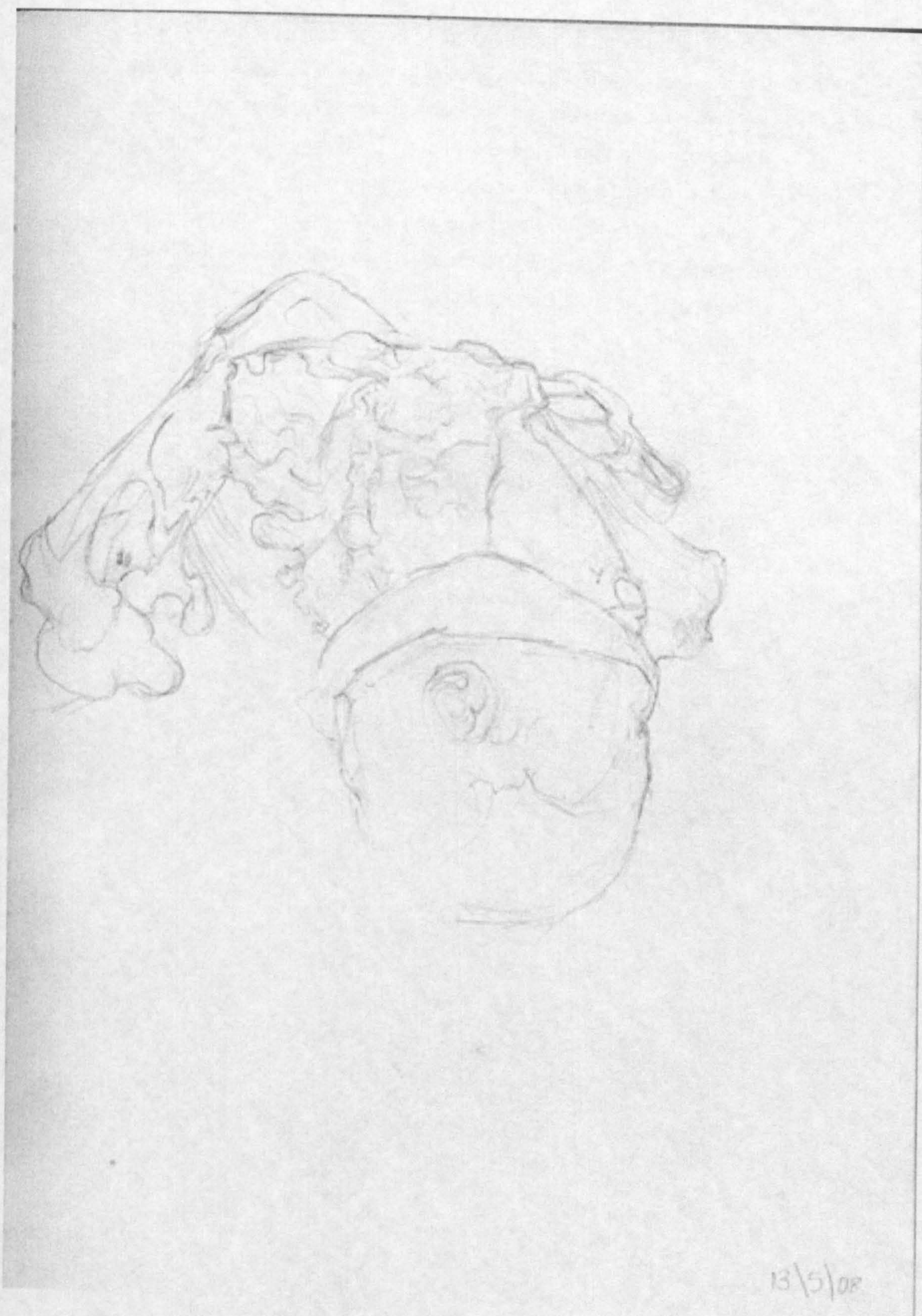
*'You clearly have the ability of making a first observation
and then using that observation as your yardstick for the
next piece'*

(Wilson, 18th April, 2007).

By this he meant there was no sign of structural foundation in my delineation. Medical illustrators are trained to put emphasis on the planning stage of their drawings, something I do not do and this is one of the differences between my practice and theirs. The activity of delineating each fugitive visual experience as it occurs means there is no pre-planned or preliminary sketches made in the system of delineation described in this thesis. The delineation is started, continued and completed in the presence of the object and understanding is developed throughout the activity of making the drawing.

I made 4 delineations with the archaeologists, Delineations 63, 64, 65 and 66. These were the last delineations made as part of this inquiry.

Delineation 63 (p. 177) again depicts the torso of donor 7646 from head on and face down.



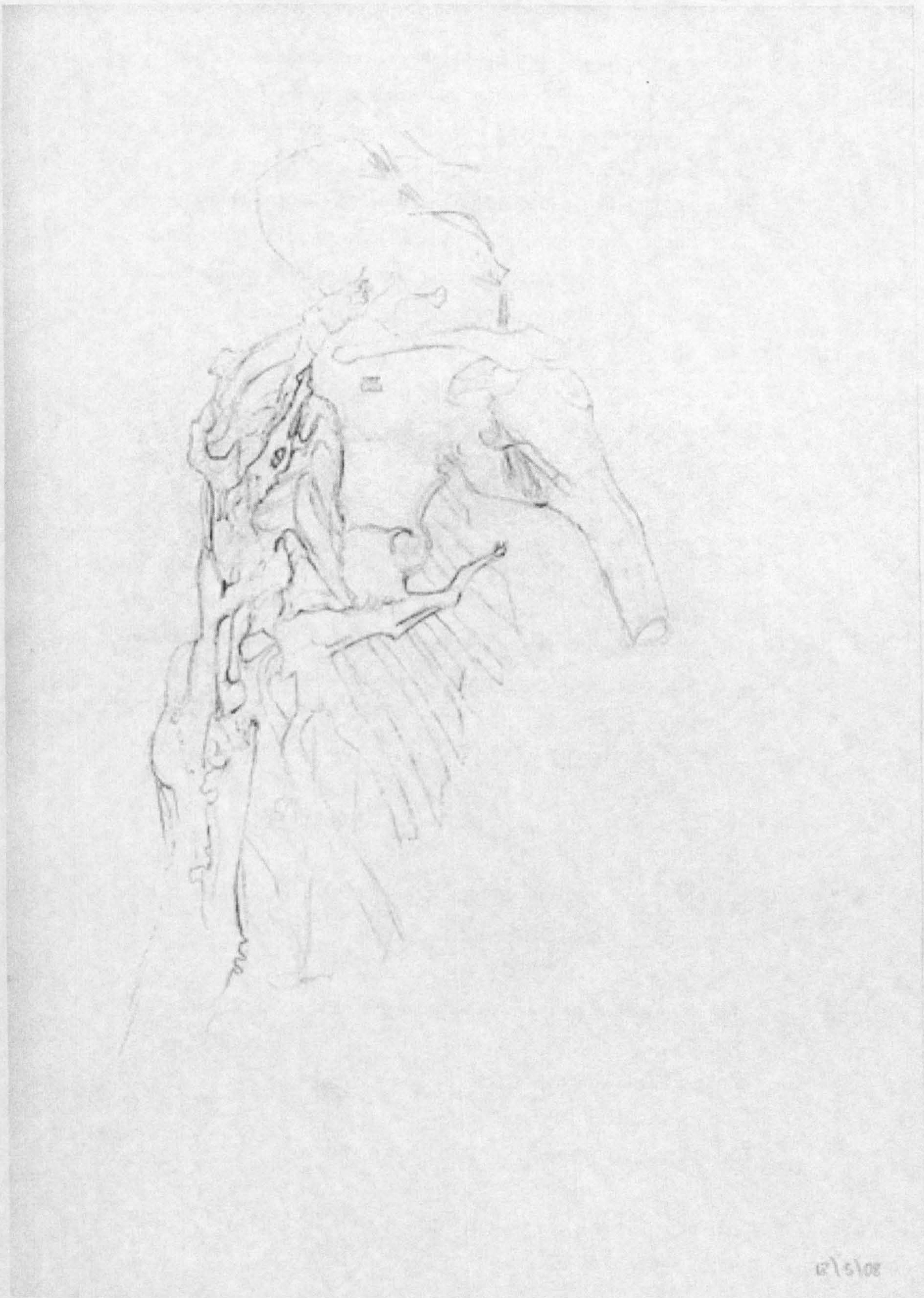
Delineation 63. 7646 Sketchy Face Down with Archaeologists (13/5/08).

This time the specimen was drawn in the conservation lab on a low table. This meant I again had the opportunity to have a new view of the object and record these experiences. This delineation was made quickly and has a roughness with little clear information as I was distracted and trying to make the archaeologists feel at ease. Delineation 64 (p. 179) is seen from a similar angle as the drawing made with the medical illustrators. Whilst there was not enough time to make a detailed delineation of the visual experience, it offers a basic visual understanding of where the extra bone is.



Delineation 64, 7646 Sketchy Face Down 2 with Archaeologists (13/5/08).

Delineations 65 and 66 are relevant as they present new understanding of the encounters with FOP. For the first time I drew the specimen in an upright position. This new experience allowed a fresh perspective on my encounter with the phenomenon. In Delineation 65 (p. 181), the secondary skeleton appears to act as a cage around the skeleton. Professor Wordsworth later described it as looking like a Homunculus on her back. The more heavily defined lines that depict the bone communicate the horrific nature of this encounter and the activity of drawing it can be revealed clearly through the methods of changing weight of line and focusing on only crucial visual data.



Delineation 65. 7646 Homunculus with Archaeologists. (13/5/08).

Delineation 66 (p. 183) is the last of the drawings made of FOP and she is presented in an upright position and facing forwards. The curve of her spine is made evident because of the obvious lack of thorax. Detail is emphasized on areas where heterotopic bone have formed, bridged and created spurs around her shoulders and rib cage. Her mandible is missing and the deformity of her spine is stressed because her head is tilted and her eye sockets look to her left but her spine bends to the left on one plane and turns to face us head on in the other.

The activity of making these drawings has lead to my understanding of how the bodies of FOP sufferers are shaped and twisted. The evidence of my experiences and the understanding gained is presented to an audience.

Main project delineations

These are the other 22 key delineations that in my opinion reveal how I have gained understanding through the activity of drawing and which convey visual information to others offering knowledge of both the object presented and visual experiences of the phenomenon. They are Delineations 25, 29, 32, 33, 37, 40, 41, 42, 43, 44, 45, 47, 48, 49, 50, 54, 55, 56, 57, 58, 61, and 62.

This category separates into 5 sub-sets in the following way:

Set 1; Delineations 25, 37, 42, 45 and 47

This set includes delineations that give the clearest examples of bone growth and intersections of tissue change.

Set 2; Delineations 29, 32, and 33

This set focuses on particular details of marrow and intricacy of spurring.

Set 3; Delineations 40, 41, 43, 44 and 55

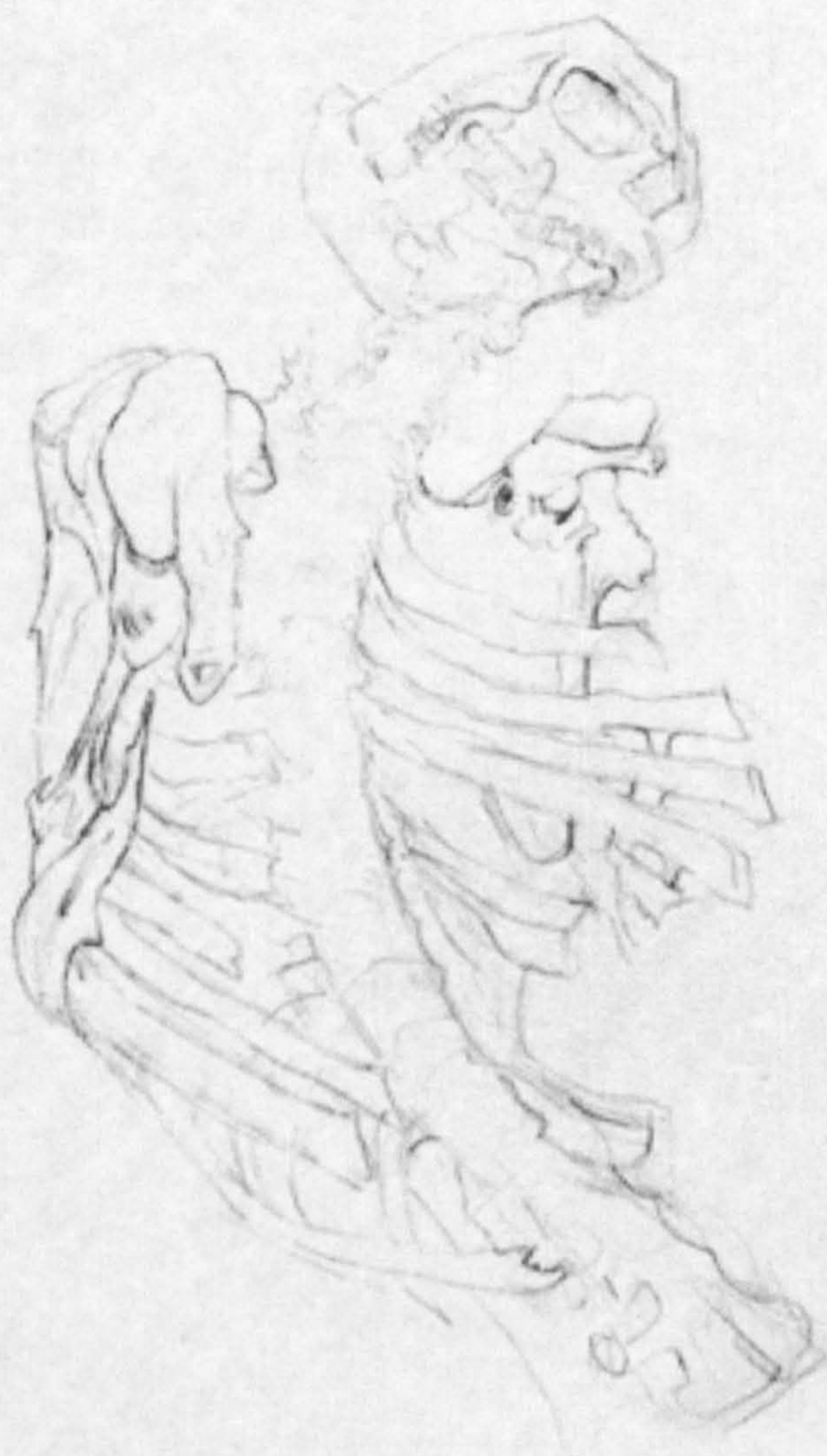
Portray a single limb in isolation.

Set 4; Delineations 48, 49 and 50

Histology sequence and uses different drawing effects.

Set 5; Delineations 54, 56, 57, 58, 61 and 62

Portrays donors near completion; three viewed lying on the back and three lying on the front.



13/5/08

Delineation 66. 7646 Upright Final View with Archaeologists (13/5/08).

Set 1

These delineations present my experience of areas of bone growth and delineate clearly the places where tissue metamorphosizes. They demonstrate the insight I gained as my understanding of different tissue types became more and more clearly defined.

In Delineation 25 (p. 185) the donor is depicted from the chest up in profile and the top of her head is missing. This delineation was not included in the exhibition as the detailed portrait was thought to be too recognizable. The delineation shows the intricacy at the intersection between regular skeletal bone and where new bone has formed. It also portrays the quality of the tissue still attached which had been affected by being frozen, then placed in heated water and then re-frozen continuously throughout the duration of this main project. Lightly made fleck like marks have been used to present the character of this tissue and the difference between the soft tissue, the ectopic bone and the skeleton are recorded clearly, even at the points of the body where they have merged together



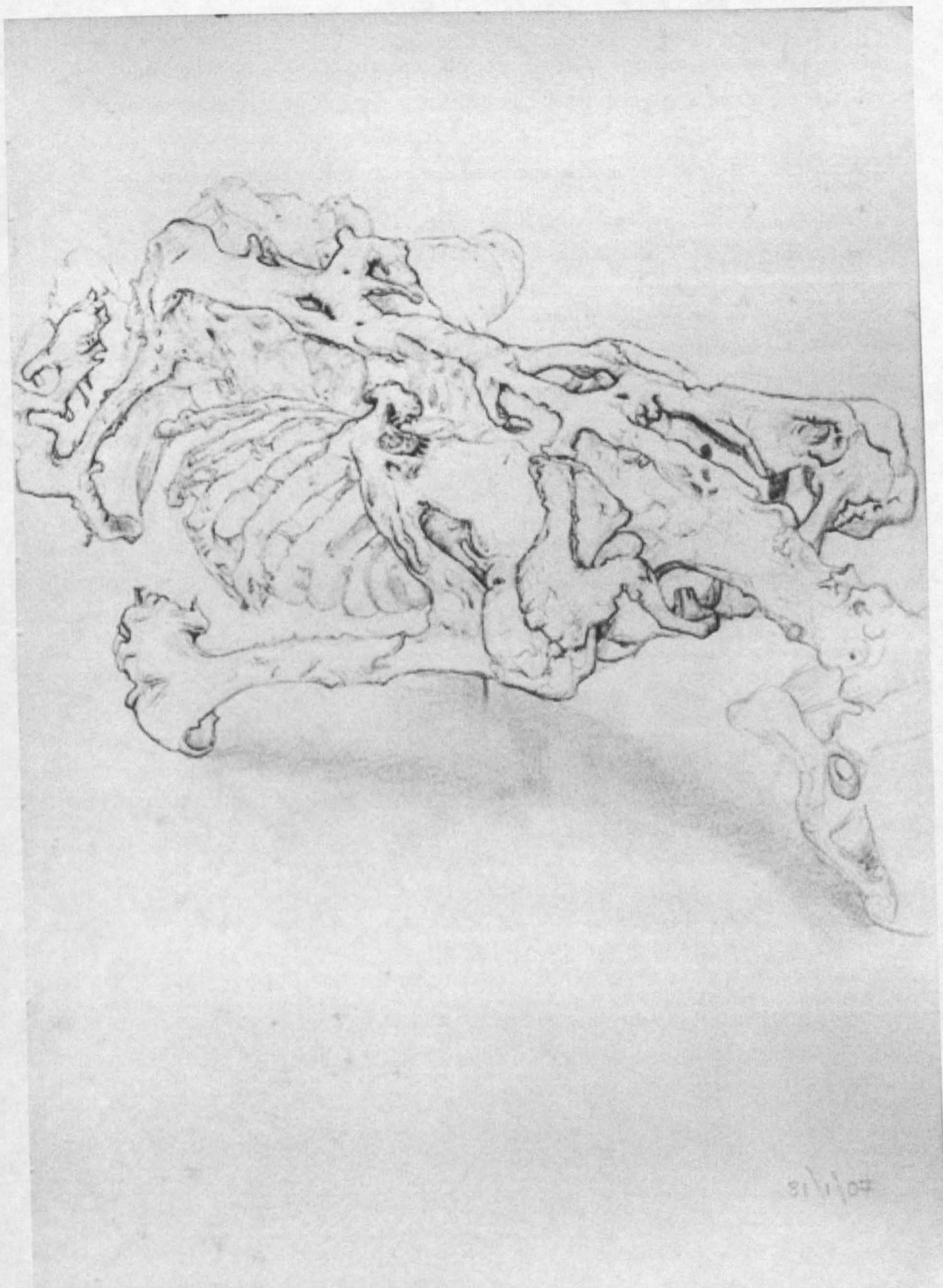
Delineation 25. 8149 Detailed Profile (28/3/06).

Delineation 37 (p. 187) of 8149 was made on 2nd August 2006. Delineation 42 (p. 189) was made on 31st January 2007 nearly five months later and they demonstrate the progress of the preparation. Drawn from a very similar angle, these two delineations are close enough in appearance to make a useful comparison. Both show the same view of the donor, placed face down. There is more tissue around the spine in Delineation 37 and areas between the ribs are still joined by tissue. Marks in the delineation are quite uniform as there is enough tissue covering the body to make the changes between normal and heterotopic bone less distinctive.



Delineation 37. 8149 Back Face Down (42) (2/8/06).

In Delineation 42 (p. 189) the ribs appear separated and there is greater clarity in visual information between where heterotopic bone starts and normal tissue ends. This is evident due to the advancement of the preparation and through the delineator gaining greater visual understanding of the phenomenon from the continuing relationship developed by the activity of drawing. More tissue has been removed and the secondary skeleton is more distinctive and separate to the regular skeleton. This is distinguished in the delineation by the use of heavier lines. These remain soft in response to the nature of the quality of the remaining tissue that still covers many areas of the body. As more detail of the skeleton beneath the tissue is revealed, the more detailed the delineations become. Delineation 42 will be discussed in a comparison with corresponding photos later in this chapter (p. 266).



Delineation 42. 8149 Back Face Down (37) (31/1/07).

Delineation 45 (p. 191) portrays the donor on her back, viewed in profile and is a good example of the way drawing as an activity allows the delineator to record in detail the intersection between the skeleton and sites of flare up. The amount of tissue remaining overall is clear and the weight of line used to delineate this phenomenon makes apparent the areas of ossification and the areas where they connect with normal tissue. Soft tissue still remains on the skeleton and the intricacy of the twists and spurs of the ankylosed bone as it locks parts of the body together are visually explained. The detail of complex bridging between the upper arms and the chest is particularly emphasized in this delineation.



Delineation 45. 8149 On Back, Jaw Still Attached (21/3-3/4/07).

Delineation 47 (p. 193) made nearly four months after Delineation 45 (p. 191) is also of the torso but closer up and at a slightly different angle. The donor is presented face down and revealed in close detail. The twists and dramatic spurs of the FOP bone are portrayed very clearly. The back and thoracic areas fill the page. The point of focus is a large spur that has twisted and bridged across the back under the right scapula. It is recorded as emerging from the skeleton and forms a bridge from the upper arm to the rib cage. The heterotopic skeleton has spread and locked over her spine. The bridge is shown as raised well above the ribcage. Close attention to detail, defined perspective and the use of a clear, sharp dark line; demonstrates with clarity my understanding of where and how this bone is in relation to the rest of the body.

The exact locations where ectopic bone grows and spreads from the ribs are made explicit. The precision and weight of line used in this delineation provides visual information about my encounter with FOP. That insight conveys the terrible consequences of the effects of FOP. These exact, clear lines contrast with the softer swirling lines that record the tissue still surrounding some parts of the body.



Delineation 47. 8149 Close Up of Torso on Front (25/4/07).

Set 2

These delineations are all of donor **7646**. Each took 3 days to complete. Delineation 29 (p. 195) presents the head and torso of the donor placed face down and the base of the spine is shown to be nearest to the viewer. The curve of the backbone is so severe that her head is almost at a 45° angle to the base of her spine. The delineation records relevant detail in the ectopic skeleton. Dotted marks have been made to record the marrow present there. Delineation 29 is discussed again later in this chapter when I compare it with its corresponding photograph (p. 262).



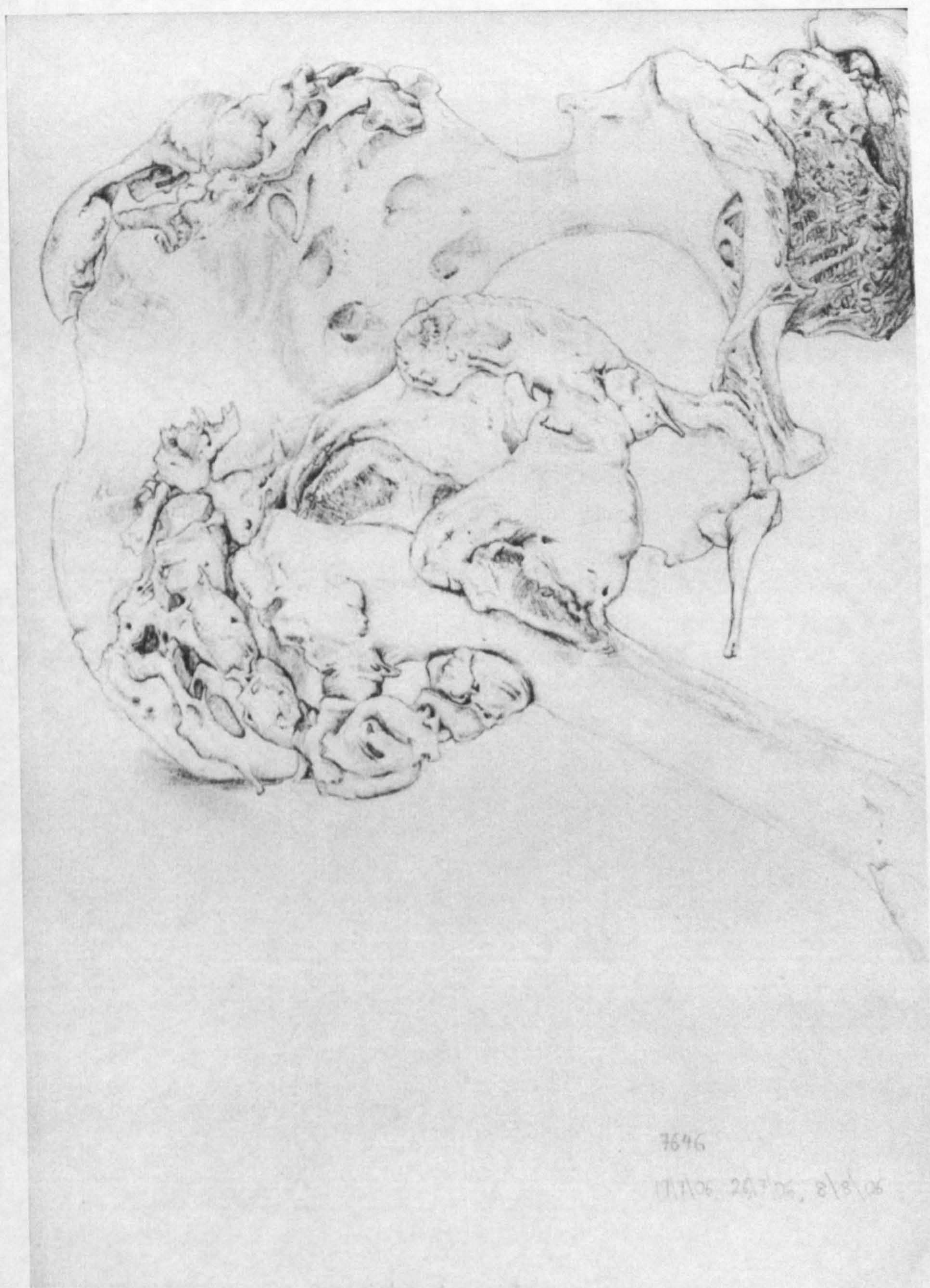
Delineation 29. 7646 Marrow (2/5-10/5/06).

The pelvis has been placed face down in Delineations 32 (p. 197) and 33 (p. 199) and both record intricate twists and turns of bone. In Delineation 32 the complexity of the spurring is recorded in detail. This will be discussed later in the chapter in comparison with its corresponding photograph.



Delineation 32. 7646 Main Detail Hip Ossification (14/6-12/7/06).

Delineation 33 (p. 199) is of the same part but at a different angle and also shows the mass on the right hand side of the hip where a sample of tissue was later removed and examined. Small, close knit marks are used to record the complex network revealed in this tissue. It is very different from the soft rounded curves and sharp, harsh jagged lines of the heterotopic bone and its spurs.

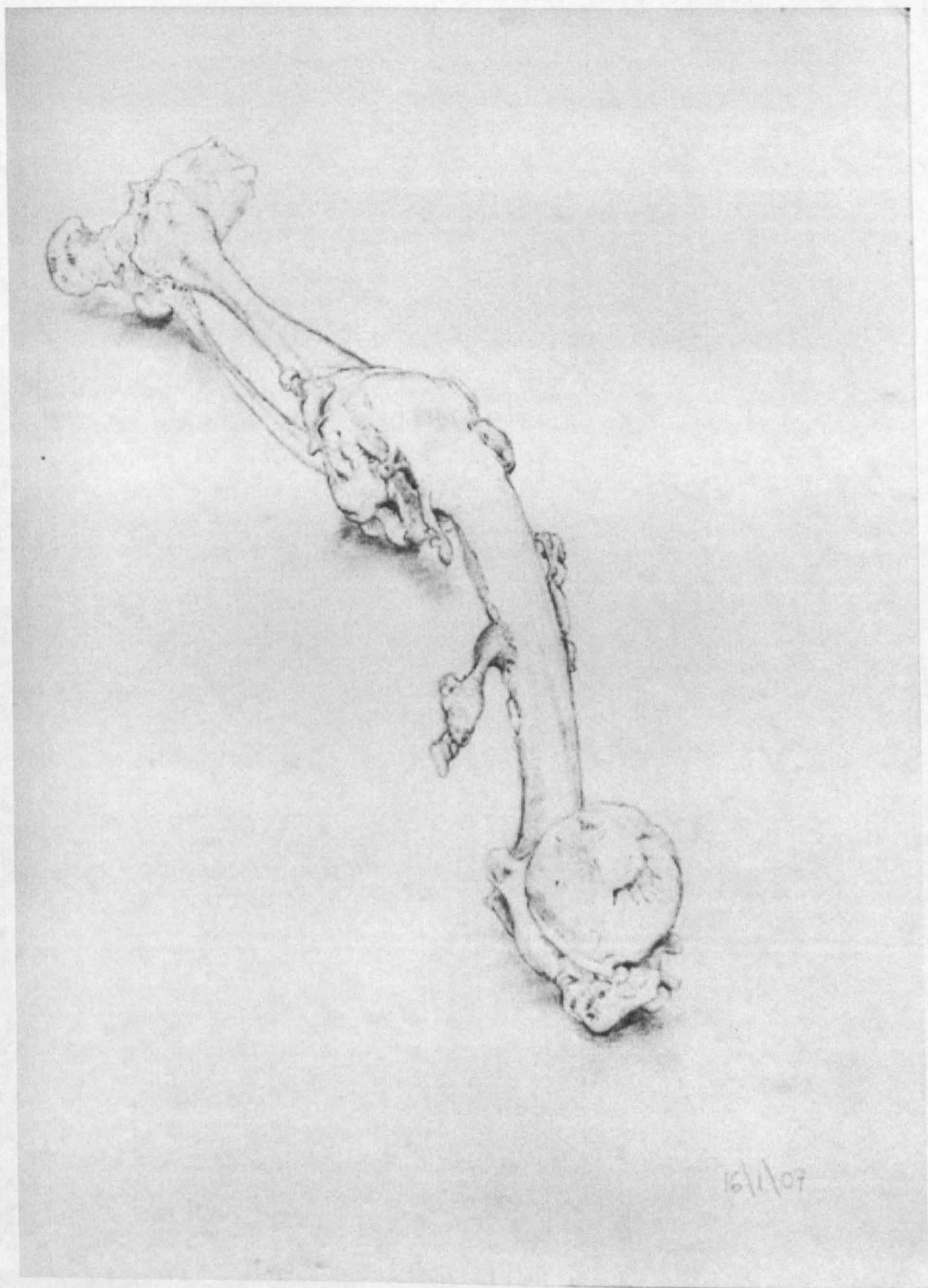


Delineation 33. 7646 Hip Ossification and Mass (19/7-8/8/06).

Set 3

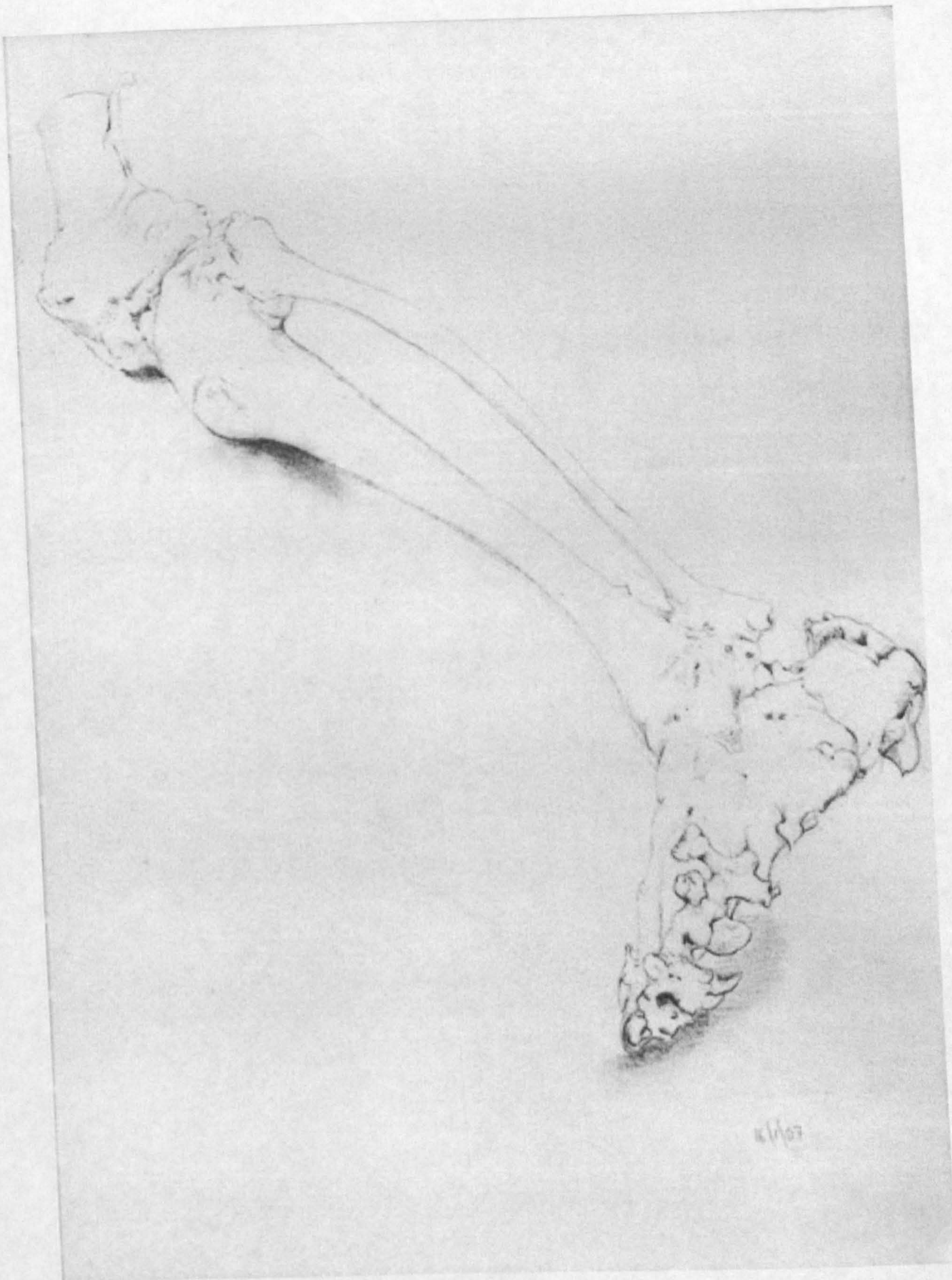
Delineations in this sub set all portray single isolated limbs presented in process of preparation and extraneous visual information including tools and containers are excluded.

Delineations 40, 41, and 55 (pp. 201, 203, 205) are of legs.



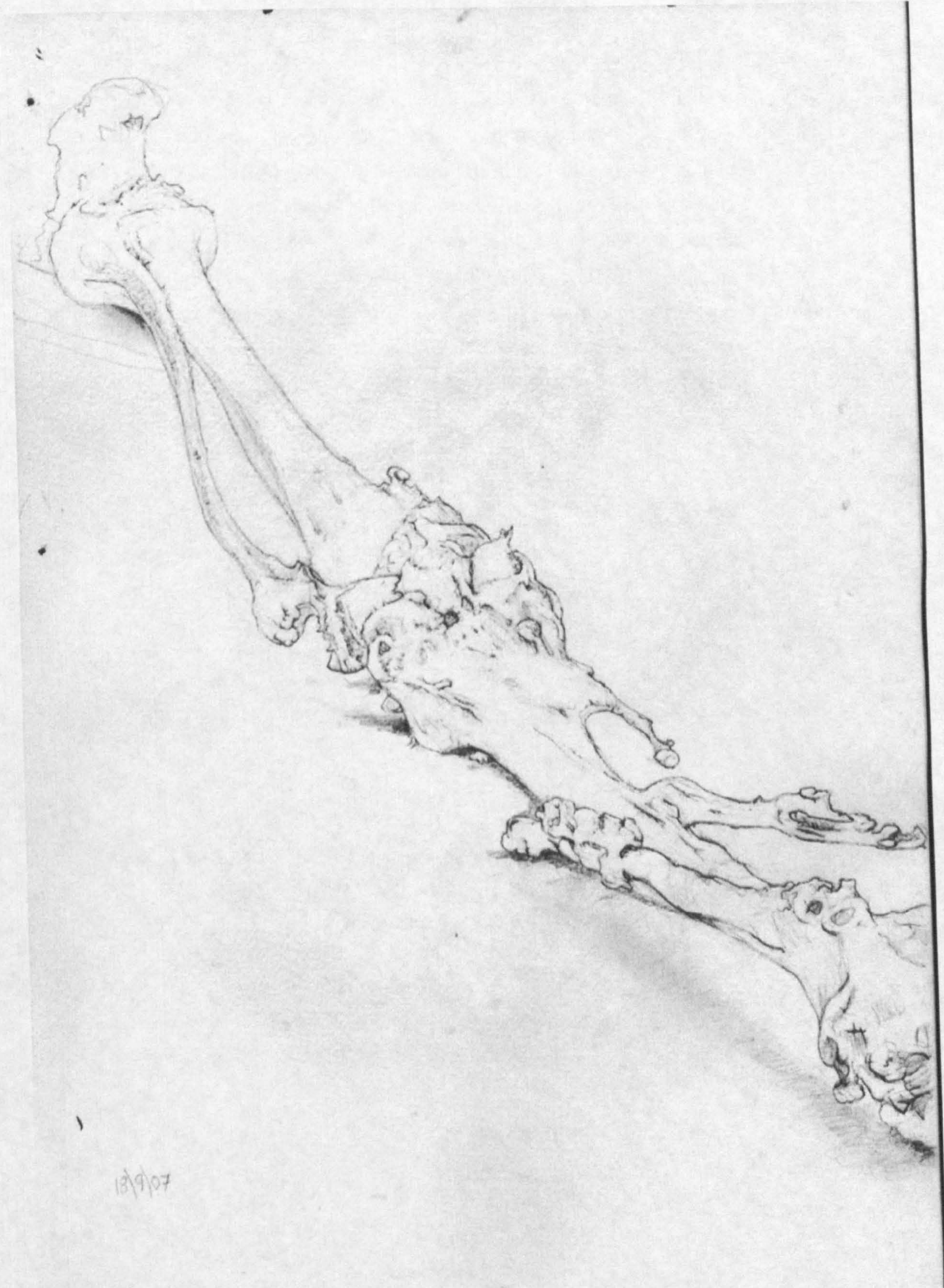
Delineation 40. Leg (16/1/07).

They present clear understanding of continuing methods of preparation and detail of spurring heterotopic bone.



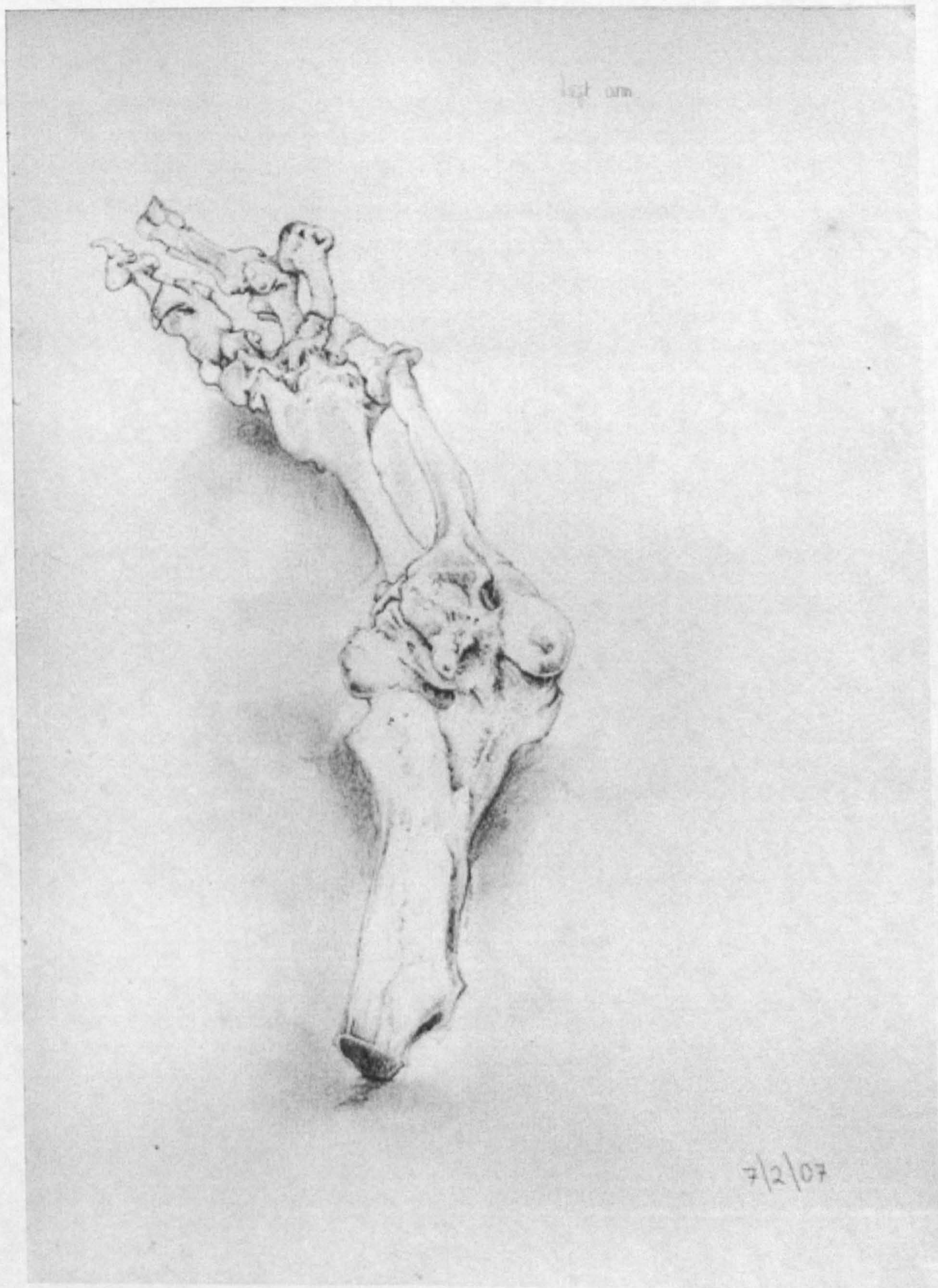
Delineation 41. 8149 Leg with Foot Facing (16/1/07).

Delineation 55 (p. 205) particularly shows the detail of heterotopic bone that has formed around the knee area.



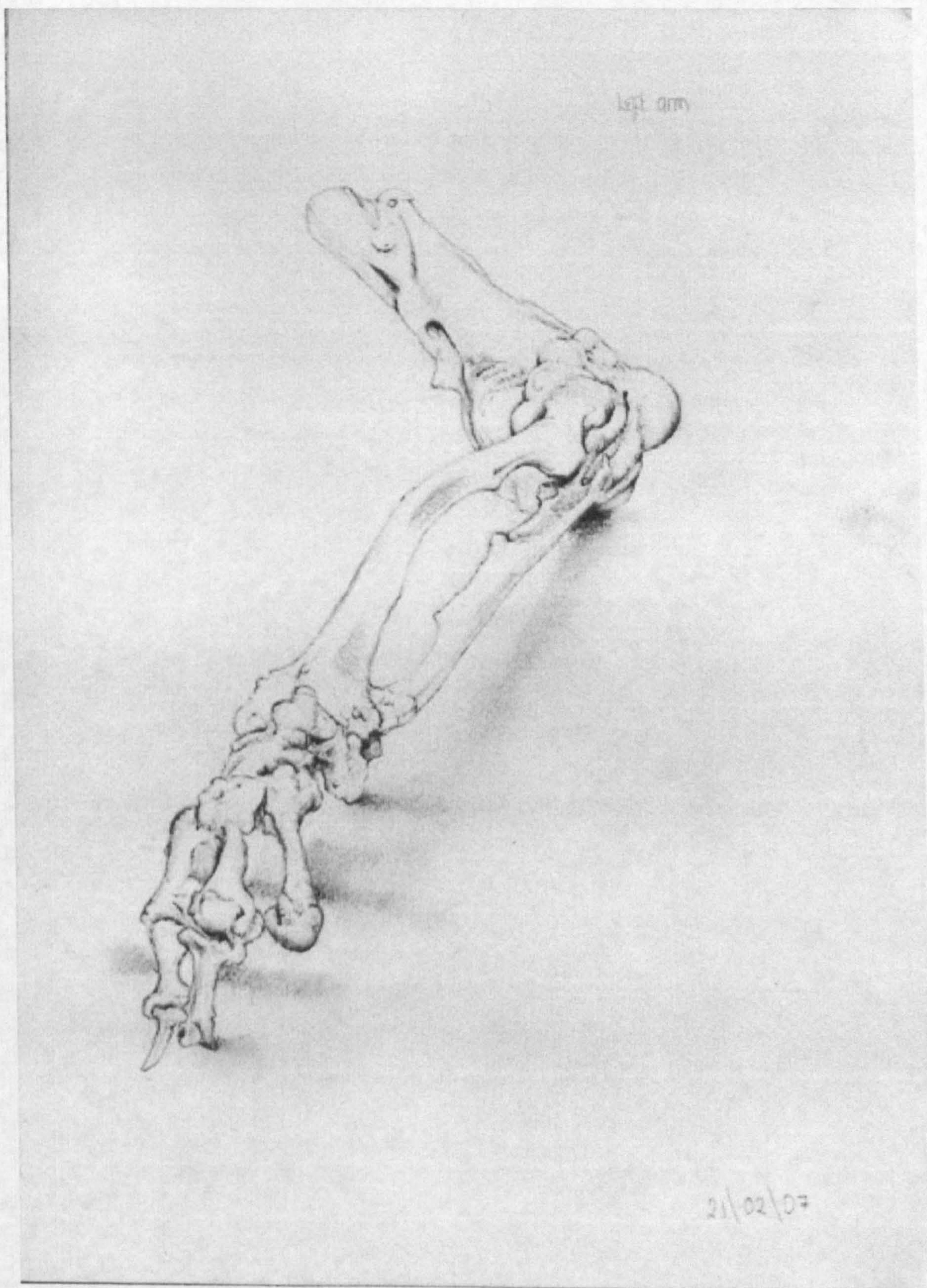
Delineation 55. 8149 Long Leg (18/9/07).

43 and 44 (pp. 207, 209) depict the same left arm but from different viewpoints. They present several experiences of the same object: the effects of the disease, the effects of the process used to reveal the skeleton and encounters with the body fragments. They are clear portrayals of this collection of encounters. Lines are bold and defined, showing relevance through the physical weight of the marks. The effects of FOP do not appear to be so extreme in this instance but the subtle detail and softness is presented to mark the difference between bone types.



Delineation 43. 8149 Forearm Face Up (7/2/07).

The delineations in this set are the most linear. They were not made at the speed of the process preparation drawings, but have an immediate, precise feel to them. The lines are economical without negating relevant detail. They did not take as long to draw as the previous set where there was more intricate spurring to record. This set demonstrate how I have gained further understanding and with that more confidence in placement of the lines. This is further supported by the evidence there is less rubbing out and correcting. The lines are bold contrasting with the experience I had of feeling the fragility and isolation of these fragmented and disconnected limbs. For me, they had become more vulnerable. The delineations are all detailed and unambiguous yet devoid of superfluous information whilst remaining as precise as possible. Delineations 40 and 43 will be discussed further later in this chapter (p. 264).



Delineation 44. 8149 Left Arm Face Down (21/2/07).

Set 4

Delineations 48, 49, and 50 form a sequence of events concerned with the removal of tissue from a tumourous mass on the hip of 7464 and the process of histology used to investigate this. The drawing of histology, Delineation 48 and the close up of the site of excision Delineation 50, took six days each to complete, longer than any other drawings made during this project.

Delineations 48 (p. 211) and 50 (p. 215) are different from the other delineations. There is a different use of pencil marks whereby some heavier pencil work has been applied as a way of filling and defining areas rather than to shade. These two are also the only delineations where the view of the object has been mediated by the use of a lens which altered the scale of the object being encountered.

Unlike the mapping histology project described in Chapter 4, when making Delineation 48 (p. 211) I did not make use of a drawing lens but drew from the histology slide 'by eye'. I would look down the microscope lens, then move my head away to look at my opened sketchbook placed next to it. I would make a mark to correspond with what I had observed and then return to looking down the lens. This is a very different experience from using a Zeichenokular lens. Delineation 48 is also the only example in this inquiry of the experience of a two-dimensional object rather than three. The marks used to present this phenomenon are perhaps more varied than in previously discussed delineations. Many soft, closely placed lines form large areas contrasting with delicate but sharp lines that detail flecks and curves observed in the histology slide. The side of the pencil has been used to define the perimeter of the image as it was encountered when viewed down the microscope lens.



Delineation 48. 7646 Histology (16/5-13/6/07).

In Delineation 49 (p. 213), the drawing of the mass where the excision was made is placed just higher than the centre of the page. The pelvis and leg are recorded using very loose, light but precisely observed lines that surround this area and place this mass in context. Spurring on the femur is recorded using heavier, darker lines. The area of mass is presented in detail. Minute flecks of spicule have been recorded and the experience of the spongy quality presented using softer, darker lines. Placing thicker, heavy dark lines closely together has built up areas of darkness. My understanding of areas of relevance has become more evident in this delineation.



Delineation 49. Mass (23/5/07).

Delineation 50 (p. 215) is the only drawing of an object that has been observed through a wide-angle, magnifying lens and incorporates the use of smudging. This drawing is a close up of the mass, focusing on the area where the excision was made. This deep cut and the use of a wide-angle lens, lead to the experience of the phenomenon including the greater depth of field viewed. The only way I felt I could precisely convey the experience I had of this encounter was to use smudging and rubbing and to use the side of the pencil to make broad marks. However, the delineation still demonstrates precisely observed bone spicules using sharply defined lines and various weights as well as light, delicate, flecking marks that record the spongy quality of areas of the mass.



Set 5; Delineations 54, 56, 57, 58, 61 and 62

Delineations 54, 56 and 61 form a final sequence of the project and the donor has been portrayed lying face up, near completion. All 3 delineations took a day to produce and were made between September 11 and November 28 2007. Each presents the skeleton from a slightly different angle. In Delineation 54 (p. 217) she has been tilted slightly to her left. Lines are light and almost sketchy around the skull and rib area to reinforce the severity of the bridging heterotopic bone that has formed to connect the right clavicle with the humerus.



Delineation 54. 8149 In Tray, Face Up (11/9/07).

The angle at which the skeleton has been viewed in Delineation 56 (p. 219) allows the experience of the effect of FOP to be communicated. The lower viewpoint has presented the extreme tilt of the pelvis and curvature of the spine. The coccyx is lower than her upraised pelvis. Intricate ectopic bone has formed around the iliac crest and a bridge has formed between the pelvis and her left femur. The extra bone recorded that has formed around the pelvic region has greatly increased the width of her hips.



2/10/07

Delineation 56. 8149 On Back (2/10/07).

Delineation 61 (p. 221) made nearly two months after Delineation 54, shifts the viewpoint to slightly above the skeleton. The skeletal bone has been lightly and precisely drawn and the heterotopic bone has been drawn using a stronger, darker line. There is attention to the detail in curves and shapes formed in the new bone and the sharpness of spurs that have bridged is emphasized. The advancement made in preparation is visible. Flesh that is still attached in Delineation 54 (p. 217) particularly around the spinal area has gone in the third delineation in the sequence. There is clarity in the delineation and the lines are precise in conveying my further understanding of where heterotopic bone has formed and how it has connected and fused with the regular skeleton.



Delineation 61. 8149 On Back, Face Up (28/11/07).

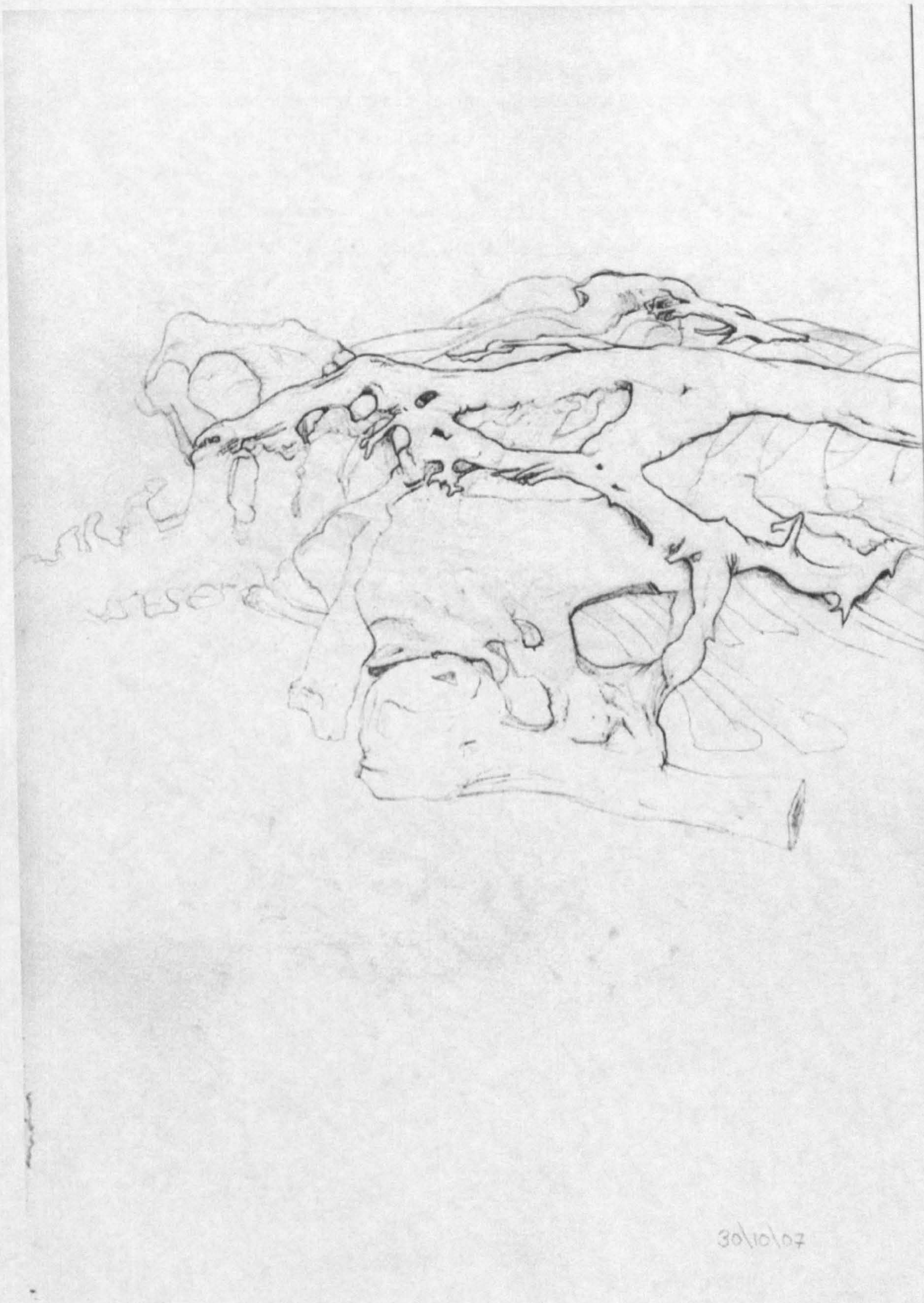
Delineations 57, 58 and 62 form a sequence where the donor has been viewed in the final stages of preparation, face down. Each has been made from a slightly different angle. The first 2 were made on the same day and the last was made over three months later and is the last delineation made as part of the main project.

Delineation 57 (p. 223) and 58 (p. 225) show the back in close up. Delineation 57 is viewed at an angle where the back is seen in three quarter view and in profile.



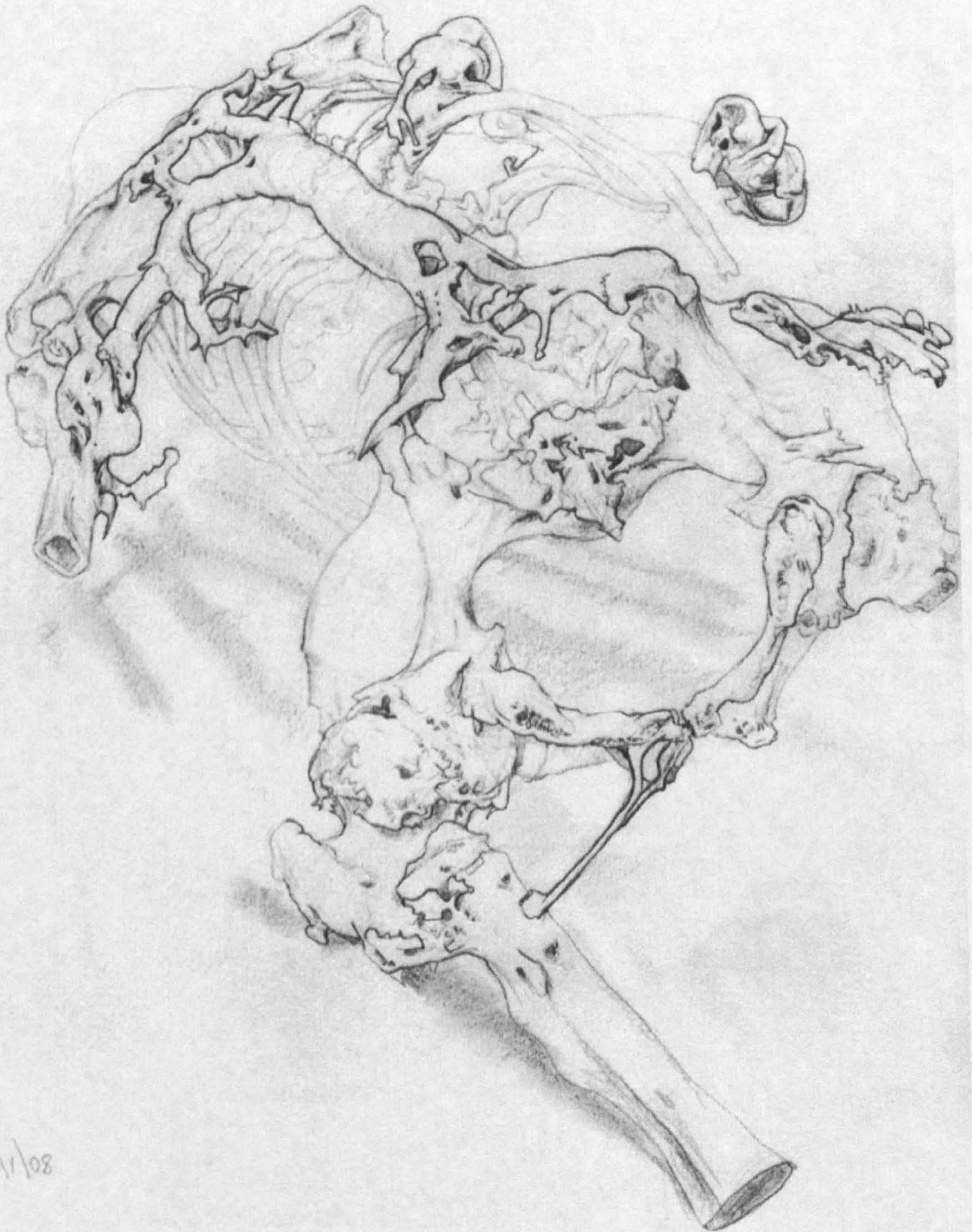
Delineation 57. 8149 Close Up of Back, Face Down (30/10/07).

Delineation 58 (p. 225) shows the back in profile. In both, lines used to record the ribs are even lighter than before and the heterotopic bone has been defined clearly in sharp, dark, bold lines.



Delineation 58. 8149 Close Up of Back, Face Down 2 (30/10/07).

My further understanding is revealed in the views of her back in Delineations 57 and 58 and culminates in a clear presentation of the visual experience of encountering her prepared skeleton in Delineation 62 (p. 227). This is the last delineation in the main project and conveys the experience of my understanding of the phenomenon I encountered as it developed during the activity of delineating. The skeleton has been placed face down and the head is furthest away from the viewer. There is very little evidence of rubbing out or correcting in the delineation. The fine, light lines that have been used to record the ribs are very faint but precise. The heterotopic bone that has formed like a girdle around the spine and pelvis has been recorded clearly and in detail using very dark lines that vary in weight in response to areas where the detail is more delicate. The thin sliver of bone that has bridged between the pelvis and the left femur has been recorded in detail. Its strength and rigidity is conveyed by the weight of the line and the sharpness of the spurs around the chest is recorded using hard, sharp lines. Delineation 62 reveals the nature of this disease; evidence of the insight the activity of drawing brought to my knowledge of the process of preparation and presents my experiences with the phenomenon.



9/1/08

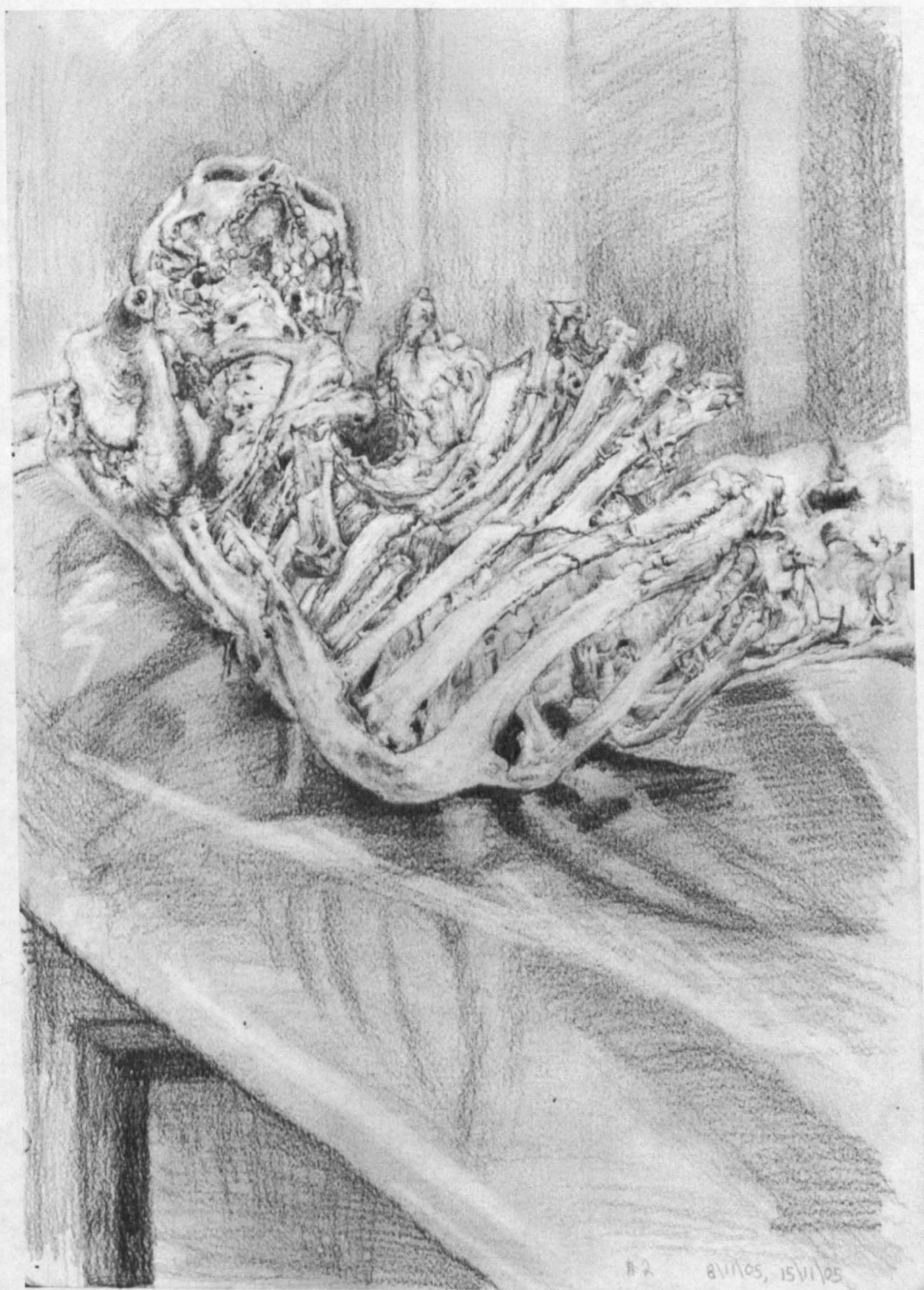
Delineation 62. 8149 Face Down, Final (9/1/08).

This category of other key delineations is the largest. It includes delineations from the main project, the preparation of two donors for display and spans a large time frame from 28th August 2006 to 9th January 2008. The development of my understanding of FOP, the experiences of my encounters and the processes of preparation are revealed in this category.

Problematic delineations

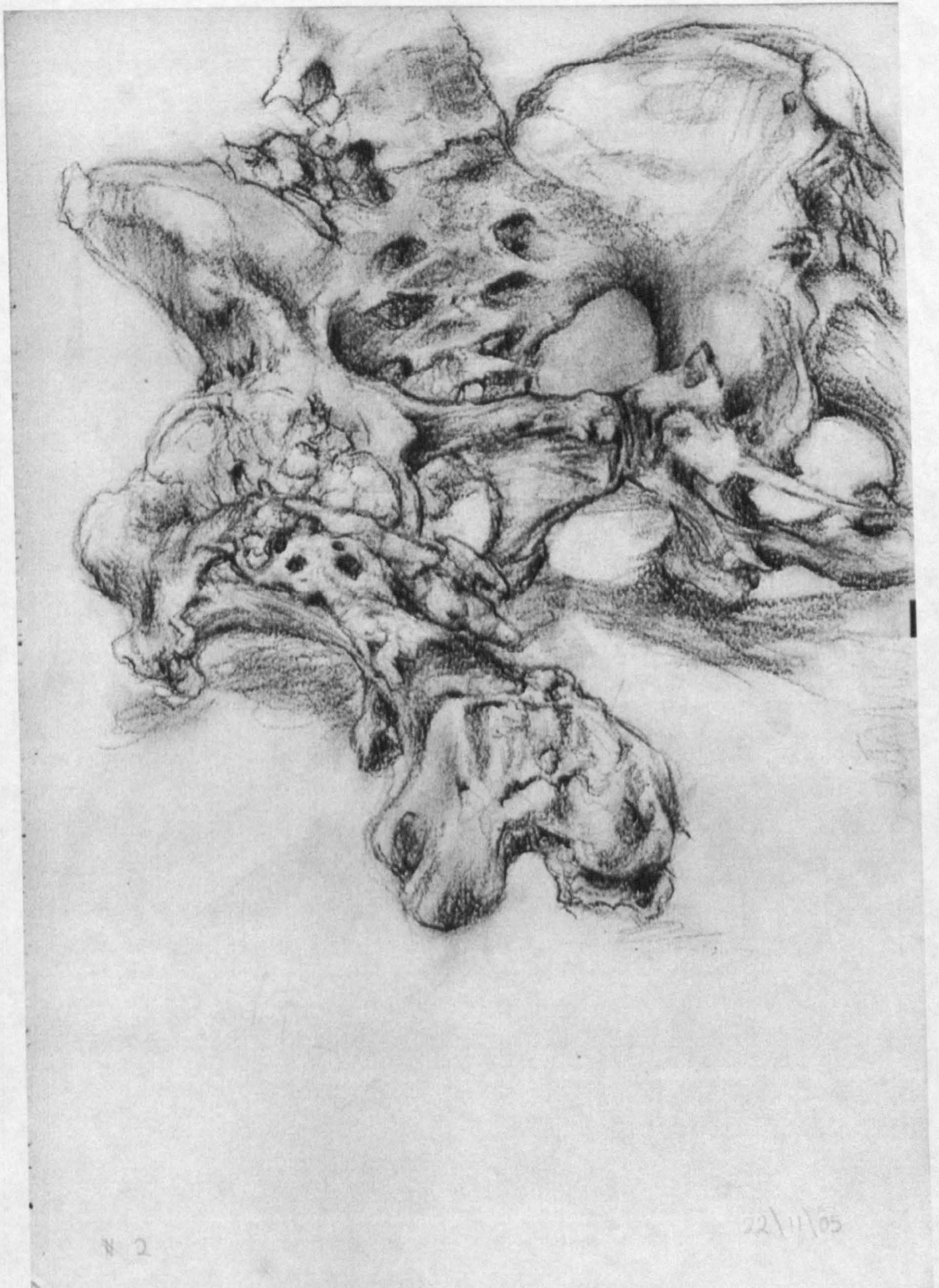
Included in this final category are Delineations 9, 10, 11, 27 and 39. I consider them to be less successful delineations for a number of reasons.

Delineations 9 (p. 229) and 10 (p. 231) were the first drawings I made of the donors. Delineation 9 (p. 229) shows the donor lying on her back. The delineation was made using charcoal and includes the metal autopsy table and the wall. There is a lot of shading and no difference in the weight or type of line used in the drawing. Every part of the page has been filled and the emphasis is on making a complete drawing with an overall balanced composition. The use of charcoal does not allow for the fine detail that it is necessary to reveal intricate detail. By adding all the reflections and shadows it is even harder to understand the portrayal of an already difficult subject. The overall result is one of confusion.



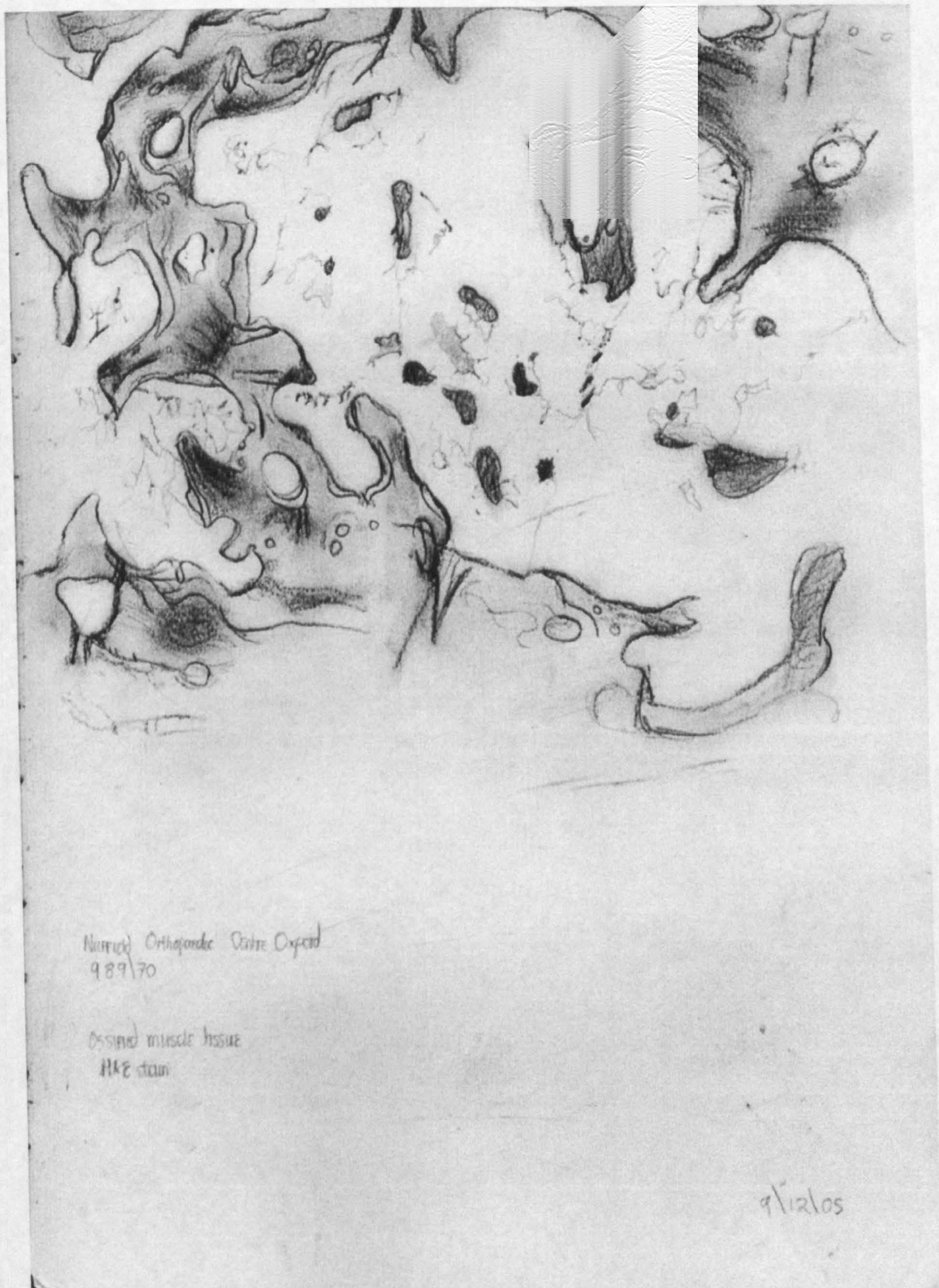
Delineation 9. 7646 On Table, Charcoal (8/11-15/11/05).

Delineation 10 (p. 231) has also been made using charcoal. This drawing shows the pelvis and right femur as if the donor were sitting up. A spur can be seen on the right of the drawing. There is a lack of detail and definition. The overall effect is of dark, smudgy sculptural shapes. This delineation was made on 22nd November 2005 and although there is still tissue remaining at this point, the difference between this and Delineation 49 (p. 213) made on 23rd May 2007 is very strong. The composition is similar enough to allow a comparison to be made. It is clear in Delineation 10 that I have not understood where and how the new bone has formed. Reviewing this work later with the clinicians revealed that it was not particularly helpful in presenting the phenomenon and it also revealed to the experts my own inexperience with the FOP material at that stage in the project.



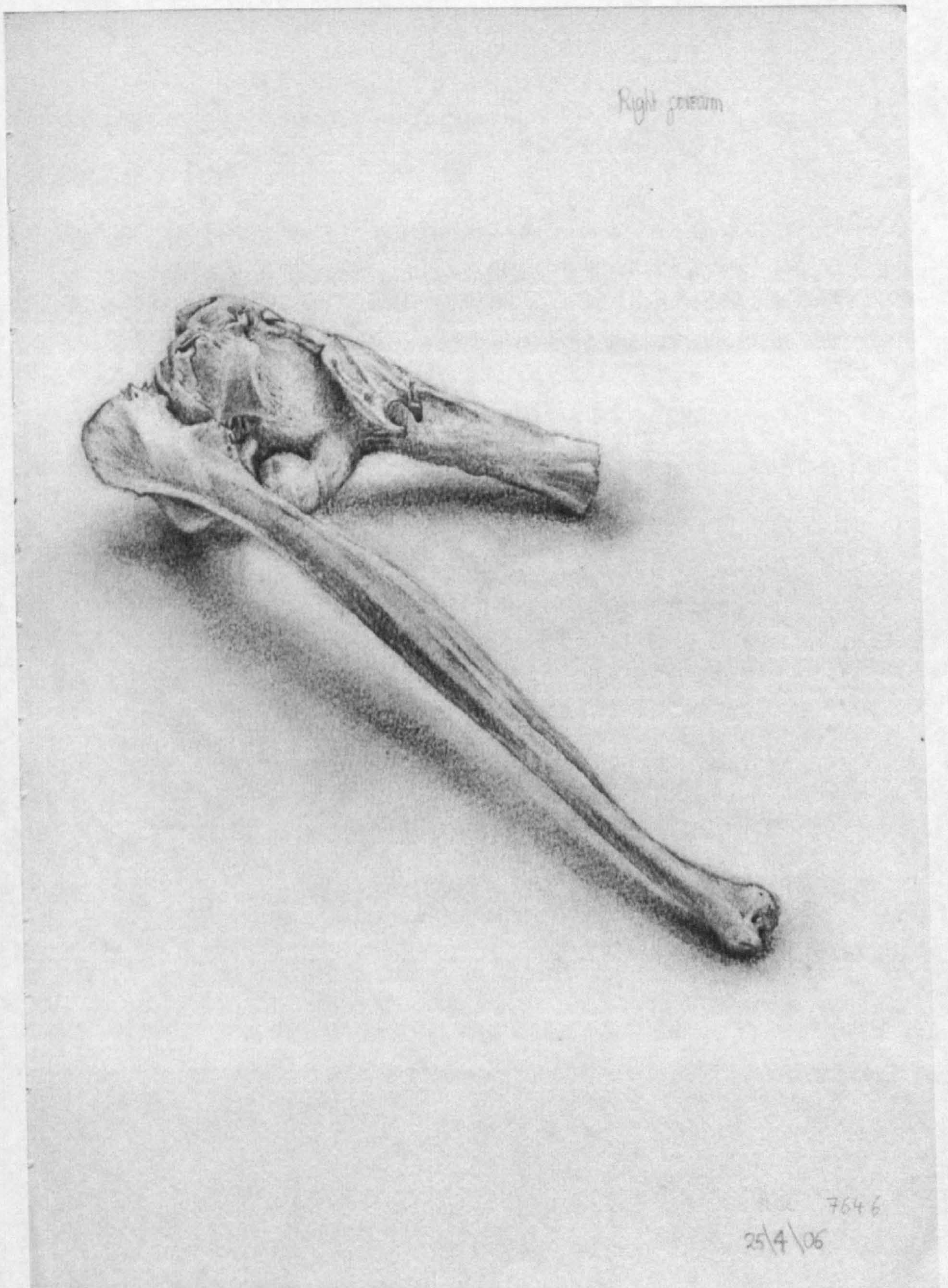
Delineation 10. 7646 Charcoal Pelvis (22/11/05).

Using charcoal to attempt making a histology drawing renders Delineation 11 (p. 233) a good example of an unsuccessful delineation. Made in December 2005 this is a drawing of ossified tissue taken from a sample in University of Oxford. It is crude and unclear especially when compared with the drawing of histology, Delineation 48 (p. 211), made nearly a year and a half later.



Delineation 11. Oxford Histology, Charcoal (9/12/05).

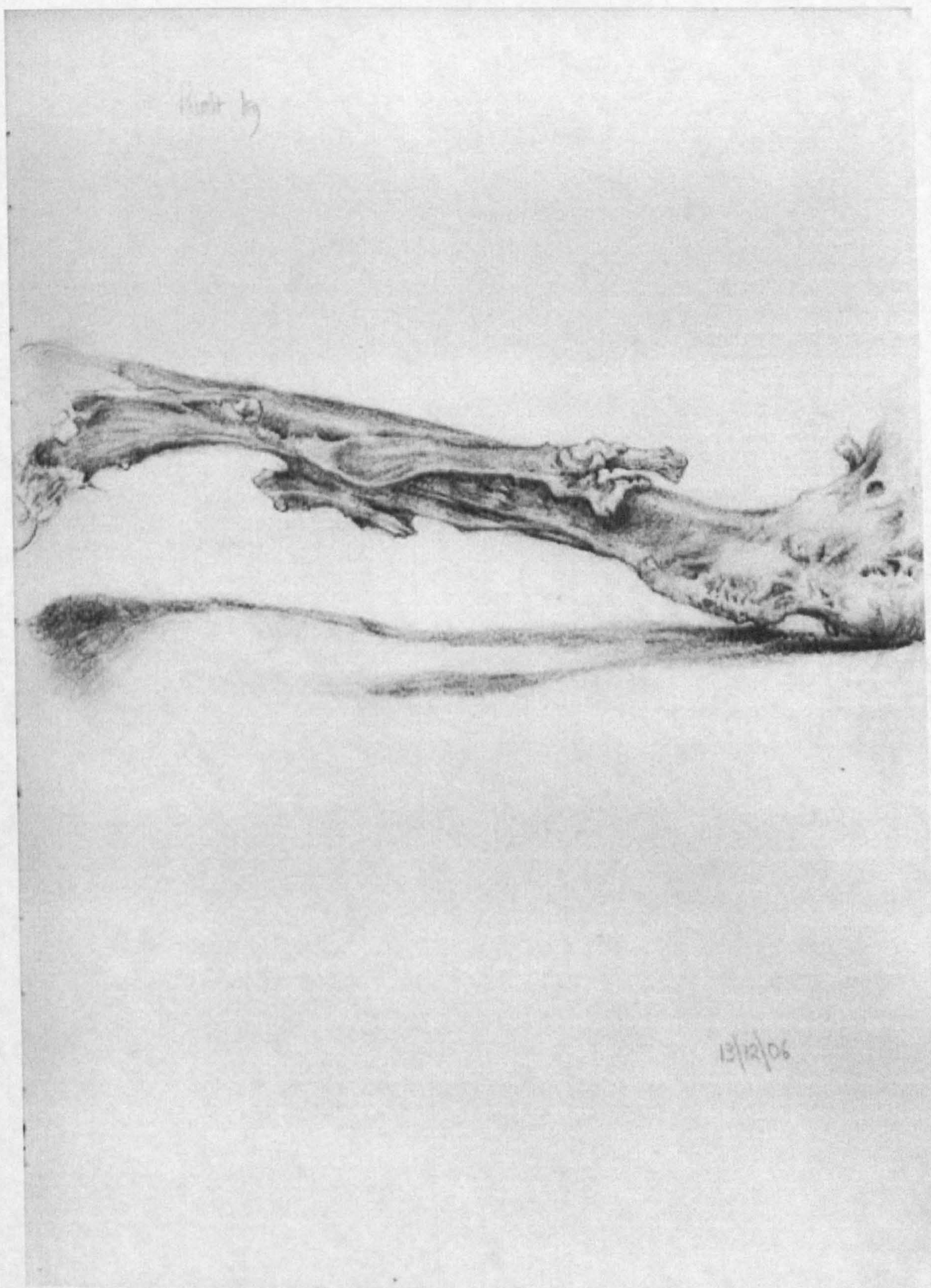
Delineations 27 (p. 235) and 39 (p. 237) are both made using pencil but I have reverted to using lots of smudging to create shadows and tonal contrast. They do not convey my experience with the encounters, information about the preparation methods used or about FOP.



Delineation 27. 7646 3D Right Forearm (25/4/06).

Both delineations seem to be an exercise in how to make a well executed drawing of an interesting object rather than offering insight or knowledge. Their purpose is unclear and they do not convey any relevant information.

All these examples do not comply with the system of delineation as developed within this investigation. They are not precise, detailed and do not portray the lifelike specificity of an object without the use of tonal contrast and shading to create modelling. The use of charcoal is particularly inappropriate to this effect and drawings made using this material are not seen to be delineations as such. However, in the interest of balanced research, it is important they remain in the thesis to support the claims of how useful delineations are to present and convey understanding of objects and the delineator's experience of phenomena.



Delineation 39. 8149 Shaded Right Leg and Spur (13/12/06).

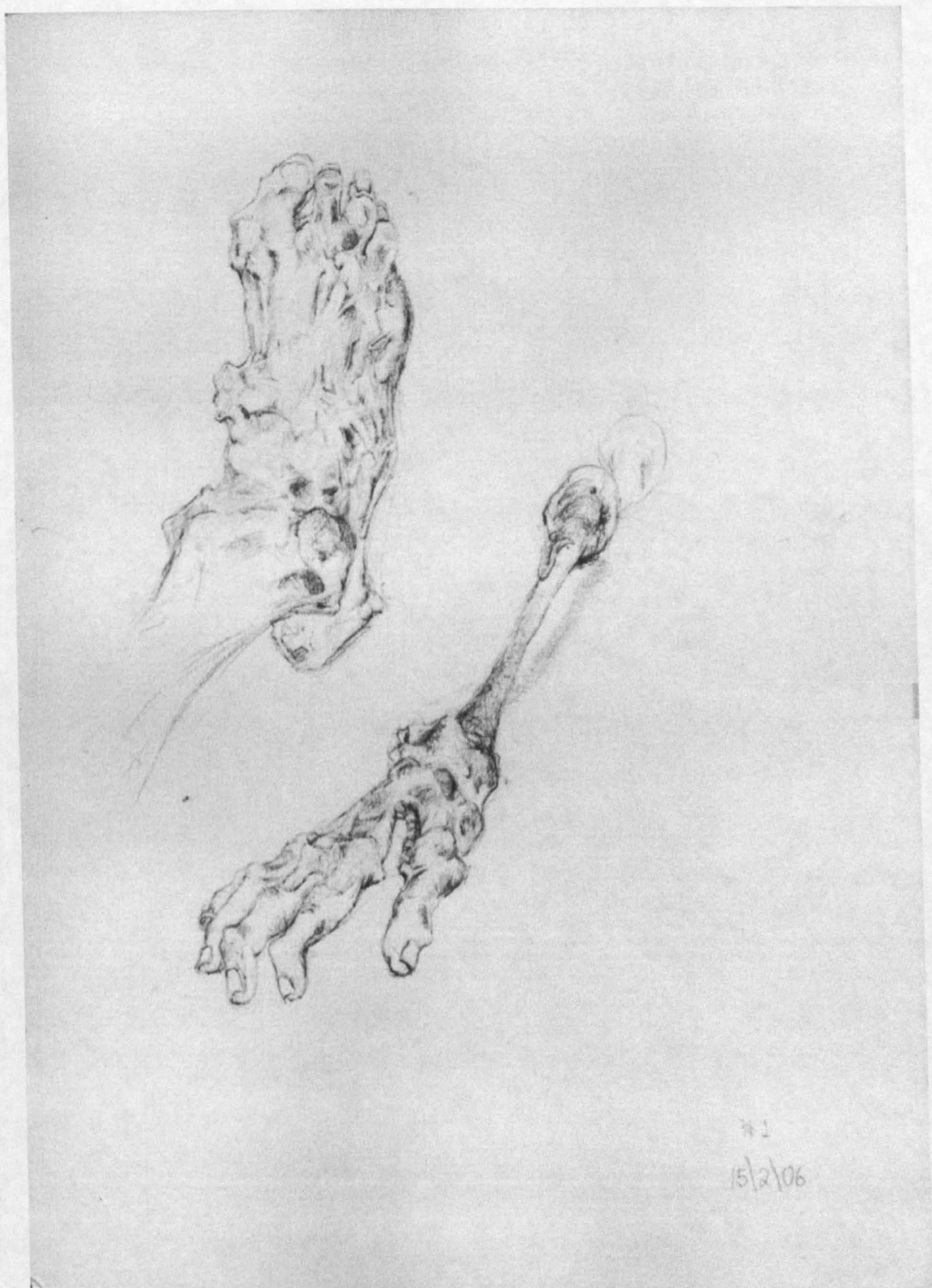
Summary of delineations

I have examined in detail 55 of the 66 delineations made. All these delineations are hand drawn. They are gentle in that the sensitivity of the line is shown clearly in the marks on the page. There is no need to resort to strong dramatic lighting or any other props, intended or unintentional as can be seen in photos described in Chapter 5. What we know from the delineations is that I, as agent am in the room, looking at the object as I draw it and I remain in this relationship until the delineation is complete. The remaining 11 delineations, 12, 13, 19, 20, 24, 30, 31, 38, 51, 53 and 60 can be found on the following pages but are not discussed.

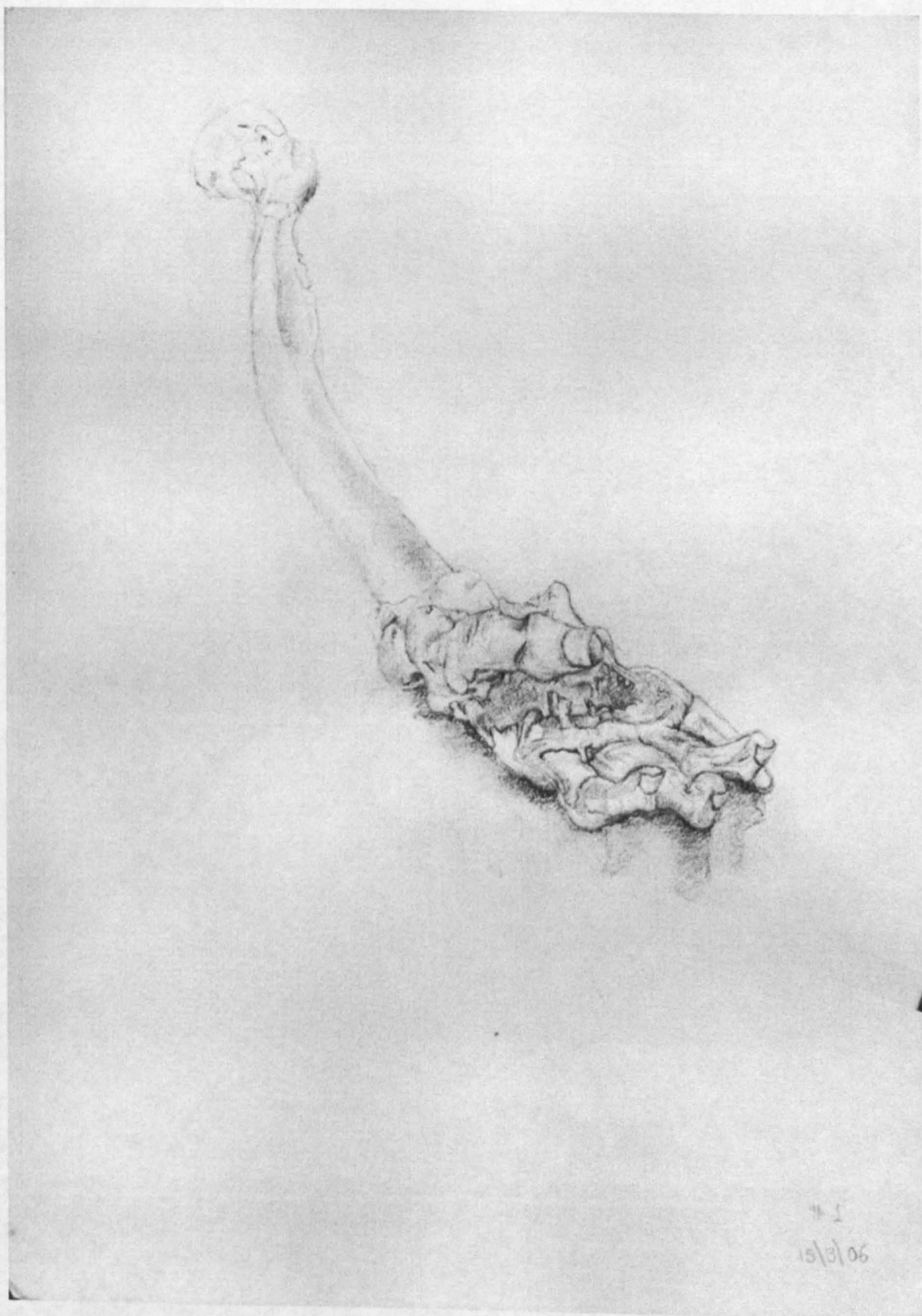


#1
12/2/06

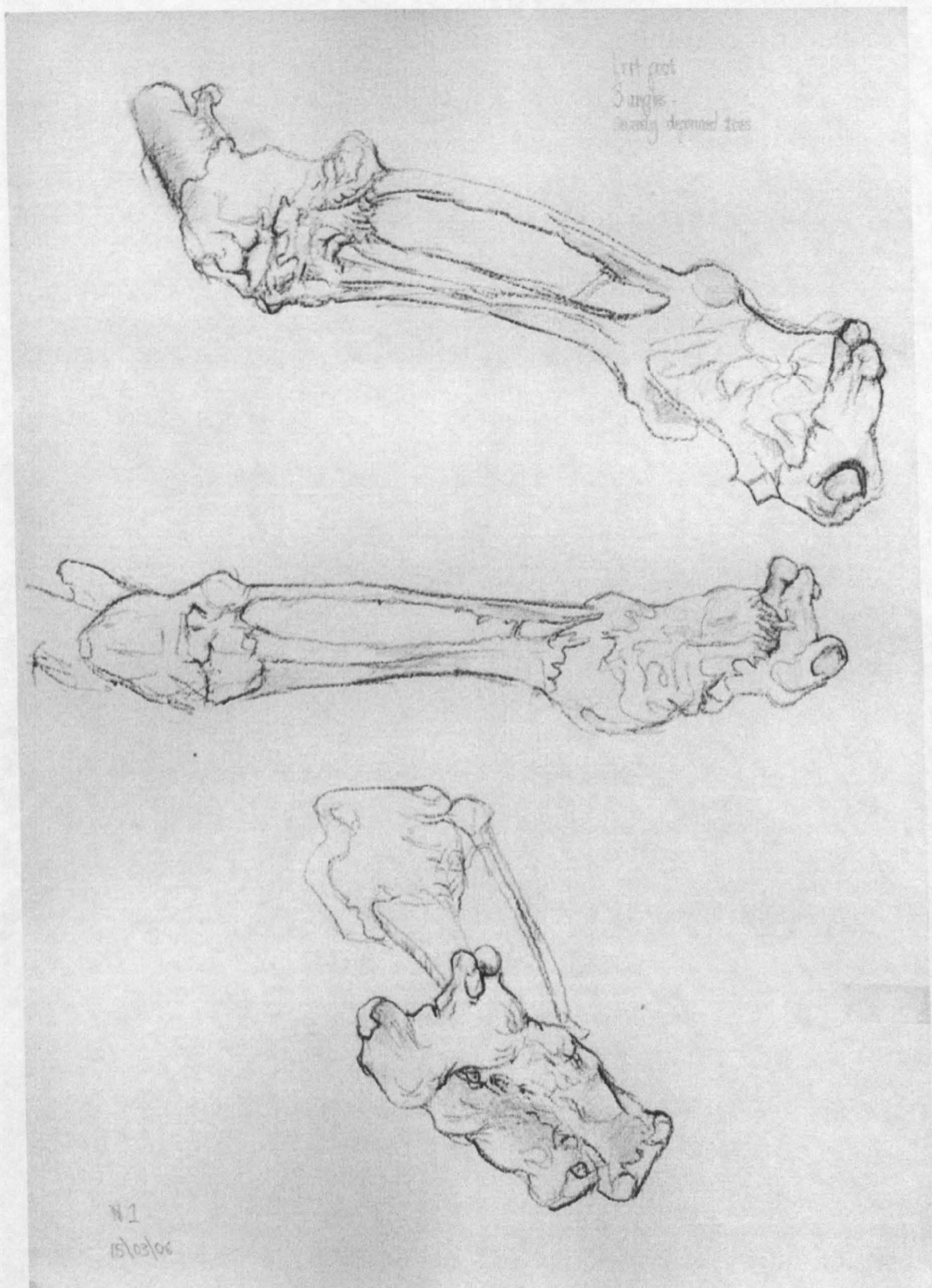
Delineation 12. 8149 Underneath Foot (12/2/06).



Delineation 13. 8149 Right Foot and Right Arm (12/2/06).



Delineation 19. 8149 Right Arm Face Up (13/3/06).

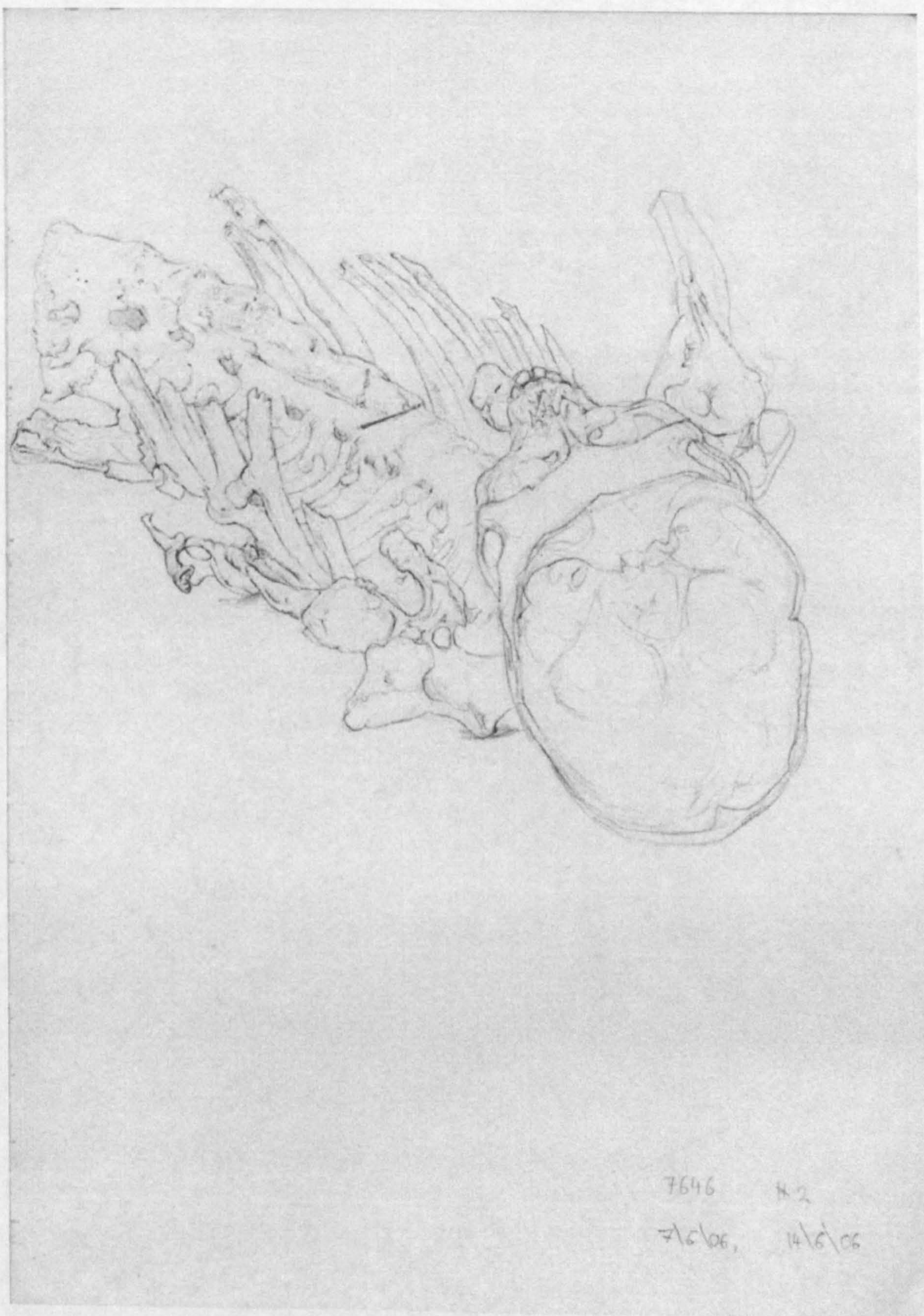


Delineation 20. 8149 Three Views of Leg (15/3/06).

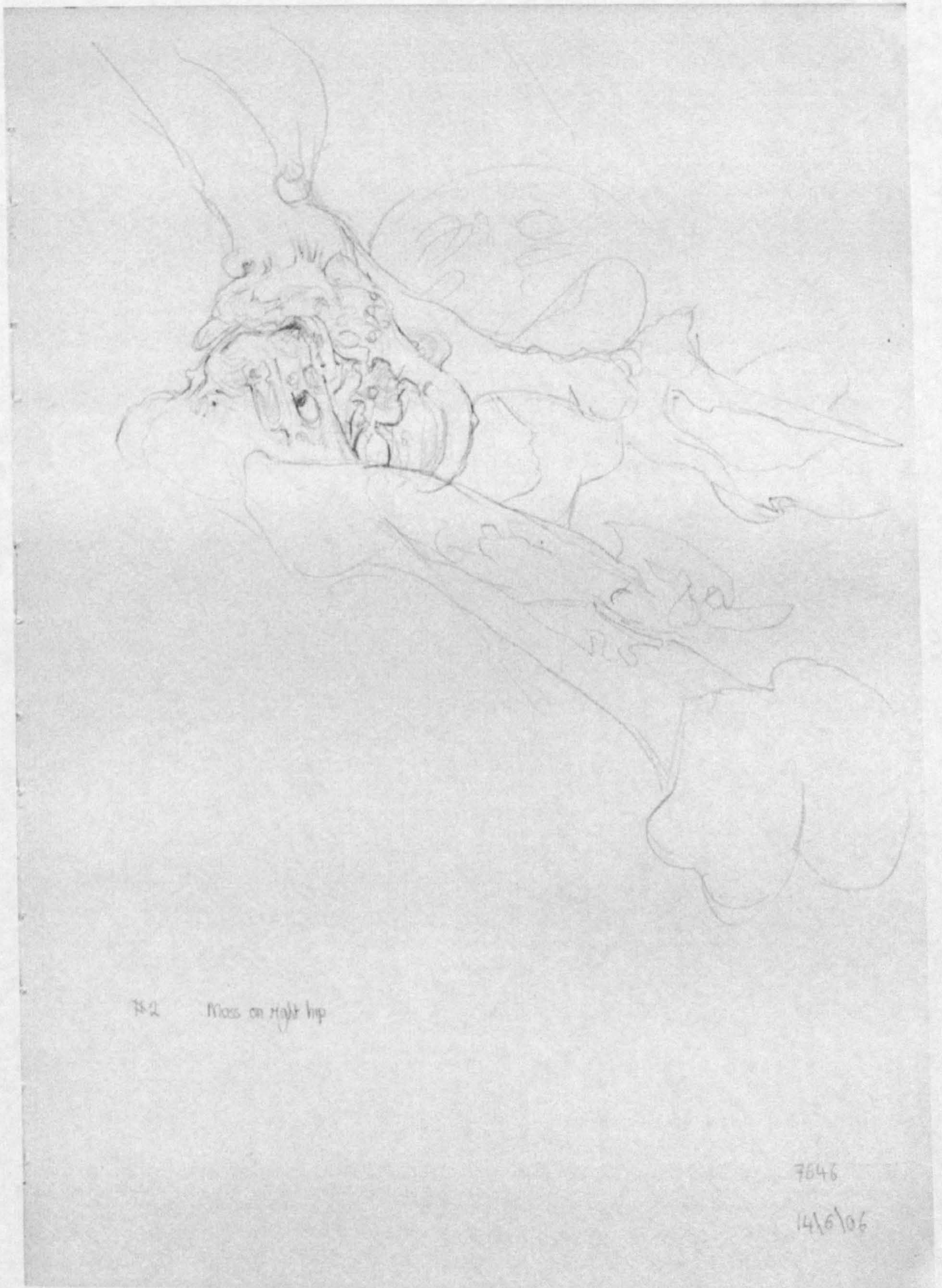


11
22/3/06

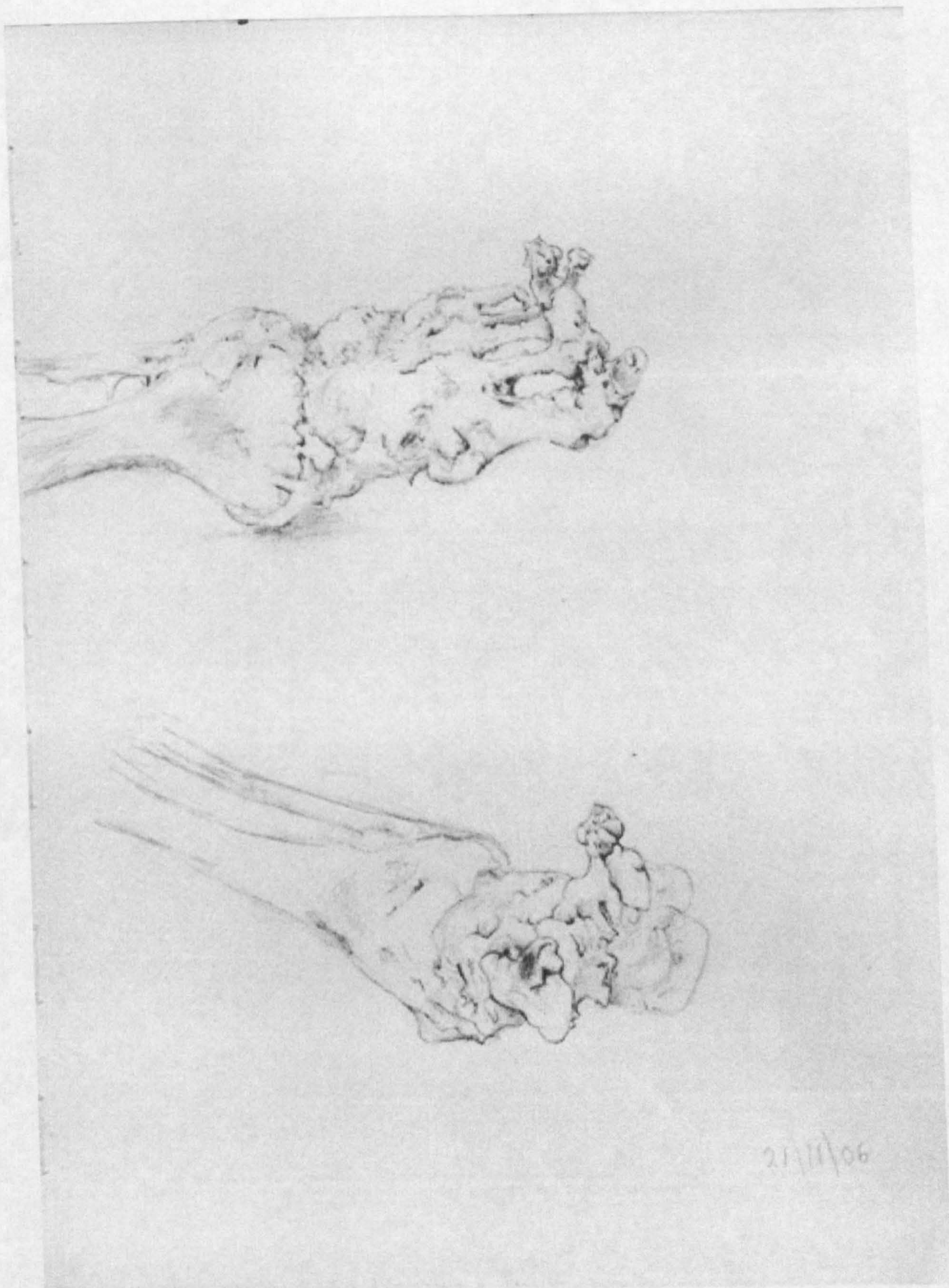
Delineation 24. 8149 Right Leg (22/3/06).



Delineation 30. 7646 On Back Top of Skull Head On (7/9-14/6/06).



Delineation 31. 7646 Rough Mass Right Hip (14/6/06).

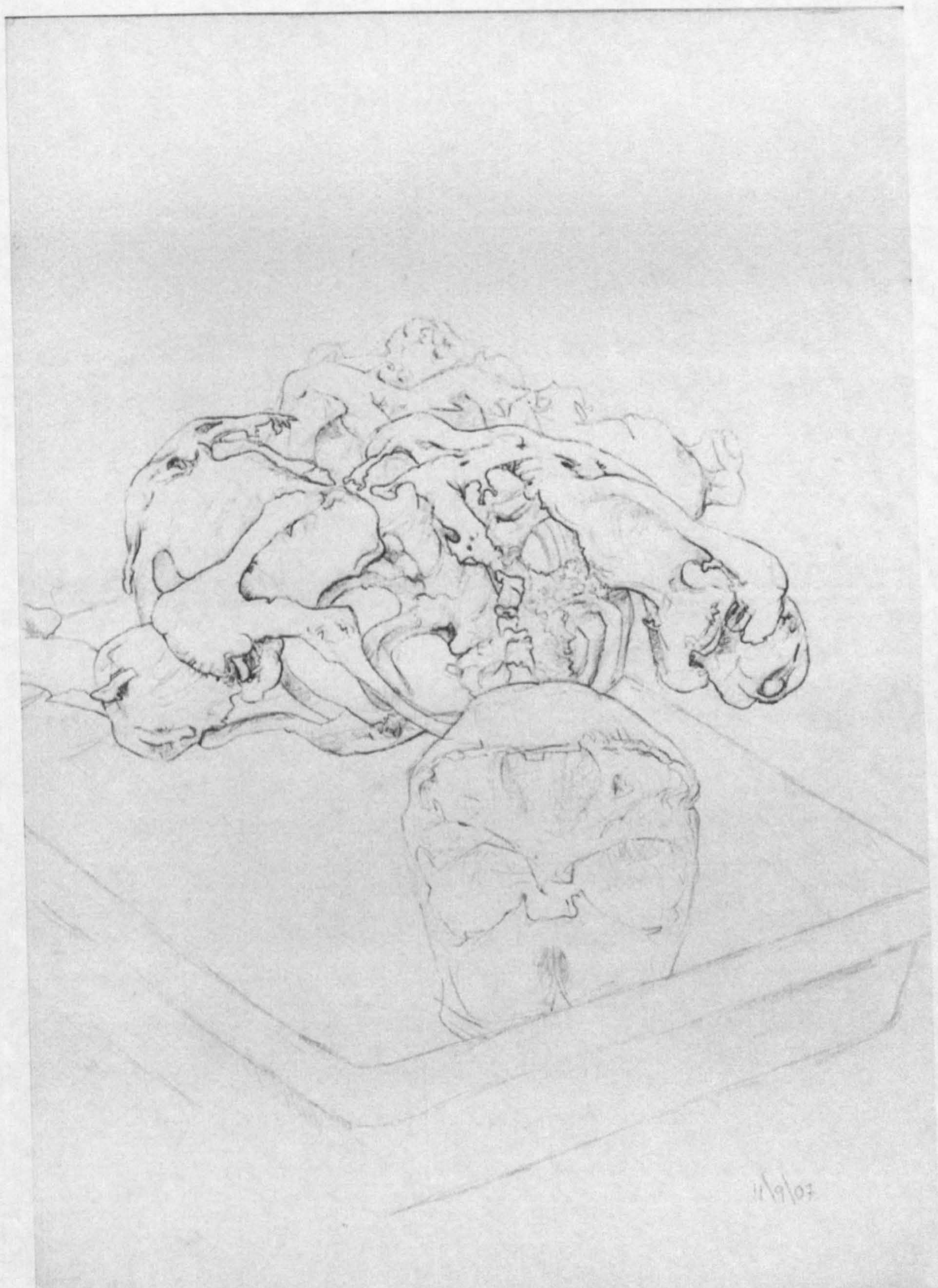


21/11/06

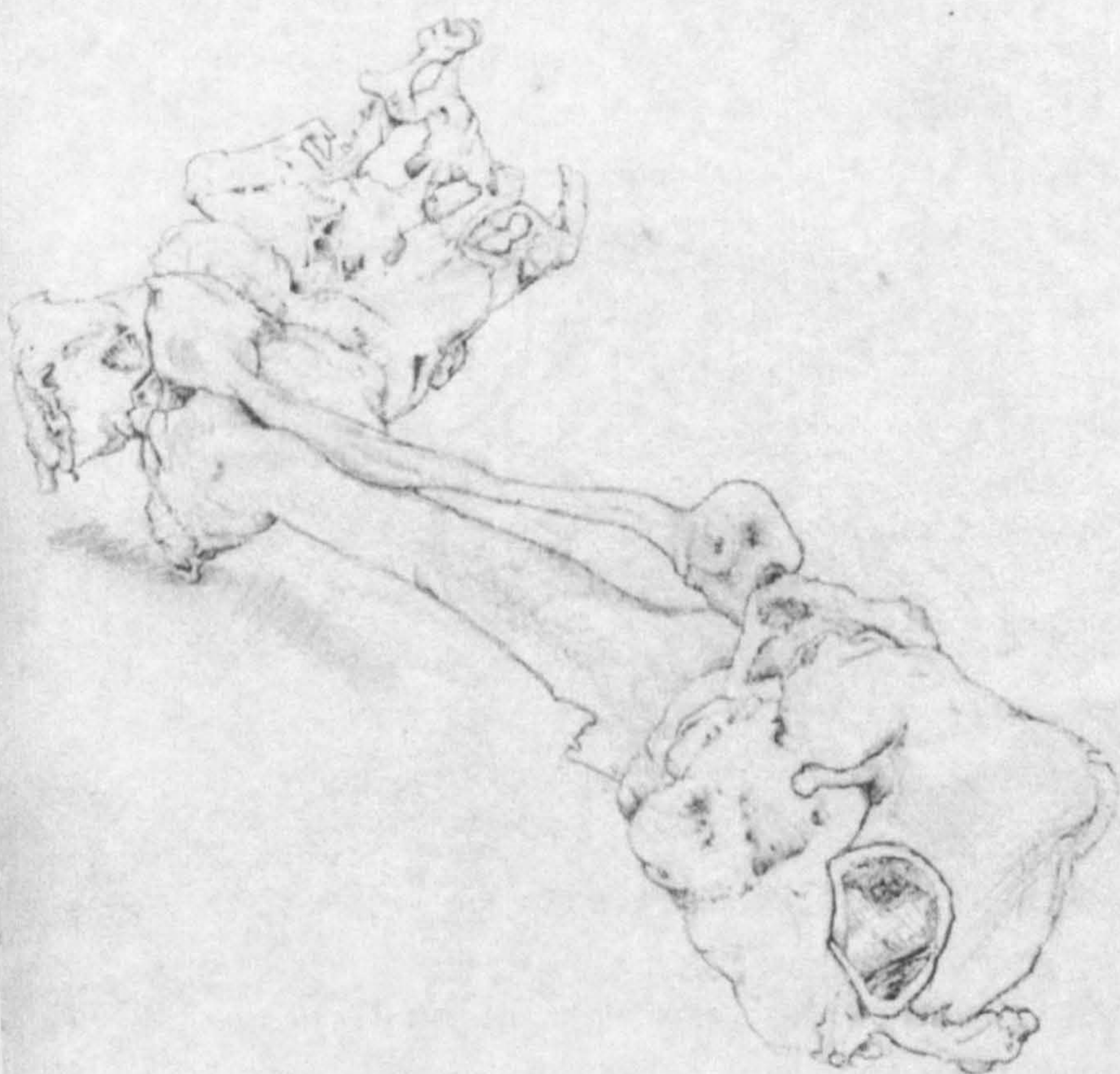
Delineation 38. 8149 Two Feet (21/11/06).



Delineation 51. 8149 On Back, Facing Towards Us (11/9/07).



Delineation 53. 8149 In Tray, Head Down (11/9/07).



14/11/07, 28/11/07

Delineation 60. 8149 Leg, End On (14/11-28/11/07).

The delineations that were seen to be successful in communicating the experiences of this disease through the activity of drawing have several things in common. Unlike early drawings made using charcoal, ones that offer new visual information are all made in graphite pencil. The ones that convey the most understanding and new information have incorporated the system of delineation to the best effect; that is they are precise, make use of line as if tracing the actual object and are a specific portrayal emphasising the uniqueness of each individual object, each different time it is encountered and where possible, present each experience as directly and immediately as possible. They contain detail and ignore extraneous information.

The application of weight on certain lines and emphasis on relevant details produces delineations that communicate knowledge of the phenomenon being encountered and a clear understanding of the experiences and processes involved. Specific detail of heterotopic bone is portrayed as precisely and closely to the encounter as it happened.

Although the donors appeared less human as preparation continued and more flesh was removed, the secrets of this dreadful disease were being revealed and the more I felt I knew them. The evidence of the effects of FOP was laid bare. Having such a clear view of the extent of their disease made me feel closer to precisely presenting the visual experience of the encounters. As I drew more, the more I understood. The more flesh Martyn scraped away, the more was revealed. He saw the drawings as recording this process and conveying my experience of it. The system of delineation as described in this investigation, demonstrates the cumulative collection of fugitive experiences as they were encountered.

The delineations are handmade but during the main project I also took 737 photographs (Appendix d.). These documented the main project and I will now describe the activity of taking photographs in this inquiry.

Role of photography

Throughout this project I have photographed the progress of maceration of the two donors. Whilst the photographs have a vital role documenting

the processes employed, they are seen within this research as supporting material and it is the activity of drawing that is being investigated in this thesis. I have selected five photographs for discussion here, choosing examples that corresponded to particular delineations.

Although the aim here is not to compare accuracy, it is important that the precision of visual information presented through the activity of delineation is acknowledged and an examination of the photographs helps to reinforce this. I have never made any delineations from a photograph. Delineations are only ever made directly and immediately during the ongoing visual experiences in the presence of the object.

During the course of this inquiry, I found actions performed throughout the process of maceration could occur very quickly. The activities were often repeated and completed in a short time. Others, like scraping with a scalpel were ongoing and took much longer to finalise. I often took photographs of an activity while I was drawing something else. For example, if Martyn was using a scalpel to remove tissue on an upper limb, I might be drawing the other end of the arm or maybe a leg. If this activity needed to be documented, I would quickly take a photograph and then return to the delineation being made. On other occasions, I would photograph his actions at the same time as delineating them.

Importantly the activity of photographing this information was almost instantaneous so the image became the source of information, a thing to be scrutinized and looked at in detail.

With the system of delineation in this research, it is the activity of continuously looking and drawing whilst in the presence of the object that is vital. This relationship and activity is where further understanding and knowledge is formed and presented to others.

The photographs were taken at the same time as the delineations were made. I have chosen 5 to compare with the delineations. I have selected examples of ones that are very close in composition to the drawings making it easier to find correlations and differences. They are of the same

objects drawn from the same angle at the same time as the photographs, but they are different.

Comparison of photographs and delineations

5 delineations, Delineations 29, 32, 40, 42, 43, will be described in detail in comparison with the corresponding photographs made as part of the documentation of the procedure.

Delineation 29 is of the torso of donor **7646** and reveals significant, previously unseen information. The marrow in the heterotopic bone is made evident as the bone types are differentiated and portrayed clearly without detracting from the overall visual experience (Fig. 27). Delineation 29 is a systematic, closely observed, lifelike portrayal that makes use of a variety of weight of line and little tonal contrast. It took three days to complete. There is no evidence of the background or reflective plastic covering on the table that might distract from the relevant detail recorded in the delineation. The object has not been centrally placed and it appears to 'float' as there is no pictorial surface for it to rest upon. This would be unconventional if this were an example of another type of drawing that is also sometimes drawn as a life like, closely observed, precisely rendered object, for example a still life.



Fig. 27 Delineation 29.

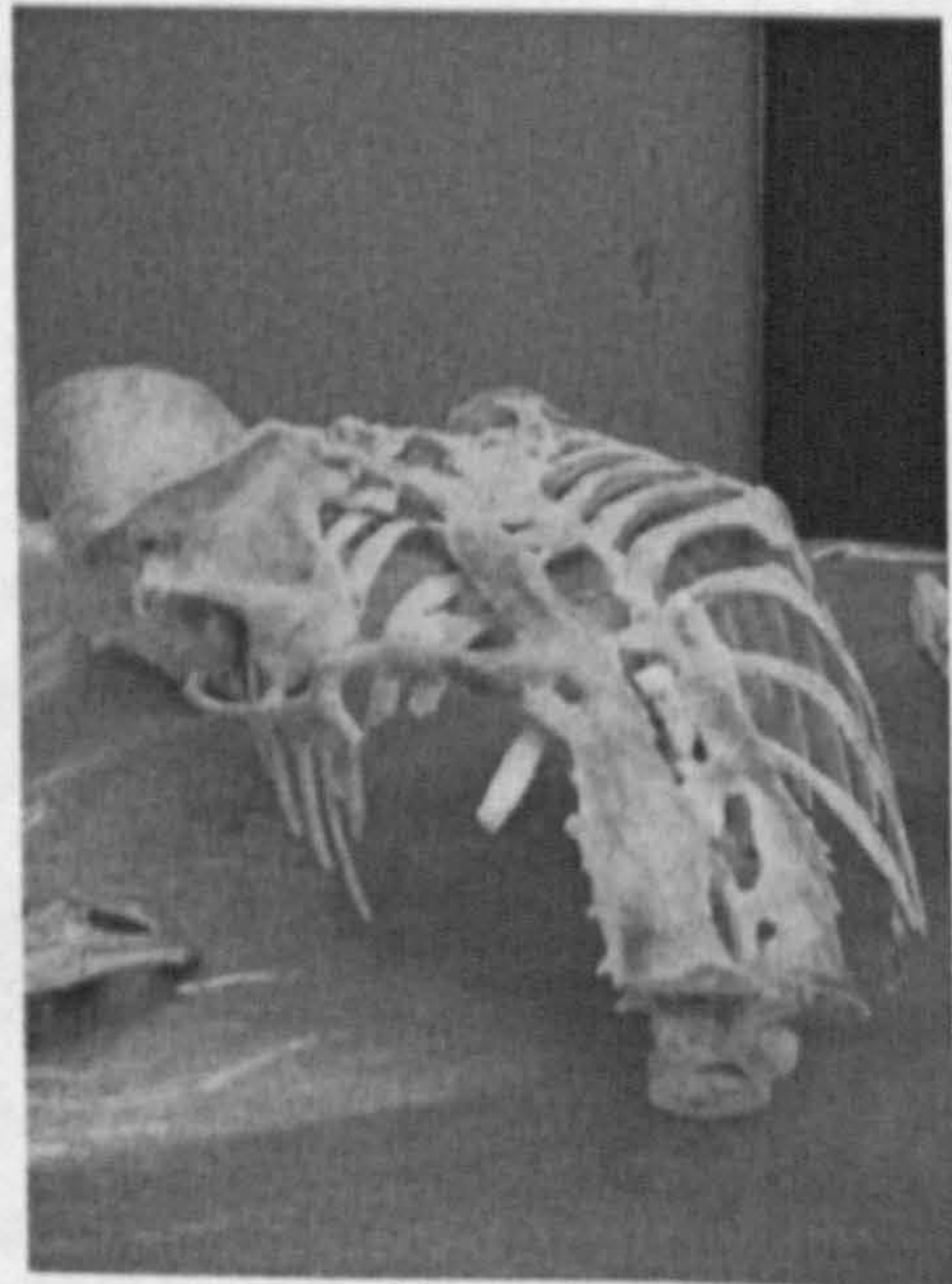


Fig. 28 Comparison photo to Delineation 29.

Marks made in relation to experiencing the regular skeleton remain light and less defined. The heterotopic bone is presented using clearer, shaper, darker lines. The pencil marks that present evidence of the marrow in the heterotopic bone are more clearly portrayed in the delineation. Their emphasis was instinctive as I was unaware of their significance before Professor Wordsworth commented on the finished delineation which is described further in Chapter 7. I understood that both kinds of bone were the same but treated them slightly differently without altering the level of accuracy I aimed to achieve. The heterotopic bone can therefore be seen to be part of the skeleton but different to it, by the system of delineation used in this investigation.

Compositionally the photograph taken at the same time is almost identical but the heterotopic bone is visually difficult to separate from the normal skeleton (Fig. 28). Photography also seems to visually flatten areas so the curvature of the spine does not appear to be as dramatic as when experienced first hand. In the background the cream wall can be seen and a dark rectangular area of space. The torso of **7646** is shown clearly on a table covered with clear, shiny, plastic. The use of different lines and the attention to specific details allows the delineation to more reliably present the visual encounters.



Fig. 29 Delineation 32.



Fig. 30 Comparison photo to Delineation 32.

Delineation 32 presents the complexity of ossification in the left hip of donor 7646 (Fig. 29). It took three days to complete and the visual experience of encountering this phenomenon is presented through close observation and a system of alternating weight of line so areas seen to be relevant have a stronger line whilst others appear much fainter. The hip is positioned facing down and the focus is on the intricate detail formed by the heterotopic bone. The delineation begins to visually unravel the complex patterns the spurs have formed and informs the viewer how I began to understand and make sense of what I was looking at.

The experiences encountered throughout this time have allowed the accumulated insights of each fugitive experience to be brought together. The detailed aspects of the phenomenon are recorded and have become clearer as the delineation progressed. Further details, beyond those documented in the single photograph, became apparent as the continuing activity of observing and drawing reveals more and more specific traits.

The act of photographing an object takes far less time than looking and drawing. The photograph shows an instantaneous snapshot of the complexity of the extra bone that has formed around the pelvic girdle. In my opinion, the detail has become lost in the general melee of patterns and shapes documented at the same level of intensity. All detail has been picked out by the camera rather than relevant specific areas that clearly present insights into the object and my experiences of it (Fig. 30).

Delineations 40 and 43 are good examples of depicting limbs that are comparable compositionally to their equivalent photographs.

Delineation 40 was made in one day and records a right leg while Delineation 43 presents an arm and hand lying face up. The lines used in both are clear, strong and confident. The delineations are devoid of the extraneous surroundings like plastic sheeting and buckets but present precisely and directly the experiences of each encounter with the phenomenon. The detailed, clear lines used allow the visual experience to be communicated better when reflections from plastic and other unnecessary items are not included.

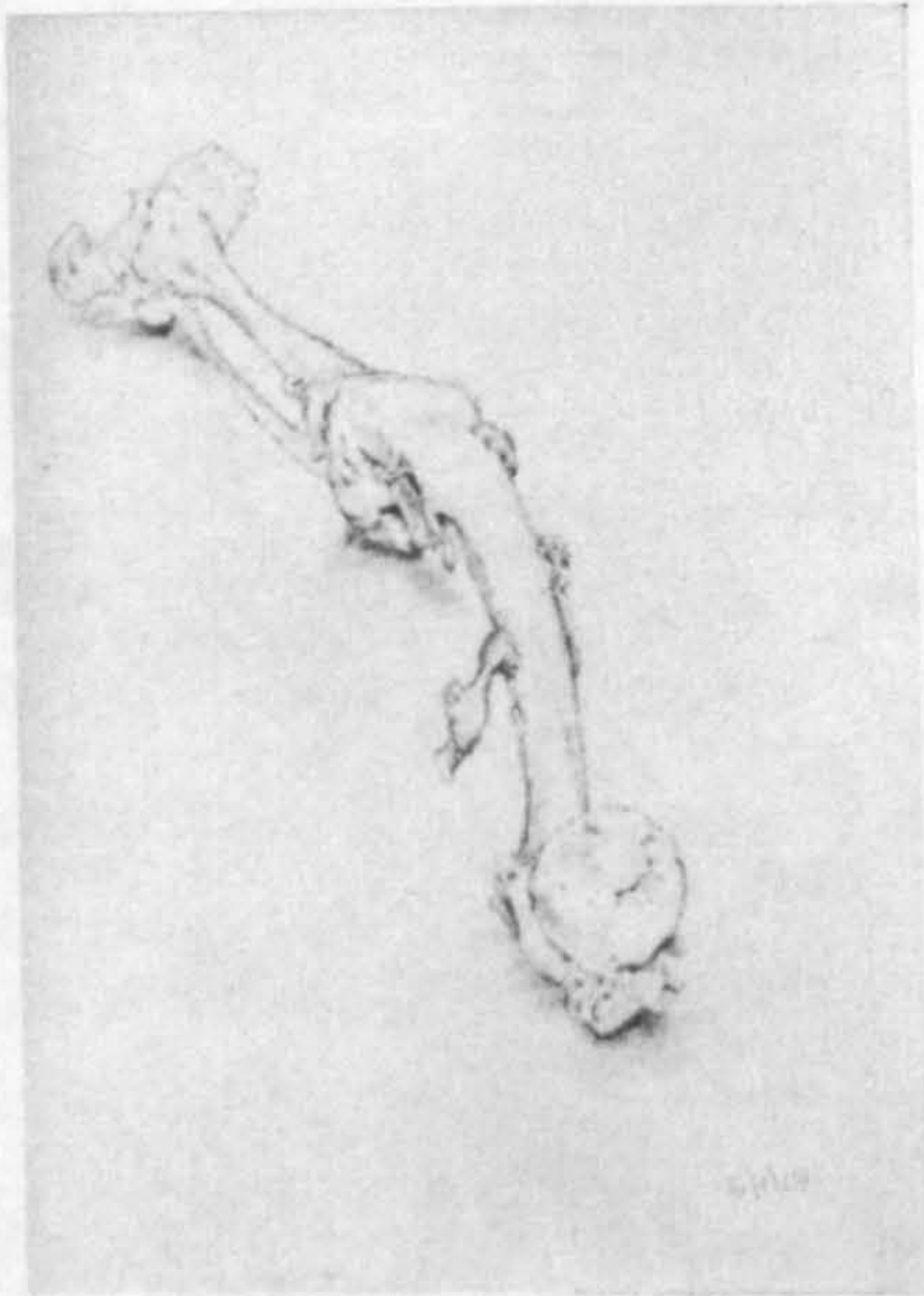


Fig. 31 Delineation 40

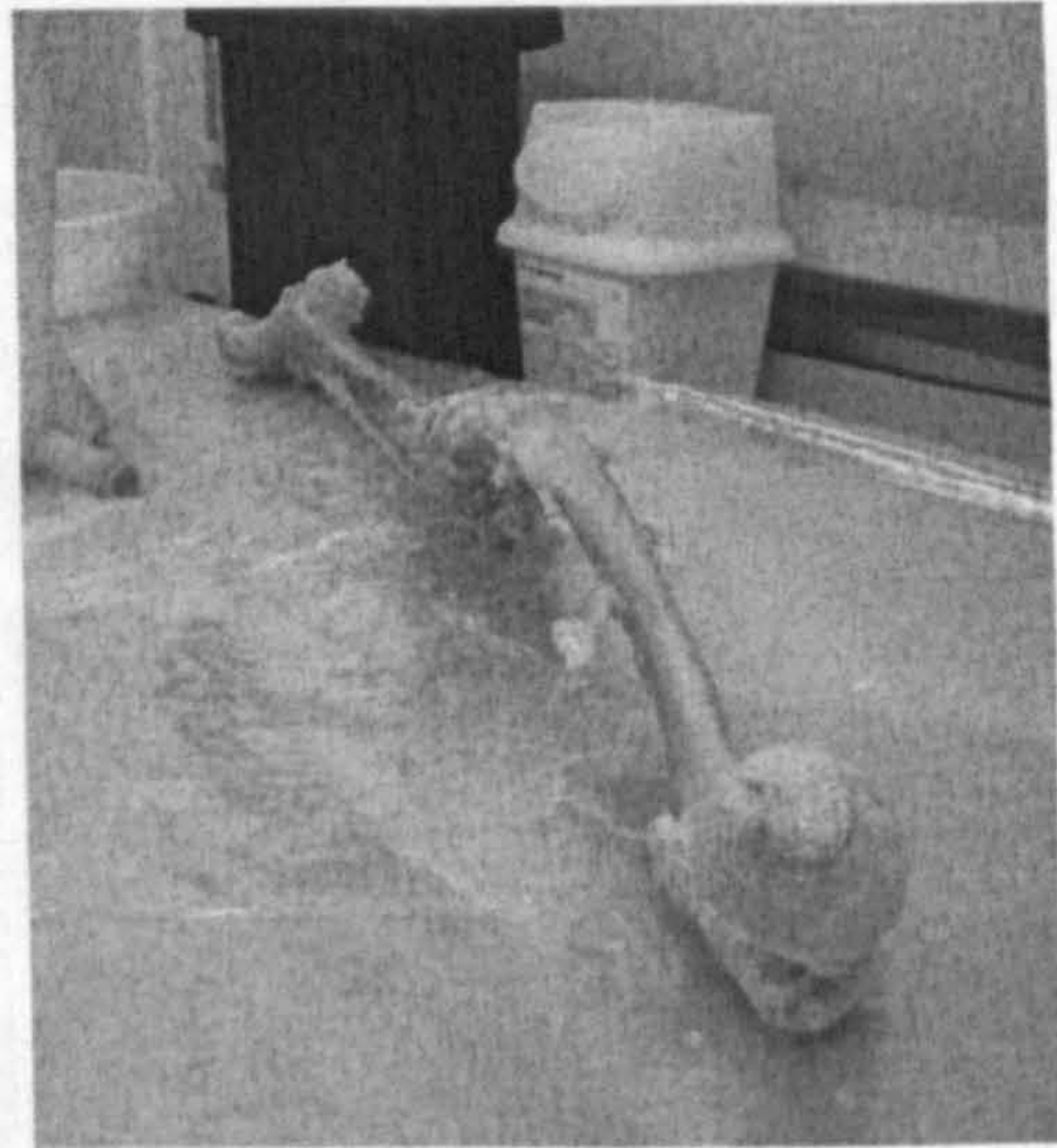


Fig. 32 Comparison photo to Delineation 40

In delineation 40 (Fig. 31) the weight of line changes between the gentle curve of the smoothness of the regular bone in the femur to the heavier, darker twisting of the spurting heterotopic bone. In my opinion the experience of how I have observed the object is presented through the activity of drawing it whilst remaining in visual contact with it.

The photograph that is equivalent to Delineation 40 shows a lower limb placed on the table which is covered in clear, shiny plastic (Fig. 32). There is reflection caused by the use of a flash. The blue rectangular object and particularly the bright yellow sharps bin in the background are visually distracting.

In Delineation 43 the confusion of visual information is made clearer due to the lines used to record the phenomenon (Fig. 33). The slight shift in viewpoint is evidence of the delineator being in the presence of the object at all times and corresponds to the natural eye movements and shifting body position that occur when engaged in the activity of intense observation. Both delineations show the slight variations of composition and they demonstrate the consequences of eye movements that occur naturally as I look up to see, look back to my page to draw and look up again etc. These movements present the understanding I gain as I scrutinize each particular area then re-encounter areas as I look again to draw. These are the fugitive collections of experiences I have when

encountering objects and are presented as directly as possible in these delineations.

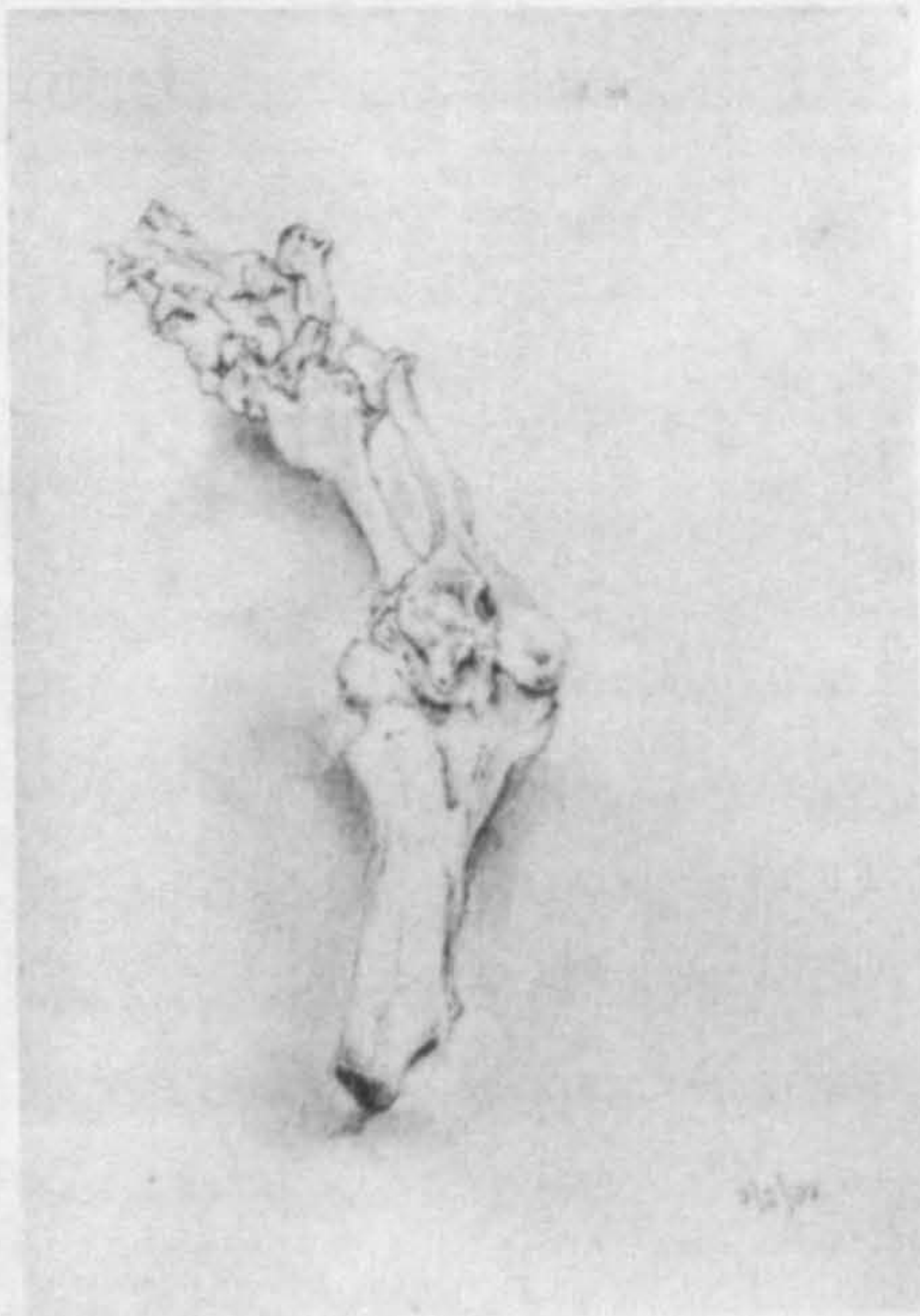


Fig. 33 Delineation 43

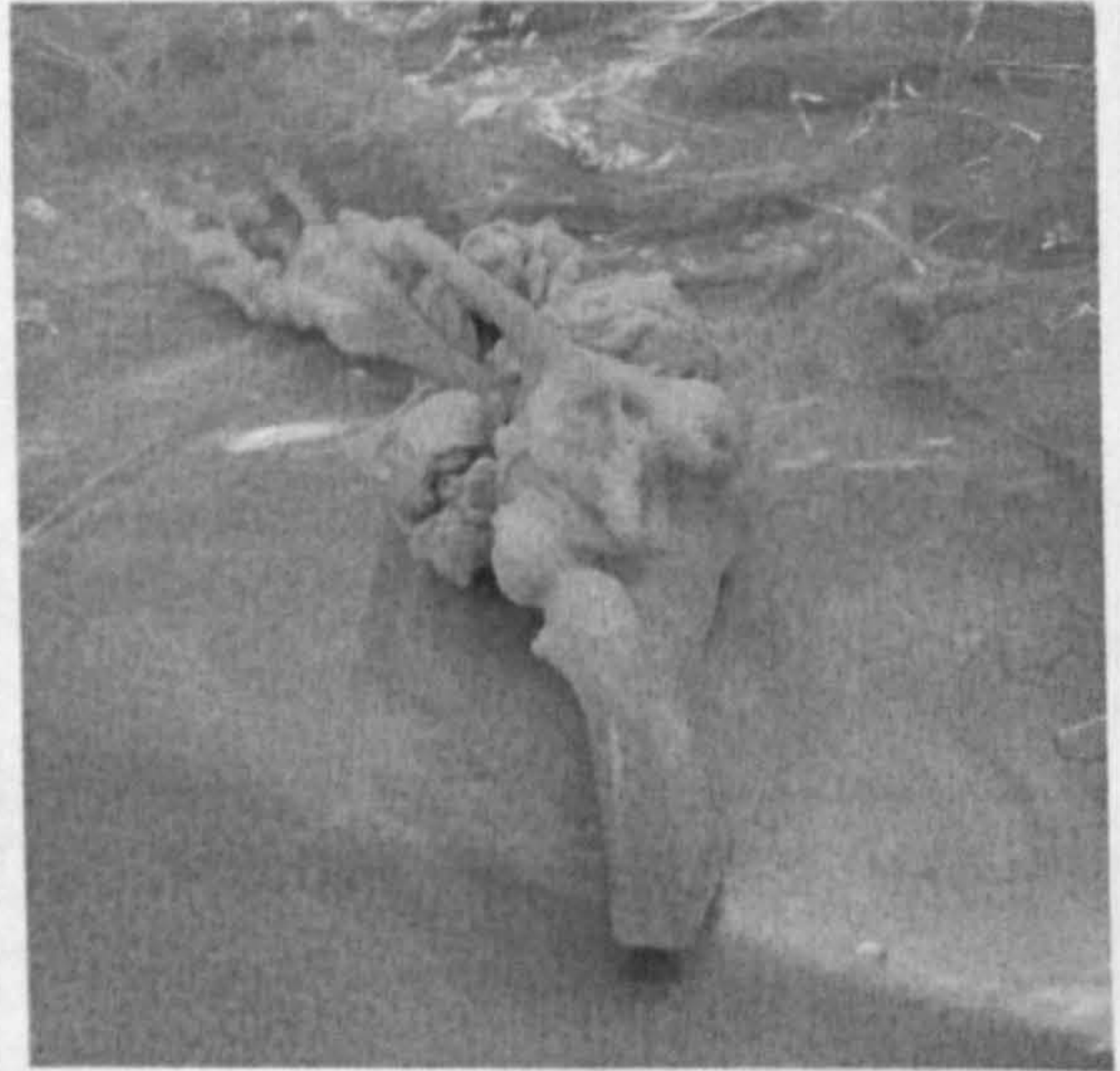


Fig. 34 Comparison photo to Delineation 43

The photograph of the forearm shows not only the specimen, but also the tissue it lies upon and the pattern of light created by the flare from the flash reflecting in the plastic sheeting. In my opinion it is very distracting (Fig. 34). Although the same, it is evident that rather than remaining in a fixed static position as the instantaneous action of taking a photograph involves, there is a sense of movement in the activity of drawing the object as it is seen in situ.

Delineation 42 is of the torso of **8149** and presents both my further insights into FOP and records the progress of the preparation (Fig. 35). The lighter, more delicate lines used to draw the rib cage are visually separated from the heavy, darker lines of the ectopic bone. The details of these are picked out as precisely as possible and clear, sharp lines are used to present the complex arrangement of bone. Areas where tissue intersects with the skeleton and where the original bone merges to become heterotopic bone are more explicitly revealed and more accurately presented in the delineation. This is because of the change in weight and definition of the line used to record these significant areas.

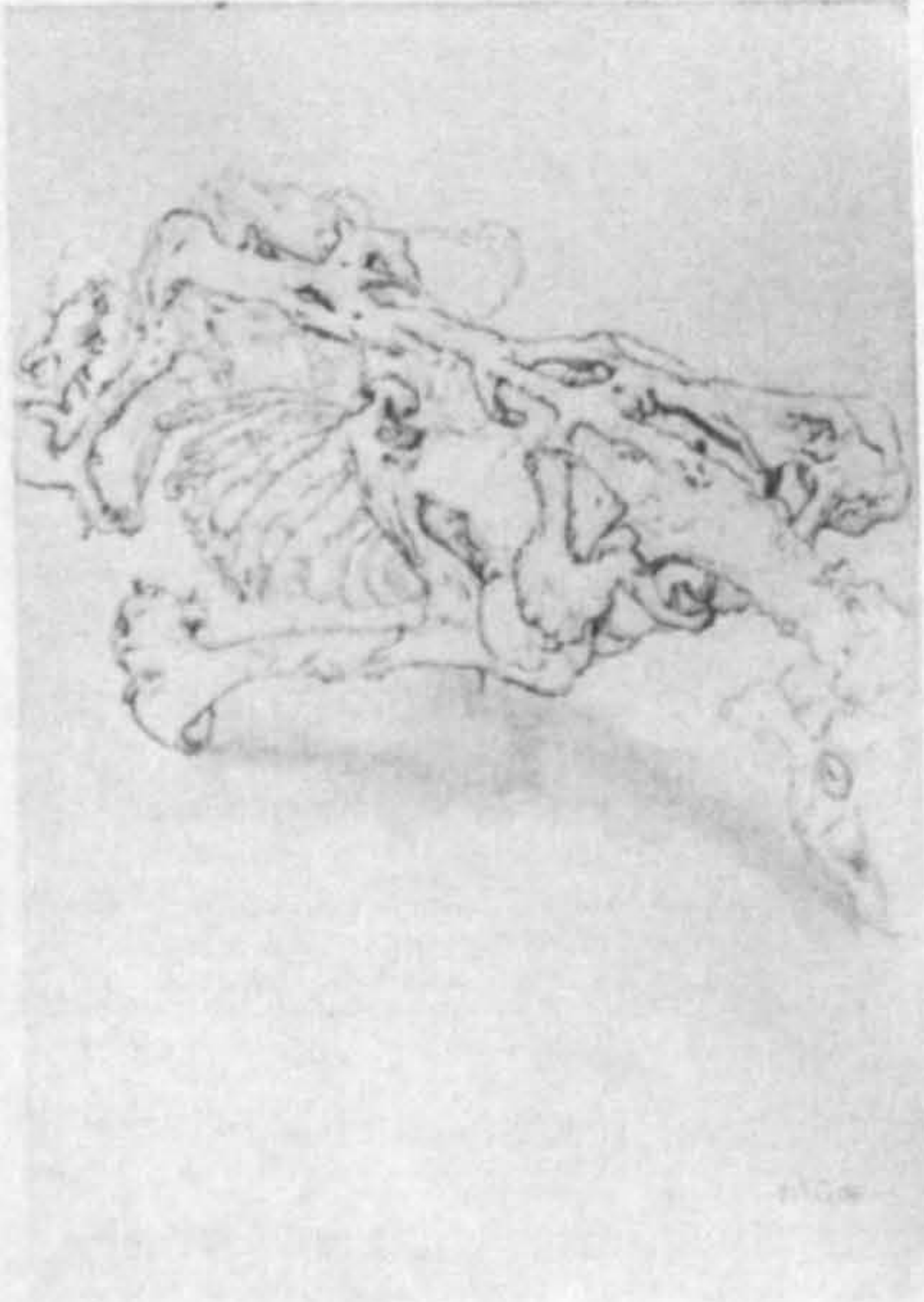


Fig. 35 Delineation 42

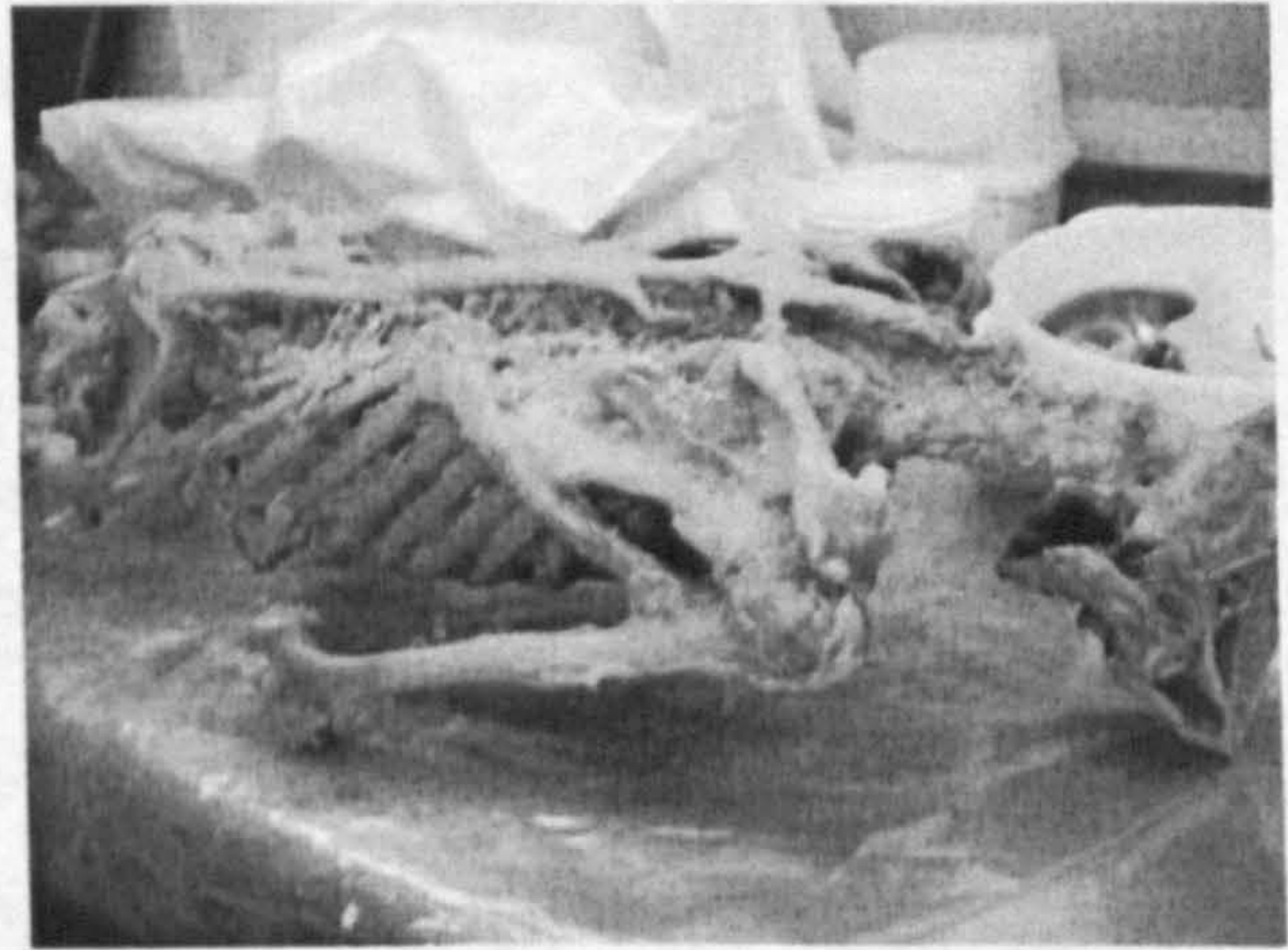


Fig. 36 Comparison photo to Delineation 42

The photograph of the torso of **8149** shows her face down on plastic sheeting (Fig. 36). Glare from moisture and fatty tissue adds to the visual confusion and it is difficult to differentiate between the areas of remaining tissue and bone. In the delineation, extra visual data has once again been left out.

Whilst the photographs and the delineations depict the same things, they have a very different appearance. The photographs are not intended to replace, stand in for or be used instead of either the encounters themselves or the delineations made at the same time.

They are not meant to be seen alone as a way of communicating understanding or as artistic objects. They are a part of the inquiry and act as additional information into investigating the visual information experienced when encountering the phenomenon of both the activity of preparation and of the disease being revealed.

The photographs help to demonstrate the precision of the delineations since they depict the same objects in very similar compositions. They also demonstrate how confusing it can be to show all visual information including extraneous and non-essential data with equal weight. For example, the delineations de-emphasize the shiny, reflective layer of fatty grease that obscures some detail and causes flare in the images.

Conclusion

In this chapter I have described my delineations in detail by placing them into categories using a model developed according to the criteria used for choosing which were to be displayed in an exhibition at the Hunterian Museum. 5 delineations have been compared with corresponding photographs to support the claim that drawing is a phenomenological activity and that understanding is gained from this process of delineation and conveyed to the viewer.

In Chapter 7 I will present the evaluations and responses to my delineations from clinical experts, patients and other informed viewers. Two drawing workshops are outlined and their outcomes described.

CHAPTER SEVEN

Responses and outcomes

The first aim of this chapter is to evaluate the delineation work described previously in several ways. Most significant is direct evaluation with clinicians, patients and other informed observers, artists and researchers in related fields.

I have pursued research that explored methods through practical work. My reflection of this development is dependent on reasoning within the process as set out in previous chapters. With two experts we had open discussion in which they were asked to go through all the sketchbooks with no preliminary guidance or questions. Part of the response is their commentary on the unmediated delineations from my sketchbook. Although they were aware of drawing work they had not been exposed to any of the theoretical framework as set out above. Later in the meeting I asked them to pick out any delineations that had taken their attention for more detailed discussion.

Other key stakeholders were patients. My discussions with the patients were more necessarily opportunistic and less structured taking advantage of occasions I met them. Some discussions reported took place early in meeting whilst negotiating work I would be doing with those individuals and comments reported are of other individuals. I also described patients' responses as their own delineations progressed.

Patients reported that delineation made the nature of the disease much more real to them. All felt the delineations were valuable and wanted copies to show people, however both patients and families had some concerns about potential impact on others, for example, parents of young children did not want them to see them. Patients reported enjoying having attention paid to them in this way.

A third category is the broader, knowledgeable audience who came to the private view at the Hunterian Museum on 24th September 2008 and includes people who had no prior knowledge of FOP. While many people

found the material shocking all recognized the sensitivity and respectfulness in the process. All subjects reported strong emotional response to material and focused on the sensitivity, intricacy and detail.

This third group were visitors to the exhibition and included artists, clinicians and curators. I did not approach them for comments and all their reported comments were volunteered either in conversation or correspondence initiated by them. I have also included comments from published reviews.

With experts, a number of specific observations were made that were confirmation of theories not fully supported by previous evidence. By having material from a broad range of individuals available, the experts were able to see breadth and diversity more clearly. The accessibility of this is an important issue.

Experts also observed that the delineations provided a way to highlight significant detail and technique and indicated new questions that had not been taken account of. Experts also indicated ways delineation might be used in various areas of work.

In the second half of the chapter I have set out to test the phenomenological aspect of delineation as developed in this thesis and how objects are experienced by other people who use drawing in related professional practice. To do this I organized workshop events with medical illustrators and archaeologists. Drawings made by medical illustrators and biology and forensic archaeologists have been documented and analyzed.

Expert evaluation- introduction

Two professors in the field of orthopaedics and rheumatology based at the University of Oxford have supported and contributed to this research. Professor Paul Wordsworth examines and treats FOP sufferers at the Nuffield Orthopaedic Unit and Professor James Triffitt studies the genetic causes of FOP at the Botnar Research Unit.

There are a limited number of skeletons available to view world wide, and it is not surprising to learn that few medical specialists in this field have seen an FOP skeleton first hand. Most visual knowledge has come from seeing FOP as it presents itself in the living patient and in medical imaging. My delineations have presented these visual experiences directly and offer further insight to professionals.

Both Professors advised me continually during this investigation. They had known the donors personally. We all agreed that FOP is very rare and unusual so nothing could be thought of as insignificant. Each experience should be treated as unique and any correlations would be analyzed later. They suggested I approach the project by drawing everything first and examining evidence later. This approach complies with the phenomenological aspect of delineation as it progressed in this research and with the model described in Chapter 5 used to analyze the delineations. Their suggested working practice also supports my argument for including all the delineations, even those that are not deemed to be as helpful as other drawings.

In the opinions of Professor Wordsworth and Professor Triffitt, close observation is a good way to collect and generate information. They felt the concentration and focus required in the activity of observational drawing, makes it a very good method of gathering information and prevents important detail from being overlooked. These are some of the characteristics embodied in the system of delineation as described in this research. An example of the ability of delineation to communicate detailed, useful evidence of the phenomenon is described in the following description. On one occasion I showed Professor Paul Wordsworth Delineation 29 (p. 195). He reacted to seeing it by clamping his hand over his mouth and gasping. He admitted his amazement at seeing marrow in the heterotopic bone. It is not unexpected for it to be there, but he found the impact of seeing it revealed to him so clearly in the delineation, surprising. In his opinion, the delineation was useful evidence and offered him helpful insight into FOP.

On 27th May 2008 I met with Professors Wordsworth and Triffitt. They spent the morning giving their opinions on the delineations. They saw my

project as examining the previously unseen breadth of the disease. They began by discussing all the delineations in general. I asked them to look through all the delineations again and choose ones they wanted to talk about in detail. This discussion is described here and I have also included their evaluation of those delineations they felt were not successful.

Evaluation of specific delineations

The relevance of Delineation 29 was revisited because it reveals marrow in the ectopic bone. This is the term for bone that grows outside the usual site of growth. Delineation 29 reveals the complex micro architecture found in bone marrow the medical experts confirmed that bony architecture is clearly evident in the mass presented in Delineations 33 (p. 199), 49 (p. 213), and 50 (p. 215). This supports the theory that the tissue was undergoing a process of ossification. It would also indicate these delineations present a transformative point in the disease. Delineation 50 presents a detailed delineation of the site of the excision. Professor Wordsworth commented on the use of varying depths of focus whilst retaining clear visual information. The detail is uniform but without being confusing, something he felt could not be achieved in photography.

The histology drawing, Delineation 48 (p. 211) was described as being a valuable delineation. It depicts bone in the tissue sample. The experts confirmed this is not tumourous bone, recognizable by its randomly organized patterns, but is bone marrow. The delineation offers little more useful information on a cellular level. However, it demonstrates that a delineation of ectopic bone could be mistaken for a delineation of normal bone histology. Like normal bone, ectopic bone also begins as cartilage. This delineation reveals bone that is not from early stages of bone formation but would seem to be mature bone. The implication is the section from the mass was already in the process of changing from one tissue type to another. The professors felt the delineation presented clear information.

Both are interested in the process of looking down the microscope and making histology drawings. Their view is that they see far more when looking at the drawings they made and those made by others than from the photomicrographs. They think the information is clearer. They discussed

the idea that when time is spent drawing, it makes you observe more carefully and see things in a very specific way. They felt it is easier to see the information in the delineation than it is to look down a microscope. Delineation 48 is larger than a tissue sample, it is more practical to access and does not require a microscope to view it. It is visual evidence that both bone types look identical and are in fact the same.

Professor Wordsworth was interested in drawings showing the union between the bones. He felt that some delineations were telling him about remodelling and revealed visual information about forming and joining of bone.

'Drawing is a very successful way of bringing out the information about where all the new bone is'
(Wordsworth, 27th May, 2008).

Two drawings presenting close detail around the thoracic region, Delineation 45 (p. 191) and 47 (p. 193) were seen as offering constructive information about bone remodelling which is the process of new bone tissue replacing old bone. The delineations make use of close observation of tissue variety seen close to the site of the original skeleton and at the point of newly formed bone.

The delineations were seen to present an informative range of examples showing ongoing changes and effects of FOP rather than just the appearance of the skeletons.

It was agreed that photography could also achieve these results. However, both Professor Wordsworth and Professor Triffitt had the opinion that a photograph can only accomplish the same sort of three dimensionality and depth of focus by manipulating the image afterwards.

'That's [drawing] manipulated in real time. For a photographer you'd have to manipulate it at a time when you weren't actually looking at it [the object]'
(Triffitt, 27th May, 2008).

This underscores a vital element of the system of delineation as the drawings are not continued or added to in anyway after each encounter. Delineations are made only in the presence of the object.

When discussing the quality of information presented in delineation, the professors felt they were precise in a different way to the information revealed in photographs. Professor Wordsworth used the example of a programme called DotBlots to explain his doubts about the accuracy of digital images. This is a method used to detect a specific sequence of DNA encoding by looking at a particular pattern. However, the contrast and the brightness etc. can be manipulated digitally with DotBlots to such a degree that a positive or a negative can be achieved on just about anything. This appears to be similar to the problems of inter-variability encountered with histology staining discussed earlier (Chap. 2, p. 55).

Another example they cited was the vital role of CT scans which produce clear and detailed images but are not *real*. They are generated in the computer and made up from points on the body that have been scanned at intervals and then digitally *reconstructed* from that information into 3D generated images. X-rays, whilst hard to read are *real* images taken of the patient in real time rather than a post-encounter generation.

Other delineations evaluated were Delineation 3 (p. 133), 15 (p. 139) and 34 (p. 155). Both Professors chose Delineation 3. This was my first encounter with a whole FOP skeleton. They found it demonstrated my visual experience of the entire specimen clearly and gave an overall sense of FOP in the whole body.

In Delineation 15 a drawing of a skeleton in Basel, they were shocked to see an example of FOP that formed as they described, an ossific beard. The delineation presents a unique case they felt was both fascinating and horrific. It gave them an insight into the specific variations the effects of FOP have on the skeleton.

Professor Triffitt chose Delineation 34 a drawing of K in hospital as he knows her personally and has looked after her for many years. He felt the portrayal captured the characteristics of her features with which he is

familiar. He found it useful to see one of his own patients presented in a physical position different to one he is used to when he examines her. The delineation presented her in a new perspective.

Both professors chose Delineation 62 (p. 227), the last drawing I made of 8149. They agreed it demonstrates clearly that I have learned what areas of FOP are most relevant through the activity of drawing. In their opinion it is the delineation that reveals most clearly my understanding of the phenomenon and conveys the most knowledge to them about the condition. For them it is a good example of a drawing of clear, detailed attachments that emphasize the recent weight of evidence that FOP involves a process that affects the tendons and connective tissue, or myofascial planes, but not the muscle tissue itself.

The negative responses to the work are equally important and concur in my own analysis in the previous chapter. However, the views the experts held about delineations presenting the process of preparation had not been predicted.

A delineation seen to be unsuccessful by the clinical experts is the drawing of the hip, Delineation 10 (p. 231). It was made using charcoal and both experts felt that it is both unclear what I have understood from the visual encounter or what visual information I wanted to present. Professor Wordsworth also felt it failed to give any sort of impression of how FOP affects the patient

This is a view I hold with. The other delineations I feel have the same problems are discussed in the analysis in Chapter 5.

Professors Wordsworth and Triffitt found it difficult to look at drawings where the focus is on presenting the visual experiences of processes of maceration. These include Delineations 21, 22, 23, 26, 28, 35, 36, and 59. They were uncomfortable with the drawings themselves, the information they conveyed and found them gruesome. They described the visual information revealed in terms of being gory and presenting an unpleasant mess.

However, they did find the delineations recorded the length of time taken and the sheer hard work involved in the process of maceration and preparation. They appreciated that despite the process appearing dehumanizing, these delineations demonstrate the importance of donors allowing their skeletons to be put on view to promote understanding of a disease.

In comparison, I find the photographs of the de-fleshing procedure almost impossible to look at. To me they are shocking as images because the gore and mess created by this process is a violent one and in the photographs the results appear as bright, colourful and vivid. The actions are recorded as glaring snapshots. The delineations do not have this instantaneous quality. They record my experiences of an unpleasant process as a series of fugitive encounters.

Professor Triffitt also found the delineations of 7646 to be very dramatic and disturbing due to the detail showing the damage the donor had sustained at the time of her autopsy.

Surprised as I was by their negative reactions to these delineations, their responses have a positive outcome. They are further evidence to support my claim that experience and knowledge about this process is recorded and communicated in a more clear and understandable way through creating hand made delineations than in photographs.

Summary of experts' evaluations

The ability of the delineator to highlight particular features was felt to be an important and useful way to make the viewer more aware of specific areas of interest. Whilst emphasis important to the delineator may not necessarily be of equal relevance to others, the delineations were seen to be successful in offering a different perspective of FOP as they present clearly what I have seen and understood. It was agreed that the system of delineation, as developed in this project, demonstrates how I have experienced and accumulated knowledge from these encounters and have gained further understanding of which details are more relevant in the object being observed.

As they are experts in their field, it is unrealistic to expect the delineations to offer groundbreaking new clinical information. However, the delineations were felt to clearly demonstrate the extent of ossification and deformity produced by FOP and raise interesting questions. The experts felt that the delineations proved to provide:

- Essential visual material as there are very few skeletons available and it is not possible to keep returning to them as you can to the delineations
- A clear way to show how the bone actually joins up
- Much clearer visual information than X-rays or CT scans
- Clear demonstration that the myofascial planes and connective tissue are affected rather than the muscle fibres themselves
- Confirmation of lack of ossification in the diaphragm and smooth muscle
- Many new impressions about the disease

The professors felt that delineations raised interesting questions;

- Where does one sort of bone stop and the other begin?
- Can the drawings tell us why does ossification happen exactly where it happens?
- Where is the bone growing, where should experts be looking?

Professors Triffitt and Wordsworth agreed the delineations succeeded in revealing information to the viewer as well as demonstrate evidence of my understanding of the subject through the activity of drawing. Depictions that work best incorporate simplicity, clarity, yet are detailed. These are all elements that form the system of delineation.

'Now the interesting thing about this [Delineation 10 (P. 231)] is that there is a fuzziness to this which is not present in the drawing three years down the line where you're really cutting to the chase and bringing out what the important thing is but during that three years you've actually learned what the important things are. This, basically if you like is what you see. You can't actually distinguish what should be there, and what shouldn't. Here, [Delineation 62 (P. 227)] you've quite clearly had a

learning process over the three years and you now know pretty much when you go in now, how much to leave out'
(Wordsworth, 27th May, 2008).

Even with their vast experience with patients and of medical images of FOP, there was still a sense of shock at the way drawings reveal how devastating the effects of the disease are. The delineations were seen to show the complexity of ossification in a way that has a three dimensional depth of field yet remains clear and is not overburdened with extraneous visual information. As an example, the first specimen drawn in Delineation 1 was described as offering pathological information and new insights into what this disease actually looks like as if it were being viewed beneath the skin, something an X-ray could never do. Despite knowing what the reality entails, the delineations,

'illustrate[s] some of the beautiful arrangements of the tissue that you see when you actually see the specimen itself'

(Triffitt, 27th May, 2008).

The delineations were seen by Professor Triffitt to bring to light the extent of the process of ossification, particular orientations and the spread of the process across the whole skeleton. They also emphasize the wishes of both donors to contribute to further research. Importantly the delineations bring insight to the whole process in a way he felt could be seen by anyone so that they may understand what these patients were going through. He considered the delineations gave much more information than a patient documentary could and highlight the effect of FOP as a major process in these people.

The professors saw great potential using delineation in the future to capture something of the difficulty and anguish that people with the condition have either as a result of long term deformities and disabilities or problems they experience during an acute episode. Despite the view that from a clinical perspective the delineations did not capture the degree of disability, the professors felt they offer useful insights and the patients' perspectives are presented more expressively and with greater empathy through drawing than by using photographs.

In the medical experts' opinion the delineations would have an impact when shown to a variety of professionals in the medical field. Suggestions ranged from medical students and nurses to rheumatologists and orthopaedic surgeons. It was also thought that the delineations would offer very useful knowledge to senior clinicians specializing in any other fields of surgery,

'The insights it would give them into what actually is going on in this disease would be enormous.'

(Wordsworth, 27th May, 2008).

Professor Triffitt and Professor Wordsworth think these professionals could benefit greatly from seeing the delineations and would gain greater understanding from the information conveyed than from other methods of visual communication.

It was agreed that the delineations demonstrate not just what FOP looks like but by spending time in the activity of drawing, they present the visual experiences of each encounter and offer information into what these processes of ossification are doing to the body. They were seen to present progress from explaining to understanding.

As contributors to the research the evaluation of the delineations by FOP sufferers is essential. Their views and opinions have been described in the following section of this chapter.

Patients' responses to delineations

As explained in Chapter 4, L was the first FOP sufferer I met. On 4th October 2005 whilst she and Professor Paul Wordsworth were being filmed for a documentary, I spoke with her mother who works hard promoting awareness of this condition. She was positive about my research and looked at my drawings to date, Delineations 1 – 4 (pp. 129, 131, 133, 135), the museum specimen and Mr. Jeffs. L's mother told me she had seen X-rays previously and did not find them uncomfortable to view. However, in her opinion the delineations were powerful presentations of FOP but almost too realistic and she found them

shocking. She felt they were too explicit and revealed too much information.

She decided not to show her daughter the delineations because she wanted to protect her from the horror of further effects of FOP. She felt these delineations reveal this process far too clearly and she did not want L to have this information at that time. The strength of this response is further demonstrated by her actions in the documentary *The Girl Whose Muscles Are Turning to Bone*. In this, she visits other sufferers with increasingly progressive forms of FOP. She does not allow L to go with her to meet them, as she does not want L to see how much progressively worse the condition is likely to become.

Both L and her mother agreed I could draw L but due to changes in their circumstances this was postponed. Later in this research I decided not to draw L for several reasons; I felt I had enough visual information for the purpose of this investigation and any further would be superfluous, I had little time left as my main project took up all my remaining time and because I felt I would become too emotionally involved. It has been emotionally challenging studying this condition. Meeting patients has been emotionally demanding. I found it particularly difficult to spend time with L, the youngest person with FOP I have met, without allowing my personal feelings to interfere with the practicalities required for pursuing this inquiry.

The next person I met with FOP was P and this was on 19th October 2005. He looked at Delineations 1- 4 and felt they described the hidden reality of what was going on inside, under the skin. He said they were powerful and told him far more about the disease he had than medical images he had seen. He was shocked at seeing FOP presented so precisely and stated that even though he had seen X-rays of the effects of FOP on his own body, the delineations made him see what was really happening to him. He explained that somehow the delineations were more real to him than the X-rays. They have given him an understanding he had previously lacked and knowledge of the visual experience of FOP. For him, the reality of the visual information presented in the delineations was more 'real' than in

digital or scanned images and presented what the disease looks like more clearly than images he had seen made in other media.

He had encountered other sufferers who did not wish to have information about the long-term affects of FOP, particularly parents of young children with the disease. Initially he advised me against showing them to other sufferers as he was concerned they may be too upset at seeing the reality of what was happening to them. However, he felt everyone should see the delineations as, in his opinion, they presented understanding of what FOP looks like and what it does to the sufferer.

I made three delineations of P, Delineations 5 (p. 147), 6 (p. 149), and 7 (p. 151). He was pleased with Delineation 5 and thought it was a good likeness. He had never been drawn before and said he enjoyed the process. The other occasions he is observed so intensely are during medical examinations or when people stare at him in the street. He was equally positive about the drawings of his hands and feet and understood the clinical relevance of drawing his feet but found the whole experience amusing. He requested several photocopies of the drawings, which I sent. He later told me he had one of the copies next to his computer and enjoyed looking at it frequently.

On 29th October 2005 I drew K. Her response to seeing Delineations 1- 4 was positive but less overt than the other patients. She and her elderly mother were extremely receptive to the delineations and saw them as a potential vehicle for promoting awareness of FOP. Rather than shocked, both K and her mother thought the delineations were helpful. They found medical images confusing and difficult to understand but thought the delineations were clear and the information conveyed easy to understand.

I made Delineation 8 (p. 153) and initially K seemed shy and uncomfortable but became more confident as the delineation progressed. She admitted to finding it hard being stared at. Her response to the completed delineation was positive and she asked for photocopies which I sent.

In July 2006 K's mother informed me that K had broken her leg and was in hospital. She asked if I would come and draw her. On 25th July 2006 I made Delineation 34 (p. 155). During the day, they both looked at the Delineations I had made so far and responded positively. They felt they were very 'real' and showed FOP very precisely. K wanted to see Delineation 34 as it progressed and was very happy with the final result. At their request, I made numerous photocopies of Delineation 8 and Delineation 34. They informed me these had been sent to friends and family. Other copies were put up on the living room wall. K's mother was particularly pleased with the delineations as in her opinion they showed how beautiful K is.

The patients and carers who evaluated the delineations found them to be somehow 'real' in a way that offered more clarity than other forms of visual media. For some, this was negative, as the delineations were seen to present unwanted detail to those who do not wish to have information communicated so overtly. For others, the 'realness' of the delineations was seen as positive, that is, they conveyed the information clearly, sensitively and in detail and were found to be easy to understand.

Other responses

The experiences and understanding gained through the activity of drawing were conveyed to an audience in the form of an exhibition at the Hunterian Museum from 16th September – 23rd December 2008.

An opening evening was held on 24th September 2008 and the overall response from viewers was that it was sensitive and respectful but shocking in its content. Two artists said they were moved to tears and one said that they found the delineations too difficult to look at.

Many visitors to the exhibition had never heard of the disease. This included many medical and surgical experts who attended. Some told me they found the delineations presented the experiences of FOP to them very clearly. Several claimed to have understood what the effects of the disease are to the body from looking at the delineations. One artist told me she knew nothing about FOP previously, but the delineations helped her understand where the regular skeleton ended and the extra bone began. In

her opinion, she understood this clearly from the delineations yet had no previous knowledge of the condition (Personal communications, 24th September, 2008).

In two reviews, the delineations are perceived as sympathetic and respectful. Anna Hales, an art theorist and writer based in London wrote,

*'The detail in each piece is extraordinarily exquisite.
However gruesome this disease, these images are not - they
display a genuine sense of humanity'*

(Hales, 2008, Interface, Reviews, a-n website).

In the second review, Jennie Gillions, writer and museum worker, found the delineations to be respectful, gentle and sympathetic. She described them as,

*'profoundly affecting, neatly tying together the medical and
emotional aspects of this condition...All of Lucy's drawings
demonstrate an affinity and compassion for her
subjects...[and the] ability to look deep into her subjects
and build a relationship with them, while still directly
interpreting what she sees'*

(Gillions, 2008, Review, 24 Hour Museum).

I have examined evaluations and responses from clinical experts, people with FOP and their carers and other informed observers. Whilst these evaluations and reactions are important they are formed by those viewing the information conveyed in the delineation. I will now move on to explore the second aim of this chapter, the evaluation of the system of delineation through an analysis of two practical workshops held with medical illustrators and archaeologists. The purpose of this is to establish if the activity of delineation can inform others participating in the process of drawing.

In the second half of the chapter I have set out to test the phenomenological aspect of delineation as developed in this thesis and how objects are experienced by other people who use drawing in related professional practice. To do this I worked with two groups, medical illustrators and archaeologists. My choice was restricted by ethics and

legalities concerning who has access to medical tissue of this nature. These two groups are regular visitors to the Wellcome Museum at the RCSEng and have experience of working with specimens. The only artists beside myself allowed access are the medical illustrators, as they have to complete a professional Masters qualification and are then granted a license to practice. I will now give an account of the drawing workshop with medical illustrators.

Drawing workshop with medical illustrators 18th April 2007

As discussed previously in this thesis, the work of the medical illustrators appears to be very similar to mine. This is mainly due to shared subject matter. The aims of this day were to:

- Examine their drawing practice in progress
- Compare the way drawing informs them and how that differs from my own experiences
- Discover where our practice and intentions were similar and where and how they differed

As the objective is to understand their practice within the context of the development of delineation in this inquiry, I did not ask a list of questions as in a formal interview. Instead, I worked alongside them discussing how we were drawing and what we were thinking in a more informal way. Conversation was then steered back towards the concerns of the inquiry.

The workshop took place in the Wellcome Museum of Anatomy and Pathology at the RCSEng. One first year, two second year students and a tutor participated in drawing the torso of 7646. We spent a day working together and throughout they voiced their thoughts regarding what they were seeing and how they were drawing. Due to tutorials, the periods of time they spent drawing were staggered and they left or arrived according to the times of their tutorials. They used their own drawing equipment and I did not specify medium or size. At the end of this session they each produced one drawing.

Medical illustrators are taught to place the object being drawn into what is known as the anatomical position. This means the body is viewed in an upright position, facing forwards with palms turned outwards. In the same

way archaeologists are trained to draw pot fragments as if they are part of the complete pot, illustrators are told to draw body parts as if they are being viewed in the correct position in a complete body, in situ. For example, even when making dozens of drawings of a femur the one that is in the correct anatomical position is regarded as being finished.

Initially, C had problems with the size of the specimen as she is used to drawing much smaller pieces. The issue of positioning was raised and even though the effects of FOP are most evident on the back, the medical illustrators stated a preference for drawing the skeleton in the anatomical position, viewed from the front.

Methods of planning drawings were discussed. C said she would normally make a rough sketch to place the image of the specimen in the middle of the page. She would then walk around and make ten or more sketches before deciding where to begin. Jn's method to help her understand what she is looking at was to make lots of different sketches to get the *feel* of it.

C's method was to begin by locating something familiar and then attempt to draw how it *should* look rather than how it *actually* appeared. She felt knowledge of anatomy in this instance hindered her attempts to draw a complex and unusual pathology.

C stated her view that once you have drawn something even the most complex specimen, you know exactly how to draw it. This led to an important implication, her assumption that if you know exactly how to draw something, you would no longer need to look at it.

The medical illustrators felt drawing is based in observation, but there has to be some simplification otherwise the impact of a piece of information will be lost if the image has equal intensity all over. It is unnecessary to record everything with the same intensity otherwise information will become confusing and focus on what is important will be lost. It was agreed that in this respect drawing was more useful than photography as a method to translate visual experiences. They understood the vital role of drawing to visually explain complex objects and visual experiences,

'You need an artist to decipher it [the FOP specimen] for you'
(Jn, 18th April, 2007).

All the illustrators had different opinions as to what the specimen reminded them of. C thought the bones look soft and cheesy like the shapes made by Swiss cheese. P was reminded of Holocaust victims or florets of cauliflower. Jn felt at first it was like coral then decided the skeleton was architectural and made her think of La Sagrada Familia, the unfinished Cathedral in Barcelona designed by Antoni Gaudí in 1882.

C drew it in terms of her knowledge of anatomy and struggled to adapt her perception.

'I try to start off doing this as a scapula with the ribs underneath it. But as soon as I got on to the back I lost sense of where the vertebrae were so I've just been drawing a shape rather than an actual anatomical object. It's just become a shape now'
(C, 18th April, 2007).

P saw it more holistically and attempted to present the visual experience rather than a representation of an object,

'I see it as a specimen. I draw the whole thing. I just keep working through it really. I was drawing J there and the things that were going on around it'
(P, personal communication, 18th April, 2007).

Description of medical illustrators' workshop drawings

Three medical illustrators produced one drawing each and one produced two.

Jn's drawing looks the most stylized (Fig. 37). The ribs of 7646, are deformed and some are missing. These have been described visually in a generic, cage-like way. Shapes have become normalised and standardized.

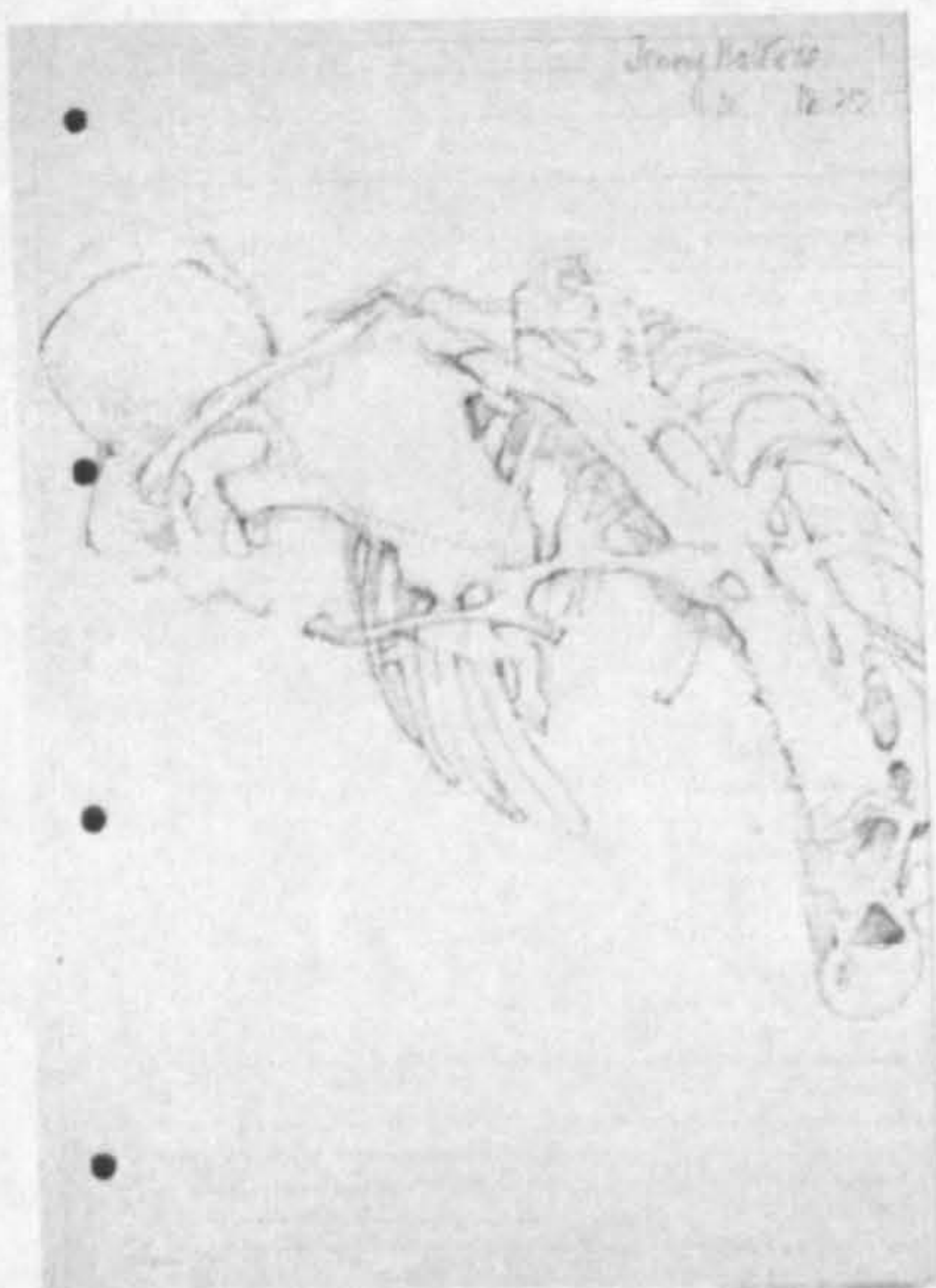


Fig. 37 Jn's drawing (Medical Illustration).

Idiosyncrasies have become lost and replaced with the generalized version. This has also happened in C's drawings, where the depiction of ribs follows the same formula.



Fig. 38 & Fig. 39 C's drawings (Medical Illustration).

In both examples, the bones can be read clearly as being representative of a ribcage. The drawings, however, do not present us with the precise information on what *these particular bones* are like and the illustrators' visual experiences of them (Fig. 38 & 39).

J's and **P**'s drawings are similar. **J** has attempted to *feel* her way into the drawing and concentrated on one particular area, rather than attempted to depict the whole thing (Fig. 40).



Fig. 40 **J**'s drawing (Medical Illustration).

She has used hatching to shade. **P** chose to depict a scene, rather than just the specimen. The torso of **7646** is shown lying on a table and **P** has included other visual information in his drawing. This includes those of us participating in the exercise as well as the microphone used to record the session and the surrounding specimens (Fig. 41).



Fig.41 **P**'s drawing (Medical Illustration).

Summary of workshop with medical illustrators

All the illustrators admitted they were drawing without looking properly. They were drawing what they *thought* they saw, what they had learned *should* be there and overlooking the specificity of the actually object in front of them.

At one point Jn realized she had drawn a part as separate from the skeleton only to look again and see the sections of bone were in fact fused. She had to rub it out and correct it. She and C said they kept making assumptions and then having to make a lot more corrections.

When depicting an object medical illustrators will gather clinical information about it. However, ultimately the purpose of the activity of drawing for them is not to gain knowledge of the object they are drawing and their experience of this, but to visually explain certain aspects and improve the way they portray that object through familiarity and practise.

The medical illustrators used their training in anatomical studies as their model for this workshop. This meant their interpretation of their experience of FOP was produced using a method which entailed drawing what they *knew* the skeleton *should* look like and then finding differences and altering them as they went along.

From the conversation and the drawings produced on the day, it is clear that there are some key differences between the disciplines. Several points were defined as different from the aims of my own work. These are that:

- That medical illustrators are providing a service and have to work to someone else's brief rather than their own
- Illustrators have to simplify by making a composite to create a generic example
- There is a right way round for illustrators and it is the anatomical position
- Medical illustrators will draw what they *know* something should look like and then try and adapt it
- They are expected to draw the object according to where it should be on the body, in situ, like archaeologists do with pot fragments

The following similarities were highlighted:

- Drawing can be more informative than photography as it can visually explain complex data more clearly.
- It can be detrimental to understanding information easily if everything is recorded with the same intensity

- Drawing begins with observation

The workshop helped to demonstrate that knowing more about an object through drawing it, which is the subject of this investigation, is different from the expectation of perfecting your ability to draw that object through practise. Improvement of the art form is necessary to be a successful illustrator but is not an objective or a concern of this research.

To make a comparison with the medical illustrators, I will now describe the drawing workshop event with archaeologists, a group who are familiar with working with human remains, make use of drawing to record, and have permission to draw from specimens at the RCSEng. Unlike the medical illustrators, they have not had any training in drawing.

Drawing workshop with archaeologists 13th May 2008

As I was working alongside students in a science field who lacked drawing experience, the aims were different from those in the drawing workshop event with medical illustrators. The aims of this day were to:

- Examine how archaeologists use drawing
- Observe how they overcame their lack of experience in drawing
- Determine whether they learned about the object they drew, through the process of drawing

I did not ask a list of questions as in a formal interview. Instead, I chose to work alongside them discussing how they were drawing and what they were thinking in a more informal way. Conversation was then steered back towards the concerns of the inquiry.

The workshop took place in the Conservation Unit laboratory at the RCSEng. where we drew the torso of 7646. Three students from University College London participated. Although they had met before, they specialize in different aspects of the field. One is a physical anthropologist, one a bio archaeologist and one a forensic archaeologist.

Throughout the day they voiced their thoughts regarding what they were seeing and how they were drawing. They used their own drawing equipment and I did not specify medium or size. The day was more

structured than in the previous workshop. The specimen was repositioned twice and each participant was asked to move places on four occasions. By the end of the session, each had produced four drawings.

In archaeology visual information is usually recorded using digital photography alongside hand made drawings. Visual data is gathered using a method where archaeologists draw over standardized, generic diagrams of skeletons (Fig. 42). These allow them to record differences and abnormalities. This method is opposite to delineation as it relies on adding to a generic, previously made diagram and noting the particular bone fragment found but without detailing any information about it. A specimen is only seen in terms of how it compares to something else.

Fig.42 Bone identifier chart (Kipfer, 2007, p. 158).

All the participants agreed they saw a specimen in terms of how it differed from a normal skeleton. Drawing on site involves looking down at the body and using a 6H pencil to make very fine lines. All distances between points are carefully calculated using measurements to standardize everything. Sketches are used for personal notes as well rather than as evidence.

Archaeologists, unlike forensic archaeologists, would not normally have time to make detailed drawings as they have so many bodies to catalogue

on one site unlike forensic archaeology, which deals with one individual at a time. The overall aim in forensics is to identify the person and then try to determine probable cause of death but in archaeology and anthropology, the individual skeleton is not of such great importance. It is seen as part of a population whereby a number of skeletons from one burial would be compared for the purpose of extracting data.

They initially saw the skeleton of 7646 in terms of being different and as having extra, different bits. They wanted to differentiate between the two and draw just these other bits as separate. H felt she might understand this better by drawing it but said she would rather photograph it to inform others.

Some began by attempting to draw what they expected to see rather than what they perceived. This proved a difficult method as ligaments that should be present disappear into ossified bone and physiology that should be there is obscured by fused bone. They grew frustrated at not being able to gather the information they wanted. They became visually lost as they tried to work out where they were looking by counting vertebrae only to find that the specimen was so deformed they could not recognize the bones.

Unable to find the visual data they would normally obtain they agreed that they still would not get the same information from a photograph but would prefer to have a normal skeleton or picture of one next to the specimen to allow them to make comparisons and focus on the differences. They also had little experience of drawing a whole skeleton, as in archaeology one would normally find individual bones or fragments.

After an hour, E began to find it easier once she stopped trying to identify everything and started to draw the elements separately. Instead of attempting to draw what she knew should be there, she just tried

'to see the way in which everything is fused to the scapula'

(E, 13th May, 2008).

They also decided against having another skeleton to compare it.

Photography rather than drawing

On asking what they thought the benefit of photography might be, the answer was that it was right. A photograph could not get it wrong or miss something. According to the archaeologists, only the person examining the photograph could miss something and made an error. A photograph is something reliable that an archaeologist can keep going back and referring to. It has the ability to document exactly and is not subject to interpretation. Generally in archaeology, photography is the dominant recording resource in a field where very few people can draw properly, not in terms of how they draw, but what they draw. The belief that the photographs will have accurately recorded everything on a dig means the general consensus is there is no need to also use drawing.

They said drawing is only useful to the person making the drawing and that it is biased but it could be of use as we would all pick out different things and offer wider interpretations on a subject.

Drawing rather than photography

C discussed an example of how drawing rather than photography is used in forensics to understand blunt force trauma. She described being taught to tap a boiled egg with a spoon an action that accurately mimics the effect of this sort of trauma.

'Drawing it really, really helps in that case because the way you figure it out is through the radiating break patterns. And so if you figure it's all cracks right because it's still malleable so when you hit it, it stays together, and so this crack goes into that crack so you can figure out I would say by drawing, or it would be easier to explain through drawing, this crack hits this one so this one's first and that one's second. In a photograph you would just look at it and say ok, there's a bunch of lines. Whereas if you drew it, I think the way that you drew it, it would be easier to understand yourself, for sure'

(C, 13th May, 2008).

E pointed out when you use photography, you spend more time looking at the lighting etc. than the object itself. When mapping a burial site,

especially different soil textures, it is impossible to light and accurately photograph it, so drawing is used.

Perceptions of visual experiences

For archaeologists the way in which information is documented is dependent on two main factors. First is the question of how much previous documentation of the object already exists. Second is the issue of differences in drawing the specimen if it had been found in situ, where it would be viewed from the top down. If this were the case, a particular kind of drawing would have to be employed where every angle and distance is accurately measured and recorded.

As the specimen 7646 was presented in the lab, she was out of context so these considerations were not as relevant although the angle she was placed in became an issue. As with the medical illustrators, there is a concept of right way round despite the fact there is more visual information seen on the back. They were uncomfortable with the specimen not being presented in an anterior position.

The idea that we see the world in different ways was discussed. I see detail and think of the world in terms of how I would paint or draw it, C sees it relation to forensics examining any anatomical anomalies in the people around her.

Asked if they felt drawing made donor 7646 more human again, both H and C said they thought the opposite. At first they felt drawing distanced them from her and de-humanized her. When asked if I felt she was very human because I was familiar with her, I pointed out it was *because* I have drawn her that I am familiar with her, I had a relationship with her and come to know her through drawing her. H told the story of her 'talking' to bones on a dig and the bond she had with them from touching them which made them personal to her. She then changed her mind and agreed there is a connection through the activity of drawing in the same way and it is not unique to a skeletal specimen that was once alive but can happen with pots as well.

The group considered how colour could be used as a way to visually explain the separation between bone types, but they realised not only would it be hard to decide which colours to use to differentiate between them, but as it is hard to see where tissue ends and ossified bone starts, it could not be used accurately.

Description of archaeologists' workshop drawings

H was the most confident as she went to life drawing classes. **C's** drawings gained in confidence as she progressed. **E** was the most hesitant and found drawing the hardest out of the three but made the most interesting and significant developments.

All three drew the whole specimen, not fragments but **E** was the only one to draw three on one page rather than each one on a separate page. All used pencil though chose to use thicker 2B pencils rather than the 6H pencils they are more accustomed to using. All developed systems to visually differentiate between bone and tissue types. This helped them to understand what it was they were looking at and gain knowledge of what had happened to the specimen's tissue.

C produced drawings that immediately sought to unravel the visual conundrum she was experiencing. Initially supported by copious detailed notes, (Figs. 43 & 44) these disappear in drawings 3 and 4 as she gains confidence and visual knowledge of the phenomenon.

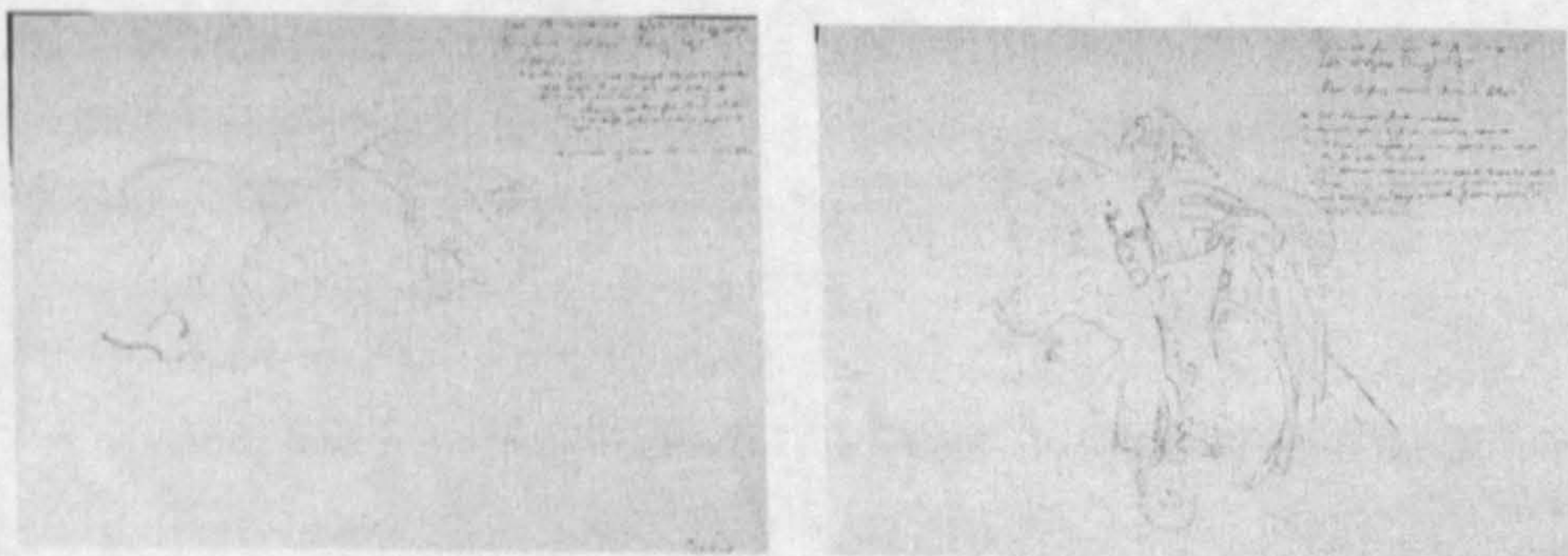


Fig. 43 & Fig. 44 C's drawings (Archaeology Illustration).

She uses a heavier line to present the heterotopic bone and visually separate it from the normal skeleton, something that naturally developed as a system in delineation. This continues to the extent that in drawing 3 where the normal skeleton is almost completely excluded from the picture.

In the final drawing, it has completely gone leaving her understanding of the ‘girdle’ of ossified bone standing alone. Her visual experience and development of understanding is clearly presented in this series (Figs. 45 & 46).

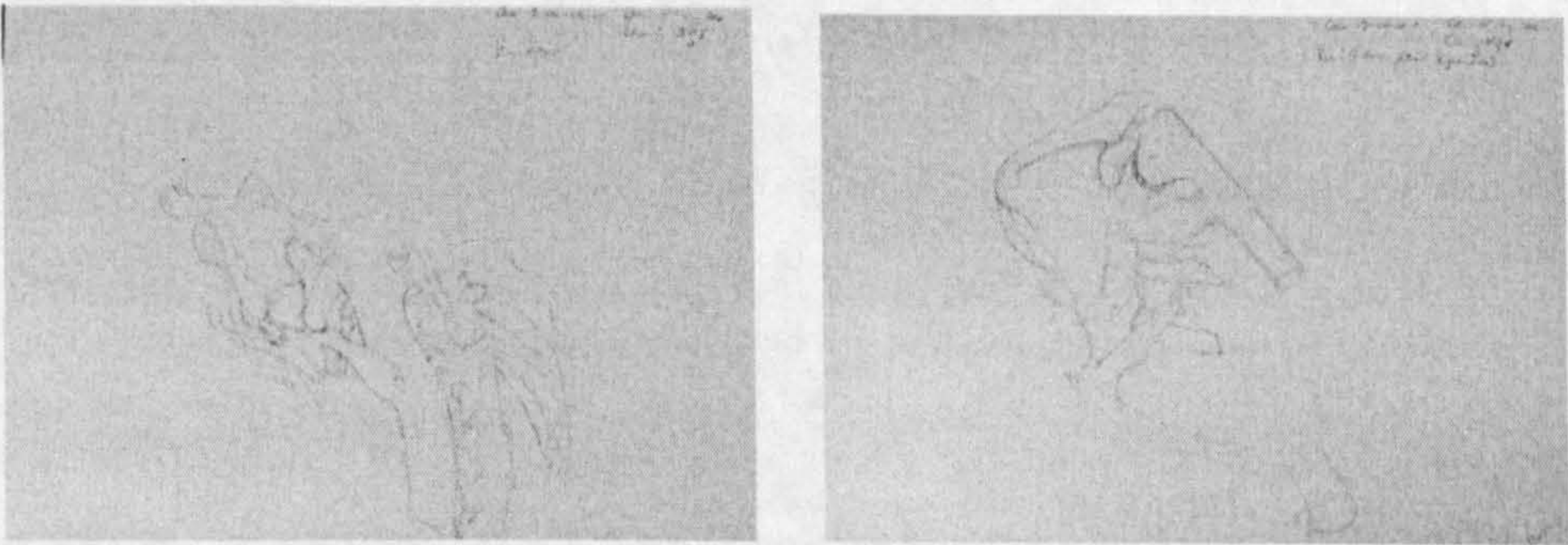


Fig. 45 & Fig. 46 C’s drawings (Archaeology Illustration).

There are similarities in H’s drawings in levels of confidence and observational skills. H also makes her understanding of the visual experience present using altered weight in line but uses slight tonal contrast as well (Figs. 46 & 48).

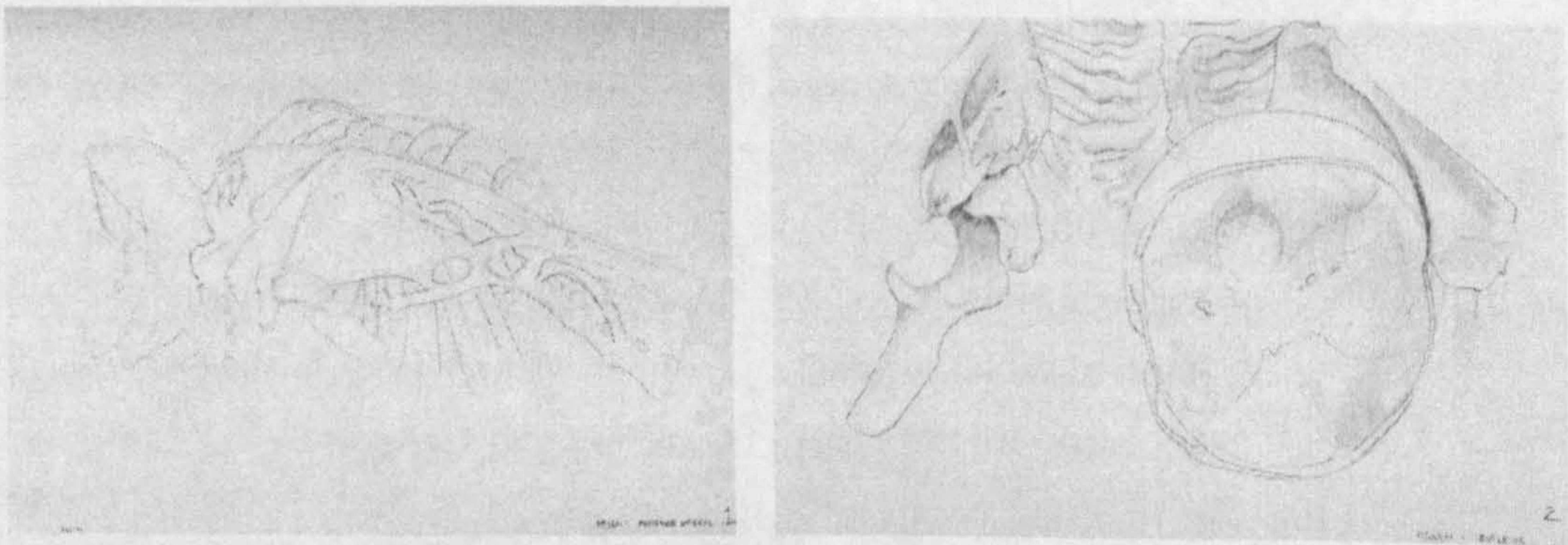


Fig. 47 & Fig. 48 H’s drawings (Archaeology Illustration).

Her use of smudging is less an attempt to make the object appear to be three-dimensional by shading it, but is a visual way to differentiate between heterotopic and normal bone. This combination works well as she observes more closely and includes more detail. This helps her to understand the visual information she experienced far more clearly and also makes the information in the drawing clearer to anyone looking at it (Figs. 49 & 50).

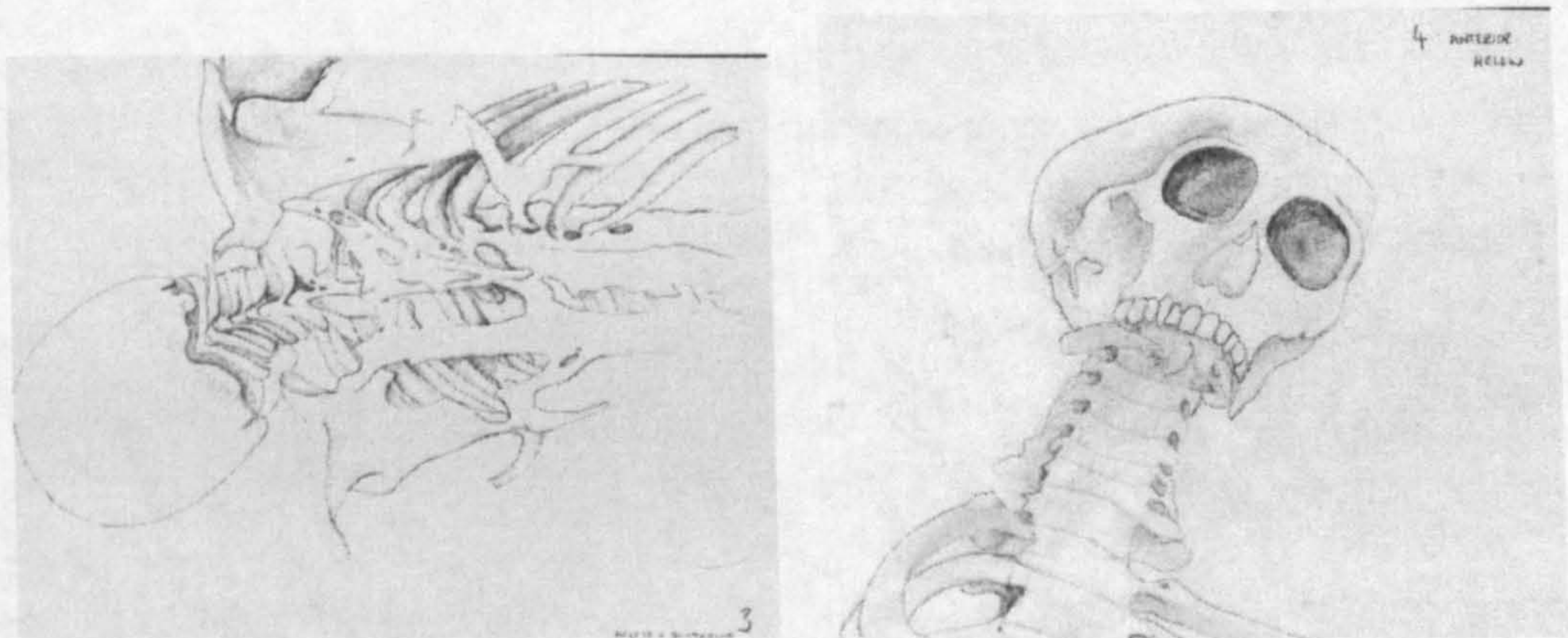


Fig. 49 & Fig. 50 H's drawings (Archaeology Illustration).

Lacking the confidence and possessing more limited drawing skills than the others, E's small nervous drawings demonstrate she made the greatest progress in her understanding of her encounter with the specimen. By drawing 3 she has used the activity of drawing to help her understand what she is looking at and again employs the use of tone and altering weight of line to translate her understanding of the encounter as she is experiencing it (Fig. 51)

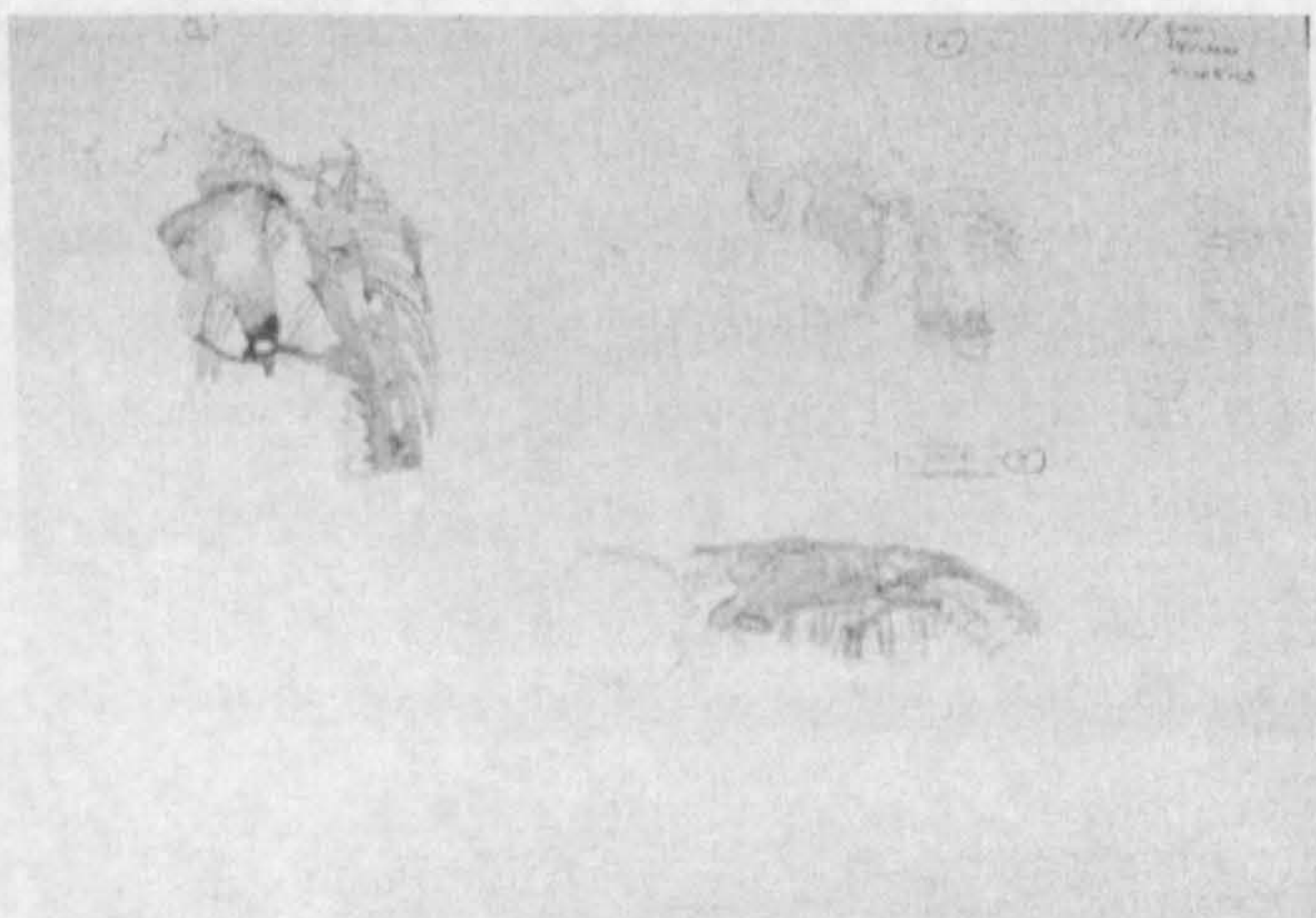


Fig. 51 E's drawing (Archaeology Illustration).

Crucially for E by the time she reached the fourth drawing she realized,

'when I'm drawing I feel like, in the beginning I was following the anatomy, like you would expect, and then I was following the lines of the pathology and now I want to draw the texture but I feel there's a sort of progress'
(E, 13th May, 2008).

She has understood how this system of drawing forces the drawer to look and see detail and not to make assumptions (Fig. 52).

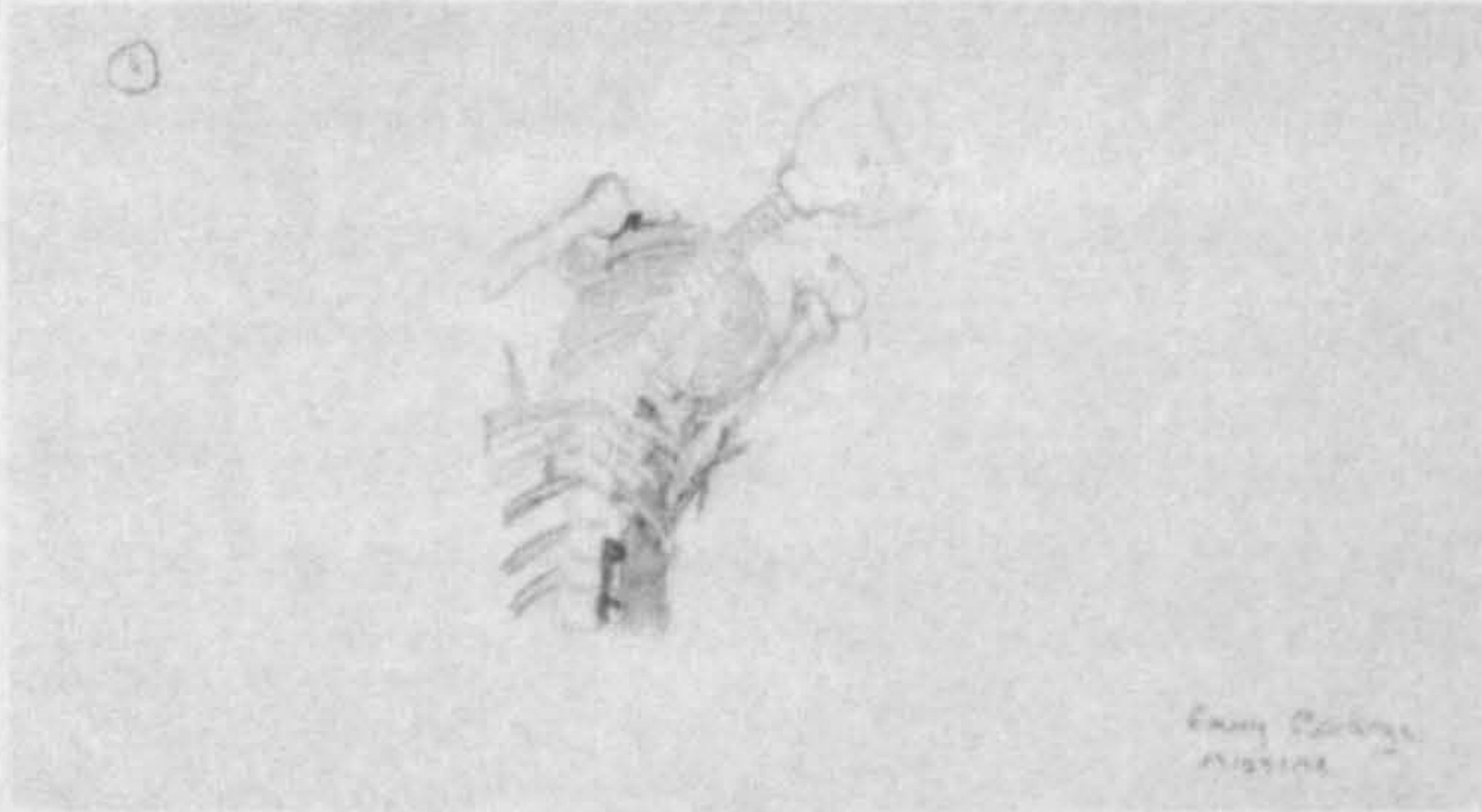


Fig. 52 E's drawing (Archaeology Illustration).

Summary of workshop with archaeologists

From the conversation and the drawings produced on the day, it is clear that the archaeologists found the act of drawing beneficial.

They all agreed that:

- The act of drawing makes you spend more time looking and this action makes you see more detail
- Drawing raises questions of where bone finishes and ossified tissue begins
- There is a need for a drawing module to be included in their courses. They all felt they would benefit greatly from this inclusion
- The most important thing drawing teaches you is how to look
- Things they did not understand visually became clearer as they continued the process of drawing and they could see better how everything fitted together

Whilst it is the action of drawing that leads to understanding, **H** concluded that we use the actual picture to re-enact and appreciate the parts previously focused on. **C** felt the activity stops her seeing information in only two dimensions but forces her to understand it in three.

From the evidence presented in the outcomes of this workshop I would conclude not only that drawing as an activity does present visual experiences and with that understanding but that this is not dependent on the quality and experience of the drawer. When conveying knowledge further to an audience, there must be a level of skill in the activity to produce delineations that can offer enough detailed information as to prove informative, but at the stage when the drawer is gaining insights into the object being experienced, it is through the activity itself, the

continuous act of observing and drawing, that knowledge is acquired. It is the process of attempting to achieve accuracy rather than the success that encourages the type of intense scrutiny that is part of the system of delineation. This dialogue is how understanding is achieved. Through it, the visual experiences unique to each participant reveals not just that the FOP skeleton is different, but how different it is.

E's shift from trying to grasp the changes in the anatomy to understanding the pathology led her to insights into the spread of the ossification by using drawing to allow her to follow the lines of fusion and understand what is happening to the specimen. In E's opinion a photograph would not have had the feeling of how it fitted together.

Importantly C observed that,

'the amount of detail that you can get when you focus harder to draw it is helpful. Because you see little things like I find here especially in these areas just little tiny, tiny bits and just so tiny compared to such thick well established bone which is here. I mean I don't know enough about FOP but it helps a person ask how or why this is going on. It starts asking questions'

(C, 13th May, 2008).

Development and outcomes observed in this brief session make a strong case to support the claim in this research that delineation does inform as an activity and communicates knowledge as an end result.

Overall summary of the drawing workshops

The two groups that participated in drawing workshops had different aims. The medical illustrators' aim was to present archetypes. The archaeologists' aim was to produce drawings that looked like the object they were looking at. The participants used different processes of delineation and were of different abilities. Medical illustrators despite having a greater familiarity with clinical contacts and having better developed drawing skills did not demonstrate aptitude for delineations in terms of this thesis. Their ability to observe was corrupted by the archetype. Whereas the archaeologists who lacked professional drawing

skills but whose practice is concerned with finding meaning in objects were generally able to engage with process to a good effect.

As the medical illustrators already knew how to draw and were already achieving successful results with their work, they employed their own styles to draw their encounters with FOP. The archaeologists on the other hand ranged in drawing experience but were not trained in the practice. They were willing to adapt their drawings, as they had not developed their own individual styles. Drawing is an activity only one of them spends time doing and that is as a relaxing hobby.

It was more problematic for the illustrators to present as genuinely as possible the visual experiences they encountered as they not only had preconceived ideas of what to expect, but also were more stuck in their own styles and bound within the formulas and methods set by their own profession. Their desire to provide the images expected of them as medical illustrators, prohibited them attempting to look in a new way. The archaeologists, lacking any preconceptions, were free to attempt more successfully gaining insights into their visual experiences.

It is interesting to note the difference in attitudes between the two groups. The first, confident in drawing, were trying to find out how they could draw an unusual specimen with the hope of achieving a high level of perfection in doing so. The second group, were keen to get anything down on paper at all and wanted to succeed in getting their drawings to resemble what they saw. Importantly, the illustrators did not naturally differentiate between bone types, something the archaeologists automatically attempted to do in different ways. Whilst the medical illustrators have achieved highly skilled outcomes that are stylistically and observationally skilled and aesthetically pleasing, the archaeologists have produced drawings that demonstrate greater understanding of the object and have had to develop their own systems for visually explaining difference in bone types and complexity of architecture. The progress of their understanding as it grew is charted in the development of the drawings. These have more in common with the aims of delineation than the drawings by the medical illustrators and work in the same way as they attempt to not just describe what is perceived but understand and present the experiences.

Conclusion

In this chapter I have brought together external evidence on key aspects of the research as set out at the start of the chapter, described the views and evaluations of medical experts, people with FOP and their carers and given examples of the opinions of others who have viewed my delineations. For example, propositions made within this inquiry that delineation offers a record that is respectful and gives the object dignity are endorsed by the responses made by patients and visitors to the exhibition.

I have compared how drawings are made by medical illustrators and archaeologists for the purpose of examining how the activity of drawing both informs the delineator and can convey information to an audience. I found that medical illustrators produced drawings of how they *thought* the specimen should look and aimed to achieve well executed drawings that improved with practise. Evidence presented in this chapter points to the archaeologists finding the activity of delineating offering them greater insight and further understanding of the object being viewed. This knowledge is conveyed to the viewer. I would suggest from this that delineation as a phenomenological activity is not solely dependant on the ability of the delineator and is a system that relies on appropriateness of application and intention.

I will now go on to conclude the research in the last chapter.

CONCLUSION

In this chapter I will begin by describing the main attributes of delineation as described in this thesis. 6 main themes of the research are outlined and developed further later in the chapter. A summary of the main contributions to knowledge follows and the chapter concludes with a summary of these conclusions.

Core characteristics distinctive to delineation as developed within this inquiry include the following:

- Demonstration of the way closely observed detail attempts to present the visual experience as directly and precisely as possible throughout the duration of time spent in the presence of the object being portrayed.
- Delineations are not formed from imagination or composites of remembered images but are observational drawings that reveal the unique and specific details of each encounter.
- They both present the journey of understanding taken by the delineator and communicate new insights revealed by the activity of drawing information observed directly in the presence of an object.
- They are made using lines rather than tone and do not make use of colour. Marks made on the paper remain part of the record of understanding achieved by the delineator, even if removed. Areas rubbed out, smudged, indented, and re-drawn create lines and marks that are sensitive and reflective of the accumulation of experiences. These marks reveal the development of the delineator's understanding as the drawing progresses and demonstrate sensitivity and respectfulness towards objects being observed.

These activities are comparable to other forms of observational drawing, for example life drawing and make use of similar skills and actions. They differ in their intention as delineation aims to communicate understanding gained by the delineator, to reveal insights to the viewer and show the importance of maintaining the dignity of the object whilst paying close attention to detail and presenting as much specific detail as possible.

The subject of this research is delineation. Knowledge about delineation gained through the progress of this inquiry is as follows:

1. The thesis argues that Delineation is a phenomenological process that allows the delineator to develop and reveal understanding of the material of pathology.
2. From that process other viewers can develop their own relevant insights into this material, drawing on a combination of their own experience and the content of the delineation.
3. Delineation provides an environment where the act of recording disease can be respectful of individual sufferers, the donors and historical specimens.
4. The knowledge gained by the delineator through the activity of delineation is not so much reliant on skill as on intention. The relatively unskilled archaeologists were more able to engage in delineation than the highly skilled but differently focused medical illustrators. However, the level of knowledge conveyed to an audience is more dependent on skill.
5. Whilst outcomes of delineation have not found a natural home in art practice, the activity has been shown to be a useful method for students and can help them to appreciate observational skills. Delineations in this research have been best located in the scientific context to which it relates through engagement with relevant professions and through the museums and other forms of dissemination relevant to those professions.
6. Delineation has value as an educational tool that has been lost in the age of medical imaging and digital photography.

1. The research establishes that Delineation is a phenomenological process that allows the delineator to develop and reveal understanding of the material of pathology.

Taking David Smith's description of phenomenology as a descriptive approach from the first person, delineation in this research has been shown to be a phenomenological activity in several ways (Chap. 2, p. 43). The delineator uses a system of close observation and immediate drawing action to record as directly and precisely as possible. The aims of

delineation are to record both the object and the delineator's experience of the object.

Unlike other practices, images made using delineation are dependant on being in the presence of the object throughout the duration of the activity of making. As John Searle points out, the object perceived causes the delineator's visual experience (Chap. 2, p. 47).

Delineation is also different from caricature (Chap. 3, p. 72), which conveys to an audience the experience of disease but through the use of symbol and allegory rather than precise, observational portrayal of a subject.

Two things occur simultaneously that allow the delineator to develop understanding of the material of pathology. First the system of delineating demands the use of close observation. By scrutinizing an object thoroughly, the delineator forms a relationship with the object and learns more about the object by seeing it. Secondly, whilst looking closely, the delineator engages in the activity of delineation. This reflects Heidegger's principle that we come to understand the world through tools used to make or interpret it (Chap. 2, p. 49). Delineation as developed in this research presents evidence of this principle. The tool used in the activity of drawing, in this case a pencil, connects directly with the paper. My understanding of the experience as it progresses is recorded immediately. Evidence remains on the paper as indentations, lines marks and smudges made with the pencil. These present my collection of insights and reveal the presence of the delineator holding the pencil. This reflects the way Merleau-Ponty defines the body in terms being a vehicle through which we experience being in the world (Chap. 2, p. 50). The object, the tool and the delineator are all part of the process of delineation.

This research has established delineation as a phenomenological process by demonstrating how the object is the cause of the delineator's experiences, how they are encountered through the body as a vehicle and how they are recorded through the tools used to draw. The techniques used in the activity are subjective and from the first person perspective.

I have provided illustrations from both history and my own work that demonstrates how understanding of an object is achieved through the activity of delineation. In the example of Leonardo da Vinci I describe how he was not just representing the body but gaining knowledge of how it works. As demonstrated in Wells and Crowe he achieved this through the activity of drawing (Chap.1, p. 29).

Delineation 62 (p. 227) provides another example. The line that differentiates between the skeleton and the heterotopic bone is defined without any intrusive changes in style. The understanding of the imperceptible intersections between the two bones is referred to by the techniques of delineation. The knowledge I gained is thus revealed to the viewer. Delineation 62 provides evidence of how I developed and revealed further understanding of the object. Professor Paul Wordsworth supports this claim by stating the delineation offers him a clear indication of what I have learned through the process of drawing (Chap. 7, p. 275).

The drawing workshop with the archaeologists provides a third example showing that drawing allows the delineator to develop understanding. C describes in detail how drawing the radiating patterns on a cracked egg, rather than taking static photographs, allows her to plot the movement in a way that is easier for her to understand and clearer for a viewer to interpret. She states that the experience and manner of her drawing leads to her insight (Chap. 7, p. 293).

The presence of the delineator is an intrinsic part of delineation and the traces of marks and smudges embedded in the paper are evidence of the activity and make that presence clear. In other forms of drawing, the presence of the investigator is not always revealed or significant to the image. With the system of delineation as developed in this investigation, the presence of both object and delineator is not only made explicit, but is essential to convey the relationships that formed between delineator and object.

2. From that process other viewers can develop their own relevant insights into this material, drawing on a combination of their own experience and the content of the delineation.

Different viewers gained a variety of insights into this material. Expert clinicians saw that the delineations highlighted relevant areas bringing particular features to their attention and offered new perspectives on the disease (Chap. 7, p. 273). Delineation also revealed information about where new bone is to be found (Chap. 7. p. 272). A private viewing of the *Delineating Disease* exhibition at the Hunterian Museum was held for the delegates of the *Bones in Unwanted Places* seminar, 13th – 15th November 2008. Dr. Fred Kaplan, a leading US authority on FOP was amongst the visitors. In a personal email sent to me on 17th November 2008, he revealed the insights he gained from seeing the exhibition of delineations.

'I learned an enormous amount from it and saw things I never saw before. More importantly, you showed us an aspect of "looking" and "observing" that brought us to the patients in a participatory way, something that most never get to do'

(Kaplan, 17th November, 2008).

The delineations of the skeletons from Basel have provided a practical demonstration of the how delineation can reveal knowledge to experts who have not seen the original material. These skeletons had not previously come to the attention of the experts as examples of FOP and Delineation 15 (p. 139) raised particular interest amongst medical experts attending the exhibition at the Hunterian. It records the ankylosis caused by heterotopic bone growth between the chin and the sternum. This is seen as an unusual example as there is no connective tissue in that area and it has raised new questions about the pathways of progression of ossification and what cells are affected.

The other groups who developed insights into this material were patients and other artists and researchers.

As people with first hand experience of FOP, the sufferers saw the delineations as offering information that they understood more clearly than other forms of imaging. However, they also thought they were too 'real'. The two patients who participated by allowing me to draw them showed intense interest in the delineations demonstrated by their repeated

requests to have copies of the delineations to give to friends and family. Conversely, there is evidence that the insights the delineations conveyed to the patients were too overt and revealed too much information (Chap 7, p. 279).

For others who had no knowledge of FOP, the delineations brought awareness of a rare and terrible disease. The detailed and precise nature of delineation gives viewers an insight into FOP in a way that reflects the understanding and compassion of the delineator. Comments made in two reviews of the exhibition demonstrate this (Chap. 7, p. 283). In another example the medical experts felt that delineations engender more empathy with the subject than photographs (Chap 7, p. 278).

3. Delineation provides an environment where the act of recording disease can be respectful of individual sufferers.

I have shown how dignity is important and how the intensity of observation and time spent engaged in the activity of delineation is all part of the subject of respectfulness (Chap. 1, p. 12).

To explore this I developed an approach based on respect of the condition and circumstances of patients and with a view to retaining the crucial element of dignity in the process of delineation. I asked patients who participated to choose how, where and when they wished me to draw them (Chap. 4, p. 102).

The objective of delineation is to record and present experience of phenomenon in a way that dignifies the subject. This was achieved. This can be confirmed by various responses from medical experts already referred to in this conclusion and by the views of artists and researchers who volunteered their opinions as documented, all of whom remarked on having observed the compassion for the subject in the delineations (Chap. 7, p. 283).

Analysis of photos, particularly medical photos, provides evidence to support the claim that unlike the activity of delineation as pursued in this research, photography is a useful and necessary form of documentation but tends to offer the patient little dignity. The use of effects like strong,

dramatic lighting in these particular examples places emphasis on the drama of the disease rather than present understanding brought about by the recording of the encounter (Chap. 5 p. 113).

Within this thesis I see dignity as a vital element of delineation. Dignity in this context encompasses aspects of respectfulness and empathy. Involving people with FOP decision-making processes, ensured dignity was maintained. They were given freedom to choose where I drew them, when and whether they wished to be drawn at all. These decisions remained in their control. Certain criteria for how images were made were maintained. For example, when drawing donors I would draw body parts sensitively, without overtly emphasizing areas that might be construed as grotesque other than to gain useful insight and reveal further detail of the effects of FOP. Conversely, areas which might not be seen to be aesthetically pleasant were not neglected for the sake of artistry but regarded as equally important to the visual experience and significant in holding important visual information.

The effects of FOP are shocking. To photograph the donors, the specimens and the people with FOP would serve to record this shocking effect. The activity of drawing, dignifies the subject in several ways. When drawing, a considerable length of time is spent engaging with the subject, building a dialogue and striving to communicate rare and sometimes emotionally intense encounters. The duration spent in the activity of looking and drawing allows the delineator to see first hand and experience the object being viewed. This is different to the encounter with an image of that object, for example a scan or a photograph. Rather than an image of a shocking object, delineations can reveal detailed aspects of the condition and attention is spent attempting to capture as precisely as possible the uniqueness of each of these continuing phenomenal experiences. The action itself of placing the tip of the pencil on a page and moving it to present the encounter as it is being experienced allows for a depth of detail and insight to be revealed. Paying such attention to detail allows every idiosyncrasy and nuance particular to each object to be portrayed. The emphasis on these elements of individuality specific to each encounter, dignifies the donors, the people with FOP and the specimens. No additions or embellishments are made to the delineations

and the drawing activity presents explicitly visual experiences of a human condition.

The intention has been to develop a method of visually presenting my encounters with FOP that moves away from relying on the use of technology and avoids presenting the patient in only medical terms or specimens only in terms of being museum artefacts. Delineating as a subjective, phenomenological activity seeks to achieve this by showing the care and time spent in the act of looking and presents the experience of this to the viewer. This inquiry has offered the opportunity for me to explore the notion of dignity with the aim of establishing criteria for what this entails for its integration with the activity of drawing. The delineations have been described as being quiet, dignified and full of empathy for the subjects, evidence that it is possible to communicate information about the subject without losing these vital elements.

4. Delineation is not so much reliant on skill as on intention. The relatively unskilled archaeologists were more able to engage in delineation than the highly skilled but differently focused medical illustrators.

In this research it has been shown that there are two stages when insight gained through the activity of drawing. The first is the understanding gained progressively by the delineator throughout the duration of the activity of drawing. Evidence of this is demonstrated in the workshop with the archaeologists. During this stage the understanding gained of the phenomenal experiences remains limited to the delineator. As every unique encounter is observed and simultaneously drawn, knowledge grows. Realization of where bone has grown, how it has spurred and bridged and clarification of where ossification has happened and how these areas visually connect with each other, develops continuously through the action of drawing. Along with this is the increasing realization of the catastrophic consequences these pathological developments have made on the object being drawn. The complexities of the visual experiences of the subject and level of insight the delineator gains through continual drawing is one stage of knowledge accumulated from engaging with the object and attempting to portray their visual experiences of it immediately by delineation.

The next layer of knowledge revealed in delineations is more dependent on skill. The level of insight the delineator can offer a viewer

During this project there has been an assumption that the success of delineation as developed in this inquiry, is mainly dependent on the skill of the delineator. This proved to be incorrect from the outcomes of the two drawing workshop events.

The medical illustrators who participated are highly skilled, trained artists. Their aim is to improve their styles and technical abilities through practise. One stated her view that once you had seen something a few times you no longer needed to see it as you knew how to draw it (Chap. 7, p. 285). The knowledge and drawing ability of the medical illustrators hampered their development of delineation as an activity. Their method involves drawing what they know a specimen should look like and then adapting it where it looks different. They produced high quality archetypes and variations on the archetype.

The archaeologists are relatively unskilled in drawing. They are not taught drawing as part of their studies but are given a small amount of training in photography. During the progress of the drawing workshop they developed their own systems to allow them to record and accumulate insight into the object they observed. They focused on specifics, an example of which is clearly shown in the fourth drawing by C (Fig. 46, p. 296). Her understanding of the disease and the development of her drawing system have allowed her to produce a drawing that shows only the heterotopic bone. She has chosen not to include the normal skeleton at all. The knowledge she has gained can be clearly seen in the development of her drawing. The drawing records the effects of FOP successfully and conveys this to a viewer.

The success of delineation is therefore not dependent on skill alone but on intention and development of process.

5. Delineation as practiced in this research does not have a natural home in art practice. The research has demonstrated that it is best located in the scientific context to which it relates through engagement with relevant professions and through the museums and other forms of dissemination relevant to those professions.

Previous experiences of displaying the delineations have been explored during this research. It was found that problems arose when the delineations were displayed in a gallery environment. They were assessed within the context of their surroundings rather than within a research context. Judged according to these rules, they were critiqued within the framework of aesthetics, use of materials and level of skill. Their role as a vehicle to explore delineation as a research tool was overlooked. So too was the information recorded during the activity of delineating and the insights conveyed to the viewer (Lyons, 2006, Appendix a.). The contribution made in the exploration of the process of delineation is not reliant on drawing skill. The evidence from these workshops demonstrates that intention is key to the activity of delineation rather than skill.

Often the process of the creation of paintings and drawings in fine art is not as important as the final outcome (Chap. 3, p. 73). This is not true of delineation as developed in this research. Central to this investigation is delineation as a phenomenological activity rather than the appearance of the outcome. I have shown that on occasion, delineations felt to be distasteful and unpleasant demonstrate evidence of insight and convey knowledge of the experience to the viewer. The delineations in the *Process and preparation* category are an example of this. Descriptive analysis of these show their role in evidencing understanding of the processes and communicating the experience of this to the viewer, in this case, Martyn Cooke (Chap. 6, pp. 157 – 173). Professor Wordsworth stated they conveyed valuable insight into the processes that took place but he had a negative reaction to them as drawings (Chap. 7, p. 275).

The role of delineation in this research is to communicate and engender experiences of phenomena and present understanding of the object rather than provide an aesthetic generalized example of an object to illustrate a theory or procedure. Delineation has been defined in this inquiry as a

phenomenological activity that provides a system of drawing which involves continuous observation, is detailed, lifelike and can record precisely the specificity of an object (Chap. 1, p. 15, 27).

A museum is a repository where one seeks out information and has a different role to the gallery. The Hunterian Museum provides an appropriate vehicle to display the evidence of this research. The delineations are housed within an environment where experts and members of the public would expect to find information. The setting provides the correct context and demonstrates the role of delineation as a process to record and communicate encounters with pathology.

The exhibition at the Hunterian museum has provided a good arena for experts and others who are able to see the work in its wider context, as they would not in a gallery. The delineations have been requested by the Mütter Museum at the College of Physicians, Philadelphia, USA where they will be on display in 2009. This is also a medical museum and displays the skeleton of FOP sufferer Harry Eastlack. In a personal email sent on 24th October 2008, Dr. Robert Hicks, Director of the Mütter Museum wrote,

'Your drawings afford the opportunity to interpret your images both as vehicles of scientific information as well as how they depict an unusual condition of the human body in an engaging way'

(Hicks, 24th October, 2008).

6. Delineation has value as an educational tool that has been lost in the age of medical imaging and digital photography.

The action of observing an object and drawing it is one that can be perceived as being too simplistic and its value can often be overlooked. Educationally, it is an activity that can train students how to look and hone observational skills. By requiring my students to investigate the world around them by drawing, they are forced to spend more time looking at objects and analyzing what they are looking at and attempt to gain insight into that experience. In this thesis I would suggest that skills gained from this process would be valuable to those also studying medical imaging. The activity would serve to enhance their observational skills

and support their developing knowledge of technical imaging equipment. This step in the process of imaging has been neglected and it would be beneficial to students to learn the art of observation before applying its use to digital photography etc. The activity of delineation provides a suitable system in which to acquire, present and build upon these skills.

This thesis has contributed to the field of art practice by demonstrating the significance of the role of drawing. Evidence shows that delineation is a phenomenological drawing activity that can reveal detailed insight into a rare disease whilst remaining respectful of the subject. The research also acknowledges the value of a system that is based in observation and focused on the unique and the specificity of each encounter but is simultaneously subjective as it presents the delineator's visual experience of the phenomenon from the first person.

The corpus of delineations of FOP forms a significant contribution to knowledge as it provides a portable archive that can also be easily reproduced. This allows artists, those in the medical profession, other related sciences, museum profession, and patients and carers access to the information. The collection can also be easily added to and built upon by future researchers

The application of the approach used within this thesis to the study of other areas would allow for possibilities of developing this research further. Drawing has been shown here to be an adaptable and flexible phenomenological activity. Within this investigation, the system of delineation has been used to understand the unfamiliar within the setting of pathology. There is scope for this to develop beyond this to other scientific fields and into teaching practice. A previous description of the educational use of this method to hone the observational skills of art students is a basis for this theory. Other potential future research would involve using drawing as a way to gain further insight into the already familiar. Scientists often work with the same material and repeat processes over long periods of time. Drawing here would be a useful and valid way to re-see all too familiar phenomena and gain fresh insight by the use of close observation coupled with the activity of drawing. The potential for the role of drawing to be used as an activity that reveals new

insight and understanding in the observer and communicates knowledge to an audience, is far reaching.

To summarize; delineation has been shown in this research to make use of traditional drawing skills to record and present insight into a medical condition. It provides a way of learning and developing understanding for the delineator engaged in the activity of drawing and conveys information to both those who are professionally interested and informed members of public in a way that complements medical imaging.

The ability of delineation to be accessed by researchers, medical experts, museum visitors and other interested audiences demonstrates the relevance of its role as a viable tool for inquiry. This investigation provides a repository of information that can easily be built upon and developed further by experts and other researchers. Delineation as an activity that records encounters with objects is not dependent on skill so has the capacity to be utilized as a system by any who find it an appropriate method of research.

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BIBLIOGRAPHY

Abad Vila, M. (2008). Freaks (1932): Dysmorphisms, Solidarity and Revenge. *Journal of Medicine and Movies*, 4(2), 58 – 65.

Abrahams, P. H., Hutchings, R. T. & Marks, S. C. Jr. (1998). *McMinn's Colour Atlas of Human Anatomy*, (4th ed.). Mosby International Ltd.

Albert Schwartz (1896). [Photograph]. From the Wellcome Library.

Allen, P. W. (1998). Adelaide's Blackbirding Pathologist, *Annals of Diagnostic Pathology*, 2(3), 208 – 211.

Anderson, E. J. (2008). [Image]. Retrieved 15 August, 2008, from http://www.phreeque.com?j_r_bass.html

Anderson, E. J. (2008). Retrieved 15 August, 2008, from http://www.phreeque.com?roy_bard.html

Archer, P. M. A. (1998). A History of the Medical Artists Association of Great Britain 1949-1997. (PhD, University College London).

Baysal, T., Elmali, N., Kutlu, R. & Baysal, O. (1998). The Stone Man: Myositis (Fibrodysplasia) Ossificans Progressiva, *European Radiology*, (8), 479 – 481.

Behan, P. O. & Behan, W. M. H. (1982). Sir Robert Carswell: Scotland's Pioneer Pathologist. In F. Clifford Rose & W. F. Bynum (Eds.), *Historical Aspects of the Neurosciences* (pp. 273-292). Raven Press Books, NY.

Beittel, K. R. (1972). *Mind and Context in the Art of Drawing An Empirical and Speculative Account of the Drawing Process and the Drawing Series and of the Contexts in Which They Occur*. Holt Reinehart and Winston, Inc.

Boyd, W. (1977). *An Introduction to the Study of Diseases* (7th ed.). Wolters Kluwer Health.

Brödel, M., (1993). Testimonial Dinner to Howard Atwood Kelly on his seventy-fifth birthday, *Bulletin Johns Hopkins Hospital*, 53(2), 65–109.

Brosterman, N. (2005). Retrieved 22 August, 2007, from <http://www.brosterman.com/architectural.shtml>

Burden, E. (1992). *Architectural Delineation* (3rd ed.). McGraw-Hill.

Burnett, P. (2008). [Diagram]. Retrieved 4 October, 2008 from <http://www.marathondrafting.com/wp-content/uploads/2008/04/architectural-symbols.jpg>

Carswell, R. (1829). *Subcutaneous Cancer*. [Delineation]. Held at University College London Special Collections.

Caswell, R. (10 April, 1830). [Letter]. Held at University College London Special Collections.

Caswell, R. (25 June, 1831). [Letter]. Held at University College London Special Collections.

Carswell, R. (1838). *Pathological Anatomy. Illustrations of the Elementary Forms of Disease*. London: Longman Orme Brown Green and Longman.

Connor, J. M. (1983). *Soft Tissue Ossification*. Springer-Verlag.

Connor, J. M. & Evans, D. A. P. (1982). Fibrodysplasia Ossificans Progressiva, The Clinical Features and Natural History of 34 Patients. *The Journal of Bone and Joint Surgery Britain*, 64 B(1), 76–83.

Cosby, R. W. & Cody, J. (1991). *Max Brödel The Man who put the Art into Medicine*. Springer-Verlag, NY.

Crawford, W. H. (2004). The Scope and History of Pathology, *University of Southern California website*. Retrieved 26 February, 2004 from <http://www.usc.edu/hsc/dental/PTHL312abc/312a/01?reader.pdf>
site updated to <http://www.usc.edu/hsc/dental/PTHL312abc/312a/index.html>

Crawford, R. & Lockwood, H. (1899, April 15). A Case of Myositis Ossificans Progressiva. *The Lancet*, 1021–1024.

Crotty, M. (1998). *The Foundation of Social Research Meaning and Perspective in the Research Process*. Sage Publications Ltd.

Da Vinci clue for heart surgeon. (28 September, 2005). Retrieved 30 September, 2005 from <http://news.bbc.co.uk/1/hi/health/4289204.stm>

De Santo, N. G., Bisaccia, C., De Santo R. M. & Touwaide, A. (2002). The Pre-Vesalian Kidney: Gabriele Zerbi, 1445-1505. *American Journal of Nephrology*, 22, 164–171.

Dreyfuss, H. (1955). *Designing for People*. Simon and Schuster, NY.

Edwards, B. W. (1992). *Understanding Architecture Through Drawing*. (1944 ed.). London: E & F N Spon.

Edwards, J. J., Edwards, M. J. (1959). *Medical Museum Technology*. OUP.

Eroschenko, V. P. (2005). *diFore's Atlas of Histology with Functional Correlations*. (10th ed.). Lippincott Williams & Wilkins.

Foster, W. D. (1961). *A Short History of Clinical Pathology*. Edinburgh: Livingstone.

Gassier, P. (1973). Allen, R. & Emmons, J. (trans.). *The Drawings of Goya The Complete Albums*. Thames and Hudson, London.

Gassier, P. (1973). [Drawing]. *Claude Ambroise Seurat*, by Goya, 1826. *The Drawings of Goya The Complete Albums*. Thames and Hudson, London, p. 643.

Geschickter, C. F. & Maseritz, I. H. (1938). Myositis Ossificans. *Journal of Bone and Joint Surgery*, 20(3), 661-674.

Gillions, J. (2008). Review. *Hunterian Museum exhibits drawings of rare disease*. Retrieved 5 October, 2008 from http://www.24hourmuseum.org.uk/exh_gfx_en/ART61332.html

Gould, G.M & Pyle, W. L. (1897). *Anomalies and Curiosities of Medicine being an encyclopaedic collection of rare and extraordinary cases, and of the most striking instances of abnormality in all branches of medicine and surgery, derived from an exhaustive research of medical literature from its origin to the present day, abstracted, classified, annotated, and indexed*. Philadelphia, W.B. Saunders.

Griffiths, N. & Jenner, A. (1990). *Drawing Archaeological Finds A Handbook*. Archetype Publications Ltd.

Hales, A. (2008). Review. *Interface, a-n website*. Retrieved 10 September, 2008 from <http://www.a-n.co.uk/interface/reviews/single/462218>

Heidegger, M., (1982). Albert, H. (trans.). *The Basic Problems of Phenomenology*. Indiana University Press Bloomington.

Herford, A. S., P., Boyne, J. & Linda, L. (2003). Ankylosis of the jaw in a patient with Fibrodysplasia Ossificans Progressiva. *Oral Surgery, Oral Medicine, Oral Pathology*, 96(6), 680-684.

Herrlinger, R., (1970). Uitgeverij, G. F. & Callenbach, N. V. (trans.). *History of Medical Illustration from Antiquity to A.D. 1600*, Pitman Medical and Scientific Publishing Co. Ltd.

Hollman, A. (1995). The paintings of pathological anatomy by Sir Robert Carswell (1793-1857). *British Heart Journal*, 74, 566-570.

Hone, W., (July 26th 1826). *Every-Day Book, Vol. I, 1825-1826*. London Tegg. 30 – 42.

Hone, W., (July 26th 1826). [Drawings]. Cruikshank's Claude Ambroise Seurat. *Every-Day Book, Vol. I, 1825-1826*. London Tegg. p. 30 – 42.

Hooper, G., (1992). Goya's Living Skeleton, a letter. *British Medical Journal*, 304, 509.

Husserl, E. (2001). *The Shorter Logical Investigations*. Routledge.

Jannoff, H. B., Tabas, J. A., Shore, E. M., Muenke, M., Dalinka, M. K., Schlesinger, S., Zasloff M. A. & Kaplan F. S. (1995). Mild Expression of Fibrodysplasia Ossificans Progressiva: A report of 3 cases. *Journal of Rheumatology*, 22, 976-8.

Kaplan, F. S., Le Merrer, M., Glaser, D. L., Pignolo, R. J., Goldsby, R. E., Kitterman, J. A., Groppe, J. & Shore, E. (2008). Fibrodysplasia Ossificans Progressiva. *Best Practice & Research Clinical Rheumatology*, 22(1), 191-205.

Kaplan, F. S., McCluskey, W., Hahn, G., Tabas, J. A., Muenke, M. & Zasloff, M. A. (1993). Genetic Transmission of Fibrodysplasia Ossificans Progressiva. *The Journal of Bone and Joint Surgery America*, 75A(8), 1214-1220.

Kaplan, F. S., McCluskey, W., Hahn, G., Tabas, J. A., Muenke, M. & Zasloff, M. A. (1993).[Photograph]. Male Patient. Genetic Transmission of Fibrodysplasia Ossificans Progressiva. *The Journal of Bone and Joint Surgery America*, 75A(8), 1215.

Kaplan, F. S., Tabas, J. A., Gannon, F. H., Finkel, G., Hahn, G. V. & Zasloff, M. A. (1993). The Histopathology of Fibrodysplasia Ossificans Progressiva. *The Journal of Bone and Joint Surgery America*, 75A(2), 220-230.

Katanka, M. & Rickward, E. (1973). *Gillray and Cruikshank*. Shire Publications.

Kemp, M. (1989).Walker, M. (trans.). *Leonardo on Painting*. Yale University.

Kipfer, B. A. (2007). *The Archaeologist' Fieldwork Companion*. Blackwell Publishing.

Kocyigit, H., Hizli, N., Memeis, A., Sabah, D. & Memis, A. (2001). A Severely Disabling Disorder: Fibrodysplasia Ossificans Progressiva. *Clinical Rheumatology*, 20, 273-275.

Leibing, R.W. (1999). *Architectural Working Drawings* (4th ed.). John Wiley & Sons Inc., New York.

Letts, H. & Jacques, J. (1981). *A History of Pathology and Laboratory Medicine in Canada*. Retrieved 13 May, 2005 from http://www.cap.medical.org/history_pathology_laboratory-med.htm

Lopes, D., (2005). *Drawing in the Social Sciences: Lithic Illustration*, Interdisciplines: Art and Cognition Workshops. Retrieved 19 June, 2008 from www.interdisciplines.org/artcognition/papers/7/3

Lowe, S. (2000). *Pathology*. (2nd ed.). Harcourt Publisher Ltd.

Macfarlane, P. S., Reid, R. & Callander, R. (2000). *Pathology Illustrated*. (5th ed.). Churchill Livingstone, Harcourt Publishers Limited.

Maeder, T. (1998). A few Hundred People Turned to Bone. *The Atlantic Monthly*, 281(2), 81-89.

Mallery, C. (2007). [Diagram]. Retrieved on 4 October, 2008 from <http://porpax.bio.miami.edu/~cmallery/255/255hist/mcb5.43.microtome.jpg>

Mappes, T. (2002). [Photograph]. Zeichenokular lens. Retrieved on 20 March, 2005 from http://www.musoptin.com/leitz_zeichenokular.html

Mappes, T. (2002). [Diagram]. Camera Lucida. Retrieved on 20 March, 2005 from http://www.musoptin.com/leitz_zeichenokular.html

Mappes, T. (2002). [Diagram]. Camera Lucida. Retrieved on 20 March, 2005 from http://www.musoptin.com/leitz_zeichenokular.html

Mappes, T. (2002). [Diagram]. The projected image and hand holding a pencil. Retrieved on 20 March, 200 from http://www.musoptin.com/leitz_zeichenokular.html

Masquelet, A. C. & Dorn, L. (2005). *An Atlas Of Surgical Anatomy*. Taylor & Francis Group, London, NY.

McFee, J. (1961). *Preparation for Art*. Wandsworth Publishing Company Inc.

McHugh, R. C. (1982). *Working Drawing Handbook A Guide for Architects and Builders*. (2nd ed.). Van Nostrand Reinhold Company Inc.

Medical Artists Association. Retrieved 10 April, 2006 from <http://www.maa.org.uk/>

Medical museum (1763). *The Medical Museum, Or, A Repository of Cases, Experiments, Researches, and Discoveries, Collected at Home and Abroad: Whether in Anatomy, Medicine, Pharmacy, Botany, Chemistry, Surgery, Physiology*, Vol. 1 of 3 Published Bristow, located in Bodleian Library, Oxford.

Merleau-Ponty, M. (1992). Smith, C. (trans.). *Phenomenology of Perception*, (1962 ed.). Routledge & Kegan Paul Ltd.

Moore, K. L. & Agur, A. M. R. (1995). *Essential Clinical Anatomy*. Lippincott Williams & Wilkins, USA.

Moran, D. (2004). *Introduction to Phenomenology*. Routledge.

O'Malley, C. D. (1983). Saunders J. B. (trans.). *Leonardo on the Human Body*. Dover Publication Inc. NY.

Park, R. H. R. & Park, M. P. (1991). Goya's Living Skeleton. *British Medical Journal* 303(21-28), 1594-1596.

Pathology as Art Appreciation: Melanoma Diagnosis. (1997). *Bandolier Journal*, Retrieved 6 April, 2004 from <http://www.jr2.ox.ac.uk/bandolier/band37/b37-2.html>

Patin, G. (1688). *Lettres choisies de feu Mr. Guy Patin Doctor en Medicine de la Faculté de Paris, & Professeur au Collège Royal. Dans lesquelles sont contenuës, plusieurs particulrités Historiques, sur la Vie & la Mort des Savans de ce Siècle, sur leurs Ecrits, & sur plusieurs autres choses curieuses depuis l'an 1645, jusqu'en 1672*. (2nd ed.). Paris, chez Jean Petit, rue S. Jacques.

Peltier, L. F. (1998). Commentary on Freke J. (1740) A case of extraordinary exostoses on the back of a boy. *Clinical Orthopaedics and Related Research*, (336), 5-6.

Prodger, P. (1998). *An Annotated Catalogue of the Illustrations of Human and Animal Expression from the Collection of Charles Darwin*. The Edwin Mellen Press, NY.

Quinn, V. (Ed.). (2005) *The Girl whose muscle turned to bone* [Television broadcast]. Zig Zag production for Channel Five, Channel 5 Broadcasting Ltd.

Rawson, P. (1987). *Drawing*. (4th ed.). University of Pennsylvania Press.

Rust, C., & Wilson, A. (2001). A Visual Thesis? Techniques for reporting practice-led research. *Proceedings of 4th European Academy of Design Conference*, Aveiro, Portugal, April 2001.

Sage, M., (Ed.). Rugg, S. (Dir.). (1999). *The Skeleton Key* [Television broadcast]. October Films: Horizon: BBC.

Schultheiss, D., & Jonas, U. (1999). Max Brödel (1870-1941) and Howard A. Kelly (1858-1943)- Urogynecology and the birth of modern medical illustration. *European Journal of Obstetrics & Gynaecology and Reproductive Biology*, 86(1), 113-5.

Scruton, R. (1989). But is it Art? *Modern Painters*, 2(1), 62-65.

Scruton, R. (1998). *Art & Imagination a study in the Philosophy of mind*. St Augustine's Press.

Searle, J. R. (1983). *Intentionality An Essay in the Philosophy of Mind*. Cambridge University Press.

Simblet, S. (1998). *Drawing as a Method of Analysis and Transformation in Relation to the Human Form*. (PhD, Cheltenham and Gloucester College of Higher Education and the University of Bristol).

Smith, D. W. (2005). Phenomenology. In E. N. Zalta. (Ed.), *The Stanford encyclopaedia of philosophy*. Retrieved 9 August, 2006 from <http://plato.stanford.edu/archives/win2005/entries/phenomenology/>

Stafford, B. M. (1991). *Body Criticism Imaging the Unseen in Enlightenment Art and Medicine*. MIT.

Stickney, B. M. (n.d.). *Turned to Stone A Rather Brief Biography of Niagara County's Jonathan Bass, the World Famous 'Ossified Man'*. Retrieved 15 August, 2008 from <http://www.sideshowworld.com/tgodBS-JonathonBass.html>

Taylor, K. T. (2001). *Forensic Art and Illustration*. CRC Press.

The Association of Medical Illustrators. Retrieved 10 April, 2006 from http://www.ami.org/ECOMAMI/timssnet/common/tnt_frontpage.cfm

The Free Dictionary. (2006). Retrieved 13 April, 2006 from www.thefreedictionary.com

The Skeleton of Harry Eastlack (n.d.). IFOPA website. Retrieved 6 October, 2005 from <http://www.ifopa.org/fopskeleton.html>

Tobey, G. & Hilderton, N. (1992). *Delineation a resource book for architects and illustrators*. Van Nostrand Reinhold N.Y.

Trikha, V., Kumar, R., Khan, S. A. & Rastogi, S. (2005). Characteristic Appearance on Bone Scintigraphy of a 'Stone Man', *Clinical Nuclear Medicine*, 30(7), 517-518.

Tufte, E. R. (1997). *Visual Explanations Images and Quantities Evidence and Narrative*. Graphics Press.

Wagman, R. B., Kantanie, S. L. & Kaplan, F. S. (1997). *What is FOP? Fibrodysplasia Ossificans Progressiva a Guidebook for families*. (2nd ed.). Winter Springs Florida.

Wakita, O. A. & Linde, R. M. (2003). *The Professional Practice of Architectural working drawings* (3rd ed.). John Wiley & Sons Inc., N.Y.

Weber, F. P. & Compton, A. (1914). The early development of myositis ossificans progressiva multiplex, illustrated by an apparently congenital or almost congenital case. *The British Journal of Children's Diseases*, Vol. XI, 497-508.

Weber, F. P. & Compton, A. (1914). [Photograph] Child's feet. The early development of myositis ossificans progressiva multiplex, illustrated by an apparently congenital or almost congenital case. *The British Journal of Children's Diseases*, Vol. XI, 498.

Wells, F. C. & Crowe, T. (2004). Leonardo da Vinci as a paradigm for modern clinical research. *The Journal of Thoracic and Cardiovascular Surgery*, 127(4), 929-44.

Wolpert, L. (10 March, 2002). Which Side are you On? The Observer newspaper.

Wood, P. (1994). *Scientific Illustration a Guide to Biological, Zoological, and Medical Rendering Techniques, Design, Printing, and Display*. (2nd ed.). Van Nostrand Reinhold, NY.

Yankowski, A. (n.d.). [Diagram]. Pot Illustration. Retrieved 4 October, 2008 from http://www.bohol-archaeology.com/pot_illustration%20001.jpg

Zigrosser, C. (1955). *Ars Medica: a collection of medical prints by great artists of the past presented to the art museum by Smith, Kline and French Laboratories*. The Philadelphia Museum of Art.

APPENDICES (~~CD attached~~) CD removed.

- Appendix a. Lyons, L. (2008). Delineating Disease. *The Bulletin of the Royal College of Pathologists*. 143.
- Appendix b. Lyons, L. (2006). Walls are not my friends: issues surrounding the dissemination of practice-led research within appropriate and relevant contexts. *Proceedings of Research into Practice (R2P) Conference*, July 2006. (*Working Papers in Art & Design Vol. 4*, 1st November 2006).
- Appendix c. Lyons, L. (2006). Visual thinking: can drawing contribute knowledge to medicine? *Proceedings of Wonderground Design Research Society Conference, Lisbon*, November 2006.
- Appendix d. 737 photos documenting the process of maceration.

Appendices
Delineating Disease

Lucy Lyons