

## **Scottish Public Services Ombudsman Act 2002**

### Report by the Scottish Public Services Ombudsman of an investigation into a complaint against:

Lothian University Hospitals NHS Trust<sup>1</sup>

#### **INTRODUCTION**

1. Mrs C's son Stewart<sup>2</sup> was born on 28 January 1980 at the Simpson Memorial Maternity Pavilion, Edinburgh (SMMP). He had hydrocephalus (a condition in which there is an abnormal accumulation of cerebro-spinal-fluid within cavities inside the brain – for further information see Annex B) and was transferred to the Royal Hospital for Sick Children, Edinburgh (RHSC) where he was under the care of a Consultant Paediatrician (Consultant 2). Stewart died on 6 February 1980.

2. During 2000 and 2001 there was extensive publicity about organ retention, (see paragraph 10). As a result Mrs C became anxious that organs might have been retained following Stewart's death. She made enquiries of the Trust but remained unhappy about their responses and complained to the Health Service Commissioner for Scotland<sup>3</sup>. The Commissioner's office had made enquiries but reached no decision on whether to carry out a formal investigation when my office was established in October 2002 and I assumed responsibility for the case.

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<sup>1</sup> Lothian University Hospitals NHS Trust (the Trust) was established by the Lothian University Hospitals NHS Trust (Establishment) Order 1998 which came into force on 2 November 1998. The Trust was dissolved under the Lothian University Hospitals NHS Trust (Dissolution) Order 2003 which came into force on 1 January 2004. On the same date an Order transferring the liabilities of the Trust to Lothian Health Board (the Board) came into effect. To avoid confusion, this report continues to refer to the Trust when describing actions taken by, or on behalf of, the Trust. However, the recommendations within this report are directed towards the Board.

<sup>2</sup> A key to the names and abbreviations used in this report is set out at Annex A.

<sup>3</sup> The Ombudsman responsible for considering complaints about the NHS in Scotland before my office was established.

## **MY INVESTIGATION**

3. My work is governed by the Scottish Public Services Ombudsman Act 2002. Among other things, the Act says that I must not consider a complaint made more than 12 months after the day on which the person aggrieved first had notice of the matter complained of, unless I am satisfied that there are special circumstances which make it appropriate to consider a complaint made outwith that period. One of the reasons for this provision is that it can be hard to establish facts when investigating complaints about things which happened many years ago.

4. In this case, before I decided whether to start an investigation one of my Investigators met with Mrs C and her family to explain that it was very unlikely that an investigation so long after the event would be able to establish the circumstances in which a post mortem on her son was carried out (this being one of Mrs C's main concerns). However, I decided to investigate whether:

- a) the Trust failed to investigate adequately and reply to Mrs C's complaint that a post mortem had been performed on Stewart against Mr and Mrs C's wishes; and
- b) the Trust failed to respond adequately to Mrs C's complaint that she was not provided with reasonable genetic counselling following Stewart's death in 1980.

5. My investigation formally commenced on 23 December 2002. The Trust's comments and relevant papers, including Mrs C's GP medical records; her medical records from SMMP; Mr C's GP medical records; and Stewart's medical records from RHSC were obtained from the Trust and examined. Advice was sought from five Clinical Advisers. My Investigator contacted the Procurator Fiscal's office; and obtained and examined papers from the Scottish Executive Health Department (SEHD) and Audit Scotland (the latter had undertaken a general review of issues relevant to this investigation – see paragraph 18). In addition, my Investigator interviewed Mr and Mrs C; staff from Audit Scotland; staff from SEHD and the Independent Review Group on the Retention of Organs at Post Mortem; and a number of current or previous members of staff from the Trust and its predecessors.

6. I have drawn on all of this material in the preparation of this report. I have not put into this report every detail investigated but I am satisfied that nothing of significance has been overlooked.

7. Mr and Mrs C and the Board have been given an opportunity to comment on the key facts contained within this report. Where appropriate their comments have been reflected in the text.

8. I am aware that my investigation has been a difficult experience for Mr and Mrs C and for a number of the people interviewed. Additionally, while the matters subject to investigation are specified in the two headings of complaint, my investigation has inevitably involved some consideration of events which occurred many years ago. I am very grateful for the contribution from all the people interviewed in connection with my investigation.

9. Before dealing with the specific facts of Mrs C's case I next set out some general background which is relevant to the issues addressed in this report.

## **BACKGROUND INFORMATION**

### **Concern about the retention of organs and resulting action**

10. During the Inquiry, started in 1998, into the management of the care of children receiving complex heart surgery at Bristol Royal Infirmary, it emerged that the retention of hearts removed during post mortem examination of the child's body had been commonplace. In many cases it appears to have taken place without parental consent or indeed knowledge. At around the same time, an Inquiry at Alder Hey Children's Hospital in Liverpool found that collections of children's hearts and other organs had been accumulated over several decades, in some cases as long as 50 years. The Inquiry established that it had been common practice to retain organs without express parental knowledge and agreement.

11. These disclosures led to concern that similar things might have happened at other hospitals, including hospitals in Scotland. In September 2000 the then Minister for Health and Community Care

announced that she would be setting up an Independent Review Group to review past post mortem practices in Scotland.

12. The Review Group made two interim recommendations which SEHD drew to the attention of Chief Executives and Medical Directors of all NHS Trusts in Scotland on 17 January 2001. These were that:

- a) Trusts should nominate a specific member of staff with a dedicated helpline to act as a liaison officer for enquiries from bereaved parents; and that
- b) Trusts should, in appropriate cases, meet the burial costs where organs have been retained without proper consent.

13. Further recommendations were made by the Review Group in their preliminary report which was published on 6 February 2001. These included:

- h) Where relatives do decide to inquire, hospitals should, where appropriate, offer them a meeting to discuss any concerns they may have.
- i) Under no circumstances should relatives be approached by the hospital regarding the current retention or disposal of organs about which they will have no knowledge. Relatives should be given every opportunity to inquire, but the wishes of those who do not wish to know must be respected.

14. On 1 February 2001 SEHD alerted Chief Executives and Medical Directors of all NHS Trusts to the imminent publication of the Review Group's preliminary report. SEHD highlighted that Trusts and hospitals were likely to receive a large number of calls from people requesting information about organ retention and indicated that Trusts should consider urgently how they would respond to such enquiries.

15. SEHD also enclosed a copy of guidance on how such enquiries should be handled. This had originally been prepared by the Department of Health and issued to English and Welsh Trusts at the end of January

2001. Among other things, this guidance provided a suggested script for responding to telephone enquiries, which referred to looking into whether organs or tissue samples had been retained, and contained a number of pro-forma letters for communication with people making enquiries.

16. The pro-forma letter to be sent where a post mortem had been carried out by a Trust with a Pathology Service, but where organs were not retained, stated:

‘(In your letter/enquiry you ask whether a post mortem had been carried out on [name].)

I have carefully checked our records and have ascertained that a post mortem was carried out on [name].

It might be helpful if I first explained that generally, once a cause of death has been confirmed at a post mortem, any organs involved are not retained. In any circumstances where it would not have been possible to return any organ or tissue for internment or cremation with [name’s] body because of the post mortem process these remains would have been [respectfully] disposed of [in the normal way] by the pathology service once they were no longer needed for the post mortem process.

I hope this information is helpful but please let me know if I can be of any further assistance.’

17. The pro-forma letter to be sent where a post mortem had been carried out by a Trust with a Pathology Service and some organs/tissue had been retained stated in part:

‘I am now arranging for urgent enquiries to be made to find out whether any organs or tissues from [name] [your – state relationship if known] are still being retained. ...’

18. As part of the work of the Review Group all NHS Trusts in Scotland were asked to provide information about the number of organs retained at post mortem. During 2001 Audit Scotland began an exercise to

validate the information provided by the Trusts and also, among other things, to review the systems to record all materials held (including tissue blocks and slides). Audit Scotland visited the Trust in December 2001 and concluded that they 'had taken a very robust approach to the whole subject of organ retention'. Audit Scotland reported in February 2002 that all NHS Trusts in Scotland had systems in place for identifying organs retained following post mortems and for dealing efficiently with relatives' enquiries. Procedures varied from place to place but all hospitals were able to produce the information required to identify which organs had been retained and where they now were.

### **Past practice for obtaining consent for a post mortem**

19. A post mortem may either be carried out on the instruction of the Procurator Fiscal or following a request on behalf of the hospital itself. The latter are commonly referred to as 'hospital post mortems'. The Procurator Fiscal has a common law power to instruct a post mortem examination so the consent of relatives is not required. However, the Trust has always accepted, and the Procurator Fiscal's office confirmed to my Investigator, that the post mortem on Stewart's body was a Hospital post mortem.

20. Hospital post mortems are governed, in the main, by the Human Tissue Act 1961 (the Act). So far as is relevant to Mrs C's complaint, the Act indicates that 'the person lawfully in possession of the body' (which the Review Group noted as seeming to mean the hospital in which the death took place) may proceed to authorise a post mortem once they have made reasonable enquiries to ensure that the deceased had no prior objection to this and nor do surviving relatives. Thus the Act focuses on the absence of objection to a post mortem examination rather than on the provision of consent for that post mortem.

21. The Review Group, as well as others, found that in the past the medical profession took a paternalistic attitude towards post mortem examinations, believing that it was in the interests of bereaved relatives not to describe the details of how post mortem examinations were carried out when enquiring whether the relatives objected to a post mortem. There was an associated tendency to use vague or euphemistic terminology. Consent for the retention of organs, for whatever purpose,

was viewed as being implicit in the granting of permission for a post mortem examination.

22. In this context I note that the form which relatives were asked to sign by the RHSC in 1980 to consent to a post mortem actually asked them to 'authorise the Inspection' of the deceased's body (see Annex C).

23. The Review Group did not come across any evidence that, in the past, hospital post mortems were performed without some form of consent having been obtained from the deceased's relatives. However, the Review Group did have concerns about the way in which consent was obtained in the past. These concerns were such that in many cases it could be questioned whether the consent obtained had been meaningful.

24. It is widely recognised that past practice for obtaining consent for post mortem examinations and the retention and use of tissue or organs removed during post mortem is no longer acceptable, if it ever was. It is also clear that practice has changed. The form in Annex C has not been used for some time and the Trust has indicated that since 1996 relatives have been given much fuller information about post mortem examinations when their consent was sought.

25. The Review Group also noted a number of concerns about shortcomings in the Human Tissue Act itself and made recommendations for reform. I understand it is intended that new legislation will be brought forward shortly.

### **Standard clinical practice during post mortem examinations**

26. My Clinical Advisers explain that standard clinical practice in 1980 was, as it is now, to take small tissue samples (normally about 20 mm square and about 5 mm thick) from a range of organs during a post mortem even if the cause of death seems to be clearly related to one particular organ. In a baby born at full-term these small samples are normally only a relatively small proportion of the organ that they are taken from. However, in a smaller baby or a foetus, a tissue sample could represent a substantial part of an organ or possibly the whole organ.

27. Once tissue samples have been taken, they are normally embedded in paraffin to make a paraffin block. Embedding within paraffin allows tissue samples to be stored and allows extremely thin slices (normally less than one hundredth of a millimetre thick - thinner than a human hair) to be cut from the paraffin block so that slides of the tissue sample can be prepared. Slides allow microscopic examination of the tissue which can be very important as often significant factors in a person's illness or death can only be identified at a microscopic level. Commonly more than one slide is prepared from the tissue contained within a single paraffin block because it may be necessary to see tissue from different parts of the tissue sample within the paraffin block or a number of slides might be prepared in order to receive different specialist stains. As a result, the number of slides made may not match the number of paraffin blocks held. The extremely thin slices which have been cut from a paraffin block, but which are not made into slides, are disposed of.

28. My Advisers explain that it is standard clinical practice to retain paraffin blocks and slides more or less indefinitely as part of the person's medical record because of the possible need for further investigations in the future. Indeed, both my Advisers and Trust staff pointed out that the use of stored tissue for future tests was precisely what happened in this instance. The continued retention of tissue from Stewart's brain meant his DNA could be analysed after Mrs C's nephew was born (see paragraph 43). This allowed the genetic cause of hydrocephalus within Mrs C's family to be unambiguously identified in the early 1990s.

29. The preparation of paraffin blocks and slides is also standard clinical practice after tissue samples have been taken from living patients during biopsies or surgery. This, combined with the preparation and retention of paraffin blocks and slides from tissue samples taken at post mortem, means that hospitals can hold a very large number of paraffin blocks and slides which can in turn cause significant logistical and storage problems.

30. My Advisers confirm that once an organ has been examined at the post mortem examination and tissue sample(s) taken from it as required, it was not in 1980, nor is it currently, standard clinical practice to retain that organ unless there are good clinical reasons to do so. Normal



practice would have been to return the examined organs with the person's body.

31. The Alder Hey Inquiry (see paragraph 10) showed that at that hospital standard clinical practice was not always followed and organs were sometimes retained after a post mortem examination when there were no good clinical reasons to do so. However, the Review Group (see paragraph 11) concluded that there was no evidence of such practice in Scotland.

32. My Advisers explain that the situation is more complex when examining and/or taking tissue samples from a brain. The brain is very soft and so it has to be treated to harden it before it is possible to properly examine it and take tissue samples. This process is called fixation and is normally achieved by removing the whole brain from the body and storing it in formaldehyde for several weeks. This process was standard clinical practice in 1980, and continues to be.

33. My Advisers have reviewed all the relevant papers relating to the post mortem on Stewart and the information gathered in the course of my investigation. They note that the post mortem report is unusually brief and does not contain information which they would have expected. The post mortem report focuses on the brain and relies upon the neuropathologist's examination of the brain to confirm both the diagnosis and the genetic implication of this diagnosis. The report makes no comment on other organs and my Advisers consider it likely that this was because the cause of death was thought to be obvious.

## **HISTORY OF COMPLAINT**

34. Mrs C's first son was born on 2 January 1973 at her local maternity hospital. He had hydrocephalus and died the same day. Her second son was born on 26 January 1974 at the same hospital. He also had hydrocephalus. Mrs C is aware that it is unclear from the clinical records whether he was stillborn or whether he died shortly after birth.

35. After a number of meetings with Mr and Mrs C, a Consultant in Medical Genetics (Consultant 1) wrote to Mrs C's GP at the time (GP 1) on 28 May 1975 explaining that, after using mathematical analysis, he

calculated that the chance that Mrs C's two sons had had hydrocephalus due to an X-linked inheritance was low at around 0.5% (see Annex B for explanation of the cause and inheritance of X-linked hydrocephalus).

36. Mrs C's third son, Stewart, was born on 28 January 1980 at SMMP. He too had hydrocephalus and was transferred to RHSC where he was under the care of Consultant 2. Stewart died at 10.30 pm on 6 February 1980.

37. The ward staff were unable to contact Mr and Mrs C. Mr and Mrs C were eventually contacted the following day, 7 February, by the police and Mr C attended RHSC that afternoon. An entry in Stewart's medical records, dated 7 February 1980 but not signed, (Figure 1) states:

- ✓PM request
- ✓GP contacted by phone

Father spoken to by [Consultant 2]  
Appointment apparently has been made to see mother and father [with] [Consultant 2] [and] [Consultant 3] (SMMP) in [six weeks' time].

Result of PM should be ready.'

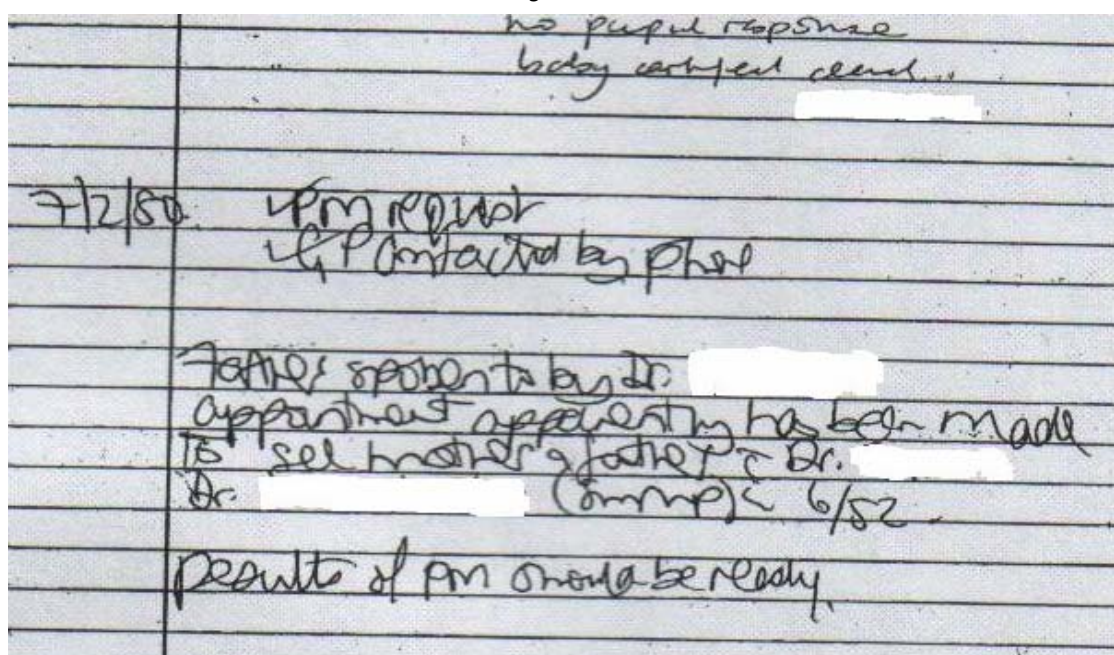


Figure 1: Extract from Stewart's medical records.

38. Mr C recalls being asked to consent to a post mortem when he visited the hospital on 7 February 1980, but also recalls refusing consent.

39. The following day, 8 February, a post mortem examination was carried out at RHSC on Stewart's body. The post mortem report shows that Stewart's brain was removed intact for neurological examination at the Western General Hospital (WGH). The post mortem report does not mention Stewart's other organs but the Mortuary Day Book shows that a total of 16 blocks of tissue were taken.

40. RHSC records show that Stewart's brain was sent to the Department of Neuropathology at the WGH on 28 February 1980. That Department's records show that Stewart's brain was received by them on 4 March 1980.

41. Mrs C had a follow up appointment with her Consultant Obstetrician (Consultant 3), at SMMP on 19 March 1980. Consultant 3 subsequently wrote to GP 1 explaining that, based on Mrs C's history of three sons all diagnosed with hydrocephalus, it was 'very likely' that the hydrocephaly was of the X-linked recessive type and it was 'quite probable' that a future female child would not be affected but could be a carrier. He offered to perform an amniocentesis if she became pregnant again to establish the sex of the baby. Consultant 3's letter did not indicate that he had discussed the outcome of the post mortem on Stewart with Mrs C.

42. On 12 June 1980 the Department of Neuropathology completed the final report from the neurological examination of Stewart's brain. The Department's records indicate that two blocks of tissue were retained from Stewart's brain and that the remainder of his brain was disposed of on 22 August 1980.

43. Nearly 10 years later, on 2 February 1990, Mrs C's sister gave birth to a son who also had hydrocephalus. Mr and Mrs C explained to my Investigator that subsequently there were a number of contacts with various staff from the South East of Scotland Clinical Genetic Service.

44. Papers from WGH show that a Senior Lecturer in Human Genetics (Senior Lecturer 1), wrote to the Department of Neuropathology on 15 September 1992 to enquire whether there was retained tissue from the

post mortem on Stewart as analysis of his DNA could improve the accuracy of the mapping of the gene for the disorder in Mrs C's family.

45. It seems that some or all of the brain tissue retained by the Department of Neuropathology was sent to Senior Lecturer 1 in the Human Genetics Unit to assist with their analysis, and this was then returned to the Department of Neuropathology. There are no existing records of the transfer of this tissue between these Departments. However, it was explained to my Investigator that the Department of Neuropathology recorded such transfers by placing a tracer, or note, in the relevant file detailing when and where the tissue had been sent, and then removed the tracer when the tissue was returned to them. The absence of any such tracer in the file relating to Stewart meant that it could be presumed that the tissue from his brain sent to Senior Lecturer 1 had been returned to the Department of Neuropathology, less the small amount used during the genetic analysis. It was explained to my Investigator that any tissue used in this process would have been destroyed by the process.

46. As a result of media reporting during 2000 and 2001 about organ retention, Mrs C became anxious that organs may have been retained following Stewart's death. Mrs C spoke to her current GP (GP 2) who wrote on her behalf to SMMP on 29 May 2001 as follows:

'... No PM examination was carried out since this was against the wishes of both parents. [Mrs C] came to see me recently requesting that I write to the hospital to ensure that none of her deceased infant's tissues were retained for any reason. I have explained that in the absence of a post mortem [examination] no tissue samples would have been available for further study. However, she feels that she would like the reassurance of hearing this from the hospital and I would be most grateful if you could respond directly to the parents with a copy letter to myself for information.'

47. Mrs C explained to my Investigator that she understood that GP 2 wrote to the Trust on a second occasion but there was no copy of a

second letter in GP 2's records. The Trust has no record of receiving either the above letter or the possible second letter.

48. On advice from GP 2, Mrs C telephoned the Trust on 12 July 2001 to pursue her enquiry. The Trust's note of this enquiry records that she wanted to know whether a post mortem was carried out and whether any 'organs' were 'retained'.

49. On 17 July 2001 the Trust wrote to Mrs C in response to her enquiry as follows:

'... Recent media coverage has raised concern for many parents and I appreciate that this must be a difficult and painful time for you.

[Consultant 4], [a] Consultant Paediatric Pathologist, has reviewed [Stewart]'s post mortem report. For the purpose of detailed examination, it was necessary for the brain to be fixed in formaldehyde. The record shows that this procedure was followed so that the pathologist could investigate [Stewart]'s brain abnormality. After completion of the examination, remaining brain tissue was respectfully and separately disposed of. I can confirm that there is no suggestion that any organs were retained following completion of the post mortem examination.

I am sorry for the distress this matter has caused you ...'

50. Mrs C telephoned the Trust in response and explained that consent for the post mortem had been withheld.

51. After Mrs C made enquiries with her local Registrar of Births, Deaths and Marriages, the Registrar contacted the Trust to enquire whether consent was given for the post mortem and to ask for a copy of the post mortem report. The Trust's record of the Registrar's enquiry is undated but it seems to have been copied within the Trust on 23 July 2001. This enquiry appears to have been the source of some confusion as, among other things, Stewart's name was recorded in a manner that gave his middle name as his surname. It is not clear what caused this confusion.

52. Inevitably there were difficulties tracing the post mortem details using the wrong surname. When they were traced the Pathology Department identified that the wrong surname had been used but then mis-spelled Stewart's surname by transcribing an 'O' as a 'D'. This mis-spelling substantially changed the pronunciation of Stewart's surname. Consultant 4 showed my Investigator the Pathology Department's handwritten notebooks from the period which had been used to trace Stewart's post mortem details. The handwriting in these was not clear and this could easily explain the mis-spelling of Stewart's surname.

53. In response to Mrs C's and the Registrar's further enquiries, the Trust wrote to Mrs C on 3 August 2001 as follows:

'... There is a written record that [Consultant 2] spoke with your husband at the time of Stewart's death and that a post mortem examination was requested, however the signed consent form for a post mortem has not been filed in Stewart's medical record. ... I cannot explain why there is not a signed consent form in Stewart's medical notes, as this is normally where it would be filed.

I also see from the medical notes that you met with [Consultant 3] at the Simpson Memorial Maternity Hospital on the 19<sup>th</sup> March 1980. I regret if it was not made clear at that time that the examination Stewart underwent as part of his post mortem enabled [Consultant 3] to discuss future management should you decide to have another baby.

On behalf of the Trust I apologise most sincerely for the distress that this has caused to you.'

54. The Trust also invited Mrs C to contact a Patient Liaison Officer should she wish to discuss this matter further. Mrs C did so and a meeting was agreed. This took place on 5 September 2001 and involved Mrs C, her daughter, the Divisional General Manager (Officer 1) and a Patient Liaison Officer at RHSC (Officer 2).

55. Among other things, the note of this meeting indicates that Officer 1 accepted that GP 2 may have made an enquiry but there was no record of

this and he sought to reassure Mrs C that the Trust had not been avoiding the issue. Mrs C explained that consent for the post mortem was requested first by hospital staff and then by GP 1 but this was refused. The note of the meeting also records that Officer 1 explained that, at the time of Stewart's death, post mortem consent forms were filed with the pathology notes. He explained that it is recommended that pathology notes be kept for 10 years and it was likely that the written consent for the post mortem on Stewart was among the records destroyed in the early 1990's. He also acknowledged that on the information available the Trust could not tell Mrs C who gave permission for the post mortem to be performed and apologised that the Trust was unable to provide her with all the information she sought. Officer 1 is noted as agreeing with Mrs C that her family had been let down very badly.

56. At the end of this meeting Mrs C accepted an offer to arrange a further meeting. This second meeting was held on 13 September 2001 and was between Mr and Mrs C, a representative from their local Health Council, Consultant 4 and Officer 2.

57. The note of this meeting indicates that Consultant 4 explained the process of fixing and examining a person's brain and that 'any remaining brain tissue, other than tiny samples which may be held as part of the record, is subsequently disposed of in keeping with national guidelines'. Consultant 4 explained that at the time it was normal practice for a copy of the post mortem consent form to be sent to the Pathology Department and a copy to be retained in the medical records. Consultant 4 also explained that it was apparent from the post mortem findings that Stewart's condition was hereditary and that she would have expected Mr and Mrs C to have received feedback on the post mortem results from either Mrs C's obstetrician, the paediatrician or her GP. Mr and Mrs C are noted as being clear that they were not told about Stewart's post mortem findings nor were they told that doctors knew the condition was hereditary. They maintained it was after the birth of their nephew that the whole family were told this. It was noted that Consultant 4 and Officer 2 were not able to explain why genetic information obtained from the detailed examination of Stewart's brain was not followed up at the time. The note of the meeting records that Mr and Mrs C found the meeting helpful.

58. Consultant 4 wrote to Officer 1 on 19 September 2001 summarising her impression of her meeting with Mr and Mrs C. She also explained that she had been incorrect when she told him that the post mortem request and consent forms for the whole of 1980 had been destroyed, as they were in fact missing.

59. Following the second meeting, Mrs C wrote on 21 September 2001 asking:

‘Could you please tell us if any brain tissue is still remaining for further teaching purposes, or slides of brain, or any information that you may have? ...’

60. It is not clear where this letter was initially addressed but it appears to have been directed to the Department of Neuropathology at WGH and to have been present in the Department by at least 27 September 2001.

61. On 28 September 2001 Officer 2 wrote to Mrs C acknowledging, among other things, her enquiry to the Department of Neuropathology and explaining that the Honorary Consultant of Clinical Neuropathology (Consultant 5), would reply to her directly. She also explained that it was the Trust’s policy for all enquiries to be directed to the Patient Liaison Office at RHSC to ensure enquiries were managed to their expected standard.

62. Consultant 5 responded to Mrs C’s enquiry on 8 October as follows:

‘... I can confirm that [Stewart’s] brain was examined in the Neuropathology Laboratory at the Western General Hospital by my predecessor [Consultant 6] who was a consultant neuropathologist. A report was issued on the 12<sup>th</sup> June 1980 in which a diagnosis of aqueduct stenosis was made ... A copy of the report was sent to [Consultant 7] who performed the autopsy. ....’

I can also confirm that we have two paraffin-embedded blocks of tissue which were taken from the brain at the time of the initial examination, in order to prepare microscopic slides which were



examined and formed the basis of the neuropathological report. The other brain tissue was disposed of on the 22<sup>nd</sup> September 1980. I was contacted by [Senior Lecturer 1] in the Human Genetics Unit at the Western General Hospital in September 1992 concerning the remaining brain tissue in our Department. ... I provided this material to [Senior Lecturer 1] who completed his examination and returned the material to our Department. It is clear that this residual material has been helpful for further genetic examination and I hope the information arising from this examination has been helpful to your family.'

63. Prior to being sent, this letter had been reviewed and approved by Consultant 4 and Officer 2.

64. Mrs C wrote to Officer 2 on 5 December 2001 making a formal complaint as follows:

'It is of utmost concern that this post mortem went ahead without any authorisation from either my husband or myself. My husband was asked on 7 February 1980 whether he would be willing to authorise a post mortem, however, he refused since, at that time, he considered there to be no benefit gained from this exercise.

It is also of concern that there is no documented evidence of any authorisation despite there being firm information that a post mortem was conducted. ...

At a recent meeting with ... [Consultant 4], it was confirmed that it was unusual for parents not to receive feedback from the post mortem examination. As you know this would either be given by the obstetrician, paediatrician or the family GP. It is concerning, however, that this information was not relayed to myself and family.

As a result, [neither] I nor any member of my family were offered genetic counselling following Stewart's death and hence the sex-linked genetic factor was only confirmed twelve years later when

my family attended the genetic clinic at the [WGH] after my sister had given birth to a baby boy with a congenital abnormality. ...'

65. Officer 2 acknowledged Mrs C's letter on 12 December 2001 and Officer 1 responded on 27 December 2001 as follows:

'I fully appreciate your concerns, and the anxiety that these are causing you. As we discussed when we met, post mortems are performed only once the Pathologist is in possession of a signed consent form. This form should have been filed within Stewart's pathology record, and a copy within the medical notes. As you know, Stewart's pathology record was culled after about 10 years, and the Trust is therefore unable to confirm whether or not a consent form was completed. I share your concern that this post mortem went ahead without your knowledge, and I apologise unreservedly for the distress that this has caused you.

You met with [Consultant 3] a few weeks after Stewart's death, in March 1980. At that time he discussed X-linked congenital aqueductal stenosis with you, which seemed to be the most likely cause of Stewart's hydrocephaly, because your two previous baby boys had both had hydrocephalus. He understood that you were undecided about having another baby at that time, and he raised the probability that a female baby would not be affected, but might be a carrier. In his letter to [GP 1], he states that he explained to you that if you did have another pregnancy, he would be willing to do an amniocentesis to check the sex of your baby so that you could decide whether or not to continue with the pregnancy in light of that knowledge. I fully appreciate that this must have been a most distressing time for you and your husband. I hope that the support from [Consultant 3] and [GP 1] you both received, as documented in your medical records, was of some comfort.

I note that you and your husband met with [Consultant 1], Consultant in Medical Genetics in 1974, and at that time he explained that he had not been able to determine the specific X-linked factor in your case. However he anticipated that over the next few years investigative procedures would have developed

which might be able to determine the genetic condition affecting your babies. I am unable to explain why you were not offered a follow-up appointment with the genetic clinic, and you may wish to discuss this with [GP 1].'

66. Consultant 4 reviewed a draft of this letter before it was sent.

67. Mrs C subsequently sought the advice of her MSP who wrote to the Trust on 25 March 2002. The Trust's response was delayed while consent was sought from Mrs C for them to respond.

68. In the interim Mrs C telephoned Officer 2 on 1 April 2002 to request that tissue from Stewart be returned for burial and that she be given written confirmation that the Trust held no other material from Stewart. The note of this conversation indicates that Mrs C had already instructed a Funeral Director.

69. On 9 May 2002 the Funeral Director collected a total of 13 paraffin blocks and 17 slides from the Trust.

70. Consultant 4 wrote to Mrs C on 13 May 2002, in line with her request for confirmation that the Trust held no other material from Stewart, stating:

'I confirm that on the 9<sup>th</sup> May 2002, 13 paraffin blocks and 17 histological sections from Stewart's organs, including the brain, were handed over to the undertaker nominated at the Western General Hospital.

This material comprised the whole of the material from your son which was held in the Pathology Departments within the Trust.'

71. In response Mrs C wrote to Consultant 4 asking:

'Could you please explain in more detail 13 paraffin blocks 17 histological sections from Stewart's organs including the brain, does this letter suggest there were more organs than his brain'.

72. Mrs C's letter is undated but Consultant 4 responded on 16 May 2002 explaining:

'Two blocks and seven slides were brain material, there were additionally 11 paraffin blocks and 10 slides of other tissue. These were small samples taken at the time of the post mortem examination. Reading the report, I see no evidence that any other organs were retained.'

73. The Trust responded to Mrs C's MSP on 21 May 2002 reaffirming the position as outlined in previous correspondence with Mrs C. The Trust reiterated that it deeply regretted the distress and anxiety this matter caused Mrs C and her family but also explained that they did not accept that the post mortem examination was carried out without consent.

74. A meeting was held on 12 June 2002 between Mr and Mrs C, their MSP, Consultant 4, the new acting Divisional General Manager and Officer 2. The note of this meeting indicates that, among other things, Consultant 4 explained that she did not believe that the pathologist in post at the time of Stewart's death would have carried out a post mortem without consent. She also explained that it was usual practice for the original consent form to be sent to the Pathology Department and a copy placed in the medical records, although she was not sure whether this was the case for each post mortem. Mrs C explained her husband had gone to the hospital and signed to release Stewart's body but Mr C contradicted her as he did not recall signing anything. He was also clear that he specifically refused the request for a post mortem. Mrs C indicated she believed that medical staff went ahead with the post mortem despite consent being refused to further their knowledge of Stewart's rare condition. It was acknowledged by the Trust staff at the meeting that the information available as to whether consent was obtained is inconclusive and that this was regrettable. Officer 2 is noted as having reiterated the Trust's commitment to working with Mr and Mrs C towards a satisfactory conclusion and Mr and Mrs C's MSP suggested that efforts be made to identify the doctor who made the entry in Stewart's records. Officer 2 also explained the NHS Complaints Procedure and acknowledged that Mr and Mrs C should have been informed of their

right to request an Independent Review of their complaint if they remained unhappy. Officer 2 apologised that the Trust had not done so.

75. Following this meeting, Mr and Mrs C's MSP wrote on their behalf on 13 June 2002 to request that their complaint be taken to the next stage of the complaints procedure. On 16 July the Complaints Convener wrote to Mrs C explaining that he had decided that further action should not be taken on her complaint.

76. In response to the commitment given during the meeting on 12 June 2002, Officer 2 wrote to Mr and Mrs C on 17 July 2002 explaining she had contacted the Medical Staffing Department and the Trust's Human Resources Department but it was not possible to identify the member of staff who made the entry in Stewart's notes from their records as they were only held by the Trust for seven years.

77. Following the Complaints Convener's decision, Mrs C wrote to the Health Service Commissioner for Scotland in August 2002. Under the provisions of the Scottish Public Services Ombudsman Act of 2002 the functions of the Health Service Commissioner for Scotland were transferred to me on 23 October 2002. My Investigator made initial enquiries and met with Mr and Mrs C and their daughter.

78. I decided to formally investigate Mrs C's complaint on 3 December 2002 because there were a number of questions about the adequacy of the Trust's responses to Mrs C's complaint. On 23 December 2002 the Trust responded to the notification of that decision stating:

'... On behalf of the Trust, [Officer 1] apologised to Mrs [C] that the documents giving permission for the post mortem of her son are no longer traceable. It is implied within Stewart's notes that a request was made and consent given for a post mortem examination. At the time of these events, written consent would have been filed with pathology notes: it is recommended that these are retained for ten years. These papers are likely to have been destroyed in the early 1990s. [Officer 1] assured Mrs [C] that in the light of present experience, corrective action has been taken by the Trust to ensure that such a situation would not arise in the future.

The Trust responded to Mrs [C]'s need for genetic advice and counselling when Mrs [C]'s nephew was born, suffering from hydrocephalus. ...

There is no record within the Royal Hospital for Sick Children of the request for information made by Mrs [C]'s GP re whether a post mortem had taken place and/or organs retained. The Trust acknowledged that Mrs [C] has experienced considerable distress in relation to this difficult situation, and apologised unreservedly for this but reassured her that there is now a system in place to manage all enquiries, both written and those made by telephone. ...

The Trust has endeavoured to respond to the queries made by Mr and Mrs [C], as documented in the enclosed papers. Considerable effort has been made to trace staff and documents in relation to this case. Where the Trust has not been able to provide clear evidence, this has been acknowledged and the Trust has apologised for any historic faults within the organisation.'

79. After I had decided to investigate Mrs C's complaint a representative of an advocacy group (Mrs A), acting on behalf of Mrs C, initiated two additional meetings with staff from the Trust. A different Patient Liaison Officer at RHSC (Officer 3) attended these meetings. Officer 3 explained to my Investigator that the first meeting had been to allow Mrs C to see the Mortuary Day Book so no note of the meeting was made. Mrs C did raise additional questions and Officer 3 agreed to make further enquiries.

80. The second additional meeting was on 17 January 2003 and was between Mrs C, Mrs A, Consultant 5 and Officer 3.

81. The note of this meeting indicates that Mrs C explained she was seeking reassurance that all tissue retained from Stewart had been returned to the family. Consultant 5 explained that the two blocks of brain tissue which had been retained by the Department of Neuropathology were accounted for and how they had been used. Mrs C said that she believed the failure to explain the genetic nature of the disorder led to her extended family not being told of the risk of having

similarly affected children. Consultant 5 is noted as explaining that while diagnostic DNA testing was not available at the time of Stewart's death, he agreed that a genetic risk could have been presumed given their history and appropriate counselling given. Officer 3 responded to Mrs C's additional questions during this meeting but had not been able to identify any further information although Officer 3 did explain that one of the mortuary technicians had confirmed that in 1980 the consent form would have been filed in the pathology records and a note made in the patient's medical records. She agreed to try to arrange a further meeting to establish whether Consultant 4 had any documentation which would identify the type of tissue on the slides returned to Mrs C.

82. Consultant 4 wrote to Officer 3 on 20 January 2003 and explained that she had no information on the identity of the type of tissue on the slides. Consultant 4 explained this information had not been recorded in the post mortem report and she had not reviewed the slides herself as (a) when she first met with Mr and Mrs C they had made it clear that they did not want to know anything about the findings of the post mortem examination and (b) she had not been instructed to examine the slides before returning them to Mrs C.

83. Officer 3 explained to my Investigator that Consultant 4 had not felt a further meeting with Mr and Mrs C would be helpful as she could not provide any additional information. Officer 3 recalled writing to Mrs A explaining this and offering to pass on such information as she had gathered from Consultant 4. She suspected she did so by making a note on a compliments slip as she did not have a copy of her letter. Officer 3 had no further contact from Mrs C or Mrs A and so took no further action.

## **ANALYSIS OF COMPLAINT AND FINDINGS**

**Complaint heading (a): that the Trust did not adequately investigate and reply to Mrs C's complaint that a post mortem had been performed on Stewart against his parents' wishes**

84. I acknowledge at the outset that the Trust accepted the consent form should have been available and, in its absence, accepted that it could not be established whether or not consent had been granted for the post mortem on Stewart's body. The Trust also fully acknowledged that this uncertainty was extremely unfortunate and has repeatedly apologised

in its correspondence with Mrs C, and during meetings with her and her family, for the distress they have experienced. Additionally, senior members of Trust staff have met Mrs C on a total of five occasions in response to her concerns. Furthermore, during the course of this investigation, Trust staff reiterated their apologies for the distress Mrs C and her family had experienced and a further offer to meet with her was extended if she would find that helpful.

85. I consider all of these actions to be indicators of a genuine endeavour by the Trust to respond sympathetically to Mrs C's complaint. However, as I noted in paragraph 78, I decided to investigate this aspect of Mrs C's concerns because it seemed to me that there were several unanswered questions about the adequacy of the Trust's investigation and responses. I now address each of these.

*Was there an effective attempt to seek Consultant 2's comments on the complaint?*

86. The mis-spelling of Stewart's surname during the Trust's initial internal enquiries brings the effectiveness of the enquiries into question. In particular, the only enquiry made to Consultant 2 was in the form of an e-mail to his secretary on 27 July 2001 from one of the staff in the Patient Liaison Office at the RHSC. This e-mail used the mis-spelt surname and did not outline the history of hydrocephalus in Mrs C's immediate and extended families. Consultant 2's secretary discussed the e-mail with him but he did not recall Stewart. It should be noted that Stewart's surname was spelled in a variety of ways in his medical records and so it is not clear with which spelling Consultant 2 might have been familiar. Furthermore, the e-mail to Consultant 2 was sent shortly after Mrs C's initial enquiry and at this stage it appears the Patient Liaison Office had not been made aware of Mrs C's family history of hydrocephalus. However, no further enquiry was made of Consultant 2 after the mis-spelling and Mrs C's unusual history became clear to the Patient Liaison Office.

87. I should record that when Consultant 2 was interviewed as part of my investigation and after having had access to all the available information, he remained unable to recall Stewart.



88. Consultant 2 explained that, at the time of Stewart's death, it would commonly have been the doctor who led the patient's care who would request consent for any post mortem as they were likely to have had the most direct relationship with the family. From the records, Consultant 2 identified that a Senior Registrar (now a Consultant - Consultant 9) appeared to have led Stewart's care.

89. My Investigator interviewed Consultant 9. While he did recall Stewart, he had no recollection at all of the circumstances around the request for consent for the post mortem. He explained that, at the time of Stewart's death, it would normally have been the Registrar, Senior Registrar or Consultant who would ask a family for consent for a post mortem, although the timing of such a request would be sensitive to the family's circumstances and so, on occasions, someone else might ask the family for consent.

90. The wording of the entry dated 7 February 1980 in Stewart's records implies that it was not written by Consultant 2 (see paragraph 37). Consultant 9 confirmed he had not made this entry in Stewart's records and he noted that the Registrar had certified Stewart's death at 10.30pm on 6 February 1980 and the handwriting was different (see Figure 1 on page 11). Accordingly, it seems this entry was not written by any of the staff who either Consultant 2 or Consultant 9 felt would have been likely to have requested consent for the post mortem. Consultant 9 commented that this entry may have been written by a more junior doctor from the Ward or by a doctor from another Ward, but he was unable to identify who this person was.

91. Consultant 2 was the only person identified in the records as having spoken to Mr C at the time of the request for consent for the post mortem on Stewart. He was therefore the person most likely to be able to clarify whether consent had been granted and by whom. For this reason it was particularly important that his comments were effectively sought and I consider the shortcomings in the approach to him were unsatisfactory.

*Did the Trust sufficiently investigate the possibility that consent for the post mortem might have been requested by Mr and Mrs C's GP as well as staff at RHSC?*

92. Mr and Mrs C explained to Officer 1 and Officer 2 on 5 September 2001 that they recalled consent for the post mortem was requested not only by hospital staff, but also by GP 1, but they refused consent on both occasions. If GP 1 had requested consent for the post mortem it was possible that either he, or his records, might have been able to explain why he did so. Such an explanation might have shed some light on what happened when Mr C was asked for consent by staff at RHSC.

93. Officer 2 explained to my Investigator that after Mrs C mentioned that GP 1 had sought consent for the post mortem on Stewart's body, she asked Mrs C whether her GP had a record of this, but Mrs C told her there was no such record (my Investigator has confirmed that that is the case). Officer 2 also commented that it would have been extremely unusual for a GP to seek consent for a post mortem in such circumstances and that the reason for GP 1's visit might have been to provide Mrs C with support following Stewart's death. I am satisfied that the Trust adequately investigated this matter.

*Was sufficient account taken of the possibility that the results of the post mortem were not explained to Mr and Mrs C contrary to normal practice?*

94. Mr and Mrs C maintain that they were not told of the outcome of the post mortem examination on Stewart. Consultant 4 commented during the meeting on 13 September 2001 that this was unusual and she explained at a later meeting that she would have expected a copy or summary of the post mortem report to be sent to the GP.

95. There is no record that the outcome of the post mortem examination on Stewart's body was explained to Mr and Mrs C by anybody. However, Mrs C's GP medical records contain a copy of the report from the post mortem examination at RHSC on 8 February 1980. This copy is date stamped as having been received by the GP surgery on 13 March 1980. It is also clear from the records that Consultant 3 did explain to Mrs C on 19 March 1980 that it was very likely that Stewart's hydrocephalus was of the x-linked recessive type and did explain the implications of this diagnosis for any future pregnancies she might have

(see paragraph 41). Consultant 3's comments could not have been based upon the full results of the post mortem as the neuropathological examination of Stewart's brain was only reported on 12 June 1980. However, when this was reported it confirmed the diagnosis Consultant 3 had previously explained to Mrs C.

96. Mrs C believed that the apparent failure to explain the outcome of the post mortem on Stewart was because medical staff had proceeded with the post mortem, despite her husband's refusal to grant consent, to further their knowledge of Stewart's rare condition. She suspected that in those circumstances staff could not explain the outcome of the post mortem as this would have involved letting her and her husband know that one had been carried out.

97. In the absence of records to the contrary, Mrs C's concerns cannot be dismissed. However, I am mindful that the Review Group did not come across any evidence that post mortems were performed without some form of consent having been obtained (see paragraph 23) and I accept the point made by a number of Trust staff that they found it hard to believe that a post mortem would have been performed contrary to the relatives' wishes because doing so might be illegal. Furthermore, the fact that GP 1 was sent a copy of the post mortem report was in line with what Consultant 4 explained would have been normal practice and is, in my opinion, inconsistent with there having been an attempt to conceal the fact that a post mortem had taken place. I see no grounds for criticising the approach the Trust took in relation to this aspect of Mrs C's concerns.

*Was information about the extent and range of tissue retained from Stewart's body only given to Mr and Mrs C in a piecemeal fashion?*

98. The Trust initially explained in their letter of 17 July 2001 that it was necessary for Stewart's brain to be fixed in formaldehyde but after completion of the examination the 'remaining brain tissue' was respectfully and separately disposed of. The Trust confirmed that 'there is no suggestion that any organs were retained following completion of the post mortem examination'. The fact that the Trust continued to retain tissue from Stewart's body was not mentioned.

99. The first mention of tissue retention seems to have been during the meeting on 13 September 2001. Consultant 4 is noted as having explained to Mrs C that tissue samples may be held as part of the record. Consultant 4 explained to my Investigator that she had not personally checked that samples had been retained but she was confident they would have been and she emphasised to Mrs C that this was standard post mortem practice. This is consistent with Officer 2's recollection that Consultant 4's comments were a general description of what happened at a post mortem rather than a specific explanation that the Trust retained such tissue samples from Stewart's body. Furthermore, the note of this meeting indicates that Consultant 4 referred to brain tissue samples and not to tissue being retained from a range of organs. Mr and Mrs C confirmed to my Investigator that they had only been made aware that brain tissue samples would have been retained and this is consistent with Mrs C's subsequent enquiry about the retention of brain tissue.

100. Mrs C's enquiry about brain tissue (see paragraph 59) seems to have been directed to the Department of Neuropathology at WGH. Consultant 5 replied confirming that the Department had two paraffin-embedded blocks of tissue taken from Stewart's brain and that the other brain tissue was disposed of on 22 September 1980. This was an accurate statement of the tissue held by the WGH. However, despite a draft of Consultant 5's letter having been reviewed and approved by Consultant 4 and Officer 2 (see paragraph 63) both of whom were based at RHSC, no mention was made of tissue from Stewart's other organs which continued to be held by the RHSC.

101. On 1 April 2002 Mrs C requested that tissue from Stewart be returned for burial. Mr and Mrs C maintain that they had only been aware of the two paraffin blocks of brain tissue mentioned by Consultant 5, but in the event a total of 13 paraffin blocks and 17 histological sections were returned to them. Mr and Mrs C told my Investigator that the Funeral Director had been the first person to tell them about the full extent of the tissue the Trust had been holding.

102. Consultant 4 told my Investigator that, prior to returning them, she offered to review the slides and blocks containing tissue retained from Stewart's body to establish precisely from which organs the tissue had

been taken. This implies that tissue had been taken from a range of organs. Consultant 4 was not sure when she made this offer and it is not noted in the record of the meeting on 13 September 2001 or indeed anywhere else. Given this apparent offer it is possible that Mr and Mrs C may have been given an indication that the Trust held tissue from a range of Stewart's organs prior to them being told this by their Funeral Director.

103. A number of Trust staff commented to my Investigator that the information given to Mrs C and her family accurately answered her specific enquiries. The Pathology Service Operations Manager (Officer 4) commented that the Pathology Service aimed to respond only to the enquiry received and this was based on guidance from the Government and was in response to concerns that it would be inappropriate to provide information to people making enquiries which they had not requested as this might add to their distress. More generally, a number of Trust staff noted that it was important to be sensitive when responding to enquiries as providing more information than was requested could be very upsetting for the person making the enquiry. It was also pointed out that Mrs C had asked not to be told what happened during the post mortem examination on her son's body.

104. Additionally, in one interview with my Investigator reference was made to 'Government' guidance as supporting the view that responses should only address the enquiry received because it would be inappropriate to provide information to people making enquiries which they had not requested as this might add to their distress. It is also the case that Mrs C acknowledges that in the course of her enquiries she asked not to be told about what happened during the post mortem examination of Stewart's body, although her request to this effect was not recorded anywhere.

105. I accept that if Mrs C's enquiries are interpreted narrowly then the Trust's various responses were generally accurate. For example, the Trust seems to have understood that Mrs C had initially asked if organs had been retained (see paragraph 48) and it was true, from a clinical perspective, to say that organs had not been retained. Likewise, Mrs C's enquiry on 21 September 2001 asked about retained brain tissue (see paragraph 59) and the response accurately informed her of the extent of

brain tissue retained. However, while the Trust's responses may have been strictly accurate, I consider the more pertinent question is whether they were sufficient.

106. I also acknowledge that the guidance issued to Trusts by SEHD and the interim report of the Review Group both make it clear that it would be inappropriate to pro-actively provide information to relatives or next of kin about organ retention if they had not made an enquiry. However, in my opinion this refers to situations where no enquiry had been made, not to situations such as this where an enquiry had been made but the enquiry did not specifically ask about all relevant issues.

107. I accept that if a person making an enquiry says that they do not wish to be told certain information, then their wishes should, as far as possible, be respected. However, this can be problematic. It could make it difficult to answer their enquiry meaningfully and the person may go on to make further enquiries which are inconsistent with their request not to be told certain information. I consider good practice would be to explore with the person making the enquiry the sorts of difficulties which could arise and to record any agreement reached about the extent and type of information requested and any subsequent changes to it. Again, I accept such a situation will require great sensitivity.

108. In this case, in my opinion, the Trust should have explained to Mrs C at the outset that they continued to hold tissue from Stewart's body rather than simply referring to retained organs. The Guidance issued by SEHD is ambiguous on this point, but such an explanation would have been more consistent with the Trust's policy that responses to enquiries should be 'as open as possible' and at this stage Mrs C had not given any indication that she did not wish to be told certain kinds of information. Mrs C did subsequently make such a request, but she also went on to make specific enquiries about whether any tissue from Stewart's brain was retained by the Trust. This made it clear that she wished to know about retained tissue, rather than simply retained organs. I consider the Trust ought to have either taken this opportunity to explain the full extent of their holding of tissue from Stewart's body or, if they were confused about what information Mrs C wished to be told, they should have clarified this with her. The Trust did neither.

109. I note that Officer 2 felt that it was 'unusual' that the information provided to Mrs C appeared to evolve as she pursued her complaint. It could well be that the way the Trust responded to Mrs C's enquiries was not typical of the way they responded to other similar enquiries. However, it is my view that in this instance, for what ever reason, the Trust failed to provide Mrs C with the information about the extent and range of tissue retained from Stewart's body in the open fashion to which it aspired and which Mrs C was reasonably entitled to expect.

*Was there ambiguity in some of the Trust's responses?*

110. The Trust's initial response to Mrs C's enquiry stated that Stewart's brain had been fixed in formaldehyde, but it did not make clear that his brain had to be removed from his body in order to so<sup>4</sup>. The same letter states that 'remaining brain tissue' was separately disposed of, but does not make clear that this would have actually been virtually his entire brain. I do not consider Mrs C could have reasonably been expected to appreciate these points without them being explained to her.

111. The Trust's initial response to Mrs C also stated that 'there is no suggestion that any organs were retained following completion of the post mortem examination' when Stewart's brain had in fact been removed and retained.

112. In my opinion the Trust's responses to Mrs C were ambiguous in important respects. For example, the Trust's letter of 17 July 2001 (see paragraph 49):

- a) Failed to make clear that Stewart's brain had been removed from his body in order to be fixed;
- b) Referred to 'remaining brain tissue' having been respectfully disposed of but this obscured the fact that (i) the 'tissue' in question was virtually Stewart's entire brain and (ii) a small quantity of brain tissue had in fact been retained; and

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<sup>4</sup> My investigation has not been into how the post mortem examination of Stewart's body was carried out. However, my Advisers inform me the practices followed – the removal of the whole brain for fixation and examination; the taking of tissue samples from a range of organs; the subsequent disposal of the remainder of the brain; and the retention on a long term basis of the tissue samples taken - are an essential part of the work of Pathology Departments and were considered to be good practice by the standards of 1980 and they remain good practice today. My Advisers are satisfied that, leaving aside the issue of consent and the brevity of the post mortem report, there is no evidence that the post mortem examination on Stewart's body was carried out in any way that was not in accordance with standard clinical practice. I consider it appropriate to note that I accept this advice.

- c) Stated that there was 'no suggestion that any organs were retained following completion of the post mortem examination' when Stewart's brain had been removed and retained. I acknowledge that from a clinical point of view the neurological examination of Stewart's brain can be considered to be the final stage of the post mortem examination which had otherwise taken place 4 months earlier. Accordingly, from this point of view it is accurate to state that no organs were retained following completion of the post mortem examination. However, I do not consider Mrs C could have reasonably been expected to appreciate this distinction.

113. I note that if the Trust had used the explanation in the pro-forma letter issued by SEHD (see paragraph 16) much of this ambiguity would have been avoided.

114. Additionally, in my opinion Consultant 4's confirmation that '13 paraffin blocks and 17 histological sections from Stewart's organs, including the brain, were handed over to the undertaker' (see paragraph 70) implied, but did not clearly state, that tissue had been retained from Stewart's other organs. As a result, it was necessary for Mrs C to seek further clarification.

115. I acknowledge that the wording of the Trust's responses to Mrs C's enquiries may have been an attempt to provide information sensitively. However, in my opinion the continued use of vague terms and explanations which were not clear to Mrs C was not helpful.

*Was sufficient attention paid to an apparent discrepancy between the number of blocks retained and the number of blocks returned?*

116. The day after her meeting with Officer 3 on 17 January 2003 Mrs C forwarded a photocopy of the Mortuary Day Book to my office and indicated that she had asked during the meeting where the apparently unaccounted for blocks<sup>5</sup> were but had been told by the 'RHSC and

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<sup>5</sup> The entry in the Mortuary Day Book shows that 16 blocks of tissue were taken from Stewart's body during the post mortem at RHSC. Only 11 paraffin blocks were returned to Mrs C by the RHSC. Accordingly, there is an apparent discrepancy with five blocks seemingly unaccounted for. There is no such discrepancy in the number of blocks of tissue taken and returned by the Department of Neuropathology at WGH as their records show that two tissue blocks were taken from Stewart's brain and two paraffin blocks were returned to Mrs C by the WGH.



Western General' that they did not know. However, when interviewed by my Investigator, Officer 3 said she had not been aware of this apparent discrepancy and that this issue was not raised during her contacts with Mrs C. The differing recollections which Officer 3 and Mrs C have of the meeting on 17 January 2003 are not clarified by the note of the meeting. In the circumstances, I cannot establish with certainty whether the issue of the apparent discrepancy was raised then. However, I have considered whether, even if the issue was not raised then, the Trust should have been aware of the apparent discrepancy and sought to address it.

117. Consultant 4 explained to my Investigator that when the Department of Pathology at RHSC was asked to return blocks and slides to relatives, the technicians would cross-reference the total number of blocks retained in the Department's store with the Mortuary Day Book records. If the number of tissue blocks did not match, efforts would be made to establish the reason(s) for this as blocks could be misfiled or lost and on occasions more than one tissue sample would be embedded within a single paraffin block. While it was normal procedure to try to locate missing blocks, Consultant 4 could not state with certainty that this happened in Mrs C's case. She did recall offering to review the tissue in the paraffin blocks held by RHSC prior to returning them to Mrs C in order to establish which of Stewart's organs they had been taken from, but Mrs C had indicated that she did not wish to be told this information and so Consultant 4 did not do so. Consultant 4 was not sure when this conversation took place.

118. Officer 4 also explained to my Investigator that it was common practice for mortuary technicians to embed more than one block of tissue in a single paraffin block and this could explain the apparent discrepancy in this case. Officer 4 confirmed that he would expect the mortuary technician to check the Mortuary Day Book to establish the number of blocks of tissue taken, and then to check that the same number of blocks of tissue were embedded within the paraffin blocks held. If there was a discrepancy, he would expect the mortuary technician to notify him and to try to establish the reason(s) for this discrepancy.

119. A similar explanation was provided by a Senior Biomedical Scientist (Officer 5) at the RHSC (Biomedical Scientist being the more appropriate title for staff commonly referred to as mortuary technicians). Officer 5 explained to my Investigator that normally more than one block of tissue would be embedded within a single paraffin block. When collating tissue to return to families it was his practice to visually check that the number of tissue blocks contained within the paraffin blocks matched the number of tissue blocks noted in the Mortuary Day Book as having been taken at the post mortem. He would list the number and type of tissue blocks embedded within the paraffin blocks and give this to Consultant 4.

120. Officer 5 confirmed he had collated the blocks and slides held by RHSC containing tissue from Stewart's body. However, he recalled being told by Consultant 4 that in this instance he should not check the blocks and slides to identify the type and number of tissue blocks. This was the only occasion he had been asked not to do this and he understood that the reason for this was that the family did not want this information to be gathered or provided to them.

121. Officer 5 accepted that, because the blocks had not been checked, it was not possible to confirm that the 11 paraffin blocks returned to Mrs C contained all of the 16 tissue blocks taken at the post mortem at the RHSC. Having said this, Officer 5 reiterated that it was common practice to embed more than one tissue block within a paraffin block and he explained that while paraffin blocks could be misfiled or mislaid, there were relatively few opportunities for this to happen as, once slides had been made, the paraffin blocks were stored in cardboard boxes, and in all likelihood, these would not be touched again. Furthermore, he stressed that there was always an attempt to ensure that all tissue blocks were identified and returned to families.

122. I accept that Consultant 4 understood that Mrs C did not wish to know details of the tissue contained in the blocks (although it is not clear how she came to this understanding as it appears Mrs C was only aware of the blocks containing tissue from Stewart's brain) and so she did not review the blocks herself and she also seems to have asked Officer 5 not to do so. I also accept that, given Consultant 4's understanding of Mrs C's wishes, it would not have been appropriate to tell Mrs C details of the

tissue contained in the paraffin blocks. However, I do not accept that this meant it was inappropriate to check the paraffin blocks prior to returning them to Mrs C to establish and record whether all the blocks of tissue retained during the post mortem were contained within them. Doing so was the only way the Trust could establish a complete audit trail and Officer 5 explained it could be done by simple visual inspection. In my opinion, the Trust should have done so for its own records and audit trail purposes even if Mrs C had said she did not wish to be told this information.

123. In this instance, the Trust has been able to provide records from 1980 which show the number of blocks of tissue taken during the post mortem on Stewart's body at the RHSC and the subsequent neurological examination of his brain, and that the remainder of his brain was respectfully disposed of. Audit Scotland considered that, within the general context and bearing in mind that the post mortem in question took place in 1980, this represented a relatively high standard of record keeping. I agree. This high quality of record keeping back in the 1980s meant that if a record had been made of the number of blocks of tissue, rather than paraffin blocks, returned to Mrs C there would have been a complete audit trail of the tissue removed from Stewart's body. It is therefore particularly unfortunate that no such record was made.

124. However, from my Investigator's subsequent enquires, and in particular Consultant 4, Officer 4 and Officer 5's comments, both I and my Clinical Advisers are satisfied that the most likely explanation for the apparent discrepancy between the number of blocks of tissue taken during the post mortem at RHSC, and the number of paraffin blocks returned by RHSC, is that more than one block of tissue was embedded in some of the paraffin blocks returned to Mrs C. As a result, I consider it probable that all of the blocks of tissue taken from Stewart's body during both the post mortem examination at the RHSC and the neurological examination of his brain at WGH, have been returned to Mrs C and her family. I am also satisfied that there are no reasonable or practical steps that could now be taken to try to clarify this matter any further.

125. Finally, for the sake of completeness, I should note that as well as tissue from Stewart's body being retained in paraffin blocks, some tissue

was retained on slides held by both the Department of Neuropathology and RHSC. In 1980 neither kept records of the number of slides made from tissue retained at post mortem. Such records as there are suggest that a total of seven slides were made by the Department of Neuropathology (six slides from one of the blocks of brain tissue and only one slide was made from the other). This is the same as the number of slides returned by the Department of Neuropathology. I am satisfied that the Trust has endeavoured to return all the slides containing tissue from Stewart's body and there is no evidence to indicate that any slides have not been returned to his family.

*Why was a second pathologist who had been present at the post mortem not identified and asked to comment?*

126. Mrs C explained to my Investigator that she recalled being told by Consultant 4 that the pathologist who had performed the post mortem examination on Stewart's body had died. This is not recorded in the minutes of her meeting with Consultant 4 but I note that the Convener's rationale for not taking further action on Mrs C's complaint was because 'all that could be done has been done' in part because the pathologist concerned had died. However, the entry in the Mortuary Day Book shows two sets of initials indicating that two pathologists were present during the post mortem on Stewart's body.

127. There was no indication that the Trust had appreciated this fact. At the request of my Investigator, the Trust identified that the second pathologist was a Consultant (Consultant 10) who continues to work within the Trust.

128. When interviewed by my Investigator Consultant 10 had no recollection of the post mortem examination on Stewart nor did she have any recollection of who had authorised or given consent for it. Consultant 10 was a Senior Registrar in pathology at RHSC at the time. She suspected that her initials had been added to the Mortuary Day Book in this instance as part of her training record and she pointed out that it was clear that Consultant 7 had completed the post mortem report. The entry in the Mortuary Day Book had only been brought to Consultant 10's attention in June 2003. Prior to this, while she had been aware of Mrs C's

complaint, it had not occurred to her that she might have been involved in the post mortem examination.

129. Officer 3's note of her meeting with Mrs A and Mrs C on 17 January 2003 indicates that she was going to follow up 'why have 2 people been involved' in the post mortem, and that she would respond directly to Mrs A. Officer 3 told my Investigator that she was confident she did so, but she could not recall what action she took and she suspected her response to Mrs A had been on a compliments slip which she did not copy.

130. If Officer 3 did indeed follow up the point after the meeting on 17 January 2003 it seems that she did not contact Consultant 10. The failure to do so then or earlier raises further questions about the thoroughness of the Trust's internal enquiries into Mrs C's complaint.

*Were the explanations given that records had been destroyed, and that this was in line with policy, inaccurate?*

131. The Trust initially explained in their letter dated 3 August 2001 that the signed post mortem consent form would normally have been filed in Stewart's medical notes (see paragraph 53). In their subsequent explanations the Trust stated that the consent form should have been filed within the pathology records and a copy should have been placed in Stewart's medical records. However, Consultant 4 was uncertain whether it was the case that a copy was placed in the medical records for each post mortem (see paragraph 74) and one of the mortuary technicians explained to Officer 3 that while the consent form would have been filed in the pathology records, only a note would have been made in the patient's medical records (see paragraph 81).

132. The Trust also explained that the pathology records relating to Stewart were destroyed in line with Trust policy that such records are kept for only 10 years, and that it was likely the written consent for the post mortem on Stewart was among the records destroyed. There is no record of the Trust explaining what may have happened to the copy of the consent form which may have been filed in Stewart's records although Mrs C understood it would have been 'culled' to reduce the size of the file.

133. However, it was not the Trust's policy for the pathology records to be destroyed. Consultant 4 explained to my Investigator that post mortem request forms, which in 1980 contained the statement which relatives were asked to sign to consent for the post mortem examination (see Annex C), were an important adjunct to the actual post mortem report as they contained an outline of the patient's clinical history. As a result, they were kept permanently, although they were now scanned and stored on discs. This is consistent with the Trust's current Records Management Policy and Procedure which states that post mortem request forms should be scanned and stored permanently.

134. Additionally, the relevant pathology records have been mislaid rather than destroyed. Consultant 4 explained to my Investigator that when the archived post mortem request forms were being scanned, the records relating to 1980 could not be located. Consultant 4 confirmed that attempts had been made to locate these papers and the post mortem request forms had been moved on two occasions since, but the missing papers had still not been found.

135. I note that Consultant 4 seems to have originally informed Officer 1 that these records had been intentionally destroyed. It is not clear why she would have done so given the explanations she gave my Investigator. However, she wrote to Officer 1 on 19 September 2001 explaining that this was incorrect as the post mortem request forms for the whole of 1980 were in fact missing. Officer 1 did not recall Consultant 4's letter and he reiterated to my Investigator that he understood that these records had been destroyed as explained in his letter to Mrs C dated 27 December 2001 (see paragraph 65). I note that Consultant 4 approved a draft of this letter despite the fact that she had previously pointed out that the explanation that these records had been destroyed was incorrect.

136. I accept that Officer 1 was genuinely under the mistaken impression that these records had been destroyed and so this is what Mrs C was told. While this is clearly unfortunate, I recognise that such misunderstandings can occur at times. What I consider to be of greater concern is that Mrs C was repeatedly told that the destruction of such records would have been in line with Trust policy when it was not. It is not clear how this statement came to be included in the Trust's responses to Mrs C but it

raises concerns that, having identified that the consent form for Stewart's post mortem was no longer available, the Trust failed to consider in detail why this was the case. However, I accept that these records have been genuinely lost and that all reasonable and practical steps have been taken to try to locate them.

*Summary of Findings (Complaint a)*

137. As I have noted above (paragraph 85) I accept that the Trust have genuinely tried to respond sympathetically to Mrs C's complaint and have devoted considerable time and resources to doing so. However, I have found that their attempts have been undermined by a number of shortcomings, in particular failures to follow-up all possible avenues of enquiry; and some ambiguities in information provided to Mrs C. Taken together, I consider that these shortcomings represent a failure to investigate and respond adequately to Mrs C's complaint. I uphold this aspect of her complaint to me.

**Complaint heading (b) that the Trust did not respond adequately to Mrs C's complaint that she was not provided with reasonable genetic counselling following Stewart's death in 1980**

138. Mrs C first raised her concerns about the genetic counselling she received in her letter dated 5 December 2001. She explained that she was concerned that the outcome of the post mortem examination on Stewart had not been explained to her or her family and that as a result neither she nor her family were offered genetic counselling following Stewart's death and the sex-linked genetic factor was only confirmed 12 years later after her nephew's birth (see paragraph 64).

139. Mrs C had raised related concerns that she had not been told about the hereditary cause of Stewart's hydrocephalus at other points during the course of her complaint. She is noted as having discussed these concerns with Consultant 4 during the meeting on 13 September 2001 and with Consultant 5 during the meeting on 17 January 2003 (see paragraphs 57 and 81). The notes of these meetings do not make clear precisely how Consultant 4 and Consultant 5 responded, but it seems that Mrs C understood that it was unclear whether the advice she had received about the hereditary nature of Stewart's hydrocephalus and the implications for her and her family had been appropriate.

*Comments from my professional advisers on this aspect of the complaint.*

140. As noted in paragraph 35, following the birth and death of Mrs C's second son in 1974 it was estimated by Consultant 1 that the chances that her sons' hydrocephalus was caused by a genetic X-linked inheritance was 'low' at 'around 0.5%'. It was not clear to my Advisers how this estimate was calculated but they comment that, in the mid 1970s, there was little information available to clinicians to inform such calculations.

141. My Advisers comment that following Stewart's birth it became apparent that it was probable that his and his brothers' hydrocephalus was caused by a genetic X-linked inheritance because (a) all three of Mrs C's sons had been affected by hydrocephalus and (b) the neuropathological examination of Stewart's brain had identified an aqueduct stenosis which is consistent with X-linked hydrocephalus (see Annex B).

142. It is clear from Mrs C's records that Consultant 3 explained this probable diagnosis and its likely implications to Mrs C when they met on 19 March 1980. Consultant 3 wrote to GP 1 explaining that he had told Mrs C that it was 'very likely' that the hydrocephaly was of the X-linked type, and that this meant that it was quite probable that a female child would not be affected but could be a carrier (see paragraph 41). He also advised Mrs C about possible ways to manage future pregnancies in light of this probable diagnosis.

143. My Advisers did not have full genetic test results for Mrs C and her family, but they explain that her family history indicates that it is very probable that she is a carrier of an abnormal L1CAM gene. Her mother could have been a carrier of this gene and Mrs C inherited it from her, or the abnormality in L1CAM could have occurred for the first time in Mrs C's genes.

144. As Mrs C could have inherited the abnormal gene from her mother, the probable diagnosis of X-linked hydrocephalus made by Consultant 3 in 1980 had implications for Mrs C's siblings as they could have also inherited this abnormal gene. However, it appears Mrs C was not re-



referred to a geneticist for consideration of the possible implications for her wider family. Consultant 3 explained to my Investigator that he suspected he had not made this further referral because he was fairly confident of the diagnosis and he did not believe there was any specific genetic test for this condition at that time.

145. Mrs C's records indicate that Consultant 3 had liaised with the geneticists during the course of Mrs C's antenatal care and my Advisers consider that, given what was known about Mrs C's circumstances at the time, it would have been reasonable to conclude that nothing would have been achieved by making a further referral to the geneticists following Stewart's birth. The reason for this lies in Mrs C's family history. Both my Advisers and a representative of the South-East of Scotland Clinical Genetics Service (Consultant 8) highlighted that Mrs C had five brothers none of whom had been affected by hydrocephalus. If Mrs C's mother had been a carrier of the abnormal L1CAM gene, it would have been likely that one or more of Mrs C's brothers would have inherited this gene and so would have been affected by hydrocephalus. The fact that none of them were meant it was unlikely that Mrs C's mother was a carrier and made it more likely that the abnormality in L1CAM had occurred for the first time in Mrs C's genes. From this, it could reasonably be concluded that there was a low risk that Mrs C's sisters could be carriers of the abnormal gene. My Advisers note (as, again, did Consultant 8) that Consultant 3 was correct in stating that there was no direct test for the abnormal gene at the time. This meant that, even if Mrs C's wider family had been referred for specialist genetic counselling, nothing could have been done to clarify whether they were at risk of having children who would be affected by hydrocephalus or be carriers of the abnormal gene.

#### *Findings on Complaint b*

146. I recognise that it would have been quite legitimate within the terms of the NHS Complaints Procedure for the Trust to decline to respond on time-bar grounds to Mrs C's complaint, first raised in 2001, about the adequacy of the genetic counselling she received in the 1980s. However, it did respond in a letter dated 27 December 2001 (see paragraph 65) and I consider this to be a further indication of the Trust's genuine wish to sympathetically address Mrs C's concerns. I commend the Trust for attempting to respond to this aspect of Mrs C's complaint. However,

having decided to do so, it was incumbent on the Trust to do so adequately.

147. My Advisers have said that, given Mrs C's family history and the state of medical knowledge at the time, it would have been reasonable to conclude that it would be unhelpful to raise concerns among Mrs C's wider family that they were at risk of having affected children when (a) the information available at the time indicated the risk was relatively low, (b) there was so much uncertainty and (c) there was no satisfactory antenatal test that could be offered to allow the option of selective termination of pregnancy. More generally, my Advisers note that, at that time, there were significant concerns among GPs and obstetricians that contacting other family members about genetic abnormalities could constitute a breach of their patient's confidentiality and so the practice of doing so was less common. In light of these considerations, my Advisers conclude that the available information indicates that Consultant 3 both acted and advised Mrs C appropriately. I accept this conclusion and I note that Consultant 8 made similar comments to my Investigator about the advice which could have been given to Mrs C at that time.

148. The Trust's response to this aspect of Mrs C's complaint summarised the advice given to her by Consultant 3 and the genetic counselling she received before Stewart's birth from Consultant 1 (see paragraph 65). However, it did not provide any explanation or indication that Consultant 3's advice had been appropriate. Indeed, if anything the Trust's response seems to wrongly imply that the advice Mrs C received may not have been appropriate as it appears to suggest that, following Stewart's birth, a further appointment with geneticists for specialist advice should have been arranged, albeit that it would have been GP 1's responsibility to do so. Additionally, by simply summarising the advice and counselling Mrs C received, the Trust's response did not address her central concern that advice was not given to her wider family. For these reasons I do not consider that the Trust's response to this aspect of Mrs C's complaint was adequate.

149. It is not clear how the Trust's response was composed, but I note that both Consultant 3 and Consultant 8 told my Investigator that they had not been asked to comment on Mrs C's concerns about the genetic

counselling she received following Stewart's death in 1980, although they were both asked to comment on other aspects of Mrs C's complaint. Possibly as a result, the Trust's response failed to address Mrs C's concerns and missed the opportunity to provide her with the fuller explanation noted above which could have allayed her concerns. I uphold this aspect of her complaint.

## **RECOMMENDATIONS**

150. In light of the shortcomings identified, I **recommend** that the Board:

- i) Apologises to Mrs C and her family for the shortcomings in its investigation of and responses to her complaints as identified in this report.
- ii) Ensures that when tissue is being returned to families, or disposed of at the request of families, or because the Board no longer requires to retain it, a record is kept at minimum of the number of blocks of tissue being returned or disposed of so that a complete audit trail of all tissue is maintained.
- iii) Reviews the wording and content of letters used when responding to enquiries about organ retention to ensure that (a) complete information is given not only about organs but also tissue retained in whatever form, provided this is not contrary to the enquirer's wishes, and (b) the information provided is unambiguous.
- iv) Remind staff reviewing draft responses to enquiries and complaints that the response should be as accurate and full as possible. It is the responsibility of all staff carrying out such reviews to ensure that any relevant information of which they are aware is included in the response.

Professor Alice Brown  
Scottish Public Services Ombudsman

6 May 2005

## ANNEX A

### Key to names used

At Mrs C's request, I have continued to use her son's first name throughout this report. For legal reasons, all other names used in this report have been changed. The names and abbreviations used are:

Consultant 1	Consultant in Medical Genetics who was involved in Mrs C's care in the 1970's
Consultant 2	Consultant Paediatrician who cared for Stewart following his birth
Consultant 3	Consultant Obstetrician who cared for Mrs C at the time of Stewart's birth and subsequently
Consultant 4	Consultant Paediatric Pathologist who was involved in the Trust's responses to Mrs C's complaint
Consultant 5	Professor of Clinical Neuropathology who was involved in the Trust's responses to Mrs C's complaint
Consultant 6	Consultant Neuropathologist who examined Stewart's brain in 1980
Consultant 7	Consultant Pathologist who conducted the post mortem on Stewart's body
Consultant 8	Honorary Consultant in Clinical Genetics
Consultant 9	Consultant Paediatrician who had been Senior Registrar when he was involved in Stewart's care
Consultant 10	Honorary Consultant of Neuropathology with administrative responsibility for the Autopsy Service at the time of Mrs C's complaint, and who had been present at the post mortem on Stewart's body when she was a Specialist Registrar
GP 1	Mr and Mrs C's GP at the time of Stewart's birth
GP 2	Mr and Mrs C's current GP

Mrs A	Member of Justice for Innocents who supported Mrs C with aspects of her complaint
Mrs C	The complainant
Mr C	The complainant's husband
Officer 1	Divisional General Manager at the time of Mrs C's complaint
Officer 2	Patient Liaison Officer who was involved in the Trust's responses to Mrs C's complaint
Officer 3	Patient Liaison Officer who was involved in the Trust's responses to Mrs C's complaint
Officer 4	Pathology Service Operations Manager
Officer 5	A Senior Biomedical Scientist at RHSC
Review Group	Independent Review Group on Retention of Organs at post mortem
RHSC	Royal Hospital for Sick Children, Edinburgh
SEHD	Scottish Executive Health Department
Senior Lecturer 1	Senior Lecturer in Human Genetics involved in the analysis of Mrs C's family circumstances in the 1990's
SMMP	Simpson Memorial Maternity Pavilion, Edinburgh
Stewart	The complainant's son who died on 6 February 1980
WGH	Western General Hospital, Edinburgh

### **Explanation of the cause and inheritance of X-linked hydrocephalus.**

1. Hydrocephalus is a term used to describe dilatation (enlargement) of the ventricles of the brain due to increased cerebro-spinal-fluid around the brain. It can be caused by many different factors including anything that blocks the free movement of fluid around the brain, or anything that creates too much fluid which cannot drain away. Very commonly hydrocephalus is caused by factors external to the person's brain such as spina bifida. Sometimes it is caused by abnormal development of the brain itself which causes narrowing of the fluid channels through the brain. In this situation the original brain abnormality and the increased fluid pressure combine to cause more serious consequences.

2. A percentage of cases of hydrocephalus are caused by genetic factors. X-linked hydrocephalus is one such example. It develops because of an abnormality in the gene L1CAM which is located on the X chromosome. X-linked hydrocephalus is characterised by hydrocephalus secondary to abnormal brain development in the region of the aqueduct of Sylvius which causes a stenosis (an obstruction) which impedes the movement of cerebro-spinal-fluid.

3. Males have only one X chromosome whereas females have two. As a result, if the abnormality in L1CAM is present on the male's X chromosome he will experience abnormal brain development and will develop hydrocephalus. Females with the abnormal L1CAM gene on one of their X chromosomes will not develop the condition as it is extremely likely they will have a normal L1CAM gene on their second X chromosome as a back up. However, women in this situation could pass the abnormal L1CAM gene on to their children and so they are described as 'carriers'. There is a 50/50 chance that a carrier's son will inherit the abnormal gene, and hence will be affected by hydrocephalus. There is also a 50/50 chance that a carrier's daughter will inherit the abnormal gene and so will be a carrier herself.

4. As well as being passed from one generation to the next, gene abnormalities can start for the first time in any generation. However, once a gene abnormality is present it can pass from one generation to the next as explained above. It should also be noted that inheritance patterns can be more complex as it is possible to be a 'mosaic' carrier where the abnormal gene is only present in a proportion of the person's X chromosomes.

5. Although X-linked hydrocephalus was known about in 1980, it was not well characterised at that time and it was only in the 1990's when the abnormality in L1CAM was identified that this form of hydrocephaly was commonly recognised.

RHSC post mortem request and consent form in use at the time of Stewart's death

**ROYAL HOSPITAL FOR SICK CHILDREN**  
**REQUEST FOR POST-MORTEM**

Unit Number: \_\_\_\_\_  
Name: \_\_\_\_\_ Age: \_\_\_\_\_  
Ward: \_\_\_\_\_ Physician or Surgeon: \_\_\_\_\_  
Date of Death: \_\_\_\_\_ Date of Admission: \_\_\_\_\_

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History: \_\_\_\_\_ Place Of Birth: \_\_\_\_\_

*Resident  
Medical Officer.*

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To the Pathologist of  
Royal Hospital for Sick Children

.....19.....

Sir,  
I hereby authorise the inspection of the body of.....  
who died in this Hospital on the.....day.....

.....*Signature.*  
.....*Relation to  
Deceased.*

23/08 02 FRI 10:10 FAX 01315360010 RHSC FINANCE 002