

## Chapter 4. Special Cases for Investigation

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### Following reference to the Inquiry of Stephen White by Lord Hunt, Parliamentary Under Secretary of State (Lords), on 16 March 2000

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#### 1. Introduction

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- 1.1 On 16 March 2000 Lord Hunt requested that we investigate the circumstances of the case of Stephen White. During the course of the Inquiry we came across a number of similar serious cases, upon which we also focus in this chapter. We have carefully analysed all the evidence of each case individually. We begin with Stephen White.

#### Stephen White – 2 Weeks

#### 2. Background

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- 2.1 Stephen James White was born on 12 May 1992 with congenital heart disease. He died during cardiac surgery on 26 May 1992. A Coroner's post mortem examination was carried out.
- 2.2 His mother was told in late 1999 by Alder Hey that her son's heart had been retained. Later she received a letter saying that the heart and other organs had been retained. She telephoned to clarify what was meant by 'other organs' and was told that the lungs and brain had also been retained. On 9 February 2000 she confirmed that she wished to make funeral arrangements. On 14 March 2000 she advised Alder Hey that a second funeral had been arranged for 17 March 2000 and a pathology technician was asked to

locate the organs. At this point it was realised that the containers relating to Stephen White were empty. On 15 March 2000, two days before the funeral, the Chief Executive, Ms Hilary Rowland, visited Mrs White at home and told her that Stephen's organs had been mistakenly destroyed. She apologised for the distress that this caused.

### 3. Reaction

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- 3.1 Ms Rowland reported to the NHS Executive North West Regional Office on 14 March 2000. On 15 and 16 March 2000 they advised Lord Hunt, Parliamentary Under Secretary of State (Lords), of what had happened. He instructed the Regional Office to keep Mrs White fully informed of developments.
- 3.2 On 16 March 2000 Lord Hunt issued a press release recording his shock and anger. His reaction reflected that of parents involved in the organ retention issue. He immediately called for the resignation of the Trust Chairman, Mr Frank Taylor. He referred the Stephen White case to this Inquiry and stated that any disciplinary action, if appropriate, would be taken following publication of our findings. On the same day Lord Hunt confirmed in a media interview that the results of the report which he had requisitioned would be made public.
- 3.3 On 17 March 2000 the Trust, through Ms Rowland, provided Regional Office with the report which was sent on to Lord Hunt. He was unhappy with the lack of detail in the report and was disturbed by a number of aspects, highlighting both the lack of apparent accountability within Alder Hey and the failure to include a proper action plan. He demanded further information which Alder Hey provided to Regional Office the following day. However, Regional Office felt that the information provided remained inadequate and it was decided that Regional Office would now take responsibility for drafting the report.
- 3.4 After Regional Office had met with Ms Rowland and the Acting Director of Operations, Mrs Karen England, to clarify outstanding points, the report was redrafted and submitted to Lord Hunt on 22 March 2000. In essence the report concluded that the initial cataloguing of Stephen White's organs had listed retention of the heart, brain, lungs and abdominal organs. Mrs White had never been informed of the retention of abdominal organs. However, a routine second check of the organs, undertaken for the purpose of compiling a more detailed list, had revealed that the containers held only the heart, lung, part brain and only 'fragments' of abdominal organs. As there was a discrepancy between the two detailed visual checks the matter had been referred to Mrs England. She had given instructions for a Medical Laboratory Scientific Officer (MLSO) to dispose of the 'fragments' in accordance with an earlier decision made by

Alder Hey that fragments, which were not considered organs, should be disposed of to 'avoid any confusion'. In error the entire contents of the containers had then been disposed of with the fragments.

- 3.5 The report did not confirm the nature of the fragments, the date and place of destruction or the identity of the person responsible for disposing of the organs. However, Lord Hunt was under considerable pressure to act quickly in view of the problems since September 1999 in returning retained organs to parents. As the report reached a valid conclusion about the basic circumstances in which the organs had been disposed of the decision was rightly taken to publish the full report without further delay. Arrangements were made for the report to be released into the public domain at 7.00 am on 23 March 2000.

## 4. Publication of the Report

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- 4.1 Lord Hunt appeared on the BBC Today programme at 7.00 am on 23 March 2000. In a press release embargoed until that time he announced the appointment of Mrs Judith Greensmith as the new Chair of Alder Hey and stated that one of her first tasks would be to review the liaison with families and to ensure that they had the support they needed. Mrs Greensmith was also to review management procedures and ensure that appropriate arrangements were in place for the return of the remaining organs to families. A new Project Board, reporting directly to the new Chair, was established to handle liaison with parents. The Regional Director, Professor Robert Tinston, was to take personal responsibility for ensuring that robust monitoring procedures were in place dealing with the return of organs effectively and appropriately.
- 4.2 On 15 March 2000 Lord Hunt had instructed Regional Office to keep Mrs White fully informed of developments. Despite those instructions Mrs White did not see Regional Office's report before its contents were disseminated to the media. Professor Tinston telephoned Hugh Lamont, Head of Communications at Regional Office, between 8.00 am and 9.00 am on 23 March 2000 to obtain confirmation that Mrs White had been told about the press release and the report. She had not, nor had she seen the report. Mr Lamont tried to contact Mrs White on the morning of 23 March 2000, but only managed to speak to her later that afternoon. He apologised for the fact that the report was in the public domain before she had seen it and offered to drive to her home later that day to deliver it. Mrs White said it would not be necessary and it was agreed that Mr Lamont would post the report.
- 4.3 Mr Lamont described Mrs White's attitude in conversation as reasonable and amicable. He drafted a letter of apology to her which he posted on 27 March 2000 enclosing a copy of the report. By this time, Mrs White had already seen the report, which had been sent to her by her solicitor to whom Mr Lamont had faxed a copy on 23 March 2000.

## 5. Inquiry's Findings

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- 5.1 We accept the basic conclusion reached in the report prepared at Lord Hunt's request. The second visual check of the retained organs concluded that the fragments of tissue could not be identified as specific abdominal organs. Stephen was only 14 days old when he died, so any retained organs would have been small. Alder Hey had previously decided that fragments would be disposed of to avoid unnecessary upset to parents as in their view fragments did not constitute organs. This decision was taken without consultation with the parents and is another example of paternalism. Because of the initial decision to dispose of fragments of tissue there will be some families who sought the return of organs from Alder Hey and who have not had those fragments returned, because they have been disposed of as clinical waste. In discussions with Regional Office at the time of completion of the report for Lord Hunt, Ms Rowland accepted this inevitability.
- 5.2 In accordance with the predetermined policy and to avoid confusion arising from the discrepancies in the two visual checks Mrs England took the decision in Stephen White's case to dispose of the fragments. The histology record sheet was amended. In error the entire contents of the containers were then disposed of. There is no record as to the date, time, place or method of disposal. Even a proper system for reuniting retained organs would be undermined by this kind of slackness and lack of integrity.
- 5.3 Mrs England told us that her instruction was specific. It related to fragments and not Stephen's other organs. She had never seen the fragments for herself but relied upon information from Mrs Jackie Waring who had taken over her job as Chief MLSO in 1993. Mrs England was unable to put a date on the disposal of the organs, nor was it possible to identify which of the laboratory technicians had actually disposed of them. Mrs Waring herself observed that she could only speculate as to whether the organs had been thrown away in error or deliberately and she could not honestly comment.
- 5.4 Stephen's mother should have been told of the fragments from the outset. The problem in identification should not have been kept from her. Mrs England appears to have decided what was best for Mrs White to know.

## 6. What Did Happen to Stephen White's Organs?

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- 6.1 We have tried to establish when disposal of the organs occurred. On 23 February 2000 the Inquiry's Paediatric Pathologist, Dr Jean Keeling, visited Alder Hey. She had asked that 200 containers be made available to her for inspection. Stephen White's containers could not be traced at the time of her visit. On 8 March 2000 Mrs England signed the organ release form in preparation for the forthcoming funeral even though she did not

know where the organs were. Despite the indications of a potential problem on 23 February 2000, it was not acknowledged that the containers and the contents were missing until 14 March 2000. Had the contents of the containers been checked immediately before the release form was signed it might have avoided compounding the problem.

- 6.2 The question of when the organs were disposed of is highly relevant, as the Secretary of State had instructed Alder Hey in a letter that no further tissue should be disposed of in any case. This instruction was received and circulated, according to management, by Alder Hey on 21 February 2000. Regional Office's conclusion when preparing the reports requested by Lord Hunt was that the organs were disposed of 'between October 1999 to late January 2000' but procedures were not in place to be more precise than this.
- 6.3 Regional Office did not consider that the organs could have been disposed of after the Secretary of State's instruction was received. They noted that Ms Rowland had confirmed that no tissue had been disposed of in any case since 21 February and all staff had been made aware of the content of the letter from the Secretary of State. However, we heard specific evidence from staff at Alder Hey that the directive from the Secretary of State had not been circulated to them, so they were unaware of the express instruction not to destroy tissue. Further, in Simone's case (see paragraphs 12–24 below), it is clear that tissue was disposed of after 21 February 2000. Regional Office's assertion that the organs could not have been disposed of after Secretary of State's instruction does not therefore necessarily follow. However, we would agree that on balance it is likely that disposal did take place before the express instruction issued by Secretary of State. We are unable to date precisely the disposal of Stephen's organs due to the complete absence of proper paperwork but the date of the second visual check (between October 1999 and January 2000) identifying the discrepancy suggests disposal took place before the directive.
- 6.4 Mrs White should have been told of the contents of the report before it was published on 23 March 2000. Mr Lamont's explanation for failing to contact Mrs White is that he was so busy preparing the ground for the announcement of Judith Greensmith as the new Chair and dealing with other matters associated with the press release that he forgot to tell her. He also relied on the fact that the press release was only completed relatively late on 22 March 2000. Nevertheless Lord Hunt's instruction that Mrs White should be kept informed was not complied with. Someone should have been delegated to inform her of what was going on and provide her personally with a copy of the report.

## 7. Conclusions

### 7.1 The Stephen White case reveals errors and incompetence.

- In late 1999 Alder Hey sent a letter to Mrs White informing her that Stephen might be involved in the organ retention issue. Stephen's name was mis-spelt and the surname given was Little, not White.
- Mrs White telephoned Alder Hey and was told that his heart had been retained.
- Later she was told that the heart and 'other organs' had been retained.
- She was subsequently told that these other organs were the brain and lungs.
- She had thought she had buried all of Stephen at the original funeral.
- On 15 March 2000, two days before the second funeral, Mrs White was told that the organs had been mistakenly destroyed. The funeral had to be cancelled.
- On the evening of 22 March 2000 she should have received a copy of Regional Office's report explaining the loss of the organs and the reasons why the funeral had to be cancelled before it became public knowledge.
- The letter of apology from Mr Lamont was posted five days after the event, on 27 March 2000. She received a copy of the report from her solicitor, faxed to him on 23 March 2000 by Mr Lamont.

We are disappointed that no explanation has been forthcoming as to the circumstances in which the organs were destroyed. The report to Lord Hunt refers to laboratory staff being frightened to come forward. This does not reflect good personnel management. Any future reuniting of organs must prevent even fragments of organs being destroyed without parental consent. The policy adopted by Alder Hey was paternalistic and inappropriate. Mrs White had a right to know the details of everything retained from Stephen's organs.

### 7.2 We respectfully recommend that:

- every hospital keep proper records (preferably computerised) as to the source, consent to retain, usage and disposal of organs and tissue;
- every authorisation for release of organs for burial or cremation must not be completed until the content of the container is confirmed and the form counter-signed;
- a moratorium must be declared if records of organ retention are inadequate during which there should be an immediate cataloguing of organs retained;
- parents must never again be drip-fed information but should be kept fully informed.

## Christopher and Kathryn

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- 8.1 A fundamental prerequisite for the performance of a hospital post mortem examination is the consent of the surviving relatives. It is important that the various options open to relatives are fully explained and discussed. One option is to consent to a limited post mortem examination only. In such cases the pathologist must limit his post mortem examination to the organ(s) specified on the consent form. However, we found clear evidence that on occasions Professor van Velzen simply ignored parents' wishes and did not limit his post mortem examination as specified on the consent form or in any way. Remarkable examples of this are the cases of Christopher and Kathryn. In Christopher's case Professor van Velzen's actions came to the attention of senior management and yet no disciplinary action was taken.

## Christopher – 15 Years 3 Months

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- 9.1 In April 1993 Christopher was diagnosed as suffering from Hodgkin's disease. Later that year he was admitted to the Intensive Care Unit at Alder Hey. He died two weeks later. The death was not reportable to the Coroner but his treating consultant wanted to know whether there had been an infection which the medical staff had not been able to isolate.
- 9.2 Christopher's parents were asked if they would consent to a hospital post mortem examination and after discussion consented to a limited examination only. They agreed that a small chest incision could be made so that a biopsy of the lung could be taken. They specifically did not want a full post mortem examination to be performed. Their wishes were confirmed on no fewer than three separate documents prepared by the medical staff: the form sent to the mortuary attendant requesting a 'limited post mortem'; the mortuary registration form which recorded 'parents have agreed to biopsy through small chest incision'; the post mortem consent form which was said to be 'limited to a chest incision to biopsy of the lung'. Professor van Velzen, who performed the post mortem examination, had all three documents.
- 9.3 Professor van Velzen exceeded that authority in performing the post mortem examination. The report refers to 'opening' of the heart, trachea, bronchus, stomach, bowel and bladder and to the findings 'on section' of the lungs, pancreas, spleen and liver. The report also records the weights of both lungs, the heart, liver, spleen, pancreas and both adrenal glands and kidneys. Clearly the weight of those organs could only be accurately recorded if they had been removed from the body and weighed separately. The post mortem report was not sent to Christopher's parents.

- 9.4 Christopher's mother had a number of questions about her son's death and pursued those with the hospital. She learned that a post mortem examination had been performed when she had given consent only for a lung biopsy. In May 1994 she wrote to Ms Rowland requesting a meeting to discuss her concerns, writing 'a post mortem was done when I clearly stated that I did not want one'. Ms Rowland did meet her but was unable to answer all her queries. She sent a memo to the treating consultant and to her Medical Director, Dr Martin. There is no record of any written response from Dr Martin and in oral evidence he was unable to recall the case. However, the treating consultant made it very clear to Ms Rowland that what Professor van Velzen had done was unacceptable. She wrote,

'Professor van Velzen who performed the post mortem took it upon himself to look at various other organs through the incision he made to do the biopsy. Mr and Mrs X did not give permission for this and this has caused them extreme distress. I actually showed Mrs X the written request I had made for the biopsy and the documentation in the notes. I can understand that she feels her wishes were not taken into account.'

The consultant suggested it might be easier for Ms Rowland to discuss the case with her.

- 9.5 Ms Rowland did not take up that offer but instead sought Professor van Velzen's comments. His response was a tissue of lies. He wrote to Ms Rowland claiming that he had made an incision of 'no more than 7cms, just enough to allow my right hand to pass into the body cavity'. He enclosed a letter addressed to the parents purporting to explain the position. That letter claimed that he was able to assess many organs by gently touching them and feeling for abnormalities including general assessment of size; tissue samples taken would not have exceeded 1 x 1 x 1 mm; no post mortem was carried out 'in the classic sense'; he had not interfered with Christopher's skull or damaged his body; he had not removed organs from the body to be only partially replaced, but Christopher had been buried with all his organs in exactly the same position as in life. He claimed that wherever he had quoted organ weights in his report these were based on his assessment by hand, a technique he had learnt through years of practice and in which he was usually accurate to about 10 per cent – 15 per cent.
- 9.6 Any reasonable assessment of Professor van Velzen's response would have led Ms Rowland to conclude that that letter was nonsense. Indeed, in giving oral evidence to us Ms Rowland subsequently described it as 'pure fantasy'. However, she did not reach that conclusion at the time, and instead a letter was prepared in her name to the parents. This repeated Professor van Velzen's lies, stating that a small incision only had been made, that there had not been a full post mortem examination but only a very limited investigative procedure through that incision, and that all the internal organs had been left in place. She said that there had been no damage to the body save for the incision necessary to take lung tissue. Her assistant drafted the letter but in her oral evidence Ms Rowland accepted full personal responsibility for the letter.

- 9.7 Ironically, that letter, which was based on wholly inaccurate information provided by Professor van Velzen, did not actually reach the parents who, hearing nothing and feeling that they were being fobbed off, elected to leave matters due to the stress the whole process was causing.
- 9.8 In March 2000 the parents discovered that Christopher's organs had been retained. Their distress on being told that their son's heart, lungs, spleen and stomach had been retained, after the assurances given when the consent to the lung biopsy was obtained, can only be imagined. In her questionnaire Christopher's mother said that she felt she had buried 'an empty body' and 'felt that I had been raped because I said no'. In discussions with her link worker at Alder Hey, Sue McQueen (whom she describes as 'marvellous'), Christopher's mother became aware of Ms Rowland's 1994 letter which she had never received, which distressed her further. The denial in the letter that there had been a full post mortem examination and the statement that the organs had been returned to Christopher's body in the correct place seemed contradictory. The parents naturally began to wonder whether the letter was accurate. They wondered whether they had buried organs belonging to another child. They had endured a second funeral in June 2000. A meeting was arranged with the treating consultant to clarify the position. She explained that the letter was inaccurate.
- 9.9 Christopher's case is remarkable. Professor van Velzen acted without authority. The parents' wishes were flouted. In oral evidence to the Inquiry, Christopher's treating consultant described Professor van Velzen's actions as 'outrageous' and a 'total travesty of what had been agreed'. She felt that he had 'betrayed the medical trust of all people caring for Christopher'.
- 9.10 Dr Keeling, the Inquiry's clinical expert, confirmed that it was impossible for Professor van Velzen to have come to his conclusions about the state of Christopher's organs by carrying out an examination through a 7cm upper abdominal incision. On inspection of the containers prior to the return of Christopher's organs she found substantial tissue including five large and two smaller pieces of lung, amounting to the major part of two lung lobes. There was a slice through the heart which involved the full circumference of both ventricles. She was able to state that the organs retained were consistent with those of a child of Christopher's age.
- 9.11 Professor van Velzen's behaviour was unacceptable and justified disciplinary procedures. Ms Rowland failed to deal with the parents' complaint despite the clear advice of the treating consultant who exposed Professor van Velzen's actions. In oral evidence Professor van Velzen admitted that he had not acted in accordance with the instructions on the consent form, agreed that his letter to Ms Rowland/the parents was 'rubbish' and accepted that he should have been severely disciplined. The Medical Director, Dr Martin, confirmed that Professor van Velzen's letter was 'nonsense', and agreed that a final warning at least, and possibly dismissal, was merited in the light of his actions. Proper assessment of the parents' complaint at the time should have led to

disciplinary action and referral of Professor van Velzen to the General Medical Council. Ms Rowland and Dr Martin, who had been asked for his comments on the case, must take responsibility for their failure to take appropriate action at the time.

## Kathryn – 15 Years

- 10.1 Christopher's case was not the only one where Professor van Velzen exceeded the consent given by parents when performing post mortem examination. Kathryn's parents gave consent to a limited post mortem examination and were told that small tissue samples only would be taken through a restricted incision of the lung, liver and kidney. The consent form actually signed by the parents was somewhat broader. Permission was given 'for the removal of tissue for diagnostic and other purposes other than transplantation' but the agreement to limit post mortem examination was clear and accepted by the treating consultant in a report annexed to the post mortem report. Indeed, Professor van Velzen's post mortem report itself referred to a small mid-sternal incision having been made which enabled 'only the upper organs and the lower aspects of the chest organs' to be brought into view for inspection, the rest of the post mortem assessment being 'done on palpation'.
- 10.2 As in Christopher's case, however, the post mortem report itself belies Professor van Velzen's claim. There is reference to the 'opening' of the heart and bowel and to findings 'on section' of the lungs, pancreas, spleen, liver, kidney, thymus and adrenal glands.
- 10.3 In December 1999 Kathryn's parents received a letter from Ms Rowland confirming that her heart, lungs, liver, spleen and kidneys had been retained, clear evidence that Professor van Velzen had exceeded his authority.
- 10.4 We are also aware of another case involving the same clinical team where consent was given to a limited post mortem examination of the lungs only. In the post mortem report, however, Professor van Velzen clearly described that the organs of the chest and abdomen were removed from the body in order that the examination could be done. Histology was reported on the heart, aorta, lung, thymus, spleen, liver, pancreas, kidney and adrenal glands. The examination exceeded, by a considerable margin, the consent given by the parents.
- 10.5 There can be no justification for Professor van Velzen's actions in these cases. His behaviour exemplified his lack of respect for the parents and their children.

## Stephen – 2 Years 1 Month

- 11.1 Stephen died at Alder Hey Hospital shortly after admission in October 1994. The clinician in the Intensive Care Unit asked his parents to consent to a hospital post mortem. She told them that a small sample of tissue was required for microscopic examination.
- 11.2 They were eventually persuaded to sign a consent form and Professor van Velzen carried out a post mortem examination. They would have liked more information about post mortem examination and now feel that the consent form should have been read out and explained to them.
- 11.3 In September 1999 they were told that Stephen's heart and brain had been retained and sampled following post mortem examination. The way in which they were told of the retention lacked dignity or sympathy. They have never received an apology.
- 11.4 A second funeral was arranged to take place in November 1999. Shortly before the funeral, they received the organ release form from the undertaker and realised that the casket included organs other than the heart and brain. This caused great anxiety.
- 11.5 In January 2000 Stephen's parents received a letter from Alder Hey stating that not all the organs had been returned. They were devastated, asked for their immediate return and began arrangements for a third funeral. A week later they received another letter explaining that all of Stephen's organs had been returned in November and the information contained in the January letter was just an administrative error. This left his parents in a state of uncertainty and they decided that the only way they could secure peace of mind as to precisely what they had buried was to exhume Stephen's casket from the second funeral and check its contents.
- 11.6 Initially Alder Hey were resistant, but after involvement of the family solicitor and the Solicitor to the Inquiry they agreed to fund the exhumation. Dr Keeling examined the contents of the casket. Stephen's parents had originally been told that the organs returned included the kidneys and liver, but these organs were not to be found. There was no spleen, an organ which, judging by the post mortem report, had been removed at the post mortem examination.
- 11.7 After two funerals and an exhumation the parents are still left with the following questions:
  - Why were they informed in a letter in January 2000 by Alder Hey that the liver and kidneys had in fact been returned when they had not?
  - Where are Stephen's liver and kidneys?
  - Where is Stephen's spleen?

Stephen's parents feel that they will never be able to put their son to rest, or free themselves of the turmoil consuming their family until they have answers to these questions.

- 11.8 The parents complain that throughout Alder Hey have treated them arrogantly and insensitively. The information they have received has been misleading and inconsistent. They feel that in the circumstances Alder Hey should have sent someone to visit them and explain what was going on.
- 11.9 Stephen's is one of the most unsatisfactory and distressing cases it is possible to imagine. Alder Hey has still not provided a proper answer to any of the questions raised by his parents. The parents also feel that because Stephen died so soon after admission to hospital the death should have been reported to the Coroner. They have now reported the death to the Coroner who is to make further enquiries.

## Simone – 3 Years 4 Months

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### 12. Background

- 12.1 Simone was born in 1989. She suffered from transposition of the great arteries, enlargement of ventricular septal defect and hypoplastic left ventricle. She underwent surgical intervention in 1990 and 1993. Before the first operation, undertaken by Miss Roxanne McKay, Consultant Paediatric Cardiac Surgeon, her mother was told that Simone had an even chance of surviving. Before the second operation she states that Mr Roger Franks, Consultant Cardiothoracic Surgeon, told her that the prospects of survival were as high as 75 per cent. Simone deteriorated following surgery and died in 1993.

### 13. Involvement of the Coroner

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- 13.1 Simone died three days after the operation from which a successful outcome had been expected. The present HM Coroner for Liverpool, Mr Andre Rebello, states that any death occurring within 48 hours of an operative procedure should be reported to the Coroner, as should any case where the death might be related to a medical procedure or treatment. This was clearly the case here, although Regulation 41 of the Registration of Births and Deaths Regulations 1987 is not quite so specific. In all the circumstances it would have been sensible to report the death to the Coroner. Mr Rebello has confirmed to the Inquiry that the death was not reported at the time, but it has been now and he is investigating formally.

## 14. Consent to Hospital Post Mortem Examination

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- 14.1 Simone's mother gave evidence that the possibility of a Coroner's post mortem examination was used as a threat to induce her to give consent to a hospital post mortem examination. She says Mr Franks made it clear that if she did not sign the post mortem consent form then he would ask the Coroner to order a post mortem examination. She did give her consent, although she rang the cardiac department later that day to say that she wanted an independent pathologist to carry out the examination. She was told her wishes would be respected. However, correspondence shows that those wishes were treated as a request for a second opinion, but no steps were taken to arrange any such second opinion.
- 14.2 Mr Franks gave evidence that in his view Simone's death was not reportable to the Coroner. He denied that he would have made any reference to a Coroner's post mortem examination. However, he also told us of other deaths reported to the Coroner where a hospital post mortem examination was not just discussed with parents but on occasions actually performed. In these circumstances we prefer the mother's recollection and conclude that the nature of the discussion was inappropriate.

## 15. Independent Pathologist?

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- 15.1 A hospital post mortem examination was performed by Professor van Velzen. Simone's mother's request for an independent pathologist was ignored. Mr Franks says it was Professor van Velzen's responsibility to organise the independent post mortem but the correspondence does not confirm that he was asked to make appropriate arrangements. Had Simone's death been reported to the Coroner then, under Rule 6 (1)(c)(iii) of the Coroner's Rules 1984, her mother would have been entitled to ask that the examination be performed by a pathologist not associated with Alder Hey. After the post mortem examination the findings were not disclosed to her.
- 15.2 Simone's mother queried whether there had been a 'cover up'. We have no evidence of this, but the lack of transparency surrounding the post mortem procedure is a matter for concern. General issues surrounding the Coroner's process are addressed in Chapter 9.

## 16. Initial Enquiries Regarding Organ Retention

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- 16.1 Simone's mother was one of the first parents to make enquiries of Alder Hey after the news of organ retention became public. She telephoned in September 1999 asking if Simone's heart had been retained and was told that it had not. Some time later she

made a further enquiry asking whether any of Simone's organs had been retained. She was told that someone would ring her back, but she became tired of waiting and went to the hospital demanding an answer. She was told that no organs had been retained. This was confirmed in writing a few weeks later.

- 16.2 Simone's organs had in fact been retained. The initial information given to Simone's mother was inaccurate. Ms Valerie Mandelson, who co-ordinated the Family Support Team from October to December 1999, was told within a few days that inaccurate information had been given. She surmises, probably correctly, that the initial check had been made under an incorrect name. Ms Mandelson's initial reaction was that Simone's mother could not be told of the error because of the distress it would cause. She says she acted out of a wish to protect her. She knew how devastating parents found it to be told about organ retention, so receiving such information, in the light of the assurances previously given, would be dreadful. However, Simone's mother had made it clear she wanted to have the information and she should have been told. Ms Mandelson now accepts that and admits that she was misguided in her actions. She was open and apologetic in her evidence to us.

## 17. Amendment of the Database

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- 17.1 Ms Mandelson then removed Simone's name from the paper printout detailing the children whose organs had been retained. The printout was the first port of call for other administrative staff to check organ retention in any particular case. She also ensured that the enquiry database on the computer indicated that the mother had been told 'no' in relation to her query regarding organ retention. She stuck a post-it on the computer in the Incident Room saying '(Mother's name): do not allocate'. Ms Mandelson says, quite frankly, that she took this action of her own accord and not as a result of any instruction.
- 17.2 Ms Mandelson then spoke to her line manager, Ms Sally Ferguson, the acting Director of Nursing. The two have slightly different recollections of the discussion. Ms Ferguson recalls advising Ms Mandelson to inform Ms Rowland and Mrs England of what had happened, so there could be further discussion about what should be done. Ms Mandelson believes it was 'understood' that Simone's mother 'could not' be told what had happened and the need to speak to Ms Rowland and Mrs England was purely to keep them informed.
- 17.3 Ms Mandelson met with Ms Rowland and Mrs England and told them what had happened. She accepts she did not ask what should be done and that no instruction was given not to tell Simone's mother the truth. However, it was understood by the three of them that unless a specific instruction was given at this point to tell the mother then there would be no further contact with her.

- 17.4 Ms Rowland and/or Mrs England had the opportunity to ensure Simone's mother was told immediately but did not do so. The position in early November 1999 was therefore that Simone's mother, despite having made two specific enquiries to establish whether Simone's heart and/or other organs had been retained, remained under the misapprehension that there had been no retention. Alder Hey knew this to be inaccurate. The database and printout had been amended to reflect what Simone's mother had been told, rather than what was actually the case.

## 18. Identification of the Organs

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- 18.1 In December 1999 Simone's retained organs were routinely examined and listed as part of Alder Hey's general cataloguing process. Mr Liam Nolan, a locum Medical Laboratory Scientific Officer (MLSO) employed by Alder Hey, prepared a 'full details list'. Organs were transferred from Myrtle Street to Alder Hey and afterwards were returned to the pathology stores in Alder Hey. Mr Nolan did not know that Simone's mother had not been informed of the retention.

## 19. Further Enquiries Regarding Organ Retention

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- 19.1 After Professor van Velzen's appearance on the BBC programme 'Close Up North', in February 2000, Simone's mother contacted Alder Hey again. She requested a copy of the post mortem report and saw that Professor van Velzen had performed the post mortem. She asked more questions, which came to the attention of Ms Russell, a member of the Incident Team responsible to Ms Therese Harvey, the Director of Human Resources. Ms Russell recalled the post-it on the computer, and recognised the writing. On 21 February 2000 she spoke to Ms Mandelson who explained the sequence of events. Ms Russell then went to see Ms Harvey. She explained that Simone's mother had been given inaccurate information previously and a decision had been made not to go back and tell the truth. Ms Harvey made it clear that the mother would have to be told but demanded a physical check of the organs be undertaken. This check confirmed that Simone's organs remained in the pathology department. Ms Harvey informed Ms Rowland who agreed with the decision to tell Simone's mother the truth.
- 19.2 Ms Sue McQueen, a help line worker, spoke to Simone's mother. She told her that part of Simone's brain, liver, spleen, kidney, reproductive organs and intestine had been retained. Subsequent correspondence confirmed that the pancreas had also been retained but there was no mention of retention of Simone's heart and lungs. The information coincided with the 'full details list' completed by Mr Nolan. Simone's mother told Ms McQueen that the organs should not be disposed of and said that she

had been in touch with the Coroner, to bring Simone's case to his attention. In the interim, on 18 February 2000, Secretary of State had issued a written directive to Alder Hey making it clear that no organs should be disposed of without further instruction. We were told that Alder Hey circulated this instruction on 21 February 2000.

## 20. Disposal of the Organs

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- 20.1 Despite this instruction, and unknown to Simone's mother at the time, Mr Dearlove, one of the MLSOs, disposed of Simone's organs on or around 23 February 2000. Prior to the disposal, Mr Nolan had seen the two containers holding the organs near Mr Dearlove's work area in the laboratory and had wondered why they were there. He did not pursue the issue, assuming there was a valid reason why the organs had been taken out of storage.
- 20.2 Mr Dearlove said that he disposed of the organs quite deliberately because he had been instructed to do so by Mrs England 'because of discrepancies in the database system'. He said that Mrs England had explained to him that 'the parents had not been told about these organs, they had been told no (organs had been retained) on several occasions and that she thought it better, rather than cause them any more distress, would I dispose of the organs'. Mr Dearlove said that he was unaware of Secretary of State's directive that organs should not be destroyed.
- 20.3 Mrs England denies that any such instruction was given stating that there was no reason to dispose of the organs as Simone's mother had been told of the retention. However, she accepted in oral evidence that she found Mr Dearlove 'utterly trustworthy' and that he would never have taken it upon himself to deliberately destroy organs. One of Mr Dearlove's fellow MLSOs, Ms Elizabeth Clapham, recalls Mr Dearlove returning from a meeting with Mrs England and informing her that he had been requested to dispose of the organs. This gives support to Mr Dearlove's contentions.

## 21. Why was an Instruction to Dispose Given?

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- 21.1 Mr Nolan's duties included production of detailed lists to families, returning organs and casketing arrangements for families. In early/mid February 2000 he reviewed the contents of approximately 400 containers at Mrs England's request. At the conclusion of that process he advised Mrs England of a number of queries. In particular he had recognised that Simone's name was not on the histology database, but organs had been retained. At the very least, therefore, Mrs England knew that there was a discrepancy on the database, which again supports Mr Dearlove's evidence. She may even have

recalled that Simone's mother had been told previously that no organs had been retained as she had been present at the meeting in October with Ms Mandelson and Ms Rowland when this had been discussed and the enquiry database also reflected this. An instruction to dispose of the organs might have been an attempt to extricate Alder Hey from an embarrassing situation.

- 21.2 If Mrs England knew, however, that Simone's mother was to be told the truth about the retention of organs, then clearly an instruction to dispose of organs to protect Alder Hey would have been illogical. Mrs England gave evidence that she, Ms Russell, Ms Harvey and Ms Rowland all knew that the organs had been located and that Simone's mother was to be told. She says Ms Russell told her this was to be done. She says there was therefore no motive for her to instruct Mr Dearlove to dispose of the organs.
- 21.3 However, Ms Russell was clear in her evidence that she did not communicate such information to Mrs England and had no cause to do so as she was directly responsible to Ms Harvey. She did not recall Mrs England being present when she told Ms Harvey of the position. The evidence therefore does not confirm Mrs England's involvement in that loop of information. We accept Mr Dearlove's evidence that Mrs England instructed him to dispose of the organs because of the database discrepancy. We are satisfied that Mr Dearlove would not have disposed of the organs without receiving specific instruction to do so.

## 22. What Organs were Disposed of?

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- 22.1 The 'full details list' of retained organs given to Simone's mother did not include Simone's heart and lungs. Simone's mother telephoned Professor van Velzen who told her that his practice was to retain all the organs including heart and lungs. He said he would have sent the heart and lungs to the Institute of Child Health (ICH). Mr Dearlove gave evidence that 'one pot was in the ICH and the rest had been down at Myrtle Street and somebody removed them to Alder Hey'. This would suggest that the heart and lungs had been retained. However, the two containers which Mr Nolan observed in Mr Dearlove's work area were Myrtle Street containers, neither being a glass container of the type which he had seen in the ICH. His expectation was that one of the containers would have held the brain, and the second the other organs. If the heart and lungs were retained, they have never been successfully located by Alder Hey.

## 23. The Disposal Revealed

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23.1 In early May 2000 Simone's mother made a further enquiry of the help line. The list of retained organs had included 'partial brain' and she wanted to know exactly what part and what had happened to the rest of the brain. The enquiry was passed by Ms McQueen to Mr Nolan who was unable to locate the containers. It was at this stage that the previous disposal of the organs came to light. On 11 May Mrs Kate Jackson, the Serious Incident Project Board Director, spoke to Simone's mother and asked to see her at home. She agreed and Mrs Jackson broke the news of the disposal of Simone's organs. On 12 May Alder Hey issued a press statement pledging a full investigation. The press statement made public Simone's name. This was contrary to her mother's wishes and further distress was caused. Mrs Judith Greensmith, Chair of Alder Hey, whilst of the view that there was public interest in the incident, accepted that Alder Hey should have been more aware of the sensitive nature of the situation.

## 24. Conclusions

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- 24.1 The story of Simone's case is extremely disturbing from start to finish.
- Pressure was exerted on the mother to consent to a hospital post mortem examination.
  - A hospital post mortem examination was performed when a Coroner's post mortem examination was more appropriate.
  - Simone's mother was denied the independent pathologist she specifically requested.
  - The findings of the post mortem report were not communicated to Simone's mother and her understanding of Simone's death was incomplete.
  - Organs were retained without the mother's knowledge.
  - When Simone's mother enquired about organ retention she was given inaccurate information.
  - When it was discovered that Simone's mother had been given inaccurate information she was still not told the truth, at best because a paternalistic attitude prevailed, at worst because there was a cover up. Ms Rowland and Mrs England should have instructed Ms Mandelson to tell Simone's mother what had happened.
  - Simone's mother had requested specific information about organ retention on many occasions and it should have been provided at the earliest opportunity.

- It was wrong to amend the database to cover Alder Hey's tracks and turn misinformation about organ retention into a lie.
- The mother's persistence forced Alder Hey to reveal that Simone's organs had been retained. She is still unaware as to the whereabouts of her child's heart and lungs.
- Retained organs were disposed of contrary to Simone's mother's instructions, Secretary of State's instruction and despite the involvement of HM Coroner.
- Disposal was carried out to Mrs England's instruction.
- The press release contravened the mother's right to confidentiality.
- Alder Hey has failed to explain properly to Simone's mother the circumstances of disposal of the organs.

24.2 This sorry sequence of events has incrementally increased the grief and distress of Simone's mother. There was a concerted attempt to conceal the fact of organ retention from her. There is a high incidence of suspicion that there has been a cover up. The treatment of Simone's family has been tardy, disrespectful, insensitive and totally lacking in understanding or compassion.