Chapter 3. Handling of the Organ Retention Issue September 1999 to date

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1. Organ Retention is Revealed

1.1 On 7 September 1999 Professor R H Anderson, Professor of Morphology at the Hospital for Sick Children in London (Great Ormond St Hospital), described to the Bristol Inquiry the benefits of heart retention for the purpose of study and teaching. He identified heart collections around the country and made particular mention of the excellence of the collection at Alder Hey which dated from 1948. His evidence brought the issue of organ retention at Alder Hey into the public domain.

1.2 At Alder Hey, however, organ retention had not been limited to hearts and lungs. Between 1988 and 1995 (which we describe as 'the van Velzen years'), there had been systematic full-scale removal of organs. The organs were retained from Coroner's and hospital post mortem examinations carried out in the mortuary at Alder Hey. They were stored in the pathology department at Alder Hey until late 1989 when Professor van Velzen's department moved to virtual sole occupancy of Myrtle Street. The organs continued to accumulate within Myrtle Street until 1995.

1.3 In 1995 Alder Hey and the University had considered how to deal with this accumulated material. This matter is more fully analysed in Chapter 8. On 24 April 1995 Professor Helen Carty, Clinical Director of Support Services at Alder Hey, circulated a memorandum to a number of clinicians enclosing a list of post mortem examinations where histology had not been completed on retained 'organs'. The following day she also wrote to the Chief Executive at Alder Hey, Ms Hilary Rowland, about delay in carrying out histology on retained 'organs'. The memorandum was circulated on three or four occasions. Clinicians marked those cases in which they wanted the organs retained for histology. These organs were then transferred to Alder Hey. The hearts and lungs in some cases were sent to the Institute of Child Health (ICH) at Alder Hey. The large majority of organs remained at Myrtle Street to be used for research purposes as and when required. These arrangements were confirmed at a meeting in the Department of Pathology at Alder Hey on 21 November 1995. An opportunity was therefore missed by the University and Alder Hey to list and catalogue all the organs which had accumulated at Myrtle Street until April 1995. This was the background against which the revelation of the heart collection was made in September 1999.

1.4 The revelation generated some local media interest and on 18 September 1999 the issue of organ retention was reported on the BBC North West Regional News. On 20 September Ms Rowland gave an assurance that the practice of organ retention at Alder Hey had not differed from that at other hospitals. The collection of organs at Myrtle Street was such that this assurance was inaccurate.

1.5 Following the revelation many parents telephoned Alder Hey to find out whether their child's heart had been retained. On the second day of receiving calls Ms Rowland asked Mrs Karen England, Acting Director of Operational Services, to manage the incident. Mrs England was chosen because of her background and experience of having worked in the histology laboratory. For the first few days management arrangements were informal but soon a team of senior staff, managerial and clinical, was convened. The purpose of the team was to agree the strategy for managing the incident and to make decisions which would be carried out by those individuals with delegated responsibility.

1.6 Later in the first week parents began to query whether, if hearts had been retained, other organs had also been kept. It was at this point that Mrs England told Ms Rowland that multiple organs had been taken at post mortem examinations and had remained at Myrtle Street when the histology department had left the building in 1995. Ms Rowland gave evidence to the Inquiry that until this point she had no knowledge of the full extent of the organ retention. However, the documentary evidence discussed in Chapter 8 Part 8 of 'the van Velzen years' suggests that in 1995 Ms Rowland should have known of the existence of a substantial collection at Myrtle Street.

1.7 Mr Paul Dearlove, a senior Medical Laboratory Scientific Officer (MLSO), was instructed to go to Myrtle Street to establish the position. Multiple organs had been retained from approximately 850 post mortem examinations carried out between

September 1988 and December 1995. There were between one and three containers for each child. In total there were approximately 2,000 containers holding multiple organs and many pieces and fragments of tissue.

1.8 The Myrtle Street building (see photographs at page 12) consisted of two floors and a basement, with many rooms off the main ground floor area and the first floor. The basement had two rooms and a series of cellars at the rear (see photographs on page 32). All had low lighting and low ceilings and it was not possible to stand up straight in all the areas. The majority of the containers were stored in the cellars in the basement, with others in the 'cut-up' room and two storerooms off it on the ground floor.

1.9 The containers in the basement were dirty and covered with thick black dust. The area has now been cleaned and is illustrated in the photographs at page 32. The cleaned containers are now stored at Alder Hey in the pathology department as illustrated at page 33. Identification of some was difficult due to the conditions in which they had been kept. Some of the labels were damp and had come off. The writing on some of the containers had faded over time. On closer inspection some of the organs were poorly preserved because adequate levels of formalin had not been maintained.

1.10 Mr Dearlove explained to Mrs England that at the time the histology department had left the building in 1995 all the containers were filed in chronological order with multiple containers on the same case stored together. It was obvious that the containers had been accessed since then. Some were out of sequence and multiple containers on the same case had not been kept together. Many other containers were spread around the building, some containing animal tissue, some human tissue taken from the organs stored following post mortem examination, presumably for research work undertaken by University staff. It was therefore clear from the outset that there could be no guarantee that organs which remained in the containers were those originally taken at post mortem examination.

1.11 Between 1988 and 1999 there was no proper record of retained organs, or of access to them for research purposes at Myrtle Street. This factor alone has prevented the University or Alder Hey from providing information to parents about organ retention which was completely accurate and reliable.

1.12 On 27 September 1999 Ms Rowland briefed Professor Robert Tinston, Regional Director at NHS Executive North West (Regional Office), and warned that this constituted a major issue. He assured her that additional resources could be made available if required.

1.13 As the number of queries from parents grew Ms Rowland decided to write to all families whose child had died at Alder Hey, where the post mortem examination had been performed at the hospital and where they had the addresses. She did not write to the wider group of parents affected by the retention of hearts generally because the age of the collection made the addresses unreliable. The letter was sent to parents affected by deaths between 1988 and 1995. They were invited to contact Alder Hey to be told whether their child's organs had been retained.

1.14 Over the weekend of 2–3 October 1999 Alder Hey attempted to catalogue the organs in Myrtle Street. The containers were removed from the basement and other areas to the ground floor and sorted in order of post mortem number and year. Twelve members of staff worked a total of 151 hours and completed cases from 1988 to 1990. For the full classification process two people worked together, one identifying the organs and the other recording the data. Post mortem number, year and the name of the child were verified by both individuals prior to identification of the organs. The organs were then listed on an 'histology record sheet'. Containers which could not be clearly identified were kept to one side. If on further checking it was agreed that identification was impossible they disposed of the specimens.

1.15 On 4 October 1999 the exercise continued but instead of individual organs being listed they were classified into four groups: the brain, the heart, thoracic and abdominal organs. The histology sheet was revised to reflect this. In her witness statement to the Inquiry Ms Rowland explained,

> We felt that generally that would be as much information as parents would want or could emotionally cope with and the limitation of four groups would speed the process up.'

Eleven members of staff worked a total of 123 hours over 4–5 October and completed the outstanding cases from 1991 to 1995. When the later data was subsequently entered into the computer the earlier data was amended to reflect the revised categories.

1.16 The following weekend, 9–10 October 1999, the hearts and lungs in the ICH were catalogued. Eight pathology staff worked a total of 71 hours. The organs were classified as 'hearts' or 'hearts and lungs' and whether they were 'whole' or 'part'. This information was recorded on the 'ICH record sheet' together with the unique alphanumeric identification code from the container. The record sheets were then cross-checked against the ICH heart books so that the code could be linked to a name and post mortem number.

1.17 Over both weekends Alder Hey asked the University for their help. Their request was declined.

1.18 The cataloguing exercise was a priority and should have been carried out under the direction of senior management with an experienced paediatric pathologist in day-to-day control. The necessary staff should have been deployed to ensure that all organs at Myrtle Street and the ICH were properly identified, listed and catalogued in relation to the name of the baby or child and the relevant post mortem number. Even at this early stage, the exercise identified the difficulties with existing records of organ retention particularly at the ICH (see Chapter 7 Collections).

The basement cellars at Myrtle Street (where containers were stored)

Containers holding organs – now stored in accommodation at Alder Hey

2. Press Release Denies Knowledge at Alder Hey

2.1 In the interim Ms Rowland had issued a press release on 6 October 1999 saying that,

> 'The hospital is devastated to learn that so many organs have been retained for research without the knowledge of the hospital, its doctors or the parents.'

2.2 Dr Campbell Davidson, the Medical Director at Alder Hey, was present at the meeting that sanctioned the press release. There is no evidence that he took instructions from the clinical directors as to the contents of the press release before it was issued. Neither did he check the accuracy of the statement for himself.

3. The Early Enquiries

3.1 In the first month of enquiries Alder Hey received 618 calls from parents. All parents affected by organ retention were sent a letter of apology and offered three options:

- return of the organs to the family for a second funeral;
- retention of the organs for further research;
- retention of the organs at Alder Hey pending the family's decision.

3.2 Consideration was also given to a communal cremation for those who would find it too distressing to organise a second funeral. Alder Hey offered to pay for the second funeral providing the parents used a nominated funeral director.

3.3 When organs were returned to families they were firstly rechecked and a full list made on a second histology record form. This replaced the first list (of four categories) in the file as it contained more detail. A further list was completed when organs were put into caskets in preparation for funeral. More tissue was lost in the casketing process. Some parents came to witness the preparation. To avoid distress Alder Hey had disposed of any messy or liquefied fragments and pieces of faecal matter. On one occasion a tongue was deliberately disposed of in such circumstances.

3.4 In early October Dr Davidson asked the Royal College of Pathologists for assistance with an internal inquiry into the practice of organ retention. The College nominated Dr Stephen Gould, a respected consultant paediatric pathologist at the John Radcliffe Hospital, Oxford. He undertook an enormous amount of work to provide an early provisional report on 20 December 1999. His efforts were overtaken by the appointment of this Inquiry and so his report is incomplete. We have obtained great assistance from his expert professional involvement.

3.5 Meanwhile, some parents began to express concern about the broad description of organs they had received and requested more detail. Alder Hey's response was that any request for a full list of organs would be held for 48 hours to allow parents time to reflect on whether they really wanted the information. In the meantime the list was prepared. The intention was to save parents from further distress. The policy was questioned by Mrs Wendy Natale from the Liverpool Eastern Community Health Council (CHC) who said that waiting 48 hours for a list was likely to aggravate distress and not save it. A further complaint was that communication with parents was by telephone or in writing rather than face to face. Alder Hey was by now overwhelmed at the extent of the crisis.

3.6 At a meeting of parents on 1 November 1999 they discussed their difficulties in obtaining information from Alder Hey, calls not being returned and long delays in securing the return of organs. All these difficulties should have been apparent to Alder Hey. Despite assurances that parents would receive complete lists of retained organs promptly, delays in excess of two weeks were common. The CHC told Ms Rowland that she had a disaster on her hands which required a different strategy if the situation were to be retrieved. It was described to her as 'a juggernaut rolling down a hill out of control'. Ms Rowland declined to attend a meeting with parents on the basis that she had not been formally invited and it was inappropriate for her to attend.

3.7 Parents only received information if they asked for it and many did not know what to ask for in the first place. They began to describe the attitude of Alder Hey as deliberately obstructive and quite simply they did not trust Alder Hey. A support group for parents called 'Parents who Inter Their Young Twice' was set up. It became known as PITY II. This group was to represent and support parents and did so with resolve. The group was instrumental in obtaining a change in the law to allow organs to be cremated when a body has previously been buried (Statutory Instrument 2000 No 58).

3.8 In late November 1999 Alder Hey management offered to meet with PITY II when the Gould report was completed to discuss its findings. However, on 3 December 1999 the new HM Coroner for Liverpool, Mr Andre Rebello, suggested that organ retention was unlawful and the Alder Hey situation became national news again, creating a media scrimmage. Parents' anxieties and concerns heightened. The Government responded immediately by announcing that there would be an independent Inquiry.

4. Counselling

4.1 Facilities for counselling were urgently required. The Alder Centre had been offered but was unsuitable to many parents. They did not wish to visit the site of their grief and distress and they trusted Alder Hey even less by this stage.

4.2 Before Christmas 1999 the CHC had compiled a list of local counselling services which it passed on request to one of the social workers on the Alder Hey help line. Only then did Alder Hey have a list. It is surprising that they had not obtained one from the outset.

5. Unauthorised Sampling of Retained Organs

5.1 In January 2000 it became public knowledge that Alder Hey had been taking small samples of organs before their return without obtaining any further consent, or indeed even telling the parents. It was justified by management as being necessary to complete histology and to preserve the opportunity of advising parents as to any genetic consequences following the death of their child. In most cases this would involve histology on organs preserved in formalin for many years, rendering examination difficult if not impossible. Alder Hey claimed that they had consent to sample organs before return, based upon the consent given for the purpose of the original post mortem examination. Witnesses from Alder Hey were later to concede to the Inquiry that the original 'consent' was invalidly obtained. It was also insensitive not to ask the parents if they objected to the proposal to sample. This was accepted by Alder Hey when they ceased taking further samples without specific consent. We have seen no evidence to demonstrate that histology has yet been attempted in those cases.

5.2 Alder Hey continued to underestimate the effect of organ retention upon parents. Following the publication of the Gould report Ms Rowland compounded her earlier refusal to meet parents, indicating that it would now be inappropriate to discuss the report due to the setting up of this Inquiry. Instead she suggested parental involvement in revising the post mortem consent form.

5.3 Ms Therese Harvey, the Director of Human Resources, took over management of organ retention in February 2000. Some parents found her to be helpful and approachable. There were some improvements with the help line. Better information was made available and administration improved.

5.4 This improvement was not maintained, with increasing complaints of delay, misinformation, missing post mortem reports and discrepancy between post mortem reports and medical records. Parents continued to complain about delays in second funerals and enquire whether organs had been used in research. Alder Hey's attitude was regarded as defensive and unco-operative. There was still a lack of trust. Although some parents felt that Alder Hey was helpful, attentive and considerate, they were a minority.

5.5 A natural consequence of providing more detailed information to parents was that more questions were generated. For example, they wanted to know why organs had been stockpiled, why in some instances their child had been taken from the hospital where death occurred to Alder Hey for post mortem examination without their knowledge or

consent and why the bodies of stillborn children had been stored for many years. It was impossible to provide complete answers in the absence of proper records relating to the source and usage of organs from each child.

5.6 On 23 March 2000 the Chair of the Trust, Mr Frank Taylor, resigned. The trigger was the Stephen White case, the full facts of which are reported in Chapter 4. Firstly Stephen's mother had been told that his heart had been retained. Later she was told that the heart and other organs had been retained. These were subsequently identified as brain and lung. A second funeral was arranged for 17 March 2000. On 15 March Ms Rowland visited Mrs White and told her that Stephen's organs had been mistakenly destroyed. This led to the Parliamentary Under Secretary of State (Lords), Lord Hunt, demanding a report on the incident within 24 hours from the Chief Executive. Ms Rowland provided the first report. There was insufficient detail in it and Lord Hunt asked for a second report which was prepared by the Regional Office. Lord Hunt remained concerned about the level of detail in the second report. However, there was an overriding priority to respond to the parents. He asked officials to inform them and the media, in that order, as a matter of urgency.

5.7 Lord Hunt's reaction to both reports was in our view correct and justified. The explanation of what had happened was publicised together with the announcement of a new Chair of the Trust and new interim guidance from the Chief Medical Officer to the NHS on how to deal with bereaved parents and post mortem examinations. Lord Hunt asked this Inquiry to investigate the circumstances of Stephen's case. He had every reason to act as he did and we confirm his action.

5.8 The case of Stephen White also raised an issue about fragments of organs. The report prepared for Lord Hunt suggested that the hospital had a policy of destroying fragments, which were not considered 'organs'. If this was so then until 21 February 2000, when an instruction from Secretary of State was received to the effect that no further tissue should be destroyed, fragments of organs were destroyed without reference to parents.

5.9 In her evidence to the Inquiry Mrs England explained the reason for the policy. A decision was taken at the outset to inform parents of the retention of either whole organs or substantial parts of organs, but not the many small pieces of fragments, some of which were unidentifiable. Small fragments would have been present in most of the containers. The stated justification was to avoid misleading parents into thinking whole organs had been retained when they had not. The real significance of the concealment of the fragments lies in the inherent disrespect shown to the children's organs. As information unfolded the parents' reaction resulted in them seeking everything belonging to their child including wax blocks, slides, X-rays and photographs.

5.10 As a result of the Stephen White case Ms Rowland ordered a further visual check of all organs retained to prevent further errors. She gave assurances that errors of this kind would not be repeated. However, as the cataloguing of the organs in July 2000 by Dr Gordan Vujanic, Consultant Paediatric Pathologist from Cardiff, shows (see below), these assurances could not be supported.

5.11 In succession to Mr Frank Taylor, the Secretary of State appointed Mrs Judith Greensmith as Chair of the Trust. She surveyed her inheritance and in her evidence to the Inquiry confirmed her initial view that the issue of organ retention had been 'handled on the hoof and people had reacted to crises as they arose'. She gained no sense of any 'audit trail' over what had been decided and why. Ms Rowland stood down and a new Acting Chief Executive, Mr Anthony Bell, was appointed. Mrs Greensmith, with assistance from Regional Office, recruited Mrs Kate Jackson, Director of Primary Care at Morecambe Bay Health Authority, as Project Director to handle the organ issue. She was to manage return of organs and liaison with families.

5.12 A Serious Incident Project Board (SIPB) was set up with a wide group of people represented. In addition to Mrs Greensmith there was Mr Bell, Mrs Jackson, Ms Harvey, Mr Colin Brown from Regional Office, Mr Allan Mowat (the solicitor representing the Trust), representatives from the University, Liverpool Women's Hospital, Liverpool Health Authority, the CHC and two family representatives. Mrs Greensmith also decided to establish a Family Liaison Group comprising ten representatives of affected families with the intention of looking at policy issues and how best to deal with family sensitivities. It was intended that the work would be closely monitored by Regional Office who were to receive fortnightly reports coinciding with the fortnightly Project Board meetings.

5.13 Mrs Greensmith knew that information had dribbled out to parents in two, three or four letters over a period of eight months and she regretted it. Information had had to be gathered from different locations. Mrs Greensmith intended to pull everything together. Following her appointment the atmosphere was said to be optimistic. The policies of openness, better relationships with parents and resolution of long-standing problems were the stated aim. Alder Hey apologised for past handling errors and expressed a willingness to resolve the situation.

5.14 In a press release of 23 March 2000 announcing the appointment of the new Chair, Lord Hunt confirmed that he had instructed the Regional Office to establish robust monitoring procedures to ensure that Alder Hey carried out its responsibilities in dealing with the return of organs effectively and appropriately. Professor Tinston was to take personal responsibility for ensuring arrangements were in place. As a further step, at the instigation of Lord Hunt, Alder Hey retained the services of Professor James Underwood, a respected paediatric pathologist from Sheffield, to advise on the future structuring of pathology services.

5.15 The task for the new regime was daunting. They inherited continuing problems related to sloppy mistakes, poor preparation, incomplete and incorrect information and staff working under excessive pressure. Mrs England and Mrs Waring should have been asked what the protocol was for organ retention following post mortem examination carried out by Professor van Velzen and his team (see Part 2 of 'The van Velzen Years', paragraphs 10.3 and 10.4). The practice, followed in nearly every case, was to retain every organ. The high incidence of containers lacking a full set of organs, coupled with the relatively low level of documented research, leads to the irresistible inference that organs have been lost. There is evidence of disposal as this section illustrates but none of commercial use. Alder Hey should have told the parents from the outset that what remained at Myrtle Street, unless all the organs were present, was simply what was left following research, the records of which were virtually non-existent.

5.16 Alder Hey still did not appear to fully appreciate or understand the parents' concerns. They sent out badly copied and illegible case notes. They promised information that did not arrive or arrived late. Link workers were re-allocated without the knowledge of parents involved. As the number and seriousness of problems increased they did not have any heightened sense of concern or urgency. They sought no additional resource despite the adverse handling outcomes with all the regrettable implications for parents.

5.17 The parents' representatives and the CHC described most of these problems in detail to Mrs Greensmith. They told her how Alder Hey had mishandled the situation so far. Mrs Greensmith could not have been in any doubt about the problems which she had inherited and which persisted.

5.18 In line with the stated policy of openness, the new management team now decided to send a definitive list of all organs retained to the parents. For some parents this was the third of its kind. The first communication with some parents had simply been information as to whether the heart (possibly with lungs) had been retained. The second described four groups of organs retained. In many cases there was a third more detailed list. Now there was this 'definitive' list. The list specified organs from brain to reproductive organs, skin, bone and muscle.

5.19 The content of the letter and the comprehensive nature of the list revealing that all internal organs had been retained shocked many parents. They questioned how and why it differed from previous lists they had received. Questions relating to organs missing from the earlier lists remained unanswered and parents could not trust the information received. Alder Hey should have informed parents that the only information they could provide related to what remained and not to what was taken.

5.20 Finally Alder Hey declared a 'moratorium' in June 2000 under which they would refrain from further disclosure for six weeks in an effort to catalogue precisely what remained. Dr Vujanic, the independent paediatric pathologist from Cardiff, was retained

to carry out the exercise. For the first time Alder Hey seemed to have recognised that this was the starting point for answering the parents' questions. However, even this exercise was doomed to failure because of past mistakes and the lack of records.

5.21 The 'moratorium' prompted a further deterioration in the relationship between parents and Alder Hey in July and August 2000. The parents commented that the situation had reverted to the way it had been before March 2000. They called into question the independence of the SIPB.

6. University Perspective

6.1 At this stage it is necessary to put the position of the University into perspective.

6.2 Between 1989 and 1995 Professor van Velzen worked at Myrtle Street on clinical duties for Alder Hey and on research for the University. He favoured the research work as will appear in 'The van Velzen Years'. The organs removed at post mortem examination at Alder Hey were collected at Myrtle Street where they were regarded as invaluable research material. Research records, the responsibility generally of the University, were unreliable throughout. The collection grew unmonitored and unchecked.

6.3 In 1995 Alder Hey and the University negotiated over the future of the organs. As discussion in Chapter 8 Part 8 of 'The van Velzen Years' will show, most of the organs were left to the University at Myrtle Street where they remained until 1999. During this period the University had sole occupancy of Myrtle Street and still made no attempt to catalogue either the organs or their use. They failed to assist Alder Hey in recent months and in fact have never fully catalogued the organs.

7. University and Alder Hey Relationship

7.1 By July 2000 the parents' representatives were also well aware from attending the SIPB of the poor relationship between Alder Hey and the University. The University was difficult about providing and sharing information. Invited to join the SIPB, they had attended only 4 out of the first 11 meetings, claiming that they were merely observers. The University has consistently failed to acknowledge its proper responsibility on the issue of organ retention.

7.2 One week after the 'moratorium' was lifted in August 2000 a special meeting of the SIPB was convened. The purpose of the meeting was threefold:

- to confirm that the new detailed lists were complete and revealed that organs had been retained from 62 children whose parents Alder Hey had previously told were not affected;
- to reveal the existence of a previously overlooked cerebellum collection;
- to reveal that many hearts at the ICH could not be identified.

7.3 Alder Hey issued a press release referring to the first two issues but omitting reference to the third. Parents on the SIPB had argued for and obtained a 24-hour embargo on the press release to give them the opportunity of warning parents of the impending revelations. There was insufficient time to complete this exercise. Further distress for parents was the inevitable consequence.

7.4 Alder Hey chose to inform parents of this latest 'definitive' list by telephone. They did not check if they were alone, or had support before telling them about the list of organs. It was another example of lessons not having been learned from September 1999. Link workers were described as caring in the way in which they passed on the news, but this did not reduce the impact of receiving over the telephone yet another version of what organs had been retained.

8. Cerebellum Collection

8.1 The cerebellum collection was gathered from brains retained by Professor van Velzen and used for research from 1995 onwards. In August 2000 Alder Hey revealed that 146 families were affected and in particular 58 sets of parents who had already had second funerals had to be told that there were cerebella yet to be buried. Examination of the brains before their return for burial would have revealed the absence of the cerebellum. The University surely held back the existence of the collection in late 1999 for a reason rather than inadvertently. The only reason that occurs to the Inquiry is in order to complete research. They retained the collection despite public knowledge of return of organs for second funerals and the inevitability of third funerals or else concealment.

8.2 The consequence of the announcement of the collection was that parents were yet again dismayed, disillusioned and distressed. Parents were telephoned at home with the news and were told that the cerebellum belonging to their deceased child had been retained. One parent was told that their child's cerebellum had been retained and was later told that it had not. Alder Hey thought they were in a position to give parents clear answers to all the outstanding issues and resolve past errors. They still have not told the parents that the general practice was to remove every organ from every child between September 1988 and the end of 1995.

8.3 Another issue emerged. Some parents became aware that Alder Hey was still retaining blocks and slides taken from organs and requested their return. Alder Hey's response has been inconsistent, depending upon how they perceived the likely reactions of parents. Sometimes they have denied the existence of blocks and slides. On occasions they have returned them. Sometimes they have claimed that they cannot be returned as they constitute a medical record, on other occasions they have claimed that the blocks and slides constitute a medical record which may not be returned until ten years have elapsed. The policy of openness and honesty was compromised.

8.4 The case of Christopher, who died in 1988, aptly summarises general feeling among parents. On 5 September 2000 Christopher's father wrote to the Inquiry complaining that he had asked the SIPB what had happened to the remainder of his son's organs. At the outset he had been told that his son's heart, lungs and brain had been retained. Later he received a comprehensive list of other organs which had been removed at post mortem examination. He asked where these organs were, but the response was inconclusive. Karen England misrepresented that Professor van Velzen's practice was to return organs to the body before burial. Christopher's father contacted Professor van Velzen directly and he correctly denied the practice. The organs remain unaccounted for even by the end of October 2000. Christopher's father was also told that blocks and slides taken at post mortem examination were part of the medical record and could not be returned, despite the fact that Christopher had died more than ten years earlier. The pious hope was expressed that explanations given would help to put his father's mind at rest. The central concern remains unanswered.

9. Conclusions

9.1 We have come to the following conclusions:

- The University and Alder Hey missed many opportunities to rein in and control Professor van Velzen in the period 1988 to 1995.
- The University and Alder Hey failed regularly to record access to the containers for whatever purpose.
- The University and Alder Hey failed to investigate post mortem practice in the period 1988 to 1995 which would have indicated that all organs were to be retained in every case.
- The University and Alder Hey should have retained a paediatric pathologist to head a team to catalogue the retained organs and fragments in September 1999.
- The catalogue would have revealed that it was impossible to account accurately for all the organs retained.

- The University and Alder Hey will never be able accurately to tell parents what has happened to every organ of every child who died between 1988 to 1995.
- The University has never accepted its responsibility in the matter and has left Alder Hey to make a sequence of mistakes.
- Alder Hey have made four or five separate attempts to provide parents with accurate information relating to organ retention, not learning from and compounding mistakes made in each previous attempt.
- The cerebellum collection should have been identified and revealed earlier by both the University and Alder Hey.
- Alder Hey failed to make provision for face to face communication of the news to parents.
- Alder Hey failed to make appropriate provision for advice, counselling and support to affected families.

9.2 We appreciate that in September 1999 Alder Hey was faced with a unique situation in terms of the amount and condition of organs at Myrtle Street. They had no control over the timing of the revelation at Bristol relating to the heart collection at the ICH. This was followed by an unprecedented number of parents requiring detailed information about organs retained from their children over an extensive period of time.

10. Recommendations

10.1 To prevent mishandling of this kind in the future we make the following recommendations:

- Serious Incident Procedures should be developed and put in place.
- In the event of a serious incident the Chief Executive and Trust Board shall devise a suitable Serious Incident Procedure similar to those already in place for major disasters and review it from time to time making any necessary alterations.
- When the procedure has been devised and prior to implementation the NHS Executive Regional Office shall assess its suitability and thereafter manage its performance, devising and instigating any necessary alterations from time to time.
- In devising a Serious Incident Procedure the Chief Executive and Trust Board shall consider the need for a serious incident team independent of the hospital.
- In devising a Serious Incident Procedure the Chief Executive and Trust Board shall consider the need for urgent professional counselling:

  - A proportion of individuals within any group is always likely to require psychological support in the aftermath of disaster.
  - An individual within the serious incident team shall be nominated to take responsibility for the arrangements and the identification of all those in need.
  - Suitably trained practitioners shall provide the counselling.
- In devising a Serious Incident Procedure the Chief Executive and Trust Board shall take advice from and where necessary include within the serious incident team appropriate experts in bereavement, pathological reactions to bereavement and therapy.
- The Chief Executive and Trust Board shall make available suitably trained staff for implementing the Serious Incident Procedure.
- The Chief Executive and Trust Board shall inform all staff when a Serious Incident Procedure is in force.
- The Chief Executive and Trust Board shall ensure the proper debriefing and support of all staff associated with a serious incident.
- Universities and other public bodies shall adopt compatible procedures when acting in conjunction with an NHS serious incident.

10.2 Records should be reviewed and updated and an audit trail should be developed and put in place.

- The Chief Executive and the Trust Board shall review and update medical and pathology records to include, preferably on computer and cross-referenced, the following information:
  - name, medical record reference number and date of birth;
  - date, place of death and death certificate;
  - name and address of next of kin;
  - whether Coroner's or hospital post mortem examination;
  - date of consent for hospital post mortem examination;
  - names of pathologist and those in attendance;
  - post mortem examination reference number;
  - date of examination;
  - date of preliminary/final post mortem reports;

  - date histology completed;
  - record of specific instructions from the Coroner or clinicians;
  - record of retained organs, samples, wax blocks, slides, photographs, X-rays, date and method of dispersal or disposal;
  - case notes;
  - signed consent form;
  - copy of any other relevant correspondence or notes;
  - name and address of general practitioner;
  - date post mortem report sent to general practitioner;
  - record of communication of findings to the next of kin.
- University records shall provide a confidential audit trail back to the clinical record.
- University records shall identify receipt, use, dispersal and ultimate disposal of any organ or sample.