

Chapter 14. Parents' Evidence

The strength of the parents' evidence is such that the only way to do it justice is to set out faithful summaries. Wherever possible we have endeavoured to use the parents' own language in the narrative. We have adopted the simple strategy of introducing each summary with the child's first name, age and year of death. We do this as a mark of respect and also as a permanent memory of their involvement in and contribution to the Inquiry, while preserving the anonymity of their family. On occasions the word stillbirth has been used by parents but not always in the strict legal sense.

We commend the summaries to all who read them for their compelling content, understandable and reasonable expression of emotion, consistency of response and identification of recurrent concerns.

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Oral Evidence

Craig – 10 Days

Craig was born with congenital heart disease. He died while undergoing heart surgery at Alder Hey Hospital in 1986. His parents were told by telephone that he had died at 6.45pm.

In late 1999 they discovered that the medical records and post mortem report recorded the time of death as 7.50pm. Immediately prior to death his parents offered to donate his liver and kidneys if Craig died. They were told that his condition was too poor for his organs to be of use.

Shortly after they were told about his death his parents rang the hospital to make arrangements to see him. The nurse was insistent that they did not visit because it would be very upsetting and that they should leave it for a day or two.

They visited the hospital two days later and were told that a Coroner's post mortem would have to be carried out as a matter of procedure. When they saw the post mortem report in 1999 they discovered that post mortem examination had in fact been carried out on the previous day without their knowledge. They were never seen by the paediatric cardiologist or surgeon following Craig's death.

They received a letter from the paediatric cardiologist explaining the death but were not told that his heart and lungs had been retained. They were devastated to learn of this in 1999. They thought that they had buried their son intact.

In retrospect they would not have given consent for retention of the heart and lungs in a collection. They would have postponed the funeral to permit tissue sampling from the heart and lungs. They offered to donate organs to save the life of another child.

On learning of the organ retention in late 1999 they contacted Alder Hey who refused to answer even the most basic question and were told that the medical records had gone astray. His mother said that if the surgeon or paediatric cardiologist had told her of the benefit to medical science and to other children of keeping the heart and lungs in a collection in order to advance medical science, she would have considered donation but only after discussing it with her husband.

The question of genetic counselling following his death was never addressed. His parents expected an interview following death to explain the cause of death. It did not happen. They were never provided with a copy of the post mortem report at the time.

In 1999 they were provided with the post mortem report but it was not explained to them. After their initial contact with Alder Hey they had to wait three days for information about retention of the heart and lungs.

They express the need for the secrecy to end now and for the truth to come out. They wonder whether experimental surgery was carried out on their child. They did not know how seriously ill Craig was when surgery was carried out. Had they known they would not have consented to it.

They do not expect medical research to stop. They do not know how much truth will emerge at the Inquiry from Alder Hey. It is their view that there will be a lot of people with very loose memories stating that they cannot remember events so far back.

They want changes in the culture within the departments they dealt with. They feel they were entitled to full knowledge of what was being done to their son at the time of death and not so long after the event.

Sean – 15½ Months

Sean was born with congenital heart disease. He died while undergoing heart surgery at Alder Hey Hospital in 1997. His parents had been told that the chance of successful surgery was 80 per cent. Twelve hours after death the cardiac surgeon told them that they could have a Coroner's post mortem examination but that a hospital post mortem examination would be quicker. They had no opportunity to take independent advice nor time for reflection. The consent form was marked 'limited to heart and lungs only'. Apparently the death had been reported to the Coroner but a hospital post mortem examination was carried out.

His parents expressed to us a primal need to protect Sean even in death. They thought that tissue was a microscopic sample of an organ. Had they been told that the heart and lungs would be removed at post mortem and retained after burial they would have forbidden post mortem examination.

Their treating clinician met with them to discuss the post mortem report but merely stated that Sean's heart could not cope with the operation. There was no proper explanation.

They felt a sense of revulsion on discovering that the heart had been retained. They felt betrayed because the cardiac surgeon and paediatrician had not told them that the heart and lungs were to be removed and retained. It is their view that they would still have been ignorant of the retention but for Professor Anderson's evidence at the Bristol Inquiry.

In memory of Sean and to reflect the outstanding treatment in life he had received from Alder Hey, family friends and work colleagues raised £2,000 for Alder Hey. Shortly after this charitable effort they were informed by Alder Hey that Sean's heart and lungs had been retained. This was late 1999.

On initial contact Alder Hey made a mistake as to Sean's name. It took weeks of telephone calls to secure the release of his heart. Without seeking permission from his parents and immediately before return of the heart and lungs the hospital sampled them. The parents felt

betrayed by retention and last minute sampling. In consequence they question whether it was Sean's heart which was returned to them. They regard Alder Hey's handling of the organ retention issue as unprofessional. They are concerned that as Sean died in surgery there should have been a Coroner's instead of a hospital post mortem.

On the issue of organ retention they cannot accept that the Chief Executive and management knew nothing about it. They should have done if they were proper managers. The parents said it was appalling that the hospital should blame loss of income from charitable donations upon the issue of organ retention.

On the evening prior to surgery they were given a very detailed explanation of what the surgery would involve. They expected but were denied the same detailed explanation of what a post mortem examination involved. They also want to know why at post mortem samples were taken from the thyroid, oesophagus and trachea.

They identify the need for proper management procedures, fully informed consent and the need for truth. They say an upheaval is needed in all these areas to prevent the Alder Hey experience occurring again.

Philip – 3 Months

Philip was one of twins. He died in his pram in 1988 apparently from Sudden Infant Death Syndrome. His body was taken to hospital and removed from his parents by a nurse. They were not told where the body was held for four days. During this time a Coroner's post mortem was carried out without their knowledge. All the organs including the heart and brain were removed and retained without parental consent.

A nurse at Alder Hey eventually told them that Philip's body was in the mortuary at Alder Hey. His twin was being investigated at Alder Hey for signs or symptoms of any condition which might cause him to die in similar circumstances.

When the family saw Philip in the mortuary the post mortem had caused his features to drop to the back of his head. Mother described his appearance as horrible. This was the first time that the family had seen him since he had been taken from them on admission to hospital. Neither his father nor his mother had been offered any time with Philip before he was taken from them.

Subsequently at a Foundation of Infant Deaths Conference they met Professor van Velzen who had carried out the post mortem examination. He said that Philip's organs were normal and there was no explanation for his death. He said 'it was rather like buying a light bulb and the shop testing it before taking it home yet when the bulb was fitted at home it failed'!

Philip's twin was detained in hospital on and off for three months and underwent very extensive, distressing tests. In the end there was no obvious conclusion to the tests and his parents took him home.

His parents discovered that Philip's organs had been retained in December 1999. Initially they were told of partial retention. They were then told of the full extent of the retention, from brain to reproductive organs, and were shocked. A second burial took place in January 2000. It had always been their desire to bury their child intact.

They feel that they were told lies by Alder Hey in December 1999. This has left them with concerns about whether Philip's organs have been used for pharmaceutical research and whether his eyes were removed. They were incredulous at retention of his reproductive organs and this in itself raised the incidence of suspicion.

Their overriding concern is why the organs were retained. If some useful research had been carried out it might have comforted them. They regard storage without research as totally futile.

They feel that they were treated cruelly in not being given time to grieve in Philip's company shortly after death. They feel deceived about the organ retention issue. They were distressed on discovering the extent of the retention 11 years after the event.

They have done their best to protect themselves and their children from the consequences of their loss. Their view is that to be left ignorant of the retention and then finding out about it 11 years later is too cruel in all the circumstances and no parent should go through that.

They feel that the hospital should have talked them through every stage of bereavement including post mortem examination. They would have wanted to know the basic post mortem procedure and this might have alerted them to the possibility of retention. They feel they might have been able to prevent it.

Sisters: Claire – 7 Days
 Heather – 2 Days

Claire was born with congenital heart disease. She died in theatre at the Royal Liverpool Children's Hospital in 1982. Her parents were told that there was no need for them to attend the hospital immediately. They were told to wait until Monday for the paper work to be completed to secure release of Claire's body. There was no mention of a post mortem examination. They did not see Claire for eight days.

They contacted Alder Hey Hospital on 18 October 1999 and discovered that Claire's heart and lungs had been retained. It took 11 weeks 3 days for them to be provided with legible medical notes relating to Claire. They then discovered, 17 years after the event, that there had been a Coroner's post mortem examination! They are still awaiting a copy of the post mortem report.

They first saw the death certificate in early 2000. They feel guilty for showing blind faith in everything they were told by the doctors. They were referred for genetic counselling by their General Practitioner.

The parents are left with the feeling that after Claire died the only thing that was wanted of them by the medical profession was to come over to conclude the paper work.

Heather was born like her sister Claire with congenital heart disease. She died in theatre at the Royal Liverpool Children's Hospital in 1984. The cardiac surgeon reported the death to the Coroner and a Coroner's post mortem was carried out. After the death of Heather the parents felt they were treated as though they did not exist.

When she became pregnant with Heather her mother expressed concerns over Claire's death to the doctors but they thought she was overreacting. They said that she had no need to worry. Claire was the last time and it was not going to happen again. They seemed dismissive about the chances of Heather being born with congenital heart disease.

They discovered in October 1999 that Heather's heart had been retained. There had been no discussion with the cardiac surgeon of the possibility of retention or the benefits of medical research or teaching.

They wanted an explanation from the doctors as to the death of both daughters. The parents were merely told that the post mortem examinations confirmed the causes of death but the reports themselves were not explained to them.

They feel that Alder Hey has handled the issue insensitively. They discovered the fact of organ retention on 18 October 1999. Their link worker left in December 1999 and thereafter every contact was beset with the problem of having to explain the whole situation with regard to both daughters to a new person. They feel that Alder Hey should have set up a special unit to deal with enquiries. They should have been invited to sit down and see everything concerning their daughters. They could have taken decisions there and then instead of having to deal with the stress of repeated enquiries. They were stunned that at the time of the death of each daughter they were not told that the hearts would be removed and retained in a collection.

Until recently both parents had carried organ donor cards for many years. They would have donated their daughters' organs to another child. They would have seriously considered the organs being used for research but they were never asked. The right to decide the fate of their daughters' bodies was taken away from them. After the death of Heather her parents were even more inclined to agree to their daughter's heart being used for medical research and teaching purposes.

They should have been told what was involved in the post mortem examination. If they had known that organs were removed they would have ensured that they were replaced in the body before burial, or used or disposed of in accordance with their wishes. They were denied the opportunity of asking what the organs would be used for, where they were to be taken and what the final outcome would be.

The parents fully accept that the medical profession will never discover anything in the future without research. They remain uneasy as to whether other organs were retained. This is fuelled by Alder Hey's inability to confirm anything to them.

They were prepared, in 1999, if they had been reassured by Alder Hey, to have allowed their daughters' organs to have remained at the hospital for medical research and teaching purposes.

They did not discover that Heather's heart was in the heart collection at Alder Hey until they gave evidence at the Inquiry. Had they been told that their children's hearts were being used for teaching purposes they would have allowed them to stay there. Alder Hey were not prepared to give this type of information. The parents cannot now decide whether to bury the hearts or leave them where they are.

They are concerned that the hospital took away their basic right of making a choice. They want to know who took the decisions to keep the organs without consent, why they did it, what the organs have been used for and what the purpose was.

They say that the Coroner should have been more alert to what was going on at Alder Hey. They did not even know the Coroner was involved with Claire. They had no contact with the Coroner at all. They think it should be up to the Coroner's office to make sure the parents are fully aware of what is going on.

Kathryn – 15 Years

Kathryn developed Hodgkin's disease and died at Alder Hey Hospital in 1993. Because of the extent of her condition she had undergone a bone marrow transplant. Her parents are concerned as to whether she died from complications arising from 'Beam' chemotherapy, which they subsequently discovered to be an experimental treatment for a 15-year-old.

Less than one hour after her death the clinician asked for permission for a post mortem examination. They were told that small tissue samples only would be taken through a restricted incision from the lung, liver and kidney. They consented to a limited post mortem examination. This failed to isolate any causative organism for infection causing or contributing to Kathryn's death.

Shortly after Kathryn's death her parents signed a handwritten consent form which read as follows:

'We the parents of Kathryn give permission for removal of tissue for diagnostic and other purposes other than transplantation.'

In a letter dated 27 September 1993 from the consultant haematologist to the parents' general practitioner there is reference to permission having been granted for a limited post mortem.

Prior to her death, Kathryn had been deteriorating under her chemotherapy regime for 7½ weeks. On 19, 20, 22 and 23 August 1993 Kathryn and her parents requested that she be allowed home but this was refused. Her parents feel that had she been allowed home she would not have been stripped of her organs and she would have been buried with respect and dignity.

On 8 December 1999, her parents were informed by Alder Hey that Kathryn's heart, chest and abdomen had been retained. On 20 December 1999 they received a letter from Ms Hilary Rowland, Chief Executive at Alder Hey, indicating that the heart, lung, liver, spleen and kidneys had been retained. In the post mortem report Professor van Velzen said that only a small mid-sternal incision approach was made with splitting of the caudal sternum. Only the upper organs and the lower aspects of the chest organs were brought in to view and inspected. The remainder of the assessment was done on palpation. Only organ biopsies were taken. This was a fiction confirmed by the list of organs described by Ms Rowland in her letter of 20 December 1999.

When matters came to light on 8 December 1999 the parents had to wait 13 weeks for Kathryn's clinical notes. They make the point that they did not consent to the 'Beam' treatment nor the sampling of organs beyond the lung, liver and kidney. They did not know she had been buried without her lungs, liver, kidney, heart and spleen. They remain concerned that other organs may have been retained. They do not trust the management at Alder Hey.

Their view is that parents are generous when a child dies. Even now they want to make things better. They do not want others to go through what they have been through. People should be given as much information as possible to make informed decisions, whether it is life or death. There is a need to respect human beings, their wishes, and all human beings should be treated with dignity. Society owes the truth to the children who have died. They have been lied to on several occasions not only by Professor van Velzen but also by management. Parents feel that they have been deceived and treated with insensitivity. They cannot trust anything the hospital says.

Gareth – 2 Months

Gareth was born with congenital heart disease and referred to Alder Hey where he died in 1993 following major heart surgery. The clinicians had advised the parents that the surgery had an 80 per cent chance of success. Shortly after death the cardiac surgeon told the parents that there had to be a post mortem examination.

In describing the failed surgery the surgeon was angry, incredulous at failure, blunt and insensitive. He upset the parents by referring to the need for an Inquest. The paediatric cardiologist was insensitive when he said words to the effect – 'Do not worry. You can have another baby.' The parents' overriding concern with Gareth was that he died despite the cardiac surgeon describing the operation as a complete technical success.

They telephoned the Alder Hey help line in the first week of October 1999 and it was confirmed on 8 October 1999 that Gareth's organs had been retained. At first it was only the heart and then later heart and organs and finally heart and lungs. Alder Hey would not answer questions raised by the parents about what use had been made of the organs. In a letter dated 21 January 2000 Ms Rowland wrote to the parents stating that the hospital did accept that many parents felt misled and did not fully understand that their child's organs had been retained. She did not answer the question whether the organs had been used for research purposes.

The parents were taken through the post mortem report by their general practitioner. The report indicates that the post mortem examination was carried out ten minutes after death. This is likely to be yet another mistake. If it is not a mistake then the post mortem was carried out before the parents had had the chance to say goodbye to Gareth.

The parents found Ms Rowland's letter dated 21 January 2000 incredibly insensitive. They never remotely anticipated organ retention. It was never broached with them and they had not signed a consent form. They had difficulty obtaining information from Alder Hey. A second burial was only possible in December 1999 because Gareth's father intervened to secure the organ release documentation. Even so the time scale was too tight and caused unnecessary distress. It had been a fight to secure release of the organs.

They described the handling as appalling, incompetent and insensitive. Even after discovering retention of their son's heart and lungs without their knowledge or consent they would have considered leaving the organs with Alder Hey had they been useful for research/training purposes. Alder Hey would not answer their questions with regard to use of the organs and therefore they reclaimed them for burial.

In her letter dated 21 January 2000 Ms Rowland admitted that the heart and lungs had been used for research/training. Prior to giving this information Alder Hey had commented in the Daily Post (11.12.1999) that hearts had been kept for extensive research and had been used regularly for teaching and by consultants. The parents feel that they have been treated with complete lack of respect. Had this information been conveyed to them earlier then the second funeral would not have been necessary because they would have allowed the organs to remain with Alder Hey for research.

They are grateful that the hospital is attempting to put something right. There is an opportunity to improve the chances of survival for children born with congenital heart disease. Parents should consider leaving organs for research purposes. If the reasons are sympathetically explained they feel many parents would agree.

In their case they would have preferred Gareth's body to be buried intact but if the case for retention had been put forward properly they would have seriously considered it. Alder Hey has failed to answer their questions as to what the organs have been used for.

For the future the parents want a situation where it is clear in whose power the body rests so that if the hospital wants organs it has no option but to go back to that person for their consent. There is a need for doctors to be honest and open about things. More time is needed at the point of death with appropriate counselling and sufficient opportunity to consider what has happened and what the arrangements should be for the future. They would prefer all the arrangements they discuss to be in a legislative framework.

Ross – 5 Months

Ross was born prematurely at 27 weeks and died in 1990 at Liverpool Maternity Hospital. The cause of death was cardio-respiratory arrest consequent upon chronic lung disease. His parents consented to a post mortem examination to determine the cause of death if it would help other children who had the same disease. No steps were taken to explain the consent form to them. Because of their distress they describe signing it 'blind'. They realised that samples would be taken from organs in the post mortem procedure but understood that to mean a small piece of tissue for microscopic examination.

They were never told that whole organs would be removed and retained. The question of retention of organs was never mentioned. They thought they had buried their son intact whereas in fact they buried a husk. They insist on the need for fully informed consent and the right to bury a body intact unless express consent is obtained for retention of organs.

In early November 1999 his parents were informed that all Ross' organs had been removed and retained. His mother was employed as a nurse by Alder Hey and she was expected to continue working. She was offered neither counselling nor medical treatment. Her husband's employer provided counselling and appropriate leave of absence. In short they looked after their own which Alder Hey did not.

In November 1999 the whole of Ross' organs were returned by Alder Hey and buried. As they interred the organs they discovered that the casket bore the inscription for a child of 4 years 2 months yet Ross was only 5 months old when he died. This caused additional unnecessary grief and anguish.

His parents were angry that there was never any discussion following death of the desire or intention to retain organs. Had they been asked for retention of the heart and lungs to investigate and research chronic lung disease they would have agreed. His parents at death asked Alder Hey if they wanted the heart or other organs to use for the benefit of other children. They would have agreed to the heart entering the heart collection for medical research and teaching purposes at the time.

Had the hospital wanted other organs and explained the need fully they would have discussed the matter in depth. They would have welcomed counselling following the death of Ross. That person could have helped them understand the consent form they signed. As it was they felt pressurised by the circumstances.

His parents knew that body parts were removed for weighing at post mortem examination and that tissue samples would be taken for microscopic examination but they assumed that the body parts would be returned for burial. Nobody told them to the contrary. As to donation of the heart and lungs the parents said it was not a problem because they believed it was helping and it was their contribution to help other children with similar problems to Ross. They said that they were great ones for research and everything else. There was never a problem. Had the hospital turned round and said that it wanted to take the heart for research purposes or for teaching students or whatever the parents would have agreed.

They feel deceived and cheated at the way removal and retention took place without their knowledge. Alder Hey lost the opportunity of benefiting others from Ross' death. It appears that Alder Hey were not even aware that a nurse was involved in the issue of organ removal and retention until somebody brought it up at a meeting several months after the event. This seems to reflect the insensitive and unprofessional way Alder Hey had handled the issue.

Thomas – 3 Months

Thomas was born with a congenital cardiac defect which had been diagnosed before birth. Following birth he was transferred to Alder Hey where he underwent major heart surgery and died in 1992 in the intensive care unit. The cardiac surgeon requested a post mortem examination which was refused by the parents. They were told it would help other children in similar cases and they agreed. They were then asked whether organs could be retained after post mortem examination. They replied 'Absolutely not, no way'.

When his father was asked to sign the consent form for post mortem examination he was asked again if organs could be retained. Before signing the consent form he asked whether he was consenting to organ retention and the doctor said he was not. His parents did not consent to retention of the heart. They regarded tissue removal as being unrelated to organ retention.

The funeral took place four days after death and his parents thought that Thomas was cremated intact. On the basis that Alder Hey had done everything possible to save Thomas' life his parents sponsored a raffle and raised £250 for Alder Hey. They were not offered counselling by Alder Hey. They received genetic counselling from another hospital.

His parents contacted Alder Hey about organ retention in September 1999. It took three telephone calls before organ retention was admitted. His parents described the way they were treated by Alder Hey as very bad, dishonest and patronising. They feel they have been lied to on several occasions. They feel betrayed, let down and angry.

They eventually received a letter of apology from Alder Hey. It was addressed to their deceased son Thomas. This caused further upset. They asked, but were never told, where the heart had been kept for more than seven years. Had their wishes at post mortem examination been complied with there would have been no need for a second funeral in December 1999.

They were told by Alder Hey that most parents were trying to rebuild their lives and were getting on with it. The parents feel that Thomas was butchered and are furious. The post mortem consent form was altered after father had signed it in that 'heart only' was included. This was at a time when both parents had refused anything other than sampling of tissue so that Thomas would be cremated intact. They say that on the issue of post mortem examination Alder Hey acted contrary to their consent. They were lied to and deceived.

Michael – 4½ Months

Michael was born with congenital heart disease. He died nine days after major heart surgery at Alder Hey in 1989. His parents had been told there was very little risk at surgery. They were told of his death by Mr Roy Barter, HM Coroner of Liverpool. The purpose of his call was to inform them that a Coroner's post mortem examination was to be carried out. They were told by Alder Hey when the post mortem examination would be carried out after which the body would be available for the funeral. They received a telephone call of condolence from the treating clinician but no mention was made of organ retention.

They discovered the fact of organ retention on 11 October 1999 and were told that the heart, brain, chest and abdomen had been retained. They were told that Alder Hey would pay for the second funeral and the Co-operative funeral directors would be retained. The hospital wanted a disposal decision immediately. His parents requested more information from Alder Hey. They were asked whether they really wanted to know and what difference would it make. They were treated with indifference.

Twenty-four days after their first request they were told that the brain, heart, lungs, liver, spleen, kidneys and intestine had been retained. There was no mention of the thymus, pancreas or adrenal glands. In one of the post mortem reports, however, these were recorded as retained but have not been located. They discovered that there were two post mortem reports, each with a different cause of death. The first provided by Professor van Velzen was incomplete. The Coroner appears to have acted upon an incomplete post mortem examination report and not chased the completed report.

They have received no apology from Alder Hey. The hospital seems to have been reluctant to give information as well as being defensive and insensitive.

His parents' aim has been to try to restore faith and confidence in Alder Hey. In fact they feel that the hospital has treated PITY II and the parents generally as enemies. Michael's parents feel an intense need to know what happened. They have asked to speak to Mrs Karen England,

the senior laboratory technician working with Professor van Velzen in 1989. They were told such contact was inappropriate. Ms Hilary Rowland, Chief Executive at Alder Hey confirmed that Mrs England was a key figure and this was possibly the reason why it was inappropriate for her to be seen by the parents.

His parents describe a catalogue of errors, disasters, misinformation, insensitivity, long delays, missing medical notes and post mortem reports on the part of Alder Hey. No explanation has been provided as to why there are two post mortem reports.

They were told by the clinician that it was Professor van Velzen's decision to retain the heart and other organs to allow further studies so that a more accurate cause of death could be established. They were told by Professor van Velzen that the Coroner never questioned the fact that the post mortem reports were preliminary. The parents gave no consent, either before or after the post mortem examination, for the removal of tissue or organs.

Any parent receiving the body of their loved one back for cremation or burial should have the confidence that the body is intact. They would have agreed to microscopic examination of tissue from the body so long as the body was intact for funeral purposes. In failing to do this the hospital deprived the parents of choice. Their views were never taken into consideration.

They also complain that the hospital restricted the supply of information to the link worker who then passed on limited information to them on the basis that they were being told everything, only to find out that the information was incomplete. Eleven years after Michael's death they remain in a state of anguish and turmoil.

Jake – 2 Months

Jake was born with congenital heart disease. He underwent treatment at Alder Hey and Great Ormond Street. He died in 1998. His parents have great admiration for the help and treatment received from Alder Hey during Jake's life and in particular from the intensivists.

His parents wanted to know precisely why Jake had died. They were told that there could be a limited post mortem. They signed a consent form limited to chest only. They understood that only the heart and lungs would be examined and this was written in bold on the consent form. Tissue was to be taken for microscopic examination. They were told that the body would be returned intact.

They were not told that the heart and lungs would be retained. A leaflet was supplied to them which stated that tissue samples would be taken and nothing was said about organ retention. His parents had already offered to donate Jake's organs but this had been declined on medical grounds. They assumed that the heart and lungs would be removed for examination, tissue taken and the organs returned to the body for burial.

During Jake's life they had the utmost admiration for the doctors, nurses and staff on the intensive care unit at Alder Hey. They told us that to this day they would still support Alder Hey and refer any of their other children with a serious illness. It was only after Jake died that things went wrong and were not properly explained. Retention of organs has caused them distress.

In September or October 1999 they rang Alder Hey to enquire whether Jake's heart had been retained. They had to wait for three weeks before retention was confirmed. In February 2000 they were informed that the lungs had also been retained. There was a second funeral in March 2000 which caused immense distress. They buried the casket containing the heart and lungs on top of the coffin which they had laid to rest 18 months earlier. It was particularly difficult for them when the casket was lowered on top of the coffin. They cannot describe their precise emotions.

In life they were told everything about Jake's treatment. In death they should have been told everything about post mortem examination. They had a right to know.

There should have been better and quicker communication about organ retention. There should have been a proper inventory of what was retained. There should not have been a three month gap between discovering that the heart had been retained and subsequently that the lungs had also been retained. They have not had an explanation from Alder Hey. They were offered counselling but declined because theirs is a strong family.

A proper explanation as to what post mortem examination involved and of the need for removal and retention of organs would have resulted in consent. In addition they would probably have consented to the heart being examined and retained in the heart collection.

They hoped that what was actively requested at post mortem examination was to further their own and the clinician's knowledge. They were both willing to consider organ retention if only someone had bothered to ask them openly and frankly. Post mortem consent forms need to be clearer.

They told us 'Jake nearly died a couple of times over a couple of weekends. Where else do you get the actual doctors and nurses crying with you! That is how close and how caring they were. They were actually heartfelt with us.'

They are saddened that the concealment of organ retention has threatened their appreciation and admiration of all that was done to save Jake's life.

Georgina – 3 Days

Georgina was born with a congenital heart disease. She died in theatre in 1995. Her parents were told quite bluntly that a Coroner's post mortem was required as a matter of law and that one reason was to make sure surgeons were performing properly. Their complaint is that the matter was dealt with arrogantly and that there was a lack of communication about the reason why a Coroner's post mortem was necessary.

They asked whether any organ would be useful for donation. Their offer was refused. They asked whether the heart would be needed for future reference and were told that the hospital did not retain organs for future study. Nobody told them why Georgina was a 'cardiac' baby. Her mother thought they might have needed organs to research the illness more thoroughly. The parents would have considered organ donation to another child or for medical research so that Georgina's life was not useless.

They were told to register the birth in Manchester and the death in Liverpool. Later they discovered both could have been dealt with in Liverpool.

They discovered the issue of organ retention in mid-October 1999. They contacted Alder Hey and asked if Georgina's heart had been retained. Three days later they were told that Alder Hey was having problems finding out. The following Monday they were told that Alder Hey did not have Georgina's heart. Her parents asked if they had anything else. Alder Hey told them that there was something else but they were not too sure what it was. Alder Hey telephoned three days later and said that they had still not heard. This message was repeated the following day. Following the intervening weekend they were told that the brain had been retained and it had not been examined.

Her parents requested the post mortem examination report. Alder Hey was reluctant to provide it. Subsequently they obtained one report of six pages and a second report of 16 pages. Each was carried out by a different pathologist. No explanation has been provided.

They never received an apology. They have lost trust in Alder Hey and feel that there has been a cover-up. They were invited to the hospital to ask questions but no apology or answers as to why the brain had been retained were given. They asked to see a brain surgeon but were told none was available. At the hospital they were told that it had done nothing wrong and everything was in the interests of furthering scientific development.

A letter from the Chief Executive Ms Rowland failed to answer the question as to why the brain was retained when Georgina had died from a heart defect. Ms Rowland was unable to answer the question about what information had been gathered from examination of the brain at post mortem. Similarly she was unable to answer what subsequent information and research was gathered from the brain and if no research had been done why it had been retained.

The parents feel that the hospital has lied and tried to justify its actions. Having been told by the cardiac surgeon that Georgina's heart was too badly damaged to be retained they are distressed that they were not told that other organs and in particular the brain might be retained.

They had a distressing second burial on New Year's Eve 1999. Their overriding view is that the hospital has just covered up and that it never had any intention of ever telling them of the retention of the brain until the revelation at the Bristol Inquiry. Alder Hey confirmed in writing that they have retained the brain but they will not put in writing that they have not retained anything else.

Delay in receiving information of brain retention, the distress of the second funeral and the realisation that they had not buried their daughter whole in 1995 has had a profound effect upon the family.

However, throughout it all her mother says that when she closes her eyes tight her baby comes through with blond hair, chubby legs and cheeks and bright blue eyes. The smell of her when she held her and the feelings when she was born all rush through her. Nobody can destroy that but Alder Hey's handling of organ retention has come very close.

Marie – 6½ Months

Marie died in 1962. The delayed diagnosis was of congenital heart defect. Prior to death her parents' general practitioner had told them that he did not want anything more to do with them because they were complaining to him on a daily basis about Marie's allegedly declining health. He told them to take her to hospital and he rang the hospital to tell them they were coming. At the hospital they were kept waiting and eventually a house officer came and asked them if they were the couple who did not want their child. They were staggered at the general practitioner's representation to the hospital. The house officer rang the GP and confirmed that Marie was extremely ill.

Marie remained in hospital for three months and died quite suddenly. On the evening of her death her parents had been sent home by the hospital to rest. They were then told by a policeman, who came to their house, that they were required back at the hospital. They sat in an office and waited for someone to tell them what had happened. While looking over the desk mother saw Marie's death certificate. She went straight to Marie's room but was not allowed to hold her.

Her parents would not have given consent to the taking of organs for medical research or teaching but they would have considered organ donation to save the life of another child. They did not sign a post mortem consent form.

In 1973 Marie's mother trained as a nurse and worked at the hospital where she was allocated to the same ward on which Marie died. She told her tutor who said that she either got on with it or went home and that would be the end of her training. She thinks the tutor did her a favour in helping her get over the problem!

She rang Alder Hey to enquire about organ retention on 2 February 2000 and was told on the 13 February that Marie's heart and lungs had been retained and subsequently this was altered to heart only. She was physically and mentally devastated when she realised that she had not buried Marie intact.

She is concerned that the medical profession should be stopped from walking over the rights of patients and their families. She complains of the long-winded release procedure for the second burial which occurred in April 2000. Her faith in the medical profession has been rocked. The second funeral caused her to rake over memories of losing Marie in the first place.

She commends the co-ordinator Ms Betsy Fitzgerald who gave her the bad news in a very humane and helpful way. She could not have been told in a nicer way and would have picked Betsy if anyone had to tell her such bad news. However, she was not offered counselling facilities by Alder Hey.

She feels a compelling need that the medical profession should be open and that families and relatives should be given full information about post mortem examination. Her general practitioner explained the post mortem report to her in 1962 and she found this to be helpful.

Alexandra – Stillborn

Alexandra was stillborn in 1995. Her parents agreed to a hospital post mortem in order to establish the cause of death. They were provided with a leaflet describing post mortem procedure. They were not told that organs would be retained, neither were they told that they had a right to object. They were informed that only tissue samples for microscopic examination would be taken and that anything removed would be put back and the body buried complete. They were told that the post mortem results would be available within six weeks of the stillbirth. Later they were told that the results would not in fact be ready within six weeks because Professor van Velzen who had conducted the post mortem examination was out of the country on a project in Canada.

Subsequently they contacted the Health Authority who told them that Dr Khine had actually performed the post mortem examination. They asked the Chief Executive to investigate and were told that it was an unexplained stillbirth and that the gross pathology was normal. The matter was investigated by the relevant clinical director who was not a pathologist and could not provide the answers the parents wanted. They asked for a copy of the post mortem report.

They were told that there was a placental report which was provided. They were told that part of the delay in dictating the report was due to the necessity to compare the organs removed with normal standards.

In December 1999 they could not escape the national news of the organ retention issue at Alder Hey. They realised that Alexandra was probably involved. Twelve days after contacting Alder Hey they were told that Alexandra's heart and other organs were retained. They requested return of the organs and a funeral as soon as possible before Christmas. Alder Hey refused. A second funeral was held in January 2000. This would not have been possible had the family's funeral director not intervened to force the issue of return of the retained organs with Alder Hey.

After the second funeral they received an unsigned post mortem report which at one time it was alleged that Professor van Velzen had carried out. Later they were informed that it had been carried out by a different pathologist.

More particularly the recorded weight of the child examined was 950 grams whereas Alexandra weighed 4kg. However, the remainder of the weights of individual organs appear appropriate.

Their overall view of the handling of the news was that every step of the way they had hassle and had to battle just to have returned that which should never have been taken in the first place. They rang Alder Hey yet again and spoke to Ms Therese Harvey, the Human Resources Director, and the first thing she asked them was whether they were contacting a solicitor. The parents replied that they would if they did not get the answers they required. They explained to Ms Harvey exactly what they wanted but never heard from her again.

They feel that Alder Hey has consistently refused to answer questions relating to why organs were retained, why they were not informed of the retention, why they have had to contact Alder Hey and why it took so long for a definitive answer after the initial inquiry.

Alder Hey did not keep to deadlines nor keep in contact with parents. They did not have people available to answer calls. They felt that Alder Hey put up brick walls and tried to pass the buck to the Chester hospital and the crematorium where the second funeral was to take place. Alder Hey should have met the parents and admitted that they were unable to answer all the questions. Alder Hey should have been honest and replied promptly to all the parents' requests. The parents say that they have been treated arrogantly, without sympathy or compassion. They feel that there has been a total disregard of the respect to which their dead child was entitled. Their trust has been betrayed, they have been deceived and their child desecrated. They remain angry.

Alexandra's mother said she wanted to talk about the emotion involved because she knew that to people not involved it must seem incomprehensible why anybody could get so upset about a dead person's organs because at the end of the day they are dead. Nothing more could happen to them and the organs would be disposed of anyway so what does it matter that they have been taken away even without consent.

Had she been asked at the time for consent to organ retention she may well have agreed. The question is why is she so emotional about it? She accepts the logic of the argument and has repeatedly gone over it in her mind since discovering the fact of organ retention in an effort to try and cope with the situation. Nevertheless she finds the emotion overpowering and it controls her daily life.

She is emotional for several reasons. The first is the deceit involved. She did not know what had happened to her daughter or that she had been desecrated. Alexandra had been stripped bare of everything and somebody believed they had the right to do it and to return her apparently complete for funeral purposes but in fact without her internal organs. For five years she believed Alexandra was intact and at rest.

The second reason for her emotion is the feeling of immense betrayal by Alder Hey. She believed that the hospital owed a duty of care to her daughter and that they had breached that duty.

The third and most compelling reason for her emotion as a parent is that she would have done anything and everything in her power to protect her child. That was what she was there to do even more so in death because it was only thing she could do for her child at that stage. She had put her trust in the doctors, the midwives, the clinicians, the pathologists that they would respect her child and that they would deal with her in the way one would wish to deal with a dead person. They did not, they desecrated her. She feels let down. There was only one thing she could do and that was to protect her in death and she did not do it and she has to live with that. Alexandra's parents thought they did the right thing in consenting to post mortem examination and now they know they did not.

Sarah – 5 Weeks

Sarah was born at Preston with congenital heart disease. She died within 24 hours of major cardiac surgery at Alder Hey in 1992. Her parents were given excellent prospects of success for surgery and cannot understand what went wrong. They are concerned about the surgical performance in the cardiac department. There should have been a Coroner's post mortem examination. In fact the cardiac surgeon informed them of the death six hours after the event and told them that there would be a hospital post mortem to find out what went wrong. Her parents have no recollection of signing a consent form but Alder Hey has recently produced a consent form signed by the father. They asked if the hospital wanted them to donate any of Sarah's organs and this was declined. They think they should have been told precisely why there was to be a post mortem examination, where it was to be carried out and what it involved.

They are of the view that Alder Hey is trying to blame Professor van Velzen for what has in fact been going on for a very long time. They cannot understand why their child died after the second major cardiac procedure and why it was necessary to harvest all the organs from the

brain to the pelvis. They were not told that any organs would be retained. They were pleased for what had been done for them at Alder Hey and invited donations instead of flowers for the funeral and raised £400 for the hospital.

They contacted Alder Hey about organ retention in late 1999. Two weeks later they were told that there had been a full retention of organs. They have never been told the reason for organ retention. Ultimately they want a return of the organs but not until this Inquiry has reported.

They make the point that having offered to donate organs it is very difficult for them to understand why Alder Hey would want to keep them after that. They would have discussed retention of the heart in the heart collection and would probably have said yes if they had they been fully informed as to the reasons.

They have lost their faith in the medical profession. They thought that they had buried their child intact. Their lives have been devastated by the disclosure of organ retention. They cannot believe their daughter is involved in such a horrific scandal. They cannot understand why the Coroner was not informed about the death of their daughter within 24 hours of the second major cardiac procedure which she underwent.

Laura – Stillborn

Laura was stillborn in 1993. Her mother was not told that a hospital post mortem examination would be carried out at Alder Hey. She told the funeral director to collect the body from the hospital where Laura had been left, and she thought her baby had been buried intact.

There had been a discussion about organ donation and a nurse said that her eyes could be handy but there was no mention of post mortem examination. Three minutes after the stillbirth she was asked to sign a consent form but could not recall that she had signed it and did not know what she had signed. In any event she told a nurse to leave her baby alone.

In October 1999 Laura's mother contacted Alder Hey and was told that the heart and stomach had been retained. A second funeral took place in November 1999. Shortly before the second funeral the undertaker informed her that the release form from Alder Hey referred to many more organs including the heart, brain, lungs, liver, spleen, kidneys and intestine. Prior to the second funeral mother made many calls to Alder Hey which were not returned. She did not receive full information as to what precisely was retained.

The whole event caused her eldest son to become very upset and he refused to go to school. He saw a counsellor. He was obsessed with cutting pictures of Professor van Velzen out of the newspaper.

Mother wanted to know where the organs had been kept and whether they had been used for research. She received uninformative letters from Alder Hey, the envelopes of which were open. Samples had been taken from the returned organs without consent.

She feels someone independent should have been with her when the original consent form was signed. She needed help with understanding the document and the process of bereavement.

She complains that Alder Hey have dealt with her insensitively. How does she know all the organs retained have been returned? She would have considered transplantation from her child to another child but not the retention of organs for medical research or teaching purposes. She wants to find out why the organs were retained. She feels sick about the organs having been kept for no purpose.

On 12 May 2000 she rang Alder Hey and asked whether she had buried her daughter with her eyes and was told 'you will never know'. She said that if she dug her up she would find out. She was told, 'go on then but you still would not find out'. She has still not been told whether or not the eyes were removed and retained. She feels guilty that she let her daughter down in death by letting the pathologist 'butcher' her.

Kenneth – 5 Weeks

Kenneth died in 1987. Post mortem examination was carried out at Chester. He was cremated. His mother was told by the Coroner that he died because his heart defect was worse than the scan had shown.

In December 1999 his mother contacted Alder Hey and two weeks later was told that the heart only had been retained. She had difficulty obtaining details. She was concerned that other organs might have been retained. She was told again that it was the heart only but she wanted written confirmation.

She has subsequently seen a letter from the paediatrician at Chester to the paediatric cardiologist at Liverpool offering Kenneth's heart either to be sent to or collected by Liverpool. This letter is dated 8 April 1987 but mother was not told. The hospital at Chester has apologised for heart retention and said that it should never have happened. It amounted to a secret interchange of organs between hospitals.

The family has been bitter at the discovery of heart retention. They remain concerned about the cause of death. They have in fact been told of three different causes of death on three different occasions namely heart defect, cot death and virus. His mother is very distrustful of the medical profession. Her grief has been exacerbated by the discovery of heart retention. She feels she has been lied to by Chester Hospital as well as Alder Hey. She would never have

consented to retention. She was asked if samples could be taken from the heart before it was returned but said no. She had been threatened that unless she consented the heart would not be returned.

Her eldest son has become distressed at the issue of heart retention.

Kenneth's mother remains concerned as to the cause of death. She feels she should have been told what a post mortem examination involved. She would have liked an independent bereavement adviser to have been present at the time. Had the hospital asked to examine the heart she would have held the funeral back until it was completed.

She says that the memory of her child has been ruined by living under the illusion that he was buried intact when in fact he was missing his heart. She cannot even look at pictures of him now because she just sees him in a different way.

David – 2½ Months

David was born with liver disease and died in 1987 at Alder Hey. His parents refused a hospital post mortem because he had been through enough in life and was like a 'pin cushion'. They were persuaded to sign a post mortem consent form on the basis that only microscopic samples of the liver, rather like a biopsy, would be taken. The purpose would be to find out the precise cause of death. The only content of the post mortem report which they were informed of was that David died of acute liver failure. He had been awaiting a liver transplant.

They would have considered donation of his organs to another child to save that child's life. They would not have consented to removal of organs for medical research and teaching purposes.

They had been led to believe that organ retention only related to the period 1988 to 1995 whilst Professor van Velzen was in post. They did not expect to be told on 3 December 1999 that any of David's organs had been retained. They thought that they had buried him whole. They were told that samples had been taken and there were incomplete post mortem reports. Post mortem histology had been carried out and reported upon in David's case by November 1988! They were told that the heart was removed for research yet there is no record of nor data relating to research work.

Alder Hey has failed to answer the parents' questions satisfactorily. They were told by Ms Harvey that the brain had probably been removed and clinically disposed of. Ms Harvey then told them on 1 February 2000 that block samples had been taken from the brain, kidney, heart and bowel. His parents cannot understand why the brain and heart were retained if the cause of death was liver failure.

On 8 March 2000 they were told by the treating clinician that it was likely that the liver had been retained and was in the deep freeze at Alder Hey. They were then told on 10 April 2000 that there was no evidence of retention of the brain. The information they have received from Alder Hey has been conflicting and unsatisfactory in every respect.

They say that in life the care of David at Alder Hey from the staff and doctors was marvellous. When they were told by Alder Hey through their solicitor that there was no evidence of retention of the liver and brain they could not understand this because there is reference in the post mortem report to the brain being fixed in formalin. This could not have been done prior to burial!

The parents feel that they should have been told what the post mortem examination involved. They were given full details of his treatment in life. It might have alerted them to the possibility of organ retention. Certainly they would have asked whether organs removed for examination would be returned to the body before burial. They would have liked an independent person to advise them on bereavement and the issues immediately following death.

They see this as further protection against organ retention. The last piece of information they received in April 2000 from the treating clinician is that he did not know why the heart and brain were retained.

His parents say that in the circumstances they are never going to be able to lay David to rest now. They have already been told that his brain and liver have been clinically disposed of. His father feels guilty that he signed the consent form for the post mortem examination.

Tony – 11 Days

Tony died in 1994. His precise cause of death is still under investigation. After he was admitted to Alder Hey his parents were put in a side room and told the nurse and doctors that they did not want a post mortem examination. They were told that there had to be a Coroner's post mortem examination. The difference between a Coroner's and a hospital post mortem examination was not explained to them. They asked the clinicians to promise to put everything back as it was. The hospital said that they would only take slivers of tissue for examination. They were also reassured by the nurses that Tony would be put back together again intact after post mortem examination.

When they rang Alder Hey in late 1999 to enquire if any organs had been retained they were told the following day that there had been retention. They asked what had been taken and the reply was 'everything basically'. A list was reeled off to them including brain, heart and chest and whatever. On the Friday prior to the second cremation his mother asked for a guarantee that the returned organs belonged to Tony. They had also been promised that no samples would be taken prior to release of the retained organs. His mother told the hospital that they had

stolen the organs and she wanted a 100 per cent guarantee that Tony's were not being retained, to which the hospital said 'alright you have got a 100 per cent guarantee' after previously refusing to give such a guarantee.

His parents feel that Tony was not given the rights he was entitled to at his first cremation. This rendered it a sham. Faith in the hospital and clinicians has been lost. Had they been asked the parents would have waited for two months to find the proper answer as to why Tony died provided they put him all back together again ready for his funeral.

When Alder Hey were giving them information about organ retention they felt that when they asked too many questions Alder Hey became very sharp and rude. They feel it would have been better if Alder Hey had offered to come to them to talk to them about the problem. The parents say that if Alder Hey wanted organs because another child was dying they might have considered it. However they are appalled at the hospital taking everything without telling them particularly as they had insisted upon everything being put back prior to the funeral.

They have an overriding impression that everything will be swept under the carpet and blame will not be properly apportioned.

Kirsten – 4 Months

Kirsten died on her first day in intensive care in 1991. It was described as a cot death. A Coroner's post mortem examination was carried out. There was no explanation given to her mother about what was involved in a Coroner's post mortem examination or the difference between a Coroner's and a hospital post mortem examination.

She implored the hospital to treat Kirsten as a baby and not an object and to put everything back which they removed for examination. The hospital told her that they were always gentle and compassionate. She never thought it was legally possible to retain organs without permission or knowledge. She thought she had cremated Kirsten complete. In fact six months after Kirsten's death she received counselling during the course of which she was told that nothing was retained following post mortem examination, not even tissue. At one stage she even saw Professor van Velzen and he said he always treated babies gently.

After post mortem examination the parents were allowed to see Kirsten. Her swollen appearance shocked her mother so much that she gave instructions for the coffin to be closed rather than left open.

Kirsten's mother contacted Alder Hey in September 1999. She was made to feel that on death she had no rights over her baby's body. There were weeks of telephone calls and then one Sunday she was told that the heart and brain had been retained. She nearly vomited. The following day she was told to choose between return and cremation of the retained organs or to leave them with the hospital for research or to commit the organs to a mass communal burial.

She was greatly offended by the second alternative, namely retaining the organs for research, when the organs had remained untouched and not examined in the eight years following death. She never received an apology or an explanation for what had happened.

Later she received another letter stating that there were other organs. She was drip-fed information because it was felt that giving all the news at once would be too distressing for her to receive. She did not see the post mortem examination report until late 1999.

The mother says that the way she was treated at Alder Hey has destroyed her heart, soul and memory. She needs answers to ensure that her baby is given the respect she deserves. It might have been more acceptable if the hospital had said the research on the retained organs had saved the lives of other children.

She cannot contemplate that her baby's organs have been stored and not touched for eight years. She feels violated. Her daughter was butchered. She was let down, betrayed and lied to. She poses the question, 'would they have done it to one of their own?'

Learning of the retention has been a complete nightmare. She should not have been given bad news over the telephone but face to face. She should not have been told by a nurse 'try not to look at it emotionally it is just tissue'. Her request for group counselling should have been granted.

Lindsay – 7 Months

Lindsay was born with congenital heart disease and was a Down's Syndrome child. She died eight days after cardiac surgery in 1991. A Coroner's post mortem examination was carried out shortly after death. Her mother did not discover that a post mortem examination had been carried out until the day before the funeral.

Lindsay's death itself involved her parents making a decision on medical advice to switch off the life support machine which had sustained life following surgery. After death her mother offered to donate Lindsay's organs but this was declined. Her mother was not provided with counselling. Even when she discovered that there had been a post mortem examination she thought that the body would have been opened and all the organs examined would have been returned. She did not even consider the prospect of retention of organs.

Had microscopic examination of the organs been necessary she would have delayed the funeral until that had been completed. She would have been willing for her daughter's organs to have been used for transplantation as well as medical research. She would have considered Lindsay's heart being used in the Alder Hey heart collection. None of these matters were discussed with her other than refusal of donation because of Lindsay's condition.

She discovered the fact of organ retention in October 1999. It took eight days for Alder Hey to confirm that the brain, heart, lungs and abdominal organs had been retained. She received a written apology but no explanation has ever been given as to why the organs were taken and kept. She asked repeatedly for an explanation and to date there has been none.

She feels that she did not properly lay her daughter to rest and only buried a shell. The second burial took place in November 1999 and re-opened grief from the first burial. At the second burial the original coffin had to be exhumed to accommodate the small casket containing the returned organs. It was extremely distressing for the family.

She feels her daughter has not been treated with the respect she deserved in death. She feels guilty that having loved her daughter so dearly in life she let her down when she needed her most, namely in allowing her organs to be retained without consent. Overall she feels let down, disgusted, angry, upset and betrayed.

Having regard to the delay, apology and lack of explanation as to why the organs were retained despite repeated requests for an explanation, unbelievably Alder Hey rang Lindsay's mother in August 2000 as she returned home from work to tell her that Lindsay's cerebellum (part of the brain) had also been retained. At the time of the call she was with her other young children and became distressed. She feels she should not have been given this information without the support of a friend or relative at the very least. The correct method of communication was face to face.

She has been given no reasonable explanation as to why the cerebellum was retained. She is now considering whether to have a third funeral. She feels more devastated this time than on the initial return of the organs because she thought she had reburied Lindsay to render her intact.

Jordan – Stillborn

Jordan was stillborn in 1994. His parents were told that it was important to discover why he had died particularly as it was their first child and there might be genetic considerations.

His parents refused a post mortem examination at first. They said that Jordan had been through enough already. They were reassured by a nurse and social worker that the organs would not be used for medical science. They were told that if they consented to a hospital post mortem examination to establish the cause of death everything would be put back. They had a short time to discuss matters with a social worker and were persuaded to sign the consent form for the removal of tissue. They were told the result of the post mortem examination by the gynaecologist.

They contacted Alder Hey on 13 October 1999 to enquire whether any of Jordan's organs had been retained. They received a reply on 27 October 1999 telling them that every organ had been kept. They felt despair and anguish. They thought they lived in a civilised, caring society and trusted doctors. Although they were offered counselling at Alder Hey they wanted independent counselling away from the hospital but this was not provided.

They cannot face asking Alder Hey for the return of the organs to bury them and this matter is being looked into by their solicitor. They are anxious to have a second burial but are fearful of the consequences.

At the original burial they thought they were putting their child to rest. They thought he was complete and that he had a nice funeral and burial.

They now feel that they signed the consent because they were under pressure and lied to. Their child lost his dignity and was treated like a piece of meat in a butcher's shop. They feel let down. They feel that their child's dignity was taken away when his organs were retained. Had they been told at the time it was necessary microscopically to examine the organs they would have delayed the funeral until this had taken place. If they had been given full information they would have considered donating organs to save the life of another child.

They feel guilty that they did not protect their child in death and did not prevent all his organs being removed at post mortem examination. Both parents are unwell as a result of discovering the fact of organ retention.

Lisa – Stillborn

Lisa was stillborn in 1985. On return to the ward after delivery her mother was tired and confused and had received pethidine for pain relief. She was told that a hospital post mortem would be routine procedure to discover the cause of death. Confused and distressed she signed the consent form. She was not told she could object. She would have liked a counsellor present at the time to help her with the bereavement and its consequences. She was not told that organs would be removed and retained at post mortem examination.

The post mortem examination itself was carried out at Alder Hey. Lisa's mother has only recently discovered this fact. She was not told the result of the post mortem examination.

In October 1999 she rang Alder Hey enquiring whether Lisa's organs had been retained. Two weeks later she was told that they had not. She feels she should have received more sympathy and understanding and a quicker response. She should have been given more detail.

On 11 March 2000 she was told that Lisa's heart had been retained. She feels it will be a long time before she can ever trust Alder Hey again. She is hoping to arrange a second burial. She thought she had buried Lisa intact. The second burial will cause great distress in the family.

Discovery of the retention of Lisa's heart has had a bad effect on the eldest child who has gone to pieces. Sooner or later the other children will discover that they had a sister who was stillborn. Their mother is fearful that they will react in the same way as her eldest child.

Lisa's mother feels that her daughter came into the world whole and should have been buried whole. She feels guilty for not preventing the heart being removed and retained. Her major concern now is how she can arrange to unite the heart with the body which was buried in a public grave. She is receiving assistance from her solicitor and has the support of this Inquiry.

James – 1 Day

James was born in 1990 with complex congenital heart disease. He died in theatre the next day. His parents knew that everything possible was done for him. They were 'totally dashed' by his death.

Following his death his father was asked in the hospital corridor to sign a consent form for post mortem examination by the cardiac surgeon. No understanding of the plight of the parents was shown. He recalls that he was in no fit state to read what he signed. He trusted the surgeon and signed the form. He felt that James had been through enough in his short life and that he did not want a post mortem to be carried out.

The surgeon told him that he needed to have a post mortem so he could make sure he had done everything right and it could help him improve in future. James' father only agreed to sign the consent form because he wanted to do something to help another child. Nobody told him what a post mortem examination involved nor that organs would be retained. He was not told that it was to be a Coroner's post mortem or what that meant. In fact it was a Coroner's post mortem examination and a consent form was not necessary. James' parents now feel that it was always known that it was to be a Coroner's post mortem and they were asked to sign the consent form so that organs could be retained for other purposes. They would never have agreed to the retention of their son's organs.

After reading of the organ retention scandal in a national newspaper their first thought was that it could not happen to their son. They contacted Alder Hey and had to wait for four or five days to be told that James' heart and some organs had been retained. When they pressed for further details they were told that the lungs, brain and abdominal organs had also been retained. Later they were told that his intestines, liver and kidneys had also been retained.

In November 1999 all James' organs were returned. A second funeral service and burial took place. The organs were placed in a casket next to the coffin. It was very distressing.

They then learnt that tissue samples had been taken from the organs before they were returned without their consent. They had been informed that it was unlikely that further examination of the samples would be completed. They are still waiting for the return of the tissue samples so that the histology report can be completed.

They describe the way they have been treated by Alder Hey as the epitome of arrogance. They would have appreciated being told where things had gone wrong and then been offered some emotional support.

They thought that they had done everything they could as parents for James and now are left with a tremendous feeling of guilt. A religious ceremony was held and they felt that they had laid James to rest in a dignified way at the first funeral. To them, burying only part of James has made a mockery of it all.

They want to know why this practice went on for so long. Why did it happen and why have so many parents been put through such distress? They still require a full explanation of the post mortem report and remain doubtful as to whether they have even now buried all their son's organs.

Katy – 15½ Months

Katy was born with immunodeficiency syndrome. She died in 1990. Her parents know that Alder Hey did everything they could to try and save her and they want to pay tribute to Katy's doctor Dr David Heaf, 'the best doctor they have ever met'. They think of Alder Hey as a caring and professional hospital. They are now deeply saddened for the doctors and nurses who work so hard to save lives.

Katy's parents agreed to post mortem examination to try and help other children like their daughter. A nurse explained what would happen at post mortem and assured them that Katy's body would be treated with dignity and respect. They felt the pressure of time was upon them to make an immediate decision. They should have been told the full facts from the outset. Katy's parents would never have agreed to organ retention.

They found out about organ retention at Alder Hey from a radio programme. They were informed that Katy's heart, brain, some of her intestine and her ovaries had been retained. The post mortem report does not reveal that organs were retained. The report does not state that the post mortem was incomplete. By not giving Katy's parents full information Alder Hey gave themselves the opportunity to retain her organs without parental consent. They knew that her parents would say no. Her parents understand the need for the study of organs.

The sad result is that the first funeral was not a proper funeral. They were just burying part of her. They can find no words to explain their view on the second funeral. People feel sick at what they have had to do. Normal society did not know what to do when the scandal broke. It was unthinkable to people. They are further outraged that samples were taken without consent before the organs were returned.

Her parents want to know who knew that organs were retained?

They want to know who authorised that the organs be taken. They want to know what the justification was to do it. They want to know if any of Katy's organs assisted in research into immune deficiencies or were used for any other purpose.

They are left unsure as to whether they have buried the correct organs at the second funeral.

Lee – 18½ Months

Lee died unexpectedly in 1989. His mother knew that staff at the hospital did all they could to resuscitate her son. She thanked them for all they had done. She now feels it was all a front.

She was told that a Coroner's post mortem examination would be done. She was also told that it was to find out why he died as he was such a healthy child. She accepted the need for post mortem examination. She needed to know the reasons why her son had died. She was never asked if organs could be retained. She might have considered donating organs had she been asked.

The Coroner's Office informed Lee's mother that her son had died of Sudden Infant Death Syndrome (cot death).

The first funeral was a full Requiem Mass. His mother feels that her son did not have a decent funeral. Because of Lee's changed appearance following post mortem examination the coffin had to be closed. The first funeral was very hard to get through. There was a lot of anger at the second funeral. It was a smaller funeral by Lee's graveside.

She learnt of the organ retention scandal from a newspaper and the television news. She then phoned Alder Hey. The next day she was told that her son's heart had been retained. She was later told that her son's brain and all other internal organs had been retained. She was given no explanation as to why organs had been retained.

She knows that her son's post mortem report is incomplete. The report states that further tests need to be done to determine the cause of death. These have not been done. She does not know for certain why her son died.

Lee's mother wants to put right the wrong and make sure this never happens again. She feels cheated and let down. All the trust she had for the hospital has gone.

Samantha – 1 Month

Samantha was born with congenital heart disease. She died in 1997. She had undergone cardiac surgery on three occasions in the three weeks preceding her death. Five to ten minutes after her death her parents were asked to consent to a hospital post mortem and refused. They were told that it was necessary and the death was then reported to the Coroner who asked for a post mortem examination.

Her parents' attitude was that in her short life Samantha had gone through enough. They also asked the nurse to keep the Sacred Heart medallion with Samantha but this was not done.

Their clinician attended the post mortem examination. They were never told why it was necessary. They assumed a small amount of tissue had been taken at the post mortem examination but otherwise that when they buried Samantha they had buried her in her entirety.

They also raised the question of the second consent form to surgery which referred to tissue being taken in the event of death. The meaning of 'tissue' was not defined by the cardiac surgeon who said that the second form was a new form and he was surprised that it had come into use so quickly.

The Coroner told the parents that the post mortem report was too upsetting for them to read and sent it to their general practitioner. Alder Hey denied that they had received the report from the Coroner despite numerous telephone calls from the parents. The Coroner said they had. In fact Alder Hey subsequently went through the results of the post mortem examination with them and the clinician was most sympathetic and understanding and told them everything.

They discovered on 14 December 1999 that Samantha's heart had been retained. They remain concerned that they have not been told the full extent of organ retention. They have concerns about the possibility of the brain and lungs being retained. They feel that it is very clinical to obtain consent to a post mortem examination within five to ten minutes of death at a time when the parents are grief stricken. They feel that up to 24 hours should elapse before the post mortem is requested.

They want the following points answered.

- Parents should be told why a post mortem examination is necessary.
- Twenty-four hours should be given to parents to grieve before consent is requested for a post mortem examination.
- Parents should be told what rights they have if they refuse a hospital post mortem examination.
- There should be a clinical summary from the hospital before the matter is reported to the Coroner.

- It is necessary to define the terms 'tissue' and 'organ'.
- Parents should be told if anything is to be taken from their child, what it is and why it is to be retained.
- Parents should be told what organs have been retained beyond burial and why.
- Parents should be fully informed as to the wording of the operation consent form.
- Nothing should be removed from a child's body without the consent of both parents in writing and on the basis that the parents have been fully informed as to what they are consenting to.

Kathleen – 18 Months

Kathleen was born with congenital heart disease. She died at Alder Hey in 1991. The cardiac surgeon had discussed post mortem examination before Kathleen died. There was a discussion about organ donation to save another life. Her parents agreed to donation of the corneas and the pulmonary valve. After death her mother consented to post mortem examination but her father did not know that it was going to happen. He took her death very hard. Neither parent knew that Kathleen would be opened up and organs retained. They would not have consented had they known.

It is their view that Alder Hey should remain what it always was 'a fantastic hospital with a fantastic staff and hopefully it will continue with its excellent work'. The medical interest shown in Kathleen was prodigious in life but no doctor came to see or speak or discuss the death with them. They were not informed of the post mortem results. They repeatedly wrote to Alder Hey for a meeting with the doctor and finally one took place in Preston which lasted for ten minutes. It had taken eight months to arrange the appointment.

They were invited to contact Alder Hey in October 1999. Their daughter's name was wrongly spelled. This caused distress. They were informed that a number of organs had been retained and subsequently that fragments of bone and muscle had also been retained. They asked for the medical notes. When they received them they were badly copied. Information came to them in dribs and drabs.

On 9 May they were devastated to hear that their daughter's tongue had been retained and father protested silently outside Alder Hey. Her parents complained that Alder Hey did not follow the requirements of the Human Tissue Act and retained organs illegally. They were devastated to find that they had not buried their daughter whole. This involved a breach of trust and exploitation of a beloved daughter's beautiful body.

They describe the hospital as having stolen their daughter's body which was 'as white as driven snow. It was reduced to skin and bone by predators and it must never happen again'.

Their view is that those involved should be severely and publicly censured. They remain disgusted, damaged and devastated by what has happened. They describe the way they were informed about the organ retention on an ever increasing basis as 'abysmal'. They made repeated calls during which they could have been told the truth. They complain about repeated provision of incomplete information.

They have a host of questions left unanswered by Alder Hey, the NHS Executive – North West Regional Office and the Government.

Anthony – 3 Years 10 Months

Anthony was born with congenital heart disease. He died in 1996 within 24 hours of major heart surgery. The first major procedure had been carried out in 1996 and the cardiac surgeon told the family it had been a complete success. It was not and had to be reversed.

About five hours after death his parents were asked to consent to a hospital post mortem examination to help others and find out why the surgery had been unsuccessful. They were not asked if they had any questions. They consented to help others. They were never told that there would be organ retention. His parents had not slept and were in a state of distress when the question of consenting to post mortem examination was raised.

In late September 1999 they contacted Alder Hey and although they were treated professionally they always felt that certain information was being withheld. The hospital was evasive in certain areas. However their link worker was honest and extremely helpful. At first they were told that the heart had not been taken. They asked for a copy of the post mortem report. As an afterthought they asked what tissue samples had been taken and to their surprise were told brain, stomach, one kidney and one lung.

They then contacted the treating clinician who told them that the heart had been taken as well. They received a letter stating that the heart and other organs had been taken but they have not received a list in confirmation. They question the cause of death being heart failure. They feel that there were other potential causes of death including surgical damage to the liver. Anthony's medical records were drip fed to them. They received new information each time they received a section of the records. They were told that the heart had been retained at the request of the cardiac surgeon who attended the post mortem examination. They were told that other organs had been sampled. These organs were returned.

His parents feel that there should have been a Coroner's post mortem because the death was within 24 hours of surgery. They feel that they should have been told what was involved in a post mortem examination. They would never have consented to the retention of organs. They wanted the body to be buried intact but would have delayed the funeral to allow examination

of organs which needed to be fixed (see Chapter 5, paragraph 4.8). They feel that a bereavement adviser should have been present to help them with the issues of consent and the consequences of death.

They were shocked to find out that the cardiac surgeon who was responsible for taking care of Anthony in life and during surgery was also the person who requested removal of the heart without telling them that this would happen. He must have known that it would be retained.

They want the law to be changed to render it illegal to retain organs without proper parental consent. Medical research must not be carried out at the expense of innocent children. It is their view that there should be a criminal penalty for unauthorised organ retention.

They had an interview with the paediatric pathologist Dr George Kokai and found him to be honest but another member of Alder Hey was present and prevented him from answering certain questions put to him by the parents which he was willing to answer. Alder Hey did everything possible to stop Anthony's father opening the casket containing the retained organs to find out what precisely was there.

His father feels that Anthony was the bravest person he had ever met. He had immense inner strength to tolerate his condition and surgery. He is proud to have been his father.

His parents now know that his heart went to the heart collection at the Institute of Child Health. They also know that his other organs were transferred out of the hospital to the University but would like to know where they went, for what purpose and whether they were ever used for research. They have not had any answers to these questions.

Claire – 14 Years 11 Months

Claire died in 1988. She died from a paracetamol overdose. There was a Coroner's post mortem and an inquest. Her parents thought they had buried their daughter's remains intact. They were not told what was involved in a post mortem examination. Neither were they told the difference between a Coroner's and a hospital post mortem examination. They were not told that organs would be retained. However, they say their treatment at Alder Hey at the time of loss was extremely sensitive and sympathetic.

In October 1999 they responded to a letter from Alder Hey suggesting they call the help line. They are angry at the deceit, grotesqueness and obscenity of removing without their knowledge or consent their daughter's brain, heart and lungs. The cause of death was a formality. Although the person dealing with them from Alder Hey was very pleasant and helpful nevertheless the whole attitude was defensive and unco-operative. It appeared to be a damage limitation exercise. They requested the return of the organs which were subsequently cremated.

This is an unusual case. The usual attempt at justification for organ retention is not applicable. It cannot have been to assist research into infant mortality because Claire was almost 15 years of age when she died. It cannot have been to assist research into congenital heart disease because her heart was strong and healthy. There cannot be any justification for stockpiling organs awaiting final post mortem reports. Her parents have not been given any explanation as to why Claire's organs were retained. They were not given the reason for post mortem examination being carried out.

Her father says that he thinks everybody has a right to lay the dead to rest. It is a critical right because it is part of the grieving and healing process. It is doubly important with the loss of a child because that in itself is an obscenity of nature. Nobody expects to survive their own children. It is a long and very painful grieving and healing process. It cost him his marriage, his career prospects and a heart attack. To be pushed back into the situation 12 years on is unforgivable.

The treating clinician said that whether you tell somebody that the brain has been retained depends on whether, in the clinician's view, telling them would cause unnecessary trauma. He admitted he knew that hearts were systematically retained but was not aware of retention of other organs.

Claire's father says there is a whole moral issue around the basic right of somebody being able to bury their dead in a dignified and complete way. This right must be defended and protected. He thinks the common perception of the word 'organ' involves the entire organ, and tissue by definition means part of that organ and probably a fairly small part of that organ. This definition should be incorporated in the Human Tissue Act 1961.

Sam – 18 Months

Sam was born with congenital heart disease. He died in surgery in 1990 at Alder Hey. A Coroner's post mortem examination was carried out. The post mortem examination procedure was not explained to his parents. The distinction between a Coroner's and a hospital post mortem was not explained. They feel that they should have been allowed more time to come to terms with their grief before post mortem examination was discussed. They also feel that their objections to post mortem examination should have been considered even though it was a Coroner's post mortem.

The surgery had been delayed for almost 12 months because of unavailability of intensive care beds. There were several last minute cancellations. They are left wondering whether this delay contributed to Sam's death. They had been allowed to hold Sam in their arms after he died for two hours. They then wanted to hold him again after the post mortem examination. When they

went to see him in the Chapel of Rest at Alder Hey mortuary his hair was pink and standing up and blood was oozing from his scalp and nose. They were so distressed that they ran out of the mortuary.

They reported the situation to Alder Hey who denied it. The matter was subsequently verified by the social worker who had been with them and subsequently Alder Hey apologised. They wrote letters about the delay in surgery to the Department of Health and Social Services, to their MP and anyone else who would listen. They complain that when the post mortem issue was raised with them no mention of organ retention was made.

They received news of organ retention in January 2000. Eventually they were told that there had been a full retention. They demanded immediate return and a second funeral was held in April 2000.

They feel let down and deliberately misled. They were not told the facts and procedures they were entitled to know. The impression given by Alder Hey was that an individual's identity ends at post mortem examination if not death. They describe Alder Hey's handling of the issue as appalling with denial of knowledge. They tried to fix blame solely upon one person, Professor van Velzen. However, the immediate representative of Alder Hey who dealt with them was very helpful and available, open and honest but only so far as permitted by management at Alder Hey.

They say it would have been nice to have been asked about donating organs and leaving the heart for the heart collection. They would have considered the matter seriously had they been approached properly. Everyone should be told what is involved in a post mortem examination. They feel that they protected their child in life but in death when he needed their protection more than ever, they feel guilty that they let him down in allowing or permitting organ retention.

They feel that the meaning of tissue and organ is very clear. It is their view that an organ is the whole organ and tissue is a thin slice of organ usually for examination. They were told precisely what was involved in the major cardiac surgery their son underwent. They should have had similar full information about post mortem examination, organ retention and the results of post mortem examination. Alder Hey should have divulged the news about organ retention and been totally transparent and honest from the outset.

Philip – 5 Years 3 Months

Philip was born with a congenital heart defect known as Noonan's Syndrome. He died in 1989. He never regained consciousness from an operation to correct the heart defect. He had very bravely undergone a lot of treatment in his short life. His parents know that the clinical teams did all they could to save their son's life and are grateful.

A Coroner's post mortem was carried out two days after his death. Nobody told them that a post mortem examination was to be carried out. They should have been told what, if any, organs would be retained. They should have been informed of the result of the post mortem examination. They were fully informed of the details of all the operations their son had to go through. They consented to these operations. They should have had extended to them the same fullness of information at death as in life.

If everything had been explained to them they would have agreed to organ donation. As nothing was explained the hospital denied themselves the opportunity of organ donation to save the life of another child. The parents have no objection to research. They understand why there was interest in their son's heart and lungs. They do not understand why his other organs were removed and retained.

His parents first heard of the organ retention on the radio on 21 September 1999. His mother rang the hospital the following day. Two days later she was told that they had his heart. On Saturday 9 October 1999 they received a letter from the hospital informing them that they also had his chest organs, abdomen, brain, lungs and 'other organs'. There was no-one at the hospital to help them until the following Monday. They still do not know what 'other organs' means. They are still waiting for written confirmation of the organs that were returned to them.

The first funeral was a Catholic burial. The Church was packed with friends, family and work colleagues. Their son should have been buried intact. His body was desecrated.

The second funeral was very low key. Seven people attended. Their eldest son could not face a second funeral. They feel cheated that the first funeral was indecent. They were not sure what they were burying at the second funeral.

They are suffering from social exclusion as friends and family do not know how to handle seeing them. They want someone to be held responsible for what has happened. They want a change in the law. Parents must be fully informed about what is to happen to their children immediately upon death.

Nicola – 13 Years 5 Months

Nicola suffered from epilepsy. She died in 1989 of septicaemia at Alder Hey. Nicola had been in hospital many times and her parents held the hospital and its staff in the highest regard. Their daughter had always had wonderful treatment.

Nicola's clinician told her parents that as she had died suddenly a post mortem examination would have to be carried out. Her parents were very distraught. They could not bear the thought of their daughter being disfigured or cut in any way. They understood why a post mortem examination had to be carried out although they did not fully understand what it involved. They should have been told at the time.

They said that under no circumstances were any organs to be taken. They were given a personal assurance by the clinician that nothing like that would happen. They were assured that any procedures would be unnoticeable and the brain would be examined and replaced. They were misled about the extent of the post mortem examination. They would not have agreed to organ donation. It was very important to them that their daughter be buried intact.

When the news first broke in September 1999 they did not think it involved them. They had been given assurances by their daughter's doctor that no organs would be removed or retained. They received a letter from Alder Hey inviting them to contact the hospital if they wanted to check if they were involved. They were then told on the telephone that 'basically they had taken everything'.

At the second funeral they did not realise how big the casket would be. The second burial brought back all their pain and suffering. They are uncertain if they will ever know if things have been put right.

They think they should have been seen personally by Alder Hey not contacted by letter or telephone. They have a right to know everything relating to their daughter's death. They have a right to control what happens to their daughter's organs after her death. She was their daughter. Sending a letter to tell them the distressing news is too impersonal. Anyone can send a letter. It is not the same as seeing someone face to face. They used to think Alder Hey was absolutely wonderful and feel that there has been a breach of trust. They feel let down by all involved and always will.

Nicola's parents want to know why it was done. It appears someone was a collector. Parents must be given the fullest of information about what is going on with their children. They feel really badly let down. Their daughter was abused and treated like a piece of meat. They feel guilty that their daughter's organs were removed without their knowledge.

Robert – 21 Months

Robert was born with a congenital heart defect. He underwent a high-risk operation and died three weeks later in 1989. He was in his mother's arms when he died.

Nothing was said to the parents about post mortem examination. The cause of death was renal failure due to septicaemia. The Coroner did not accept this cause of death and ordered a post mortem examination. The Coroner informed Robert's mother that he had ordered a post mortem examination and explained why it was necessary. The cause of death on the death certificate was changed to cardiac failure. Robert was then placed in the Chapel of Rest where his mother noticed that he looked very odd.

Nobody asked her if organs could be retained. She might have allowed them to take the heart but only if it would have been used to help other children.

His mother learnt of organ retention from the newspaper and on television in the Autumn of 1999. She knew her son had had his post mortem examination at Alder Hey but did not contact the hospital. She would rather not have gone over the threshold and made enquiries. She then received a letter from Alder Hey in October 1999. They informed her that she might be involved in the matter. She then felt that she had to telephone Alder Hey to find out. After a few days she was told that they did have her son's chest, abdominal organs and heart. She was absolutely devastated. She had not wanted to know. She would have rather made the decision herself to know or not to know.

She feels that it is her fault that she buried her son without his organs. She understood that the organs would be put back when the post mortem was completed. She would have allowed them to keep his heart to try to save future lives. She would not have agreed to organ donation. She understood that all her son's organs were damaged. She thought she had done all she could to protect him in life and in death. She now feels guilty, angry and inadequate as a mother. She could not bring herself to attend the second funeral. Her son's organs were laid with his ashes in his grave.

She wants there to be clear guidelines for the pathologists, to include what they can and cannot do. Parents should be told everything that is going on.

William – Stillborn

William was stillborn in 1989. His mother was told that there would need to be a post mortem examination. Prior to birth she was told her baby had spina bifida. She wanted a post mortem examination to confirm that he would have been born with spina bifida. It was the reason why she had her pregnancy terminated. She needed to know whether she was right to have consented to the termination. She has had a terrible feeling of guilt throughout. She has never been offered counselling to help her cope with her loss.

The hospital told her that they would arrange the burial. They told her he would be buried in the hospital grounds. Mother believed the hospital would bury him respectfully. She thought that they would tell her where her baby was buried so she could visit him. After the midwife's visits to mother she asked to see her baby as he had not yet been buried. She spoke with Professor van Velzen. She was told it would be too distressing for her to see her child. He told her that he had been put in solution and he would not look the same. She understood that she did not have any rights in the matter.

William's mother asked the hospital for two years for the results of post mortem examination without success. She heard of organ retention in September 1999. She thought it did not apply to her as her baby was not born at Alder Hey. She called the hospital to find out the results of her baby's post mortem examination. In November 1999 she went to see her gynaecologist to be told what she thought would be the results of the post mortem examination.

Instead she was told that her baby was still in solution in a jar. She was then informed that post mortem examination had only been carried out that same week. It was confirmed that the baby had spina bifida. The doctor read the post mortem report to her. She was distressed to learn that the first post mortem report was 11½ years after William's stillbirth.

She would never have agreed to organ donation for research. He was such a small baby. She just wanted to lay him to rest. Mother finally buried William in March 2000. She wants to know why this happened to her baby. Steps must be taken to make sure that it never happens again.

Brother and Sister: Paul – 8 Months
 Gemma – 6 Days

Paul was born with a hole in his heart. Following cardiac surgery he died in 1984. Nobody mentioned to his parents the need for a post mortem examination. They received details of the post mortem report from their general practitioner two months later.

Gemma died in 1986. She was found to have a heart murmur. Her mother thinks that if the hospital had acted more quickly her daughter's life would have been saved. Again nobody mentioned that a post mortem examination would be carried out.

She learnt of the organ retention scandal from her sister who had contacted Alder Hey. She was informed the next day that Gemma's heart had been retained. The following day, she was also told that Paul's heart had been retained.

Her wishes and feelings were totally disregarded and her opinions ignored. She should have been informed step by step of the proceedings following each bereavement.

Organ retention is something which requires parental consent. It should not be a 'free for all pick and mix'. If she had been asked if they could keep the hearts to save the lives of other children she would have given them with her blessing. She would also have agreed to organ donation. It is hard to be told your child has died. You are devastated. If some good can come out of it and help other families then she supports that, if it is done properly with full parental consent.

She does not understand how an infant's body can be returned to the parents and for them not be told that organs have been retained. She regards the retention of her children's organs as theft. Gross incompetence has been demonstrated and the situation has been spiralling out of control. She has no confidence that the post mortem examinations carried out on Paul and Gemma are complete. She wants those responsible for doing this to her children barred from practising medicine again. It should not stop at the pathologists themselves. It includes anybody who has had anything to do with denying her rights and more particularly the rights of her dead children.

Christopher – Stillborn

Christopher was born prematurely stillborn in 1987. His mother never saw her baby. He was taken away from her at birth. His parents do not know why their baby died. At the time they were told that the hospital would bury the baby. The hospital insisted that the baby be buried in hospital grounds. They were told that it would be a dignified ceremony. They asked if they could see their son buried. They were told it would not be possible and that seeing the burial grounds would only further upset them.

They were told to have another child. The parents had no control over what was to happen to Christopher. They wanted to bury him themselves. They are a Catholic family and burial is important to them. To bury their child intact is part of their religious belief. They wanted to name their child and did not get the chance.

They were told that their baby would be sent for post mortem examination to Alder Hey to find out why he had died. They agreed to slivers of organ being taken to find out why Christopher had died. They were told that examination of the slivers did not reveal an obvious cause of death.

His mother heard of the organ retention scandal in the autumn of 1999. She did not associate it with her baby. She realised later that she might be involved. After numerous attempts to contact Alder Hey she went to see a solicitor for help. She then found that her baby had been sent to the University from Alder Hey without her knowledge or consent. Christopher had never been buried. His parents never gave authority for anyone to keep their child neither did they authorise anyone to retain his organs. They wanted to find out why their son had died. They would have agreed to organ donation to save the life of another child.

They eventually buried their baby in March 2000 almost 13 years after his death. They were then told that their son's pancreas had been retained together with a small piece of duodenum and gastrointestinal tissue. They do not know why or where their child has been stored for 13 years. They believe every parent has the right to their own child. Whether they want to give the organs to help another child, whether they want to give the organs for research or whether they just want to take the baby and bury it themselves is a matter for them.

They want to know why this happened. They want to know what was gained from the organs being taken and stored.

Ryan – 19 Days

Ryan was born with congenital heart disease. He died following open-heart surgery in 1995 at Alder Hey. Immediately after surgery the cardiac surgeon said that the procedure had seemed to be a success but nevertheless Ryan died shortly afterwards.

Some hours later the cardiac surgeon asked Ryan's parents to consent to a hospital post mortem examination. Mother replied that her son had been cut up and mauled enough. She was told that there would be no more cuts because his chest was already open following surgery. For one hour the cardiac surgeon tried to persuade them by playing on their heartstrings despite their continuing refusal of consent.

They did not understand the consent form. They thought they were being asked for microscopic samples from the heart and lungs only. They were told that the heart and lungs would be put back into the body following examination. They were further told it would be as though he had never been touched. They could not understand this because they had already been given the death certificate two hours before being asked for their consent and found it very confusing.

They received news of the organ retention issue in mid-September 1999. They feel that the way they were treated was a fiasco. They felt that there was an attitude of non-co-operation with parents. They asked for information. They were told that someone would ring back. No one did. Mother told Alder Hey that she alone should be contacted about what organs had been retained because her husband was too distressed. She gave them her home and work numbers. She and her husband work at the same establishment. After seven days Alder Hey rang work specifically asking for the husband. Fortunately mother was able to intercept the call and could not believe that Alder Hey had made such a mistake.

Eventually after being told that the heart, lungs and abdominal organs had been retained, Alder Hey rang them every other day pressing for a decision as to whether or not they wanted the organs to be returned, donated for medical research or sympathetically disposed of. The parents were having difficulty making their mind up and felt unnecessarily pressured just as they had been on the issue of consent to a post mortem examination by the cardiac surgeon.

They were never offered counselling. They were informed that counselling was available for siblings only. They are devastated by what has happened. Husband blames mother for having signed the consent to surgery. Mother blames husband for signing the consent for post mortem examination. Husband is in denial and mother is depressed. Their marriage is threatened. They feel that Alder Hey should have come out to them rather than dealing with matters over the telephone. They remain concerned as to the accuracy of details relating to retention of organs and will never trust Alder Hey again.

They thought they had buried their son whole. They would have donated his organs to save the life of another child. They would not have consented to donation of the heart to the heart collection. Mother has not been able to return to the same church where her son was buried because she is too upset. His parents would have been greatly assisted by counsellors coming to the home because they need counselling and they did not know how to explain to their 10-year-old son what happened in order that he might understand thoroughly.

They feel that Alder Hey used the word 'tissue' when it suited them, and if they were looking to have an organ from a child and put it into another child that would be organ donation but because the organs have been retained for medical research purposes they are then classed as tissue samples. Mother is unhappy at this false distinction. Tissue should be regarded as small pieces of an organ and the meaning of organ is obvious.

Nicholas – 11 Months

Nicholas was born with congenital heart disease. After several major cardiac procedures he died at Alder Hey in 1990. The doctor asked his parents what they felt about a post mortem examination. They said 'no way, leave him alone, he has been through enough. He is like a road map already'. They refused a request for a hospital post mortem. Shortly afterwards the doctor returned and said it was out of his hands as the Coroner had ordered a Coroner's post mortem examination. They were left in the room. No-one else came to see them and they left when they wanted to.

The post mortem procedure had not been explained to them. There had been no suggestion of organ retention. They had no bereavement advice. They were left to their own devices. They are extremely concerned that the hospital ignored their wishes without explanation as to why a Coroner's post mortem was necessary.

In mid-September 1999 they telephoned Alder Hey to enquire whether they were involved in the organ retention issue. The next day they were told that Nicholas' heart had been retained. They asked if any other organs had been retained. They were told that a check would be made. Two days later they were told that there were no other organs retained. Two weeks later they received a letter from a clinician at Alder Hey. He reeled off that the heart, lungs, liver, kidneys, spleen, pancreas and brain had been retained as though it was a shopping list. The parents were devastated.

Following the death of Nicholas they went back to the hospital and saw the treating consultant. After discussion the consultant said he would have another look at the heart. The parents said 'are you saying that we have buried him without his heart?' 'No' replied the doctor 'I can assure you everything after a post mortem goes back.' The consultant explained that he really wanted to look again at his reports. The parents, even now, remain concerned over the treatment they received from the cardiac surgeon. This is being investigated elsewhere.

In May 2000 they received an even fuller list of the retained organs which referred to heart, spleen, kidney, adrenals, bladder, reproductive organs, diaphragm, trachea, larynx, oesophagus, stomach, intestines, lymph nodes, thyroid, pancreas, part of the brain, part of the liver and fragments of tongue, bone and muscle.

On 16 June they received further information to the effect that a rib had been retained and a clavicle in two parts. Their distress has increased with each piece of news relating to further details of what organs were retained. Their sleep is disturbed and their relationship is threatened. They are receiving treatment for depression. Their children are having bereavement counselling at school. They feel that in their case there should be an inquest.

Mother says that each time she has asked why organs have been retained she has asked about research and has been told that no research has been carried out. She needs to know why the organs were retained.

They were offended when they were told that Alder Hey did not need to tell them about organ retention. They were told that the organs could quite easily have been disposed of in the middle of the night. Several parents were told of this possibility which they found unimpressive. They remain appalled at the way Alder Hey has taken so long to tell them the full nature and extent of the organ retention, in all a period of nine months.

Katy – 5 Months

Katy was an identical twin who died in 1990 from what was eventually diagnosed as bronchospastic syndrome. Her parents know that the clinical teams tried everything they could to save their daughter.

She was transferred to Alder Hey for a Coroner's post mortem examination. Nobody told them that their daughter had been taken to Alder Hey and they were not told that a post mortem examination would be carried out. They were not asked whether they wished to donate organs. They would not have agreed.

They wanted to bury their daughter whole in accordance with their religious beliefs. They discovered that a post mortem examination had been carried out when they were told that they could collect the death certificate. They feel betrayed because they were never consulted.

Katy's brain, heart, lungs, liver and intestine were retained. They were told over three stages that organs had been retained. They still do not know if all their daughter's organs have been returned. The first funeral was a full Catholic Mass. They thought they had buried their daughter whole. They thought they had put their daughter to rest. They did not know they had buried only the shell of their daughter. They have had to inform their four children of the death of their sister. The second funeral was more horrific than the first. The parents had to try to console their distraught children. The children are finding it very hard to understand what has happened and why. They hope they have now buried their daughter so she can finally rest in peace.

They want to know why this was allowed to happen. Why did the medical profession support it? How many years has this gone on for and how many people are involved? They now know they have only a preliminary post mortem. They know that samples were taken and have not been reported upon. They have still not received a complete post mortem report. They have been left in a great state of uncertainty against a background of mistrust.

Written Evidence

Karl – 11 Days

Karl was born with congenital heart disease. He died in 1972 at Myrtle Street Hospital. Two weeks later his parents were informed by letter that a post mortem examination had been carried out and were given the results. When Karl died his mother was insistent that there should be no post mortem examination. He had suffered enough and was entitled to rest in peace. His father had to explain to Karl's mother that he had tried hard but unsuccessfully to resist the clinicians relentless pressure on him to sign the consent to a post mortem examination. He described it as emotional blackmail. He signed on condition that his wife never found out. When she did there was great distress and the marriage was imperilled. Karl's mother believes that this has been the cause of her grieving today. Her feelings and opinions as a mother should have been respected. Karl's father believes even today that she has not fully forgiven him. Both parents thought that they had buried Karl whole.

In September 1999 a link worker at Alder Hey rang Karl's parents informing them that his heart had been retained. Three weeks later they had a letter stating that his lungs had also been retained. For 27 years his heart and lungs had been stored in a jar of formalin on a shelf. In their nightmares his parents could not imagine this happening.

Some time before 5 November 1999, when Karl's organs were buried, the organs were cut and examined microscopically. Tissue samples were taken although the original excuse given for retention was that the organs were to be used for teaching purposes only. Karl's parents believe it was ethically and legally wrong to take samples in 1999 without consent. They are not against medical research. Their faith in the medical profession has plummeted. Parents must be made fully aware of the consequences of consenting to a post mortem.

Andrew – 11 Months

Andrew died at Alder Hey in 1980. He had been transferred from another hospital with breathing problems. His mother was told by telephone that he had died from Sudden Infant Death Syndrome and that a post mortem examination would be necessary to confirm the diagnosis. She begged them not to cut her baby up but was told she had no choice. She asked if everything would be put back in its right place and was told 'yes'. She was not in a fit state to question anyone. Someone rang Andrew's mother at home to give her the post mortem results but she was in hospital suffering from shock. His grandmother took the message. His mother does not know why the post mortem was done. She says no one knows how parents feel. She felt lost and alone when Andrew died. His heart was kept on a shelf for 19 years. When she visited his grave she never thought she would be burying the rest of him 19 years later.

On 4 October 1999 an Alder Hey link worker rang Andrew's mother and told her that his heart had been retained. She felt like a zombie. The grief was the worst she had felt since Andrew died. The only communication with Alder Hey has been when she telephoned them. They never give a straight answer to questions. They never return her calls.

Mrs Karen England, Acting Director of Operations at Alder Hey, sat with Andrew's mother at the hospital and told her how upset she (Karen England) was at what had happened. Andrew's mother did not believe her. His mother found everyone she spoke to untruthful, uncaring and frightened because the issue of organ retention was now public. The only thing Alder Hey appeared concerned about was for Andrew's mother to hurry with the funeral arrangements. Later she was told that his kidneys, adrenal glands and thymus were also retained. His mother was not told about this until after she had buried his heart so they still remain at Alder Hey along with 36 other 'samples'.

For 19 years Andrew's mother believed that the cause of death was Sudden Infant Death Syndrome. She has now discovered that he had two heart attacks on the day he died. She was never told this. She has no trust in anyone. Alder Hey took it all. This must never happen to anyone again.

Christopher – 5½ Years

Christopher was born with congenital heart disease and died in 1988 while undergoing surgery. His parents were told that a post mortem examination would have to be done as Christopher had died on the operating table. They begged that he was not cut any more. They wanted to take him home and bury him. The clinician and ward sister promised that everything taken from Christopher would be returned to his body. He would be treated with the utmost respect.

His parents had no idea that his organs would be removed and retained. They understand why a post mortem was necessary but not why his brain was removed. His parents feel extremely let down by the clinician for not being honest with them.

His parents contacted Alder Hey in September 1999. They were told about Christopher's organs in stages and feel that this was not the correct way to do it. The first phone call told them that his heart and brain had been retained. Later they were told that his lungs had also been kept. The hospital link worker did his best in the circumstances.

Under no circumstances would Christopher's parents then or now have given permission to retain any part of their much loved son. They feel totally betrayed by the clinician. The post mortem report states that his spleen, kidneys, pancreas, liver, heart, lungs and brain were removed and weighed. It is hard to believe that the hospital retained only the brain, heart and lungs and put the other organs back into his body.

After Christopher's death and during the post mortem process his parents were assured he would be cared for. Christopher was as precious in death as he was in life. His parents can never forgive or erase the memory of what happened to him following his death.

Stephen – Stillborn

Stephen was stillborn in 1990. No one spoke to his mother about a post mortem examination. She does not remember giving consent. When she had her post-natal check the locum consultant obstetrician informed her that a post mortem had taken place. Stephen had died from a form of cot death in the womb.

Stephen's parents wanted to know the cause of his death. If they had been told that tiny samples of tissue were needed for research they would have given permission. They would not have agreed to the retention of whole organs. To take all Stephen's organs from his body and store them for almost ten years without establishing the definitive cause of death is unacceptable. His parents buried him ten years ago as a shell. It is like grave-robbing before being put in the grave. His body has been mutilated.

In mid-October 1999 Stephen's mother telephoned Alder Hey. A couple of days later someone from Alder Hey rang to say that his heart and other organs had been retained. Later Stephen's parents went to see a consultant from the maternity hospital to ask exactly what organs had been kept. The consultant said 'You really do not want to know!' On numerous occasions his parents have asked for a detailed list of organs retained. All they have been told is heart, brain, chest and abdominal organs. What does 'chest and abdominal organs' consist of? No-one will tell them exactly.

Alder Hey's handling of the situation has been atrocious. Nobody knows what anyone else is doing. Stephen's parents feel totally let down.

Charlie – 13 Years

Charlie died at Alder Hey in 1990, having been in hospital for many weeks. During this time his mother lived and slept at the hospital. When he died she agreed to a post mortem examination. His mother believed that this would make sense of his suffering and would assist research in finding an effective treatment or cure. A nurse told her that tissue samples would be taken, all the organs replaced and incisions hidden. Charlie would look normal. No-one was with his mother when she signed the consent form 30 minutes after his death.

Three months later one of Charlie's clinicians rang his mother to confirm the cause of his death. Six years after this his mother contacted another of Charlie's clinicians to ask for the post mortem results. He did not send her a copy of the report, saying that it was detailed and technical, but he did outline the major findings. These were characteristic of that particular disease. He did not refer to any microscopic examination or to the retention of any organs.

Charlie's mother is bitter and angry. Her trust was abused and she is having to relive her grief. She has nightmares and terrible memories of Charlie's last hours. If told the truth about the post mortem process she could have made an informed choice and not been shocked and horrified ten years later.

In October 1999 Alder Hey wrote to Charlie's mother saying that his organs might have been retained. Two weeks later she had a telephone call from Alder Hey to say that Charlie's heart, respiratory organs, abdomen and brain had been kept. She had buried an empty body. His mother was told that a dead body belongs to no-one, but it was her responsibility to dispose of the parts. A letter was to be sent outlining her options. Despite numerous telephone calls no letter was received.

In February 2000 Alder Hey wrote asking for consent to samples being taken before the organs were released. It appears that no research was done following the initial retention. Charlie's mother felt betrayed. She was horrified and refused this new request. Alder Hey would not abuse her son's remains again. When Charlie died his mother was relieved that his suffering was over. The disclosure of organ retention has opened wounds she thought long healed. She has feelings of loss, guilt and anger. Charlie was abused by an arrogant system that failed to protect the interests of those it is meant to serve.

Scott – 9 Months

Scott was born with congenital heart problems and died at Alder Hey in 1990 following surgery. His clinician told his parents that a post mortem examination would be performed as standard procedure. It was to make sure that no hospital procedure had gone wrong. The post mortem was carried out a day later than expected. Scott's parents were told to walk round Liverpool and come back later for the death certificate. His mother was distressed as she was

then five months pregnant. She never thought that organs could ever be removed and retained without consent from the next of kin. Scott's parents assumed that his body would be returned to them complete.

In 1999 a social worker from Alder Hey telephoned Scott's mother at home. She was in the middle of a christening party for her younger daughter. His mother describes the way Alder Hey handled matters as like going back to Hell again. His brain, heart, lungs, liver, kidneys, bowel and lower stomach have been retained. She doubts they will all be returned.

A further concern is the parents' question about whether Scott's heart was sent to another hospital for research and if so, was it returned. So far their enquiries have not produced a conclusive answer.

Jason – 14 Days

Jason was born with congenital heart disease and died at Alder Hey following surgery in 1994.

Immediately after his death his parents were advised that a post mortem examination would determine the exact cause of his death and might help future children. It was not compulsory but would help the hospital modify future surgical procedures. His skull would be opened, but he would look no different except for stitches at the back of his head. Samples of tissue would be taken. His father agreed provided nothing major would be retained, by which he meant organs. He was categorically reassured about this.

Several weeks later his parents saw the surgeon and were told that Jason had died from heart failure resulting from a blood infection. They were advised not to read the post mortem report as it was technical and might be distressing. The surgeon did not tell them that organs had been removed and retained. Jason's father believes that they were deliberately misinformed about the post mortem. A cynical, exploitative exercise was carried out in order to obtain their consent by the back door. The intention was to stockpile organs without parents' knowledge. Jason's organs have still not been used for research. His father is disgusted.

In November 1999 his parents received a letter from Alder Hey saying that his organs might have been retained. In December this was confirmed. His parents describe the way in which Alder Hey has handled the situation since the news first broke as damage limitation and crocodile tears. They have now seen his medical records which contain much more information about his death than they were told by the surgeon. His parents were just palmed off.

Katy – 12 Days

Katy was born with serious heart problems. She died at Alder Hey following cardiac surgery in 1995.

The surgeon told Katy's parents that a post mortem examination would have to be performed. He said that the Coroner would prefer a full post mortem, but in the circumstances would accept a partial post mortem involving the heart and lungs only. Only minimal disturbance would be caused to her body. Her parents did not want her body disfigured any more and agreed to a partial post mortem. They now feel let down because the surgeon did not explain what was going to happen. Three months after Katy's death her parents were told that she died of a heart defect.

On 5 October 1999 her parents received an unsigned letter from Alder Hey saying the hospital had 'carefully examined all our records' but it could not give them any definite information about Katy's organs. Two weeks later they were told that her heart and lungs had been retained. Her parents were told they would be sent forms requesting information necessary for the internal inquiry. The results of the inquiry would be sent to them before publication. The forms were never sent. Her parents were not contacted during the inquiry nor were they sent a copy of the inquiry report.

Her parents now fear that much malpractice will be brushed under the carpet and those responsible never held to account.

Philip – 7 Months

Philip was born with congenital heart disease and died in 1996 at Alder Hey. The clinician told his parents that a post mortem examination was necessary as he had died shortly after surgery. His parents were told they could have an independent or hospital post mortem done. They were happy with Philip's care and so chose a hospital post mortem. They thought they had put all of Philip's body to rest.

His parents rang Alder Hey when the news broke of organ retention. First Philip's clinician rang back and then a link worker to confirm that his organs had been retained. His parents cannot understand why the clinician took the trouble to give them detailed explanations of his care and treatment while he was alive, but when he died told them so little. His parents would have willingly donated his organs or agreed to his heart being kept for education and research. All Alder Hey had to do was ask. Instead his parents are disgusted. They feel robbed and cheated.

Oral/Written Evidence Relating to the Cerebellum Collection

Craig – 3 Years 5 Months

Craig was born with congenital heart disease. In 1995 he collapsed at nursery school. He was taken to the Royal Liverpool University Hospital where he was pronounced dead. His parents were told that a post mortem examination would be necessary. The post mortem procedure was not explained. His parents were informed by a telephone call from the Coroner's office that he had died of myocardial ischaemia.

They were not told that this was a preliminary finding only as the organs had not yet been examined microscopically. Because Craig had previously had a heart 'switch' operation his parents thought only his heart and lungs would be examined. They assumed that the death certificate would state the actual cause of death not an educated guess. His mother feels deceived and cheated. His body was stolen and abused.

In January 2000 his parents were contacted by Alder Hey, firstly to say that Craig's organs were not at the hospital, and secondly that there had been a mistake and his brain, liver, heart, lungs and kidneys had been retained. His parents found this quite sickening. Later the help line link worker rang to ask if they would consent to samples being taken. Then they were told that samples had probably been taken at the post mortem examination in 1995.

Eventually Alder Hey sent Craig's organs to the undertaker. They were not in a casket but 'an awful white box', roughly put together, painted and in a shoddy state. The box showed no respect for either Craig or his parents. The undertaker gave Craig's parents a proper casket free of charge. The Alder Hey box was fitted into this. Craig's father complained to Alder Hey and was referred to Mrs Karen England, Acting Director of Operations, who was neither apologetic nor concerned. Her whole attitude was one of complete indifference.

Craig's parents are still very angry.

In August 2000 an Alder Hey link worker telephoned Craig's mother with the news that his cerebellum had also been retained. She advised Craig's mother to sit down as the news was distressing but did not ask if she was alone. A third funeral was mentioned but Craig's mother put the telephone down. In a further telephone call she was asked about her plans for a funeral and whether she had spoken to her solicitor. She was invited to meet with the Serious Incident Project Board (SIPB) Director, Mrs Kate Jackson, but still had not had a letter confirming retention nearly a month after the first telephone call.

Essentially the parents are burying Craig in little bits and pieces. Alder Hey do not understand the anguish caused to siblings. His twin brother is still too young to understand fully. Grief is a very difficult emotion for them to live with as adults let alone for a child. His parents are now living with this new grief. Craig was a beautiful little boy who was violated and abused and deserves justice.

Jessica – 2 Months

Jessica was born with congenital heart disease. She died in August 1991. A Coroner's post mortem examination was carried out. Her parents originally contacted Alder Hey in December 1999 about organ retention. Three days later they were told by telephone that Jessica's chest organs, abdominal, partial heart and brain had been retained. They were shocked and distressed. They asked for a full list of organs and were told it was very upsetting and did they really want it. They were then told that the heart, brain, lungs, liver, spleen, kidney, intestines, reproductive organs and pancreas had been retained. A second funeral took place in February 2000. Thereafter they thought they would only have to wait for the report from this Inquiry.

In August 2000 they were advised by a co-ordinator of PITY II to telephone Alder Hey to check whether Jessica was involved in the cerebellum collection. On 16 August 2000 they were told by Alder Hey on the telephone that Jessica's cerebellum had in fact been retained. They were immediately asked whether they had any plans for a third funeral. They asked for time to consider. They also asked if there were any wax blocks or slides in relation to Jessica. They were told that Alder Hey could categorically state that there were no more retained organs, bone or tissue. They were told that the cerebellum had been used for a PhD study. They were not told how the cerebellum came to be at Myrtle Street when the post mortem examination had been carried out at Alder Hey.

They describe Alder Hey's handling of the whole issue of organ retention as disgraceful. They are highly critical of the failure to provide correct information in relation to retained organs. They say that their marriage is threatened, as are family relationships.

Kayleigh – 4½ Months

Kayleigh was born with congenital heart disease and died at Alder Hey in December 1990.

On 5 October 1999 Kayleigh's parents received a letter from Alder Hey saying that her organs might have been retained. This was confirmed by telephone at the end of October. Her parents had not known that she had undergone a post mortem examination. They understand why post mortems are done, but they had not given their consent. They do not understand why all her

organs were removed. They feel let down. Their daughter was let down and shown no dignity. The attitude of Alder Hey in handling the news of organ retention has been unbelievably uncaring and unsympathetic.

In November 1999 the family grave had to be reopened for Kayleigh's second funeral. The dignity and respect of the first funeral had been undermined. Her mother feels guilty that she was not able to protect her daughter in death as she had done in life. Now the family faces a third funeral.

Kayleigh's mother is a member of the Serious Incident Project Board. She was not invited to a Board meeting on 7 August 2000. No reason was given. However, Kayleigh was involved in the cerebellum collection. Alder Hey telephoned at about 12 noon on 13 August 2000 and spoke to her mother. They did not enquire whether she was alone. Alder Hey stated that they had Kayleigh's brain stem and immediately enquired whether or not her mother wanted to proceed by way of a third funeral. The caller must have heard Kayleigh's mother's children in the background. She said she was far too upset to discuss funerals and that she would ring back later in the week.

Kayleigh's mother drove immediately to Alder Hey to speak to Mrs Kate Jackson, Director of the Special Incident Project Board. Mrs Jackson explained that containers of organs were transferred from Myrtle Street to Alder Hey. One of them belonged to Kayleigh and had been identified by post mortem number. Mrs Jackson said that the cerebellum had been passed by Professor van Velzen to a PhD research student. The thesis was not available. Kayleigh's mother said that she wanted all Kayleigh's blocks and tissue samples returned with the cerebellum. They would have a third funeral and wanted to bury the cerebellum with the wax blocks. Mrs Jackson said that she did not intend to return the wax blocks until at least ten years had expired from death during which time medical records had to be preserved. Alder Hey were awaiting advice from the Secretary of State. This contradicts what has been said to other parents.

The distress caused by the cerebellum collection has to be understood in the context of a meeting Kayleigh's parents had in May 2000 with Ms Therese Harvey, Director of Human Resources at Alder Hey and Dr Ian Peart, Consultant Paediatric Cardiologist, about the extended list of organs. They asked whether any experiments or research had been carried out on Kayleigh while she was alive or dead. Dr Peart stated categorically that no experiments whatsoever had been carried out on Kayleigh. They feel this is directly contradicted by Mrs Jackson's explanation relating to the PhD student.

They are left with the impression that Kayleigh's organs have been scattered round various premises like a jigsaw. They feel that all they appeared to have buried was her eyes, her skin and some bones. They feel worse now than they did about the organ retention issue in 1999. Their home life has been affected and their children have been adversely affected. They have refused to proceed with the third funeral until the wax blocks are supplied to them. The University has refused to meet with Kayleigh's parents until after this Inquiry has reported.

Dean – 2½ Months

Dean died in 1994. His post mortem examination was carried out by Alder Hey. His parents first heard of the organ retention issue on television news. They rang the Alder Hey help line and were told that he was not involved. This was confirmed in a letter from Alder Hey dated 12 October 1999 signed by the Chief Executive at Alder Hey, Ms Hilary Rowland.

However, in August 2000 they re-contacted the help line and were told that Dean was involved in the cerebellum collection and Alder Hey had supplied wrong information in October 1999. They were then told that the original organs retained included half the heart, full brain, liver, spleen, pancreas, tonsils, both lungs, tongue, part bladder, trachea, some glands, bone tissue, skin, testicles, kidney, diaphragm, intestine and sinuses. They were devastated that Dean had been stripped of all internal organs.

He was a suspected cot death. There had been a Coroner's post mortem. He had been taken to Fazakerley Hospital. They were not told that he had been transferred to Alder Hey for post mortem examination until they turned up to view his body. They had specifically told Fazakerley that they did not want any organs to be taken even for the purpose of donation. They were reassured that no organs would be retained and only small samples would be taken from them.

They feel bitter towards Alder Hey not only because of the issue of retention but also the misinformation which they lived with from October 1999 to August 2000. They feel guilty that they did not protect Dean in death. They now want assurances from Alder Hey that all the organs have been returned to them before they carry out a second funeral.