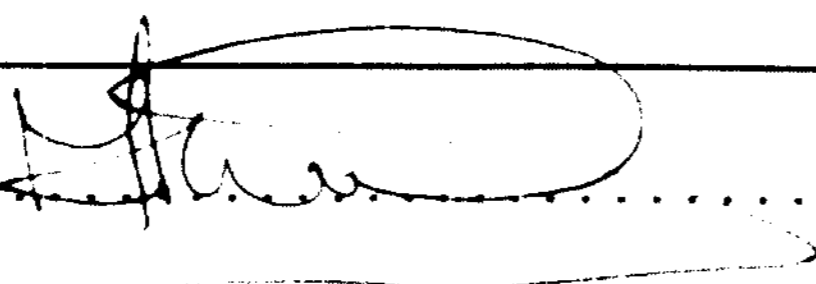


This is the Statement of Michaela Willis.

This Statement concerns both my and the Bristol Heart Children Action Group's involvement in the discovery and disclosure of the position relating to the retention of organs/tissue following post-mortem examinations on children who died after cardiac surgery in Bristol.

1. I have been the Chair of the Bristol Heart Children's Action Group since the AGM of the BHCAG in September 1998. The executive of the Action Group had been aware since its inception that in at least two occasions (including that of Helen Rickard's child, Samantha) that hearts had been retained. It had been discovered when their deceased children's medical records had been released that their hearts had been removed and retained following post-mortems carried out on the children. It had concerned us all that there may be other deceased children who had had their hearts removed. I had hoped and wished to believe that these were isolated cases but I feared that they were not.
2. I and my Committee had a continuing dialogue with Mr Hugh Ross, the Chief Executive of the UBHT, Professor Berry, the Head of the Pathology Department and Mr Ian Barrington, the General Manager of the Bristol Children's Hospital. During this dialogue and specifically since October of 1998, I raised the question of retained hearts on a number of occasions. I was seeking reassurance from Mr Ross

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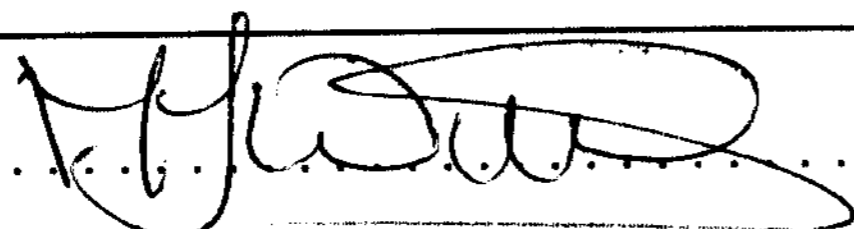
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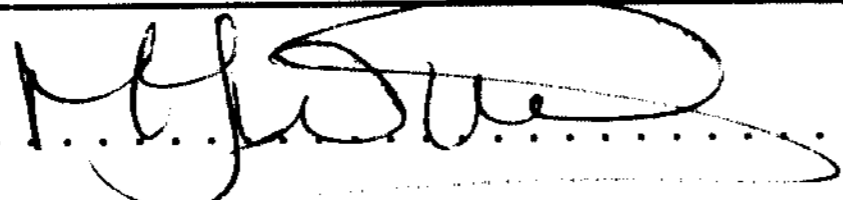
that the cases that we knew of were the only cases of their type. I was assured by Mr Ross that Professor Berry was undertaking extensive research to ascertain the correct position and we would be given the information as soon as possible.

3. It was not until a meeting on Thursday the 4th of February 1999 that we finally received information from UBHT as to the full devastating position. Present at the meeting were Hugh Ross, Professor Berry and Ian Barrington for the Trust and myself and Helen Rickard for the Action Group. The Trust admitted that it had in its possession at least 179 hearts. These organs had, so far as I understood it, been removed and retained without the knowledge or consent of the parents following the deaths of children at the unit in operations carried out between 1983 and 1995. Mr Ross also stated that organs and tissues were removed and retained prior to 1983 but that he was unaware of the numbers.
4. I was deeply shocked by this revelation. As I have said previously, I was hoping that the two incidences that we already knew of were isolated. At the very worst, I thought that there were possibly only a few more. It was difficult to comprehend the sheer scale of the retention. At this meeting there was no mention of the destruction of any hearts that had been retained or any reference to other organs having been removed, retained or destroyed.
5. I must admit that I was absolutely shattered by the revelations. I could not begin to comprehend at that time how the knowledge of the retention was going to impact

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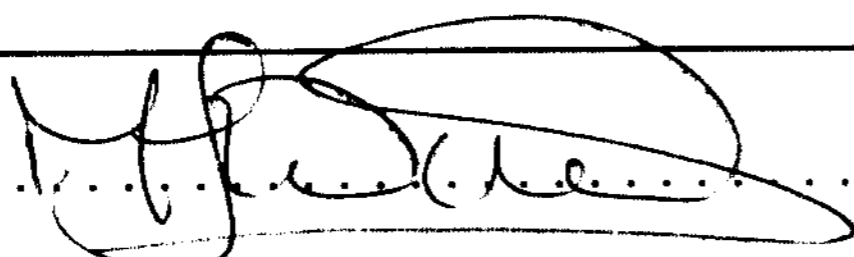
not only on myself and my husband if it applied to our son Daniel but also to the wider family of the members of the BHCAG. The prospect at this point was appalling.

6. I immediately telephoned the Executive and one of the BHCAG Solicitors, Mervyn Fudge. He advised me to request a further meeting as a matter of urgency and to prepare a list of all the families who were members of the BHCAG to see if we could not assist the Trust in identifying the parents of the deceased children from whom hearts had been removed. This meeting took place on the 8th February 1999 and was attended by Mr Ross, Mr Barrington, Professor Berry, myself, and Mervyn Fudge. Unfortunately the Trust was not in a position to assist us in identifying the families because Professor Berry's research had not been completed. They were therefore unable to confirm identification and were unwilling to go through the data which Malcolm Curnow had put together to see if we could at least identify the unfortunate families. During this meeting we informed the Trust that we could no longer await their further deliberations because we had been informed that the press had become aware of the story by a Trust leak. We further told the Trust that we were not prepared to allow our members to find out about the retention issue via the media as had happened in the past in relation to other revelations. As they were unready to write to the parents with an agreed letter, we intended to write to our members immediately, issue a press release and hold a press call to make sure that, as far as possible, the full facts were presented. The reason for doing this was I would have been no better than what we accused the Trust of doing "withholding"

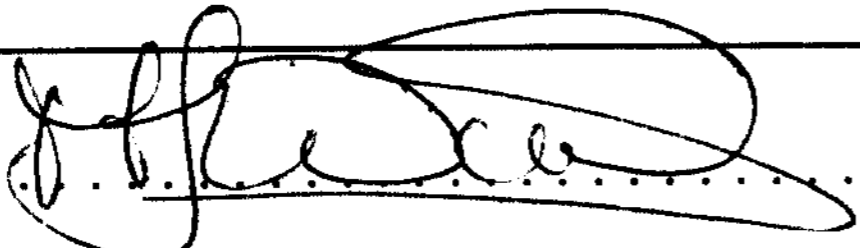
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information and I could not be party to this.

7. A further meeting took place on the 15th February 1999. At this meeting were myself, Steve Parker, Trevor Jones, Helen Rickard and Malcolm Curnow for the BHCAG and Hugh Ross, Professor Berry, Ian Barrington and Sara Garrett for the UBHT. Paul Haynes from Messrs Tozers was also present. Hugh Ross confirmed that Professor Berry had been checking and rechecking his records with a view to identifying the children whose hearts had been retained . We were also informed that other organs had been retained in addition to the hearts. We felt outrage at this new revelation. At our request, Professor Berry agreed to check with other hospitals to make sure that organs were not held elsewhere. At some time Professor Berry confirmed that 15 to 20 other colleagues in the Pathology Department had been involved in the practice of removing and obtaining hearts and organs. It was also the first time the destruction of tissue/organs was mentioned.
8. It was pointed out most forcibly that many of the families were unaware whether or not a post-mortem had been performed following the death of their child. Mr Ross stated that research had shown that 85% of the post-mortems were carried out on the instructions from HM Coroner with 15% being what he termed 'Hospital post-mortems'. He further stated that if it was the parents' wish that there should not be a post-mortem the hospital would endeavour to act in accordance with those wishes. However, he did say, rightly, that HM Coroner had the legal power to override such an instruction.

Signed  Dated 1-9-99 4

9. I then asked Professor Berry why hearts and organs had been removed and retained. The reply was that organs such as the heart and brain would be retained so they could be looked at in further detail to establish the cause of death. He stated that the Surgeon who had performed the operation would then have an opportunity to examine and study the work that he had done during the operation in an attempt to help him understand what had happened so that he could learn for the future. The Surgeon and Cardiologist would also be able to compare the findings with the information that they had available pre-operatively. Professor Berry continued that research also played a large part in his practice and he actually referred to a paper he had co-written in the late 1980s. The paper was entitled 'Postmortem Audit in a Paediatric Cardiology Unit' and appeared in the Journal of Clinical Pathology of 1989, reference 42.912-918.
10. In addition, Professor Berry also stated that organs retained since 1983 had been used for audit purposes. In response to Professor Berry's comments, I immediately stated that the UBHT must have know what was going on. Mr Ross confirmed that this was so, but that the 'practice', as he put it, was to be looked at by the Public Inquiry but he also said that this was "standard practice at all hospitals and Bristol had done nothing wrong.
11. At the time of the parents being told of the retentions ,I spent many hours (day and night) for around a period of three weeks and had to speaking to many devastated

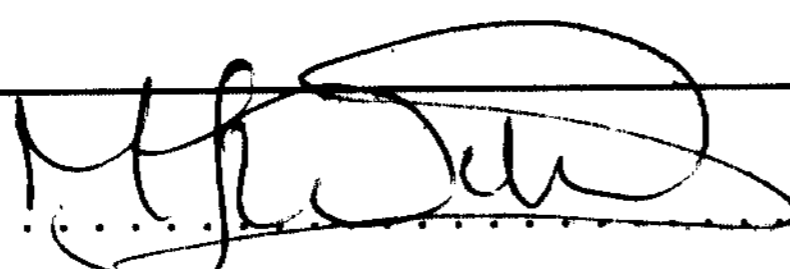
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parents, some childrens organs had been removed and sent to other hospitals and at least one child's heart had not been found. I was a go-between the Trust and had to cope with traumatised parents whilst coping with my own grief. I tore myself apart to do the best for everybody and that thought that Ian Barrington and myself had mutual respect ; on reading some of the Trust documentation this is quite obviously not so.

12. As a result of the revelations over the removal and retention and disposal of hearts and other organs, I have in my capacity as a Chair of the BHCAG seen a large number of letters sent to the families by the Trust as a result of the meetings in February of 1999. These letters state whether or not a post-mortem was performed, the date and whether the post-mortem was on the instructions of the Coroner or whether it was an internal Hospital post-mortem (for which I understand parental consent was required). In addition, these letters confirm whether hearts, brains and other organs were removed and whether they have been retained or disposed of.

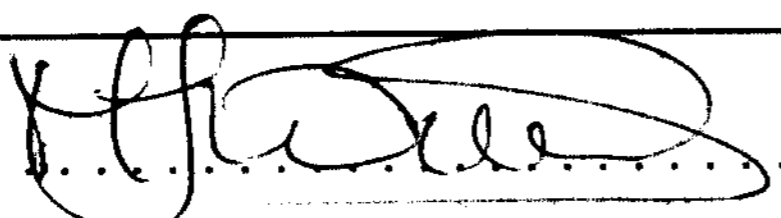
13. Where hearts and organs have been disposed of, the Trust confirms a specific date. The majority of these letters contain a standard paragraph which reads as follows:-

"The reason for retaining the heart is that, due to its small size and complexity, it cannot be properly examined during the post-mortem procedure itself. Furthermore detailed examination is required to insure that the diagnosis of the heart condition was correct and to study and learn from the Surgery that was

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undertaken. This process has contributed significantly to the major advances that had been made in Paediatric Cardiac Surgery over the years”.

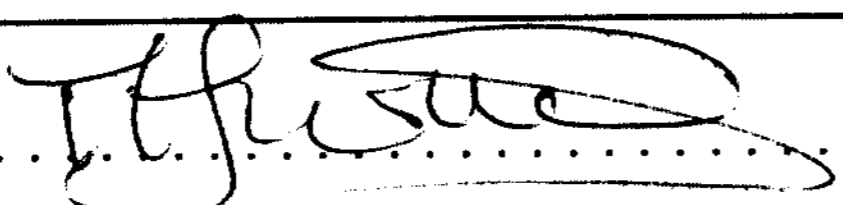
14. There are further variations on these letters which relate to whether hearts, brains or other organs were removed and subsequently disposed of. More disturbing, is the revelation in one letter sent by the UBHT to a family confirming that ‘The retention of the heart was standard practice following post-mortem examinations undertaken at Bristol Children’s Hospital. We have now found that this was not necessarily the standard practice of the pathologist who had took post-mortems at the Bristol Royal Infirmary. In [REDACTED] case the post-mortem examination was undertaken at the Bristol Royal Infirmary and it is therefore probable that (her) heart was returned to (her) body before it was released. However, I am very sorry to say that are records are able to confirm this definitely’.
15. I appreciate that the Trust and its employees have attempted to collate the information which they have and to provide as accurate an explanation as possible to each of the families who are involved in this distressing episode. The BHCAG is grateful for this. However, it cannot undo the hurt and emotional distress which has been occasioned by this appalling practice. I know for a fact that if many of the families had had their consent sought and had it explained to them that the conclusion of a post-mortem and the retention of their child’s heart for research would have assisted the saving of a life they may well have agreed. However, for whatever reason and with whatever justification, to remove the Child’s organs

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without the knowledge of a parent cannot ever be justified in my view whether morally or legally. This practice should be stopped immediately and there should be no justification for undertaking a post-mortem without the consent of the parents and without the request of a Coroner.

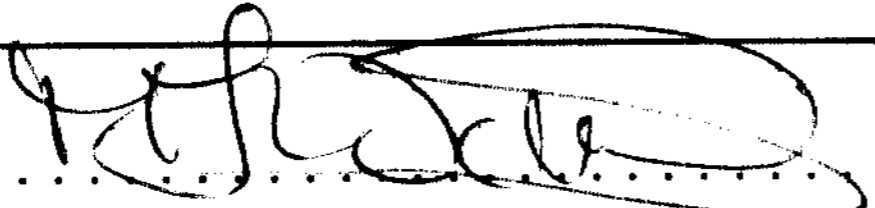
16. The knowledge that our son's heart was retained has been devastating. This emotion has been felt by all those who have learnt the news following the death of their child. The damage caused to both individuals and families is incalculable and for such a practice to have been discovered on such a wide scale without parental knowledge is in my view a scandal. I am also sure that when the members of the BHCAG were informed of the fact that by 30th November 1998, at the latest, the Trust were aware of the exact numbers of childrens hearts retained and nevertheless chose to inform the Public Inquiry first and withhold the information from the families, their mistrust of the Institution will increase even further. Neither I nor my executive can comprehend why the Trust did not inform us as soon as they were aware of the scale of the retention and associated disposals and why when they were aware in November were they still unable to give an immediate response to parents in February.

17. I have also been made aware that both Hugh Ross and Ian Barrington have sought to criticise the Executive of the BHCAG in their statements for what they consider to be the precipitative disclosure of the information they wished me to withhold this information from our members for a while longer. It took me 3 working days to

Signed  Dated 1-9-99 8

inform families and for this I was subjected to being verbally attacked in a meeting that was held that this was too long and I was no better than the surgeons. This reduced others in the meeting to tears and I had to take a break. This is just some of the damage that has been caused. I entirely refute such an allegation. The Trust and its managers deliberately withheld the scale of the retention of the childrens hearts for over 10 weeks. This led to the press being aware of the story by a Trust leak and caused the events which I have described. I was in constant contact with Hugh Ross and he had every opportunity to inform me of the scale of the problem. I consider the Trust's conduct to be a continuation of the morally reprehensible behaviour which created the need for this Inquiry. It again shows that the Trust for all its fine words has still failed to learn the fundamental lesson that it is wrong to withhold information from any patient for whatever reason, especially when it is simply a justification for its own purposes.

18. Finally, I want to say that the Trust asked me to withhold information about retention from BHCAG members. I was not prepared to do this; that was how the surgeons (and others in the Trust) had behaved. As it was, I spent 3 working days telling the families concerned. At one BHCAG meeting, I was verbally attacked and told that I was no better than the Trust's doctors for waiting as long as I did. The meeting was very emotionally charged and it showed the damage that the Trust's attitude has caused.

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