

THE BRISTOL ROYAL INFIRMARY INQUIRY

**FURTHER CLOSING SUBMISSIONS
ON BEHALF OF UBHT**

1. Generally

1.1 The Trust does not intend to abuse the concession made on 9th February 2000 to the effect that it could respond to submissions made on behalf of the BHCAG which were circulated too late for a considered response on that date.

1.2 There are only two specific areas where comment is required. However, the Trust would wish the point to be made that the adversarial tone of submissions which are condemnatory of almost every aspect of the provision of care and treatment at Bristol and give scant recognition to any of the obviously positive features, is unhelpful.

2. The split site

2.1 It is unnecessarily emotive and an exaggeration to describe the split site as a “disaster”. The Inquiry must keep in perspective the development of paediatric cardiac surgery over the relevant time. It is probable that at the beginning of the period with which the Inquiry is concerned “cardiac surgery” was the recognised surgical specialty, rather than “paediatric cardiac surgery”. In other words, the emphasis was on the type of surgery, not the age of the patient. It would have followed naturally that surgery would be carried out in the operating theatres where cardiac surgeons operated. In the same way, ophthalmic surgery and neurosurgery during the same period took place at operating

theatres elsewhere in the Trust and not in the Children's Hospital.

- 2.2 The recognition of the difference between paediatric and adult cardiac surgery has evolved over a number of years, and with that recognition has come the acknowledgement of the need to provide dedicated children's services. The BHCAG concentrates on the evidence, given in 1999, about what would be expected now for the proper running and staffing of a dedicated children's cardiac operating theatre and paediatric cardiac ITU, and treats this evidence as if it held good for the whole period from 1984 to 1995 as well. No allowance has been made for the difference in perceptions and expectations over the relevant period, and the specialist experience acquired in the meantime, which enabled paediatric cardiac surgery to become a recognised and viable sub-specialty in its own right, with its own resources and facilities. Indeed, that position was attained in Bristol in 1995, since when all paediatric cardiac surgical work has taken place at the Children's Hospital. This will be further developed with the facilities in the new Children's Hospital currently under construction.
- 2.3 The evidence is clear that for many years the Health Authority and latterly the Trust had it in mind to create paediatric cardiac operating facilities and a cardiac ITU in the Children's Hospital; but that there was competition from other areas for the resources necessary to achieve this.
- 2.4 In the Trust's original Closing Submission, the point was made at paragraph 3.6 that it had not been suggested that patient safety was put at risk as a result of the split site. This is true. Dr Joffe's observation that the steep hill between the two hospitals was a physical obstacle did not prevent him (or, for that matter, the other paediatric cardiologists) going to the BRI. It is an inaccurate paraphrase of his evidence to suggest that "...*cardiologists at the BCH avoided going [to the BRI] whenever possible*". In fact he said that there was

a paediatric cardiologist at the BRI every day, who would see each of the paediatric patients there and make treatment recommendations if necessary (Day 90 page 65). No doctor suggested that geographical separation had had an impact on the safety of their patients or that, indeed, any identifiable patient had suffered as a consequence. Mr Pawade, who came from an internationally renowned specialist centre, although noting the inconvenience of the arrangement which he inherited, did not condemn it as a potential cause of risk to his patients or as affecting patient care. (see his witness statement dated 26 July 1999)

- 2.5 Again, as already observed, the immediate motive force behind the decision that was ultimately taken to go ahead with creating the cardiac surgical and ITU facilities at the Children's Hospital was the planned increase in adult cardiac surgery. It reflected a long term objective which was generally recognised as being desirable, but it was not as a consequence of any clamour for an end to the split site because of its deleterious effect on paediatric cardiac surgery. Of course, the physical separation between the Children's Hospital and the BRI had an effect on the overall care of the children and their families, to the extent that the two environments and the staff teams were different, and moving between the two hospitals (which did not affect every family) was bound to involve disruption. But, on the information given to the management, the problem was at that level rather than associated with patient safety or poor clinical outcomes.

3. Retained Organs and Tissue

- 3.1 It is wrong to suggest, as the BHCAG does in the Introduction to its submissions, that organs had been "illegally" retained.
- 3.2 While it may now seem morally repugnant to retain organs or any other tissue from

children long-term without parental permission, this is to judge the issue by recently developed ethical standards, rather than by those pertaining at the relevant time. During the period with which the Inquiry is concerned, those seeking consent to *post mortem* undoubtedly believed that it was kinder not to give explicit details to parents of what was involved in the *post mortem* examination, at a time of already great distress for families.

- 3.3 It is suggested in paragraph 1.5 of the BHCAG submission on **Post-mortem: practice and procedure** that there was a policy of “paternalistic secrecy”. This is an overstatement of the true position. There is no suggestion from any source that information about organ or tissue retention was withheld from parents who asked for it. Rather, doctors preferred not to volunteer details in individual cases in the interests of sparing parents’ feelings, and the vast majority of parents did not ask about how *post mortem* affected the body in the short or the long term. There was no secret about professional practice at the time generally as is evidenced, for example, by published studies on retained hearts.
- 3.4 It is important to remember that the reason for retaining organs and/or tissue was to provide, in some cases the Coroner, and in other cases doctors and parents, with information about the cause of death, and indirectly to improve the chances of survival of future children with serious heart disease.
- 3.5 There are several misconceptions in this part of the BHCAG submission about the nature of Coroners’ *post mortems*. First, it is suggested that the pathologist owes a duty to parents in carrying out such examinations. But pathologists are independent of both parents and the hospital to which they are attached, and are answerable only to the Coroner. Even were some other body or institution to replace the Coroner’s Court that would have to remain the case, because that element of detachment would have to be

preserved. It is important to recognise that the same rules apply to all Coroners' autopsies, regardless of whether the death occurred following a surgical procedure, a road traffic accident, an industrial accident, murder or a suicide. While it is obviously important to respect the views of parents or other relatives, it would not be appropriate or in the wider public interest to give them a veto over, or even a defined interest in, how a particular Coroner's *post mortem* examination is conducted.

3.6 Reliance is placed on paragraph 3.1.5.4 on Professor Knight's article in the Bulletin of the Royal College of Pathologists. This was not an academic paper, but a short article in a professional journal. The article pointed out that in a Coroner's *post mortem* pathologists have a duty to retain tissue and organs having a bearing on the cause of death, but the author confirmed that they could not remove what they wanted indiscriminately. However, he was understood at the time (and has been understood by pathologists since) to have been advocating that once legally obtained, the tissues could be retained long term.

3.7 The above should not be taken as suggesting that UBHT is opposed to greater involvement of parents and relatives in both types of *post mortem* in the future. On the contrary, there is every reason why there should be discussion about the need for *post mortem*. If it is envisaged that it will be necessary or advantageous for tissue to be retained longer term, or indefinitely for a general or specific purpose, then the reasons should be sensitively explained and agreed to.

3.8 In relation to hospital *post mortems*, it is suggested in paragraph 2.3.1 of the BHCAG's submissions that pathologists should have been more active in ensuring that proper consent was always obtained by clinicians. Despite assertions to the contrary, it became obvious that a consent form had been obtained in each of the non-coronial *post mortem*

cases which was reviewed. It is said that the inability of the parents to remember giving consent reflects upon the poor standard of communication between doctor and relative, but that ignores the effect that grief may have had on the parent concerned.

- 3.9 Professor Berry was ahead of his time in raising questions and concerns about the consent issue in the 1980s and early 1990s. He and UBHT have welcomed guidance on how this difficult subject can best be tackled and at what level. It would not seem sensible for the treating doctor to have the necessary discussion, only for the exercise to be repeated by the pathologist who, up to that point, would have had no contact with either the patient or the relatives. The key must be to ensure that the consenting process enables the parents/relatives to achieve an understanding of why *post mortem* is taking place, the benefits which will flow from it, and the arrangements which will be made after it is concluded. Coupled with this, must be transparency of the necessary documentation in use to support the consenting process.

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