

From the Editor-in-Chief

THE FALL-OUT FROM THE BRISTOL INQUIRY continues, even though it is now more than four years since the Secretary of State for Health for the United Kingdom published the definitive report of the Inquiry,¹ and five years since Sir Ian Kennedy presented his interim report.² In the supplement that will accompany this issue of the Journal, Jacobs et al. discuss the impact of the reports concerning the Inquiry on the collection and validation of data relating to surgical and interventional procedures for the correction and palliation of congenital cardiac malformations.³ Very recently, further analysis of the results of such surgical procedures in the United Kingdom has suggested that Bristol might not have been the only centre that could be described as an “outlier”, with the analysis using statistics collected for episodes in hospital⁴ suggesting that other centres dealing with low volumes of cases might have been underperforming, albeit that the statistics collected for the period subsequent to 2000 by the United Kingdom Central Cardiac Audit Database indicated that all centres by this time were performing within comparable standards.⁵ Both these analyses are open to question, since those who used the statistics derived from hospital episodes argued that the methods used by the central database were less than rigorous,⁴ while those representing the database argue that the statistics concerning episodes in hospital have not been validated.⁶ The question concerning the issues of volumes of cases, therefore, continues. In this respect, it is salutary to note that, in the report commissioned by the Department of Health in the United Kingdom subsequent to the publication of the Bristol Inquiry, a committee made up of paediatric cardiologists, paediatric cardiac surgeons, intensivists, anaesthetists, nurses, parents, and the patients themselves, unanimously recommended that surgical activities should be concentrated within a smaller number of centres.⁷ After consideration, however, the government announced that it was “not minded” to adopt this proposal. With the publication of the data from the analysis of hospital episodes,⁴ this debate should surely be reopened.

One of the other major concerns to emerge from the Bristol Inquiry, of course, was the issue of retention of organs subsequent to autopsies. I have a particular interest in this issue, since it was the evidence that I gave to the inquiry, on September 9, 1999, that

triggered the wave of public indignation that subsequently emerged. The ramifications of these disclosures have been even wider than I had imagined. At times, I have wondered whether I was justified in opening “Pandora’s box”. My recent experiences, however, have removed whatever doubts I might have harboured, and reinforce my belief that these issues needed, and still need, to be the subject of public debate.

For the past 4 weeks, it has been my privilege to be Visiting Professor at Royal Children’s Hospital in Melbourne, hosted by Dan Penny and the Australia and New Zealand Children’s Heart Research Centre. Part of my duties was to facilitate discussions amongst all the tertiary centres dealing with Cardiology in the Young in Australia and New Zealand. This aspect was particularly successful, and it is encouraging for me to report that all these centres are now committed to work in collaboration, pooling their data in a fashion comparable to that achieved in the United Kingdom through the central database,⁵ but also pooling their considerable resources in a series of collaborative research projects. I predict that we will hear much more of these exciting developments. Another of my duties was to participate in a debate at Royal Children’s Hospital on the issue of retention of organs. Also participating in the debate was Paul Monagle, who had led the response of the hospital to the issue of retention when it surfaced in Australia in 2000,⁸ and also a parent, Meryl Quarrel. Meryl had discovered only in 2000 that the hospital had retained the heart of her daughter, who had died as a neonate in 1977. I learned much from both their presentations, and I believe that these matters still deserve more widespread dissemination.

Paul emphasised that, even though the retention of organs within Victoria, and elsewhere in Australia, had been legal, this had been inadequate, since as professionals, we had failed to understand the needs of the families.⁸ In this respect, it is of interest that, although the outrage that greeted the publication of my evidence given in Bristol triggered similar reactions in Australia and New Zealand, the reaction has been much more muted in Europe and the United States of America. I know that, as in Melbourne, the retention of organs in Pittsburgh, for example, has also been conducted entirely within the law, permission being granted for all organs to be retained for

the purposes of research and education. It is also my understanding that retention within the Netherlands has been lawful, but I am unsure of the situation elsewhere. Irrespective of the legal position, as stated by Monagle et al.,⁸ “we have to instil in paediatricians the need to listen to and talk with families as a culture within our institutions and our profession”. Subsequent to their experience in 2000, the team in Melbourne analysed the response of the first 40 families they interviewed. When considering the response, we need to remember that, in each instance, the organs had been retained entirely lawfully. All of the families interviewed believed that they should have received full and explicit information about autopsies at the time they were asked to consent to the procedure. Over nineteen-twentieths believed that failure to provide this information represented a breach of trust by their doctor.⁸

Subsequent to these experiences, booklets have been produced in Melbourne providing information about the autopsy, and about retention and its legal implications, for the parents,⁹ but equally importantly, also for health professionals.¹⁰ These booklets are excellent. Their content was crystallised by Meryl, in her contribution to the debate. She explained how, when suffering the loss of her child as a young mother in 1977, the dead baby was removed from her care and taken to a different hospital for autopsy. The next time she saw any part of her baby was when she was shown a photograph of the body, taken during the autopsy, but not revealed to her until she met with Paul Monagle in 2000. Meryl’s response has been exemplary. Whilst outraged by the actions occurring in 1977, she has looked beyond her own feelings, and those of her husband, and sought to establish what has been learnt from us as professionals from the retention of the organs within the archives that exist world-wide. In Melbourne, the existing archive has been re-catalogued, and is now housed in appropriate premises where it can be used for ongoing research, and for the education of all those still concerned with the diagnosis and care of those born with congenital cardiac malformations. A plaque is now posted on the door of the archive, which expresses the indebtedness of the profession to the parents whose children’s organs are preserved within the archive, and apologises in appropriate fashion for our failure in the past appropriately to recognise the rights of these parents. Equally importantly, the archive contains not only the heart of Meryl’s baby, since Meryl was gratified to appreciate that the heart could still be of value, but also a beautiful quilt that Meryl has designed and crafted specifically for the archive (Fig. 1). The quilt is a traditional pattern called “New York Sunrise”. It has been made by Meryl in memory of all the babies and children whose



Figure 1.

Mrs Meryl Quarrel is pictured together with Dan Penny, Chief of Cardiology at Royal Children’s Hospital, Melbourne, to either side of the quilt made by Meryl that will hang in the archive of hearts retained at Royal Children’s Hospital.

hearts are in the collection. The tragic loss of life in New York, in September, 2001, added to the significance of her chosen pattern, since she visited “ground zero” no more than 10 days after the disaster. As she commented, to some extent the archive itself reflects her own “ground zero”. The quilt now hangs in the archive as a reminder to medical staff that use the collection of the great losses and ongoing connection families still have with deceased children. It emphasises their generosity in donating organs to assist the staff.

We may all think that the ramifications of retention of organs are now behind us. It remains appropriate, nonetheless, to ponder on the generosity of Meryl and similar parents, and to echo the conclusions made by Paul and his colleagues subsequent to their experiences. “The task of listening to and talking with bereaved families is not an easy one, and considerable time and effort need to be put into developing appropriate teams within hospitals to support families at this time. As one parent said, ‘I couldn’t do that (talk to a bereaved parent) for anything, but as a doctor, it is your job, and if you can’t look me in the eye and do it properly, then you shouldn’t be there’.”⁸

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