

## Chapter 15. Epilogue

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1. We set out to discover how so many parents were induced into thinking that they were burying their children intact when in fact the large majority were buried without their vital organs. In our search we discovered the long-standing widespread practice of organ retention without consent. The practice arose from a sense of paternalism on the part of the medical profession which served to conceal retention in the supposed best interest of the parents. Such practice was misconceived and was bound to cause upset and distress when, inevitably, it came to light.
2. We believe that the Liverpool experience is a considerable exaggeration of the national picture because of the exceptional practice of Professor van Velzen in the wholesale systematic retention of organs between 1988 and 1995. The large store of organs at Myrtle Street remained largely unused for medical education or research purposes throughout this period.
3. The problem was compounded by the inept handling of the return of organs for burial or cremation by Alder Hey following disclosure of the heart collection at the ICH in September 1999. The result is that some parents are contemplating third or fourth funerals because their child's organs have been returned piecemeal. Whatever system there has been for return, the task has been made even more difficult by late disclosure of various collections of organs by Alder Hey and the University.
4. A further aggravating feature has been Professor van Velzen's behaviour, including exaggeration, falsification of accounts involving both financial and human resources, fabrication of post mortem reports and a failure to provide the essential service of histology. He did not even fulfil his clinical contract at Alder Hey. He has imperilled future generations by fabricating post mortem reports and not reporting histology, thereby depriving parents of the opportunity of seeking genetic advice when appropriate. His conduct will be reported to the General Medical Council and the Director of Public Prosecutions. He must never practise again.
5. Managerial inadequacy indulged Professor van Velzen's aberrant behaviour. Alder Hey and the University must now consider whether disciplinary action is appropriate in light of our findings.
6. We have striven to unravel the history of events in order to provide an answer to the multitude of questions raised by the parents. Some will be answered in full. Some will be answered in part. Many will receive inadequate answers or on occasions no answer at all. The hope is that our trawl through the evidence over many months has provided as much by way of explanation as possible. The reader can draw his or her own conclusion from our close analysis of the evidence.

7. The parents have been a source of inspiration and focus throughout. They are entitled to consider the facts as we have laid them out. We have told the story exactly as we have found it without interpretative slant, mitigation or modification. We realise that this might be upsetting for many readers but we have faithfully discharged our duty to report on the evidence, of which there is a daunting volume.
8. Many retained organs have been returned for burial or cremation but many have not been reclaimed. There will always be parents who do not want to know, as well as parents awaiting the outcome of this Report before deciding what to do. The parents have a right to dispose of the organs and tissue respectfully. They also have a right to leave them for research.
9. Tissue and organs which have been archived are an invaluable asset for medical research. Children who have survived serious illness or disease may well have benefited as a result. Some parents may wish to ensure continuing research as the best resolution hoping that retention of their children's organs will not have been in vain. The simple proposition is that for therapeutic, medical education and research purposes human tissue is an essential requirement. The ultimate control should be a proper system of fully informed consent. The evidence indicates that many parents will readily consent to retention for these purposes, if sensitively approached with openness, honesty and transparency. Whether that would extend to organs being retained in collections is a matter of personal choice but an open and honest approach to the obtaining of consent will have its own reward for the medical profession which must consign paternalism to the annals of history.
10. We commend this Report to parents as representing our best effort to establish the truth. We encourage reconciliation with Alder Hey which continues to provide a medical service of distinction and renown for sick children. Alder Hey and the University should learn from their many errors and mistakes which we have identified. A full and humble apology from both would be an excellent starting point. A cathedral service or a memorial at Alder Hey or other act of reconciliation might be appropriate.
11. The abiding message must be that the distress and grief suffered by the parents should be channelled into rebuilding and obtaining strength from the fact that so many people contributed to the Inquiry despite the risk of personal criticism. The whole process has been assisted by the willingness of Alder Hey and the University to disclose documents, even those with obvious damning content. Their co-operation has not come without individual cost.
12. We are conscious that our Report will bring further pain and distress to parents who must live with the knowledge of what happened to their children after death. They have done everything in their power to ensure that never again will children's organs be retained without fully informed consent. We have made strong recommendations to that effect. Safe in that knowledge, may they direct their feelings towards the everlasting memory of their beloved children in life.