

## THE GREEN LANE HEART REGISTER

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In 1948 a collection of human hearts with congenital heart disease was started at Alder Hey Hospital in the UK. By 1999 the collection included 2,128 hearts together with 1,564 hearts from stillbirths or pre-viable foetuses. The resultant outcry when the existence of this collection became public knowledge, together with the issues around absence of written consent and similar collections elsewhere in Britain, made international headlines.

The subsequent Royal Liverpool Children's Inquiry produced a Summary and Recommendations ordered by the House of Commons to be printed January 30 2001. Excerpts from this report stated:

"We set out to enquire into the removal, retention and disposal of human tissue and organs following Coroners' and hospital post mortem examinations and the extent to which the Human Tissue Act 1961 had been complied with. ... The clinician's obligation under Section 1 (2) of the Human Tissue Act is to ascertain if, having made such reasonable enquiry as may be practicable, he has no reason to believe that any surviving relatives of a deceased child object to the body being used for therapeutic purposes, medical education or research. The starting point must be that the clinicians do have reason to believe that parents might object. ... There is abundant evidence of failure on the part of clinicians to make the requisite enquiries of parents to see if they objected. ... If there is an intention to retain organs for medical education and research upon conclusion of the Coroner's jurisdiction, the clinician should obtain consent from the Coroner and the parents at the outset, otherwise retention following completion of a Coroner's post mortem examination is illegal. ... In mitigation, it is stated that the heart collection has served to reduce the mortality rate following cardiac surgery for some serious heart conditions and malformations from 33% to 3%. This benefit cannot be ignored, but it is no justification for ignoring parent's rights".

In New Zealand, the legal issues were reviewed by Professor P D G Skegg in his paper, "The Removal and Retention of Cadaveric Body Parts: Does the Law Require Parental Consent?". He concluded:

"In terms of the law, the conclusion is straightforward. The Human Tissue Act 1964 does not require that the consent of parents or other relatives be obtained, before cadaveric body parts may lawfully be removed and retained for the purposes of medical education and research (or for therapeutic purposes). Sometimes there is no need to ascertain the views of parents or other relatives. However, in the case of a young child (amongst others) the person lawfully in possession of the body has no authority to authorise the removal and retention unless, having made "such reasonable enquiry as may be practicable", that person has "no reason to believe" that there is a relevant objection. There are then additional requirements to be met if the removal and retention is to be lawful by virtue of the Act: parental consent is not simply unnecessary; it is not sufficient. Right 7 (10) of the Code of Rights does not supplant or supplement the provisions of the Human Tissue Act."#

Understanding Congenital Heart disease is a very complex task and great progress has been made both in diagnosis and treatment over the latter half of the last century. However, as Sir Brian Barrat-Boyes said "You can look at pictures and textbooks but we were able to hold these hearts in our hands". The Green Lane Heart Register, commenced in the late 1950's, came to comprise over 1350 hearts and was a major

contributing factor to the progressive improvement in infant survival after heart surgery from the early 60's to the late 90's.

Following the Alder Hey revelations, there was a meeting in August 2000 to discuss the paediatric Heart Collection and issues that might arise as a consequence. The meeting agreed that parents were always informed whether or not there was a post mortem undertaken on their deceased child, but prior to 1988 it was not always made explicit to parents that organs were retained. It had been the usual practice at Green Lane to write to parents about the findings of the autopsy and all hearts could be identified.

On January 30<sup>th</sup>, 2001, the New Zealand Herald ran an Alder Hey Story captioned "Child's Head In Jar Part of Collection" and a follow-up article February 2<sup>nd</sup> stated "Prof. Liam revealed that more than 100,000 organs, body parts, stillbirths and foetuses were held in 210 hospitals and medical schools around the UK, many taken or kept illegally."

In March 2001 Colin Feek, NZ Ministry of Health Chief Medical Advisor wrote to all district Health Boards asking for confirmation about collections of "pathological material" to establish which material might have been taken or kept illegally. In April, the Chief Operating Officer, Neil Woodhams, replied that ADHB did not hold collections of pathological specimens without informed consent, but acknowledged there was a collection of paediatric hearts. That month the Bristol Report was also published and the General Manager of Green Lane requested a report on the status of consent of retained hearts (number approx. 1350 in total).

The reply, based on a limited audit of hearts, stated "Permission was probably not obtained in most instances for hearts kept before 1990. Since 1992 only for cases where permission from the families had been obtained had the heart been retained. Permission was not obtained for a coroner's autopsy to be performed. If the family requested or gave permission for the heart and other organs to be kept this was documented in the patient's medical chart and also written on the form which was sent to the pathologist who would perform the autopsy." A subsequent, more thorough review, showed hearts retained over the last 10 years with no documented evidence of consent.

In April 2001 the Green Lane Heart Steering Group was set up with the aims "To preserve the Green Lane Heart Library, for the purposes of teaching and learning in a manner that respects the wishes of the families of the people/children whose organs are in the collection". The Group decided that some families might not want to be contacted "out of the blue" and there was, for example, the delicate issue of women who might have concealed a pregnancy and had a late termination. They felt information needed to be fed to the public sensitively, asking concerned parents to approach the hospital. Two advertisements were placed in Wellington and Auckland newspapers, but between April and November that year only six families contacted the hospital and only two hearts were returned.

On the 6<sup>th</sup> April 2001, the ADHB issued a media statement, including "Our present and future policy is that hearts with defects important for teaching and research are retained indefinitely only with permission from the family." The next day the Wellington Evening Post ran the story "They Kept my Baby's Heart" followed up by the Herald April 9<sup>th</sup> "Hospital stole my baby's heart". In July, A new Body Parts

policy was drafted for the Board and expert ethical and legal opinion sought in September and October. The Woman's Day ran an article on November 5<sup>th</sup> "They Stole my Baby's Heart". Finally, on February 14 2002, Rob Harley approached Green Lane looking for a story to front the new Sunday current affairs program. Green Lane agreed to supply information about the Heart Collection and it was planned that the program to air on March 17 would include interviews with parents and the paediatric surgeon Kirsten Finucaine, perhaps with her demonstrating a defect from a heart in the collection. In this way the public could be informed allowing enquiries as people chose.

On February 20 the Heart Steering Group submitted a routine report to the ADHB Board, only belatedly realising that because the content would fall into the public domain it would be available to the attending Herald reporter. Realising the Herald planned to run a "scoop" February 28, the incomplete Sunday material was released to Paul Holmes to pre-empt this February 27<sup>th</sup>. A sensational story aired at 7 pm that evening; "Last year Dawn Bailey followed up on a long held hunch that her baby was not complete when they buried her". A fairly safe hunch as it turned out since Green Lane had confirmed in writing many years earlier that it held her baby's heart and Dawn had declined the offer of return stating she was content for the specimen to remain in the collection.

Although infrastructure to handle enquiries had been prospectively established, the dimensions of the tidal wave of human emotion this program released was unprecedented and overwhelming. The next day, February 28, 990 phone-calls were received, of which only 13% were relevant to a heart in the collection. The staff finally quit at midnight and returned at 6am to find a further 70 calls logged on the answer-phone. About 3000 calls were fielded the first week and 4000 in total. The practice in the 1970's of preventing women from seeing their dead baby, because this was believed harmful to their recovery, meant many women had never properly been able to grieve. For many mothers, this phone conversation was the first time they had been able to properly confront and talk about their experience and some spoke for up to one and a half hours. One mother was only allowed to see her baby's foot. Many enquiries were from women now in their 50's who were unable to be present when their baby died, the baby having been flown ahead as an emergency.

Staff were often dealing with two families as not infrequently the baby's death was followed by a relationship breakdown; one couple who had not spoken since the death of their child left hand-in-hand. Non-medical staff volunteers, clerks and secretaries manning the phones were suddenly faced with situations outside their everyday experience, and intuitively negotiated uncharted waters. Obtaining medical records from other centres was often complicated, with sometimes reluctance from other hospitals to co-operate ("why do you need it if you have the heart?") in turn raising family suspicions of a cover-up. Some centres initially wanted to manage their own returns, but most when they realised the complexity of the process were happy to leave responsibility with Green Lane.

The heart return team, undertaking handovers, was initially 2 people. They had no blueprint to follow and learnt as they went along. Families were angry, upset, grieving, wanted retribution, wanted someone to pay. It was a very emotional experience and staff needed to be flexible and mentally tough. A glimpse into the

emotions involved is captured in this excerpt from a letter written by one of the team members:

“Returning hearts to parents can only be described as a life changing experience. I cannot put into words what it feels like to hold a child’s heart in my hands, show the parents the anatomy, surgical incisions, sutures and grafts and explain the benefits these treasures have been to other children. K. and I have witnessed the grief, anger and hurt first hand. We have laughed, cried, been yelled at, thanked and hugged by parents and families. It has been a privilege to be part of what should be a very private experience for these people.”

The one feature which stands out with the heart return process is the diversity of human responses. Of many anecdotal experiences one may suffice. A mother was delighted to find the nurse on the paediatric ward was the same nurse who was present at her baby’s death 23 years earlier. The custom at that time was to tell parents their child was dying and encourage them to leave the hospital. The mother had always wondered what her daughter’s last moments were like, worrying whether she had perhaps died in a lonely corner. The nurse in turn was able to tell the mother that the death of her daughter was the nurse’s first experience of a child’s death and because of that, the event was still engraved on her memory. She was able to ease the mother’s mind by reassuring her the daughter had not died alone and telling her the details of how she had cared for the child until her last moments.

The tangi’s were a very special experience which I felt privileged to have attended. No-one who participated could not feel cut to the heart at the plainly evident grief etched on the families faces, the terrible pain at an old wound reopened and an acute sense of shame at having been however unwittingly an agent of this hurt. Face to face there was nowhere to hide from the responsibility of involvement, to answer the unanswerable accusation of how could you have done this without asking, what right to inflict such terrible pain. I gained enormous respect for the He Kamaka Oranga Maori Staff, who despite in no way condoning what had happened often had to endure the most vitriolic criticism for lowering themselves to be seen with staff who had behaved so despicably. Despite also being sometimes personally related to the grieving whanau and kaumatua, they did not waver in their loyal support of the participating clinicians and steadfastly followed protocol.

I was humbled how, with only one exception in my experience, reconciliation was achieved. Maori protocol is to stand and get whatever you want to say off your chest, nothing off limits, but at the end to Hongi and reconcile. The act of accepting responsibility and apologising for the breach of trust which had occurred allowed the start of a healing process with many families. Talking afterwards over a cup of tea in an atmosphere free from hostility, one was often saddened to learn of the fragmentation of families that the child’s death had set in train. No-one participating in those ceremonies emerged unchanged.

On reflection, what did we learn?

Firstly, for the media ratings always justify 30 pieces of silver.

Secondly, whatever the rights and wrongs of the situation, the hospital and its staff fronted up, accepted responsibility and apologised. Regardless of whether it was legal, it was not morally defensible to retain children's hearts without the knowledge and consent of their parents. The deceptively simple act of saying sorry was very powerful. Face to face, corporate jargon will not substitute for simple humanity.

Thirdly, we have a responsibility to correct our ignorance of Maori Tikanga and custom, which we are actively addressing through the Tuhonohono program and dissemination of Tikanga best practice.

Finally, we seem to have become very blasé as a society. Despite protests at the rising tide of litigation, as doctors we are secretly flattered at being cast as larger than life supermen and women who have the latest technological solution to every problem, if only the money comes through. We need to regain a perspective that includes death as an integral part of life, that there comes a time when it is okay to hold back and let people die in some dignity beyond CPR or a respirator. Instead of shock and awe perhaps we need to recapture the sense of wonder about the preciousness of life itself. We need the poet's sensitivity;

To see the World in a grain of sand  
And Heaven in a wild flower  
Hold infinity in the palm of your hand  
And eternity in an hour.

#The removal and retention of cadaveric body parts: does the law require parental consent? S Skegg, PDS: Otago Law Review 10 (3) 2003: 425-443.