

## FROM THE EDITOR'S DESK

At the time of writing, a tragic and significant case that has received a great deal of media attention and public interest has just concluded in the Auckland High Court. Judge Harrison has sentenced a Northland couple, the Moorheads, to a five-year jail term for manslaughter and failure to supply the necessaries of life to their child. The case relates to the death of their six-month-old baby (Caleb) who died following complications associated with a lack of Vitamin B12. His parents followed a strict vegan diet, which contained no meat, fish, or dairy products. When their son became ill they put their faith in God and herbal treatments to cure him and they removed him from the hospital against medical advice. Despite efforts by authorities to track the parents down, Caleb died.

The Moorhead case comes close on the heels of an earlier case where parents refused treatment for their child who subsequently died. The case involves a five-year-old boy (Liam Williams-Holloway) with a progressive neuroblastoma whose parents' refused chemotherapy in favour of alternative treatments. One interesting thing here is the marked shift in public support for such acts by parents since the Williams-Holloway case. In that case, chemotherapy offered approximately a 50-70% chance of survival. However, the parents opted for alternative treatment and despite the hospital taking legal action to bring the child in for treatment the parents went into hiding with a great deal of public and media support. In the latest case however, the response from the public and media has mostly been strong condemnation of the actions of the parents.

Why the change in public response? There are some differences in the cases that could have motivated the shift in public support. In the Moorhead case, the parents were seen as religious fanatics and in our secular society actions motivated by religious extremism are not tolerated. The cause of the illness may also have been a factor, cancer is considered to be a random event, whereas the cause of Caleb's illness was his parents' adherence to a particular lifestyle. Also Caleb's illness was considered to be eminently rectifiable by a change in diet early on, or Vitamin B12 injections. These treatments were considered to be minimally invasive with an almost total chance of success whereas for Liam the medical treatment offered was far from guaranteed and involved invasive and difficult on-going chemotherapy. Very early on in the Liam Williams-Holloway case the then Health and Disability Commissioner, Robyn Stent, came out with strong statements supporting the family. This may have helped lead public opinion. Perhaps the difference in public support can be attributed to the public only getting to know about Caleb after he had died, whereas we felt we got to know Liam and his family because they were the daily fare of the media well before his death. Or maybe people have reconsidered their views since Liam's death. In the public perception it is these differences that matter. However, despite the differences between the cases, there are strong similarities. Both sets of parents rejected standard medical treatment and opted for a form of treatment that was unproven and likely to be ineffective.

There are a wide variety of lifestyles that we as a society are happy for parents to decide is appropriate for their children. This is because we generally consider that parents are best placed to make such decisions and therefore be in control of their children's lives. While we might not be sure about where exactly the limits of that control might be, we are usually clear when a parent has gone too far or possibly not far enough. However it is the position of the limits that raises questions and poses problems. In the provision of health care for children, this becomes an issue when parents are not thought to be acting in the best interests of their child. There is a need to strike a balance that ensures parents remain confident to seek medical care for their children and yet which also protects children who may be at risk.

The Moorhead case continues in another form. Mrs Moorhead is six months pregnant with another child, who will now be born in prison. Discussion is currently around removing the child from her at birth.

## In this issue

In February this year it was revealed that children's hearts had been retained for teaching and research purposes at Greenlane Hospital in Auckland. The collection of hearts had been going on for the last 50 years, many collected without the consent of the parents.

The central issue in this case concerns the balance between the learning needs of researchers and future doctors and the needs for parents to consent to the removal and storage of their baby's heart. In the New Developments section in this issue we are fortunate to have three reports examining the different components of the Greenlane hearts story. The first from Sharron Cole and Dr Michael McCabe from the Nathaniel Centre in Wellington examines the issue of consent. The second from Professor Gareth Jones examines the issue from an anatomist and educationalist perspective. The last is from Professor Donald Evans, who takes an outsider's view of the use of human tissue.

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Lynley Anderson Editor