

INFORMED CONSENT LACKING FOR CORD BLOOD BANKING

The February 2005 issue of *Metro* featured an interesting article on a new highly profitable business that is being promoted to pregnant women and their families – that of the collection and storage of the umbilical cord blood of their newborn baby. For a mere \$2,000 paid in advance plus ongoing storage fees, expectant parents are paying to have approximately 80mls of cord blood “banked” at Auckland’s Cordbank. It’s a kind of biological insurance policy against the possibility that the stem cells it contains might be needed to fight one of “more than 45 diseases, including leukaemia and Hodgkin’s disease, with no risk of rejection.”

However, one of New Zealand’s leading child cancer specialists, Dr Michael Sullivan, Director of Research at the Children’s Cancer Research Group at the Christchurch School of Medicine, disputes the list that appears in Cordbank’s pamphlets and on its website. “That list is inaccurate – there are very few indications for which it can be used at present,” he maintains.

***NZ Medical Journal* article**

In the 28 January issue of the *NZ Medical Journal* Dr Sullivan and two other haematologists took issue with the claims being made by Cordbank about what can be done, and what modern medicine might be able to do in the future. Describing the statement – “*Saving your baby’s umbilical cord stem cells could save your baby’s life*” – which appears on the front page of Cordbank’s leaflet as emotive and misleading, the three haematologists recommend that parents seek independent advice “before committing to what is an expensive procedure of unknown benefit.”

Autologous vs allogeneic transplants

They also take strong exception to the fact that it is not made clear in any of Cordbank’s promotional material that there is a huge difference between autologous transplants in which the donor of the cord blood (the baby) is also the recipient, and allogeneic transplants in which the patient is treated with stem cells taken from someone else. Unlike the facilities that have been established overseas, Cordbank is licensed for autologous use only – parents are banking their baby’s cord blood for his or her use only. Although statements have been made in the media and in medical journal articles that there have been around 5,000 transplants using stem cells from cord blood, almost universally these involved another donor. For most of the diseases in Cordbank’s list, no specialist would recommend an autologous transplant, including the most commonly recognised one – childhood leukaemia. Faced with the possibility that the mutations that gave rise to childhood leukaemia were already present in the blood at birth, specialists would routinely recommend an allogeneic transplant.

At the birth

Aside from the emotive marketing that is going on, there is also the issue of what happens at the moment of birth when the focus of parents and midwife that would normally be on the baby, gets transferred instead to the need to achieve the required amount of cord blood from the baby’s umbilical cord. Some midwives describe the tense moments after the birth as they attempt to get the 80mls of blood by inserting a syringe into the cord after it has been clamped and cut. Whereas once the ideal was an unhurried and hands off approach to mother and baby after the birth as the two of them got acquainted, and leaving the clamping and cutting of cord until after it has stopped pulsating in order to ensure the baby has a good supply of oxygenated blood, the drama of the need to get an adequate amount of cord blood has now taken over. And for what? A one in 10,000 to one in 200,000 chance that the child might get one of the questionable list of diseases.

Parents pressured to sign up

Haematologists point out that even if a child does develop cancer or leukaemia there are other equivalent or sometimes even better transplant options than cord blood. It's not as if there is nothing that can be done and the child will die because his parents could not afford – or decided against – collecting and storing their baby's cord blood. Yet this is probably not well understood by the vulnerable new parents who are choosing to or being pressured to sign up. The *NZ Medical Journal* article states: "We are personally aware of families who have faced considerable pressure and urgency to store cord blood and have done so genuinely believing they are doing something in the best interests of their child."

Complaint from Haematology Society

Peter Browett, an Auckland adult haematologist wrote a letter of complaint on behalf of the Haematology Society of Australia and New Zealand about the misinformation in Cordbank's promotional material about what cord blood could be used for. Cordbank was claiming that even a child suffering from genetic metabolic diseases could be treated with their own banked stem cells – which given that such conditions affect every cell in the body, including the cord blood, would obviously be a bad idea! Cordbank have removed the untrue statements, but its list still includes adult diseases rarely diagnosed in children.

New fact sheet

Even haematologist and paediatric oncology expert, Lochie Teague, Cordbank's own medical advisor, is so unhappy about some of the statements in Cordbank's promotional material that he is writing a fact sheet of unbiased information that he wants given to any couple considering banking their baby's cord blood. So if such experts are not only voicing their concerns but are driven to put pen to paper in order to get the reality of the situation regarding the possible uses of cord blood to parents, the question needs to be asked why are those involved in this highly profitable business so reluctant to tell it like it is?

The fact is that no one knows what storing a baby's cord blood is going to be used for in the future. In the light of what is known now a baby's stored cord blood stem cells are far more likely to be useful for some one else – but Cordbank's licence doesn't permit them to be used for anyone else.

So just who is going to benefit most from this fancy new cryogenic facility? Obviously very few of the 2,000 babies whose cord blood has been stored at great expense with Cordbank.

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References:

Michael Sullivan, Peter Browett, Nigel Patton "*Private umbilical cord blood banking: a biological insurance of dubious benefit!*" *NZ Medical Journal*, 28 January 2005.

Matt Philp "*Cold Comfort Farm*" *Metro*, February 2005

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