

The cord blood DILEMMA

By Monique Balvert-O'Connor

Should you bank your baby's cord blood? The parents of one little girl think it was the best decision they ever made, but some experts are sceptical

Five-year-old Maia Friedlander dashes up the stairs calling, "Where are you Arielle?" Nothing startling to the average person, but it's of huge significance to this Auckland family. To Maia's mum, dad and twin sister, it's like witnessing a miracle.

Maia suffered a brain injury from lack of oxygen at birth. She'd been slow to meet any of her developmental milestones and, amongst other things, lacked mobility, talking skills, focus and energy.

All that started to change in August last year, when Maia's parents Daniel and Jillian had their daughter infused with stem cells collected at birth from her umbilical cord blood.

While it sounds like a miracle cure, many medics remain sceptical about such a procedure.

The American Academy of Pediatrics says claims that stored cord blood can serve as "biological insurance" against future disease have not been borne out – this despite the fact Duke University in

North Carolina, USA reports successful treatment of more than 50 children infused with their own cord blood.

Until recently, the American College of Obstetricians and Gynaecologists (ACOG) viewed the private storage of cord blood with "considerable circumspection". In February of last year, however, the College began recommending physicians inform pregnant patients about private cord blood banking.

New Zealand may now have its own walking, talking success story in Maia

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PHOTOGRAPHS BRUCE MERCER

evidence." The Friedlanders tell how Maia's improvement started only days after she was infused with her cord blood.

This is the blood that, after birth, remains in the blood vessels of the placenta and the part of the umbilical cord that is attached to it. It's rich in goodies, including potentially life-saving stem cells, which are the body's master cells. Stem cells hold healing powers – they form the white cells that fight infections, the red cells that carry oxygen, the platelets that promote clotting and the cells of our immune systems.

Before the cord blood infusion, Maia never sprinted up the

stairs.

She was unsteady on her feet and lacked energy. She needed help climbing the stairs and would hang on to the rail, dragging one leg behind her. And she never used words to call her sister – or anyone.

While Maia was the first New Zealander to have

the procedure to help with brain injury, she is the 51st child worldwide to have successfully been treated in this way.

The Friedlanders say the infusion has worked for Maia where all other therapies failed. It's nearly a year since her infusion and the improvements keep on coming.

Before, she would gaze off into space for hours, she would tire very easily, and she would make a breathy sound or shout to communicate.

Now she is completely focused on whatever she does, she is a bundle of energy, her vocabulary has grown to about 40 words and she can comfortably string three or four words together.

She used to visit her speech therapist four times a week and was getting nowhere. Now it's down to a weekly visit

and progress is noted each time. Maia's mother says banking her cord blood has given her a second chance at life.

"We've witnessed a miracle and are so thankful we banked her cord blood. The transfusion completely unlocked the door to her development and personality – before, we couldn't reach her," Jillian says.

"Our family GP, who has known her since she was born, is amazed by the change – as we are. Friends who haven't seen her for a while say she's a different child. She is going to preschool, something she could never have done before, and she interacts there happily. She eats pizza and she has a skateboard.

"It's a new beginning for all of us.

We are so grateful our two girls can now grow up together as sisters and friends."

Daniel says it's only going to get better. "She is moving forward at the rate of knots," he says. "Before, she didn't have a future really. Now we can see she will have a fulfilling life."

Maia is only the second New Zealander to be infused with privately stored cord blood. The first procedure – in 2007 – involved successfully regenerating a child's immune system after cancer treatment.

Banking cord blood has only been an option in New Zealand since privately owned CordBank was established in Auckland six years ago. Before then, families had no choice but to discard cord blood as medical waste. Since then, however, thousands of parents have banked their babies' cord blood as people become aware of its increasing uses.

CordBank director Jenni Raynish says interest in cord blood banking is growing every year. So who is banking their child's cord blood? Raynish says the answer is more about mindset than socio-economic grouping. It's about people who like to plan ahead, think about the future and show concern about health, she says.

Parents feel it gives them peace of mind. Some, such as Mike and Lucia Steadman, who have banked their son's cord blood, say they see it as a form of life insurance.

Raynish says for the past 20 years unrelated cord blood has been used to rebuild children's immune systems after they've been destroyed by cancer



Maia Friedlander on her dad's shoulder and (right) her parents Jillian and Daniel Friedlander.

Friedlander, but that hasn't won over New Zealand doctor Michael Sullivan to the merits of private cord blood banking.

Ask this consultant, researcher and child cancer specialist if there's any benefit in storing your baby's stem cells and he'll say the answer is "a big no".

Dr Sullivan, who has a PhD in cancer genetics and molecular biology, has had his views on private cord blood banking published in *The New Zealand Medical Journal*, and his conclusion is that it carries "dubious future benefits".

Daniel Friedlander says he's pleased he never let such medical resistance sway him. "For me, the huge change in my daughter – and other cord blood recipients I have met from around the world – is my

treatment. "However the challenge for families in that position was finding a suitable match so their child's body wouldn't reject the re-infused cord blood."

Raynish says the promise was always there that a child's own cord blood would be useful in regenerative medicine – repairing damaged brain or heart tissue.

"From the beginning it made sense that this would happen. Over the past few years evidence began appearing that cord blood was being trialled in regenerative situations. Now some medical experts talk about significant improvements or cures children can look forward to in the future if they have access to their cord blood."

Maia's family flew her to Duke University to be infused with her cord blood by paediatric oncologist Joanne Kurtzberg, a leading specialist in this field. The waiting list for the procedure at Duke University is now nearly three years long.

Recent research in the USA indicates the probability of a US citizen needing a stem cell transplant – using either their own stem cells or a donor's – is as high as one in 200 people.

Raynish says whether or not a baby's cord blood will be needed is not about the statistical odds or necessarily having a genetic pre-condition. "It's about having your child's personal stem cells there as a back-up in case you need them. The reality is, children worldwide are using their cord blood for an increasing range of conditions. Just about every day we read of new trials using cord blood starting somewhere in the world."

Promising results are coming from Florida, for example, where researchers are looking at whether cord blood can help the pancreas restore its own insulin function for those with Type 1 diabetes.

In Melbourne, research is being carried out into the use of sibling cord blood to aid children with cystic fibrosis.

Professor Bob Williamson from the University of Melbourne's Faculty of Medicine says cord blood is a very exciting resource, full of different kinds of stem cells. "These have already been shown to form liver, brain and skin cells, and we know umbilical cord blood is safe and effective when used to treat childhood

WHAT DOES IT COST?

❖ **The cost of banking your child's cord blood at CordBank is an initial \$2,500, which covers the collection kit, training, courier, testing, processing and storage equipment. Plus there's an annual fee of \$200 for storage.**

❖ **A growing number of grandparents are paying to bank their grandchildren's cord blood as a gift at birth.**

❖ **The cord blood is stored in liquid nitrogen and stays frozen at -196°C until it is needed.**

❖ **CordBank is licensed by the Ministry of Health, regulated by Med Safe, and audited annually.**

cancers and leukaemia. Now we hope cord blood will provide cells with the potential to rebuild damaged lungs in people with cystic fibrosis."

There's a feeling among experts like Dr Williamson that stem cells are a medical resource for the future.

New Zealand's Dr Michael Sullivan is "absolutely certain" some form of stem cell based technology will come into clinical use for regenerative medicine sometime in the future. But he's convinced it won't be from umbilical stem cells.

"Firstly, the technology for stem cell therapy itself has to be developed. But to spend perhaps hundreds of millions researching umbilical cord blood stem cells is unethical as this would only benefit those in a financial position to store their babies' cord blood – benefiting less than one per cent of the population.

"Secondly, new stem cell technology developed over the past two years will most likely make storing umbilical cord blood stem cells redundant.

"These techniques use a patient's own cells from tissues like the skin, and reprogramme them into cells identical to stem cells, without the need for embryonic or umbilical cord blood cells. These methods have recently been developed and are now being researched for human use."

Proponents of cord blood storage, however, say these cells are as old as the person from whom they are taken, whereas cord blood is taken at birth

and the stem cells are brand new.

Dr Sullivan sees private cord blood banking as a "superfluous service". He says nearly all the cancers and genetic and metabolic diseases that are treatable with cord blood require a foreign source of stem cells from a matched relative or an unrelated matched donor.

"This is why public cord banks are so unequivocally beneficial – because they store unrelated donor stem cells. You can use your own stem cells for a few diseases, but most people have perfectly good stem cells in their own bone marrow, which can be harvested at any time – so storing cord blood is not necessary," Dr Sullivan says.

But CordBank refutes Dr Sullivan's belief that a foreign stem cell source is needed to treat the majority of cancers and genetic and metabolic diseases. Furthermore, the American Society of Hematology says waiting lists for marrow donors can be long and the process of contacting and testing donors listed in a registry takes weeks to months. People die waiting for a suitable donor. In contrast, stored cord blood is ready for use as soon as it is needed.

While public cord blood storage facilities have yet to be established in New Zealand, our doctors source unrelated cord blood units from public cord banks around the world. These public cord banks are usually set up by national blood services – and accept gifts of cord blood from families.

As for Maia and other success stories coming out of Duke University, Dr Sullivan says these are not truly controlled trials and they are not supported by published scientific literature or medical evidence. Without this level of evidence, he says, he cannot support cord blood stem cell therapy. "It's an invasive, risky procedure that needs good evidence to justify its use."

Raynish disagrees: "It's not risky, it's a very simple procedure. Harvesting umbilical cord blood poses no risk to mother or child, whereas a bone marrow donor must undergo a surgical procedure."

Besides, she says, success stories like that of Maia Friedlander simply speak for themselves.



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