

Safe & sound

MARCH/APRIL 08



An extraordinary journey for a mother

When Ryan Schneider was diagnosed with cerebral palsy at the age of two, it was a tough time for his mother Mary. But amongst all the stress and sadness, Mary also thought of something hopeful. She had banked Ryan's umbilical cord blood when he was born.

Cerebral palsy wasn't one of the conditions generally associated with cord blood stem cell usage (most commonly it is childhood cancers),

but Mary Schneider thought she should definitely put some time and energy into finding out more about what was possible. An extraordinary journey had begun.

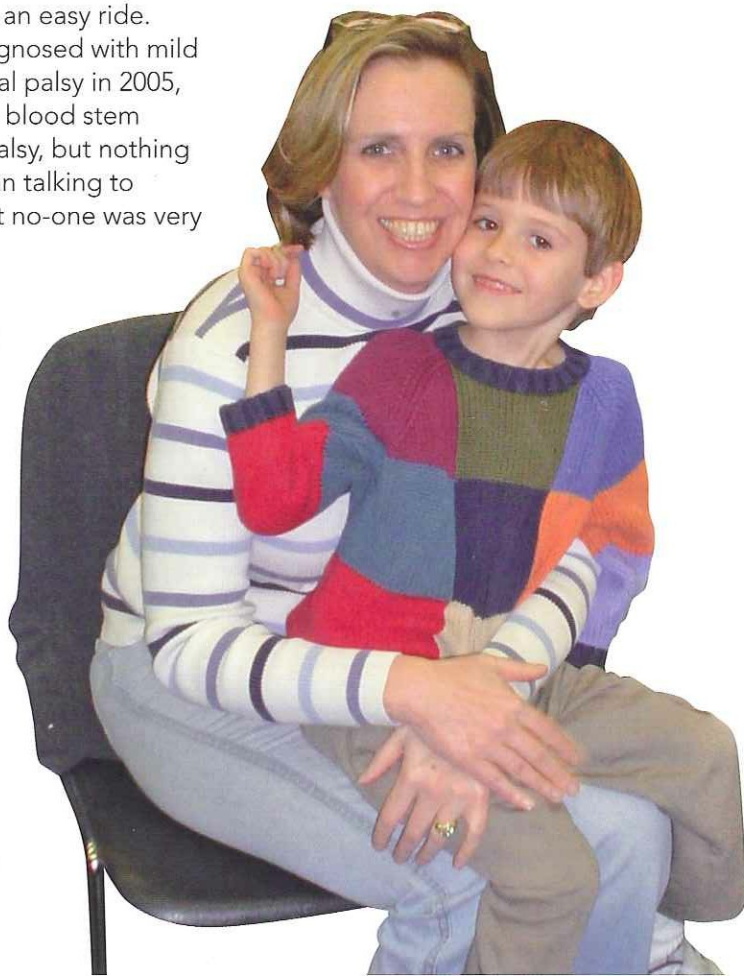
Three years later, Ryan is a healthy and happy five-year-old boy, and Mary is a leading campaigner for cord blood storage, and also a Democratic candidate for the General Assembly in her home state of Illinois.

But it hasn't been an easy ride. When Ryan was diagnosed with mild to moderate cerebral palsy in 2005, Mary Googled cord blood stem cells and cerebral palsy, but nothing came up. She began talking to medical people, but no-one was very receptive.

"When I started looking for a doctor who could do a stem cell infusion with Ryan's cord blood, it was heart-breaking. It was just so hard at that time. I thought it was absurd that I couldn't find anyone in the States who would do the procedure. It just seemed unacceptable, unreal. Here was my son desperately

struggling with his health every day, and I had his cord blood and couldn't get anyone to do anything."

Mary spent long hours on the internet doing research. She had worked in medical administration management for years so at least had the ability to "navigate through medical terminology." But it was still a huge challenge as she kept on pushing and refusing to take no for an answer.



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An extraordinary journey continued...

Eventually Mary and Ryan found their way to Dr Joanne Kurtzberg, a paediatric oncologist at Duke University in North Carolina, whose main work had been with bone marrow transplants. Dr Kurtzberg agreed to perform the procedure to infuse Ryan with his own cord blood stem cells.

Mary didn't know exactly what would happen. She would have been happy with any improvement in Ryan's condition, and she knew that the worst that could happen was that nothing would happen – Ryan's body wouldn't reject his own cells.

"Because they were from his own cord blood, I knew Ryan's stem cells couldn't harm him. I also knew his stem cells couldn't be affected by his condition, because I knew that it had happened just before, during or just after his birth. It was a brain injury due to lack of oxygen."

The medical procedure went well and – much to his mother's delight – Ryan's speech and physical development began to improve almost immediately.

An MRI scan at Duke University nine months after Ryan's treatment showed white matter regeneration in areas of his brain that had previously been affected. Although they can not say for certain that this is a result of the infusion, the timing is provocative.

Three years on, Mary says Ryan is "clear of all issues, needs no more therapies, and is completely well – a typical five-year-old boy."

Mary made the decision to use Ryan's stored cord blood for a life improving situation rather than a life saving one, but that doesn't mean there is no more cord blood available to Ryan should he ever need it again. "We still have one sample left. We had two, and we used one the first time. And there is the technology to expand the remaining sample if necessary, not by much at this stage, but the technology is improving all the time."

Mary and her husband Steve live in Batavia, Illinois, and also have a daughter Katie, aged 10. Cord banking was relatively new in America when Katie was born and Mary was unaware of its existence, but by the time Ryan was on the way, she was aware and keen to make use of the service. "I knew it had value and I knew you had just one opportunity, and that was at birth. My cousin's four-year-old son had died of leukaemia after an unsuccessful search for a match for a bone marrow transplant. It was just heart-wrenching, and I think seeing the family go through that also influenced my decision."

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Since Ryan's ground-breaking treatment, Mary knows of about 20 other children with cerebral palsy, or similar conditions caused by oxygen deprivation at birth, who have gone through the procedure at Duke University. She says some of the children who had more severe conditions than Ryan still have some issues but all have seen some level of improvement in their condition.



Meanwhile Mary has become a tireless campaigner for cord blood storage and responsible stem cell treatment. "I really couldn't bear to see another parent go through the struggle that I did. I want it to be that when someone goes to the internet and Googles cerebral palsy and cord blood, all this knowledge comes up.

"I'm nobody special, but it really wouldn't have been responsible for me to keep what I had learned to myself. My son's fine now and I

guess I didn't have to work for a year on a cord blood bill for the state of Illinois. But it was important to me to be able to help others.

"It's not easy being an advocate in this area. But I'm strong enough to take the hits. If you've got it in you to do something like this, then you really have to do it."

Mary's intensive campaigning experience has now led her to politics. She is running as a Democratic candidate for the Illinois State Legislature 50th district house seat, and has a good chance of being successful at the U.S. general election in November.

"I learned how to navigate the political arena through a lot of hard work and would like to put it to good use for the needs of the people in the 50th district."

Asked why she thinks there is resistance to cord blood banking among the medical profession, Mary says this is due to the politics of science and the science of politics. "But the medical landscape is changing every day. Here in the U.S., the typical reaction by the organisation that governs paediatricians would once have been that there's really not much point storing cord blood unless you have a family history of disease. Slowly but surely, the tide appears to be turning. This is a new frontier and we must be patient as well as diligent in educating the public and medical community."

"In America, there are private cord blood storage facilities and public facilities (editor's note: at this time there are no public cord blood storage facilities in New Zealand). I just say choose one or the other. But whatever you do, don't throw your baby's cord blood away. This whole area – of doctors giving cord blood storage information to parents, and letting them know the options – is improving all the time. And if you are in the situation where you are pushing for treatment for your child, don't listen to those who say 'it's just not being done.'"

Mary says she can see a time when people routinely bank cord blood as a matter of course for every baby that is born and mothers will soon know as much about cord blood as they do about the epidural. Asked what her key message to the prospective parents of New Zealand would be, she says: "You have a one-time opportunity. You need to bank your cord blood for every child. We don't know exactly what the future holds, but I see wonderful possibilities on the horizon."

CordBank is delighted to be bringing Mary Schneider...

and her family to New Zealand at the end of March to share her inspirational story. If you have any questions you'd like to ask Mary, please send them to us at customerservice@cordbank.co.nz



Meet the Yiappos family

Androulla and Ioannis Yiappos and their beautiful new addition to the family, baby Anthoulla are our October promotion winners.



Androulla and Ioannis, of Hataitai, are the proud parents of Fotene and new baby Anthoulla, who are both CordBank babies.

When they were expecting Anthoulla, they entered CordBank's competition to be in the draw to win the full cost of registration, processing and storage (valued at \$5,000). The competition was drawn on 31 October 2007, and Androulla and Ioannis were thrilled to hear they had won.

They first heard about banking stem cells through their midwife, who gave them a CordBank brochure. They both thought of it as an insurance policy for the future and an opportunity not to be missed.

"My sister-in-law had also heard about it and we registered for our first baby Fotene," said Androulla. "The process was very easy. It all went smoothly and was very straightforward."

"I was very organised for my first baby, but registered a bit

late for our second, so this win was a truly unexpected surprise," Androulla said. "You hear so many stories of children getting sick and we just wanted to do what we could for our kids. When I received the call from CordBank saying that we had won the registration, I told my husband that this is our lucky baby and that he should buy a lotto ticket now!"

"This win is a great help for our expanding family," said Androulla's husband Ioannis.

"We're thrilled about our win and equally thrilled with the service that CordBank has provided for us and our children's future health."

The Parker Pechan family share their story

I recently received your newsletter with news of international developments and stories from New Zealand. I wanted to share our story as I think we may also be one of your earlier adoptees of cord blood banking.

Magnus was born in August 2002, about 8 months after we moved to Wellington after a couple of years in London. We were well aware of the concept of cord blood storage at that time as my brother Guy had recently died in London following a bone marrow transplant from a MUD donor, the transplant had been rejected. Guy had been diagnosed with Multiple Myeloma and had sustained a course of chemo before the transplant. None of the family were compatible donors and therefore he had had an unrelated donor.

At that time we were well read in terms of options available for stem cell transplants in Europe and the States including cord bank storage. We were therefore absolutely delighted to find that the option to store cord blood had become available in New Zealand in time to coincide with the arrival of Magnus Guy Pechan.



Magnus with his Dad in 2003.

Magnus turned 5 in August this year and I was so proud to see him starting school and thriving. I was only so very sorry that my husband Lars was not there to join me as Lars had died in January after a 3 year battle with brain cancer. Magnus has now lost 3 members of his immediate family to cancer, it is my hope that having stored his stem cells, this may provide options for him and his brother at some point in the future if it is needed.

Kate Parker Pechan



Magnus on his first day of school



Share your story

A big thank you to the families that have sent in their beautiful baby photos and stories. We'd love to hear about your baby and the reasons you decided to bank your baby's cord blood. If you'd like your photos returned, please enclose a stamped, self-addressed envelope. Please include parent's name and CordBank kit number with your baby's photo.



Umbilical cord blood may help the aging brain

When human umbilical cord blood cells (UCBC) were injected into aged laboratory animals, researchers at the University of South Florida (USF) found improvements in the microenvironment of the hippocampus region of the animals' brains and a subsequent rejuvenation of neural stem/progenitor cells.

Published online at BMC Neuroscience earlier this month, the research presents the possibility of a cell therapy aimed at rejuvenating the aged brain.

"Brain cell neurogenesis* decreases dramatically with increasing age, mostly because of a growing impoverishment in the brain's microenvironment," said co-author Alison Willing, PhD, of the USF Center of Excellence for Aging and Brain Repair. "The increase in

neurogenesis we saw after injecting UCBCs seemed to be due to a decrease in inflammation."

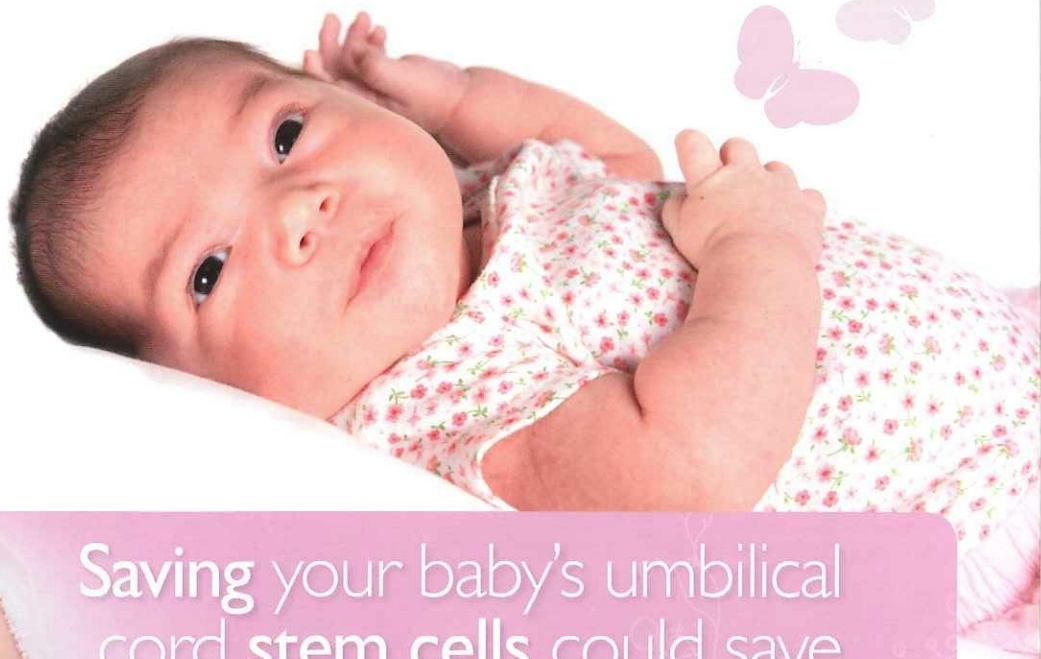
"We think that UCBCs may have the potential to reduce inflammation and to restore some of the lost capacity of stem/progenitor cells to proliferate and differentiate into neurons," said Dr. Bickford.

The study found that the number of proliferative cells increased within 24 hours following the UCBC injections into the aged laboratory rats and that the increased cell proliferation continued for at least 15 days following a single treatment.

"We have shown that injections of UCBCs can reduce

neuroinflammation," concluded co-author Paul R. Sanberg, Ph.D. D.Sc. director of the Center of Excellence for Aging and Brain Repair. "Our results raise the possibility that a cell therapy could be an effective approach to improving the microenvironment of the aged brain and restoring some lost capacity."

**Neurogenesis (birth of neurons) is the process by which neurons are created. Most active during pre-natal development, neurogenesis is responsible for populating the growing brain.*



Saving your baby's umbilical cord stem cells could save your baby's life

Register before **30 April 08**
and you go into a draw to win the full cost of registration, processing and 18 year's storage valued at

\$5000

New study shows 1 in 200 will use stem cells

New data published in the March issue of *Biology of Blood and Marrow Transplantation* indicates the probability of an individual in the United States needing a stem cell transplant, using either one's own stem cells or those from a donor, is much higher than previously stated.

The new research says that as many as 1 in 200 people will receive a stem cell transplant during their lifetime, based on current therapeutic use of hematopoietic (blood forming) stem cells. These outcomes stand in stark contrast to previous estimates that suggest a much lower probability.

The study calculated the lifetime probability (age 0 – 70) that an individual in the U.S. will undergo a stem cell transplant, reporting that: 1 in 435 people will receive their own stem cells for treatment; 1 in 400 persons will receive someone else's stem cells; and the combined total number of stem cell transplants will be 1 in 217 persons.

The study calculated these probabilities based on the number of transplants performed in the U.S. between 2001 and 2003 where stem cells from one of three sources – cord blood, bone marrow or peripheral blood – were used to treat the diagnosed condition. They also looked at the number of patients diagnosed with transplantable diseases like blood disorders, immune diseases and certain cancers where stem cell treatment is considered an established therapy. Because the number of diagnosed patients in the study is much higher than the number of patients who received transplants,

it is possible in the future that the number of transplants could increase further.

"Previous estimates have drastically underestimated the likelihood that an individual may need a transplant in his or her lifetime, because they only looked at the first 20 years of life," said Frances Verter, Ph.D., co-author of the study and executive director of Parent's Guide to Cord Blood Foundation. "This study used a methodology that explored a longer time horizon, assuming a 70-year lifespan. What we learned is that even though the number of transplants is low in childhood, the numbers increase rapidly during the adult years."

Historically, stem cells from bone marrow and peripheral blood have been used for more than 40 years to treat disease. During the last 20 years, cord blood stem cells have increasingly been used as a preferred source of stem cells in transplant medicine and have demonstrated significant benefits.

When compared to other stem cell sources, those found in cord blood don't require as close of a match between donor and recipient. Researchers have shown that patients who received a cord blood transplant have a decreased incidence of graft-versus-host disease, a transplant complication which can be fatal. Despite its proven therapeutic value, cord blood from approximately 95 percent of births across the nation today is still discarded as medical waste – largely due to lack of awareness of the importance of cord blood banking.

"In some cases, healthcare

providers have not recommended cord blood banking because they believe that the odds of using cord blood stem cells are low," said Verter. "The mission of the Parent's Guide to Cord Blood Foundation is to make more expectant parents aware of the value of cord blood banking, so that saving it becomes a routine practice at birth. This study suggests that we need to re-evaluate the information we're sharing with expectant parents so that they have a better understanding of how these stem cells might be used now and in the future."

"It is very important that medical societies consider this new data for their opinions on cord blood banking" said J.J. Nietfeld, Ph.D., lead author of the study and associate professor/senior scientist in the Department of Pathology of the University Medical Center in Utrecht, Netherlands. "Parents should be able to trust that the advice they receive from their physicians on whether to preserve cord blood, is based on the most up-to-date scientific literature."

Ref - March issue of *Biology of Blood and Marrow Transplantation*, the official journal of the American Society for Blood and Marrow Transplantation.

Study Methodology

The authors of the study relied on two U.S. national databases that are maintained to serve the public. One is the annual rates of disease diagnoses obtained from the Surveillance, Epidemiology and End Results (SEER) Program of the U.S. National Cancer Center. The other is the annual rates of stem cell transplantation obtained from the Center for International Blood and Marrow Transplant Research (CIBMTR).

About Parent's Guide to Cord Blood Foundation

The mission of the Parent's Guide to Cord Blood (PGCB) Foundation is to provide parents with impartial education about cord blood medical research and cord blood storage options, as well as to conduct and publish statistical analyses on medical research or policy developments which could expand the likelihood of cord blood usage.



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