

A photograph of a woman with dark hair, wearing a floral patterned top, holding a newborn baby in her arms. The baby is wrapped in a red blanket and has a medical device on its face. The background shows a hospital room with medical equipment.

Under the microscope

Thank you!

Thank you so much for your support. With your help, researchers at Children's Medical Research Institute are working every day to better understand serious genetic diseases and are developing new life-saving treatments.

Last year, we shared Evie's story with you. Evie's daughter Genevieve lived for just 13 days. Born with Congenital Myotonic Dystrophy, a severe genetic condition that causes profound muscle weakness and respiratory failure, Genevieve never had the chance to grow up.

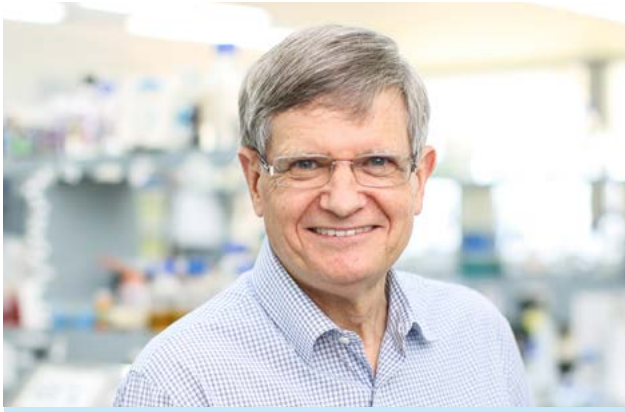
Today, Evie honours Genevieve's life by sharing her story in the hope that no other family endure the same heartbreak. Stories like Genevieve's are exactly why genetic research matters.

Thanks to your generosity, our scientists can continue vital research on devastating genetic diseases and develop new treatments to give these children the chance to thrive and live the childhoods they deserve.

You are bringing hope to families and helping change the future for some of our sickest children with the most challenging medical conditions.

Evie and Genevieve

AUTUMN EDITION 2026



From the Director

Thank you for your continued support of Children's Medical Research Institute. Because of donors like you, our scientists can pursue bold ideas, tackle some of the most complex diseases affecting children and families, and translate discoveries into real-world treatments.

Professor Hilda Pickett and her collaborators have been awarded a National Health and Medical Research Council (NHMRC) Synergy Grant to develop first-in-the-world precision therapies for aggressive cancers that rely on a process known as ALT (Alternative Lengthening of Telomeres). Even though ALT drives the growth of up to 15 per cent of cancers worldwide, there are currently no treatments specifically designed for them. Led by Professor Pickett, this Synergy research program brings together leading experts, including CMRI's Professor Tony Cesare, to develop the first targeted therapies for ALT-dependent cancers.

We have also been delighted by the response to our partnership with the NSW Return and Earn program. Thanks to the generosity of people across the state who chose to recycle their cans and bottles for research, more than \$200,000 has already been raised to support CMRI's work.

Supporters like you continue to inspire our work. Nikki Kegg, who first became involved with Jeans for Genes Day as a school student living with cystic fibrosis, is now preparing to run her first Sydney Marathon to raise funds for CMRI – a powerful reminder of how research and community support can change lives.

Thank you for helping us advance discoveries that will improve and save the lives of children and families everywhere.

Roger Reddel AO
Lorimer Dods Professor and Director,
Children's Medical Research Institute

Professor Hilda Pickett



Advancing Cancer Treatment

Children's Medical Research Institute's Professor Hilda Pickett is leading an Australian team that has been awarded a \$5 million National Health and Medical Research Council Synergy Grant to develop first-in-world treatments for some of the most aggressive and difficult-to-treat cancers.

The project focuses on developing precision therapies for ALT-dependent cancers. ALT (Alternative Lengthening of Telomeres) is a pathway used by 10-15 per cent of cancers that allows the cancer cells to proliferate relentlessly.

"The lack of targeted ALT therapies is internationally recognised as an urgent and key unmet need in modern oncology," Professor Pickett said.

It is estimated that 1 to 1.3 million people worldwide, including 5000-7000 Australians, die from ALT cancer every year. ALT is particularly prevalent in bone and soft tissue sarcomas, in many aggressive brain tumours, and a subset of pancreatic cancers.

The grant has been awarded to a multidisciplinary research team that also includes Professor Tony Cesare from Children's Medical Research Institute, and other leading researchers from hospitals and universities across Australia.

"We are bringing together Australian experts in ALT, telomeres, DNA metabolism, DNA repair, and cancer therapeutics, to systematically address a significant knowledge gap," Professor Pickett said. "Our ultimate goal is to deliver the first precision therapies for difficult-to-treat ALT cancers, thereby transforming outcomes for many thousands of Australians and millions of children and adults worldwide diagnosed with ALT-dependent tumours each year."



Nikki Kegg

Nikki's Run for Research!

It's hard to think of a fundraiser who has more history with Jeans for Genes than Nikki Kegg. She started out collecting gold coins at her school as a young girl with cystic fibrosis. Now a mum of four, Nikki will be running a marathon to raise funds for Children's Medical Research Institute.

"I'm turning 42 this year, a few days before the Sydney Marathon when I'll do my first 42km," Nikki said. "It really is about training your mind, as much as your body."

"I've never been happier, all the running is making me optimistic about the future for the first time, especially now I'm past the average cystic fibrosis life-expectancy and they tell me I'll likely die of old age."

When Nikki was diagnosed with cystic fibrosis, like others, she was told her life expectancy could be around her mid-to-late 30s. She was in and out of hospital as a child, always taking medication and doing physiotherapy.

When Jeans for Genes Day started in 1994, she already knew about Children's Medical Research Institute because she had walked past our labs so often on her way to hospital.

"At the time that Jeans for Genes started I was in and out of hospital and really unwell," Nikki said. "I was in primary school and I just decided I wanted to get involved. I knew that it would work toward helping kids with chronic genetic conditions like cystic fibrosis and I wanted to fundraise and spread the word."

Nikki said she was embarrassed about CF, but it got to a point where she didn't want to hide it anymore.

"It was inevitable that they find out when you're doing physio and taking medications. I was a very physical kid and when I played sport I always had to stop and eat a Mars Bar or do something to replace my calories."

Nikki knew that becoming a Jeans for Genes fundraiser would give her a chance to talk to her peers in primary school about her condition.



Fundraiser Nicole Tuite helps out on Jeans for Genes Day
 money for research on Genes Day was something Nicole Tuite, a girl with
 Research Institute. The student from Our Lady Queen of Peace School at Greystanes had an operation in 1992
 confronts the problem. "I'm in hospital a lot and see

"At my primary school, Our Lady Queen of Peace in Greystanes, we had around 1000 kids and I got everyone to buy a badge and I did a speech. The school really got behind me. I went to every classroom to sell badges. I got a certificate for being one of the highest fundraisers and I won a computer. I went into the CMRI offices to collect it. It was our family's first computer."

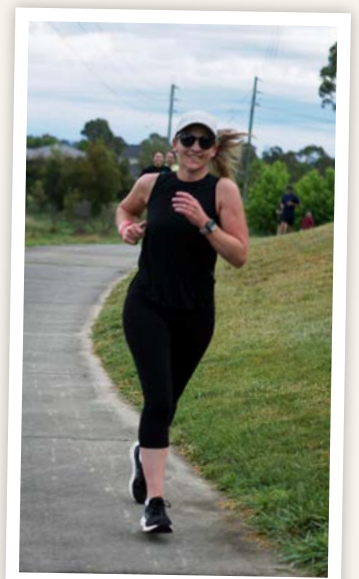
As she got older, Nikki developed a greater appreciation for her health and started to focus more on exercise.

"I hadn't done any fundraising for CMRI in so long and I started to think that I was taking my health for granted so I decided it was time I gave back," Nikki said.

"The situation for people with CF has changed a lot. People were always talking about how your health would deteriorate and life expectancy was 38. Things have come such a long way – because of medical research."

"I was told I was going to die very young – so when I was around 14, I wrote a bucket list. In it I said I wanted to run a marathon."

Since she started training for the marathon, Nikki has been told she has the best lung function she's ever had. Nikki is a true inspiration! She continues to inspire our researchers to do more – to one day help beat CF – which is why she is running the Sydney Marathon to raise funds for CMRI.



To support Nikki's incredible efforts for children's medical research, donate to her fundraising page at: <https://sm26.grassrootz.com/cmri/nikki-kegg>

Jeans for Genes® Day

is on Thursday 6 August this year!

Don't forget to visit
fundraise.jeansforgenes.org.au
to find out all the ways you can support us.



Alessia taking part in Return and Earn



Recycle for Research

We're excited to share that Children's Medical Research Institute's partnership with Return and Earn has raised more than \$200,000 – and there's still time to make your cans and bottles count!

For the past few months, CMRI has been the featured charity partner of Return and Earn in NSW – giving people the opportunity to recycle for research every time they used a container deposit machine.

You can still recycle and donate your returns to benefit our science. Now, when you visit a Return and Earn machine, all you need to do is scroll through the charity partners and find Jeans for Genes or Children's Medical Research Institute to donate your refund to us.

Children's Medical Research Institute Director, Professor Roger Reddel, said it was a unique way for the Australian public to support research.

"Our scientists are always striving to innovate and change the lives of children, and we are incredibly grateful to be part of this impactful program that allows everyday Australians to fund our research, by simply donating their recycling to our cause," Prof Reddel said.

Return and Earn is a partnership of the NSW Government, scheme coordinator Exchange for Change, and network operator TOMRA Cleanaway. Since it started in 2017, more than 14 billion containers have been returned.

So far, thousands of generous NSW residents have raised an astounding \$82 million for charities through this recycling scheme.

To find your nearest Return and Earn machine, visit <https://returnandearn.org.au>

1800 436 437

research@cmri.org.au



Children's Medical Research Institute,
Reply Paid 71005, Wentworthville, NSW 2145



CMRIJeansForGenes.org.au/donate

Scan to
Donate

