CHILDREN'S MEDICAL RESEARCH INSTITUTE

Jeans for Genes®

2025 Year in Review

Thank you

for joining the fight against childhood genetic diseases.

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Cover image: Sophia, Cystic Fibrosis

WELCOME

2025 was a year of extraordinary momentum for Children's Medical Research Institute (CMRI), supported by people like you who believe in a better future for children.

In a rapidly changing world, where new technologies emerge just as quickly as funding challenges grow, your support has remained the constant driving force that turns possibility into progress for children and their families.

Across our research programs, we saw meaningful advances that bring us closer to our ultimate goal: a future where every sick child with a devastating genetic disease has access to safer, more effective treatments. Our ProCan® team made progress toward delivering fast, precise tools that help clinicians choose the best treatment plan for each individual cancer patient. Our gene therapy researchers reached important new milestones. This work will be strengthened by the opening of Australia's first clinical-scale Viral Vector Manufacturing Facility, an essential step toward making transformative therapies more accessible for Australian children. Our teams in cancer biology, and stem cells and organoid research continued to push forward knowledge that will shape the medicine of tomorrow.

But at the heart of every major advance is a child.

A child like Audrey, Jett, or Ollie, whose courage reminds us why our work cannot slow, and whose families' hopes give every discovery its purpose.

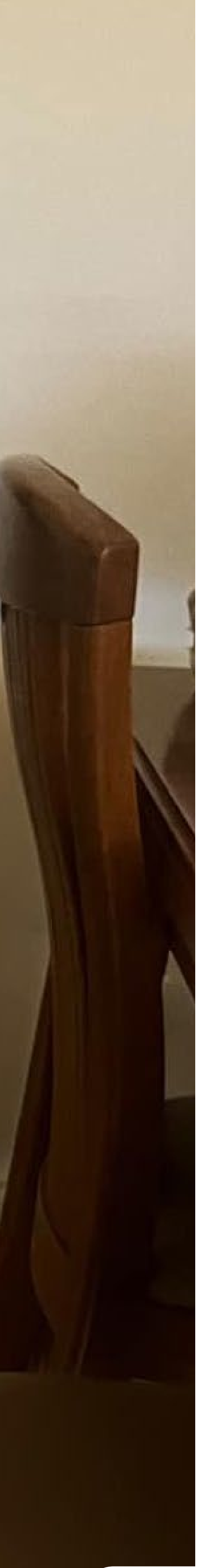
Your generosity makes progress possible. It empowers our scientists to think boldly, explore new frontiers, and pursue ideas that will change the future for children facing life-threatening genetic diseases like cancer, cystic fibrosis, degenerative brain and muscular diseases, inherited blinding eye diseases, and many more. Together, we are building a world where more children thrive and grow into the lives they deserve.

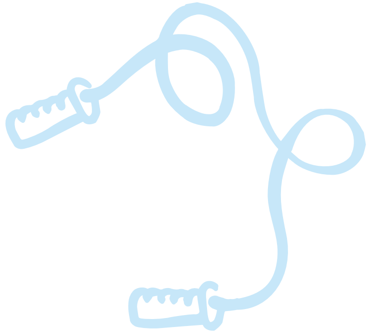
As you read this Year in Review, I hope you feel proud of what you have made possible. Every achievement belongs to you as much as it does to our scientists, and every step forward brings us closer to a brighter future for children everywhere.

Sincerely,

Roger Reddel AO
Lorimer Dods Professor & Director, CMRI

Stacy and Angelo Buttigieg are skipping **in memory of Everleigh.**





SKIPPERS raise record amount for research

It was a record-breaking year for the Jeans for Genes 100 Skips a Day Challenge, with more people than ever skipping for those they love who are impacted by genetic conditions.

100 Skips a Day started in 2023 as a fun way for Jeans for Genes supporters to get active while raising vital funds for research. In 2025, more than 5,000 skippers raised an incredible $426,000.

But what makes the skipping community truly special are the stories of the children people were skipping for – from loved ones living with genetic conditions, to children who lost their battle with illness.

Stacy and Angelo Buttigieg have been taking part since the beginning, in honour of their daughter, Everleigh, who died from a rare genetic condition known as WOREE Syndrome.

Everleigh experienced daily seizures, and the condition causes profound developmental delay and severe cognitive impairment. Tragically, most children with WOREE Syndrome do not live beyond four years old. Everleigh passed away just before her third birthday.

"We started skipping to support the much-needed research into childhood genetic conditions," Stacy said.

As well as skipping themselves, they also held a BBQ and cake stall in their Perth neighbourhood and their local café, Little Olive Leaf Café, donated $1 from every coffee sold. In three years, they have raised more than $54,000 for CMRI's research!

"The skipping always feels a little bit challenging at the start of the month, but quickly it becomes just part of your daily routine," Stacy said. "And if you think that many children will never have the privilege of using their own legs to skip, skipping instantly feels like the easiest thing to do.

"We couldn't be more grateful for the outpouring of love and support we receive each year from Everleigh's village. They continue to show up in more ways than one, hyping us up, supporting our family physically and mentally. Words don't even brush the surface with the gratitude we have for our community."

> "We also made a promise to Everleigh that we would keep advocating and raising money, with the hope that one day there will be a cure for childhood genetic conditions."
>
> **Stacy, Everleigh's mum**

NEW LAB fighting childhood cancer

When Dr Rebecca Poulos started our newest lab in early 2025, she had one clear goal: to change the lives of children like Audrey, who has been fighting an extremely aggressive brain cancer since her first birthday.

“Cancer is the leading cause of death from disease in Australian children,” Dr Poulos said. “There is an urgent need to improve precision medicine to advance outcomes in hard-to-treat paediatric cancers.”

Audrey’s mum, Maddy, is living the terrifying experience of guiding a child through challenging cancer treatment. It was just after her first birthday, at a routine health care check, that a nurse noticed her head circumference had increased and recommended further testing.

“Everyone at her first birthday party was saying what a happy, smiling, bubbly baby she was,” Maddy said. “She was just so content with life.”

Days later, Audrey was diagnosed with grade 4 medulloblastoma, which had spread within her central nervous system. Since then, her treatment has included six surgeries, blood transfusions, and chemotherapy.

The family agreed for Audrey to become the face of our riding event, Great Cycle Challenge, as a way of “paying it forward”.

“It’s deeply moving to know that Great Cycle Challenge riders were pedalling for Audrey and kids like her. More awareness, more funding, and more research are desperately needed because our babies deserve better outcomes.”

Funding from the Great Cycle Challenge will help Dr Poulos’ new lab, the Multi-omics in Childhood Cancer group, which aims to change the way some of the most challenging childhood cancers are diagnosed and treated.

They will study the proteins of paediatric cancer samples, aiming to produce a report for clinicians within 72 hours that will help them determine which treatment will be most effective.

“Proteins should better predict cancer treatment response than DNA or RNA because most anti-cancer drugs interact directly with proteins,” explains Dr Poulos.

“Rapid results will have clinical benefit by improving diagnostic accuracy and informing better treatment options for precision medicine in childhood cancer.

“We’re making a lot of advances in children’s cancers, but there is still a low survival rate in some cancer types, and children are still dying from cancer in Australia – much more work needs to be done.”

> **“This is why we are doing this, to raise awareness and try to improve outcomes for other kids. It makes you feel like you’re doing something because otherwise you feel so helpless.”**
>
> **Maddy, Audrey’s mum**

Cancer research aims to help children like Audrey.

Jeans for Genes® brings nation together

Jeans for Genes Day 2025 experienced a powerful surge of solidarity across Australia. Communities, schools, retailers, workplaces, scientists, and families came together in creative events and everyday acts of giving to raise more than $2.8 million for CMRI.

At the heart of the campaign were five extraordinary kids – Alessia, Amelia, Jett, Ollie, and Sophia – who show courage and resilience every single day while living with genetic conditions like cancer and cystic fibrosis. They not only spread awareness about the significance of investing in medical research, but took on huge fundraising roles themselves. From luncheons to art stalls and a disc golf tournament, they rallied their communities and turned the spotlight on finding treatments and cures for kids like them.

Support continued to grow in inspiring and unexpected ways.

In Leichhardt, Sara and Dom turned their restaurant into a force for good, donating money from every panini sold in honour of their daughter Valentina, who was born with an ultra-rare genetic condition. What started as a simple act of generosity quickly captured hearts, raising $27,000.

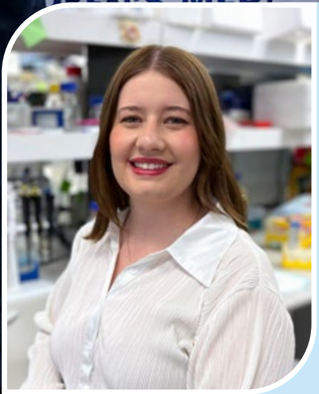
They were joined by many others across the country who hosted sporting events, formal dinners, and denim days; communities baked, danced, and even took on burpee challenges – all to give sick kids hope by advancing science. Volunteers braved torrential rain at merchandise stalls, proving once again that perseverance and generosity are stitched into the fabric of Jeans for Genes.

Our researchers stepped out from behind the lab bench to meet the people who make their work possible.

Retail partners continued the momentum. Lowes contributed more than $200,000 by donating $10 from every pair of jeans and denim shorts sold in August, while Williams, Mathers, and The Trybe shoe stores raised $200,000 through a special back-to-school shoe promotion and in-store donations.

Jeans for Genes Day has become more than a fundraiser: it's a shared promise. A promise to help children with genetic conditions live healthier, fuller lives. And in 2025, Australia showed that when we band together, we can change their future – one breakthrough at a time.

Researchers on Jeans for Genes Day



> “Stepping out of the lab to experience the dedication of volunteers and contributions from the public brings into focus how we achieve cures and treatments for children together, as a community.”
>
> **Researcher Imogen Astruc**

> “I said when I was sworn in as Governor-General that I would put care and kindness at the centre of everything I do – this is care at its most acute and accountable.”
>
> **Her Excellency the Honourable Ms Sam Mostyn AC**

The Governor-General tours the CMRI labs with Roger Reddel

GOVERNOR GENERAL visits ProCan

2025 marked a year of significant progress and international recognition for the ProCan team and their exciting scientific discoveries.

The year began with ProCan’s Jennifer Koh and Erin Humphries both publishing their work in scientific journals, on new methods for analysing cancer samples that advance the field of cancer proteomics.

In March, ProCan co-founder, Professor Phil Robinson, identified a novel way to predict which patients are most at risk of recurrence of a type of throat cancer – a breakthrough with the potential to inform more precise and timely treatment decisions.

In May, the ProCan team was thrilled to welcome Her Excellency the Honourable Ms Sam Mostyn AC, Governor-General of the Commonwealth of Australia, to the ProCan labs following her appointment as Patron of Children’s Medical Research Institute.

Her Excellency said the work she saw in ProCan and CMRI was “going to change the trajectory of so many children’s lives who may not have otherwise ever had a cure for whatever disease or cancer they might have started life with”.

In June, ProCan published another major scientific discovery, demonstrating a new, AI-enabled approach to analysing thousands of patients’ cancer samples.

ProCan co-founder and CMRI Director, Professor Roger Reddel, said the work represented a critical step forward. “The purpose of CMRI’s ProCan research program is to develop proteomic tests that will assist cancer clinicians to choose the best treatments available tailored to each patient’s cancer. By overcoming several major barriers to assembling and analysing large cancer proteomic datasets, we have made a major step towards achieving this goal.”

Finally, ProCan ended 2025 on a high – being named as winner of Australia’s first AI-F1 National Innovation Challenge, awarded by Australian technology leader ResetData. ProCan’s winning entry was selected for its potential to deliver nationwide impact, addressing one of Australia’s most pressing challenges through the power of artificial intelligence. As the winner, ProCan will receive up to 200 billion AI tokens valued at $1 million, along with input from leading AI and technology experts.

Prof Reddel said it is a turning point for the project.

“By combining our unique proteomic data with ResetData’s cutting-edge AI, we’re unlocking new possibilities for personalised treatment that has the potential to benefit every cancer patient.”

> **“Behind every clinical outcome is a long, protracted period of hard work to develop new therapies and it is rare to see the impact on a child’s life.”**
>
> **Professor Ian Alexander**

The Viral Vector Manufacturing Facility launch

CELEBRATING
30 years of gene therapy

It was 30 years ago that Children’s Medical Research Institute made the visionary decision to establish Australia’s first Gene Therapy Research Unit, and invest in this field of medical research that, at the time, many considered to be “science fiction”. That decision has since helped position CMRI as a global leader in gene therapy.

CMRI’s Gene Therapy Research Unit – founded as a joint initiative with The Children’s Hospital at Westmead – is led by Professor Ian Alexander. Over three decades, he has witnessed the field evolve from theoretical possibility to clinical reality.

“The majority of my career has been about the possibility of being able to treat children in the future and now the field has got to the point where that possibility has become reality, and it’s incredibly exciting,” Prof Alexander said.

A major milestone in making gene therapies more accessible in Australia occurred in 2025 with the official opening of the Viral Vector Manufacturing Facility (VVMF) next door to CMRI. CMRI research leaders have been central to this work and continue to play a key role.

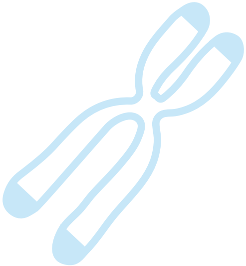
Established by the NSW Government, the facility represents a huge step change in Australia’s gene therapy capability. Prof Alexander is Chief Medical Officer of VVMF, and CMRI’s Professor Leszek Lisowski is its Chief Technology Officer.

The VVMF is Australia’s first and only commercial-scale clinical viral vector manufacturing facility, enabling gene therapies to be produced locally at the highest quality required for use in patients. This is a critical capability for accelerating access to life-saving gene therapies for Australian children and adults with serious genetic diseases, and for improving quality control and reducing reliance on overseas manufacturing.

Prof Alexander said the VVMF would allow scientists to take therapies from the lab and into the clinic with “speed and safety”.

“The overall aim is to bring the best possible therapies to people at the earliest possible moment. We intend for those therapies to not only be available to patients around Australia, but around the world, so it really is global impact starting here in NSW.”

GROUNDBREAKING
telomere research



The kind of fundamental research conducted at Children's Medical Research Institute is key to leading significant clinical advances. That hope is what families like Ollie's cling to as they celebrate his cancer being in remission and remember those still waiting for successful treatment.

"When Ollie was having his treatment, I just started envisioning him finishing high school and doing a Year 12 speech about his journey and that gave me the optimism to think that Ollie will be alive in those years; that he would beat this," his dad Nathan said.

Professor Hilda Pickett's team has published some impressive work in 2025 with the potential to shape future cancer treatments.

One of the greatest challenges in treating certain cancers is treatment resistance. Even when cancer therapies initially work, tumours can adapt and survive, making them extremely difficult to cure. Addressing this challenge is a critical focus of cancer research worldwide.

In a landmark study, Dr Alex Sobinoff identified a previously-unknown group of proteins that guide the powerful enzyme telomerase, which allows cancer to remain effectively "immortal". The discovery has opened new avenues for developing treatments for cancer, ageing, and genetic diseases.

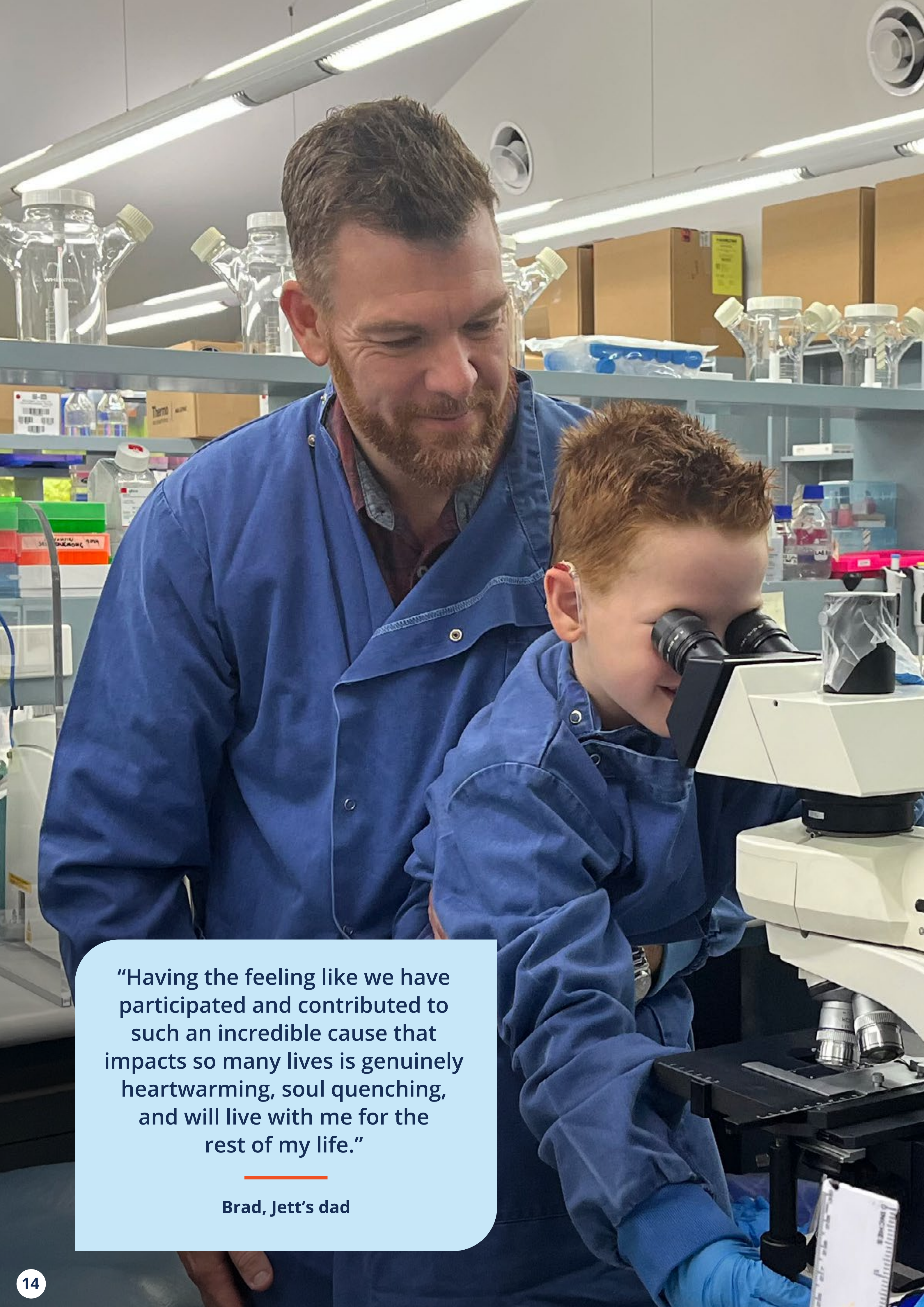
"Our findings show that these proteins act like molecular traffic controllers, making sure telomerase reaches the right destination inside the cell," Dr Sobinoff said. "Without these proteins, telomerase can't properly maintain telomeres, a finding which has significant implications for healthy ageing and cancer progression."

In another study, Dr Chris Nelson investigated the proteins that drive the growth of aggressive cancers such as neuroblastoma, a childhood cancer, and glioblastoma, one of the most dangerous and fast-growing brain cancers. His research focused on inhibitor drugs that can block these proteins, revealing a new way to target cancer cells that have become resistant to standard treatments.

"We found that these inhibitors can target the key survival mechanisms that cancer cells rely on," Professor Pickett said. "Because these survival pathways are used in many different cancer types, this discovery could help improve treatment for a broad range of cancers."

> "But as you're sitting here feeling grateful for your son's life, you think about the children who don't make it, and that's the importance of research."
>
> **Nathan, Ollie's dad**

Dr Alex Sobinoff with Ollie



> “Having the feeling like we have participated and contributed to such an incredible cause that impacts so many lives is genuinely heartwarming, soul quenching, and will live with me for the rest of my life.”
>
> **Brad, Jett’s dad**

NSW CHIEF SCIENTIST praises organoid work

When a child is diagnosed with a genetic condition, parents can feel powerless, searching for something, anything, they can do to change the future. For Beth and Brad, Jett's parents, finding a way to contribute to research at Children's Medical Research Institute has transformed that sense of powerlessness into purpose.

Jett lives with Usher Syndrome, a rare genetic condition that severely affects vision and causes hearing loss at birth. By donating a blood sample to CMRI's Stem Cell Medicine Group, led by Associate Professor Anai Gonzalez Cordero, Beth and Brad knew they were playing a small but meaningful role in the search for future therapies. They also agreed for Jett to become one of the faces of Jeans for Genes, helping raise awareness of children like him.

"The science supports and delivers tangible results for many Australians that are impacted by childhood genetic conditions. The work provides a genuine beacon of hope of a better future for the multitude of families currently living with genetic disease, and those who in the future will be experiencing or facing an incurable or lifelong condition," explains Brad.

"The science is mind-blowing. The people behind the microscopes and in the lab coats are passionate and incredibly resourceful, creative and always willing to share their work. Every time we stepped foot into CMRI, we could see and feel that every individual was working with every fibre and brain cell to conceptualise, research, test, and validate the complex scientific methods and processes that deliver outcomes.

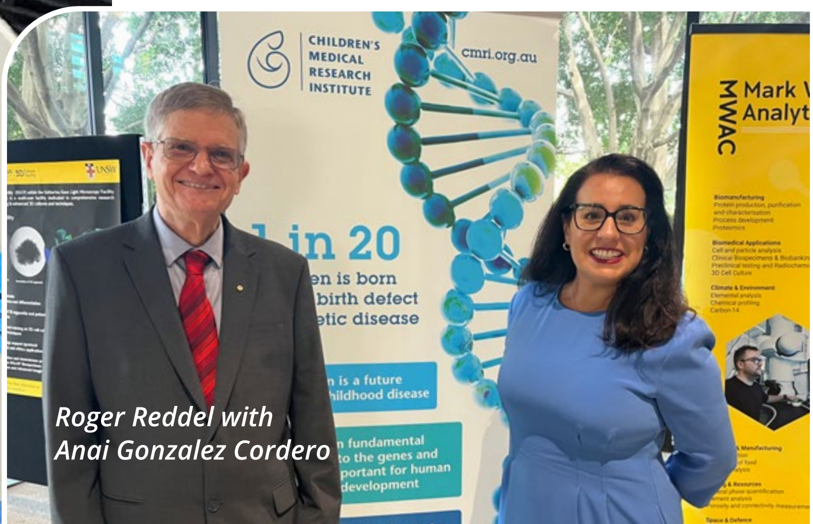
"You can see their genuine desire to achieve their objectives and to be the shining light that every child and parent who has experienced the dark days of diagnosis is reaching for."

An exciting step in organoid and stem cell research in 2025 was the official opening of the NSW Organoid Innovation Centre, of which CMRI is a founding member. The centre includes a key site at CMRI.

The first of its kind in Australia, the centre was made possible by a $2.5m investment from the NSW Government. CMRI's A/Prof Gonzalez Cordero is one of the leaders of the centre.

NSW Chief Scientist, Professor Hugh Durrant-Whyte, who is an expert in robotics said he believes the "biological research revolution is going to overtake the AI digital revolution".

"Organoids are at the heart of where biological research is going," Prof Durrant-Whyte said. "This is so fantastic to see, and I think it is ground zero for what will happen next."



Roger Reddel with Anai Gonzalez Cordero

Stem cell lab

COMMITTEES
mark major milestones

This year has been nothing short of extraordinary for our fundraising committees, whose tireless efforts bring communities together in creative, heartfelt, and joyful ways to raise funds for our research and to celebrate magical milestones.

The **Canberra** Committee marked its 65th anniversary with a special reception at Government House, hosted by CMRI's Patron, Her Excellency Sam Mostyn, Governor-General of Australia. Having raised $2.5 million over six-and-a-half decades, the event was a powerful reminder of what sustained community spirit can achieve. Volunteers, past members, and loyal supporters were honoured for their hands-on work, while Jon, a former face of the Jeans for Genes campaign, reminded everyone just how deeply their efforts matter to families.

> Celebrations continued in Strathfield, where the Committee welcomed a record 266 guests to its 65th anniversary event. Dancing, laughter, and the presence of Joseph – another face of Jeans for Genes – made the night unforgettable.

Strathfield 65th Birthday

Despite flooding postponing the **Quirindi** Committee's new Meet the Authors event in August, the rescheduled November gathering was amazing. Featuring bestselling debut authors Leesa Ronald and Sam Guthrie alongside local writer Richard Anderson, enthralling conversations were had with sunset views across the Liverpool Plains. The magical atmosphere even included a sneak preview of Leesa's upcoming novel.

The **Maroota** Committee's annual Fashion Parade at Windsor brought familiar faces together, while **Wagga Wagga's** Christmas Fair delivered festive cheer through stalls and homemade treats. In **Goulburn**, the quirky ferret race proved that creativity and fun go hand in hand when supporting medical research.

The **Hills** Committee's annual Mothers' Day luncheon packed a crowd of 400 enthralled by former Australian netball captain, Liz Ellis.

Trivia nights continued to unite communities, from **Gerringong's** lively evening of laughter and music with 230 supporters to the **Judith Hyam** Committee's $40,000-raising triumph, and **Strathfield** Committee's popular long-standing event – proving the enduring power of community and volunteer dedication.

And of course, Committees across the country turned out in force for Jeans for Genes Day, especially **Mudgee** with their famous street bake sale!

2025 has been a year of resilience, creativity, and community. CMRI is profoundly grateful to every committee member – past and present – whose generosity, friendship, and belief in our mission continues to bring hope to families and accelerate life-changing discoveries.

Maroota Committee's annual fashion parade

Wagga Wagga Christmas Fair 2025

Patti Payne at Mothers' Day luncheon

Quirindi Committee's Meet the Authors event

Get involved!

We rely on the generosity and dedication of people like you to continue fighting against childhood diseases. Here are some of the many ways you can join the team!

Volunteer
with us

Leave a
gift in your Will

Fundraise

Sign up to become a
research champion

Donate now

cmrijeansforgenes.org.au


Alessia, 6
Spinal Muscular Atrophy

Alessia

is alive and smiling because of gene therapy! She shares her story so scientists can find more cures.

Jett

has conquered many challenges, and his parents hope that science can give him less struggles and more opportunities.


Jett, 5
Usher Syndrome


Amelia, 8
Kabuki Syndrome

Amelia

lights up every room she enters, and her parents want research to ensure she continues to shine bright.

Ollie's

parents are grateful to have him after two years of cancer treatment, and they want every child to have a chance at life.


Ollie, 9
Cancer

Thank you

once more for your support.

We can't do what we do without you.

Children's Medical Research Institute
Postal: Locked Bag 2023, Wentworthville
NSW 2145 Australia

Freecall: 1800 436 437
Email: research@cmri.org.au
CMRIJeansforGenes.org.au

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