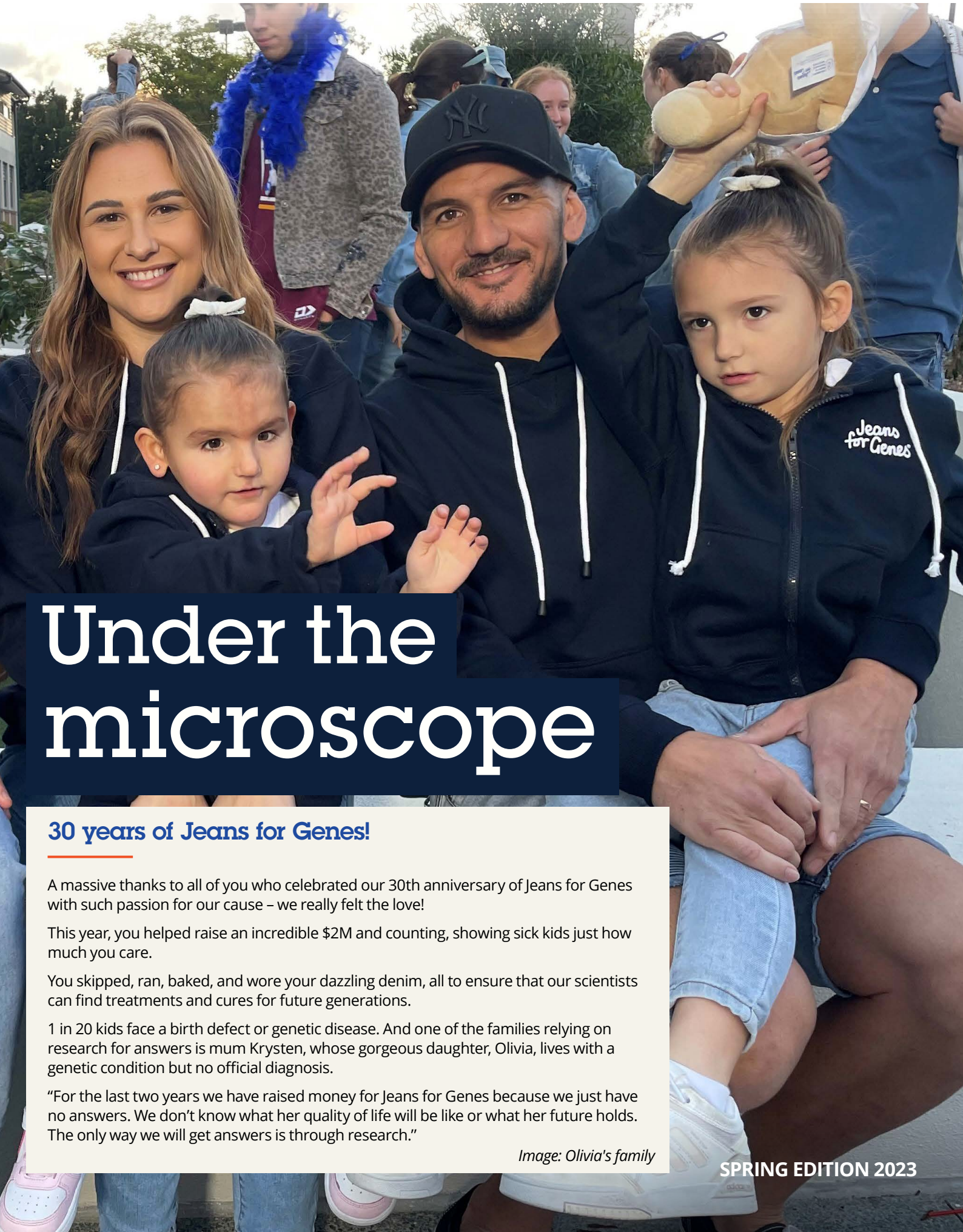
CHILDREN'S MEDICAL RESEARCH INSTITUTE

Jeans for Genes®

Finding cures for children's genetic diseases



Under the microscope

30 years of Jeans for Genes!

A massive thanks to all of you who celebrated our 30th anniversary of Jeans for Genes with such passion for our cause – we really felt the love!

This year, you helped raise an incredible $2M and counting, showing sick kids just how much you care.

You skipped, ran, baked, and wore your dazzling denim, all to ensure that our scientists can find treatments and cures for future generations.

1 in 20 kids face a birth defect or genetic disease. And one of the families relying on research for answers is mum Krysten, whose gorgeous daughter, Olivia, lives with a genetic condition but no official diagnosis.

"For the last two years we have raised money for Jeans for Genes because we just have no answers. We don't know what her quality of life will be like or what her future holds. The only way we will get answers is through research."

Image: Olivia's family

SPRING EDITION 2023

Great Cycle Challenge registrations are open! Ride throughout October and join the fight against kids' cancers.

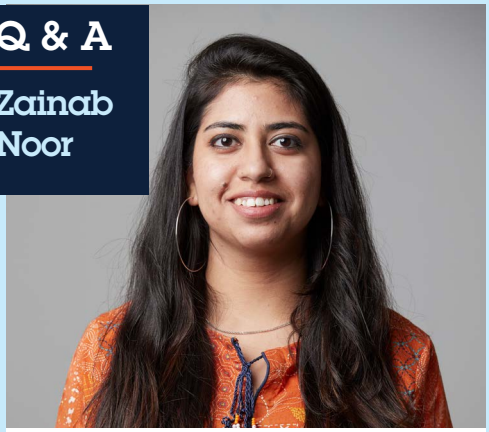
Register now:
greatcyclechallenge.com.au

Our new Christmas catalogue has a huge range of gifts that friends and family will love—and it will help find cures!

Shop now:
shop.cmri.org.au

Q & A

Zainab Noor



Dr Zainab Noor is a Senior Research Officer in the ProCan Cancer Data Science team, who are key contributors to the success of our world-leading cancer research program.

What made you interested in science?

During my early years of education, I became fascinated by the study of the human body. The complex yet systematic biology which drives our everyday activity amazed me. My love for biology and passion for computers motivated me to pursue my career in the emerging field of bioinformatics.

What is your role in ProCan?

I use my skills to highlight and understand the genes, proteins, and the biological mechanisms which are responsible for the onset and progression of disease, specifically children's cancers.

What excites you about ProCan?

Each day brings us new and exciting research opportunities. While working on a variety of projects, I've also widened my understanding of clinical research by having collaborative interactions with professional oncologists and biologists.

What do you hope to achieve with your work?

I am hopeful that my work will be used to better diagnose cancer and predict its severity, so that one day we can improve on current cancer treatments.

Our Research

Cost of Blindness

For the first time, the lifetime cost of living with an inherited eye disease in Australia was calculated, and **it's a staggering $5.2 million per person.**

Thanks to your support, this research was led by Professor Robyn Jamieson, who heads our Eye Genetics Research Unit, and her collaborators.

Distressingly, a significant portion of the cost associated with the progressive loss of vision is absorbed by the individuals affected and their families.

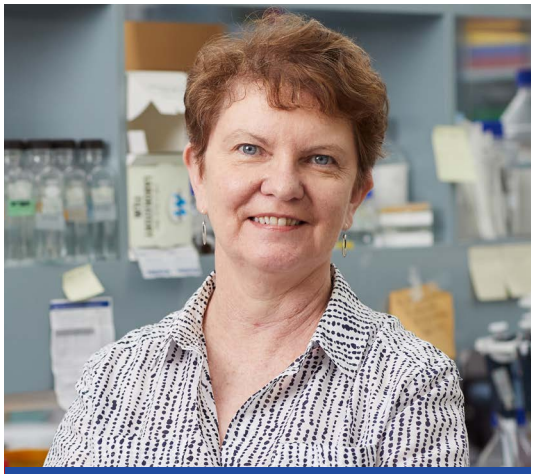
Inherited diseases of the retina include blinding eye conditions such as Stargardt disease, retinitis pigmentosa, Leber congenital amaurosis and many more. Some appear in childhood, and some in adults who all suffer from progressive deterioration of eyesight, typically leading to blindnes

"In 20 years, I have seen such incredible progress. Research in the field of genetic eye diseases offers immense possibilities – to maximise the ability to deliver definitive genetic diagnoses and develop many kinds of cutting-edge therapies to stop, and even reverse, vision loss and restore sight. However, lack of research funding has been a major challenge."

Junko has watched her 11-year-old son, Arato, lose his vision due to Stargardt disease.

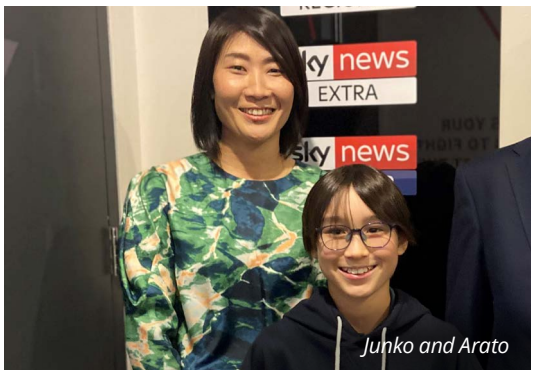
"The impact on an individual's quality of life, independence, and future opportunities is immense. It's crucial that these conditions receive equitable support, research funding, and access to innovative therapies."

This is why your support for research into treatments for genetic blindness is so vital and so powerful.



"We urgently need more investment in research for patients with these conditions."

- Prof Jamieson



Junko and Arato

Purples Lam

"Mum loved to travel and was an avid photographer. She was always active and kept herself busy with many social groups."

- Fiona Lam, Purples' Daughter

Part of the Team

One of our long-time supporters, Purples Lam, passed away recently but her support of Children's Medical Research Institute will continue through the gift she left in her Will, and help us strive for a future where no childhood is lost to genetic disease.

Her daughter Fiona tells us:

"My mother and father migrated to Australia in the mid-1970s and quickly settled into their new life. They established their Chinese grocery store in Haymarket, and through their hard work the business boomed, and they were able to retire in their early-50s and enjoy life.

Mum's passing was sudden and unexpected, and she never had the chance to discuss the gift in her Will to CMRI with me. But, to be honest, it was not a surprise! Mum was not only generous to her family and friends, but also to the charities she supported over many years.

Having a difficult upbringing herself, I think she always wanted to help children and give them as many opportunities as possible to have a good life.

I do know that she chose her charities with care and that I am sure her gift will support the scientists – and their research – at Children's Medical Research Institute which will ultimately improve the lives of generations of children to come."

Mudgee Committee

Qurindi Committee

Wagga Wagga Committee

Community & Committees

Committees Wave the Denim Flag

We have such loyal and hard-working Fundraising Committees here at CMRI! As part of the Jeans for Genes 30th anniversary celebrations this year, they went above and beyond with high teas, winter luncheons, cocktail parties, and gatherings around a fire pit!

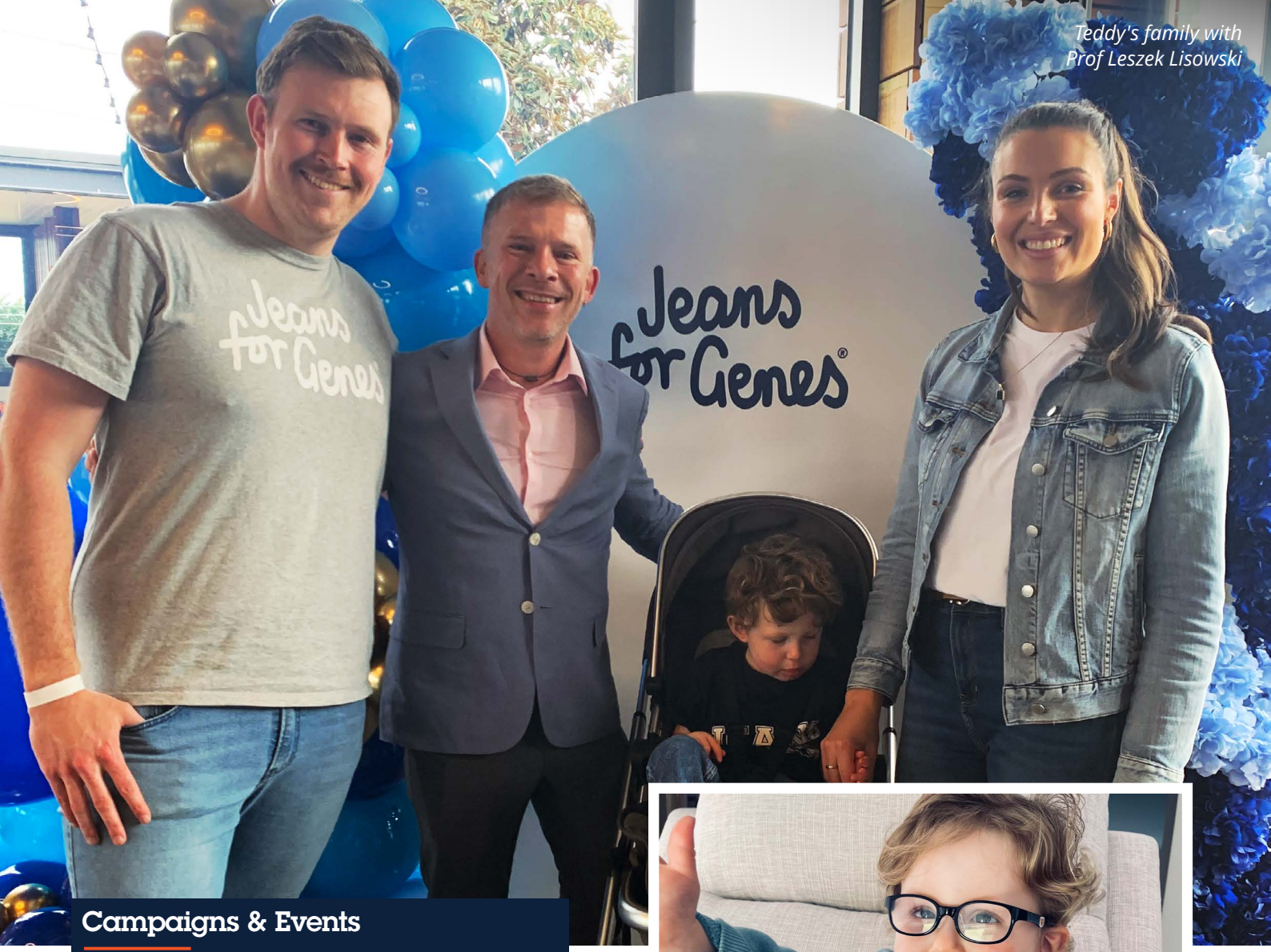
The Mudgee Committee held a Winter Wonderland Luncheon with live entertainment and a huge turn-out to support research that will benefit all the families in their region who live with genetic diseases.

The Canberra Committee had a special guest appearance by MC and former Hockeyroo, Louise Dobson OAM, and former Canberra Raiders' star, Ricky Stuart AM, for their High Tea.

Wagga Wagga held a very glamorous Jeans and Jewels Cocktail Party.

Out at Quirindi, the committee gathered together for their Denim and Diamonds Party which included food, fire pits, dancing, raffles, and auctions. Robina Burns from the committee said it was heart-warming to see the whole community support the cause.

"We are a very small regional community, but everyone believes in supporting each other and we really felt the love of the entire district at our event," she said. "Everyone knows the importance of investing in medical research, because it's not just about who it helps today, but about helping future generations."



Teddy's family with Prof Leszek Lisowski

Campaigns & Events

Changing the future starts here

You may know Teddy, but if not, he's a 2-year-old with CTNNB1 syndrome, and he's particularly special to all of us here at CMRI.

Unfortunately, there are a lot of unknowns with Teddy's condition and his parents Lucy and Peter don't know if he'll ever walk or talk.

But they're committed to getting answers for Teddy and have been supporting our gene therapy program for years now. They recently held a Drinks and Denim event at a local venue with their loved ones.

Associate Professor Leszek Lisowski, who is working on gene therapy for Teddy's disease, spoke at the event, and Lucy said it was important that those close to her understood the importance of research.

"Our friends and family would do anything for us and Teddy, but we wanted them to really understand how close CMRI is to a real treatment for CTNNB1," Lucy said.

"These scientists are working so hard, but their work can't continue without investment, so we wanted them to see where their money is going and how important it is – not just for Teddy – but for all the kids around the world with a genetic disease. A discovery in one condition often leads to therapies for many others, and we want to be a part of changing the future for millions of kids."

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Reply Paid 71005, Wentworthville, NSW 2145

CMRIJeansForGenes.org.au/donate

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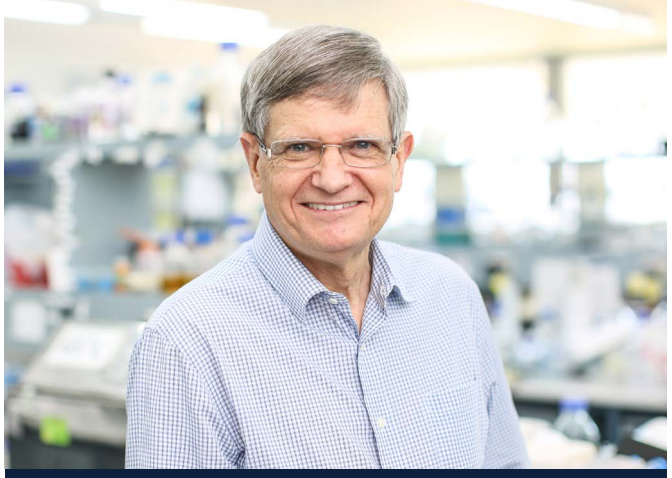

From the Director

It's been a very special year for us, with the 30th anniversary of Jeans for Genes, an event which quickly captured the spotlight and helped raise awareness for genetic research.

Many of you may also be aware that 2023 marks the 65th anniversary of the Institute, which was founded in 1958.

We celebrated this milestone at our Annual Meeting of Committees in May, where we awarded Life Memberships to three amazingly devoted supporters and Board members, Mrs Carolyn Forster OAM, Mrs Patti Payne OAM, and Mr Christopher Cullen AM.

While we have a rich history, Children's Medical Research Institute has always been about the future. Our mission is to give every child the best possible opportunity to live a long and healthy life. This is what continues to drive us. While our research programs have developed continuously over the decades, they remain at the leading edge – because they must. It is simply essential that we continue striving to find treatments and cures where none currently exist, to provide answers to the most difficult questions, and to give hope to those who need it most.

This is what we do every day, and we cannot do it without your continuing support.

I hope you enjoy reading the stories in this issue - the research and the highlights of the inspiring efforts of so many in the community. Thank you for making our mission achievable.

Roger Reddel AO
Lorimer Dods Professor and Director, CMRI

DCS23

Thanks to your support, we've been able to continue our work on the most serious problems affecting children's health.

Please give a gift today to help find even more treatments and cures for children's genetic diseases.

☐ **Yes, please accept a single gift of**

$ _____

or

☐ **Yes, please accept my monthly gift of**

$ _____ **per month**

Please find enclosed:

☐ Cheque ☐ Money Order

(payable to Children's Medical Research Institute)

Please debit this card:

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☐ Please send me more information about including a gift in my Will to Children's Medical Research Institute.

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Thank you for your generous support.

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