

Annual Review Highlights 2021



Children's
Cancer
Institute

A Message from the Executive Director



2021 had us again dealing with the COVID-19 pandemic, with more lockdowns, and restrictions to contend with, and – like everyone else in the country – we found ourselves wondering when things would get back to normal.

While lockdown inevitably disrupted some of our laboratory research for a short time, the silver lining to this cloud was that our researchers were able to make extraordinary progress in writing up completed studies and publishing these in internationally renowned scientific journals. A number of these studies will lead to new clinical trials in children with cancer – a wonderful achievement that will bring fresh hope to many families affected by the worst childhood cancers.

It was exciting to see the plans for our new home, the Children's Comprehensive Cancer Centre continue at a rapid pace. Detailed design of the centre is now complete and we expect to see construction begin shortly, on course to open in 2025.

Front cover: Carys was diagnosed with pre-B acute lymphoblastic leukaemia at just 6 years old.

We were also delighted to welcome Minderero Foundation as naming rights partner, making a significant philanthropic donation of \$20 million that builds on the previous contributions of the State and Federal governments, and support of UNSW.

Zero Childhood Cancer (ZERO), our national personalised medicine program led in partnership with Kids Cancer Centre at Sydney Children's Hospital, Randwick, continued to make exciting progress. More than 700 children have now been enrolled on ZERO's national clinical trial, which is achieving some remarkable results and teaching us more about childhood cancer every single day. We were absolutely thrilled to see ZERO featured in the American Journal of Human Genetics Top 10 significant accomplishments in applying genomic information into clinical care (published December 2021) – true recognition of the contribution ZERO is making to global progress in this field.

In preparation for the ZERO program expansion to be available for all Australian young people diagnosed with cancer by the end of 2023, the team has been hard at work building capability and capacity, so we are able to provide personalised treatment recommendations for as many children as possible, more quickly and more accurately.

Another highlight this year has been the progress our Brain Tumours Group has made in their research into the devastating childhood brain cancer, DIPG. The team has been testing a whole range of drugs against DIPG in the laboratory and has found a number of therapies that appear to be very effective. As a result of this research, two new treatments have now progressed to clinical trials for children with DIPG here and in North America.

We also made important research discoveries that we hope to see lead to improvements in the treatment of two other aggressive cancers, high-risk acute lymphoblastic leukaemia, a difficult to treat blood

cancer, and high-risk neuroblastoma, a malignant tumour that mainly affects children under five. Exciting times are ahead, and we are so thrilled to have you join us on this journey. The pace of medical research today is breathtaking, and there is much to feel optimistic about. Advances in technology, combined with the huge expansion in our knowledge of childhood cancer through programs like ZERO, are creating research opportunities that we've simply never had before. The future is looking bright.

Thank you so much for your support and your belief in our vision. We can only make this extraordinary progress because of you. Working together, we can and will reach our goal of one day curing all children with cancer. It's not if. It's when.

Professor Michelle Haber AM
Executive Director, Children's Cancer Institute

Financial Report

Statement of profit or loss or other comprehensive income For the year ended 31 December 2021

	2021 (\$'000)	2020 (\$'000)	2021 (%)
Revenue			
Research	52,069	29,115	63%
Fundraising	28,637	16,432	35%
Other	1,805	6,489	2%
Total	82,511	52,036	100%
Expenses			
Research and scientific activities	58,113	42,199	84%
Fundraising	6,694	5,998	10%
Support and administration	4,567	3,919	6%
Total	69,374	52,116	100%
Surplus/(Deficit) for the year	13,137	(80)	

Statement of financial position As at 31 December 2021

	2021 (\$'000)	2020 (\$'000)
Assets		
Cash, receivables, other financial assets	61,389	36,580
Property, plant and equipment, intangible assets	8,678	8,378
Lease asset	9,512	12,471
Total assets	79,579	57,429
Liabilities		
Current trade & other payables	6,046	3,512
Provisions	3,818	3,498
Financial liabilities	23,719	15,802
Lease liability	3,074	3,958
Total liabilities	36,657	26,770
Net assets	42,922	30,659
Equity		
Reserves	10,778	10,652
Retained surplus	32,144	20,007
Total equity	42,922	30,659

Note: Total equity includes project-specific research funding received in advance to specifically support identified multi-year research programs.

Our Year in Review

January

A boost for sarcoma research Thanks to the generous contribution and drive of parents, we have been able to establish several new research projects for sarcoma, a devastating group of tumours that particularly affect teenagers and young adults. **The Cooper Rice-Brading Foundation** and **The Kids Cancer Project** awarded a grant of over \$370,000 to **Dr Emmy Fleuren** (pictured, right) to advance her sarcoma research. While **Anya's Wish**, a new research project in memory of Anya Zuber, a vivacious 19-year-old who lost her life to sarcoma in 2020, was established to help find a cure for osteosarcoma.



March

World-first research paves way to new neuroblastoma treatment Researchers in our **Gene Regulation in Cancer** theme uncovered a new way to target the childhood cancer, neuroblastoma, which may also have important implications for some other aggressive cancers. Published in internationally leading journal **Nature Communications**, the research showed that a cellular protein called ALYREF controls the cancer-driver gene MYCN – a discovery that could lead to new treatments for several types of cancer.

April

Brain cancer researchers find new way to target DIPG Building on a discovery from our Experimental Therapeutics Group into neuroblastoma, our **Brain Tumours Group** discovered an exciting new therapeutic approach for the treatment of the fatal brain cancer, DIPG. After showing that a drug called **CBL0137** has a profound effect against DIPG tumours in the lab, the researchers then added another drug called **panobinostat** to the mix, finding that the combination of the two was even more effective at killing DIPG.

May

New drug combination effective against high-risk leukaemia Studies by our Blood Cancers researchers, published in the international journal **Leukemia**, showed that a new drug called ruxolitinib significantly enhances the effects of several other drugs used to treat a type of high-risk leukaemia known as Ph-like acute lymphoblastic leukaemia. Combining these drugs could therefore prove to be an effective way to treat this cancer in some children.

Multimodal therapy for aggressive childhood cancers Researchers in our **Molecular Targets and Cancer Therapeutics** theme found a combination of therapies that appears very effective against high-risk neuroblastoma and some other forms of aggressive childhood cancer. The therapies not only work synergistically to inhibit the growth of cancer cells, but also heighten the body's immune response to cancer.



September

New DNA-based test on horizon for children with solid tumours Our scientists published an exciting study in internationally leading scientific journal **British Journal of Cancer**, showing that whole genome sequencing technology can be used to monitor treatment response in children with solid tumours. This could lead to the development of an important new clinical tool that allows clinicians to monitor disease progression and treatment response, enabling the early detection of relapse.



December

Improving personalised medicine for high-risk cancers The **Zero Childhood Cancer** team published world-first research showing that the practice of **'pre-clinical testing'** – developing laboratory models based on each patient's cancer, then using these models to test potential therapies against – can reveal important additional treatment options for children with high-risk cancers, compared to genetic testing of patient tumours alone.

Accelerating towards our new home

We were delighted to confirm **Minderoo Foundation** as the naming rights partner for what will now be known as the **Minderoo Children's Comprehensive Cancer Centre**. The contribution of \$20 million and commitment to help attract the further \$30 million required through philanthropic donations is a significant step towards our new home. Detailed design of the world-class research and clinical facility is now complete, opening the way for construction to begin in 2022.



October

Future Impact Awards Our **Future Impact Awards** brought the brightest emerging talent together to award funding for exciting future projects. Despite the challenges of isolation, clinicians, researchers, supporters and families got to hear from five pairs of **ambitious young researchers** about their new ideas, in the hope that the projects receive the funding to get off the ground, and hopefully lead to new discoveries.

November

Building for a Cure Thanks to the generous support of our partners **Mulgoa Sanctuary**, **Mulgoa Quarries** and **McDonald Jones Homes**, we built a four-bedroom house in just 28 days, an extraordinary effort given the challenges of lockdowns and staff limits. Titled the **'house that love built'**, the home was sold on Sunday 14th November for an incredible \$1.795m, with all proceeds going towards our childhood cancer research.

CEO Dare to Cure In just its fourth year, our annual CEO Dare to Cure event is now becoming a must-do on all C-suite executives' calendars. Over 100 CEOs and business leaders came together in Sydney (and some virtually) to complete a dare and raise awareness for the Institute. Together, they **raised an incredible \$1.6m**, funding the equivalent of 15 senior researchers working in our labs.





Carys' Story

Carys was a bright, happy child. She was active, loving activities like swimming lessons and riding her bike. Her parents, Mark and Laura say she had a positive attitude and polite demeanour.

"She'd always give things a go. She wasn't a shy child or a sensitive child. She had good manners. So she was a very well-liked, likeable sort of kid," says Laura.

The family, including Carys' little brother Cohle, were about to fly to Fiji for a much-anticipated holiday when Carys suddenly took ill. First she had an ear infection, then constant nose bleeds, easy bruising, and a complete lack of energy. After three visits to the GP and several rounds of antibiotics, it was clear something was seriously wrong.

When Laura took Cohle in for his 4-year-old immunisations, she decided to take Carys in as well "just for another look". The GP sent them straight to Sydney Children's Hospital, Randwick, where blood tests were done immediately. It was here Carys was diagnosed with leukaemia.

"They were all exclaiming at the computer and putting their arms up," says Laura. "It seems her white blood count was the second highest count they'd ever seen. I went into shock. I just remember sitting there and feeling sick."

Carys had pre-B acute lymphoblastic leukaemia, which fortunately had a high cure rate and a well-known or understood treatment plan. Chemotherapy was to start immediately. However, Carys wasn't responding to treatment.

"It took her so long to stabilize, we were warned that we might lose her," says Laura.

For Carys, this began a traumatic eight-month journey that no child should have to suffer through. There were many days and nights of being in extreme pain and discomfort because of her treatment. She gained a lot of weight, then she lost a lot of weight. Her skin peeled, she lost her hair, her mouth bled, she had sores on her skin, and she had endless needles and tests. At one point, the drugs caused Carys to stop communicating.

For her parents, life changed instantly. There were many late Friday nights at home when Carys' temperature would spike and they had to take her into hospital, knowing they be in for at least 48 hours and any resemblance of a normal home life and routine would be upended.

The added complication of the Covid-19 pandemic, which was just taking hold at the time, meant that Laura and Mark could never be in the hospital together. They would take each day in shifts, confined to the hospital room for most of the day, sleeping on a fold out bed at night.

Fortunately, Carys' condition improved over time. She finished her frontline treatment in December 2020 and continues on maintenance treatment. She is back at school doing so many of the things she loves, including swimming and horse riding.

"We're now just dealing with the normal attitude that comes with 8-year-olds as opposed to intense chemo treatment!" Smiles Mark.

He praised the expertise and dedication of researchers at Children's Cancer Institute for giving children like Carys access to better treatments and cures for cancer.

"We're extremely lucky that all the research that's been funded by people to date means that Carys got better," says Mark, who is now doing regular bike rides to raise money for childhood cancer research.

Laura agrees. "If we don't want children like Carys to suffer from cancer, we've got to look towards research."

"We're extremely lucky that all the research that's been funded by people to date means that Carys got better."

Mark, Carys' dad



**We will cure
childhood cancer.
It's not if.
It's when.**



Donate today at ccia.org.au/donate

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