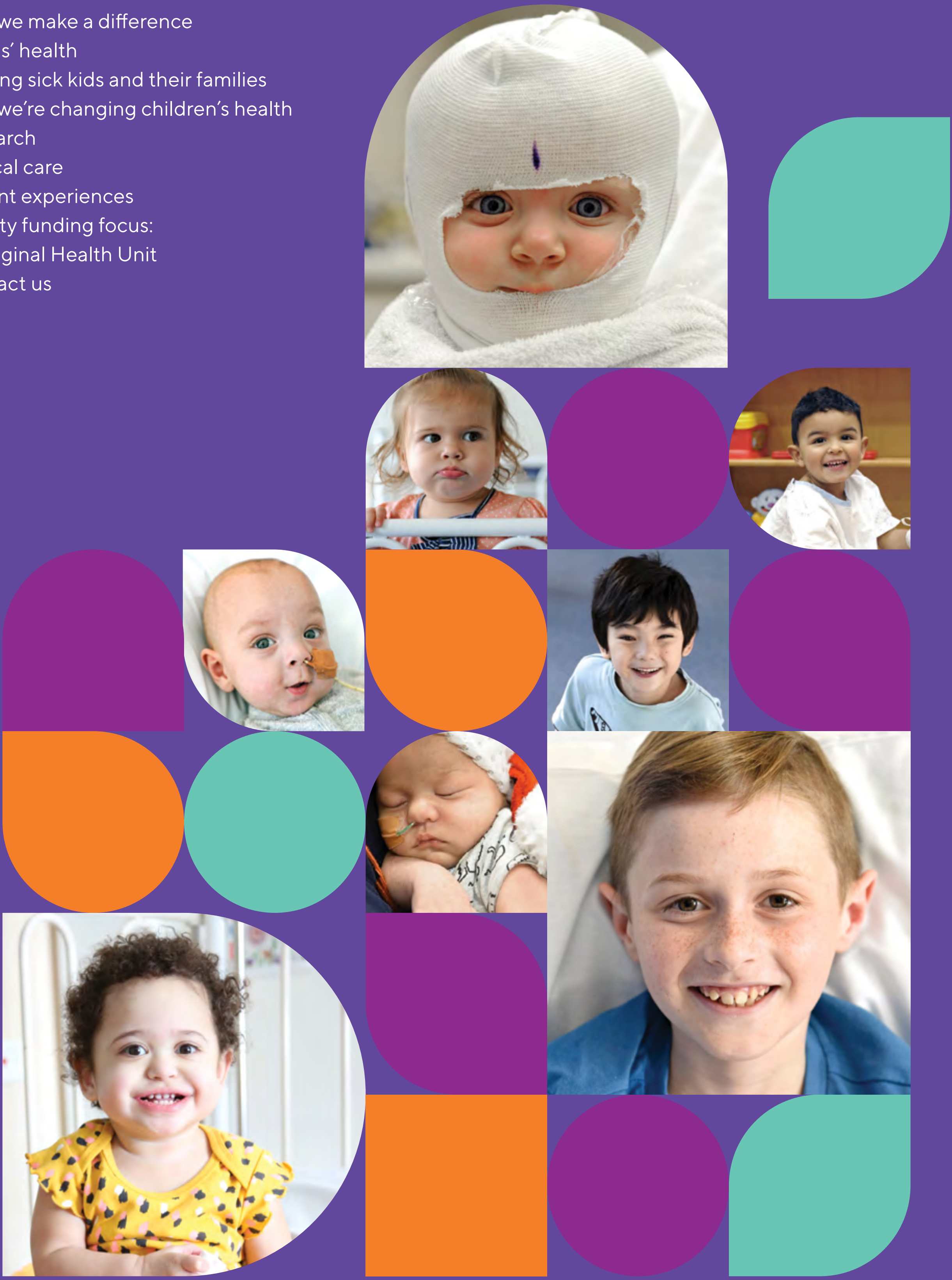
Impact Report 2021

Sydney
Children's
Hospitals
Foundation

Contents



One of the largest and most trusted kid’s health charities in the country, Sydney Children’s Hospitals Foundation exists to help provide all children with access to the best possible healthcare, whenever and wherever they need it.

We truly believe there is no possible greater impact for a donated dollar in kids’ health.

All in 💜 for kids’ health.

Acknowledgement of First Australians

Sydney Children’s Hospitals Foundation acknowledges First Australians and recognises their continuous connection to country, community and culture. We are committed to helping to close the gap to achieve equality in health and life expectancy for Aboriginal and Torres Strait Islander peoples.

Purpose, Mission and Vision

Our purpose

Healthy kids –
whatever it takes

Our mission

Connecting donors with world-class research and clinical excellence so children can live their healthiest lives

Our vision

A world where every child receives the best health care, when and where they need it

From Sydney Children's Hospitals Foundation

All in for kids' health

Thanks to your generous support, together we make a positive impact that lasts a lifetime even though for some kids, childhood is far from what it should be. For sick kids, instead of playdates there are appointments. Instead of sleepovers there are stays. Instead of firsts, there can be lasts.

Reporting on our impact on kids' health is important, as their wellbeing will influence nearly all aspects of their lives. A child's health can affect their links with family, schooling, friendships, and the things that give them joy, such as sport, music and art.

That is why I am delighted to present our inaugural Impact Report and share some of the breakthroughs, milestones and turning points that will help sick kids today and future-proof children's health tomorrow. These achievements wouldn't have been possible without your support. Together, we're all a part of something bigger: a Movement of Many, fighting for the health and wellbeing of children in this ever-changing world.

Research shows that investing in children's health helps save or improve the lives of sick children by allowing them to enjoy their formative years and to reach their greatest potential for years to come.

Thanks to your unwavering commitment during a very challenging time, we have had another incredibly successful year. We raised $55.8 million for children's health in FY21, which allowed us to donate almost $39.8 million towards improving children's health, including $36.4 million to help kids and families receiving treatment or care from the Sydney Children's Hospitals Network.

One of this year's highlights was funding the first stage of a state-of-the-art 14-storey clinical building at The Children's Hospital at Westmead to provide welcoming, child-friendly spaces supporting new models of care. Another was helping to improve the survival rates of children with aggressive cancers, through the innovative Zero Childhood Cancer Program. Our funding is also improving the child's wellbeing by funding initiatives such as the Aboriginal Children's Memorial Garden at Westmead, and a path to the sea for children at Bear Cottage hospice in Manly.

Together, we have funded more than 1,045 immediate and future research, clinical excellence and patient experience initiatives, ensuring children get the best care today while elevating the outcomes of tomorrow – we are going all in to change the landscape of children's healthcare, for all kids, always.

I hope that reading this report makes you as proud as I am for what we've been able to achieve, together, for sick kids.

Nicola Stokes

Nicola Stokes
Chief Executive Officer
Sydney Children's Hospitals Foundation

From Sydney Children's Hospitals Network

Working together delivers endless possibilities for kids' health

Across the Sydney Children's Hospitals Network, we deliver world-class care to some of the state's sickest and most vulnerable children, young people and families. This is a team effort and the community is a large part of that team.

Every day we are making progress in health care. As technology advances, clinicians and researchers are finding new ways to treat and manage diseases that previously had no cure, giving hope to families that previously had no answers.

From the purchase of state-of-the-art equipment to investments in life-changing research, support for vital services and so much more, every dollar makes a difference to the lives of so many in our care.

I am proud to work alongside Sydney Children's Hospitals Foundation (SCHF) as we help children live their healthiest lives, both now and into the future.

The COVID-19 pandemic has been tough for everyone working in health care. Our staff members have shown true resilience and compassion as they adapted to the numerous challenges that a one-in-100-year pandemic brings.

As a result, our ways of working have also changed. Telehealth and virtual care have become integral to caring for our patients and families, and have ensured that we keep them and our staff as safe as possible.

Despite the challenges presented over the past year, our staff's dedication hasn't wavered. I am proud to be part of a team that is committed to helping children and young people during some of the most difficult moments they will experience individually and as a family.

The generous support from SCHF and its donors has been so important during these tough times. It continues to help our staff members, who are working tirelessly to respond to the changing needs of our patients and families. And for this, we are grateful.

When we work together, the possibilities for the future of kids' health are endless.

Cathryn Cox

Cathryn Cox PSM
Chief Executive
Sydney Children's Hospitals Network

How we make a difference to kids' health

70,000

donors

1 Foundation

3 core areas of investment

Ground-breaking research

Excellent medical care

Positive patient and family experiences

1 Network

8,423 staff across 5 entities

The Children's Hospital at Westmead

Sydney Children's Hospital, Randwick

Bear Cottage

Newborn and paediatric Emergency Transport Service (NETS)

Kids Research

173,941

children with an illness or injury

Potentially millions of children across the world benefiting from research

Bryson and Ryder's story

Brothers Bryson and Ryder are the youngest of four boys who both needed life-saving treatment for rare brain conditions.

At just 2.5 years old, Bryson was diagnosed with a tennis-ball sized cancerous brain tumour that needed urgent surgery and six months of intense chemotherapy at The Children's Hospital Westmead.

Five years later, their premature baby Ryder, was rushed to Sydney Children's Hospital, Randwick with a dangerous bacterial infection. At just two weeks old, Ryder had the first of 18 life-saving brain surgeries.

Today, Bryson, 8, and Ryder, 3.5, are both growing up fast. While living with the effects of his cancer treatment, Bryson loves running around with his older brothers, roller skating and playing football. As a result of his condition, Ryder has cerebral palsy and epilepsy so he has his ups and downs, but you can't wipe the cheeky grin off his face.

Helping sick kids and their families

Thanks to your support we donated $39,784,146 to help children receive the best health care, when and where they need it. Our support focuses on kids and families receiving treatment or care from the Sydney Children's Hospitals Network, and we also help fund child health research and programs with the potential to help children across Australia and the world.

173,941

children received medical care

56,937

hospital admissions

1,269,841

occasions of care for non-admitted patients

97,786

Emergency Department presentations

4.5

days average length of stay

264,530

community and home delivered occasions of care

21,114

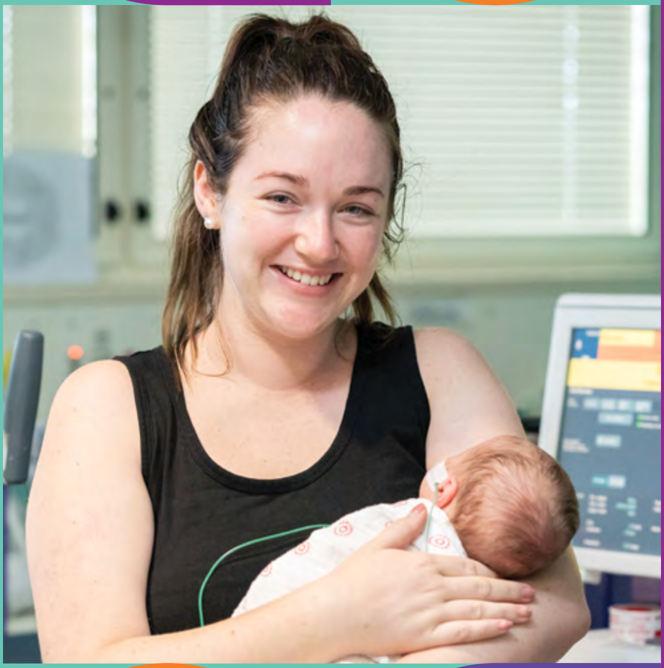
operations

2,702

patient and family members supported at Bear Cottage

3,702

emergency transport retrievals by NETS



Everleigh's story

Shortly after Everleigh was born at her regional hospital, she stopped breathing and had to be resuscitated. Later that night, Everleigh was flown by the Newborn and paediatric Emergency Transport Service (NETS) to the Grace Centre for Newborn Intensive Care at The Children's Hospital at Westmead.

Brooklyn said: "The NETS team gifted Everleigh and I two blue, fabric hearts so we could each hold onto one while we were apart. Just before she left, we switched hearts and I held onto hers for those two days we were separated."

After emergency surgery and numerous tests, Everleigh was diagnosed with a rare medical condition known as Pierre Robin Sequence (PRS). Everleigh spent her first five weeks in the Grace Centre and will continue to see specialists from across the hospital over the next six years.

"Everleigh has had three NETS transfers," added Brooklyn. "The team has always been so supportive and informative."

How we're changing children's health

Your generous support helped us donate almost $39.8 million to fund innovative research, the best clinical care and positive patient experiences for the prevention and management of childhood illness or injury. This amazing contribution can help sick kids today and transform children's health tomorrow.

$23,596,800*
Best clinical care

$12,751,623
Innovative research

$3,435,723
Positive patient and family experience

*Includes $848,490 distributed to Curing Homesickness Alliance partners across Australia for funds raised in their state or territory to support initiatives that help get kids home from hospital sooner.

Research

Research that's transforming children's health

Across the Network in FY21

240 studies conducted across Sydney Children's Hospital, Randwick and The Children's Hospital at Westmead

600+ research staff and students

1,116 peer-reviewed publications

55 research units working on hundreds of different childhood diseases.

SCHF funding FY21

- **$12.75 million** invested in childhood health research
- **77** research and key research support positions*
- **16** grants or scholarships for early-career researchers
- **8** projects funded through our Greenlight Pilot.

With your support, we continued to invest in research that accelerates the transition of crucial discoveries into innovative treatments, prevention strategies and cures that will deliver life-changing outcomes for children.

Funding supported child health researchers working within the Network's research division, Kids Research, across the children's hospitals and through partner organisations such as universities.

"The generous support of SCHF and its donors is a massive driver of discovery in research," said Professor Chris Cowell, Director of Research, Sydney Children's Hospitals Network. "Many of our researchers work in the hospital, which ensures our studies address the most critical child health issues and that discoveries are rapidly converted into new prevention, diagnostic or treatment options."

Kids Research's strategic priorities are to accelerate research in collaboration with national and international partners; to enable work in the field of Precision Health through cutting-edge research and models of care to deliver unique solutions matched to individual patients; and to ensure its Population and Practice division delivers on best health and wellness outcomes for the community.

Professor Cowell said: "The real power of focusing on these seemingly distinct fields of research will come from integrating the strengths and discoveries from each. Researchers and healthcare teams can collaborate to identify the populations of children with the greatest needs and then work with the affected community to develop evidence-based care models to improve patient outcomes. This, in turn, can drive large-scale, population-wide change in child health."

---

* Fully or partly funded positions.

Research highlights

Unrestricted funding offers unlimited possibilities in children's health

Generous changemakers who donated, raised funds or left a gift in a Will to support the Network's highest-priority funding needs played a critical role in collectively funding specialist Kids Research positions. This unrestricted giving has unlimited possibilities for transforming children's health across a range of childhood illnesses. The funding underpins groundbreaking research, and supports positions such as clinical trial nursing and pharmacy staff, experts in microscopy and biostatistics, clinical psychologists and research officers.

Clinical trials test the safety and efficacy of promising new treatments, which must be done before governments can approve a treatment as standard care. These trials offer families hope with early access to novel therapies that can improve or save their child's life. Unfortunately, children are involved in only a third of clinical trials, which can often delay access to potentially life-changing therapies. SCHF continues to support clinical trials by investing in expert paediatric clinical trial staff to support the complex needs of these studies.

.

Support for cancer clinical trials opens up projects

DOOLEYS is just one of our clinical trials supporters. It has donated $2.1 million over the past decade and has committed a further $1 million over the next five years to support the Cancer Centre for Children at The Children's Hospital at Westmead, through its Clinical Research Trial grant and the Children's Cancer Research Unit (CCRU) Bridging Grant Scheme. In the first year alone, this funding helped open seven new clinical trials by funding clinical trials staff. With DOOLEYS' continued support, CCRU has been able to open 15 new research projects since this granting partnership was established, while maintaining a fully staffed Clinical Trials Centre.

The Big Brain Project helping little brains

To help the one in 10 children with brain disorders, we funded the launch of The Big Brain Project, which is partnered with the Kids Neuroscience Centre. The project is led by Professor Russell Dale and Associate Professor Michelle Farrar. The Big Brain project is helping children with neurological and neurogenetic disorders by defining disease mechanisms and finding new targeted treatments. Generous support from The Ainsworth Foundation funded a Senior Clinical Research Offer position to implement Stage 1 of the project. This will help families access new treatments, clinical trials, evidence-based resources and support. Stage 2 will expand the project by creating a nationwide collaborative research program.

Leading the way in child health research

Fostering the future leaders of research today is critical for the ongoing advancement of children's health tomorrow. With funding from many of our donors, SCHF invests in seed project grants and scholarships to develop early-career researchers.

In FY21, we funded 10 innovative research projects through our Small Grants Program for early-career to mid-career researchers to help children across a range of illnesses and injuries including epilepsy, rare genetic disorders, asthma and concussion. One project will consider the impacts of the COVID-19 pandemic on paediatric health services.

We have funded a PhD scholarship focused on neuromuscular conditions such as the devastating genetic conditions, spinal muscular atrophy (SMA) and Duchenne muscular dystrophy. Paediatric neurologist Dr Sandi Kariyawasam is evaluating new management pathways from diagnosis to treatment as part of The Freedman Foundation PhD Scholarship in Child Neurology. This includes the assessment of the first state-wide newborn bloodspot screening (NBS) pilot for SMA, spearheaded by Dr Michelle Farrar from Sydney Children's Hospital, Randwick. This work will be crucial in supporting an application for the routine national adoption of NBS for SMA.

Mini organs help children with genetic diseases

Innovative organoid research involving the growth of mini organs in the lab are improving experts' understanding of diseases and treatment options for children with genetic diseases such as cystic fibrosis (CF), brain tumours, inherited eye diseases and epilepsy.

Every four days, a baby is born with CF, a disease affecting the lungs, digestive system and other organs, resulting in an average life expectancy of just 38 years. Vital funding from SCHF over the past four years helped establish the Molecular and Integrative Cystic Fibrosis (miCF) Research Centre at Sydney Children's Hospital, Randwick, which is led by Professor Adam Jaffe and Dr Shafagh Waters. A key achievement of miCF Research Centre is the CF AVATAR Platform, which creates gut and respiratory tissue from the stem cells of patients with CF. This tissue acts like an avatar for each child to predict how likely they are to respond to available therapies. This simple, accurate test is important because breakthrough medications can cost up to $300,000 a year for each patient but may not work for every child and can cause unwanted side effects including organ damage. The miCF team has proven the CF AVATAR Platform's benefit on a small scale and now plans to test its clinical and health system benefits nationally.

A mini brain has also been developed by the Children's Cancer Research Unit (CCRU) and Cancer Centre for Children at The Children's Hospital at Westmead, with significant funding from the Balance Foundation and Chris and Marina Antoniou from Antoniou Fillo Pastry.

Professor Geraldine O'Neill, Head of CCRU, and her team have successfully created a 3D organoid that closely replicates a child's brain. Mini brains will be used to trial cutting-edge treatments for childhood brain cancers, including a new immunotherapy known as chimeric antigen receptor (CAR T-cell) therapy, which uses specially altered T cells to target and destroy cancer cells.

Accelerating discoveries for rare diseases through gene therapy

Your support is helping researchers from the Network, along with partner organisation, the Children's Medical Research Institute, to accelerate world-leading gene and gene-modified cell therapies to help children with rare diseases.

Gene therapy involves a once-only injection and has the potential to transform the lives of children. Expert clinicians and families have witnessed the incredible benefit of giving Zolgensma to children with spinal muscular atrophy, a devastating life-threatening condition that leads to the rapid loss of motor function in the first year of life. Children receiving this therapy are now walking and developing normally at age two. Another example is ocular gene therapy, which involves an injection into the retina of children who are deficient in the RPE65 protein and at risk of blinding eye disease. The therapy has lead to the partial restoration of the vision in two teenagers allowing them to see stars for the first time in their lives.

Leading researchers have unique opportunities to develop novel gene therapies focused on rare genetic diseases of the liver, eye and brain – the latter of which can lead to childhood dementia.

Transforming patient data into better care

Australian hospitals capture vast amounts of patient data in real time. To help convert this data into valuable information that can improve patient care, SCHF has provided Stage 1 funding to establish the Sydney Kids Learning Initiative. Led by Professor Tom Snelling, this game-changing initiative aims to create a nationwide system that can collect and present findings from real-time, patient-specific treatments, and from outcomes in clinical settings.

One example of how this data might be used is in improving the diagnosis and management of children with fever in emergency departments, which may reduce the number of days children spend in hospital by up to 20%.

Innovative projects get the green light

After seeking inspiration from various industries, SCHF has adapted a financing model from the film industry to create a new model for funding research.

Developed in partnership with the Compton School, the 2020 Greenlight Pilot taught researchers film industry techniques they can use to develop a compelling research story. This will better engage forward-thinking donors who are willing to invest in new ideas in novel ways, such as via a digital platform where they could cast votes for projects.

In FY21, we secured funding for eight Greenlight projects to help children with cerebral palsy, autism, brittle bone disease, asthma and infectious diseases, and rare disorders such as oesophageal atresia and fatty acid oxidation disorder.

Research spotlight

Zero Childhood Cancer Program

- 3 children die each week from childhood cancer
- First precision medicine program in Australia for children with aggressive, high-risk cancer
- 700 children enrolled in ZERO since it began in 2017
- Up to 70% of patients can be recommended a new potential treatment – with some successfully halting or shrinking tumour growth.

The Zero Childhood Cancer Program (ZERO) is a joint research initiative launched in 2017 by the Kids Cancer Centre at Sydney Children's Hospital, Randwick and the Children's Cancer Institute. ZERO is Australia's first precision medicine program treating children who have been given less than a 30% chance of surviving. ZERO uses rapid genome sequencing and treatment testing to identify the unique genetic profile of a child's cancer and match it with new therapies that are likely to target the cancer with greater precision.

Professor Tracey O'Brien, Director of the Kids Cancer Centre, said new cancer treatments for children are urgently needed. "This research program is disrupting how we think about treating childhood cancer, which is very exciting," she said. "We are generating new knowledge and applying this to help rapidly accelerate the use of experimental therapies where traditional chemotherapy has failed or is unlikely to work. We won't stop till we improve cure rates for all kids."

Clinical trial results have been reported in *Nature Medicine* and other leading international journals. The ZERO program was awarded the NSW Health Award for Innovation in 2020 and recently recognised by a leading US authority as one of the top 10 genomics research programs globally improving patient outcomes.

With the support of a group of generous donors, SCHF played a crucial role in helping to establish ZERO with a capacity fundraising campaign. FY21 is our final year of the ZERO Capacity Campaign and one of our early supporters, Lenity Australia, generously donated $1 million, taking its five-year support to $1.65 million. SCHF also thanks other change-making ZERO supporters, including the Minderoo Foundation, the Medich Foundation, Paul Henry and his Pedal 4 Kids team and supporters, The Lott, Golden Casket, Macquarie Group Foundation, Tim and Bella Church, Bing Lee, Arab Bank, Amazon Australia, Carapiet Foundation, K & J Prendiville Foundation and Atlas by LJ Hooker.

Left: Ellie was 11 months old when a scan revealed a large tumour. ZERO helped identify a treatment to target the genetic alteration likely to be causing the growth.

Based on the early success of ZERO, the program has been awarded $67 million in funding from the Australian Government and Minderoo Foundation collectively. This will be used to expand the ZERO trial to encompass all children in Australia diagnosed with cancer, regardless of risk type, stage or cancer type. This will mean up to 1,000 children and young people with cancer around Australia will have access to ZERO's state-of-the-art precision medicine.

Ellie's story

Ellie was just 11 months old when her mum, Mina, and dad, Rob, took her to Sydney Children's Hospital, Randwick. A scan revealed a tumour so large it was pushing on her tiny heart and lungs.

Within days, she was on life support in the Intensive Care Unit because she could no longer breathe on her own.

Ellie's oncologist and Clinical Lead for ZERO, Professor Glenn Marshall, treated her with chemotherapy, but after two weeks her tumour still wasn't responding. In fact, it had grown and her condition had worsened.

"It was urgent to find a way to shrink the tumour as time was running out," Professor Marshall said. "We enrolled Ellie into ZERO and the team were able to have her tumour DNA fully sequenced within two weeks."

The ZERO team diagnosed Ellie's cancer as a soft tissue sarcoma known as infantile fibrosarcoma, and they found the genetic mutation that was likely driving its growth. The team also identified a drug in the United States designed to target that genetic mutation. The pharmaceutical company agreed to supply the treatment on compassionate grounds and treatment began immediately. Within four weeks, Ellie's cancer had shrunk to the point that she was able to come off life support, and within six weeks she was moved out of the Intensive Care Unit.

Today, Ellie is a lively (almost) five-year-old girl with an outgoing attitude. Ellie will start school soon, and she and her parents are very grateful to be able to experience this exciting milestone.

"We know that if Ellie had been diagnosed with this cancer even two years earlier she would have died. She is only alive today because of the Zero Childhood Cancer Program," said Mina.

Mya's story

Mya, 18 months, was born with nail-patella syndrome, which is a genetic condition that often causes changes in the nails, elbows, knees and hips.

Since birth, Mya (pictured here at 6 months of age) has been treated by a multi-disciplinary team of paediatric specialists, nurses and allied health professionals from The Children's Hospital at Westmead to monitor and manage her condition.

Mya's mum Ely said: "Mya's condition is one that presents so differently in every child but the treatment from the dedicated team looking after Mya has made such a huge difference. Mya now has a good range of motion in her arms; she can pick things up, put things in her mouth and just explore like other babies."

Clinical care

Best clinical care for children today

Across the Network in FY21

8,423 dedicated staff members

173,941 children who received care

1,269,841 occasions of care for non-admitted patients.

SCHF funding FY21

21 fellowships to create paediatric specialist positions*

94 medical, nursing, allied health, education and support positions*

775 vital pieces of equipment

3 clinical building and refurbishment projects.

With your support, we have continued to invest in clinical care for one of Australia’s largest children’s hospitals network and paediatric services, to ensure all children receive the very best care, always.

Our donations helped fund crucial equipment, critical positions, accelerated clinical education programs, and major and minor building projects to transform patient care now and into the future.

“The generous support of SCHF and its donors plays a vital role in helping our teams deliver the best possible care to hundreds of patients and their families every day,” said Dr Joanne Ging, the Network’s Executive Director of Clinical Operations.

“While we faced added challenges from the COVID-19 pandemic in the past year, the day-to-day care of patients and families remained a top priority. The shift towards virtual care has been prominent across the health sector, with the Network taking the lead on paediatric virtual care for the state. The focus on a strong workforce and advanced medical equipment is now more important than ever.”

Clinical care highlights

Fellowship program creates front line leaders

Funding a young doctor on the front line to undertake a fellowship ensures the best possible care for young patients today, while also training a future leader to help thousands of children over the course of their career.

SCHF’s Fellowship program allows paediatric trainees to undertake the essential training required to become a specialist paediatrician in a selected field. In addition to providing specialist patient care, Fellows also train junior doctors and nurses, and conduct at least one innovative research project.

* Positions partly or fully funded by SCHF.

In the past year, we helped fund 21 Fellows across Sydney Children's Hospitals Network to support 14 paediatric specialist areas: oncology, cardiology, neurology, emergency, general surgery, sleep medicine, community child health, Aboriginal health, intensive care, anaesthetics, nephrology, clinical trials, simulation training and neonatology.

A new ambulance for critically ill babies and children

- 7 months in operation by end of FY21
- 187 retrieval missions for critically ill babies and children
- 22,512 kilometres travelled.

A new specialist ambulance fitted with advanced paediatric equipment was added to the fleet of the statewide Newborn and paediatric Emergency Transport Service (NETS), thanks to funding from Sargents Pies Charitable Foundation.

NETS is a specialist paediatric emergency service for the medical retrieval of critically ill newborns, infants and children up to 16 years old across NSW. This occurs when a baby or child needs intensive care that isn't available at the hospital they are being treated in, and when they are too ill for normal ambulance transfer.

In just the first seven months of operation, the new NETS Paediatric Ambulance travelled 22,512 kilometres to make 187 retrieval missions across NSW, including to Tamworth, Wollongong and Port Macquarie.

Building the children's hospitals of tomorrow

Plans to deliver state-of-the-art infrastructure with a focus on innovation, research and cutting-edge technology across the Network, resulted in the completion of Stage 1 of a major redevelopment program at The Children's Hospital at Westmead.

The new Central Acute Services Building, shared with Westmead Hospital, opened its doors in March 2021. It houses a new Children's Emergency Department and Children's Short Stay Unit, as well as a medical imaging satellite unit and pharmacy to support those services. SCHF has donated $5.2 million towards this transformation in health care for children in NSW thanks to major donations from the Wiggs Family, the Minton Family, James Fairfax and Sargents Pies Charitable Foundation.

Exciting redevelopment initiatives are continuing across the Network. Stage 1 of redevelopment at the Sydney Children's Hospital, Randwick will include the Children's Comprehensive Cancer Centre and a new Neurosciences Comprehensive Care and Research Centre. Stage 2 of the redevelopment at The Children's Hospital at Westmead will create world-class digital operating theatres equivalent in size to a football field, and an advanced statewide burns unit.

Specialist nursing and allied health positions

SCHF and our supporters funded 32 specialist nursing and allied health positions across the Network, including clinical nurse consultants, nurse educators and nurse specialists, social workers, occupational therapists and dietitians. People in these vital roles work across various departments, including emergency, Bear Cottage, neurology, oncology and child protection.

Better equipping front line workers

Doctors, nurses and allied health professionals rely on advanced medical equipment and technology to help deliver the best possible care for sick and injured kids. In FY21, our supporters helped us buy 775 individual pieces of equipment, from small essentials such as wheelchairs and diagnostic scopes, through to a smart operating theatre and an interventional radiology suite.

We funded bilevel positive airway pressure, or BiPAP, machines for the Grace Centre for Newborn Intensive Care and Sleep Medicine Service at The Children's Hospital at Westmead.

The Grace Centre is a specialist unit caring for more than 600 premature newborns, neonates and critically ill infants each year. These babies suffer from complex medical conditions, such as serious cardiac and surgical disorders. In the Grace Centre, the BiPAP machines ensure babies can be safely transitioned off invasive mechanical ventilation when it is time to leave the Centre, helping speed up a baby's discharge home by up to 10 days.

The Sleep Medicine Service cares for children experiencing breathing difficulties caused by respiratory, neuromuscular and cardiac conditions, as well as children with life-limiting conditions requiring palliative care. Without support, children's breathing problems from these illnesses can worsen during sleep and lead to poor health in the daytime. Treatment with non-invasive ventilation breathing support, given through a face/nose mask during sleep, corrects children's breathing problems to keep them healthy.

The machines were funded by generous donations from Humpty Dumpty Foundation, Montford Foundation, John Paul Foundation, Metasoft, and Honda Foundation.

Building on a generous gift in Will from the Late Alfred and Kaye Al-Rae Hynard in FY20 that helped upgrade more than 900 infusion pumps across eight care units at The Children's Hospital at Westmead, community support helped SCHF continue the upgrade of the fleet of smart pumps with an additional 710 advanced infusion pumps funded at Sydney Children's Hospital Randwick. These pumps are critical in administering medication and fluids intravenously for pain relief, sedation, chemotherapy, hydration, nutrition and to replace fluids such as blood. The new pumps are supported by advanced technology with intuitive settings, enhanced monitoring, improved integration with the Hospital's IT system, and quick history access. Upgrading the fleet of smart pumps is a great example of how SCHF funding can ensure the use of best evidence and modern technology for the safest and best quality care for the sickest children of New South Wales.

World-class health care at home with virtual hospital

If there's one thing COVID-19 has taught us, it's how we can adapt to different situations. With lockdowns and restrictions, it's been more important than ever to ensure families can access medical services, even when they're not physically at a hospital. This is where telehealth or virtual services have become a vital part of treatment plans for many families.

The introduction of the virtualKIDS service – Australia's first paediatric-specific virtual hospital – is an exciting new initiative from the Network. SCHF is proud to support this initiative thanks to generous donations from the Curing Homesickness Alliance, through its partnership with Coles, and along with thousands of donations from individuals and community supporters who chose to donate to the highest-priority funding needs of the Network.

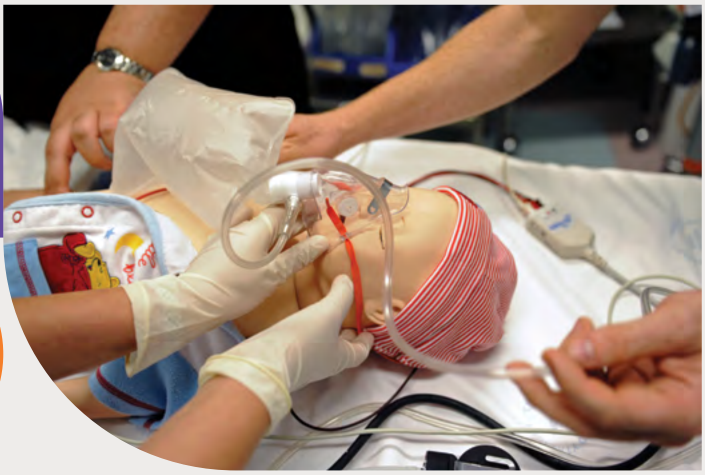
This innovative program will ensure equitable access to specialist care for chronically ill patients and their families, regardless of where they live. virtualKIDS will expand the current telehealth program to provide families with the additional benefits of virtual care, including 24-hour access to nursing support, expert clinical care at home, greater collaboration with local teams, and education and assistance for carers.

This means patients can receive virtual care in the comfort of their own home. Alternatively, they can stay in their local hospital where they'll be closer to support networks, allowing parents to travel to and from home as they need.

The virtualKIDS model of care was developed from initial funding from the NSW Health Virtual Care Accelerator program, a multi-agency partnership led by eHealth NSW and the Agency for Clinical Innovation.

Efforts are currently focused on the COVID-19 response, with the COVID-19 service fully funded by NSW Health. The next phase of the virtualKIDS service will see the rollout of virtual services to children with respiratory conditions, using funding from NSW Health's Virtual Care Accelerator and SCHF.

Right: Simulated scenarios allow front line staff to practice emergency drills in a secure environment.



Clinical care spotlight

Simulation training prepares teams for emergencies

- 38,191 Emergency Department presentations at Randwick last year
- 10 Simulation Program education courses each year
- 2,825 staff members, students and health professionals trained since launch
- 46 new simulation educators developed across the Network, NSW and internationally.

The Emergency Department (ED) is one of the busiest departments at the Sydney Children's Hospital, Randwick, with a specialist team looking after more than 38,000 critically ill or injured children each year. In the ED, every second counts. To ensure the ED team continues to deliver safe, high-quality emergency care, the ED Simulation Program provides a comprehensive education to support the development of key knowledge, skills and attitudes.

The ED Simulation Program involves the delivery of skills stations, workshops and rehearsal of real-life procedures using manikins, actors and smart technology. Scenarios are designed to create 'simulated' situations, to allow the practice of emergency drills without risk to children. Training also covers key skills vital for providing quality care, such as teamwork, leadership and handling difficult conversations with staff and families. Simulation practice allows front line staff to learn and practice in a secure environment, further developing the skills and confidence needed to manage real-life situations.

Since the start of the ED Simulation Program in 2015, it has delivered intensive, life-saving training to 2,825 people including staff members, students and external health professionals. Curriculum has been developed for more than 10 courses, which are held numerous times each year. The ED Simulation Program team has established international collaborations and shared learnings with groups locally and overseas. Through their collaboration with the Network's Kids Simulation Australia, Boston Children's Hospital in the US, and Starship in New Zealand, they have delivered an annual three-day Simulation Faculty Development Program, helping develop more than 46 additional simulation educators across the Network, NSW and internationally.

With the proven success of the program and further funding in the past year, the team have expanded the Simulation Program to other critical care areas such as the Intensive Care Unit, Paediatric Anaesthetic Department, operating theatres and the Recovery Ward.

"Ideally, we see the Simulation Program as a vehicle that can support work and learning across all areas to further reduce the number of risks to patients, families and staff, and improve the quality and safety of care we provide," said ED Nurse Educator and Nurse Simulation Lead, Jane Cichero.

Kai's story

Shortly after the birth of Kai and his twin brother, Kai experienced a major seizure that resulted in significant brain injury. Kai, 15, has epilepsy, global developmental delay and vision impairment due to his severe cerebral palsy. His condition means Kai mainly communicates through noises and actions, and moves around with the help of his wheelchair.

For the families of children with life-limiting conditions, Bear Cottage is the perfect home away from home, providing love, support, care and respite. It's a special place for parents like Yuki and Scott where they can recharge as a family, make memories and connect with other families, while meeting the complex needs of their beloved son, Kai.

Yuki says: "The staff at Bear Cottage are amazing and basically an extension of our own family. They care for Kai like he's their own and spend time with him playing his favourite music, massaging his feet and hands."

Patient experiences

Creating positive patient and family experiences

SCHF funding FY21

- **14** Child Life, Music and Art Therapy positions*
- **2** Art Program positions*
- **2** chefs for Bear Cottage families
- **3** new or revitalised patient and family spaces
- **4** specialised patient and family programs
- **2** major technology projects
- **$2.192 million** in goods or services donated for positive experiences.

Delivering extraordinary health care extends beyond the medical care of a child. It also means supporting positive patient experiences for children and their families.

Thanks to your ongoing commitment, SCHF was able to fund key allied health positions, programs, spaces and technology to support children and young people, delivering relief and smiles during their most difficult times.

“Thanks to SCHF and its generous supporters, we have been able to deliver on a range of positive patient and family initiatives,” said Chrissy Ceely, Director of Safety, Quality and Governance at the Network. “These include providing laptops and data packages to help vulnerable children and families access virtual care during COVID-19, and supporting Child Life, Music and Art Therapy positions to help children cope with hospitalisations.

“We have also helped children and families celebrate special activities such as treatment milestones and birthdays, and important events like Carers Week, Christmas, Hanukkah, Chinese New Year and Ramadan.”

Patient experiences highlights

Creating calm and healing spaces

Children and families in hospital need close and easy access to welcoming outdoor spaces for much-needed respite from long periods spent in wards or attending appointments.

In FY21, SCHF funded the renewal of the Aboriginal Children’s Memorial Garden at Westmead (see page 29) and transformed the Sunny’s Cafe courtyard at Randwick with more than $340,000 worth of donated goods and services from 25 companies including Vittoria Food & Beverage and Horizon Built.

---

* Fully or partly funded positions.

Virtual care for vulnerable children

The COVID-19 pandemic has affected the entire community and challenged the way we work. To help protect vulnerable and high-risk patients and families from COVID-19, teams across the Network adopted telehealth or virtual care so families could receive care from the comfort of their home by attending consultations through a web-based video platform.

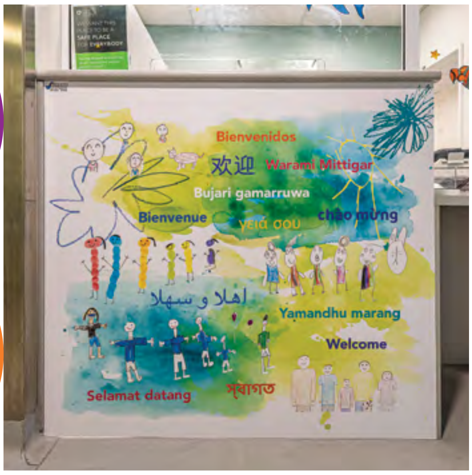
The Network's use of virtual care has increased 2,128% in the past 18 months, saving patients and their families 5.6 million kilometres in travel. During the pandemic, 80% of community child health appointments took place via telehealth. However, there were also vulnerable children who could not afford the technology needed to continue care virtually.

To ensure equitable access, SCHF helped secure generous financial support for Healthcare at Home Technology Packages from the NAB Foundation, providing 40 laptops to vulnerable families. We also worked with Optus to secure 1,114 SIM cards (with a total value of $174,600) from the company's Donate Your Data initiative, which invites Optus customers to donate their unused data allowance to people who need it the most. The cards were distributed across the Network, as well as via Aboriginal Health Services and Local Health Districts across the state.

Rallying support during essential COVID-19 restrictions

Patients, families and staff members were challenged by daily changes to health advice and essential visitor restrictions. SCHF and our wonderful supporters rallied to support patients, families and front line staff during the pandemic.

Our Movement of Many swung into action, with help coming from individuals and large corporations. For example, Costco donated toys and clothing, and store gift cards to purchase items for wards, such as coffee machines, coffee, snacks and lunches. Costco also raised $67,000 by converting registration fees from its cancelled fundraising golf event into donations. Hasbro donated a large number of toys, and pledged vital financial support across the Network for the Child Life Therapy Departments. Long-term supporter Lindt also put smiles on faces with chocolate gifts, bringing the company's lifetime value of support to more than $300,000.



A long-awaited beach path for Bear Cottage

After 18 years, we finally fulfilled the long-held dream of creating a wheelchair-accessible path to the beach for children with a terminal illness receiving care at Bear Cottage in Manly.

In 2002, the Tony McCullough Foundation donated funds for a wheelchair ramp to be built in Bear Cottage's back garden. Since then, the foundation has worked alongside a determined group of supporters to bring this dream to life. In September 2020, with help from the Sydney Catholic Archdiocese, local architect Vivianne Marston, and long-term supporter John Holland Group CPB Ghella, Bear Cottage officially opened the new, longer pathway through the St Patrick's Estate.

Bear Cottage mum Jennifer and son Alexander were the first to enjoy the path once Kerrie McCullough from the Tony McCullough Foundation officially opened the path by cutting a ribbon.

The pathway is named McCullough Way. It will enable the 2,702 children and family members who stay at Bear Cottage each year to more easily enjoy the nearby beach.

Above left: Bear Cottage mum Jennifer and son Alexander were the first to enjoy the new path to the beach. Above right: Using art to create welcoming spaces within the hospital is a key part of the SCHF Art Program.

Providing welcoming spaces through art

- 636 patient interactions
- 172 workshops
- 26 exhibitions.

COVID-19 restrictions didn't stop SCHF's Art Program team from delivering their popular activities to patients, parents and staff at Sydney Children's Hospital, Randwick. By adopting COVID-19-safe protocols and embracing virtual technology, Timothy and Rose from the Art Program continued to brighten the corridors and wards, and deliver custom virtual art programs for kids in hospital.

In FY21, a beautiful mural was created at the Intensive Care Unit (ICU). Children in ICU are often in a critical state with life-threatening illnesses and injuries. To help create a more welcoming space and provide comfort for patients and families, SCHF's Art Program enlisted illustrator Cate James to create the mural from patients' drawings of their families and loved ones, along with a welcome sign in 11 different languages. This project was funded by long-term ICU donor Sell and Parker.

Patient experience spotlight

Child Life Therapy and Music Therapy: a creative approach to caring for kids in hospital

- 13 Child Life Therapy and Music Therapy positions*
- 12,348 hours of Child Life Therapy, Music Therapy and Art Therapy sessions
- 4,776 occasions of care delivered to children across the hospitals at Westmead and Randwick
- Specialist Child Life Therapy and Music Therapy positions at Bear Cottage available 7 days a week.

Play, music, education and self-expression activities are central to the Child Life and Music Therapy team's work to minimise stress and anxiety, and help children and young people cope with their illness and hospitalisation. SCHF and its supporters are proud to help fund 13 Child Life Therapy and Music Therapy positions across the Westmead and Randwick hospitals, and Bear Cottage.

Child Life Therapists and Music Therapists use evidence-based play and music interventions to create positive experiences, so children and young people in hospital feel confident, empowered and supported to cope with their illness and hospitalisation. This approach was used to help four-year-old Laili during her stay at hospital.

Laili was diagnosed with a rare brain tumour, called craniopharyngioma, which causes cysts to form. These cysts put pressure on Laili's brain, affecting her appetite, the sight in one eye and her ability to walk. Laili's mum, Nicole, remembered how a visit from a music therapist during Laili's first stay in the ICU at Sydney Children's Hospital, Randwick, significantly improved Laili's quality of life.

"Her first music therapy session was so powerfully uplifting. It reminded me that my daughter is so truly special, inspirational, strong and brave, and would fight the battle in front of her and that ahead. She changed as a patient that day. She was far more content and definitely a little less fiercely opposed to the nursing staff doing their two-hourly observations," said Nicole.

Laili has endured seven brain surgeries, multiple MRIs and five weeks of radiotherapy treatment. She is recovering well and getting stronger every day. Her family couldn't be more thankful for the Music Therapy team.

"As a family, we love music and play it often when we cook, study and play at home. Music therapy brought a piece of home to the hospital for Laili, which helps distract her but also energises her to keep fighting this battle. Having music therapists at the hospital has improved and truly changed our lives," said Nicole.

Many Foundation supporters helped SCHF fund Play and Music Therapy positions during FY21. The funds came from one-off donations, gifts in Wills, and major supporters such as the Australian Children's Music Foundation, Camp Quality, Carnival Cruise Lines, Curing Homesickness with Coles, George and Janet Parker Memorial Trust, Hasbro, Hyundai Help for Kids, Ottomin Foundation, Sydney Airport, Tour de Cure and University of NSW's ARC Phil team.

* Fully or partly funded positions.

Laili's story

Laili, 4, was diagnosed with a rare brain tumour, called craniopharyngioma, which causes cysts to form. These cysts put pressure on Laili's brain affecting her appetite, sight and ability to walk. Laili has endured seven brain surgeries, multiple MRIs and five weeks of radiotherapy.

Music therapy helped to bring a piece of home to the hospital to help distract and energise Laili during her treatment.

Priority funding focus: Aboriginal Health Unit

Partnering for change in Aboriginal child health

Aboriginal children and young people across the Network in FY21

11,319 outpatient occasions of service

4,299 admissions.

SCHF support in FY21

- **4** positions funded to improve access to health services*
- **1** outdoor space upgraded
- **3** specialist programs supported.

With your support, SCHF has been able to fund vital positions and programs to help the Aboriginal Health Unit make a difference in the lives of Aboriginal children and young people and their families.

The Network's Aboriginal Health team is turning around health disparities through research, advocacy, leadership and high-quality services, ensuring safe, reliable and evidence-based care. The Network has made significant progress against its *Aboriginal Strategic Health Plan 2018–2021*, and SCHF is proud to be part of this move to close the gap in Aboriginal child and family health.

Conjoint Professor Karen Zwi, Head of Community Child Health at Sydney Children's Hospital, Randwick, and Director of Priority Populations at the Network, said, "The advantage of addressing Aboriginal health as part of a children's hospital network is that we have a wide range of services and, therefore, an opportunity to intervene early in the life course. This is likely to alter a child's health and affect the rest of their life. A reduction in chronic disease and mental health conditions means improved school performance, better job opportunities and reversing the cycle of disadvantage."

*Positions were fully or partly funded by SCHF and our supporters.

Aboriginal Health Unit highlights

Supporting the creation of safe, healing spaces

Taking a child to hospital can be stressful for any parent, but it can be especially confronting for Aboriginal families because of Australia's history of forcible removal of children from their mothers when they went into hospital. Creating healing and welcoming spaces is critical for Aboriginal children and their families to feel safe when attending the Network's facilities.

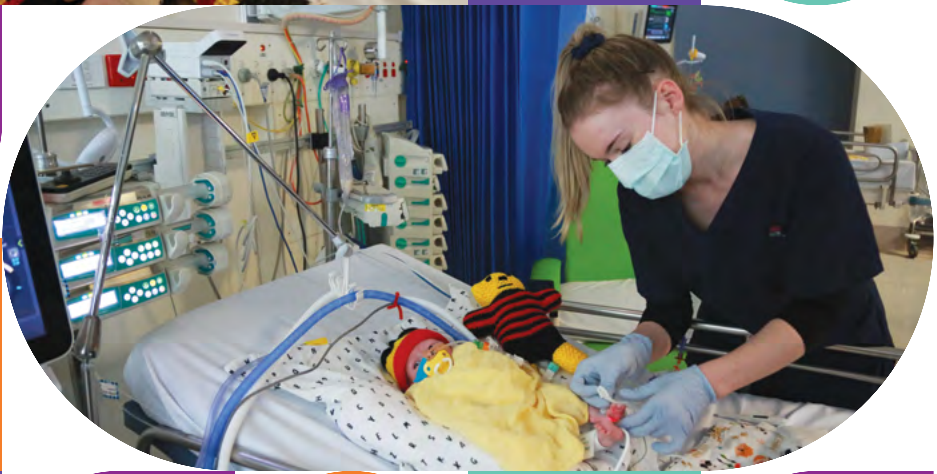
One of the aims of the Aboriginal Health Strategic Program is to create culturally appropriate, safe spaces, with Acknowledgement of Country signage to welcome Aboriginal children and their families.

As part of this approach, SCHF supported the facelift of the Aboriginal Children's Memorial Garden at The Children's Hospital at Westmead, to create a healing reconciliation space for patients, families and staff, and to memorialise those children who have passed away or who were removed from their families.

The refurbished garden was officially relaunched on National Close the Gap Day in March 2021. It includes a boulder from Dharruk and Gundungurra land in the Blue Mountains, along with Australian native plants, and a plaque acknowledging the Burramattagal people, the Traditional Custodians of the Darug Nation land on which the hospital stands. A poem from Dharruk Nation Elder Aunt Edna Watson is displayed alongside a formal Apology from the hospital for the part it played in the removal of Aboriginal children.

Brinae, mum of patient Durakai, described the importance of the garden after doctors told her they couldn't guarantee Durakai's recovery.

"I collapsed in this park crying alone because I told everyone I needed space," Brinae said. "I asked my grandmother in the Dreamtime to help me and give me answers. The next morning, I had a message from my cousin that a friend, who can speak to people in the Dreamtime, had told her that my grandmother had shared a message that Durakai's spirit hadn't left his body – he was still very much with us. A few weeks later, I found out this park was the Aboriginal Children's Memorial Garden."



Aboriginal health trainees improving the care of their mob

Natasha Larter, Seaneen Wallace and Larissa Karpish are paving the way for Aboriginal people and their children through a unique health training program that uses both their lived experience and academic knowledge.

The Aboriginal Public Health Trainees, co-funded by SCHF and NSW Health, deliver high-quality healthcare programs for Aboriginal children and young people and create future Aboriginal health leaders. The three-year training program comprises part-time study towards a Master of Public Health, combined with a series of work placements in the population health services of NSW Health.

Natasha, Seaneen and Larissa have been involved in a diverse range of activities including contributing towards the development of the Aboriginal Health Strategic Plan, analysing the Aboriginal Health Live data dashboard to monitor the Network's performance against critical health indicators, facilitating school-based screening programs, undertaking research and publishing national vaccination coverage reports. Seaneen and Larissa also assisted with the localised COVID-19 pandemic response for Aboriginal children and their families, including developing culturally appropriate resources and setting up an Aboriginal vaccination clinic.

The trainees are also involved in key Aboriginal health research projects. In her final year as a trainee, Natasha worked on summarising the findings from a decade of research into the health status of urban Aboriginal children and their access to specialist outreach services, including a local clinic the team co-developed with the community. Natasha presented preliminary findings at a major health conference in FY21. She highlighted how intensive local services result in promising reductions in maternal smoking, premature delivery and low birth weights, earlier access to developmental and learning services, and improved health and wellbeing.

Natasha has secured a permanent role within the Network as the first ever Aboriginal Health Outcomes and Equity Project Manager, where she helps to ensure the constant delivery of high-quality, equitable services to Aboriginal children.

SCHF has committed to continue co-funding three Aboriginal Public Health Trainees at any one time by supporting the appointment of a new trainee each year to commence the three-year program.

Fellow supports Aboriginal health services and research

The Aboriginal Health Fellow position is co-funded by the Australian Government and SCHF to allow a paediatrician to specialise in Aboriginal child health.

Fellow for FY21 Dr Anna van Beek works with the Aboriginal Health team, helping to deliver a large suite of services and programs at the La Perouse Aboriginal Community Health Centre, where engagement with the local community has been highly successful.

Dr van Beek also offers comprehensive paediatric assessments at the Aboriginal Child Health Clinic, where she works alongside the team's social worker, early childhood nurse, Aboriginal health workers, speech pathologists and external partners to run monthly case conferences and ensure children and carers with multiple needs receive the right support. The accessible outreach programs have improved the early detection of speech and developmental issues, chronic disease management, injury awareness and hospital avoidance.

Early identification and services to reduce hearing loss

Hearing loss is 12 times higher in Aboriginal Australians compared to non-Aboriginal Australians. Thanks to an amazing legacy from the Late Lois Edwina Sharp, SCHF were able to help fund a project with Hearing EAr health and Language Services (HEALS) to help end avoidable deafness through prevention, early detection and improved access to services for middle ear infection and hearing loss among Aboriginal children. The Late Ms Sharps' generosity has created a profound legacy and lasting gift that ensures the best quality care for this vulnerable community. The funding supports ear, nose and throat surgery and speech therapy services for children identified by their local Aboriginal Community Controlled Health Organisation. In FY21, the project's structure, processes and systems were established, working towards a service launch in late 2021.

Above: Ngala Nanga Mai pARentT Group Program brings Aboriginal mums and their children together through art making to support their health, social, cultural and emotional wellbeing.

Aboriginal health spotlight

Healing and health through art-making program for Aboriginal mums

- 28 Aboriginal mothers and their children under five attended each week on average*
- 7+ positive outcomes delivered through the program, including improved social connection and personal empowerment; access to child health services; parenting skills; education and career opportunities; and child health information
- 2 weekly online sessions delivered for mums and their kids during essential COVID-19 restrictions.

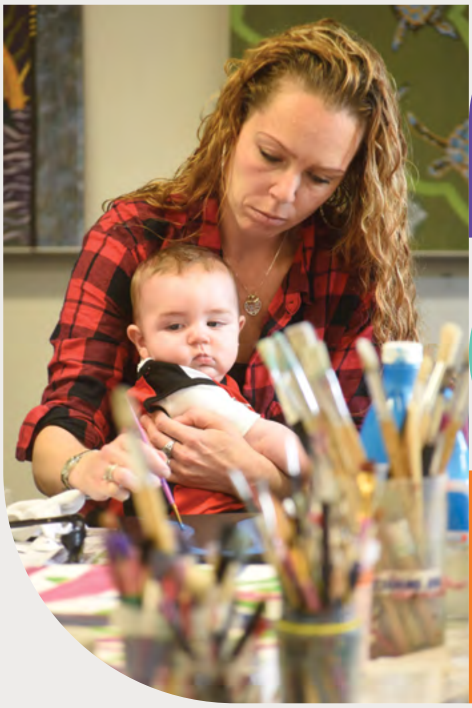
Culture is an important aspect of Aboriginal health and wellbeing. The Network's Ngala Nanga Mai pARenT Group Program delivers key services through cultural and art-making sessions, helping to strengthen a sense of identity, belonging and resilience.

*Prior to COVID-19.

Co-developed and named by local Aboriginal mums, Ngala Nanga Mai (which means 'We Dream') was created in 2009 after an Aboriginal Health Education Officer at Sydney Children's Hospital, Randwick found that local Aboriginal mothers felt isolated from social support and child health services.

Run by the Community Health department of Sydney Children's Hospital, Randwick, Ngala Nanga Mai is a multi-award-winning program delivered at the La Perouse Aboriginal Community Health Centre. It brings Aboriginal mums and their children together through art making, helping to support their health, social, cultural and emotional wellbeing.

Program Manager for Arts in Health and Community Development, Michelle Jersky, said, 'Previous evaluations have shown that Ngala Nanga Mai participants have improved use of health services, improved mental health, new aspirations for further education and employment, enhanced resilience and a keenness to give back to their community.'



SCHF is proud to be a longstanding supporter of Ngala Nanga Mai, continuing to work with our supporters to fund key elements of the program such as the provision of art-making materials and childcare services.

Building on the success of the Ngala Nanga Mai program at Sydney Children's Hospital, Randwick, the Community Child Health team is evaluating opportunities to expand the program by using the model to co-develop a program at a new site. SCHF is working closely with the team to identify potential supporters to fund this project.

Improved access to health services

Ngala Nanga Mai is run by an Aboriginal Health Worker with support from a Program Manager, who both work closely with early childhood nurses, other Aboriginal health workers, speech pathologists, social workers, and paediatricians including an SCHF-funded Fellow. Healthcare workers interact with the children during the art-making sessions to conduct informal health assessments, flagging issues with mums to coordinate follow-up care in the health clinic located within the La Perouse Aboriginal Community Health Centre. They also provide mother-and-child health talks for mums while they work on their art. This increases the mums' understanding of key health issues and encourages them to access services when needed.

Above left: Ngala Nanga Mai delivers key services through cultural and art-making sessions to help strengthen a sense of identity, belonging and resilience. Above right: During art-making sessions, healthcare workers flag issues with mums to coordinate follow up care in the child health clinic.

Below left: Ngala Nanga Mai fosters improved social connection for local Aboriginal mothers.
Below right: Improved access to child health services is just one of the positive outcomes of Ngala Nanga Mai.

Childcare fosters healthy development

On-site childcare is provided at the Community Health Centre to support mums and their children. Some of the mums are unable to access affordable formal childcare services, so Ngala Nanga Mai gives their children crucial development opportunities. Children gain critical physical, language, social and cognitive skills through play. Qualified childcare workers also teach mums about attachment and positive parenting techniques.

Education and career opportunities

The childcare support also allows participating mums to access education and career development opportunities. These include exploring potential education and career pathways, resume and application support for jobs and educational courses, and on-site tutoring services provided by the Indigenous Tutorial Assistance Scheme run by the TAFE Digital Aboriginal Education Training Unit.

Contact us

Connect

Visit our website at www.schf.org.au for more ideas about how you can get involved.

Connect with us on social media to be inspired every day by stories and news.

Our contact details

Phone

1800 770 122

Email

info@schf.org.au

Mailing address

Darug Country
Locked Bag 9002
Westmead NSW 2145
Australia

Registered office

Gadigal Country
Level 12, 680 George Street,
Sydney NSW 2000
Australia

Registered charity

Sydney Children's Hospitals Foundation is an independent Health Promotion charity and registered as an Item 1 Deductible Gift Recipient (DGR) by the Australian Tax Office.

ABN 72 003 073 185

Donate

With your help we can go all in to change children's health for all kids, always. Please use this QR code if you would like to make an online donation today.

We are the Movement of Many, different people from all walks of life.

With one foot on the front line, and one in the future, we’re here for those who deserve our all.

To help all sick kids, no matter where, no matter what.

All in ♥ for kids’ health.

All in for
kids' health

SCHF
Sydney
Children's
Hospitals
Foundation