

Impact Report

2022



All in for kids' health.

We are the Movement of Many, different people from all walks of life. With one foot at 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.

Acknowledgment 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 close the gap to achieve equality in health and life expectancy for Aboriginal and Torres Strait Islander peoples.

Contents



2

Purpose, Vision, Mission



6

Helping sick kids and their families



10

Research



40

Priority funding focus:
Mental Health

4

From Sydney Children's Hospitals Foundation

7

How we're changing children's health

5

From Sydney Children's Hospitals Network

20

Clinical Care

30

Patient Experience

Purpose, Vision and Mission



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 healthcare, when and where they need it



158,000 kids

across NSW treated by the Sydney Children's Hospitals Network last year with potentially millions of children across the world benefitting from research

1 network

The Children's Hospital at Westmead, Sydney Children's Hospital at Randwick, Bear Cottage, Kids Research, NETS

1 foundation

Funding:
Ground-breaking research
Excellent clinical care
Positive patient and family experiences

70,000 donors

Changemakers for childhealth

From Sydney Children's Hospitals Foundation



With one foot at the front line and one in the future of kids' health, Sydney Children's Hospitals Foundation (SCHF) is here for those that need our all. That's what we continue to strive for, helping to provide all children with access to the best possible healthcare, whenever and wherever they need it.

Sick kids want nothing more than to experience a normal childhood. Instead of doctor's appointments, they want to be on the playground; instead of hospital stays they want to be at sleepovers, and instead of experiencing things for the last time, they should be going through many more firsts. Sick kids are extraordinary, but what they and their families long for are just the ordinary days that many of us take for granted.

What we do together for kids' health is truly extraordinary. As a Movement of Many, fighting for the health and wellbeing of all children in this ever-changing world, I cannot thank you enough. Whether you attend our events, participate in personal challenges, volunteer, or donate what you can, every contribution helps to create revolutionary change in the lives of all children.

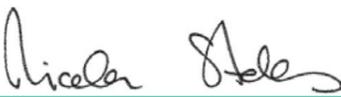
This year, with your unwavering support, we raised an extraordinary \$76.6 million to go to the front line of children's healthcare. This remarkable amount allowed us to donate \$39.1 million to help children and families receiving care across the Sydney Children's Hospitals Network and \$1.1 million to our Curing Homesickness partners across Australia. This funding fully or partially supported 196 staff, 11 research projects, 3 clinical building and refurbishment projects, 97 pieces of equipment, 21 programs, and

other immediate and future research, clinical excellence and patient experience initiatives that will ensure kids get the best care today and elevate the outcomes of tomorrow.

While I reflect on what these achievements mean for me as CEO, my own feelings seem insignificant when I know what this figure means for the children we serve. It gives families hope that a breakthrough is one step closer, it gives healthcare professionals hope for new treatment options and equipment, and it gives sick kids hope that one day soon they can get back to the lives they love.

On that note, I am thrilled to present the 2022 Impact Report; where we look back at what we've achieved so far and look ahead to the positive impact those achievements will have on the future. As this report marks the end of my tenure as CEO at SCHF, I am so honoured that it ended on such a wonderfully high note.

I hope that reading this report and reflecting on what we've been able to accomplish, together, for all sick kids, makes you just as proud as I am.


Nicola Stokes

Chief Executive Officer
Sydney Children's Hospitals Foundation

From Sydney Children's Hospitals Network



Delivering world-class healthcare to children and young people relies on many partnerships – partnerships with our patients and their families, with Sydney Children's Hospitals Network (SCHN) clinical, allied health and community care colleagues, with the people we serve and importantly with the donor communities who so generously support us all.

Working together as a team with our donor community, we are able to make a difference to the lives of so many in our care.

Through this generous support, we can continue to invest in the delivery of state-of-the-art technology to provide enhancements to our services, discover innovative treatments and find cures through world-leading research. This support helps children and young people have access to the best clinical care.

We are continually evolving the way we work and deliver services to make progress in healthcare. This has been supported by donors with capital investment in our facilities, additional allied health services, enabling our teams to undertake ground breaking research, enhancing our workforce and digital capabilities to support virtual care which keeps children and families together and provides care close to home where possible.

Healthcare workers have encountered many challenges from the COVID-19 pandemic and have continued to respond to these challenges each and every day. Across the Network, staff have been flexible and adaptable and worked tirelessly through these changes. Knowing the donor community is there to acknowledge, support and enhance the care they provide is invaluable.

I am proud to work hand in hand with the Foundation with our shared mission to help children live their healthiest lives, both now and into the future.

On behalf of the patients, families and staff of Sydney Children's Hospitals Network – thank you.


Cathryn Cox

Chief Executive
Sydney Children's Hospitals Network

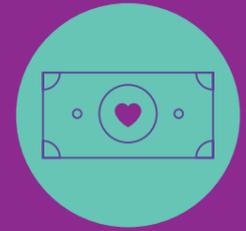
Helping sick kids and their families

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 change children's health across Australia and the world.



How we're changing children's health

Thanks to your ongoing support, we donated \$40,226,553 towards research, clinical care and patient experiences.



Your vital donations help to prevent and manage childhood illness or injury, with a focus on kids and families receiving treatment or care from services provided by Sydney Children's Hospitals Network (SCHN). To help deliver further impact for SCHN's staff and patients, in partnership with our Movement of Many, we were able to provide an additional \$4,996,711 in gift-in-kind support.

Clinical Care

\$23,887,019



Research

\$13,176,859



Patient Experience

\$3,162,675





Patient Story

Making Mia’s cancer journey more bearable

Mia was a healthy and active 12-year-old who loved karate, gymnastics and athletics. But all that changed when she discovered a painful lump on her neck.

When CT and MRI scans failed to identify the cause of Mia’s lump, she was transferred to Sydney Children’s Hospital, Randwick for a biopsy.

She then had an agonising wait for the results.

When Mia’s mum, Mary, got a call from the hospital a week and a half later, the news was heartbreaking. Mia had been diagnosed with Ewing sarcoma, a rare and life-threatening cancer of the bones and soft tissue around the bones.

“Telling Mia was the hardest thing I’ve ever had to do as a parent,” Mary remembers.

The next day, Mia was back at the hospital to begin her treatment, which involved regular chemotherapy and radiotherapy. Mary estimates Mia spent 8 to 9 of the next 12 months in hospital either receiving treatment or with complications like high temperatures.

She says the hospital team were an incredible source of strength and support on what was a very long and difficult journey.

“The nurses and doctors were so comforting and gentle. They were the family we never knew we needed. They were really good at listening to Mia and what she wanted. Wherever possible they made sure she had a say in what was happening to her.

“They always talked to her, never over her, about what was happening, and they understood her mental health was important. They truly are angels on earth.”

Mia says she was grateful for the opportunity to get involved in things like art and music therapy to pass the time and focus on something positive.

SCHF funded 22 Child Life, Music and Art Therapy positions at the Network across oncology, emergency, gastroenterology, mental health, and at Bear Cottage.*

*including part time and full time positions

Research

Innovative research to transform child health

Across the Network in FY22



600+
research staff and students



821
peer-reviewed publications



55
research units working on hundreds of different childhood diseases

The research you help SCHF fund supports children with a wide range of childhood conditions and diseases, such as childhood cancers, cystic fibrosis, cerebral palsy, spinal muscular atrophy, encephalitis, osteogenesis imperfecta, metabolic conditions, COVID-19, and more.

Improving children's health today and into the future is a major challenge that no single person or group can solve on their own. Delivering world-class child health requires working within an 'ecosystem' around the child. Patients, families, healthcare staff, researchers, educators, and organisations are interconnected and play important roles in delivering positive outcomes.

Kids Research Director Paula Bray said: "The Sydney Children's Hospitals Network (SCHN) is optimally positioned to achieve our ambition of delivering research enabled care; being the largest paediatric care provider nationally. It is through our research that we strive to learn and deliver the best possible care for our young patients and their families. The strong success and research impact already achieved is testament to the strong partnership with the Sydney

Children's Hospitals Foundation (SCHF). The critical philanthropic investment in research enables an ecosystem where everyone works together to deliver personalised, intuitive and integrated care to patients and their families. Through the generous support of the SCHF, we have unlocked potential through providing the ability to support outstanding researchers, support lifesaving clinical trials, invest in excellent new ideas and provide the necessary infrastructure and environment for our expert hospital teams and researchers. The researchers at SCHN are at the forefront of their fields, delivering ground-breaking research projects and leading globally. Above all else, our research is planned and delivered with the child and family at the centre of everything we do, every day. Thanks to all the SCHF donors, SCHN are in a leading position to transform the lives of children and their families."

SCHF Funding in FY22



\$13.18 million
donated for child health research



80
researchers and key support positions*



3
PhD scholarships for emerging researchers



11
research projects including 5 Greenlight Pilot projects

*fully or partly funded by Sydney Children's Hospitals Foundation

Funding PhD Scholarships to support emerging researchers

Children with cystic fibrosis (CF) are prone to repeated, life-threatening, bacterial lung infections that can be difficult to treat.

A re-emerging area of treatment uses bacteriophages, a kind of virus, to attack and kill drug-resistant bacteria. To advance knowledge in bacteriophage therapy, SCHF has funded a PhD Scholarship to respiratory and sleep paediatrician Dr Jagdev Singh at The Children's Hospital at Westmead. Dr Singh and team plan to identify suitable bacteriophages to open new frontiers for treating antibiotic-resistant infections.

The vital funds for this PhD Scholarship were raised by The Team Simon Foundation for Cystic Fibrosis, established by parents Harry and Teresa Bazouni to raise awareness and funds for CF in the name of their son Simon, who lives with this genetic condition.

\$50 million+ return to Australia

For every \$1 invested in Australian medical research, there's an estimated return of \$3.90 benefits to the population¹. With your support, in FY22 we donated \$13.18 million to research, so you helped us create an amazing \$50 million+ return to the Australian community.

¹ Association of Australian Medical Research Institutes, Economic Impact of Medical Research in Australia, August 2018, KPMG.



Dr Jagdev Singh

Greenlight: innovative pilot to fund research proves successful



5
Greenlight projects in FY22



\$1.04 million
funding Greenlight Pilot projects in FY22



68%
agree Greenlight has stimulated innovation in paediatric research*

*Respondents to Greenlight pilot evaluation

In FY22, SCHF completed delivery of the pilot Greenlight Program. Since the program commenced in 2020, our generous donors have helped us raise funds for 19 research projects. This innovative model of funding research took inspiration from the movie industry, providing researchers with specialist training from the Compton School to pitch potentially game-changing research projects directly to philanthropists.

“Greenlight brought many innovative ideas to light and highlighted the depth of talent across the Sydney Children’s Hospitals Network. It created new opportunities for our donors to be more connected to research and gave us unique insights into the vital role of philanthropy in delivering long-term impact,” said Greenlight Program Director Yvonne Stewart.

Some of the Greenlight projects funded in FY22 include the OA Kids Story Book (page 35) and the following:

Gene therapy to cure brittle bone disease

Osteogenesis imperfecta or “brittle bone disease” is a genetic condition for which there is no cure. It creates fragile bones in children, resulting in frequent fractures. To address this, Associate Professor Aaron Schindeler and his team have created the first bone-targeted gene therapy vector able to specifically modify cells in the skeleton. A significant gift from the Teicke Family Foundation and a matched gift from SCHF allowed preclinical studies to demonstrate “proof of principle” of this new technology. Eventually, the team are hopeful they can create a lifetime cure for brittle bone disease.



Associate Professor Aaron Schindeler

SCHF Movement of Many matches innovative research funding

Generous donations to SCHF for the highest or most urgent priority needs provided vital matched funding to support many of the innovative research projects in the Greenlight Program. These vital funds come from individual donations, gifts in Wills, corporate donations and people raising funds with donations from their family, friends and community.

When food is your biggest hurdle

One in 10,000 children in Australia are born with the inability to process and use fat, carbohydrates, or protein, and need special nutrition supplements to participate in physical activity and optimise their medical management. Dr Kaustuv Bhattacharya, Kiera Batten and Associate Professor Carolyn Broderick have combined their expertise in a new approach to explore novel supplements and develop more effective treatment of these rare conditions. Their aim is to reduce preventable hospitalisations and allow kids to enjoy a better quality of life. This project was generously funded by Arthur Laundry, Bennelong Australian Equity Partners (BAEP), and a matched gift from SCHF.



Left to right: Associate Professor Carolyn Broderick, Kiera Batten, Dr. Kaustuv Bhattacharya

Breaking the cycle of disadvantage so all kids with CP can thrive

Cerebral palsy (CP) is the most common physical disability in childhood, affecting around 1 in 700 babies born in Australia. Children with CP have very different outcomes depending on where they live, with children growing up in poorer neighbourhoods experiencing reduced access to care and greater difficulties. Unmet social needs such as financial difficulties, poor housing and lack of transport make it harder for families to access the health and social care services they need to thrive. Associate Professor Sue Woolfenden and Dr Katarina Ostojic are leading the EPIC-CP project to address these inequalities by developing an integrated pathway to help clinicians routinely identify unmet social needs and link families to the social care they need. This pathway has been codesigned with children and families from a range of backgrounds and their health professionals and will be tested for feasibility in 2023 at the 3 NSW children’s hospitals. This project is funded by Cerebral Palsy Alliance Research Foundation with matched funding from SCHF.

With funds raised at the sunSCHine event and funds from individual donations, fundraising and bequests, SCHF provided funding to support a trial of an integrated care model called **Strengthening Care for Children (SC4C) trial.**

Transforming the lives of children with genetic diseases



2

senior Gene Therapy Unit positions funded by SCHF

World leader in treating genetic diseases and a complete pathway from design, development and testing of gene therapies

Gene therapies are ‘genetic medicines’ that deliver healthy copies of genes into diseased cells to replace or repair faulty genes to treat, or even cure, disease. Healthy genes are delivered via a “vector”, which is typically a modified virus such as adeno-associated virus (AAV). With your support, SCHF funds 2 key positions in the Gene Therapy Unit including the unit’s leader Senior Staff Specialist Professor Ian Alexander and Program Manager Margot Latham.

Professor Alexander played a key role in establishing the Australian Genome Therapeutics Centre (AGTC) to create a world-leading facility in Australia to support the treatment of genetic and acquired conditions. The AGTC covers the full translational pathway from the development of idea, through to laboratory testing and all the way through to therapeutic treatment.

The clinical team at SCHN has become a leading global centre in using AAV-based viral vectors in gene therapy for infants with spinal muscular atrophy (SMA) and with those at risk of blinding eye disease.



In 2022 Professor Ian Alexander was awarded the prestigious Peter Wills Medal, in recognition of his outstanding contribution to building Australia’s international reputation in the area of health and medical research, and fostering collaboration for better health.

Supporting GPs to provide the best care for kids close to home



10

practices involving 57 GPs in the Sydney arm of the trial



719

co-consults with GP, paediatrician, children and their families



78

paediatrician-led educational case discussions held with over 350 clinical staff

With the support of Central and Eastern Sydney Primary Health Network (CESPHN) SC4C is being trialled over 12 months.

Expected outcomes of Strengthening Care for Children



Reduced Emergency Department referrals



Reduced outpatient referrals



Improved GP prescribing in line with best practice guidelines



Improved GP confidence in delivering paediatric care



Improved parent confidence and satisfaction in GP area

Strengthening primary care is essential to the prevention and early treatment of disease, especially in child health. To support a robust trial of a model of care designed to increase collaboration between GPs and paediatricians and improve management of chronic conditions, SCHF funded a paediatrician, a digital care platform and travel. The researchers leveraged this financial commitment to secure an additional \$2 million from the National Health and Medical Research Council to expand the trial.

In the SC4C model, paediatricians work closely with GPs in their practices to provide the best care for children closer to home. This includes weekly co-consults, case study discussions, and paediatrician support by email and phone. This provides children with the specialist care they need close to home and improves GP capability to care for children. Conditions treated include asthma, autism, seizures and mental health.

The researchers are also planning to assess alternative models of SC4C in 2023 such as an online GP health training program and a model adapted for children living with chronic illness in rural areas of NSW and Victoria.

If these additional studies are successful, the SC4C model will be implemented ‘at scale’ to improve GPs ability to deliver better, more equitable care for families and children across Australia, especially children from priority populations and living in remote areas.

Clinical Research Centre offers hope to families



CRC snapshot for FY22



Clinical trials test the safety and efficacy of promising new treatments, which must be done before governments approve a treatment as standard care. Trials can offer earlier access to treatments for children and their families who otherwise would need to wait years, or travel overseas. Although there are no guarantees that any trial will be successful, trials can offer hope to access potentially life-changing and life-saving therapies.

The two Clinical Research Centres (CRC) within Sydney Children’s Hospitals Network together form the most active paediatric clinical trial centre in Australia. They support clinicians to lead clinical trials across all stages of trial development and implementation including Phase I-IV drug trials, advanced therapeutics (gene and cell therapy) and device intervention trials. These trials involve various child health areas such as rheumatology, anaesthesia, surgery, gastroenterology, immunology, endocrinology and diabetes, bone and mineral, rehabilitation, neuromuscular/genetics, neurology, general medicine, haematology and respiratory medicine, and vaccines. SCHN is the first approved clinical trials site in Australasia for conducting novel gene therapies in paediatrics and has hosted neuromuscular trials that were previously only conducted in the United States.

“It is the dedicated Clinical Research Centre team who underpin the trials, and their continued work often results in faster translation of clinical trials into practice for sick kids and their families,” said Dr Laura Fawcett, Paediatric Staff Specialist and the Clinical Trials Medical Lead at Sydney Children’s Hospital, Randwick.

As Clinicals Trials Medical Lead, Dr Fawcett and her counterpart Dr Michelle Lorentzos at The Children’s Hospital at Westmead support investigators with meeting complex trial requirements, connect relevant teams for collaboration, and advise on which trials to undertake.

“The Clinical Trials Medical Lead ensures that every trial we conduct has the ability to deliver impact to our patients and their families.”

The recognised expertise of the CRCs means SCHN is increasingly approached for early-stage trials or to be the first international site in a large trial. Dr Fawcett said: *“Participating in trials gives clinicians at the Clinical Research Centre access to information about significant findings across all the trial sites globally. This gives us a big head start in understanding the new therapies and side effects which can make their translation from research to clinical practice much smoother.”*

SCHF funds key clinical trial research staff across the Network including clinical trial centre managers, clinical trial nurses, and pharmacists, who are essential for the CRCs to participate in so many high-quality clinical trials each year. The CRCs aim to continue the Clinical Trials Fellowship position with the help of SCHF funds to ensure continued growth as an international leader to bring the most advanced treatments in the world to Australia.



Dr Laura Fawcett has been supported by SCHF since 2017, including a two-year subspecialty Respiratory Fellowship to develop her advanced clinical skills and a year of a Clinical Trial Fellowship to develop her clinical trials expertise. Dr Fawcett explained this advanced training was essential in her current role.

“Without that Fellowship, I wouldn’t have the combination of expertise, knowledge and experience that I need in this role.”

Dr Fawcett is currently completing a PhD, which will further sharpen her clinical trials knowledge and research skills, with support from SCHF and Rotary Club of Sydney Cove.

Positions funded by long term supporters Save our Sons Duchenne Foundation help to bridge the interface from research to clinical care, supporting more families to participate in ground-breaking trials.

Patient Story

How research changed the future for Maddy & Briella

Generous support from our donors to help fund the EPIC lab has helped kids like sisters Maddy and Briella.

When Nicole and Bernard were living in Hong Kong and pregnant with their second child, Maddy, a 17-week scan showed she had unusually short arms and legs. More tests confirmed that Maddy had something known as skeletal dysplasia - abnormalities of the skeletal system. She was diagnosed with diastrophic dysplasia, a rare and non-lethal form of dwarfism. Three years later, her sister Briella, was born with the same condition.

"Maddy is a bit of a joker, loves sport at school and is exuberant. Briella's a lot more serious and loves dinosaurs and reading," says Nicole.

One debilitating challenge Maddy and Briella have faced due to their dwarfism is a spinal deformity called kyphoscoliosis. Their spines were curving sideways and bending forwards.

In 2018, both girls were admitted to The Children's Hospital at Westmead, where they spent more than six months undergoing a life-changing but potentially risky procedure.

The first stage involved putting the girls in halo gravity tractions to help straighten their twisted spines. The procedure was not without risk. The surgeon had to attach a lightweight metal ring to each of the girls' skulls with small pins, and then gradually stretched their spines in the months ahead.

But thanks to kind SCHF supporters, the girls could get the safest, healthiest outcome.

It's vital funding that has enabled the Kids Research EPIC (Engineering Prototypes & Implants for Children) Lab team to use 3D technology to improve the quality of care of children. They created 3D models of Maddy and Briella's skulls to guide safe pin placement for their halo tractions.

The sisters spent 6 months in hospital, never taking their halo tractions off, even while sleeping. Afterwards, they each endured an 8-hour marathon spinal fusion surgery to stop the curve in their spines returning. 3D modelling was also used to identify the safest place to guide the drill bits into the vertebrae, making the surgery a lot safer.

Today, the girls are back to their fun, happy lives. Nicole is so grateful to the 3D technology donors who support the Kids Research EPIC Lab and made the care her girls received possible.

SCHF donors like Hyundai Help for Kids have supported the EPIC Lab



Clinical Care

Best patient care for children and young people today

Across the Network in FY22



6,537

dedicated staff members



1,108,321

occasions of care for non-admitted patients

Your generous support in the past year helped the dedicated teams across Sydney Children's Hospitals Network continue to deliver world-class healthcare to more than 158,000 babies, children and young people.

Sydney Children's Hospitals Network Director of Clinical Operations Dr Joanne Ging said: "To continue to deliver the very best healthcare to help children live their healthiest lives relies on many partnerships across the community, including the generous donors and supporters of Sydney Children's Hospitals Foundation.

"Our frontline staff, Executive team and Board are very grateful for all the generous support you have given to the Sydney Children's

Hospitals Foundation," said Dr Ging. "Your donations allow our doctors, nurses and allied health staff to have the most advanced technology and medical equipment, improved patient care spaces, and specialist training and education to help children live their healthiest lives."

Following are just a few examples of how your generous support in FY22 helped sick kids and their families.

SCHF Funding in FY22



18

clinical fellowships to create paediatric specialists*



69

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



2

Aboriginal Public Health trainees



97

vital pieces of equipment



3

clinical building and refurbishment projects

*Fully or partly funded by Sydney Children's Hospitals Foundation

Building world-leading, innovative and future-focused children's hospitals

The Sydney Children's Hospital Stage 1 and Minderoo Children's Comprehensive Cancer Centre (SCH1/MCCCC), and The Children's Hospital Westmead (CHW2) redevelopments are currently underway, following the completion of Stage 1 at Westmead in 2022.

The new Children's Comprehensive Cancer Centre in Randwick will be known as the Minderoo Children's Comprehensive Cancer Centre (MCCCC), in recognition of a generous \$20 million donation from the Minderoo Foundation. The support of our generous donors is helping us transform the future of healthcare in New South Wales to ensure children and young people live their healthiest lives possible.

With your support, funding this redevelopment will help transform both hospitals into globally recognised paediatric healthcare centres with state-of-the-art infrastructure, cutting-edge technology and world-leading clinicians and researchers.

Patients and their families are at the centre of each project. During the design phase, more than 100 staff and hospital families provided valuable feedback on the design and functionality of planned areas including in-patient rooms and intensive care units. Through this process, the diverse experiences of SCHN hospital community members will help ensure the hospitals' design and functionality enhance the patient and family experience.

Future paediatric leaders funded through Fellowships



18

fellowships in 12 paediatric fields such as oncology, cardiology, neurology, emergency and intensive care

In FY22, SCHF funded 18 Fellows to create specialist paediatricians and future leaders. Two former SCHF-funded Fellows demonstrated how funding a Fellow to create a future child health leader can have a significant impact on child health.

Advancing diagnostic and treatment options for devastating genetic condition

Associate Professor Farrar completed a Neurology Fellowship in 2007-08 at Sydney Children's Hospital, Randwick funded by Allens Linklater. Over the past decade, Associate Professor Farrar has spearheaded diagnostic and treatment advances to help babies born with the devastating genetic condition spinal muscular atrophy (SMA). She led both the only Australian site for the global clinical trial for a new gene therapy for SMA called Zolgensma and a four-year pilot study of testing for SMA as part of the newborn bloodspot screening program.



Associate Professor Michelle Farrar

Thousands of kids helped by SCHF-funded Fellows each year

In FY22, her efforts were instrumental in two life-changing outcomes for babies with SMA and their families:

- Zolgensma was approved for government subsidised funding in May 2022 for babies up to 9 months diagnosed with SMA
- NSW Health permanently added SMA to the newborn bloodspot screening in NSW and the ACT in July 2022 to ensure early diagnosis.

Paediatric oncologist leading cancer control in NSW

Professor Tracey O'Brien was the first Oncology Fellow funded by Coles in 2001-02. The Coles team and customers have been proud supporters of Oncology Fellows for the past 21 years.

In FY22 Professor O'Brien took on the most senior role in cancer control in New South Wales with her appointment as Chief Executive of the Cancer Institute NSW and Chief Cancer Officer. This is the first time a paediatric oncologist has held the top position of NSW Health's key organisation to reduce the impact of cancer. This latest appointment follows a 25-year career improving the lives of children with cancer in Australia and internationally, including leading the Kids Cancer Centre at Sydney Children's Hospital, Randwick and advancing knowledge through extensive research.

Your support helps deliver state of the art medical equipment for children

Kids deserve the best care and the doctors, nurses and allied health professionals that look after them rely on advanced medical equipment and technology. In FY22, our supporters helped us buy 97 individual pieces of equipment, from essentials such as wheelchairs, syringe drivers, and a baby weighing scale, to air purifiers and ultrasound machines, through to cutting edge equipment such as the SPECT-CT Gamma Camera (see more details on page 27 and page 28).

Sick babies breathe easier with new ventilators

Access to medical equipment plays an important role in saving the lives of critically ill babies in the intensive care environment. For many years, the Humpty Dumpty Foundation has provided invaluable support to the Grace Centre for Newborn Intensive Care at The Children's Hospital at Westmead. In FY22 they provided two highly specialised and extremely gentle ventilators that provide breathing support for sick and premature babies. The Grace centre cares for more than 600 infants each year and this new equipment will help ensure that every child is being offered the best possible care.

Specialised equipment for life-saving rescues of the tiniest babies

The Newborn & paediatric Emergency Transport Service (NETS) provides intensive care and transport for critically ill babies and children, many of whom need mechanical support to breathe. Thanks to the generous support of Sargents Pies Charitable Foundation, NETS introduced a new Paediatric Life Support System in FY22.

The new equipment provides better ventilation for very small infants and has more pumps to administer lifesaving infusions to critically ill children. It enables more comfortable forms of non-invasive ventilation that allow children with asthma and bronchiolitis to breathe more comfortably. It also has an in-built defibrillator to give the NETS team immediate access to life-saving heart rhythm management via Bluetooth when required.

The new system includes a new stretcher and mattress with supportive layers which is more comfortable especially for long journeys of many hours. It also includes features to help reduce patients' stress and anxiety during transport such as USB outlets to allow for play therapy, music and video to distract and soothe sick kids.

The new Paediatric Life Support System was used for 280 missions, approximately 5 per week in the year to July 2022, to help newborns and children up to 15 years old. Almost half of these patients were treated for respiratory conditions. Other children were treated for a range of neurological, endocrine, ear nose and throat, heart, and digestive conditions, as well as infections and trauma.

Transforming children and young peoples health through choice, access, and digital healthcare



80

SCHN departments are currently using telehealth and 99% of families have a digitally enabled device



38,500+

families cared for virtually in more than 97,000 service events



80%

of families thought their telehealth consultation was 'about the same' or 'better' than a face-to-face appointment



75%

of families transferred to SCHN would prefer to receive care closer to home when safe to do so

Location of patients accessing SCHN virtual care



Families saved over 12.8 million kilometres in travel, the equivalent of more than 374 return flights from Sydney to London

virtualKIDS delivers innovation in virtual care



\$1 million

in funding for virtualKIDS over 2 years

virtualKIDS is an innovative program supported by SCHF. It is a 24/7 state-wide collaborative virtual model of care supporting access to specialist paediatric care in settings outside the hospital.

The much-anticipated launch of VirtualKIDS in June 2021 coincided with the start of the "Delta wave" COVID outbreak in Sydney and the team were ready and able to quickly support the COVID Positive Outpatients Response Team (CORT), consisting of specialist nurses, allied health staff and paediatricians trained in audiovisual clinical assessment. One of 8 virtualKIDS models of care, the CORT team supported more than 16,000 COVID-positive children and their families via telephone, SMS, and video calls, with a "flying squad" providing in-home clinical review where needed. Together, these services reduced Emergency Department (ED) presentations and risk of community transmission by providing quality care at home.

virtualKIDS launched additional models of care such as Acute Review, Sleep Studies at Home, support for the most vulnerable patients and their families with an after-hours hotline and support for day-only tonsillectomies and knee surgery. The virtualKIDS team also provided care for children in remote areas such as Broken Hill Hospital and assisted NETS during the winter surge. Following the success of virtualKIDS, SCHN has been able to expand telehealth to more than 80 departments and deliver more care closer to home.

'Being closer to home changes everything'

'An extra hour in the real world makes a huge difference'

Patient families' feedback on virtual care

virtualKIDS Model of Care	Patients treated	Outcome
 Acute Review providing treatment, support and advice 24/7 for acute illness	1,669 patients supported with 3,200 occasions of service	Admissions avoided, reduced length of stay, decreased ED re-presentations
 24/7 support line for vulnerable patients and families	More than 200 patients with chronic and complex conditions received after-hours support	ED and travel to hospital avoided through expert virtual clinician advice and troubleshooting
 Day-only knee surgery Day-only tonsil removal	10 knee surgery patients 3 tonsillectomy patients	High quality care with 24 hour support for children at home avoiding overnight stays
 Sleep Studies at Home	48 children and families supported to complete sleep studies in the comfort of home	Overnight hospital stays avoided providing earlier access to sleep study with faster access to treatment

SCHF has donated \$1 million over the past two years to support this initiative thanks to generous donations from Curing Homesickness, through the sale of Coles Mum's Sause products and special donation cards sold in Coles stores, along with thousands of donations from individuals

and community supporters who chose to donate to the highest-priority funding needs of the Network. Thanks to this generous donation, these innovative models of care enabled more children to spend less time in hospital while still receiving the quality care and support they need.

Funding nursing positions to support patient care

Thanks to your support, SCHF funded 16 clinical nursing positions in FY22, supporting clinical teams across the Network to provide safe, high-quality care to their patients. This includes a specialist full-time Emergency Mental Health Nurse in the Emergency Department (ED) at Sydney Children's Hospital, Randwick (see page 41). At the Kids Cancer Centre (KCC) the Nurse Educator develops and delivers education resources to nursing staff so that nurses remain up to date with the knowledge and skills they need to provide the best care and safely deliver the latest advances in medicine to their patients. The nurse educator supports all KCC nursing staff to complete intensive and ongoing education to ensure that care delivered at the bedside is in line with international gold standard practice. This includes on-the-job education, study days, in-service sessions, journal clubs and conferences, mentoring all KCC nursing staff undertaking postgraduate study, and overseeing the on-boarding and orientation of around 15 nursing staff each year across inpatient and outpatient units.

Ending avoidable hearing loss for Aboriginal children

Aboriginal and Torres Strait Islander children have some of the highest rates of middle ear infection in the world, which frequently leads to hearing loss, speech and language delays, and subsequent difficulties at school, often with lifelong consequences. These problems can be avoided with appropriate prevention, early detection and access to services.

Thanks to an amazing legacy from the Late Lois Edwina Sharp, SCHF provided funding to re-establish the Hearing Ear health And Language Service (HEALS) to help end avoidable deafness among Aboriginal children. Although progress was delayed due to COVID, this project currently supports 4 Aboriginal Community Controlled Health Services (ACCHS) to identify children in need and to source and provide appropriate ear, nose and throat surgery and/or speech therapy services. It has so far resulted in 24 surgical procedures for First Nations children. Speech services in the 2 rural ACCHS will also commence soon.

24 surgical procedures for First Nations children to support hearing health

Faster, safer, better: new state-of-the-art camera helps improve patient outcomes

Nuclear Medicine scans can be long procedures sometimes taking 2 hours or more, which can be scary and uncomfortable. To help kids who need these vital scans, a new Single-Photon Emission Computed Tomography (SPECT) Gamma Camera was installed at The Children's Hospital at Westmead thanks to a generous \$1.4 million donation from Sargents Pies Charitable Foundation. This camera reduces scan times and radiation, so it is faster and safer. It is the first such camera for any dedicated children's hospital in Australia and one of only 5 in the world.

The state-of-the-art Gamma Camera is used to evaluate, diagnose and assess the response to therapy of a range of illnesses in children including cancer, infections, fractures, gastrointestinal disorders, and neurological conditions. "Not only is it faster and more efficient than previous generation gamma cameras, the quality of the exams is also consistently higher, which can help detect, diagnose, and monitor the effect of treatment in cancers and other medical conditions," said Theo Kitsos, Deputy Chief Nuclear Medicine Scientist at The Children's Hospital at Westmead.

Dr Kevin London, Co Head of the Department of Nuclear Medicine said: "We have been using the new gamma camera to monitor tumours in a way we have not been able to do before. We can image over multiple time-points how tumours and normal body organs interact with nuclear medicine treatments to calculate the best treatment dose to maximise the effect on the tumours and minimise any side effects to the child".

The Nuclear Medicine examination room was also redesigned to provide a bright, comfortable, and inviting space for kids to be scanned. Child Life Therapist Lisa Carnovale said, "We have used the many years of paediatric experience to work towards designing a room that will be very child friendly, helping to reduce the stress and anxiety some children can feel during this time."

Access to this ground-breaking technology will have a lasting impact on kids' health helping kids like Lillyn.



Patient Story

Australian-first paediatric Gamma Camera helps kids spend less time in hospital

First time parents, Aaron and Jacinda, began noticing that their little girl Lillyn wasn't putting on any weight. A few months later, she was eating less and couldn't walk in a straight line.

"We took her back to the doctor and they didn't know what was wrong with her," said Aaron, Lillyn's dad.

A matter of days after Lillyn's second birthday, she was given the devastating diagnosis of stage four Neuroblastoma. This is a type of cancer that is almost exclusively found in infants and children under 5 years old.

Lillyn was rushed to The Children's Hospital at Westmead that very same day.

"It was hard to try and tell her she couldn't do everything she wanted to. She couldn't go home every night. She had to always say goodbye to mum or dad at the end of the day. She couldn't be a normal kid," explained Aaron.

Chemotherapy, biopsies, operations and scans became Lillyn's new normal, and the family of three slowly said goodbye to the life they once knew.

Scans quickly became a big and routine part of her journey. It was an instrumental tool that allowed Lillyn's clinical team to track her progress and monitor the growth of her tumour. Unfortunately for Lillyn, even the thought of these scans filled her with fear.

"We had to have three people in the room just to try to comfort her," explained Aaron.

Thankfully, over the course of Lillyn's treatment, SCHF supporter Sargents Pies Charitable Foundation generously funded a new Gamma Camera. This state-of-the-art camera not only decreased the amount of time Lillyn had to spend inside the scan, but also reduced the radiation dose, provided a more comfortable bed for Lillyn to lie on and a big TV to distract her from the anxiety she used to feel.

"It's amazing how quick the scan was, and she isn't dreading going back for another scan anymore," said Aaron.

"Because of this amazing technology, my daughter can get the care she needs, spend less time in hospital and more time being a kid," added Aaron.

After 18 long months, 5 rounds of chemotherapy, bone marrow transplants, operations, immune therapy and scans, Lillyn's family were finally given the great news that the tumour was gone, and Lillyn was in remission.

The new Gamma Camera produces better images and reduces scan time and radiation



Patient Experience

Creating positive patient and family experiences

Across the Network in FY22



88%

of people rated care they received in hospital as good or very good*



82%

of people rated Emergency Department care as good or very good



96%

rated virtual care they received as good or very good

*Source: SCHN patient surveys

Creating positive experiences for children in hospital and their families remained important due to the ongoing challenges they faced due to COVID and the essential measures in place to protect everyone.

The unwavering support from your generous donations, helped SCHF fund creative, educational and fun experiences right across the Network.

“Delivering the best health care means ensuring we do everything to treat and manage all aspects of a child’s health. Positive patient and family experiences can help reduce anxiety and make their stay in hospital more comfortable. This is important for every child but especially for those who have to stay in hospital for long or repeated visits,” said Sydney Children’s Hospitals Network Director of Safety, Quality and Governance, Chrissy Ceely.

“Your donations have helped SCHF fund all types of positive patient or family experiences such as supporting Child Life, Music and Art Therapists to help educate, entertain and

support kids in hospital, helping SCHF Art Program staff to create special memories, creating special spaces, and celebrating different events like Party Day, Mother’s or Father’s Day, National Carers Week and World Kindness Day.”

New equipment helps distract, educate and entertain

Thanks to you, we have funded equipment, technology and materials to help distract, entertain and educate children who may need to stay in hospital or undergo painful procedures. This includes items such as the Buzzy Bee, which is a small vibrating bee with blue ice-pack wings that uses cold and vibration to help block sharp pain and provide distraction when giving injections or other painful medical procedures.

SCHF Funding in FY22



22

Child Life, Music and Art Therapy positions and 1 chef*



70+

new pieces of children’s play, music or entertainment equipment including 20 iPads



\$1.9 million

in goods or services kindly donated to create positive experiences

*Fully or partly funded by Sydney Children’s Hospitals Foundation

You’ve also helped kids play, build resilience, and enjoy being a child during their treatments, with iPads, virtual games, art materials, bravery beads, specialist toys and other items to help a child in hospital be a kid first and a patient second.

Creating a calming and safe treatment space

A beautiful new mural of an underwater coral reef in the treatment room offers a creative way to distract and calm children with neurological conditions undergoing essential but often painful procedures. Thanks to the ongoing support from the Commercial Travellers Cot Fund, the Commercial Travellers Ward at The Children’s Hospital at Westmead now has this seascape painting to create a welcoming environment and help doctors and nurses to take children’s minds off often invasive procedures by encouraging them to focus on finding sea creatures in the ocean-inspired mural. The team on the ward has already had so much positive feedback about how helpful it has been and how good it looks. Other new features on the ward include new wall and floor decals for kids to interact with and medical staff to check how well children are moving as part of their recovery.



Love, laughter and life: 21 years of care at Bear Cottage

Caring for a child with a life-limiting illness is one of the most daunting challenges a parent can ever face. As NSW's only paediatric palliative care service, your generous support helps Bear Cottage deliver much-needed respite, support and care for these families to create special experiences and memories.

"Bear Cottage is not a place of darkness and despair, but one of light, love, laughter and most importantly life. It is a place where each child and family member are encouraged and supported to live life to the full and make precious memories that last a lifetime," says Narelle Martin, Nurse Manager at Bear Cottage.

Bear Cottage marked 21 years of delivering this vital care in FY22 - care that is only made possible from the generous support of the community. Your donation helps this very special place and its dedicated team to continue to support children and their families during the toughest time imaginable. Thanks to overwhelming community support, in FY22 SCHF funded programs, clinical support staff

and Music, Child Life, and Art Therapists as well as a qualified, in-house chef. Chefs prepare all daily meals and snacks for children and their families and also cater for special events including, patients birthday parties, Christmas in July, Christmas Party and many family support programs throughout the year.

Child Life and Music Therapists educate, engage and empower kids in hospital

SCHF funded 22 Child Life, Music and Art Therapy positions across Sydney Children's Hospitals Network including oncology, emergency, gastroenterology, and Bear Cottage.

Play is the language that children use to make sense of their world, and Child Life therapy uses play as a powerful tool to alleviate anxiety and give children opportunities for self-expression, which helps promote a sense of control. Play therapists conduct group and one-to-one activities with children including cooking, outings, family focused events, and having special visitors such as musicians, artists and storytellers.

Thanks to your support music therapy at Bear Cottage provided comfort to children and their families, supporting their emotional and spiritual needs, and helped create lasting memories. Music therapy was delivered online during COVID lockdowns to continue to provide support to children in Bear Cottage and also in their homes. We are grateful to the generous support of the Ottomin Foundation and Hyundai Help for Kids, which have provided funding for the Music and Child Life Therapist along with other needs at Bear Cottage for many years. We also thank Sydney Airport, Arc Phil' UNSW Student Life, Celebration Sing Out, Camp Quality, KCC General, Australian Children's Music Foundation, Hasbro, EVT, and the George and Janet Parker Memorial Fund who help fund Child Life and Music Therapy positions across the Network in FY22.

Donated goods support families and frontline staff

Thanks to the generous support of many of our donors, we were able to share almost \$2 million of goods and services in kind to create wonderful experiences for sick kids and their families.

Symbio Wildlife Park helped to gift over 100,000 entry tickets for use by patients, families and staff across the Network. Symbio encouraged thousands of families across New South Wales to redeem their \$25 Discover NSW Vouchers with Symbio Wildlife Park and on-gift their Entry Passes to SCHF, as part of their 'Help kids be kids and Discover a Wild Life' campaign. Symbio kindly donated the additional \$14 per pass.

Children in the hospital wards across the Network also continued to unleash their creative powers thanks to more than 3,500 packs of pencils, crayons, and felt tip pens donated by BIC to over 40 departments every 2 months. The BIC Foundation and BIC Australia also generously provided both funding and art supplies to support the SCHF ArtEx program in FY22 (for more details on our Art Program visit page 36).

Our wonderful Ward Angels gathered gifts from the community to make parents' and patients' lives easier while in hospital and delivered them all through the year. This included a Mother's Day gift for every mother with a child in hospital or Bear Cottage, gift cards for Christmas for every adolescent in hospital, musical equipment and toys for use by therapists and more.

Disney put smiles on faces with Star Wars costumes and toys on "May the 4th be with you". Toys were also donated by Hasbro, Spinmaster and others while Lindt & Sprugli continued its generous support with chocolates to mark special days such as World Carer's Days, Mother's Day and Father's Day. Bunnings also generously donated craft packs for the Child Life Therapists to use with kids in hospital.



Tony Kandalaf, Bear Cottage chef



Janet Burke, Co-head of Child Life Therapy at Sydney Children's Hospital

Kids with cancer get Back on Track with school



284

K-12 children received support including 82 in regional areas



117

children (41%) successfully returned to/completed school



165

schools worked with Back on Track

A cancer diagnosis and the treatment it requires can be incredibly disruptive to school, friendships, families, and finances. Thanks to the amazing support of our donors including Fight Cancer Foundation, The Profield Foundation, Waratah Education Foundation and BNP Paribas, in FY22 Back on Track supported 284 children with cancer to return to or complete school, including 136 new enrolments and 31 HSC students.

By facilitating virtual and in-person school visits, Back on Track helps kids with cancer maintain connections with friends, school and education so they can continue their life beyond treatment. It also helps lift the burden of education off parents so they can focus on being a family.

One Year 9 child's mum said: *"I am grateful to live in a country where money is donated to services such as Back on Track, so that children like my son can work on living a normal life after childhood cancer."*

The Back on Track team went virtual for 4 months during COVID to deliver online school staff meetings, peer presentations and tutoring, which was helped by schools being better equipped to support virtual learning. This approach was so effective Back on Track will continue to deliver support online in future.

Back on Track trialled a new program in FY22 to help the siblings of children with cancer by working with schools to help them understand the needs of the sibling to give them the skills to reach out and offer the social support these brothers and sisters need.



Cartoon book helps children understand their rare condition

Babies born with Oesophageal Atresia (OA) and Tracheo-Oesophageal Fistula (TOF) need major surgery to survive, and often grow up to be children who have ongoing difficulties with feeding and breathing.

This special comic book will help almost 200 children with OA-TOF who are being looked after in the only dedicated multidisciplinary clinic in Australia for OA at Sydney Children's Hospital, Randwick as well as thousands of children across Australia living with these conditions. The book has also been endorsed by the International Network on Oesophageal Atresia and parent support groups for the condition in Australia and overseas, so it's set to help children with OA-TOF on a global scale. The OA Kids Story Book and an online download link was made possible by Western Earthmoving and Jumo Health as part of the SCHF Greenlight Project (page 12).

Oesophageal Atresia (OA) is when the feeding tube does not connect to the stomach

Tracheo-Oesophageal Fistula (TOF) is an abnormal connection between the breathing tube and feeding tube

"Parents usually get information about the condition when their baby is diagnosed, but the information is not designed to help them explain the condition to their child when they get older or to extended family," said paediatric gastroenterology specialist Associate Professor Usha Krishnan who was instrumental in developing this book. *"The OA Kid's Story cartoon book uses a superhero comic-style format to explain OA-TOF and its complications, investigations, treatments, and medical and surgical procedures to young children. The book helps the child and their family gain a better understanding of the condition to reduce anxiety and stress, and improve quality of life for all affected by the disease."*



Associate Professor Usha Krishnan together with Hassan and his family, who feature in the OA Story Book, and Graham Ragg from Western Earthmoving with his family

SCHF Art Program

Since the Sydney Children's Hospital, Randwick opened in 1998, the SCHF Art Program has been using art to help improve the lives of patients, families, carers and staff. Our permanent collection and rotating exhibitions transform the hospital into a bright, reassuring, and colourful place of healing and culture where children and young adults feel safe and happy.

The SCHF Art Program works with hospital staff and artists to provide meaningful opportunities for artistic expression for patients and their families. This includes group and one-on-one Art Experience (ArtEx) workshops where children and young people of all ages can relax and enjoy the process of art making, share their stories, and make new friends. Some of these artworks are then included in seasonal exhibitions in the hospitals.



514

participant interactions



193

Art Experience workshops



26

exhibitions

A Little Piece of Me – creating memories for children with a life-limiting illness

Now in its fifth iteration, A Little Piece of Me is a project which celebrates the many influences that shape the personalities and identities of children and young people who are supported by paediatric palliative care teams at the Sydney Children's Hospitals Network and John Hunter Children's Hospital.

This project, delivered in collaboration with artist Andrew Christie, enables families to create a photographic pixel portrait - a technique that uses small images to create a singular large image. The process involves the families reflecting on all the people, places and things that have helped shape their child's life. The final artwork creatively captures the wonderful lives of the children and adolescents outside of their illness and offers the families a tangible memory they can keep, and most importantly, tells their unique story.

"It has been an honour to be involved in this project over many years. So many incredible families have generously opened their lives through photos and shared their journeys while paying tribute to their precious child," said Timothy Talty, Art Program Manager.

The portraits are exhibited each year and highlight how patients and their loved ones create an atmosphere of resilience, adaptability and creativity during often trialling times.

A Little Piece of Me is an initiative of Sydney Children's Hospitals Foundation Art Program and is supported by Bennelong Australian Equity Partners (BAEP), The Nicholas Trust and Photoking Randwick.



Patient Story

Lili's lifetime of memories captured in a single portrait

Lili was just 15 months old when she suffered her first seizure due to an untreatable form of epilepsy. Sadly, Lili passed away at just four years of age.

"She just started convulsing. It was so bad, I thought we lost her in that very moment," explained Sara, Lili's mum.

Hoping it was just a one-time thing – a reaction to an illness, a temperature, anything – Sara tried to push it to the side. But it wasn't long until little Lili suffered her second and third seizures.

She was later diagnosed with epilepsy, and a number of tests followed, trying to determine what exactly was going on.

"I really had no idea what we were in for. I thought children diagnosed with epilepsy were prescribed some medication and that was that."

Unfortunately for Lili and single mum Sara, that was far from the case. As Lili's condition deteriorated, she was admitted into The Children's Hospital at Westmead. Here, Sara and Lili became known as 'frequent flyers' with one hospital admission lasting more than 11 months.

Over the next three to four years, the incredible teams at The Children's Hospital at Westmead and Sydney Children's Hospital, Randwick tried everything they could. From treatments, to trials, to brain surgery, but nothing seemed to work for Lili.

Lili lost the ability to sit up, stand, take steps, hold things, speak, and eat on her own, but despite everything, she still showed amazing

strength. At just a few years old, she inspired everyone around her, showing incredible love and determination, constantly surprising everyone by always fighting back.

"I watched my beautiful little girl come out of a seizure, look at me, smile, hold my hand and kiss me to reassure me that she was ok, only to fall asleep moments later to recover from what her little body just endured."

In July 2018, Sara was given the devastating news that there was nothing more the doctors could do.

"I didn't want her passing away in hospital because she grew up there, so I decided to take her to Bear Cottage, the only children's hospice in NSW."

It was at Bear Cottage that Lili got to spend her final days.

"The beautiful nurses at Bear Cottage went above and beyond in preparing us for our final goodbyes."

Lili took her final breath and passed away in her mother's arms at just four years old.

"No matter what Lili went through, she was so amazing. She taught me the true meaning of love, she taught me strength, she taught me resilience and she taught me the true meaning of bravery and courage."

Marking the four-year anniversary of Lili's passing, Sara decided to be involved with Sydney Children's Hospitals Foundation Art Program's A Little Piece of Me project.

"Taking part in this amazing project couldn't come at a better time. It's a way to keep my beautiful Miss Lili's memory alive."

This collaborative art project between artist Andrew Christie, Sydney Children's Hospitals Foundation Art Program and Sydney Children's Hospitals Network's Palliative Care teams provides families with a portrait they can treasure forever.

Made up of hundreds of tiny images, Lili's portrait tells her life story. It captures her incredible style, her gorgeous smile, and her tenacious personality.

"It's one portrait that perfectly sums up her whole life. Every single photo has a story, a memory, and a meaning behind it. Together they tell her story, from the very beginning to the moment I laid her to rest."

"All I want is to keep her beautiful memory alive, so the more I talk about her, the more I do things in her honour, it makes me happy and it really helps me with my grieving. I am so thankful and grateful to be a part of Sydney Children's Hospitals Foundation Art Program's A Little Piece of Me project."

**In FY22,
67 families participated
in SCHF's A Little Piece
of Me project, with the
portraits displayed across
Sydney Children's Hospital,
Randwick, The Children's
Hospital at Westmead, Bear
Cottage and John Hunter
Children's Hospital.**



Priority funding focus: Mental Health

Responding to the mental health crisis in children and young people

Across the Network in FY22



141%

increase in mental health presentations to Emergency at Sydney Children's Hospital, Randwick since 2013



19.2%

increase in self-harm or suicidal ideation presentations in NSW Emergency Departments each year since COVID. Prior to COVID, this was rising 8.4% each year



47%

growth in 13 to 17-year-old girls coming into Emergency Departments for suicidal ideation or self-harm since COVID

1 in 10

young people in NSW are reporting high levels of psychological distress

Half of mental health conditions occur before the age of 14, which means early access to mental health care for children is crucial.

The mental health teams across the Network are addressing the mental health crisis in young people through research, advocacy, leadership and services to ensure safe, reliable and evidence-based care.

Dr Katherine Knight, Medical Head of Department, Psychological Medicine, Sydney Children's Hospitals Network, said: "Across our hospitals, we have seen the effects extended lockdowns have had on our children and young people and how the stress of the pandemic has impacted psychological development, not only in our patients but in family units as a whole.

"Enhanced nursing and medical care, therapeutic interventions like art, music and movement and specialised mental health nurses are all essential in caring for these children and families, your support has helped ensure this can continue."

Thanks to the generous support of the Gold Dinner 2021, SCHF has been able to fund additional positions and programs at the Network to help make a positive difference in the lives of children and young people affected by mental illness.

SCHF Funding



11

new mental health positions* and 1 specialist training program



3

mental health research projects and 1 Postgraduate position



\$4.1 million+

funding commitment from SCHF for mental health over the next 3 years

*including part time and full time positions

We are grateful to Gold Dinner 2021 committee members, partners and donors whose generosity funded these new staff and services to support kids' mental health needs



Highlights

Helping families and children to stay safe at home

Over the past year, more than 2,000 children were admitted to SCHN Emergency Departments in urgent mental distress. Your support has helped SCHF fund a specialist full-time Emergency Mental Health Nurse in the Emergency Department (ED) at Sydney Children's Hospital, Randwick to help these children and their families.

Working in this new role, Clinical Nurse Consultant Bibi Kennedy provides comprehensive assessment, counselling, education, and connection with community-based services to families in ED. By guiding families through the handover to external services, such as Safe Haven and Help 2 Win, children will be able to remain safely with their families at home. Bibi also plans to provide 10-week virtual skills training to help teens regulate their emotions.

Additional in-hospital support for patients with eating disorders

A new senior clinical registrar position at Sydney Children's Hospital, Randwick will provide more support for patients with eating disorders. Dr Michael Coffey has started working within the specialist team to provide critical assessment and treatment plans of children and young people with an eating disorder.

Peer support to help young people's mental health recovery



1

Peer Support Worker with a personal experience of mental health challenges funded by SCHF



680

hours of support delivered by the SCHF-funded Peer Support Worker across Safe Haven and the Suicide Prevention Outreach Team

The Peer Support program at Sydney Children's Hospital, Randwick, helps to connect young people with a Peer Support Worker with lived experience of mental health issues. With your help, SCHF have been able to help grow this program by funding an additional Peer Support Worker to assist young people feel less isolated and learn skills to regulate their emotions. In FY22, the SCHF-funded position delivered 680 hours of support across the mobile Suicide Prevention Outreach Team (SPOT) and the age-appropriate, culturally sensitive, drop in-service Safe Haven. Patients and families have expressed their support for this wonderful service and the benefits of being heard and understood by someone who shares their experiences.

Elevating vital research for better mental health outcomes

A new research position at Sydney Children's Hospital, Randwick has also been funded to help our existing team understand mental health conditions in children and identify the critical factors contributing to it.

A Postgraduate Fellowship in Psychology will fund an early career researcher to identify new ways to understand and intervene in mental health issues.

With research and modelling suggesting mental health in the community will get worse before it gets better over the next 5 years, the research conducted now can greatly impact the care and intervention to help kids and their families get the diagnosis, care, and treatment they need sooner.

Giving frontline workers at the Network access to the latest training

The crisis response to mental health requires the ongoing support, training, and supervision of specialist mental health frontline workers. Thanks to your generosity, clinical teams across the Network have access to the latest education and training.

In FY22, the team received Aboriginal Mental Health First Aid training for culturally sensitive support and Tuning into Teens training for working with parents and carers.

Mental Health Research

A legacy of hope: a gift in Will helps the future of mental health for children and young people

The late Lois Sharp was a long-term supporter of The Children's Hospital at Westmead and left a generous gift in her Will to a cause very close to her heart – research into mental health in children. The significant gift was beyond what Lois was able to donate in her lifetime and shows the power that a gift in a Will can have to ensure children live their healthiest lives.

Through her generous gift, Lois has funded 3 key mental health research projects at The Children's Hospital at Westmead leaving a legacy to help children living with mental health issues and their families.

Developing Stronger – Mental Health Service Research Program in SCHN

Led by Dr Iain Perkes, this Network program aims to develop a service-research-policy partnership program to use statewide NSW Health data to identify high prevalence presenting problems. The focus of this project is to investigate the link between youth self-harm and climate change, especially heatwaves, to understand the implications for NSW Health clinical services.

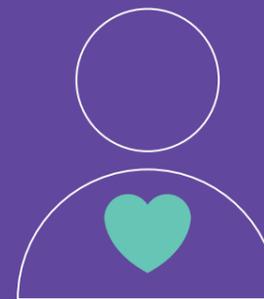
Helping adolescents with chronic illness manage mental health

Clinical Nurse Consultant and PhD candidate Jane Gauci at The Children's Hospital at Westmead is leading a project focused on finding ways to improve mental health outcomes for adolescents with chronic illness. Following her published systematic review investigating the effectiveness of self-management programs for children with chronic illnesses, this project will test the effectiveness of an adolescent version of a well-established adult self-management program.

Reducing carer stress in families of children with Type 1 Diabetes

Dr Daniel You will investigate the effectiveness of the widely used parenting program, Circle of Security-Parenting, which aims to reduce high levels of stress and burnout of carers of children with Type 1 Diabetes.

Improved carer skills and wellbeing is associated with improved children's mental health, behaviour, and diabetes management.



Leaving a gift in your Will, no matter how large or small, is a powerful way to make a positive difference to the health and wellbeing of children and young people far beyond your lifetime

Healing and health through music, art, and movement at the Network

Acute Mental Health Unit admissions across the Network have doubled over the past 5 years, with 450 children and young people coming through the doors in the last year alone.

Introduced as a temporary COVID-19 service, the Mental Health Therapeutic Program has become an important health initiative and service within the wards at both Sydney Children's Hospital, Randwick, and The Children's Hospital at Westmead.

With Gold Dinner 2021 support, we have been able to fund additional positions at the Network to provide these therapeutic services, including music, art, and physiotherapy. This is in response to young people expressing that art therapy, music therapy and physiotherapy were some of the most important programs to include in the Therapeutic Program.

What young people think about the Mental Health Therapeutic Program at the Network

'I find art therapy helpful because it's relaxing and therapeutic to vent our emotions into art'

'I enjoyed physio as it just helps as a distraction and it's fun, and movement feels nice'



6 part-time positions funded to deliver art therapy, music therapy and physiotherapy



1,544 hours of art therapy and music therapy service delivered by SCHF-funded positions



711 hours of mental health physiotherapy service delivered by SCHF-funded positions

Music Therapy



Helps children self-regulate, reduce anxiety, connect with peers, learn new skills. Music Therapy sessions at the Network were seen as fun, empowering, mood enhancing and relaxing.



Activities include Music Therapy Songwriting, with a goal of giving young people a safe space and medium to voice their experiences through lyrics and music.

During an 8-week period there were no restraints, seclusions or personal threats at the Network on days where music therapy services were rolled out.

Art Therapy



Provides a safe space for self-expression with an Art Therapist, (re)connect with creativity, and opportunity to regulate and express emotions through art. The emphasis is on the process of creating and meaning-making rather than on the end product.



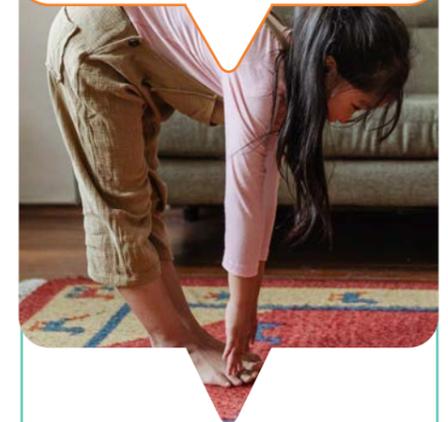
'The range of materials available gives the young people choice over how and what they share; giving them the valuable hospital experience of having agency'
- Allied Health team feedback

Art therapy at the Network was rated as one of the most enjoyable, helpful, and important activities by young people in the mental health units.

Physiotherapy



Involves guided exercise with mindfulness techniques to help manage stress, anxiety and depression. Movement empowers young people to develop a sense of their bodies, improve fitness and help them manage strong emotions in a healthy way.



This included activities such as strength training, swimming, volleyball, basketball, soccer, hockey, agility circuits, yoga and pilates, touch football, hula hooping and skipping rope.

The schedule at the Network is being designed to reflect young people's preferences for activities and time of day.

Contact us

Connect



Visit www.schf.org.au for more information about how you can get involved.

Connect with us on social media @schf.kids 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
Suite 5.01, Level 5,
77 King 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 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.



All in for kids' health

