Impact Report

FY23

SCHF Sydney Children's Hospitals Foundation

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 (SCHF) 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.

“In Unity We Heal.” Artwork by David Williams of Gilimbaa.

Cover image

Fifteen-year-old Ollie, a former patient of Sydney Children’s Hospital, Randwick, features in SCHF’s first mural located at Harmony Park in Sydney’s CBD. Ollie has received care from so many different specialist teams within the Hospital, he truly does represent all 159,000 children cared for every year.

The mural was brought to life by street artist Reuben Boughtwood, also known as Reubzz.

Read Ollie's story

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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

159,000 kids

Across NSW treated by the Sydney Children's Hospitals Network (SCHN) last year, with potentially millions of children across the world benefiting from research

1 network

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

1 foundation

Funding: Groundbreaking research, excellent clinical care, positive patient and family experiences

70,000 donors

Changemakers for children's health

Our ambition

To create a transformative positive impact for children by raising more money to invest in both the front line and future of kids' health

A message from our CEO

I am filled with immense pride and gratitude as I reflect on the profound impact SCHF has had on the lives of countless children and families over the last 12 months.

It is with your unwavering support that we can continue making a positive difference to the lives of the 159,000 children who come through the doors of our Network's children's hospitals each year, those who receive care closer to home thanks to remote technologies, and many thousands around the world who will benefit from new treatments and new models of care.

This year, we raised a remarkable $88.3 million, including $23.5 million in pledges. This enabled us to contribute $51.6 million towards the front line of paediatric healthcare, with $50 million helping the children and families receiving care across SCHN.

This impressive achievement is a testament to the power of philanthropy and your direct impact on the lives of the children and families we serve.

Thanks to you, we are turning dreams into reality. We are helping to build world-first comprehensive complex care centres, leading the way with life-changing clinical trials and introducing game-changing technology to help get kids home from hospital sooner.

Through your generous contributions, we have been able to fully or partially fund 257 positions, 132 pieces of equipment and technology, 28 programs, and many other initiatives that are saving lives today and shaping a brighter and healthier future for generations to come.

As we celebrate this year's milestones and achievements, I want to thank every supporter, volunteer, and staff member - our amazing Movement of Many - who has contributed to this success. Together, we are transforming the lives of children and their families – offering hope, healing, and the promise of a brighter future.

SCHF has come so far and there is so much more we can achieve. We are a team bursting with ideas, energy, and ambition, ready to take things to the next level in pursuit of our mission to go all in for kids' health.

Thank you for standing alongside us, and more importantly, alongside every sick child who receives care across SCHN. You are ensuring every child gets the healthcare they need, no matter when and no matter what.

Kristina Keneally

Chief Executive Officer
SCHF

From the Network

Our goal at SCHN is to help all children and young people live their healthiest lives.

Our partnership with SCHF is helping us achieve this vision and transform the way we deliver care for long-term impact.

Paediatric healthcare is always evolving, and we don't always have all the pieces to solve every puzzle. The philanthropic community, brought together by SCHF, becomes an integral part of the search for solutions.

When our expert clinicians and researchers identify emerging needs and opportunities in children's health, SCHF helps us to respond. We are extremely grateful to all the committed individuals and organisations whose generous support is helping us to deliver world-class paediatric healthcare.

Over the past year, thanks to your generosity, we have launched our new Base of Skull Service, the first integrated paediatric multidisciplinary skull base unit in the southern hemisphere. We have also seen the power of philanthropy transform treatment and survival rates for children with cancer, funding new ideas that are pushing the boundaries of research. We are determined to be equally bold in our efforts to change the future for children suffering from other currently incurable conditions, including neurological and gastroenterological disorders.

Together, we are working to find answers to rare diseases, faster ways to diagnose illnesses or treat injuries and support clinical trials to test new treatments. We are also enhancing existing investments in clinical and patient family-centred spaces in our redevelopments to create positive experiences for children and their families. Thanks to SCHF, philanthropy continued to propel the redevelopment projects forward. At the annual Gold Dinner alone, close to $20 million was pledged to support Australia's first complex care centre – the Kookaburra Centre – thanks to our generous supporters.

We're dedicated to providing the best possible care for children no matter where they live. From training paediatric specialists, to providing emergency and intensive care, respite and palliative care services, driving innovative research programs and clinical trials, delivering our virtual care services, through to our work with partners locally, nationally and internationally, our reach extends far beyond our walls.

On behalf of all of us at the Network, thank you for your support.

Cathryn Cox

Cathryn Cox, PSM

Chief Executive
SCHN

Theory of Change

In FY23, SCHF commenced work on our Social Impact Measurement Framework, to add structure and rigour to our reporting on the impact of our work. This will help us to demonstrate with even greater clarity the positive changes that your support is helping to drive.

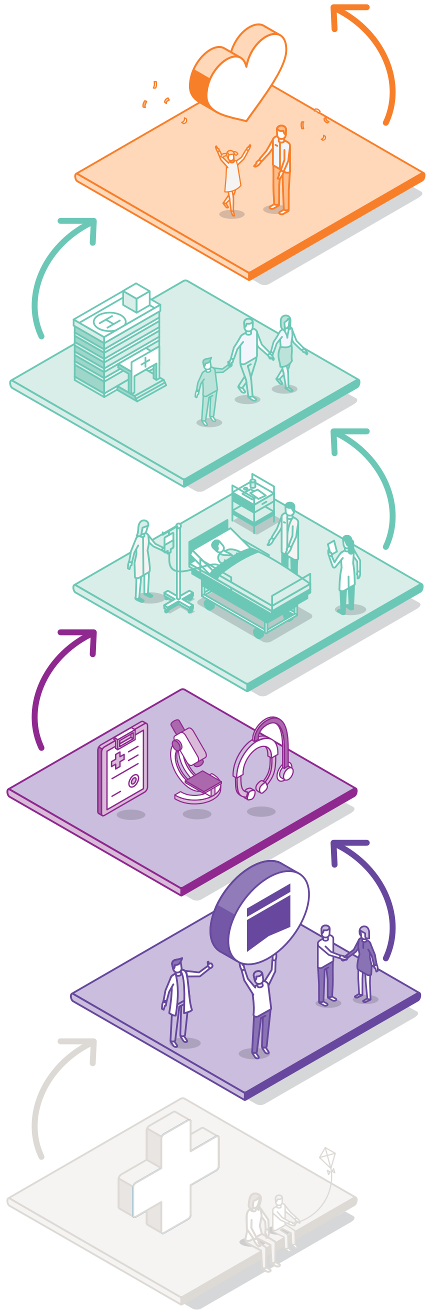
We are proud to share our Theory of Change, which communicates how our work together contributes to better health for kids.

> **"As SCHF approaches its 40th anniversary in 2026, we are proud to continue the legacy of philanthropic work that has supported children across hospital sites in Randwick, Glebe, Camperdown, and Westmead since 1858. As we prepare to mark this significant milestone, we are excited to take things to the next level in pursuit of our mission of going all in for kids' health".**

Kristina Keneally

Chief Executive Officer,
SCHF

Our impact: Every child receives the best possible healthcare, when and where they need it.



To ensure children have

- The best possible care
- Improved healthcare equity
- Improved health outcomes
- A positive patient experience with their families
- Improved wellbeing with their families.

So that children and their families

- Have improved access to the best paediatric healthcare
- Have improved access to new and / or improved treatments
- Benefit from faster translation of research into practice
- Are more able to 'cope', feel supported and content.

Enabling

- State-of-the-art equipment, procedures, and technology
- Reduced barriers to care
- More opportunities for the best talent in child health
- Clinicians and researchers to pursue breakthrough research
- A caring environment where children are positively engaged
- Physical and emotional support for children and families.

We fund

- The best paediatric clinical care
- Transformative research
- Positive patient and family experiences.

Through the Movement of Many

- Our growing community of over 70,000 philanthropists, supporters, friends and partners collaborate to drive transformation in children's health.

The situation

- Existing funding doesn't cover the groundbreaking projects and research needed to transform children's healthcare
- Without SCHF and the generous changemakers we work with, some children will be left without the care that they deserve.

Children will continue to get sick with illnesses, injuries and conditions that require medical treatment, and hospital experiences can be traumatic. Paediatric medicine is rapidly evolving, offering a brighter future for many children. **Philanthropy is needed to make great healthcare excellent.**

FY23 Snapshot

Thanks to your ongoing support, we donated $51,572,814* to prevent, treat and manage childhood illness and injury, focusing on services provided by SCHN.

In partnership with our Movement of Many, we provided an additional $4,059,747 in gift-in-kind support for SCHN's staff, patients and families.

Clinical Care

$28,586,688

3 Aboriginal Health Trainees

24 Allied health professionals including 9 social workers

30 Fellows

125 Pieces of specialised medical equipment

42 Medical and clinical support staff including 1 psychiatrist, 7 staff specialists, 3 registrars, and 1 visiting international surgeon

1 New outpatient clinic and garden for immunosuppressed children

Research

$16,833,846

99 Researchers and key research support positions

1 3D printer to create prototypes for orthopaedic and other devices

14 Research projects including 8 Greenlight projects

1 PhD scholarship

Patient Experience

$6,152,280

OneView

Patient Experience System to educate and entertain patients in hospital

22 Child Life, Music, and Art Therapists and 2 chefs

Therapeutic & sensory toys

For Child Life Therapy and Music Therapy

Family support packages

To assist with essentials for families in need

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*including Curing Homesickness (now Hospitals United for Sick Kids)

SCHF commitment to reconciliation

SCHF is committed to the journey of reconciliation and to helping close the gap to achieve equality in health and life expectancy for Aboriginal and Torres Strait Islander peoples.

973

Aboriginal and Torres Strait Islander patients/families cared for by SCHN

36,852

Outpatient occasions of service for Aboriginal and Torres Strait Islander patients

20%

Aboriginal children are 20% more likely to have potentially preventable hospitalisation

Every 15 minutes

The Aboriginal Health Unit live dashboard updates to inform when an Aboriginal child is waiting anywhere in the hospital or ED and should be seen by an Aboriginal Health Worker

As part of this commitment, we contribute all unrestricted funds raised during National Reconciliation Week each year to initiatives of SCHN's Aboriginal Health Unit. These initiatives include the development of culturally safe spaces in the hospitals, celebrations of culture and contributing to costs for Sorry Business for the families of Aboriginal and Torres Strait Islander children who pass away while in hospital.

SCHF also supports three Aboriginal Population Health Training Initiative (APHTI) trainees per year to support the growth of the Aboriginal workforce. You can read about recent graduate Seaneen on page 23.

Picture: Recent graduates Natasha and Seaneen.

In FY23, SCHF began developing our first Reflect Reconciliation Action Plan (RAP) with support from Reconciliation Australia. Our Reflect RAP is a plan of action that outlines our commitment to reconciliation with Aboriginal and Torres Strait Islander peoples, helps us discover new opportunities and deepen our learning and appreciation for the histories and culture of Aboriginal and Torres Strait Islander peoples. This includes the role healthcare entities have played in the past.

We proudly launched our bespoke Indigenous motif in March, to strengthen our relationships with Aboriginal and Torres Strait Islander communities. The artwork concept and narrative were developed by David Williams, a proud Wakka Wakka artist at Gilimbaa.

Learn more

Access to the best paediatric healthcare

"Our vision to become a global leader in paediatric healthcare is achieved by cutting-edge research which changes the way we provide care. This research is informed and guided by the questions that clinicians need answers to for their patients.

Our objective is to have models of care centered on the outcomes and experiences that our patients and families want, provided by highly skilled interdisciplinary teams.

We will also focus on increasing our international collaborations and mentorship programs, expanding the number of clinical trials our teams and families are involved in, expanding advanced therapeutics and embedding personalised and transformative care, which delivers the right care to the right patient, first time.

Philanthropic support helps us achieve these goals faster and brings hope into healthcare."

Dr Joanne Ging

Director Clinical Operations,
SCHN

Clinical care

Surgery without scars

State of the art equipment, procedures and technology for improved health outcomes

Medical technology is constantly evolving to improve patient care. Thanks to our wonderful donors, surgery teams at Sydney Children's Hospital, Randwick and The Children's Hospital at Westmead are now working in newly upgraded operating theatres, so they can perform less invasive surgeries for the thousands of babies and children who undergo surgery at these hospitals each year.

2

New digital operating theatres

1

Neuro microscope

1

Digital theatre upgrade

20,214

Surgeries performed across SCHN in FY23

2.9 days

Average length of stay (including day procedures)

This means reduced recovery times, lowered infection rates, less pain and scarring and shorter hospital stays for kids like Valentine.

The new theatre upgrades include the installation of 4K high-definition imaging, which provides sharper resolution, clearer images and far greater surgical precision. This extraordinary technology means that when surgeons perform complex and lifesaving operations on even the tiniest patients, they have all the tools needed to provide world-class treatment.

The new and improved operating theatres were made possible by generous donors including The Minton Family Foundation, Mayrin Group and Miranda Kerr.

Picture: Teams in Perioperative Services celebrate the official opening of their new operating theatres in the Central Acute Services Building at Westmead.

Valentine's life-saving surgery in the Smart Operating Theatre

Thanks to the cutting-edge procedures made possible by the upgraded operating theatres, baby Valentine survived a life-threatening abnormality. Like any first-time mum, Lourdes was thrilled to welcome her baby boy into the world. But joy soon turned to worry when little Valentine started making unusual breathing sounds and had to be rushed to Sydney Children's Hospital, Randwick by a Newborn and paediatric Emergency Transport Service (NETS) ambulance for urgent, life-saving surgery.

Valentine had been born with a rare condition called a tracheoesophageal fistula (TOF). Affecting just one in 4,500 kids, TOF occurs when a child's windpipe is connected to their food pipe. This can cause air to enter the stomach and fluid to enter the lungs, which in turn can cause severe breathing problems.

While she waited anxiously for her newborn son to undergo a complex, six-hour procedure, Lourdes started researching TOF.

Pictures below and right: Valentine and family.

"I kept seeing these confronting images of children with large incisions down their neck and chests," she remembers. "I worried Valentine would be left with a huge scar for the rest of his life and this was the start of long-term health problems," recalled Lourdes.

Instead, Valentine had minimally invasive 'keyhole' surgery in the Smart Operating Theatre, with doctors operating through three small incisions under his armpit.

Today, Lourdes says Valentine is a "healthy, vibrant, cheeky and affectionate" little boy who is obsessed with cars and is rarely seen without his pink toy hippo.

Lourdes could not be more grateful for the medical team who operated on Valentine, and for the wonderful SCHF supporters who made this upgrade possible through their generous gift.

Read Valentine's full story

Clinical care

Surgery without scars continued

First paediatric team in the southern hemisphere operating in the most complex part of the human body

The base of the skull is the most complex area in the human body. It is home to the nerves that allow you to see, hear, smell, taste, talk, swallow, move and feel, along with the vessels that supply blood to the brain. Operating in this area requires utmost precision and years of intensive training. Each year at Sydney Children's Hospital, Randwick over 100 children are treated for conditions that require base of skull surgical access. These conditions range from aggressively spreading sinus infections, inflammation, traumatic lesions and skull fractures, and tumours. Children with these conditions normally face repeated and disfiguring surgeries and lengthy recoveries, as well as multiple general anaesthetics, time in hospital and major impacts to their normally active lives.

Thanks to your support, the new Base of Skull Services (BOSS) at Sydney Children's Hospital, Randwick is changing that. The new service, and the groundbreaking new equipment to access the base of skull via the nose, offers more precise surgery that often leaves no scars. The BOSS is the southern hemisphere's first dedicated, integrated multidisciplinary care team that cares exclusively for children and their families with trauma, tumours and invasive infections in and around the base of the skull. This means children like 11-year-old David can receive comprehensive care while spending less time in the hospital and, importantly, less time under anaesthetic.

"The Base of Skull Service is game-changing for children undergoing surgery. It significantly lowers risk, leaving no large and disfiguring scars, and reduces trauma and long-term complications," said Dr Catherine Banks, a skull base surgeon.

As the BOSS continues to develop it will cover all aspects of patient care including nutrition and dietetics, speech pathology, physiotherapy and child life and music therapy.

100+

Children per year are treated for conditions that require base of skull surgical access

David's cutting-edge procedure

David was diagnosed with an allergic fungal infection in 2023 and was rushed to Sydney Children's Hospital, Randwick for care under the new BOSS.

Under the new model of care, the highly trained specialist and multidisciplinary team used an endoscope and specialist equipment to remove the infected tissue through David's nasal passage.

"He coped very well through the whole process, it was so much less stressful for him, and my wife and I could see that he didn't experience any of the effects you would normally expect following surgery," said David's dad, George.

The minimally invasive approach was performed without the need for a full general anaesthetic or any direct incisions into his skull, shaving hours off his surgery time and days off his recovery.

Picture: David and his mum, Sherin, are all smiles following the success of David's Base of Skull Service procedure.

Read David's full story

Specialist emergency transport supported by philanthropy since 1977

Described as a mobile Intensive Care Unit for children up to the age of 16, the Newborn and paediatric Emergency Transport Service (NETS) is the only service of its kind in Australia. Operating across NSW, NETS provides expert clinical advice, clinician co-coordination, emergency treatment and stabilisation and inter hospital transport for very sick or injured babies and children. NETS operates 24 hours a day, 7 days a week.

In FY23, nearly 4,000 sick and injured children across NSW were collected and cared for by NETS.

Picture: Baby Valentine being rushed to hospital in the NETS ambulance.

Clinical care

Surgery without scars continued

Faster, better care for kids needing skull surgery

"A friend of mine once said, 'If you're doing the same operation for ten years in a row, it's probably time to rethink how you're doing it," says Professor Chris Forrest, Paediatric Plastic Surgeon at The Hospital for Sick Children (SickKids) in Toronto.

Thanks to a generous bequest, SCHF sponsored Professor Chris Forrest to elevate the incredible skills of the neurosurgical and paediatric plastic surgeons across SCHN from great to world-class.

Now upskilled with advanced surgical techniques, teams across SCHN are more equipped to treat children with abnormal skull diseases, such as craniostynosis. Craniostynosis is a condition where babies are born with a fused skull, limiting the capacity for the brain to grow, that can have disabling and even deadly consequences if left untreated.

While previous treatments were a burden to children and families, the innovative method taught by Professor Forrest can be done at a younger age and is less invasive, with fewer intra-operational complications, shorter hospital stays and a nicer cosmetic appearance.

In FY23, Professor Forrest also initiated Australia's first clinical network of paediatric plastic surgeons working in neurosurgery. This network enables doctors across Australia to connect with each other, share new ideas, techniques and procedures and support each other in clinical decisions on complex or unusual cases. Professor Forrest's ambition is to link the North American and Australian clinical networks to elevate the profession.

Professor Forrest has generously educated Australian neurosurgeons, plastic surgeons, paediatricians and general practitioners in the community to recognise and appropriately diagnose and treat babies and children with skull abnormalities. This training will mean children will receive improved intervention in a timelier manner with fewer side effects and complications.

"Children are remarkable human beings, and being able to do something when they're very young that's going to influence the rest of their lives is incredible," Professor Forrest said.

Picture: Professor Chris Forrest in one of the new operating theatres.

Celebrating our donors and brightening our hospitals

A possum kicking a football, a lizard holding balloons and a group of acrobatic pies. These are among the different personalities that come to life in new murals that have been installed across nearly 100 different surfaces at 22 locations across The Children's Hospital at Westmead, including the new Smart Operating Theatres (page 14). These vibrant murals not only recognise the incredible donors who have generously supported the development of these hospital spaces, but they also provide engaging and immersive environments to enrich the patient experience.

Picture: Operating theatre murals

Clinical care

More opportunities for the best talent in paediatric health

Preparing clinicians across Asia-Pacific to provide newborns with the very best start to life

The first 2,000 days of a child's life (from conception to age five) is a critical window for physical, cognitive, social and emotional health. Early life experiences have lasting impacts on a child's learning, behaviour and health outcomes well into their adulthood.

To ensure babies have the best chance to thrive, the Australasian NIDCAP Training Centre (ANTC) delivers specialist education to neonatal healthcare professionals. Located in the Grace Centre for Newborn Intensive Care, it is the first and only Newborn Individualised Developmental Care and Assessment Program (NIDCAP) training centre in Australia.

The research-informed education empowers doctors, nurses and allied health staff to create a positive and supportive hospital experience for the baby and their family. It teaches clinicians how to help parents connect with their baby, read infant behaviour to better understand what they want and need and support healthy development through sensitive care-giving.

The team have provided specialist neurodevelopmental education to more than 2,000 clinicians across Australia, New Zealand and the Asia-Pacific region, and in 2023 awarded 146 scholarships to rural and remote clinicians to raise the standard of paediatric care across Australia.

In 2023, the Grace team were joint winners of the Health Research category at the NSW Health Awards for their project, Research Based Care through the Neonatal Admission and Beyond.

Picture: NIDCAP lead Nadine Griffiths demonstrates individualised infant support approaches with caregiver Jess, a clinical nurse educator (above), and mum Roxanne (below)

"By donating, people are becoming a part of our team. They are contributing in a meaningful way to the care of sick babies, who with their help are given the best chance at recovering. They are making it possible for us to extend our services beyond the expected to the extraordinary," said Professor Nadia Badawi AM, Medical Director and Co-Head Grace Centre for Newborn Intensive Care at The Children's Hospital at Westmead.

Picture: Professor Nadia Badawi baby Everleigh and mum Brooklyn.

600+

Premature newborns, neonates and critically ill infants with complex medical conditions are cared for by the Grace Centre each year

Learn more

Supporting paediatric trainees returning after parental or extended leave

Returning to the workforce after parental leave can be challenging. Thanks to the Critical Care Simulation Team at Sydney Children's Hospital, Randwick, and the support of philanthropists who contributed to SCHF's Gold Dinner 2022, the Paediatric Trainees Returning After Maternity or Extended Leave (PRAM) program ensures trainees are supported in their return to work.

"There was an overwhelming need for a course to re-educate our staff so that their knowledge is up to date, enabling them to re-enter the workforce feeling supported," said Dr Sasha Symonds, a Paediatric Emergency Physician and Co-Medical Lead of the Critical Care Simulation Team who co-developed the program.

The first of its kind, the free full day PRAM workshop provides hands-on education and mentorship for paediatric nurses and doctors returning to the workforce after parental leave. Senior staff specialists lead sessions to refresh key clinical knowledge and share the latest clinical guidelines and any recent changes in clinical practice. With a core focus on wellbeing, these workshops are a safe space for discussions around the challenges and differences individuals face following parental leave.

"PRAM made returning to work much less daunting... It helped me realise that even though I had been away from work for a long time, the muscle memory and knowledge of years of work experience before I had taken a break was still there," said Dr Ritu Chaurasia, a Paediatric Registrar at Sydney Children's Hospital, Randwick.

Clinical care

More opportunities for the best talent in paediatric health continued

Championing nursing expertise to deliver the best outcomes for kids

34

Clinical and research nurse positions supported, including:

3 Nurse educators,
15 Clinical nurse consultants,
4 Clinical nurse specialists,
1 Nurse-led research project

Every day SCHN nurses provide exceptional care to children and their families. Nurses are at the very heart of the hospital and play an important role in coordinating patient care, clinical decision making and research. We're proud to support nurses in a range of expert roles across SCHN to ensure kids get the very best healthcare.

Clinical Nurse Consultants (CNCs) act as the bridge between the bedside delivery of care, the wider clinical decisions of the medical team and the patient's world beyond the hospital. For example, the Anaesthetic Quiet Pathway CNC plays a key role in developing a new care pathway for children and young people with special needs, for whom the hospital environment can be overwhelming.

Nurse Educators deliver ongoing professional education to translate best-practice clinical guidelines into real-world practicality. They draw on their expertise of delivering care to create the frameworks that deliver that care, helping to ensure all patients can receive the best, high quality care available to them.

Nurse-led or supported research is informed by the insights of those closest to the front line of caring for children in hospital and can inform key changes to the delivery of care to ensure patient and family needs are met throughout their hospital journey.

SCHF is grateful to all the donors who have funded vital nursing positions and sponsored special events like the Nurses Ball. Most importantly, thank you to SCHN nurses for their ongoing compassion, resilience, and commitment to making a positive difference to the live of sick and injured kids.

Picture: Nicole Bacalhau & Robyn Shoemark, nurses at the Children's Hospital at Westmead.

Celebrating the incredible nurses who go all in for kids' health

Swapping scrubs for suits and ball gowns, more than 400 nurses from across SCHN let their hair down to celebrate their achievements at the 2023 Nurses Ball. The event returned for the first time in five years after the COVID-19 pandemic put celebrations on hold.

The ball expresses our gratitude to the remarkable nurses who devote themselves to providing the highest quality healthcare to some of NSW's most critically ill and vulnerable children. Thank you to all our partners who helped make it a special and memorable evening.

Removing barriers to care: meet Seaneen

Seaneen Wallace is passionate about driving change in health systems to deliver improved outcomes. Originally trained as a dietitian, Seaneen recently completed a Master of Public Health within the Aboriginal Population Health Training Initiative (APHTI) program, supported by SCHF. As part of this program, Seaneen completed placements across SCHN which led to her supporting a very important project.

Led by the Aboriginal Health Outcomes and Equity manager (also a former APHTI trainee), Seaneen assisted in the development of the SCHN Aboriginal Health dashboard. The dashboard delivers real-time updates to help the Aboriginal Health Unit staff (AHU) know when Aboriginal children are in the hospital and ensure they have fast access to culturally safe care and ultimately improve their health outcomes.

Of the traineeship, Seaneen said, **"The program reporting is stringent, and you have to prove competency across eight different areas. Getting all the different projects done during COVID was a huge achievement."**

Seaneen is now working as a Care Navigator in the Providing Enhanced Access to Health Services (PEACH) program, using data-driven solutions to help improve access to healthcare for children and families with specific needs. It was the perfect opportunity to blend her public health expertise with her passion for supporting Aboriginal communities and priority populations.

"We are guided by our research questions of wanting to better understand the patient experience and co-design solutions to challenges. We then collaborate widely across the Network to share co-design implementation ideas and empower them to embark on these implementation ideas," explained Seaneen.

The program has already led to the implementation of electronic medical record prompts to easily flag when a child is Aboriginal or Torres Strait Islander, the development of appointment letters in languages other than English to support families from culturally and linguistically diverse backgrounds and increased awareness about concessions for children with disabilities to help ease the financial burden of healthcare.

Seaneen says the most rewarding part of her current role is bringing different teams together to make tangible and positive changes to the care they provide to kids.

SCHF has committed to part-funding three Aboriginal Population Health Training Initiative (APHTI) trainees per year, to support the growth of the Aboriginal workforce. See page 10 for more on our commitment to Aboriginal health.

Clinical care

Supporting children and families to heal from the trauma of abuse

4

Child protection positions funded across the Network

1

Artist engaged to update a treatment room with a calming mural

Most children grow up in an environment where they are cared for and loved, but sadly child abuse and neglect affects too many children. The amazing and dedicated clinicians at Sydney Children's Hospital, Randwick, and The Children's Hospital at Westmead go above and beyond to support children, adolescents and families affected by child abuse, and help them to rebuild their confidence and lives. Thanks to beautiful wall murals, comfortable furnishings and treatment spaces funded by generous SCHF donors, these services are provided in calm and colourful spaces that help participants to feel more relaxed and at ease.

Our generous donors provide the much-needed funding for services such as the Links program at the Children's Hospital at Westmead. This unique early intervention service is available for children under five years. It provides a comprehensive assessment and connects the child and family with appropriate services in their local community. Links takes a trauma-informed approach and holistically assesses children and their carers to fully consider the impact of a range of psychosocial complexities including finance, drug and alcohol, mental health and family violence on family functioning and the child's development.

At Sydney Children's Hospital, Randwick, the Group Therapy program is funded by philanthropy. The power of group therapy for survivors of abuse is to shine a light on their shared experience in a safe space. Children and adolescents can arrive at the Child Protection Unit (CPU) with the idea that they are the only person who has ever experienced abuse, and that they are alone in their trauma.

The group work programs have an important role in breaking down this myth and helping children and adults to overcome the shame, secrecy, embarrassment and guilt about what has happened to them. Participants consistently report that they really value meeting and learning from others who have had similar experiences. In FY23, the Group Therapy program at Sydney Children's Hospital, Randwick, underwent a refresh, building on the public narrative led by young women survivors of sexual abuse, and connecting with community-based support groups to help build a pathway for girls to transition into adult care.

"Love you guys so much. Literally saved my life." – Group Therapy participant.

1 in 32

Australian children were receiving child protection services in 2021-22[1]

Every 11 ½ minutes

An Australian child experiences abuse or neglect[2]

15,582

Children in NSW each year are confirmed to have experienced abused and neglect[3]

Connecting through creativity

Artwork: "Burri Burri", by Lesley Ryan

This painting of a whale mother and calf hangs in the main foyer of the Child Protection Unit at Sydney Children's Hospital, Randwick.

The artist, Lesley Ryan, first began to paint as a participant in the Ngala Nanga Mai pARenT program. 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. Ngala Nanga Mai aims to improve the health of parents and their children and provide opportunities for education and for building connection through culture and creativity. 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 providing art-making materials and childcare services. Thanks to the support of the Rotary Club of Sydney Cove, the Department of Community Child Health is undertaking a scoping and community engagement project with Aboriginal families to determine the feasibility of implementing the Ngala Nanga Mai program in Western Sydney.

1-3 Source: Australian Institute of Health and Welfare (AIHW) 2023. Child Protection Australia 2021-22. Cat. no: CWS 92. www.aihw.gov.au

Clinical care

Unwavering support for children with a life-limiting condition

22

Positions supported in FY23 including specialist doctors and nurses, social workers, music, art, and play therapists, and chefs

$4 million

In forward funding

Caring for a child with a life-limiting condition can be exhausting and heartbreaking. At Bear Cottage it can also be joyful. Bear Cottage opened its doors in 2001 thanks to community support. Since then, generous changemakers have continued to help provide respite and end of life care for children and families in a home-like environment, helping to bring joy and laughter into each day.

In FY23, SCHF changed the way we contribute to Bear Cottage. In addition to funding key positions, SCHF also provided an unprecedented $4 million in forward funding to ensure Bear Cottage can plan ahead and offer staff security so that children and families can continue to receive the very best palliative care.

Each new stage of illness progression can bring new challenges, and it takes a very special team to care for families attending Bear Cottage as they adjust to these changes and face ongoing experiences of grief and loss. The impact extends to the wider family as they try to maintain the routine of normal family life for other siblings while learning to cope with this devastating life experience.

Thanks to your generous support, the dedicated staff and volunteers at Bear Cottage create uniquely precious and memorable moments for children and families during some of the most difficult times of their lives.

Celebrating each child's life and experiences

Art therapy at Bear Cottage provides a safe space for children and their families to creatively express what it's like to be or care for a child with a life-limiting illness. Art Therapist Judy spends time getting to know patients and families – listening to their stories, learning more about their lives and what is important to them, and then helping them express this creatively. Each art-making experience creates lasting memories and is individualised to each family and situation, creating imagery in celebration of that child's life and experiences.

260

Admissions to Bear Cottage in FY23

Transformative research

"We are entering one of the most exciting times of our generation where research is truly helping to transform the care we provide to children, young people and their families.

We are beginning to introduce therapies for conditions once considered incurable and are providing hope to families in a way we once could have only dreamt about.

The impact of this is not just lifesaving but life changing.

We are seeing children diagnosed with Spinal Muscular Atrophy who are meeting their developmental milestones, young people who have had very limited vision regaining their sight and patients diagnosed with cancers who are responding better than ever to their treatment thanks to personalised medicine. It is remarkable and fills us with a great deal of hope about what can be achieved in the future.

These incredible outcomes are made possible by the thriving ecosystem and excellent people we have at SCHN which ensures the discoveries made in the lab can be taken direct to the patient, whether this be at the bedside, through a clinical trial or through our outpatient and allied health programs."

Dr Paula Bray

Director of Research
SCHN

Research

Harnessing the power of philanthropy to solve childhood cancer

Celebrating 25 years of banking biospecimens

The Tumour Bank at The Children's Hospital at Westmead was established through philanthropic funding and has been integral to transforming outcomes for kids with cancer for 25 years. As the first biobanking facility focused solely on paediatric cancer, The Tumour Bank provides an essential service for researchers seeking to understand and solve paediatric cancer.

"Our biobank has contributed to worldwide studies for rare cancer that has led to new knowledge of this disease. We want to learn about what is happening to children with cancer so we can do the best for each child who comes in with the same sort of disease," said Professor Daniel Catchpoole, Head of The Tumour Bank at The Children's Hospital at Westmead.

52,345	Tissue specimens stored in the biobank
4,845	Patients who have donated specimens
115+	Research studies supported in Australia and worldwide

Over the past 25 years, thousands of patients from The Children's Hospital at Westmead and hundreds of donors have played a pivotal role in advancing our understanding of paediatric cancer. Thanks in part to this work, almost every child with cancer now has the opportunity for their tumour to be tested, so that individualised treatments may be offered or developed. This supports clinicians to diagnose, treat and ultimately prevent kids' cancers, providing hope to families and a new future for kids. SCHF is proud to continue supporting this incredible work.

>300	New cancer diagnoses across SCHN
>100	Clinical trials focused on cancer across SCHN
>3,000	Active oncology patients across SCHN
400	Staff working in oncology across SCHN

Delivering treatment breakthroughs with CAR-T cell therapy

Thanks to generous donors from Silver Party 2022, two new apheresis machines at the Kids Cancer Centre (KCC) at Sydney Children's Hospital, Randwick offer a lifeline for very sick children in their hope for cancer remission and recovery.

The machines collect stem cells and T-cells, a type of white blood cell, and in a process called CAR-T therapy, the collected T-cells are genetically engineered to carry special structures on their surface, known as chimeric antigen receptors (CARs), to target cancer. The cells are then grown, multiplied and infused back into the patient's body as CAR T-cells, where they fight the child's cancer.

"Treatments like CAR T-cell therapy have shown promise for kids with cancer who have exhausted all other options. The impact is that we have treatment we can now offer when previously there was no hope. When you support SCHF, you are helping fund research and clinical trials that help uncover better treatments for kids with cancer," said Dr Richard Mitchell, Director, Kids Cancer Centre

Building on these successes, SCHF is proud to support the cancer research teams across SCHN through the long and difficult process of finding and developing effective CAR-T therapies for more cancer types, like bone cancer.

Picture: (Above) Dr Richard Mitchell, Director, Kids Cancer Centre.

One young man's extraordinary legacy

In his final days after a heroic eight-year fight with cancer, 19-year-old Steven Walter wrote a powerful letter to his family and friends asking them to raise money for childhood cancer research **"so that one day no other kid would have to go through what I've been through".**

Since his passing in 2000, The Steven Walter Laboratory, established in his name and led by Professor Glenn Marshall, has conducted pioneering research to reduce the impact of cancer on children. This work continues to improve our understanding of the genetic basis of childhood cancers and environmental risk factors, with the aim to both treat and ultimately prevent many childhood cancers. The laboratory has been instrumental in developing precision medicine treatments for children with cancer. These individualised treatments, designed to target a specific cancer for an individual child, have resulted in improved cure rates, reduced side-effects, and reduced treatment resistance.

The Steven Walter Childhood Cancer Research Fund, established by an endowment in 2023, continues his amazing legacy.

Picture: (Above) Following his first 12 months of chemotherapy, Steve was very happy to be back riding.

Research

Improved access to new and improved treatments

Award-winning commitment to kids with cancer

Thanks to donors like you helping to fund oncology clinical trials over many years, even more children diagnosed with cancer can now receive potentially life-changing treatment even earlier. The team at SCHN was the winner of the 2022 NSW Premier's Awards Outstanding Cancer Clinical Trials Unit Award, recognised for steadily increasing the number of investigator-initiated and commercially sponsored cancer trials open to recruitment from 2019 to 2022. SCHF recognises and celebrates the commitment and dedication of the staff who make themselves available day and night to give kids with cancer the chance to participate in a clinical trial.

Picture: Dr Draga Barbaric, Paediatric Oncologist at Sydney Children's Hospital, Randwick, and Anthea Ng, Clinical Research Manager at The Children's Hospital at Westmead (R) accept the award from Susan Pearce AM, Secretary, NSW Health.

Watch the presentation

Coordinating care and helping kids to access clinical trials

1000+ scans organised

To measure tumour burden, including PET, CT, MRI, MIBG, Ultrasound and bone scans

100+ insertions
80+ removals

Of central line/ports which deliver lifesaving intravenous medicines without needles

Participating in clinical trials and undergoing experimental treatment can be daunting. At the Kids Cancer Centre, the Family Care Navigator provides patients and their families with the logistical and emotional support that they need. The Care Navigator ensures the whole family is equipped with all the information they need to make an informed choice and provides guidance through the chosen diagnostic and therapeutic pathways. The Care Navigator is a consistent and reassuring point of contact for children and their families from the moment of diagnosis, and they offer a personalised, family-friendly and child-focused service. By coordinating tests and treatments for families within the complex hospital system and streamlining care, the Care Navigator can reduce time in hospital and associated costs, thereby reducing the burden on patients and their families. The Family Care Navigator position was made possible by attendees of Silver Party 2022.

World-leading clinical trial expertise

It can take up to 17 years for research to translate to clinical care – that's an entire childhood. With the help of generous donors, SCHF invests in research that accelerates the ability to take crucial discoveries and turn them into innovative treatments, prevention strategies and cures to make a bigger impact on children's health, sooner.

SCHF funds crucial clinical trials infrastructure and key clinical trial research staff across the Network, such as clinical trial centre managers, nurses and pharmacists. These spaces and support staff are essential for the Network's researchers to participate in high-quality clinical trials each year.

Thanks to the support of our Movement of Many, including long-term donor Kids with Cancer Foundation, we are able to fund world-first clinical trials.

182

Clinical trials across SCHN in FY23

Trial phase: Phase 0 / Pilot

Type of studies
Preclinical studies, Laboratory research

7 clinical trials

Trial phase: Phase 1

Type of studies
Proof of concept, first in patient studies

20 clinical trials
33 clinical trial participants

Trial phase: Phase 2

Type of studies
Multi-patient studies, Treatment effectiveness, Comparative studies

51 clinical trials
221 clinical trial participants

Trial phase: Phase 3

Type of studies
Multi-patient studies, Treatment effectiveness, Comparative studies

63 clinical trials
585 clinical trial participants

Trial phase: Phase 4

Type of studies
Treatment evaluation, Implementation studies

12 clinical trials
76 clinical trial participants

Research

New hope for kids with rare genetic conditions

1 in 12

Babies are born with a rare disease

6,000+

Rare genetic disorders that affect children

30%

Of children born with rare genetic disease do not live to see their fifth birthday

95%

Of rare diseases have no cure

2,000+ new patients

With rare diseases each year at SCHN

Duchenne Muscular Dystrophy (DMD) is a genetic condition that affects just 1 in every 3,500 boys. It triggers rapid muscle weakness that typically leads to the need for a wheelchair by the age of 12. Currently, there is no long-term effective treatment and no known cure, but there is hope.

Thanks to many years of investment by generous SCHF donors into clinical trial capability and neurogenetics research at SCHN, 2023 saw three Australian boys become the youngest in the world to receive therapy for DMD. A world-first international clinical trial for children under four uses gene replacement therapy to target DMD at its root cause, replacing the faulty or mutated gene with a healthy, functioning version in a one-time, single-dose infusion.

This is an exceptional milestone and very exciting for Australian kids. International Advanced Therapeutics trials like this one are highly competitive, with only a very small number of patients, and this trial will recruit just 10 boys worldwide. Dr Michelle Lorentzos, Clinical Trials Medical Lead at The Children's Hospital at Westmead, is hopeful that the trial will be life-changing for boys with DMD.

"We think by treating boys earlier, we may be able to prevent much of the weakness and disability that has already occurred in older patients," Dr Lorentzos said.

This groundbreaking trial also holds the promise of unlocking new treatments for other genetic diseases. This trial was made possible by sustained investment into building the research infrastructure to manage the highly complex clinical and regulatory requirements of clinical trials in Advanced Therapeutics. The amazing Kids Advanced Therapeutics (KAT) program is at the forefront of an era of innovation pioneering Advanced Therapeutics, transforming the future for children living with rare disorders and offering kids in Australia the chance to receive world-leading care close to home.

"The impact of this achievement is beyond potential benefits for Duchenne muscular dystrophy. Many of the capabilities utilised in this trial can be directly translated into treatments for these other diseases," said Dr Lorentzos.

Picture: Dr Michelle Lorentzos, Clinical Trials Medical Lead at The Children's Hospital at Westmead.

Learn more

Research

Improving the runway from science through to clinical care for brain disorders of childhood

1,244

Rare neurological disorders are caused by a single faulty gene

Only 6%

Of neurological conditions have approved treatments

$8-10 billion per year

Is the estimated cost in Australia of autism alone

Less than 1%

Of kids with neurological disorders seen at SCHN are accessing clinical trials

220% increase

In the number of children registered for clinical trials in the first 2 years of the NeuroCONNECT registry

5,000 families

Across SCHN will benefit from the NeuroCONNECT registry

Around one in ten children are affected by childhood brain disorders such as autism, cerebral palsy, epilepsy and rare neurological conditions. These can cause chronic, debilitating and lifelong symptoms. Despite their large numbers, the differences between conditions can make them difficult to diagnose and treat. SCHN looks after the largest number of children with brain disorders in Australia – around 10,000 children per year.

SCHF is proudly supporting the 'Big Brain' research team of clinicians and scientists who are collaborating across Australia to understand the cause and the best treatment of these conditions. Thanks to philanthropic support, the NeuroCONNECT registry of children with neurological disorders is helping clinicians to match families to clinical and research expertise. With standardised information collected from patients and families, the registry is helping to streamline access to clinical trials of new treatments, including for rare genetic conditions.

In a remarkable indicator of success, the number of children registered on clinical trials has more than tripled in the first two years of the registry – giving hope to more children and families affected by neurological disorders.

The NeuroCONNECT registry is directly enabling research that will result in transformational therapies though the power of identifying the cause of disease in every child with a neurological disorder. The first stage of this important project was made possible by a generous gift from The Ainsworth Foundation.

Collaborative research in neurology and neuroscience to solve the big brain disorders of childhood

Childhood Dementia

$595,000

Developing new diagnostic tests using biomarkers in blood and cerebrospinal fluid

Brain-Aid

$200,000

Providing parent/family education and information for precision medicine treatment decisions

Gene CP

$300,000

Improving investigation of genetics in cerebral palsy

NeuroCONNECT

Collecting standardised data across different conditions

- Genetic epilepsy
- Dementia
- Genetic movement disorders and deep brain stimulation
- Neurofibramatosis
- Ketogenic diet
- Tic/OCD
- Epilepsy surgery
- Epileptic spasms

10,000

Children with brain disorders seen across SCHN each year

Results

- **$1.1 million+ competitive funding enabled**
- **10+ research studies enabled**
- **Increased clinical research capacity & PhD student opportunities**

Research

Giving the green light to new ideas to transform kids' health

SCHF's innovative Greenlight Pilot Program connected researchers and clinicians with philanthropists, funding projects that might otherwise not be funded and making remarkable progress for kids' health.

$4.6m

Invested since 2021

19

Greenlight Research projects funded

As the final year of Greenlight wraps up, we are thrilled with what has been achieved.

Learn more

The Greenlight projects mentioned in this report were supported by donors including Arthur Laundy, Cerebral Palsy Alliance Research Foundation, Cure4CF, Lenity Foundation, The Teicke Family Foundation, donations to The Children's Hospital at Westmead Critical Care Departments, the Greenlight TFN crowdfunding event, and matched gifts from SCHF's Movement of Many.

Supporting children with autism to reach their full potential

The Westmead Feelings Program is the world's first evidence-based mental health program proven to significantly improve emotional competence in autistic children. Thanks to Greenlight and your support, the team created videos and a web-based program to support caregivers to grow the emotional skills and social awareness of children and young people with autism. The Greenlight funding has also led to further funding to progress the program, with the goal of making the program freely available online.

"Through our research and development projects, and our decades of clinical experience, we have the skills and knowledge to help so many children and families. But it is only with your support that we have been able to design and create innovative digital solutions to help families support their child's emotional needs," said Dr Michelle Wong, Senior Clinical Psychologist and Director of the Westmead Feelings Program.

Picture: Dr Michelle Wong.

Redesigning the future for children with Cerebral Palsy

In 2023, the EPIC-CP team successfully completed a feasibility study to test their co-designed screening tool for unmet social needs. This was done in close collaboration with healthcare professionals and an advisory group of young people with Cerebral Palsy (CP) and their families. The advisory group was instrumental in ensuring that the screening tool effectively supports children and young people with CP and directs care where it is needed most. In the first stage of the project, the team successfully trialled matching families with a community linker. The community linker assisted families in areas such as schooling support, accessing allied health services and cost of living challenges.

The EPIC-CP tool has potential to enhance the lives of children with CP in NSW, and the 8,000 people with CP in Australia.

"Having a research advisory group gives young people with lived experience a way to give back to the community and to build a better future for those who come after us. It is easy to 'hide' this part of us but with EPIC-CP we can create meaningful programs that are tested before they go into practice, we can tell from experience, and adapt the research to skip the teething issues that most programs without lived experiences face," said Mackenzie Woodbury, Research Advisor for EPIC-CP.

The EPIC-CP research team have been awarded a $1.46million MRFF Grant to continue this vital work.

Bridging the gap between current care and brilliant care for kids who tube feed

Based on the findings of their world-first research, the Supporting Children with Complex Feeding Difficulties (SUCCEED) team has created a tube feed training program to empower parents and carers to tube feed outside of hospitals. Facilitated by parents and clinicians, the workshops will help to reduce the enormous stress placed on primary caregivers by training other family members to safely tube feed. The team has also produced a series of videos alongside these workshops, and other practical resources.

Picture: SUCCEED workshops use donated Hungry Manikins to help caregivers learn how to tube feed.

Watch the SUCCEED training videos

Research

Giving the green light to new ideas to transform kids’ health continued

GENEie® machine learning software tool goes live

Congenital anomalies affect an estimated 1 in 50 infants and are most commonly the result of genetic defects in the DNA. The GENEie® tool for early identification of genetic disorders removes some of the guesswork in interpreting harmful genetic variants. The tool is now live and is on track to be introduced into diagnostic labs in early 2024 and support clinicians to diagnose genetic conditions.

Collecting big data to improve care for small people

Big Data for Small People harnesses the power of artificial intelligence and big data to predict and prevent poor outcomes for critically ill children, giving them the best possible chance of survival. This work is pioneering a new era in healthcare. In Phase 1, the technology was installed in 98 beds across The Children’s Hospital at Westmead. Now in Phase 2, the system setup will be tested in the Intensive Care Unit and operating theatres through a clinical research study that aims to inform diagnosis and allow more precise, predictive care.

Picture: Big Data for Small People uses AI to predict and prevent poor outcomes for children in intensive care.

Progress towards a cure for brittle bone disease

Associate Professor Aaron Schindeler and his research team are one step closer to creating a brighter future for the 2,000 Australian children affected by osteogenesis imperfecta (OI), or brittle bone disease. In the past year, the team have successfully collected preclinical evidence to demonstrate the effectiveness and safety of their world-first approach to enable gene editing in bone. They expect to begin clinical trials to correct genetic mutations that cause OI within the next 3-4 years.

Picture: Associate Professor Aaron Schindeler is leading the Gene Therapy to Cure Brittle Bone Disease project.

Picture: Jason Borrie, Himanshu Joshi and Professor Sandra Cooper, co-founders of the GENEie® project

Research

Giving the green light to new ideas to transform kids' health continued

Using phage therapy to clear persistent bacterial infection in children with cystic fibrosis

It was through the Greenlight Pilot Program that SCHF first heard about Dr Jagdev Singh's groundbreaking idea to help treat infections in kids with cystic fibrosis (CF).

CF is an inherited genetic disorder that causes damage to the lungs, digestive system and other organs in the body, and results in a weakened immune system that is prone to infection. Pseudomonas aeruginosa is a common bacteria found in damp places such as showers and swimming pools that can be particularly dangerous for kids with CF. Currently, the only treatment for the infection is prolonged and repeated courses of strong antibiotics, but this is not always effective and can have serious side effects.

In FY23, The Children's Hospital at Westmead launched Dr Singh's research into a world-first clinical trial, using phage therapy to directly target pseudomonas aeruginosa infections in kids with CF.

"Phages are specific and specialised viruses that can be exactly matched to eliminate bacteria without harming human cells," explained Dr Singh.

The trial is the first major step in demonstrating the suitability of phages as routine treatment.

Of the ten children who will be a part of phase one of the trial, Abby (pictured page 43) paved the way as the first participant. Thanks to the trial, Abby came away from her most recent hospital stay fully cleared of her pseudomonas aeruginosa infection. Following this exciting result, a second young person has now been enrolled as a participant in the study.

Dr Singh said his hope is for the trial to lead to more effective treatment options so patients like Abby can spend less time in hospital and more time at home, where they belong. If successful, the trial will then expand nationally and internationally. It may also then be expanded to target other bacteria that causes lung damage in patients with CF.

Dr Singh added, **"We couldn't do what we do without the support of SCHF and communities and organisations like Cure4CF. Their funding has been integral to this trial and we are incredibly grateful for their continued and generous support."**

Picture: Dr Jagdev Singh is pioneering phage therapy to treat children with CF.

A world-first clinical trial for kids like Abby

Bubbly Abby, from Lighting Ridge in outback NSW, was only 8 years old when she contracted the infection that has impacted her life ever since.

"It feels like you can't really breathe as much as normal, and your lungs feel really tight", Abby said.

Until now, Abby has travelled 700km from her home to The Children's Hospital at Westmead twice a year for her two-week tune ups, where she receives strong IV antibiotics and intensive physiotherapy to help clear the infection. During Abby's most recent hospital stay, in addition to the routine antibiotics, Abby received phage therapy as the first patient on the trial.

"While it was initially a bit nerve-racking to be the first, we are thrilled to have the opportunity to try this new treatment option that may be able to keep Abby healthier for the future," Abby's mum, Chloe, said.

Picture: Twelve year-old Abby is the first patient enrolled in the Phage Therapy trial.

Watch Abby on The Project

Research

30 years of identifying, monitoring, and responding to paediatric disease

2nd

Rare disease surveillance unit established worldwide

70+

Studies into rare conditions affecting children and adolescents

1,385

Paediatricians and other child health clinicians report data to APSU each month[1]

16

Conditions studied in 2023

For more than 30 years, the Australian Paediatric Surveillance Unit (APSU), established and headed by Professor Elizabeth Elliot, has been quietly monitoring rare communicable and non-communicable conditions in children and adolescents.

Each month more than 1,000 child health clinicians report on children newly diagnosed with key conditions studied at the APSU. This population-wide clinical data has directly informed public health policies affecting children. Their study on congenital infection with human cytomegalovirus (cCMV) commencing in January 1999, is the longest running of its kind in the world.

The very first APSU employee was Dr Kerry Chant, now Chief Health Officer in NSW. Over the past 30 years the APSU has been first to identify significant threats to child health and safety and have delivered an evidence-informed approach to drive change. Thanks to their work, Australia was the first country in the world to introduce mandatory regulations for safer button battery packaging. Other achievements include driving changes in child seatbelt laws, changes to food safety laws following a major foodborne outbreak, introduction of new laws for pool fences and safety guidelines for home pools and national surveillance of polio to ensure that the Western-Pacific region is polio free. SCHF is proud to support this international leader in child safety.

"I love working with children. I love that they want to get better, that their families want them to get better... That's a real opportunity to have an impact on their health for the rest of their lives," said Dr Elizabeth Elliot.

Picture: Professor Elizabeth Elliot (right) receives the 2023 University of Sydney Alumni Award for Professional Achievement from Chancellor Belinda Hutchinson AC (left) in recognition of her outstanding contribution to paediatric medicine. Photo courtesy of Bill Green.

Learn more

Source 1: Australian Paediatric Surveillance Unit (APSU) Annual Surveillance Report 2022 Communicable Diseases Intelligence 2023, 47 https://doi.org/10.33321/cdi.2023.47.46. http://health.gov.au/cdi

Research

Kick starting early career research

$194,510

In small grants funding contributed in FY21

10

Small grants projects funded including laboratory and clinical research

More than $3 million

More than $3 million in successful grant applications to progress the research

For researchers who are just starting in their careers, small grants (up to $20,000) can help deliver the "proof of concept" needed to attract competitive grant funding.

Thanks to your support, early career researcher small grants funded in 2021 have since generated more than 16 times the initial investment, supporting the most talented minds to deliver innovative solutions for kids' health.

Researcher: Nusrat Homaira

Project
Care From Home: Comprehensive community-based care coordination for management of paediatric asthma (CoMPAs study)

Target group
Children aged 5-16 years old, who have been to hospital with asthma in the previous 12 months

Goal
Connect all the key stakeholders involved in a child's asthma management to provide comprehensive asthma care close to home

Progress and findings
Delivered educational webinars to health professionals and parents/carers. After 6 months, children receiving comprehensive care had improved asthma control and health-related quality of life, and reduced visits to GP, hospital and emergency department. Currently developing translations into 3 languages and an animated video

Next steps
Implement the model of care across four rural local health districts (LHDs) in NSW with $50,000 funding received from NSW Ministry of Health based on pilot data from this study

Research

Kick starting early career research continued

Researcher: Michaela Yuen

Project
MyoD-Myogenesis for RNA-Diagnostics in Undiagnosed Families

Condition
Muscle conditions

Goal
To develop a diagnostic test using skin and urine cells that will eliminate the need for invasive muscle biopsies

Progress
Completed key project milestones for developing MyoD-transdifferentiation methodology and a new diagnostic test. Analysing results

Next steps
More than $2.5 million awarded in competitive MRFF grants to continue this research

Researcher: Hiba Jebeile

Project
Identifying adolescents with or at risk of mental health concerns during obesity treatment

Condition
Mental health and obesity

Target group
Children, adolescents and young adults being treated for obesity

Goal
Develop a screening protocol to identify risk of mental health

Progress and findings
A mental health screening protocol and questionnaire was developed and implemented in clinical setting and is valuable for identifying adolescents at risk of mental health issues. The process has been continually improved through regular evaluation in the clinic

Next steps
Shared protocols and resources with another interstate children's hospital to implement mental health screening. Data on the change in mental health outcomes following treatment in the clinic will be reviewed periodically.
NHMRC Investigator Grant (2023-2027) $605,150 will support ongoing evaluation and analysis of these data

Researcher: Suzanne Nevin

Project title
Collaboration on Genetic Epilepsies and Neurogenetics, SCHN (cogenes)

Condition
Genetic developmental and epileptic encephalopathy

Target group
Families of a child with a genetic developmental and epileptic encephalopathy

Goal
Implement a psychological intervention to support families into clinician practice

Progress and findings
The resources were useful to help conversations about psychological supports and clinicians felt comfortable using them because they were codesigned by families, resulting in increased awareness and access to the resources and understanding of the perceived benefits and barriers to implementation

Next steps
Extend the program to a broader population, seek sustainable funding, collaborate with interdisciplinary teams and researchers, ongoing evaluation

Researcher: Erica Tsang

Project
The ketogenic diet in children with epilepsy: investigating epigenetic and gut microbiome mechanisms of action for improved patient selection

Condition
Medication-resistant epilepsy

Target group
Children with medication-resistant epilepsy

Goal
To predict which patients could be treated with the ketogenic diet

Progress
Study recruitment is more than 60% complete, and staff have completed training. Proposed that protein dysregulation may be a biomarker for certain neurodevelopmental disorders, including Kabuki syndrome. The study has provided insights into how the ketogenic diet works for some neurological disorders, and is under review at a prestigious international scientific journal

The study has provided more opportunities to bridge research and clinical practice for Network staff

Next steps
Applying for funding to further this work

Positive patient and family experiences

"Spending time in hospital can be challenging for adults, let alone children and young people, so it's important we do what we can to help make this time a little less difficult.

We are fortunate to have a number of services and programs dedicated to enhancing the patient experience and supporting families during their time of vulnerability, and we see this impact of this every day, whether it be through a smile, a hi-five or new hurdle overcome.

The fundraising efforts of SCHF help make these moments possible and give us the ability to elevate our care from the good to the extraordinary."

Chrissy Ceely

Acting Director of Nursing at
The Children's Hospital at Westmead

Patient experience

Elevating the voices of young people with lived experiences

1 in 6

Australians have a lived experience of disability[1]

51%

Of young people with disability avoid situations because of their disability[2]

1 in 4

Young people with disability are underemployed*

16%

Of young people with disability experience discrimination

The young people in the Chronic Illness Peer Support (ChIPS) community are all too familiar with the often isolating experience of living with a chronic health condition(s) and/or disability.

Harbouring a desire to create space for conversations to authenticate lived experiences, they searched for innovative solutions to find, connect and support the broader community. The result is the 'Chronic Conundrums' podcast series, created for and by young people living with chronic health conditions and/or disability.

The podcast officers, four young people with lived experience of chronic health conditions and/or disability, teamed up with healthcare professionals, Directorate of Communication and Engagement (DCE) SCHN, Youth Council SCHN, the Australian Film Television and Radio School and the University of New South Wales to create this engaging podcast series. Throughout the project, the officers worked in accordance with the key milestones outlined in SCHF's Art Program.

They collaborated to discuss, brainstorm and materialise ideas relating to content, audiences, representation and narrative structuring. To read more about the work of our Art Program see page 52.

3 month

Internship for 2 young people with lived experience to support planning, research and project implementation

10

Young people completed an Auslan interpretation course to support accessible programming and projects

100+

Young listeners during the initial testing phase

Throughout the project, podcast officers developed valuable project design, implementation, evaluation, podcast production and media strategising skills. They also gained experience in collaborative work, building connections and partnering with external organisations.

One of the key themes explored in the series was accessibility. Conversations illuminated the underlying sociocultural complexities of living with a chronic health condition(s) and/or disability. Podcast officers realised a medium that can disrupt historical narratives of stigmatisation, discrimination and inadequate support systems, imbuing their episodes with stories of resilience, compassion and renewal.

The podcast officers shared an important message throughout the series: illness does not define who you are. Ultimately, the podcast officers strived to orchestrate an inherently humanising journey through chronic illness and disability, empowering young people everywhere. By using this podcast to elevate their voices, they are actively shaping healthcare services in innovative, meaningful and relevant ways. This will have an immense impact on the everyday lives of people living with chronic conditions now and in the future as these young people are taking control of the systems that affect them.

"We wanted the episodes to feel like you're at a dinner table talking with your friends about the complexities of chronic illness, but also to be a resource that can accompany treatment and support people through the diagnostic experience," said Charlotte, Chronic Conundrums Podcast Officer and Writer.

Picture: (Top) The Chronic Conundrums team in action putting together the podcast released September 2023. (Middle) The Chronic Conundrums team with family members. (Below) The Chronic Conundrums team in action putting together the podcast released September 2023.

Listen to the podcast

Source 1-2: Australian Institute of Health and Welfare. (2022). People with disability in Australia. Retrieved from https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia

* Aged 15-24

Patient experience

Healing through art with SCHF's Art Program

318

Workshops delivered across 2 hospitals

932

Patient engagements

451

Art packs distributed

21

Exhibitions

For many children and young people across NSW, the mental health services delivered by SCHN are a crucial lifeline. These dedicated teams of mental health professionals, including physicians, doctors, nurses and peer support workers, all share a common mission: to assist and support young individuals in their time of need.

Within the Saunders Mental Health Unit at Sydney Children's Hospital, Randwick, the SCHF Art Program collaborates with clinicians to enhance the care provided to patients through their weekly art experience workshops. Each session is crafted to provide patients with a creative source of engagement, providing them with space for self-expression, experimentation, and collaborative work.

The Saunders Mental Health Unit is grateful for the support of the Saunders Family Foundation. The SCHF Art Program is proudly supported by the BIC Foundation, the Page Family Endowment and SCHF's Movement of Many.

50%

Of all mental illnesses experienced in adulthood begin before age 14[1]

In Australia

Suicide is the leading cause of death for people aged 5-17 years old[2]

More than 1 in 8

Australian children aged 4-11 are experiencing a mental health disorder, especially anxiety and ADHD[3]

Learn more about our Art Program

Reimagining ideas of home with artist Camille Green

Following her exhibition in the corridors of Sydney Children's Hospital, Randwick, artist Camille Green generously volunteered her time to co-facilitate a workshop session at the Saunders Mental Health Unit alongside SCHF Artist Educators.

The workshop encouraged patients to produce an artwork which represented their dream space, reimagining what their idea of home could be in a fictitious world. Camille offered her knowledge of artmaking techniques and how to use the materials, and encouraged the young patients to engage in ways in which they were comfortable.

The small group of patients were taken by the artist's own work, and quietly took to the concept, pausing to discuss what home meant to them, and finding connection by sharing their personal experiences. As they did, whimsical scenes of giant mushrooms with cubby houses, tea pots with houses inside them, a city within a love heart and a home adorned with purple Jacaranda flowers began to take shape.

Each artwork provides a glimpse into each patient's imagined home. Not limited by the walls of the Unit, these works transported participants to another world.

At the end of the session, participants commented on this being the highlight to their week and expressed joy and thanks to Camille Green and our Artist Educator.

Pictures: Artist Camille Green facilitates a workshop at Sydney Children's Hospital, Randwick and some of the artwork created by workshop participants.

Source 1-3: Children's mental health and wellbeing Black Dog Institute, May 2021

Patient experience

Educating, engaging and empowering kids with Child Life, Music and Art Therapists

22

Child Life, Music and Art Therapy positions supported across SCHN

Delivering 24,891

Child Life and Music Therapy sessions in FY23

Supporting 805

Patients who participate in music therapy

And using 1278

Kilograms of donated Playdoh

Thanks to your ongoing support, specialist Child Life, Music and Art Therapists are using play music and art to help minimise the stress and anxiety that hospitalisation may cause to children and young people.

They encourage self-expression, boost confidence and support physical, mental and emotional recovery.

SCHF's support of Child Life, Music and Art Therapy is made possible by our incredible network of donors, including Camp Quality, Redkite and our amazing Movement of Many.

"Play is an essential part of care for every child and young person we see. It can take them to a world away from the hospital, when they are immersed in games and fun.

It can relieve stress and boredom, help them through painful procedures and can connect them to their world outside of hospital. It can also be helpful to allow them to explore what is happening on their medical journey.

Through the use of play, music, mindfulness, sensory and self-expression activities, we can help create positive experiences for the children and young people we treat, increasing their resilience and feelings of empowerment, and decreasing medical anxiety.

The difference this makes is enormous and it's the community who help make all of this possible, from helping to fund some of our specialist staff positions through to providing amazing toys and equipment.

I don't know where we'd be without their continuous and incredibly generous support," said Janet Burke, Manager of Child Life and Music Therapy at Sydney Children's Hospital, Randwick.

Lightening the load on patients and families

Having a child in hospital can be a stressful experience for the whole family, and moments of joy and relief can be hard to come by. From the very beginning of Judah's journey in hospital, Music Therapy has been an incredibly powerful source of support for him and his family. Even when Judah needed a tube to help him breathe, music helped to lower his heart rate and he became more settled as the music played. Every time he settled, parents Jaxon and Kirsten also settled. Now, when his music therapists stop by, Judah interacts with bells and rattles. When they sing 'You Are My Sunshine' and 'Somewhere Over the Rainbow', he smiles. And every time he smiles, everything for Jaxon and Kirsten feels lighter.

Picture: Judah with Music Therapist Monica.

Patient experience

Helping sick kids get Back on Track with school

Children undergoing cancer treatment are often in hospitals for prolonged periods, disrupting their entire life.

5

Education coordinators including 1 focusing on French-speaking families from New Caledonia

313

Patients supported, including 6 from New Caledonia

SCHF endeavours to bridge the gap between the world a child experiences in hospital and the world they are longing to get back to.

Part of this world includes education and schooling. SCHF is proud to support the world-leading Back on Track program, a wraparound education service. Back on Track is run by five Education Coordinators across Sydney Children's Hospital, Randwick and The Children's Hospital at Westmead, who help keep children connected with schools and their education.

One of the Education Coordinators, Maîtresse Justine, works with children from New Caledonia and focuses on the specific needs and education objectives of the French National Education curriculum. International patients often experience challenges adapting to their temporary relocation to Australia, sudden separation from family members and classmates, being unfamiliar with the English language and the cultural codes of Australia. This year, she supported six children aged from two to 16 with their schooling and adjustment to their long treatment. Back On Track, sponsored by donors including The Profield Foundation, provides a smooth transition through education whilst undergoing treatment, and a smooth transition back to school after treatment.

Picture: Artwork by students Laure and Wawa during their hospital stay. It symbolises the links between Australia and New Caledonia as well as the attachment to their country of origin.

Meet the Movement of Many

The Movement of Many is the name of our community of 70,000 donors, supporters, volunteers, friends and partners fighting for the health and wellbeing of all kids in an ever-changing world.

They are the thinkers, doers, planners and creators, the helping hands and the guiding lights that make the Foundation what it is.

Movement of Many

Meet the Movement of Many, our community of unstoppable changemakers

Our incredible team of volunteers are an essential part of the Foundation and the heart and soul of the Movement of Many.

3,044

Volunteers including 1,290 new volunteers

8,737

Volunteering hours

$436,825

Value of volunteer hours*

From helping out at a wide range of different fundraising events and appeals, to contributing in the office, virtually or behind the scenes, we simply couldn't do what we can do for sick kids and their families without our amazing volunteers.

Award-winning volunteer program

In 2023, SCHF was accredited by The Centre of Volunteering as an Exemplary Volunteer Involving Organisation in NSW for our adoption of the National Standards for Volunteering. SCHF is the first and only organisation to fully implement these standards and receive this accreditation in NSW.

Leaving a lasting legacy

Our Movement of Many supported the health of children in NSW and beyond by funding key positions, vital research and unparalleled patient experiences. These incredible contributions are underpinned by the many generous Gifts in Wills from those donors who honoured us with a lasting legacy.

Thank you for going all in for kids' health.

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*Based on 2023 Australian Bureau of Statistics (ABS) figures estimating volunteers labour costs at $50.88 per hour

Running and walking for kids' health

365+

Community fundraising events and activities

Whether they showed support by lacing up their walking and running shoes, putting on their volunteer t-shirts or encouraging friends and family to donate, thousands from our Movement of Many came together for walking and running events over the last year, as fundraisers, volunteers and supporters.

At City2Surf, SCHF was the leading charity and raised $545,000 with 2,132 runners.

Our annual Walk for Kids with Cancer saw the largest crowd in the event's 16-year history, with 1,059 supporters and 94 teams travelling from all over Sydney and beyond to walk 27km from Circular Quay to Manly and raise funds for the oncology departments across SCHN.

To thank our supporters, seven-year-old Ollie created a beautiful artwork for our certificates that his proud parents, Nathan and Naomi shared with us in the hopes of raising awareness about his devastating disease, rhabdomyosarcoma.

"It's so important we shine a light on this illness and a child's cancer journey. The reality is that it's hard, really hard, and affects the whole family," said Ollie's dad, Nathan.

At this year's 65k 4 65 Roses Walkathon, 94 SCHF volunteers gave their time to encourage walkers and ensure their safety on the course. SCHF volunteers stood in the rain with their pom poms singing, dancing and cheering on every walker.

Our final walker crossed the 65-kilometer finish line after 14 hours, and our volunteers were there to support him the whole way, staying back in the cold, dark rain to cheer him on right to the finish line. He shared he was walking for his little girl who passed from Cystic Fibrosis. Despite blisters at the 20km mark and wanting to give up, he kept going, thinking of his girl. He would have crossed the line alone if not for our staff and volunteers.

Pictures: Ollie spent hours drawing a colourful thank you message during his latest round of chemotherapy treatment.

Read Ollie's full story

Movement of Many

Meet the Movement of Many, our community of unstoppable changemakers continued

Supporting families and the environment

When SCHF replaced laptops across the organisation in FY23, our Information Technology team refurbished the old laptops to give them new life.

SCHF distributed the old laptops for use by patient families in multiple hospital departments such as Social Work, HARK Refugee Clinic and Community Child Health, as well as participants in the Back on Track Program.

Sydney Swans join our Movement of Many

This year, SCHF teamed up with the Sydney Swans to create fun and engaging experiences for kids and young people that emphasise the importance of nutrition, sports and physical activity.

No one was more excited about this partnership than Lachie, one very special patient and avid Sydney Swans fan. In July, SCHF and the Sydney Swans hosted Lachie and his dad at the SCG, where they joined the Guard of Honour to welcome the team onto the field and got to meet some of their favourite players. SCHF was honoured to help facilitate this magical day, where Lachie could create memories that he and his family will hold close to their hearts forever.

Picture: Lachie with the Swans.

Read Lachie's story

The price of a gift? Just a smile at Mother's and Father's Day stalls

7,000+

Individual items given away at the Father's Day stalls

550

Goodie bags delivered across 24 wards for Father's Day

Powered by our dedicated volunteer army, SCHF hosted Mother's and Father's Day stalls at Sydney Children's Hospital, Randwick and The Children's Hospital at Westmead. Using a smile as currency, kids looked through the stalls and carefully picked out a heartfelt gift for their beloved parents and carers.

Reflecting on the Father's Day Stall, our Volunteer and Supporter Engagement Lead Kylie shared a heart-warming tale of one tired mum from the ACT, who had spent four challenging months at the hospital since her baby boy's cancer diagnosis. This mum tearfully shared that she hadn't had the time to get her husband his very first Father's Day gift, but thanks to SCHF, she left with an enormous bag filled with goodies and groceries to take back to their motel room.

"The day was nothing short of amazing, filled with countless smiles and a few tears from mums, moved by the impact the stall had on their families", said Kylie.

These events were possible thanks to Ward Angels, their community of supporters, and SCHF volunteers.

Picture: Our wonderful volunteers powering the Mother's Day Stalls (top) and the gift bags they prepared to deliver to wards around the Hospital (below).

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.

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Registered charity

SCHF 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

REGISTERED CHARITY
acnc.gov.au/charityregister

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.

Donate today

SCHF Sydney Children's Hospitals Foundation