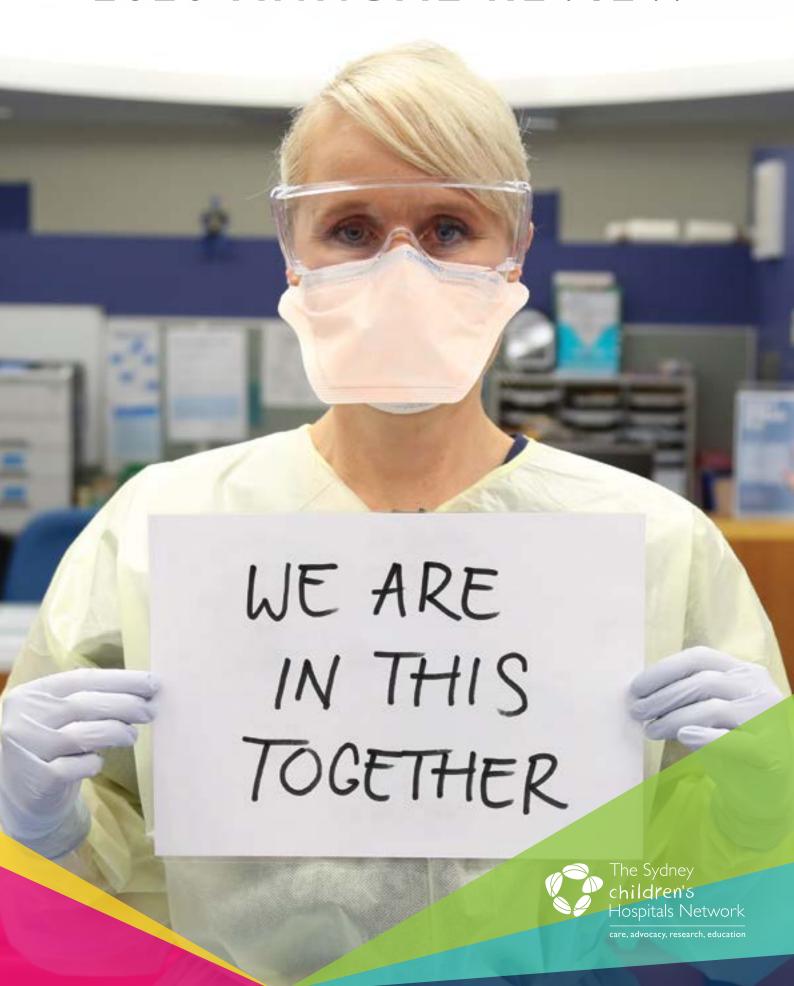
SYDNEY CHILDREN'S HOSPITALS NETWORK

### 2020 ANNUAL REVIEW





Network (SCHN) sits upon the spiritual lands looked after for many thousands of years by the Gadigal and Bidjigal peoples who traditionally occupied the Sydney coast at Randwick, the Burramattagal people of the Darug Nation, at Westmead, the Gayamaygal people of Manly and the Darak people at Bankstown.

SCHN also acknowledges that no matter where you are today, under all the asphalt and concrete, this is, was and always will be, Aboriginal Land.

SCHN would like to acknowledge and pay respect to all Elders, past and present, our Aboriginal children who are our future leaders and all other Aboriginal people, who form the oldest continuous living culture on earth. Particularly those from the stolen generations who never made it home.

SCHN also acknowledges events of the past continue to cause pain and suffering for Aboriginal people and communities today. We acknowledge further uncomfortable conversations, truth telling in reconciliation and action is necessary, to truly heal the wounds of our shared history.

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## ACTIVITY DASHB & ARD



OCCASIONS OF SERVICE FOR NON-ADMITTED PATIENTS

963,893

SCH: 295,051 CHW: 668,842



EMERGENCY DEPARTMENT PRESENTATIONS

88,829

SCH: 33,265 CHW: 55,564



HOSPITAL ADMISSIONS

50,642

SCH: 16,137 CHW: 34,505



NUMBER OF CHILDREN CARED FOR

153,027

SCH: 68,055 CHW: 84,972



ADMITTED PATIENT OCCUPANCY (%)

84.3%

SCH: 74.3% CHW: 89.7%



AVERAGE LENGTH OF STAY (DAYS)

(excluding same-day cases)

4.9

SCH: 4.7 CHW: 5.0



COMMUNITY AND HOME DELIVERED OCCASIONS OF SERVICE

309,175

SCH: 105,311 CHW: 203,864



**OPERATIONS** 

(elective and non elective)

18,434

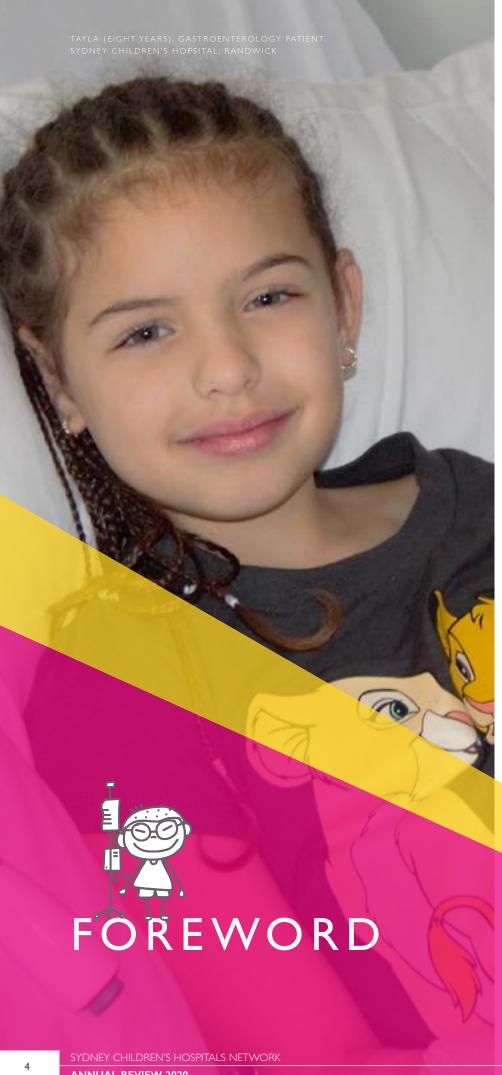
SCH: 5824 CHW: 12,610



TOTAL NUMBER OF BED DAYS

151,029

SCH: 46,798 CHW: 104,231



Sydney Children's Hospitals Network is proud to report on the 2019-2020 outcomes for its patients and families.

2020 has been a year like no other, with the global COVID-19 pandemic bringing significant change to the way we operate. It has also been a year of exceptional achievements in research and clinical care.

Our focus, as always, continues to be on providing the very best care for our patients and their families. In 2019-2020, teams cared for a total of 153,027 children from Sydney, NSW and beyond, our hospitals had 50,642 admissions and our emergency departments saw 88,829 presentations.

Oncologists at Sydney Children's Hospital, Randwick delivered the state's first CAR T-cell infusion to an II-year-old patient, following a three-year battle with a rare form of leukaemia. This type of therapy is an exciting breakthrough in leukaemia treatment, which offers hope to children who have relapsed on standard therapies.

Surgeons at The Children's Hospital at Westmead performed a ground-breaking liver transplant on a four-year-old boy, the youngest Australian patient to undergo this type of 'split liver' transplant. The Auxiliary Partial Orthotopic Liver Transplantation (APOLT) procedure, involved removing one half of the damaged liver and attaching a portion of the donor liver in its place, to allow the native, damaged liver to slowly recover before removing the donor liver.

Driving world-class research is integral to what we do. It has been an unprecedented year for our research division, Kids Research, with more than \$70 million committed to new research projects aimed at improving the lives of children suffering from conditions including rare genetic diseases, cancer, heart, kidney and infectious disease. This investment will help us continue to accelerate the way research improves patient care.

At the start of 2020, NSW Health announced the outcome of the review into the state's paediatric services, which recommended that The Children's Hospital at Westmead and Sydney Children's Hospital, Randwick remain under network governance, as comprehensive children's hospitals with tertiary and quaternary services on each site. Implementation of the review's recommendations has commenced and brings renewed opportunities to build on our foundations and strengthen the specialised paediatric services the Network delivers to children, young people and their families across NSW.

The COVID-19 pandemic continues to impact us at home, at work and in the community. Our priority remains to help prevent the spread of the virus and keep our patients, staff and community safe. In response to the pandemic, the Network enacted detailed disaster management plans, introduced and delivered new models of care, contributed to vital research and maintained regular communication with staff, patients and families, our partners and other stakeholders.

Mandatory state-wide restrictions led to a marked increase in the use of telehealth. At 1 July 2020, 128 teams had been set up for telehealth across SCHN – a 412% increase compared to the previous financial year. Wards were reconfigured and working practices adapted daily, to prepare for a possible surge in patients. The Clinical Data and Analytics Platform (CDAP), developed through the Digital Health Cooperative Research Centre, was established to provide nationally available real-time analytics on the progression of COVID-19 patients to severe disease, to support front-line care. It's a measure of the quality, capability and commitment of our people that we achieved this while still delivering essential care to sick and injured children.

The challenges brought on by COVID-19 have also been felt by the fundraising community. Sydney Children's Hospitals Foundation has been agile in pivoting their fundraising efforts following forced cancellation of public events and activities. We continue to work closely with our Foundation colleagues to maximise new opportunities as well as assisting with the re-framing of some of the Foundation's headline events.

Over the last year, the Network has renewed its strategic focus on building our Aboriginal workforce and strengthening our support for Aboriginal patients, families and communities. This year saw the establishment of a Network Aboriginal Health Unit which aims to improve experiences, access and health outcomes of Aboriginal and Torres Strait Islander children and their families and ensure the Network's services are culturally responsive and inclusive.

In 2019-20 redevelopment milestones were met with major construction completed on the Central Acute Services Building at Westmead in May 2020, three months ahead of schedule. Change management and commissioning will continue throughout 2020-21 when the new Emergency Department, Children's Short Stay Unit, Operating Theatres and satellite pharmacy and medical imaging open in the new building. Located on two thriving world-class health and education precincts, redevelopments at Randwick and Westmead will transform paediatric care in this state by enabling the rapid translation of research to the patient's bedside, improving the patient and family experience and fostering health partnerships.

As part of our redevelopments, SCHN has been exploring how virtual care can help us deliver the next generation of children's care, to support care anywhere. The vision produced for our virtual care services, is an innovative, digitally enabled health network supporting paediatric service delivery and care across NSW and Australia, and builds on the Network's successes in the digital advancement, integrated and ambulatory care spaces.

Despite the challenges presented over the past year, staff have worked together to ensure continued delivery of safe, quality care with our purpose always at the forefront – helping children and young people live their healthiest lives.

We would like to thank our staff, volunteers, donors and supporters, whose commitment ensures we continue to evolve as we strive to be international leaders in paediatric healthcare, for children first of foremost.

SCHN Executive Team and SCHN Board

As our Network moves forward, we warmly welcomed Elizabeth Crouch AM as the Board Chair in March 2020 and Cathryn Cox PSM who joined SCHN as the new **Chief Executive in August** 2020. We thank Interim Chief Executive Adj A/Prof Cheryl McCullagh for her unwavering dedication to the Network and her role in positioning the SCHN for a strong and vital future.

### SYDNEY CHILDREN'S HOSPITALS NETWORK



The Network is made up of seven specialised children's health services:



The Sydney children's Hospitals Network

Inpatient and outpatient care provided in the eastern suburbs of Sydney with more than 1700 staff members.





The Sydney children's Hospitals Network

Inpatient and outpatient care provided in the western suburbs of Sydney with more than 3500 staff members.



A very special place on Sydney's northern beaches, dedicated to caring for children with life-limiting conditions. Bear Cottage in Manly is the only children's hospice in NSW and provides paediatric palliative care 24 hours a day.



The Sydney children's Hospitals Network

Located at both hospital sites in Sydney's east and west, 600 researchers, support staff and students are dedicated to discovering new ways to improve the health of children.





A statewide service of NSW Health, hosted by Sydney Children's Hospitals Network. The only of its kind in Australia, NETS provides 24 hours a day clinical advice, coordination and emergency treatment and transportation to sick babies and children across NSW.





A service that works to improve the quality and safety of maternal and neonatal care in NSW, especially for women and their families at high risk of an adverse outcome.

**NOTE:** PSN is currently in the process of realignment of roles and functions across to the Ministry of Health, Agency for Clinical Innovation and Clinical Excellence Commission.





Located in Parramatta, the Clinic undertakes independent clinical assessments to help magistrates and judges in NSW Children's and District Courts make a decision in the best interest of children.



### **OUR AMBITION**

'International leaders in children's health'

#### **OUR PURPOSE**

'Helping children and young people live their healthiest lives'

#### **OUR IDENTITY**

'Working together ...
for children'

### OUR GUIDING PRINCIPLES

- Children first and foremost: both in what we do, and what we advocate for
- Safe, reliable and effective care
- Partnership with children and families
- Value based: focusing on what makes the difference
- Equity in access, with a focus on the vulnerable and at risk children and young people

### **OUR VALUES**

- **Collaboration:** The Network recognises that each staff member and profession contributes to the provision of excellent patient care. This is enhanced by working in partnership with families and co-workers to provide patient-centred care.
- **Openness:** The Network is committed to open communication and transparency in decision-making for patients, families and staff.
- **Respect:** The Network respects all staff, students, patients and families in our care. We are committed to being kind, respectful and compassionate in everything we do.
- Empowerment: The Network is committed to the provision of patient-centred care and working in partnership with families to provide the very best for the state's children and young people. We'll continue to empower patients and their carers to participate in decision-making and create a culture for staff that is safe and supportive at all levels.

We've developed a model for driving great patient experiences and health outcomes for children and families. This includes:

- **Delivering child and family-centred care:** more than just a positive experience child and family needs and desired outcomes will deeply inform how we deliver and design models of care.
- Supporting and empowering staff and families: education that supports and empowers engagement by families, and effectiveness of our staff.
- **Applying great research:** leveraging and developing the game-changing ideas of the century.
- Expanding our reach: through prevention-focused efforts, advocacy, and partnership.
- **Building a solid foundation:** developing infrastructure, systems, and finances that support what we do.

### **ENABLERS**



Infrastructure



Systems and Processes



Finance

### **KEY ACTION AREAS**



Child and Family-Centred
Clinical Care at the
safest and best level



People and culture



Education



cation Resea



Research



Advocacy



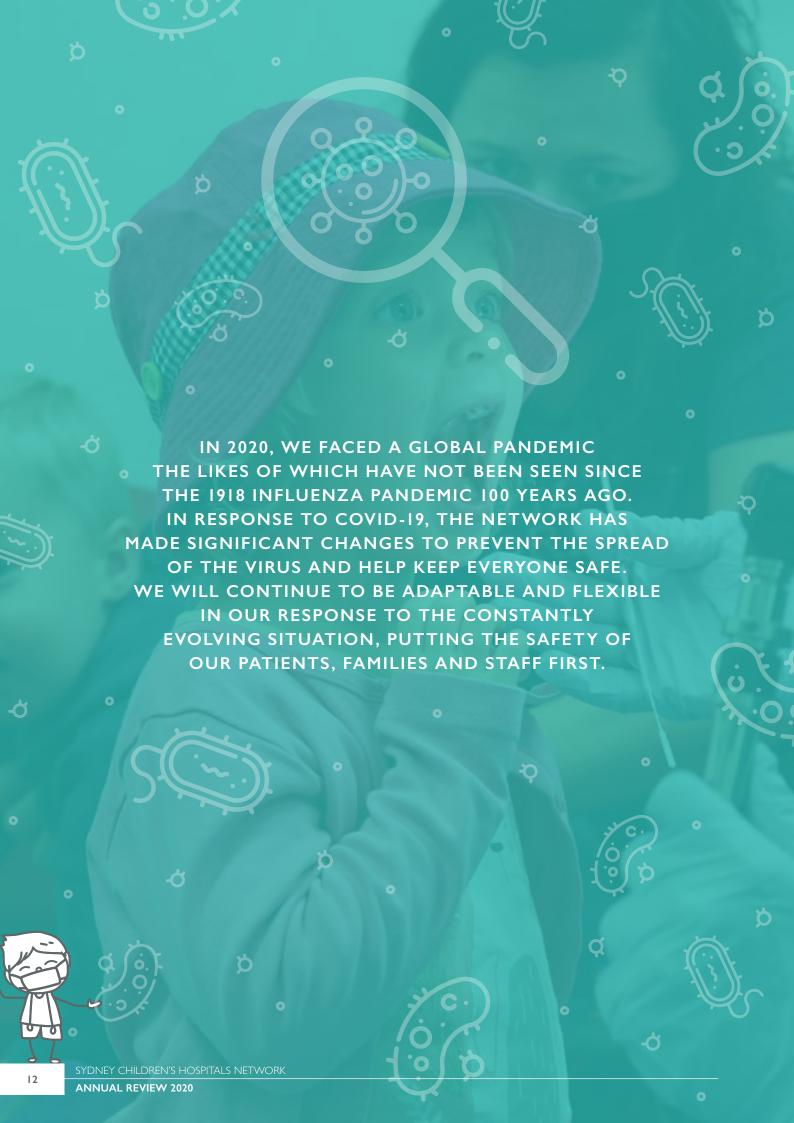
**Early** intervention



Partnerships and Networks



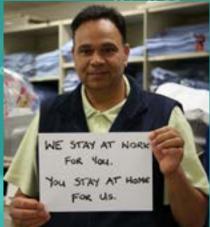




















































The SCHN COVID-19 response has been an enormous logistical operation. To coordinate SCHN's preparedness for the anticipated effects of the pandemic, the SCHN Emergency Operations Centre (EOC) was established on 30 March 2020, led by Dr Mary McCaskill, Network Incident Controller, supported by the SCHN Disaster Coordinator Kristy McLeod, site leads Verity Luckey (SCH Director of Nursing) and Alan Gardo (CHW Director of Nursing), and the EOC Coordination team. The response was divided into functional areas: Operations, Planning, Logistics, Communications, Liaison and Infectious Diseases/Infection Prevention and Control. The SCHN EOC follows directives and guidelines established by NSW Health, the NSW Public Health Unit and Clinical Excellence Commission to protect our patients, visitors and staff.

A number of changes were implemented across the Network to prevent the spread of COVID-19 and keep our patients, families, staff and volunteers safe. Our response to the pandemic included:

### **LIAISON**

- Partnership with Westmead Precinct, Randwick Hospitals Campus, NETS and regional partners to ensure a coordinated response
- Representation at state and national COVID-19 taskforce meetings
- Collaborative care agreements with private hospitals to assist with surgical lists
- Exploration of production of 3D printed shield attachment, scrubs and training gowns
- Procedures were set up for international and Australian patients requiring exemption, in partnership with the Australian Border Force and international charitable organisations

#### **OPERATIONS**

- 90 Standard Operating Procedures developed
- 18 working groups established
- Changes to age limits to accept patients up to 19 years and help support heavily impacted adult facilities
- Visitor policy changes to allow only one parent/carer to visit, to reduce the number of people entering our hospitals
- Establishment of the COVID-19 Outpatients Response Team (CORT) – to care for COVID-19 positive patients in the community
- Established COVID-19 assessment clinics providing free tests for patients, families and staff
- Supported other Local Health Districts with pop up testing clinics
- Elective surgery and outpatient clinics moved to telehealth where possible, rescheduled or cancelled following government directives
- Implementation of support plans for vulnerable patients and families affected by COVID-19 restrictions
- Suspension of non-clinical support services to limit the number of people entering our facilities
- Agile changes to our facilities, systems and processes, including essential building works, to enable establishment of designated COVID-19 wards, Emergency Department and Intensive Care Unit (ICU) hot and cold zones and increased capacity in ICU
- · Virtual teaching in hospital schools
- Gradual return to business as usual, incorporating COVID-19 restrictions



#### **PLANNING**

- Staff training and up-skilling to allow redeployment to areas of high need (for example training allied health staff to care for patients in the ICU)
- Staff coordination to ensure appropriate staffing in all areas
- Recruitment of more cleaners to enhance infection control practices
- Personal Protective Equipment (PPE) training and support measures implemented
- Preparation of SCHN pandemic response plans to plan for continued COVID-19 risk and possible increase in COVID-19 positive patients
- Implementation of work from home and return strategies
- Identification and redeployment of vulnerable workers, including volunteers
- Virtual meetings via Skype and Pexip
- Development of staff wellbeing initiatives

#### **LOGISTICS**

- Ensuring adequate supply of PPE, ventilators, hoods, shields and powered air purifying respirators
- Development of COVID-19 dashboard to provide testing information and other real-time data to help plan the COVID-19 response
- Establishing and maintaining health screening stations at all entrances to SCHN facilities
- Developing and supporting technology platforms needed to inform patients of their test results and assist with contact tracing such as the SMS messaging system
- Changes to the SCHN electronic medical record (eMR) system to capture COVID-19 data
- Weekly PPE audits
- Increased bandwith and loan of laptops and equipment to enable staff to work from home

#### COMMUNICATIONS

- Developed communications for staff, patients and families with the aim of clear, transparent, supportive messaging
- SMS screening messages sent to families with Outpatients Department and surgical appointments
- Developed patient resources (including translated resources) such as letters, videos, social media, handouts, posters, billboards and signage to communicate changes to our services, physical distancing requirements and new hospital guidelines
- COVID-19 section created on the SCHN website for the community
- Daily communication to all staff via emails from the Network Incident Controller
- A dedicated EOC inbox for staff to ask questions and provide feedback
- Creation of a COVID-19 intranet hub and SCHN website shared with state paediatric services and remote SCHN staff
- Development of a Community Transmission Risk Indicator
- Virtual staff forums and Grand Rounds presentations with our infectious diseases teams





#### VIRTUAL COVID-19 CLINIC

Children who have tested positive for COVID-19 with mild symptoms have been cared for at home by the COVID-19 Outpatients Response Team (CORT). Since it was established, CORT has supported 24 COVID-19-positive patients in the community.

4

It's been really reassuring to have the same staff member ringing every day, offering clear advice and answering questions, and speaking directly to the kids when they were worried. That support has been immensely beneficial for our whole family.

Fleur, whose 9-year-old daughter tested positive for COVID-19 in March.



As the Network Nurse Manager for Ambulatory Services I am privileged to be able to work with a team who are incredibly innovative, flexible and adaptable. Ambulatory Services, like many others have been significantly impacted by COVID-19 but these teams have taken each challenge in their stride.

The biggest addition has been the establishment and management of the COVID-19 assessment clinics and the CORT across the Network. The COVID-19 assessment clinics have been supporting the COVID-19 testing requirements for patients attending planned appointments along with members of the community presenting specifically for COVID-19 testing. The staff have worked tirelessly and have adapted to the many changes along the way to make this possible, which I am so proud of.

The CORT team have also been working in the background providing virtual care for all COVID-19 positive children residing in the community. They work closely with the Infectious Diseases team and Public Health units to ensure the child's care is managed safely in the home, that care is family-centred and is coordinated with the adult clinical teams across the Local Health Districts. The team is made up of senior staff within the Ambulatory Unit who have embraced the virtual care approach to this work.

In addition to this, the Medical Day Units at both Westmead and Randwick were relocated and despite the changes, were back on their feet in no time. The Outpatients teams have gone above and beyond to ensure that specialist outpatient clinics can continue for patients and families while also sharing their space with the COVID-19 clinics. The Hospital in The Home (HiTH) team have tackled the challenge of COVID-19 in the community and have found ways to work around this, particularly for patients requiring physiotherapy and the Kids GPS Care Coordination Service has been continuing to work with local care teams to support care for patients closer to home and avoid patient travel.

It has certainly been trying times as we tackle this COVID-19 pandemic, however working as part of this amazing team has been refreshing and is helping us all get through the tough times.

Nadine Shaw, Network Nurse Manager for Ambulatory Services.



### SYSTEMS AND TECHNOLOGY

CHANNING (6 YEARS), ONCOLOGY PATIENT,

SYDNEY CHILDREN'S HOPSITAL, RANDWICK

Our IT team helped a large number of staff to work from home with ease and efficiency – helping reduce the number of people in our facilities. The app portal service was accessed 231,973 times in a four-month period – a six-fold increase compared to the same period in 2019. Bandwith was increased to support the increased demand for telehealth services and staff working from home.

To assist in effective planning, the Clinical Integration team developed a real time COVID-19 dashboard that pulls data from multiple sources, including eMR and NSW Health Pathology. The dashboard provides:

- Assessment clinic testing data including number of tests carried out at each site and data based on result or patient cohorts
- Patient co-morbidity information for conditions like asthma, diabetes, epilepsy or cystic fibrosis
- Simulation modelling that facilitates the evaluation of cause and effect and gives a predictive analysis of usage and need

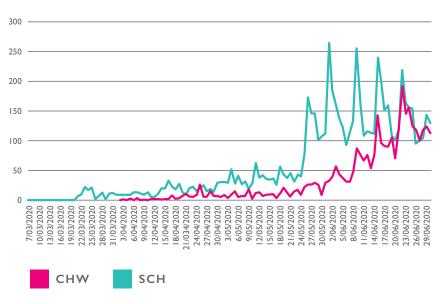
The dashboard assists with planning the COVID-19 response including PPE and staffing requirements.

STAY HOME FOR Me

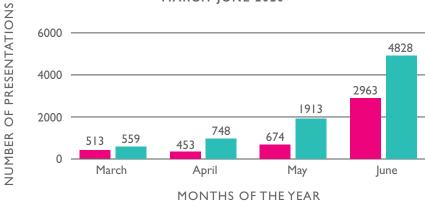
### **ASSESSMENT CLINICS**

Free assessment clinics for staff and children were established at SCH and CHW. Between March and July 2020, the clinics tested 2265 staff and 10,507 patients and families. The busiest day at CHW was 12 August when the clinic had 336 presentations and SCH on 24 August with 374 presentations to the assessment clinic.

#### SCHN COVID-19 PATIENT PRESENTATIONS MARCH-JUNE 2020



### SCHN COVID-19 CLINIC DATA MARCH-JUNE 2020









### **TELEHEALTH**

As of 1 July 2020, 128 teams have been set up for Telehealth across SCHN – a 412% increase compared to the previous financial year.

- A 1513% increase in Telehealth Service Events (appointments) in the second quarter of 2020 (15,405) compared to the second quarter of 2019 (955).
- In FY 2019-20, families have been saved approximately 2,691,855kms in travel by attending their appointment via telehealth.

Staff have been interviewed regarding their telehealth experience and have noted its benefits have included:

- Providing families a more relaxed, natural and comfortable environment to attend their consultation.
- Allowing both parents to join the consultation whereas normally only one attends face-to-face.
- Reducing the need for travel, particularly for our rural families and allowing families and children to remain safe throughout COVID-19.
- This echoes patient survey results which indicate more than 70% families say telehealth is convenient and saves them time.

Telehealth as a result of COVID-19 pandemic has enabled more equitable access to health care for our paediatric patients and families. The removal of residential location and distance from the hospital requirement for Medicare bulk billing has allowed all our patients and families to access telehealth which was once restricted to regional and more remote areas. This has been extremely well received by both our clinicians and our patients and families. Telehealth has enabled parents and carers to attend appointments with clinicians without having to take significant time off work, and time off school for children. Both parents have been able to join the same consultation and to hear first-hand the information, management plans and/or health education relating to their child. Parents who may be in different locations have been able to join in on consultations.

Through telehealth, we have been able to reach our patients and connect with their therapists or their local health provider or school teacher/counsellor with greater ease. The clinic appointment and outcome was enhanced, for example, being able to assess and witness directly the feeding practices and set up within a patient's home allowed the multidisciplinary feeding clinic team to understand more clearly the issues that may be contributing to the patient's oral aversion and feeding difficulties. This enabled the team to be able to provide detailed specific advice to address these potential factors and issues.

For some cases, the ability to observe children with developmental delay and concerns of autism within their home which is a familiar environment has been beneficial. Children with developmental delay or autism may find new or unfamiliar environments such as hospital clinic rooms difficult. Conducting the assessment in their own home allows for parents to be able to keep their child safe and entertained during the conversation with their clinicians.

Dr Christine Lau, General Paediatrician, The Children's Hospital at Westmead.

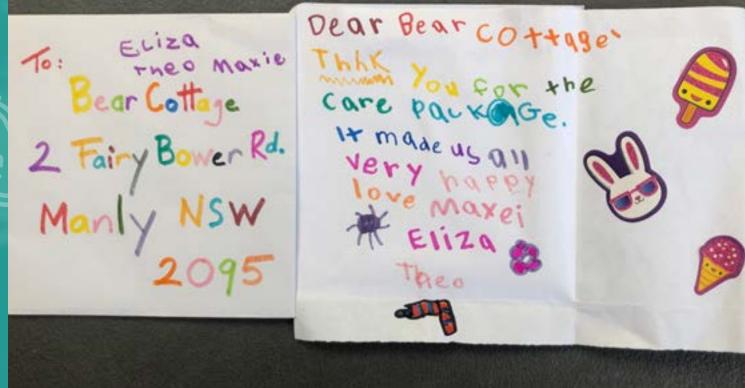
Here's what other staff have to say about the benefits of telehealth:

Before we were using telehealth more consistently it was really not uncommon for the parents to say 'when I start approaching the Harbour Bridge, I start feeling sick in my tummy' and they have this kind of anxiety about coming back to the hospital... [telehealth] removes that kind of physical anxiety that they experience.

I think it has been great. There has been an amazing acceptance of being able to interact with people online...and real enthusiasm by a number of the families. They don't have to get parking, they don't have to drive here, they don't have to wrangle wheelchairs and kids, and carers and afterschool care...an enormous amount of time saved, mileage and money.

We had all the team talking and discussing the patient at once. They didn't have to then re-tell their story and that's a big thing... they could just give an update of what was happening in the last few months and everyone could hear at the same time.





### HELPING KIDS BE KIDS - VIRTUALLY

### **DELIVERING CARE DIFFERENTLY**

Feeling isolated can be the norm for some Bear Cottage families, and COVID-19 restrictions meant access to support was limited. Bear Cottage staff and volunteers came up with innovative ways to continue providing support from afar, including care package deliveries, online art and music therapy and even virtual cooking classes from Bear Cottage chefs.

Our volunteers have quickly and effectively adapted to the different ways in which they can support Bear Cottage and our children and families. Children, siblings and their parents have had the chance to 'virtually' meet volunteers, to chat about their day, have a story read to them, play an online game or even navigate the intricacies of Google Classroom to support online learning of students. Bear Cottage has a breadth of skills and knowledge within its volunteer cohort from tutors and teachers to ex-nurses, counsellors and play therapists. Each and every volunteer can bring something unique to their role.

Their ability to show such compassion and selflessness during this difficult time is really humbling. It brings home the additional challenges that Bear Cottage parents have in these uncertain times. It reinforced the value of the respite stays at Bear Cottage that many parents benefit from and when that is not possible due to COVID-19, how much more difficult their lives can be.

Rachel Simpson, Bear Cottage Volunteer Manager



I just wanted to thank you all at Bear Cottage for your (care package) delivery. It was so very thoughtful and I'm sure our neighbour heard us squealing with excitement as we unpacked. We were so excited to see a friendly volunteer at our doorstep, we even made him some fresh Anzac biscuits and a drink to keep him going.

Bear Cottage mum

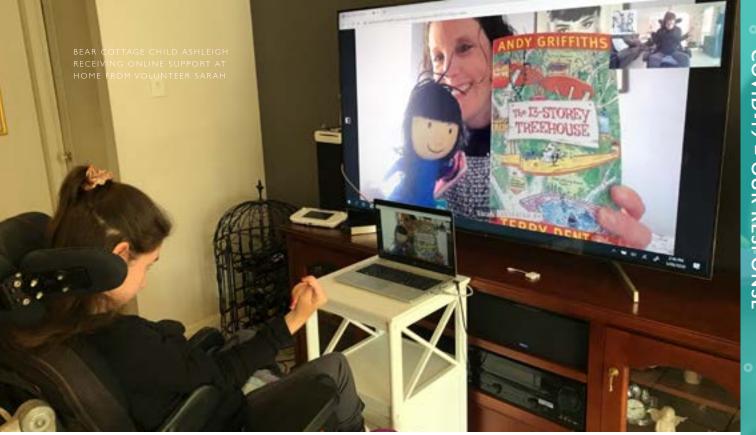


When working onsite at Bear Cottage, much of my work is around providing social interactions for the children and their families through music on a daily basis and, very importantly, using music for memorymaking towards the end of children's lives. During this pandemic, however, my role has expanded and has enabled me to provide music therapy sessions in a whole new way.

By providing music therapy via Zoom, I have been able to connect with families on a much more personal level. I am essentially being invited into their living rooms, into their private space, which is quite different from running sessions in the garden or sensory room at Bear Cottage. This has meant that I am able to connect with people in their own space and tailor my music to the specific situation they are in.

Annabelle Keevers, Bear Cottage Music Therapist

SYDNEY CHILDREN'S HOSPITALS NETWORK



Play is an important part of any child's life. One of the unique challenges facing children's hospitals during the pandemic has been bringing joy to children when visitors to our facilities are restricted. With a bit of creativity, staff have thought of alternative ways to bring a smile to our patients' faces, from virtual play clinics to celebrity visits beamed to patients' bedsides.



Typically the play clinic for palliative care patients operates face-to-face. It provides our patients and families with an opportunity to connect, socialise and most importantly have fun. However, with precautions in place to protect our most vulnerable patients, we can't invite them to the hospital at the moment. Even though play is incredibly important, we don't want to risk their health in any way.

To overcome this challenge and stay connected, we've created a 'virtual play clinic' which operates via Pexip. From the hospital to their homes, we offer play opportunities, read stories, sing and support each other, without being physically together.

The families are all excited that we can stay in touch during this time, and this has actually presented new opportunities for those families who couldn't attend in person previously because of distance and location.

Kirsty-Leah Goymour, Manager and Senior Child Life Therapist, Palliative Care and Chronic Pain at SCH



Pre-pandemic, on any given day I would be introducing the likes of Spiderman, Jessica Mauboy, Chris Martin or the team from Bondi Rescue to our little patients. As the Community Relations Officer an important part of my role is bringing entertainment and special guests to help brighten the day for kids in hospital.

When COVID-19 hit, for everyone's safety, the visits went virtual, and guests are now beamed to bedsides with the help of Starlight TV. So far we've staged over 30 virtual visits from musicians, celebrities, sports stars, and cameos from some of our furry and feathered friends at SEA LIFE Sydney Aquarium and WILD LIFE Sydney Zoo.

Despite the current challenges, I'm so glad we have found new ways to entertain our patients and keep the smiles on their faces during a long day in Hospital.

Jess Cooper, Community Relations Officer



### CICU TWO OF HEARTS INITIATIVE

Charlotte Kelly, a Clinical Nurse Specialist for Education at SCH's Children's Intensive Care Unit (CICU), started the 'Two of Hearts' initiative after hearing about the idea from a paediatric nurse friend in the UK. As a parent herself, Charlotte empathised with how difficult the situation must be for the patients' parents, particularly with tightened, yet essential, visiting restrictions due to COVID-19.

A knitting pattern for a pair of hearts was sent to CICU nurses, who passed them on to their mums, friends and grandparents, and before Charlotte knew it everyone was

knitting pairs of little hearts to be given to families One heart is given to the patient, and the matching heart is given to the parent to take with them when they can't be with their child.

66

I really think this helped others feel useful and connected in the community at a time of such uncertainty. It started during COVID-19 but we hope to continue this long after COVID-19 so that every family in CICU can feel how much we care.

### HOME SPIROMETRY HELPING AT-RISK PATIENTS

Children with difficult to treat asthma and cystic fibrosis are a vulnerable group of the community that we are working hard to protect during the COVID-19 pandemic.

COVID-19 is a respiratory illness that presents risk to this group of patients – should they become infected the chance of them requiring hospitalisation is high. To minimise the risk of contracting the illness from someone within the community, we are identifying suitable patients to undertake home spirometry.

Spiro home devices are a portable smart spirometer which is compatible with smartphones via Bluetooth. This device enables the clinician to determine if the patient's lung function has declined or if their current treatment therapy is working as expected.

6

Being able to access this device during the pandemic will support the management of their chronic respiratory condition and make a long-term positive difference to the lives of these children and their families, and importantly keep them closer to home.

Melinda Gray, Asthma Clinical Nurse Consultant, Respiratory Medicine, SCH.

#### THANK YOU TO OUR CLEANERS

Our cleaners are an integral part of the Network, ensuring cleanliness and hygiene levels are kept at the highest standard. During the pandemic, the role of our cleaners was highlighted, as was the importance of stringent hygiene practices to prevent the spread of COVID-19. The Network acknowledged its 170 cleaners on International Cleaners' Day on 15 June with gifts and messages of thanks.





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#### **PSYCHOLOGICAL WELLBEING WEEK**

This year SCHN held Psychological Wellbeing Week, an initiative to support the psychological wellbeing of all staff during COVID-19 and beyond. The week aimed to initiate open and honest conversations about psychological wellbeing, connect staff with helpful information and resources, and encourage all staff to take small, sustainable steps together to look after their wellbeing.

#### **GROWING KINDNESS**



Immediately we identified that the pandemic would be a stressful, challenging, emotional and confronting time for not only our patients and families but for the entire hospital staff. The team on C3 South came up with the idea of having a kindness tree to acknowledge the healthcare crisis to all whilst instilling positivity and acknowledgement of all staff, patients and families on the ward. Hearts were created for people to put their messages on. We received amazing feedback from families and decided to extend the blossoming heart to all departments on the Randwick campus. Bigger hearts were made with kindness quotes and placed on department doors. We have received many comments from staff all over expressing their appreciation and thanking C3 South for the acknowledgment.

While we monitor the growth in new coronavirus cases in Australia, our nursing staff on C3S want to grow and spread something of a different nature.

Kara Munro, Nursing Unit Manager for C3 South, SCH



#### **POSITIVE MESSAGES**



Keeping our Botox clinic up and running during the pandemic has been crucial for so many of our patients, including some who are undertaking their HSC this year and need regular Botox treatments to be able to study comfortably. To make this happen, we removed excess furniture from our waiting room, and set up zoned and themed areas for families to wait while safely practicing physical distancing.

We also have stars stuck on the floor to indicate where it is safe to stand to maintain physical distancing, and when able, our Botox patients are writing positive messages for other patients and staff members on the stars.

We have been encouraging other teams to come up to the Rehab2Kids department to see our patients, to prevent patients and families having to travel through the Hospital. Clinicians from Neurology, Orthopaedics and Orthotics have all seen patients at Rehab2Kids during a Botox appointment.

Families have been very appreciative of the extra steps the Hospital has put in place to ensure the safety and health of children and families who need to come to SCH for their appointments.

Pene Ingle, Clinical Nurse Specialist and Kerry Hanns, Physiotherapist, Rehab2Kids, SCH



#### **GIVING PATIENTS THE BEST CARE**



We have moved whole wards and teams to prepare for COVID-19 patients, which has been a challenge but everyone has really stepped up. I think it is important that we are all in this together and we are all here to support each other. I tell my staff there is a solution to every problem if we stay calm and think creatively. One of the positives to come out of this is that everyone is stepping out of their comfort zones and realising there are different ways of working. We are breaking down barriers, collaborating and working within other teams. Most importantly we are all still here with the common goal – to give the patients the best care we can.

Pam Bold, Nursing Unit Manager of Variety Ward, CHW



### COVID-19 RESEARCH

The speed and scale of the global spread of COVID-19 has precipitated worldwide research on the virus and the race to develop a vaccine. Expert teams at Kids Research are driving vital national and international research into the virus, from the study of its transmission in schools to developing a digital solution that improves the way clinicians understand, and treat people with COVID-19.

### TRANSMISSION OF SARS-COV-2 IN AUSTRALIAN EDUCATIONAL SETTINGS: A PROSPECTIVE COHORT STUDY

The National Centre for Immunisation Research and Surveillance (NCIRS), with the support of the NSW Ministry of Health and Department of Education, conducted an investigation into COVID-19 cases in schools and early childhood education care (ECEC) services to understand the transmission of SARS-CoV-2 in these educational settings in NSW.

The research was the first comprehensive population-based assessment of coronavirus transmission in educational settings worldwide. It found the rate of COVID-19 transmission in NSW educational settings was minimal, particularly between children and from children to adults.

Lead author Prof Kristine Macartney said COVID-19 transmission in schools appeared to be considerably less than that seen for other respiratory viruses, such as influenza. The findings were consistent with other data that show lower rates, and generally milder disease, in children than in adults.

### USING REAL-TIME DATA TO GAIN INSIGHT INTO COVID-19

A new digital data platform, developed through the Digital Health Clinical Research Centre (CRC), will give frontline health workers access to real-time data about COVID-19 which will aid them in decision-making when treating patients.

The Clinical Data and Analytics Platform (CDAP) will provide nationally available real-time analytics on the progression of COVID-19 patients to severe disease and will enable clinicians to use this data almost immediately.

The \$4 million digital health project is a partnership between Digital Health CRC, NSW Health, Queensland Health, Commonwealth Health, Queensland University of Technology, Monash University and the University of Sydney and will be piloted in NSW by Sydney Children's Hospitals Network.

CDAP has been built to rapidly extract and organise clinical data which will not only help health professionals better understand COVID-19, but it will help to improve management of the disease and support clinical trials that are assessing different treatments.

We don't have any known effective treatments for COVID-19 – it is a completely new virus. So our main focus is on trying to give the clinicians and healthcare workers on the frontline of this epidemic access to as much information as we can.

Prof Tom Snelling, infectious diseases physician at SCHN and Director of the Health and Clinical Analytics team at the University of Sydney, is the clinical lead for the CDAP.



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#### **BRACE TRIAL**

The BRACE trial, BCG vaccination to Reduce the impact of COVID-19 in Australian healthcare workers following Coronavirus Exposure is investigating whether the Bacille Calmette-Guérin (BCG) vaccine, typically given to prevent tuberculosis, can protect healthcare workers exposed to SARS-CoV-2 from developing severe symptoms.

The BCG vaccine is one of the most widely used vaccines in the world, given to over 130 million babies worldwide each year. In addition to preventing tuberculosis (TB), this vaccine also boosts immunity to a variety of other infections.

The clinical trials team at the National Centre for Immunisation Research and Surveillance (NCIRS) and Kids Research will be coordinating the trial in NSW with other sites across Sydney, including Westmead Hospital, Prince of Wales Hospital and St Vincent's Hospital.

The randomised controlled trial will test 10,000 healthcare workers across Australia, and other countries including the Netherlands and Spain. Half of the participants will receive the BCG vaccine while the other half will receive a placebo. Participants will then be tracked over a period of 12 months to record if they contract COVID-19 and the severity of their symptoms.

### ANALYSING THE HUMAN IMMUNE RESPONSE TO COVID-19

The Infectious Diseases and Immunology teams at The Children's Hospital at Westmead are working closely with Immunologists at Nepean Hospital to better understand the evolution of COVID-19 by analysing the human immune response amongst children and adults.

The study began in April 2020 and involves engaging with patients and their families through the COVID-19 Outpatient Response Team (CORT) to collect paediatric samples for analysis.

Early evidence suggests that coronavirus infection in children is very uncommon and severe disease is rare, with a majority of COVID-19 infections being adults.

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Even though disease is infrequent in children, we think understanding disease in children may well be the key to understanding severe disease across all age groups.

Dr Phillip Britton, Staff Specialist in Infectious Diseases

#### LITERATURE REPOSITORY

A COVID-19 Literature Repository was created which gives all SCHN staff access to research papers that have been sourced by a collaboration of SCHN researchers and staff. The articles are made available through the SCHN Medical Library subscriptions and selected free-access publishers during the COVID-19 pandemic. Researchers and clinicians use the repository to prepare regular syntheses and topic reviews on key subject areas.

SYDNEY CHILDREN'S HOSPITALS NETWORK







# PATIENT SAFETY DASHB ARD



REPORTED CLINICAL INCIDENTS

6753



ROOT CAUSE ANALYSIS (RCA) INVESTIGATIONS

(investigations of death or serious harm to a patient)

2



PRESSURE INJURIES INCIDENTS

337



**MEDICATION INCIDENTS** 

(excluding drug discrepancies)

1696



**FALLS INCIDENTS** 

164



**IN-HOSPITAL DEATHS** 

109



CARDIO RESPIRATORY ARRESTS ON THE WARD

3

(this represents a significant decrease from 2018-2019)



**RAPID RESPONSES** 

Teams responded to 4601
Rapid Response calls
(16 calls from the REACH program)

### QUALITY AND SAFETY

Quality is central to all the services and programs within Sydney Children's Hospitals Network. Staff are united by their focus on one goal – providing care and support of the highest standard for every patient, every time.

### SCHN QUALITY IMPROVEMENT ACADEMY

Embedding a culture of safety requires the education of as many staff as possible and support to make improvements in their day-to-day work and therefore improve the quality of care and safety of the patients. The aim of the SCHN Quality Improvement Academy is to build the confidence and capability in SCHN staff to lead medium scale improvement projects and foster a culture of staff-led, continuous improvement.

- 35 staff members graduated from the Quality Improvement Academy in 2019-2020
- II improvement projects were developed and implemented across the Network

### QUALITY IMPROVEMENT FUNDAMENTAL COURSE

The SCHN Quality Improvement Fundamental Course has the same aim as the SCHN Quality Improvement Academy but focuses on smaller scale projects.

- 51 SCHN staff undertook the Quality Improvement Fundamental Course in 2019-2020
- To date 352 SCHN staff have completed the two-hour course.

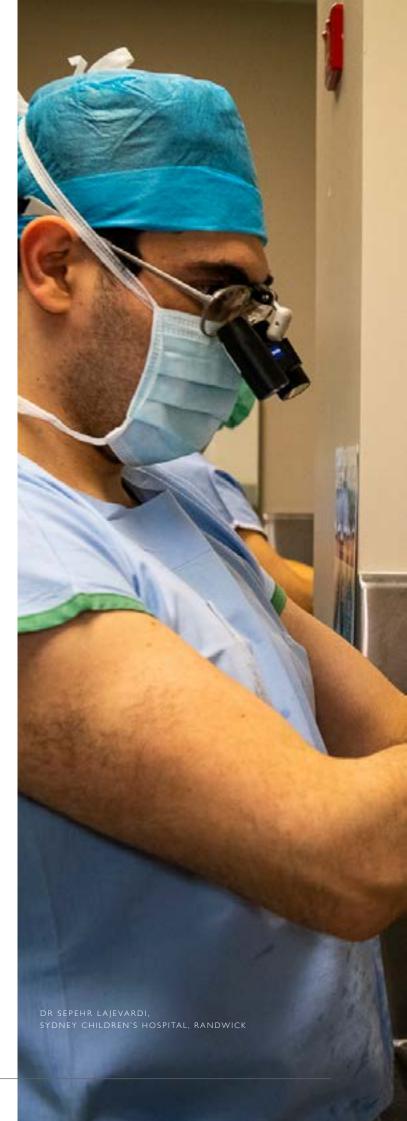
SCHN places great importance on continually improving care and service for patients, families and staff. Children's Hospital Achievements Research\* Links and Improvements Database (CHARLI) is the Network database used to document quality improvement activities. The Clinical Governance Unit (CGU) Quality Improvement team provides training in CHARLI, with 353 Quality Improvement submissions in the last 12 months.

### QUALITY AUDITING REPORTING (QARS)

The audits completed in QARS help to improve patient safety, healthcare quality and the patient experience.

A total of 4444 audits were completed across SCHN from July 2019 - June 2020.

Highlight: The past year has seen an increased completion rate of the 'observation and documentation' audits and increased staff awareness in QARS functionality. The growing culture of embedding quality and safety is highlighted by a rise in areas within the Network wanting to create audits to monitor and evaluate the work they do.



#### **REACH**

REACH is a system that enables parents/carers with a child who is admitted to SCH or CHW to escalate their concerns if they are worried their child's condition is deteriorating. Our staff understand that parents know their child best, and we want to work together with parents/carers to achieve the best outcome for their child











**RECOGNISE** 

**ENGAGE** 

ACT

CALL

HELP



### ACCREDITATION REPORT 2020

SCHN underwent an organisation-wide assessment in March 2020 in collaboration with Quality Innovation Performance (QIP), our accrediting agency. The achievement of accreditation is measured against the sector specific National Standards which have been set as the minimum benchmark for quality. Compliance with the National Standards is demonstrated through an independent assessment.

A great deal of work took place behind the scenes to ensure we were prepared for accreditation, and that all staff were able to contribute to the process. The assessors reported a strong focus on safety and quality throughout the onsite survey noting many positive comments about the staff and services provided at SCHN.

The Australian Safety and Quality Commission has advised that all accreditation cycles will be suspended until the nation moves into the recovery phase of COVID-19. Despite this, the Network is continuing to work hard to monitor, evaluate and demonstrate how we provide quality, safe care for our patients, families, carers and staff at all times.

### PAEDIATRIC IMPROVEMENT COLLABORATIVE

SCHN is working together with the Paediatric Improvement Collaborative (PIC), which was formed in partnership with Safer Care Victoria, Clinical Excellence Queensland and NSW Agency for Clinical Innovation. In the past year, SCHN has contributed to 40 acute care PIC guidelines. The intention of the PIC guidelines is to have standardised practices across the three states.

SYDNEY CHILDREN'S HOSPITALS NETWORK

### CLINICAL CARE

### **GROUND-BREAKING LIVER TRANSPLANT**

Last year Brayden fell gravely ill and was diagnosed with a rare liver condition called Fulminant Liver Failure. The condition affects just a handful of children in Australia each year and is characterised by the sudden onset of acute liver failure in people who have had no previous liver problems.

Brayden was placed on the organ transplant waiting list and thankfully, after just two days, his family received the news that they had found a match and Brayden could have his transplant.

Brayden's surgeons, Dr Gordon Thomas and Dr Albert Shun from CHW, performed the APOLT procedure on Brayden's liver – a surgery that has been performed successfully on one other patient in Australia, by these same two surgeons.

The APOLT (Auxiliary Partial Orthotopic Liver Transplantation) procedure, also known as a split liver transplant, involves removing only half of the damaged liver (instead of removing the entire liver) and attaching a portion of the donor liver in its place. This procedure enables the donor organ to perform the vital function of the liver, while allowing the native, damaged liver to slowly recover. Once the native liver recovers, the donor liver can be removed.

Brayden has now had his donor liver removed and his liver had not only grown back and recovered, but is performing even better than the donated organ, which was still in prime condition.







# A MESSAGE FROM JAKE, AUSTRALIA'S 2000TH LIVER TRANSPLANT PATIENT

To my organ donor,

You don't know me but my name is Jake, I'm 13 years old and my life was saved because of you.

When I was three years old, I was diagnosed with a condition called Alpha-I antitrypsin deficiency. This is a genetic disorder that mainly affects the lungs, but a small percentage of people with this condition can also get liver disease. Unfortunately I was part of that small per cent and I was told that I would probably need a liver transplant in about eight -10 years.

I was well for about eight years then in 2018, my doctor said that my regular tests weren't looking so good and it was time to go for a transplant assessment. I had to go to The Children's Hospital at Westmead because they don't do paediatric liver transplants in Perth and I spent the week having all sorts of tests as well as meetings with the doctors, nurses and surgeons over there.

I didn't really understand much about organ donation back then and I was a bit shocked to learn that donor livers usually come from deceased people (because you don't have one to spare like you do with your kidneys) but I did know that it was what I needed to help me get better.

I was one of the very lucky ones with my transplant because I was only on the list for about three months before they found my perfect liver. I was so happy and grateful to you and your family for helping to save my life. After my transplant, I felt a million times better! I have so much more energy now, I don't have bloody noses all the time, my tummy doesn't hurt like it used to, I can eat all sorts of food, my eyes aren't yellow anymore and I don't have bruises all over me. I also get to play sport with my friends and don't miss out on things like I used to.

Something really cool happened during my operation too – I became the 2000th person in Australia to receive a liver transplant! That was pretty special because unfortunately they only get to do about 300 liver transplants per year, so it's taken a long time to get to 2000. I'm hoping that the 3000th won't take as long to come around.

I am so grateful to you and your family for giving me a new liver and helping me get better. It has changed my life! I will always remember you and the gift of life you gave me.

To everyone else reading this, I would encourage all of you to talk about organ donation so we can help even more people like me. You don't need your organs when you die, but other people do, including kids.

By becoming an organ donor you get to save other people's lives and that's a very, very special thing to be able to do. So it's very important to talk to your family about your wishes and to sign up to be an organ donor online so more people can live longer and healthier lives.









## FIRST PATIENT IN NSW TO BE TREATED FOR BATTEN DISEASE

In late 2016, 4-year-old Tayla was diagnosed with CLN2 disease (Batten's disease), a rare and rapidly neurodegenerative disorder. At that time in Australia there was no treatment available for CLN2 disease that would change the course of the illness.

Tayla and her family moved to the US in 2017 to take part in a clinical trial, where Tayla was given the drug Brineura – an enzyme replacement therapy – delivered as an infusion directly into the ventricles inside her brain. The treatment works by replacing the enzyme that is lost in CLN2 disease. International trials indicate that this treatment delays the progression of the disease.

In May 2019 the drug was accepted on the Life Saving Drugs program in Australia and Tayla and her family were able to come home for treatment. Since returning to Australia, Tayla has infusions at Sydney Children's Hospital, Randwick every two weeks. Tayla is the first child in NSW to be treated in this way for Batten disease.

#### **HALO-GRAVITY DEVICE**

Three-year-old Kiveyn is the youngest child in Australia to be fitted with a halo-gravity device.

Born with serious curvature of the spine, Kiveyn has spent the majority of his life in a cast

In mid-2019, Kiveyn was fitted with a halo, an apparatus that will help straighten his spine with some traction.

## MENTAL HEALTH

# THE SCHN MENTAL HEALTH AND INTELLECTUAL DISABILITY (MHID) HUB

Children and young people with intellectual and developmental disabilities (IDD) experience emotional, behavioural and mental health difficulties at rates significantly higher than their typically developing peers. In 2019, the NSW Ministry of Health identified people with a mental health and intellectual disability as a state priority and SCHN was successful in obtaining funding to establish the SCHN MHID Hub.

The SCHN MHID Hub, based out of CHW's Department of Psychological Medicine, draws on the Developmental Psychiatry team's expertise in assessment, diagnosis and treatment for co-occurring mental health issues in children and adolescents with intellectual disability and/or autism spectrum disorders (ASD). Funding has allowed the appointment of a dedicated part-time multidisciplinary team to provide short-term consultative services to Child and Adolescent Mental Health Services (CAMHS) and Paediatric and Community Child Health Services in NSW.

The Hub aims to enhance local capacity for managing these often complex cases, partly through providing consultations, either by videoconference or face-to-face, but also through telephone support, case-centred discussions and supervision, advice on local services and triaging and through skill building and education. The team will work in partnership with the broader Developmental Psychiatry team members including the School-Link Initiative for IDD, the Westmead Feelings Program for emotional learning in ASD and the newly funded Transfer of Care Program.

#### MENTAL HEALTH SUPPORT OFFICERS

SCHN provides mental health services to children, adolescents and their families. In 2019, two Youth Peer Support Workers joined the Network's Mental Health team, further strengthening the service.

Youth peer support workers are in a unique position to use their lived experience of mental illness to form collaborative, supportive relationships with young people. By harnessing their own experience of mental illness with recovery they support young people to make the transition from inpatient care to life in the community. The peer support officers use their lived experience of mental illness to model recovery and provide hope for young people experiencing mental illness.

#### TOWARDS ZERO SUICIDES PROJECT AT SCH

The objectives of this project are to co-design and implement a rapid response youth suicide prevention model tailored to local need.

A new dedicated team at SCH will rapidly respond to children and young people in suicidal crisis and provide support to the Emergency Department's (ED) management of these young people. The team will provide assessments, crisis management, culturally responsive support, peer support, short-term outreach and service-linking. A component of the service will also include innovative alternatives to the ED including community capacity building and online supports/linkages.

The project aims to:

- Provide assistance with initial ED assessments of young people in acute suicidal crisis
- Provide short-term management of young people in acute suicidal crisis
- Facilitate referral of young people to appropriate mental health treatment services and/or other support services in the community
- Avoid hospital admission of young people, where possible
- Reduce the number of young people who present repeatedly to the ED.







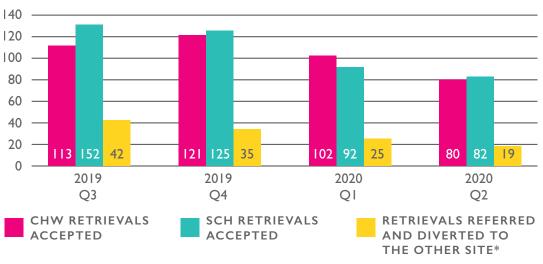


#### **DESTINATIONS FOR NETS PATIENTS**

NETS retrieves most patients to tertiary hospitals but some from rural hospitals to regional specialist hospitals when tertiary care is not required. Patients transported to tertiary hospitals include 35% to one of the ten Neonatal Intensive Care Units in NSW/ACT, 20% into PICU at SCH, CHW and JHCH and 39% to children's hospitals EDs.

When transporting into SCHN, the patients are distributed across our hospitals as seen below. \*Those referred but not admitted are usually accommodated by the other Network hospital.

#### NETS RETRIEVALS REFERRED TO SCH AND CHW BY QUARTER



#### **ALESSANDRA'S STORY**

NETS was called one night in April, close to midnight, about 9-month-old baby Alessandra with severe croup in Albury NSW. Alessandra was at imminent risk of losing her airway and the first NETS team tasked identified that her airway was so at risk that they were unable to transport her and called back to base for further support. Given her deteriorating respiratory function, an ENT surgeon and an experienced anaesthetist were added to the standard NETS team – something rarely required but key to success on this night.

On arrival in Albury, an airway was established and little Alessandra was transported safely to the Children's Intensive Care at Sydney Children's Hospital, Randwick. She has recovered well.



THE LATE DR NEIL STREET AM AT WORK STABILISING ALESSANDRA INTO THE NETS INTENSIVE CARE SYSTEM. DR STREET PASSED AWAY IN SEPTEMBER. HE CARED FOR GENERATIONS OF CHILDREN AND FAMILIES AND HAD A MAJOR IMPACT ON PATIENTS LIKE ALESSANDRA AND ON HIS COLLEAGUES. DR STREET DISPLAYED THE VERY BEST OF WHAT A CLINICIAN CAN BE, DOING EVERYTHING POSSIBLE FOR CHILDREN IN HIS CARE.





## ABORIGINAL HEALTH

SCHN has a renewed strategic focus on building our Aboriginal workforce and strengthening our support for Aboriginal patients, families and communities. Ensuring they are seen quickly by an Aboriginal Health Worker, and that they feel welcome, safe and respected when coming to our hospitals is our priority. Our Network is committed to providing services that are culturally responsive and inclusive.

#### ABORIGINAL HEALTH UNIT

One of SCHN's major achievements over the last year was the establishment of the Aboriginal Health Unit (AHU) in 2020. The AHU aims to improve experiences, access and health outcomes of Aboriginal and Torres Strait Islander children. It offers cultural support and advocacy for CHW and SCH patients, families and communities. The Aboriginal Health Unit is made up of skilled and experienced Aboriginal staff. It offers:

- General support for patients, parents and carers
- Additional support for extended family
- Practical 'away from home' support
- Assistance with emergency resources
- Attendance at meetings with a patient's medical team
- Advocacy
- A cultural space for families to connect and feel safe

#### ABORIGINAL STAFF SUPPORT NETWORK

The Aboriginal Staff Support Network is an initiative to bring all of our Aboriginal staff together. The aim of the group is to provide peer support and promote the recruitment, retention and professional development of Aboriginal staff within the Sydney Children's Hospitals Network.



# INAUGURAL ABORIGINAL WORKFORCE FORUM

The Network's first Aboriginal Workforce Forum was held in November 2019. Its purpose was to gain an understanding of the needs of our current employees and stakeholders and identify culturally appropriate opportunities for the Network to ensure we are well-equipped to welcome, support and retain Aboriginal and Torres Strait Islander staff. The forum provided the first step towards developing a Strategic Aboriginal Workforce Plan.

#### RESPECT, LISTEN, COLLABORATE

The below graphical image will form part of our ongoing Aboriginal health communications. This was developed in partnership with our Aboriginal staff and consumers. It is a visual reminder of our need to respect, listen and collaborate in all that we do.

## ABORIGINAL HEALTH DASHBOARD

In the past year, we have established an Aboriginal Health dashboard which enables automatic data collection for Aboriginal patients. We are currently trialling an email alert system that is sent to our Aboriginal Health Workers when a patient identifies as Aboriginal or Torres Strait Islander. Our aim is to have every Aboriginal family seen by an Aboriginal Health Worker within 24 hours of admission, where possible.









# PATIENT EXPERIENCE DASHB ARD



COMPLAINTS RECEIVED

648

(438 CHW, 208 SCH, 2 NETS)



COMPLAINTS ACKNOWLEDGED WITHIN 5 DAYS 96%



COMPLAINTS RESOLVED WITHIN 35 DAYS 88%



SUGGESTION BOX SUBMISSIONS RECIEVED 241



PATIENT REPORTED
EXPERIENCE MEASURES
(PREMS) SURVEY
RESPONSES RECEIVED

More than 1000



FAMILY FEEDBACK RECEIVED ON RESOURCES

28

## PATIENT AND FAMILY ENGAGEMENT

# IF IT IS IMPORTANT TO YOU, IT IS IMPORTANT TO US

Here are some of the initiatives that have resulted from feedback from patients, parents and carers:

- Changes to the parent/carer communication strategies in relation to COVID-19.
- Following parent feedback, Nurse Unit Managers do ward rounds when any significant changes are implemented.
- Consumer involvement in creating communications for families.
- Improvements to the parent and carer areas at SCH (C2 West Oncology parent and carer lounge area, CI South parent and carer kitchen and ICU family meeting room) to make them more comfortable and welcoming spaces.
- Ramp installed to improve access to the SCH COVID-19
   Clinic for patients with accessibility issues and families with prams.

#### A PLACE TO TAKE A BREAK

The Parent and Carer Resource Centre (PCRC) at CHW provides a non-clinical, homely environment where parents and carers can take a break. There were 6206 visits to the PCRC from July 2019 until March this year when it was temporarily closed due to COVID-19.

# CONSUMER ADVISORY COUNCILS

Consumer Advisory Councils are an important part of ensuring that the Network continues to respond to the needs of its patients and families.

The Sydney Children's Hospitals Network Families and Consumer Council focuses on providing advice and direction on improving the patient and family experience across the Network.

The Sydney Children's Hospitals Network Youth Advisory Council provides young people with opportunities to have a voice and create change within the Network.











# TRANSLATING RESEARCH INTO CLINICAL PRACTICE

Kids Research, the research division of the Network, is made up of more than 600 researchers, affiliated academic staff, support staff and students who are dedicated to finding new ways to improve children's health outcomes and drive excellence in paediatric health. Our researchers are currently conducting more than 200 clinical trials.

We are committed to discovering new insights into childhood diseases, and developing better diagnostic methods and treatments. Through effective collaboration with universities, other research organisations and donors, Kids Research aims to transform the way research improves patient care.

Translation of our world's best research into clinical practice within the Sydney Children's Hospitals Network and the community is our ultimate goal.





# UNPRECEDENTED GRANT SUCCESS A WIN FOR SICK CHILDREN

It has been an unprecedented year for Kids Research, with more than \$70 million committed to new research projects aimed at improving the lives of children suffering from conditions including rare genetic diseases, cancer, heart, kidney and infectious disease.

In the past 12 months, more than \$49 million in funding has been awarded to researchers from KR and its affiliate partners, University of New South Wales and the University of Sydney for new projects, with a further \$21 million awarded to joint projects with partners like Murdoch Children's Research Institute and the University of Queensland.

Prof Chris Cowell, Director of Kids Research says the grant success is a reflection of the team's world-class expertise and commitment to creating a better future for sick children.

"Projects have already begun in novel areas like acute care genomics, with new innovative clinical trials and laboratory research set to begin in coming months. Thanks to incredible grant success, we will be able to roll out many exciting new research projects that we hope will be life-changing for children now and into the future."

# VIRAL VECTOR MANUFACTURING FACILITY – ANOTHER WIN FOR RESEARCH

The idea of gene therapy is to introduce and deliver normal healthy genes into cells, using it as medicine to compensate for abnormal genes or to make a beneficial protein in cells.

The delivery of these genes is complicated. One of the most effective ways to do so is to use a viral vector - a transport 'vehicle' that uses faulty and disarmed viruses as a means to transport genes to the targeted cells.

The NSW Government is investing \$25 million to build an advanced viral vector manufacturing facility at the Westmead Health and Innovation Precinct. The manufacturing facility will produce clinical grade viral vectors, key components of gene and cell therapies, giving patients with genetic diseases, cancers and viral infections across Australia faster access to groundbreaking trial therapies. The facility will support our aim of translating research into better health outcomes for the community.

#### WORLD-FIRST TRIAL OF Q FEVER VACCINE FOR YOUNG PEOPLE

Q fever is a debilitating bacterial infection most commonly spread to humans from cattle, sheep or goats. A/Prof Nick Wood, Associate Director, Clinical Research and Services at National Centre for Immunisation Research and Surveillance is leading a multi-centre team across Australia that will measure the safety of Q fever vaccine in young people aged 10–15 years. It is currently available for those aged over 15 years.

It is hoped that the use of Q fever vaccine in younger adolescents could prevent the severe consequences of this disease, which can include chronic fatigue and endocarditis osteomyelitis.

## PAEDIATRIC PRECISION MEDICINE

The establishment of the Paediatric Precision Medicine Program has allowed SCHN to develop and build early-phase clinical trials capability, as well as work towards an enhanced clinical trials capacity – accelerating the delivery of novel drugs and gene therapy clinical trials.

# ACUTE CARE GENOMICS PROGRAM HELPING TRANSFORM DIAGNOSIS AND TREATMENT

SCHN is involved in the Acute Care Genomics program, a national rapid genomic diagnosis program for critically ill children. This ground-breaking program is helping to transform the diagnosis and treatment of children in intensive care, fast tracking result turnaround time from three months to three days. The ability to obtain a precise genetic diagnosis is a key step for every family affected by a rare inherited disorder to receive personalised medical care. Our hope is that in the future, rapid genomic testing will be available to all babies and children in Australia who are critically unwell, where a genetic diagnosis is suspected.

# NEWBORN SMA SCREENING PILOT SUCCESS

SCHN has successfully implemented the first state-wide newborn screening program (NBS) for Spinal Muscular Atrophy (SMA). SMA is the leading genetic cause of infant death in Australia, with the disease occurring in one in every 10,000 births. SMA affects motor nerve cells in the spinal cord, causing progressive muscle weakness through to adulthood.

The NBS pilot, funded for two years by the NSW Government through Luminesce Alliance (previously known as Paediatrio), started in August 2018. With over 180,000 newborns screened in the first 22 months of the program, the pilot has demonstrated that NBS is effective for the early identification and treatment of SMA. This screening supports early parental decision making, improves access to specialist neuromuscular expertise and facilitates initiation of personalised therapeutic strategies.

The successful implementation of the first state-wide NBS program for SMA in Australia was published in *Genetics in Medicine*, the journal for American College of Medical Genetics and Genomics.





# RESEARCH IDENTIFIES NEW GENETIC TESTING MECHANISM

Genetic research led by Professor Sandra Cooper has identified a new genetic testing mechanism that means researchers can now test for genetic errors in the non-coding part of a gene, mistakes that were previously undetectable.

Approximately 50 per cent of children admitted to paediatric hospitals have an underlying inherited condition. These inherited disorders, though individually rare, are collectively the most common cause of severe disability in childhood. Defining this new mechanism will give clinicians the ability to diagnose families with different genetic conditions including neurological, cardiac, metabolic and hereditary cancer and offer precision medicine to directly treat their condition.

#### PUBLICATION: ACCELERATING GENE THERAPY RESEARCH

A collaborative study between Children's Medical Research Institute and Kids Research, led by Prof lan Alexander and Dr Leszek Lisowski, has been published in the journal *Human Gene Therapy*. The study looked into building a kit that could quickly test the efficiency of different vectors (nanoscopic transporters for genes targeting human tissues) – the kit will enable the acceleration of vector design and gene therapy research.

### CANCER RESEARCH

# MAJOR FUNDING BOOST FOR ZERO CHILDHOOD CANCER PROGRAM

The world-leading Zero Childhood Cancer program (ZERO) has received \$67 million from both the Federal government and Minderoo Foundation, to help give all children and young people with cancer the greatest chance of survival.

Led by the Kids Cancer Centre at SCH, together with the Children's Cancer Institute, Zero has changed the way we diagnose and treat children with the most aggressive or relapsed cancers. The funding commitment will ensure ZERO is expanded, with the aim of it being offered to all children diagnosed with cancer by 2023.

The funding boost will also support the development of a comprehensive genomic databank of each patient's healthy and cancer cells which will allow researchers to better understand the causes of childhood cancer, identify genetic markers that may help predict those at risk of the disease, and increase the ability to make better informed treatment recommendations. By enabling all children access early in their cancer journey, the program aims to reduce the chance of relapse.

Built on a collaborative network of all eight children's hospitals in Australia and 23 international research partners, the first ZERO national clinical trial for children with aggressive cancer was launched in September 2017. The results have been remarkable with over 370 children enrolled, and potential personalised treatment recommendations made for more than 70% of the children, which are now being reported to the children's treating doctors within nine weeks on average.

66

Just as every child is different, so is every cancer. This program is shifting our thinking on how we best treat childhood cancer, delivering new hope, and novel treatment options based on better understanding of what is causing each child's cancer to grow. No child should die of cancer and although we have a long way to go to achieve this, that's the ultimate aim of the Zero Childhood Cancer precision medicine program.

Prof Tracey O'Brien



#### KAYLEE'S STORY

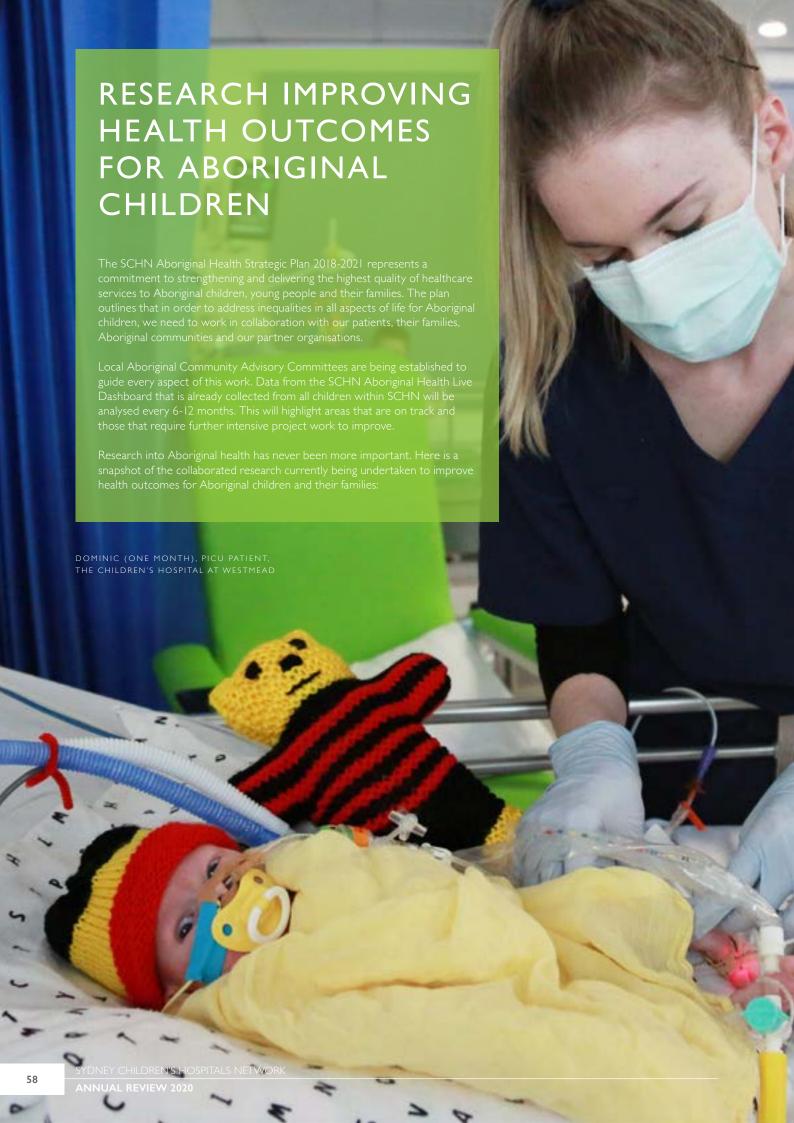
Each year, almost 1000 children and young people are diagnosed with cancer around Australia, and is unfortunately still the most common cause of death from disease. ZERO provides treatment options for kids like Kaylee, who was diagnosed with stage 4 neuroblastoma in 2018. For 18 months she was given every treatment possible – none of which proved effective. In mid-2019 her oncologist discovered that Kaylee's tumours had begun to grow rapidly and she was enrolled in ZERO, where the genetic footprint of her tumours was tested and a specific mutation was discovered in her tumour's DNA. Lorlatinib, a drug typically used to treat lung cancers, was identified in the laboratories to possibly help target Kaylee's specific cancer cells.

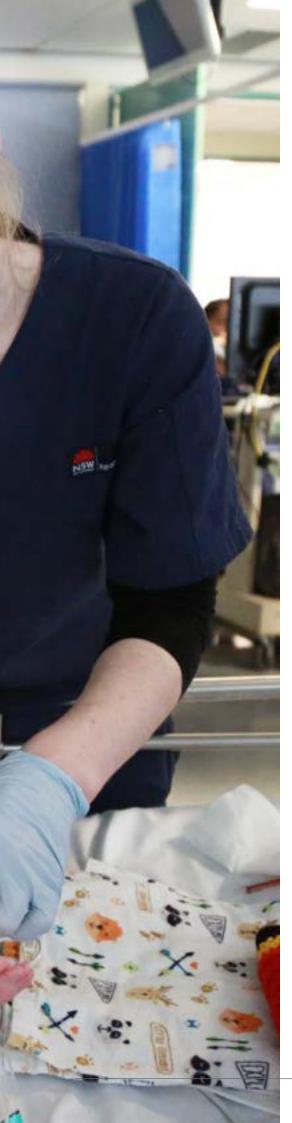
6

Every child deserves something like this, it's so needed and it makes everything so much easier, it works like a miracle.

Kayle







#### EAR HEALTH IN ABORIGINAL CHILDREN

Associate Professor Hasantha Gunasekera, Clinical Academic and Staff Specialist General Paediatrician at CHW is one of the leading investigators into health research in Aboriginal children. In 2020 he was awarded a new grant for his Aboriginal Community Controlled Ear Health Support Systems (ACCESS) project to develop, embed and evaluate best practice models of care in Aboriginal communities.

About a quarter of Aboriginal children living in urban areas have ear disease, which often causes hearing and speech problems and can impact on their ability to learn at school. SCHN's extensive work in ear health in Aboriginal children includes the WATCH and INFLATE projects, and the HEALS project which funds audiology, speech therapy and ear, nose and throat services for Aboriginal children across five NSW Aboriginal Community Controlled Health Organisations. Through this project, more than 300 children have been assessed and provided therapy or surgery as needed, which showed early intervention can lead to significant improvements in these children.

# ARDAC – ANTECEDENTS OF RENAL DISEASE IN ABORIGINAL CHILDREN AND YOUNG PEOPLE STUDY

Research has shown that Aboriginal Australians are up to ten times more likely to suffer from chronic kidney disease. Started back in 2002, the ARDAC study, a community-based, longitudinal cohort study aims to find answers to why the risk of chronic conditions such as kidney disease, heart disease and diabetes are so much greater for Aboriginal Australians. There are now 3758 participants in the study from across NSW. ARDAC will establish the life course for chronic disease among Aboriginal people from childhood to adulthood. It will also extend partnerships with Aboriginal Community Controlled Health Services into sustainable, evidence-informed programs and services to prevent chronic disease in high risk young Aboriginal people.

# PATHWAYS FOR CLINICIANS TO IMPROVE CHILD HEALTH

There is strong evidence that screening for social determinants in healthcare can address inequity. This project will test the feasibility, acceptability and appropriateness of an equity focused pathway to families at risk of or experiencing poor health, due to housing issues in South East and South West Sydney. It aims to increase the accurate "diagnosis and treatment" of housing problems that directly impact on children's health and improve referral of families to the correct services.

#### SEARCH STUDY OF ENVIRONMENT ON ABORIGINAL RESILIENCE AND CHILD HEALTH

An estimated 60% of the health gap between Aboriginal and non-Aboriginal people in Australia is attributable to the health of people living in non-remote, urban areas. This is the largest cohort study (approximately 1700) of urban Aboriginal children in Australia. It enables assessment of the variables associated with good health, including ear health and speech and language skills, child development, as well as mental health, housing and resilience.

\*see pages 26-27 in the COVID-19 – Our response section for details of SCHN's involvement in COVID-19 research.







# WORKFORCE DASHB CARD





NUMBER OF VOLUNTEERS
618



NUMBER OF STAFF HIRED 830



% OF STAFF WHO HAVE BEEN WITH THE NETWORK FOR MORE THAN 10 YEARS

34%

#### **NUMBER OF STAFF PER SITE:**



SCHN 6288 (paid staff)



SCH 1785



**CHW** 3737



NETS 102



Research directorate 246



Network directorate 325 (excludes PSN)

NUMBER OF STAFF AT SCHN SERVICES LOCATED AT OTHER SITES:



Bear Cottage 54



Children's
Court Clinic



Pregnancy and Newborn Services Network

П

(at 30 June 2020)

# INTERNATIONAL YEAR OF THE NURSE

The World Health Organisation declared 2020 the International Year of the Nurse and Midwife to coincide with the 200th Anniversary of Florence Nightingale's Birthday. Florence Nightingale is regarded as the founder of modern nursing. Nurses and midwives are the cornerstone of the Network, providing compassionate and skilled care 24 hours a day, seven days a week. The International Year of the Nurse and Midwife provided the Network with an opportunity to profile the work that our nurses do in caring for children, young people and families.

In February 2020, we launched the International Year of the Nurse and Midwife with a Paediatric Nursing Showcase – celebrating our paediatric nurses and the depth and breadth of the work that they undertake.

Nurses play an invaluable role in our healthcare system. Their role is pivotal in not just caring for patients at the bedside, but in educating their colleagues, facilitating research, and supporting the community with innovative ways to keep patients at home, where they belong. What unites them above all else is their passion for making a difference.

On International Nurses Day, the continued compassion, commitment and professionalism of nurses was even more greatly highlighted as the world responded to the COVID-19 pandemic. Fittingly, the theme for 2020 is Nursing the World to Health, focusing on the true value of nurses not just during the current health crisis, but all year round.



Never has it been more important to celebrate the work nurses do in caring for families and children than as we face the current health crisis that has affected so many. Our nurses have adapted to the COVID-19 outbreak with true professionalism and remained focused on providing the very best care. I am so very proud of all our nurses across the Network.

Sally Whalen, Director of Nursing, Midwifery and Education



#### THE YEAR OF... NURSING RESEARCH EXCELLENCE



Nurse led research projects completed



Publications in peer-reviewed journals



Participation in 5 external national/internationa



New research projects commenced



Research presentations



International conference presentations (5 as keynote/invited speaker)



Research projects currently in progress



Research workshop



Research student awarded best 3 minute doctoral presentation



Leadership of Australian Paediatric Nurse Scientists



Research internships enrolled in higher degree



Representation on 3 national health committees



Drop -In sessions



Supervision of 9 higher degree students



Representation on I international and 2 national professional organisations





## SCHN CELEBRATION WEEK

Across Sydney Children's Hospitals Network, our staff and volunteers work extremely hard every single day, connected by the same goal – to make a difference to the lives of sick kids. In September, the Network held its annual Celebration Week, dedicated to showing appreciation for the hard work of our staff and volunteers.

### **OUR VOLUNTEERS**

The Network is fortunate to have more than 600 volunteers, who generously give their time and expertise to help our patients and families. Our volunteers make such an enormous difference to the work we do.

Janelle (Jan) Menzies is one of our volunteers, supporting the Back on Track program, which keeps children connected to their learning while undergoing treatment for cancer. Jan is a retired school teacher. For the last two years she has been volunteering her time to teach SCH oncology patients once a week. During COVID-19, Jan's lessons moved to online learning via Zoom video sessions. Over the four peak months of the pandemic, Jan held 115 lessons and taught 10 children online.

# INAUGURAL ALLIED HEALTH PROFESSIONALS DAY

Allied Health Professionals Day was celebrated for the first time across Australia on 14 October 2019 with the theme of Celebrate, appreciate and inspire. At SCHN, we celebrated our allied health staff with a BBQ lunch for all.

Across the Network, there are 17 different professions that make up Allied Health and who treat patients from all areas, bringing their diverse range of skills together to help children and young people live their healthiest lives. These areas include Art Therapy, Audiology, Child Life Therapy, Exercise physiology, Genetic Counsellors, Music Therapy, Nuclear Med Technologists, Nutrition and Dietetics, Occupational Therapy, Orthotics, Orthoptics, Pharmacy, Physiotherapy, Psychology, Radiographers, Social Work and Speech Pathology.







### HEALTH LEADERSHIP PROGRAM

In 2020, SCHN is facilitating the fifth year of the Health Leadership Program (HLP) with the Heath Education and Training Institute (HETI). This year, the HLP has 50 participants, bringing the total participants across the Network to 250 since the program began. The program is being co-designed and co-facilitated by SCHN and HETI with the view to transitioning the program into the Network to ensure sustainability for future HLP cohorts. This year, the program adapted to an online format to enable it to continue in the current environment.

Here's what HLP 2019 graduates said about the program:

The content of the HLP was engaging and provided practical tools and skills that I was able to utilise immediately in my current role. This leadership program also enabled me to understand my leadership style and how I could utilise my strengths to ensure I am an effective leader. One of the most valuable parts of the program was the opportunity to network with people from a broad range of positions across the Network.

Dr Jennifer Cohen, Project Manager, Weight Management



Participating in the program has been an exciting and rewarding journey that challenges conventional notions of leadership. Being able to understand and respond to complex problems adaptively has helped considerably with better and sometimes surprisingly different outcomes.

Robert Ivcec, Data Integrity Manager, Health Information Unit



The course has really stretched my comfort zone, but as a direct result of participating in the course our unit has had its first ever planning day, which has been invaluable to our team, this was helped by contacts made during the course.

Michelle Zacchini, Nurse Unit Manager PICU



## SYDNEY CHILD HEALTH PROGRAM

The Sydney Child Health Program (SCHP) is a graduate-entry, non-award, online program providing the best paediatric education to healthcare professionals all around the world.

The SCHP has been restructured and a new Director, Dr Annemarie Christie, has been appointed. Thank you to Dr David Lester-Smith for his work in the Interim Director role of the SCHP over the past two years.

The SCHP was established in 1992 and now in its 27th year, SCHP boasts over 9000 alumni in 49 countries with recent new sites in Namibia and Nepal. In 2019-2020 local and international SCHP enrolments remained sound and the financial position robust – both are overseen by SCHP Steering Committee – a collaboration of representatives from SCHP, Sydney Children's Hospitals Network and the University of Sydney.

The program continues to evolve, adapt and remain contemporary for today's healthcare professionals who seek paediatric education direct to their preferred digital device and delivered at their own pace.

Supporting the continued changes in both education delivery and technology, the SCHP office team has undergone realignment with a greater focus on business development and digital technology. Australian enrolment and participation remain the focus of SCHP with product promotion at local healthcare conferences and exhibitions.

SCHP maintained international strategic links with visits to existing sites in India, Bangladesh, Cambodia, Kenya and Indonesia as a prospective country.







### SCH CICU DEVELOPMENT WARD ROUNDS

A weekly developmental care round began at SCH's Children's Intensive Care Unit (CICU) this year. Made up of nurses, speech therapists, physiotherapists and occupational therapists, the ward round is for babies under four months old and parents/carers are encouraged to take part.

The aim is to support the baby's development and reduce their stress while they are in the CICU. It can help parents connect with their babies and assist with bonding, settling, feeding, support recovery and focus on positive long-term outcomes.

### QUAD BIKE STANDARD TO SAVE LIVES

The Network has long had concerns about the serious risks quad bikes pose to children and young people and has advocated for improved safety measures.

On behalf of the Network, the health promotion team participated in extensive consultation on the safety of quad bikes conducted by the Australian Competition and Consumer Commission (ACCC), to combine its voice with others around the country to support the development of new regulation for quad bikes.

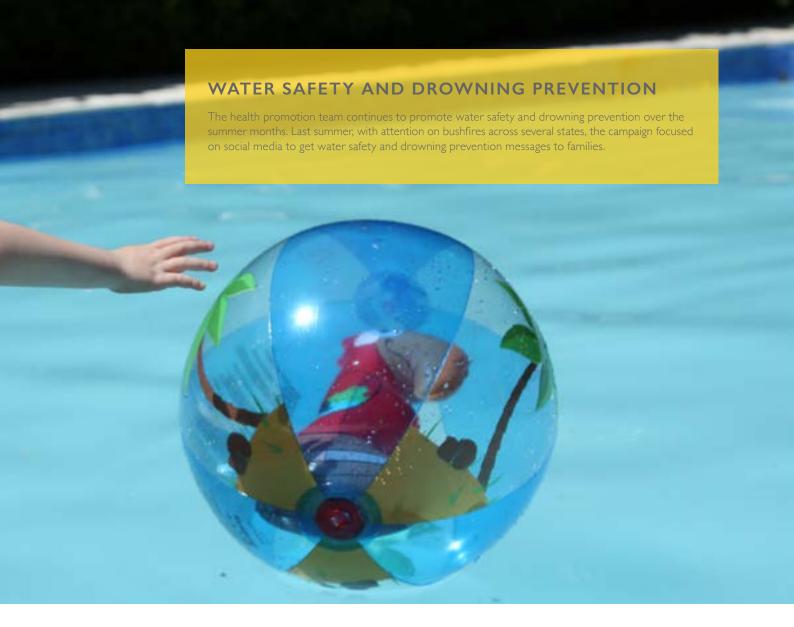
The Consumer Goods (Quad Bikes) Product Safety Standard 2019, came into effect in October 2019 and requires that within 12 months, all quad bikes must:

- have a warning label alerting the operator to the risk of rollover
- meet specific requirements of the US or European quad bike Standards
- test for stability and display the results on a hang tag at the point of sale

Within 24 months, all general-use model quad bikes must also:

- be fitted with, or have integrated into the design, an operator protection device
- meet the minimum stability requirements

In Australia, children below the age of 16 years account for approximately 14 per cent of all recorded quad bike fatalities and the majority of these fatalities involved a child operating an adult sized general-use model quad bike and experiencing a rollover incident. These requirements will improve the safety of quad bikes in general and the Network will continue to advocate for measures that will ensure that children under 16 do not drive or be passengers on quad bikes.



# CHW NEWBORN INTENSIVE CARE NURSES' RESEARCH HELPS EMPOWER PARENTS

Grace Centre for Newborn Intensive Care has had two of its nurses, Priya Govindaswamy and Nadine Griffiths, internationally recognised in prestigious medical publications for their research into the vital role parents have when their baby is in intensive care.

Priya's research titled Fathers' needs in a surgical neonatal intensive care unit:
Assuring the other parent, which was published in Plos One, identified that reassurance of fathers is a priority, particularly around their baby's pain and comfort. Conducted over 19 months, the research showed that fathers often experience a sense of helplessness when their baby is in the NICU and a desire to be more actively involved in the care of their child. Fathers are often overlooked around the time of birth and when a baby is unwell, but this research highlights their

desire to be actively involved in their baby's care and the need for greater recognition of their role as parents. There is a plan to implement training during orientation so nurses are more conscious of involving dads in conversations and increasing accessibility to the unit (post-COVID-19).

Similarly, Nadine's research titled The Evolution of an Interdisciplinary Developmental Round in a Surgical Neonatal Intensive Care Unit, which was published in Advances in Neonatal Care, investigated the importance of engaging parents in the NICU to overcome barriers to parent-infant interactions and help improve the developmental outcomes after discharge from hospital. Through implementing developmental rounds – a strategy that incorporates both the multi-disciplinary clinical team

and the family – the baby's neurodevelopment was able to be supported and families were able to feel in control of their child's care.

### HEALTHY WEIGHT AND HEIGHT

Childhood overweight and obesity is a major public health issue, with around one in five Australian children above a healthy weight. It is now policy for all children who present to our centres to have their height and weight recorded during their visit. This allows early intervention if the child's growth trajectory is deviating away from a healthy weight.

To support these changes and ensure we are leading by example we have implemented changes across the Network, including height and weight equipment upgrades, creation of measurement stations, including a handout for families, prompts in eMR, mandatory Weight4KIDS online training for nurses, dietitians and Junior Medical Officers and trained Network Weight4KIDS clinical champions.

### CHILDHOOD INJURIES

Injury is the leading cause of hospital admission for children aged I-16 years, however there has been almost no change in the number of injury related hospital admissions of children in almost 20 years. Many injuries are however preventable.

The health promotion team have worked on a number of behind the scenes advocacy activities working toward a greater focus on prevention of injury to children and young people. These include:

- Contributions to the development of a new National Injury Prevention Strategy
- Active participation in the Child and Young Persons Injury prevention Working Group (ACYP) and the preparation of the NSW Children and Young People Unintentional Injury Report (to be released later in 2020)
- Publication of the Child Injury Report, which found that in the 2016-17 financial year, 13% of admissions to SCHN were due to injury, making it the leading cause of admissions to our hospitals.







# NSW POISONS INFORMATION CENTRE

The NSW Poisons Information Centre (NSW PIC) provides a 24-hour telephone emergency advisory service (in collaboration with three other Australian PICS) for the Australian public and health professionals, via a national telephone number: 13 11 26.

Specialists in Poisons Information (mostly pharmacists) are supported by medical toxicologists to provide phone-based information, risk assessment and management advice relating to accidental and deliberate ingestion and/or exposure to medicines, drugs of abuse, agricultural, industrial and domestic chemicals, venomous bites, poisons, toxins and other substances.

From January to June 2020, the NSW PIC handled 55,443 calls, an increase of 6% from the same period in 2019. In addition, the service implemented remote working, training and clinical professional development, made possible with the implementation of a new telephony system.

In 2019-20, NSW PIC published more than 10 papers in peer reviewed journals including *The Medical Journal of Australia* and *Addiction*. Dr Rose Cairns, Director of Research, was awarded an NMHRC Emerging Leadership Investigator Grant, funding work on self-poisoning and suicide prevention.

NSW PIC data continues to be of value for health policy and industry, with increased request volume in 2019-20. A new, streamlined data request process is enhancing efficiency. In 2019-20 the NSW PIC enhanced collaboration with the NSW Ministry of Health, Centre for Alcohol and Other Drugs through appointment of a joint PIC and Public Health Fellow. Initiatives in public health and toxicovigilance include preventing unintentional harm from inappropriately packaged hand sanitiser and poisonings due to counterfeit alprazolam, through more extensive data collection and follow-up.

In 2019-20 NSW PIC has continued to improve clinical quality and safety through enhanced rostering, implementation of regular mortality and morbidity review, upgraded information systems and maintains a robust communication and media presence.





### REDEVELOPMENTS

Major capital works continued at Randwick and Westmead during 2019-2020, with some significant milestones reached. The total investment in capital works programs for the Network is now \$1.3 billion.

Located on two thriving world-class health and education precincts, these redevelopments will improve the patient and family experience, enable the rapid translation of research to the patient's bedside and foster health partnerships – transforming paediatric care in NSW.

### **CHW STAGE I**

### CENTRAL ACUTE SERVICES BUILDING COMPLETED

A major milestone was reached in May 2020, when major construction of the Central Acute Services Building (CASB) was completed three months ahead of schedule to make the building available as part of the COVID-19 response if required.

The Westmead Health Precinct's CASB will provide the residents of NSW access to additional world-class health services, research and educational facilities.

For Sydney Children's Hospitals Network, the CASB will accommodate a new emergency department, children's short stay unit, additional digital operating theatres as well as satellite pharmacy and medical imaging.

Our services will begin relocating into the building in early 2021 when our new emergency department opens.

The facilities in the CASB will help future-proof health outcomes and experiences for patients, carers, families, staff, students and the community.

The CASB is a partnership between The Children's Hospital at Westmead, Western Sydney Local Health District and the University of Sydney.

#### KEY HIGHLIGHTS

#### August 2019

The Hospital School has been involved since the very start of construction of the CASB – receiving regular building updates and being taken on site walks, led by Health Infrastructure's Senior Project Director. Tim Mason.

### December 2019

Completion of the linkway that connects the new CASB to The Children's Hospital at Westmead, Westmead Hospital and The Westmead Institute for Medical Research (WIMR) This allows crucial patient transfers as well as staff and public access between the health and research facilities.

#### December 2019

The installation of the 60-metre long mural, The River by Danie Mellor, was completed. The artwork depicts a stretch of the Parramatta River, the local Darug people's unique relationship with it, and the importance of the river to all cultures. The River was the result of community consultation and features at the entrance of the CASB and continues through to the University Clinics at Westmead Hospital.









### January 2020

The University of Sydney shares its historic roots in education and training with the Westmead Health Precinct through the donation of two symbolic trees - one for Westmead Hospital and one for The Children's Hospital at Westmead. The trees were propagated from the University's Tree of Hippocrates at Dubbo and donated for planting in the CASB forecourt.

### April 2020

### May 2020

major construction of the CASB and NSW Minister for Health and Medical Research Brad Hazzard visits the new building for





### **CONSULTATION AND FEEDBACK**

### SCH STAGE I AND CCCC

Sydney Children's Hospital, Randwick Stage I and the Children's Comprehensive Cancer Centre (SCH Stage I and CCCC) brings world-leading clinical care, research and teaching to deliver improved models of care for sick and injured children. In partnership with University of New South Wales and the Children's Cancer Institute, this once in a generation project is an opportunity to transform paediatric services and meet future needs of the community.

The redevelopment will include a new children's emergency department with short stay unit, Children's Comprehensive Cancer Centre, a new children's intensive care unit, surgical short-stay inpatient unit, pharmacy and back of house logistics services.

### **CHW STAGE 2**

The new Paediatric Services Building for The Children's Hospital at Westmead, in addition to the Central Acute Services Building, is part of an expansion of children's health services within the Westmead Health Precinct and will include operating theatres, neonatal intensive care unit, paediatric intensive care unit, cancer services and pharmacy.

### **KEY HIGHLIGHTS**

- Selection of Billard Leece Partnership (BLP) as architects for SCH Stage I/CCCC and CHW Stage 2.
- Master planning completed at Westmead and Randwick.
- More than 200 people involved in more than 20 Project User Groups focused on developing functional design briefs for both redevelopments. This is in addition to engaging with more than 40 families, patients and community members.
- Concept design completed, confirming the overall building envelope and location of departments.

# ACROSS THE NETWORK, THERE'S A COMMITMENT TO CONSUMER ENGAGEMENT

- We have established a framework for consumer and community engagement that will be deeply integrated into planning for the redevelopment.
- The project is undertaking a co-design approach to engaging with patients, families and community throughout the full life cycle of the redevelopment.
- We know that when we put the consumers at the centre of our decision making, we can create enduring partnerships with the community, which supports the Network in delivering its vision of a healthy, integrated and connected experience.





### CLINICAL SERVICE DIRECTIONS

In 2019, the Sydney Children's Hospitals Network embarked on the 'Clinical Service Directions, 2025 and beyond' project, to develop a strategic framework that reimagines how we will deliver healthcare to children into the future. The project was about bringing patients and clinical teams together to think innovatively about the future direction of its clinical services.

Eleven groups were formed, with excellent engagement from our clinicians and families, setting the groundwork to consider new and innovative ways of working. The purpose was to shift the focus from models of care that are centred on service delivery and the way clinicians work, to a model focused on the needs of the patient and family.

The groups included:

- Patients coming through the Emergency Departments
- The Intensive Care patient
- The Oncology patient
- The Surgical patient Perioperative Suite
- General medicine, both the short stay and long stay patient
- Mental Health patient
- Ambulatory Care services
- Genetics and Personalised Medicine
- Medical Imaging/Nuclear Medicine/Interventional Radiology
- Pharmacy
- Pathology

With innovation remaining at the forefront of this project, the II groups reviewed and developed future directions to support the development of new, and enhancement of existing, service models.

The emerging approaches included a matrix operating model - focusing on aligning care to patient needs, the care navigator model to support navigation of the health care system, a virtual care model, the enhancing of translational research and dissolving boundaries that impede the delivery of seamless care.

In addition, the project has highlighted additional ways in which research, education and training can be integrated with clinical care.

The clinical service directions framework has provided the platform to transform services across the Network that will lead to integrated, seamless and interdisciplinary care.

### VIRTUAL CARE

As part of our redevelopments, SCHN has been exploring how virtual care can help us deliver the next generation of children's care, to support care anywhere. The model places children and their families at its core, guiding their healthcare and wellbeing under the principles of personal and appropriate choice, to provide options to families, equitable access and family-led care with enhanced education and support to carers. Implementation of this initiative and delivering care virtually has expected benefits and outcomes of:

- Improved support for primary and secondary care teams to deliver care closer to home
- Improved health system efficiency
- Decreased travel and significant disruptions to work, schooling and family life
- Improved experiences for children and families navigating the health system
- Improved health outcomes
- Greater access to clinical trials and novel therapies for patients located in regional, remote and rural areas

# EMM – REDUCING PRESCRIBING ERRORS

A major patient safety initiative was met when Electronic Medication Management (eMM) went live at SCH in November 2019.

In early 2020, the Network played an important role in a project conducted by the Australian Institute of Health Innovation at Macquarie University – an evaluation of eMM systems at The Children's Hospital at Westmead which found a reduction in prescribing errors across the board.

The study, the first of its kind in Australia, found that electronic medication support technology can reduce drug errors in children's hospitals by 40%.







## SUSTAINABILITY

- CHW Bike Fleet launches 10 bikes, gifted by NSW Police, are available for staff to book for up to two weeks at a time, to try cycling to and from work, encouraging healthy, active transport choices.
- Randwick Green Travel Plan initiatives rolled out such as Ride2Work Day breakfast, Travel Census Survey and Light Rail information pop up stalls to promote active, low carbon transport choices to staff and the hospital community.
- Waste reduction and re-use initiatives including the donation of medical equipment, items and furniture no longer required, including ventilators, beds, and patient trolleys to local and overseas health facilities and community groups.
- CHW fortnightly farmers markets is now in its third year, expanding to 13 stalls offering fresh, local produce and food to the CHW community and local area. Due to COVID-19 the farmers markets have been put on hold.

- SCHN Green Champion Network more than 100 staff have signed up as a green champion to participate in SCHN sustainability initiatives.
- SCHN became a member of the NSW Government program, Sustainability Advantage to receive tailored support in their sustainability program, access government incentives, investment opportunities, expert forums and networking events.
- First pass climate risk screening undertaken to identify key climate related risks and opportunities for SCHN and recommended mitigation and adaptation strategies.
- Sustainability Project Working Group established representing all precinct partners to develop the sustainability strategy for Stage 2 CHW Redevelopment and Stage I Randwick Redevelopment.
- PVC Recycling in FY 2019/2020, a total of 1.52 tonnes of PVC was collected from CHW, three times more than the previous year.



- Theatre recycling in FY 2019/2020, a total of 6.3 tonnes of theatre recycling was collected (operating room plastics, surgical devices and kimguard) at CHW.
- Toner cartridge recycling in FY 19/20 at SCHN diverted 1.2 tonnes from landfill, 16% more than the previous year.
- Telehealth services have reduced the need to travel, resulting in a reduction in transport related carbon emissions.
   In FY19/20, close to 3 million kilometres in travel were avoided through the SCHN telehealth program, which is 8 times more than the previous year.
- Our processes and systems in transactional services, recruitment, onboarding and IT procurement are now completed online which has significantly reduced the need to print.
- Paper use in FY2019-2020 reduced by 7% compared to the previous year.





### BOARD

#### CHAIR

Ms Elizabeth Crouch (March 2020)

### **BOARD MEMBERS**

Prof Louise Baur AM

Dr Abby Bloom FAICD

Mr Jack Ford

Ms Jane Freudenstein

Mr Bruce MacDiarmid

Dr Elizabeth McEntyre

Mr David Nott

Emer Prof Kim Oates AO

Prof Donna Waters

Emer Prof Les White AM

Mr Jeremy Wright

Ms Joanna Capon (to December 2019)

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#### **INTERIM CHIEF EXECUTIVE**

Adjunct A/Prof Cheryl McCullagh

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Dr Joanne Ging

### **ACTING DIRCTOR OF CLINICAL INTEGRATION**

Mr Michael Dickinson

# EXECUTIVE MEDICAL DIRECTOR AND ACTING DIRECTOR OF CLINICAL GOVERNANCE AND MEDICAL ADMINISTRATION

Dr Mary McCaskill

# ACTING DIRECTOR OF NURSING, MIDWIFERY AND EDUCATION

Ms Sally Whalen

# ACTING DIRECTOR OF FINANCE AND CORPORATE SERVICES

Mr Colin Murray (September 2019)

# DIRECTOR OF FINANCE AND CORPORATE SERVICES

Mr Brian Jackson (to September 2019)

# DIRECTOR OF WORKFORCE AND ACTING DIRECTOR OF PUBLIC RELATIONS

Mr Ian Fuller

### **DIRECTOR OF RESEARCH**

Prof Chris Cowell

### **DIRECTOR ALLIED HEALTH**

Dr Paula Bray (June 2020)

#### **DIRECTOR ALLIED HEALTH**

Ms Ruth Baker (to June 2020)

### **DIRECTOR OF MENTAL HEALTH**

Dr Michael Bowden (to June 2020)

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Dr Mary McCaskill

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Dr Joanne Ging Acting Director Clinical Operations

Adjunct A/Prof Cheryl McCullagh Interim Chief Executive

Ms Sally Whalen Acting Director of Nursing, Midwifery and Education

Ms Paula Bray Acting Director of Allied Health

Mr Tim Hoffman Director Planning

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Dr Paul Benitez-Aguirre Staff Specialist Endocrinology (CHW)

Ms Angela Casey

NUM Paediatric Intensive Care (CHW)

Dr Bruce Currie

Head of Department Surgery (SCH)

Dr Jacqueline Dalby-Payne Medical Staff Council Representative (CHW)

Ms Elizabeth Giles NUM Short Stay Surgical Unit (SCH)

Dr Deirdre Hahn Head of Department Nephrology (CHW)

Ms Louise Hallett CNC (CHW)

Dr Shihab Hameed Staff Specialist Endocrinologist (SCH)

Dr Donald Hannah Director Anaesthesia (SCH) Dr Luke Lowes Advanced Trainee (SCH)

Ms Kellie Crameri

SCHN Clinical Governance Unit

Ms Melissa Mroz

Nursing & Midwifery Workforce Project NM (SCHN)

Dr Duncan Nass Chief RMO (SCH)

Dr Ted O'Louglin

Senior Staff Specialist Gastroenterology (CHW)

Dr Hari Ravindranathan Staff Specialist ICU (SCH)

A/Prof Davinder Singh-Grewal Senior Staff Specialist Paediatrics and Rheumatology

Ms Justine Trpezanovski Chief Nuclear Medicine Scientist (CHW)

Mr Andrew Wallis
Eating Disorder Coordinator (SCHN)

Dr Susan Woolfenden Senior Staff Specialist Community (SCH)

## FINANCE AND PERFORMANCE

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Mr Bruce MacDiarmid

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Dr Abby Bloom

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Mr Colin Murray Acting Director Finance and Corporate Services

Prof Chris Cowell Director of Research

Ms Sally Whalen

Acting Director of Nursing, Midwifery and Education

Dr Joanne Ging

Acting Director of Clinical Operations

Dr Mary McCaskill

Acting Director of Clinical Governance

Mr Ian Fuller

Director of Workforce and Public Relations

Mr Michael Dickinson

Acting Director of Clinical Integration

Mr Mark Cartwright Internal Audit Executive

Mr David Loy

Manager Corporate Services SCH

Mr Paul Gissel

Acting Associate Director of Finance

# QUALITY AND SAFETY COMMITTEE

#### **CHAIRS**

Mr Jeremy Wright
CO-CHAIR / SCHN Board Member

Prof Donna Waters
CO-CHAIR / SCHN Board Member

#### **BOARD MEMBERS**

Adjunct A/Prof Cheryl McCullagh Interim Chief Executive

Dr Mary McCaskill Acting Director of Clinical Governance

Ms Paula Bray Acting Director of Allied Health

and Medical Administration

Mr Michael Dickinson Acting Director of Clinical Integration

Dr Joanne Ging Acting Director of Clinical Operations

Mr Colin Murray Acting Director of Finance and Corporate Services

Ms Sally Whalen Acting Director of Nursing and Midwifery, and Education

Dr Hala Kaft Deputy Director CGU and Medical Admin SCH

Ms Chrissy Ceely Network Head CGU

Ms Patsi Michalson Network Manager Medicolegal

Ms Lauren McGrath Network Manager Patient and Family Engagement Mr Ben Hamlin

A/Network Manager Patient Safety

Ms Shirley Warren Network Manager Policies and Procedure

Ms Kellie Crameri Network Manager Quality

Sarah Wood

CHW Patient Flow Manager

Dr Marino Festa/Ms Angela Casey CPD Critical Care

Ms Georgette Danyal/Dr Craig Munns CPD Diagnostics CHW

Dr Brad Ceely/Dr Ken Peacock CPD Medical CHW

Ms Kirsten Adnum/Prof Richard Cohn CPD Medical/Diagnostics SCH

Ms Christie Breen/Dr Karen Zwi CPD Priority Populations

Dr Grahame Smith/Ms Fiona Filtness CPD Surgical and Anaesthetics CHW

Ms Margaret Allen/Dr Matthew Crawford CPD Surgical and Anaesthetics SCH

Ms Sandra Pengilly CPD CARPA CHW and SCH

Mr Angus Rennie Workforce Representative

Dr Ashfaque Quadir CRMO CHW

Dr Duncan Nass CRMO SCH Ms Alan Gardo

Director of Nursing CHW

Ms Verity Luckey Director of Nursing SCH

Kathleen Gray

Clinical Integration Representative

Ms Kimberley da Silva Education Representative

Joanna Newsome

Allied Health Representative CHW

Ms Andrea Worth

Allied Health Representative CHW

Ms Paula Bray

Allied Health Representative SCH

Mr Michael Morris Consumer Representative

Mr Laurence Hibbert Consumer Representative

Dr David Lester-Smith/ Gary Williams CERS Chairs

Simon Paget/ Dr Hala Kaft PSIRC Chairs

Mr Andrea Worth Mental health representative

Ms Kathryn Weir Nursing Representative CHW

Ms Helen Bullot

Nursing Representative SCH

Dr Michael Plaister/Ms Helen Said Clinical Leads NSOHS

# AUDIT AND RISK MANAGEMENT COMMITTEE

### CHAIR

Ms Dianne Hill

### INDEPENDENT MEMBER

Mr Stephen Horne

### **BOARD REPRESENTATIVE**

Mr David Nott

### **SCHN ATTENDEES**

Adjunct A/Prof Cheryl McCullagh Interim Chief Executive

Mr Colin Murray Acting Director Finance and Corporate Services

Dr Joanne Ging Acting Director of Clinical Operations

Ms Tamara Petty Network Manager Corporate Governance and Risk Management Mr Mark Cartwright Internal Audit Executive

Mr Craig Phillips Internal Audit Consultant

Ms Sally Bond Financial Audit Services

Hong Wee Soh Audit Leader





For the financial year 2019-2020 the Sydney Children's Hospitals Network's overall Net Result was \$15.0 million unfavourable compared to budget. The general Fund Net Result was \$11.7 million unfavourable and the Restricted Financial Assets Fund Net Result \$3.3 million unfavourable. The 2019-20 year marked the eighth year of operation in an Activity Based Funding (ABF) environment. The Network was funded according to activity determined by the efficient price across a range of program areas.

FINANCE MANAGEMENT TO JUNE 2020	YTD RESULT	YTD TARGET
Acute Inpatient Services (excl. Mental Health)	74,997	75,249
Acute Inpatient Mental Health Services	2586	2260
Emergency Department	9846	10,411
Non-Admitted Patient Services	19,026	19,073
Sub and Non-Acute Inpatient Services	2218	2052
Non-Admitted – Dental Services	85	67
Non-Admitted – Mental Health Services	1268	1189
	110,026	110,301



The Foundation's mission is to connect paediatric research and clinical practice with donors who are inspired to create positive change. The philanthropic funds we raise amplify government investment in the Network, and help to ensure the care provided to sick children across the Network remains world-class.

When the year began, we were on track for a record year of raising funds. Then COVID-19 changed the world. But they say the worst of times brings out the best in us all, and 2020 has proved this to be true.

Our supporters share our belief that protecting and improving children's health is vital for society and they have stayed by our side throughout these difficult times. They made it possible for the Foundation to contribute \$26,241,288 to Sydney Children's Hospitals Network during FY20.

There is also \$13,862,554 in reserves for the Network to call on as required. Given the difficult fundraising landscape this year, we are proud of what we have been able to achieve with our supporters, although it is less than last year.

These vital funds will be invested in capital campaigns, research, clinical excellence and patient experience and collaborative research projects such as Zero Childhood Cancer.

We have secured pledges of \$12.5M for new hospital buildings in Randwick and Westmead.

Our 2020 reputation research results showed donor trust in the Foundation has increased since our benchmark study last year and our investment in innovation is helping to deliver impact. We are receiving positive feedback from researchers about our Greenlight Pilot and our national Curing Homesickness initiative continues to deliver strong results.

We anticipate ongoing economic and health challenges will affect our ability to raise funds, but the Foundation remains committed to supporting a research-led Network, thanks to the extraordinary generosity of the whole community.

Together we are making a real difference to the current and future health of children everywhere.

Nicole Stokes
Chief Executive Officer
Sydney Children's Hospitals Foundation



Sydney Children's Hospitals Foundation is an independent charity with Item 1 DGR status (Health Promotion Charity). To find out more and make a donation online visit schf.org.au



# FUNDRAISING DASHB ARD

During the 2020 Financial Year the Foundation contributed \$26,241,288 to Sydney Children's Hospitals Network across four core areas:



**RESEARCH** including Zero Childhood Cancer \$8,414,736



**CLINICAL EXCELLENCE** including Fellowships, clinical care, education and training and IT projects \$17,015,984



PATIENT EXPERIENCE including patient and family support \$356,876



including ward refurbishments \$87,688



INDIVIDUAL **DONATIONS** 60,809



CORPORATE **DONATIONS** 7458



**WORKPLACE GIVING DONATIONS** 4393



**DONATIONS** TO REMEMBER A LOVED ONE 1357





**DONATIONS IN CELEBRATION OF** A SPECIAL EVENT 1255

**RECEIVED** 87



**FUNDRAISERS** 2025

# CURING HOMESICKNESS TO GET KIDS BACK HOME WHERE THEY BELONG

The Curing Homesickness initiative has been a resounding success thanks to great partnerships and overwhelming community support. In just over a year, we've raised \$1.6 million to help sick kids in hospital across Australia get home sooner!

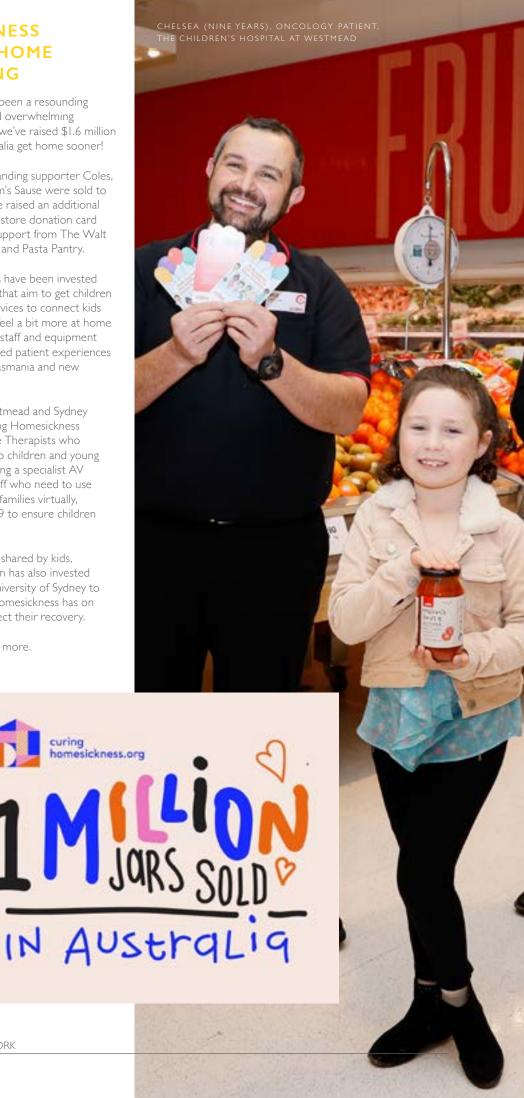
Partnering with the Foundation's longstanding supporter Coles, more than one million jars of Coles Mum's Sause were sold to raise over \$500,000 in the first year. We raised an additional \$910,000 nationally through a special in-store donation card campaign. We also received generous support from The Walt Disney Company, Assembly Label, eBay and Pasta Pantry.

Funds raised from Curing Homesickness have been invested in a range of vital state-based initiatives that aim to get children home from hospital sooner, develop services to connect kids to home while in hospital or make kids feel a bit more at home during their hospital stay. These include staff and equipment for a dedicated play area in WA, improved patient experiences in Victoria and SA, clinical research in Tasmania and new equipment in Queensland and the ACT.

At both The Children's Hospital at Westmead and Sydney Children's Hospital, Randwick, the Curing Homesickness initiative has funded Oncology Child Life Therapists who provide crucial support and education to children and young people with cancer, as well as part-funding a specialist AV Coordinator in Randwick to support staff who need to use telehealth to connect with patients and families virtually, which has been critical during COVID-19 to ensure children can receive the care they need.

To build on the stories of homesickness shared by kids, families and hospital staff, the Foundation has also invested in further strategic research with the University of Sydney to build our understanding of the impact homesickness has on children in hospital and how it might affect their recovery.

Visit curinghomesickness.org to find out more.





### THE GREENLIGHT PILOT - A GAME CHANGER FOR RESEARCH AND INNOVATION

In the movie industry, the Greenlight is the process by which the decision is made to produce and finance a film, based on the concept of the 'wise crowd'.

It's a process of search for the best ideas and the best talent, and a validation process, all rolled into one and the Foundation is exploring how it can be applied to decision-making about philanthropic funding in research.

Our aim is to unearth new research ideas that would not otherwise be funded, and secure investment to bring them to life. At the official launch event the Foundation's Chair also announced a \$1 million matching gift which will amplify funding secured from philanthropists.

Our Greenlight Class of 2020 includes doctors, nurses, academic researchers, allied health specialists and patient parents and we're excited about the diverse mix of participants and ideas covered by the projects currently going through the program.

Through a series of training workshops, videos and 'sounding board' panels, we are helping to enhance the pitching skills of participants and offer networking opportunities to connect them with donors in the early stages of their projects, to generate interest in investment.

Dr David Court, a Foundation board director and founder of Australia's first business school for creative people, the Compton School, is leading the Pilot with the Foundation's Chief Executive Officer, Nicola Stokes.

Feedback to date has been very positive, and although we don't yet have all the answers, we believe the potential benefits are significant.

We have found this whole experience to be really fantastic. It has helped us sharpen our 'ask' and drill down into what we need to do.



Whether or not we are successful in our pitch our team has really valued all the insights and advice. Another side benefit, in addition to linking research groups with donors, is that you have effectively made a research roadmap of the depth and breadth of truly fabulous research going on within the Sydney Children's Hospitals Network.



The Greenlight Pilot will end in December 2020 and an evaluation report will be presented to the Foundation's Board in May 2021 with recommendations for the future delivery of the program.









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