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Aleah (5 months) sharing a hug with her Dad on Edgar Stephen Ward.
Welcome to our 2018 Annual Review
This year’s Annual Review takes us on a journey.

And like all journeys it embodies our evolution. It describes the way we have moved forward and are striving to be better than before.

We’re moving from the past to a future where research, new infrastructure, technology, improved quality of care and collaboration deliver better outcomes for sick children.

One of the ways we are preparing to meet opportunities of the future is through changes to our fundraising structure.

The Hospital’s fundraising team now falls under the umbrella of the Sydney Children’s Hospitals Foundation, where teams and resources combine to greater effect.

You can still direct your support to the causes closest to your heart, and you will still deal with the people you have connections with.

With this new fundraising structure now up and running, I invite you to meet the new Chief Executive Officer of Sydney Children’s Hospitals Foundation, Nicola Stokes, on page 59.

As always, enhancing the health and wellbeing of young people is at the heart of everything we do. In paying tribute to all of our patients and their families, we have chronicled significant progress in the personal journeys of some of them. From Beau (page 19) to Maddie (page 37), these inspiring kids and their families share their travels.

In the clinical environment we have made mileage on liver transplantation, digital integration and in high-dependency and research capacity.

Your generous support has seen many children benefit from improved diagnostics, treatment, and access to medicines and equipment.

On behalf of every patient, family and staff member of The Children’s Hospital at Westmead, I extend a heartfelt thank you.
PHILOSOPHY OF CARE

Our Network purpose
Helping children and young people live their healthiest lives

Our identity
Working together for children

Our values
Collaboration Openness Respect Empowerment

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 vulnerable and at risk children and young people
Lia (7 months) and her mum on Surgical Ward.
FAST FACTS

2017/18

13,964 Operations

59,297 ED presentations

91.4% Occupancy

14,676 Day cases

4.9 Average length of stay (days, excluding day patients)

32,345 Admissions
337
Hospital bed capacity

163
Clown Doctor rounds

49,280
Jelly pots served

139
Helicopter landings

3985
Arrivals by ambulance

84,107
Children cared for

99.3%
of arrivals in ED had transfer of care within 30 mins

75
Children completed their chemotherapy journeys

2614
Concrete trucks used in the Hospital redevelopment

30,000
Steps our porters walk per day

6.7
Tonnes of theatre waste diverted from landfill

688,826
Service events (non-admitted patients)
Funds raised for The Children’s Hospital at Westmead go towards vital research, which translates into better treatments, improved outcomes and potential cures for sick children.

Your donations also help us purchase equipment, medicines and therapies, which enhance our diagnostic and treatment capabilities, moving us into the future where more is possible.

Many of these milestones were achieved thanks to your support.
Record tally of liver transplants

During one month at the Hospital, a record number of desperately ill children received the gift of life, thanks to organ donors.

The Transplant Unit conducted 11 liver transplants in just four weeks. “We did a large proportion of what we do in a year in that one month,” Dr Gordon Thomas, Transplant Surgeon, said.

Transplantation has come a long way since the first liver transplant in 1967. With more and more people joining the Australian Organ Donor Register, the number of children on the waiting list for organs is falling.

Teams at the Hospital completed 30 transplants in the last financial year. That’s the highest number to date.

Each transplant takes between eight and 15 hours; and from diagnosis to recovery each child may see 100 healthcare staff.

“Our thanks go to all the families who have generously donated their loved ones’ organs,” said Vicki Jermyn, Clinical Nurse Consultant for the Liver Transplantation service.
Close Observation Unit opens

The Hospital’s Close Observation Unit opened in June, expanding the Hospital’s capacity to care for infants, children and young people with complex medical and/or nursing needs.

The unit is part of a $4.95 million investment by the NSW Government and consists of six single high-dependency beds, including a state of the art N-Class isolation room.

The unit is run and managed jointly by the Hospital’s Paediatric Intensive Care Unit and Transplant Unit. Two of the beds have been used extensively for patients post-transplant. In a year, with record numbers of transplant patients, this has been an excellent development for our patients and their families.

Each room has its own en-suite and carer zone with a single fold-out bed, making it easier for parents to be at their child’s side at all times. The new space also houses two staff stations, a staff tea room, meeting rooms and a parent kitchen.

Australasia’s first NIDCAP centre opens

The Hospital opened the first Newborn Individualised Developmental Care and Assessment Program (NIDCAP) training centre in Australasia.

The program is the only comprehensive, family-centred, evidence-based approach to newborn developmental care and focuses on adapting the newborn intensive care nursery to the unique needs of individual patients. For ill or premature newborns, intense stimuli (such as bright lights, cold temperatures, loud sounds, pain and discomfort) may interfere with normal development, causing serious health issues later in life. The NIDCAP approach strives to create a supportive, gentle environment for the most fragile babies.

Nurse Manager of the Grace Centre for Newborn Intensive Care, Angela Casey, said this development was many years in the making, and the training centre would have a huge impact on patients and their families. “We now have hope, we have opportunity and we have so many exciting times ahead.”
One of Nature’s 10

Professor Jennifer Byrne, Head of the Children’s Cancer Research Unit at the Hospital and Professor of Molecular Oncology at the University of Sydney, was named in international journal, *Nature*, as one of the top 10 people who mattered in science in 2017.

Professor Byrne received the accolade for her work developing a program that detects errors in gene sequences reported in experiments. The program, called Seek & Blastn, has since helped to identify flaws in more than 60 research papers, almost all of which relate to cancer.

She secured competitive grant funding from the US Office of Research Integrity to continue collaborating with computer scientist, Dr Cyril Labbé of the University of Grenoble Aplles, France, on an algorithm.

Their goal is to develop an automated system to check for errors in papers submitted to journals, and limit cases of academic misconduct.

“Published errors hold back research progress and translation. We are trying to reduce the source of some of these errors, particularly in the cancer research literature,” said Professor Byrne.

First wrist plates for kids

In a world-first, a wrist implant that helps children with severe wrist deformities perform daily tasks will be made available.

Paediatric Orthopaedic Surgeon, Professor David Little, devised the concept, which was developed with his engineering colleagues in the EPIC 3D printing lab at Kids Research. Staff members from US-based OrthoPediatrics Corp joined the collaboration ensuring the plate was compatible with their current devices.

The OrthoPediatrics Wrist Fusion Plate is the first of the 3D Lab’s implants to be commercialised.

“Positioning of the hand is important for all of us, and in children with severe contractures [permanent shortening of muscles] this is not possible. Daily tasks such as getting dressed can be difficult and painful for these children and surgery can help,” said Professor Little. “These are the first plates designed specifically for children.”
Clinical Research Centre opens

The new Sargents Pies Charitable Foundation Clinical Research Centre opened at the Hospital. Based within Kids Research, the clinical trials facility is expected to welcome 1000 children annually. For families, the centre allows access to novel therapies and innovative research in a safe, friendly environment; while for clinicians, it provides the resources to support the translation of interventions from bench to bedside.

“This research facility will foster collaboration between researchers, doctors and nurses to discover new treatments and greatly improve the health care of thousands of children,” said NSW Premier, Gladys Berejiklian MP, who opened the centre.

The centre, which will focus on areas such as allergy and immunology, respiratory, cardiology, rheumatology, endocrinology, obesity, neurology, autism and psychology, features:

- 13 outpatient spaces
- The NSW Paediatric Gait Analysis Laboratory
- A multi-purpose clinical assessment room
- A dedicated reception and waiting area
- Interactive kids’ zone and parents’ lounge
- Biospecimen laboratory
- Shopfront clinical trials pharmacy.

New Consumer Advisory Groups at Bear Cottage

2017 saw the inception of a Consumer Advisory Group at Bear Cottage, made up of eight parent representatives (both bereaved and non-bereaved), five Bear Cottage staff members and a representative from the Sydney Children’s Hospitals Network.

The purpose of this group is to:

- Provide advice to ensure that Bear Cottage is responsive to patient and parent/carer feedback, needs and experiences
- Provide a consultation forum to review documents, incidents or events and make recommendations for promoting and improving patient and family-centred care
- Ensure that patients, parents and consumers are involved in strategic and operational planning, safety and quality improvement activities and the evaluation of patient feedback relating to Bear Cottage.

The parents, who represent a diverse demographic, offer a broad perspective on the many different facets of care at Bear Cottage and participate in fundraising.
My Health Memory app goes live

Designed for patients and families to communicate with their healthcare teams, the My Health Memory app was launched at the Hospital with the following features:

- Emergency Department and inpatient discharge summaries
- Kids GPS plans
- Automated appointment management
- Configured appointment reminders
- Messaging between family and clinician via the electronic medical record (eMR) when initiated by clinical team.

Mother, Naomi Smith, was one of the first to use the app. “It’s great to be able to see when our appointments are, especially if we need to book other things in. Being able to have a conversation with the doctor and team was great too, we were able to leave a message at any time,” she said.

Australian Healthcare Week Award Finalist

The My Health Memory app was given an honorary mention for the Best Digital Transformation Project Award at the Australian Healthcare Week conference. The award recognises facilities, teams and individuals who are making the greatest contributions to patient wellbeing in Australia.

Microsoft Health Innovation Award

Sydney Children’s Hospitals Network and technology solution partners, Oneview Healthcare, won a Microsoft Health Innovation Award in the ‘Engage Your Patients’ category for the My Health Memory app.

Adjunct Associate Professor Cheryl McCullagh, Sydney Children’s Hospitals Network’s Director of Clinical Integration, said, “We’re not just giving our patients data, we’re giving them contextualised data they can act on and someone they can talk to about it”.

Mum, Zaineb, with her sons Yasin (1) and Taha (4) who use the My Health Memory app to keep track of appointments.
AMU celebrates 40 years of achievement

The Adolescent Medicine Unit (AMU) at the Hospital has been at the forefront of developments in the field of adolescent health and medical care for the past 40 years. As well as pioneering a comprehensive, integrated and creative model of care linking inpatient, outpatient and community-based services for young people, the department has undertaken focused research, provided undergraduate and postgraduate education and training and supported policy planning activities at both state and national levels.

Here’s a look at the AMU’s journey

1977
First AMU established
Australia’s first hospital-based Adolescent Medical Unit (AMU) is established at the Royal Alexandra Hospital for Children by Dr David Bennett and Dr Suzanne Robertson.

1980
Championing adolescent health care
World Health Organization invites Dr Bennett to chair an Expert Working Group on Health Needs of Adolescents in the region. AMU initiated at Westmead Hospital.

2010
A research journey
The Sydney Children’s Hospitals Network is established; Professor Kate Steinbeck is the inaugural Medical Foundation Chair in Adolescent Medicine and embarks on an ambitious research program.

2014
Eating Disorders Day Program established
The Eating Disorders Day Program is established in collaboration with the Butterfly Foundation.
Isla (16) in the Adolescent Medicine Unit’s Art Room.

**1983**
First adolescent ward opened
Australia’s first adolescent ward is opened at Westmead Hospital.

**1984**
Success with arts program
AMU’s Youth Arts Program is established with visual artists working with hospitalised young people with profoundly positive outcomes.

**2001**
Recognition for Eating Disorder Program
A joint Eating Disorders Program is established in conjunction with the Department of Psychological Medicine and becomes a recognised Centre of Excellence in NSW.

**2008**
Addiction Program set up
Adolescent Medicine Addiction Service is established at the Hospital.

**2015**
CICADA Centre NSW
The CICADA (Care and Intervention for Children and Adolescents affected by Drugs and Alcohol) Centre NSW is established.

**2015**
Addressing gender dysphoria
A rapidly increasing need within a very high-risk group of young people was recognised and service planning commenced.

**2017**
Approved as a specialised specialty
Royal Australasian College of Physicians approves Adolescent and Young Adult Medicine as a specialty. The Department of Adolescent Medicine is accredited as a training site.

**2017**
A Centre of Excellence
The Academic Department of Adolescent Medicine establishes a Centre of Excellence in Adolescent Health Research to address adolescent health services in the digital age.
A student historian at The Children’s Hospital at Westmead made a remarkable discovery – revealing the secret journey of the country’s first dose of penicillin.
Peter Harrison and Beth Robinson view the Penicillin Papers.
The Children’s Hospital at Westmead has a long legacy built on the goodwill of benefactors. It was founded by a group of women from the community who raised half the money to set it up by public subscription. The converted school soon outgrew its 40-bed capacity.

As infrastructure grew over time, so did expertise. Much of this history is well known, documented and complemented by relationships with universities and research institutes. So it came as a surprise when details of the first use of penicillin in Australia were recently uncovered in the Hospital archives.

Although it was known that the Royal Alexandra Hospital for Children, now The Children’s Hospital at Westmead, treated the first Australian civilian with penicillin, details had not been made public nor had the evidence for the claim ever been examined.

When Beth Robinson, a Masters of Museum and Heritage Studies student at The University of Sydney, began a review of the inventory of the Hospital archive, she heard about the ‘Penicillin Papers’. She set out to find them, with no inkling of what the yellowed envelope and its 24-page contents would reveal.

The documents needed conservation before they could be read. After a process of re-humidifying and flattening, a team of specialists then gathered and a period of fevered research began.

The documents tell a poignant story: It’s mid-1943, at the height of the war and a six-year-old boy lay dying in hospital. Suffering from severe pneumococcal meningitis and despite administration of three types of sulfa drugs used to treat infectious diseases, the boy’s condition was worsening, and doctors feared for his life.

A cable from the Commonwealth of Australia War Supplies Procurement in Washington dated 10 July 1943 confirms the dispatch of penicillin by “special messenger with the highest priority on the 4.54pm plane”. At that time, penicillin was still experimental and stocks were limited and tightly held, mostly trialled on war casualties in Sicily. There was no routine supply of penicillin to civilians. How the request came about and why this particular six-year-old was destined to receive it, remains unclear.

The following day, a million units of sodium salt of penicillin, packed in dry ice, began its flight on a Liberator bomber from San Francisco to Australia, courtesy of the American Army.

“We know that two days after penicillin therapy started, the boy’s temperature had returned to normal, he sat up and had bacon and eggs for breakfast,” said Clinical Associate Professor Alyson Kakakios OAM, who interpreted the medical charts located within the Penicillin Papers.

The report reads, “The child’s condition improved amazingly,” Professor Kakakios said.
On 16 July 1943, a request came from Alan Newton, Chair of the Department of Defence Medical Equipment Control Committee beseeching Dr Vickery, the prescribing doctor, “to refrain from mentioning penicillin to the relatives of any other patient who may be similarly afflicted... as we will be inundated by requests for similar action... and we will be unable to meet the demands.”

From then until mid-1944, the incident remained secret, and although released by the Censor in April 1944, the information remained outside the accepted history of the use of penicillin in Australia.

“...this will rewrite the accepted story of the introduction of penicillin in Australia,” said Tilly Boleyn, Science, Health and Medicine Curator at the Powerhouse Museum.

With the support of Adjunct Associate Professor Glen Farrow, Sydney Children’s Hospitals Network’s Director of Clinical Governance, investigation into the military connection is ongoing.

The Hospital recently made contact with the ‘boy’, Peter Harrison, now 82 years old, to alert him of the discovery. “It was wonderful to finally meet the man whose story I had been tracing”, said Ms Robinson.

“It’s almost 75 years to the day that he was discharged from Hospital, so meeting Peter and his family really makes the research worthwhile and breathes life into the story for everyone.”

Peter still remembers the frightening ride to the Hospital in an ambulance, receiving painful injections, and meeting the American pilots who delivered the penicillin to the Hospital. The pilots gave him a set of ‘wings’ that Peter says was highly-prized by his sisters.

Even better, he remembers being discharged after three months of hospitalisation.

When Peter left hospital on 4 August 1943, the word ‘Cured’ was written on his chart.

"This will rewrite the accepted story of the introduction of penicillin in Australia."
After heart surgery at 10 days old, Beau Cudmore (5) and his family are having the adventure of a lifetime.
“My pregnancy with Beau was perfectly normal, I loved every minute of it,” said Gemma Cudmore. “He was born via an emergency Caesarian section after my labour failed to progress (he was a big lad at 4.1kg).

“Although he did spend a few days in special care with breathing issues, we went home three days later, ready to start life with our beautiful son.”

But at nine days old Gemma and her husband, Brent, noticed Beau was a little lethargic and not interested in feeding, which was highly unusual for him. On the advice of Campbelltown Hospital staff and just to be on the ‘safe side’ they took him to the Emergency Department to get checked out. “Within minutes of arriving, we realised things were serious,” said Gemma. “In the 15-minute drive from our home in Appin to the Hospital, Beau had deteriorated at such a rapid rate that the doctors rushed him into resuscitation where they worked on him for what felt like eternity.”
like eternity, just to keep him alive. We still didn’t have a clue what was going on, we just knew our baby was fighting for his life.”

Initially doctors thought it was an infection. Thankfully, Campbelltown Hospital was equipped with ‘Vision for Life’ – a camera system which allows live streaming of video to specialist doctors at the Newborn and paediatric Emergency Transport Service (NETS). On reviewing Beau and discussing his examination with paediatrician, Dr Raymond Chin, they felt that Beau most likely had a heart condition called coarctation of the aorta – a congenital narrowing of the aorta leading from the heart, restricting blood flow. The local team and the NETS team focused on improving blood flow from Beau’s heart. Once stable, NETS transferred him to The Children’s Hospital at Westmead urgently so he could undergo heart surgery to repair his malformed artery. An accurate diagnosis and early treatment saved his life.

“As first-time parents to a nine-day-old baby, who only a few hours earlier had seemed perfectly fine, our hearts felt broken. When the NETS team arrived they packed him into the little travel cot and off they went by ambulance. We arrived at the Hospital’s Grace Centre for Newborn Intensive Care, where the diagnosis was confirmed.”

Beau’s heart surgery was scheduled for the next day. “Our little fighter made it through the next 24 hours and underwent surgery on his tiny heart at just 10 days old. It was a complete success. The incredible journey we had been on made our heads spin and our hearts ache. He survived only because of the incredible doctors at Campbelltown, the amazing response and attention received by NETS, his safe transfer, and of course the entire team at The Hospital. We were so incredibly blessed to have had the absolute best of the best looking after Beau, we will be forever grateful.”
“Walking into newborn intensive care felt like walking onto another planet, but the exceptional staff there cared not only for our son, but also for Brent and myself, with such kindness and respect it was truly mind-blowing. These people are angels on earth and we cannot thank them enough for everything they did for us.

“Seeing Beau for the first time after his successful heart surgery was one of the best moments of our lives, there are no words to describe that feeling of relief and joy. The day we walked out of the Hospital with our son in our arms, we were devastatingly aware that many other beautiful families weren’t as lucky. When we got home I’m pretty sure I held him for about two weeks straight and wouldn’t hand him over to anyone else! We had been forced to appreciate just how fragile life is and we were so thankful to have our baby home with us where he belonged.”

This appreciation for life led the family to make some dramatic changes. Brent, a builder, and Gemma ran their own construction business. With the long, demanding hours, Brent in particular felt he was missing out on the precious years of their boys being little.

“We saw that living our life together was more important and more valuable than any possessions. It took a crisis with our newborn son to realise that life can change in the blink of an eye, we want to live every minute we have doing what we love with the people we love most, so that’s exactly what we’re doing.”

Currently the Cudmores’ home is a 20-foot caravan that has no fixed address. They packed up everything they owned and hit the road to adventure indefinitely. “For now, our lives are about travelling and showing our children how amazing life can be. It has been the most incredible experience so far and we are making memories with Beau and his younger brother Flynn that we will cherish forever.”

Beau turned five this year, and he is fit, healthy and strong. He is such an incredibly beautiful little boy and he is very smart. Since they have been travelling he has grown in confidence and the family’s bond is stronger than ever. He is brave and has a cheeky, funny side to him, says Gemma. “He loves playing with his little brother and they are never far apart – usually in a pile of dirt somewhere. You certainly wouldn’t be able to tell just by looking at him the rough start he had to life,” she said.

Beau’s blood pressure has stabilised enough to come off his blood pressure medication. “We keep a pretty close eye on his blood pressure and we see his cardiologist, Dr Ayer, at the Hospital every year for an echo [ultrasound of the heart],” Gemma said. “There are still a few ongoing concerns with his heart that could possibly require another surgery one day down the track, but for now everything looks great and we are so grateful for that. He is one tough kid!”
Aneisa Kalra (12) was diagnosed with cancer at the age of one and was not expected to survive, let alone face another health challenge and grow into the exceptional young woman she is.
Just days after arriving in Australia, the Kalra family received news that their baby girl, Aneisa, had cancer.

“She had a bit of flu and we thought she was just tired from the journey and the packing and running around. But as Aneisa’s health deteriorated over the next two days, we took her to the GP. He asked us to get a chest x-ray, and after that he asked us to go straight to the Emergency Department,” said mum, Shaagu. “Within a few hours we were told our baby had stage four neuroblastoma.”

Neuroblastoma is a solid tumour developing in certain nerve cells that run up a child’s abdomen and chest and into the skull following the line of the spinal cord. The most common site for the tumour to grow is in the abdomen.

“Thinking about it still gives me shivers down my spine as we were just finding our footing in a new country let alone facing a crisis like this,” said Shaagu.

Aneisa started treatment right away. After several rounds of chemotherapy failed to make an impact on the disease, and with Aneisa becoming more and more ill, Shaagu and dad, Sarabjeet, were advised Aneisa wouldn’t make it.
After more treatment, Aneisa began to respond at last. She faced 10 harrowing cycles of chemotherapy, a bone marrow transplant and radiation. After her treatment, which spanned two years, she finally went into remission.

For 10 years, Aneisa enjoyed growing up with her family and brother, Urav, at their home in Greystanes. Then one day last year Aneisa developed pain in her leg. “It was exactly the same scenario we faced 10 years earlier but we went straight to oncology and she was diagnosed with osteosarcoma (bone cancer),” said Shaagu.

The bone tumour, which was totally different to her earlier neuroblastoma, was in her right femur. Her doctors removed the affected section of femur, radiated it to kill all cells, then took a portion of fibula bone from her lower left leg, grafted it onto the affected femur and put it back into her right leg.

“The most challenging time I’ve faced in this journey with Aneisa was when she started chemo again and her hair fell out. Her hair was her crowning glory. She asked me: ‘Why me Mum... what have I done wrong that God is so angry with me?’ That just shattered my heart into a million pieces and we both cried our lungs out. I felt so helpless to stop her suffering. But, together we walked towards being positive in this grave situation. Aneisa has such a big heart, she forgives and moves on. Nothing can keep her down for long,” said Shaagu.

“The clinicians and staff at Westmead were simply amazing. I have no words to describe their efforts. The Hospital was a home away from home for us. I cannot thank them enough.”

In total, Aneisa endured 27 cycles of chemotherapy. After her treatment ended and surgeries were complete, she was confined to a wheelchair. Not short of raw courage, determination and ambition, Aneisa said earlier this year that she wanted to walk into high school on her first day. “That is my goal. I feel like the more I push, the more it will happen. I want to go to school on my crutches because in the wheelchair you are just not independent,” she said.

And she did. She has made lots of new friends in Year Seven and is excited at all she is discovering. “She’s just getting into makeup and is developing a
liking for hip hop music. She likes art and craft and has signed up for drama class this year,” said Shaagu.

It is immediately evident that Aneisa has a very big, positive personality, with a very big heart. “She is very confident as to what she wants and how in her life. She has a perpetual, infectious smile on her face and wins everyone over in a short period of time,” said Shaagu.

While heart-breaking to look back on, Aneisa’s story is also full of special moments. “To see Aneisa fighting with all her will to get out of the wheelchair after such a major surgery; to see her ringing the bell in the oncology ward after completing treatment and beating cancer a second time; looking forward to high school; and watching her hair grow back inch by inch, these little and beautiful memories we make every single day make life worth living,” said Shaagu.

While Aneisa may still have some way to go in her recovery and she continues to have three-monthly check-ups, her spirit has shown its power to overcome anything life throws at her.
Life has just begun for Montana Lockett (6), since she received a liver transplant.
‘Let’s go Mum. We can do this,’ said Montana Lockett the night the phone call came. It was 3:45am, but Montana was dressed and ready. It was a call the family had been awaiting for months.

Montana was born with ornithine transcarbamylase (OTC) deficiency, a rare genetic disorder in which an essential enzyme is lacking. Without this enzyme, her body couldn’t remove wastes as she digested protein.

In OTC deficiency, toxic levels of ammonia build up and have the potential to poison the blood and brain, leading to death. Without being able to eat proteins like meat, dairy, eggs and even nuts, Montana struggled to get enough nutrients, leaving her tired and lethargic all the time. She couldn’t concentrate at school or play, and had no interest or energy for anything. She would fall asleep in class and would often be disorientated and confused by the end of the week.

“We tried feeding her through a tube in her stomach but these feeds would last hours, sometimes overnight, and she would also have to have them at school,” said mum, Sarah. “She hated being pulled out of class for a feed. The kids would ask questions and she would cry in the morning before school. She asked: ‘Why aren’t I normal?’”

“2017 was our worst year by far. In July Montana had a really scary episode in which she collapsed at home. She couldn’t walk, was slurring her words and had no idea where she was. It was the worst we had ever seen her. I was so scared she would be left with some form of brain damage. We rushed her to The Children’s Hospital at Westmead. We watched and waited for 12 hours as staff worked to get her ammonia levels down. When her doctor did his rounds I remember just looking at him and breaking down, saying we can’t do this anymore. There has to be something else we can try. I can’t sit here and just watch her suffer, she has suffered enough.”

That’s when her specialists started discussing a liver transplant for Montana. “I had seen a transplant as a last resort. But I could see she was getting worse. She had such a poor quality of life, I felt I owed it to her to try and give her a better life,” said Sarah.

Sarah and her husband, Cameron, heard on Montana’s birthday that she had been approved and was on the waiting list for a liver transplant. “While this was exciting we were also filled with fear as we knew it was a big surgery and came with complications and lifelong changes,” said Sarah.

When the call came that a potential match had been found, Montana knew what it meant.

“She was up and dressed faster than I’d ever seen,” said Sarah.
They handed her over to the doctors, and after an anxious seven-hour wait they were told all had gone well. It was a full 13 hours until they could hear more and see Montana. “I’ll never forget when the surgeon walked out the doors towards us. His smile said it all.”

Since her recovery, Montana has been discovering life as if for the first time. “We have seen our desperately sick little girl transform into a very happy, healthy, bright little girl. We never realised how sick she was before. Now she has so much energy and she doesn’t stop eating!” said Sarah.

The first thing she requested when she got home was lamb cutlets. “It was amazing to watch her eat. She would try anything we suggested and tell us how yummy the food was. Eventually we had to tell her to get out of the cupboards as she was putting something into her mouth every hour of the day.”

**We have seen our desperately sick little girl transform into a very happy, healthy, bright little girl.**
“Seeing her eat normally for the first time was miraculous. To be able to pack her lunch box for school; to tell her she could go to the canteen and order anything she wanted was amazing. Best of all was telling her she never had to be pulled out of class again to have her feeds.”

The organ donation changed Montana’s life and her family has seen first-hand how powerful a change can be. Montana loves to run and play and ride her bike like all her friends. She has always wanted to dance and since the transplant she has been able to fulfill that dream. She now does ballet, jazz and troupe. Her little sister, Indiana (3), also has a love of dance.

“She asked if she could thank the donors in person for giving her their liver. I explained that no, unfortunately they’ve had to go to heaven but she could thank their family. Montana said, ‘That’s a lovely thing they’re doing for me.’”

“She’s free from disease and it was all because of someone’s generosity to donate their organs,” Sarah said. “I hope the donor family will remember their loved one for the life they lived and the life they’ve given. Thanks to them she’s living for the first time. We get to see Montana smile every day now and fulfill all the hopes and dreams we had for her from the moment we laid eyes on her,” said Sarah.
Maddison Ryan (4) has overcome more than her fair share of challenges.
You could say the Ryan family were fairly typical. Dad, Ged, ran a coffee roasting business in Western Sydney, mum, Sally, worked in the airline industry, and a two-year-old daughter, Matilda, kept them on their toes, along with their beloved Labrador, Charlie.

They had a lovely home in the Hills District, and weekends were full of family fun, friends and lots of visits to run around the nearby park. Then a series of events changed all that.

“In September 2013 I went into premature labour with our beautiful twins Poppy and Oliver. They were born at 22 weeks and passed away a short time after birth,” said Sally.

“Three months later on Christmas Day, at a time when we should have been celebrating the birth of our twins, Ged had a freak swimming pool accident
and broke his neck. He shattered the sixth vertebrae in his cervical spine and is very lucky to be alive today, let alone walking. The day Ged was checked out of the spinal unit we discovered I was pregnant with our fourth child.

"Initially my pregnancy with Maddison went smoothly, and my 12-week scan was perfectly normal. However at my 20-week scan we were told Maddie had a couple of limb issues. Her hand and foot on her left side were in the right locations but they were pointing in the wrong direction. We were then told that the doctors' best guesses were Trisomy 18, a chromosome-based problem which would be fatal either in the womb or shortly after birth. Luckily, their guesses were wrong. Following that we had numerous tests and scans which eventually resulted in a diagnosis of arthrogryposis. Arthrogryposis directly translated means multiple limb contractures.

"As the condition presents differently depending on the underlying cause, we didn't know how she would be affected until she was born.

"The possible outcomes were infinite. Our baby girl could have anything from a couple of limb issues, to severe breathing and nervous system problems. We were given the option to terminate our pregnancy, but this was never an option for us just because she was going to be a different kind of ‘perfect’.

"The day finally came when I was induced at 38 weeks as Maddie’s heart rate was going through the roof. Maddie was born at Norwest Hospital and whisked away from me immediately as she did unfortunately have breathing issues and was unable to breathe on her own. She was immediately transferred by ambulance by the Newborn and paediatric Emergency Transport Service (NETS)
to The Children’s Hospital at Westmead. She was admitted to the Grace Centre for Newborn Intensive Care. Maddie spent the first four months of her life in Grace and then transferred to the Paediatric Intensive Care Unit (PICU) for a further four months as she outgrew the neonatal beds. It was after eight months in a PICU environment and a few weeks on the respiratory ward that we were finally able to take her home for the first time,” said Sally.

Sally gave up her job to become Maddie’s full-time carer. “Maddie is sweet-natured, but has a very cheeky side too!” she said. She is adored by Matilda (now 6) and both girls dote on baby brother, William (2). Matilda is gentle with Maddie (most of the time), whilst William is a bulldozer. Even though Maddie can’t chase her siblings away, she is as tough as nails and rarely gives in to the ‘bundle of terror’ her brother is!”

Maddie spent 257 days in hospital in her first year of life. Since that initial stay Maddie has required numerous operations on her hips, knees and feet to assist with the correction of the limbs. “One of her operations fell over her first birthday which in a way was quite fitting as she had spent so long in PICU it was lovely to be surrounded by her second family.”

Maddie is still a ‘frequent flyer’ at the Hospital (she is one of the five most frequent visitors ever) with recurring respiratory issues. “Winters are tricky for Maddie as she often needs extra breathing assistance,” said Sally.

Maddie loves to play on her iPad, watch Peppa Pig and The Wiggles. “She loves getting messy in the sandpit, with paints or water. She loves books and would read thousands a day if possible.” Her favourite books at the moment are a rotation of four Peppa Pig books which she can remember almost word for word.

“We still don’t know what lies ahead as she has ongoing limb issues and also has an undiagnosed neuromuscular disorder which requires breathing support when asleep.” Maddie’s condition is so rare and complex it doesn’t have a name. The family refers to it in jest as Maddison Ryan Syndrome. “But she’s here and she’s a fighter.”

“The vast team at the Hospital has saved and bettered our Maddie’s life on more occasions than we can count. Ged is constantly astounded that there are such wonderful people in the world. They care for our daughter as if Maddie is their own. There is no way we can ever repay the team for what they have done for our daughter, and our family,” said Sally.

The Ryans consider family above and beyond all else. “We just circle the wagons,” said Sally. It is this strength that has seen them face and overcome so many challenges, and seen Maddie travel so far, to live with vigour and spirit, when she was not even expected to survive.

It’s clear the Ryan household is filled with love and laughter, with kindness and understanding, and appreciation for every day. There is an extraordinary thread that binds them together. The Ryans are anything but typical, in the best possible way.
The Children’s Hospital at Westmead and Bear Cottage thank all the generous supporters who have helped us in so many ways over the last financial year. Our supporters come from all walks of life and from every sphere of the community and we are truly grateful for your commitment.

On behalf of the Board, staff, children and their families, thank you for your care and generosity.
I hope the Bob ‘Tug’ Wilson’s Walk for Kids with Cancer will be an ongoing event long after I am able to manage it to keep Bob’s legacy alive.

Carol Wilson
Fundraiser

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We want other families in our situation to have all the latest information and support available and we are committed to funding research to impact this disease in the long-term.

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Over the years, funds raised have made a huge difference to our patients and families, helping us to expand the Cystic Fibrosis Clinic, employ specialty staff and lessen the time children need to spend in hospital.

Professor Dominic Fitzgerald
Senior Staff Specialist
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We believe that together we can make a difference. The power of hope and belief... it’s a really beautiful feeling.

Ann Touchard
Fundraiser

The Touchard family with Dr Michael Brydon at the finish of the City2Surf

We believe that together we can make a difference. The power of hope and belief... it’s a really beautiful feeling.

Ann Touchard
Fundraiser

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We do what we can because kids don’t deserve to be sick.

Gary Pontifex
Fundraiser
Roll of Honour

A gift in a Will is an expression of what is most dear to you. The Children’s Hospital at Westmead and Bear Cottage were fortunate to be beneficiaries of so many people who believed passionately in the health and wellbeing of children and young people. We are honoured to recognise the gifts received from the estates of the following individuals.

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“After a lifetime of supporting good causes, the late Ms Salisbury’s final generous gift has provided the Hospital and Bear Cottage with the means to invest in research, projects and programs that will impact the lives of some of the sickest children in the state.”

Anne McFadden  
Bequest Manager
Your generous support of The Children’s Hospital at Westmead and Bear Cottage is greatly appreciated by our patients, families and staff.

Parker (6 weeks) being comforted by his Mum in Edgar Stephen Ward.
Leaving a gift in your will, no matter how large or small, is a wonderful legacy to leave for the next generation.

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ONWARDS AND UPWARDS

Nicola Stokes, Chief Executive Officer, Sydney Children’s Hospitals Foundation shares her plans for the future of fundraising for the Network.
As an expanded Foundation we are committed to delivering even greater impact for children’s health. Together, inspired by the children and families we help, I know we will deliver.

We will work with investors with an interest in ‘de-risking’ the future of paediatrics; philanthropists willing to help us push boundaries and prove where investment will deliver better treatments and improved care that will ultimately help sick kids live their healthiest lives. I hope you will continue to partner with us on our mission.

I know that many of you have a special connection with one or more of our hospitals and services. The organisational changes associated with the Foundation’s expansion will mostly be seamless – often invisible to your interactions. All your connections and relationships will stay the same. I am committed to making sure your connection with us is always a great experience and I want to assure each and every one of you that we are here to support you in your choice.

Our hospitals, Kids Research, Bear Cottage and NETS can’t succeed without your support. We know some children may only be with us a short time but no matter for how long, they deserve the very best.

I value greatly the role you play in helping make that a reality. I applaud every one of you for your wonderful generosity. Whether as a volunteer, or by making a $10 or a $10 million gift, I want to show you how you help us deliver our vision and what that means for sick kids.

Over the next three to six months I want to meet with as many supporters as possible. I’m open to receiving advice and invite conversations to help understand your dreams and how we can work together to help kids live their healthiest lives.

We’re at the beginning of an exciting era and I look forward to meeting many more determined individuals willing to shake up the status quo.