

THEN AND NOW



BY
JIMMY
POZARIK

Capturing the unique moments that reflect
25 patients' Hospital journeys, telling their stories
through the eye of the lens, then and now.

*“Then and Now” is dedicated
to the memory of May Somerville.*

ARTIST'S
STATEMENT

I have been a volunteer at Sydney Children's Hospital, Randwick for 12 years - first in Oncology and then Emergency. Since 2012 I have also been Sydney Children's Hospitals Foundation's Photographer-in-Residence. I have interacted with thousands of children and their families. It has been, and continues to be, the most rewarding experience of my life.

Not a day goes by when I'm in the Hospital that I don't encounter a parent or child I have met before. Some I remember well, some look familiar, and some I don't even recognise.

One day in early 2017 it happened again. A mother stopped me in the corridor to say hi and ask, "*do you remember my son?*" I looked down to see a boy about seven. I had no idea who he was. I apologised.

So she proceeded to tell how I helped distract her son during a medical procedure many years ago in Emergency. I looked at the boy again. Nope - still no idea who he was. How could I recognise him? He was only a toddler then. Kids can change a lot from two to seven.

That's when I began to think how interesting it would be to see what some of the kids I had photographed in the past look like today. And to hear about their journeys.

I chose a diverse group of 25 kids to re-photograph and thought what a fun and easy project it would be. I was right, and I was wrong. Organising and taking the photos was effortless. But I never anticipated the crushing emotional impact seeing the kids again would have on me.

To walk into the home of an eight-year-old who seven years ago was on life support and not expected to survive, and to now see a happy, active, healthy child - is ridiculously overwhelming.

To spend the morning with a family of a totally dependant child whose parents both work from home and whose grandparents live in the same building so they, too, can help - is awe-inspiring.

To watch a laughing little kid bounce non-stop on his trampoline all morning when almost three years ago he spent 176 days in Intensive Care fighting for his life - that's solid gold.

To see a boy who had open heart surgery as an infant now standing by his dad's truck because he also wants to be a trucker - melts my heart.

To hear how a single Mum, for the past eight years, has had to battle every single day of her life for the future of her son - makes me angry.

To see a once seriously ill oncology patient morph into an intelligent, poised, beautiful young woman - is such a relief.

To the parents, relatives and kids who all so enthusiastically participated in "Then and Now," I thank you so much. You welcomed me into your homes, you fed me, you shared your stories with me, you gave me figs from your tree for my wife, and you drove me all over Coffs Harbour. But most of all, you supported me, befriended me, and trusted me.



ALPER

THEN: 4 YEARS OLD (2012)

NOW: 10 YEARS OLD (2018)

APPENDICITIS



"Alper was admitted to Sydney Children's Hospital, Randwick for appendicitis. We had just moved to Australia from the UK. Alper was four, my daughter six and my youngest son was two and we were just starting to get settled.

Those 10 days in Hospital were very hard, I didn't have many friends or people to count on. But then Jimmy Pozarik came in. After taking the photos he gave me this hug that meant the world to me. I really admired all the time that Jimmy devoted to the

Hospital. Five years after this, I bumped into him again in Emergency (my daughter had broken her foot) and when I said hello to him and he remembered who I was, I got very emotional again. I think anything/ anybody that reminds me of that moment, makes me cry. I'm even crying as I write this.

Now we are really settled here. We love this country and our kids are growing up happy. We have a nice circle of friends and my kids' school, Rainbow Street Public School, is like my family here in Australia.

Luckily, we no longer need to visit SCH or any other hospitals. But this year I started studying with the DELTA society to become a Therapy Dog Trainer so hopefully in the future I'll be able to visit with a trained dog!"

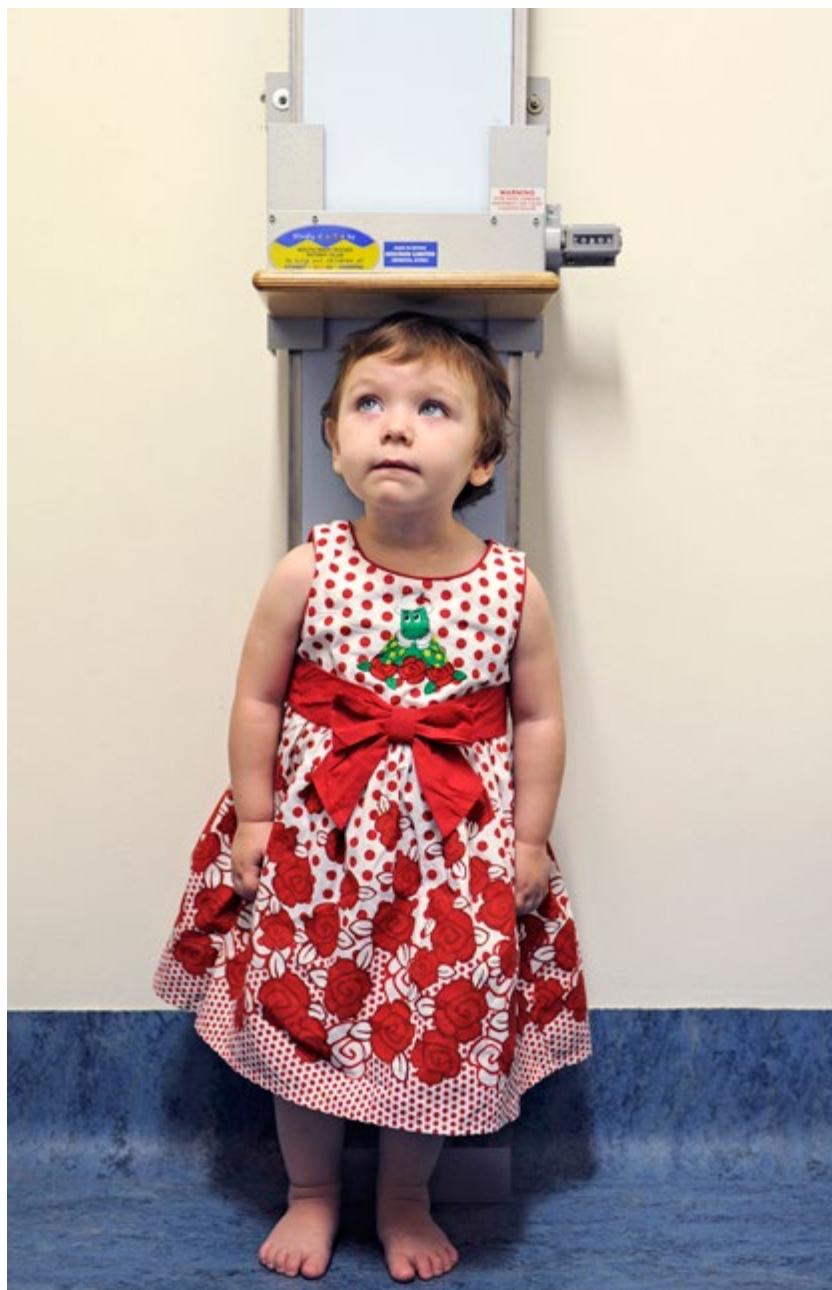
ISABEL
ALPER'S MUM

ALYSSA

THEN: 2 YEARS OLD (2012)

NOW: 8 YEARS OLD (2018)

**INFANT ACUTE
LYMPHOBLASTIC LEUKAEMIA**





“Alyssa was diagnosed with infant acute lymphoblastic leukaemia when she was 10 months old.

When we look at her photo from then we see a fighter who’s full of hope. At that time, Alyssa was no longer an inpatient and we were starting to get back to a normal life away from the wards of the Hospital. We were able to live as a family of four together, catching up on lost time with our eldest daughter Madeleine.

Since then we have gone from monthly follow-up visits to Hospital to now only needing to attend annually. Alyssa is now in year four at school and loves to dance. We have learned to live in the moment and take nothing for granted.

Seeing Alyssa now we feel pride, happiness and gratitude, and see a future filled with spectacularly ordinary family milestones.

We will be forever grateful for the treatment, support and expertise demonstrated by our Hospital family, especially Associate Professor Tracey O’Brien. We also value the friendships that developed with other families in a place we never expected to be.”

AMANDA AND SCOTT MILLER
ALYSSA’S MUM AND DAD



CALEB

THEN: 9 YEARS OLD (2016)

NOW: 12 YEARS OLD (2018)

**MEDULLOBLASTOMA -
BRAIN CANCER**



“The photo from back then reminds me of Caleb being incredibly ill and very anxious about the future. After his brain cancer diagnosis, we didn’t really know what the future would hold for him and it was very scary.

We were away from home so often and missing so much. We felt isolated. We had been thrust into a new world that we didn’t want to be a part of.

Since then it’s been a huge rollercoaster ride for us. Caleb has now finished treatment

and is going really well. He recently had surgery at the Chris O’Brien Lifehouse to help get movement back on the right side of his face which was amazing.

We are still trying to find our ‘new normal.’ We spend a lot of time away from our home in Port Macquarie as we have so many appointments back in Sydney. But life has settled a little.

I was overcome with emotion in the early stages of Caleb’s shock diagnosis, but found Sydney Children’s Hospital, Randwick to be

a huge comfort. The nurses are a credit to the Hospital. They’re just amazing people who provide a lifeline to the families. The doctors are remarkable too, and we felt like they treated Caleb like a person, not a number.

We now see a future for Caleb. He has been given a chance to be like any other child his age and to live an inspiring life.”

SUZANNE
CALEB’S MUM



COOPER

THEN: 6 WEEKS OLD (2016)

NOW: 2 YEARS OLD (2018)

ENTEROVIRUS / MYOCARDITIS

“At 10 days old Cooper contracted an enterovirus which resulted in myocarditis. It was a blur - we remember living and breathing every second of everyday in Intensive Care with our little fighter. Cooper was horribly sick and fighting for his life, but somehow, he managed to open up his big blue eyes, smile and reassure us that things were going to be okay.

Life was an endless emotional roller coaster back then. Each and every day we stayed by his bedside with the fear that Cooper may



not survive. Life for Cooper was horrendous. Words can't describe how critically ill he was. He lay there lifeless having to deal with the endless poking, prodding, and procedures. He even suffered a cardiac arrest and endured 26 minutes of CPR, but he continued to defy the odds. Gradually as he made it through each day, week, month - he went from strength to strength. The unconditional and overwhelming love, support and faith from all our loved ones got us through.

Now Cooper is thriving. He is a big, strong, delicious, beautiful, resilient and healthy boy who is a lover of life. He takes everything in his stride and amazes us each and every day. Looking at him we feel pure joy and happiness. His infectious personality and smile lights up everyone's lives and we are truly honoured and blessed to call him ours.

The future is looking bright for us. We still visit the Hospital for regular check-ups but we live life to the absolute fullest, enjoying

and cherishing every single moment with our two gorgeous kids, Cooper and Jersey.

We would like to say a huge thank you to all the Hospital staff and Sydney Children's Hospitals Foundation for everything they have done and continue to do for our family. We will be forever grateful for your ongoing support and friendship, it means the world to us. "

JESS AND PETE
COOPER'S MUM AND DAD



DEE - ANNE

THEN: 15 YEARS OLD (2012)

NOW: 21 YEARS OLD (2018)

SCOLIOSIS

“I was diagnosed with scoliosis and had to wear a back brace, but this didn’t work, and my curve got worse. Because of this I received a seven-hour operation called a spinal fusion.

Memories of how scared and nervous I was are the first to come back when I look at the photo from back then, but I was also excited to be fixed. I remember just before I went into the operating theatre there were people and lights everywhere, crowding my thoughts and vision. My mum stood next to me holding my hand, and when I noticed

her crying, fear began to creep its way up my body. *“If my mum was scared and sad does that mean something is wrong? Will I not wake up afterwards?”* The gas mask was horrible, it tasted bad and was scary too. Then I blacked out and when I woke up, everything was fine.

After my operation the journey was rough to begin with, as most journeys are. It felt like I had to learn to walk again. When I left the Hospital, I was glad to be home. I spent a lot of time in bed and I didn’t like it when my dad made me get up and go for walks - but



I knew I had to. I also had to wear a hideous back brace. The first few weeks of having to wear it were terrible, I would fight with my parents and ask to stay home from school. Eventually I got over myself though, and it no longer bothered me. I know it was hard for my parents to take time off work and help me, but I know they would do anything for me.

As time went on it got easier, I often forget that any of it even happened! Sometimes people will point out my scar and ask about it and I'm shocked, I simply reply with "oh, just an operation" and people begin to coo

and say how horrible it must have been. I say it wasn't too bad. Because really it wasn't. Just a few weeks of craziness and hardship is worth everything the great people at the Hospital did for me. Now I'm a normal 21-year-old, buying cars and studying at university so that I can (hopefully) get a career that I love.

I look at the 'now' photo and it's just another photo of me, plain, old, boring me. However, the longer I look at it and understand the story the photographer was trying to capture, I see someone brave and strong,

who went through something not so great and came out on top. Not saying I'm some great survivor or anything, I know plenty of people who go through worse. I feel proud that I went through that and it's made me the person I am. I'm proud to be me.

Next for me is to survive university and just live the best life I can with the opportunities I have been given."

DEE - ANNE



ELKE

THEN: 13 MONTHS OLD (2012)

NOW: 7 YEARS OLD (2018)

CRANIAL VAULT REMODELLING

“Elke had to have cranial vault remodelling when she was 13 months old. I can’t recall too many memories of this time - just lots of appointments with different specialists monitoring and planning what was going to happen on the day of the operation. It still doesn’t really feel like it all happened. I knew it was incredibly serious, but don’t remember actively worrying about it until a week before the operation.

Anna, conversely, remembers everything and was worried for the whole year leading up to

it. But life also had to go on: looking after our (then) two-year-old son, family, work, life...

I remember our friends being incredibly supportive before, during and after the operation. Perhaps because we were all at that same life stage, so the realisation it could be any of us going through the same thing was quite powerful.

Elke was in theatre for around nine hours (the operation complicated by a bleed on the brain), followed by Intensive Care for



24 hours, and then a high-dependency ward. And then home - literally five days after such a huge operation.

Since then, life has been nothing short of fantastic. There are things we need to keep an eye on, however, and an annual check-up until she's 18 but otherwise Elke has been amazing.

When I look at her now I see the same beautiful, strong, funny little girl from way back. It's hard not to get emotional about it

now when the enormity of what she actually went through is re-lived. I'm so proud of Elke - and Anna and Henry, what a little team!

I want Elke to continue showing us the determination and humour she's displayed at every turn. And I want us as a family to continue taking those bold decisions and making the most of life.

There's an army of wonderful people at SCH who you'd never know about unless you've been in this sort of situation. It's humbling

to know they're doing their best day in, day out, for your daughter. Alongside Associate Professor Mark Gianoutsos and his team, they are all heroes in our eyes."

OLIVER
ELKE'S DAD



EMILIA

THEN: 12 MONTHS OLD (2012)

NOW: 6 YEARS OLD (2018)

**COMPLICATIONS FROM
ISCHEMIC TRAUMA IN UTERO**

“Emilia suffered an injury in utero for unknown reasons. The pregnancy had progressed well until about 35 weeks when she appeared to have difficulty getting out of the breech position. During the 35th week I had another ultrasound and all hell broke loose! Rapidly my husband and I were counselled about my daughter’s compatibility with life and the need to deliver her via caesarean section.

The caesarean went well although I was acutely aware there was something wrong. The operating theatre went from a busy humming place to dead silence. The anaesthetist comforted me like something

terrible had just happened although I didn’t know what it was.

Emilia was born with severe ischemic damage to her left arm as a result of an internal haemorrhage. She had clots in many of her other organs too. My husband and I felt helpless in a totally uncontrollable situation.

Within minutes of birth Emilia underwent scans and then vascular surgery. After the first lot of surgery Emilia was taken by road ambulance to Sydney Children’s Hospital, Randwick while I was flown in the air ambulance. It was a harrowing time knowing that as soon as she arrived she would



undergo further surgeries. My health was not optimal either, so I felt helpless being an inpatient of the Royal Women's Hospital which meant that for the first few days I was away from her.

Her inpatient journey at SCH had many ups and downs, lots of surgery and uncertainty. We were amazed at the skill of the medical, nursing and allied health teams that supported us and were continually reminded of how precious life is.

Looking at the photo from then makes me smile, it makes me think of that point being the start of her cheeky nature. It

also reminds me that even though it was taken when she was about one year old that we hadn't seen too many occasions when she was genuinely 'over the moon' happy. That day, in clinic, maybe because the photographer Jimmy was happy, she was too. She giggled and laughed in front of the camera like that was what she was supposed to do and that made me confident that we were going to be okay.

Since then Emilia has gone from strength to strength, like many other amputees her resilience and courage are demonstrated on a daily basis. She is a role model to her peers demonstrating positive attributes of

how to be respectful of people with limb differences. She makes people laugh, likes to be surrounded by others and has a caring and compassionate nature. Emilia loves her sports; swimming, Brazilian jujitsu, snowboarding and is determined to do anything that people say she can't.

Between then and now there have been many milestones reached, we look forward to what the future holds. We feel blessed that SCH saved her life because it is a life that is truly worth knowing."

SHARON
EMILIA'S MUM



EVE

THEN: 9 YEARS OLD (2015)

NOW: 12 YEARS OLD (2018)

OSTEOSARCOMA

“Eve was diagnosed with osteosarcoma, a type of bone cancer, in her leg. We were referred from Coffs Harbour to Sydney Children’s Hospital, Randwick and we lived between the Hospital and Ronald McDonald House during her treatment. She had four months of intensive chemotherapy and then major surgery to remove the tumour and insert an expandable prosthesis to replace her knee and tibia. After surgery Eve’s leg was immobilised in bed, then in plaster or a brace and on a plank on the wheelchair. She then had daily physio to start to learn how to walk again. Throughout all this she endured



another five months of intense chemo, and a lung surgery, it is amazing how children manage it all.

To me, the original photo reflects the incredible care that Eve received at SCH. It was taken close to the end of a year of challenging treatment, with lots of rehabilitation still to come - yet she is happy and positive. So many people contributed to Eve's care and they always used their great skills with such kindness and humour. The photo brings warm memories and a feeling of huge gratitude.

Eve returned to full time school in Coffs almost straight after finishing treatment in early 2016. Her central line was removed some months later and she used crutches for another year or so. It is almost three years from treatment and Eve now walks very well.

Eve has check-up scans every three months and her leg is lengthened regularly via a simple non-invasive process. When I look at Eve now, I see a happy and energetic 12-year-old with lots of exciting things in her future! She enjoys school, keeping busy with all her friends and being part of a local acting group.

Our time at SCH was very special - when we return there, it is lovely to see people who made such a difference to Eve's life. We feel so lucky to have received such amazing medical care and compassion from everyone."

REBECCA
EVE'S MUM

FLYNN

THEN: 5 YEARS OLD (2012)

NOW: 11 YEARS OLD (2018)

**ACUTE LYMPHOBLASTIC
LEUKAEMIA.**





“Flynn was diagnosed with acute lymphoblastic leukaemia in October 2011, a day before his fourth birthday.

When I look at the original photo I think of what an incredibly hard time this was in our lives. Flynn says it makes him think of how happy he was even in those sad, sad times. I had just been newly separated and on my own for four weeks, so already times were pretty tough. But my boys and I pulled through and proved that even in the darkest hour there is light at the end of the tunnel. Flynn showed true courage and determination throughout his treatment and it made the journey a lot easier having tremendous staff and great friends and family around.

Flynn has now been in remission for five years and continues to amaze us all. We have moved to a new town, I have remarried and had another son. Flynn is playing Rugby League and shows strength on and off the field, he isn't the biggest on the field but shows he has the biggest heart.

We will continue to grow as a family and stick together through thick and thin. We are planning many trips away and winter weekends will be spent cheering on the Roosters!”

KELLYANNE
FLYNN'S MUM



GEORGE

THEN: 5 YEARS OLD (2015)

NOW: 8 YEARS OLD (2018)

**GLIOBLASTOMA MULTIFORME -
GRADE 4 BRAIN TUMOUR**

“George was two years old when the original photo was taken. I can’t believe how relaxed he looks in it. The photo was taken during his fortnightly hydro and music therapy time at Sydney Children’s Hospital, Randwick. We did not go out much in those days and George did not have any social activities, so it was a big outing for us even though we only lived five minutes away.

Back then, George frequently visited the Hospital for various check-ups and meetings. All the doctors and nurses at SCH were very



nice to us, but most of the visits were formal and none of them were ‘fun.’ Don’t get me wrong - this was necessary at that time as George suffered from numerous daily seizures and his day was filled with a cycle of episodes, recovery and sleep. Playing and having fun with other kids was not at the top of our agenda. The hydro and play therapy sessions were the only fun that George and I got to have. During these visits I was asked not to talk about George’s health issues in front of him. It was like George went on a play date rather than a Hospital visit.

George is now eight years old and after a successful brain surgery in 2016, he has not suffered from any seizures. Even though George still has lots of other health and developmental challenges, post-surgery George has started to play, read books with his big sister and even shows an interest during story time. His love of music also makes his Dad very proud.

When George was gravely ill, my husband’s wish was for George to smile someday. Looking at him now, I am very grateful to

report that his humble wish has come true. There are just no words for us to adequately express our gratitude. To everyone at SCH please accept our thanks from the bottom of our hearts.

Lots of Love from the Yu Family.”

MEI-YEE
GEORGE’S MUM



HASSAN

THEN: 5 YEARS OLD (2015)

NOW: 8 YEARS OLD (2018)

VACTERL ASSOCIATION

“Our journey with Sydney Children’s Hospital, Randwick began the day Hassan was born. He was instantly transferred to have surgery to increase his chances of survival after a diagnosis with VACTERL association. At the time this was all overwhelming medical jargon that was incredibly complex and hard to comprehend.

Hassan was in Hospital at the time of the original photo as he was having a test to determine why he was waking up with croup and experiencing breathing difficulties on a regular basis.

I always recall Hassan’s positive, vibrant and pleasant nature despite any health issues he experienced. I specifically remember this photo shoot as being enjoyable and easy as the photographer worked really well with him. The bubbles were an amazing idea that really encouraged Hassan to cooperate and truly embrace the moment that produced a priceless image.

Due to Hassan’s medical needs much of our time as parents was dedicated to our precious little boy. Fortunately, we had a strong support network to help with our



daughter and she herself brought much joy to her little brother.

Life for us as a family has been quite unpredictable as Hassan's health improves at times but, it can also rapidly and unexpectedly deteriorate. We have learnt to take each day as it comes.

When I look at Hassan now I see a young boy who is growing physically, mentally and emotionally, and has overcome every obstacle that has been thrown his way. He is a strong-willed young boy who does not

allow his daily medical needs to affect his way of living or his happy nature. He is often complimented for his genuine smile that is described as a 'winning.'

Hassan has started the next chapter of his life and is in year three at school where he constantly strives to achieve the best for himself. He wants to be a "Clown Doctor" when he grows up and his passion gets stronger every time we visit the Hospital and they visit us!

Our relationship with the Hospital is expected to continue into Hassan's adulthood. If it

weren't for the dedication of countless medical teams, Hassan would not have made it to where he is today and we, as a family, are forever thankful for this."

FATIMA
HASSAN'S MUM



JAKE

THEN: 3 YEARS OLD (2015)

NOW: 7 YEARS OLD (2018)

BRAIN INJURY

“Jake was admitted to Sydney Children’s Hospital, Randwick after he was involved in a motor vehicle accident. It was a head-on collision that left Jake with a significant brain injury and he was paralysed from the chest down. I was called by a friend travelling in the car behind and I arrived at the scene which was horrific to see.

The first day at SCH was so hard. It is still a blur. Jake was placed in a coma for close to six weeks and during this time I spent most of my hours sitting by his side hoping for

improvement. We nearly lost him a couple of times but due to his strength and the incredible staff, he survived.

The rehabilitation stage was super hard on Jake, he was tube fed and had a tracheostomy. Jake’s photo from then reminds me of the hardest most painful time in our lives, but I also see a brave young man who tried his very best to learn how to sit, eat and speak again. The most basic of things were a new challenge. He was amazing, as were the staff. Jake especially



loved his occupational therapist, Kath. She was extraordinary. One of the best staff members I have met.

Jake has come a long way since then. We still regularly visit for check-ups and clinics and we love seeing the faces that were like family to us during our long stay. He has learned to adaptive swim, been involved in wheelchair basketball and scuba diving and his next wish is to start boxing. But with the positive comes the hard times as Jake knows he is different from other kids. He is becoming more aware

of that with age, so he has counselling to help with his emotional needs. He has also recently been diagnosed with ADHD from his injury, so he struggles with concentration, learning and making friends.

We continue to take each day as it comes and stay positive. We strive to make Jake's future one that is full of ambition, strength and fulfilment - regardless of his disability. We are constantly on a learning curve - we have good days, we have bad days, but we are so glad we still have him to love and hold.

We would like to say to all the staff that were involved with Jake, from the early days until we could go home (you know who you are), that you all contributed to ensuring my son had the best chance at life. We love you, and thank you just isn't enough."

SARAH
JAKE'S MUM

JAMES

THEN: 7 YEARS OLD (2012)

NOW: 13 YEARS OLD (2018)

**CEREBRAL CAVERNOUS
MALFORMATIONS**

“James was in Sydney Children’s Hospital, Randick because he needed emergency lifesaving brain surgery.

The photo from then stirs memories of a time when I was so scared.

Scared my son wouldn’t make it through the surgery.

Scared that he would have a relapse while in the ICU.

Scared because of the ramifications of the bleed in his brain and what his life would be like.

Scared of all the ‘what ifs.’

Life was damn hard.

Life was living in a blur as a family torn apart by the chronic illness of a child.

Life was a worry for my boy.

Life was missing my boys at home.

Life was a myriad of specialists, doctors, nurses and teams.

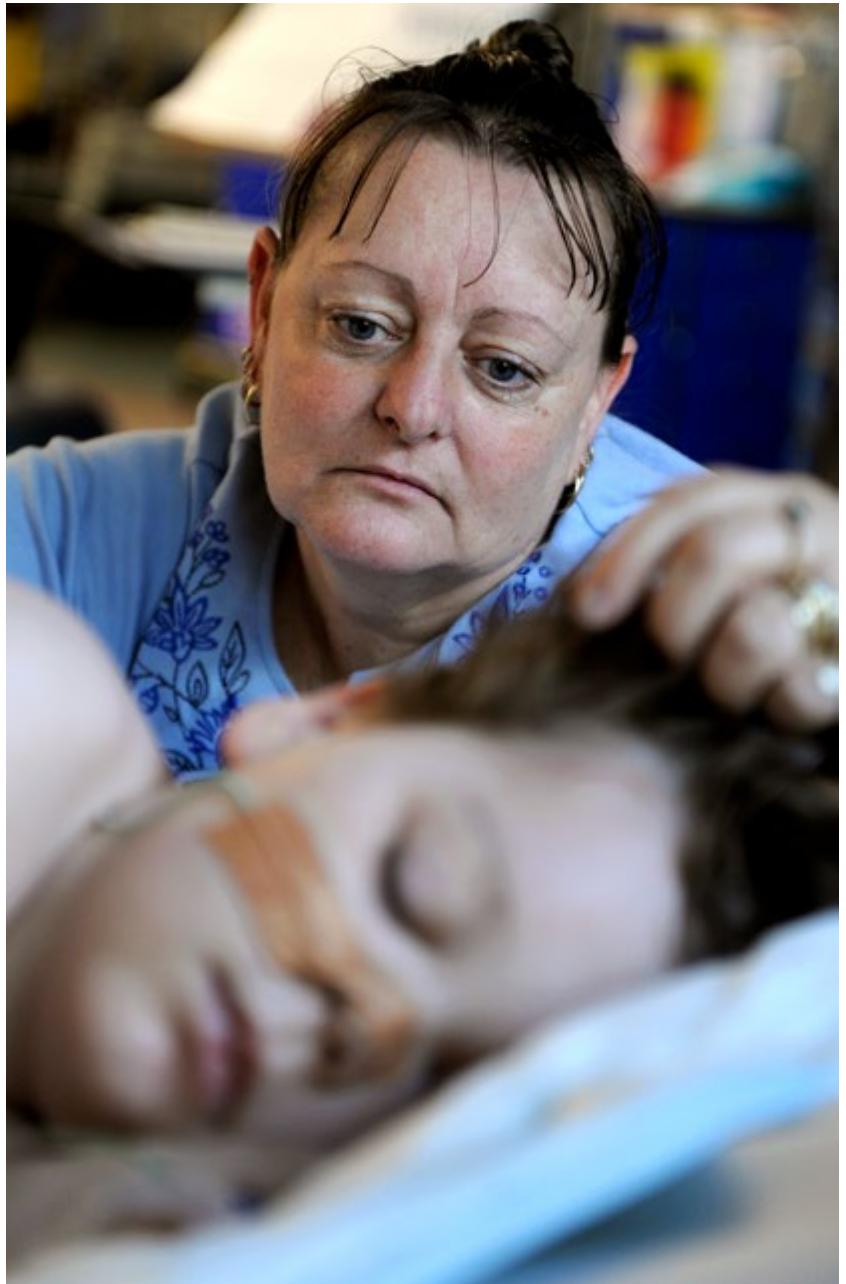
Medications, tests and beeping machines.

Tears and hope.

This journey will not stop while James has breath - as there is no cure.

The journey is that of a child growing and finding his way in life.

The journey is seeing him get stronger but knowing that he could regress at any moment.





The journey is transitioning from a child to a teen with a rare condition.

The journey is fighting to be heard at times. The journey is that of a mum who won't stop being the best advocate she can be for her son, even when he hates her because of restrictions.

The journey of the siblings is not being able to do things that regular families do.

The journey for them is having the family together and apart, together and apart.

The journey is sad for the want of normal but knowing this is our normal.

The now is finding the happy in the hell.

The now is a boy who is determined to be the best he can be.

The now is a boy who hates the amount of appointments he has.

The now is a tired boy who just wants to go home.

The now is a boy who says, "never give up," even when his hand won't do what he wants it to.

Next for our family is to keep on keeping on. Keep running on our hamster wheel.

Next is knowing I can't plan things in advance. It's hard but it is what it is.

My thoughts are that if you blink, a decade will fly by.

My thoughts are that I'm doing my best as a mum with what I have learned over the years after being dropped in the deep end of cerebral cavernous malformations.

My thoughts are those of eternal gratitude to the staff in this amazing Hospital who have done what they do best.

My thoughts are that I have the joy of having my son to love, to hold and to just breathe him in."

MOIRA
JAMES' MUM



KELERA

THEN: 10 YEARS OLD (2015)

NOW: 13 YEARS OLD (2018)

**JUVENILE IDIOPATHIC
ARTHRITIS**



“Back then Kelera was in Sydney Children’s Hospital, Randwick to have her monthly infusion as part of her treatment for juvenile idiopathic arthritis.

We have been on a continuous journey of the same thing every month. Infusions, doctor visits and medications. Her condition has its ups and downs, but Kelera is strong and resilient.

We are on this journey as a family. We are all learning how to cope and deal with this chronic disease, but most importantly help Kelera lead a happy and painless childhood.

We don’t know what the future holds so we are taking each day as it comes. Kelera has grown up a lot but is still the same bubbly child without a care in the world.

I would like to thank Dr Chaitow’s team and everyone at the Hospital for making Kelera’s appointments bearable and fun, every time she visits.”

TUTANA
KELERA’S MUM



KENNETH

THEN: 4 MONTHS OLD (2012)

NOW: 5 YEARS OLD (2018)

HEART SURGERY

“Back then Kenneth was being treated in Coffs Harbour. He had a heart condition and doctors were coming from Sydney to treat him. Three weeks later it was decided he would need surgery and so Kenneth and I travelled to Sydney Children’s Hospital, Randwick.

It was a very hard time and looking at the photo it reminds me how difficult it was to see my child like that. I really relied on friends and family at the time as my mum was also undergoing treatment for breast cancer – her surgery was booked for the same day as Kenneth’s.



He needed to be in the Intensive Care Unit (ICU) before and after the operation. Throughout all of this Kenneth was a curious and inquisitive baby. I remember he would always whinge when he couldn't see what was going on, so the nurses in ICU always made sure his bed was raised up.

When looking at the photo with all the tubes, monitors, and so many doctors for that one tiny baby, I can't believe we were in Sydney for just two weeks and then ready to go home.

Since then he's had check-ups along the way, but after his five-year appointment, doctors advised there was no need for further treatment. He's been so well since that I can't even remember the name of the condition or the surgery! The only sign it ever even happened is Kenneth's big scar. As he was so young at the time, he has no memory of the whole ordeal, but he knows he has his scar. When people ask he doesn't really know where it came from, he just knows he has the same scar as his uncle.

Kenneth is now this happy-go-lucky kid who loves his dad's trucks. Life has been pretty cruisey with Kenneth starting school and just making friends with everyone. He has also recently been made sandpit monitor which he takes very seriously.

It has been a very eye-opening journey and we would love to thank all the wonderful doctors, surgeons and nurses for all their amazing work."

KARINA
KENNETH'S MUM



LIBERTY

THEN: 1 YEAR OLD (2012)

NOW: 7 YEARS OLD (2018)

**DILATED CARDIOMYOPATHY
WITH SVT**

"Around her first birthday, Liberty seemed off-colour, but we just thought it was teething. After a day or so we took her to the doctor who thought he heard some fluid on the lungs, and suddenly we were in the Intensive Care Unit (ICU). She had dilated cardiomyopathy with SVT (supraventricular tachycardia). It was touch and go for a long time. We spent about two months in ICU all up, first at Sydney Children's Hospital, Randwick then transferred to The Children's Hospital at Westmead.

It was like being catapulted into a nightmare. Hospital was where hope was, but it was also a place where our lives were on hold while this all-important situation played out. It was like being in limbo. At the time it meant a lot to us that Jimmy wanted to take photos of Liberty. We remember thinking, whatever happens, we want people to

remember her and that photo was part of our coping.

We're not sure how Liberty felt about her time in ICU, partly because at one year old, she wasn't yet speaking. Not only was she having arrhythmias, she was ventilated and had to be suctioned regularly, which she found very distressing. She had never been left alone in her life, so we made sure that one of us was constantly with her, sleeping in shifts with help from her grandmother.

Even though Liberty had to stay immobilised in bed, often with her hands splinted to stop her from pulling out her feeding tube, she was still the same active kid who we needed to keep engaged. There are a lot of hours to fill when you are confined to a bed. We held toys for her, sang to her, told her stories and treasured the times the music



therapist or Miss Primrose the therapy dog were able to come.

It must have been a supremely strange time in Liberty's life. When we look back at our photos of this time we are so glad we were always there to keep her going. We see a lot of smiles on her face, despite all the equipment she's hooked up to.

We returned home with a live baby. We weren't sure that was going to happen. She had become very thin and fragile with a big pacemaker scar, a lot of medications, and some statistically scary medium-term prospects. It was hard to know how to make sense of everyday life, or how to care about anything at work, when you don't know how long you have with your child. We came to the conclusion that all you can do is make the most of today.

We think we've been (understandably) hypervigilant about her health since then, and it's been hard to trust anyone else to look after her. But over time, as she's grown and stabilised, we've regained confidence that things are probably going to be okay. She's been off all medications now for about two years, which feels amazing. She's still got the pacemaker, but it's turned down low. She is also still having arrhythmias but doesn't seem to notice them.

At some point soon, Liberty will have an electrophysiology study (EPS) to see if she's a candidate for an ablation. Based on how that goes we'll have a new pacemaker, or not... we're still on a long path.

When we look at Liberty now we see a happy,

strong, confident child who's amazingly physically active and fully engaged with life. Seeing her turning cartwheels in her gymnastics class is just wonderful. It's the most we could have possibly hoped for.

The staff at SCH helped us through one of the hardest times of our lives, and so did the other parents in ICU. It's a strange, dark netherworld. People face things that we didn't know existed. It still feels weird sometimes to think about how ridiculously confident we were that everything was going to be okay, when we first walked in. It did end up okay though, for us."

REBECCA AND JOEL
LIBERTY'S MUM AND DAD



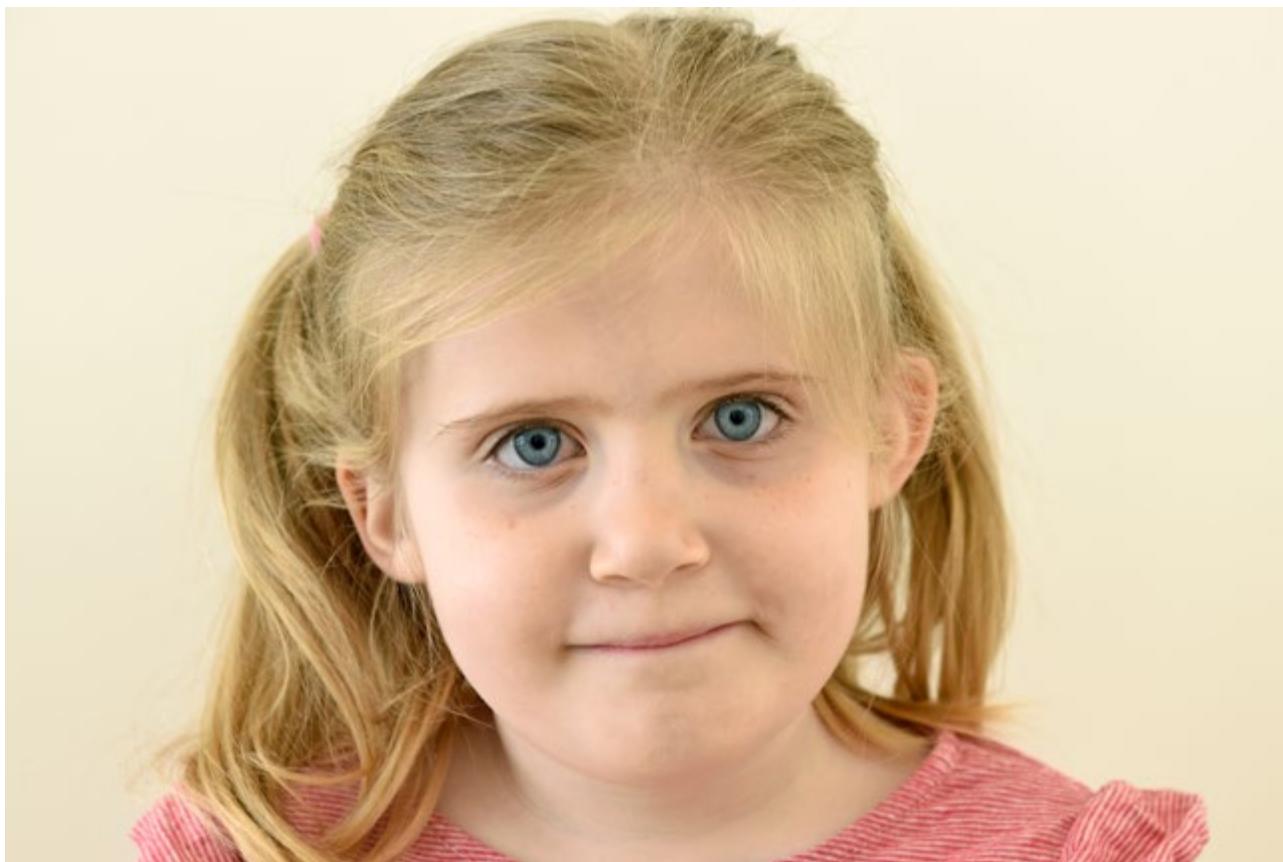
LIZZIE

THEN: 9 MONTHS OLD (2012)

NOW: 7 YEARS OLD (2018)

1P36 DELETION SYNDROME

“Back then Lizzie was in Sydney Children’s Hospital, Randwick to get a helmet fitted. She used to have seizures and the medication made her sleep more which gave her a flat head. That procedure was the least upsetting at the time as it was for cosmetic reasons. We had only just received Lizzie’s diagnosis of 1p36 deletion syndrome, so our heads were spinning. As well as physiotherapy, speech therapy, occupational therapy, early intervention and sleep studies, we were monitoring any seizures, handling her medications, juggling



work and settling her older brother into primary school. We were shell shocked.

We were told she may never walk, talk or be able to do many things other typically developed children can do. Everything we have done over the last seven years of Lizzie's life has been geared towards making things easier for her. From toys to weekend activities and holidays, where to stay and who to visit, or who to invite to our house. All decisions have been tailored to how Lizzie might fit and whether she'll enjoy it.

We still struggle with getting everything right, but she is managing at mainstream school. Albeit the gap is getting bigger between her and the other children her age. We are lucky she is such a happy and smiley child with an amazing sense of humour.

When I look at Lizzie now I think about how amazing she has been. She can walk now! She learned when she was almost four. She can write, is learning to read and she can talk - she is getting more understandable each week.

We'll continue to monitor her development, try to get her socialising more independently and involved in the community while also finding a balance between supporting our family and giving her a 'normal' upbringing.

We often think about her future, how we will be forever caring for her, looking out for her and worried about her. But wow, she has come so far!"

GEORGINA
LIZZIE'S MUM



LUKE

THEN: 3 YEARS OLD (2012)

NOW: 9 YEARS OLD (2018)

CYSTIC FIBROSIS



“The photo from back then was taken in the old Ambulatory Care Unit at Sydney Children’s Hospital, Randwick. Luke was going to theatre for a bronchoscopy and lavage - an annual procedure for children under five with cystic fibrosis.

I remember I was putting a gown on Luke in preparation to go into theatre. He thought it was hilarious to be wearing a dress! Life for Luke at the time was just like any other child his age, he was in preschool and enjoyed playing outside with his friends.

Luke is now in year four and doing well at school. He loves soccer and playing Xbox. Luke’s health has remained good with very few Hospital admissions. We look forward to being able to access new medications to treat cystic fibrosis as soon as they become available on the Pharmaceutical Benefits Scheme.

Anything is possible for our future. We don’t let cystic fibrosis stop us - it just takes a little extra planning.

We really appreciate the support of the entire cystic fibrosis team at SCH. Our heartfelt thanks go to each and every one of them.”

MELINDA
LUKE’S MUM

MAY

1995 - 2018

THEN: 17 YEARS OLD (2012)

NOW: 21 YEARS OLD (2017)

LEUKAEMIA

“If you are very lucky, sometime during your life, you will meet and befriend someone who resonates far beyond the norm. And if you are equally unlucky, that someone will be taken from you far too soon, and everyone else who loved her.

The first time I planned to photograph May in early 2012 she had visitors. It was a weekday afternoon and a group of giggling teen girls in school uniform had surrounded her bed. Totally intimidated, I decided not to interrupt and instead made a quick getaway, saying I would come back another day.

I returned a few weeks later. May was undergoing her monthly lumbar puncture for leukaemia and I photographed the process from beginning to end. It is an unpleasant procedure, but she never complained. She put the clinical staff at ease. Her inner strength was formidable. Her composure calm. I was so impressed.





Something 'clicked' between us that morning and a friendship was born. A few weeks later I was asked by the Department of Education to be her tutor for her HSC art project in photography. And the friendship grew. Over the following six years we always stayed in contact. I continued to photograph her in hospital, and when she was in remission we would go on photo expeditions and have lunch at her local Thai restaurant.

When she became a young adult and needed references for higher education and employment opportunities, she would ask me to write references. It was an honour to do so. And all during this time, with her family's support, May fought on. Relapse - remission - relapse - remission - relapse. And still, I never heard her complain.

Years ago, I bought two toy solar hula dancing girls in grass skirts that you place on your window sill. One for May and one for me. Mine still sits in my kitchen window and rarely stops dancing. Not a day goes by that I don't think of her. She was the first person I photographed for the 'now' section of this exhibition, and at the time, though nothing was said, we both knew she might not be with us to see the completed project. On February 14, 2018, May lost her final battle, and everyone who knew her lost a part of themselves.

May was an earth angel and will forever be in my heart."

JIMMY POZARIK
MAY'S FRIEND



MIA H

THEN: 9 MONTHS OLD (2012)

NOW: 7 YEARS OLD (2018)

WHOOPIING COUGH



“Back then Mia was in Sydney Children’s Hospital, Randwick as she caught whooping cough at six weeks of age. We were in and out of Hospital for a year as every time she picked up a little bug or something afterwards she would stop breathing in her sleep.

It was a very emotional time for me living in and out of the Hospital for that long. Life was difficult as we had two other children at home who were missing their mum and sister. Luckily, we lived close enough that they could call in and I could duck home whenever possible.

Once she got the all clear at the age of one, life returned to normal and she has been healthy ever since.

When I look at her now I see a beautiful, strong little girl and I’m so thankful she made it through that first trying year. I don’t think I would have got through those days without the amazing SCH staff and I’m forever grateful to them for that.”

ASHLEIGH
MIA’S MUM



MIA L

THEN: 2 YEARS OLD (2012)

NOW: 8 YEARS OLD (2018)

PNEUMONIA



“The photo from back then was taken when Mia had pneumonia. She was nearly better by that point, but I remember when we first came in it was the middle of the night. She was having trouble breathing so I took her straight to Emergency at Sydney Children’s Hospital, Randwick. I was very stressed at the time because she was only 18 months old and I needed to take her by myself so her older twin brothers could stay at home with their dad.

After being treated in Emergency we were moved to a ward. She needed intravenous

antibiotics, so they put a canula in. Mia had never really been sick before, so she found it pretty agitating. A beautiful lady who was a volunteer would sit with her while I had a shower or went to the bathroom as I didn’t like leaving her alone.

Mia bounced right back. We knew she was okay when another family on the ward were eating fish and chips and she was standing up in her cot licking her lips – it was obvious she was good to come home.

Now Mia is a healthy, smart and strong kid – you would never know she spent time in hospital. We are very lucky our visit was short-lived, as that’s not the case for lots of families. We are incredibly grateful for the treatment we received and for the wonderful staff.”

RACHEL
MIA’S MUM



MOUSTAFA

THEN: 2 YEARS OLD (2012)

NOW: 8 YEARS OLD (2018)

VACTERL ASSOCIATION

“Moustafa was born with VACTERL association which has devastating effects on his body. He has over 30 serious health issues including bone disease, bladder disease and heart disease. And he only has one lung and one kidney. Since birth he has had countless surgeries and procedures to manage the many ways his condition affects him.

Back then, when the photo was taken, Moustafa was in Sydney Children’s Hospital, Randwick for a heart operation. We were there for two and half years. It brings back painful memories, but also good ones. He was so sick, and no-one thought he would make it.

At the time, I never thought about how hard it was. But looking back at how our family lived, it really tore us apart. I stayed at the Hospital with Moustafa for the whole time and his sisters lived with their grandmother while his father worked. Because of all the times we almost lost Moustafa, it was very hard on all of us. But then I think about how far he has come. It is all because of the effort everyone put in to get him there. It breaks my heart, but seeing his smile makes me so happy.

After being discharged from that long stay, I can’t really say that things got better.



Moustafa was diagnosed with ulcerative colitis and this meant we were having to be in the Hospital every two weeks. He got sick so often we were constantly in and out, and his father had to stop working for some time to help with the family.

Now that Moustafa is getting older it makes it harder because he is more aware of what's happening. When we drive to the Hospital, he knows what it means so he will say "no hospital - no hospital!" We try to tell him that we are taking him there to make him better.

He is still visiting the Hospital for procedures and check-ups. For any of his treatment, we always go to SCH. When we are away from the Hospital for longer times we start to miss the place. It is our other home. It is part of our family. Even now when he is admitted, I stay with Moustafa while his dad looks after our other children. He'll bring them all into the Hospital so that we can still have some family time together.

There are still a lot of question marks because we don't know what the future holds. The doctors give us advice, but we take every day as it comes. We don't

know when his last day will be, so we cherish every one. When I look at him, I get scared because doctors said he wouldn't make it. But I'm so happy because he is still with us.

SCH is absolutely amazing. All the staff at are kind, welcoming and comforting. We find peace with them. When we are there, a simple smile reduces our pain by half. I wouldn't go to any other Hospital."

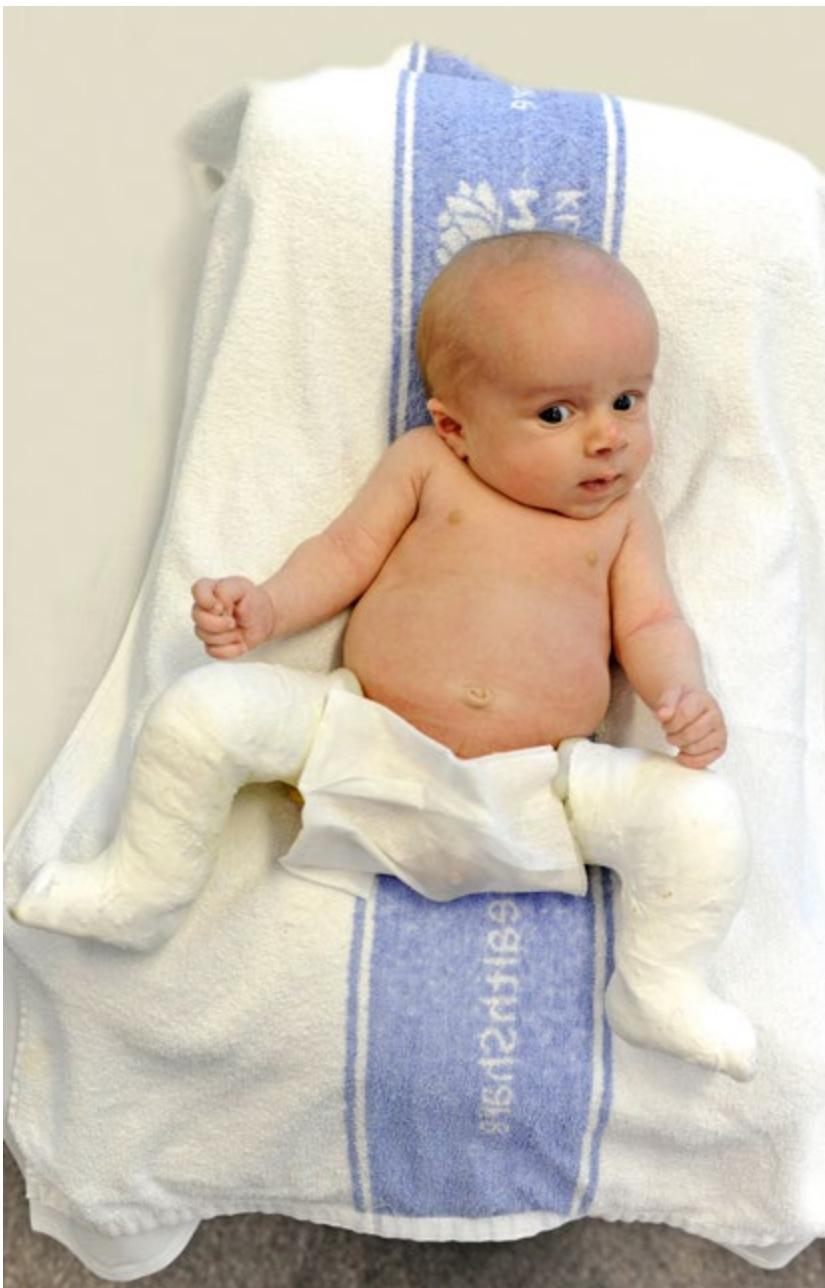
EMAN
MOUSTAFA'S MUM

OLIVER

THEN: 9 MONTHS OLD (2015)

NOW: 4 YEARS OLD (2018)

**BILATERAL TALIPES /
SHORT STATURE /
EHLERS-DANLOS SYNDROME**





“Oliver was born with bilateral talipes - in toddlerhood he was also diagnosed with a short stature and Ehlers-Danlos syndrome – Sydney Children’s Hospital, Randwick has been there for us every step of the way.

The original photo feels like a lifetime ago. Oliver was in the first stages of the Ponseti treatment and he looks cool as a cucumber. I must say he has remained the same determined and easy-going young man ever since!

Oliver’s condition means life for him can feel a bit like a puzzle with the pieces missing. We have tried to piece these together with many specialists and appointments. We are getting there slowly but it hasn’t been easy. Our family and friends have been so supportive and have helped us to get through it all. And of course, Oliver’s positive outlook has also kept us smiling.

We just take each day as it comes with Oliver - there are still a lot of question marks regarding his growth and physical needs, however we will just go with the flow and see where it leads us.

Although Oliver’s condition will affect him for the remainder of his life, we are always extremely grateful that we have a smart, happy and healthy boy. When I look at Oliver now we see a boy who has come a million miles. From the first stages - to now being able to walk and run around with his sisters - it brings a tear to my eye.

A very special thanks to everyone who we have dealt with at SCH - his Ponseti team, cardiologists, geneticists, endocrine team, physiotherapists and orthopaedic surgeons. We could not have got through it without the love and dedication from all of you - for this we are truly grateful.”

JEMMA AND MICHAEL
OLIVER’S MUM AND DAD

ZACHAEUS

THEN: 2 YEARS OLD (2015)

NOW: 6 YEARS OLD (2018)

DOWN SYNDROME

“Zachaeus was born in Lismore and was diagnosed with Down syndrome and he’s been in my care since he was 14 months old. The original photo was taken when he was two years old, which feels like such a long time ago. I had brought him into Sydney Children’s Hospital, Randwick for a check-up.

He was a cheeky little baby at that age. Playful, very friendly and always happy. He didn’t mind any of the tests he needed – I always joke you could operate on him while he was awake, and he would be all good! We’ve had a long history with this Hospital. I’ve been bringing him here since I started caring for him. I know when I come here, the moment we walk through the door, Zachaeus will be cared for.

Now he is still that same cheeky boy. His interests are Koori dancing, the ochre and music. His dancing and culture is where his heart is – he dances day and night. He also loves to dance with his sister, Zavannah.

Zachaeus’ dad is Bundjalung and his mum is Kamilaroi. In 2017 Aunty Calita and Uncle Dean got Zachaeus into his culture, which means he has been able to grow up with it. As a child I was never taught my culture or my language as my mum was never taught her culture and language. It was always hidden. It’s really sad, because I could have learnt it and passed it on to my children and grandchildren. But when I met Uncle Dean and Aunty Calita I was able to learn and appreciate my roots. It made me feel so good because now I can dance with my grandchildren.





As his grandmother I will always be there for Zachaeus and so will his Auntie Teresa. We will always want the best for him. To teach him our values, the rules and standards in life, and how he can apply them to himself as he grows. What I would like to see is all my grandchildren get an education and make something of themselves – be a somebody, not a nobody.”

AUNTY SUGAR
ZACHAEUS’ GRANDMOTHER

“The painting design Zachaeus wears has a story, and where the story starts is where we come from. The three lines on his leg represent the land, which represents the past. We as Aboriginal people need to live in the present. The three lines on his stomach represent grandfather sun rising in the morning - this tells us we are in the present.

The line up his middle is his spirit line. The “V” that it leads to is his warrior line. On his face and head is his future - thinking about the future but not living in it. There are nine lines altogether which represent where we come from. In our culture we read that as mother earth as it takes us nine months to come into this world. We have three mothers and these three lines represent that - mother earth, our birthing mother, and the mother of our children.

The three lines across his chest represent respect, patience and observation. These are the disciplines for living. Yuin teachings is where all these lessons come from. Respect for the land, respect for women and learning to become better men.

I see Zachaeus as a strong little warrior and for him to have a good future, he needs to be connected to his culture. His culture and his spirit will guide him to be a strong cultural man in the future. And whatever that entails, I’ll be there to help him – and make sure he is ready.”

UNCLE DEAN

ZAK

THEN: 8 MONTHS OLD (2015)

NOW: 4 YEARS OLD (2018)

NECROTISING ENTEROCOLITIS

“After many years of IVF and the loss of our two daughters, we were blessed to have Zak come along – our rainbow baby and miracle child all in one. He was born prematurely at 26 weeks and weighed a tiny 970 grams. At just two weeks of age he contracted necrotising enterocolitis (NEC) which caused his bowel to perforate. He became gravely ill and we were told that he probably wouldn’t survive. That’s when he was transferred to the Neonatal Intensive Care Unit (NICU) at The Royal Hospital for Women to have life-saving surgery. We had to pack our bags and move in with family just so we could be close to our baby.





We left NICU and went home but when Zak was five months old, he became very ill again and was rushed to Sydney Children's Hospital, Randwick. He had a twisted bowel and blockage and needed emergency surgery. We spent many weeks over the next few months in and out of the Intensive Care Unit.

That's when the original picture was taken. When I look at that photo, I remember how helpless and vulnerable we all were, and I still can't believe we got through it. It feels like it was a movie, like it happened to someone else. Now, we are so lucky that Zak is your average four-year-old, but it's taken a lot of hard work to get him to where he is today. He is gifted academically and a real social butterfly, but he's very stubborn and determined. Zak will not stop until he gets what he wants - I guess that's how he fought his health battles at such a young age.

Our family will forever be grateful to all the staff at SCH and The Royal for helping us to finally take our baby home."

FILIPPA
ZAK'S MUM

**SYDNEY CHILDREN'S
HOSPITALS FOUNDATION**

We connect the best paediatric research and practice with donors who are inspired to create change.

Sydney Children's Hospitals Foundation has a vision to ensure that every child, now and in the future, can access extraordinary healthcare whenever they need it. We fund state-of-the-art equipment, the best and brightest practitioners and cutting-edge research and clinical trials.

But we know delivering extraordinary healthcare extends beyond the medical. It means doing everything we can to give sick kids a positive experience. It's about finding ways to make life easier for families, creating a healing environment and bringing smiles to faces in the most difficult times. The Art Program is a perfect example of one of the ways we do this.

We support The Sydney Children's Hospitals Network, which incorporates Sydney Children's Hospital, Randwick, The Children's Hospital at Westmead, Bear Cottage, the Newborn and Paediatric Emergency Transport Service, Kids Research and other vital children's services.

Every year, more than 155,000 sick and injured children receive care from the Sydney Children's Hospitals Network. Young patients come from across New South Wales, and even from outside the State and from the Pacific Rim, if they need access to specialist expertise which is only available at our Hospitals.

Our success is only possible because of the ongoing generous support of the community, our partners, Hospital staff, patients and their families.

THE ART
PROGRAM

The Art Program uses the visual arts - in all its forms - to improve the lives of patients, families, carers and staff at Sydney Children's Hospital, Randwick.

Our permanent art collection includes over 900 items from highly acclaimed artists which help make the Hospital a bright and reassuring space, reducing the anxiety and stress often associated with a traditional hospital setting.

Rotating exhibitions give artists a chance to share their talent in a meaningful way while transforming the space into somewhere that's dynamic and cultural. They also ensure that new artworks are displayed throughout the year, so the Hospital environment is constantly changing. Change within a health space has been shown to inspire change within a patient, helping to accelerate their healing process.

The Art Program also delivers Art Experience (ArtEx) Workshops in the Hospital School and on the wards.

ArtEx Coordinators collaborate with local artists to give patients, their families and staff an opportunity to engage with the visual arts. Being able to create art offers a welcome distraction for children coping with serious illness, who may have to spend weeks or months undergoing treatment.

For some children art also offers respite from the intense emotions associated with illness and gives them a way to express their feelings. Many of them feel proud and excited about their finished work, and love seeing them included in exhibitions.

Through both workshops and exhibitions, the Art Program fosters creativity which resonates across the Hospital and beyond. Above all it makes patients and their families feel happy and safe. The Program is fully funded by Sydney Children's Hospitals Foundation and would not be able to make a difference without the generous support the community.

As the Foundation's photographer-in-residence since 2012, Jimmy Pozarik has given visual insight into the incomprehensible world of seriously ill children through his photos. Revisiting 25 patients from past projects, this exhibition captures the unique moments that reflect their Hospital experience, telling their stories through the eye of the lens, then and now.

A whole spectrum of narratives are told. Fleeting Hospital encounters that were barely thought of again, traumatic accidents, miracle survivals, medical journeys that will last a lifetime, and even ones that have ended too soon.

Whether happy or sad, every image is significant, and together they are a true reflection of the diversity that graces a place like Sydney Children's Hospital, Randwick.

Then and Now would not have been possible without the dedication of Jimmy Pozarik, the Foundation's Helen Thorpe and Timothy Talty, and the courageous families who allowed us into their worlds.

If you would like to find out how you can support Sydney Children's Hospitals Foundation and our Art Program please visit schf.org.au/art

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Sydney Children's
Hospitals Foundation

