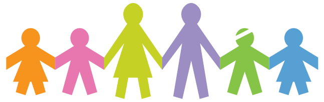
Children's Health Queensland Hospital and Health Service

Living with limb difference

Queensland
Government

Living with limb difference



Queensland
Government

ACKNOWLEDGEMENTS

Thank you to Kingston, Mia, Michael, Connor, Annabelle, Lewis, Matthew, Noah, Brendan, Zoe, Jonty, Harry, Zion, Abbey, Kyle, Sophie, Max, Angela, Vajk, Charlie, Nathan and their families for sharing their inspirational stories.

The Limb Difference Team at Queensland Children's Hospital, particularly Shail Maharaj (Physiotherapist), Samantha Donaghey (Occupational Therapist), Alana English (Social Worker) and Lachlan Dale (Clinical Photographer).

Children's Hospital Foundation

The production and printing of this book was funded by the Children's Hospital Foundation.

Living with limb difference: Published by the State of Queensland (Queensland Health), June 2020.

For more information contact the Children's Health Queensland Hospital and Health Service, South Brisbane by emailing chq_comms@health.qld.gov.au

CONTENTS

Foreword

Uncertainty and fear of the unknown is challenging. This is the place you may find yourself when you are told that your child will be born with a limb difference, or that amputation is being considered following an illness or injury your child has suffered.

Gathering more information is one of our first means of managing this uncertainty. Often internet searches become a place to start, but this may lead to anxieties being heightened rather than eased.

At the Queensland Children's Hospital Limb Difference Clinic, we seek to provide families with the information they need after learning that their child will have a limb difference. In our experience, having access to a team of professionals helps diminish some of these fears, anxiety and uncertainty.

What is often difficult to convey to families is the experience of living with limb difference, such as:

- how your child will engage in the world around them, and
- how they will find their own ways to achieve their goals and ambitions in life.

This book was developed to address that need.

We hope that these stories and images shared by families who have already been on this journey allow you to see children with limb difference and their families doing everyday things, as well as some extraordinary things.

These are just some of the stories we have had the privilege of hearing within our clinic. We hope it gives you a new perspective on living with limb difference.

> **Shail Maharaj** (Physiotherapist) *on behalf of the Limb Difference Team, Queensland Paediatric Rehabilitation Service, Queensland Children's Hospital*

Kingston Thorby

Partial left hand (symbrachydactyly)

By Kirrily Thorby (Kingston's Mother)

I'm the type of mother who does everything by the book when I'm trying to conceive and when I become pregnant. I take the multivitamins and minerals months before I try to conceive. I'm very in touch with my mind, body and soul. So, when I found out I was pregnant I was thrilled and couldn't wait to expand our little family.

I remember going into a scheduled ultrasound at around 20 weeks into my pregnancy. I was so excited to find out the gender of our new baby. After the appointment, the hospital rang and asked if I could come back in for another ultrasound. My heart sank. I knew something was wrong. I remember crying to my husband and praying to God to bless our baby, and make sure he was healthy and okay.

When the doctor confirmed that my son had symbrachydactyly, my heart sank. I had no idea what this meant for my baby. I had never heard of it before. I had never seen it before. I was so scared for my baby. I Googled and researched it for months. I never told anybody. I felt like I had done something wrong as a mother. I asked God thousands of times, "Why did this happen?".

I had the support of my husband, and no matter what, the love we had for our baby boy was already unconditional. We would do everything in our power to love, guide, and protect him.

The day I gave birth to Kingston was such a roller coaster of emotions. I was so scared to look at his little hand because I felt so bad for him. I was overwhelmed with anxiety, emotion and sadness. I didn't know if it hurt him or what to expect.

I lay in bed cuddling him with tears running down my face. Once I saw his little hand, I kissed it. He was born special, but nothing would stop him from living his best life. I instantly became very protective of him and would do anything to keep him safe.

My husband, on the other hand, let him be a typical little boy. Climbing things, hanging off things – nothing ever stopped him or slowed him down. Especially not his special hand. He could do everything his big sister could do, and he found a way to adapt to everything.

It has not stopped him one bit. He comes up with his own imaginary stories to tell the kids at school who ask him what happen to his baby hand. His reply is, that he was bitten by a crocodile, he cut it off with a sword, or he was hunting with his dad and a pig got it. The list goes on.

Now six, Kingston is such an active little boy. He plays soccer, football, does little athletics, and rides his bike, scooter and quad bike, with no help at all. He is very independent, and he has the best personality. We are so proud as parents. He has taught us a lot. He has given us strength, determination and such a positive outlook on life. We thank God for giving us such a beautiful blessing. He is very loved by everybody.

Mia Wilkinson

Quad amputee (bilateral below elbow; bilateral below knee)

By Amy Wilkinson (Mia's mother)

I hear a lot that Mia is "Just so amazing!".

I think so too. I'm constantly amazed that she can move so well in prosthetic legs which must feel like balancing in hot, heavy stilts. I'm amazed and proud that she is so happy, cheeky and joyful. Mia is a sepsis survivor and a quad amputee but more importantly she is a beautiful seven-year-old girl. She is full of life, with an abundance of infectious energy and determination. Her personality attracts people to her. She is noticed because she is a quad amputee, but she is loved because of who she is.

At the age of four, Mia became critically ill with sepsis in October 2017. Just two-and-a-half years on, Mia has built up her strength, agility and confidence in her prosthetic legs to the point where some days she is spending the entire school day in her legs. She can climb stairs, navigate rough, rocky ground and run a little.

She has three sets of legs, everyday legs, running blades and waterproof legs. When she isn't in her prosthetic legs, she is speedy on her knees indoors or in her power wheelchair out and about.

She has impressed us with her adaptability to be able to complete daily tasks, such as writing, playing and eating, with her arms. Mia has a pair of myoelectric arms for some tasks and as a training tool. We are very keen for her to retain her muscle memory to be able to use more advanced arm prosthesis in the future.

Mia is in grade 2 at school. She enjoys attending school and is doing very well. She has a wonderful group of close friends and very supportive teachers. Most weeks, she attends four days at school. The other days, she has hospital or prosthetist appointments.

We have discovered wonderful support groups and individuals through social media. We also have fabulous support from our family, friends, school and the local community which has been invaluable. Another key to Mia's success is finding medical and allied health professionals whom Mia connects and enjoys spending time with. Therapy and appointments are part of our life but they are fun and enjoyable experiences.

The journey we have been on, as a family, to get to this point, has been extremely challenging, physically and emotionally. There have been many extreme lows and at other times, heart-bursting moments of pride and joy.
We are extremely grateful to have Mia still with us.
Her future is different to what we thought it would be but we are already seeing that it will be a very bright, happy future!

Michael Heynatz

Bilateral through knee amputations

By Athol Heynatz (Michael's father)

Michael has been an amputee for almost his entire life, having had both of his legs amputated below the knee when he was around 11 months old after contracting meningococcal.

While he faces many challenges in life, such as limited access to some public spaces due to inaccessibility, and sometimes struggling doing certain things independently, such as showering or taking the stairs on his prosthetic limbs, he still manages to live a mostly normal life.

Michael, 17, currently attends high school full time, and participates in a variety of sports, including swimming, athletics, and ten-pin bowling. So far, he has attended 'Amp Camp' (a very active camp for kids living with limb loss or limb difference) three years in a row, and is looking forward to going again next year. Michael has recently won several inspiration awards and hopes to be a positive influence on other people who are living with limb loss or difference.

Connor Wyvill

Born without a left hand (left transradial deficiency)

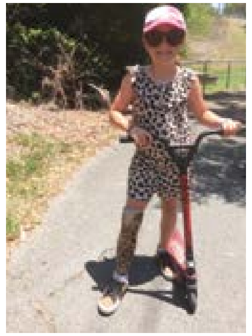
By Connor Wyvill

I was born without my left hand, but I believe I am just as capable as any person with two hands. I just want to be treated the same as anyone else. I love to play rugby league and enjoy keeping fit in the off season. In my relaxation time, I play Xbox with my friends and my sister.

I graduated in 2019 and really enjoyed my primary school years. For the first couple of months at school, I got bullied, mocked and teased by some of the kids in other grades. However, if you look at me now, I'm friends with everyone, and everyone has accepted me as I am.

For my future, I am looking to be a professional rugby league player or a police officer because I really like to help people out and keep the world as safe as possible for younger kids. One of my role models is Sam Thaiday, because of how rough and tough he was on the field, and how friendly and generous he is off the field. I aspire to be like him, and have even adopted some of his footy techniques to my game.

To anyone who has any type of disability at all, never let it affect you because the only opinion that matters is yours and your family's. One more thing, always believe in yourself no matter how hard it seems, because you can do anything you put your mind to.



Annabelle Moloney

Fibular hemimelia (longitudinal deficiency of the fibular)

By Megan Moloney (Annabelle's mother)

I'm not great with words, but I can say our angel Annabelle is amazing! From the day she was born, she has coped with her condition, and in turn we learned to cope as a family. She is no different to any other child in our eyes – in fact, she is stronger and more capable. Annabelle is our second child. Noah is 12, Annabelle is 10 and Lily is 6.

Annabelle, 10, has grown up like any other child her age and participates equally in all aspects of her life. We live on the Gold Coast, so our life is the beach. We beach it every other day, with the kids swimming, surfing and playing in the sand.

Annabelle attends the local Catholic primary school with her siblings, she is currently finishing grade four. She is very studious, popular among her peers and participates in all school activities. Annabelle has tried the lot!

In terms of sports and activities, Annabelle currently participates in karate, swimming, netball, hip hop and touch football (her favourite).

Over the years Annabelle has been involved in gymnastics, ballet, tap, nippers and AFL. She continues to be part of a chess club, does speech and drama and plays the ukulele. Annabelle is just a normal happy child. She loves all sports, riding bikes, scooters and camping. Plus, she does all of this in style, loving her fashion and makeup, too, as all little girls do.

Now I'm not saying there haven't been some tough times, but you get that with having children. Annabelle has had a couple of surgeries over the years to straighten her leg and has another one coming up next year. But with her attitude to just be the best she can be (better than most) she is an inspiration! I can definitely see great things in the future for our girl. Who knows, she may well be up there as a backstroke champion at the Paralympics one day.

Lewis Bishop

Right leg amputation (through knee)

By Clare Bishop (Lewis's mother)

At the time of Lewis's accident, our family was living overseas in Papua New Guinea due to my husband's employment in a local mine. As one of five children, Lewis was a sporty nine-year-old who loved running, swimming and being active with his friends.

On 8 March 2015, Lewis was invited out with friends to go kneeboarding on their boat. Unfortunately, during this activity Lewis's leg came in contact with the boat motor which resulted in extensive trauma to his right lower leg.

Lewis was immediately transported by aerial emergency services back to Australia. On arrival in Townsville, the surgical team informed us that the wounds to Lewis's leg were too severe to be repaired, and he would need to have his right lower leg amputated.

We were all devastated by this news. As well as enduring extreme chronic pain, Lewis had to deal with the prospect of living a restricted life from losing his leg. The idea of wearing a prosthetic leg for the rest of his life was inconceivable. As Lewis's parents, we were simply overwhelmed and in shock that this had happened to our active and sporty son. Our grief was a roller coaster of emotions as we dealt with our own sorrow while also trying to support Lewis through his journey.

After Lewis's amputation, we were transferred to Brisbane for rehabilitation, and to prepare for the fitting of a prosthetic leg. At this time, we were incredibly fortunate to be under the care of the rehab team at the Queensland Children's Hospital, who gave us the support we needed to get through this difficult time, both emotionally and physically. There were many ups and downs, but as time passed we eventually came to terms with the unexpected change in our life. Our earliest desire was to meet other amputees who have gotten on with life despite their limb loss and led happy and fulfilling lives. We just wanted to know that life could still be OK.

With great gratitude, Lewis was introduced to Paralympian swimmer, Brendan Hall. Brendan showed Lewis, from very early on that with hard work, courage and determination he could have an amazing life, and still compete as a sportsman at an elite level. We also met Scott Reardon, a Paralympian 100m track sprinter. Again, another positive role model that demonstrated that his physical limitations have not stopped him living life to the fullest.

Lewis is now 15 and has gone from strength to strength. Lewis is not defined by his disability. He has won many gold medals at state level in track racing with his awesome running blade. Lewis's swimming achievements have included medaling at the National Swimming Titles. He swims with a regular squad who support and encourage his achievements. Hopefully Lewis's story can provide hope and courage to other families out there who find themselves in a similar predicament.

Matthew Wheeler

Absent right hand
(right transradial deficiency)

By Laithe Wheeler (Matthew's father)

Matthew's story began at the routine 18-week ultrasound for my wife Caroline. Matthew was the last of our four children. His three sisters before him were regular pregnancies, and natural deliveries with no issues identified before birth or at delivery.

The sonographer advised us that Matthew's right hand was absent, and that Caroline would need further advanced ultrasound examinations to determine if there were any other possible challenges. For me, the days before the next ultrasound were very difficult. Thoughts of termination littered my mind, and I hated myself for it. However, upon reading a story about parents who had terminated their pregnancy on aesthetic appearances alone after discovering their child had a limb deficiency, I knew I could not follow their path.

And so, Matthew's growth continued inside his mother's belly, and after an advanced ultrasound it was determined that Matthew's only anomaly was having no right hand.

Caroline was also able to have the same natural birth plan as she had with our three daughters. This return to the routine of previous pregnancies gave us comfort as a family moving forward.

In June 2012, Matthew was born without any major issues and settled in to our family quickly. I am a very pragmatic person, and I took note of the medical report for Matthew. It recorded the following: "right hand absent". For me it was a simple matter of fact. I also recall our first appointment at the limb deficiency clinic for Matthew, the doctor was more intrigued with a dimple on his ear lobe than his absent right hand.

As an infant and young child, Matthew reached all the usual development milestones on time or earlier. He continually amazed us all with his determination to do things his way, and he would let us know in no uncertain terms if we were helping him too much! For me, functionality has, and continues to be, my biggest concern for Matthew. However, in the years leading up to school, he became independent in his own actions. Both Caroline and I ensured that he had the opportunity to complete jigsaws and build LEGO to stimulate problem solving skills.

We all also encouraged him to be a very active child and ensured he played all the sports that he was interested in, which have been many and varied. He has shown outstanding skills and abilities in cross country, athletics, soccer and cricket. Matthew is also a keen fisherman. He can cast a rod without assistance, and without special aides. To date, on our trip around Australia he can claim both the biggest and best tasting fish caught.

He has been able to ride a bike for the past three years, and last year we had an adjustment made to his handlebars to assist with keeping his shoulders level.

Matthew, now 8, is a gifted boy, blessed to be above average in both sporting and academic fields. He has a genuine love of life and possesses the energy and enthusiasm for it that both Caroline and I sometimes struggle to match. The only assistance we provide for him everyday is helping him tie shoelaces and cutting up food.

We have raised Matthew in acknowledgment of his challenges, but we have not yielded to them. He interacts with his peers confidently and while we are travelling, he has no problem joining in games with other children on holiday.

There will always be people who stare and ask why Matthew doesn't have a right hand. Children are usually completely uninhibited in asking questions and Matthew is now confident enough, most of the time, to just say, "It didn't grow when I was in my mum's tummy".

Noah Robinson

Missing right hand (transverse radial deficiency)

By Sharon Robinson (Noah's mother)

Five months into my pregnancy, I was at a scan not worrying about anything other than whether it was a boy or a girl. I was told casually that if I was worried about anything, I should see my obstetrician. I wasn't, but was told maybe I should.

In another office, they explained to me that my baby boy was missing his right hand and wrist. I had two days to decide whether to keep my baby. My fiancé, and father of my child, wanted to terminate the pregnancy. Going ahead with the pregnancy would mean that I would be on my own. We parted ways that day. I went ahead with the pregnancy and it was the best decision I have ever made.

Noah was born missing his right hand and wrist. My incredibly supportive parents and I vowed to never say no to anything that he wanted to try. We didn't ever want him to have the mindset that he couldn't do things because he was missing a hand. Everything I thought Noah might struggle with, like holding a knife and fork, tying shoelaces, dressing himself, and crawling, he did. He crawled for just two weeks before he started running! He managed all these things before I even thought about how I could help him.

Noah's many achievements include being a champion swimmer. At 10 years old, he was in the top nine able-bodied swimmers in Queensland. He also holds most of the records for 10-13 year old multi-class swimmers in the state, and is captain of his school swimming team. Noah has made the Dean's list six times, was awarded the sports jacket and gold pocket; the highest accolade a boy can receive, for his success in the finals of the Commonwealth Games trials.

Noah is now at the Australian Institute of Sport (AIS) camp in Melbourne, being considered for the Tokyo Paralympics. He is a qualified life saver, doing patrols with Northcliffe Surf Life Saving Club. He has always had something to prove, and I think is more capable than most able-bodied people.

Noah is a joy and inspiration. He is hoping to study law next year, and I know his future will be as incredible as the past 17 years. Children like Noah see more, try harder, have so much substance and usually an incredible sense of humour. Every day of his life has been the most incredible journey. I learn something from him every day, especially how to be humble, patient and caring. I implore everyone to look at the things they can do, not the things they can't.

Brendan Booth

Longitudinal deficiency of the fibular

By Brendan Booth

I am 17 and currently completing my final year of high school. I live with my parents and my sister Ella, 13. I was born with fibula hemimelia, a congenital lower limb deficiency. Amputation in my first few months of life was advised, however I walked at 15 months with a prosthesis worn over my residual limb. Whilst I was unstoppable with this prosthesis, my parents always talked openly to me and, at 10 years of age, I made the decision to have my residual limb amputated so that I could be fitted with a better functioning prosthesis.

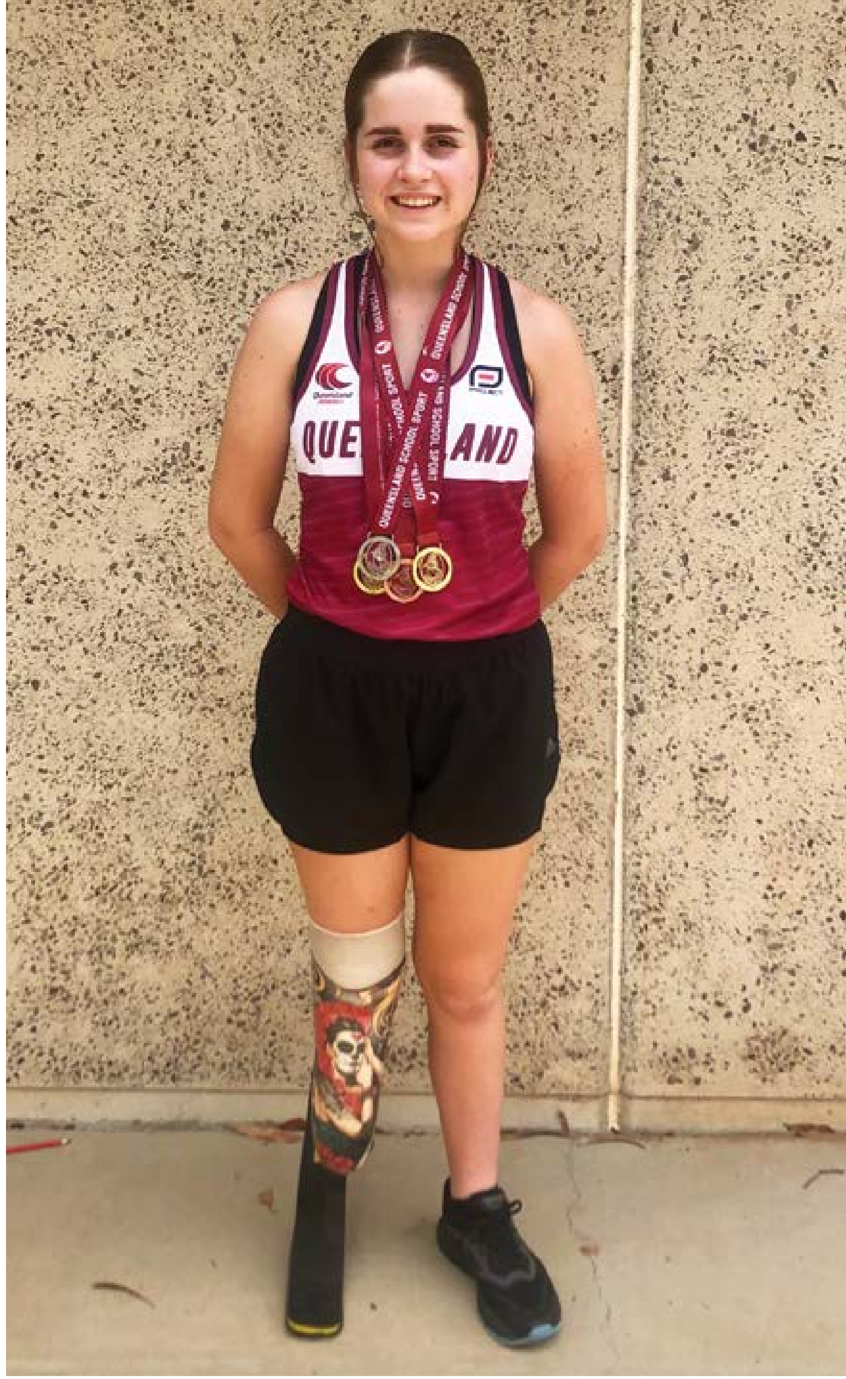
At eight years of age, I took up recreational go-kart racing at Lakeside Raceway with my dad. My love of driving my kart may have contributed to me being able to drive an unmodified, manual vehicle with ease now. I joined karate when I was 11 and earned my green/brown belt. My other interests have included parkour, skating, gym and kayaking. Throughout primary and secondary school, I always participated and performed well at school athletics and swimming.

I competed with able-bodied peers, at their level, at a Districts swimming carnival. When I was in grade 11, I came first in high jump for my age group at the school athletics carnival.

I have worked part-time for the last 18 months in a fast-paced kitchen whilst studying grade 11, and currently enjoy playing social inline hockey. I have never viewed my condition as a disability and have always participated, giving 100%. I have always been respected by friends and peers because of my positive attitude.

Some things to remember:

- There are no limitations, only those which you create yourself.
- There are some people who will doubt your capability – don’t let others decide what you can’ t do.
- Make sure you can have a laugh – don’t be too sensitive.



Zoe Larsen

Longitudinal deficiency of fibular leading to Syme's amputation

By Shannon Larsen (Zoe's mother)

Zoe was born with the fibula bone missing from her right leg. This meant that her right leg was shorter than her left. Her right foot was small and had only three toes. Despite her limb difference, Zoe was on the go from the moment she could scoot along the ground. At 12 months, she was fitted with her first prosthetic leg, and was soon up and walking. We started to realise that life wasn't that different after all, although when she was a toddler, we seemed to be constantly hunting for the lost leg that Zoe had heaved off somewhere in her travels.

When Zoe was three, she was booked to have a Syme's amputation of her little foot. This operation was to help her prosthetic leg fit better. This was a heartfelt moment when we hoped we were making the right decision, and we know now that we did. Zoe recovered quickly from her amputation. From that moment on she was in charge of choosing her own prosthetic patterns, and we never had a skin-coloured leg again until she was 14.

As a parent, it was hard not to worry about whether she would be able to do the things her friends could do. Thankfully, Zoe did it all. She danced, she swam, she played netball, she walked to school; she just had to put her leg on first. These days Zoe, 15, is into athletics and has found success as a para-athlete.

In 2018 Zoe competed at her first State titles where she won gold medals for sprinting and shotput. This allowed her to compete at nationals, which was an exciting experience. In 2019, through the NDIS, Zoe had a blade leg and cheetah leg made to assist her with her running and throwing. She competed at the State titles again and won a silver in shotput. She is still developing her confidence with her blade, but she is determined to keep competing. We can't wait to see where Zoe's leg takes her.





Jonty Oddy

Rotationplasty

By Robyn Farley (Jonty's mother)

Looking at our happy, well-adjusted 13-year-old boy right now is like looking at any regular teenager – technology addicted, carefree and becoming cheeky, focused on himself and his friends, whom he communicates with constantly through social media whenever he's not at school.

We no longer notice his right foot, which is aimed backwards at the level where his knee should be. When he wears his prosthetic leg, it looks more like a brace on an existing limb than a prosthetic on a leg that has an ankle in place of a knee.

At school, Jonty's a bit of a legend – known even to the higher grade kids as the boy with the fake leg who rides a Segway to school, and has a key to the lift (both to the envy of many, we think). His ability to do pretty much everything they can, and his audacious nature has made him fit right in and become accepted for who he is.

While he has certain privileges to assist him in his everyday life, he is fully able to climb the three flights of stairs to his classroom and walk the two kilometers to school and back each day.

In fact, the rotationplasty surgery is so good that there is really nothing Jonty can't do, if he puts his mind to it. While Jonty does tire quicker than other kids his age, he can walk, run, play sport, climb, dance and swim. In fact, in the pool he excels, beating half his grade across the lengths despite them being able-bodied. Some of these activities, like swimming, he chooses to do without his prosthetic, and often his ability is even greater without it. Jonty can do just about anything an able-bodied thirteen can do, to varying competencies, with or without his artificial limb.

While he isn't a very active and outdoorsy boy, just by his nature, he does love walking his two dogs, swimming, going to the beach, jumping on the trampoline and wrestling with his little sister. He has had great fun over the years at camps and on family holidays, doing rock climbing, horse riding, canoeing, obstacle courses and hiking up mountains. He also participates annually in his school athletics and swim carnival days. He's looking forward to continuing to do well through high school, and living his best life with his friends and family, who are all immensely proud of him and support him all the way.

Harry Barnett

Right partial hand (transcarpal deficiency)

By Catherine McQuade (Harry's mother)

I always say, 'Harry was born different, to make a difference'. It's hard to believe that I was initially scared and a bit heartbroken when I found out that my baby's right hand had not fully developed at my 20-week ultrasound. Those early days came with a lot of uncertainty and emotion. Harry was born with what is called a right upper limb difference at a transcarpal level.

We had extra ultrasounds to ensure that everything was going smoothly. It was great to see him on the monitor so often. The scans showed that Harry looked perfectly healthy, he just happened to be missing one of his hands. Now I look at my 2 year old baby boy and I wouldn't want him born any other way! Right now, Harry is meeting all of his milestones and doing everything that kids his age are doing. He just has his own way of doing them.

The hardest part about parenting a child with a limb difference is managing my reactions to peoples' stares and comments. Children are curious and want to know, 'why?' and 'will it grow?'. I just explain that he was born that way and he is perfectly fine. It's the rude comments that I still struggle with, but thankfully are few and far between. It's how we as parents react now that will shape the way Harry reacts when he gets older.

Zion Cruz

Absent right leg (hip disarticulation level)

By Rebekah Cruz (Zion's mother)

Zion is an active six-year-old boy with a contagious smile. He was born with a congenital limb difference which affected his entire right leg. Zion was adopted from China at the age of three and now lives in Australia with us, his family. He is the youngest of five children. Zion did not have a prosthetic limb until after his third birthday, but took to it quickly! Zion uses a hip disarticulation prosthesis and a croc walker for the majority of his mobility needs.

Zion loves school and is currently in grade one. He enjoys playing video games, singing, swimming, LEGO and going to the beach with his family. We spend time riding bikes together, going to the park and hiking on occasion. Zion is very social and has lots of friends who he likes to spend time with. One of Zion's favourite things to say is, "I can do it!", and that statement says a lot about him. He loves life and refuses to miss out on anything! He is creative in his approach to things and always finds a way to participate. Zion is resilient, brave and always willing to try new things. He is a happy kid and his laughter can be heard long before you see his smiling face.

Abbey Currie

Rotationplasty

By Abbey's family

Abbey is a bright, engaging nine-year-old. She has always lived at Wicklow Station (our sheep and cattle grazing property), 45 kilometers west of Augathella, in western Queensland.

In July 2013, Abbey and her Mum, Pen, were visiting good friends at the neighbouring property when Abbey fell onto the lawn and broke her right leg. This was the first indication that there was something wrong with Abbey's health. She was flown to the Queensland Children's Hospital in Brisbane that night by the Royal Flying Doctors Service. Days later, we were informed that cancer had eaten into Abbey's bone, causing her leg to break.

While we were aware of the seriousness of her condition, it wasn't until sometime later that it became apparent just how much Abbey's life was at risk.

Over the following months, Abbey underwent chemotherapy, full body radiation, and the amputation of her right leg at the hip. The surgical team performed a procedure called a rotationplasty. The best way to describe the outcome is that her leg from under the knee, which had not been affected by the cancer, was saved, rotated and placed into her hip. The result allows her right ankle to act as a knee, which gave her greater mobility once her prosthesis was fitted. This all occurred within six months of Abbey being diagnosed. The following nine months saw more chemotherapy and the introduction of the rehab team. In October 2014, Abbey was deemed to be in remission and we were able to take her home, where she was met by her very best friend – her dog, Buzz the Jack Russell.

While we still had to make regular trips to Brisbane, Abbey slipped back into country life with ease. In 2015, Abbey joined the Augathella play group. This group of children has stayed largely in touch, and have moved through to year four together at Augathella State School. At school, Abbey joins in all the activities. Apart from school work, Abbey particularly enjoys spending time with her friends, music, art and sport. Her favourite sports are swimming and ball games.

It's a 90 kilometre round trip to go to school each day, but Abbey gets time to enjoy rural life as well. After school, on weekend and on holidays, Abbey helps our family with whatever it is that needs doing around the property. She musters on a motor bike, drives a buggy, rides a horse for fun, and helps with shearing and lamb marking. It's not unusual to see Abbey in her school uniform, helping on the shearing boards after school.

Abbey has had some big challenges in her young life, but she has met them bravely, with good humour and a maturity well advanced of her age. What advice would Abbey give to others facing challenges like her own? *"Be confident about your treatment. Be brave, and after your procedures make sure you have a go at everything"*.

Kyle Haslam

Amputations in all four limbs (bilateral through knee and multiple fingers)

By Dominique Haslam (Kyle's mother)

At 14 months of age Kyle fought a deadly disease. He contracted pneumococcal septicaemia which lead to both of his feet amputated, losing most of his fingers and suffering a stroke. Kyle spent two weeks in intensive care unit and another 10 weeks in a ward at the Mater Children's Hospital. Kyle attended intensive physiotherapy, speech therapy and occupational therapy. After the stroke, Kyle needed to learn how to sit up, feed himself, drink, crawl and talk all over again. The doctors tried to save Kyle's feet, but after several weeks had to amputate.

After the amputation and leaving hospital, Kyle went from strength to strength. Several months later, Kyle was running around on what we call his, "stumpies". Fast forward another six months, and Kyle was fitted with his first prosthetic limbs. I remember so clearly the prosthetist putting on the "plastic legs" and Kyle running around the room. There were lots of tears - tears of joy. There was no stopping him. The journey to school was about to start. This was such a stressful time for me, but off Kyle went making friends and amazing everyone that he met along the way. Simply put, Kyle just had special plastic feet. The teachers quickly learned that Kyle could jump down off the pirate ship in the playground just like any other kid.

Around the age of 10, Kyle took part in a pilot project at the Royal Children's Hospital, and was lucky enough to be given his first set of prosthetic running blades. The day we picked up the running blades we came home and joined our local Little Athletics Club.

This day was challenging, as it wasn't just a matter of put them on and go. Kyle thought he was going to take off – he wanted to be the fastest, but he quickly found that technique and skill had to be learned. Kyle spent around four years training and attending competitions. I remember one of the first competitions was a relay, Kyle got half way around the track and his running blade fell off because I hadn't strapped his leg on tight enough. In 2016 he was part of the Queensland team at the Australian Athletics Championships in Perth, and he brought himself home two gold medals and two Australian records for his T43 classification.

Later that year Kyle was struggling and had been diagnosed with epilepsy. Due to medications, Kyle was very lethargic for about six months. Kyle decided athletics was going to be a constant struggle and started playing wheelchair tennis. In wheelchair tennis, Kyle can compete without his prosthetics. We have learned that to participate well, it sometimes means adjusting/modifying equipment – it often takes some trial and error. Kyle has found a love for tennis. Even though it can be a struggle with fatigue, he loves the game. Kyle also enjoys indoor rock climbing. This was something he found he was good at, having good upper body strength. When Kyle ended up about one metre from the ground upside down in his harness while rock climbing, the staff quickly realized that he was top heavy and needed to wear an extra harness up top.

Sport has always been important to Kyle, as well as me as his mum. Sport is inclusive and can make you feel like you're a part of a team, and part of your community. Kyle is a fighter – often teaching me how to approach life, take risks and try new things.

Sophie Parsons

Longitudinal deficiency of fibular leading to Syme's amputation

By Sophie's family

Sophie was born with a congenital limb difference that resulted in her undergoing a Symes amputation of her right leg when she was just 13 months old. She is now a bright and happy six-year-old who has just finished Prep.

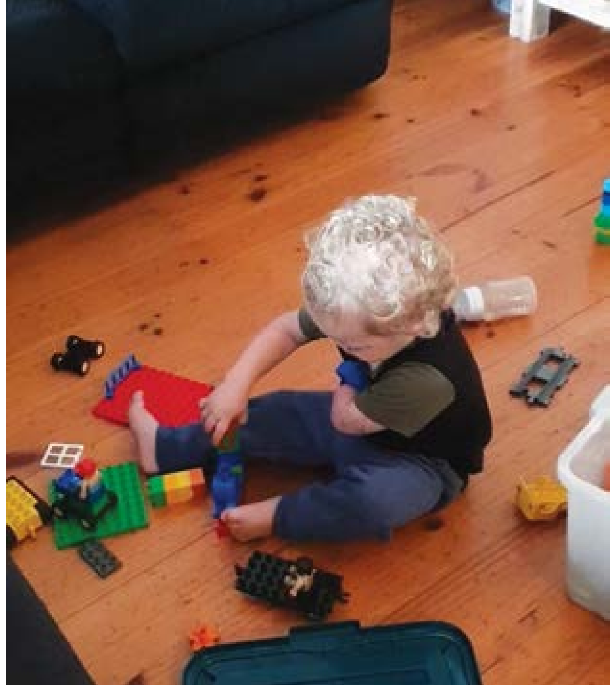
In raising Sophie, we have done our best to always focus on the positives of being an amputee. As hard as it was at times, that meant starting with our own thoughts and attitudes, because these are what very young children quickly pick up on. We found assistance from a psychologist to be very helpful in doing this through cognitive behavioural therapy.

To develop confidence in her body, when Sophie has asked about her leg we have always been open in talking with her about it and why she had the operation. While Sophie occasionally gets questions in the playground about her leg, her school's leadership team has been proactive in working with her to develop a short presentation on who she is and why she uses a prosthetic to show classes in her year level.

A significant positive outcome of Sophie's amputation has been her participation in activities with the broader amputee community. She has been able to making new friends and engage in fantastic new experiences.

Through her commitment to make the most of what some would see as a limitation, Sophie has been able to do things that she would otherwise not have had the opportunity to do, such as learning to surf and ski at age five, and making some wonderful friends from across the country.

Sophie is passionate about science and technology and is working with a mentor to enhance her prosthetic. Integrating her prosthesis into her broader interests has opened avenues for her to celebrate and embrace the ways in which she is unique.



Max Everill

Born without left hand (transradial deficiency)

By Nadine Everill (Max's mother)

My husband and I found out we were pregnant with our fourth child six weeks into the pregnancy. We were still wrapping our heads around the idea of four children, all under the age of six, when we attended a routine 13-week scan. Due to a previous miscarriage, we were elated to find a healthy baby growing. It was during this scan we discovered our baby was missing his left hand. We were told they didn't know why, and wouldn't know more until he was born. At the time, the doctors suspected amniotic banding. My husband and I managed to process this news and accept that was our baby.

I did spend a lot of time researching what I would need and what I could do once he was born – trying my hardest to be prepared for anything. There really was nothing to do except find support from friends, family and the wonderful hospital staff. The best thing we did was tell everyone before he arrived, that way there was no awkwardness.

Now four years on, we have the most active, vibrant, cheeky and confident boy. We could not imagine our lives without him. All the fears and concerns are nearly forgotten as we do not notice his limb difference. Max has managed to find a way to do things on his own without any help from us.

Nothing has stopped him. At 13 months Max bum-shuffled, at 17 months he was crawling up the stairs, by 19 months he was walking, 20 months climbing on tables, and at 22 months he was pulling Duplo apart and building towers. By the age of two Max was already navigating climbing frames at the park. Today, he is swimming and getting himself out of the pool. Max is adored by all of his siblings and their friends.

Angela Bubb

Absence of right foot and small hand

By Stephanie Bubb (Angela's mother)

Angela, now 14, has been full of surprises from the moment she was born. We were not aware of her differences before she was born. We had the routine 18-week pregnancy scan and everything was looking fine. When she was born it took our doctor to point out to us that she was missing her right foot, her right hand wasn't 'normal', and that she had a cleft palate. We were so in awe of our beautiful first born baby that we hadn't noticed.

Angela received her first prosthetic leg at 13 months, and quickly learnt to walk, run, skip and do everything that any other kid could do – sometimes just a little bit differently. As she got older, she became eligible for a 'running leg' which has enabled her to continue participating in school competition running and cross country events.

At a very early age, Angela fell in love with the water and now competes in many swimming events as a multiclass swimmer, which enables people with various impairments to compete on a 'level playing field'. Being right handed was handy (pun intended) as this encouraged her to keep her hand strong and dexterous. In her early years Angela needed some slightly modified equipment, but usually worked out her own way to manipulate objects.

Nothing has stopped Angela giving everything a go.

Vajk Horvath

Absent left hand (left transradial limb deficiency)

By Sabi Horvath (Vajk's father)

Vajk was born with Poland syndrome, which meant that Vajk's left arm stopped developing in the womb. This resulted in a shortened arm and only a small palm developing instead of a hand and fingers on that arm. Due to his condition, a part of Vajk's left upper pectoralis major (chest) muscle is also missing. With these differences, Vajk never crawled, but would rather scoot on his bum, using his right arm for support. He knew no different and was a happy little boy.

Although Vajk, now 11, has no hand or fingers on his left arm, he always seeks to put it to good use and can do just about anything with it. At two years of age, Vajk was diagnosed with Autism. Despite this diagnosis and his missing hand, he has adapted remarkably. It has made him even more determined and stronger than ever.

Charlie Christensen

Absent right hand (partial transverse carpal deficiency)

By Charlie Christensen

I am the eldest of three children (soon to be four). I have a sister who is four-and-a-half and a brother who is two. Like many seven-year-olds, I enjoy riding my scooter and bike, playing on the trampoline, swimming, playing soccer, reading chapter books and going camping with my family. I also like building and constructing with LEGO, and spending time with my extended family. I was born with a left hand and my little hand, which we call my 'nubby' or 'nub'. When I was inside my Mum's tummy, my right hand went outside of the safe sac I was growing in and wasn't able to grow anymore. It didn't hurt and I don't remember it. The doctors called the condition, amniotic band amputation.

I may do things a little differently, but I have become very good at problem solving and doing things using one hand and my 'nub'. I've learned that with lots of practice and effort, I can figure out a way to do things that might seem hard at first. I also know I can ask for help when I need it. We like to think about my 'nub' as my little difference, just like people are different heights or shapes. My Dad is seven feet tall and my little brother has achondroplasia (the most common form of dwarfism). We think being different and kind is our family's superpower. Sometimes being different is hard, but we know together, as a family we can do hard things.

Nathan Pukallus

Amputated left leg (hip disarticulation)

By Jill Pukallus (Nathan's mother)

Growing up on a farm in a household of competitive boys, where pushing each other's limits (and buttons) is a regular day, it was only natural for Nathan, as the youngest brother, to quickly learn resilience; a trait which he would really need in the year of 2017.

A year spent in and out of hospital, receiving treatment for what was initially just a small lump in his leg. Nathan's one goal that year was to beat cancer so that he could return to school the following year and graduate with his mates. Along with the support of family, friends and teachers, Nathan completed year 11 in hospital amid chemotherapy and surgeries, fulfilling his goal.

Nathan quickly learned to adapt with one leg and continued his life as a normal 17-year-old; riding his bike to the bus, getting his driver's licence and graduating at the end of 2018.

In his last year of school, Nathan went on to complete a Certificate III in Fitness, topped his English class and achieved an Academic Excellence Award.

Nathan now enjoys life working on the farm, camping with mates and maintaining his fitness and strength. He continues to push his physical limits, both in his prosthesis and without it. Climbing grain silos, landing flips on the trampoline, canoeing, indoor rock climbing and swimming are just a few of Nathan's physical pursuits to date, and he endeavours to add to this list.

Queensland Children's Hospital

The Queensland Children's Hospital in South Brisbane is the major specialist paediatric hospital for Queensland and northern New South Wales, and a leading centre for teaching and research. We provide general paediatric health services for children and young people in the greater Brisbane metropolitan area, as well as tertiary-level care for the state's sickest and most seriously injured children. Our paediatric speciality services include burns, rehabilitation, cardiology and cardiac surgery, cerebral palsy, cystic fibrosis, gastroenterology, oncology, neurology and haemophilia care.

For more information, visit **www.childrens.health.qld.gov.au/qch/**

Queensland Paediatric Rehabilitation Service

The Queensland Paediatric Rehabilitation Service, based in the Queensland Children's Hospital, provides coordinated family-focused rehabilitation, health assessments and interventions for children and adolescents with a range of disabilities resulting from injury, illness or disease. Our goal is to maximise function, prevent or minimise predictable complications and improve quality of life for children. Our Limb Difference Clinic cares for children with a limb difference that they were either born with or have acquired during their life. Our aim is to help children with limb difference reach their full potential and achieve a rich and functional life.

For more information, see **www.childrens.health.qld.gov.au/service-queensland-paediatric-rehabilitation/**

AUDAX AT FIDELIS

Queensland
Government

www.childrens.health.qld.gov.au

childrenshealthqld

queenslandchildrenshospital