

Thrive



NEWS FROM LIMBS 4 KIDS

**DRUMMING TO
HIS OWN BEAT
KNOX GIBSON**

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FOR THE NDIS?**

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SUMMER 2015 EDITION

Knox Gibson

Drumming to his own beat

As many parents and carers of children can appreciate, the life of a child is often one full of activity, adventure and trying out new things for the first time. Knox Gibson, an eight year old boy from Orange in New South Wales, is no different. Knox plays soccer, rugby, swimming, cricket and is learning the drums. Knox is the son of Kate and Jack, and little brother to eleven year old Hamish and nine year old Arabella.

Knox is described by his parents as being "very confident, stubborn, determined, independent and cheeky". Knox also has a limb difference, having had his right arm amputated below the elbow after a traumatic accident when he was four years old.

Orange is a small city in the central west area of New South Wales. Orange is a region that is surrounded by agriculture, well known for its fruit growing and food and wine culture, and was the birthplace of renowned Australian poet Banjo Patterson. Both Kate and Jack grew up in small towns close to Orange, lived in Sydney for a time, but returned to live in Orange when they learned they were expecting their first child. "When we found out we were pregnant we made the decision to move back to Orange as we wanted our children to grow up in a regional town that we loved and was close to our families and friends," explained Kate.

The Gibson family is a "busy

one" with all children attending school and participating in various sports. In addition, the children might soon be able to create their own band that would see Hamish play guitar, Arabella play piano and Knox play drums. Both Kate and Jack also work full time meaning that, in addition to being an extremely organised household, they are also supported by their very involved extended family members.

It was the support and love of their close family and friends that Kate and Jack called upon when Knox had a farm accident which led to the amputation of his arm in 2011. "Knox was being cared for by his grandparents when, despite being under the careful watch of his Grandad, he accidentally walked behind a ride-on lawnmower and became trapped underneath," told Kate. "The accident was no one's fault, just one of those things that can happen, particularly when it comes to very active and adventurous children on farms," explained Kate.

Kate and Jack were notified by family members about Knox's accident just as they arrived home from work; a very frightening experience for both. "Jack's father called to tell us that there had been an accident and, because they live 45 minutes outside of Orange, they were driving to meet the ambulance along the way. That they were going to meet the ambulance part way made us realise that it was a





pretty severe accident,” said Kate. “We met Knox at Orange Hospital and learned that his right arm was gravely injured, and that he also had deep lacerations and a fracture of his right leg. Initially, and before we even knew what Knox’s injuries were, we were taken to a small private room at the hospital so knew we were facing some very serious news,” explained Kate. Within a short time, doctors advised Kate and Jack that Knox would need to be transferred by helicopter to The Children’s Hospital at Westmead in Sydney, and were alerted to the possibility of an arm amputation. “My sister was a nurse and, due to her knowledge and experience, she also thought an amputation might be necessary so did a great job preparing us for that possibility,” said Kate.

The helicopter could only accommodate one parent, so Kate accompanied Knox to Sydney. Meanwhile, Jack drove three and a half hours to meet them at the hospital in Sydney. Kate recounted that “it was the longest few hours in my life, as I was alone in the hospital receiving information about Knox’s condition while he underwent emergency surgery”.

It was during this time that the Orthopaedic Surgeon came out of surgery to inform Kate that two options were available. One was to continue surgery that would last for up to sixteen hours, could possibly save a “non-functioning arm” but would come with significant surgical and post-operative risks that could be fatal to Knox. The second option was to amputate Knox’s arm below the elbow and leave him with a residual limb that had a much better chance of functionality,

would pose less risks to his life and allow Knox to be fitted with a prosthetic arm.

Kate recounted asking the doctor “what would you do if it was your child” to which he responded with “I would amputate”. Kate knew that Jack, who was still en-route to the hospital and out of contact, would agree with her decision. It was decided, that for Knox to have a normal life and to survive his injuries, amputation was the best option.

Knox’s accident was so serious that it was the first news item on the national breakfast television ‘Today Show’. “I understand that journalists were trying to reach us but the hospital staff acted as gatekeepers and thankfully we weren’t contacted by the media, especially so soon after Knox’s surgery had ended,” related Kate.

“I can’t thank the staff at The Children’s Hospital at Westmead enough for saving Knox’s life and for performing a successful amputation that now allows Knox to do virtually anything that any other eight year old can do,” Kate emphasised.

Knox spent four weeks recovering in hospital after his surgery; a time that included treatments, a final surgery to close his wound and meeting with various specialists from the Westmead Limb Clinic. “For the first few days Jack and I were running on adrenaline and we barely slept. It took a couple of days for Knox to come out of the ‘danger period’ but until that we just couldn’t sleep. After that, and while Knox was recovering, we would take it in turn alternating who would stay with Knox, as we didn’t want him to ever feel alone,” explained Kate.

Family were of enormous support to Kate and Jack during Knox’s hospitalisation. “We were in Sydney the whole time so relied on our family in Orange to take care of Hamish and Arabella”, said Kate. This didn’t just include keeping up their school and extracurricular routines, but also providing them with the emotional support that being away from their parents and sick brother brought. “Our parents and extended family members were amazing in looking after our children, Jack and I. Each weekend our parents would bring Hamish and Arabella to Sydney so that they could spend time with Knox and us. We couldn’t have got through that time without our family,” recounted Kate.

Friends and their children’s school were also enormously supportive during Knox’s time in hospital. Kate commended the school attended by Hamish and Arabella “who kept an eye on them and ensured they were coping OK” and thanked friends “who brought food, fresh clothes and anything we needed to the hospital and the motel we were staying at”.

While Knox was recovering he was attended to by the Westmead Limb Clinic which provided the family with medical, social work and occupational therapy support. “The Limb Clinic team were fantastic and nothing but caring and Knox-centred throughout,” said Kate.

The Limb Clinic introduced Kate, Jack and Knox to a number of Prosthetists, allowing them to choose one that best suited Knox’s needs. “In the end we chose APC Prosthetics and have worked closely with

Cameron Ward, from APC for four years now. Cameron has a great relationship with Knox and clearly loves working with children”, expressed Kate. Being so active Knox has had many limbs replaced due to ‘rough and tumble’ breakage and because he is growing, and has been introduced to a range of prosthetic arms to test and try over the years.

“Cameron is always available to assist us when Knox needs a new prosthesis, and we tend to see him in Sydney every six months,” explained Kate. Knox now uses a myoelectric prosthesis as well as a fixed recreation one. In addition, Knox has a variety of assistive devices that are screwed onto his ‘recreation arm’ to allow him to ride his bike, play cricket, play the drums, use a skipping rope as well as a range of other activities. Knox took up drumming lessons a year ago, driven by a love of AC/DC’s music and beats. Indeed, the whole family are going to Sydney in November to see AC/DC perform and “Knox will no doubt be mime-drumming throughout the concert,” laughed Kate.

“Knox doesn’t wear his prosthetic arm all of the time but often uses it for specific activities. All the assistive devices are incredible, but the one Knox uses to hold a drum stick and play music to is quite amazing,” said Kate. “As Knox loves pirates, he also has a ‘hook arm’ which he likes to use for dressing up and fun,” laughed Kate.

Since his accident Knox has been undertaking occupational therapy through the Westmead Limb Clinic to ensure he is using his prosthesis to the best of his ability. “Knox has been working



Kate also praised the Limbs 4 Kids program. "We love that Limbs 4 Kids now exists, as there was nothing like this available when Knox had his accident. The Limbs 4 Kids website means that vital information is all in one spot, and being able to connect with other families and share experiences via the facebook group is just fantastic," enthused Kate.

Limbs 4 Life would like to thank Kate for taking the time to be interviewed and allowing the story of Knox and her family's story to be profiled in this edition of Thrive. We also wish Knox, Hamish and Arabella all the best with their sporting and music activities!

with Nadia, an Occupational Therapist in Sydney, for many years now. Nadia has played an important role in assisting Knox to learn to use his left-hand, because previously he was right-handed, and she has always assisted him to adjust to a new prosthesis and any assistive devices," explained Kate. As Nadia is located in Sydney, she is now working with the family to source an Occupational Therapist in Orange who can assist Knox with more regular fine motor skills training for his left hand.

Knox is a very confident child who is not self-conscious about his limb difference. "Knox accepts that his limb difference is just a small part of who he is and is quick to say 'it got chopped off by a lawnmower' if anyone asks why he is missing his arm," said Kate. Knox is also a very adventurous and curious child who amazes anyone who encounters him with what he can do. "Knox is incredibly fearless and nothing holds him back, you only have to

see him tackling the opposition on the rugby field to see that," revealed Kate.

Knox is incredibly close to his two siblings, his grandparents, extended family members and family friends. "Knox knows he is loved and supported by so many people and, the fact that he has lost an arm, is secondary to who Knox is. Knox is himself first and foremost, and his limb difference is just a small part of who he is. No one treats him any differently, and I think it is that attitude that has helped him to continue to be an active kid who will give anything a go," said Kate.

Kate firmly believes that having a positive attitude has helped Knox and the family adjust to life since his accident. "We are so lucky that Knox is alive, he could have died that day. We are so grateful that Knox is still with us and, while his life path is now a little different, he can still do anything he sets his mind to despite the loss of his arm," said Kate.

Are you preparing for the National Disability Insurance Scheme (NDIS)?

The National Disability Insurance Scheme (NDIS) is currently being rolled-out across most Australian states. This will continue until full roll-out happens over the next few years. As the NDIS is a significant policy change, it is being gradually introduced into regions over a number of years.

Whether the NDIS is coming to your region very soon or whether it is a little while away, it is a good idea to start familiarising yourself with how the NDIS can support your child. The following article briefly outlines the NDIS and provides information about the Limbs 4 Life 'NDIS Parent Checklist', a tool we hope will assist you when preparing for the NDIS.

NDIS Summary

Most children with limb differences will be considered as having a 'permanent disability' by the NDIS and, as such, should be deemed eligible for NDIS support. If a child acquired a limb difference as a result of a compensable accident (eg. car accident) he or she may not be entitled to NDIS support.

The NDIS is designed to look beyond immediate need and focus on what is required across a person's lifetime. It is a new way of providing individualised support

to people with a permanent and significant disability, their families and carers.

Key elements of the NDIS are:

- *A lifetime approach.* Long-term and sustainable funding, ensuring that the individualised care and support that people with disability receive will change as their needs change.
- *Choice and control.* People with disability can choose how they receive support, control how the support is provided and may be able to self-manage their funding allocation.
- *Social and economic participation.* People with disability will be supported to live a meaningful life in their community in order to reach their full potential.
- *Focus on early intervention.* Investment in remedial and preventative early intervention to improve outcomes.

The NDIS provides ongoing funding for all 'reasonable and necessary' disability equipment, care and support services. The NDIS sets out guidelines to assist in determining eligibility and what can be funded. Once deemed eligible, children with

limb difference may use their NDIS funding to cover the cost of prostheses, aids and equipment, home modifications, some therapy services and other resources they need to have 'a good life'. If deemed eligible, you may find that your child will be entitled to products and items that are of greater value than is provided through current government funding.

As a parent or carer, once your child has been approved as eligible for NDIS support you will meet with a 'NDIS Planner' to collaboratively determine what your child's needs and goals are. It is likely that you will be meeting with your Planner many times over the course of your son or daughter's childhood. Once your child reaches 18, he or she will continue to meet with a Planner, as NDIS will continue to provide support through adulthood.

The best way of staying up-to-date with NDIS information and to find out when it will be available in your local community visit www.ndis.gov.au You can also register to receive NDIS updates if you wish to do so.

NDIS Parent Checklist

Limbs 4 Life has developed an **NDIS Parent Checklist** (available in the NDIS section on the Limbs

4 Kids website) to assist you, as the parent or carer of a child with limb difference, to prepare for a NDIS meeting. This Checklist is broken into two parts, one section exploring your role as a parent / carer and the second looking at the unique needs and goals of your child. A brief summary of the NDIS, and online links for further information, is also provided.

The Checklist includes an array of questions regarding your role, your child's needs and goals, support needs, prosthetic device/suspension needs, aids and equipment needs, and assistive devices and technology needs. Tables and tick boxes are also provided so you can record responses. It can also be used as a thinking tool, as you will benefit from being prepared prior to meeting with your NDIS Planner.

The Checklist can be used to initiate discussions with your NDIS Planner and will help you to record key issues that you may need to raise with NDIS staff. We hope it helps you, and your child, to prepare for a smooth transition into the NDIS.

Don't hesitate to contact Limbs 4 Life at any time if you have any questions about the NDIS.



Planning for education in 2016

With the 2016 school-year just around the corner, you may want to review content on the Limbs 4 Kids website and/or download related Fact Sheets. These pages provide general information about early childhood learning, primary schooling and secondary schooling; as well as information specifically related to the education needs of children with limb differences. Some specific resources look at enrolment, preparing for school meetings, returning to school after a limb amputation and tips for assisting fellow students to understand limb difference.

For more information visit the **'Education and Employment'** section on the Limbs 4 Kids website. You may also want to download specific **Fact Sheets** (in the publications section of the Limbs 4 Kids website) that can then be shared with others, or get in touch with Limbs 4 Life to request for hard-copies to be mailed to you.

Össur Mobility Clinic



Össur, one of the world's leading orthopaedic and prosthetic manufacturing companies, recently hosted Australia's first 'Mobility Clinic' for lower limb amputees and children with limb differences. Held in Brisbane in September, this event combined a mix of presentations and physical activities as well as opportunities for participants to connect with other amputees of all ages and abilities.

This successful event saw 62 adult and 15 child participants enjoy the chance to build overall mobility skills under the guidance of the world's leading expert in amputee rehabilitation, Professor Bob Gailey from the University of Miami. Professor Gailey is a physiotherapist, author, researcher and lecturer with a passion for assisting amputees and children with limb differences to build mobility confidence and skills.

Professor Gailey, known as Bob, was a passionate motivator who took the time to get to know each participant and provide them with personal advice and

encouragement. Hearing Bob say "you can do it", "don't be afraid to try" and "well done, I knew you would achieve that" to individuals illustrated not only Bob's interest in each participant but highlighted the intimacy of the event.

The Mobility Clinic also included the involvement of physiotherapists, prosthetists and parents who had the opportunity to build upon their own knowledge and work one-on-one with adult amputees and children with limb differences. Over the course of the two-day event improvements in mobility, balance, speed and confidence was evident amongst all participants. As one therapist said "I feel so privileged to have been part of this event, support amputees, meet new people and learn some new tips I can use when working with my patients too".

Individual videos were taken of participants enabling Bob to personally evaluate each individual's gait patterns. Bob then provided each person with tips and exercises aimed at enhancing their mobility, walking,

balance and/or running skills. When reviewing the videos of children, Bob was overawed and enthused by what he witnessed. Bob remarked that "my American counterparts should be nervous about the future Australian Paralympian Team, as there are many children and young people here who already possess the skills to become Paralympic champions of the future".

Harvey Blackney, Regional Director of Össur Australia, said "It was an absolutely wonderful two days, seeing some people achieve things they never thought they could. It was also tremendous to have people from around Australia come and enjoy the days with Bob, improve their performance and ultimately live life without limitations."

Limbs 4 Life would like to thank Össur for hosting the Mobility Clinic and allowing us to be an event partner. In addition, we are extremely grateful to Össur for the very generous donation made to Limbs 4 Life; a donation that will allow us to continue to support Australian amputees and people with limb differences.



Going toe-to-toe with Ben

Ben Brizzi was born with a congenital lower limb difference which resulted in an amputation when he was toddler. Now in his early 40s, Ben has seen significant changes in technology and support for people with limb differences over that time. Ben's limb difference has never held

him back from pursuing sports, volunteering in the community, entering into a professional career in telecommunications and being a passionate advocate for children with limb differences.

Ben was born and raised in Melbourne, in Preston to be

precise, and has lived in that suburb his whole life. Ben has an identical twin brother, who wasn't born with congenital limb differences, and grew up in a family with an Italian father and Australian mother. In addition, Ben has an older brother and younger sister.

Ben was born in 1972 with an unformed tibia and heel bone, a condition which resulted in his right lower leg amputated when he was 14 months old. "I consider the impacts of my leg amputation to be quite small and, as I don't remember that time in my life, my family say that I really 'took off' in terms of walking after I had the surgery," said Ben.

Ben has witnessed significant changes in prosthetic technology between when he was a child and what is available today. "When I was young my prosthetic leg was an old style where chords, cased in plastic, allowed the leg to move and leather was strapped from my waist and then around my right thigh to keep the leg in place," explained Ben. "While my original prosthetic leg, compared to what child and adult amputees are fitted with today, might have seemed very cumbersome I don't remember complaining. It was just the way it was and it was part of me! I could run, walk and play and I never felt that I was missing out on anything; something that was very beneficial growing up as a twin in a competitive environment!" stated Ben.

In comparing the prosthetic leg he used as a child with the one he now uses, Ben said "the changes are so remarkable and different, it really does blow you away". Ben now uses a Total Surface Bearing (TSB) socket and Freedom Foot, which he finds comfortable for both general and active mobility, and also recalls being "so excited when the rubber foot casts were first moulding 'veins' on the prosthetic foot".

Although Ben was aware that his prosthesis meant he was a little slower than others when

he was a child, it never stopped him from trying sports. "From the age of five I competed in Little Athletics in summer and football in the winter, and I was also introduced to the now defunct Amputee Athletics Victoria after my Dad spoke to an older amputee," recalled Ben. Competing in the Australian Amputee Championships at the age of eleven, Ben won two gold medals (200 metres and 400 meters) and two silver medals (100 meters and long jump) and was "stoked by receiving the really heavy medals".

Ben feels that having a limb difference hasn't really held him back from anything, that he's had great life experiences and has a great support network of family, friends and colleagues. "The only I thing I couldn't do, and still can't, is long distance running. I found that running more than 800 metres would result in blisters on my stump and, while I tried stockings and ointments, lengthy runs just weren't for me. Instead it allowed me to focus on other sports and shorter distance competitive running, so it really wasn't a problem," shared Ben.

Ben was born into a family with strong connections to the sport of boxing. "In 1968 my father and uncle established the 'Brizzi Bros Boxing Gym' in Melbourne and have had some great success training amateur and professional boxers over the years. So naturally, my twin brother and I learned how to box. We participated in some amateur bouts but due to having enlarged spleens we couldn't continue," said Ben.

While Ben concedes he is biased he does believe that his Dad is one of the best boxing trainers in

Australia; something backed up by the fact that their family gym has been successfully operating for almost 50 years. Ben is now a part-time boxing trainer himself, and feels lucky to have been able to learn under his Dad's guidance and develop "great coaching methods and techniques". Indeed Ben recommends boxing as a good fitness sport that can cater to individual needs and abilities. "Boxing can accommodate people regardless of whether they are sitting or standing, and I've trained people who use wheelchairs. At the end of the day the most important thing is that the person is comfortable, confident and hopefully exhilarated after a session," Ben explained.

In thinking about his family, and the support he has had from them throughout his life, "they are awesome" is the way Ben sums them up. "Even though I had a limb difference, and a twin brother as a point of comparison, I was never treated any differently apart from the obvious times where I may have needed help. I was never talked about or spoken to any differently by immediate or extended family members. My leg was just part of who I, Ben Junior, was," recounted Ben.

Ben concedes that things did get a little bit harder for him as he entered adolescence; a time when he felt more self-conscious about his limb difference. It was also the first time that other young people giggled or stared at his limb difference and consequently his "self-confidence took a bit of a hit". Ben admits to getting into a "few scraps as a boy" but when taunts about his leg arose he used to think to himself "Is this the only angle they've got? They have to mention my leg to get a rise out of me?" "Once I thought of it that

way I felt more confident and started to think it was them that had the problem and not me," said Ben.

As an adult Ben has had great support from his employer, the Victorian Telecommunications Ombudsman. Getting older has seen Ben develop cysts in his stump from time to time, and has nothing but praise for the understanding that he has received from his workplace when this occurs. "My colleagues and the Human Resources Department always check if I am OK, ask if there is anything they can do to assist and are quite comfortable with me taking my leg off anytime I need to," said Ben.

Ben often wears shorts, thus exposing his prosthetic leg, which naturally leads some people in the community to ask why he has a missing limb; a question that Ben is more than happy to respond to. "I usually say that when I was born I had no bone here, at which point I point to my shin, and then say I also didn't have a bone here, and then point to my heel and ankle. Once I've pointed those differences out, I then tell the person that because of those conditions the doctor removed part of my leg so I could walk properly," explained Ben. Ben feels it important to respond to questions about limb difference "so that people, who may never have met an amputee previously, learn about amputees in a positive and educative way".

Ben finds the growth in online and organisational support for amputees in recent years to be "absolutely phenomenal and important". Support, exposure

and the reduction in community stigma related to amputees are significant positive changes that Ben has witnessed increasing since his own childhood. "While there was some community support when I was a child, the growth of organisations like Limbs 4 Life and the Limbs 4 Kids program has increased support tenfold," said Ben. Ben feels that the Limbs 4 Kids program "is great for providing a network for kids and families who can now reach out for any advice or help they may need; a support that is invaluable and can't be measured".

Ben also feels that the increase in support organisations is also helping professionals working in the amputee field as "you can speak to your prosthetist or clinic and they can put you in touch with someone who can assist you in any way you need".

Ben recently undertook the inaugural Limbs 4 Kids 'Parent Peer Support Volunteer' training via webinar; training that is open to parents of children with limb differences or adults who, like Ben, grew up with a limb difference. While Ben already volunteers his time to Boxing Victoria, Boxing Australia and Future Stars Cricket Academy he was keen to become a Limbs 4 Kids volunteer as he "wants to give something back, share his story with others and show people that having a limb difference can actually open up doors that you never thought were possible".

Ben recognises that everyone is different in some way, his just happens to be a leg difference.

"I might not have part of my leg, but I really do believe that there are no limits to what people can achieve with the right support," said Ben. "I also like to let people know that although I might wear a prosthesis I can dance like a demon," laughed Ben.

Limbs 4 Life would like to thank Ben for sharing his story in this edition of Thrive, as well as congratulate him on becoming a new Peer Support Volunteer with the organisation!



*Photo courtesy of 'Looks Like Me Surf Photography'

Let's go surfing with the Disabled Surfers Association of Australia

The Disabled Surfers Association of Australia (DSAA) are a volunteer-run organisation that enable people of all ages and abilities to take part in one of Australia's most popular past-times, beach surfing! Your family might want to consider attending one of their events after reading about amputees who are engaged with the DSAA as well as the vision, commitment and safety the organisation puts in place at each of their surfing events.

The Disabled Surfers Association was established in 1986 by Gary Blaschke after a traumatic accident which saw him undergo extensive rehabilitation. As a surfer himself, Gary saw that many surfers who developed a disability or condition then felt they couldn't return to the water as they didn't have support to do so. Gary also felt that many people with disabilities, who had never surfed before, should have

an opportunity to try out the sport he is so passionate about. As a result Gary, and his supporters, started DSAA to allow people to surf under the supervision of trained volunteers.

Over many years people with all classes of disability and conditions, including amputees and children with limb difference, have been able to enjoy surfing. Indeed, some amputees are volunteers within DSAA, and this article includes feedback from amputee volunteers and participants. The DSAA has set an international best practice model for disabled surfers.

The DSAA have 14 branches across most states in Australia, and have even branched out into New Zealand. The DSAA have hundreds of volunteers who are trained to work with people with disability both in and out of the water. Each event includes

Beach Marshalls who oversee the event, Team Leaders who coordinate groups of participants and volunteers in the water, and other volunteers who coordinate participant sign-ins and post-event BBQs and get togethers.

Volunteers supporting people in the water undertake 'Train the Helper' and first-aid training so that participants are well supervised and provided with support that accommodates their needs. Participants include people with a variety of disabilities and conditions ranging from joint problems, paraplegia, intellectual and neurological impairments, and limb difference; so volunteers are very competent at supporting people with a variety of needs and abilities.

Each branch is run by a volunteer Board of Management which ensures that their branch is well structured, that volunteers are

regularly trained and they are providing exciting beach events during the summer time. The DSAA also take out considerable insurance, which is quite costly and very important when it comes to the provision of water activities, to ensure that participants and volunteers are protected.

Ian Gay, President of the Gold Coast DSAA branch and passionate surfer, said that "safety and fun are the key priorities of our organisation and we get such a buzz seeing people enjoy their time in the water. Some of our participants have been coming to events for years, while others are just starting out and beginning to learn to love getting out in the water on a surfboard". In addition, some participants and/or their caregivers also train to become volunteers over time.

At the end of each event, some branches give out awards to participants to recognise the achievements gained. Ian said that his branch offer out awards such as 'Best Surfer', 'Best Wave' and 'Biggest Smile', to name but a few. Importantly, the end of an event is a chance for everyone to get together, chat about how much fun they've had and meet new friends. "It's a really supportive and inclusive environment for everyone," said Ian.

Bruce Peel, an amputee and member of the Limbs 4 Life community, is extremely involved in DSAA. Bruce, who is paralysed in one arm and an above-knee amputee, has been involved in the Western Australian DSAA group for 11 years and is also the Vice-President of the National DSAA Board. "The advantage of being an amputee and surfing is that once you are in the water your disability disappears as

you are weightless. Being in the water is good for the soul and it's wonderful to smell the water because you are in it rather than only smelling it from the beach," highlighted Bruce.

Bruce is passionate about children and young people trying out surfing. "We've had many young people with limb differences take part across Australia over the years, and I can assure parents that the safety of children is critical to us. Equally important is building confidence in water; so if you attend an event you will hear very loud cheers from volunteers and other participants when children overcome fears," expressed Bruce.

Holly Franklin, an upper-limb amputee and member of the Limbs 4 Life community, began as a participant "surfer" at the Gold Coast DSAA branch in January 2012, but switched to a volunteer role in late 2012. Holly began attending events, saying "I wanted to learn to surf but wasn't sure if a regular surf school would suit my needs as an amputee".

As an amputee Holly sees DSAA events as extremely beneficial for both children and parents, and said "you gain confidence in your abilities, develop a respect for the ocean, join a community of support and encouragement, and can gain access to the beach without using a prosthesis. It's also really safe, as each participant has a number of volunteers surrounding them in the water to ensure that nothing, except the odd dunking, will go wrong". Holly also feels that parents get a chance enjoy watching their children build skills as well as have the opportunity to engage in informal peer support and comradery with other parents. "DSAA focuses

on safety and smiles, so parents can relax while their kids can try an activity that they (the parents) might otherwise not be willing or able to do without the support of the DSAA," said Holly.

For more information about DSAA, local branches and dates of upcoming events visit their website at www.disabledsurfers.org. You are also encouraged to contact the local branch if you have any questions or want to RSVP for an event in your area. You can also visit the Limbs 4 Kids [website calendar](#) where upcoming DSAA events are also listed.

If your child is considering attending an event and wears a prosthesis, because it is a beach activity, it is a good idea to speak with your child's prosthetist to ask about whether the prosthesis can be worn on the sand and/or in the water. Unfortunately, if sand gets into your child's prosthesis it may cause damage to the functionality of the components so it is a good idea to check before going to the beach. Your prosthetist may be able to advise of ways of ensuring your child's prosthesis isn't damaged or compromised, or recommend an assistive device (such as crutches or a wheelchair) so your child can be transported on the beach. Alternatively 'water legs' may be available. Water legs (specifically designed for use in the shower, swimming pool or beach) are completely covered so the effects of the sand and salt water do not have an impact on prostheses, and may be used for surfing or beach based activities. Again, speak to your prosthetist for professional advice.

Thanks to DSAA for allowing us to interview members and learn more about the great work this organisation does in the community.

Award winning photos of children with limb differences

Child photography is a regular feature of professional photography awards but, until recently, images of children with limb differences had not been. That was until Melbourne-based photographer Zaharoula Harris met five-year old Alex.

Alex, who was born with bi-lateral limb differences which resulted in amputations of both feet when he was just a toddler, is well known in the Limbs 4 Kids community. Alex, along with his parents Allison and Marta and twin brother Mark, is child who is full of beans. Alex plays an array of sports, recently received his first set of running blades and already aspires to represent Australia as a Paralympian in the future. Like most parents Allison and Marta have sought to capture their twin boys as they grow, which led them to meet with Zaharoula for a family photo-shoot.

Not only did the family receive stunning photos but a particular image of Alex stood out as one that not only captured his personality but was of such high quality that Zaharoula thought it worthy of entrance into the 'Victorian Professional Photography Awards'. The photograph scored a 'Silver with Distinction' at these awards, with the judges commenting that they were all drawn to the courageous look in Alex's face well before they even noticed his missing limbs. The success of Alex's photo resulted in Zaharoula being invited to enter into the Australian Professional Photography Awards.



It was at this point that Zaharoula thought she would like to photograph children with limb differences and use her lens to “share their beauty and stories with, not only families, but the wider community”. Zaharoula contacted Limbs 4 Life to enquire whether we could put a ‘call out’ for two other Melbourne-based families to have portraits taken of their child. Two families responded to the call and had wonderful photos taken of their beautiful children Milla and Angus.

Milla, who was born with a congenital lower limb difference that resulted in an amputation when she was a toddler, is a gorgeous and captivating little girl who features in a number of Limbs 4 Kids materials and videos. Angus, who is nearly nine and had his foot amputated as a result of an infection, is a determined and tenacious boy who is amazing everyone with how quickly he is recovering from his very recent amputation.

In reflecting on the photo-shoot, Zaharoula said “I felt quite nervous photographing the children as the most important thing to me was that the parents would look back and fall in love with the images”. The day of the photo-shoot was a great success “full of fun and laughter”, providing Zaharoula with an opportunity to learn more about Milla and Angus. It also allowed Zaharoula to present their families with an array of beautiful pictures of their children.

Zaharoula and her colleague Lisa Saad (who, incidentally, took out the 2015 Australian Commercial Photographer of the Year Award) worked collaboratively to develop two breathtaking images of



Milla and Angus that both sets of parents “were thrilled with”. Along with the photo of Alex, all three images were entered into the National Awards held in October.

The competition, which is an extremely competitive Australian-wide award, saw Zaharoula receive ‘Silver with Distinction’ for her photo of Alex. The photos of Milla and Angus did not receive awards but Zaharoula feels that “those photos are ‘gold rated’ in my eyes and, no doubt, in that of their parents also”. Indeed, Zaharoula would like to continue taking photos of all three children as they get older.

While Zaharoula has been photographing for over 30 years, prior to taking it up professionally six years ago, she worked in the area of disability with the Victorian Department of Human Services. In reflecting on both her previous and current professions, Zaharoula said that “over the years I had the pleasure of meeting many people with a variety of disabilities, and what is important is that you see the person first and foremost. That

is the same with photography, you try to use the lens to capture the essence of the person first and foremost”. Indeed, it was that approach Zaharoula felt enabled her to take beautiful pieces of art featuring Alex, Milla and Angus.

Zaharoula is keen to work on a book with the Limbs 4 Kids program that will assist in raising awareness of children with limb differences and, as she says, “assist a small organisation like Limbs 4 Life to continue to offer support to parents when they need it the most”.

Limbs 4 Life congratulates Zaharoula on her recent photography successes, and thanks her for taking the time to support the Limbs 4 Kids community and her ongoing commitment to improving outcomes for children with limb differences.

For more information about Zaharoula visit

www.zedphotography.com.au

Can you support an Australian fibular hemimelia research study?

Does your child have diagnosed fibular hemimelia and you would like to assist Australian researchers to enhance the quality of life of others in the future? If so, you may want to take part in this national research study.

Purpose of the Study

To compare the quality of life and lower limb function of children and adolescents with longitudinal fibular deficiency (also known as fibular hemimelia) to typically developing populations of the same age and gender.

Who can participate?

Anyone in Australia who has a diagnosis of longitudinal fibular deficiency aged 7-21 years.

Why should I participate?

The study has a goal of aiming to improve the education provided to families on the likely function of their child as they grow older. This information is very significant and it often weighs in on discussions about possible treatment options. It is a great opportunity to be a part of helping others in the future.

What does it involve?

3 short questionnaires that take approximately 20 minutes in total will be mailed to you and you return them in the stamped self-addressed envelope enclosed. The answers provided will be compared to peers of the same age and gender to determine if quality of life and lower limb function are affected in this condition.

Who is conducting the research?

Dr Louise Tofts and the rehabilitation teams at The Sydney Children’s Hospitals Network in conjunction with researchers at Macquarie University. Joshua Pate is a physiotherapist that is completing a Masters of Research and this study is contributing to this higher degree research.

The team involved would like to thank you for your time taken to consider participating in the study.

For further information about this study, please email Joshua.pate@healthnsw.gov.au or call (02) 9845 2823

Meet the Limb Clinic Team at Sydney Children's Hospital, Randwick



In this edition of Thrive, we were privileged to speak with members of the Limb Clinic at the Sydney Children's Hospital, Randwick; a clinic that works with children and families prior to the birth of a baby and right through to 18 years of age. Limb Clinic members were able to talk about their roles, goals, ways they work with families and thoughts about developments in the field of limb difference.

Interviewed members of the Limb Clinic were Dr Adrienne Epps (Paediatric Rehabilitation Specialist), Margaret Patterson (Physiotherapist), Laura Sidharta (Social Worker) and Leslie Wollin (Occupational Therapist and Limb Clinic Coordinator). Unfortunately other integral members of the team - their specialist Paediatric Orthopaedic Surgeon, Geneticist and Plastic Surgeon - were not available to take part in the interview.

In the context of children with limb difference please explain what each of your roles are?

The Limb Clinic is comprised of a collaborative group, with each holding a specific role that relates

to their area of specialty. The following summarises the roles of each member who took part in this article. The Limb Clinic is held every two weeks, and members of the team identified as required for the assessment and review meet with attending families and children.

Rehabilitation Doctor

Dr Adrienne Epps is a specialist with a particular focus on childhood limb difference and the functional implications for each child. In her role, Dr Epps conducts an overall assessment of a child's condition and function as well as an overall assessment of a child's family and their needs. Dr Epps is the manager of the Limb Clinic and works with all members of the team to develop a Management Plan for each child. Dr Epps' responsibility is to assist children with limb difference to achieve functional goals and ensure they are supported by the Limb Clinic team throughout their childhood. Dr Epps, and members of her team, also work together to identify and support children to be fitted with appropriate prostheses and assistive devices that enhance children with limb difference to become confident, active and participating members of the community.

Physiotherapist

Margaret is the Limb Clinic's Physiotherapist who assesses each child's mobility and motor skills, developing exercise plans that assist children with their gait

and body movement training. Margaret provides families with information about what to expect during key physical development milestones and assure parents that their child will develop to their potential. Other roles include pre amputation assessment, exercise prescription and counselling, post amputation follow up, rehabilitation and prosthetic gait training. Margaret also assists in identifying local Physiotherapists and Prosthetists to work with children, particularly if the family comes from regional or remote areas.

Social Worker

Laura is the Limb Clinic's Social Worker, providing emotional and practical support to children and their families. Laura provides counselling to families in the adjustment of the child's limb difference and assists them to better understand what support is available to them whilst in hospital and upon return to their home communities. Assistance includes specific support during key transition points (such as starting school), the preparation of government and school forms, and guidance should specific issues emerge (such as body image, self-esteem).

Occupational Therapist

Leslie is not only the Occupational Therapist but is now also the Limb Clinic Coordinator. As an Occupational Therapist, Leslie assists children to maximise their abilities and

learn to undertake everyday activities at home, at school and in the community. In addition, Leslie also assesses and supports the prescribing of upper limb prosthetic equipment and assistive devices that facilitate a child's participation in everyday life. Leslie also liaises with schools and community organisations so that these can best understand a child's needs and, where required, how the setting can be modified to accommodate a child with limb difference. The Limb Clinic Coordinator role is a new one within the hospital with Leslie the first person to hold this important role. As the Coordinator, Leslie assists families to understand what the Limb Clinic does, triages new referrals and ensures children and families are able to see necessary medical and allied health specialists within the service. As the role develops, it is hoped that the co-ordinator role will provide a link between hospital services and community organisations and supports the development of clinical services to support children with a limb difference and their families.

Can you explain what a 'multi-disciplinary' approach to health care means and why it is so valuable and important for children and young people with limb differences?

The Limb Clinic is underpinned by a multi-disciplinary approach; a methodology which combines a number of factors. Multi-disciplinary means bringing together different disciplines and health professionals with different areas of expertise to assess the child and together make recommendations for the management of the child. It means that the professionals

can assess and discuss a child's condition in clinic together to address the comprehensive needs of the child so they don't have to go to different professionals and appointments. It makes it easier for the child and family by reducing the number of appointments on different days and helps communication with members of the treating team.

What does 'early intervention' support mean and why is it so important for children and young people with limb differences?

Early intervention incorporates a number of approaches underpinned by an overarching goal "that all children reach their full potential". Dr Epps sees early intervention as an approach that incorporates putting the necessary physical, psychological and social supports in place, and providing families with diagnostic information and plans early in the child's and family journey. Dr Epps views early intervention as a way of also ensuring that families receive the correct information as soon as possible, thus minimising the possibility of families receiving incorrect information, for example from the internet. Early intervention allows experts within the Limb Clinic to provide a common message to families that "their child is going to be OK and that, by working with you and your child, we expect full participation in life and the community". Early intervention also enables the team to identify any issues that may be holding a child back from reaching their full potential and intervene to minimise or mitigate the issues. In addition, early intervention includes connecting families with one another so that they know they are not alone.

A patient-led approach doesn't just involve the children and their parents, but also their family members. Can you explain how you work with siblings and extended family members?

Members of the Limb Clinic consider siblings and extended family members to be important members of a child's life. Having other members of the family attend Limb Clinic meetings allows for those individuals to ask questions, better understand limb difference and identify ways they can assist the child. As part of a child's Management Plan, members of the Limb Clinic team also identify if siblings need specific assistance or if they can be incorporated into the overall plan. The Limb Clinic noted that older siblings sometimes need assistance, particularly in the areas of better understanding their brother or sister's limb difference or needing specific counselling. In addition, the Limb Clinic supports siblings to develop scripts they can use when speaking to others about their brother or sister's limb difference; something that they have found can reduce sibling anxiety. The team have also found that including siblings in therapy can be extremely beneficial, as siblings learn how to engage with their brother or sister when playing sports or games and normalising the limb difference in their family.

Why did each of you choose to work with children and young people with limb differences?

Dr Epps chose to work in this field as it is a medical area that provides great job satisfaction, allows for cross-disciplinary collaboration, enables her to see the continuing progress

and development of a child over time and celebrate their achievements. Margaret enjoys working with her colleagues and learning from their various expertise while also being able to support inspiring children and families. Laura appreciates the opportunity to assist children and families to access support both inside and outside of the hospital, and provide ongoing practical and emotional support while a child moves through key childhood milestones. Leslie fell in love with it as an area where she could support families and children to achieve all they can do and work in a field experiencing advancements in technology and componentry.

How do you assist children who experience 'fears or worries' during appointments?

Fortunately, the Limb Clinic doesn't tend to see many children going through negative experiences during appointments. Where a child does have any concerns, the team talk to parents prior to the appointment to better understand the underlying issue and identify ways the issue can be addressed prior to and during the visit. For example, a child might be scared about coming to the hospital because it represents where they had previous surgeries or interventions; in which case the team works with the family to reduce associated fears. Sometimes a child may feel worried because of the number of Limb Clinic staff in a meeting, in which case they try to reduce the number of staff to a minimum. The provision of toys and fun activities is also a good way of distracting children, particularly if they are very young. The team also encourage each

child to take an active role in the discussion.

Do you offer peer support to families just commencing on the limb difference journey?

The Limb Clinic consider themselves very fortunate as they have many parents of children with limb difference willing to speak to and support other families. The team views peer support as a great way for families to share experiences, provide tips and encourage each other. Sometimes the team will contact 'experienced' families and ask them to speak to another family, while at other times it occurs because families informally meet in the waiting area. The team also refer families to Limbs 4 Kids and Aussie Hands on a regular basis. The team also wanted to thank two young people with limb difference, and their families, who have provided significant support to families and Limb Clinic staff over many years. Sarah Walsh, who was born with a congenital leg difference, and her mum Patricia have provided enormous support to other families over many years and are called upon by the team on a regular basis. The team also expressed gratitude to Jake Widjaya, who was born with a hand difference, and his parents for the role Jake has played in promoting the Limb Clinic and sharing his story with other young people and their families as well as in his Conference participation that assists with the professional development of staff and colleagues. It is worth noting that Limbs 4 Life has had wonderful support from both of these young people and their families also.

Are there developments in the field of childhood limb difference, prosthetics or other areas that excite and interest you?

The Limb Clinic team members expressed excitement in a wide array of areas, ranging from research through to componentry, feeling that these areas can enhance children's ability to reach their full potential. Dr Epps advised that the team is working with the NSW prosthetic funding body, 'Enable', via robust research that will hopefully lead to the provision of high performance prosthetic feet for children. Leslie is excited by myoelectric prostheses for children with upper limb differences as she has seen the positive outcomes it has for children, but as these are quite expensive she is hoping to see government funding make these prostheses more widely available. Margaret has witnessed the positive outcomes that micro-processor knees have for young people with above-knee limb differences, and hopes to see funding increase so that all suitable children have access to this componentry.

Is there any critical information or advice that you give to all children and young people living with limb difference and their families?

Most importantly the Limb Clinic team advises parents to take a positive approach, to normalise expectations as much as possible and encourage their child with a limb difference to participate in all the usual everyday activities and things that interest them and to achieve whatever goals they set for themselves but it might just be in a different way to other children.

The team recommends that parents don't restrict their child's life and allow them to participate in as many opportunities and activities as is possible. Finally, they want to remind parents that Limb Clinic members are available to talk with families any time, as the team is on the same journey with each child and family.

Do you think the Limbs 4 Kids program and resources are beneficial?

The Limb Clinic team said they have confidence in the Limbs 4 Kids resources, and frequently share them with families. The team feel that the resources are well structured, flow well and of great benefit to families and community members. The team said that parents are often provided with a significant amount of information during a Limb Clinic appointment, and the provision of Limbs 4 Kids Fact Sheets, magazines and website allow for parents to digest information in their own time.

After working with children (and their families) over a significant period of time, how does it feel when they reach adulthood and you will no longer be working with them?

While saddened when a young person reaches 18 years of age and it is time for them to move into adult services, the Limb Clinic team are also pleased because they are there to see their transition to adulthood. The team also felt it is a rewarding and humbling experience, as it means they have played a part in assisting young people to develop independent skills and confidence which prepares them for adult limb difference services. The Sydney Children's Hospital, Randwick also holds a

bi-annual 'Graduation Ceremony' for young people who have been part of their services over the years. The Graduation Ceremony provides a chance for patients and families to say goodbye to teams of clinicians who have cared for them for so long, many since birth, and provides staff the opportunity to formally farewell young people, wish them well and celebrate their successes. The Limb Clinic staff said that some young people stay in touch, but it tends to diminish over time which is a positive reflection that the young person has developed independence and is no longer dependent on the hospital.

Do you have any final comments related to working with children?

The Limb Clinic team all agreed that a very refreshing and enjoyable aspect of their job is how honest and funny children can be. They also agreed that they feel privileged to see children's personalities grow over the years, achieve personal goals and watch them mature into independent young adults.

Limbs 4 Life would like to thank the members of the Limb Clinic at the Sydney Children's Hospital, Randwick for taking the time to be interviewed for this edition of Thrive. In addition, Limbs 4 Life would like to congratulate and thank the team for the wonderful work they do in supporting children with limb differences and their families.



Limbs 4 Kids Information and Communications Survey

We invite you take part in a survey exploring Limbs 4 Kids resources, publications and the information you would like to receive in 2016. We are also keen to find out if you are able to assist us in ensuring the program is informative, supportive and sustainable in the future. Your feedback will greatly assist us in enhancing the program and planning for 2016.

The survey takes approx. 10 minutes to complete and can be accessed at

www.surveymonkey.com/r/Limbs4Kids

We thank you so much for taking part!

2015 Limbs 4 Kids Program Achievements

This year saw the launch of the national Limbs 4 Kids program; a year where we witnessed significant successes and achievements. Some key achievements have included:

- **Program launch.** Media releases and program information sent to close to 9,500 state and federal Members of Parliament, local councils, peak bodies, medical and allied health professionals, community organisations, educators and media.
- **Limbs 4 Kids website.** Launch of the Limbs 4 Kids website which contains 135 pages across the Learning Centre, Stories, Publications, News and Support sections. The website has had outstanding results with 4,438 unique visitors review 15,258 pages since its launch.
- **Fact Sheets.** Development of twelve Fact Sheets covering topics such as limb difference, education, funding, hygiene, self-advocacy, and transition to further education and employment.
- **Thrive magazine.** Four editions of Thrive magazine have been produced during 2015, containing a variety of articles featuring parents, young people with limb differences, adults born with limb differences, medical and allied healthcare providers, community organisations and information of relevance to the Limbs 4 Kids community. Readers of Thrive magazine total close to 3,200 individuals and organisations across Australia.
- **Peer Support.** Phone calls and visits provided to 61 families of children with limb differences by our Parent Peer Support Volunteers.
- **Enquiries.** Just over 310 enquiries requesting information, support and advice have been provided to families, healthcare professionals and community members.
- **Research.** Monash University has conducted a baseline evaluation of the Limbs 4 Kids program and enquiry as to the health and wellbeing of parents / carers of children with limb difference. This evaluation has been conducted with 42 participants and in 2016 participants will be provided with an opportunity to participate in interviews with the researchers.
- **Partnerships.** Partnerships and relationships have been established with a range of Australian and international peak bodies, prosthetic providers, hospitals, medical and allied healthcare facilities and community organisations.
- **National Health and Wellbeing Advisory Committee (NHWAC).** The NHWAC is comprised of an array of medical and allied health professionals (Gynaecologist and Obstetrician, Rehabilitation Consultant, nurses, hospital executive, paediatric physiotherapist, prosthetist, social worker), parents of children with limb differences, adults born with a limb difference and amputees. This Committee has a particular responsibility to provide Limbs 4 Kids

program oversight, review of program resources, identify gaps in information and servicing, and assist in building program linkages.

- **Stakeholder growth.** Over the course of the year Limbs 4 Kids has seen an exponential growth in subscribers to our publications and resources. Since January the number of families subscribing has increased by 89% and the number of healthcare professionals by 28%.
- **Australian reach.** Limbs 4 Kids has visited five states during the year; meeting with healthcare professionals, community organisations and families during these meetings.
- **Speech in the Australian House of Representatives.** The Hon. Warren Entsch MP (Federal Member for Leichhardt) gave a **90 second speech** about the Limbs 4 Kids program in June 2015, and referenced that his grand-daughter was born with a congenital arm limb difference.

"This is fantastic! It's been put together so well. Well done Limbs 4 Kids" (Parent)

"Thanks for getting in touch, and congratulations on the launch. It sounds like an incredibly worthwhile program. Feel free to let me know if there are any activities occurring in my electorate of Wentworth." (The Hon. Malcolm Turnbull, MP, Prime Minister of Australia)

"Outstanding program!!!" (Sean Gray, CEO, New Zealand Artificial Limb Service)

"Fantastic news about Limbs 4 Kids - well done. I applaud all your hard work and commitment to helping us all. Thank you." (Parent)

"Congratulations to all of you! Limbs 4 Kids looks fantastic and will be a great resource for many. Very well done." (Tim Matthews, Australian Paralympic Committee)

We would like to extend our gratitude to **nib foundation** for their funding of Limbs 4 Kids and their commitment to supporting children with limb differences and their families.

We would also like to thank every person, family, professional and community member that made the first year of Limbs 4 Kids such a success. We look forward to working with you all and expanding the program even further in 2016.

Season's Greetings from Limbs 4 Life



On behalf of all the Limbs 4 Life staff and Board members we wish you and your family a very happy, relaxing and safe Christmas and New Year. We look forward to supporting and working with you again in 2016.

The Limbs 4 Kids program office will be closed from the 21st of December 2015 to the 11th of January 2016.



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