

Thrive

limbs
4 kids

NEWS FROM LIMBS 4 KIDS

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OF SUNSHINE

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MEET OUR
VOLUNTEERS

KYLIE HAS 'NO
LIMB-ITS'

ÖSSUR MOBILITY
CLINIC

SCORE!

AUTUMN 2016 EDITION

LIMB-itless Conference

On the 30th of April 2016, Limbs 4 Life, in conjunction with conference partner Ottobock, will be hosting the LIMB-itless Conference. This conference will include presentations designed to be educative and empowering for attendees.

The presentations, to be delivered by experts in relevant fields and across both adult and paediatric fields, will cover areas such as: the NDIS; developing self-advocacy skills and confidence; prosthetics; physiotherapy; pain management; mobility; child education; and, child body image.

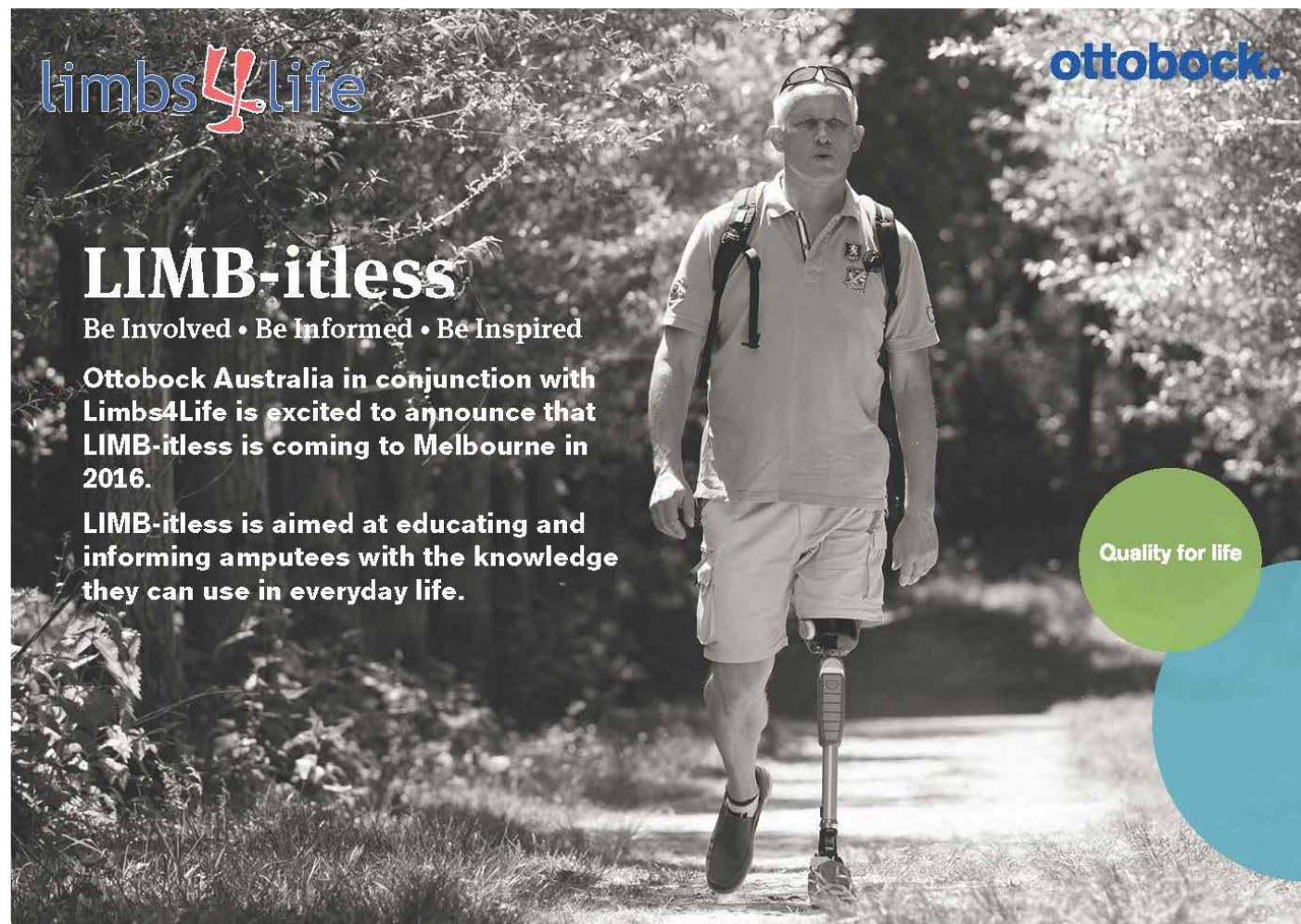
Stephanie Gotlib (CEO of Children with Disability Australia) will be conducting a presentation on 'The

education rights of children and young people with disability' and Dr Gemma Tatangelo (Australian Catholic University) will present on 'Building positive body image in children with limb differences'. Videos of sessions will be made available online for those who can't attend the conference.

To register for the conference visit - www.trybooking.com/147667

Our accommodation conference partner is Mantra Bell City.

To receive accommodation at the discounted rate please call **03 9485 0048** and quote the promo code Limbs4Life (discounted bookings cannot be made online).



limbs4life **ottobock.**

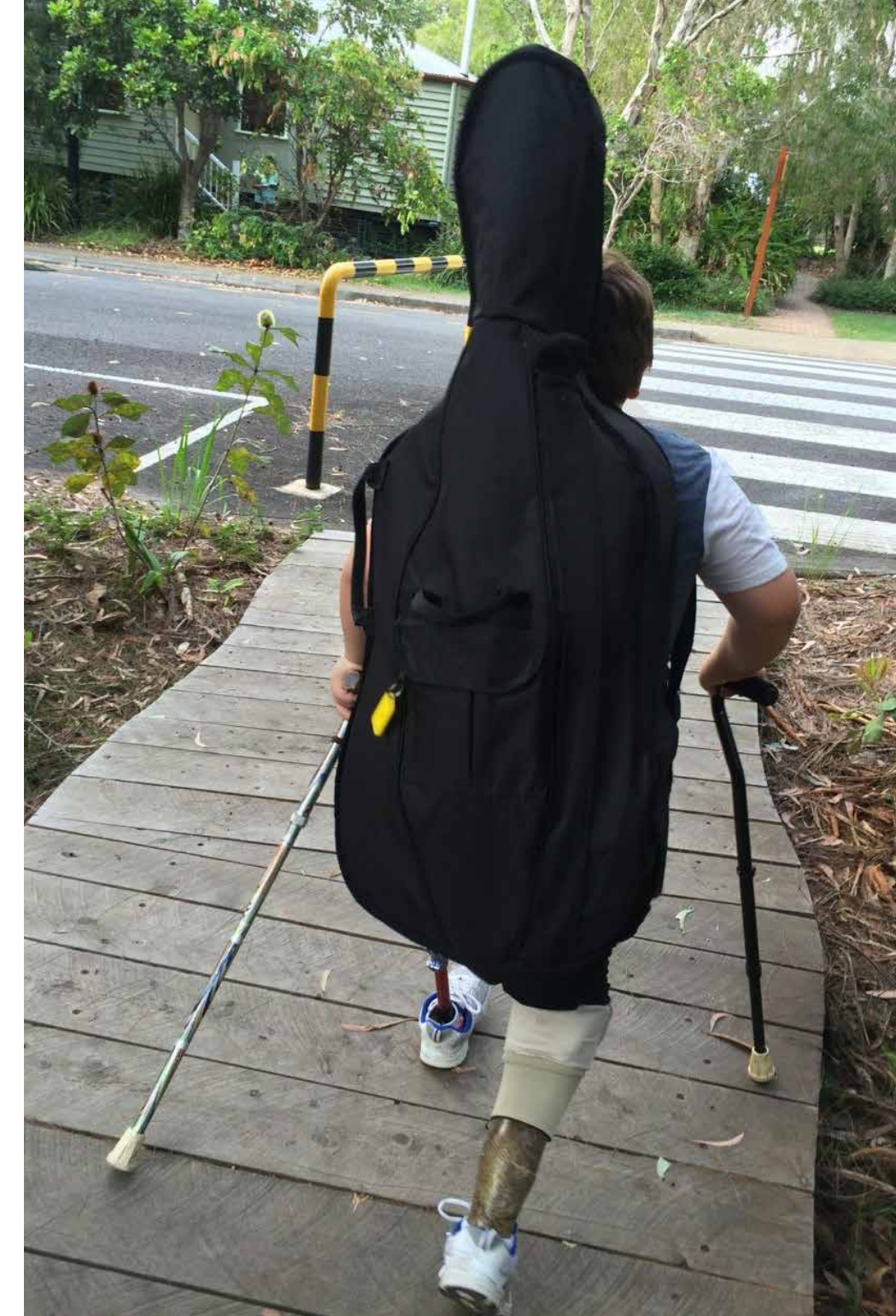
LIMB-itless

Be Involved • Be Informed • Be Inspired

Ottobock Australia in conjunction with Limbs4Life is excited to announce that LIMB-itless is coming to Melbourne in 2016.

LIMB-itless is aimed at educating and informing amputees with the knowledge they can use in everyday life.

Quality for life



Rohan the ray of sunshine

The Sunshine Coast in Queensland is not only an apt name for this beautiful part of Australia, but is also reflective of the 'sunshine' personality of eight year old Rohan McDonald.

Rohan is the son of Justin and Lyn McDonald and little brother to eleven year old Neil. Rohan and Neil are very close brothers, supportive of one another's interests in caring for the many reptiles that also form part of the family, as well as participants in an array of sporting activities.

Rohan is described by Justin as "a very bright, outgoing child who is willing to give anything a go". Rohan is also showing an early interest in engineering and construction using his Lego collection, and love of maths, to build complex movable buildings.

Neil is showing an early orientation towards zoology, with a specific interest in reptiles and a desire to become a crocodile handler when he is an adult. Neil is not



only described as an incredibly supportive big brother, but also as a child who is “older than his age, wise, caring, imaginative, perceptive and insightful”. Neil is a natural carer of animals, spending considerable time in animated conversation with them. Neil is equally just as caring about his brother and peers. Indeed Justin wonders if the future will see Rohan build a crocodile sanctuary in which Neil will be the manager!

Rohan was born with congenital limb differences affecting both legs, one of which was identified pre-natally while the other was not apparent until after his birth, resulting in bi-lateral amputations when he was a toddler. “At the 20 week scan we were told that Rohan had a club foot but, at that stage, other limb differences were not apparent,” Justin said. “However, when Rohan entered the world it was obvious

that his left leg was also affected, as he had multiple joint fractures and twisted tendons with this leg turned up and positioned under his bottom,” explained Justin. Upon birth tests were conducted to determine the condition that was affecting Rohan’s left leg. Initially Rohan was mis-diagnosed with Arthrogryposis, a rare condition where a child is born with joint contractures which means that some joints don’t move freely and may be stuck in one position; often resulting in muscles around these joints being thin, weak, stiff or missing. However, this diagnosis was revised some months later in Melbourne.

Shortly after birth, Rohan went through ten months of left leg strapping by a Physiotherapist in Brisbane as well as numerous scans and x-rays to determine his post-birth development. While Rohan

was going through considerable assessments and physiotherapy, Justin began on an international search for further information about Rohan’s conditions and possible interventions that would improve his immediate and long-term outcomes. Fortunately Justin was also able to call upon a good friend who is a Cranio Maxillofacial Surgeon in Melbourne, who recommended that he meet with Dr Ian Torode at the Royal Children’s Hospital.

“Meeting Dr Torode was a life changing experience, as he quickly identified that Rohan actually had Tibial Hemimelia and the bones in Rohan’s lower left leg would never develop. Dr Torode recommended a Syme amputation of Rohan’s right foot, a centralization of his right fibula to give him a functioning patella and through-knee amputation of his left leg to provide improved mobility, less pain and ultimately a better life,” Justin explained. After this meeting in Melbourne, Justin and Lyn met with a number of doctors who also discussed amputation or bone lengthening surgeries. “We looked into bone lengthening but were told that given Rohan’s limb differences, surgeries would need to occur over many years and there could be no guarantee of success,” Justin said.

Justin and Lyn met with an Orthopaedic Surgeon in Brisbane who concurred with Dr Torode’s assessment and recommendation to take the path of amputations. “We took about six months before we decided to go ahead with Rohan’s amputations, which included a few surgeries overall, and took place when Rohan was around 20 months of age,” Justin recounted. Naturally, the decision to amputate was a time of worry and concern for Justin and Lyn and something that wasn’t made without considerable questioning of various healthcare professionals and personal researching. “Something that assured us we were making the

right decision was a comment made by Rohan’s orthopaedic surgeon in Brisbane. He said to us that he felt honoured to work with Rohan because this is a surgery where he has the chance to improve a child’s life,” Justin revealed.

Justin and Lyn experienced the joy of seeing Rohan walk for the very first time, a month after his surgeries and immediately after he was fitted with his first prostheses. “It’s hard to express in words the emotion, thrill and pleasure we experienced when we saw little Rohan walk for the first time. We knew we had made the right decision,” Justin said. As Rohan adjusted to wearing his “new legs”, Rohan came under the care of Physiotherapist Shail Maharaj, who is now the Lady Cilento Hospital’s Limb Clinic Coordinator. “The amazing rapport built between Shail and Rohan was integral to Rohan’s early

development and adjustment, and we can’t thank him enough for being there to support Rohan and the rest of us in such a holistic manner,” Justin emphasised.

Being located on the Sunshine Coast, Rohan now attends regular physiotherapy sessions with Amanda Fairbank from the organisation *Montrose Access*. “We were so lucky to have moved from outstanding physiotherapy sessions led by Shail to the equally outstanding Amanda. Amanda is an inventive, creative Physiotherapist who listens to our ideas and develops plans, strategies and paperwork that reflect her holistic approach and dedication to Rohan,” Justin explained. Locally, Rohan is supported by Prosthetist Dewet Heyns from *Sunshine Orthopaedic Services* who, for many years, has been fitting him with new prostheses and recreational

devices. “Dewet and the team really understand Rohan and the complexities of his limb differences. Consequently Rohan’s ‘everyday legs’ are adjusted regularly due to his growth, and he has also been fitted with ‘swimming fins’, ‘running legs’ and ‘beach legs’ that have allowed him to participate in activities individually, with peers and with his brother Neil,” Justin outlined.

Rohan experiences some exhaustion at times, and when that occurs he uses a walking frame or walking stick for mobility. However, where possible, Justin encourages Rohan to walk without assistive devices for exercise and to build independence and confidence.

Rohan participates in a wide range of activities. At the moment the local Seahorse Nippers is a regular weekend activity, where



Rohan is joined by other nippers to participate in kayaking, water activities and one-on-one support that sees Rohan confidently and safely swim into deep waters. In the past Rohan also attended his local Riding for the Disabled centre, an activity that Justin feels is very beneficial for children and amputees because it “not only teaches children responsibility and commitment to an animal, but is also good for building core strength and improving balance”. Rohan also uses a hand-cycle to ride and is learning the cello this year.

Rohan attended the 2015 Össur Mobility Clinic in Brisbane, developing skills and confidence that have contributed to improvement in his overall mobility and confidence. “The Mobility Clinic allowed us to meet some amazing adult amputees, parents, children with limb differences and allied health practitioners that we could really connect with,” Justin shared. Rohan and Justin are pleased that even more amputees and children with limb difference to will be able to partake in the Sydney Össur Mobility Clinic this year.

One of Rohan’s most remarkable life experiences was being invited to a local meeting of *Mates 4 Mates*, an organisation that supports current and ex-serving Australian Defence Force members (and their families) who have physical or psychological wounds, injuries or illnesses as a result of their service. Rohan was invited as an ‘honorary ambassador’ to meet group members. Rohan started chatting with group members, showed off his prostheses and asked to try on prosthetic legs being worn by muscular and much taller members. Justin recalled that “one ex-serviceman, who was struggling with adapting to life as an amputee, spoke to me afterwards and told me that meeting Rohan significantly helped him to move forward emotionally. This man saw

confidence in Rohan that made him think that he could process what he had been through and accept life as an amputee. I was honoured that Rohan’s attitude made a difference in the life of this man who gave of himself to our country”.

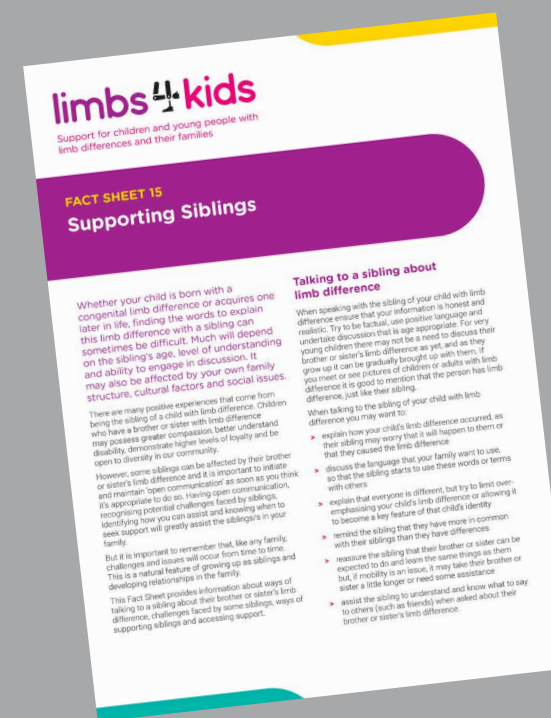
When asked about his limb differences by adults and other children, Rohan explains it in a simple, accurate and forthright manner – “The doctor cut off my leg and foot because I didn’t have all my bones, and now I have new legs”. Justin has worked with Rohan to ensure that he feels confident responding to questions, and if further information is required he is there to step in and provide more details. “I appreciate honesty and am pleased when people ask questions, as it is an opportunity to explain Rohan’s limb differences and reduce stigma in the community. Many people have never met an amputee or a child like Rohan, so their questions and desire to learn more is something I really appreciate. In the same way, if people are narrow-minded or make inappropriate statements about Rohan we are quick to inform these people because you never know if it is just a lack of knowledge or that something negative, completely unrelated to Rohan, is going wrong in that person’s life,” Justin emphasised.

Justin, who has worked professionally in the disability sector for over 20 years, is a firm believer in self-advocacy and encourages other parents to “never be afraid to ask questions, seek different professional opinions and speak to others”. Justin feels that this approach applies to support for any children, but is particularly important when it comes to achieving the best outcomes for children with limb differences. Justin also feels that the Limbs 4 Kids Facebook Group is a great way of meeting other families and gaining insight and new strategies from other parents. “I like being able to share

my experience and knowledge with other parents, while at other times I use it to gather practical tips and strategies posted by other parents – it’s a two-directional relationship that you can tap into any time of the day or night,” Justin said.

Justin hopes that ‘meeting’ Rohan via this article will assist other parents already on or just entering the world of childhood limb difference will assist them. He also wanted readers to know that Rohan and Neil would “like to say hello” to everyone out there.

Limbs 4 Life thanks Justin for taking the time to be interviewed and allowing Rohan and his family’s story to be profiled. We wish Rohan and Neil all the best with their many activities, and look forward to hearing more about their budding interests in construction and reptile care over the coming years!



Limbs 4 Life Fact Sheets

Five new Fact Sheets have just been released - ‘Grief and Loss’, ‘Body Image and Self Esteem’, ‘Supporting Siblings’, ‘Bullying’ and ‘Transport and Travel’.

There are now 17 Fact Sheets available for families to use and share with others. Fact Sheets can be downloaded at www.limbs4kids.org.au/fact-sheets or contact us for hard-copies to be posted to you.

ndis

National Disability Insurance Scheme

Are you wanting to learn more about the National Disability Insurance Scheme (NDIS) and how it can assist your child?

If so, visit the NDIS page on the Limbs 4 Kids website which has information, links and a ‘Parent Checklist’, that is limb difference specific, which can assist you when preparing for the NDIS

www.limbs4kids.org.au/funding/national-disability-insurance-scheme-ndis

Local Parent Networks



Limbs 4 Life is keen to support parents who would like to establish a Local Parent Network in their community. Parent Networks provide an opportunity to families, children with limb differences and their siblings to meet and for friendships to be forged.

Meetings might take place in local play centres, parks or community centres. Limbs 4 Life can assist with establishing a group, provide small funding to get the group ‘off the ground’ and promote groups with Limbs 4 Kids families.

If you are interested get in touch with Fiona on 1300 782 231 or fiona@limbs4life.org.au



Kate's story

We have recently welcomed to the world, our precious little Izabella. She is our second child and is very much loved after two previous losses. We lost a little girl at 19 weeks last year due to Trisomy 15, so when we found out that there were abnormalities at our 20 week scan this pregnancy, we were devastated.

Thankfully, due to our history, we were seen by a specialist straight away and were reassured that it appeared to be a developmental abnormality, rather than another chromosomal condition. Any news after that was actually a relief.

Obviously everyone wants a baby that is healthy, with 10 little fingers and 10 little toes, but knowing that our little girl would have some

physical differences, actually seemed like good news, as she would be alive! We were told that her left arm had not grown past her wrist, but we wouldn't know any more than that until she was born. Being a fairly proactive person, I requested a referral to the Limb Deficiency (I really don't like that word!) Clinic at the children's hospital and also got in touch with Limbs4Kids. I was blown away at how much support there is available for families like us and it really put our minds at ease, knowing we could connect with other families and have professional support so easily accessible.

During our pregnancy, we only told family and friends who have a regular presence in our life, as we didn't know whether there would be any

other issues discovered after birth. Initially we weren't telling people the gender of our baby, but it felt strange calling her 'it' and 'the baby'. We were really clear that we wanted her to be welcomed into a loving and accepting community and having an identity before she got here, was important. In hindsight – it would always have been that way anyway and people's reactions have been nothing but positive and supportive.

The most challenging conversations were with our two year old. We wanted her to know before her sister was born, so that it wasn't a shock for her. Again, in hindsight, we made much more of this than it needed to be. Our daughter asked one question at the hospital about her baby sister's hand and has never mentioned it since. It has surprised me at how accepting the kids have been. It is usually adults that ask questions and offer (often unsolicited) advice.

My mother bought a doll and removed its left hand. This gave us a talking point for our daughter, but it was really just an abstract concept for her. Her sister arrived two weeks after her due date, so I think she was beginning to wonder if we were actually even telling the truth about this mythical baby! At our first hospital appointment after Izabella was born, they gave us a doll with an arm that comes off. We have decided to keep this for Izabella when she is old enough, as her sister is doing just fine on the understanding and acceptance front!

We have discussed and requested that people use words such as 'different ability' rather than disability and 'limb difference' rather than limb deficiency. As she is still so little this hasn't really come up yet, but it will be good to have consistency as she starts to talk about it and understand it herself.

One of the biggest considerations for us was what (if anything) to

share on social media. I have a social media company, so I know the amazing benefits, but also the shadow side of social media. I was quite concerned about creating a digital footprint for our little girl that might limit her opportunities in the future. There were also many connections on Facebook that we hadn't told yet, because we hadn't seen them. Initially every photo we shared just didn't show her left hand. That started to feel weird. I definitely don't want Izzy growing up feeling like it was something we hid or were embarrassed by.

So after much discussion and asking for people's advice, opinions and experiences, through the Limbs4Kids Facebook page, we decided to do a post that just explained her little hand and since then have not worried whether photos do or do not include her hand. All of our connections are people we are related to or know well and we have security settings fairly tight.

We may change how we approach this later on, however someone in the Limbs4Kids group said something that really resonated and I can see now that we made more of it than it needed to be. Jana said "She will feel about her difference how you react to it and how you respond to others reacting to it ... the less you make her difference an issue, the stronger kid you're going to raise."

The great news is that although her left arm is shorter than her right and her muscles are a little under developed, she does have a wrist joint and a small pad like the palm part of her hand. So the likelihood is that she will only need a prosthetic if there is a particular sport or musical instrument she wants to play.

She is perfect in every way and a very happy and contented little soul at just five weeks. The adventure is just beginning!

Limbs 4 Life thanks Kate for sharing her heartfelt and informative story.

Congratulations to Kate and her family on the arrival of little Izabella!

The Limbs 4 Kids program is supported by a number of wonderful Parent Peer Support Volunteers who give of their time to speak to other families of children with limb difference seeking the support of 'someone who has been there before'. In this edition we are profiling some of our trained Peer Support Volunteers, and will continue to profile others in future editions of Thrive.

All of our Peer Support Volunteers go through an application process, training and are police checked. Our volunteers include parents of children with limb difference and adults who grew up with limb difference themselves. Most importantly each of our volunteers are keen to 'give back' to the community and support other families. Enjoy 'meeting' some of our wonderful volunteers...

Meet some of our Peer Support Volunteers

My name is Allison.



My son Alexander was born with bi-lateral fibula hemimelia and a small hand difference. From birth to three and a half years Alex underwent five surgeries on his hand and two Syme's amputations. I know how hard it was to not have people to talk to before he was born as it's not a common condition. I just want to be able to support other parents with young children or during pregnancy who are faced with all the "what ifs?" that come with having a child with a limb difference. Most importantly Alex is an outgoing five year old that parents can meet, talk to and see that he is no different to other children and doesn't miss out on

anything. Between us I believe we are a strong team to help parents and kids overcome some of those scared feelings. Alex also has a twin brother who doesn't have a limb difference, which can sometimes be hard, so I turn to others for twin advice, information about schooling or ideas to provide the best outcomes for both boys.

It is important, as parents, that we are there for each other to offer peer support on the 'down days' and the 'why me' days with someone who just gets it. It's also a chance to celebrate the milestones and achievements that our children and ourselves experience!! I am also a very open person and am happy to share my story if it will help others.

Sometimes you just need to ask questions of someone who has been there before, not a doctor or a professional, but a parent who has had similar life experiences. The information we share together through peer support helps our children. Without the support I have received I don't know where I would be and most of all Alex benefits by being part of a community that 'gets it'.

I believe that by working as a Peer Support Volunteer I can assist others and help them negotiate sometimes tough situations, and that by acting in this role I'm also aiding Alex to grow up to be a young man that also gives back to young kids. The more he sees me help and the more I include him as he grows up he will understand that assisting others is just as important as being free to ask for help on days he may need it. I want to offer my support to others, share Alex's story, and talk about how I have made it through the last five years. The one thing we can all relate to is that sometimes we just need someone to talk to and, to me, having a child with a limb difference means we are just one big family!

My name is Ben.



I decided to become a Peer Support Volunteer so that I can share my experiences of being born with a congenital difference and thriving through to be the lucky person I am today. The role allows me to let people know just how good things will be, and to ensure they remain positive and share as much information as I can about the network these people have at their disposal to help them through any tough times.

I feel that by providing peer support I can assist them to know that they have someone that can directly relate

to their child's limb difference and that they have someone they can refer to. If they have questions or just want a chat or a laugh or a visit, this can really make a big difference sometimes to someone's ongoing treatment and processes.

As a Peer Support Volunteer I enjoy seeing people relieved that a lot more information and people are at their disposal. Advising parents, relatives or friends that there is a very large network out there that they can refer to and also the endless possibilities that can be achieved is the benefit of peer support!

My name is Holly.



Not long after my amputation, at age 29 after living with a limb difference since childhood, I decided to get involved in the limb different community. I joined to find out more about living with a limb difference, later on it also became an opportunity to share the 1-UP one hand hair ties I make with other limb different people.

At the time I was living in the United Kingdom and joined the Reach Charity and the Limbless Association. On my return to Australia I became aware of Limbs 4 Life and its great work across all of Australia.

While being interviewed for the Thrive Summer 2015 edition, about my experiences with the Disabled

Surfing Association, I heard about the Limbs 4 Kids peer support training and signed up for the next session. I thought it would be a great opportunity to give back and be of service to kids, parents, carers or medical professionals that have questions about being limb different or are looking for help to adapt.

I think I have continued to be involved in limb different groups because I know the value of being able to speak to others who had already been through a similar experience. After my amputation I got in contact with a childhood friend who had gone through amputation at 18. After limb loss you realise that there is more than just having to adjust to physical changes; talking to my friend helped with my mental recovery.

By being a Peer Support Volunteer with the Limbs 4 Kids community I look forward to talking to people and sharing my experience. I hope that after speaking with me they take away a pinch of courage, a sprinkle of creativity and a chunk of self-belief that will inspire and empower them to take the next step in their journey.

My name is Kate.



I decided to become a Peer Support Volunteer because my son has an upper limb difference following from an amputation. He's 4 years old now and I have recent experience with those scary, and difficult

development stages of crawling, learning to walk, self-feeding etc. Before all of that you wonder, as a parent, how your child will cope, handle and adapt to all manner of things. If I can support another family in any way, I'd like to offer that.

The most rewarding part of the role as a volunteer is seeing what these kids can accomplish but also helping other family members get the right results too. I think peer support is very valuable for others. Emotionally it can be a minefield! Sometimes just another person who 'gets it' can help minimise concerns/fears and maximise enjoyment and outcomes.

As a Peer Support Volunteer I'd like to be able to give something back for all of the amazing support and encouragement we have received so far on our journey. Also, we have a lot ahead of us and we'll be seeking more support as our son progresses, so I feel being part of this community is a great starting point.

My name is Patricia.



I became a Peer Support Volunteer because I wanted to ensure that other parents of children born with a limb difference, especially lower limb difference, had as much information as possible to help alleviate any fears they may have about how they and their child would manage a limb difference as there was little or no information or support available to us when our daughter was born almost

18 years ago. Our daughter was born with Fibular Hemimelia, had a Syme's amputation at 17 months and now is hoping to qualify for the 2016 Paralympics in Rio in the long jump.

I believe the Peer Support Volunteer role is valuable because receiving first-hand knowledge and hearing the experiences of families who have travelled down the same road often makes new families more at ease with the journey ahead for them and their child.

I think providing peer support can assist other families, as there are so many questions they and their wider support network have, by being able to reassure them that their beautiful child can and will grow up to fulfil their life's potential.

By being a Peer Support Volunteer I have already made contact with some wonderful and amazing families whose children have been born with or have acquired a lower limb difference. The feeling of being able to chat, answer questions, talk about our life's journey as parents of a child with a lower limb difference, and seeing and hearing the relief on their face and in their voices when they realise everything will be ok, is a wonderful feeling. Also, connecting with the very special people who run organisations like Limbs 4 Life (Limbs 4 Kids).

My name is Sara.



Being an amputee myself, born with a congenital deficiency and missing both of my lower limbs, I am aware of the issues that kids and family members may face growing up. I hope to use my experience to help others in similar situations overcome challenges. And of course to learn from being a Peer Support Volunteer as well, as I am sure everyone I meet will be inspirational.

Being a Peer Support Volunteer means I will be in a position to answer questions (to the best of my knowledge) using my experiences, and help others by just listening.

I feel that peer support is really valuable. Sometimes all one needs is to relate to people that have been in similar situations - to understand that there really are NO limits for an amputee and determination is key.

As a Peer Support Volunteer I hope to be able to help children with limb differences, their family and friends by sharing my experiences. I also hope to learn from being a Volunteer with Limbs 4 Life.

My name is Renée.



Finding out our unborn son would be born physically different to other children was quite a confusing and isolating experience. No one can really understand it quite like someone who has been through it themselves. As a Peer Support Volunteer I would be very thankful to

be able to help someone through this challenging time in their lives.

Peer support is incredibly valuable. Whilst friends and family will support you in the best way they can, emotional and practical support from someone who has experienced similar concerns and fears is priceless. Shared experience is one of the most meaningful connections we can have with each other.

Providing peer support and being in touch with someone who can help you find information and resources means you are not alone. The journey of living with a limb difference is a lifelong one and the support needed is ongoing, not just at the beginning of your journey. Having access to that kind of personalised support can drastically reduce anxiety and helps to build confidence.

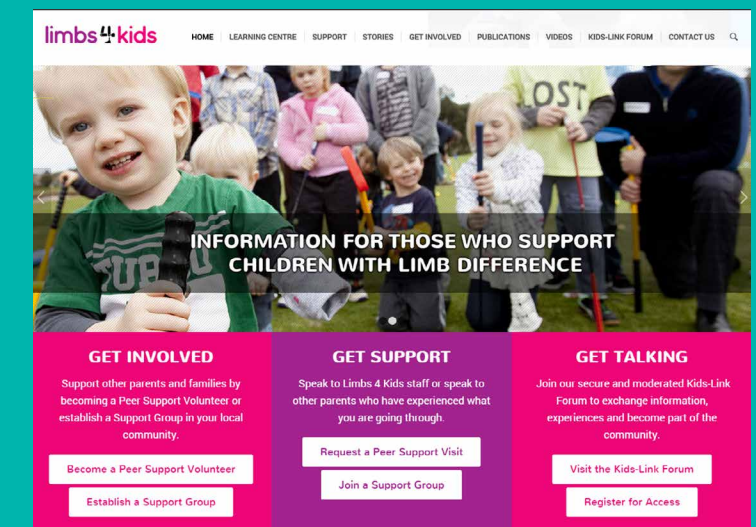
As a Peer Support Volunteer I hope to be able to empower myself and others through making someone's journey a little easier. I also hope to learn new information and share meaningful experiences with others. Thank you Limbs 4 Life for the opportunity!

Webinar-based training of Parent Peer Support Volunteers is held regularly. If it something that interests you please contact Fiona by emailing fiona@limbs4life.org.au or call 1300 782 231.

Limbs 4 Kids Website

The Limbs 4 Kids website offers a wide range of information, personal stories, news items, videos and publications that may be of interest to families, healthcare professionals and community members. The 'Learning Centre' section is a library housing information about limb difference, your child, family and friends, education and employment, funding, health and wellbeing, and advocacy and inclusion.

www.limbs4kids.org.au



Limbs 4 Kids Facebook Group

Did you know that Limbs 4 Kids has its own closed and moderated Facebook Group? This group is made up of parents and family members of children with limb difference, young people, adults who grew up with a childhood limb difference and healthcare professionals. It is a safe space to connect with others, share ideas, view articles and stay in touch.

Limbs 4 Kids Facebook Group - www.facebook.com/groups/349205931872070

Össur Mobility Clinic

Össur presents a 2-day Mobility Clinic which is designed for amputees of all ages and activity levels for a truly unique experience where they improve their overall mobility while connecting with other amputees.

The Clinic is being held in Sydney on the **21st and 22nd of April** at Newington College (Stanmore). This is the second year of the Mobility Clinic and Limbs 4 Life is a proud partner of this event.

For more information, read about the previous Össur Mobility Clinic and to register visit - www.ossur.com.au/ossur-mobility-clinic

MOBILITY CLINIC

21 & 22 APRIL 2016,
NEWINGTON COLLEGE
STANMORE NSW

FOR EVENT DETAILS
& REGISTRATION

ossur.com.au/ossur-mobility-clinic

APRIL
21-22
SYDNEY, NSW

MOBILITY CLINIC

Össur presents a 2-day Mobility Clinic designed for amputees of all ages and activity levels for a truly unique experience where they improve their overall mobility while connecting with other amputees.

JOIN US AND LEARN:

- Techniques to maximise prosthetic capabilities
- Leg-over-leg running mechanics
- Proper methods for improving speed and balance
- How to move in multiple directions for a variety of recreational activities
- Training routines and sport-specific exercises

LIMITED PLACES AVAILABLE, GET IN QUICK!

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A Score! for active kids

Children don't come with a training manual; parents are expected to figure things out as they go along, and with a world of information at your fingertips, "Google it" has become the catch-cry for many.

But finding the right information it isn't as straightforward as it seems. For parents whose child has disability, the challenge is even greater and Google doesn't always solve the problem.

That's where Score! comes in. Developed by Victorian peak body Disability Sport & Recreation, in partnership with the nib foundation, this free, interactive online directory helps parents find sports and activities that meet their child's interests and abilities. Manager Community and Member Services, Tim Nield, said the organisation's goal was to help as many people with disability find a sport or recreational activity they could play for life.

"We know it's absolutely vital that people with disability do some form of physical activity. There are

mountains of research showing that exercise improves your health, reduces the long-term risk of chronic illness like diabetes and cardiac disease, and has a positive effect on a person's mental health as well.

"We want to help people develop the habit of exercise from a young age, so that every Victorian can enjoy the health benefits being active brings. "Score! is just one tool we have developed so parents have the knowledge they need to give their child those opportunities," Tim said.

How does Score! work?

Anyone wanting to use Score! needs to register; the information you provide allows you to filter your search.

Once you are registered and have logged in, you can look for events in your local area, venues that are accessible, or programs that suit your abilities.

Everything on Score! can be rated, so once you have found an activity you would like to try, you can read what others have said about it. Score! is a fully moderated site, so it is a bully-free zone; insults, epithets and derogatory language are not allowed.

Each activity, venue or event listing has contact details or websites listed so you can find out more information before you head off, and the map function can help you visualise where everything is in relation to your home.

Importantly, Score! is completely free, and if you can't find something your child wants to do on Score!, the team at Disability Sport & Recreation are more than happy to research opportunities for you.

Call them on **1800 23 46 48** or visit www.dsr.org.au

SCORE!

Kylie grew up with 'No Limb-its'

Kylie Franson is a very busy woman who holds many varied and important roles. Kylie is the mother of two young boys, Jacob and Mitchell, and is married to Kyle. Kylie also runs her own business 'No Limb-its' and is the founder of the South Australian charity 'Kidney Kids SA'.

Kylie, who is 33 years old, was also born with a congenital upper limb difference. "I was born missing my left forearm, and to this date I don't know what caused my difference," Kylie explained.

Reflecting on her childhood, Kylie feels that her limb difference didn't present many difficulties while growing up. Although in adulthood Kylie has had some corrective surgery, to improve elbow joint movement, and thinks that not using a functional prosthetic arm may have contributed to some more recent physical difficulties.

"The prosthetics available in the 1980s were not as advanced as they are today, so I was initially fitted with a heavy arm with a 'metal hook' hand when I was 10 months old. I never really took to it, had falls and consequently I would rarely wear it. If I was a child today, with the better options now available, I think I would have persevered with a prosthetic arm," Kylie said. At the age of 10 Kylie was fitted with a cosmetic arm (cosmesis), with no functionality and a primary purpose of 'filling

out' clothing. Kylie didn't wear her cosmetic arm for very long as, like the functional prosthetic arm, she found it "got in the way of things and

I operated better without it". As an adult, however, Kylie has started to experience some back issues that she attributes to not wearing a prosthetic arm. "I overused my residual limb and have put excessive force on parts of my back because of not wearing a prosthesis. As a result, I can't perform some everyday tasks, such as vacuuming, without pain. I wish that I had persevered with a prosthesis when I was a child, or that today's ones were available then, as I've not been able to adjust and wear one as an adult," Kylie explained.

Born in Adelaide, Kylie moved to the small country town Wallaroo when she was a child and stayed there until recent years. Prior to moving to Wallaroo, in Grade 6, Kylie's Mum contacted the school so that staff and students could be prepared about her limb difference. "My Mum did the right thing letting the school know that I was missing my arm, but as no one had met or encountered an amputee previously they didn't know what to expect. Maybe they thought a green monster was coming to school, so it came as a shock when I arrived and the students just started saying 'nice to meet you, but you're normal and we thought you'd be different',"



Kylie recounted. Naturally fellow students asked questions about why Kylie's arm was missing, to which she responded "I was born this way" and with curiosity sated the matter was no longer discussed. Kylie was, well, just 'the new kid at school'.

Over the course of her childhood Kylie did come across a handful of negative comments regarding her limb difference. "In primary school I wanted to do calisthenics and when I joined the group we all had to get in a circle and join hands. Well, the poor girl next to me freaked out that she would have to hold hands with someone without one. While it was a little distressing at the time it was one of those experiences that helped me to build resilience, so I treat it as a positive experience," Kylie said.

Kylie recognises that "you can't stop the way people feel but you can change the way you respond to people who are inappropriate, and it's useful to use humour and information as influential tools when it occurs".

Kylie's family didn't treat her any differently to her younger brother and supported her to be "open, honest and assertive" and she was reluctant to let her parents interfere when she encountered any trying situations. Kylie feels that this played a significant role in her building personal resilience and self-confidence.

Kylie's open approach to discussing her limb difference, along with a desire to positively educate others, led to her conducting presentations at her sons' primary school in recent years. "I realised that teachers and students were wondering why I had a missing arm and what it's like to live life without use of two arms, so I asked the school whether it would be useful to make student presentations," Kylie said. Over the

last few years Kylie has conducted many information sessions to students. Kylie outlined that "it has helped my sons who have not had to repeat the same story about their Mum each year, and it has also allowed me to educate students about limb difference, as well as have great fun talking to curious children".

After receiving positive feedback from educators and a push from them to conduct similar presentations in other schools, Kylie developed her business 'No Limb-its' during 2015. Kylie has structured her presentations, with the assistance of her step-mother and best friend who are both teachers, so that they align with the National Curriculum for Education requirements in 'health and physical education' and 'civics and citizenship' at both primary and secondary levels. Kylie uses these presentations to share her life experiences, brings props (upper and lower-limb prosthetics and adapted assistive devices), and discusses what it's like to live with a physical disability. More importantly, Kylie's key focus and message is that being a person with a limb difference presents 'No Limb-its' to her.

Kylie's presentations are age-appropriate and suited to the curriculum being studied by the students. The most frequent question posed by students is "why don't you have an arm?" For older students the response is generally a detailed explanation, along with medical information, about the common causes of limb differences. For younger students the most appropriate and acceptable answer is generally "I came out of my Mum's tummy with only one arm".

Many students, and particularly those in secondary school, "want to talk about my personal experiences and disability more generally as it

is something they are becoming more aware of and relates to their studies". Consequently Kylie has developed a program that incorporates information about health and wellbeing, ethics, equality, respect, fairness and establishing positive social skills when supporting members of the community who live with disability.

Kylie has a growing bank of hilarious questions and responses to her presentations, particularly during encounters with young children.

One eight-year old girl asked a question both funny and borne out of serious concern. "At the conclusion of my talk, this little girl asked me whether my Mum had been to a doctor recently to have an x-ray to make sure that my arm wasn't still stuck in her tummy. She was genuinely worried about my Mum, but I was able to allay her fears by further explaining that my arm didn't grow so it hadn't 'been left behind' inside my Mum," Kylie laughed.

Another student approached Kylie at the end of the school day, presenting her with a cut-to-size 'hand' made out of blue paper. Kylie recalled that this girl said "I know you have that arm thing going on - so here's a hand for you, I hope it helps". Kylie is amazed by the honesty, empathy and understanding of all the students she has encountered, and hopes that they go home to share their learnings and build positive awareness of limb difference and disability with their families.

Kylie's experience with disability extends to her immediate family also; with her oldest son Mitchell living with Autism and younger son Jacob living with kidney disease.

Jacob was born with a chronic kidney disease which requires ongoing assessment and treatments. This experience

and meeting families in a similar situation led Kylie to establish the 'Kidney Kids SA' charity in 2012. "During Jacob's early life we were living in regional South Australia and travelling over 300kms roundtrip on a regular basis to attend the paediatric hospital renal clinic in Adelaide. I saw first-hand how hard it is for rural families who sometimes have to leave home and spend weeks or months at a time in Adelaide. It is a draining and expensive experience for these families, with little financial and other assistance available to them," Kylie explained.

Kylie, along with some friends, decided that something could be done to support families in these circumstances. "We launched Kidney Kids SA so that families in South Australia could apply for financial assistance. We are a volunteer-only run organisation that fundraises and attracts sponsorship to support the families of children with kidney disease," Kylie stated.

Kidney Kids provides families with travel assistance, accommodation funding, hospital meal vouchers and other support to make their stay in hospital more comfortable and less stressful. "I can't thank our Committee Members, volunteers and sponsors enough for making Kidney Kids a reality. It's hard enough having a sick child, but when you also have financial concerns the situation can be overwhelming. So, it's great we can play a small part in making things a little easier for Kidney Kids families," Kylie emphasised.

Kylie has recently begun using the National Disability Insurance Scheme (NDIS) to obtain support for Mitchell. "As a new program it hasn't been without some issues, but it's improving as the NDIS becomes more settled and stabilised," Kylie said. "The biggest learning I have had, and would

say to any parent, is make sure you are prepared to advocate for your child and be across what his or her current and future needs might be. I would also suggest that you use the skills of allied healthcare professionals that you respect. These professionals will be of enormous assistance when it comes to planning, advocacy, helping you to navigate the system and completing the reports that NDIS require," Kylie highlighted. Having looked over the 'Limbs 4 Kids NDIS Parent Checklist', Kylie thinks this will be a valuable tool for parents of children with limb difference preparing to enter into the scheme.

Kylie is a keen advocate for Limbs 4 Life and our Limbs 4 Kids program, and has been formally trained as a Peer Support Volunteer. "Until I came across Limbs 4 Life many years ago, I didn't know of any specific support for amputees in Australia. But since then I feel like I have joined a community where people can connect and share experiences," Kylie stated.

"I'm also really passionate about the Limbs 4 Kids program, and want to be able to support families to feel less worried about their child's future and show them a 'normal, everyday Mum' who has had a limb difference since birth," Kylie expressed.

In drawing upon her personal and professional experiences, Kylie wanted to share some thoughts and tips with readers. Kylie wanted readers to remember that children are curious, may not have met someone with limb difference, and thus sometimes say inappropriate things. Kylie highlighted that "generally this is because of a lack of understanding, rather than a desire to hurt your child's feelings".

Kylie also suggested that it is a good idea for children to prepare their own

limb difference story, but ensure that their other interests or skills form part of that narrative "as that way their limb difference doesn't become the key focus of their identity".

Limbs 4 Life thanks Kylie for taking the time to be interviewed and sharing her story in Thrive.

• If you are interested in learning more about 'No Limb-its' visit - www.nolimb-its.com

• If you are interested in Kidney Kids SA, need support or would like to donate visit - www.facebook.com/KidneyKidsSAInc

Christmas Parties for Special Children

During November and December last year, 143 Limbs 4 Kids children, siblings and families attended 'Christmas Parties for Special Children' in Brisbane, Canberra, Melbourne, Perth and Sydney. This was the first year of Limbs 4 Life being invited to take part and was a wonderful chance for families to enjoy a fun day out.

Paul Munro, the Brisbane General Manager, outlined that the parties have a lengthy history with clear objectives. "The Parties were born out of a request from The United Nations, in 1979, to help celebrate the International Year of the Child. Since that time they have given children, who may otherwise have missed out on the round of Christmas activities, the chance to gather and share the magic of the Festive Season with a group larger than their immediate circle of family and carers," Paul explained. "Our goal is gather children who are sick, seriously ill, physically or intellectually challenged, or disadvantaged through circumstance and help them forget their troubles for a few hours. We want to help children to see that they are not alone and help them to just be children at an exceptional time of the year," Paul enthused.

The 'party' went into a hiatus for a few years and was then slowly established around Australia in capital cities, regional centres and across New Zealand; with both Brisbane and Melbourne established in 1995.

Lynne Cavanagh, the Melbourne Party Manager, said that just about everyone has a soft spot for kids, but when a child has specific needs, struggles on a daily basis and faces those challenges with such bravery your heart melts even more. Our events are not only for those children but it is for their important siblings. Similarly, it also for parents to spend a great day with their children and meet other families who might share similar issues".

Through the generosity of sponsors, children were afforded the opportunity to play on a range of rides, meet superheroes travelling around the grounds, dance to DJs, meet an array of animals in the petting farm, have faces painted and, of course, meet Santa who came laden with gifts!

One parent who attended the Melbourne Party enthused that "it was a fabulous day for our son. He kept saying it was the best party ever. He did so many different things and he just loved his present and the soft toy! He said he is a very lucky boy".

Another parent who attended the Melbourne Party shared that "it was a great function and we feel very lucky for the kids to be invited to this event!!" while another said that "we couldn't get the kids off the rides, it was a fantastic day".

The organisation was pleased to have members of the Limbs 4 Kids family take part in 2015. "As we find

out about groups, organisations and individuals who would benefit from attending the event we gladly extend an invitation for them to participate. We became aware of Limbs 4 Kids through Zaharoula Harris, who also volunteered her time photographing the Melbourne event," Lynne explained.

The parties are funded through significant contributions from corporate sponsors and volunteers who believe in the value of accessible parties for children.

Of the Canberra Christmas Party, one Limbs 4 Kids parent who attended said that "it was an amazing event and so well organised, the generosity of the sponsors and everyone who gave up their time to be there was incredible ... It was lovely that both boys could attend and a welcome break from the intensity of hospital visits etc".

Limbs 4 Life are extremely grateful to the organisers, their sponsors and all the volunteers who made the parties so special, and we look forward to offering the chance to take part again in 2016.

For more information about the Christmas Parties for Special Children visit -
www.christmasparty.com.au
www.sccpau.com.au





Play abounds in the ePlayground

If you are looking for a free, creative and imaginative online computer game for your children to play then you may want to visit the 'All Abilities ePlayground'. Developed by Sonokids Australia, this game is an initiative of the Gold Coast City Council and supported by the Queensland Department of Communities (Disability Services).

The ePlayground features entertaining actions and four games - IbisBuster, Memory, TrixMix and Roo Hill Thrill. The ePlayground can be played by children using one or two hands via use of a mouse, keyboard, touchscreen, trackball or joystick. If a child is unable to use both hands, he or she can equally participate in the ePlayground by way of switch access (which can be controlled using their foot, elbow or head) or Puff2Play (allowing a child to blow air into a normal computer microphone which imitates the use of mouse click).

The ePlayground is also self-voicing, as children are accompanied by their online game mate 'BuddyFly' who talks them through game instructions and provides tips along the way.

IbisBuster is an adventure game that also comes with a great story, whereby children collect different 'good things' and 'shoo' Iris the ibis who tries to steal them. Memory is a puzzle-type game with sounds and images where children are encouraged to find the matching pairs. Trix Mix is a creative game with music and animations, allowing children to record musical sounds to a set beat and then re-play their own musical remix. Roo Hill Thrill is

an action game in a fantasy setting, where the gamer plays the role of a kangaroo and must surf over green hills and stay clear of beachballs.

The ePlayground offers an all-inclusive and safe play environment that stimulates imagination, skill development, independent play and cognitive learning. It also allows for children, their siblings and friends to play and interact together.

The ePlayground was developed with the needs of all children in mind, and pleasingly the standard or adapted versions of the game can be enjoyed by children with varied abilities. For all of these reasons ePlayground was a very worthy 2012 winner of the 'Internet for Good Gold Standard Award' (Asia Pacific).

While the ePlayground is an online game, it is actually the 17th official playground of the 'Queensland All Abilities Playground Project'. The other 16 playgrounds are 'real' outdoor playparks located across Queensland; with the ePlayground an online representation of the inclusive play that children can experience in such playparks.

So, if your children are looking to play some new games why not get online and try out the All Abilities ePlayground - www.allabilitiesplayground.net.au



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