Thrive

NEWS FROM LIMBS 4 KIDS

LIMBS 4 KIDS WEBSITE GOES LIVE!

MEET THE VIVACIOUS AND DETERMINED GEMMA

THE NDIS AND YOU, RESEARCH AND MUCH MORE...

WINTER 2015 EDITION

Limbs 4 Kids Website Launched

Limbs 4 Life is proud to announce the launch of our new Limbs 4 Kids website:

www.limbs4kids.org.au

This website is the first of its kind in Australia and made possible through generous support from nib foundation. This website, which complements the Limbs 4 Life website, has been developed to support children with limb difference as well as all those who support them.

The website has a number of key goals: support children, young people and families; support medical, allied health, education and community workers who support children with limb difference; and, inform the community about congenital and acquired limb difference.

The Limbs 4 Kids website has a number of key features:

Learning Centre. This online library provides information relating to limb difference and is of particular benefit to young people, parents families, healthcare providers, educators and community workers. The Learning Centre covers key physical, social and education milestones and issues experienced by children and their families.

Kids-Link. This online forum is a safe and moderated space where young people with limb difference (16+), parents and extended family members can connect with one another and discuss issues that matter to them.

Stories. A mix of written and video stories from young people, parents, health care providers and adults who were themselves a child with limb difference.

Calendar. The calendar provides information about upcoming events and activities offered by Limbs 4 Life, Limbs 4 Kids and other external organisations.

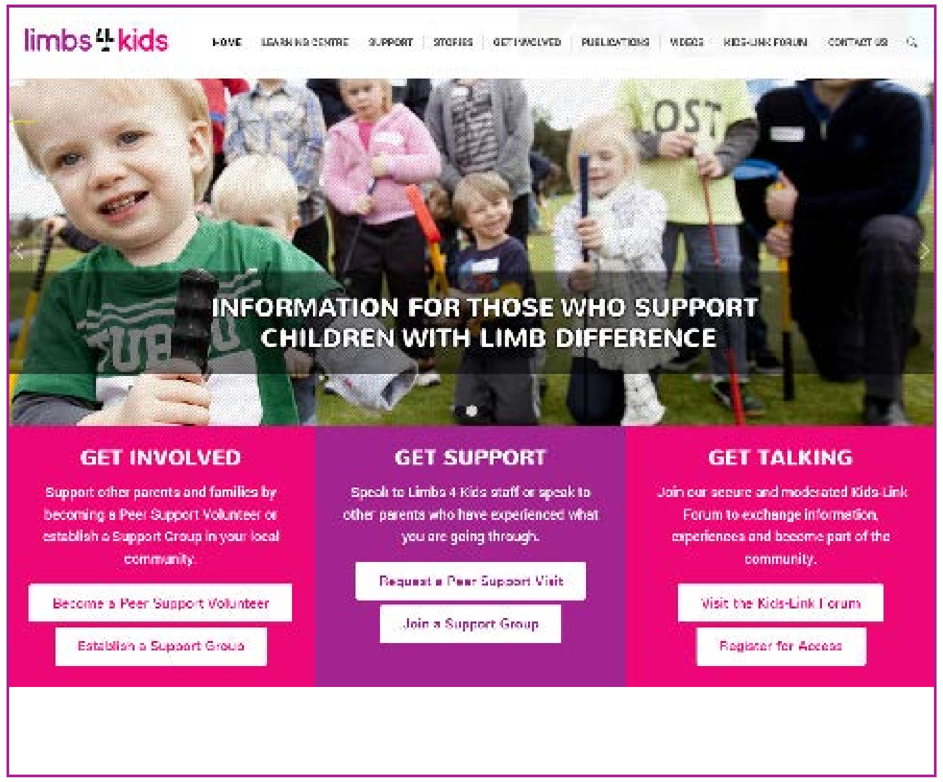
Publications. This section is a repository of resources and publications, such as Fact Sheets, that can be downloaded and used by visitors.

Current news. Information and news from Limbs 4 Kids and external organisations.

Peer support. Information about how to request peer support, apply to become a Peer Support Volunteer or set up a Local Support Group.

We are truly excited at the possibilities presented by our new website to expand our reach and influence across Australia. We want this website to not only be a resource for children and families but one that assists all members of the community to better understand limb difference.

We want our community to use this website and welcome any feedback, suggestions and ideas you have that will make it the best it can be.



Support other parents and families by becoming a Peer Support Volunteer or establish a Support Group in your local community.

Speak to Limbs 4 Kids staff or speak to other parents who have experienced what you are going through.

Join our secure and moderated Kids-Link Forum to exchange information, experiences and become part of the community.

Gemma's Story

Five-year-old Mia stood at the gate to the playground. She wanted to see her friend, but couldn't open the gate.

"Can you get Gemma for me please," she shouted to one of the teachers in the playground. The teacher was new. "I'm sorry, I don't know which one is Gemma." "Oh everyone knows Gemma," replied Mia. "She's the one with blonde hair."

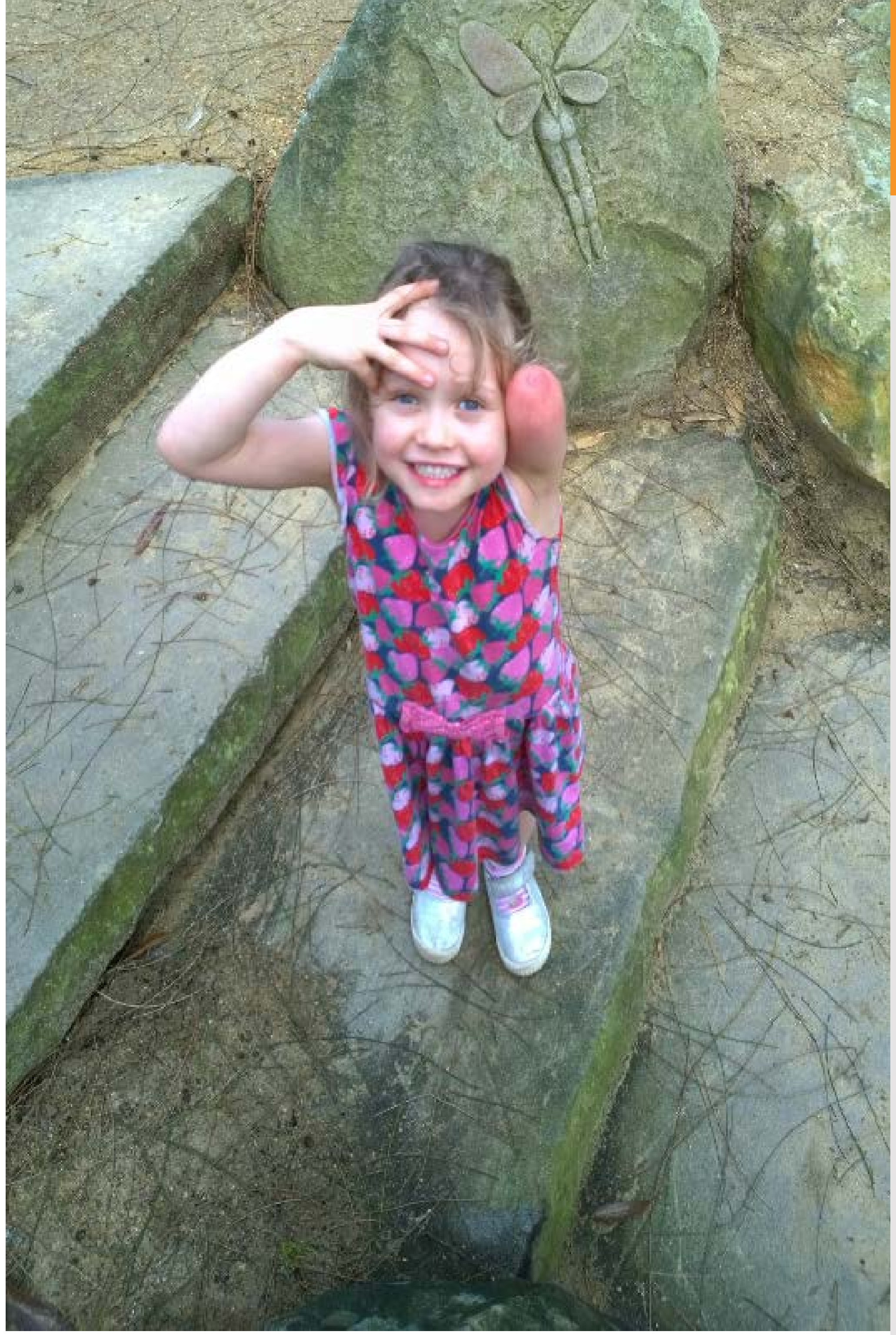
Mia could have used any number of adjectives for Gemma. Having blonde hair is just one, others would include tall, fast, sharp, talkative, blue-eyed, caring, determined, vivacious (perhaps a stretch for a five-year-old to use!), a climber, playful, inventive, imaginative, skilful, dexterous (maybe, see 'vivacious') or wilful.

And this sums up Gemma's interactions with her friends. They see a tall five-year-old girl with blue eyes and blonde hair, who likes to have fun playing games, running around and using her imagination. Gemma responds in kind. She loves playing with her friends, but is also able to entertain herself for hours with her toys or drawing or making things with whatever's lying around. Her determination is legendary at her daycare centre. Nothing fazes Gemma, and she will stick at a task until it is done, only sometimes asking for help. You can offer to help Gemma, but never presume to give it until it is asked for!

In the playground, with other children who don't know her, Gemma can be an object of fascination. Some children take one look, and ignore. Others know there's something different and don't know why – they're inquisitive and just want an answer. A few aren’t satisfied with that and hang around long enough for their parents to realise they’re now in the way. Gemma will provide her one answer to the obvious question, “I was born like it,” and then carry on playing.

In the playground, Gemma likes everything – swings, slides, climbing walls, up and down ladders and stairs, running around, in the cubby house. Parents will sometimes offer to help Gemma as they see a child who isn’t as able-bodied as their own. Gemma will probably tell them she doesn’t need it, and finish scaling the climbing wall up to the top of the slide before disappearing down it, and off somewhere else.
The parent might then come up to us and comment on how wonderfully able and polite Gemma is, as she would have declined the help with a “No, thanks.” They might even satisfy their own curiosity and ask what happened. They get the same answer that Gemma gave, “She was born like it,” before we’re tugged in opposite directions to watch over our respective children.

Gemma goes to school in 2016. Many of the children at her local school already know her as Zoe’s little sister. They know about Gemma and what she can do, and don’t bother either getting in the way or offering to help – they know Gemma will ask. Many there, though, don’t know Gemma, so she will go through the whole routine of meeting new people and their reactions many more times in the coming couple of years. It does seem of interest to children aged 5 to 7. Younger than that, and they just don’t notice. Older than that and they notice, but either don’t want to pry, or don’t really care.



There will be more parents that won’t be sure what Gemma can or can’t do and whether she can be invited to a particular birthday activity – Gemma will tell them, and we’ll leave it up to her to decide. We’ll help those parents, and teachers, who aren’t sure what to say or do, and we’ll make sure that Gemma gets to do what she wants. Within reason, just like any other five-year-old child.

Gemma’s Story was written by Gemma’s parents Lee and Kate

Family Networking and Information Event

Limbs 4 Life hosted its first Limbs 4 Kids event for 2015 at the Sandhurst Club in Melbourne.

Our first Limbs 4 Kids event consisted of a golf clinic for children, an information session for family members, an afternoon tea and Easter egg hunt. Despite it being a bitterly cold and rainy Melbourne afternoon the event was attended by over 50 children, young people, parents, siblings and extended family members.
A summary of key aspects of the event is outlined below.

Golf Clinic

Golf is an activity that benefits people of all ages and is a sport that promotes physical wellbeing and friendship opportunities.
This was particularly true for the children and young people who took part in Golf Clinic which was conducted by accredited Professional Golfers Association (PGA) trainers at Sandhurst Club. Under the guidance of Christian Hamilton from Sandhurst Club, Brian Hill from Golf Victoria and PGA Trainee Professional Zac Morwood the children were given an opportunity to ‘try golf’. Using specialised golf clubs and putting kits, as well as some of the latest high-speed video golf technology which records and analyses gait and swing, the children had a chance to practice target ball hitting. Held in Sandhurst Club’s PGA Centre for Learning and Performance, the children were able to practice in a training facility used by amateur and professional golfers.

All the trainers offered their time and expertise voluntarily as a means of providing the children with an extraordinary golf experience. “Golf is an excellent sport for children with limb differences as it builds confidence, enhances balance and is something that the whole family can participate in”, said Christian.

The Golf Clinic saw over 20 children with limb differences and their siblings take part and it was pleasing to see all the children have fun, learn skills and build new friendships during the activity. As one child said, “I loved playing golf and the man said I was really good at it”.

If you are interested in learning more about golf and ways your child can get involved visit the ‘My Golf’ website which provides details about this national junior introductory program to develop and promote participation in golf.

www.mygolf.org.au

Information about the National Disability Insurance Scheme (NDIS)

Catherine McAlpine and Leah van Poppel from the Australian Federation of Disability Organisations (AFDO) gave a presentation about the NDIS and what the roll out of this initiative might mean for children and young people with limb difference.

Catherine and Leah manage the new AFDO program called 'Disability Loop' which is not only assisting people to better understand the NDIS but is also providing feedback to government regarding the needs of those who will access the NDIS.

Key information provided by Catherine and Leah included:

- The NDIS is currently only available in trial sites in Australia, with the full scheme roll-out to start in July 2016. The NDIS will be completed by July 2016 in the ACT, July 2018 in NSW and SA, and July 2019 in NT, Victoria, QLD and Tasmania. No specific timelines have been provided for WA yet, which is running a parallel trial of a state designed program called My Way.
- The NDIS is designed to be a new way of better supporting persons with disability in Australia; providing people with access and control over the services, supports and equipment they need to ensure they can participate in their community, education and employment.
- Persons with a permanent disability and the need for communication, self-care, self-management or mobility support will be deemed eligible for NDIS assistance. The vast majority of children and young people with a limb difference will receive access to NDIS assistance, but it will be important for parents to talk about support needs (not just diagnosis) to ensure requirements are met.
- While some parents may not see a need for NDIS support for their child in the near future, support may be required at different times of their child's life (for example, a young person with a limb difference wanting to drive may need modifications to their vehicle or a young person may need support to access inclusive sporting/recreational activities in the community).
- Those using the NDIS will work with two types of staff members – a 'Planner' and a 'Local Area Coordinator'.
- Planners work closely with each participant to identify what current and future supports are required so that the individual can work towards their goals and aspirations in life.
- Local Area Coordinators work with individuals to ensure their needs are being met as well as work strategically with communities to identify barriers to support or gaps in services (eg. making sure the local Scout Group is comfortable to take on a child with limb difference and talking to them about any programs or grants they might need to access to support that child well).
- The NDIS is all about imagining a 'good life' and putting in place all the supports that will make a good and fulfilling life possible.
- For more information about the NDIS, to identify whether you are located in a trial site and to determine your child's eligibility visit **www.ndis.gov.au**
- The 'Disability Loop' project website provides information, tips and resources for people wanting more information about the NDIS **www.disabilityloop.org.au**

Research into the Limbs 4 Kids program

Dr Narelle Warren from Monash University presented on the independent evaluation that she and her colleague Barbara Hogarth are conducting with the parents and carers of children and young people with limb differences.

Between 2012 and 2014, Dr Warren was engaged by Limbs 4 Life to research and evaluate the Victorian-based 'Carers, Children and Youth (CC&Y) Program'. This pilot study was a pre-cursor to our Limbs 4 Kids program.

This research involved online surveys and interviews in order to both evaluate the program itself while also gathering information about the specific needs and goals of parents of children with limb difference. This research resulted in a number of recommendations, which have been incorporated into the design of the new national Limbs 4 Kids program. Key aspects of the research and resulting recommendations included:

- The CC&Y program was meeting the needs of families
- Simple online surveys and face-to-face / telephone interviews best suited parents
- Parents wanted to engage in the program in different ways and that a mix of physical and web-based modes of engagement were desired
- Parents were keen to engage in the planning and development of events
- Provide whole-of-family engagement opportunities that allow for the involvement of siblings and extended family members
- Provide safe environments for parents to share their experiences of coping
- Provide multi-age activities whereby children with limb differences can meet adults with limb differences
- A need for the program to be expanded nationally
- Evaluation should only occur once per year.

The recommendations drawn from this research greatly contributed to ongoing funding from nib foundation and have been incorporated into the design of the new national Limbs 4 Kids program. The full evaluation reports can be accessed by contacting Fiona at **fiona@limbs4life.org.au** and are also available on the Limbs 4 Kids website.

Dr Warren will be leading new research into the Limbs 4 Kids program and the needs of parents between 2015 and 2017. It is anticipated that the outcomes of this research will not only strengthen the program but also enable Limbs 4 Life to advocate on behalf of parents and children with government and policy-makers. The research will consist of online surveys (once per year) and optional interviews. As this research is independent of Limbs 4 Life, all responses will be provided to Monash University directly in order to allow for participants to be frank and anonymous.

Anyone engaging in Limbs 4 Kids activities - whether that is attending an event, engaging in online activities through the website, being part of the facebook group or reading Thrive magazine – is eligible to participate in this research.

Anyone interested in learning about or taking part in the research can speak to Dr Warren directly on 03 9903 4046 or **Narelle.Warren@monash.edu**

To access the online survey visit **https://monashmnhs.qualtrics.com/SE/?SID=SV_9RF3r5la6vo6k4t**

The Power of Networking

Geoff Adams-Spink, Chairperson of DysNet

Like almost 500 others in the UK, I am one of the lucky thalidomide survivors - lucky in the sense that the vast majority of foetuses damaged by the drug either died in the womb or just after birth.

Our story is well-known and I won't repeat it here. One of the remarkable things about thalidomide though is its ability to punch above its weight in terms of attracting the attention of the media. That remains the case today. But while we were growing up we also attracted the attention of the medical profession - specialist clinics were opened and some of us were forced to wear the rather cumbersome prosthetics of the 1960s and 70s.

As adults, the medical profession seemed quickly to lose interest but the complications of living with our impairments seemed to multiply: using our bodies to do ordinary things in extraordinary ways caused severe wear and tear on muscles and joints - in my case, a prolapsed disc when I was in my mid-thirties which made me rethink my entire approach to my disabilities.

Together with Swedish thalidomide survivors, we cooked up a plan to address the health inequalities that both sets of thalidomiders were experiencing. The solution was EDRIC (European Dysmelia Reference Information Centre) - an umbrella body not just for thalidomide but for all forms of congenital limb difference. That way, we would attract the critical mass necessary to gain the attention of policy makers. That way, peer networks could be formed for self-help. That way, the remaining specialists could be brought together in their own network which could interact with our peer network which we call DysNet.

Six years down the line and EDRIC has 31 member organisations in 20 countries, including Limbs 4 Life. DysNet is all over social media and the internet. We reckon that we represent upwards of 6,000 people living with limb difference. We're about to host a conference to bring together those living with the condition with experts in Stockholm in October this year. We're also about to launch an information portal for parents who discover that they have or are about to have a limb different child.

As the cohort of thalidomide survivors advance through middle age, it's great to be able to pass our learning onto young people with limb difference and to draw on their youthful energy and enthusiasm to carry on the good work. Together, we are stronger.

Limbs 4 Life is proud to be an international member of DysNet. To find out more about DysNet and join their network visit **www.dysnet.org**

EDRIC DysNet

The Dysmelia Network

Meet a Physiotherapist

Shail Maharaj, Queensland Paediatric Rehabilitation Service

In this edition of Thrive we conducted an interview with Shail Maharaj, a paediatric physiotherapist who works with children with limb difference at Lady Cilento Children's Hospital in Brisbane. Shail shared with us his professional story, his role in the lives of children and family, emphasised the importance of early intervention and 'whole-of-team' healthcare support, and reflected on advances in prosthetic technology.

What are your qualifications?

I completed a Bachelor of Physiotherapy with Honours in 2001. Since completing my tertiary studies I have also undertaken additional training in physiotherapy to ensure that I remain abreast of changes in the field, and in particular the paediatric physiotherapy arena.

I have also undertaken post-graduate studies in Paralympic Classification, which means I am accredited to assess and classify Paralympic athletes. Currently I classify athletes in Boccia (a wheelchair based sport) and Wheelchair 7-a-Side Football (soccer). I really enjoy being a classifier as it allows me to guide children into sports from a participation level all the way through to representing their country. I also get to meet professionals and athletes from all over the world.

Why did you choose to study physiotherapy?

To be quite honest when I finished my secondary studies I really wasn't sure what I wanted to do. I had never undertaken work experience in physiotherapy whilst I was at school, so it wasn't on my immediate post-school studies radar.

However, towards the end of my

secondary schooling I looked into physiotherapy and, after learning more about it, I though it did sound like something I might be suited to. I wasn't interested in a 'desk job' and I really enjoy talking to and helping people; so I decided I would enrol in a Bachelor of Physiotherapy. When I started the course I still wasn't completely sure if physiotherapy was for me; that was, until I completed a subject called 'Physiotherapist - Teacher of Movement'. This subject made me aware that physiotherapy is about more than just 'sports physio' but also about mentoring patients to achieve goals in many areas. After completing that subject I was hooked and knew I had chosen to enter into a profession that would be my career for life. Indeed the notion of 'Teacher of Movement' is my own professional and personal ethos now.

Why did you choose to then focus on paediatric physiotherapy?

In my final year of physiotherapy studies I was required to undertake eight placements in a variety of settings ranging from hospitals to rehabilitation facilities. I completed placements across a number of disciplines, ranging from geriatric to paediatric physiotherapy. To be honest, until I completed a placement in paediatrics I had never really considered it as an area I was interested in.

I was very fortunate to complete a placement at the Royal Children's Hospital in Brisbane (which has now merged with the other major children's hospital in Brisbane and is called The Lady Cilento Children's Hospital) and found that working with children brought me a lot of personal and professional joy. It was a joy to assist children to get better physically and help them achieve their goals (and have fun at the same time!). It was then that I decided paediatric physiotherapy was the field I wanted to pursue and I was lucky to be offered employment at the Children's Hospital once I received my degree.

What is your role in working with children and families with limb differences?

I wear a couple of hats at work. I am Clinic Coordinator and the Senior Physiotherapist in the Limb Deficiency Clinic within the Queensland Paediatric Rehabilitation Service at the hospital. I also work with children with brain injury, spinal cord injury and cerebral palsy.

As a physiotherapist I work with children and young people with limb differences, as well as their families. This happens as early as when the family first find out that they will soon be welcoming a baby with limb difference into their lives. As a team we provide education and anticipatory guidance and then see the family soon after their child is born. We then follow these families all the way through their growing years until they leave high school.

I also work with children and families pre and post a limb amputation by preparing them for upcoming surgery and initiating training soon after a child's amputation. I work with children who have a congenital or acquired limb difference to determine whether a prosthesis is suitable and, if so, assist them to learn how to use it. Overall, what we work on is shaped by what the child and family are hoping to achieve. This may be achieved through prosthetic training, aids and adaptations or simply advice. As the Coordinator of our Clinic I also undertake managerial and advocacy tasks. I coordinate the incredible team of professionals who form part of the Clinic. I also sit on some Advisory Boards, sit on the Committee of the Queensland Artificial Limbs Service and try to advocate on behalf of patients and colleagues when I can.

Although I have a few roles, put simply, I see my job as being someone that is there to maximise functions and expand the horizons of children with limb difference and their families. I want to see that all of the children that I work with receive the support and education they need to meet their goals and aspirations.

What other professionals work with you deliver best outcomes for children?

We take a multi-disciplinary approach to supporting children with limb difference in our clinic. I'm fortunate to work with experts in Rehabilitation including Rehab Medical Consultants, Nursing, Occupational Therapy, Social Work, Neuropsychology, Rehab Engineering, Prosthetics and Orthotics. By having a 'whole of team' approach we can provide a developmental service that addresses the individual needs of not only the children and young people but also their families.

As a child grows they might require additional support in particular areas, whether it is physical or emotional, and we can facilitate this quickly because of the array of experts that form that work within our service.

Why is early intervention important for children with a limb difference and their families?

Early intervention is critical as it means we can give children and families timely assistance, advice and support and by doing so hopefully mitigate issues down the track.

Often we see parents before their child has been born and just after they have learned their child will have a limb difference. Naturally, when parents learn their child will have a limb difference they have lots of questions, can feel quite anxious and are keen to learn what this will mean for them and their child. So, by working with parents at this early stage we can help to minimise fears, build an early rapport between the team and the parents and ensure they feel supported prior to their baby's birth.

Once a baby is born with a limb difference or acquires one during childhood we then aim to provide support immediately. Although not all children will use a prosthesis we know that when it is suitable it is critical to encourage a child to accept and use their prosthesis as soon as possible. In my experience, early acceptance of a prosthesis generally leads to positive physical and psychological outcomes for children. We know that children both 'learn to move' and 'move to learn' and so we try and get in as early as we can to ensure that this is happening well (with or without a prosthesis).

We also know that for positivity to occur it is important that parents, siblings, extended family and friends also accept the child's prosthesis and encourage him or her to use it. In addition to parents, siblings can play a vital role in assisting a child to accept their limb difference and we try and involve all members of the family. Because siblings play a significant amount of the time together we have found that educating siblings can often be just as important as educating and training parents. By taking a 'whole of family' approach we can help to ensure that all members of the family have a positive attitude towards a child's prosthetic use.

At our Clinic we like to work with the entire family as we know that by doing so the child we are supporting will generally have positive lifelong outcomes.

How do you involve 'the whole family' in maintaining good physiotherapy activity in the home?

I'm the father of three young children myself, so I know just how busy households can be! In our Clinic we understand that and we try to get to know each family so that we better understand their household pressures and interpersonal dynamics.

By understanding family needs we are then better placed to develop physiotherapy activities that can be integrated into the everyday household or structural environment. We often try and involve siblings in this planning, as siblings can be incredible supports to brothers and sisters with limb difference and can even join in on physiotherapy activities – making it a fun, rather than disliked, activity!

Are there any new developments in the area of limb difference that excite and interest you?

I think one of the most interesting areas right now, and into the future, are 3-D printers. We are just now starting to see how these can benefit amputees and children with limb difference. We actually have a few producers of this technology in Australia which is very exciting.

I think the advances in recreational prosthetic limbs are also very exciting. More and more children are now able to use a suitable recreational limb that then allows them to participate in the same activities as their peers. This is not only beneficial from a physical body perspective but also from a wellbeing perspective. It means that children with limb difference are getting more opportunities to 'try new things' and 'have a go'.

While the National Disability Insurance Scheme (NDIS) isn't fully rolled-out I think this marks a new era for disability support in Australia. I think the NDIS has the potential to provide great support to children with limb differences and ensure that they have adequate support throughout their lives.

Any final comments?

I'm really proud of our Clinic and the work we are doing. However, we know we can still improve things and make our service better – we are never fully satisfied and want to ensure the needs of all of our children and families are met.

I believe that partnering with Limbs 4 Life and other community organisations allows us to provide the support we can't offer in a hospital and rehabilitation setting. The Limbs 4 Kids program, website, Fact Sheets and peer support opportunities are resources we can't offer. But by working collaboratively we can provide full-service support to parents and for that we are truly grateful.

The Importance of Self-Advocacy

Self-advocacy means standing up for the rights of yourself and your child. It means that you are able to ask for what you and your child need and being able to share those thoughts with others. Self-advocacy is empowering and means knowing your rights and responsibilities, speaking up for your rights and being able to make choices that affect you and your child.

Self-advocacy is important for ensuring that you and your child are listened to, assessed appropriately, have complaints heard and able to contribute to developing individual care and education plans.

There are many places and situations where you may want to exert self-advocacy on behalf of yourself and your child, including: with doctors and health care professionals; in hospitals; NDIS staff; at schools; in community organisations; and, in everyday life.

Some people can find self-advocacy intimidating as it means standing up and exerting your own personal power. However, self-advocacy is important to ensure that the needs, goals and aspirations that you and your child have are being met.

If you are unsure about how to self-advocate and prepare for situations where you may need to advocate for yourself or your child, you may find that the following tips will assist. As your child ages you may want your child to be more involved or self-advocate on their own. Remember, your child learns from you and if you can demonstrate positive, effective and courteous self-advocacy he or she is likely to develop self-advocacy confidence along the way.

Tips for self-advocacy:

- Be an active participant in the process
- Clearly express what your child's needs are
- Set realistic goals for what you hope for your child to achieve
- Get enough information to make informed choices
- Get information about other resources
- If necessary, have an advocate, family member, or friend at meetings
- If your request is not responded to in a timely manner ask to speak to a more senior person
- If you feel you are not being responded to, writing a letter may be an effective way to communicate
- Keep a folder of all materials, plans, and correspondence so that you can refer to these in the future
- Take notes when you attend meetings and document all phone calls
- Ensure that any agreed upon care or education plan is put in writing

In addition to self-advocating there are a number of organisations and Ombudsmen in Australia that advocate on behalf of persons with disability. In addition to the ones listed below Ombudsmen operate in all states and territories and can respond to issues regarding services and disability issues.

Australian Human Rights Commission
www.humanrights.gov.au

Commonwealth Ombudsman
www.ombudsman.gov.au

People with Disability Australia
www.pwd.org.au

Are you interested in becoming a Parent Peer Support Volunteer?

Limbs 4 Life is seeking individuals that would like to become a trained Parent Peer Support Volunteer. This training is specifically for parents or carers of children and young people with a limb difference who want to volunteer their time to support other families. This training is also open to adults who were themselves a child with a limb difference and want to support families.

To find out more or express interest in this training contact

Fiona on **1300 782 231** (toll free) or **fiona@limbs4life.org.au**

Are you interested in starting up a Support Group?

Limbs 4 Life is keen to assist parents or carers to establish informal Support Groups in their local communities. Support Groups allow for parents and carers of children and young people with limb differences to meet and socialise with others in similar situations. Limbs 4 Life can assist individuals to establish local Support Groups and provide a variety of tools to get one started.

To find out more or express interest in establishing a Support Group contact **Fiona** on **1300 782 231** (toll free) or **fiona@limbs4life.org.au**

Limbs 4 Kids Facebook Group

Did you know that Limbs 4 Kids has its own closed Facebook group? This group is made up of parents, carers, young people and health professionals and is a great way to connect with others, share ideas, view articles and stay abreast of Limbs 4 Kids activities.

Visit Facebook and look for the group **Limbs4Kids** to join.

Limbs 4 Kids
1300 782 231
kids@limbs4life.org.au

limbs4kids.org.au

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