

Limbkids Support Association Inc. is a non-profit, voluntary organization comprised of parents, professionals and interested people, concerned with the care of children who have congenital or acquired limb differences.

What is an acquired limb difference?

Acquired limb deficiency is defined as the loss of limb mass or form, as the result of injury or illness occurring during the life of an individual. The loss may be the direct result of an accident, or the indirect result of an illness or condition where it is deemed medically necessary to perform an amputation.

What is a congenital limb difference?

Congenital limb deficiency is best defined as the loss of limb mass or form as the result of some prenatal injury or influence. The injury may be to a normally developing limb, but it may also result from some influence on the way the limb develops from the start. Congenital limb deficiency involves the bones of the limb, but equally can involve all of the soft tissues as well, including muscles, nerves, and blood vessels.

Looking for an answer

When a child is born missing a limb, or undergoes amputation due to an accident or medical cause, the entire family is affected. Once some of the shock wears off, you may begin a very extensive search for answers as to why this difference or loss has occurred.

Your search for an answer may leave you physically and emotionally exhausted, remembering that the causes of many differences still remain unknown, and happenstance has no reason or conscience.

At Limbkids Support Association we can provide you with counselling, social outings, library resources as well as adapted musical instruments. We will help you by sharing experiences, and celebrating the abilities and opportunities of our “Limbkids”.



Limbkids Christmas Party

Limbkids aims to:-

- Provide understanding, support and encouragement to new parents and current members.
- Provide opportunities to meet other families affected by similar limb differences, so that positive aspects of coping can be shared.
- Liaise with medical professionals whenever possible, so that a greater mutual appreciation can be achieved.
- Provide information regarding limb differences, and how to manage them.
- Encourage and maintain a high level of interest in research, into both congenital abnormalities, and prosthetics.

Limbkids Support Association pro-

- Telephone counselling
- Hospital and in-home visits
- Meetings with guest speakers
- Social outings
- Mentoring programme
- Video and book library
- Members website
- Modified musical instrument hire

Membership Form

Name	
Company Name (if applicable)	
Address	
Telephone	
email	
Signature	
Name of Child	
Description of limb difference	
Your Relationship to child	

Please forward to:- The Secretary
Limbkids Support Association Inc
PO Box 244
West Burleigh QLD 4219

A word from Limbkids' President

My name is Mark Maki-Neste, father of Amelia (our reason for joining Limbkids), Madeleine, and Ethan, and husband of Cindy. We have been members of Limbkids for many years now, and our first contact with the organisation left a positive and lasting impression.

We learned that Amelia was going to be somewhat special at our nineteen week scan, and that day was the most difficult day in our experience. Like many parents before us, when the doctor said, "there seems to be a problem with the right hand" we felt initial disbelief. I recall thinking "pinch me, this isn't happening", immediately followed by feelings of guilt, "it must be something I have done".

The only thing I could be sure of was, that whatever I was feeling, Cindy must be feeling harder, and it pained me further to see the blame she put on herself. We now understand that whilst these feelings are natural, they are unfounded. It was shortly after this that we heard of Limbkids, and picked up the phone. Our thanks go to Di Bell (then President) who seemed to know exactly what to say.

In balance, the day of Amelia's birth was the most beautiful day of our lives, and from that moment on, Amelia has continued to amaze us with her unwavering spirit, and staunch independence. She is now 5 years old, in prep at school, and helps by tying shoelaces for many of the two handed students. These things leave me a little embarrassed for the way I felt on the day of the scan.

Whilst we believe our function as parents is to give our children the best start we can in life, Cindy and I also feel that Amelia was sent to teach us many things, and we are honoured that we were chosen to be her parents. I am also honoured to be associated with Limbkids, and I believe in the value of the organisation and it's members.

My goal is to raise public awareness of the capabilities of people with limb differences, and to provide a vehicle where all our members can have a voice in the way we progress as an association, regardless of where they may live. I don't believe members belong to clubs or associations, more-so the association belongs to you, it's members. Please feel free to contact me on any matters.

Best regards,
Mark Maki-Neste
President - Limbkids Support Association Inc.

Big Mud Puddles and Sunny Yellow Dandelions

Author unknown

*When I look at a patch of dandelions I see a bunch
of weeds that are going to take over my yard.
My kids see flowers for Mum and blowing white
fluff you can wish on.*

*When I hear music I love, I know I can't carry a
tune and don't have much rhythm so I sit self-con-
sciously and listen.*

*My kids feel the beat and move to it. They sing out
the words. If they don't know them, they make up
their own.*

*When I feel wind on my face, I brace myself against
it. I feel it messing up my hair and pulling me back
when I walk.*

*My kids close their eyes, spread their arms and fly
with it, until they fall to the ground laughing.*

*When I pray, I say thee and though and grant me
that.*

*My kids say "Hi God! Thanks for my toys and
friends. Please keep the bad dreams away at night.
Sorry I don't want to go to heaven yet but I would
miss my mummy and daddy."*

*When I see a mud puddle I step around it. I see
muddy shoes and dirty carpets.*

*My kids sit in it. They see dams to build and rivers
to cross, and worms to play with.*

*I wonder if we are given kids to teach, or to learn
from.*

*Enjoy the little things in life, for one day you may
look back and realise they were the big things.*

*I wish you Big Mud Puddles and Sunny Yellow
Dandelions!!!!.*

*Life is not measured by the number of breaths we
take but by the moments that take our breath away.*

Limbkids
www.limbkids.asn.au



Living with a limb difference

First Reactions

A common reaction to the birth of a child with a limb difference can be extreme sadness and a feeling of loss. This is particularly likely after the excitement and anticipation of a pregnancy in which all seemed to have gone well. It is unlikely that parents would have seen or met, a child with such a condition, and this would make it even more distressing.

It is possible that you have searched your mind over and over again trying to pinpoint the cause. You may even have blamed yourself wondering whether your actions in some way could have caused your child's difference. You must not blame yourself. There was actually nothing you could have done to control the growth of your child's limbs. Neither medicine nor science as yet understands how to predict limb development outcomes. Until they do, they will continue to search.

Congenital limb deficiency usually does not run in families and with a few notable exceptions there is no risk of recurrence either within the family, meaning with brothers and sisters, or in future children of the limb deficient child.