



**Aussie Hands**

## Who We Are

Aussie Hands is a voluntary, not-for-profit community organisation which provides support, information and encouragement for those living with a hand difference and their families.

Aussie Hands was founded in the year 2000 by Elizabeth Borg. It is run by a team of volunteers and overseen by a Board of Management with support from Ambassadors.

We believe in peer-to-peer support, education and providing a safe space where people can exchange information knowing they are not alone in their experience of living with a hand difference.

We partner with The Royal Children's Hospital, Melbourne (RCH) and other hospitals and health professionals across Australia to raise awareness, refer appropriate support services and invest in targeted research through the Murdoch Children's Research Institute (MCRI).

**It's okay to be different.  
In fact, we celebrate difference!**

**Become part of the Aussie Hands community!  
We welcome your involvement.**

## Our Members

Aussie Hands has nearly 2,000 families nationwide, including some from overseas. Our members are children and adults with hand differences and their families and communities; volunteers, donors and health professionals.

## *How We Work*

Our mission is that members are confident in who they are, proud of their achievements and have the same opportunities as anybody else to fully participate in society.

We know from our members and from research that children generally adapt well physically and socially to having a hand difference. However, there are some challenges such as looking different, being treated differently and having to make modifications in order to do everyday activities.

What Aussie Hands aims to do is share ideas, stories, tools and strategies to help children and adults cope with these challenges. We want everyone to achieve their potential and believe they possess unique capabilities, talents and strengths.

In addition, we work to educate the community to be inclusive and treat people with a hand difference with respect.

We support access to assistive devices, therapies or other services and believe that this should be a matter for the individual to determine what is right for them.

## *Peer Support*

Our Peer Support Network connects individuals with a hand difference and their families to people who have lived through similar experiences.

Peer Mentors are there to listen, provide support and share their knowledge which can help you to consider different options, develop strategies and sometimes just feel more confident.

Find out more on our website.



# Members' Stories

## Felicity

As a primary school teacher with symbrachydactyly, Felicity understands only too well how awkward it might be for children with a hand difference starting a new school or class.



Her mantra with all children is 'assume capability'. She is always thinking about what might have helped her at school when she was a child and lets that guide her interactions with students.

## Alicia & Charlie

Talking about hand differences became part of Alicia's life after her 20-week scan revealed that Charlie was missing his ring and middle finger on his left hand.



The greatest benefit of joining Aussie Hands was being able to talk to other members who had or hadn't gone ahead with toe transfer surgery for their child and helped them look at it from different perspectives.

## Knox

Just before his 4th birthday, Knox was involved in an accident which resulted in the amputation of his right arm below the elbow.



Social media has allowed Knox and his mum to connect with other families, who want to give or receive advice or support. 'It's being part of that community, where we can relate to each other in the same way.'

## Mat - Free 3D Hands

Mat Bowtell, founder of Free 3D Hands, has built a valuable partnership with Aussie Hands, driven by a shared mission to support people with upper limb differences. His work is deeply personal and impactful - designing and providing free, 3D-printed assistive devices for anyone. Through open-sourcing his designs, Mat has empowered over 10,000 individuals and organisations around the world.



**To read the full version of these and other stories, visit the Aussie Hands website.**

# *Australian Hand Difference Register*

We believe research is important to find out how many children are born with a hand difference, learn more about the causes and help plan future support services.

The number of children born each year with a hand difference in Australia is estimated to be around 1 in every 600 babies.

Aussie Hands is a co-founder of the Australian Hand Difference Register. This project is led by Associate Professor David McCombe at the Murdoch Children's Research Institute and has been rolled out at major children's hospitals across Australia.

## *Resource Toolkit*

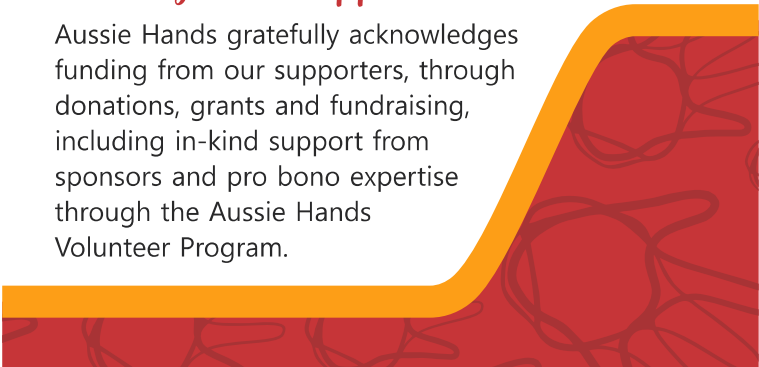
Our online Resource Toolkit includes lived experience stories, expert information, tips and services to empower, enable and facilitate the inclusion of people with a hand difference and their families.

It focuses on different life stages such as finding out, telling others, getting connected, starting school, making friends, self-care, feeling good, role models and life skills.

Find out more on our website.















## *Funding and Supporters*

Aussie Hands gratefully acknowledges funding from our supporters, through donations, grants and fundraising, including in-kind support from sponsors and pro bono expertise through the Aussie Hands Volunteer Program.



# Types of Hand Differences

Hand differences refer to hand or upper limb differences present from birth (congenital) or acquired later in life. These can range from missing one or all fingers on a hand and in some instances, missing part of or the entire arm.

-  **Amniotic Band / Constriction Ring Syndrome:** Hand or upper limb development and growth affected by the restriction from amniotic bands
-  **Aplasia:** Missing bones, tendons or other parts
-  **Arthrogryposis:** Multiple joints that are stiff and hard to move
-  **Brachydactyly:** Short fingers or thumb
-  **Camptodactyly:** A bent, often stiff finger(s)
-  **Clinodactyly:** A finger or thumb that curves to the side
-  **Dysplasia:** Bones/other parts have developed differently
-  **Ectrodactyly:** A hand with missing central finger(s)
-  **Hypoplasia:** The part is missing, smaller or less developed
-  **Macrodactyly:** Finger or thumb grows larger than expected
-  **Poland Syndrome:** Underdevelopment of the chest muscles, sometimes associated with an underdeveloped hand
-  **Polydactyly:** Extra thumb or finger
-  **Symbrachydactyly:** Underdeveloped hand, may have short or missing fingers
-  **Symphalangism:** Joined bones in fingers or thumb, stiff, straight joints
-  **Syndactyly:** Fingers or thumb are webbed/joined
-  **Synostosis:** Bones are joined
-  **VACTERL:** A syndrome where differences impact the hand and the body including skeleton and organs

## Connect



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Aussie Hands holds Deductible Gift Recipient (DGR) status and is a registered charity in Australia.