### Who we are

#### Aussie Hands supports people with a hand difference.

Aussie Hands provides support, information and encouragement to people born with a hand difference and their families.

Hand differences refer to congenital hand or upper limb differences ranging from the absence of one or all fingers on a hand and in some instances, the absence of part or the entire arm

## How we work

We are a member and volunteer led organisation.

Aussie Hands was founded in 2000 by Elizabeth Serpell. It is run by part-time staff, a team of volunteers and overseen by a Board of Management. Jessica Smith, OAM is the Aussie Hands Patron and there are Ambassadors and State Coordinators to support members. We believe in peer to peer support and education. We believe in providing a safe space where people can exchange information and know they are not alone in their experience of living with a hand difference.

We partner with Melbourne's Royal Children's Hospital and other hospitals and health professionals across Australia to raise awareness, refer appropriate support services and invest in targeted research.

# **Our Supporters**

Aussie Hands gratefully acknowledges funding from our supporters:

- membership
- fundraising
- donations
- sponsorship
- ANZ Bank
- Calvary Community Fund Tasmania
- City of Melbourne
- Mazda
- Monash College (venue partner)

## **Raising awareness**

We believe people with a hand difference should have the same opportunities as everyone else.

We are raising awareness through Limb Difference Awareness Week in order to help society to become more inclusive of people with different abilities. We believe people should be treated with respect, be included and have the same opportunities as everyone else.

# **Types of hand differences**

Below is a list of Congenital Hand Anomalies Terminology

- Amniotic Band Syndrome (ABS) or Constriction Ring **Syndrome:** Constriction of fingers or thumb by amniotic band(s)
- Aplasia: Absence of specific bones or other tissues such as tendons
- Arthrogryposis: Multiple congenital joint contractures
- Brachydactyly: Short fingers
- Camptodactyly: Congenital flexion contracture usually small finger
- Clinodactyly: Angulation in lateral (radial-ulnar) plane of finger or thumb
- **Dysplasia:** Abnormal development of bones and parts
- Ectrodactyly: Cleft hand with missing central finger(s)
- Hypoplasia: Under development or absence of bones and parts
- 48 Macrodactyly: Overgrown finger or thumb
- Poland Syndrome: Underdevelopment of the chest muscles often associated with a hand difference in the affected limb
- Polydactyly: More than normal number of fingers or thumbs
- 48 Symbrachydactyly: Underdeveloped hand with central finger deficiencies
- to. **Symphalangism:** Stiff fingers or thumb from fusion of bones
- Syndactyly: Webbed fingers or thumb
- H8 Synostosis: Bone fusion
- 18 Vacterl: A syndrome with a group of skeletal and organ anomalies including the hand difference radial dysplasia

# **Connect with us**

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

www.aussiehands.org



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

ABN 89 943 801 490



Supporting Australians living with a hand difference



Aussie Hands enriches the lives of people living with a hand difference and heir families. It is wonderful to see people supporting one another, sharing nformation and celebrating difference. I'm proud to be a part of Aussie I

- Print Obsession • Pixel Salad Studios
- The Lord Mayor's Charitable Fund, Melbourne, Victoria
- The Sentinel Foundation
- Transurban







### **Australian Hand Difference Register**

We believe research is important to find out how many children are born with a hand difference, why it occurs and what services are helpful.

Aussie Hands is a co-founder of the Australian Hand Difference Register (AHDR). The AHDR 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. The purpose of the AHDR is to find out how many children are born with hand differences in Australia, learn more about causes and help plan future support services.

Research is important because we don't have accurate information about the number of children born each year with a hand difference. The number is estimated to be around 1 in every 600 babies born in Australia.

### What difference we are looking to make from our work

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

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 kids cope with these challenges. We want everyone to achieve their potential and believe that everyone possesses 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.

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.

### Who are our members

#### Aussie Hands is nation-wide with over 900 active families

Our members are children and adults with hand differences and their families and communities; volunteers, donors and health professionals.

### Our members and their stories

#### Callie & Mandy's story – my child has a hand difference

When children with hand or limb differences start childcare. kindergarten or school, it can be a worrying time. Parents know they're not going to be there for the guestions and the stares that may occur. Callie's mum and dad explained that they tackled this up front. They provided the school and teachers with stories and resources such as Callie's Doll Like Me, to share with her classmates in the first week of school.

'She is known and loved by many in the playground, although I have witnessed a few stares and comments' explains Callie's mum, Mandy,

'Utilise the Aussie Hands pamphlet for teachers and ensure the school is confident in limb difference language and any individual support your child may need.'

Callie won her first award for being an independent worker and striving to always do her best. Any parent would be proud of these successes.

Support, awareness and understanding of hand and limb differences is important in making the transition to school successful for kids like Callie.

Callie, age 5 and her mum, Mandy.



Callie, mum Mandy and sister Phoebe (above)

#### Heather's story – I am a parent with a hand difference

I was so excited to learn that Aussie Hands existed - it's nice to have a community of people in a similar situation to me. I love seeing what people have achieved, it's very inspiring.

My name is Heather and my difference is known as symbrachydactyly where my left hand has a prominent thumb and 4 little stubs for fingers. I'm 36 and have 2 children, so it's nice to be able to offer advice or suggestions based on my experiences as a parent with a hand difference.

I currently work as a paediatric occupational therapy assistant helping kids develop new skills. In my spare time I enjoy going for bush walks and to the beach with my family, sewing guilts and I've started to learn the ukulele. To young adults, I would say...give everything a go, don't listen to negativity, be the

#### Ben's story – I have a hand difference

Hi, I'm Ben and I'm 18. I was born without my left hand and my arm finishes just above the wrist.

I come from Perth but currently live in Brisbane while doing an aircraft maintenance engineering apprenticeship with Qantas.

When I was 13, I joined the Air Force Cadets and achieved the highest rank, and learnt shooting, gliding and flying skills.

I haven't had any trouble coping with one hand and have learned to adapt. I enjoyed playing sports including soccer, cricket, basketball and squash. I can drive a car without any modifications, saved up to buy a 4WD and enjoy going four-wheel driving.

When I meet up with friends and play pool, I balance the cue on my left arm and am not too bad at it.

The only time I've used a prosthesis is when I was learning to fly gliders and needed to pull a brake lever on the left-hand side. Otherwise I find it easier to do things without one.



Ben and Qantas plane (above)

person you are inside and let that shine. To parents... teach your child to love themselves and they will be fine - we all just adapt to a task and do it in our own way.

My family and friends don't see me as a person that is different because of my hand, they see me as me, the tall girl with curly hair!

Ben, age 18

Heather, age 36

Heather Green playing ukelele (right)



Read more about these and other stories on the Aussie Hands website.

