



AHDR Newsletter

June 2025



Dear ,

We are halfway through 2025 and it is time for another AHDR update.

In this edition of the AHDR newsletter, you will find an invitation to join a family engagement workshop, updates on our latest research, meet one of our AHDR families, and a book recommendation you might find interesting.

As always, we would like to say a big thank you to you and your child. Your involvement has helped us better understand the health and wellbeing of children born and living with hand/upper limb differences - and we truly appreciate your continued support.

You're Invited: Family Engagement Workshop



Join the AHDR Family Engagement Workshop!

Are you a parent, grandparent, guardian or carer of a child with a hand or upper limb difference? Your voice matters — and we want to hear from you!

The Australian Hand Difference Register (AHDR) started in 2017 and there are now 2,823 children signed up Australia wide. This is a great achievement! The growing database means we can undertake research projects that will inform both best practice medical treatments, as well as understand the social and mental health impacts of having a hand or upper limb difference. In turn, this information will enable us plan better support services for the hand and upper limb difference community in Australia.

Share Your Experience. Shape the Future.

We're inviting members of the AHDR to be part of an online workshop, where your lived experience can directly impact the direction of our research.

What's Involved

- Join a 1.5 hour online workshop to share your insights
- Provide your feedback on ideas for research including what supports children and their families need throughout their lifespan
- Help us ensure our work stays relevant and meaningful to families like yours

What's In It for You?

- This is a paid opportunity — we truly value your time and input
- Connect with other families and carers in the AHDR community around Australia
- Collaborate with researchers dedicated to making a difference in the lives of children with hand and upper limb differences

Ready to Make an Impact?

Register your interest today by clicking below and filling out your details:

If you require any more information about this opportunity, please get in contact with Jo Kennedy at ahdr@mcri.edu.au

[Click here to register](#)

AHDR Families: Meet Candy's Family

Meet Candy, Aurora and Hannah - one of the families on the AHDR. We asked the girls and Candy some questions about their journey, what matters most to them and what they'd like others to understand.

Can you introduce your family and tell us a little bit about yourselves?

My name is Candy, I'm a single mum of 5 incredible humans. I am a real estate agent who has taken some time out of the industry to follow my passion and study Social Work full time. I am really passionate about social justice and building a world where every person has a voice and feels valued. Our family loves bush walking, sunsets, spending time together and going on adventures. We live along the top of a mountain range and feel incredibly blessed to be surrounded by the best of Australian animals and scenery. Our adventures often take us to waterfalls or picnics along the creek, we ride motorbikes and love being together and being outside. We live a blessed life.

When did you first hear about the AHDR and what made you join?

Two of my children have brachydactyly type A1, which is a condition affecting the bones in their fingers and toes. Essentially, instead of them having three finger/toe phalanges (bones), they have only two. When I attended the Brisbane hospital for one of my kids, I was offered the option to be a part of the AHDR program and I am excited to be involved with a program that is actively researching and looking for ways to improve resources for children with hand differences. I am yet to find a doctor who has seen my children's condition before and most doctors have not even heard of it. To my knowledge, there are not any resources or programs to help my kids in their day to day development and honestly, I think as parents it is up to us to advocate for more information and resources, this is why I chose to be a part of the AHDR.

What do you wish more people understood about your child's abilities?

My kids are phenomenal, they're smart and kind, they're generous and determined and yes; they have a hand difference. We are very open to talking about it. If you have a question, please ask! In our family having brachydactyly is the same as having brown hair or green eyes, it is not seen as good or bad, it's just part of what



makes us who we are. Perhaps it is different to you, but we are all different and all awesome! Their hand difference is only one tiny part of who they are, and I am teaching my kids the importance of each person being unique and different. We are all gifted with different strengths and weaknesses, but being kind and generous and inclusive is more important than anything else.

What message would you like to share with other families facing a similar journey?

Talk about it. Be open. Share freely. If a stranger in the park comments on my children's hands, one of my kids will simply state "Yeah, I have brachydactyly and I have two bones in my fingers and you have three!". People are often shocked that my kids know so much about their condition and are able to clearly explain their difference. However, my kids are confident about talking about their hand difference because it is not something we are ashamed of or have ever made a big deal about. I would encourage other parents to educate themselves about what the future may hold, what options may or may not be available to their child and what challenges may present themselves in future because we are their advocate.

Aurora/Hannah: What are your favourite things to do for fun?

A: Playing in the park and spending time with my friends.

H: Spelling at school. I love spelling and reading.

Aurora/Hannah: What do you want to be when you're a grown up?

A: Professional gymnast

H: A gamer in the afternoons, but a teacher in the day time.

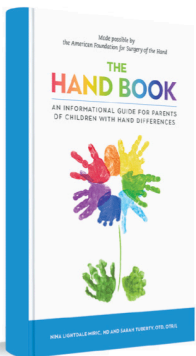
Research Update



The **APPLE study** will interview adolescents, aged 14 to 17, to understand what they care about most regarding the appearance and function of their hands and arms. Parents will also be interviewed about their experience with their child's diagnosis and the support they need. Keep an eye on your inbox for an email from Jo!

The **Appearance study** is coming to an end. It explored how children feel about their appearance of their hands and how this affects their emotional wellbeing. Thank you to all who took part! A reminder to complete the second and third rounds of the questionnaire. Meet the Appearance Study team on the left!

Resources: The Hand Book



The Hand Book (2022), written by Dr Nina Lightdale-Miric and Sarah Tuberty, is a helpful guide for parents of children with hand or upper limb differences. It offers support, information and practical advice for every stage of your family's journey.

Inside you will find easy to understand explanations of common terms; tips for everyday challenges; and worksheets and prompts to help guide conversations and reflections.

The book is designed to support both the emotional and practical sides of parenting - from early decisions to life as your child grows up.

Supporting Our Work

Being born with a hand or arm that is different is common and we are just beginning to understand how hand differences affect these children.

Supporting children with a hand difference

Children's Hand Research Group (CHRG)
Help us make a difference

Being born with a hand or arm that is different in number, affecting over 100 children here in Australia every year.

We are just beginning to understand how hand differences affect these children. We need to know more about the causes and effects of hand differences on children and families. We need to know more about which treatments work.

If you would like to support this cause, you can make a donation on the left side of the world of this email. We understand that not everyone is able to give money, and we are grateful for any help you might be able to give.



Australian Hand Difference Register



What is a Hand Difference and why do they matter?

Children born with hand differences are born with a difference in the number and/or shape of their hands or arms. They are most often born with a difference in the number of fingers or thumbs. In some cases, the hand or arm is missing or underdeveloped.

The hand is a vital part of a child's life. It is used to hold, grasp, and manipulate objects. It is also used to communicate and express emotions. Children with hand differences may face challenges in these areas, and it is important to provide them with the support and resources they need to thrive.

Supporting children with a hand difference

The AHDR relies on support to continue and grow. This allows our team of doctors, therapists, and researchers to focus on important projects that make a real difference - giving families more informed choices, improving outcomes and easing the uncertainty many parents and children feel about the future.

For more information about the Childrens' Hand Research Group and how you can help us make a difference, click [here](#) or make a [tax-deductible donation](#) before June 30.

Thank you for being part of the AHDR community. We welcome any feedback on how we can improve our commitment to better assisting children with upper limb differences, and their families.

Acknowledgement

The AHDR team would like to acknowledge the McNally Family Foundation, Aussie Hands, the Australasian Foundation for Plastic Surgery, the Australian Society of Plastic Surgeons and our donors. Their generous support has made our work possible.



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