



Dear ,

As 2025 draws to a close, we're delighted to bring you another update from the AHDR team. It's been a busy and rewarding year of recruitment and research and we're excited to share some highlights with you.

In this edition you'll meet Libby, one of our Sydney-based team members, read updates about the latest research projects, and celebrate a special milestone from our friends at Aussie Hands.

As always, we want to thank you and your child for being part of the AHDR community. Your participation in research studies, family engagement workshops and questionnaires continues to make a real difference. We're so grateful for the time, insights, and support you share with us.

## Family Engagement Workshops

A big thank you to everyone who joined our online family workshops! We ran three sessions in August and enjoyed having families take part from all over Australia.

We really appreciate all the ideas and feedback you shared. Our discussions covered topics such as how we communicate with families, ideas for research projects and general feedback about the register. We've already started putting some of your suggestions into place, and we're looking into the bigger ones to see how we can make them happen.

If you weren't able to attend a workshop but would like to provide us with your feedback or ideas, please get in touch via [ahdr@mcri.edu.au](mailto:ahdr@mcri.edu.au).

## AHDR Team: Meet Libby



Meet **Libby**, a Hand Therapist from The Sydney Children's Hospital and a valued member of the AHDR team. We asked her a few questions so you can learn more about her work, her role, and why she's passionate about supporting the AHDR.

### **What kinds of therapy or support do you provide for children with hand or arm differences?**

I'm an Occupational Therapist and our main goal is to make sure if there is anything a child can't do or is having difficulty completing and would like to – I work out a way to make this happen! That might mean using adaptive equipment, exploring prosthetic options, or thinking creatively about how to approach tasks in new ways. I also support children after hand surgery, which can involve casting, splinting, scar management, and fun, functional hand therapy like strengthening activities.

### **What makes you hopeful or excited about the work being done through the AHDR?**

It's so exciting to be collating information about what's happening in Australia as a lot of the research in hand differences comes from overseas. It's also a great way to link clinicians working in this niche field around Australia together!

### **How can research from the AHDR help improve hand therapy approaches or outcomes in the future?**

It helps to give us a clearer picture of how common the different conditions are and the ways they may impact children's lives at different ages. By recognising common themes or challenges early, we can tailor therapy proactively and offer more targeted support to children and families as they grow.

### If you had a superpower, what would it be and how would you use it at work?

I'd give myself go-go gadget arms, so I'd always have everything I need within reach (including a bubble machine or sparkly craft supplies to keep therapy sessions fun!)

## Research Update

### Appearance study

Thank you to all the families who took part in the 'A comparison of tools to assess hand appearance in children with congenital upper limb differences study' or more easily known as the 'Appearance study'. It looked at different ways to assess how children with hand differences feel about the appearance of their hands. Children and parents completed short questionnaires about hand appearance and general health, which were repeated after 14 and 28 days. The findings from this study should be available in the first half of next year.

We're also excited to share that medical student **Felicity** won first place at the 2025 University of Melbourne MD Student Conference for presenting this research. Congratulations, Felicity!



### APPLe study

The Adolescent and Parental Perspectives on Living with Congenital Upper Limb Difference study (you can see why it's easier to call it APPLe) has two parts. First, we're talking with adolescents, aged 13-19 years, to learn what matters most to them about the look and function of their hands and arms. Second, we're speaking with parents to understand their experiences following their child's diagnosis and the kind of support they need.

Recruitment is well underway, and we'd like to say thank you to all the families who have already taken part. We've learned so much from you already. If you and/or your child are interested in taking part, please get in touch with Jo at [ahdr@mcri.edu.au](mailto:ahdr@mcri.edu.au)

### PROMIS questionnaires

For families who provided consent, you may remember receiving outcome questionnaires (called PROMIS) when your child reached the ages of 5, 8, 11, 14 and 17. These questionnaires give us valuable insights into how children and young people experience their hand or arm difference, including whether it affects their daily activities, wellbeing, or behaviour.

Because of your involvement, we've been able to take our first in-depth look at how growing up with a hand or arm difference may impact health and wellbeing. We're excited to share that this research has now been published in the Journal of Hand Surgery (European Volume).

Below is a short summary of the published paper. Click the purple button if you'd like to read more about the study.

# How Congenital Hand and Arm Differences Affect Social and Emotional Health and Wellbeing

Based on recent research from the Australian Hand Difference Register

## What was the aim?

This study aimed to evaluate how PROMIS questionnaires capture upper limb function and social and emotional health and wellbeing in children with hand and arm differences.



## What were the findings?

- The PROMIS scale was able to measure the altered upper limb function in children with a congenital difference
- Upper limb function is lower in children with a hand difference than other children
- Children with better upper limb function also had better social and emotional health and wellbeing
- Generally, children with a hand difference have social and emotional health and wellbeing similar to other children
- As children with a hand difference become adolescents, pain increased and depression scores also increased.

## How was it done?



Children enrolled in the Australian Hand Difference Register were invited to complete six standardised questionnaires every three years between the ages of 5 and 17.

## What do these findings mean?

Generally, children with upper limb differences cope well and live happy lives. By improving upper limb function, we may improve social and emotional health and wellbeing.

We should be aware that challenges faced by all teenagers may be worse for those with upper limb differences and support should be offered where needed.

[Read more about the study](#)

## Aussie Hands turns 25



On Saturday 18 October [Aussie Hands](#) celebrated 25 years of empowering and connecting people with hand differences. The milestone was marked with a heartwarming gathering at The Royal Children's Hospital Foundation in Melbourne. Families, children, and supporters came together to share stories and celebrate how far the community has come. The event highlighted the organisation's enduring impact of fostering connection, confidence and understanding for people living with hand differences and their families. It was a true celebration of belonging, resilience, and the vision that continues to drive Aussie Hands forward.

[Read more about the celebration](#)

Help us make a difference

Research needs funding to keep the register running and to undertake projects that will have a direct impact on the lives of children with hand differences.

We have a dedicated team of doctors, therapists and researchers who, with funding, will have the time and resources to concentrate on this critical research. This will give families more informed choices, improve outcomes of treatments, and help to relieve the anxiety of parents and their children about what their hand difference will mean for them and their future.

Help support the AHDR and give children with a hand difference the best possible outcome by [donating today](#).



## Happy Holidays

Wishing you a festive holiday season filled with joy, rest, and time spent with loved ones.

Thank you for being such an important part of our research family. Your ongoing support and participation help us make meaningful progress and improve understanding for families across Australia. We're grateful for your involvement and look forward to sharing new updates and discoveries with you in the year ahead.



## Acknowledgement

This email was sent by MCRI - Reproductive Epidemiology, MCRI - Reproductive Epidemiology, 50

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