



AHDR Newsletter

June 2026

Dear AHDR,

Welcome to the latest AHDR participant newsletter!

As we head into the middle of the year, we're excited to share the latest news from across the AHDR. This includes a major register milestone, new collaborations and research opportunities, a behind the scenes look at our team, and updates on how your participation continues to shape future care and research for children with hand differences.

Most importantly, thank you to all the children, young people and families involved in AHDR. Your ongoing support helps us better understand hand differences and improve care for families across Australia. We hope you enjoy this edition.



Australian Hand
Difference
Register

Register Updates

A big milestone for the register

We recently enrolled our **3000th** child into AHDR. Thank you to all the families who have helped make this possible.

A new hospital is joining the AHDR

We're very close to welcoming the team at Royal Hobart Hospital to the register. We're just waiting on the final sign-off before officially welcoming our friends from Tasmania.

Sharing ideas across borders

Earlier this year, the national AHDR team came together for a meeting, which also included several guests from the USA. It was a great opportunity to share ideas and experiences, with informal discussions highlighting some of the differences observed between Australian and US children. These conversations sparked a number of exciting ideas for future research projects, and we look forward to exploring these further.

Why Your Participation Matters



Patient-reported outcome measures (PROMs) might sound a little technical, but they're really just a way for us to hear directly from children and young people about how they're feeling and how things are going in their everyday lives.

Children and young people in the AHDR are invited to complete these questionnaires every three years from the age of 5. As children grow and their lives change, these check-ins help us understand what matters most to them and what their experiences are like over time.

The information shared through PROMs helps us learn more about the challenges and successes children and families experience, and how care and support can continue to improve in the future.

Most importantly, PROMs give children and young people a chance to have their voices heard. Every questionnaire completed helps us better understand what life is really like from their perspective.

Your voice matters, and we thank you for sharing it with us.

Behind the Scenes

In this edition, we hear from **Dr Melissa Chong** at Monash Children's Hospital, who is currently completing a fellowship in China. Dr Chong shares some of her experiences overseas and what she has been learning through this exciting opportunity.

"I am a Plastic Reconstructive Surgeon based in Melbourne, with an interest in congenital hand differences. I am currently undertaking a fellowship in congenital hand surgery with Dr Jane Shen at the Children's Hospital of Soochow University in China. My time here has been amazing. The culture here is so different and the parents' expectations are extremely high. Dr Shen continues to refine her surgical techniques in order to meet these demands and as a result it has been a very eye-opening experience for me so far."



Photo (from L to R): Dr Abdullah (orthopaedic surgeon from Malaysia), Dr Loan Tran (paediatric orthopaedic surgeon from Vietnam), **Dr Melissa Chong**, Dr Jane Shen (paediatric hand surgeon in Suzhou, China), Dr Mohamed Abdelaziz (visiting orthopaedic surgeon from Egypt)

Meet the Team



Meet **Jo**, Senior Project Coordinator at the Murdoch Children's Research Institute (MCRI). If you've received an email, SMS, phone call or even some snail mail from the AHDR, chances are it was from Jo! We thought it was time to learn a little more about the person behind it all.

Tell us a little bit about yourself.

I was born and raised in Melbourne, although I spent six years living in London in my 20s. I'm not much of a coffee person, which feels a bit unusual for Melbourne, but I do love AFL (I'll keep my team to myself though!). After moving back to Australia, I studied a Master of Genetic Counselling and discovered a love for research. I've since been at MCRI for 13 years, with 8 of those working as part of the AHDR team.

What is your role in the study, and what does a typical day look like?

As the AHDR Coordinator, I'm the main point of contact for everyone involved in the register. No two days are ever quite the same, which is one of the things I enjoy most about the role. Some days are spent checking in with our recruitment sites, doctors and therapists, while others involve behind the scenes work like budgets and ethics approvals. My favourite part of the job is connecting with the families involved in the register, whether that's answering questions, following up on consent forms, or conducting one of our research studies.

What's one thing you wish participants knew about taking part in research?

It's OK to say no. We really value the opportunity to learn from participants and families, but we also understand that life can be busy, timing may not be right, or you may simply decide a study isn't for you and that's absolutely fine. We never take it personally!

Researchers are required to follow specific contact procedures, so if we don't hear back, we may send a few follow-up messages. However, if you let us know that you're not interested, we'll update our records and won't continue contacting you about that study.

Dream travel destination?

Oooh, this is a tough one. Travelling around Africa has definitely been a highlight and I have been there four times. I'd love to go back again soon. In saying that, Sri Lanka is next on the list. So, if anyone has some travel suggestions for there, let me know. My goal is to travel to 50 countries by the time I reach 50 years of age. I'm currently sitting at 46 countries and without giving away my age, I thankfully have some time up my sleeve.

Upcoming Opportunities

Webinar

We're currently planning an AHDR webinar for later this year and are excited to start bringing families together online. The webinar will be a chance to hear updates from the team, learn more about current research projects, and ask questions. We'll share more details in the coming months, so stay tuned!

Help Us Make a Difference

Research funding is essential to keep the register running and support projects that improve outcomes for children with hand differences. Our team of doctors, therapists and researchers use this support to better understand hand differences, improve treatments, and help families make informed decisions.

You can help support the AHDR and give children with a hand difference the best possible outcomes by [donating today](#).



Stay Connected With Us



Moved house? New phone? Swapped email addresses? We'd love to stay in touch! If any of your contact details have changed recently, please let our team know so we can make sure you continue receiving study updates, newsletters and important information.

You can reach out to us on **(03) 9936 6766** or ahdr@mcri.edu.au

Thank You

The AHDR team would like to sincerely thank the McNally Family Foundation, Aussie Hands, Australasian Foundation for Plastic Surgery, Australian Society of Plastic Surgeons and our generous donors for their ongoing support. Their contributions have played an important role in making our work possible.



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