AHDR newsletter

December 2024

Dear ,

Happy Festive Season from the Australian Hand Difference Register (AHDR) team!

We would like to thank you and your child's contributions which have helped us better understand the health and wellbeing of children born and living with upper limb differences.

We're excited to share the latest updates from 2024 and give you a preview of what is to come in 2025.

Australian Hand Difference Register

A Year in Review

The AHDR enrols children from all over Australia. We work closely with clinical teams from Australia's major paediatric hospitals, as well as participating private clinics.

At the end of 2024, we have over **2600 children** on the AHDR.

We are also excited to announce the addition of new site John Hunter Children's Hospital, Newcastle.

Who we are

Jo Kennedy,
Senior Project Coordinator

Olivia Gigli,
Research Assistant

Most of you have likely been in touch with Jo over the past few years.

Alongside managing the register, Jo's focus has been on research projects aimed at improving the wellbeing outcomes for children and their families to thrive.

Olivia recently joined the AHDR in October to assist Jo in keeping the register rolling.

You may receive questionnaire reminders from her and notifications about future research projects.

2025 Research Projects

Keep an eye on your inbox or mailbox for two upcoming research projects. If you are enrolled in the AHDR and meet the eligibility requirements, you may receive an email or letter inviting you to take part.

The Appearance Study will look at how children feel about the appearance of the their hands and how it affects their emotional wellbeing. Eligible children, aged 5 years or older, and their parents will be invited to complete a series of online questionnaires over 28 days.

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. The study will also interview parents to learn about their experience of receiving their child's diagnosis and what support they need afterwards.

Questionnaires: Reminder

Enrolment questionnaire

The information you provide through our initial questionnaire is invaluable to our research. Without it, we cannot provide evidence-based and practical solutions for children living with upper limb differences. Not only that, yours and your child's contributions can help shape the lives of children born with upper limb differences in the future.

PROMIS questionnaires

You will receive the Patient-Reported Outcomes Measurement Information System questionnaire (or PROMIS for short) at five key stages: **5, 8, 11, 14, and 17** years of age. These questionnaires allow us to focus research on the needs of children with upper limb differences at these important life stages. They are designed to give us an overall view, from your child's perspective, of their physical health and how they feel emotionally, and socially living with an upper limb difference as they grow.

Keep an eye out for AHDR questionnaires, they will come through your preferred contact method. If you have any questions, your contact information has changed, or if you have not received one, always feel free to get in contact with us.

Supporting Children with a Hand Difference

Supporting children with a hand difference

Childrens' Hand Research Group (CHaRG)

Help us make a difference

Being born with a hand or arm that is different is common, affecting over 500 children born 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 impacts of hand differences on children and families. We also need to find out more about which treatments work.

If you would like to support this cause, you can make a donation via the QR code at the end of this sheet. 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?

Congenital Hand or Upper Limb Differences (CULD) occur when the hand and/or arm are forming during pregnancy. They can result in the hand or arm having missing or extra parts, or having too much, or too little growth of part or all of the hand and/or arm.

The hand is a child's key point of contact with the external world and is vital for their development as they explore their environment. More than this, the hand plays an important role in communication and using technology that is becoming more common in our day-to-day life. Children with hand differences are known to adapt well, but challenges remain.

Supporting children with a hand difference

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.

For more information about the Childrens' Hand Research Group and how you can help us make a difference, click here.

Thank you

We wish you a safe and happy holiday period with your family and friends.

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, the Australasian Foundation for Plastic Surgery and Aussie Hands. Their generous support has made our work possible.

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