

AHDR Annual Report 2023

Introduction

The Australian Hand Difference Register (AHDR) is a database of children born with a congenital upper limb difference (CULD). Established in 2017, the AHDR aims to:

- find out how many children are born with a hand/arm difference in Australia
- improve our understanding of causes and risk factors
- identify the effects of hand differences on children
- decide how best to manage hand differences
- gain information to help in planning relevant services
- identify possible participants for future research

News

On the road: A/Prof David McCombe (Associate Investigator) and Jo Kennedy (AHDR Manager) visited some of the Sydney recruiting sites in September.

Jo Kennedy won the 'Best Poster Prize' for **PROMIS in a paediatric setting: The Australian Hand Difference Register** at the 2023 Australian Clinical Registries Annual Scientific Meeting. She was featured in an interview for the 'The Benchmark' Newsletter.



Photo 1: A/Prof David McCombe and Jo Kennedy at The Children's Hospital, Westmead

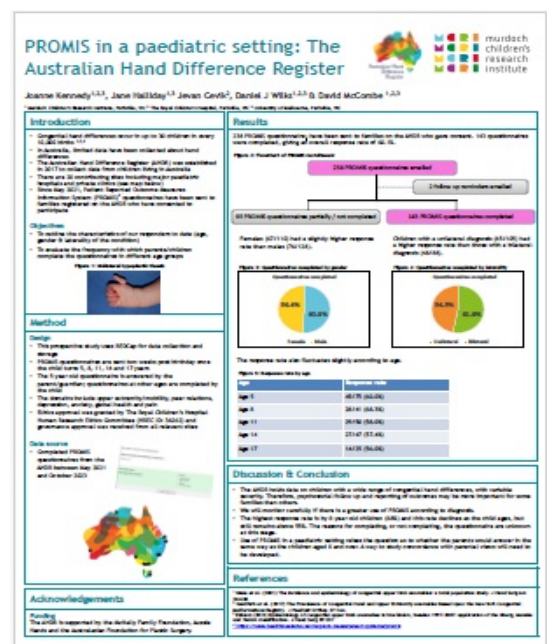


Photo 2: Jo Kennedy's poster that won best poster prize at the 2023 Australian Clinical Registries Annual Scientific Meeting

Presentations

2023 World Symposium on Congenital Malformations of the Hand and Upper Limb, Minneapolis, USA

The Australian Hand Difference Register – What data are we capturing?

Daniel Wilks

Socio-economic status in children with CULD – Data from the Australian Hand Difference Register

Daniel Wilks

Maximising registry enrolment

David McCombe

Australian Hand Surgery Society, Sydney

Where are we up to with Congenital Upper Limb Difference research?

Daniel Wilks, David McCombe

Maximising registry enrolment

David McCombe

Asia-Pacific Federation of Societies of Surgery of the Hand Meeting, Singapore

What tools exist to assess hand appearance in children: A scoping systematic review

Daniel Wilks

Australian Orthopaedic Association, Melbourne

Children's hand surgery – Facing the challenges of rare conditions

Daniel Wilks

Australian Clinical Registry Annual Scientific Meeting, Melbourne

PROMIS in a paediatric setting: The Australian Hand Difference Register (poster)

Joanne Kennedy

Current Research Projects

An Analysis of the Functional and Psychosocial Impact of Congenital Upper Limb Differences Using PROMIS: Data from the Australian Hand Difference Registry

Bilateral dorsal nail curvature of the thumb distal phalanx – A case report

Forward mapping of the OMT congenital hand difference classification between updates: complications and recommendations.

The Impact of Socioeconomic Status on Congenital Upper Limb Difference Registry Inclusion – Data from the Australian Hand Difference Register

What Tools Exist to Assess Hand Appearance in Children: A Scoping Systematic Review



Photo 3: A/Prof David McCombe presenting in Minneapolis

Summary of data for 2023

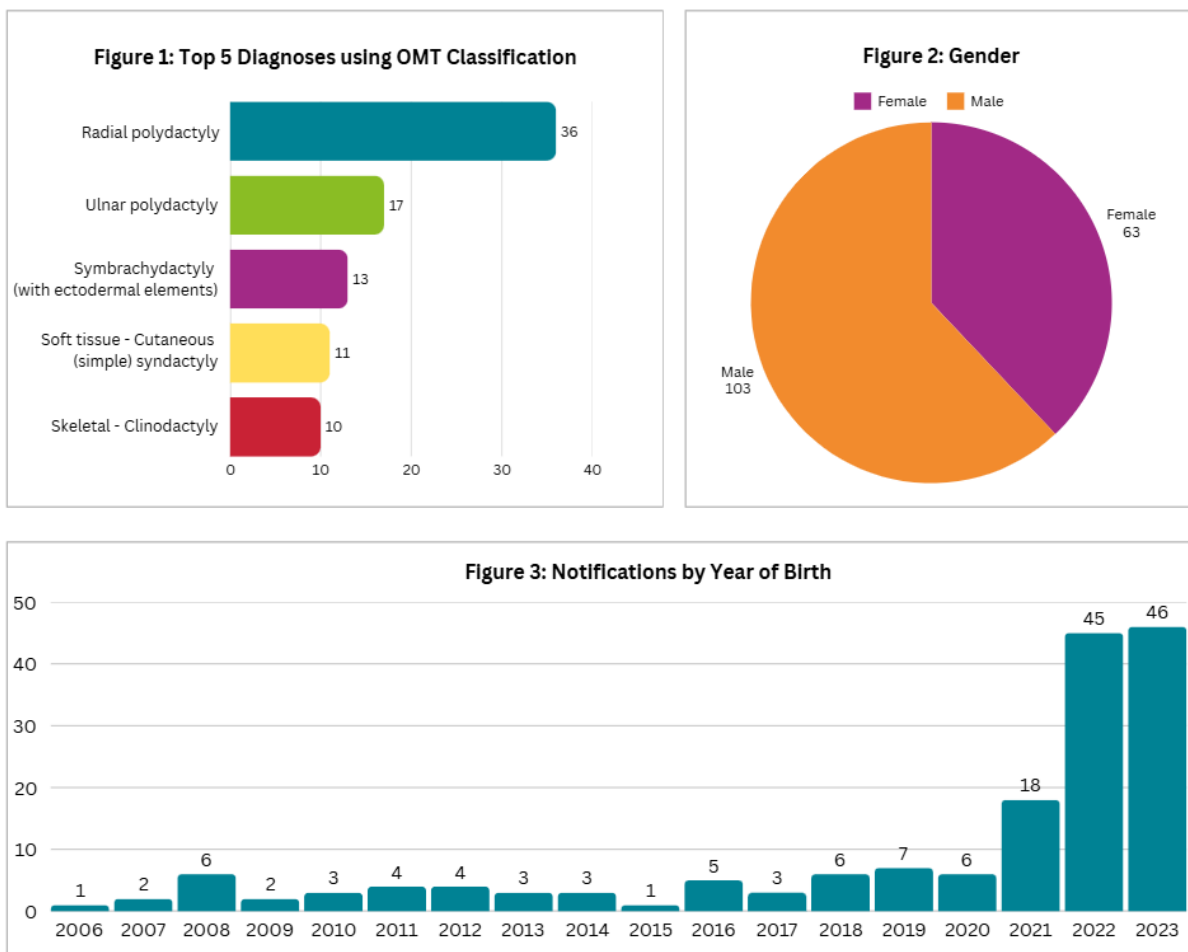
There were notifications for 166 children in 2023, with a total of 1459 children registered on the AHDR.

Using the Oberg-Manske-Tonkin (OMT) Classification, which comprises 119 conditions, the AHDR now has information on 37 conditions.

Figure 1: Top 5 diagnoses in 2023 using OMT classification. Radial Polydactyly is the most common diagnosis (22%).

Figure 2: In 2023, gender is similar to previous years with a higher number of notifications for males (62%) than females (38%).

Figure 3: The breakdown of notification received in 2023 by year of birth. The majority of notifications were received from participants born in 2022 (n=45) or 2023 (n=46).



Acknowledgments

The AHDR team would like to thank the families who have generously shared their time and experience by participating in the register. We would also like to thank the McNally Family Foundation and the Aussie Hands Foundation for their ongoing support.