

AHDR Annual Report 2019

Introduction

The Australian Hand Difference Register (AHDR) is a database of children born with an upper limb difference. The AHDR aims to:

- Find out how many children are born with a hand/arm difference in Australia
- Learn more about possible causes and risk factors
- Gain information to help plan services
- Identify possible participants for future research

We've gone national

2019 was a big year for the AHDR. We have now expanded to include children seen in hospitals across Victoria, New South Wales, Queensland, South Australia and Western Australia.

Plans are in place to add more recruitment sites throughout 2020.

Research projects

Lucy McDougall - University of Melbourne medical student

This year Lucy completed a research project titled "*The psychosocial impact of congenital hand and upper limb differences on children*". She interviewed children and parents in eight families exploring the concerns, lifestyle impact and positive aspects of having a hand/arm difference.

Results from this study will be presented at an upcoming conference, as well as published in a medical journal.

Ongoing projects

- An investigation into the parent experience of antenatal diagnosis with ultrasound
- The views of genetic testing in families with a history of an Upper Limb Difference (ULD)
- Instituting patient rated outcome measures into the Australian Hand Difference Register

Presentations and publications

Presentations

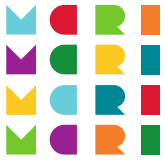
A/Prof David McCombe presented the Australian Hand Difference Register at the Plastic Surgery Congress in Melbourne.

Publications

The AHDR was promoted in two articles published during 2019. A/Prof David McCombe was interviewed about the AHDR for "Australia's Plastic Surgeons- Restoring and Transforming" - a book released by the Australian Society of Plastic Surgeons.

He was also interviewed for an article on Limb Difference for the Source Kids magazine. This featured in the Summer 2019 edition (Issue 22).





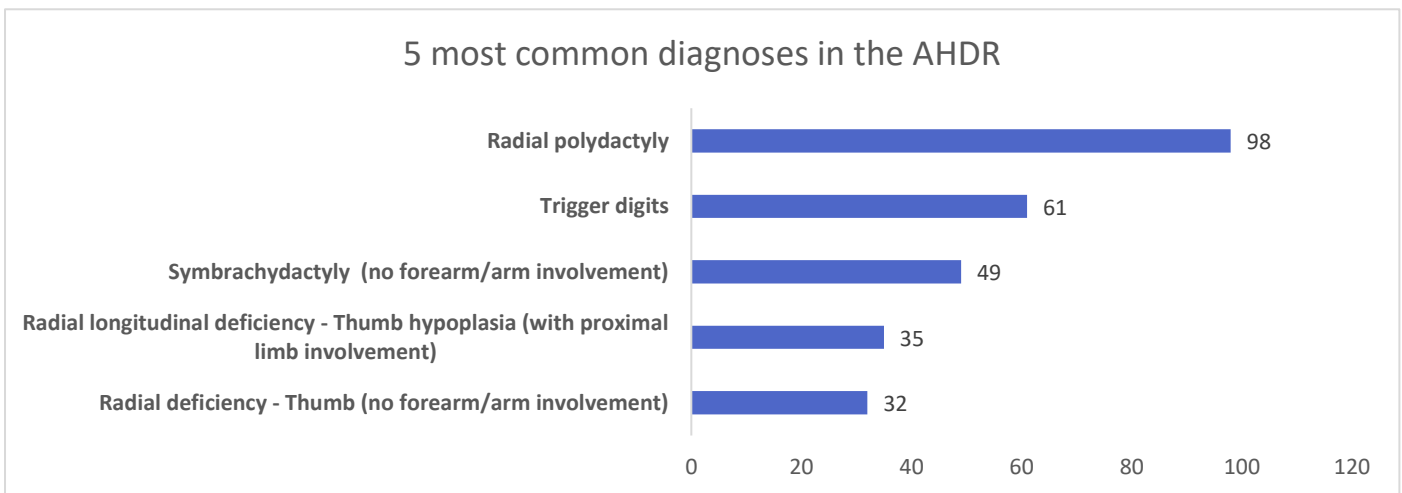
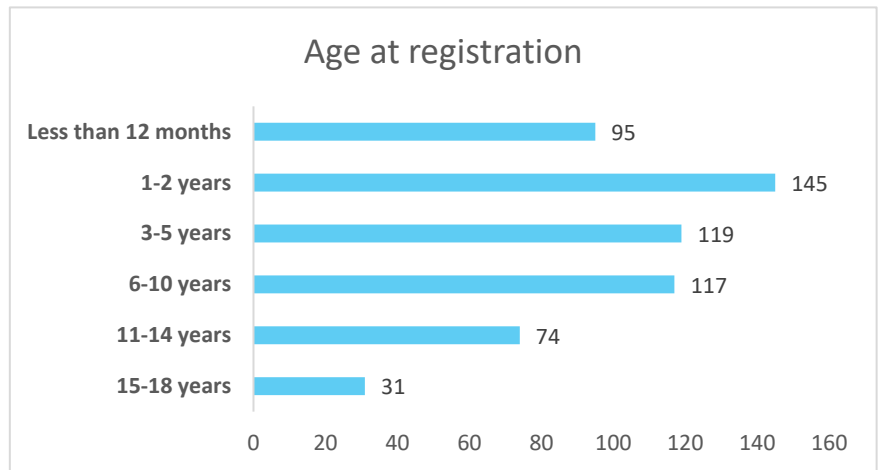
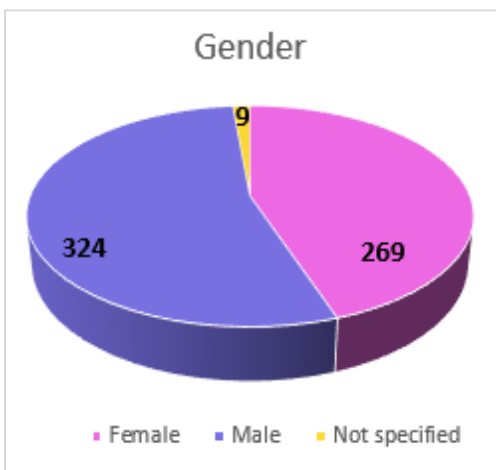
Summary of data held in the AHDR (as of 31st December 2019)

There are 602 children registered on the AHDR. Of these, 256 questionnaires have been completed.

Gender data are similar to 2018 with a slightly higher number of males enrolled into the register (54% male : 45% female, 1% gender not specified).

The 5 most common diagnoses are also similar to what we saw in 2018.

The average age of children at registration is 5.3 years of age.



Acknowledgments

We would like to thank all the AHDR families for their time to participate in the register.

We would also like to thank the Australasian Foundation for Plastic Surgery and the Aussie Hands Foundation for their support.



Australasian
Foundation for
Plastic Surgery



The Aussie Hands
Foundation Inc