AHDR Annual Report 2020

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
- identify the effects of hand differences on children
- decide how best to manage hand differences

Changes in 2020

2020 brought everyone many challenges but the AHDR continued. Recruitment slowed down nationwide, but we expanded our recruitment sites and will add more in 2021.

2020 also saw the introduction of an updated version of the Oberg Manske Tonkin (OMT) classification system. This is used by health care professionals internationally when giving a diagnosis.

Research projects

Saskia Tyas: University of Melbourne, Master of Genetic Counselling student

This year Saskia completed a research project titles "The perceptions of genetic testing among families with a history of Congenital Upper Limb Difference (CULD)". She interviewed ten parents of children with a CULD and found that participants identified a range of benefits and disadvantages to genetic testing.

"I think sometimes it's better not to know… because once you know then you have a decision to make…" (**Anna**, mother of child with isolated CULD)

"….. so the more you know the more you can understand it and plan and prepare …" (**Gail**, mother of child with isolated CULD)

David O'Keefe: Junior Doctor in Obstetrics & Gynaecology at the Mercy Hospital for Women

David did a project titled: "Prenatal and postnatal diagnosis of Congenital Hand Differences: The first 3 years of the Australian Hand Difference Register". He found that 1 in 5 (20%) of CULD had been found during pregnancy.
His poster is being presented at the conference of the Perinatal Society of Australia & New Zealand in April 2021.

Ongoing projects

- introducing some patient-rated outcome measures, called PROMIS. These surveys will be sent to participants who consent to this research.
- collaboration with the International Congenital Hand Anomaly Discussion (ICHAD) group - Controversies in Congenital Hand Difference Classifications
- Fanconi Anaemia Screening

Presentations and publications

Presentations

McCombe D. Clinical Registries and Congenital Hands Asia-Pacific Federation of Societies of Surgery of the Hand Meeting, Melbourne 2020

Publications

McDougall L, Kennedy J, Coombs C, Penington A. The psychosocial impact of congenital hand and upper limb differences on children: a qualitative study. *J. Hand Surg Eur Vol. 2020 Oct 29*

McCombe D, Coombs C, Tolerton S. Keeping up to date with classification of congenital upper limb differences: the Australian perspective. *J. Hand Surg Eur Vol.* 2020 Dec; 45(10):1111-1112.

Murdoch Children's Research Institute
50 Flemington Rd, Parkville
Victoria 3052 Australia
ABN 21 006 566 972

T +61 3 9936 6766
E ahdr@mcri.edu.au
W mcri.edu.au/ahdr

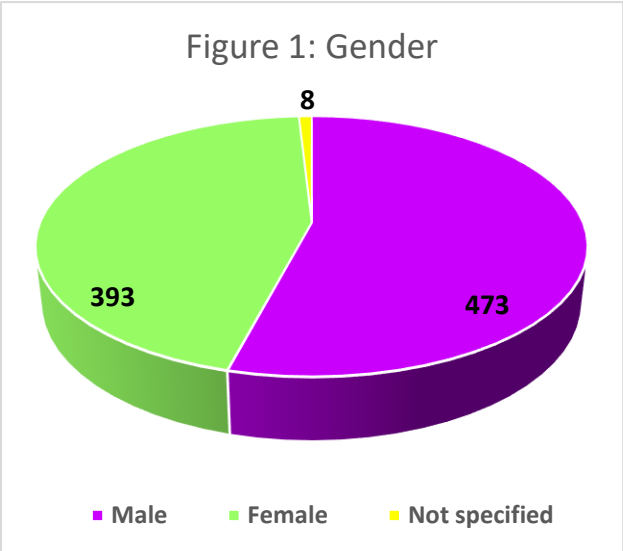
Summary of data held in the AHDR (as of 31st December 2020)

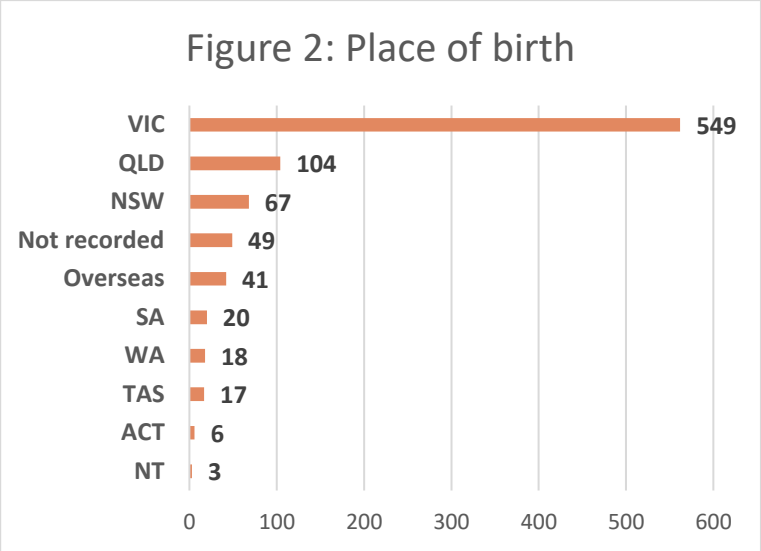
There are 874 children registered on the AHDR. Of these, 349 questionnaires have been completed.

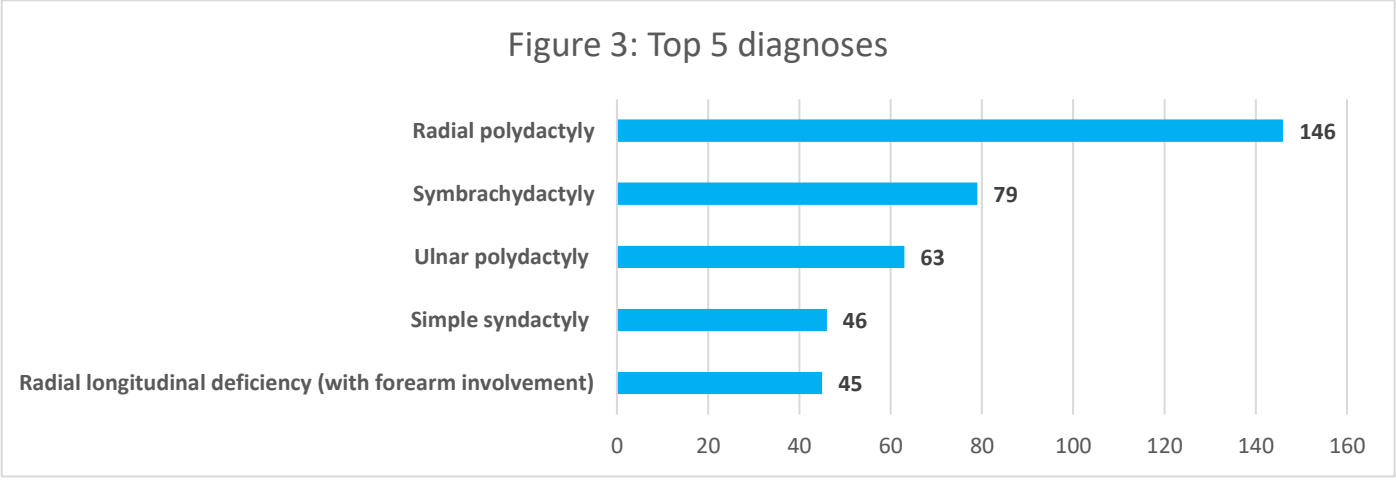
Figure 1: Gender data are similar to previous years with a slightly higher number of males enrolled (54% male : 45% female, 1% gender not specified).

Figure 2: 63% of children were born in Victoria. Thanks to the national rollout of the AHDR we now have every state and territory represented.

Figure 3: The top 5 diagnoses are slightly different to previous years due to changes in the classification system. With the introduction of the updated OMT classification system, we no longer include 'trigger digits'.







Acknowledgments

We would like to thank all the AHDR families for their time taken 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. AND a special thank you to the McNally Family Foundation who are providing funding for the next 3-5 years – we are extremely grateful for this ongoing support.

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