

AHDR Annual Report 2018

Introduction

The newly established Australian Hand Difference Register (AHDR) is a database of children born with a hand and/or arm 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

The AHDR is managed by a team comprising expert clinicians at The Royal Children's Hospital (RCH), Melbourne and researchers at the Murdoch Children's Research Institute.

The AHDR began with funding donated by The Aussie Hands Foundation (1/06/2016 – 31/03/2018; \$75,830). Recruiting began in August 2017, following receipt of ethics approval to establish the Register. Funding until December 2020 has now been obtained from the Australasian Foundation for Plastic Surgery (2018-2020: \$131,400). The funding is used to provide a Register Manager (Joanne Kennedy) and day to day running costs (stationary, printing, telephone, postage).

Launch

On Thursday 31st May, 2018, Dr Richard Barnett, Chair of the Australasian Foundation for Plastic Surgery, officially launched the AHDR at The RCH. The audience were also privileged to hear from Mrs Elizabeth Serpell, founder of The Aussie Hands Foundation; parent, Ms Alice Gower and her daughter, Miss Cassie Tibbits; and Mr David McCombe, RCH Paediatric Hand Surgeon.



Top left: Miss Cassie Tibbits wows the audience with her story

Top right: Mr David McCombe discusses how the register works

Bottom left: Dr Richard Barnett, Ms Alice Gower, Miss Cassie Tibbits, Mr David McCombe and Mrs Elizabeth Serpell

What we collect for the AHDR

Minimum data set: For each eligible child, the doctor will record a minimum data set during their clinical consultation. The data set consists of the child's initials, gender, year of birth, Australian state of birth (or country, if born overseas), whether they are a new or review patient, their diagnosis (as classified by the Oberg, Manske and Tonkin (OMT) classification of congenital hand and upper limb anomalies (International Federation of Societies for Surgery of the Hand (IFSSH) 2014), and parent contact details if permission is given to being contacted about the register.

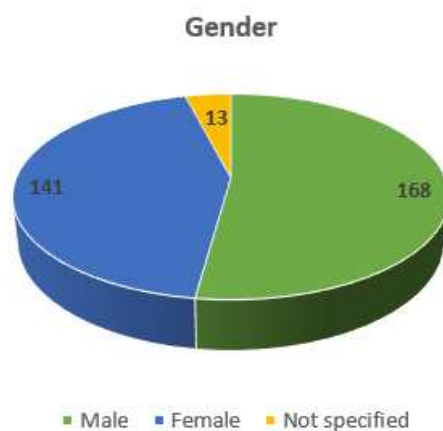
Parents who have given permission to be contacted are then telephoned by the Register Manager to discuss the study and arrange consent to put their information onto the AHDR.

Questionnaire: Once consent is received, a questionnaire is sent for completion by the parent/mature minor. The data collected from the questionnaire include demographics, perinatal data, birth anomalies, family history, functioning and treatment, and child health and development.

One of the challenges of the AHDR is the loss of potential registrants after the initial contact. Several methods are being trialled to increase the participation numbers.

For those who do participate by consenting to their child's information going onto the AHDR, we have a questionnaire completion rate of 78.9%.

Summary of data in the AHDR (as of the 14th December 2018)



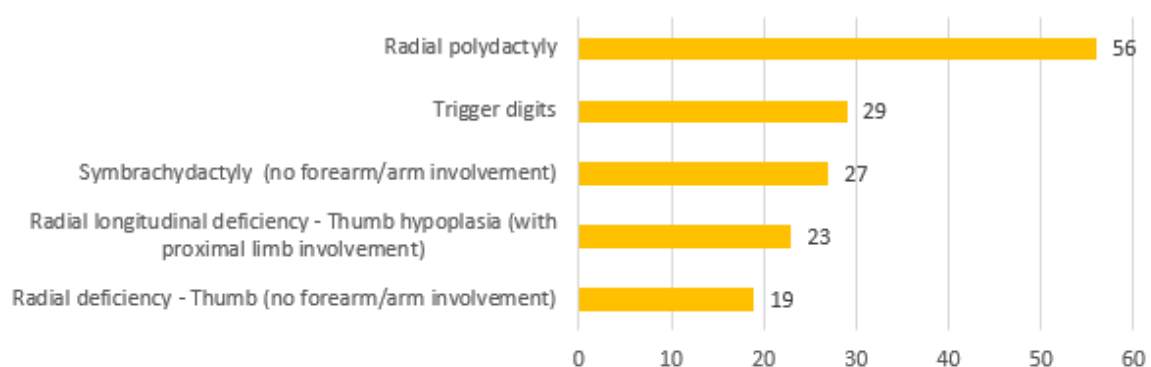
Questionnaire



* We have 142 questionnaires completed on 62 female and 80 male children.

* 126 of these questionnaires were completed by email, 15 by post and 1 via telephone

5 most common diagnoses



Presentations and Publications

The Hand Surgery community has been informed and updated regarding the development and progress of the AHDR through presentations at scientific meetings across the country including:

Victorian Hand Surgery Society Annual Meeting, Melbourne, 2017

Australian Hand Surgery Society Annual Meeting, Perth, 2018

RACS Annual Scientific Congress, Sydney, 2018

Victorian Hand Surgery Society Annual Meeting, Melbourne, 2018

The AHDR has also been promoted to Plastic surgeons by a published editorial in the Australian Journal of Plastic Surgery:

McCombe D and Coombs CJ. The Australian hand difference register: sharing clinical experience. Aust J of Plastic Surgery, 2018, 2: 19-20.

Expanding the AHDR

To begin with, the AHDR has focussed on children attending clinics at The Royal Children's Hospital, and the private practices of the RCH surgeons, but is in the process of being expanded; the sites Australia-wide are:

- The Royal Children's Hospital, Parkville, Vic –commenced recruiting in August 2017
- Monash Children's Hospital, Clayton, Vic – recruitment to commence Jan 2019

The following sites are all in the process of gaining approval to start recruiting in 2019:

- Sydney Children's Hospital, Randwick, NSW
- Children's Hospital, Westmead, NSW
- Lady Cilento Children's Hospital, Brisbane, Qld
- Women's and Children's Hospital, Adelaide, SA
- Perth Children's Hospital (formerly Princess Margaret Hospital), WA