



RACP Foundation Research Awards

PROGRESS REPORT

Project / Program Title	Improving treatment and outcomes of congenital hearing loss at the population level	
Name	Dr Valerie Sung	
Award Received	2017 Cottrell Research Establishment Fellowship	
Report Date	29 June 2017	
Chief Investigator / Supervisor	Valerie Sung / Melissa Wake (supervisor)	
Administering Institution	Murdoch Children's Research Institute	
Funding Period	Start Date:	1 February 2017
	Finish Date:	31 January 2018

PROJECT SUMMARY

Around 600 Australian babies are born with congenital hearing loss each year. Despite great advances in early diagnosis and treatment, affected children have language and other skills well below what they can potentially achieve. My research a) identifies early genetic, clinical and psychosocial factors that affect hearing loss outcomes, b) uses this information to enable early prediction of future outcomes to direct counselling and management, and c) discovers ways to prevent hearing loss progression, with a focus on congenital cytomegalovirus infection detection and management.

PROJECT AIMS / OBJECTIVES

My ultimate goal is to discover novel treatments for congenital hearing loss that can be applied systematically to ensure the best possible care and outcomes for every affected child. I aim to establish a national network to pool resources, standardise care and catalyse a platform to carry out multi-centre randomised controlled trials to advance outcomes for congenital hearing loss. Working within a whole-of-population framework, I specifically aim to:

- 1) Examine secular trends in outcomes.
- 2) Build the foundations to develop a personalised predictive tool to direct management and research.
- 3) Pilot the feasibility and cost-effectiveness of targeted salivary cytomegalovirus (CMV) testing in the early weeks of life, targeting the only known reversible cause of congenital hearing loss.

SIGNIFICANCE AND OUTCOMES

The first 6 months of this fellowship has led to the following outcomes:

- 1) Successful recruitment and baseline data collection of >50 new participants in the last 6 months such that VicCHILD now has >600 participants since its inception in 2011.
- 2) Outcome data collection from 5-7 year old participants (n~80 by the end of 2017).
- 3) An expanding congenital hearing loss biobank with rich and unique genotypic, phenotypic, hearing and psychosocial data which can be used to identify early predictors of outcomes and enable future personalised prediction medicine as well as reduction in unnecessary healthcare use.
- 4) A national network of health professionals who are in the process of publishing a national consensus guideline for the investigation of childhood hearing loss, ultimately leading to reduction in variability of care for these children. This network will in 2018 aim to commence the groundwork to establish a national congenital hearing loss registry to track outcomes and inform clinical practice.
- 5) Commencement of a qualitative study in preparation for a pilot randomised trial to determine the effectiveness of early hearing aids fitting in infants with mild hearing loss, a practice that is already widespread despite lack of evidence. The pilot trial will be essential in working towards a large multi-centre national trial. This research will alleviate the burden on audiologists and families in the decision making process for early hearing aid fitting. It will also potentially address healthcare overuse and reduce unnecessary healthcare costs.
- 6) Established groundwork in testing the feasibility of targeted congenital CMV screening throughout the state of Victoria, which is due to commence in early 2018.

PUBLICATIONS / PRESENTATIONS

Manuscripts submitted/ in preparation for submission:

1. Downie L, Halliday J, Burt R, Lunke S, Lynch E, Martyn M, Poulakis Z, Gaff C, Sung V, Wake M, Hunter M, Saunders K, Rose E, Rehm H, Amor D. A protocol for whole exome sequencing in newborns with congenital deafness – a prospective population based cohort. Submitted to BMJ Open Paediatrics May 2017.
2. Sung V, Smith L, Carew P, Poulakis Z, Burt R, Tobin S, Wake M. VicCHILD Databank Profile. Manuscript under preparation for submission to the International Journal of Epidemiology 2017.

Presentations arising from this fellowship:

1. Healthy Hearing Symposium. "Paediatric hearing services and research in Victoria: towards a personalised predictive tool to direct counselling and management", 21st October 2016, Brisbane, Australia.
2. Child Language Centre of Research Excellence Symposium. "Childhood hearing loss research: clinical and population approaches in Victoria." Melbourne, 20th April 2017 (invited speaker)
3. Deafness Foundation Hearing Symposium. "CHAMP – Australian Paediatric Guidelines for Investigation of Childhood Hearing Loss" 25th August 2017 (invited speaker)