



## RACP Foundation Research Awards

### FINAL REPORT

<b>Project / Program Title</b>	Changes in Physical Function of Young Persons with Longitudinal Fibular Deficiency	
<b>Name</b>	Dr Louise Tofts	
<b>Award Received</b>	2018 AFRM Research Development Grant	
<b>Report Date</b>	18 May 2019	
<b>Chief Investigator / Supervisor</b>	A/Prof Verity Pacey	
<b>Administering Institution</b>	The Childrens Hospital at Westmead	
<b>Funding Period</b>	Start Date:	1 January 2018
	Finish Date:	1 January 2019

#### PROJECT SUMMARY

This study aims to assess the physical function of young persons with Longitudinal Fibula Deficiency (LFD) a congenital failure of formation of the fibular bone which causes the leg to be very short and foot small. with missing toes.

The study will measure how physical function changes over time as young people with this condition grow up, and will compare their physical abilities with unaffected peers. The anatomical changes of LFD are well documented, this study will describe the impact of those differences on young people's everyday life.

#### PROJECT AIMS / OBJECTIVES

##### **Current research provides little information on a child with LFD's daily function**

We now have a paper under review with results from the baseline data collection which describes the daily function of the group in detail.

##### **Change in function during childhood and adolescence is not well understood**

In order to understand the impact of surgical and therapy interventions on a child's daily function. it is essential to first understand how a child's function changes with time. There is currently no longitudinal data on how strength, balance, mobility, physical activity participation and quality of life of children with LFD changes over time. Whether or not children with LFD progress these functional abilities at a similar or different rate to their unaffected peers is also unknown. Current management, including orthopaedic, prosthetic and therapy treatment strategies, are therefore based on point in time assessments of children without an evidence base on which to understand the likely changes in a young person's physical function as they become older. We are currently

65% through collecting progress data, with multiple interventions already undertaken, as this wave completes we will have a wealth of information on change in the group.

### **Project Objectives**

The primary aim of this study is to describe changes in the physical function of young persons with longitudinal fibular deficiency (LFD) over a 12 month period. Critical timepoints for functional changes, and clinical assessments most useful to identify change in children with LFD, will be identified.

### **SIGNIFICANCE AND OUTCOMES**

Management of this condition is becoming increasingly controversial with more drift towards limb salvage, as this can result in poor functional outcomes compared to a well fitted modern prosthesis. This study is providing much needed current data on function in a large group of patients covering both amputees and limb salvage patients with the same condition.

The baseline data has reorientated local practice to careful consideration of likely functional outcomes when planning surgery.

We are planning on completing this assessment and a 3-year assessment to have further progress data on development of motor skills and function in this group.

### **PUBLICATIONS / PRESENTATIONS**

Abstract accepted for a free paper presentation at ISPO Japan 2019:

"Physical Performance of Children with Longitudinal Fibular Deficiency (Fibular Hemimelia)" (Submission ID 398) has been accepted for presentation at the ISPO 17th World Congress, taking place from 5 to 8 October 2019

Paper "Physical Performance of Children with Longitudinal Fibular Deficiency (Fibular Hemimelia)" submitted to Journal of Paediatric Orthopaedics, currently under review

The work has been presented at Macquarie University and The Children's Hospital at Westmead (physiotherapy and orthopaedics departments). It has been presented in webinar format to the Australian orthotists and prosthetists association and will be presented at ISPO 2019.