

# Plain Language Statement

Department of Audiology & Speech Pathology, Melbourne School of Health Sciences; Faculty of Medicine, Dentistry & Health Sciences



**Project:** Exploring the support needs of parents/carers of young children with Usher syndrome.

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## Introduction

Thank you for your interest in participating in this research project. The following three (3) pages will provide you with further information about the project, so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

## What is this research about?

This research is about understanding the experience of parents/carers of children with Usher syndrome in the period between birth to 5 years of age. We would like to ask parents about the experiences they had during this early period and their needs for support. Based on the information we collate from our participating parent/carer group, we will be able to identify ways in which parents/carers can be supported more effectively.

## What will I be asked to do?

Should you agree to participate you will be asked to spend one hour of your time participating in an online video conferencing call with one of the investigators. We will

use Zoom (or another platform of your choice). The interviewer will be an individual with experience and knowledge of Usher syndrome. The interview will be video- and audio-recorded. You will be asked questions about your experiences and support needs as the parent/carer of a child with Usher syndrome. The discussion will focus on what was important to you and your family. You will also be asked to spend 5 minutes of your time answering demographic questions in an online survey before the interview. These will be questions such as your child's age at diagnosis and their degree of hearing and vision impairment, so that we can describe the sample of people participating in the research. This online survey link will be sent to you prior to the interview, and you will have an opportunity to further discuss the survey questions with our researcher at the time of your interview.

As thanks for your time, we will provide a \$50 gift voucher.

### **What are the possible benefits?**

There are no particular benefits to you. The outcomes of the research will help to develop tools and/or programs to support families of children who receive a diagnosis of Usher syndrome in the future. These will be developed and/or used by organisations such as UsherKids Australia.

### **What are the possible risks?**

It is possible that talking about your experiences soon after your child received a diagnosis of Usher syndrome may result in you feeling upset. You can stop your participation at any time during the interview, and you are under no obligation to participate in this research. The interviewer can debrief with you directly after the interview if you would like this, and/or refer you to support services such as Beyond Blue (1300 22 4636), Retina Australia (1800 999 870) and UsherKids Australia ([info@usherkidsaustralia.com](mailto:info@usherkidsaustralia.com)).

### **Do I have to take part?**

No. Participation is completely voluntary. You are able to withdraw at any time. You can request that we do not include your data in the analysis. If the analysis is already complete at the time you make this request it will not be possible to extract your individual data from the group analysis.

### **Will I hear about the results of this project?**

You can provide us with your email if you would like to receive a written summary of the outcomes of the research. We will also publish the results in a scientific journal and present them at scientific conferences to share the outcomes with clinicians, researchers, educators, and service providers.

### **What will happen to information about me?**

A written record of your interview will be typed by the researchers in this study. This will enable us to analyse the text using a method called thematic analysis. Quotes from

you may be used in publications of this research. We will not use identifying information such as names or locations in these quotes. Due to the small number of participants expected to be involved in this study, it may not be possible to guarantee that a reader of the research will not recognise a quote from you. You will be given the opportunity to review your own quotes and can ask that we do not use them. All data in this project will be destroyed 5 years after this research is published; this includes all audio/video recordings of the interviews.

### **How has this research been funded?**

This project has been funded by a Melbourne Disability Institute grant to UsherKids Australia, who are working in collaboration with researchers from The University of Melbourne, the Centre for Eye Research Australia, and the University of South Australia.

### **Where can I get further information?**

If you would like more information about the project, please contact the researcher: Associate Professor Lauren Ayton ([layton@unimelb.edu.au](mailto:layton@unimelb.edu.au), or (03) 8344 3441).

### **Who can I contact if I have any concerns about the project?**

This project has human research ethics approval from The University of Melbourne [ethics approval ID 22754]. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 8344 1814 or Email: [research-integrity@unimelb.edu.au](mailto:research-integrity@unimelb.edu.au). All complaints will be treated confidentially. In any correspondence, please provide the name of the research team and/or the name or ethics ID number of the research project.