UsherKids Australia is a parent-led support organisation which aims to empower the Usher Community through support, connection and knowledge. The organisation received a grant from the Melbourne Disability Institute which connected it to researchers at The University of Melbourne and the Centre for Eye Research Australia. Together we investigated how aware relevant allied healthcare professionals are of the cause, common symptoms, and professionals who play a key role in the care of Usher syndrome. This research will help Usher Kids Australia to provide further, targeted professional development to relevant health care workers so as to improve the care they provide to families. Here, we have summarised our research findings (refer below for the link to our full published article):

Usher syndrome is a rare genetic condition that causes deaf-blindness, affecting approximately 1 in 6,000 people worldwide. This condition involves hearing loss, progressive vision deterioration, and sometimes problems with balance. To ensure the best care for those affected, a team of different healthcare professionals is needed. In this study, we aimed to find out how aware healthcare clinicians, specifically audiologists, optometrists, and orthoptists, are about Usher syndrome.

To do this, we conducted an online survey targeting clinicians working in Australian university-affiliated clinics. The survey asked respondents basic questions about Usher syndrome, its symptoms, and which healthcare professionals were essential for managing the condition. Participants included 27 audiologists, 40 optometrists, and 7 orthoptists, with an average age of 37 and around 13 years of clinical experience.

We found that most of the clinicians knew that Usher syndrome was a genetic condition (86%) and that it affected hearing and vision (97%), however their awareness of the balance problems sometimes associated with Usher syndrome was not as good. They also did not fully recognize the importance of certain healthcare professionals in managing the condition. For example, many respondents did not realise the critical roles of speech pathologists, geneticists, and genetic counsellors. Furthermore, respondents were often not aware of specific care aspects related to their own discipline.

The results of this study highlights that healthcare clinicians need more education about Usher syndrome to provide better care. Improving their understanding of the balance issues and vision loss experienced by those with Usher syndrome is crucial. It is also essential to help them to recognize the valuable roles of different healthcare professionals in multidisciplinary care so that appropriate referrals occur. By increasing awareness and knowledge, healthcare clinicians can support individuals with Usher syndrome and their families more effectively. Future research should focus on developing effective educational tools to enhance awareness among healthcare professionals and improve the quality of care for those living with Usher syndrome.

To read the full publication, visit<https://www.dovepress.com/getfile.php?fileID=91139>

For more information about UsherKids Australia, visit<https://usherkidsaustralia.com/>

Figure 1 Child with profound sensorineural hearing impairment due to Usher syndrome using a cochlear implant to access sound. Image courtesy of K. Disher-Quill

