

Position Title: UsherKids Australia Case Coordinator

Salary: \$65,132 pro rata + super

Term: Part time fixed term 18 month (0.25 FTE), plus 3 month probation period

Reporting Manager: Director

Location: Home-based

Company Overview

UsherKids Australia is a not-for-profit charitable organisation that was established in 2016 as a parent- led support group to enhance the lives of children diagnosed with Usher syndrome and their families in Australia. The organisation's mission is to ensure children diagnosed with Usher syndrome and their families have access to an informed, committed and caring community of clinicians, service providers, educators, researchers and peer support networks to allow them to thrive in their everyday endeavours.

Usher syndrome is an inherited condition characterised by congenital hearing loss or deafness, progressive vision loss due to retinitis pigmentosa (RP), and in some cases vestibular dysfunction. It is the most common cause of deafblindness, affecting an estimated 400,000 people worldwide. There are three types of Usher syndrome with more than 13 genetic variations identified with the condition.

The organisational aims stem from three founding principles:

To identify all with Usher syndrome to assist the collaboration of research efforts both in Australia and globally.

To educate provides information to newly diagnosed families, as well as educating healthcare professionals, educators and support staff on the needs of children to maximise inclusion and best clinical practice.

To support families, children, siblings, healthcare professionals, communities, sporting clubs, schools, service providers and those involved in the care and education of these children to ensure they have the knowledge, resources and skills to help them thrive.

Advances in genetic and genomic testing make earlier diagnosis of Usher syndrome accessible to more and more children born with hearing loss. This leaves a distinct gap in the provision of

services and support for families, as well as an evidence-based clinical pathway for clinicians to guide their care for these children.

Earlier diagnosis of children with Usher syndrome can also occur before the onset of the functional impact of RP. This creates an opportunity to provide children with the building blocks to cope with the deterioration of their vision loss. The long-term goal is to better equip them to engage in education, employment and community activities, increasing their independence and quality of life into adulthood.

Position Overview

The UsherKids Australia Case Coordinator is a newly created position made possible through funding by the National Disability Insurance Scheme (NDIS) Information, Linkages and Capacity Building (ILC) program. The two-year funded project, UsherKids Connect, aims to build the individual capacity of parents, carers and families of children with Usher syndrome in Australia to better support the ongoing needs of their children in various settings. UsherKids Australia will deliver a series of workshops for both parents, carers, and families, as well as for the range of professionals working with children with Usher syndrome in clinical, service and educational settings. The workshops aim to address some of the key barriers families face with raising a child with this complex condition.

There are approximately 45 families in the UsherKids Australia community, with the project aiming to offer a variety of ways to be involved, such as on a one on one basis, in group workshops as well as having the option to access the workshop content on demand in their own time. The Case Coordinator will work from and will be responsible for working with approximately 10 families across Australia with Usher syndrome on a one on one capacity during the term of the project. As such, the Case Coordinator time commitment will be a combination of weekday, weeknight and weekend work to ensure families can be contacted at a time that best suits them.

The Case Coordinator will support the operations of UsherKids Australia to successfully deliver the UsherKids Connect project as part of the NDIS ILC grant guidelines.

Key Responsibilities

- To make regular contact and develop rapport with parents/carers of children with Usher syndrome across Australia with the aim of establishing ways in which UsherKids Australia can provide improved individual support, guidance and connections within their communities that may address their unmet needs.
- To provide support on the UsherKids Connect project throughout the year, such as with the content of the monthly online workshops, parent/carer registrations, accessibility requirements, advertising and marketing etc.
- To provide general assistance to the Directors of UsherKids Australia with the day to day management of the organisation and other ad hoc duties as required including administration tasks, parent surveys, social media, educational material, editing, proofreading, grant writing.
- Actively practise and promote all required safety, ethical and 'good practice' procedures
- Exercise initiative and offer suggestions for improving organisational processes.
- Adopt effective day to day management of areas of responsibility, maintain appropriate administrative systems to ensure an efficient and consistent approach

Selection Criteria

- Tertiary qualification in a related field or proven minimum of 2 years relevant experience
- Demonstrated intermediate skills and knowledge using the Microsoft Office suite
- Excellent time management skills and the ability to multitask
- Demonstrated high attention to detail
- Strong interpersonal skills and communication skills - both written and verbal
- Respect for confidentiality and professional boundaries
- Strong skills in digital and social media
- A strong sense of initiative and can-do attitude
- Experience working with limited supervision
- Ability to handle sensitive and confidential information and material
- Demonstrated ability to cooperate and work well with others in the pursuit of team goals

Desirable

- Experience in a not for profit, research and/or academic institution
 - Experience in project management
 - Counselling experience
 - A demonstrated interest in genetic health/supporting the genetics community
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Conditions of Employment

- Working with Children & National Police Clearance (if appointed) in compliance with the Victorian Government's Child Safety Standards
 - The right to reside and work in Australia and you meeting any applicable visa conditions
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