

Role Description:

Child and Adolescent Cystic Fibrosis Consumer Reference Group of WA

Expressions of interest are being invited for our Child and Adolescent Cystic Fibrosis Consumer Reference Group of WA.

This group is a formalized group of parents and patients with cystic fibrosis brought together to:

- Support the development of partnerships between consumers, researchers, research organizations and medical staff.
- Provide a consumer perspective to both clinical and research aspects of cystic fibrosis.
- Advise about clinical and research priorities, practice and policies.
- Enhance the quality and relevance of clinical activities and research through consumer participation.

Key duties:

- Attend meetings in person or virtually. These are planned to occur at Telethon Kids Institute, in the evening, once every 3 months.
- Provide advice and expertise relating to consumer priorities and perspectives regarding research and clinical activities.
- Where appropriate disseminate information or provide access to any relevant parent or community groups.
- Provide input into reporting of consumer participation activities.
- Provide regular updates to the group on participation activities.
- Participate and provide input into activities of the committee. These may include the following:
 - Provide advice on appropriateness of language and content of study information sheets.
 - Provide feedback about impact/burden of current research projects on participants and how this could be improved.
 - Provide insight into topics of interest to consumers that may be new areas for researchers to consider.

Support:

- Training relevant to the consumer representative role will be made available to the consumer representative.
- The purpose and structure of the group is further described in the Terms of Reference. (Available on request).

Please refer to the [AREST CF Website](#) to request further information or to express an interest in the position.