

## **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.