

WA Paediatric Bronchiectasis Community Reference Group

Inviting expressions of interest for the Western Australian Paediatric Bronchiectasis Consumer Reference Group (CRG)

This is a group for parents and carers of children who have bronchiectasis.

WE WANT THE GROUP TO BE INVOLVED WITH:

- Support the development of partnerships between consumers, researchers, Telethon Kids and Perth Children's Hospital
- Provide a consumer perspective to both medical and research aspects of bronchiectasis
- Advising about research and clinical priorities, practice and policies
- Improving the quality and relevance of research and clinical activities through consumer involvement

KEY DUTIES:

- Attend two meetings in person or virtually a year. These are planned to be held at Telethon Kids Institute, in the evening with the option to attend via teleconference, more meetings may be needed and will be determined by the group
- Provide advice and expertise on what is important to you about bronchiectasis research and care in the clinic
- Help share information or provide access to any relevant parent or wider community groups
- Provide input into reporting of consumer participation activities and development strategies
- Participate and provide input into activities of the committee. These may include the following:
 - Provide advice on appropriateness of language and content of research study information sheets and questionnaires
 - Provide feedback and input regarding the how the care for children with bronchiectasis is organised within Perth Children's Hospital
 - Provide feedback about potential research projects
 - Share ideas on areas of interest to consumers that the team may be able to research

SUPPORT:

- Free training will be provided for members on the role for the group
- The purpose and structure of the group is further described in the Terms of Reference. (Available on request).

For more information, visit: walyanrespiratory.telethonkids.org.au/projects/bronchiectasis



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