

Benefits of a cystic fibrosis consumer reference group in the paediatric clinical and research settings

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BACKGROUND

- WA has a combined clinical and research cystic fibrosis (CF) Consumer Reference Group (CRG) that provides input into services and research provided by Perth Children's Hospital and Telethon Kids Institute.
- The WA Child and Adolescent CF CRG was formed in April 2015. The first meeting was attended by 14 members, including 7 consumer members and representatives from Child and Adolescent Health Service (CAHS), Telethon Kids Institute and Cystic Fibrosis Western Australia (CFWA).
- The CRG supports the development of partnerships between consumers, researchers, research organisations and medical staff.
- Meetings are held every 3 months, and at times members are contacted to review documents in-between meetings.
- At each meeting, issues relevant to consumers' experience in the CF clinic are discussed, and researchers present their proposals for input

AIM and METHODS

- AIM:**
- To describe the contribution of the WA Paediatric CRG to both the clinical service and research teams at Telethon Kids Institute from its inception in April 2015.
- METHODS:**
- Analysis of meeting minutes and inputs from CRG have been captured through meeting minutes and have been analysed in terms of impact on the program.

RESULTS

| Meetings | Research Presentations | Clinical Initiatives | Community Initiatives | Documents developed/reviewed |
|----------|------------------------|----------------------|-----------------------|------------------------------|
| 18 | 28 | 13 | 12 | 8 |

Since the CRG's inception, 18 meetings have been held. Overall highlights and achievements have been:

- Consumer members have provided feedback on the feasibility of research proposals, study documentation and information sheets.
- The CRG has provided input for each research proposal prior to the proposal being presented to the AREST CF Scientific Management Committee (SMC). This has saved time in the approval process and allowed for valuable consumer input into research. This enables research to be tailored to meet consumer needs as well as scientific integrity. Two experienced consumer members attend SMC meetings to add further consumer perspective to the proposal.
- We provide input into the annual 'Evening with CF Scientists' program where CF related scientific endeavours at Telethon Kids are presented to the broader community.
- We disseminate information to the wider community through CFWA and the Parents Facebook Group.
- Since 2015 we have advocated to improve the process and time required to fill prescriptions at Pharmacy. Consumers partnered with Pharmacy management to develop a method to reduce pharmacy wait times. Various methods have been trialled and in July 2019 a new CF pharmacy pre-order service was implemented.

Highlights and achievements by year:

| Year | Research Highlights | Clinic Highlights |
|------|--|---|
| 2015 | <ul style="list-style-type: none"> • Review of and input into the SHIP-CT trial (Hypertonic Saline in Preschoolers) | <ul style="list-style-type: none"> • Improvement of clinic visits by implementing a way for families to identify other families with CF. • Review of an information pack for newly diagnosed families. |
| 2016 | <ul style="list-style-type: none"> • Development of research question: Led to the creation of the Circle of Care Study (a project to provide insight into how families deal with children with chronic illness and how to better support families). • Research presentation about BEAT-CF a new adaptive trial design study; the group requested ongoing updates from BEAT-CF. | <ul style="list-style-type: none"> • Provision of input into the Hospital in the Home (HITH) process • We were shortlisted for a WA Health Excellence Award. |
| 2017 | <ul style="list-style-type: none"> • Provision of a letter of support for the DEFEND CF study (a project looking at CF exacerbations using MRI in addition to lung function testing and CT scans). • Research presentation on the 'Comparison of airway epithelial cell function with organoids. | <ul style="list-style-type: none"> • Introduction of portable fridges for CF inpatients after consumers' request. • Tour of the new hospital (PCH) for CRG members. • Presentation from the KKIND program which was being implemented in the hospital to aid parents and children with their experience in hospital. |
| 2018 | <ul style="list-style-type: none"> • Presentation on e-consent for the BEAT-CF study; consumers provided a letter of support for ethics approval. | <ul style="list-style-type: none"> • Advocacy for resources for role plays for children in anxious situations |
| 2019 | <ul style="list-style-type: none"> • Creation of guidelines for researchers and consumers to consider during research presentations • Research presentation on 'Developing Novel Therapies in CF To Combat Virus Infection | <ul style="list-style-type: none"> • The medical team presented information about eligibility for Orkambi |

CONCLUSION

- The CRG has given a voice to the families of patients with CF which has brought greater awareness of consumer priorities to clinicians and researchers.
- We provide valuable input into the clinical and research programs which has led to important changes to the clinical and research services.
- We work closely with the ARESTCF research team to improve the way they consult with the community.
- Looking forward, we hope to approach researchers with suggestions of research ideas that are important to the community. We will work with the research team to ensure that researchers return to the CRG to present results of the projects that have been presented to the group. The CRG will also look at ways to distribute information to the wider community.