



# The PEP Talk\*

Fall 2019

A seasonal newsletter to keep you up to date about  
CF Clinic and Research News

## Patient Survey Results – Peer to Peer Support

By Sara Thiessen, Social Work

### The Underreported Benefits of Informal Peer-to-Peer Support amongst CF Caregivers

Thank-you to all who participated in our recently implemented 'CF Support network Survey'! The results of this survey offered much insight into the ways in which you, as CF Caregivers, support your own mental wellness and the wellbeing of others. Here is a brief summary of the literature on 'peer-to-peer' support, as well as findings from our survey and questions moving forward.

If you would like to learn more about peer-to-peer support or be connected to a peer yourself please contact me directly at (604)875-2345 ext. 7013 or by email at sara.thiessen@cw.bc.ca.

### Why peer-to-peer support?

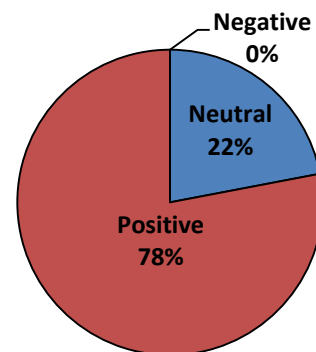
A brief review of literature amongst parent of children with chronic health conditions

- **Solidarity:** Resituating participants from individualized position of burden and isolation to confident, positive and actively connected.
- **Participation** Consistent with transitions towards increased participation and personalized medicine. Patients and caregivers have a wealth of knowledge and expertise in illness, self-management and can guide others.
- **Mutually Supportive:** The benefits of one to one peer-to-peer support extended to both the parents providing support and receiving support through mutual support, expansion of social networks and the feeling that they were supporting others.

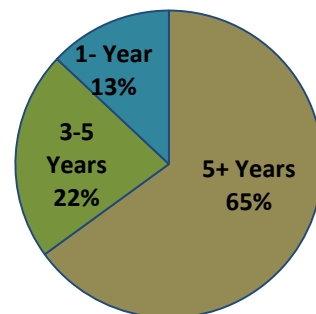
### Main findings of the 'CF Support Network Survey' (administered fall 2018)

- Many CF Caregivers are accessing peer-to-peer support informally.
- Peers are most often connecting online (e.g. Facebook).
- Lack of time and stress are reported to be the largest barriers in accessing peer-to-peer support.
- Caregivers surveyed did not access peer-to-peer support through formalized programs (0%).
- Peer-to-peer support is reported to be a positive long term social support intervention for CF Caregivers.

### Impact of Peer Support



### Length of Peer Support



### Questions Moving Forward:

- Is peer-to-peer support a mental health intervention health care practitioners should be recommending/supporting?
- Have we adequately assessed the risks associated with peer support?
  - For example, vulnerability of families or lack of regulation/training.
- Are peer-to-peer supports easier to access/more desirable than other forms of mental health support for CF Caregivers?

Recently CF Canada created an informal parent to parent support network whereby CF Canada will link up interested parents (brochure available upon request).

\*Pun Intended. PEP is the airway clearance device used by many children with CF in our clinic.

# RESEARCH NEWS

## Triple Combination Study

BCCH is excited to be participating in the VX18-445-106 Trial titled: "A Phase 3 Study Evaluating the Pharmacokinetics, Safety, and Tolerability of VX-445/TEZ/IVA Triple Combination Therapy in Cystic Fibrosis Subjects 6 Through 11 Years of Age." This open label (no placebo) study will investigate the safety and efficacy of the new triple therapy CFTR modulator tezacaftor/ivacaftor/elezacaftor in children aged 6-11 years. More information can be found at <https://clinicaltrials.gov/ct2/show/NCT03691779>

Among other criteria, participants are mainly eligible if they are:

- Between 6 and 11 years of age during the recruitment period (likely from November 2019 to January 2020)
- Have a CFTR genotype amenable to treatment with this medication:
  - o Homozygous for F508del (F/F genotype) or
  - o Heterozygous for F508del and a minimal function (MF) mutation (F/MF genotype)

We have been given 3 spots for participants in this trial (one FF and two F/MF). The number of slots and the distribution was determined by the pharmaceutical company. We know that there will likely be a high level of interest in this trial. In order to be fair, our clinic will select participants in the following manner:

- All eligible patients will be selected by a lottery process
- A non-study team member will randomly choose names and those individuals will be contacted to see they are interested in participating
- If a patient who is contacted declines participation, another name will be selected and that individual will be called to see if they are interested in participating

If you have any questions, please contact Alam Lakhani, Research Manager at 604-875-2345 ext 7606

**News Update:** Triple combination therapy "TRIKAFTA" was approved in the USA by the FDA for ages 12+: <https://www.fda.gov/news-events/press-announcements/fda-approves-new-breakthrough-therapy-cystic-fibrosis>

## CF Family Education Day

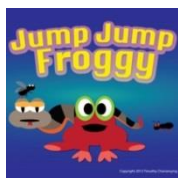
We are circulating a survey in clinic about having a family education day in the spring of 2020. Please complete when you are in clinic to let us know your interest. If you missed it we can send you a copy via email.

## Flu Season!

Flu season is fast approaching! Families should have received a letter from Dr. Chilvers with recommendations for this season's influenza vaccine (see BCCH CF website newsreel for more information).



SWORKIT KIDS



JUMP JUMP FROGGY

MOVES APP



## THERE'S AN APP FOR THAT

Here are some free exercise apps available for kids. We haven't tested them but please give them a try and let us know what you think.

GO NOODLE



SUPER STRETCH YOGA



KIDS EXERCISE ANIMAL WORKOUT



7 MINUTE WORKOUT KIDS



## FYI

Check out our website for newsreel and up to date information:

<http://www.bcchildrens.ca/our-services/clinics/cystic-fibrosis>

Questions/Comments/Ideas?  
Email: [cfqproject@cw.bc.ca](mailto:cfqproject@cw.bc.ca)

KID'S CORNER