



# **UPDATE TO MEMBERS**

Welcome to the second edition of the Elevate quarterly update to members! Elevate members have been busy these past few months, providing feedback and input on seven new opportunities. This edition of our quarterly report features a webinar focused on tips and tricks for exercise and CF, new opportunities to stay connected, an exclusive interview with Elevate member, Susan W., and so much more!

#### REPRESENTING THE CANADIAN CF COMMUNITY



- 1. **CAREGIVERS**
- 2. **UNKNOWN**
- 3. **CLINICIANS**
- **LIVING WITH CF**

SIINCE OUR LAST UPDATE, ELEVATE

MEMBERSHIP HAS INCREASED



11.3%

Many elevate members are **fundraisers** 



Elevate members have participated in 7 opportunities since our last update



## **BREATHE EASIER**

We asked Elevate members what you'd like to see in an e-newsletter from Cystic Fibrosis Canada. Nearly half of you responded, sharing your ideas and input regarding protentional topics and stories you'd like to read about.

Elevate members also helped us name our newsletter, Breathe Easier, which will launch later this month! To access informative articles about the latest advancements in research or best practices for CF care, articles by and about people living with CF, or to have your questions answered by industry and peer experts sign up today at cysticfibrosis.ca/breathe-easier!

## Ask the Experts Webinar: Trips and Tricks for Exercise and CF

On July 5th, Cystic Fibrosis Canada held our Ask the Experts Webinar: Tips and Tricks for Exercise and CF. During this hour-long session, our host, Dr. Maggie McIlwaine, Network Manager, Clinical Trial Network, at CF Canada and panelists, Dr Larry Lands CF Physician at the McGill University Health Centre, Jane Schneiderman, Exercise Physiologist, at The Hospital for Sick Children, and Nicki Perkins, a CrossFit and exercise expert who lives with CF, discussed the importance of exercise when living with CF, shared recommendations for fun, easy exercises and discussed practical tips for getting enough exercise for different age groups. Elevate members supported this initiative by sharing questions for our experts to answer during the webinar.

We'll have a recording of the session up in the next few weeks for those who were not able to join live, the recording will be available on our website.

#### THANK YOU FOR ALSO PARTICIPATING IN:

#### **Cystic Fibrosis Canada opportunities**

- Cystic Fibrosis Canada Apparel Survey
- Sharing Your Experiences with Cystic Fibrosis Canada Survey
- Resource Guide Review Focus Groups

#### Third party opportunities

- Your Experiences During the Pandemic Research Survey
- CF Carrier Screening Program (Ontario) Interviews

### Meet an Elevate Member: Susan W.

"Our CF journey is just starting and while it can be challenging, we are mostly grateful. We are grateful to have our little boy that is learning to be a strong, sensitive, and caring individual. We also have an amazing team to turn to for support. During the first week of Ewan's diagnosis our family came to stay with us and provided positivity and strength that we needed to get through those first days. We were 'Team Ewan', and we were going to be an incredible force to be going up against cystic fibrosis! We knew that cystic fibrosis would impact our lives, but we also knew that we would try very hard to not let it define our lives. We look to find a balance between being careful and just being – this balance is something we struggle with now, and probably will forever." Learn more about Susan's family journey with CF in our blog.

### **COMING UP!**

We'll have opportunities related to Cystic Fibrosis Canada's work in research, advocacy and information and support that you will not want to miss. Stay tuned!

Help us ensure many perspectives are represented through Elevate. If you know someone who would be interested in Elevate, please invite them to join today.

**Thank you for being a member of Elevate!** We are so grateful for your insights and value your input.

Elevate team

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