

UPDATE TO MEMBERS

It has been one year since we introduced our Elevate program. Over this past year, your insights and involvement have helped to ensure the work we do at Cystic Fibrosis Canada is meaningful to and resonates with our community. Thank you for giving your time, perspectives and firsthand expertise, we are stronger together!

REPRESENTING THE CANADIAN CF COMMUNITY

To celebrate Elevate's birthday, we asked for your feedback on the program. Here's what you had to say:



50% of members want to see more opportunities, including opportunities on mental health



Members feel the program provides an opportunity to engage with CF Canada in a more active role



Members hope to discuss more of the struggles and successes of the community.

MENTAL HEALTH AND CYSTIC FIBROSIS

Earlier this year, Elevate members told us that you would like to see more resources on mental health.

As a result of this feedback, we are pleased to offer an Ask the Experts webinar on mental health and cystic fibrosis on Tuesday, December 6 at 12pm ET join us along with Pat MacDiarmid MSW RSW and other experts as we discuss how to recognize symptoms of depression and anxiety in yourself or your loved ones, as well as strategies to cope with these feelings.

Register for the webinar [here](#)

THE IMPACT OF YOUR INVOLVEMENT

In September 2022, a Canada-wide survey was sent out through Elevate on behalf of Jana Kocourek, the program director of healthcare at CF Canada. The goal of this survey was to capture your experiences when it comes to accessing, Trikafta.

"As a national organization, we need to be responsive. Being able to send out a request and gather information quickly is key," - Jana Kocourek, MA, Program Director- Healthcare, Cystic Fibrosis Canada.

Jana received an overwhelming response from Elevate members. "As always, the CF community came through and provided us with valuable information about their experiences, challenges and areas to improve when it came to accessing Trikafta." said Jana. The Elevate team is excited to continue delivering chances for CF Canada staff to go further in the upcoming year.

If you want to learn more about Jana and her involvement with CF Canada, keep an eye out for her feature in our Breathe Easier newsletter, coming out next week. [Sign up today](#)

MEET AN ELEVATE MEMBER

Candice is an adult who lives with cystic fibrosis. She recently reflected on her life growing up with CF , as well as her experience being an Elevate member. "My mom told me, if I continued to do what needed to be done, I would stay healthy. I continue to live in that mindset." Learn more about Candice and her experience with CF in our blog [here](#).

THIRD PARTY OPPORTUNITY: GENETICS WORKSHOP

The Canadian Institutes of Health Research (CIHR) Institute of Genetics is [planning a workshop](#) to bring together patients living in Canada to help ensure patient and caregiver voices are heard and guide our future work. At the workshop, participants will discuss best practices in patient engagement in genetics research, focusing on equity, diversity, and inclusion.

CIHR is looking for patients and caregivers with lived experience of an inherited condition to participate in the workshop. They are especially interested in hearing from patients and caregivers who have not been engaged in research before.

This workshop will be held on **January 30, via Zoom** and participants will receive \$250 in compensation for their time. [The application form and more details about the event are here](#). Applications are due November 27!

Cystic Fibrosis Canada Opportunities	Third Party Opportunities
<ul style="list-style-type: none"> • Help determine CF research priorities • Build a better understanding of people's access to Trikafta • Help promote Elevate to a wider audience 	<ul style="list-style-type: none"> • Learn about the experiences of people living with CF in Canada that are under-represented • Survey on the 10% of the CF community that do not benefit from existing CFTR modulators • International CF survey to better understand CF research priorities

THANK YOU!

Your voices and experiences have been invaluable to work.

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!

Elevate team

