

UPDATE TO MEMBERS

It's been almost 6 months since we launched Elevate and your involvement has already greatly impacted our work at Cystic Fibrosis Canada. Your insights have also helped other organizations and researchers go further for people living with cystic fibrosis (CF) and their families.

Today, we are proud to present our first edition of the Elevate quarterly update so that you can learn more about how your participation in this community consultation program is helping the cystic fibrosis community.

SNAPSHOT OF ELEVATE MEMBERS



Elevate members represent **10 provinces and territories** across Canada.

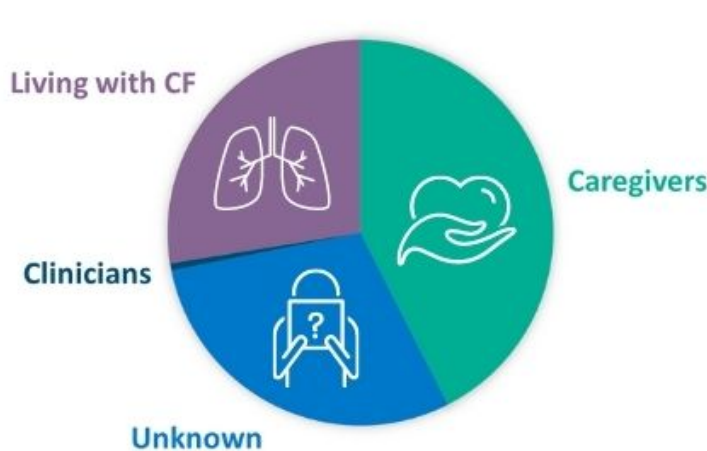
Top 3 provinces with Elevate members :

- 1 - Ontario
- 2 - Quebec
- 3 - British Columbia

38% of Elevate members are **involved with advocacy.**



Representing the CF community!



Elevate members **have participated in 10 opportunities** since the program launched.

BUILDING A NEW RESEARCH STRATEGY TOGETHER

Research is one of the most impactful ways that we can change the future of cystic fibrosis. As noted in Cystic Fibrosis Canada's new strategic plan, we are excited to reimagine our research strategy. As part of building this strategy, we sought your input in various ways to help ensure it reflects the needs and priorities of those living with cystic fibrosis and their families.

Research Priorities Setting Survey – We conducted a survey in May 2021 and heard from over 300 people living with CF and their families about their top 17 CF research priorities and interests.

Research Priorities Setting Workshop – To help further refine the list of 17 research priorities, in July 2021, we invited 28 community members to a four-hour virtual workshop. We gained insights from researchers, clinicians, people living with CF and their families and settled on the top 11 research priorities. [Read more about our steps to building a new research strategy and view the list of priorities here.](#)

Research Grants Community Reviewers – To help us determine which research proposals best align to the priorities of the CF community, in February 2022, eight community representatives from Elevate participated in our Research Grants Review. The community reviewers met with scientific experts to review the applications and provided important feedback and perspectives to help us determine which research projects to fund this year. Stay tuned for an announcement this spring about the winners.

We look forward to continuing to keep you informed and involved in the development of Cystic Fibrosis Canada's new research strategy and related research initiatives.

FURTHER EXPLORING YOUR INFORMATION AND SUPPORT NEEDS

We believe that the needs and perspectives of people living with cystic fibrosis and their families should always inform our work, as you are firsthand experts on living with this disease. We thank all of you who provided perspectives on your information and support needs, which will help guide our programming for this year and beyond.

Information and support survey – In October 2021, we asked Elevate members and our wider community to participate in a survey about your needs related to information and support, including, educational webinars, peer support, resources, and topics of interest. In total, we received over 200 responses! Below is a snippet of some of the feedback we received:

Interest in educational webinars:		Top topics of interest for info & support included:
People living with CF	84%	<ul style="list-style-type: none"> ▫ Diet and nutrition ▫ Exercise ▫ Parenting ▫ Transition of care
Parents of people living with CF	80%	
Other caregivers	68%	

Information and support focus groups – To dive deeper into the topic, we met with people living with CF and parents to better understand your information and support needs. In total, 18 Elevate members participated in three focus groups.

Stay tuned for more opportunities to come in this area as we continue to evolve our supports to address your needs.

MEET AN ELEVATE MEMBER : ARASH SORKHABI

Arash, an adult with CF who moved to Canada to be closer to his family, particularly his twin brother who also has CF, participated in one of our information and support focus groups. [Check out his blog](#) to learn about his story and experience with Elevate.

THANK YOU FOR ALSO PARTICIPATING IN:

Cystic Fibrosis Canada opportunities

- Board recruitment opportunity
- E-newsletter survey
- CF Registry sneak peek webinar

Third party opportunities

- Post-transplant models of care document review
- Impact of HPV on people with CF survey
- BC CF Care working group
- Question CF – International research priorities survey

COMING UP!

We will be in touch soon with opportunities around our resource guide and to hear about what you would like to see on Cystic Fibrosis Canada t-shirts and hats!

WE ARE RECRUITING!

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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