

## Cystic Fibrosis Canada

### Strategic Plan 2024-2027

#### **The State of Cystic Fibrosis in Canada**

Cystic fibrosis in Canada is in a state of change, rapidly evolving as we learn more and as people's health largely improves. The world we find ourselves in now is different from even a few years ago. Trikafta is now available for people aged two and up which means children diagnosed with CF today will benefit from a much different disease trajectory. This is a good thing.

We are grateful for new treatments. We worked hard to bring Trikafta to Canada and celebrated its arrival, with good reason. But it's not a cure. It will not take away the years of damage CF has had on many people's bodies. Others cannot yet access it in Canada because of their particular type of CF or because of its prohibitive cost.

Over the next three years, it is clear there will be healthier people living with CF. However, the positive impact of Trikafta on the health of the Canadian CF population will happen slowly over time. What we will see is a more diverse community with a variety of needs, needs that don't affect all of our community evenly.

This new treatment has been transformational for many people, but there are still too many people in our community who aren't able to benefit from it. People are still very sick and too many are dying far too young. And for those who may never benefit from it, we need new solutions.

We are also in uncharted territory. While more people are living longer with CF than ever, with that comes other complications, like kidney disease, diabetes, cancers, and cardiovascular issues that emerge as people age. We also don't know the long-term effects of Trikafta. How long and well will it work? We still have much work to do to ensure healthy, full lives for everyone.

The primary issues facing Canadians living with CF include:

- Access issues to Trikafta, eligibility and financial
- No treatment options for some, other than standard of care
- Large financial and treatment care burden

- Significant mental health needs
- Feelings of isolation and a need to connect with others affected by CF
- Needed clinical resources vary across the country
- Clinical care in need of redevelopment for the future

## Our Strategy

Given the overall state of change, the essence of this strategy is one of learning, adapting and investing for the future. We need a strategy that is clearly focused on the needs that are known, but also one that is nimble and positions the organization for a future that will look significantly different than its past.

Our approach is intentional in focus. We have built this plan so that we leverage our unique qualities and strengths. While our desired impact is bold, we will prioritize areas of greatest need, focusing on closing gaps, all in the interest of improving the health and wellbeing of all people diagnosed with CF in Canada.

Other key strengths to leverage:

- Our advocacy abilities, which will be important as federal and provincial/territorial governments are currently focused on rare disease drugs and disability supports
- Our clinical trials network
- Legacy work in clinical care and advancing research
- Our committed community
- Our global networks and connections - for instance, we will be able to benefit from the learning of other countries who are ahead of us in their thinking on what changes are needed in clinical care, in what data should be collected in Registries and in what new supports or programs are needed for the CF community

## Our Approaches and Intended Impact

While the disease has changed, what remains is people living with CF across the country are still the reason we do this work. We will continue to advocate, drive change, improve care, advance research, and provide information and support.

The change in this strategy comes from our more focused approach. We are here for our entire community and will continue to support everyone, but there are many with a larger burden than others—they might be sicker, have a higher travel burden, live somewhere with fewer clinic resources, be at more risk for mental health issues or stress or face a large financial burden because of the province they live in.

CF Canada will prioritize its focus on people diagnosed with cystic fibrosis who are most affected by their disease and have chosen a focused set of impacts to guide our work. We will:

Influence health and financial support systems **so that:**

- Drug access is improved and more equitable across the country
- People have a reduced financial burden

Advance knowledge about CF in priority areas **so that:**

- There is a better understanding of how to manage or treat priority health issues
- There are more clinical trials available for those with the greatest health need

Connect to people and resources **so that:**

- Emotional impacts of the disease are reduced
- People with CF are informed about priority issues related to their disease

Drive action around needed care **so that:**

- The uneven burden of care, including mental health issues, is reduced by investments that help address priority needs
- The clinical care model is adapted for current and future needs as our community becomes healthier and new needs emerge

### **What's Required to Deliver On This Impact?**

In addition to focusing on impact for our CF community as it evolves, CF Canada must evolve, too. This will include modernizing our operations so we can be most effective, ensuring we have the right data and platforms as well as a diverse and talented team to inform and deliver on our work. Importantly, as the disease is changing, we will need to focus on creating valued, meaningful connections with our wonderful community of supporters and volunteers.

We have named four Strategic Imperatives that elevate the things we believe we *must* do to achieve the impact we seek in the next three years. These Imperatives guide the major initiatives we will choose to focus on and will inform our decision making and ways of working across the organization.

### 1. Harnessing Data

A focus on our data and systems will allow our teams to connect with our community in the most meaningful ways as well as make the best fundraising decisions to deliver our biggest impact. This work will also result in CF Canada having a cohesive data framework, one that includes adaptations to our Registry, and is complemented by other Canadian data systems, so that we can best understand the changing health and social needs of our community.

### 2. Cultivating Connections

We will test out new models of connection and stakeholder engagement to determine which are the most meaningful and impactful. Through our learning, our evolved community engagement model will help us recruit new members, including people living with CF and a variety of demographics, while also retaining existing community members by providing them with a value-add experience that is truly meaningful to them.

### 3. Enabling a Thriving Culture

By delivering on this imperative, we will have our people set up with the right roles and responsibilities, and aligned to the priority work that needs to be executed. We will have a culture that supports diversity, equity and inclusion and human resource supports and structures will be in place to enable effective recruitment, engagement and retention. Importantly, we would be known in our sector as an employer of choice.

### 4. Simplifying And Modernizing

By delivering on this imperative, we will have a strategic approach to our enabling tools and a simplified technology structure in place to execute on our work. Our

processes will be optimized to deliver on our work in an efficient manner and we will have an effective way to share and collaborate across the organization and with our stakeholders. This will build an environment where staff will spend more time focusing on the most important work as well as an organization that can better leverage technology to connect with our community.

### **What We Did to Inform This Strategy**

The Cystic Fibrosis Canada staff and Board of Directors developed this strategy over the past year following consultations with many different groups within our cystic fibrosis community. We were informed by the experience of other cystic fibrosis (CF) organizations and charities, by researchers and clinicians, by volunteers, and by people living with cystic fibrosis and their families. Canadian clinicians, our Health Advisory Council and Adult CF Committee members also informed our work as well as survey with more than 600 people impacted by CF. Conversations with global colleagues as well as learnings over the past four years greatly informed this plan.