



Audrey,  
lives with CF

# TOGETHER WE GO FURTHER

2021-2022 Impact Report



FURTHER

# Going further is the only way



**Leona Pinsky**, Board Chair,  
Cystic Fibrosis Canada



**Kelly Grover**, President & CEO,  
Cystic Fibrosis Canada

Looking back, what was accomplished over the past year is truly incredible. While the COVID-19 pandemic continued to keep us virtual, we did not let that dampen our spirits. To the contrary, the Canadian cystic fibrosis (CF) community came together, stronger than ever.

In less than six months after the draft recommendations from the drug review bodies, every Canadian province and territory committed to fund Trikafta, the life-changing cystic fibrosis drug. It was the fastest approval and rollout of a CF drug ever, and it happened because of you, our community, who came together and raised your voices, donated and supported our work. Now, almost weekly, we learn of lives being changed and new hope for futures that were once unimaginable.

While it is exciting to hear these stories, we know that there are many in our community who have not yet gained access or cannot be helped by Trikafta. Whether you are struggling with private and public coverage issues, too healthy to meet access criteria, post-transplant, have a rare gene, or someone for whom Trikafta has come too late, know that we are not stopping until every Canadian with CF has a bright future ahead. That is why it was so important for us to ask for your input on our new research strategy and launch our research grants competition again in 2021, accepting applications for research projects that will benefit patients sooner rather than later, particularly for people who currently have limited treatment options.

In addition to advocating, it was a year of listening. We distributed surveys, hosted focus groups and launched our community consultation program, Elevate, to ensure that the work we do is guided by and resonates with you. Thank you to all who participated and who continue to participate in these important opportunities.

In this report you'll read about that work and more. You'll read about how Canadians living with CF are getting access to medications through our clinical trial network, the impact of the Canadian Cystic Fibrosis Registry on driving action, leveraging partnerships to double the impact of our donor dollars and about how our inspiring community and donors continue to go further.

We are excited for the year to come. As we look ahead, we'll maintain the momentum of this banner year, advocating to ensure all who can benefit from Trikafta, including children, gain access. We'll adapt our work to ensure we can support our community's changing needs, including in our approach to supporting clinical care and launch our new research strategy.

Thank you to our community members, donors, volunteers, staff, sponsors, and partners across Canada. You went further for us last year and together, we're going even further this year.

**Leona Pinsky**,  
Board Chair,  
Cystic Fibrosis Canada

**Kelly Grover**,  
President & CEO,  
Cystic Fibrosis Canada

# Thank you for making progress possible

With generous contributions from our donors, Cystic Fibrosis Canada is working to change the cystic fibrosis (CF) story. Here are a few ways your donations fueled progress in 2021:

- After relentless advocacy, all 10 provinces, three territories and federal health plans announced that they would reimburse Trikafta, a life changing CF drug
- To assist clinicians in prescribing Trikafta, new standards of care for modulator therapies were developed by our Healthcare Advisory Council
- Two Clinic Accreditation Visits were completed, ensuring Canadians with cystic fibrosis receive world class care
- New trials were supported by Cystic Fibrosis Canada's Accelerating Clinical Trial (CF CanACT) network
  - More people living with cystic fibrosis had access to clinical trials
- COVID-19 resources and support were provided
- Elevate, a community input program was launched to ensure our work is guided by people impacted by CF
- Co-funded two British Columbia researchers with Michael Smith Health Research Foundation
- Six studies published in medical journals were supported with data from the Canadian Cystic Fibrosis Registry
- Worked with community members and scientists to determine Canadian research priorities, setting the foundation for a new research strategy
- Launched new resources for parents living with cystic fibrosis and their children

Thank you for helping us go Further for Canadians living with cystic fibrosis.



**Romane, 2, and family,**  
lives with cystic fibrosis

# 2020-2023 Strategic Plan

We have embarked on a new era in cystic fibrosis (CF). People are living longer with the disease, and there is great promise for continued progress towards longer and healthier lives. Despite this, Canadians with CF are currently still living lives that are too short and too challenging. In 2021, Cystic Fibrosis Canada continued working toward the goals in our 2020-2023 strategic plan, work that will lay the foundation for our 10-year goal of improving health outcomes and quality of life for Canadians living with CF.



## 10 YEAR IMPACT

✓ IMPROVED HEALTH OUTCOMES    ✓ BETTER QUALITY OF LIFE  
FOR ALL THOSE LIVING WITH CYSTIC FIBROSIS IN CANADA

 <p><b>ADVOCACY</b></p> <p><b>PRIORITY 1</b> <b>IMPROVE ACCESS TO LIFE-CHANGING AND LIFE-SUSTAINING MEDICINES</b></p> <p><b>LEADING TO:</b> More people in Canada have access to symptom management drugs and modulators</p>	 <p><b>INFORMATION &amp; SUPPORT</b></p> <p><b>PRIORITY 4</b> <b>LEVERAGE DIGITAL STRATEGIES AND PEER CONNECTIONS</b></p> <p><b>LEADING TO:</b> Timely &amp; relevant information provided by CF Canada and peers</p>
 <p><b>HEALTHCARE</b></p> <p><b>PRIORITY 2</b> <b>IMPROVE THE QUALITY OF CF CARE AND TREATMENT EXPERIENCE</b></p> <p><b>LEADING TO:</b> Canadian CF standards developed and used by clinics  Innovations in care have reduced the burden of care faced by people living with CF</p>	 <p><b>PEOPLE &amp; REVENUE</b></p> <p><b>PRIORITY 5</b> <b>STRENGTHEN THE ORGANIZATION FOR IMPACT</b></p> <p><b>LEADING TO:</b> Mutually rewarding volunteer program Engaged, high-performing, collaborative staff teams High quality donor experience across the organization Sustained &amp; growing revenue</p>
 <p><b>RESEARCH</b></p> <p><b>PRIORITY 3</b> <b>ADVANCE RESEARCH ON PRIORITY HEALTH NEEDS</b></p> <p><b>LEADING TO:</b> Investments made on research initiatives impacting priority health needs and with potential for results in the near future</p>	

<p>Thank you to our Board of Directors</p>	<p>Leona Pinsky (Chair) Robert Sankey (Vice Chair) Ron Anderson Lee Burry Robert Deane</p>	<p>Louise Desjardins* Kathryn Deuchars Françoys Levert Barbara M. Hill Stuart Hodge</p>	<p>Stephen McCourt Hugh O’Brodivich* Ian Thompson</p> <p><small>*Stepped down part-way through 2021</small></p>
--	--	---	---



Kadeem,  
lives with cystic fibrosis

## The road to Trikafta

# #CFcantwait

Thanks to years of advocating for access to modulators in Canada, in June of 2021, the rallying cry “CF Can’t Wait” was heard loud and clear as Health Canada approved Trikafta, the greatest innovation in cystic fibrosis (CF) history. It was a stand-out milestone, the first of many approvals required to access the drug and with it came coverage of other modulators too. It was also a moment of hope and unity, in what already felt like a long journey for the CF community, who had waited far too long for the drug to come to Canada.

Drug approvals can often take years, restricted by red tape, slow price negotiations, and many rounds of approvals by various government decision-making bodies. Upon Health Canada’s approval of Trikafta, there was a shared relief, but also a bracing for the many steps that were still required to get the drug into the hands of Canadians. This small, but mighty, rare disease community banded together - complete with people diagnosed with CF, family members, clinicians, volunteers and Cystic Fibrosis Canada’s government relations team - and pushed forward, successfully advocating for access to the life-changing drug. By the end of 2021, Trikafta was approved in every province and territory across the country, the fastest drug approval in Canadian CF history.

How did this happen? In advance of Health Canada’s approval of the life-changing drug Trikafta, we worked hard to lay the ground for public drug programs to reimburse its cost. Trikafta also received a rapid review at

Health Canada, which took six months, and Canada’s cost-effectiveness bodies were able to work in parallel to that timeline. We used this time to our advantage.

“Through our #CFCan’tWait meeting challenge, community members met with anyone who could influence reimbursement decisions,” said Kim Steele, Director, Government and Community Relations, Cystic Fibrosis Canada. “We provided the plans, toolkits, templates and training and our National Advocacy Network and community members took on the challenge.” Together, we arranged briefings, sent letters, signed petitions, lobbied elected representatives, and sought commitments from Ministers of Health. In total, with the community, we sent 1,747 letters and met with 107 provincial and territory

### FUNDING OF TRIKAFTA IN CANADA



elected officials. We hosted Trikafta Today briefings, webinars and Facebook Live events and together we wrote op-eds, gave media interviews and shared on social media.

“By the time Health Canada announced its approval of Trikafta, we had secured four provincial commitments to reimburse. The other provinces and territories were primed to act quickly,” said Steele.

Unfortunately, shortly after CADTH and INESSS, the Canadian health technology assessment agencies, released a draft (CADTH) and a final (INESSS) version of their recommendations with overly restrictive reimbursement criteria. Because provincial decisions on drug reimbursement are often based on these assessments, a large proportion of the cystic fibrosis population did not meet the eligibility criteria.

Cystic Fibrosis Canada facilitated a powerful written response by CF clinicians, explaining that the draft recommendations, with their exclusionary criteria and ill-reasoned start-and-stop guidelines, could be devastating to many with cystic fibrosis.

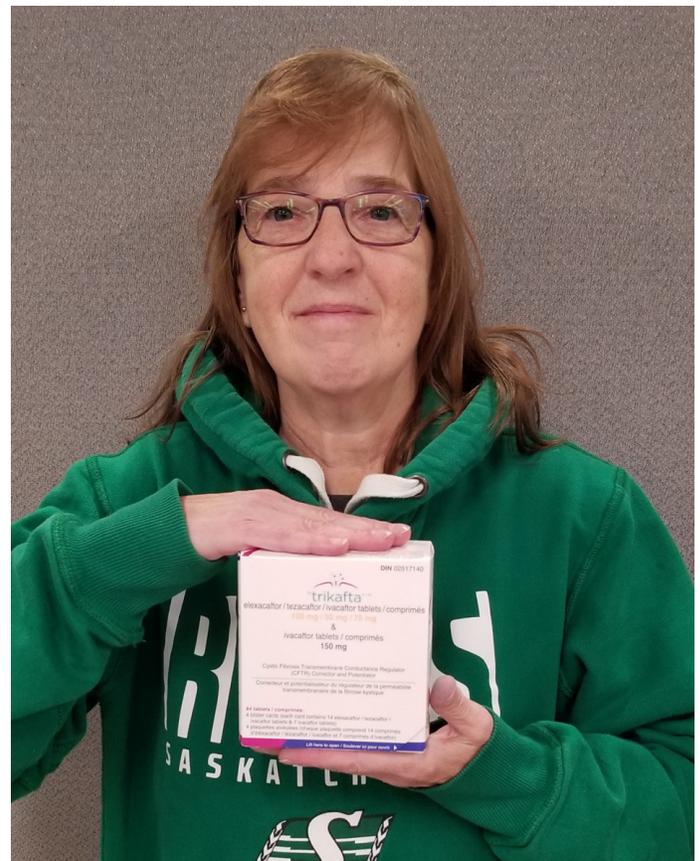
It didn't stop there. We gathered signatures from 64 physicians on an open letter calling on provincial Health Ministers to immediately fund Trikafta for all who could benefit and to empower cystic fibrosis physicians to be the experts in CF care making those access decisions. In anticipation of Trikafta's Health Canada approval, Cystic Fibrosis Canada had approached its Healthcare Advisory Council to develop [clinical guidelines for cystic fibrosis modulator therapies](#) to assist physicians with prescribing criteria. Both of these actions were critical in changing the recommendations.

Together with formal feedback from Cystic Fibrosis Canada and continued pressure from the community, this formidable response prompted CADTH to make a rare move, revising its recommendations, stripping out some restrictive criteria. Cystic Fibrosis Canada continues to work to persuade decision-makers to lift the unnecessary start/stop criteria in certain provincial and territorial drug plans, leaving clinicians free to use the clinical guidelines and their best clinical judgement to make treatment decisions. We also continue to apply pressure on private insurers, many of whom have been slow to provide coverage.

Within two months of the final CADTH recommendation, all 10 provinces, three territories and federal health plans announced that they would reimburse Trikafta. The speed of these funding announcements were unheard of in Canada and a testament to all of our relentless work. This crucial new medicine made it through the system and into the hands of many Canadians with cystic fibrosis in record time.

“The community's energetic, coordinated and committed response made this tremendous undertaking possible,” said Steele. “We are so grateful to be able to draw on such extraordinary, talented, determined folks as we work to pave the way for greater access and future innovation.”

As Cystic Fibrosis Canada celebrates this year of remarkable wins, we remain mindful of those who can't benefit from Trikafta, those who are excluded by current guidelines, and those under 12 for whom it is not yet approved. We will not falter. We will challenge decisions that don't make sense, insist on changes to innovation-chilling regulatory guidelines and support the community in advocating for the best cystic fibrosis care and treatments available.



# Adapting our work to the community's changing needs

My Cough  
is not  
Contagious

Laura Proctor Photography

It is a time of unprecedented change for Canadians living with cystic fibrosis (CF), as promising treatments are starting to create positive changes for many in our community, others, who cannot benefit from these new treatments, continue to live with a heavy burden. With a global pandemic also creating uncertainty, it was as important as ever for Cystic Fibrosis Canada to carefully understand the community's evolving needs and concerns and to adapt.

**Navigating the COVID-19 pandemic together** –As COVID-19 continued to impact the CF community, we worked closely with cystic fibrosis clinicians across the country to identify relevant community and government supports and expand the COVID-19 section of our website to include pertinent updates and resources. We advocated for people living with CF and their families to be prioritized for COVID-19 vaccines and kept our community informed as progress was made. We hosted Ask the Experts webinar sessions with a focus on vaccines, mental health and what happens next to help address concerns in the community.

**Re-imagining our research strategy with help from our community** – Research is one of the most impactful ways that Cystic Fibrosis Canada can continue to change the future of the disease, which is why we are excited to be developing a new research strategy. It is important to us that this strategy reflects the needs of people living with cystic fibrosis, particularly those with limited treatment options and is informed by extensive consultations with researchers, international experts, clinicians and Canadians living with cystic fibrosis.

How are we doing this? In 2021, we sought input from people living with cystic fibrosis and their families on their

research priorities through a survey. To further prioritize the most pressing needs, we held a four-hour facilitated virtual workshop with over 20 community members, including people living with CF, family members, clinicians, researchers and scientists. These priorities are now helping inform our new research strategy, due to launch in 2022. Thank you to our community for being such close partners as we re-imagine how research can bring brighter futures to many Canadians living with CF.

“As a CF parent there are times when I despair at my child’s illness because there is no cure at this time. I feel at a loss because I can’t take away this brutal disease and I worry about their trajectory in life. We do the daily work of physio and treatments because we know this is the necessary work to keep them healthy until there is a cure,” said Vicky, mother to a child who lives with CF.

**Vicky,**  
mother to a child with CF.



“Participating in events such as the research priority setting workshop bridges the despair I feel with hope. Hope for a cure for those with rare mutations. As our child has two rare mutations, there is always the fear that they will be left behind in the scientific advancements being made. We don’t know if Trikafta will work. We don’t know if we will gain access.”

**Quantifying the burden of disease** – Anecdotally, we know that people with cystic fibrosis live with a high burden of disease, daily hours are spent on treatments and time in the hospital. In 2021, we conducted a study that will demonstrate the impact, both in time and money, that cystic fibrosis has on people living with the disease, their families and on society. More than 500 people completed the survey, the results of which will help to support advocacy work in the coming years and for Cystic Fibrosis Canada to develop plans to lessen the burden of disease.

**Prioritizing your information and support needs** – As our community’s needs for information and support continue to evolve, we too are adapting our information and support services. In 2021, we administered a survey to gain insights from the cystic fibrosis community about their information and support needs. What resources are missing? What educational topics are most important? We learned that nutrition, exercise, mental health and parenting a child with CF are priorities. To build on the survey, we held focus groups with community members and learned in more depth about the importance of peer-to-peer support. We are very appreciative of all who shared their input, which will guide the resources, support and educational webinars planned for the future.

As an example of responding to a new and promising reality to living with CF, in 2021, support resources for parents who live with cystic fibrosis were launched. We worked closely with our Adult Cystic Fibrosis Advisory Committee (ACFAC) to develop new resources including the Parenting When You Have CF guide, Keepin’ It Rosy activity book, and held an Ask the Experts session on parenting when you have CF.

**Elevating your voice and insights** – We believe that our community’s input should drive our work and help shape the future of life with CF in Canada. That is why in

October 2021, we launched a community consultation program, Elevate, through which members receive input opportunities in the form of surveys, focus groups, document reviews and workshops. The program is flexible so members can choose to participate in as many or as little CF Canada specific and other opportunities as they wish. In the first six months, Elevate members have shared their feedback on more than ten input opportunities ranging from the information and support focus group to third party opportunities for the University of Calgary and Cystic Fibrosis Care BC.

▀▀ **As a person who lives with cystic fibrosis, it’s important to me that I use my experiences and my voice to make a difference on the future of this disease in Canada. Cystic Fibrosis Canada’s Elevate program takes the already unstoppable community of people linked by CF and help us go further to improve the quality of life and experiences of living with, or supporting someone living with, this disease.** ▀▀

- Megan Parker, Elevate member



# The Canadian CF Registry – a crucial compass guiding change

The last two years have been full of change and uncertainty, as the cystic fibrosis (CF) community weathered the ongoing COVID-19 pandemic. At the same time, some in the CF community received access to Trikafta, a groundbreaking CF drug, via compassionate access and clinical trials, or more recently, through public drug programs. Thanks to the Canadian Cystic Fibrosis Registry we have been able to measure and monitor the health impacts of our community.

Cystic Fibrosis Canada is one of very few health charities to have a patient registry. Our Canadian Cystic Fibrosis Registry is an important database that has tracked health data on all consenting cystic fibrosis patients in Canada for over 45 years. To think of it simply as a repository of data is to underestimate its role. The truth is that the Canadian CF Registry is a compass allowing Cystic Fibrosis Canada to accurately understand the current state of the disease in Canada and identify new paths forward. With the data in the CF Registry, Cystic Fibrosis Canada, clinicians and researchers can monitor disease patterns, better understand their clinic populations, drive quality improvements, respond to emerging healthcare issues and fuel research.

In 2020, thanks to the Canadian CF Registry, Cystic Fibrosis Canada and CF clinicians were able to assess and respond to the impact COVID-19 was having on Canadians living with cystic fibrosis, work that continued into 2021. The Canadian CF Registry has been a long-standing member of the CF Registry Global Collaboration, and when the

COVID-19 pandemic began, the group quickly convened meetings specifically to discuss how CF registry data can be used to monitor the effect of the pandemic on, and advocate on behalf of the CF community. This collaboration has grown to include nearly 50 countries worldwide, and in June 2021, the group led by Dr. Anne Stephenson, were awarded an Operating Grant by the Canadian Institutes of Health Research (CIHR) to continue this important work and notably to study the medium-to-long-term impact of the infection on the CF population. “In a pandemic that was constantly evolving, having data at our fingertips was crucial to understanding our community’s risk, and advocating for solutions,” says Dr. Stephenson, Medical Director of Cystic Fibrosis Canada’s Canadian CF Registry and a CF physician at St. Michael’s Hospital.



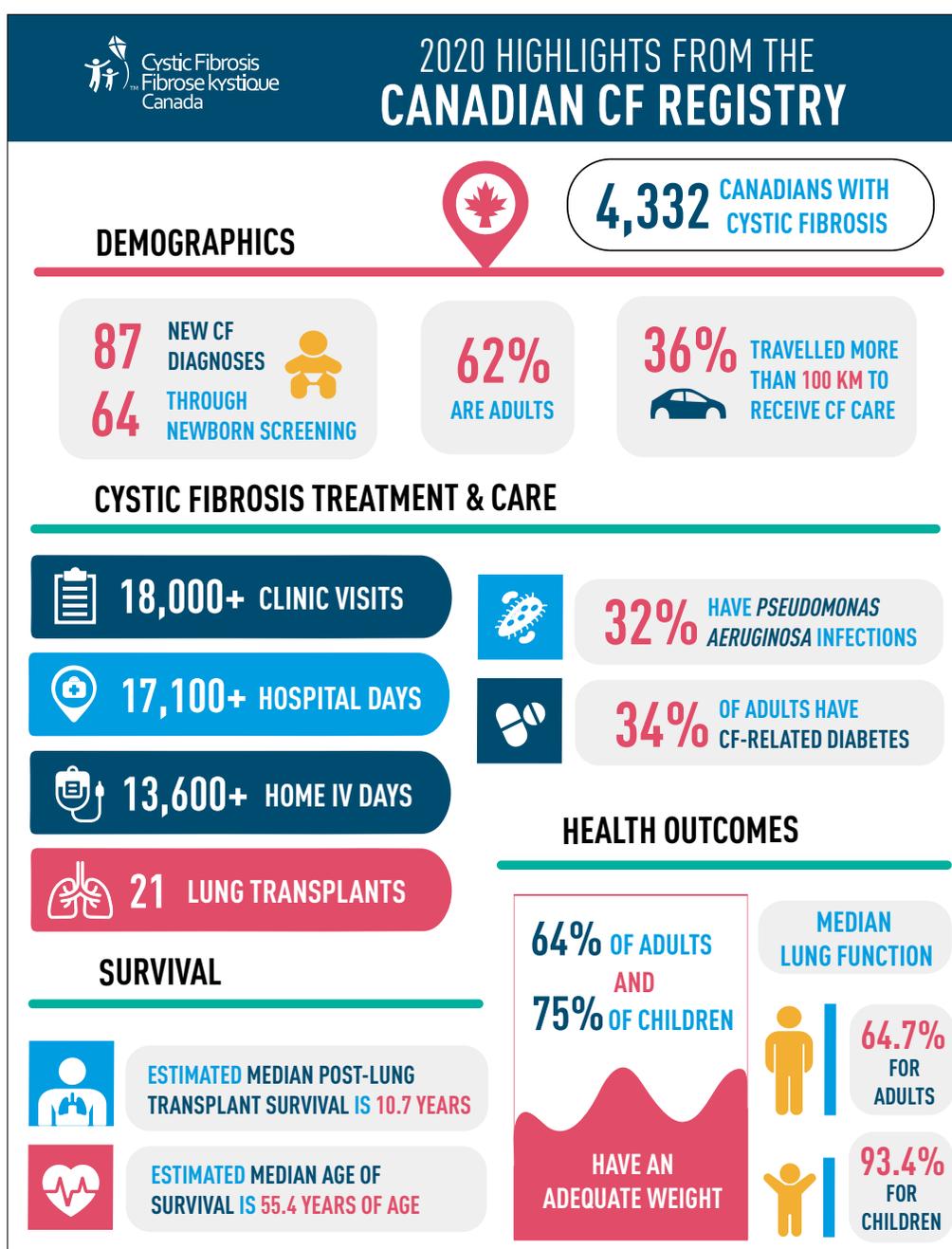
**Dr. Anne Stephenson,**  
Medical Director of  
Cystic Fibrosis Canada’s  
Canadian CF Registry  
and CF physician at  
St. Michael’s Hospital.

The Canadian CF Registry was also influential in Cystic Fibrosis Canada’s advocacy work for Trikafta. When decision makers began to contemplate restrictions on who would get the drug, Cystic Fibrosis Canada’s CF Registry team was able to query the database to determine the proportion of Canadians with CF who could be left behind. With this information in hand, Cystic Fibrosis Canada was

able to advocate for the CF community. “We were able to show the impact of the government’s decisions. It allowed us to hold government accountable as we could speak to the number of lives at risk, nationally and by province,” says Kim Steele, Director of Community and Government Relations. The fight to access CF treatments continues, as does the role of the Canadian CF Registry. CF clinics can use the Canadian CF Registry to verify who in their clinic are eligible for Trikafta as they rollout the drug. In 2021, the CF Registry also helped enable a national study on the burden of cystic fibrosis on people living with the disease and their families, in terms of time and money – a study that will undoubtedly turn heads when results are

released in 2022 to government decision-makers and the community.

The Canadian CF Registry also enables CF research. In 2021, 6 studies using Canadian CF Registry data were published in medical journals. This research focused on topics such as CF-related diabetes and lung transplant outcomes. Particularly as the disease evolves thanks to medical advancements, the Canadian CF Registry will continue to be a critical resource, helping Cystic Fibrosis Canada assess progress and new challenges and define where we must go further.





# Clinical Trials Network Having Real-Word Impact on Patients

Four years ago, Cystic Fibrosis Canada launched the Cystic Fibrosis Canada Accelerating Clinical Trials Network (CF CanACT) to facilitate the development of new treatments for cystic fibrosis as well as to encourage clinical research in Canada.

Clinical trials are an integral part of the process to bring new therapeutics and better care to Canadians living with cystic fibrosis. In 2018, there were a small number of patients enrolled in clinical trial studies across Canada, with little coordination or communication between clinical trial sites. The trials ran independent of each other, an inefficient process for the pharmaceutical companies running the trials, and a hindrance for trials to come



Dr. Maggie McIlwaine,  
Network Manager, CFCanACT

to Canada. With the establishment of Cystic Fibrosis Canada Accelerating Clinical Trials, the network of 10 sites across Canada work together under one umbrella. “Now a pharmaceutical company will reach out directly to CF CanACT and we will facilitate getting the clinical trials to each of the

**60%** of Canadians with CF have direct access to clinical trials within the network

**The network actively pursues referrals from other CF clinics**

**10 Sites:** two in Montréal, Toronto and Vancouver. One each in Calgary, Saskatoon, Quebec City and Halifax

**5 fold increase in patient participation from 2018-2021**

**18 new trials** supported by the network over the last three years

**106** participants have had the opportunity to stay on modulators, such as Trikafta, by an open-label extension of the trial after it has ended

sites,” said Dr. Maggie McIlwaine, Network Manager, CF CanACT. “We are also actively working with the companies to bring more trials to Canada. Since the inception of the network only three years ago, we have increased patient participation in trials from 63 to 304.”

The network has grown from six sites to 10, now directly accessible to 60% of Canadians with cystic fibrosis, while also available to all Canadians with cystic fibrosis through the referral system. This includes three-year-old Jordan from Victoria, BC, who has been travelling to Vancouver to participate in a clinical trial since being referred by his physicians in October 2019. “There are advantages to joining a trial,” says Jordan’s mom, Anna\*. “With Canada being so slow to cover some of the CF drugs, the clinical trial is a way to get him on a treatment,” said Anna. “In addition to knowing that Jordan is on a drug that is getting at the root cause of his disease, there are other benefits like having a relationship with another doctor, who can offer another perspective. Our treatment hasn’t changed but having another expert in my life feels good.”

Not only has CF CanACT increased the number of trials and patients involved and provided an access route to CF treatments, it is also providing information crucial to improving cystic fibrosis care. When submissions were made to the government review bodies regarding public funding of Trikafta, data from clinical trials was one of the factors on which decisions were made.

What’s next for the network? Dr. McIlwaine says that with Trikafta becoming more widely accessible, we have to rethink how we perform future trials, taking into account the changes the medication will have on the CF population. She also notes that gene therapy trials are coming, “it is very exciting to begin preparing for those.”

\*Names have been changed.



## Here are just three studies that Cystic Fibrosis Canada’s Accelerating Clinical Trials Network supported in 2021:

### CAR-CF:

A Covid-19 antibody response study, taking place at all 10 network sites, CAR-CF is part of an international study in Europe and the US. Originally looking at the number of people living with cystic fibrosis who have had COVID-19, the study is now examining COVID-19 vaccine effectiveness in individuals with cystic fibrosis.

### ELX-02:

This modulator study is exploring a treatment option for individuals who have a mutation not responsive to Trikafta. The study started in 2021 and is taking place at the Toronto, Calgary and Montreal sites.

### CAN-Impact-CF:

This investigator study is looking at the wider effects of Trikafta on patients taking the drug such as quality of life, mental health and how the drug is impacting their daily life.

Canadians living with cystic fibrosis who are interested in participating in a clinical trial can view current trials via the [CF Canada Accelerating Clinical Trials Network](#).

# World-class healthcare

## Dr. Nicole Kraus – 2021 Clinical Fellowship award recipient

Cystic Fibrosis Canada's Clinical Fellowship program provides funding to physicians interested in building their experience working with cystic fibrosis (CF) patients. It attracts and retains keen clinical minds to the field of cystic fibrosis. The program is an excellent demonstration of impact as 100% of recipients have remained in cystic fibrosis care in Canada, and several former recipients have gone on to be clinic directors.

Last year, Cystic Fibrosis Canada was proud to award the 2021 Clinical Fellowship Grant to Dr. Nicole Kraus at The Adult Cystic Fibrosis Clinic at St. Michael's Hospital in Toronto.

"It has been an incredible privilege to be awarded Cystic Fibrosis Canada's Clinical Fellowship Award, the training I have received because of the fellowship has been invaluable and I am grateful to my mentors at the Toronto adult clinic, Dr. Tullis and Dr. Stephenson," said Dr. Kraus. "Working with cystic fibrosis patients is incredibly fulfilling as they have been some of my best teachers, often giving me more back than what I had given to them. It is exciting to be part of a field where there is so much hope for the future, I look forward to a career as a CF physician."

## Canadian Clinical Consensus Guidelines for of CFTR Modulator Therapies

Continuing our efforts to ensure that all people in Canada who live with cystic fibrosis receive the care they need, Cystic Fibrosis Canada worked with our Healthcare Advisory Council and leading CF experts to develop Canadian clinical guidelines for CFTR modulator therapies. The guidelines provide clinicians across Canada with important information on best practice use of the CF modulator drugs Trikafta, Orkambi, Kalydeco and Symdeko when treating CF patients in Canada.



Dr. Nicole Kraus

Standardized care guidelines help Canadians with cystic fibrosis by ensuring that they are receiving the best care including the prescription of CFTR modulators, based on the best evidence available.

The guidelines were an important tool for our advocacy work to gain access to Trikafta. These evidence-based guidelines were instrumental in persuading the Canadian Agency for Drugs and Technologies in Health (CADTH), a government review body, to change the prescribing criteria for Trikafta, allowing it to be accessible to more people. The CFTR modulator guidelines along with two other sets of guidelines and standards for CF care are available on [Cystic Fibrosis Canada's website](#).

## Clinic Accreditation Program Goes Virtual

In 2021, Cystic Fibrosis Canada hosted its first ever virtual Clinic Accreditation Visits. These visits took place at the Royal University Hospital in Saskatoon, SK in April and the Stollery Children's Hospital in Edmonton, AB in September. Our Clinic Accreditation Program plays an important role in helping to ensure cystic fibrosis care is of the highest caliber and consistent across the country. That is why it was important to pivot to a virtual format, allowing it to continue during the pandemic.

During the visits the Cystic Fibrosis Canada team met with the CF clinic teams, had virtual tours of the facilities, and also invited all those who attend the clinic to participate in a patient survey.

Thank you to the those who participated in the Adult Cystic Fibrosis Clinic in Saskatoon visit, including Dr. Julian Tam and Niki Afseth, and volunteer accreditors Ena Gaudet and Dr. Anne Stephenson. Thank you to Dr. Tamizan Kherani at the Edmonton paediatric clinic and to the volunteer accreditors Dr. Gautam Kumar, and Karen Doyle. Thank you to the patients and families at both the Saskatoon and Stollery clinics for providing your important feedback.



## Community fundraising

### Kin Canada reaches record-breaking \$50 million in cumulative donations

At the Kin Canada 2021 Annual General Meeting, Kelly Grover, President and CEO of CF Canada, announced to members that Kin Canada has raised an incredible \$50 million over the duration of the Cystic Fibrosis Canada-Kin Canada partnership. This is the largest cumulative donation in Cystic Fibrosis Canada's 60-year history.

"We are blown away by the contributions of Kin Canada clubs. Reaching \$50 million in cumulative donations, during a global pandemic no less, is just incredible," said Kelly Grover, President and CEO, Cystic Fibrosis Canada.

"Kin Canada has been a tremendous partner to Cystic Fibrosis Canada for more than half a century, and the contributions of Kin Canada club members – be it financial with this achievement, or through their time and support, have been amazing and helped us go further for the cystic fibrosis community. We send our deepest thank you to each and every member who has been involved with Cystic Fibrosis Canada over the past 57 years."

"This achievement is a result of the time and dedication of the passionate Kin Canada club members who, since 1964, have supported Canadians impacted by cystic fibrosis," said Lisa Burechails, Chair of the Kin-CF Liaison Committee. "It is Kin Canada's mission to serve the greatest needs of Canadian communities, no matter the challenge, and there is no better example than what Kin Canada has achieved with Cystic Fibrosis Canada. I am incredibly proud of my fellow Kin, both past and present, for raising \$50 million in cumulative funds donated to CF Canada."



Together for life® Unis pour la vie™

### Community Support Across the Country

Cystic Fibrosis Canada has 50 volunteer Chapters in provinces across the country. We could not do our important work for Canadians living with this devastating disease without the support of our dedicated Chapters. Chapter members raise funds, raise awareness about cystic fibrosis, and serve as a local resource to partners and Canadians with cystic fibrosis and their families. Thank you to our Chapter volunteers who always go further for Canadians living with cystic fibrosis.



# Transformational change leads to patient centered research priorities

The year 2021 was a time of transformational change for many people with cystic fibrosis (CF), Trikafta was making its way through the review process, and many impacted by the disease began to envision life on the drug. At the same time, some in the community knew that Trikafta could not help them, whether they had undergone a lung transplantation or had a rare mutation, and there were no life-changing therapies around the corner for them. Just as the community began to change, so too did Cystic Fibrosis Canada's research program. Advancing research is the most impactful way to make a change for people living with cystic fibrosis and the research program, as always, was a key priority.

## Grant funding resumes

While the previous year saw the global COVID-19 pandemic impact fundraising, resulting in a hold on funding research grants, in early 2021, Cystic Fibrosis Canada was able to restart the grants, supporting Canadian cystic fibrosis research and researchers.

## Determining community research priorities

"The Canadian CF community is changing. People are living longer and many are getting access to Trikafta which will slow the progression of their disease. But many others do not now, nor ever will, benefit from these drugs. And still others already have a heavy burden of disease," said Dr. John Wallenburg, Chief Scientific Officer, Cystic Fibrosis Canada. "With this in mind, it was extremely important to us that the research we fund aligns with the evolving priorities of Canadians impacted by cystic fibrosis, particularly those who don't have effective treatments."

To determine those research priorities, in May of 2021, Cystic Fibrosis Canada issued a survey to community members requesting their input on research priorities. In total, 366 people participated and a total of 17 research priorities emerged. To further refine these priorities, we hosted a workshop attended by over 20 community members, including people living with CF, family members of people living with CF, clinicians, researchers, and scientists. The result was 11 research priorities:

- Cure CF with gene or stem cell therapies
- Understand mental health and emotional wellness at different stages
- Improve airway infection detection and treatment
- Prevent or treat CF related diabetes
- Reduce the treatment burden
- Understand health issues for people with CF aged 50+
- Predict and prevent pulmonary exacerbations
- Eradicate chronic *Pseudomonas aeruginosa* infections
- Reduce hospitalizations by maximizing therapies that can be done at home
- Improve GI pain management
- Help people with CF improve and sustain adherence to treatment

Cystic Fibrosis Canada's new research strategy, due in the fall of 2022, will prioritize research with near-term impact potential, funding projects that align with our community's research priorities and finding solutions for those for whom there are no 'miracle' drugs.

## Funding research that aligns with patient priorities

In the fall of 2021, Cystic Fibrosis Canada re-launched the Research Grants Competition. We asked that the applicants provide research proposals on these priority topics, ensuring the research funded by Cystic Fibrosis Canada aligns with the priorities of our community, “Through our research priorities, we are making research more responsive to what the community needs,” said Dr. Paul Eckford, Program Director, Research at Cystic Fibrosis Canada.

“While we are encouraged that Trikafta is rolling out to CF patients across the country, we have to remember that it is not a cure. And we know that some CF patients will not benefit from it,” said Dr. Eckford. “Cystic Fibrosis Canada is committed to funding the best in basic and clinical research across the country so that no one is left behind and bright futures lie ahead for all Canadians with CF.”

## Partnering to double research investments

A key principle of Cystic Fibrosis Canada’s strategic plan is to work in partnership with organizations that share our vision. One of many benefits of partnering is that it can multiply the impact of our donors’ dollars. An excellent example is the partnership with Michael Smith Health Research BC in 2021 to co-fund two British Columbia researchers.

As a result of co-funding by Cystic Fibrosis Canada, Dr. Shekoo Behroozian of the University of British Columbia received the 2021 Michael Smith Health Research BC Scholar and Research Trainee award. Dr. Behroozian is researching a non-invasive way to detect bacterial infections in people with cystic fibrosis by examining the chemicals in their breath. This research will develop profiles of various bacteria, which will ultimately help clinicians know which antibiotics will work best.

The second researcher is Dr. Jonathan Rayment who received the co-funded Michael Smith Health Research BC 2021 Health Professional-Investigator award. Dr. Rayment was also previously a recipient of Cystic Fibrosis Canada’s Fellowship award and an Early Career Investigator award co-funded with the Canadian Institutes of Health Research (CIHR). His research is focused on easy-to-perform and sensitive tools to help physicians diagnose and monitor lung disease in children.

We are pleased to support these Canadian researchers through a strategic partnership with Michael Smith Health Research BC and hope to continue to find opportunities to multiply the impact of donor support while funding breakthrough cystic fibrosis research.

## Cystic Fibrosis Canada hires Program Director, Research

Cystic Fibrosis Canada was pleased to welcome Dr. Paul Eckford to the team as Program Director, Research. Dr. Eckford has a deep background in cystic fibrosis, working in a CF lab at SickKids since 2009 and managing the CF Canada and SickKids-Funded Cystic Fibrosis Individualized Therapy Program since 2015. With a focus on driving impactful research grants and awards and developing new funding strategies, Dr. Eckford will also look to enhance the research programs and develop partnerships with other organizations to fuel more investments in CF research.

“As Program Director of Research, I am committed to working hard for all Canadians impacted by cystic fibrosis. We will focus research efforts on new types of therapies for individuals with mutations that won’t benefit from drugs like Trikafta. We have to go further and work harder than ever before, so that all individuals with CF can lead healthy, full lives.”

- Dr. Paul Eckford

## PUBLISHED RESEARCH FUNDED IN PART BY CYSTIC FIBROSIS CANADA

Cystic Fibrosis Canada has a history of funding high-quality, world-class research. Here is just some of the research that was published in the last year:

- **Genetics Medicine:** [Cystic fibrosis-related diabetes onset can be predicted using biomarkers measured at birth](#)
- **Cell Reports:** [cAMP triggers Na<sup>+</sup> absorption by distal airway surface epithelium in cystic fibrosis swine](#)
- **European Respiratory Journal:** [Ex vivo delivery of regulatory T cells for control of alloimmune priming in the donor lung](#)
- **Journal of Cystic Fibrosis:** [The feasibility of home monitoring of young people with cystic fibrosis: Results from CLIMB-CF](#)

# Community fundraisers don't let a challenge get in the way of success



The resolve of Cystic Fibrosis Canada's volunteers, supporters and fundraisers did not waiver as the COVID-19 pandemic forced many events into a virtual format for yet another year. Instead, volunteers, committed as ever, rose to the challenge, creatively executing new ways to raise funds. Across the country, volunteers wrapped gifts, hosted 50/50 raffles, managed bingo nights, casino tournaments, golf and basketball tournaments, calendar sales and more to raise funds for Cystic Fibrosis Canada.

With the common goal to lengthen and improve the lives of people living with cystic fibrosis (CF), volunteers, fundraisers, event committees, participants and donors continued to show up, supporting these virtual, in person or hybrid events. Thank you for your unwavering support in the name of Canadians impacted by cystic fibrosis, your efforts make our work possible.

## The Virtual Walk to make Cystic Fibrosis History

In 2021, Cystic Fibrosis Canada's signature fundraising event, the Walk to Make Cystic Fibrosis History went virtual for the second time in its 17-year history. As with the 2020 Walk, participants chose a challenge to complete virtually. Still, the sense of community remained strong and vibrant as participants executed their socially distanced challenges from home and shared their progress on social media. There was no shortage of creativity as participants walked, biked, ran, danced and more in the name of going further for Canadians with CF.

"Our Walkers were as enthusiastic as ever and didn't let the virtual format of the event get in the way of going further for Canadians impacted by cystic fibrosis," said Carly Schur, Chief Development Officer, Cystic Fibrosis Canada. "In total, the 2021 Walk to Make Cystic Fibrosis History raised an amazing \$2.6 million! We are incredibly grateful to all who participated, volunteered and donated to our 2021 Walk."



## Shinerama

Shinerama is Canada's largest post-secondary fundraising event for cystic fibrosis, raising over \$29 million in its 58-year history. In 2021, over 31 colleges and universities across Canada, thousands of volunteers and a passionate committee came together for the most exciting year yet! By welcoming a hybrid in person and virtual approach to events, embracing the power of social media and even using QR codes for donations, the Shinerama committee



and volunteers made sure the pandemic didn't stop them from a successful campaign! Volunteers got creative securing corporate partnerships and hosting events including a car show and a 5-kilometer walk, bike and run.

In 2021, Shinerama raised over an incredible \$207,000 to support Cystic Fibrosis Canada's mission work. Thank you to the Shinerama leadership team, volunteers, students and sponsors for supporting the 2021 Shinerama campaign.

### 65 Roses

The 21st annual 65 Roses Gala, 6-feet away Soiree Encore, was held virtually on November 6, 2021, in Vancouver, BC. The soiree was hosted by CBC's Gloria Macarenko and Fred Lee and guests enjoyed an evening of dining and entertainment, with singer-songwriter Daniel Wesley performing a song written exclusively for Cystic Fibrosis Canada. The virtual silent auction helped to ensure the event was a wonderful success raising more than \$235,000 to support Cystic Fibrosis Canada's mission work. Thank you to the organizing committee, generous sponsors, volunteers, and guests whose contributions made the evening a night to remember!



### The Fusion Gala and the Fusion Gala Research Fellowship Grant

The Fusion Gala was founded in 2001, when the Griffin and Anderson families stepped up to help friends who had a new diagnosis of cystic fibrosis in their family. Since 2001, the gala has raised over \$3.9 million for Cystic Fibrosis Canada. In 2021, the reality of the pandemic meant that the 20th anniversary of this event could not be held in person, however, the organizers were committed to going further, raising a total of \$282,000 at the virtual event. In honour of Fusion's 20th anniversary, the Fusion Gala Research Fellowship Grant was created and through the generosity of Fusion's sponsors, attendees and donors, the Grant will fund a promising young Canadian researcher who does not yet have their own lab. The grant will provide two years of funding, allowing the researcher to conduct innovative CF research while deepening the cystic fibrosis research capacity in Canada.

### La Soirée des Grands Crus

Like many events in 2021, La Soirée des Grands Crus had to reinvent itself due to the pandemic. In its 21st year, the evening that typically brings together Quebec City's business community for incredible food, wine and fundraising, transformed into an online fundraiser led by two local companies: Construction C.R.D. and Étienne Bernier Architecture. To raise funds, the organizations partnered with two families impacted by cystic fibrosis, sharing their stories to bring awareness of the disease. The now virtual fundraiser included a virtual auction where participants could bid on exquisite wines and other sought-after items.

The event took place from November to December 2021 and raised an incredible \$80,000 to help people with cystic fibrosis live longer and healthier lives. Thank you to Construction C.R.D. and Étienne Bernier Architecture, the families and all who donated to make the event a success!

LA  
SOIRÉE DES  
GRANDS  
CRUS



## Working to change lives

“Cystic fibrosis is a progressive disease without a cure. We are not supposed to improve, but here I am,” said Amanda Bartels, a wife and mom who lives with cystic fibrosis (CF), also the lead provincial advocate for Alberta.

Amanda was diagnosed with CF at only a few months old. For the most part, her health was stable, and she was a typical kid, although sometimes she couldn’t run as fast or as long as the others. Her parents made sure she understood that CF was something she had, not who she was, and it should not hold her back.

Amanda’s health remained stable into adulthood. She married her husband Gerald and soon after tried to start a family. “We tried for about five years, and nothing was happening,” she said. “We found out we were expecting a baby just as we were to begin consultations with a fertility specialist. Our daughter Abby is our miracle.”

The pregnancy wasn’t easy, but as was typical with Amanda, her health was relatively stable. That was until about six months after Abby, now 11 years old, was born. “It might have been the pregnancy coupled with the lack of sleep from having a newborn, hormones readjusting and stress, but my body was done,” she recalls. “I had pneumonia, lost 25% of my lung function and was exhausted. We have a close family and church community and they helped me get through it. Every day for over six months someone would come to help us.”

This was the beginning of Amanda’s decline in health. In 2016, through her husband’s benefits she received access first to Orkambi and later to Symdeko, both CF modulator drugs which partially corrected her cell function. While the drugs offered some stabilization and helped with weight gain, in 2019, her health took a steep decline.

Amanda was hospitalized with what she thought was an exacerbation but turned out to be a pneumothorax, or a hole in her lung. She had experienced it before, but it had always healed. After three months in the hospital, things were not any better. Transplant discussions began and while in the hospital her care team applied for compassionate access to the new drug Trikafta. In January 2020 her application was rejected. “It was a huge blow. Generally, my mental health is good, but that was crushing,” said Amanda.

That denial was what inspired Amanda to become involved with Cystic Fibrosis Canada’s advocacy work. Her options were bleak, the hole in her lung had closed but she was looking at transplant assessment or hoping for that miracle drug that was so far out of reach. She did her first radio interview about access to drugs in January 2020.

After another compassionate access application, Amanda was approved and started Trikafta in June 2020. She saw a world of difference immediately.

Amanda took her first dose in the morning and by the afternoon her lungs sounded like a coffee percolator. The thick, sticky mucous started to purge. In the first year she

saw a nearly 10% increase in lung function. For the first time in several years, she did not need extra oxygen and could do simple tasks and chores without coughing or needing a break. She had forgotten what it felt like to take a deep, clear breath. Typically, Amanda would be admitted to the hospital every few months, but since starting Trikafta nearly two years ago she has only had one hospital admission.

### From Patient to Advocate

While Amanda's advocacy work began as a means to help get the drug into her own hands, when she started taking Trikafta, her motivation changed. Seeing how her life improved with Trikafta, she knew she needed to do what she could to help others get access. "I have severe lung disease. My lungs are permanently scarred and colonized with bacteria. I will always be on inhaled antibiotics," said Amanda. "But for those who start Trikafta young, that might not be the case. I don't want others, especially youth, to go through what I did. There is a chance to change how the disease progresses and I need to do what I can to help."

She joined Cystic Fibrosis Canada's National Advocacy Network (NAN). At the time, they were focused on Orkambi and Kalydeco at the provincial level, and NAN members began meeting with federal Alberta MP's about new drug regulations and the impact they have on people with rare diseases.

The Alberta team developed relationships with Alberta representatives, which she notes was critical for accomplishing what they did with Trikafta in the province. They met with bureaucratic administrators and politicians to share the stories of people with CF, illustrating the



impact drugs, and lack of access, has on their lives. "Alberta's representatives showed extreme compassion. While not every meeting resulted in immediate action, we always felt heard," she said. "Each successive meeting we had was a stepping stone on the path to accessing Trikafta. The drug approval and public funding process is complicated and over time those well-established relationships meant that when the next step in the process for approvals came, there were several representatives, both political and administrative, that were willing to help where they could."

By mid-2021, the position for lead Alberta advocate was available and Amanda stepped up. The work continued, meeting with provincial MLA's, educating them on the drug approval process and asking them to help. Whether it was sending a letter to the Health Minister or speaking directly about CF in the legislature, they were all willing to do what they could.

This work paid off. On September 24, 2021, only one week following Canadian Agency for Drugs and Technologies in Health (CADTH)'s final recommendation on the drug, Alberta became one of the first provinces to list Trikafta and the first to list it without criteria that limited access based on lung function. Amanda was given the opportunity to be part of the announcement from the Health Minister.

What does her advocacy work look like today?

Amanda says it is a lot of meetings, phone calls, letters, some media, communicating with other advocates, NAN members and CF Canada's team. It is hard but fulfilling work.

Alberta has a great team of advocates who are currently working with Cystic Fibrosis Canada to secure access to Trikafta for the 6–11-year-old age group as well as Kalydeco for children with a very rare CF mutation. Amanda says they are ready and willing to do the work. "We are excited that we have built relationships with our provincial representatives so that the conversations can continue. They have a good understanding of what CF is and how it impacts Albertans." Volunteers like Amanda, working with CF Canada, are changing lives - and won't stop.

Visit [Cystic Fibrosis Canada's website](#) for information on how you can become a member of the National Advocacy Network.

# A lifelong promise

▀▀ **I'll never forget the day my little niece Isa-Maude was diagnosed with cystic fibrosis. She was in the hospital – a toddler in an oversized bed – intubated and surrounded by medical devices.** ▀▀ said Charles Sirois,

who has been volunteering and raising funds for with Cystic Fibrosis Canada for more than four years. When I walked into the room, her glazed eyes turned away from her mother and she looked at me. She mustered all her strength to give me a smile. At that very moment, I promised myself that I would fight with her."

Along the way, Charles made another friend, Mathis, 7 years old, who was diagnosed with cystic fibrosis (CF) at a month and a half through the Quebec newborn screening program. Charles' determination to make a change for the Canadian cystic fibrosis community became even stronger.

Charles is not the type of person to turn away from a promise. Four years later, he and his team who participate in the Walk to Make Cystic Fibrosis History, for Isa-Maude and Mathis, have raised close to \$100,000!

When the COVID-19 pandemic forced Charles and his team to cancel their in-person fundraising activities, they rolled up their sleeves and got creative, imagining new ways to raise funds for the Walk to Make Cystic Fibrosis History. Charles' typical spaghetti dinners and grocery wrapping days became covid-safe baked good sales and partnerships with local businesses. Nothing was too big or too complicated for his team, who notes they can always count on their generous donors.

Charles believes that it is possible to positively change the fate of people living with cystic fibrosis by mobilizing the community.



"Since I got involved with Cystic Fibrosis Canada, I feel like I've joined an army. From battle to battle, together we are getting closer to defeating cystic fibrosis," he says. For this unstoppable volunteer, the Walk to Make Cystic Fibrosis History is also a way to break the isolation that so often burdens families impacted by cystic fibrosis, offering the chance to feel the strength of a whole community.

In his spare time, Charles is also a determined advocate and has met with many elected officials in his region. Never afraid to take a stand for the cystic fibrosis community, he is determined to educate his friends on the impact of this disease.

"I've seen many different sides to this illness, and the struggles that these young children have to face. Countless appointments and treatments along with highs and lows," says Charles. "But I've also seen the incredible power of community when we join together to make a difference. That's why I won't stop until there is a cure for everyone living with cystic fibrosis".

When his new friend Caroline, Mathis' mother, is asked about the impact the disease has on her life, she notes the heavy treatment burden, the intense schedule and the playtime and schooltime missed because of treatments and appointments. However, Caroline is also quick to share the positives, like having a friend like Charles Sirois who is so involved. But as Charles always says, he is not alone. He is surrounded by amazing teammates and donors who all have the CF community close to their hearts, making his promise to Isa-Maude and Mathis that much easier to pursue.



## Inspired by progress, giving for the future

Reg and Julie Smith's eldest son, Iain, now 40, was diagnosed with cystic fibrosis at two years old. It was a shock to the family who at the time had little knowledge of cystic fibrosis. To support their son, they studied the disease and learned as much as they could, Reg took a keen interest in gene therapy – a science he has followed for years.

Early on Reg and Julie became active with Cystic Fibrosis Canada. Reg is a past Chair of the Edmonton Chapter and later, became President of the Victoria Chapter, with Julie as the Treasurer. Reg is also a long-time Kinsmen, supporting Cystic Fibrosis Canada through Kin Canada initiatives. Together, Reg and Julie have dedicated more than 25 years to volunteering and supporting the Canadian cystic fibrosis community. Both are previous recipients of Cystic Fibrosis Canada's Breath of Life award – honouring outstanding contributions to a Cystic Fibrosis Canada chapter in a leadership capacity.

Not only have Reg and Julie Smith given their time, but they have also supported Cystic Fibrosis Canada's work through generous contributions. We spoke with Reg about why his family chooses to support Cystic Fibrosis Canada.

### What motivates you to give?

Knowing we are on the eve of an exciting transformation for the disease as medicines like Trikafta are within reach. We were inspired to give after following Cystic Fibrosis Canada's advocacy work, including the work to inform governments about issues like the cost of hospitalizations and care for CF patients, in comparison to the annual cost

of funding new medicines like Trikafta. Advocacy is critical for progress.

### What do you hope to achieve through your philanthropy?

It is motivating to know that our pledge will have a direct impact on those living with the disease, and we are seeing that as more people begin to access Trikafta. For the future, we hope to see more work in research and we know that it takes funding to make that possible.

### What would you like to say to a person considering a gift to Cystic Fibrosis Canada?

As Trikafta has just been approved by Health Canada for those aged 6-11 years, this is not a time to let up. We must continue this momentum, to ensure that everyone has access to medicines and treatments, to continue to advance work in the areas of research. I would encourage you to get involved, volunteer or donate.

### When you think about the future for people living with cystic fibrosis?

Iain was young when the gene responsible for cystic fibrosis was discovered, and in the early days, cystic fibrosis treatments were just getting underway. Today, the science is paying off. There is great momentum, but we must continue to help it move forward. It's an absolute joy seeing the progress.

*Today, Reg is happy to announce that Iain is doing well. He is on Trikafta and his lung function is improving, he has a family and keeps busy with his work in the oil and gas field.*

# Leading the change they wish to see in the world



THE  
**LEADERSHIP**  
CIRCLE

In 2021, Cystic Fibrosis Canada launched the Leadership Circle, giving a name to the community of dedicated philanthropists who are helping change the cystic fibrosis (CF) story.

Members of the Leadership Circle are making Cystic Fibrosis Canada's life-changing work possible and are helping to transform the lives of thousands of Canadians impacted by cystic fibrosis. Members of this exclusive group of philanthropists understand that cystic fibrosis is a disease in transition and that transformational change is on the horizon. They are funding work that will spark the next great breakthrough in CF.

Members receive exclusive benefits including invitations to annual events, behind the scenes tours of clinics to see how their contributions are positively impacting the community and more. The Leadership Circle is available to donors who make a minimum contribution of \$1,000 per year. For more information on how you can join the hundreds of other leaders making a difference today, please see [our brochure](#).

Thank you to all those who are helping change lives by joining The Leadership Circle.



SUMMERHAYES  
SOCIETY

## A legacy to last a lifetime

Members of Cystic Fibrosis Canada's Summerhayes Society are leaving a legacy that will continue to have an impact for generations to come. In 2021, the program was refreshed and made fully bilingual, so that Cystic Fibrosis Canada's incredible community of supporters across the country can take part.

"We created the Summerhayes Society as a powerful way for our supporters to leave a legacy," said Kate White, Director, Leadership Giving & Corporate Partnerships. "By leaving a gift to Cystic Fibrosis Canada in your will, either through a bequest, life insurance or RRSP, legacy donors will ensure that we can continue to push further for all Canadians living with cystic fibrosis."

# Thank you to our Corporate Partners

The generosity of our corporate partners allows us to continue our work to support and invest in leading-edge cystic fibrosis research and world class care. We are profoundly grateful to have their support as they work with us towards our vision of a world without cystic fibrosis.



## F2022 FINANCIALS

Cystic Fibrosis Canada is fully committed to transparency and accountability of financial information. We remain in a favourable financial position as we continue to strategically invest generous donor dollars into vital cystic fibrosis research and care, to ensure donations achieve the greatest impact.

### STATEMENT OF OPERATIONS

(in thousands of dollars)

Year Ended January 31, 2022, with comparative information for 2021

	2022	2021
<b>Revenue</b>		
Chapter	\$5,563	\$5,294
Annual giving	2,073	1,694
Leadership gifts and sponsorship	1,339	1,754
Kin Canada	749	775
Other	1,394	2,020
Royalties	335	439
Bequests	1,468	859
	<b>12,921</b>	<b>12,835</b>
Less direct fundraising costs	2,515	2,035
<b>Net revenue</b>	<b>10,406</b>	<b>10,800</b>

	2022	2021
<b>Expenses</b>		
<b>Program</b>		
Research	2,574	1,372
Healthcare	1,094	730
Education/Public awareness	1,696	1,682
Advocacy	793	929
Other	67	28
	<b>6,224</b>	<b>4,741</b>
<b>Other</b>		
Administration	1,263	1,513
Fundraising	1,514	1,633
	<b>9,001</b>	<b>7,887</b>
Excess of revenue over expenses before the undernoted	1,405	2,913

	2022	2021
<b>Investment income (loss)</b>		
Realized gains on investment	112	180
Change in unrealized gain on investments	(224)	4
	<b>(112)</b>	<b>184</b>
Excess of revenue over expenses	\$1,293	\$3,097

### STATEMENT OF FINANCIAL POSITION

(in thousands of dollars)

January 31, 2022, with comparative information for 2021

	2022	2021
<b>Assets</b>		
<b>Current Assets</b>		
Cash	\$8,194	\$5,142
Short-term investments	950	848
Receivables and other assets	651	1,984
	<b>9,795</b>	<b>7,974</b>
Contributions receivable	158	160
Long-term investments	4,382	4,515
Capital assets	27	41
	<b>\$14,362</b>	<b>\$12,690</b>

	2022	2021
<b>Liabilities and Net Assets</b>		
<b>Current liabilities</b>		
Accounts payable and accrued liabilities	\$608	\$587
Deferred revenue	722	327
	<b>1,330</b>	<b>914</b>
Long-term deferred contributions	228	265
<b>Net Assets</b>		
Endowment	94	94
Internally restricted for research and healthcare	2,645	2,068
Unrestricted	10,065	9,349
	<b>\$14,362</b>	<b>\$12,690</b>

As a result of the COVID-19 global pandemic, existing research grants were paid at 50% in F2022.

## STATEMENT OF CHANGES IN NET ASSETS

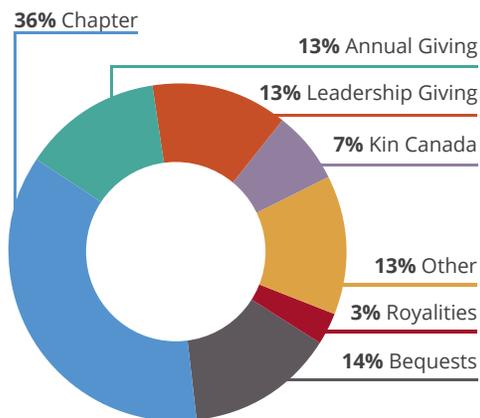
(in thousands of dollars)

Year ended January 31, 2022, with comparative information for 2021

	Endowment	Internally restricted for research and healthcare	Unrestricted	2022 Total	2021 Total
Net assets, beginning of year	\$94	\$2,068	\$9,349	\$11,511	\$8,414
Excess of revenue over expenses	-	-	1,293	1,293	3,097
Transfer between funds	-	577	(577)	-	-
Net assets, end of year	\$94	\$2,645	\$10,065	\$12,804	\$11,511

## STATEMENT OF FUNDRAISING REVENUE

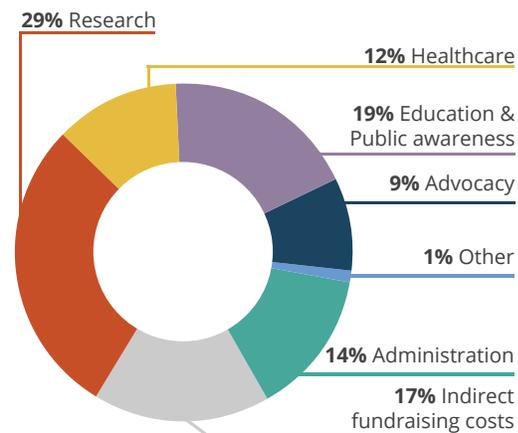
(Net of direct fundraising costs)



Note: Fundraising revenue excludes realized and unrealized gains / losses on investments

## USES OF FUNDS

(Excludes direct fundraising costs)



Complete audited financial statements are available on our website at [cysticfibrosis.ca](http://cysticfibrosis.ca).



**cysticfibrosis.ca**

2323 Yonge Street, Suite 800  
Toronto, ON M4P 2C9

Charitable registration: 10684 5100 RR0001  
Cette publication est aussi disponible en français

 [facebook.com/CysticFibrosisCanada](https://facebook.com/CysticFibrosisCanada)  [@CFCanada](https://twitter.com/CFCanada)  [@CFCanada](https://instagram.com/CFCanada)



**FURTHER**