Cystic Fibrosis Canada Impact Report 2022–2023

Creating change for the future

Maysa, who lives with CF

Cystic Fibrosis
Fibrose kystique
Canada

Reflecting on our past, planning for the future

As we reflect on the accomplishments of last year, we are reminded of the wonderful commitment of the Canadian cystic fibrosis community. We are so thankful for your continued support. Last year you showed up for us, and for each other, in many ways. You shared your stories. You advocated. You raised money. And you gave generously with your time. It is because of this commitment that we have been able to drive important change for our community, including successfully bringing Trikafta to eligible Canadians. Today, every province and territory is funding the drug for eligible Canadians aged six and older.

While we reflect on last year, we are also looking to the future. We know that the disease is changing. Some in our community are accessing modulator drugs that could change their outlook, for others, these drugs have come too late, many still struggle to access them and some will never benefit from these therapies. We know that the disease will become even more individualized in the years to come – those living with cystic fibrosis will have vastly different journeys and experiences.

We have a unique role to play across this country and we take that responsibility very seriously. Simply put, our job is to take care of people living with cystic fibrosis. Your health, your wellbeing is our priority. To ensure we are adapting to the new realities of our community and to the challenges many in our community still face, we are building a new strategic plan. We look forward to sharing this plan with you later this year and we are so thankful to the many of you in our community who provided feedback.

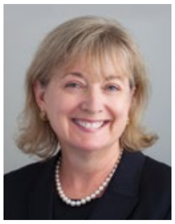
Our donors give so generously, and it is important to us that you give with confidence. In 2022, we were pleased to achieve reaccreditation under Imagine Canada's Standards Program, being an accredited member of the Standards Program since 2015. Know that we have met the stringent standards set out for charities by Imagine Canada.

We are excited for the year to come. Maintaining our momentum for our CF community is imperative and this is what we will do. We will work in the centre of the cystic fibrosis landscape, bringing together people impacted with CF, families, friends, volunteers, researchers and clinicians to ensure we continue to see improved health and wellbeing for all people living with cystic fibrosis.

Thank you to our community members, donors, volunteers, staff, sponsors, and partners across Canada. Let's continue to go further together for Canadians affected by CF.

Sincerely,

Leona Pinsky
Board Chair,
Cystic Fibrosis Canada



Kelly Grover
President and CEO,
Cystic Fibrosis Canada

Thank you to our Board of Directors:

Leona Pinsky, Chair
Barbara M. Hill, Vice Chair
Ron Anderson
(Term ended in 2022)
Lee Burry
(Stepped down in 2022)
Robert Deane
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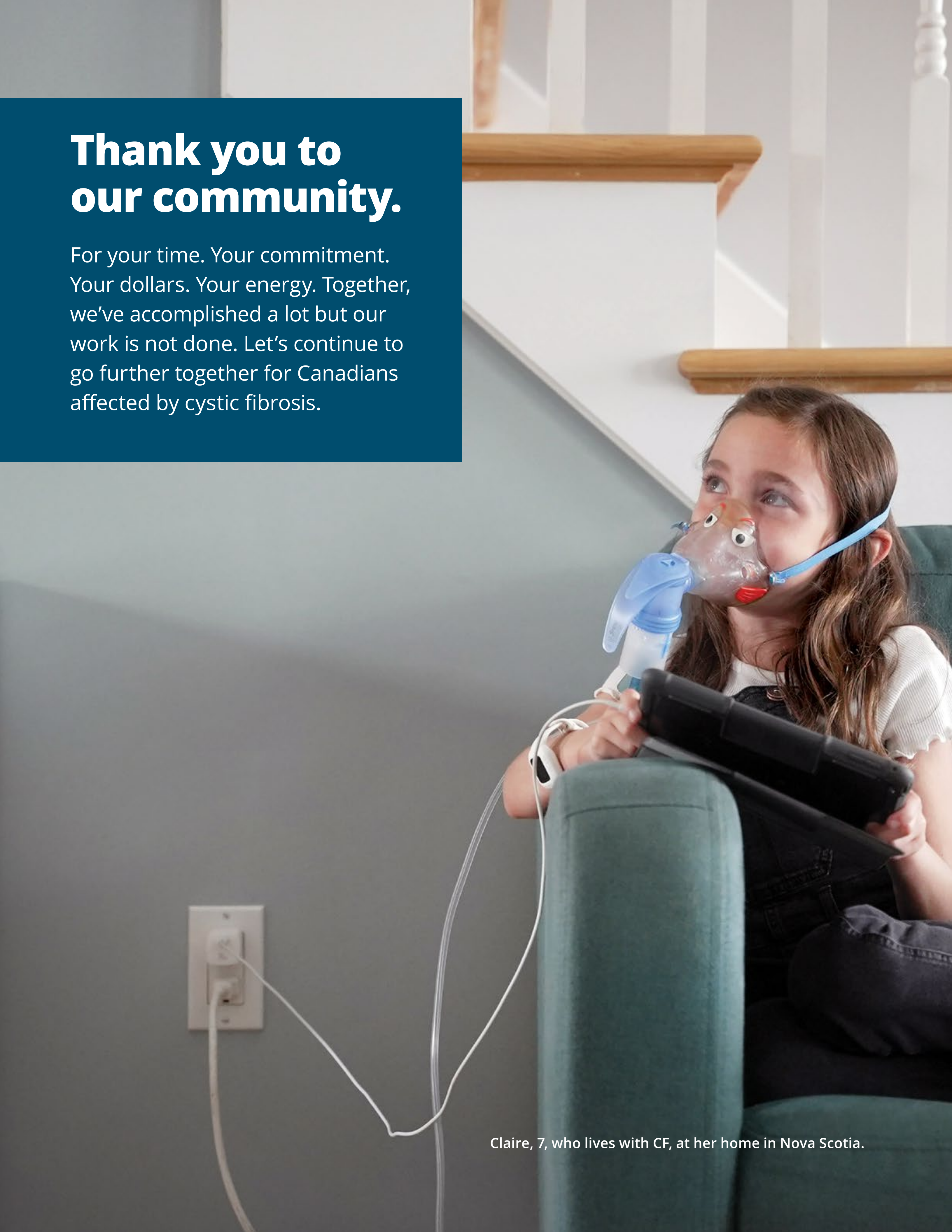
Marie-Pier Emery
Vincent Hamel
Stuart Hodge
Chelsea Jalloh
Françoys Levert
Stephen McCourt
Stephanie Nerlich
Ian Thompson
Robert Sankey

Thank you to our community.

For your time. Your commitment. Your dollars. Your energy. Together, we've accomplished a lot but our work is not done. Let's continue to go further together for Canadians affected by cystic fibrosis.



Claire, 7, who lives with CF, at her home in Nova Scotia.

Your support makes progress possible

- As of September 2022, after relentless advocacy work, Trikafta is funded by all provinces and territories for eligible Canadians aged six and older, which will significantly improve the health of many
  - To assist clinicians in prescribing Trikafta to newly eligible Canadians, our Healthcare Advisory Council led the updating of the Canadian standards of care for modulator therapies
- To advance knowledge on the disease, we funded more than $2 million in research
- More people living with cystic fibrosis had access to clinical trials with 22 trials supported by our clinical trials network last year
- Our Elevate program members participated in 25 opportunities for input ranging from weighing in on the research we funded to helping to name our *Breathe Easier* newsletter
- We launched a resource to support a challenging time for youth: the transition from pediatric to adult CF care
- Hosted information sessions for people impacted by CF on needed topics, such as exercise and mental health wellness
- Monitored important trends in the Canadian CF community around weight, lung transplants and Trikafta so we can ensure our research and clinical care meets the future needs of our community

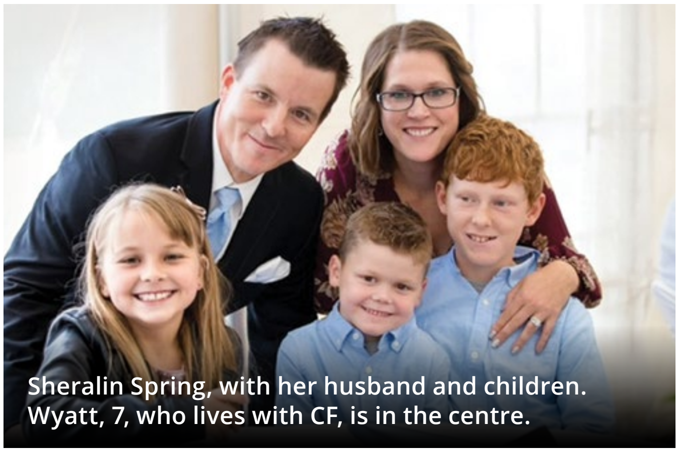
Vicky with her son Sebastian, who lives with CF, at their home in Toronto.

Advocating for life-changing medicines

Throughout the last few years, Cystic Fibrosis Canada led the largest advocacy activity for cystic fibrosis (CF) in Canada, advocating for access to the transformational drug Trikafta. To help Canadians with CF access Trikafta, we leveraged our Canadian Cystic Fibrosis Registry and our relationship with clinicians to ensure decision makers removed unnecessary access restrictions, such as minimum lung function requirements. With the strength of this community at our side, we were successful in bringing Trikafta to eligible Canadians.

Today, every province and territory is funding the drug for eligible Canadians aged six and older who have at least one copy of the most common genetic mutation of the disease in Canada. While there are still significant access barriers and we must continue to advocate to ensure all can benefit from this drug, this is an important milestone that will change the trajectory of the disease for many. We are thankful to everyone – our community, volunteers, advocates, donors and the clinical community – who participated in this work by attending meetings, writing letters, amplifying messages, sharing stories signing petitions and more.

Expanded access to Trikafta is wonderful news, however, we know this drug is not a cure, has come too late for some in our community, is not accessible to all who need it, and there are many people who will never benefit from it. We will continue to advocate and drive research to improve access to life changing treatments for all people living with CF. This will include work to ensure our community benefits from implementation of a nation-wide strategy for drugs for rare diseases.



Sheralin Spring, with her husband and children. Wyatt, 7, who lives with CF, is in the centre.

> "When Wyatt started taking Trikafta in October 2022, it was the first time I could just take a deep breath and not worry about his future," said Sheralin, mom to Wyatt, 7, who lives with CF. "It gives him the chance for a normal future. A life where he can do all that he wants. He can play sports, graduate, pursue a career, get married and have a family, whatever he wishes for his life. He can spend so much more time doing the things he enjoys instead of having to worry about his health. Trikafta just gives us so much hope that he will have a great future, which is something we didn't have when he was first diagnosed."

Bringing new treatments to Canada

Clinical trials have truly changed the course of medicine. They are critical to regulatory approval of new therapies. Without the data to support the safety and efficacy of new drugs they cannot be shared with the public.

Cystic Fibrosis Canada's Accelerating Clinical Trials (CF CanACT) network is one of the ways we are working to get new treatments to Canadians. As a rare disease, collecting the cystic fibrosis (CF) numbers and data needed for regulatory bodies to approve new drugs and therapies can be a challenge. We are proud of this network – a rarity among disease groups our size – that helps advance treatment options for our community.


A CF researcher in the SickKids lab.

Launched in 2018, the network coordinates CF clinical trials sites, making it easier for trials to be conducted in Canada, and more appealing for pharmaceutical companies to bring their trials to Canada. Reaching over 60 percent of people living with CF in Canada, our network is comprised of 10 clinical research sites that stretch from Vancouver to Halifax, plus three satellite sites in Quebec. Since its inception, a total of 247 participants from across the country have participated in 47 industry sponsored clinical trials the network has supported. As a result, many Canadians have been able to receive early access to medications and therapies, like Trikafta, before they have been approved or funded. Aside from that important, early access, people on trials provide the data needed to take these therapies to the next step and reach others who need them. Our trials also led to the approval of hypertonic saline in infants, an important therapy that helps clear mucous.

Our network has infrastructure to allow Investigator Initiated Trials to start quickly, with minimal resources. That means some of our brightest minds in CF research who are closest to our community, get to pose questions they see in their day-to-day work and answer unmet needs that might arise.

Our network works in strong collaboration with other global CF partners, to ensure results from trials for people with CF are impactful for people living with CF, right here in Canada and around the world.

> "I'm very proud to have contributed to a clinical trial", said Isaiah, who lives with cystic fibrosis and participated in a clinical trial through CF Canada's network. "To me, it means that I have contributed something great to the CF community, and I would 100% participate in another clinical trial given the chance."

Improving quality of care

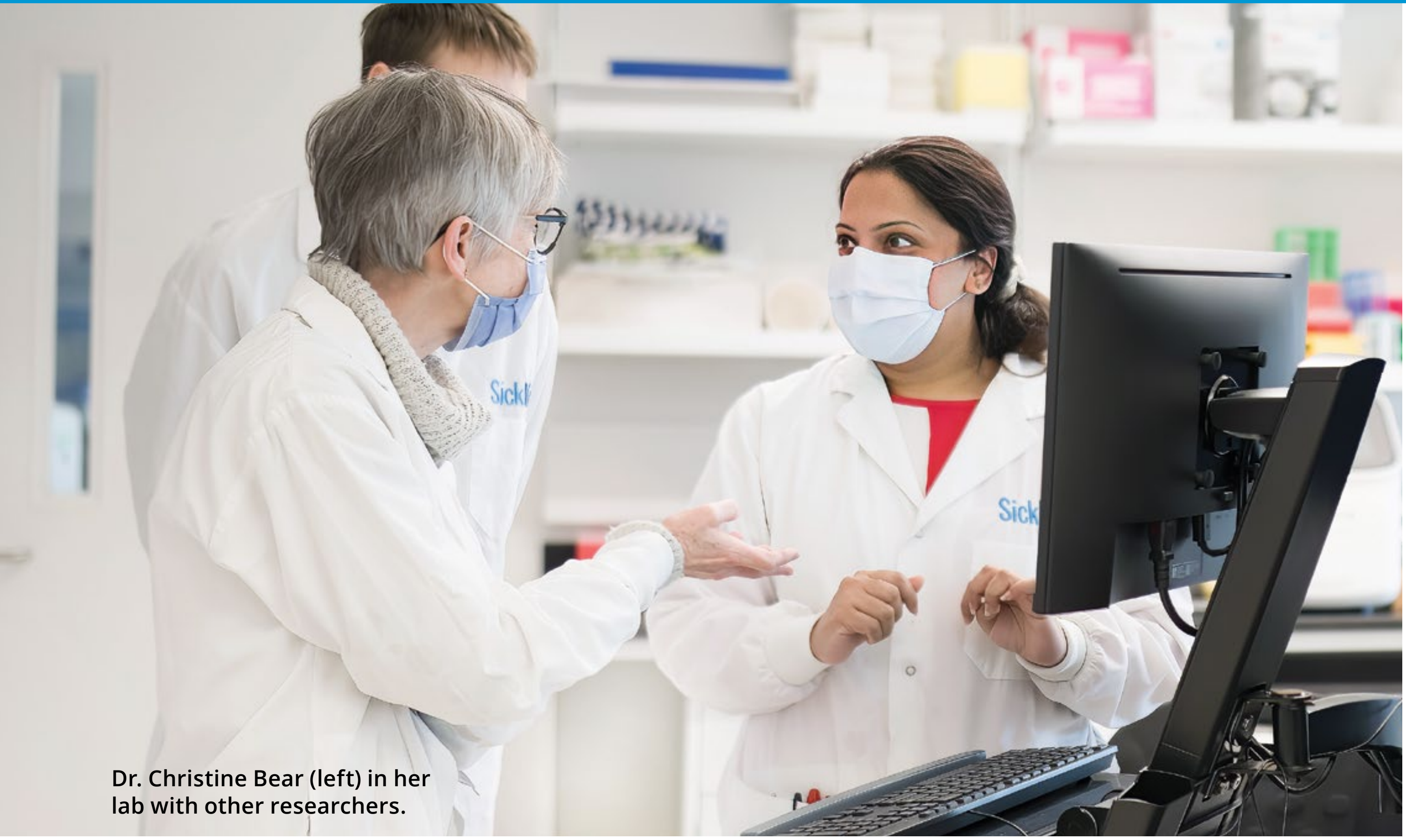
Daphnée, who lives with CF, at her home in Quebec.

To prioritize and address emerging health issues in CF, Cystic Fibrosis Canada regularly convenes our Healthcare Advisory Council (HAC), consisting of representatives from all health disciplines and people with lived experience. Last year, our HAC updated the CFTR Modulator Guidelines to account for the 6+ group and to better support clinicians in their prescribing of modulator therapies. This work helped to facilitate the rollout of Trikata in our community.

We also brought together more than 150 Canadian clinic staff at the North American CF Conference to facilitate best practices, ensuring every clinic is armed with the latest knowledge to take back to their patients. Clinic incentive grants provided to all 40 sites also promote continuous education for staff. In 2022, we awarded two aspiring CF clinicians with clinical fellowships, investing in the future of Canadian CF care.

With the disease in a state of transition, it's important that Canadians with CF continue to feel supported. To promote healthcare outside of the clinics, Cystic Fibrosis Canada hosted information sessions for people impacted by cystic fibrosis on needed topics, including exercise and mental health wellness. As well, we developed a resource in collaboration with our Adult Cystic Fibrosis Advisory Committee to support youth in the transition from pediatric to adult CF care, which is often a challenging time.

Investing in the next wave of hope for Canadians with CF



Dr. Christine Bear (left) in her lab with other researchers.

In 2022, Cystic Fibrosis Canada funded 10 new Canadian research projects totaling $2.1 million aimed at improving the health outcomes of people impacted by cystic fibrosis (CF). Cystic Fibrosis Canada worked with people with lived experience to prioritize their needs and awarded projects based on these priorities. Projects funded range from validating the use of patient-derived nasal cultures for expanding access to CFTR modulators to examining the potential of gene and stem cell therapies for cystic fibrosis.

In all, our funding supported five basic research projects studying fundamental aspects of cystic fibrosis, one clinical cystic fibrosis research study, two years of funding for an early career researcher to support a developing career in cystic fibrosis research, and three postdoctoral research fellows who will be supported for the next two years.

"We are committed to ensuring all Canadians living with cystic fibrosis have longer and healthier lives. Research is needed so that we can alter the course of this disease and leave no one behind," said Kelly Grover, President and CEO, Cystic Fibrosis Canada. "Thanks to the generosity of our donors, we are supporting promising research projects that will have outcomes that benefit patients sooner rather than later, particularly for those with limited treatment options."

Canadian Cystic Fibrosis Registry Annual Data Report

The CF Registry has made a remarkable impact on our understanding and treatment of the disease, and its importance continues. The data help us to track trends in the Canadian CF community and understand the progress and impact that has been made to advance health outcomes. It has been instrumental for Canadian cystic fibrosis research and care and has also been a tremendous tool for our advocacy efforts.

Armed with detailed, real-world data, we have been able to effectively advocate for our community's needs by providing real life evidence to those who make decisions about cystic fibrosis treatment. Last year, we used data from the Canadian CF Registry and successfully advocated for expanded access to Trikafta for those aged six and up with at least one F508del mutation, and most importantly, we informed the decision to remove any upper limits on lung function.

Not only is the Canadian CF Registry instrumental in Cystic Fibrosis Canada's advocacy efforts, as one of the longest-running rare disease registries in the country – and the world, researchers in Canada and around the world rely on our Registry data to enhance their understanding of the disease. It is extraordinary for a disease to have a registry – and one that is as complete as the Canadian CF Registry, we are profoundly grateful to have this valuable tool.

As a member of the CF Registry Global Collaboration, a group comprising over 60 countries around the world, we continue to collaborate with international registries to advance health outcomes worldwide for people who live with cystic fibrosis.

We are endlessly grateful to those that make this invaluable tool possible: to the healthcare teams at the CF clinics who enter the data, to the people living with cystic fibrosis that participate in this program; to the families and caregivers who support them; and to the donors whose contributions make this work possible.

CF patient getting a blood oxygen measurement taken at a CF clinic.

In the community

Our incredible community of volunteers and donors continues to inspire and motivate us. Because of your generosity – in both time and dollars, we have been able to make change and deliver impact. *Here are just a few of the events and initiatives you helped to make a success and that have helped fuel our organization to go further for people living with cystic fibrosis.*


Decant Gala host, Ben Mulroney

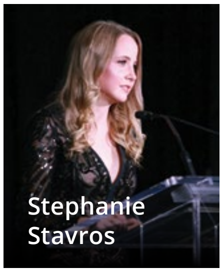

Stephanie Stavros


Table at the 65 Roses Gala


A family at the Walk to Make Cystic Fibrosis History

What a Way to Walk!

With the **Walk To Make Cystic Fibrosis History** held as a virtual event in 2020 and 2021, in 2022 we were thrilled to be able to come together again, live and in person. The 2022 Walk was a welcome opportunity to connect face-to-face at more than 70 locations across the country. Our Walk community created teams, brought families and friends, fundraised, volunteered, sponsored and participated in local Walks with great enthusiasm, which translated into more than $2.8 million raised in support of CF research, advocacy and healthcare. That's a 18-year Walk fundraising total of over $40 million. Way to go!

Gala-vanting Across the Country

For the first time in two years, guests were able to gather in person at the **2022 Decant Gala and Fine Wine Auction** in Toronto and it wasn't just the wine that was flowing! There was also an outpouring of support from guests, sponsors and volunteers that resulted in raising an incredible $298,000. Longtime CF Canada supporter and Canadian television personality Ben Mulroney hosted the event, themed around an Evening in Australia, where the sophisticated atmosphere made for a successful evening.

There was no shortage of glamour or glitter as our community came together at **Fusion, The Diamond Ball** on October 22 at Angus Glen Golf Club in Unionville, Ontario. This fantastic evening could not have happened without our supportive sponsors, our hard-working volunteers and our generous guests, who outdid themselves by raising over **$445,000!**

The 22nd Annual **65 Roses Gala,** presented by Ronald S. Roadburg Foundation, raised almost $300,000 in support of Cystic Fibrosis Canada, thanks to the unwavering support of event sponsors, donors, volunteers and guests. In mid-November, and for the first time since 2019, our BC community gathered to raise funds and connect with each other, and the results speak for themselves!

Handing out lemonade at Cassidy's Lemonade Stand, a CF Canada fundraiser and Change Maker.

Change Makers

We know how fun, creative and passionate our community is, so when we launched the new Change Makers community fundraiser program this past year, it was no surprise to see your impressive fundraising ideas. You came together in inventive ways to support those you know with cystic fibrosis, and to make a change for everyone impacted by CF. From selling homemade fudge to lip-synching Celine Dion, hosting a golf tournament dance party or charity concert, amazing sports feats to classic bake sales and lemonade stands, our Change Makers did us proud, and raised thousands of dollars in support of our work to improve the health of people living with CF. Your passion takes us further.

Cassidy and a friend fundraising for CF Canada.

Kin Canada members volunteering at a Walk to Make Cystic Fibrosis History.

Community Support From Coast to Coast

Volunteers from coast to coast raise their hands, roll up their sleeves and give their time and energy to help us deliver on our work. From sharing stories, to working at Bingos, to leading events, to reviewing research grants to providing needed input, we are deeply thankful to each and every volunteer that helps us deliver on our mission.

Kin Canada

We are proud to be the charity of choice for Kin Canada. Kin clubs have raised more than $50 million for Cystic Fibrosis Canada, the largest cumulative donation in our 60-year history. In 2022, Kin clubs from around the country continued to step up to support Canadians with CF, raising nearly $700,000 in support of Cystic Fibrosis Canada, including the Kinsmen Club of Winnipeg, which made an astounding $102,640 donation, the largest annual contribution from any Kin Canada club since the organization first began supporting CF Canada in 1964.

Leadership giving

THE
LEADERSHIP
CIRCLE

Thank you to Cystic Fibrosis Canada's dedicated donor community. Your generosity makes our work possible. We would like to thank these generous members of our Leadership Circle who contributed $5,000 and over in 2022–2023.

The Charles H. Ivey Foundation
Arrell Family Foundation
Sarah Gordon Sutherland Memorial Fund
Waterloo Region Community Foundation
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Sandra Tapper
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The Michael and Sonja Koerner Charitable Foundation
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Paul Barber Foundation
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River Philip Foundation
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Stephen and Kathleen Smith
WindsorEssex Community Foundation

Sponsors

Thank you to our event sponsors. We are thrilled to work with you on our Cystic Fibrosis Canada properties. The generous funding of sponsors is vital to the continuance of our work. We cannot succeed without the generosity of supporters like you.

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These listings include philanthropic contributions made directly to the organization. Please note these listings are not inclusive of community fundraising or community event sponsorship. If you wish to learn more about leadership donations or recognition, please contact ***leadershipgiving@cysticfibrosis.ca.***

Kadeem, who lives with CF, doing schoolwork at his home in Toronto.

2023 Financial statements

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, 2023

Revenue	2023	2022
Community events	$ 6,949	$ 5,563
Annual giving	2,097	2,073
Leadership gifts and sponsorship	1,532	1,339
Kin Canada	689	749
Other	799	1,394
Royalties	274	335
Bequests	1,452	1,468
Total	**$ 13,792**	**$ 12,921**
Less direct fundraising costs	3,108	2,498
Net fundraising revenue	10,684	10,423

Expenses	2023	2022
Program		
Research	$ 3,175	$ 2,574
Healthcare	1,073	1,094
Community engagement	1,863	1,711
Advocacy	708	778
Other	63	67
Total	**$ 6,882**	**$ 6,224**
Other		
Administration	1,566	1,263
Fundraising	1,526	1,531
Total	**$ 9,974**	**$ 9,018**
Excess of revenue over expenses before the undernoted	710	1,405

Investment Income (Loss)	2023	2022
Realized gains on investment	$ 170	$ 112
Change in unrealized loss on investment	(232)	(224)
Total	**$ (62)**	**$ (112)**
Excess of revenue over expenses	648	1,293

Statement of Financial Position

(in thousands of dollars)
January 31, 2023

Assets	2023	2022
Current Assets		
Cash and equivalents	$ 8,560	$ 8,194
Short-term investments	1,061	950
Receivables and other assets	720	651
Total	**$ 10,341**	**$ 9,795**
Contributions receivable	159	158
Long-term investments	4,258	4,382
Capital assets	14	27
Total	**$ 14,772**	**$ 14,362**

Liabilities and Net Assets	2023	2022
Current Liabilities		
Accounts payable and accrued liabilities	$ 530	$ 608
Deferred revenue	595	722
Total	**$ 1,125**	**$ 1,330**
Long-term deferred contributions	195	228
Net Assets		
Endowment	$ 94	$ 94
Internally restricted for research and healthcare	2,366	2,645
Unrestricted	10,992	10,065
Total	**$ 14,772**	**$ 14,362**

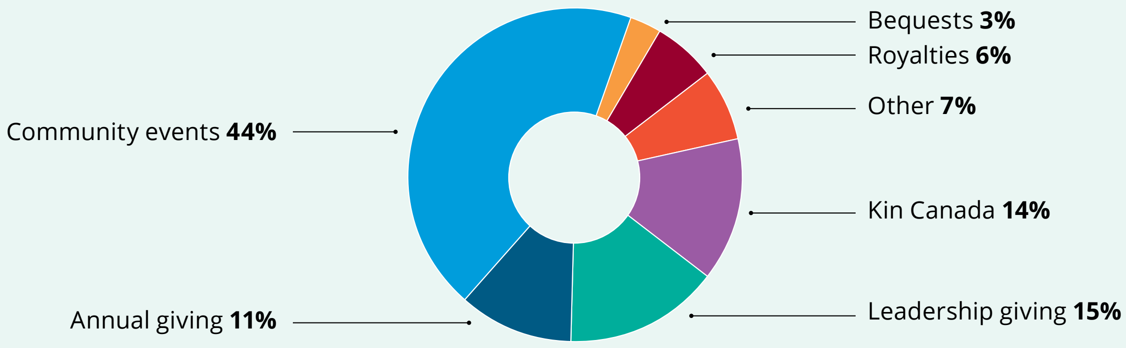
Statement of Changes in Net Assets

(in thousands of dollars)
Year ended January 31, 2023

	Endowment	Internally restricted for research and healthcare	Unrestricted	**2023 Total**	**2022 Total**
Net assets, beginning of year	$ 94	$ 2,645	$ 10,065	**$ 12,804**	**$ 11,511**
Excess of revenue over expenses	$ –	$ –	$ 648	**$ 648**	**$ 1,293**
Transfer between funds	$ –	$ (279)	$ 279	**$ –**	**$ –**
Net assets, end of year	$ 94	$ 2,366	$ 10,992	**$ 13,452**	**$ 12,804**

Statement of Fundraising Revenue

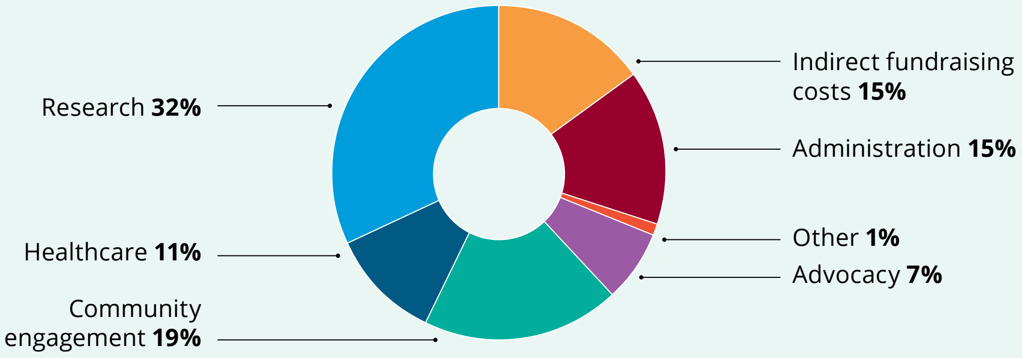
(Net of direct fundraising costs)



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

Uses of Funds

(Excludes direct fundraising costs)



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Complete audited financial statements are available on our website at **cysticfibrosis.ca.**

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 toward our vision of a world without cystic fibrosis.

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