Alice from Quebec,
lives with cystic fibrosis

GOING FURTHER TOGETHER

2020-2021 Impact report

Cystic Fibrosis Canada | FURTHER

A year of resilience

Leona Pinsky, Board Chair, Cystic Fibrosis Canada

Kelly Grover, President & CEO, Cystic Fibrosis Canada

As we reflect on the unprecedented year that was 2020, we are humbled by the resilience and support of the incredible cystic fibrosis (CF) community in Canada.

This past year was difficult for all Canadians. The COVID-19 pandemic caused many unknowns and increased anxiety about our health. With the intense sanitizations, infection control and isolation, the world experienced what people who live with cystic fibrosis deal with every day.

While leaving its mark on us as individuals, the COVID-19 pandemic also had a tremendous effect on the charitable sector, with in person fundraising events as we knew them ceasing to exist, almost overnight. Thanks to our dedicated community of volunteers and supporters and bold decision making by our Board and management, we are proud to say that we were able to weather these extraordinary times while continuing to drive important change for people living with cystic fibrosis. You supported our inaugural virtual events and showed your resilience in pivoting to virtual platforms and work alongside us. You made it possible for progress to continue.

In this report you will read about some of the highlights from last year, with the launch of our new three-year strategic plan in early 2020, and our continued work in advocacy, including Trikafta's successful entry into the Canadian market for approval. We partnered with our global peers to participate in timely international research regarding CF and COVID-19 and released our annual Registry data report. We developed Canadian Cystic Fibrosis Standards of Care and continued our highly impactful Clinical Fellowship Grant program, ensuring that all Canadians living with cystic fibrosis receive world-class care from specialists in this field. We also expanded our Clinical Trials Network, making it directly accessible to 60% of the CF population in Canada, helping to facilitate the development of new treatments for CF and attract clinical trial studies in Canada.

As we look to the year ahead it is with great optimism. We are as committed as ever to our mission and will keep pushing further until all Canadians who live with cystic fibrosis can and do enjoy everything life has to offer.

Thank you to our community members, donors, volunteers, staff, sponsors, and partners across Canada. You went further for us last year and together, we will continue to push further this year.

Sincerely,

Leona Pinsky,
Board Chair,
Cystic Fibrosis Canada

Kelly Grover,
President & CEO,
Cystic Fibrosis Canada

Megan from Alberta,
lives with cystic fibrosis

How your donations fueled progress last year:

- After relentless advocacy from Cystic Fibrosis Canada and the Canadian cystic fibrosis (CF) community, **life changing medicine Trikafta was accepted for priority review by Health Canada.** As part of this work we:
  - Held over 150 meetings with federal and provincial Members of government through our National Advocacy Network
  - Issued letters to **99% of MPs across the country** imploring action for access to CF medicines
- **Expanded our clinical trial network, making it accessible to 60% of the CF population in Canada**, because of this expansion we:
  - Realized a **42% increase** in clinical trials supported by our network from 2018 to 2020
  - **Increased patient participants** in the clinical trials network by 72% from 2018 to 2020
- Launched the first two Canadian standards of cystic fibrosis care
- Participated in international research regarding COVID-19 and cystic fibrosis
- **Provided timely information regarding COVID-19 and CF** and advocated for needed supports for people living with CF
- **Successfully moved our milestone events to virtual platforms engaging** 3,200 virtual Walk to Make CF History participants
- **Brought our volunteers together, providing connection and support during this time**

Thank you for helping us go Further for Canadians living 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 2020, Cystic Fibrosis Canada launched its new strategic plan outlining the focus of our work over the next three years. This work 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

ADVOCACY

PRIORITY 1

IMPROVE ACCESS TO LIFE-CHANGING AND LIFE-SUSTAINING MEDICINES

LEADING TO:

More people in Canada have access to symptom management drugs and modulators

INFORMATION & SUPPORT

PRIORITY 4

LEVERAGE DIGITAL STRATEGIES AND PEER CONNECTIONS

LEADING TO:

Timely & relevant information provided by CF Canada and peers

HEALTHCARE

PRIORITY 2

IMPROVE THE QUALITY OF CF CARE AND TREATMENT EXPERIENCE

LEADING TO:

Canadian CF standards developed and used by clinics

Innovations in care have reduced the burden of care faced by people living with CF

RESEARCH

PRIORITY 3

ADVANCE RESEARCH ON PRIORITY HEALTH NEEDS

LEADING TO:

Investments made on research initiatives impacting priority health needs and with potential for results in the near future

PEOPLE & REVENUE

PRIORITY 5

STRENGTHEN THE ORGANIZATION FOR IMPACT

LEADING TO:

Mutually rewarding volunteer program

Engaged, high-performing, collaborative staff teams

High quality donor experience across the organization

Sustained & growing revenue

Thank you to our Board of Directors

Leona Pinsky (Chair)
Robert Sankey (Vice Chair)
Ron Anderson
Lee Burry
Robert Deane
Louise Desjardins
Kathryn Deuchars
Mitch LePage
Françoys Levert
Barbara M. Hill
Stuart Hodge
Stephen McCourt
James Mountain
Hugh O'Brodovich
Ian Thompson

John from Newfoundland,
lives with cystic fibrosis

Making the impossible, possible

CF Canada, its National Advocacy Network and the community fight to get Trikafta to Canada

Devin with fiance, Jen

When she found out she was pregnant, Patti Tweed already knew a lot about cystic fibrosis (CF).

A paediatric dietitian at a cystic fibrosis clinic in Saskatoon in the 1980s, Patti understood the challenges and complex daily rituals of life with cystic fibrosis.

What she didn't know was that she and her husband both carried the gene.

When her son Devin was born with cystic fibrosis, Patti faced the facts. She sought to learn even more about the disease which had played a big role in her professional life and, suddenly, had become central to everything.

One other thing she knew: that she would fight. Patti knew that somehow, she had to make the impossible possible. That's where Cystic Fibrosis Canada came in.

In those days, there were no miracle drugs. Patti and her family threw themselves into raising money for research, involving Devin at every stage. He swam his first swimathon on a flutterboard when he was six months old.

In 1989, when researchers identified the cystic fibrosis gene, Patti cried tears of joy. The bake sales, meat draws, swimathons and Shineramas had paid off by helping fund the made-in-Canada discovery. Surely a cure would be close behind.

That dream remains elusive, but thanks to donors like you, the incremental innovation since that day has been extraordinary. From enzymes to disease modulators to the breakthrough drug Trikafta, each new step has made a difference.

Today, as a member of Cystic Fibrosis Canada's trained volunteer advocacy group, the National Advocacy Network, Patti is laser-focused on achieving access to Trikafta.

In 2020, advocates set out to convince each organization within Canada's complex drug review and reimbursement system to play their part to put Trikafta in the hands of the nearly 3,800 Canadians whose lives it could transform.

Supported by briefing notes, videos and technical materials provided by Cystic Fibrosis Canada, they've sent hundreds of letters and held countless meetings with government officials. Cystic Fibrosis Canada delivers the facts and the strategy, she explains, and network members help by sharing their stories and touching the heartstrings.

"I am determined that we'll get access to Trikafta in 2021," says Patti. "There are so many hurdles, but I know it's possible."

Patti thinks of the system as an orchestra, and Health Canada, Canadian Agency for Drugs and Technologies in Health (CADTH), Institut national d'excellence en santé et services sociaux (INESSS), the pan-Canadian Pharmaceutical Alliance (pCPA) and the provinces are

> **Your vision of a future without cystic fibrosis means the world to us. Thank you for your willingness to contribute to that future at whatever level you can.**
>
> – Patti Tweed, CF mom

the musicians. "We want every single player to be sitting on the edge of their chairs, ready to chime in with their piece when it's their turn."

Patti and her family have formed lasting bonds within the small but mighty cystic fibrosis community through their advocacy work. The depth of shared understanding and fellowship has made these people "the family we never thought we wanted but are awfully glad we have."

It has been decades since cystic fibrosis became personal for the Tweed/Clark family. Now 38, Devin Clark works as a city planner. He loves to hike and ran a half-marathon before the pandemic struck. He recently got engaged, though the wedding plans are on hold due to COVID-19.

The family hopes that Devin will one day receive access to Trikafta. Patti is convinced that the governments and regulators will come together in time – each member of the orchestra playing their part – so that he'll have access to it by the time he gets married.

"Devin will be a Trikafta groom," she declares with unstoppable conviction. "We will get this done. In the meantime, he's focused on being healthy enough to meet the future."

Cystic Fibrosis Canada's Advocacy work last year

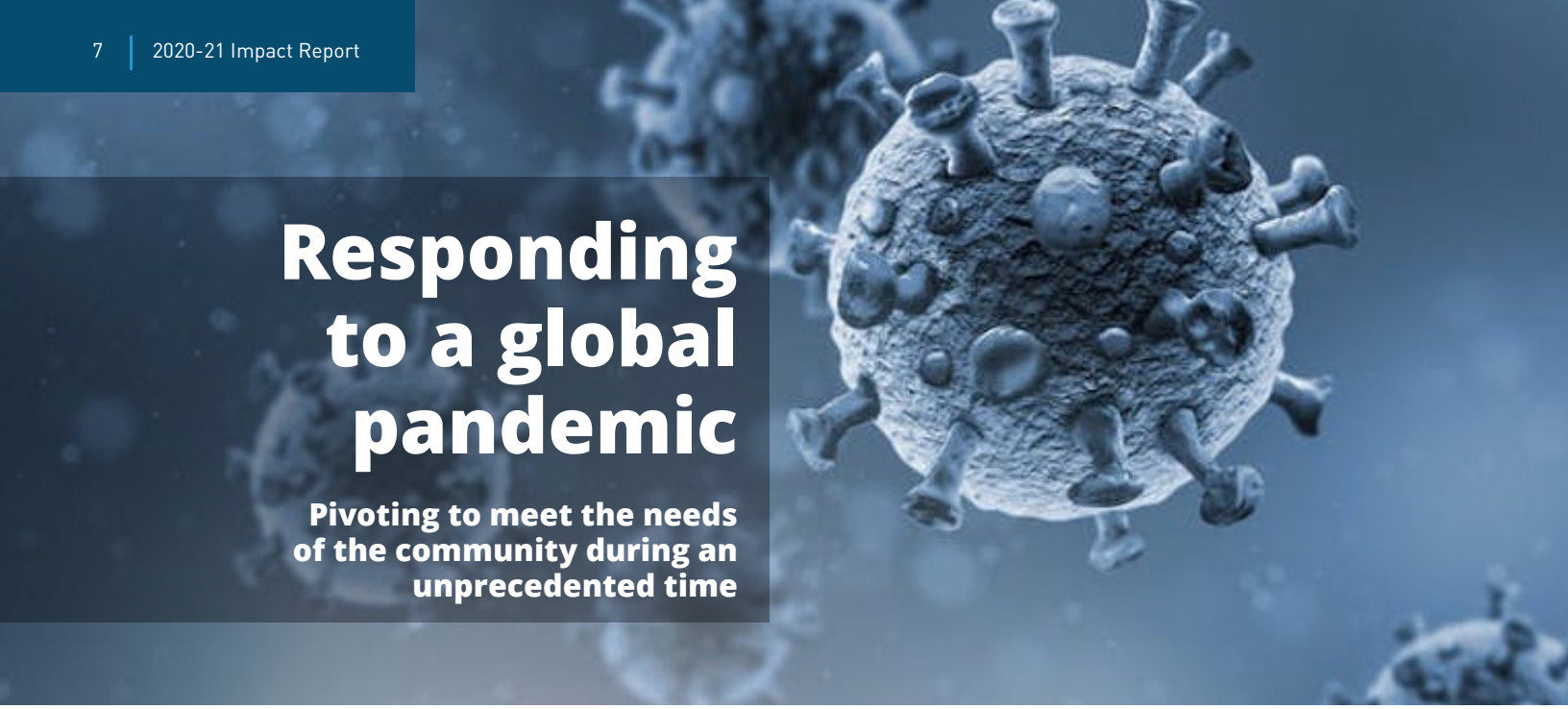
Thanks to your commitment to a world without cystic fibrosis, we...

- **Had three huge wins:**
  - **Patented Medicine Prices Review Board changes were delayed;**
  - **Trikafta was submitted for Health Canada approval; and**
  - **Trikafta was granted an aligned review, the fastest route possible**

As part of this work Cystic Fibrosis Canada, its National Advocacy Network and community:

- Held over 150 meetings with elected officials
- Facilitated over 77 CF clinicians to sign an open letter
- Community members sent 1,850 letters to the Patented Medicine Prices Review Board (PMPRB)
- Hosted a historic all-party emergency meeting
- Sent 5,500 letters to 99% of MPs
- Sent 224 letters to the editor
- Secured 40,000 signatures for a petition
- Joined a coalition of 13 health charities and patient groups

...all while 90% of Canadians with cystic fibrosis wait for the drug that could save their lives



Responding to a global pandemic

Pivoting to meet the needs of the community during an unprecedented time

On March 11, 2020, when the World Health Organization (WHO) declared COVID-19 a pandemic, organizations around the globe experienced unprecedented disruption to their operations. We at Cystic Fibrosis Canada, with support from our Board of Directors, had to make quick strategic decisions to adjust how we work, reduce expenses and pivot to virtual events. Most importantly, we needed to focus on the community. Families impacted by cystic fibrosis (CF) were rightfully concerned. What could happen to their loved ones with cystic fibrosis if they contracted the virus?

"In March of last year, the COVD-19 pandemic was still in its infancy," said Dr. John Wallenburg, Chief Scientific Officer, Cystic Fibrosis Canada. "There was conflicting information coming at us daily. We knew that our community would be looking for information on best practices and risk so we pivoted our efforts and focused on providing clarity where we could."

The team at Cystic Fibrosis Canada dedicated a section of the website to host COVID-19 related information and resources including federal and provincial financial support, mental health support services, caregiver support, vaccine information, back-to-school integration and the latest updates and information on the disease. The team also introduced a webinar series called Ask the Experts. The series enabled community members to submit questions related to COVID-19 that would be answered live from leading cystic fibrosis (CF) experts and physicians. The first of these webinars premiered on April 1, 2020 and in total, five sessions were hosted in 2020.

Agatha Bourassa with her husband, Tim Vallilee

"The webinars were an important and welcomed source of information to help me manage my stress, said Agatha Bourassa, Franco-Nova Scotian CF caregiver. "I found that if I stayed educated and informed, I felt safe. It was the webinars and the meetings with the specialists that brought me so much comfort."

In addition to the information shared via online tools, Cystic Fibrosis Canada's Information and Referral Service provided one-on-one support for families and individuals that requested information regarding COVID-19 resources and support, among other CF-related requests. In 2020, the program experienced a 12% increase in requests over the previous year.

Global COVID-19 Research

In March of 2020, Cystic Fibrosis Canada's Registry team began having conversations with its global peers to assess the risk of COVID-19 on people living with CF, and the potential to leverage existing CF Registries around the world to capture this information. The Cystic Fibrosis Trust in the UK turned to the previously established Cystic Fibrosis Registries Global Harmonization Group, an international group, with CF Registry representatives

from more than 22 countries. The group first met on March 20, 2020 and continues to meet every 2-4 weeks.

"The group mobilized at an incredible speed," said Stephanie Cheng, Director, Registry at Cystic Fibrosis Canada. "Early meetings were exploratory, with each country weighing in on how they planned to capture and report on COVID-19 related data. As the pandemic evolved, the group began to share their experiences on infection numbers, lockdown measures and more recently, vaccine roll-out. Producing timely research was always in the forefront of the group's mission, and considerable time was devoted to standardizing case definition, drafting statistical analysis plans and reviewing results," Ms Cheng noted.

It was a high priority to expand the Canadian Cystic Fibrosis Registry and capture COVID-19 data to monitor the situation in Canada, ease community concerns and enable global research regarding how COVID-19 affected people with cystic fibrosis. Without enabling the Registry to capture this data, a consolidated place for data related to COVID-19 and cystic fibrosis in Canada would not exist.

"Canada is one of the few countries that is capturing testing data," said Dr. Anne Stephenson, Medical Director, Registry, Cystic Fibrosis Canada, and CF Physician. "By capturing the negative tests, we are able to assess trends in testing in addition to prevalence of the infection itself." To date, Cystic Fibrosis Canada's Registry team has captured COVID-19 related testing data on over 20% of the cystic fibrosis population in Canada.

In April of 2020, Cystic Fibrosis Canada co-authored, alongside the Cystic Fibrosis Registries Global Harmonization Group, the first study regarding how individuals with cystic fibrosis are affected by COVID-19. "This first study was critical in understanding what impact COVID-19 could have on the CF population," said Dr. Stephenson. "The data was promising, showing that the incidence of COVID-19 in people living with cystic fibrosis may be slightly lower than the general public, potentially due to the CF community already adhering to infection prevention and control measures," said Dr. Stephenson. A second collaborative study published in November of 2020 found that outcomes for people with cystic fibrosis were not as severe as originally feared. "It was reassuring to see that most people with cystic fibrosis do not experience a severe course of disease," said Dr. Stephenson. "However, there is still a range of possible clinical outcomes following a diagnosis," she noted. A third study is well underway and the group hopes to complete analyses in the spring of 2021.

The Canadian Cystic Fibrosis Registry has been an invaluable resource for monitoring trends and driving change in the disease since its inception in the 1970s. Without the Registry, the support of CF clinic team members, and the participation of those living with cystic fibrosis who consent to having their data submitted, it would not have been possible to participate in these timely and necessary COVID-19 global research studies. Not only does the Registry make it possible for Cystic Fibrosis Canada to monitor new health issues such as COVID-19, but for decades the Registry has monitored important health trends in Canadians living with cystic fibrosis, including a consistently rising median age of survival.

The Canadian Cystic Fibrosis Registry

2019 Annual Data Report

4,344 **Cdns living with CF**

116 **new diagnoses**

- 66% identified via newborn screening

62% **of people with CF are adults**

34% of adults have CF-related diabetes

Median age of survival in 2019 was **54.3** **years**

Promising compared to the median age of survival twenty years ago of 35.5 years

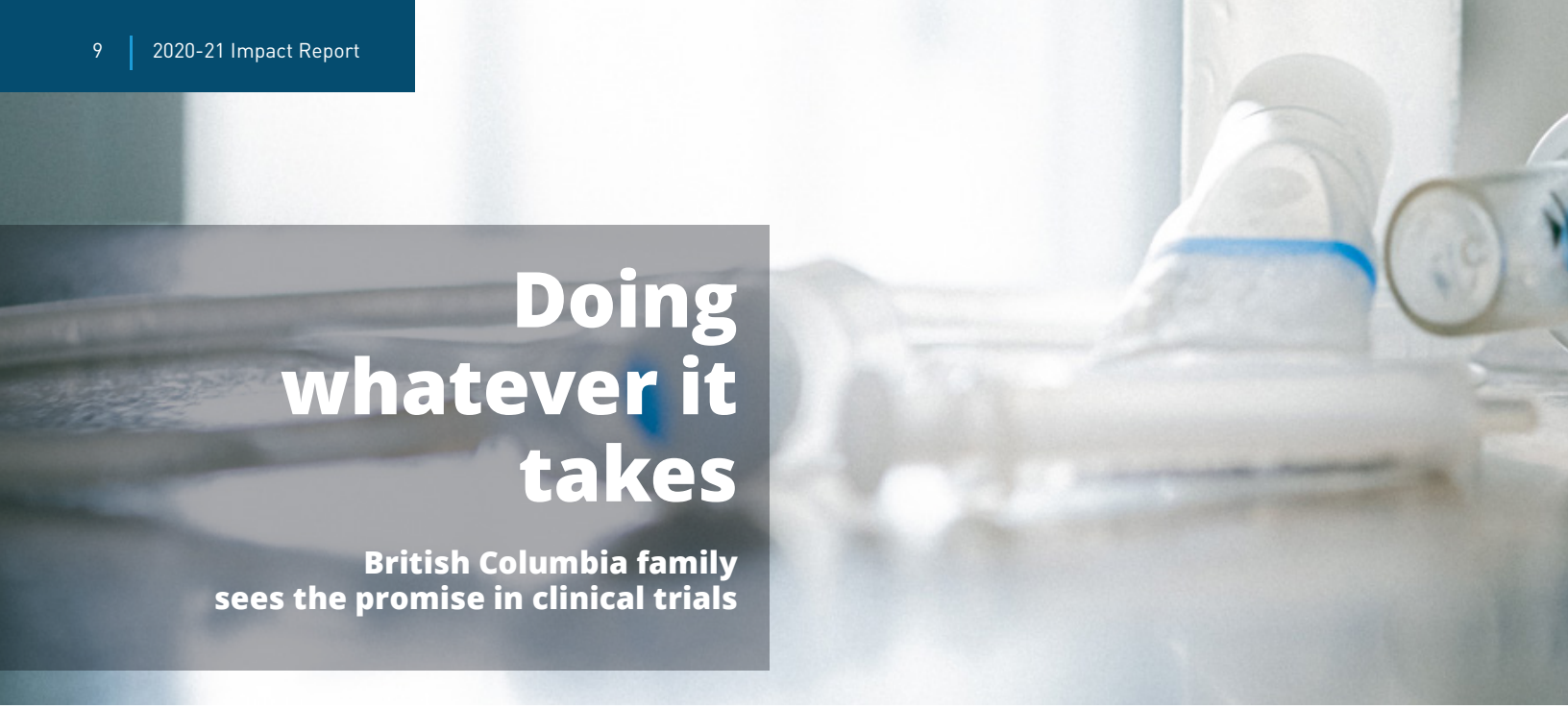
46 individuals received a lung transplant

Individuals with cystic fibrosis:

Attended **18,960** **clinic visits**

Spent **25,246** **days in hospital**

The Annual Data Report is a cumulation of the hard work of CF clinic teams, their diligent data entry makes this report possible. Thank you also to patients for sharing your information.



Doing whatever it takes

British Columbia family sees the promise in clinical trials

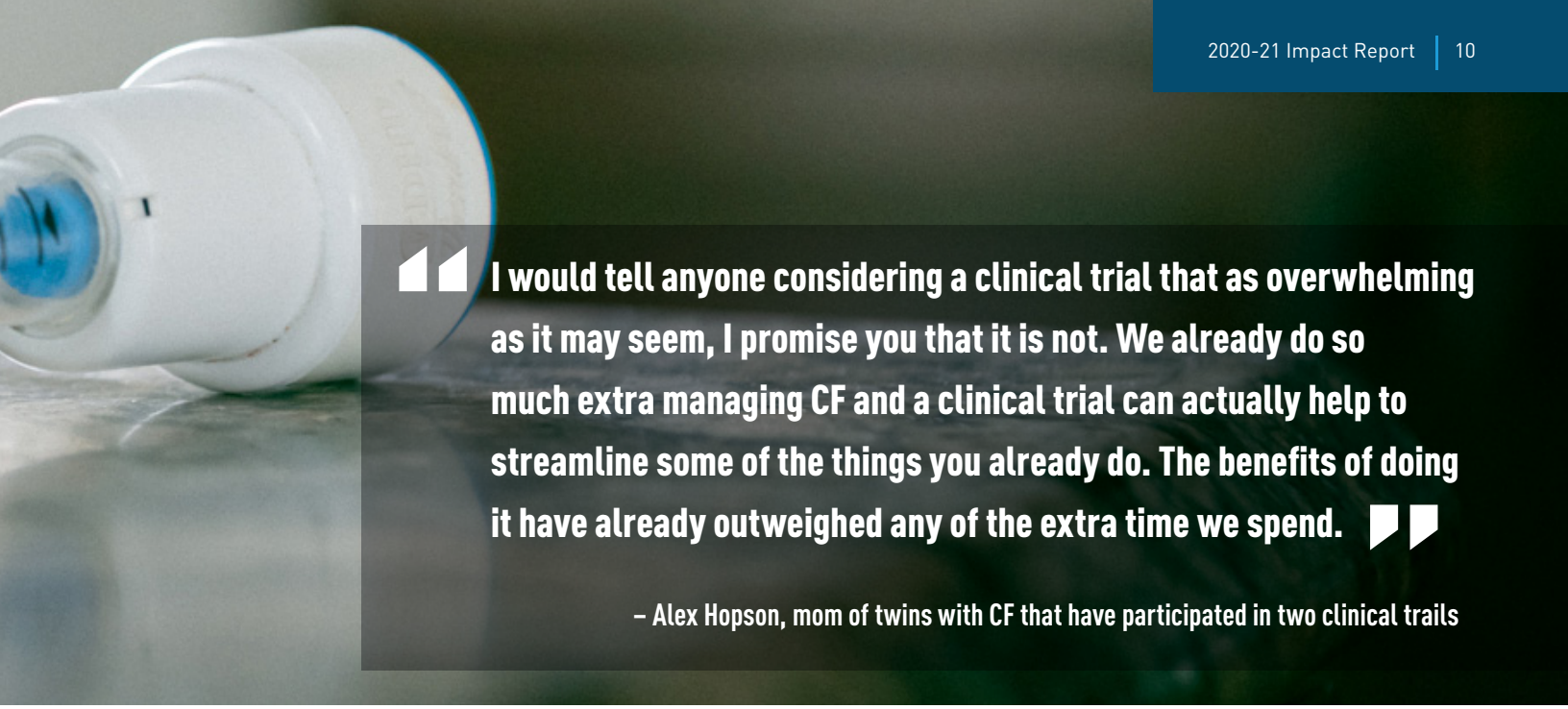
Alex and Steve's twin boys surprised everyone when they arrived eight weeks early in June 2013, spending their first five weeks in the neonatal intensive care unit (NICU). Now seven and a half years old, Andrew and Oliver are active and full of life. They enjoy playing baseball, soccer, and love to draw – their mom Alex says there is a constant flow of paper and art projects all over the house. They spend their summers making memories with family and camping. With their active lifestyle today, it's hard to imagine back to the time when they were in the NICU, struggling to gain weight. At first, the doctors thought the boys were experiencing typical preemie issues, and it was only when Andrew and Oliver's heel prick test came back with markers for cystic fibrosis (CF), that they realized something else entirely was going on. Their family's lives were about to take a new path.

At three months old, Andrew and Oliver were officially diagnosed with cystic fibrosis. Alex and Steve immediately went on autopilot, doing what they needed to do to support their precious new babies. They continued weekly CF clinic visits until CF care became their new normal, and then moved to monthly visits until the boys turned two. Alex and Steve made it through those first few years with the help of their village: the grandparents.

"We decided early on that we would do whatever it takes to help the boys live long and healthy lives," said Alex. They found their rhythm and took on their new roles as mom, dad, CF expert, physiotherapist, dietician, pharmacist, and nurse. Alex fondly remembers how the kids' television show Paw Patrol saved her; "I would perform 10 minutes of physio on Oliver while Andrew watched the show, and then they would switch." On top of the physio sessions were the enzymes; dividing the pills took a lot to manage, ensuring pills are split and ready to go. They stayed organized with an app on their phones, to keep track of who had taken their enzymes.

Alex and Steve always said they would do anything for the greater good of moving science and research along. In 2018, their CF clinic team at B.C. Children's Hospital, a site of the Cystic Fibrosis Canada Accelerating Clinical Trials network, approached them with the opportunity to have the boys participate in a 10-month clinical trial about hypertonic saline use in preschool aged children. They knew they had to say yes. Participating in the trial meant the boys would need to add 10 minutes of extra time to their daily regimen by using a nebulizer twice daily before their physio. Monthly, they would go in for the multiple-breath washout test to test their lung function. Alex and Steve knew that this study could have long-term benefits for their sons, since at the time it was not standard practice for children their age to have saline treatments.

"Clinical trials can bring incredible opportunities to patients and of course they are critical to pushing our research and new therapies forward," said Maggie McIlwaine, Network Manager, CF Canada Accelerating Clinical Trials. "This is why we at CF Canada have



> **I would tell anyone considering a clinical trial that as overwhelming as it may seem, I promise you that it is not. We already do so much extra managing CF and a clinical trial can actually help to streamline some of the things you already do. The benefits of doing it have already outweighed any of the extra time we spend.**
>
> – Alex Hopson, mom of twins with CF that have participated in two clinical trails

increased the clinical trial network in Canada – we want more patients to have access to them."

"We know that Andrew and Oliver have been lucky. They have experienced the typical cystic fibrosis related viruses and bacteria, but they have not had any hospitalizations to date," says Alex. They came close once but were able to avoid it. The family believes that this is likely due to the early intervention of the saline treatment they received through the clinical trial.

In 2020, the family received a call on Alex's birthday, informing them that the boys had been selected to participate in a modulator trial. They were thrilled at the prospect of Andrew and Oliver gaining access to a potentially life-changing drug. In August of that year, the boys began phase 1 of the trial and in January 2021, they began phase II. Alex says it became quickly apparent that the first phase for the boys had been a placebo since only a few weeks into phase two, they were able to notice a change, growth was happening quickly, and their lung function was improving. As part of this study they will be on the drug for two years, and they hope that by the time the study is complete, the drug will be widely available in Canada.

"For now, the boys are excited to participate, they're young, but they understand that they are a part of something bigger," said their mom Alex. While they have the extra clinic visits and tests, they look forward to their visits since the trials are run by their care team, who they've been with since the very beginning – they also get snacks and tablet time, an added benefit according to Andrew and Oliver!

What surprises Alex and Steve the most about their participation in clinical trials? The reassurance. They feel empowered by the data they receive monthly from the clinical trial.

Cystic Fibrosis Canada Accelerating Clinical Trials network

By the numbers:

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

72% **increase in** patient participants in trials from 2018 to 2020

42% **increase** in trials supported by the network over the last two years

10 **Sites:** **Two** in Montréal, Toronto and Vancouver in Calgary, Saskatoon, Quebec City and Halifax

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

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.

Improving quality of life begins with excellence in care and treatment

As outlined in Cystic Fibrosis Canada's strategic plan, over the next 10 years, we will work to achieve improved health outcomes and quality of life for all people with cystic fibrosis in Canada. Making this happen will require excellence in clinical care. This is why Cystic Fibrosis Canada is focused on working with the clinical community to prioritize areas of improvement for care settings.

Clinical Fellowship Program

For their cystic fibrosis care, Canadians with cystic fibrosis attend one of the 42 specialized, multi-disciplinary clinics in Canada. Providing care to people with CF is a specialty and one that isn't always a well paved path for physicians. To ensure that patients continue to have access to excellent specialty care, Cystic Fibrosis Canada supports a Clinical Fellowship Program. This program provides funding to physicians-in-training interested in building their knowledge of cystic fibrosis care and conducting clinical research in CF. The program is adjudicated by CF Canada's Healthcare Advisory Council. "In 2007, we set out to recruit and engage new physicians to specialize in cystic fibrosis care," said Dr. John Wallenburg, Chief Scientific Officer, Cystic Fibrosis Canada. "The population of individuals with cystic fibrosis is growing every year and we knew that to maintain a high standard of care, we needed to attract new physicians to work in the field. The program has been hugely successful. Since the program launched we've awarded twenty-three fellowships, many of which have included a clinical research component." Last year, Cystic Fibrosis Canada awarded grants to two physicians who will specialize in CF Care: Dr. Kirsten Ebbert, Alberta Children's Hospital in Calgary and Dr. Sana Swaleh, St. Michael's Hospital in Toronto.

> **"The program is an excellent use of funding, as to date, every single recipient of the Cystic Fibrosis Canada Clinical Fellowship program has remained in cystic fibrosis care, and some former recipients are now CF clinic Directors,"** said Wallenburg.

Knowledge Brokering

Another way Cystic Fibrosis Canada is working to ensure Canadians living with cystic fibrosis are receiving a high standard of care is by facilitating knowledge sharing between CF specialists. "Our healthcare professionals become family to our community members," said Ian McIntosh, Director of Healthcare at Cystic Fibrosis Canada. "They provide hope, guidance, support and care to Canadians living with cystic fibrosis during some of the most difficult times and have a unique understanding of the disease and what is needed both to manage and treat it." That is why Cystic Fibrosis Canada plays an active role in facilitating regular

communication between the 42 specialized CF clinics. "Our Nursing Advisory Group meets formally once per year," said McIntosh. "But through CF Canada they are in regular contact, sharing knowledge and best practices across the country from frequency of certain medical procedures, to use of administration forms." In addition, CF Canada's Healthcare Advisory Council formally meets three times per year, to oversee and provide guidance on larger clinical issues that affect all the CF clinics, including the development of Guidelines and Standards of Care, and support for advocacy issues.

Mental health pilot project

Living with cystic fibrosis can be challenging both physically and mentally. For the past few years Cystic Fibrosis Canada has facilitated a pilot program supporting mental health care out of the clinics in British Columbia. This has been made possible through a grant from the British Columbia government. "We plan to take the learnings from this pilot program and apply them nationally," said Dr. John Wallenburg. "**We know that mental health support will play an integral role in cystic fibrosis care, particularly for the percentage of the population that are not eligible for modulator therapies**".

Canadian Cystic Fibrosis Guidelines and Standards of Care

"We know that the care provided at the multi-disciplinary cystic fibrosis clinics is excellent," said Ian McIntosh. "But we started to wonder what happens when a person living with cystic fibrosis goes to the Emergency Room of a hospital or does not live close to their CF clinic". With that in mind, Cystic Fibrosis Canada worked with leading experts across the country to develop the first two Canadian Standards of Cystic Fibrosis Care, with the goal to expand the reach of clinical knowledge beyond the specialized cystic fibrosis clinics. In 2020, an Antibiotic Dosing Guideline for Cystic Fibrosis, and a Canadian Consensus Statement on Aerosolized Antibiotic Use in Cystic Fibrosis were developed and shared amongst all CF clinics, and to the CF Canada website, making them accessible to patients and allowing them to advocate for their care. "Making sure that our community has consistent, high-quality care was a priority," said McIntosh. "Particularly given cystic fibrosis is a rare disease, it is important that there is a deep and ever evolving understanding that is also shared beyond cystic fibrosis clinics, in hospitals and other stops in the medical journey."

Leadership in research

While Cystic Fibrosis Canada works to ensure high standards of clinical care, the organization also plays a leadership role in global cystic fibrosis research, with Dr. Wallenburg serving on the International Scientific Advisory Board of the Cystic Fibrosis Trust's Strategic Research Centre in Cambridge. As well, Cystic Fibrosis Canada is working with the Cystic Fibrosis Trust on Project Breathe, a study that will look at the effectiveness of at home Bluetooth devices for cystic fibrosis treatment. This study is funded by a peer organization, the Cystic Fibrosis Foundation. For a number of years, CF Canada has partnered with its peers as an active member of the CF Registries Global Harmonization Group, a partnership that enabled us to participate in timely COVID-19 research through the Canadian Cystic Fibrosis Registry.

For the past 60 years, CF Canada has invested in both research and researchers and our funding has fueled important discoveries that changed the way the world both treats and conducts research about cystic fibrosis. In 2020, CF Canada supported a targeted research study that used microsimulation to determine the impact of Trikafta on cystic fibrosis populations in Canada. "The findings were hugely important," says Wallenburg. "They predict that there would be an increase of 10 years on the median age of survival over a 10 year period. As well, there would be a reduction in the number of cystic fibrosis related transplants, deaths and exacerbations." This data has been instrumental in CF Canada's work advocating for Trikafta, as having quantifiable data that demonstrates what access to the drug could change for Canadians with cystic fibrosis is essential for making a strong case to decision makers. Similarly, CF Canada is supporting a study that is retrospectively investigating the benefits of Orkambi and Kalydeco. "There is a belief that these drugs will slow the progression of the disease and we are looking to demonstrate that with these studies," said Wallenburg.

Together Yet Apart

How CF Canada's fundraising community stayed strong during a global pandemic

When news of the global pandemic was announced two months before Cystic Fibrosis Canada's largest annual fundraising event, the Walk to Make Cystic Fibrosis History, it was clear that organizers and participants would have to get creative to succeed.

"It meant going back to the drawing board with the team and community, to find new ways of executing local fundraising events," said Carly Schur, Chief Development Officer, Cystic Fibrosis Canada. "We also knew we had to be intentional about keeping the community engaged, safe, and supported through these difficult times."

It's no surprise, however, that the passionate CF community and donors continued to support CF Canada through the pandemic. This community is incredibly strong, resilient, and tenacious. The pandemic became just another hurdle that needed to be overcome.

Here are a few examples of how the community, donors and supporters went further in 2020:

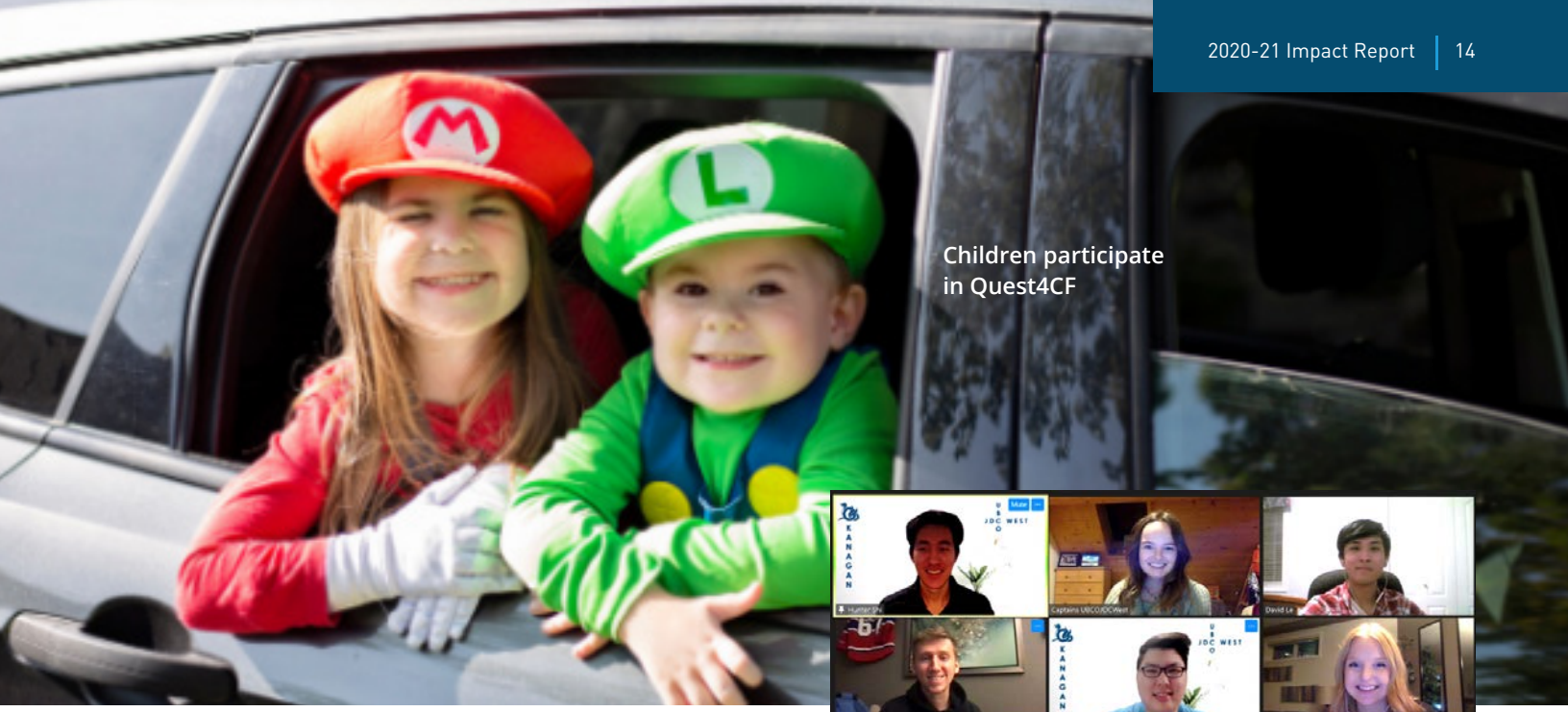
The Walk to Make Cystic Fibrosis History is *Cystic Fibrosis Canada's* largest annual fundraising event for people impacted by cystic fibrosis. For over 17 years, the Walk typically sees 7,000 participants across 70+ locations in Canada and raises upwards of $3.3 million.

At the start of April 2020, the team introduced the Walk as a virtual event - a decision that was embraced by many Walk registrants and community members who were still fully committed to participating. The virtual participants were encouraged to walk, bike, run or choose their own challenge to complete from their home. They would still raise funds in the same way, but there would be no in person event to attend on the last Sunday in May. Participants executed their socially distanced challenges from home and shared their progress on social media. Some participants used the opportunity of the virtual challenge to get creative to make an impact and instead of a walk, they learned to dance, meditate, or climb mountains. "There was no rulebook or example to follow," said Carly Schur, Chief Development Officer, Cystic Fibrosis Canada. "We were unsure of how donors would respond, particularly during such a precarious time in the world, but despite our concerns, we were humbled by the incredible show of support from our donors."

Through the collective efforts of the community, **the Walk to Make Cystic Fibrosis History: Virtual Challenge surpassed its re-forecasted fundraising goal of $1.75 million – raising an incredible $2.3 million across the 3,200 registered participants.**

Shinerama is Canada's largest post-secondary fundraiser in support of Cystic Fibrosis Canada. With a volunteer leadership conference in May and Shine Day in September, it engages thousands of students each year across 40 universities and colleges.

With the pandemic forcing students to continue their studies online, CF Canada and the Shinerama National



Children participate in Quest4CF

Leadership team had to make several modifications including pivoting the conference to a virtual format. This change led to great benefits including the conference being more accessible for students who might not have been able to attend the event in person and allowed for schools with smaller fundraising targets to gain vital learning opportunities that could help their events and campaigns grow.

While Zoom fatigue and online fundraising were some of the biggest challenges faced by participating schools, it was incredible to see how committed, determined, and creative student volunteers were to continue their partnership with CF Canada. From Sweat for CF socially distanced spin classes, online streaming fear-factor style fundraisers, drive-in movie fundraisers, Shinerama-branded mask sales and even partnering with a local brewery to make a Shinerama beer, the students didn't let the pandemic get in their way of success. Schools like Memorial University in Newfoundland raised more money than they would in a pre-COVID year. The school's nursing society, which typically raises $5,000 for Shinerama, ended up raising $11,000. In total, 30 post-secondary schools participated **raising a combined total of $168,000!**

With the decision to postpone an annual motorcycle ride event in Windsor, the team brainstormed a new event for the fall that could engage the community. Thus, **Quest4CF**, a socially distanced scavenger hunt was

Students participate in a virtual Shinerama event.

born. The inaugural event took place on October 18th in select communities across Canada including Windsor, Hamilton, Campbell River, Calgary, Toronto, Barrie and Kitchener. The event encouraged kids to dress up and Trick or Treat their way through the scavenger hunt in lieu of a traditional Halloween. CF Canada team members and volunteers played a leading role in executing the event, meeting with participants in public spaces that served as 'clue stops' during the family-friendly scavenger hunt and working with businesses to secure sponsorship and participation.

The original goal was to raise $75,000, but the community once again came out in full force raising an outstanding **$83,000!**

Pivoting to virtual events happened quickly and the fundraising success is largely due to CF Canada's outstanding volunteers and donors. One success that can't be measured but was felt by many was the sense of community, resilience, commitment, nimbleness, and creativity that the community displayed. CF Canada's supporters showed up and their passion was palpable through our screens.

Thank you for being there and for changing with us through this extraordinary time.

One volunteer's thoughts on giving back

A veteran volunteer who lives with cystic fibrosis shares her story

Having recently celebrated her 50th birthday and now looking ahead to retirement, Debra Mattson knows she has reached an important milestone, one that many people who live with cystic fibrosis (CF) have not been as fortunate to meet. Not only has Debra survived, she has thrived; attending and graduating from university, getting married, building a career, buying a home, traveling around the world, and regularly going on 10km jogs. Still, she knows that any day her health could change. She explains that having cystic fibrosis is like having a dark, ominous feeling hanging over you at every turn; that you fight with all your might in order to remain hopeful and positive. Her determination and optimism have driven her to take action, including being a steadfast volunteer for over 30 years with Cystic Fibrosis Canada.

"Volunteering is everything to me, I do not know how to not volunteer," said Debra. "It is so enriching on many levels – you make friends, you do fun things, you feel useful and accomplished, you make a difference. Some of my most treasured friends and experiences are because of volunteering." Debra believes she couldn't possibly sit around after work and do nothing when there is so much she can contribute. She feels fortunate to be in good health - and as a Canadian living with cystic fibrosis, she knows firsthand the impact that getting involved has had not only on her own life, but the lives of the thousands of Canadians living with CF and their loved ones.

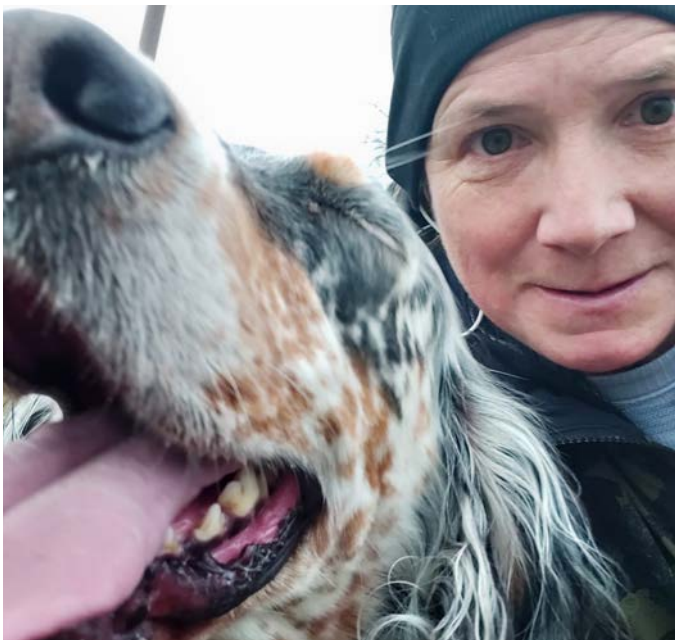
Debra's volunteerism has taken on many forms. She has helped with events and fundraising, started a support group, provided mentorship to new families, shared her story in various Cystic Fibrosis Canada publications, spoken at conferences, spent a tenure as Chapter Treasurer and has been Chapter President in both Victoria, BC, and Durham, ON.

Debra was reminded of the impact her volunteerism has on others during a routine visit to a CF clinic. After giving her name to the receptionist, a woman approached and said; "I'm sorry, but I just heard that you're Debra Mattson. I wanted to tell you that I really appreciate the articles you write in the newsletter about living with CF. It helps me understand my daughter better." Hearing that someone not only read her words but was comforted by something she put her effort into was rewarding and reinforced why she continues to volunteer after all these years.

Debra admits that she never expected to go this far in her life. Growing up with cystic fibrosis, she didn't

expect to make it to the next year, let alone running half marathons at the age of 50. Today, she makes a point of taking an exceptionally deep breath during each of her runs to think for a moment about how far she has come, and how her work as a volunteer can have a positive impact. Her work has not gone unrecognized - Debra was honoured with the national Summerhayes Award, which recognizes outstanding contributions from individuals who live with CF, from Cystic Fibrosis Canada in 2020.

It is thanks to the efforts of volunteers like Debra, our generous donors, and our community that CF Canada is able to help Canadians with cystic fibrosis reach milestones once considered impossible. Together, we will go even further.



A mother's determination to go further

Volunteering in the name of hope and Daphne

Friends of Valérie would describe her with one word: determined. This is how she showed up in March of 2019 when a health issue sidelined her scheduled fundraising trip to Machu Picchu with Cystic Fibrosis Canada. Valérie rehabilitated, trained, fundraised and that September she found herself at the Great Wall of China.

When asked why she has spent the past 20 years volunteering for Cystic Fibrosis Canada, Valérie responds without hesitation.

"It's my calling." She says, "Nothing beats the feeling of being part of the ultimate equation to make cystic fibrosis (CF) history. The crusade continues, the battle is not won, the opponent is formidable, but not invincible. We will win the battle!"

Cystic fibrosis entered Valérie's life without warning almost 20 years ago. Her new baby Daphne was showing signs and the questions from her healthcare team started: *Does your baby taste salty? Are there cases of CF in your family?* With the help of Daphne's family doctor and the Cystic Fibrosis clinic team Centre mère-enfant Soleil du CHU de Québec, Daphne was diagnosed with cystic fibrosis. Valérie recounts how she spent the first few weeks accepting the diagnosis, pouring herself into learning everything she could – and taking the word "deadly" out of her vocabulary. She decided that hope would define her family's journey with cystic fibrosis.

Above all, Valérie was determined to prioritize Daphne's health and she found hope in volunteering and fundraising for Cystic Fibrosis Canada, knowing that her efforts would inch everyone impacted by cystic fibrosis closer to a cure or control of the disease.

"I motivated the whole family," said Valérie. "I made them aware of the importance of collecting donations and participating in fundraising, to play a role in this fight." Through the challenging moments, it has been reassuring for Valérie to have the support of family.

Valérie is the Vice President of the Charlevoix chapter and over the years her fundraising efforts have raised tens of thousands of dollars. In September 2019, Valérie and her husband raised $10,050 for the Great Wall of China trek alone – almost $2,000 more than the requirement. Valérie recounts of their five-day guided trek, "this adventure is part of my desire to always go further."

Today, Daphne is 20 and is obtaining her diploma as a special educator while working part time in mental health care.

Valérie is aware that promising treatments and medications are within reach, but that we cannot slow down. "While we wait for these medications, every little gesture counts, every dollar raised is important, that is why only hope is allowed." It is thanks to the strength of the CF community, of volunteers and families, that together we will achieve the goal of ensuring all Canadians living with CF have access to treatments they need to go even further in life.

Community support

Photo taken pre-pandemic

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

Kin Canada partnership continues through this challenging year

Kin Canada is Cystic Fibrosis Canada's oldest partner, with Kinsmen and Kinettes donating and helping to raise more than $49 million for CF Canada since 1964. "We are humbled by the dedication of Kin Canada," said Jeff Beach, Chief, Corporate Services and Strategic Initiatives, Cystic Fibrosis Canada. "Not only has Kin Canada raised a tremendous amount of money over our 56-year partnership, but their spirit of true partnership is inspiring; Kin members show up for CF Canada when it counts." Each year Kin clubs and members from coast-to-coast host fundraising events and volunteer at the Walk to Make Cystic Fibrosis History and other CF Canada events.

This year, one Kin Club took it even further. The Kinsmen Club of Winnipeg raised over $130,000 for Cystic Fibrosis Canada, including a $100,000 contribution received in January 2021. "This is the largest single donation from a Kin club in CF Canada's history," said Kelly Grover, President and CEO at Cystic Fibrosis Canada. "To set a new record in a pandemic and a year of social distancing is just incredible and illustrates the dedication and leadership of our trusted partner. Thank you to all of the Kin Canada clubs that have made contributions this year."

Cystic Fibrosis Canada / Fibrose kystique Canada
Kin Canada Kinsmen • Kinettes • Kin
Together for life® Unis pour la vie™

Donor Spotlight: Charles L. Ivey

A family legacy of driving progress and innovation continues

Charles and Todd Ivey

The impact of cystic fibrosis (CF) is far reaching. The disease not only affects the individual but the family, a truth that Charles Ivey understands all too well.

Charles Ivey grew up with a deep connection to cystic fibrosis. His sister, Karna, had cystic fibrosis and his brother Todd, who was adopted into the family at two, also lives with the disease. His father, Robert (Bob) Ivey was involved in the formation of Cystic Fibrosis Canada over 60 years ago and was one of the original board members. While Bob Ivey was involved in the early days, securing the 1957 charter for the then "Canadian Cystic Fibrosis Foundation," he also participated in the design and creation of nebulizing tents which played a large role in cystic fibrosis therapy. He knew that innovation was central to treating the disease.

Looking back, Charles remembers the countless pills Karna took daily and how he worried about bringing germs into the home. "We were always conscious about our health," said Charles. "We knew that bringing any kind of a cold into the house could potentially affect her health far beyond that of a cold." Charles also recounts helping his sister with physical therapy, taking turns with his brother, Jim. "Karna used to say that my brother provided better postural drainage treatments than I did, even better than the physical therapists at the time," noted Charles. And so, cystic fibrosis continued to be a family affair.

Most of all, Charles remembers how Karna lived life to the fullest. "She loved to sing and play the ukulele", he said. "She pursued her theatrical passion of acting and singing in productions like Godspell, despite it being at odds with having a lung disease." Karna also enjoyed a happy marriage. She passed away at 49, but her legacy, and the legacy of the Ivey family has continued.

Karna Ivey

Through the years Charles has supported Cystic Fibrosis Canada with various fundraisers via partnerships with Canadian alums including Paul Shaffer and Celine Dion, but the quest for progress and innovation his father instilled is something that Charles has carried on through his work at the family-run Charles H. Ivey Foundation.

Since 2012, the foundation has supported the Canadian Cystic Fibrosis Registry. Charles knows that the Registry is a vital resource, an important and central piece of Cystic Fibrosis Canada's intellectual property. "There are so many opportunities when it comes to the Registry," he says. "Data is king, and without it, improving any part of treatment would be impossible." Last year, Charles directed a memorial grant in honour of his sister and his father, to the Cystic Fibrosis Canada Accelerating Clinical Trials (CF CanACT) network. He believes that technological advancements, combined with critical data collected from the Registry and the CF CanACT, will drive the future of cystic fibrosis care.

Charles wants anyone who is considering donating to Cystic Fibrosis Canada to know that their gift will have a real impact, not only on the cystic fibrosis community, but on the lives of those who are living with other genetic conditions as well. "Your dollar to Cystic Fibrosis Canada is far reaching," he said. "You should be comfortable donating knowing that the basic research has already benefited other genetic conditions."

In the future, Charles hopes for better efficacy of medication and improved quality of life for those living with the disease. He has already seen improvements as his brother Todd, now 53, who used to take up to 80 enzymes a day, now only takes 6 per meal.

Cystic Fibrosis Canada is fortunate to have the support of the Charles H. Ivey Foundation in addition to the many others who give their time, love and commitment. With the vision and generosity of our donors, we will go further.

Leadership Gifts

Thank you to Cystic Fibrosis Canada's incredible donor community. Your generosity makes our work possible. We would like to thank these generous Leadership Donors who contributed $5,000+ in 2020/21.

Anonymous (41)

ATCO Electric Employee Giving

Mike and Beth Brien

CIBC

Janie & Fred Drake

Ross and Anne Marie Drake

Dr. Lee and Mrs. Deborah Erickson

Fondation Bergeron Jetté

Government of Canada's Emergency Community Support Fund and Community Foundations of Canada

Barbara M. Hill

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This listing includes philanthropic contributions made directly to the organization. Please note this listing is not inclusive of event funds, community fundraising or sponsorship of various Cystic Fibrosis Canada properties. If you wish to learn more about Leadership donations or recognition in our Annual Report please contact info@cysticfibrosis.ca.

2020/2021 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, 2021, with comparative information for 2020

Revenue	2021	2020
Chapter	6,988	12,179
Bequests	859	220
Leadership gifts and sponsorship	1,754	1,870
Kin Canada	775	1,098
Royalties	439	451
Other	2,020	572
	12,835	**16,390**
Less direct fundraising costs	2,035	4,062
Net fundraising revenue	**10,800**	**12,328**

Expenses	2021	2020
Program:		
Research	1,372	5,494
Healthcare	730	2,167
Education/Public awareness	1,682	2,098
Advocacy	929	999
Other	28	79
	4,741	**10,837**
Other:		
Administration	1,513	2,003
Fundraising	1,633	1,628
	7,887	**14,468**
Excess (deficiency) of revenue over before the undernoted	2,913	(2,140)
Excess (deficiency) of revenue over expenses	3,097	(1,482)

Investment income:	2021	2020
Realized gains on investment	180	607
Change in unrealized gain on investments	4	51
	184	**658**
Excess (deficiency) of revenue over expenses	3,097	(1,482)

STATEMENT OF FINANCIAL POSITION

(in thousands of dollars)

January 31, 2021, with comparative information for 2020

Assets	2021	2020
Current Assets		
Cash and equivalents	5,142	1,847
Short-term investments	848	1,015
Receivables and other assets	1,984	943
	7,974	**3,805**
Contributions receivable	160	150
Long-term investments	4,515	6,025
Capital assets	41	55
	12,690	**10,035**

Liabilities and Net Assets sets	2021	2020
Current liabilities:		
Accounts payable and accrued liabilities	587	1,012
Deferred revenue	327	319
	914	**1,331**
Long-term deferred contributions	265	290
Net Assets:		
Endowment	94	94
Internally restricted for research and healthcare	2,068	–
Unrestricted	9,349	8,320
	12,690	**10,035**

As a result of the COVID-19 global pandemic, research grants were paused in 2020-21.

Note: Cystic Fibrosis Canada's cost of fundraising is 29%.

STATEMENT OF CHANGES IN NET ASSETS

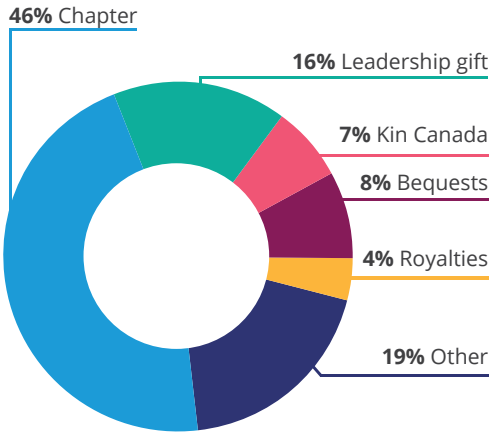
(in thousands of dollars)

Year ended January 31, 2021, with comparative information for 2020

	Endowment	Internally restricted for research and clinics	Unrestricted	2021 Total	2020 Total
Net assets, beginning of year	94	-	8,320	8,414	9,896
Excess (deficiency) of revenue over expenses	-	-	3,097	3,097	(1,482)
Transfer between funds	-	2,068	(2,068)	-	-
Net assets, end of year	94	2,068	9,349	**11,511**	**8,414**

STATEMENT OF FUNDRAISING REVENUE

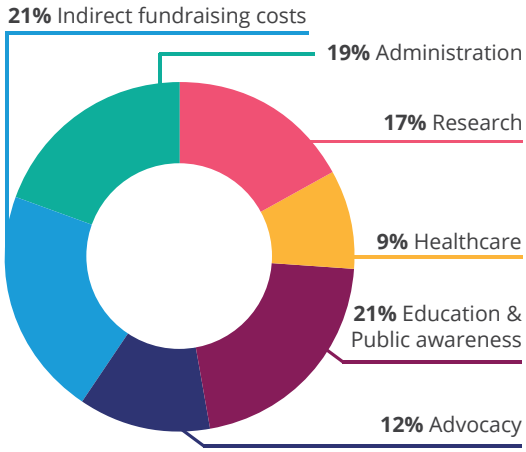
(Net of direct fundraising costs)



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.

cysticfibrosis.ca

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