Cystic Fibrosis
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Connections

SUMMER / FALL 2019

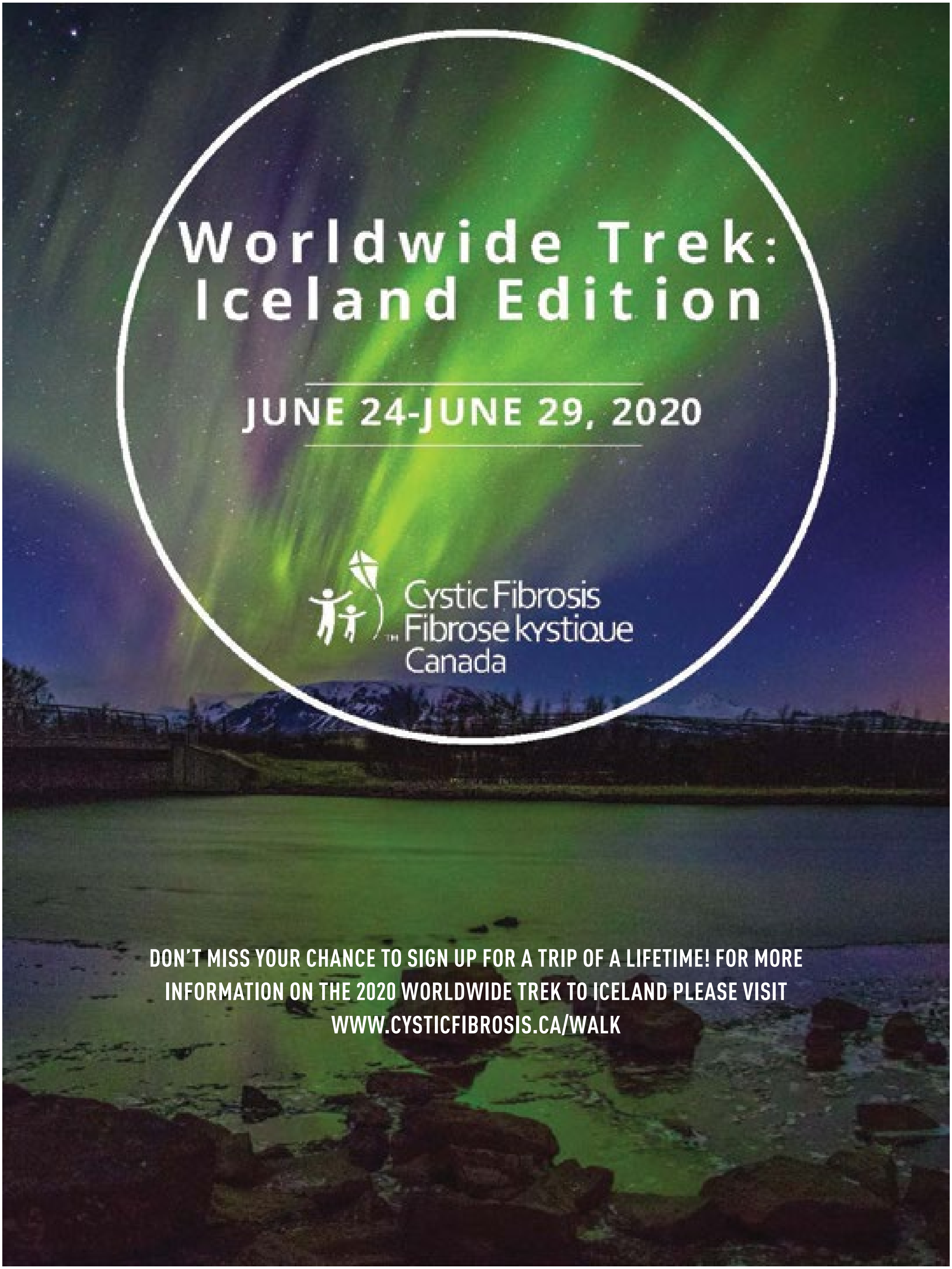
CF COMMUNITY CELEBRATES 30TH ANNIVERSARY OF GENE DISCOVERY

ADVENTURERS TREK TO MACHU PICCHU IN SUPPORT OF CF CANADA

MIKAYLA BIANCHIN ATTENDS NASCAR WITH CARSTAR

ELEVEN YEARS OF LAWN SUMMER NIGHTS!

THE WALK TO MAKE CYSTIC FIBROSIS HISTORY CELEBRATES 15 YEARS



Worldwide Trek: Iceland Edition

JUNE 24-JUNE 29, 2020

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MESSAGE FROM THE PRESIDENT AND CEO

Just like *that*, summer has come and gone!

I wanted to share some highlights of our work over the past few months. The ‘spring’ season (it was freezing out!) began with our 17th Broken Arrow Conference at the beginning of May, Cystic Fibrosis Awareness Month. Our theme, Patient Engagement, was a welcome theme and helped all of us better understand how to ensure people living with CF are at the centre of our work. Our Quebec Symposium for CF researchers and clinicians provided an opportunity for clinicians, researchers and people living with CF to come together and focus on collaboration. We are so thankful to everyone who helped to organize these events and to all of you who attended.

On Sunday, May 26, the Walk to Make Cystic Fibrosis History took place in over 70 communities from coast to coast. This is such a special event, bringing together families and friends to share their support for the CF community. The hard work to organize these walks does not go unnoticed and thank you to all of our volunteers. This year I was in Calgary and I really enjoyed meeting so many of you. At the end of May we hosted our first ever international walk – a trek to Machu Picchu. I followed the pictures of all of the walkers and shared in the stories. It sounds like it was a very special trip. A few adventurers will continue the tradition, conquering Iceland and China this fall. We are so grateful to all of those who participate and fundraise for the Walk. The funds raised are so critical to our investments in research, healthcare and advocacy; so truly, thank you.

Summer in July brings lawn bowling, and Lawn Summer Nights. I saw the greens in Halifax and continue to be so impressed by the support of all of you bowlers. This year Lawn Summer Nights took place in a record 16 cities. Thank you so much to the volunteers, many of you newer to your careers, who make this event such a great success. Throughout the summer, there have been so many other events across the country. From golf tournaments, to bike rides, to swim challenges, runs, casino nights and more, thanks to everyone for your support.

In August we celebrated a major win on the advocacy front. After five long years, we received the news that price negotiations for the remaining mutations indicated by Health Canada for Kalydeco successfully concluded. Thank you to everyone who has advocated for access to this drug.

This summer we have been busy at Cystic Fibrosis Canada working on our new strategic plan. This process has been incredibly inspiring and motivating, seeing the progress of the disease and focusing on the future. I can’t wait to share our plan with you soon.

As summer comes to a close, we prepare to celebrate a major milestone. Thirty years ago, researchers at the Hospital for Sick Children in Toronto discovered the gene that is responsible for cystic fibrosis. This discovery was made possible through funding from CF Canada, and is still regarded as one of the most significant breakthroughs in cystic fibrosis – and human genetics. Plans to celebrate that accomplishment are underway.

In this edition of Connections, you’ll read about these exciting events and milestones and more. You’ll learn about the results of our research, healthcare and advocacy investments; inspiring community stories from coast to coast, and we’ll recognize the generosity of our community fundraisers and corporate partners. We are so grateful for the support of our donors and partners, and will continue to do all we can to create a world without cystic fibrosis.

Thank you again for your support.

Talk soon,

Kelly Grover
President and CEO
Cystic Fibrosis Canada

HOPE THROUGH PROGRESS

Dr. Lap-Chee Tsui

CELEBRATING 30 YEARS OF BREAKTHROUGH CYSTIC FIBROSIS RESEARCH

On Tuesday May 9, 1989, Cystic Fibrosis Canada-funded researcher, Dr. Lap-Chee Tsui, and his team at the Hospital for Sick Children in Toronto, together with Dr. Francis Collins at the University of Michigan, made history as they became the first to discover the gene responsible for cystic fibrosis (CF). This discovery is still considered to be one of the most significant breakthroughs in human genetics in the last 30 years.

"To call the path direct would be an overstatement. The CF gene discovery happened in stages. There was no eureka moment, it was more of a slow jump," said Dr Tsui. "We had to investigate several elements, including how the gene affected patients and support that with further research before we could officially celebrate."

Why was the gene discovery so impactful for CF research?

The discovery of the gene responsible for CF, the cystic fibrosis transmembrane [conductance] regulator gene (CFTR) has helped to improve researchers' understanding of how the disease works. Ultimately, this led to breakthroughs such as the screening of newborn babies for early detection of cystic fibrosis, as well as gene carrier testing for individuals. This is critical, as an earlier diagnosis can lead to an earlier treatment plan. In fact, Cystic Fibrosis Canada advocated for the inclusion of CF screening to the panel of diseases that are screened in the standard heel-prick blood test taken from every newborn across the country. In 2007, Alberta became the first province to implement newborn screening for cystic fibrosis and as of 2018, Quebec officially added CF to its heel-prick test, resulting in the newborn screening program to be in practice for all births in all provinces across Canada. According to the Canadian Cystic Fibrosis Registry, a decade ago, less than 10% of new CF diagnoses were identified through newborn screening and today, over half of those newly diagnosed are made through the newborn screening program.

CF Gene team

The discovery of the CF gene in 1989 has paved the way for today's discoveries, playing a role in the development of CF drugs that target the underlying cause of CF and paving the way for revolutionary research projects such as CFIT. Since the discovery of the CFTR gene, the age of survival for Canadians living with cystic fibrosis has climbed to 52.3 years, compared to when Cystic Fibrosis Canada was established in 1960, and a child with CF was unlikely to reach school age.

Although there is currently no cure for CF, it is research like this that brings doctors and researchers closer to a cure and it is why Cystic Fibrosis Canada will continue to collaborate with researchers until CF is history.

2019 BROKEN ARROW CONFERENCE

Esther Halton

Cystic Fibrosis Canada's 17th Broken Arrow Conference, hosted in Toronto from May 2nd - 4th was a great success. The event brought together many of the key players in Canada's cystic fibrosis (CF) community, including physicians and nurses from CF clinics across Canada, as well as CF researchers, scientists, pharmaceutical industry representatives, CF Canada Board members, individuals living with CF and their family members.

The theme of this year's conference was Patient Engagement. Day one started with the funny and charismatic duo from Sickboy Podcast Jeremie Saunders and Brian Stever, who use humour to get to the "meat" of the conversation helping those with life threatening illnesses feel comfortable to share their stories. Day one continued with exploring patient-orientated research focusing on patient perspectives and preferences, building capacity, working with patients as partners and involving patients in the design and deliveries of research and clinical trials. In the afternoon, the conference broke into working groups, facilitated by the morning speakers, where discussions on how to implement patient engagement strategies into one's practice continued. Speakers on day one included Esther Halton from PaCER, Deborah Marshall from IMAGINE SPOR Network, Annette Majnemer from CHILD-BRIGHT, Lisa Stewart from PCORI and Jennifer Preston from GenerationR.

Jeremie Saunders

Day two of the Broken Arrow Conference continued with the theme of Patient Engagement focusing strongly on patients as partners. The underlining message of the day was that patients bring a tremendous amount of knowledge and experience to the table – and that they should be recognized for this. Speakers on day two included Nicolás Fernandez, a member of the CIHR Standing Committee on Ethics and Claire Edmondson who shared research on the CLIMB-CF study.

Day two continued with two panel discussions with the CF community. The first panel included CF patients and caregivers continuing the conversation on patient engagement in research. The panel included two patients, Ronnie Sharpe from Cystic Life and co-founder of Savvy Cooperative, Sandy Sufian, a PCORI ambassador and a Co-Founder of the Cystic Fibrosis Reproductive Sexual Health Collaborative, and Lina Bhardwaj, a mother of a 13-year-old with CF. Topics discussed were quality improvement, research, clinical trials, patient experience and breaking down barriers.

Day two finished with a panel discussion on infection prevention and control with two CF physicians, Dr. Valerie Waters and Dr. Elizabeth Tullis, along with two individuals living with CF, Chris Kvam and Brenda Chambers-Ivey. Dr. Waters and Dr. Tullis focused on the safety concerns of infection prevention and control, and discussed how the guidelines came into action and why they are so vital to the health and safety of those living with CF. Chris and Brenda shared their opinions on the guidelines speaking to the importance of understanding the consequences of infections and how they quantify risks everyday by choosing risk versus reward when they leave their home.

Graphic artists from Think Link Graphics were present throughout the conference, capturing key themes of the presentations visually live on-site, which can be found on our blog.

The 17th Broken Arrow Conference was sponsored by Vertex Pharmaceuticals (Canada) Inc., Horizon Therapeutics, Merck Canada Inc., Gilead Science Inc, AbbVie, Inc., Mylan, Trudell Medical International and Innovative Medicines Canada. We are grateful for their support.

INTRODUCING CF CANADA'S INFORMATION REQUEST AND REFERRAL SERVICE

Eunice Mamic

Did you know that CF Canada has a bilingual information request and referral service to help the CF community navigate government and community-based resources? This service assists with inquiries related to a new CF diagnosis, CF information and facts, CF health, clinical, education, employment, finances, government relations and advocacy, global affairs, research and more.

When you contact the service, you'll reach Eunice Mamic, Cystic Fibrosis Canada's Coordinator of Community Relations and Resources.

"Every time the phone rings, I never know who's calling, but I know I'll do everything I can do to help," says Eunice. "Every day we receive calls and e-mails from people, adults and children, living with cystic fibrosis who feel they have nowhere else to turn. Whether they want help navigating their often-complicated care or need to ease their fears about their daily struggles with CF, we're here to help."

Contact our Information Requests and Referral Service today:

Email: advocacy@cysticfibrosis.ca

Telephone: 1-800-378-2233 ext. 403

GILEAD SCIENCES INC. SPONSORS THE CYSTIC FIBROSIS CANADA CLINICAL FELLOWSHIP PROGRAM

Dr. Grace Lam

Cystic Fibrosis Canada is grateful to Gilead Sciences Inc. for its commitment to supporting CF Canada's Clinical Fellowship Program. For a second year, through its support of this important program, Gilead Sciences Inc. has made it possible for Canadian physicians to specialize in CF care. As the number of people with cystic fibrosis in Canada continues to grow each year, there are inadequate numbers of specifically-trained CF physicians to provide specialized CF medical care. In order to address this physician shortage, in 2007 CF Canada created the Cystic Fibrosis Canada Clinical Fellowship Program.

Cystic Fibrosis Canada Clinical Fellowships are intended for physicians who have obtained their residency training and who wish to pursue additional clinical training specifically in CF care. The purpose is to train physicians to become CF specialists, so that they can provide on-going clinical care to individuals with CF in Canada; this training includes developing competence to participate in clinical trials, and may also include a component related to lung transplantation.

Up to two highly ranked competitive Clinical Fellowships are offered by Cystic Fibrosis Canada each year, during the annual Fall grants competition. CF Canada is proud to mention that, of the 19 Clinical Fellowships awarded since 2007, all recipients have remained working in cystic fibrosis clinics. We're pleased to announce that the recipient of this year's Gilead Sciences Inc. Clinical Fellowship in Cystic Fibrosis is Dr. Grace Lam, who will be completing her fellowship at the adult CF clinic at St. Paul's Hospital in Vancouver, BC.

Thank you to Gilead Sciences for its commitment to cystic fibrosis care in Canada; and congratulations to Dr. Grace Lam, for receiving this prestigious Clinical Fellowship.

CLINICAL TRIALS: A CF PARENT'S PERSPECTIVE

My name is Lina Bhardwaj and my 13-year-old daughter Rianna lives with cystic fibrosis.

Rianna was diagnosed at two months old and luckily, she's been relatively healthy her whole life. She had some weight gain issues a few years ago, so we opted for a G-tube, but aside from one unplanned hospital stay, she's been on the right track.

My daughter is very active, and I think that's really helped maintain her health. She loves swimming, running, and is working towards her second degree black belt in taekwondo! She amazes me with her energy levels and resilience.

A decision my husband and I made early on to benefit both Rianna and the cystic fibrosis community was for her to participate in clinical trials. Rianna has participated in one clinical trial for every year of her life. I know there are so many CF families like us who want to learn more about clinical trials, so I wanted to share my family's experience with clinical trials, in hopes it will provide the insight they need to move forward:

Rianna and Lina Bhardwaj

1. **Time commitments** – between managing parenting, work, after-school programs, CF treatments, and life, adding more to our schedule was daunting at first. I was really surprised to learn that participating in a clinical trial isn't as big of a time commitment as people think. Sometimes we even coordinate our participation with clinic visits, making it really convenient.
2. **Health benefits** – the idea that my daughter's health can benefit from participating in a trial is a huge driving force for us to continue participating. Rianna was lucky enough to directly benefit from two of the trials she's participated in. We actually continued on one of the treatments via a compassionate care program post-trial that I don't know we would otherwise have access to. It's a huge relief to know that there was a positive outcome as a result of her participation.
3. **Knowing what I'm signing up for** – something that really impressed me when we began clinical trials was the amount of transparency in the process. The teams were very good at explaining everything in detail so we were fully aware of what we were in for. I felt we were selected for a reason and there was always a goal we were working towards. I never felt out of the loop or that we were wasting our time (or that our time wasn't appreciated)!
4. **Helping our small community** – the CF community is small, but special. While a treatment in a trial might not work for Rianna, it could work for others, and that's really important when we have such a small population. At the end of the day, we all need to do our part to help find a cure or control, and this is one way we help.
5. **Empowering my child** – Rianna has learned so much about her health and cystic fibrosis through participating in clinical trials. Her participation is teaching her values that I think are really important. It's teaching her to advocate for her health and her community, and it's instilling in her a sense of responsibility, advocacy and proactivity!

TO FIND A CLINICAL TRIAL THAT'S RIGHT FOR YOU, VISIT CYSTICFIBROSIS.CA/CLINICALTRIALS FOR MORE INFORMATION.

ARE YOU INTERESTED IN PARTICIPATING IN A CLINICAL TRIAL?

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Clinical Trials are presently being conducted on new treatments in the following categories:

- Modulator therapies
- Anti-inflammatories
- Antibiotics
- Mucolytic agents
- Treatment of respiratory exacerbations

New therapies are tested in people in the following order:

- **Phase I trial:** small group of healthy individuals looking at safety
- **Phase IB trial:** small group of CF adults looking at safety
- **Phase II trial:** larger group of CF adults looking both at safety and effect
- **Phase III trial:** large group of CF adults looking at effective of the therapy
- **Phase II trial:** small group of CF children (over 6 years) looking a dosage levels and effectiveness
- **Phase III trial:** larger group of CF children (over 6 year) looking at effectiveness

If you are not attending one of the CF Centres conducting a trial, you may still be able to participate in a clinical trial(s) by being referred to a clinical site conducting the trial. You can do this by either:

- Checking on the clinical trial finder at www.cysticfibrosis.ca/clinicaltrials to see which clinical trials you may be eligible for
- Asking your CF centre physician or nurse about clinical trials and how you can be referred to a clinical trial site just for the trial
- Contacting the nearest site who is conducting the clinical trial you are interested in and asking for more information
- Contacting CF Canada by email at clinicaltrials@cysticfibrosis.ca. CF Canada will put you in contact with the nearest CF Centre conducting the trial

Please note that if you are referred to another CF centre for a clinical trial, your usual CF care will continue at your local CF centre.

For information on current clinical trials including category, enrollment, Phase and age group of trial, inclusion criteria and participating centres and contact details, please visit: **www.cysticfibrosis.ca/clinicaltrials**.

BREAKING NEWS

Since March 2013, Kalydeco has been available through publicly funded drug programs for patients age six and older who have the G551D mutation in the CFTR. In July of 2014, Cystic Fibrosis Canada submitted patient input to Canada's Common Drug Review for additional mutations approved by Health Canada. Use of Kalydeco for the additional mutations received a positive recommendation from CADTH on December 19, 2014. After five long years, in August 2019, we received the news that price negotiations for the remaining mutations indicated by Health Canada for Kalydeco successfully concluded. Thank you to everyone who has advocated for access to this drug.

ADVOCATES SEE PROMISE IN A RARE DISEASE STRATEGY


Hailey Laxer

Canada is one of the few developed countries without a strategy to guide decisions around access to potentially life-changing drugs for rare diseases. As a result, there has been limited access to some rare disease therapies. The challenges in obtaining cystic fibrosis (CF) therapies such as Kalydeco and Orkambi are examples of a failed system.

Canadian drug review bodies do not have processes to fairly assess drugs for rare diseases, nor do they have a common definition of what a rare disease is. This means that rare disease therapies go through the same evaluation as drugs for more common conditions, even though rare disease populations have small numbers and cannot conduct large-scale clinical trials that are seen as the "gold standard" of evidence. Unfortunately, if the system does not change, the estimated 40 other CF disease-modifying therapies in the drug development pipeline may face similar access challenges to Kalydeco and Orkambi.

This is troubling to our community members, "For the longest time I was proud of our Canadian health care system. I thought our system was world class; I was shocked to personally experience the gaps in our healthcare system and how it under serves those with rare diseases," said Nancy Cox, CF Grandmother, and volunteer advocate, British Columbia.

There is some light at the end of the tunnel for the CF community. Developing a rare disease strategy in Canada is on the minds of Canadian politicians. The 2019 federal budget promised the creation of a national strategy for high-cost drugs for rare diseases by 2022-2023 to help Canadians get better access to the treatments they need. A strategy for helping Canadians with rare diseases is likely to be on more than one political party's platform in the upcoming election.

As a result, we have an excellent opportunity to change our system. Canada can create a rare disease strategy and, through this strategy, develop a drug review process that fairly assesses drugs for rare diseases. Cystic Fibrosis Canada supports a strategy that will close the gaps in access to medicines for Canadians with rare diseases. In particular, CF Canada supports the creation of a pan-Canadian strategy, a strategy where there is collaboration between the provincial and federal government and collaboration with private insurers and employee benefits providers.

The need for this strategy resonates with members of the CF community throughout the country.

To Chris McDougall, CF father and volunteer advocate, Saskatchewan, having a rare disease strategy means "getting my daughter access to medicines in a sustainable manner… we want to have a system that is sustainable and provides fair access to medicines for everyone. Having a strategy means expedited access to medicines for Ella."

For Hailey Laxer who lives with cystic fibrosis, "A rare disease strategy would mean the hope of being able to access rare disease medications that could change my life. The strategy would mean better criteria… criteria more geared towards rare disease

The McDougall's

medications, evaluating rare disease drugs in different ways." "To me access to rare disease drugs is my greatest hope for my granddaughter," said Nancy Cox. "The disease is being managed but is progressive. We need access to medicines to secure her health and future. A rare disease strategy would mean she could have access to life-changing therapies rather than just manage her symptoms."

Rebuilding the system is giving optimism and hope to the McDougall family. Twyla McDougall, CF mom and volunteer advocate, Saskatchewan said, "A strategy would give people in the rare disease community hope, it gives me hope. We all hope to one day find a cure but in the meantime there are developments of drugs, some very promising therapies, and we need a strategy to ensure that these therapies can get to the people who need them."

"It would free up time from constantly advocating" said Chris McDougall. "Things are developing and whether they have success or not we know we have a better chance of getting better treatments that will help our family with a rare disease drug process in place."

When thinking about life without a rare disease strategy, Ms. Laxer stressed that "We won't be able to access the drugs we need to survive," said Hailey Laxer. "We will continue to have delayed access to new therapies or even worse, no access to new therapies". If Canada doesn't create a strategy to improve access to high cost drugs for rare diseases, "We would be frustrated," says Twyla McDougall. "It's not just about us; we all know people who have had or have a medical crisis and the effort it takes in managing an illness or caring for someone with an illness."

Twyla's husband, Chris went on to say: "Realistically, the longer we go without one, the closer we get to people losing their life from limited access to drugs. The longer we go without one, the longer Ella must wait for access to medicines, so we need a strategy now."

When thinking about why our community should support a rare disease strategy, Hailey Laxer said that it is "Great to have drugs developed but if we can't access them then they won't help us."

Nancy Cox

Nancy Cox went on to say that "People with CF need drugs now! This plan is urgent. Imagine a world where people are not fighting for their lives."

In closing, Twyla McDougall noted, "It blows my mind how advocacy has impacted the CF community. At one point in some provinces Creon was not covered in patients 18 and older but advocacy changed that, and look where we are now. This is the time to do it! Time to stand together! If we get better access to treatments then it could mean we are not tying up hospital resources, it could mean less transplants, less antibiotic resistance, less waiting lists and ultimately healthier people."

For more information on a rare disease strategy in Canada please contact advocacy@cysticfibrosis.ca.

UPDATE ON MYCFLIFEPORTAL

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MyCFLifePortal
PortailMavieaveclaFK

Through Cystic Fibrosis Canada's patient portal, MyCFLifePortal, patients can login to a secure website to view their health data that is stored in the Registry. Since the portal's launch, nearly 170 registered users have been able to access their health data to help them better prepare for clinic visits and track their health over time. Cystic Fibrosis Canada is excited to announce that the Medical Test section of the Registry has been expanded to include medical test data such as bone density testing, glucose testing and other routine bloodwork.

We will continue to announce which CF clinics are actively enrolling patients into the patient portal, please stay tuned to the CF Canada blog for further details or visit mycflifeportal.ca for more information.

MYCFLIFEPORTAL IS CURRENTLY AVAILABLE THROUGH THE FOLLOWING CLINICS:

- **Foothills Medical Centre, Calgary, AB**
- **Grand River Hospital, Kitchener, ON**
- **Hôtel-Dieu de Montréal, Montréal, QC**
- **Ottawa General Hospital, Ottawa, ON**
- **Royal Jubilee Hospital, Victoria, BC**
- **Royal University Hospital, Adult, Saskatoon, SK**
- **St. Michael's Hospital, Toronto, ON**

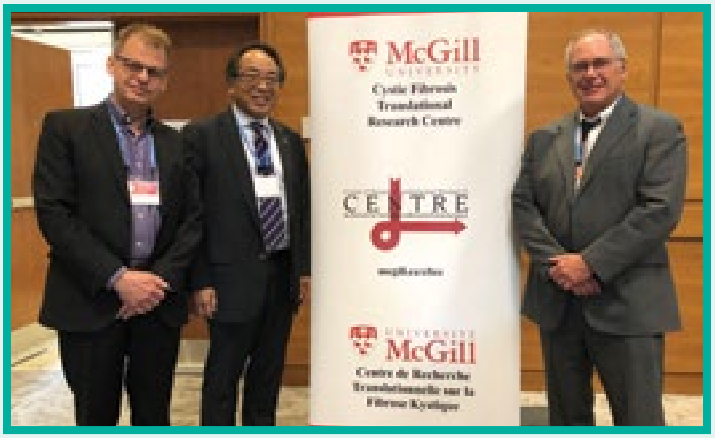
2019 QUEBEC SYMPOSIUM OF CF RESEARCHERS AND CLINICIANS: AN ERA OF COLLABORATION

On May 9th, Cystic Fibrosis Canada hosted the Quebec Symposium of CF Researchers and Clinicians – An Era of Collaboration. More than 150 representatives from our community, as well as internationally renowned guest speakers gathered for the second-largest gathering of its kind in Canada.

The event was organized by Cystic Fibrosis Canada in collaboration with the Cystic Fibrosis Translational Research Centre (CFTRc) and the Quebec Heart and Lung Institute (IUCPQ). During these two days, we had the chance to welcome, Dr. Lap Chee Tsui, Founding President of the Academy of Sciences of Hong Kong, who discovered the defective gene responsible for cystic fibrosis in 1989 in research funded by CF Canada. We were also proud to welcome Mrs. Danielle McCann, Minister of Health and Social Services for the province of Quebec.

We would like to thank Dr. John Hanrahan, Director of the CFTRc and Professor at the Department of Physiology and Research Institute of the McGill University Health Center, as well as Dr. Lara Bilodeau, Head of the Department of Pneumology and Director of the Cystic Fibrosis Clinic at IUCPQ for their involvement.

Clinic Day of the Quebec Symposium of CF Researchers and Clinicians



From left to right: Dr. John Wallenburg, Chief Scientific Officer, Cystic Fibrosis Canada, Dr. Lap Chee Tsui, Founding President, Academy of Sciences, Hong Kong and Dr. John Hanrahan, Professor, Department of Physiology and Research Institute of the McGill University Health Center.

From left to right: Dr. Larry Lands, Dr. Martha McKinney, Sarah Dettmers, Alexandre Grégoire, Minister Danielle McCann, Dr. Lara Bilodeau, Dr. John Wallenburg, Ève Routhier and Dr. André Cantin.

CIRCLE OF FRIENDS

DANIELLE WEIL: ON PARENTING A CHILD WITH CF

My name is Danielle Weil. I currently live in Brantford, Ontario. I'm the mom of two beautiful girls – my twin daughters, Mary-Elizabeth (who we call Emme) and Erin. My girls are 13 months old and they light up my world.

As first-time parents, the excitement and love my husband Matt and I felt was overwhelming. Our journey to becoming parents wasn't as straight-forward as we had hoped, and we tried for quite a while before exploring fertility treatment. The doctor warned that he didn't think the first treatment would take, and for us not to get our hopes up. He also warned that having twins, which runs in my family, was a possibility. I can still remember my smile when at our first ultrasound, we saw two little heartbeats.

I had an absolutely healthy pregnancy up until the day before the girls were born. We went in for a check-up, and both girls' heart rates were great. However, they noticed one of the babies wasn't moving. As a precaution, they decided to induce me. The girls weren't quite two days old when I visited them in the NICU. I was surprised that it was me, not the medical staff, who realized that Emme hadn't yet had a bowel movement – it still scares me that I'm the one who noticed. An abdominal scan found she had a blockage. And so while Erin and I were discharged, Emme was transferred to McMaster Hospital to investigate the blockage. Emme was diagnosed with cystic fibrosis (their first newborn screening had to be repeated due to an error) and spent the first three weeks of her life in hospital, before finally joining her sister Erin at home.

There was no indication we'd head this way. There was no history of CF in our families, and sometimes it's challenging to understand – I have twin daughters, one who has CF and another who does not – but we don't let ourselves go there. Life is hectic for us, for sure. Our days are filled with chasing our girls who are just on the edge of learning to walk, changing diapers, feedings, and treatment, but we know no different. Erin hits her milestones about 6-8 weeks ahead of Emme – I like to think she's showing her sister how it's done.

One of the first things Emme's clinic told us was: "Your daughter is healthy; it's just going to be more work to keep her that way." Hearing it put that way was a big burden off our shoulders. Perspective is everything and that approach has made such a difference for us, it was exactly what we needed to hear.

The best therapy for me has been getting involved. Going to chapter meetings, educating myself and my family about CF, and learning about the progress in research. It's all so empowering and has been a form of therapy for me. I'm not just doing it for Emme, or myself. I'm doing it for Erin, too. My girls need each other.

All I want is my girls to have their lives with each other. I don't want them to be short-changed on having one another. I hope my dreams of a cure in my lifetime come to fruition, and that both of my girls live long, healthy and happy lives.

A FAMILY AFFAIR: THE BRIEN FAMILY

The Brien family became deeply involved with fundraising for Cystic Fibrosis Canada when their son, Blake – then-five-months-old – was diagnosed with CF.

Since the first walk they participated in six years ago, they've steadily become more involved in raising funds, spreading awareness about CF, and have contributed a countless amount of time and fundraising dollars.

The Brien family recently won the Cystic Fibrosis Canada Atlantic Region Volunteer Leadership Award for the work they do to help Blake and everyone living with CF in the quest for a cure.

Led by Mike and Beth Brien, Blake's grandparents, the family leads the charge with the Atlantic region's CFIT campaign. The family stays as involved as they can. From the oldest to the youngest members of the Brien clan, they and their extended community all contribute in some way.

Every year, Blake's parents Erin and Colin participate in the Walk to Make Cystic Fibrosis History with their children Blake, James and Max. Colin is on the planning committee for the Gallivan CF Golf Tournament, a celebrity event which celebrated its 35th year in 2019.

Blake's aunt Christina is the current chair for the 'Dartmouth Walk to Make Cystic Fibrosis History,' the largest CF walk in the Atlantic Region.

"Initially, I got involved for my nephew Blake, and knew little about cystic fibrosis," said Christina. "But in university, I did Shinearama and got involved in any way I could. In Toronto, I did events like Lawn Summer Nights as well. Then when I moved back to Halifax in 2015, I continued helping out."

"I have a very personal connection to CF, and that's why I chose to chair the walk," continued Christina. "I had been volunteering and wanted to get more involved in the events scene. I started as chair three years ago, and have worked hard ever since." Christina's leadership of the Dartmouth Walk to Make CF History has breathed new life into this event.

"WE NEED TO GET THE WORD OUT BECAUSE THERE ARE SO MANY FAMILIES LIKE US, AND WE NEED TO SUPPORT EACH OTHER IN THE COMMUNITY."

Christina participates in everything from trivia nights to group workouts, and is always trying to raise money and awareness. As a family, they have done yard sales, created partnerships with local restaurants and businesses, and more.

"We have many voices and a big circle for Blake to fall back on, but this is not just about Blake," she said. "We need to get the word out because there are so many families like us, and we need to support each other in the community."

Blake does two treatments a day, including a mask to help with his breathing. His mother, Erin, says he doesn't realize yet that CF may hold him back from doing certain things.

"He's a sweet little boy and he's just super active. He loves to ski, play hockey, basketball, and baseball," she said. "He's batting 1,000 right now and hasn't struck out yet."

"He doesn't understand having CF may hold him back from doing things. He just wants to be involved with everything, and right now, he's not having trouble doing that."

The Brien family does everything they can to push for a better future for Blake and other CF patients.

"We have worked so hard to give Blake support and love, but so have so many other people. At almost seven, he will have experienced more love than people five times his age. His brothers have all learned compassion from seeing his struggles and hurdles. They love him so much and take such good care of him," said Erin.

"No one knows what tomorrow will bring, so we live our lives differently. We're so lucky to have him and we do everything we can to make a better future for him."

Before Blake's diagnosis, Mike Brien and his wife Beth were aware of cystic fibrosis, and had long been supporting CF Canada prior to their grandson's birth. Mike attended the Gallivan CF Golf Tournament, and they were involved in other fundraising efforts.

But finding out young Blake had CF would change the scope of their support for finding a cure.

"When Blake was diagnosed, my wife and I began to learn as much about CF as we could, and we wanted to push in a large way to help find a cure," said Mike.

> *I look at my own children, and we taught them to be socially conscious. We have always given back in the community, but having a family member with CF has really made us rally.*

Though Mike was happy to accept the leadership award, he and the Brien family do not raise funds for the accolades. "We do this not just for Blake, but for all those kids and families impacted by CF. Seeing it first-hand, we now have an appreciation for what it's like to live with CF," he said.

"It's wonderful to be recognized, but we also know there are so many other people and families doing great work. I think it's just important we do everything we can."

HER STORY

Q&A WITH CARA WILEY

How CF has affected her family, and why she got involved with Cystic Fibrosis Canada.

Could you please tell us a little about yourself and where you are from?

I spent the first half of my life in Toronto, and then moved to Calgary at age 16. A few years later, I met my husband Chris, and we've been married 17 years now! Two years into our marriage, we welcomed Calvin into the world, and then his sisters Abigail (age 12) and Rose (age 7). I am currently an Administrator for an insurance brokerage, and enjoy my job. In my spare time when not working, or volunteering, I enjoy; reading, playing video and board games, watching movies, spending time with friends and family, and driving with good tunes.

When was Calvin diagnosed with CF? What went through your mind when you received his diagnosis?

My son Calvin was diagnosed just after his first birthday. When it was suggested we go for a sweat test, we went into it thinking they were just ruling cystic fibrosis out. At the time, we thought that there was no possible way that he could have this genetic condition. Nobody in our family had it.

When were called back to do a second test to confirm the diagnosis, I did the worst thing a parent could do-I Googled it. I read through the symptoms of CF online and there was no doubt in our minds. I remember our first clinic being an overwhelming wave of faces, names, and information. "Take these pills, go get this nebulizer, start physio, do this, don't do that." We were terrified. But we were also relieved because we finally had an answer, and it was clear to us even then, that the doctors had a plan, and we were in good hands.

What advice would you give to parents who've recently found out their child has CF?

I would advise parents of newly diagnosed children to first and foremost take a deep breath. Take things one day at a time, as they come. There will be good times, and there will be heart-breaking times. But as crazy as it sounds, you will develop your own new normal. Make connections if possible with other CF parents... this has been my own personal saving grace. Having someone to listen, who just knows what you're going through is invaluable. But most importantly, have hope. Know that you're not alone in this fight, that there are so many people standing against this disease, looking for a cure. Never lose sight of how far research and care has come.

What are some of the challenges that come with being the parent of a child with CF?

Some of the challenges I face as Calvin's parent is to prioritize time for myself while juggling everything else. There are many times when his routine will get in the way of doing something for myself. I've missed many dinner dates with friends and teacher meetings for my girls while he was an inpatient at the hospital. The biggest challenge for me though is watching him suffer, knowing that I've done/am doing all that I can, and wondering if it's all enough.

What are some things that you've learned since Calvin's diagnosis?

Since Calvin's diagnosis I've learned so many things. Having a child on multiple medications with a crazy hectic routine forces you to become a bit more organized. I've learned to cherish life, and to not sweat the small things. I've learned how to run a g-tube, flush a port, hook up IV meds, do physiotherapy, count fat content in food, calculate how long an oxygen tank will last, and sterilize neb pieces. I've learned to roll with the punches, and allow myself to grieve, and to celebrate.

How has Calvin's diagnosis affected you and your family? In what ways?

When I think of how our family has been affected by Calvin's diagnosis, the first thing that comes to mind is how strong it has made us, and how close it has brought us. It taught us all how to make the best out of the worst situations. It brought my husband and I closer, as we support each other and work together. Having a brother with CF has helped my daughters to be such compassionate, selfless, genuine beings. It helps them to be more aware of people's differences, and struggles, and forces us all to focus on what is most important in life.

What inspired you to become involved with Cystic Fibrosis Canada?

The desire to make a difference inspired me to become involved with Cystic Fibrosis Canada. Shortly after Calvin was diagnosed, I saw a poster looking for volunteers to help with Bingo. I decided instead thinking of everything I couldn't change, and feeling sorry for myself, that I would do whatever I could to make a difference. I would help Calvin in any way I possibly could.

What is your current role with Cystic Fibrosis Canada?

My current role with Cystic Fibrosis Canada is the Calgary and Southern Alberta Chapter President. I also sit on the Walk to Make CF History and the 65 Roses Princess Ball Committees.

LÉONIE CÔTÉ: MAINTAINING A POSITIVE OUTLOOK

Can you tell us what it has been like growing up with CF?

For me, I had a normal childhood. I did not see any difference between me and my other friends. The only thing I could say is that being a CF child, we mature faster. However, I never had to stop doing something because I was sick or because I had an infection. It was part of my daily life.

In my case, the disease was degenerative from my teenage years. So it started to be more difficult at around 15 years old. But I still believe that it never stopped me from doing anything.

Your brother has CF too, right? Do you think it helps to have a brother who has had a similar experience to you dealing with CF?

Yes, my brother has CF. I think it may help on an everyday basis to live with someone who has the same disease as you, but in the end, I don't really know if it does help because I do not know what it's like to grow up without my brother who also has CF. We do our treatments together. We live our routine together.

Maybe having a brother who also has CF made the process of accepting the disease easier. For people who have brothers and sisters who are not sick, maybe it's harder to accept the disease. We grew up together with this disease. His health is much better than mine. I never envied his better health. I want all that is best for my brother. I do not wish him to live what I'm going through right now.

How has your health been?

My health, lung function and weight, have been relatively stable for a year now. But I am only at 30% lung capacity. I was put on the transplant list last March.

Of course, I'm having a hard time accepting this new reality. It's hard to accept because, if I'm on the transplant list, it kind of means that I have two years left to live. That reality is hard to accept. Especially since I've never thought of that before. I have always been super positive. I am not ready to live with a transplant. Things can change quickly, so it's better to prevent the worst. And in a way, it's a chance to be on this list. Although, I would rather be in good health.

What are your hopes for the future?

I just finished my Bachelor's degree in Kinesiology and I am starting a Specialized Graduate Diploma in Clinical Kinesiology in September. It's a one year program so it's my short term plan. I will learn about heart, lungs and metabolic diseases. I want to focus mainly in cardiac and metabolic. I have my share of pulmonary diseases. Afterwards, I would like to travel and find a job if I am physically able. Otherwise, I will have to wait for my chance to have a transplant. I have a lot of difficulty currently to see the long term. I work on it.

You have had great success organizing fundraising events for CF Canada, what inspired you to start the Spinothon 24h un Souffle pour l'espoir?

My parents organized the Léonie William Challenge for three years in a row in the early 2000s. The goal was to cross the Laurentides Park by bike to raise funds for Cystic Fibrosis Canada. A small platoon was participating, it went up to around 30 people.

I always followed them in this project. They stopped because of the workload. It was a lot of organization. I really wanted to do it again because I like people, I like to be surrounded and spend time with my family.

Last year, my uncle did the L-W Challenge. He cycled 1,350 km to raise money for CF Canada. It encouraged me to organize charity events.

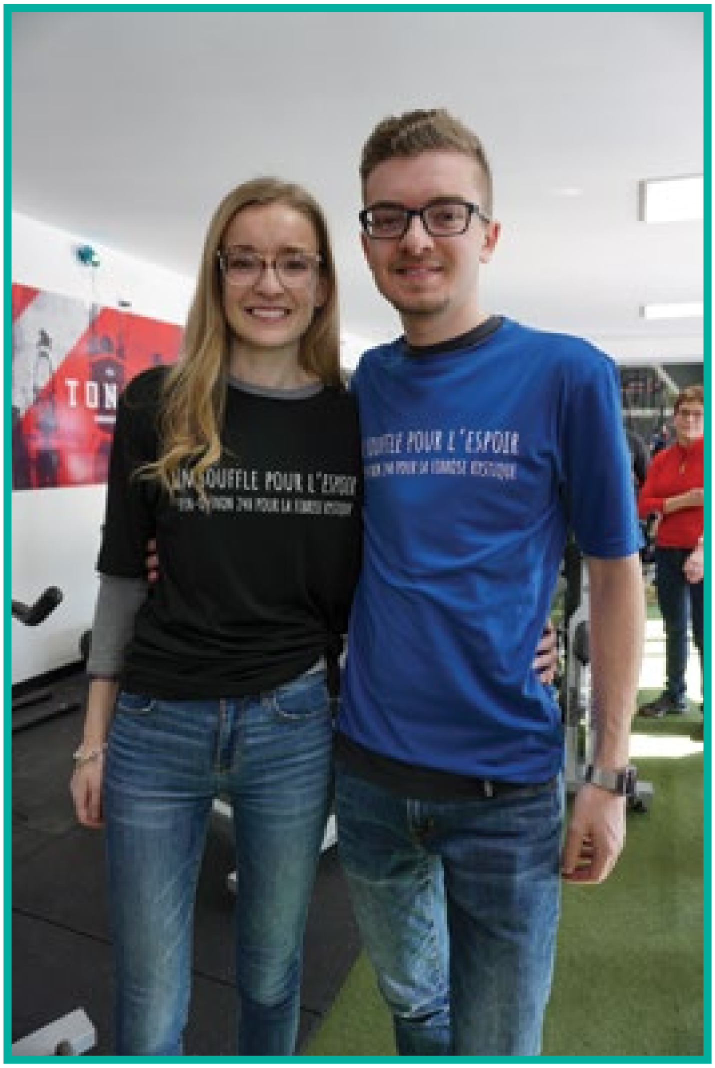
With classmates, we were looking for an activity to do for the bachelor's degree in kinesiology, so I presented a project that was at the beginning a big banquet. The idea was especially appreciated that the kinesiology program was associated with a good cause.

We created a committee, and after a few discussions, we decided to do a 24-hour Spinothon. The inspiration for the rest of the concept of the event came next, and we decided to include teams and sponsors in the project. For the Spinothon, there were 85 participants and we raised $ 21,000.

We also had a banquet that was smaller, but we still raised over $ 4,000.

In all, it's $ 25,500 that we gave to the cause.

Next year, we want to have another Spinothon.



What advice would you give to someone who is looking to organize an event?

Personally, I'm a last-minute person. Relatively organized-but last minute and I managed to create an event like this. Do not dwell on your flaws, be well surrounded and have a minimum of contact. Above all, do not be fooled by what others may think of you.

Also, with my health, I knew that I would have to pay the price of all the energy I invested in the events - especially in the Spinothon - I stayed awake for more than 24 hours! I accepted that the two weeks following the event, I would have to rest a lot and do nothing, but it was worth it.

The 2019 Ride Committee

RIDE FOR THE BREATH OF LIFE CELEBRATES 35 YEARS

2019 marked the 35th Anniversary of the Ride for the Breath of Life Run in Regina. In 1985 this run was started by Timothy Leirer and his sister Lorna McEwan (Leirer). They were both born with cystic fibrosis and while Lorna was visiting Timothy in the hospital, it happened that a group of bikers drove by on the highway. They both felt like bikers had been given a bad reputation and thought that it would be nice if the bikers were associated with an event that did some good in the community. Since both Tim and Lorna had cystic fibrosis, they decided that whatever funds were raised would go to support research for a cure for CF.

Timothy was in the hospital with a lung infection when the decision was made and the first run was planned. Lorna and a group of 5 other bikers planned the first run on May 11th, 1985. Unfortunately, Tim never got to see the run. He was laid to rest the day before the primary run.

The first run was to Davidson, SK. There were nine bikes involved in the run. Hard to believe they went from nine bikers the first year to up to over 400 participating in years later. In the 5th year, the venue was changed to its current location of Indian Head, where it has been going strong ever since.

A big dream of theirs was that the run would eventually go across Canada. It soon became a reality. There are currently CF rides taking place in 8 locations: Brandon, Calgary, Edmonton, New Brunswick, Peel & District, St. John's, Windsor, and last but definitely not least - Regina.

Lorna did step down as Chair of the run but has always kept it close to her heart. When she moved out of Regina, Gord Johnson who had been participating in the run since its second year moved into the position. Gord also has a close connection to CF as his daughter, April, is living with the disease. In fact he has said, one of his fondest memories of the run is taking April with him on the ride when she was very little. Gord stepped down from his position as Chair a few years ago, but to this day, he continues to be on the committee. The current Chair of the ride, Greg Wilchuck, has been riding in the run for many years as well. He decided to take on the Chair position in memory of his wife Donna's best friend, Karen Lackey, who lost her battle with CF, he didn't want to see the run end.

All three Chairs are most proud of the funds that have been raised and that their Regina Ride for the Breath of Life is one of the longest running charity motorcycle events in Canada.

Since the inception of the Ride for the Breath of Life, the event has raised an incredible $740,000 and counting for cystic fibrosis research and clinical care in Canada.

The event's youngest rider


Riders lined up for 2015's Ride for the Breath of Life event


Riders gearing up for Ride for the Breath of Life


Floyd and Ralph from the 2019 ride committee


Ready for the ride!


Bikes from 2016's Ride for the Breath of Life event


Riders gearing up for Ride for the Breath of Life


Gord Johnson, committee member during his Breath of Life ride in 2007


Lorna and Gord at one of the earlier Ride for the Breath of Life events

GEARUP4CF: MAKING A DIFFERENCE FROM COAST TO COAST

The GearUp4CF bicycle ride started 14 years ago in Vancouver, B.C. and has since raised over $1.97 million for cystic fibrosis research, advocacy and care. The ride was spearheaded by Dr. David Speert, a leading CF researcher, and was designed to include multiple distances for all levels of riders. Now entering its milestone 15th year, the GearUp4CF bike ride has spread from the West Coast of Canada all the way to the East Coast.

Paula Clark, a mother of two teenagers with cystic fibrosis organized the very first GearUp4CF ride in Prince Edward Island in 2013. Cycling has been a lifelong passion of hers and a long-time family hobby, so in 2012 when she returned home from the West coast GearUp4CF ride, she was inspired to host a ride on the East Coast. Since then, the ride has attracted cyclists from all over Canada.

In June of this year, West Coast riders had the choice of a one-day ride from Crescent Beach in White Rock to Chilliwack, or a more challenging two-day ride to Manning Park. This year, riders in PEI participated in a one-day 65 km ride along the Confederation Trail, a former railway line that was converted into a picturesque walking and cycling trail. Collectively, GearUp4CF raised over $170,000 in vital research and care for CF.

The GearUp4CF ride is a great way to connect with others passionate about cycling and people who are impacted by CF. It's an opportunity to participate in a fun and rewarding activity aimed at making CF a thing of the past.

Didn't get a chance to participate in the West Coast ride this year and want to get involved? Be sure to sign up for the 15th anniversary GearUp4CF ride from June 20th - June 21st in 2020! For questions related to the BC GearUp4CF ride, please contact bcinfo@cysticfibrosis.ca.

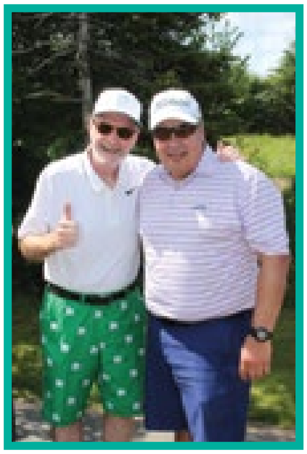
Stay tuned to 850km.bikepei.com for details related to the 2020 PEI GearUp4CF ride.

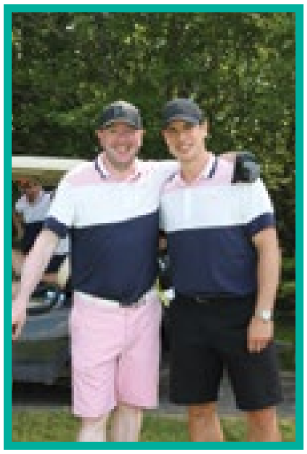
THE GALLIVAN CYSTIC FIBROSIS GOLF TOURNAMENT CELEBRATES 35 YEARS

The Gallivan Cystic Fibrosis Golf Tournament celebrated its 35th anniversary on July 4 with a celebrity tournament held at Old Ashburn Golf Club in Halifax. The 2019 Gallivan welcomed a sell-out crowd with an impressive line of celebrity supporters – including **Sidney Crosby**, **Nathan MacKinnon**, **Ian Legatt**, **Ken Reid**, **Jack Armstrong**, **Bob Cole**, and many others.

Led by chair, **Bette El Hawary**, and a team of volunteers, the 2019 tournament raised over $97,000. It featured traditions like the Friends of Robbie and Jane hole, hosted by Robbie and Jane Thompson's friends to celebrate their lives and raise funds for CF Canada. More than just an average tournament, the Gallivan brings with it a strong history of supporting Cystic Fibrosis Canada, and has raised over $2-million in its 35 years.

Thank you to all who have participated over the last 35 years!





TIMBERMART HARDWARE STORE CELEBRATES 25 YEARS OF HOT DOG DAY!

On June 1st, Timbermart Hardware Store in Saint-Augustin celebrated the 25th anniversary of its hot dog day for Cystic Fibrosis Canada. Once again, it was a huge success with more than $17,500 raised for CF Canada. Thank you to the volunteers and customers who supported the day and a special thank you to Amélie Bélisle, the dedicated owner of the hardware store.

A FAMILY TRADITION

This unique charitable initiative began 25 years ago when Mrs. Bélisle's parents owned Timbermart. Their nephew had two children with cystic fibrosis, so they wanted to do their part for the cause. Sadly, Sabrina, their niece, has unfortunately died of the disease. Their nephew became a father in 2017.

"We are very involved in our community. For us, it's a fair return to our customers. It's our way of being part of their life." said Amélie Bélisle.

WORLDWIDE TREK TO MAKE CF HISTORY: PERU EDITION

Emotional, amazing, unreal, life-changing, incredible. These are words people have used to describe Cystic Fibrosis Canada's first ever Worldwide Trek to Make Cystic Fibrosis History – a trek through the Andean mountains of Peru ending at Machu Picchu.

During Cystic Fibrosis Awareness month (May), more than 60 trekkers began their journey on the very same weekend that thousands across Canada also walked in local communities to raise awareness for the disease, which currently affects more than 4,300 people in Canada.

Our intrepid trekkers were guided across mountains, over peaks, through valleys, and along the ancient and famed Inca Trail, spending days hiking and nights camping – all with the common goal: to create a world without cystic fibrosis.

To participate in this remarkable challenge, trekkers needed to raise a minimum of $4,200 each. CF Canada was ecstatic to share with the group that together they raised more than $360,000 towards CF research and care! An incredible feat!

We are so proud of our worldwide trekkers and the people who supported them. We want to say THANK YOU for mobilizing, fundraising and caring.

Here are some testimonials from our trekkers:

"We all instantly felt connected and bonded closely like a family."

– Mel Bilko (Group 1)

"I am the mother of 3 beautiful children; the oldest has cystic fibrosis. I would recommend this challenge to everyone. In fact, I would do it again tomorrow if I could. The landscapes were magnificent, the organization was well above my expectations and we raised more money than I could have hoped. We surpassed ourselves and showed courage and determination every day of the challenge. Most importantly, what kept us going was the cause."

– Marilyne Levert (Group 1)

"I took on this challenge because as a mom of two daughters with cystic fibrosis this is exactly what I would do for my girls: carry mountains, move mountains and even climb a mountain!"

– Tammy Strong (Group 2)

To see the wonders of civilizations entirely unlike anything we are familiar with. To have an opportunity to interact with these people who live such different lives than we do! The beauty of the mountains, glaciers, waterfalls is amazing!"

– John Ross (Group 3)

TO SHARE A GLIMPSE OF THEIR EXPERIENCE, OUR TREKKERS SHARED A BIT ABOUT THEIR TIME IN PERU:

They started their journey with two days in Cusco, acclimatizing to the altitude on a walking tour of the city in the surrounding areas of Cusco while learning more about the archaeological sites in the area.

"Our connection in Cusco was seamless. We arrived a day before the tour began so we organized a taxi through The Hotel, La Casa de Don Ignacio. At the airport, we met another person who was also on Group #1 and we shared a cab to the hotel. Meeting the rest of our team at breakfast the next morning at the hotel was also very easy. All of the Peruvian guides and the hotel staff made sure that we had everything we needed at every leg of our journey. Charity challenge put together an incredible team to ensure we had a fun and memorable experience."

– Joanne Lovell (Group 1)

DAY 3

The group went to the Lares Valley (four and a half hours by drive). The group stopped at the famous Lares hot springs for a swim and lunch. After lunch the trek began with a 4-5hours hike to the small village of Cuncani, where the group camped overnight.

"Today was awe-inspiring to say the least. The bus ride to Lares Hot Springs took us along a crazy (some would say perilous) road; narrow with sheer drops off one side and a route that switch-backed the mountainside in hairpin turns like I've never experienced (especially not in a huge bus!).

We were pleased to make it in one piece and got our first real taste of hiking in the Andes on our trek today, with steep rocky terrain, incredible views, rickety bridges for river crossings and local ladies selling their hand-woven wares along the path. The entire 5 hour hike we were accompanied by a very cute stray dog, that we named Panchito.

We were hot in the sun, but as soon as it set we realized how cold it could be at night and were all rugged up by the time we reached Cuncani village school, where we were grateful to collapse into our tents and have a hot cup of cocoa."

– Aisha Champness (Group 2)

ON DAY 4 AND 5

The group hiked to the small community of Huacahuasi and had the opportunity to meet the locals. Then, they went to the Ranrayoc valley passing the small community of Puňunayoc.

"Days 4 and 5 were the most challenging days of our trek, reaching altitudes of over 4000 metres on both days. The sight of soaring mountain peaks and a peaceful lake were spectacular, although dwarfed by the insight resulting from the physical challenges of lungs struggling for oxygen and muscles pushed to the limit, which provided powerful reminders of our cause and deeper appreciation of the strength and courage of friends and family with CF.

Reflecting at the end of Day 5, each of us acknowledged having finished those days changed in some measure, and grateful for the experience"

– Diane Vetter, Group 3

ON DAY 6 AND 7

The group arrived in Machu Picchu and trekked on the traditional Inca trails towards the Sun Gate.

"Our final two days of the trek were the most awe inspiring! Hiking 8 hours in blistering sun and most of us running out of water did not diminish our excitement for hiking to revered locations such as Wiñay Wayna, the waterfall, the Sun Gate, of course, Machu Picchu. Getting to see one of the wonders of the world almost entirely to ourselves was an amazing experience. Visiting Machu Picchu the next day was equally moving.

It would be impossible to list all the amazing moments of the trip but suffice it to say, it was the journey of a lifetime."

– Joanne Lovell (Group 1)

Thank you to our incredible, brave and adventurous trekkers for taking on the challenge! We would also like to thank sponsors **SportChek**, **Canadian Tire** and **Woods** for outfitting the trekkers on their journey.

JOIN US IN ICELAND IN 2020

The Cystic Fibrosis Canada team is heading to Iceland in June 2020! Don't miss your chance to sign up for a trip of a lifetime! For more information, please visit www.cysticfibrosis.ca/walk.

Left-Right: Tracy Micallef, Christine Martysiewicz, Director Corporate Partnerships at Cystic Fibrosis Canada, Bo Ouyang, Chief Financial Officer at Siemens Canada, Chloe Micallef (who lives with cystic fibrosis), Faisal Kazi, President and CEO, Siemens Canada and Kelly Grover, President and CEO at Cystic Fibrosis Canada.

Siemens' employee band Exit Strategy wows the crowd!

Left-Right: Kelly Grover, President and CEO at Cystic Fibrosis Canada, Tracy Micallef and daughter Chole Micallef (who lives with cystic fibrosis) and Christine Martysiewicz, Director Corporate Partnerships at Cystic Fibrosis Canada.

CONGRATULATIONS SIEMENS!

SIEMENS
Ingenuity for life

On June 27, 2019, at its annual Canada Day BBQ and wrapping up its Cystic Fibrosis Canada fundraising month, **Siemens celebrated reaching $2 million in accumulative giving to CF Canada!**

Siemens and Cystic Fibrosis Canada partnered in 1997 when the company sponsored the Breath of Life Ski Challenge, founded by two time Olympian ski racer and Cystic Fibrosis Canada champion, Ken Read. It was the stories of cystic fibrosis (CF) community members like Ken and his nephew Andrew's fight with CF that first caught the attention Siemens.

Back in 1997, the median age of survival for a Canadian born with CF was only 32; today, after 22 years of partnership with Siemens, it is over 50 years of age. In its history with Cystic Fibrosis Canada, Siemens has supported the annual Walk to Make Cystic Fibrosis History, hosted fundraising events including the Siemens annual hockey tournament and soccer tournament, in its 11th year, and encourages employees to give back through its corporate match program.

Siemens employees across Canada shine in June when they participate in a month-long fundraising campaign for Cystic Fibrosis Canada, including raffles, bake sales, yoga class, garage sale, coffee day and more.

Thank you to the colleagues at Siemens for your unwavering support, creativity when it comes to fundraising and for making a difference in the lives of the more than 4,300 Canadians who live with cystic fibrosis.

Congratulations on reaching $2 million!

UP NEXT FOR SIEMENS:

There is no slowing down for this partnership! The company just hosted its 11th annual soccer tournament, raising an incredible $12,000 in support of Cystic Fibrosis Canada!

MIKAYLA BIANCHIN ATTENDS NASCAR WITH CARSTAR!

Earlier in June, our partner CARSTAR and Axalta Racing hosted the #AcceleratetheCure contest to help raise awareness for cystic fibrosis. Candidates were instructed to submit a helmet design for a chance to have it featured on racing star Alex Bowman's helmet, as well as a trip to see him in action at the Watkins Glen racetrack in New York!

Alex Bowman with Mikayla and her winning helmet design. Photo by Dale Ross.

The winner of the contest was Mikayla Bianchin, an 18 year old Canadian CF champion from Hamilton, Ontario.

Mikayla is an Illustration student attending Sheridan College. Living with CF, alongside her younger sister Madison - who also has CF, raising awareness and fundraising for cystic fibrosis research is very important for Mikayla. "I hope for a cure one day and I want to do everything necessary to ensure CF awareness is headed in the right direction for the CF community. If my art or my speaking is able to have any part in that then I am proud and happy," said Mikayla.

For her helmet design, Mikayla decided that she wanted to incorporate key images that are often associated with CF, without actually having to write the words "cystic fibrosis."

Mikayla used blue as a dominant colour for her design; given that blue is strongly associated with CF in Canada and NASCAR driver Alex Bowman also wears a lot of blue, so it worked well. Mikayla uses roses in a lot of her CF pieces so she knew she wanted a rose to be a key feature – representing growth and beauty. She chose to use a DNA strand given that CF is a genetic disease and lungs because CF mainly affects the lungs.

For Mikayla, the biggest highlight of her NASCAR experience was seeing her helmet design on display during the races. "I am overjoyed that an event as big as NASCAR held a piece of the CF community in its heart," said Mikayla.

Like all CF patients and families dealing with CF, Mikayla hopes for a world without CF. "It would not only change so many lives, but save thousands of lives. That is a day I am determined to see." Mikayla believes in the power of doctors, nurses, research labs, CF patients, and support from family and friends to prolong and improve the quality of life of CF patients until a cure is found.

CARSTAR ACCELERATION TO EXCELLENCE CONFERENCE 2019

CARSTAR, dedicated Cystic Fibrosis Canada partner of more than 20 years, hosted its annual CARSTAR Acceleration conference in Chicago in July of 2019. Never missing an opportunity to spread awareness, more than 300 volunteers took to the streets of Chicago for the "Soul Stroll" to share the message about supporting the cystic fibrosis (CF) cause. The conference also included awards for the top cystic fibrosis fundraisers in the CARSTAR network, presented by CF Canada and the CFF. At the roaring 20's themed final gala, franchise partners, vendors and corporate staff made song requests for the duelling pianos via a donation.

Not only did the North American team raise awareness but through its Soul Stroll walk, CARSTAR sock sales, 50/50 raffle and more they raised an incredible $30,000 to support CF Canada and the CFF! We look forward to joining the CARSTAR team for Acceleration 2020 in Toronto!

Congratulations to the Top Fundraising stores in Canada for Shine Month!

CARSTAR BRAMPTON
CARSTAR RED DEER SOUTH
CARSTAR JOHNNY K GROUP (EDMONTON & AREA)
CARSTAR TORONTO ST. CLAIR
CARSTAR BRANTFORD
CARSTAR MISSISSAUGA 401
CARSTAR KITCHENER KING STREET
CARSTAR HAMILTON MIDTOWN
CARSTAR COURTENAY, BC
CARSTAR LONDON EAST & WEST
CARSTAR OAKVILLE EAST & WEST

ADVOCIS AND CYSTIC FIBROSIS CANADA: A HISTORY

Advocis

The Financial Advisors
Association of Canada

Advocis, The Financial Advisors Association of Canada, has been a longstanding supporter of Cystic Fibrosis Canada for over 34 years. During this time, Advocis members have raised over $5.4 million to further fund research to help find a cure for cystic fibrosis. These vital research dollars are fundamental in helping those affected to receive adequate treatment and assist in lengthening the lifespan of these individuals. The Association continues to host a range of events including golf tournaments and Poor Boy Luncheons.

THE 2018 JULIA AWARD

Advocis South Saskatchewan was honored to be selected as the Recipient of the Cystic Fibrosis Canada 2018 Julia Award. The Saskatchewan chapter was commended for their amazing contributions in making the annual 65 Roses Golf Tournament a high impact fundraiser. Advocis remains committed to generating awareness around the cystic fibrosis cause, and building upon a long-held reputation for giving back to their communities.

43RD ANNUAL ADVOCIS WINDSOR POOR BOY LUNCHEON

Advocis Windsor, along with the support of the local community, was proud to host the 43rd Annual Poor Boy Luncheon at St. Clair Centre for the Arts. This year's event included live music, raffle prizes and 50/50 draws. Funds were raised in support of the local Cystic Fibrosis Canada Windsor - Essex-Kent Chapter. Throughout the years, Advocis has been able to make significant donations that have positively impacted young children who are living with CF, to allow them to remain in Windsor-Essex.

ADVOCIS CHAPTER LEADERSHIP CONFERENCE 2019

Advocis was proud to host Cystic Fibrosis Canada at the Annual Chapter Leadership Conference in Saskatoon. Advocis member and keynote speaker, Chris Getzlaf, donated an autographed Saskatchewan Roughriders jersey for auction. All proceeds raised were donated to Cystic Fibrosis Canada.

THE WALK TO MAKE CYSTIC FIBROSIS HISTORY CELEBRATES 15 YEARS AS A NATIONAL EVENT

On Sunday, May 26th, 2019, the Walk to Make Cystic Fibrosis History celebrated its 15th anniversary. Thousands of participants across Canada united at more than 70 locations across the country to fundraise and show their support for Canadians who live with CF.

To mark the 15th anniversary and incentivize walkers, Cystic Fibrosis Canada partner NOGU designed a special edition NOGU Kismet Links bracelet. The team at NOGU gave one bracelet to every participant that raised more than $100. Thank you NOGU!

As a result of the dedication of our supporters including volunteers, donors, partners and participants, the 2019 Walk has raised **$3.5 million**, including funds from the Machu Picchu trek! These funds continue to support world-class CF research, advocacy and care.

Since its inception as a national event in 2005, the Walk has been a flagship national event and has raised over nearly $35 million in peer-to-peer fundraising to support CF research, innovation and care.

The 2020 Walk to Make Cystic Fibrosis History will take place on Sunday, May 31, 2020. For more information on the Walk or to register for 2020, please visit www.cysticfibrosis.ca/walk.

Thank you the 2019 Walk to Make Cystic Fibrosis History national sponsors, Vertex Pharmaceuticals and Kin Canada. A special thank you to all participants, partners, donors and our incredible volunteers for making this year's Walk such a success, and for making cystic fibrosis history!

The 2020 Walk to Make Cystic Fibrosis History will take place on Sunday, May 31, 2020. For more information on the Walk or to register for 2020, please visit www.cysticfibrosis.ca/walk.

LAWN SUMMER NIGHTS

Canada's most anticipated summer event returned for its 11th year! Lawn Summer Nights hosted 16 lawn bowling fundraisers across the country in support of Cystic Fibrosis Canada. This year, LSN has raised over **$450,000** and counting, bringing its lifetime total to an incredible $3 million and counting!

Thank you to all who participated!


Charlottetown


Ottawa


Calgary

Vancouver


Victoria


Toronto


Edmonton


Regina


Saskatoon


Halifax


London


Tsawwassen






THE 5TH ANNUAL DECANT GALA

The 5th Annual Decant Gala & Fine Wine Auction was held at the Delta Toronto on Saturday, May 4th, 2019. This year's event highlighted some of the diverse and exciting tastes of Argentina, while also featuring fantastic performances from Payadora Tango Ensemble and Tango de Oro dancers Fabian & Roxana Belmonte. Those in attendance had the opportunity to enjoy an authentic Argentinian meal and an assortment of sommelier paired wines from the prosperous vineyards throughout the South American country.

Cystic Fibrosis Canada Ambassador Ben Mulroney returned as the event's Master of Ceremonies, and keynote speaker Lindsay Bishop shared her CF journey with the audience of over 350 guests, corporate sponsors, and volunteers. The evening brought in over $430,000 for cystic fibrosis research and care, increasing the event's grand total to $1.8 million raised since 2015.

Congratulations to the amazing Decant Gala committee members who worked tirelessly to ensure this year's event was the best one yet. Thank you to all the sponsors, guests, donors, volunteers, and CF community members who made the gala spectacular! We can't wait to see what's in store for An Evening in Australia next year!


A MESSAGE FROM THE CHAIR OF THE KIN-CF LIAISON COMMITTEE

Tammie Corbett

It is hard to believe that another year has passed and we are celebrating the 55th anniversary since the chance meeting of Dr. Crozier and Kin, Bill Skelly at the same bar. It is absolutely incredible that this year, being a milestone, that our Kin members raised over $47 million in support of Cystic Fibrosis Canada.

There have been many challenges and successes over the course of 55 years, but the passion and commitment of our ongoing partnership ensures that we will continue to work towards finding a cure to make CF History!

I feel grateful and appreciative of the wonderful members of the Kin community and their kinship with the CF family. We truly work "Together for Life".

I am also very proud of the outgoing Kin-CF Liaison team and would like to take this opportunity to once again thank the 2018-2019 District Service Directors for their commitment and dedication over this past year and their tremendous efforts.

The Kin-CF Liaison teams at the Orientation & Development Session in March 2019.

Please join me in recognizing the following Service Directors amazing contributions over the past year: Tracy Spalding and Curtis Thoms (District 1), Hollee Babcock (District 2), Michelle Jaindl (District 3), Dustin Bisson (District 4), Sandra Bowes (District 5), Sue Caron (District 6), Peggy Hefler (District 7) and Gil Boissonneault and Kathy McFarlane (District 8).

I would like to thank all of your for your dedication, enthusiasm, creativity and your deep commitment to Cystic Fibrosis Canada.

As my term as Chair comes to a close, I would like to acknowledge the great work we have accomplished together over the past 2 years and the great memories and friendships between the kin community and the CF community.

I would like to introduce you to Dustyn Pumfrey, the 2019/2020 Chair of the Kin-CF Liaison Committee. Dustyn told me, "I am constantly amazed at all of the work our clubs and members are doing across the country to raise funds and awareness for Cystic Fibrosis Canada. I am excited for what the next few years will bring especially in research." Also, please welcome our new team of Service Directors: Lisa Burechails and Bill Roskar (District 1), John DeBeer (District 2), Jodi Martens (District 3), Hillary Derksen (District 4), Anita Llewellyn (District 5), Donna Atwater (District 7). Staying on for another term is Sue Caron (District 6) and Gil Boissoneault and Kathy McFarlane (District 8). Please join me in introducing Vicki Andrews as the National Service Director.

Once again, I would like to celebrate fifty-five years of kinship.

Working together we will end CF!

Tammie Corbett,
Chair, Kin-CF Liaison Committee

Congratulations to the 2018/19 Kin-CF team for a successful year!

Cystic Fibrosis Canada Kin Canada Kinsmen • Kinettes • Kin

Together for life®

Cystic Fibrosis Canada would like to thank Tammie Corbett, the 2018/19 Kin-CF Liaison Committee and the 2019/20 Kin CF Liaison Team for their commitment and perseverance in helping us create a world without CF. Since 1964, Kin Canada has raised an incredible $47 million for cystic fibrosis research and healthcare. The Canadian CF community is grateful for all their outstanding contributions!

CYSTIC FIBROSIS CANADA
NATIONAL AWARD RECIPIENTS 2019

It is only through the commitment, courage and passion of our outstanding volunteers that we continue to improve the lives of Canadians living with cystic fibrosis (CF). Our volunteers take time from their busy lives to help make a difference in the CF community. Congratulations to the 2019 national award recipients, together we are working towards a world without cystic fibrosis.

The Above & Beyond Award is designed to honour healthcare & research professionals who have consistently contributed to the organization's mission, moving beyond their professional association with cystic fibrosis to wholeheartedly embrace the cause.

DR. MARK MONTGOMERY

Dr. Montgomery is a long-time physician and the former Director of the Pediatric Cystic Fibrosis Clinic at the Alberta Children's Hospital. Dr. Montgomery led the initiative for Newborn Screening, first in Alberta and then paved the way for all provinces. Because of Dr. Montgomery's trailblazing work, all Canadians with cystic fibrosis now may be identified through newborn screening, enabling access to care at the earliest possible time in their lives. Dr. Montgomery is also an experienced volunteer with many years on the Medical/Scientific Advisory Committee. He has helped to guide and shape clinical policies for Canadian clinics and has been instrumental in developing standards and protocols for CF Care. He has also been involved in Accreditation Site Visits across the country with policy and consistency of care. Cystic Fibrosis Canada is very appreciative of his contributions over the years.

The Breath of Life® Award recognizes outstanding and sustained contributions to a Cystic Fibrosis Canada Chapter in a leadership capacity by an individual, couple or family who has contributed on an ongoing basis for a minimum of three years.

JULIE CHOUINARD

Julie joined the Quebec City Chapter in 2004. Since then, she has been an outstanding Treasurer. She leaves nothing to chance and is incredibly detailed, meticulous and professional in everything that she does. Her kindness, loyalty, generosity and devotion make her a remarkable person in every way. She has made the CF cause, her cause. She is also a tremendous supporter and fundraiser for many events and projects for Cystic Fibrosis Canada. Thank you to Julie for her constant collaboration, commitment, generosity and for always going above and beyond.

CAROLINE WARREN

Caroline has been an integral leader of the Edmonton, Northern Alberta Chapter for over 20 years. Through her amazing dedication, experience, knowledge of fundraising, advice, good decision-making and lots of hard work, she has left a legacy. Thanks to these skills and talents, she has created many fundraising initiatives including: The Akita Drilling Golf Tournament, Joe's Run for the Lung, Citie Ballet Fundraiser and Faceoff for CF. She continues to actively participate in a variety of events to support CF. She graciously tells her daughter's story of CF whenever possible. Thank you to Caroline for her passion, her strong sense of community and her dedication and leadership throughout the years.

The Céline Award acknowledges a volunteer, individual, couple or family, who has made indispensable and sustained contributions to chapters at the "grassroots" (non- executive) level.

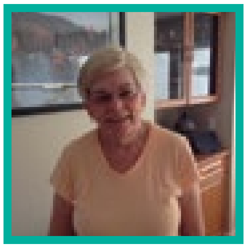
MIKE FARWELL & JENNIFER STEELE

Mike has been an integral part of the Kitchener-Waterloo District Chapter for over 10 years. Sharing his story and his experiences, Mike continues to actively raise funds in the community to make CF history. Mike had two sisters pass away from CF. Jennifer is central to their Farwell4Hire campaign. Together, this amazing couple, does public speaking, meet and greets, donates countless hours, and manages their year-long fundraising activities for CF. We thank Mike and Jenn for their dedication, enthusiasm, and creativity throughout the past few years and into the future.

CARA WILEY

Cara has a son who has CF, and despite being a very quiet person decided to become Chapter President of the Calgary & Southern Alberta Chapter. For Cara, her CF family is just as important as her own family. Cara has inspired new members and volunteers most significantly at the Princess Ball and with her Facebook page. Cystic Fibrosis Canada is proud to recognize Cara Wiley for her successes as an exemplary volunteer, and we are grateful for her creativity and dedication.

BEV READY



Bev began volunteering for the Campbell River Chapter 12 years ago with the Rod Brind D'Amour CF Golf Tournament. Prior to being actively involved in the Chapter, she and her husband supported the Walk. Bev is extremely well-organized and always on top of all of the event details. She is enthusiastic and is very actively involved with fundraising and recruiting new supporters and volunteers. Bev is very committed to the CF cause. We are grateful for Bev's increasing involvement and her dedication and commitment.

JEAN CLICHE

Jean is one of the veterans of the Quebec City Chapter with his involvement dating back to 1982. Jean is a phenomenally generous and devoted person who is persistent, diligent and totally committed. He is a vital leader for the annual Motorcycle Ride with the Blue Knights. What makes this all the more remarkable is that no member of his family has cystic fibrosis. In fact, he became a volunteer out of friendship with a former Chapter president. We are grateful to Jean for his determination, and long-standing involvement and passion to find a cure for cystic fibrosis.

SID KEAY

Sid is the Co-Founder and Co-Chair for the Mike Cassidy Legacy Golf Tournament, and has been involved with the Vancouver/Lower Mainland Chapter for the past 25 years. Sid has a lot of energy and talent which is tirelessly focused on raising awareness and donations for CF. He and his company are central to the 65 Roses Galas, GearUp4CF, and recently extended their support to the Calgary Chapter's Ladies Golf Tournament, the Alberta Raffle, LSN (Lawn Summer Nights) and the Brind'amour golf tournament. We thank Sid for his generosity, inspiration, dedication, and vitality.

The Dr. Douglas Crozier Award is intended to recognize a healthcare professional who has demonstrated exceptional support to individuals or families living with cystic fibrosis.

DR. CECILIA CHAPARRO

Dr. Chaparro's work expands across CF Clinics, the Lung Transplant Program as well as being a professor, educator, researcher, and a sought-after speaker with her involvement in both clinics and transplant programs. She is committed to raising awareness for CF, improving the lives of transplant patients and increasing research to ultimately find a cure for cystic fibrosis. Dr. Chaparro's outlook on CF is inspiring and optimistic and encourages patients. She continues to advocate for better care, better access to transplant opportunities and education opportunities for the next generation of medical professionals. Cystic Fibrosis Canada would like to thank Dr. Chaparro for her dedication and commitment.

The Leadership in Advocacy Award is offered to an individual or a group that has made a national contribution to the fight against cystic fibrosis through their advocacy efforts.

PATTI TWEED

Patti has dedicated her life to the CF community; professionally, as a volunteer, and as a CF parent. Patti has been a very active member and leader of the North Saskatchewan Chapter, the CF Canada Health Care Advisory Council and as a provincial advocate. Patti's energy, strategic advice and organizational skills have engaged and empowered many volunteers and community members. Patti is tireless in her efforts to improve access to medicine for Canadians with CF. Cystic Fibrosis Canada would like to thank Patti for all of her incredible contributions and ongoing support to every aspect of the community.

The Mila Mulroney Award honours a family impacted by cystic fibrosis that has made significant ongoing contributions to Cystic Fibrosis Canada, through their continued fundraising efforts as a family.

THE MASON FAMILY

The Mason family has spent over four decades dedicating their time and expertise to the Kitchener-Waterloo District Chapter. Their son was diagnosed with CF at 13 months and since then; they have organized many unique events and opportunities to involve the community. John, Marlene, their son Robert, and his wife Patricia, continue to be a support network for families and the CF community. They all speak publically, and Robert is always available to inspire everyone with his experiences with CF. Thank you to John and Marlene and your entire family for everything you have done to support Cystic Fibrosis Canada over the years.

THE BLACK & BURROWS FAMILIES

The Black & Burrows families' involvement in the Campbell River/Comox Valley Chapter has been extensive. Bill and Chris founded the chapter when their daughter Kim was diagnosed with CF. They have been key members of the community, and continue to help with events, fundraising, and advocacy. The whole family dedicates their time and energy, and continues to be active at local events and activities supporting CF. The next generation has stepped up as leaders – Kim, Tara and Rachel are actively involved in events and advocacy. Cystic Fibrosis Canada would like the Black and Burrows families for their volunteer work, passion, and dedication over the years.

The Summerhayes Award honours an individual with cystic fibrosis who has demonstrated an exceptional commitment of national impact to the cystic fibrosis cause.

ROB BURTCH

Rob has been involved with Cystic Fibrosis Canada his entire life. He has been an ambassador for CF Canada for over 35 years representing patients at major events such as the 65 Roses Gala, Shinerama and more. His leadership roles are extensive, but he always finds time to help other people and families with CF. Rob is now the Ontario Provincial co-Advocate for Cystic Fibrosis Canada, and during his tenure has lead regional advocacy efforts with government officials, new volunteers, events and in the corporate sector. Rob has been very involved in creating and promoting the importance of a pan-Canadian rare disease strategy. He is also a great role model for the CF community and readily shares his personal story. Thank you to Rob for his ongoing leadership, advocacy work and dedication. Rob is an inspiration in the fight for all Canadians living with CF.

The Volunteer Development Award recognizes a Chapter that has demonstrated overall excellence in the area of volunteer development.

HAMILTON CHAPTER

The Hamilton Chapter utilizes events all year long as an incredible source to recruit, train, retain, and grow volunteers, capitalizing on the enthusiasm and excitement around events. They have a wonderful way of recognizing all of their volunteers with a great sense of community. The Chapter balances a high level of professionalism with a sense of fun, laughter and community. After meeting them, you will want to be part of this chapter and play a part to end CF. We thank the Hamilton Chapter for their creativity, spirit and outstanding support.

The Youth Impact Award is designed to recognize a young individual (19 years of age or under), who is a source of inspiration to others and has displayed leadership within the CF community on an ongoing basis.

MADI VANSTONE

Madi is an activist and speaker who has been advocating for CF Care & medicine her whole life with CF Canada and SickKids Hospital. She constantly inspires others, and actively encourages people to volunteer, fundraise and become involved in advocacy. She always brings a truly excited and happy attitude to her community and to those around her. Thank you to Madi for her exceptional work in raising awareness for the CF cause and for inspiring many others to take action.

The Communications Excellence Award recognizes a Chapter that has demonstrated overall excellence in the areas of advocacy and public awareness.

THE NORTH SASKATCHEWAN CHAPTER

Through innovative events such as Cassidy's Lemonade Stand Tour and Hoops for Hope events, as well as the Walk, the North Saskatchewan Chapter has worked determinedly to bring awareness of CF to the entire province. They also utilized a wide range of social media sites and multi-media opportunities. This enthusiasm and awareness has led to new corporate partners and enhanced relationships with the Kinsmen and Kinettes. This small group seized on every opportunity. Cystic Fibrosis Canada is grateful to the North Saskatchewan Chapter for their inspiration, their community engagement, their bravery in learning new skills and their success and dedication in increasing involvement and advocating for access to medications.

The Fred Blizzard Chapter of the Year Award recognizes a Chapter that demonstrates strength in fundraising, communications, volunteer development and partner support.

CYSTIC FIBROSIS CANADA – THE KITCHENER-WATERLOO & DISTRICT CHAPTER

The success of The Kitchener-Waterloo & District Chapter is due to very passionate and dedicated volunteers. The chapter works closely with committees, and with the clinics to find new volunteers and new event participants. The Chapter utilizes media coverage, and social media platforms to increase visibility of their fundraising events, spread awareness about the disease, as well as recognize their remarkable volunteers and the generosity of sponsors and partners. The volunteers of The Kitchener-Waterloo & District Chapter are strong leaders in the CF community and Cystic Fibrosis Canada is grateful for all that they do.

WALK TO

MAKE CYSTIC FIBROSIS HISTORY

Cystic Fibrosis
Fibrose kystique
Canada

SUNDAY MAY 31, 2020

REGISTER. DONATE. FUNDRAISE.

www.cysticfibrosis.ca/walk
walk@cysticfibrosis.ca
1-800-378-2233

FERTILITY WEBINAR SERIES

Cystic Fibrosis Canada’s Adult CF Advisory Committee (ACFAC) will host a webinar series that explores aspects of fertility and family planning in relation to cystic fibrosis. Various topics will be discussed bi-monthly, with the exception of summer. This webinar series provides our community with an opportunity to learn and discuss various fertility related topics with are important to many members of our community.

All sessions will be live recorded and made available for future viewing online. You can register for the next webinar by emailing **advocacy@cysticfibrosis.ca**.

DONATE TODAY

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____

City, Province ______________________

Postal Code ______________________

Phone Number ______________________

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GIFT AMOUNT

○ $250 ○ $100 ○ $75 ○ $50 ○ Other $ __________

or donate online at www.cysticfibrosis.ca/donate

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☐ Cheque ☐ Credit Card

Card number ______________________

Expiry date ______________________

Signature ______________________

☐ I want to receive an e-receipt

I would like to learn about other ways to give to Cystic Fibrosis Canada:

☐ Monthly giving ☐ Planned giving ☐ Tribute giving

Please send your completed donation form to:

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2323 Yonge Street, Suite 800
Toronto, Ontario M4P 2C9
Fax: 416-485-5707

Thank you for your generosity. An acknowledgement of your donation and a tax receipt for donations $20 and over will be issued to you upon receipt of your donation.

**By providing your email, you're opting into receiving email communications from Cystic Fibrosis Canada.*

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