Cystic Fibrosis Canada
Fibrose kystique Canada

Connections

WINTER 2019

BYWAY BABES
THE CROSS-COUNTRY CANOE FUNDRAISER

INTRODUCING THE CYSTIC FIBROSIS CANADA **ACCELERATING CLINICAL TRIALS NETWORK (CF CanACT)**

ADVOCACY IN ACTION:
DAY AT THE LEGISLATIVE ASSEMBLY OF SASKATCHEWAN & ACCESS TO PRECISION MEDICINE FORUM

CELEBRATING 55 YEARS WITH KIN CANADA

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 learn and discuss various fertility related topics which 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**.

TABLE OF CONTENTS

MESSAGE FROM THE PRESIDENT AND CEO

To think I am months away from my first year anniversary at Cystic Fibrosis Canada is remarkable – time really does fly. It feels like just yesterday I joined the ranks of my colleagues and this inspiring community, working towards our mission to find a cure for cystic fibrosis.

In October, I attended the North American Cystic Fibrosis Conference. This was a wonderful opportunity to learn more about the state of research and to discuss our clinical trials network, CF CanACT, and MyCFLifePortal with our peers. With representation from over 40 countries, the scope of the Conference extends well beyond North America, demonstrating the international effort to combat cystic fibrosis.

We had a very successful day at the Legislature in Regina in November. It was incredible to witness the collaboration between our staff and volunteers and the advocacy day illuminated a couple of things. First, we have extraordinary advocates who are making a difference. Second, CF Canada's leadership in advocating for these new modulators is essential in ensuring their access to people in Canada with CF.

In December, the 2017 Canadian Cystic Fibrosis Registry report was released. This data is instrumental in helping those working in CF to better understand the disease and to identify and respond to key clinicial issues. We also launched an integrated holiday fundraising campaign, lifting the voices in our community and shedding light on the Tough Questions that cystic fibrosis poses. Thanks to everyone that participated and supported this campaign.

In January, CF Canada hosted *"There's Promise in the Pipeline: Now How Do We Pay for It?"* a forum on access to precisions medicines in Toronto. The forum brought together patients, patient groups, private insurers, researchers, and regulatory and reimbursement bodies together to discuss how to improve access and affordability of personalized and precision medicine. We showcased the promising potential that the Cystic Fibrosis Individualized Therapy Program could have on managing drug budgets while still providing access to precision medicines that may help some members of our community live healthier lives. By organizing this forum, CF Canada was seen as a leader in advancing the dialogue on reimbursement for rare disease treatments.

Needless to say, we have had an eventful past few months, and 2019 is shaping up to be just as exciting. Over the course of the next year, Cystic Fibrosis Canada will celebrate many significant milestones including the 15th anniversary of the Walk to Make Cystic Fibrosis History, which we'll celebrate by walking across Canada and trekking Machu Picchu! This year marks the 55th anniversary of both Shinerama and our partnership with Kin Canada. Our Kin family has raised over $47 million in support of the search of a cure for cystic fibrosis, and without their efforts, we simply would not be where we are today. We also celebrate the 30th anniversary of the discovery of the CF gene, which changed the course of treatment and research worldwide.

The next year will continue to be about listening, learning, and acting. Together we have accomplished so much, and I know that together we can make history for cystic fibrosis. Thank you for your continued support and trust.

Kelly Grover
President and CEO

MEET EARLY CAREER INVESTIGATOR, DR. JONATHAN RAYMENT

Dr. Jonathan Rayment, CIHR ICRH-CF Canada 2018 Early Career Investigator

Cystic Fibrosis Canada (CF Canada) and the Canadian Institutes of Health Research (CIHR) Institute of Circulatory and Respiratory Health (ICRH) have partnered to jointly fund the *CIHR-ICRH/CF Canada 2018 Early Career Investigator Award in CF Research*. This three-year award is designed to support the early career of a promising CF scientist, helping to build Canada's next generation of leading CF researchers.

CF Canada is pleased to announce that the 2018 recipient is clinician-scientist, Dr. Jonathan Rayment. Originally from Ottawa, Dr. Rayment earned his medical degree at McGill University in Montreal before completing his Pediatrics and Respirology training at The Hospital for Sick Children in Toronto. In January 2018, he joined BC Children's Hospital (BCCH) in Vancouver as a respirologist, CF physician and researcher.

What made you pursue a career as a CF physician and researcher?

I decided to go into pediatrics after working in a CF clinic while I was in medical school – that's how special the CF community is to me. Caring for a child with CF is a team effort. You have doctors with different specialties, nurses, dieticians, pharmacists, psychologists, social workers and physiotherapists all working together to support these children and their families. I was drawn to being part of such a dynamic group of caregivers, and I think the multi-disciplinary support we provide for children with CF is really exemplary – it's a paradigm of what the care of children with complex medical conditions can and should be.

The other thing that made me decide to work with children with CF is the amazing patient community. CF families have really gotten behind advancing care and supporting research to develop new therapies. I think the success we've seen in improving the care for CF over the last few decades is due in large part to commitment of the CF community, working in concert with an amazing, multi-disciplinary clinical team.

With respect to my drive to do research in CF, that's an easy one. I find it very difficult to have to tell a family in clinic that I just don't have the answer to their question. These moments drive my research. I use research to answer the questions that I'm faced with every day when I treat patients. It's one of the advantages of working in a centre like BC Children's Hospital that combines research and clinical care – I'm able to take dilemmas from the clinic and go tackle them directly in my research.

"I think the success we've seen in improving the care for CF over the last few decades is due in large part to commitment of the CF community, working in concert with an amazing, multi-disciplinary clinical team."

What are your research interests?

My main area of research is in developing new tests that can help us better measure how well children's lungs are working. Specifically, I am currently working on refining two types of tests that can measure lung function. One is called multiple breath washout (MBW), and it has existed in some form for decades. MBW can measure how effectively gases mix inside the lungs and how evenly this mixing is distributed throughout the lungs. MBW is a very sensitive test (much more than spirometry), so it has a lot of potential to help us detect lung disease earlier than traditional tests. We're working to clarify exactly how this test can or should be used for monitoring children with CF, and other lung diseases.

I'm also working on developing the use of magnetic resonance imaging (MRI) technology to measure lung function. Specifically, I'm studying a technique where we scan children while they breathe in tracer gas, a harmless gas that is visible on the MRI. We then look at the distribution of the gas in the lungs to see how effectively they're working.

Ultimately, we hope eventually to integrate these tests into the everyday care of people with CF. This would help CF clinicians make more informed management decisions, and hopefully result in better care for people with CF.

"I find it very difficult to have to tell a family in clinic that I just don't have the answer to their question. These moments drive my research."

Please tell us about the research that your ICRH-CF Canada Early Career Investigator Award will help to support.

I am truly honoured to be a recipient of the ICRH-CF Canada award. This funding will support a randomized, controlled trial that I will run here at BCCH and at SickKids in Toronto to investigate a question that stemmed directly from the clinical care of children with CF.

We know that *Staphylococcus aureus* (Staph) is the most common bacterium isolated from the airways of children with CF. Antibiotics are a mainstay of treatment in CF, and are of clear benefit when people with CF have increased pulmonary symptoms (cough, increased sputum, etc). However, there is controversy in the CF community over whether we should treat people who are clinically well, but have Staph in their airways. In this study, we will perform a randomized, controlled trial of oral antibiotics (cephalexin) in children with CF who have Staph on airway culture, but do not have increased symptoms. We will use MBW testing, traditional spirometry and clinical status as the main outcomes in this study. The results of this study will guide clinicians on how to best manage children who are clinically stable but have Staph on airway culture.

How will your findings impact patient care?

Because this study grew from an unanswered clinical question, the answer will have direct applicability to the clinical care of children with CF. If we find that treatment with antibiotics results in a lung function or clinical benefit, then it supports the more aggressive use of antibiotics in this clinical setting. If we see no benefit, then perhaps a more conservative approach is more appropriate. Either way, the answer will be informative and could have a significant impact on the care of children with CF.

What do you enjoy doing outside of the clinic and lab?

As a neo-Vancouverite, I enjoy taking in all that beautiful British Columbia has to offer – hiking, camping, skiing, fishing and so much more!

THERE IS PROMISE IN THE PIPELINE: NOW HOW DO WE PAY FOR IT?

This is an exciting time for the cystic fibrosis community. With over 40 therapies under development, just over half of which aim to address the basic defect of CF, there has never been greater hope for a control or cure for the majority of patients. Sadly, Canada's drug review and reimbursement processes have not kept pace with the rate of innovation.

Our current system relies heavily on evidence from large, long-term clinical trials, evidence that is difficult to produce in rare disease populations like CF. These evidentiary challenges become increasingly difficult when we consider that these CFTR modulators are often genetically tailored to specific mutations, or classes of mutation. As of early 2019, there are over 2000 mutations associated with CF. As new precision medicines become available for rare and ultra-rare mutations, it will become impossible for drug manufacturers to meet the evidence requirements of today. We want to be a leader in developing the evidence requirements of tomorrow.

To discuss solutions to these opportunities and challenges, and to inform the national pharmacare consultations, in January 2019 Cystic Fibrosis Canada hosted *There is Promise in the Pipeline: Now How do We Pay for It?,* a one day forum to spark discussion on the current access climate in Canada, and what we need to do to improve access to precision medicines. The outcomes will help us develop strategies and partnerships to ensure that Canadians with rare diseases like CF can access the precision medicines they need.

At the forum was representation from other rare disease groups, clinicians and researchers, pharmaceutical manufacturers, private payers including some of Canada's top insurance companies, as well as regulatory bodies such as Health Canada, the pan-Canadian Pharmaceutical Alliance (pCPA) and the Canadian Agency for Drugs and Technologies in Health (CADTH).

"The event was amazing. To have an open forum where members of the government, the healthcare community, and advocates can come together and speak freely without negativity was such a powerful moment," said Rob Burtch, the event's MC and Co-Provincial Advocate, Ontario.

"I believe the precision medicines forum was a huge stepping stone to building bridges across our communities and professions so that we can see access to rare disease medication and personalized health care become a regular part of the Canadian health care system."

The forum featured the Cystic Fibrosis Canada and SickKids partnership, the Cystic Fibrosis Individualized Therapy program (CFIT), as a predictive tool that government and private insurers can potentially use to help determine which CF modulators work well in which individuals. While still in its early stages, this program holds great promise to help better manage access to CF modulators and better manage drug budgets by demonstrating value for money.

The event's Keynote Speaker was Dr. Tim Caulfield, Professor of Health Law and Science Policy and the author of *"Is Gwyneth Paltrow Wrong About Everything?"*. Professor Caulfield discussed how our current regulatory and reimbursement systems were not built with precision medicines in mind, and demonstrated how the power of storytelling in mass media can influence policy.

"It was heartening to have a forum to bring all of the players into the conversation and to put words to the shared challenges, to acknowledge that we are all on the same team, to resolve to move forward, and to facilitate the solutions that will ultimately find a cure..."

"I appreciated the clearly articulated and varied perspectives in the room, conscious of the underlying generosity of spirit that seemed to guide the discussion. In the 36 years that I have been personally involved in the CF community, I have been continually struck by the indomitable spirit of its members – those who live with the disease, their families, their medical caregivers, the researchers," noted Pattie Tweed, Provincial Advocate, Manitoba. "It was heartening to have a forum to bring all of the players into the conversation and to put words to the shared challenges, to acknowledge that we are all on the same team, to resolve to move forward, and to facilitate the solutions that will ultimately find a cure. I look forward to the day when my son and his 'CF kin' will be able to say "I used to have CF."

Thank you to our sponsors Janssen, IMC, Merck, Horizon Pharma and Boehringer Ingelheim for helping to make this event possible.

DAY AT THE LEGISLATIVE ASSEMBLY OF SASKATCHEWAN

In November 2018, Cystic Fibrosis Canada and the team of Saskatchewan volunteers, as part of the Cystic Fibrosis Canada National Advocacy Program, participated in a Day at the Legislative Assembly of Saskatchewan. Throughout the day, volunteers and staff attended MLA meetings, spread awareness of CF, and encouraged collaboration between the CF community and government to improve access to medicines and quality of care for people with CF.

Advocacy volunteers and staff from CF Canada brought our community's concern with equitable patient access to drugs and treatments to the attention of many elected and appointed officials, as well as the need for supportive services for caregivers, mental health, and CF clinical care. Advocates met with 27 elected and appointed officials which included Premier Scott Moe, Minister of Health Jim Reiter, Minister of Remote and Rural Health Greg Ottenbreit, and half of the governing cabinet. Advocates also met with many members of the Official Opposition, including the Leader of the Opposition Ryan Meili, and the Health Critic Vicki Mowat.

Following some very successful meetings with elected members, the advocacy team attended Question Period. It was a special moment when the group was introduced by multiple Members of the Legislative Assembly including Premier Scott Moe and Minister of Health Jim Reiter. Elected Members stood up one by one in the Legislature to share personal stories from their morning meetings and recognized the Saskatchewan CF community.

On the evening of November 7th, CF Canada hosted a Legislative reception at the DoubleTree by Hilton Hotel & Conference Centre Regina. Approximately 30 Members of the Legislative Assembly, including Premier Moe, many cabinet ministers, and oppositional members attended the reception.

Elected members had the opportunity to meet Cassidy Evans, a spirited 10-year-old girl with a zest for life! Cassidy was diagnosed with cystic fibrosis at four years old. In 2013, along with her family, she started Cassidy's Lemonade Stand which to date, has raised over $40,000 to find a cure for cystic fibrosis. Cassidy, along with her mother Kimberly Evans (Provincial Advocate for Saskatchewan), were Co-Masters of Ceremonies for the evening, and served Cassidy's famous lemonade to all attendees.

Minister of Health Jim Reiter, and Oppositional Health Critic Vicki Mowat, both shared some kind words and expressed their dedication and commitment to helping improve the lives and livelihoods of those living with CF.

We are grateful that the Saskatchewan government is taking the lead in Canada with a commitment to improve access to future CF medicines. Congratulations to all Saskatchewan volunteers, whose efforts have allowed CF Canada to build a strong unpartisan relationship with the Saskatchewan government.

On February 20, we learned that Saskatchewan, Alberta and Ontario collectively agreed to establish prescribing criteria to provide access to Orkambi on an exceptional, case-by-case basis. Quebec was the first province to provide exceptional, case-by-case access. Orkambi is now available in those provinces for paediatric patients between 6-17 years old who have experienced at least a 20% relative decrease in ppFEV1 in the last six months sustained for at least six weeks despite appropriate treatment.

We are grateful for Saskatchewan's leadership on this file and applaud the Saskatchewan government for working with Minister Elliott in Ontario and Minister Hoffman in Alberta to develop this criteria, and for considering the input of CF clinicians in doing so. While we are pleased that this decision may benefit a small amount of children and youth with CF those who need Orkambi the most will be able to access it, we are disappointed that the criteria are not more inclusive. Cystic fibrosis is no longer a childhood disease; 61 percent of Canadians with CF are adults.

We hope these events will inspire others to get involved in the Cystic Fibrosis Canada National Advocacy Program. Together we can influence public policy to help Canadians with CF. Email **advocacy@cysticfibrosis.ca** to learn more.

CYSTIC FIBROSIS CANADA LAUNCHES MyCFLifePortal

In the fall of 2018, Cystic Fibrosis Canada launched a patient portal called *MyCFLifePortal* that provides Canadians living with cystic fibrosis the opportunity to access their CF health data online – anytime they want.

MyCFLifePortal is a secure, online read-only website specifically designed for participating CF patients and their caregivers to enable them to access their (or their child's) Canadian CF Registry (CCFR) data from the comfort of their own home. This website is fully bilingual and will include features such as interactive graphs and summary reports. *MyCFLifePortal* is provided free for any eligible user and participation is completely voluntary.

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MyCFLifePortal
PortailMavieavecla FK

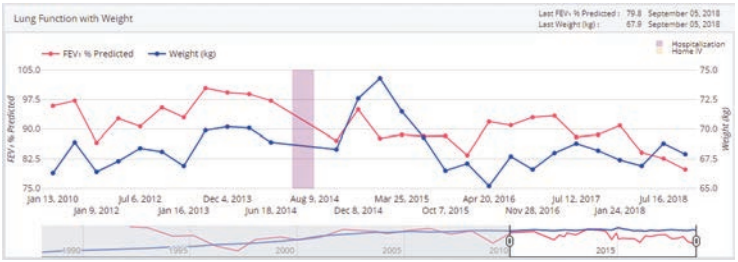
HOW DO I SIGN UP?

Patients can register through their clinics. *MyCFLifePortal* has launched in seven clinics and will be available at all 42 Canadian CF clinics by end of 2019. 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.

CURRENT LIST OF PARTICIPATING 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

Members of the CF Canada community and those living with CF may be familiar with the CCFR – a collection of national CF clinical information on participating CF patients that is managed and maintained by CF Canada. The CCFR is an incredible resource that supports the CF community by advancing our knowledge and understanding of CF. It has been instrumental in many initiatives that include research studies to monitor important epidemiological trends, advocating for more funding and resources, responding to emerging healthcare issues and educating and promoting awareness about CF.



Prior to the launch of *MyCFLifePortal*, the CCFR was only accessible to healthcare professionals from the 42 CF clinics who manually enter in data. We have listened to the CF community who have asked to see their CCFR data. ***MyCFLifePortal* will enable patients to take ownership of their healthcare and their health data and bridge the health information gap encouraging patients to more fully engage with their CF healthcare team.** Patients will be able to prepare for clinic visits through better knowledge of their current health status and how it has changed over time and watch their progress.

WHAT PATIENTS ARE SAYING

Cystic Fibrosis Canada | Fibrose kystique Canada

My CF Life Portal | Portail Ma vie avec la FK

"Having access to the CF portal would mean having more control over my health. I have been too busy in the past to write down notes after clinic visits, but with this I'll be able to access my own information whenever I want it. Being able to track my Pulmonary Function Test (PFTs) over time is something that I've always wanted to do, and now my chart will be at my fingertips."

CHELSEA GAGNON, QUEBEC

"Living with cystic fibrosis is demanding, relentless, and can often leave you with the overwhelming feeling that you are losing control of your health. I feel that having access to the Patient Portal would help give back a little bit of that sense of control. In order to best manage my CF, I frequently depend on my knowledge of CF in general and my understanding of my current level of functioning. The Patient Portal would be an easy and accessible way to see and track your CF health over time. In my opinion, more knowledge will only contribute to better understanding and self-management. Furthermore, the Patient Portal would be a valuable communication tool between patients and their CF healthcare teams. This would enable you to best prepare for clinic visits by having an accurate and clear understanding of your own current CF health trends. This can only lead to more effective visits with the CF healthcare teams to the benefit of the patients and healthcare providers."

MEGAN PARKER, ALBERTA

"I am 25 years old and deal with my cystic fibrosis medications and exercises every day of my life. Using the Portal, I would be able to see what trend my health is on and if my efforts are paying off. Knowing that my daily struggle is working, I would be encouraged to keep going. Also, seeing that my lungs/weight is suffering, I could reflect on my habits and look for ways to better my routine. Knowledge is power, bring on the Portal!"

MICHAEL TIMMERMANS, BRITISH COLUMBIA

For more information, please visit the **mycflifeportal.ca**.
If you have any questions or comments, please contact CF Canada at **cfregistry@cysticfibrosis.ca**.

2017 HIGHLIGHTS FROM THE CANADIAN CF REGISTRY

Cystic Fibrosis Canada

DEMOGRAPHICS

OVER 4,300 CANADIANS WITH **CF** WITH **MEDIAN AGE** OF **22.8** YEARS

66 NEWBORN SCREENING **11** ADULT DIAGNOSIS

115 NEW CF **DIAGNOSES**

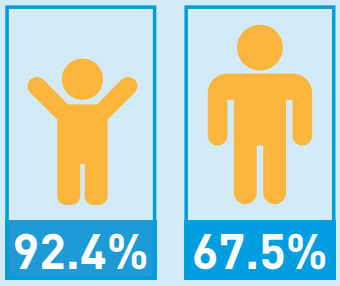
18.7% TRAVELLED **MORE** THAN **250 KM** TO RECEIVE **CF CARE**

60.9% ARE ADULTS

89.1% CARRY AT LEAST ONE COPY OF THE MOST COMMON CF-CAUSING MUTATION, **F508DEL**

HEALTH OUTCOMES

MEDIAN **FEV_1** PERCENT PREDICTED



68.7% OF FEMALE ADULTS **63.5%** OF MALE ADULTS

HAVE A NORMAL WEIGHT
(BMI BETWEEN 18.5 AND 24.9 KG/M²)

48.7% OF **CHILDREN UNDER 2** YEARS

45.9% OF **CHILDREN BETWEEN 2-17** YEARS

ARE ABOVE THE NATIONAL GOAL OF 50TH BMI PERCENTILE

CF CARE AND TREATMENTS

COLLECTIVELY MORE THAN
19,000 CLINIC VISITS
OVER **26,000** HOSPITAL **DAYS**
& ALMOST **1,000**
COURSES **OF HOME IV THERAPY**

22.4%
HAVE CF-RELATED
DIABETES

84.9%
TAKE PANCREATIC ENZYMES TO DIGEST FOOD & ABSORB NUTRIENTS

42 **SPECIALIZED CF CLINICS**
BASED IN HOSPITALS ACROSS CANADA

40.2% HAVE ***PSEUDOMONAS AERUGINOSA*** INFECTIONS

SURVIVAL

MEDIAN AGE OF SURVIVAL
ESTIMATED TO BE
52.3 **YEARS OF AGE**

50%
OF THOSE TRANSPLANTED TODAY
EXPECTED TO
LIVE BEYOND 10.3 YEARS

60 DEATHS
HALF WERE **UNDER**
33.6 YEARS OF AGE

46 TRANSPLANTS
WITH A **MEDIAN AGE** OF **28.1** YEARS

Source: The Canadian CF Registry 2017 Annual Data Report

For information on ways to support Cystic Fibrosis Canada, please visit us at **www.cysticfibrosis.ca**

CYSTIC FIBROSIS CANADA ACCELERATING CLINICAL TRIALS NETWORK (CF CanACT)

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CF CanACT
FK ÉCLAIR

In keeping with its vision of a world without cystic fibrosis, Cystic Fibrosis Canada has established a Canadian clinical trials network, Cystic Fibrosis Canada Accelerating Clinical Trials (CF CanACT). World-class clinical trials are an integral part of the process that brings new therapeutics and better care to Canadians who are living with cystic fibrosis. The establishment of CF CanACT will help to facilitate the development of these new treatments for cystic fibrosis, as well as increase capacity and enhance participation of people with cystic fibrosis in clinical trials.

The CF CanACT network presently consists of six sites across Canada (one in Montréal, two in Toronto, one in Calgary and two in Vancouver). Gradually, the network will expand to include more sites. In the meantime, anyone with cystic fibrosis living in Canada is eligible to be referred to one of these sites to participate in a clinical trial, and can participate if they meet the inclusion criteria of the specific trial.

The investigators and research coordinators from the six sites, along with an adult patient representative and a CF parent, collaborate to review research protocols, standardize outcome measures between sites, and ensure that the clinical trial is feasible to perform and relevant to their patients.

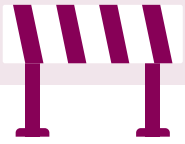
If you're interested in participating in a clinical trial but don't know where to begin, we encourage you to familiarize yourself with some of the benefits, barriers and risks associated:

BENEFITS

- ✓ Taking an active role in your healthcare
- ✓ Understanding your diagnosis better
- ✓ Helping others living with the same condition
- ✓ Gaining access to new treatments not yet available to the public
- ✓ Receiving a treatment that may work better for you than your current treatments
- ✓ Receiving close and extra follow up care
- ✓ Many studies have shown that participants involved in clinical trials have better overall health outcomes, compared to those who are not involved in trials

BARRIERS

- ✓ Being required to travel to the study site
- ✓ Time involved in attending study visits (especially Phase I and II) and length of trials
- ✓ Potential monetary value of missing work
- ✓ Potential need for childcare while participating in a trial
- ✓ Potential of missing school to participate in a trial



RISKS

- ✓ Experiencing side effects or adverse reactions to medications or treatments
- ✓ Receiving a treatment that does not work for you
- ✓ Not being part of the treatment group (taking placebo)

For more information, or to see a listing of all available CF clinical trials in Canada, visit **www.cysticfibrosis.ca/clinicaltrials**.

CIRCLE OF FRIENDS

BYWAY BABES

Claire Davis, Rylea McEvoy and Kendra Hurley are the Winnipeg trio behind the Byway Babes, the cross-country canoe fundraiser in support of Cystic Fibrosis Canada.

“Adventuring has always been a part of my daydreams. I’ve admired adventurers and travelers for about as long, imagining myself in their shoes on my own journeys and telling myself: someday. Then, sitting across the table at my family’s cottage in Ontario, Rylea handed me the possibility of my very own adventure. “Would you want to?” and “*yes*” constituted most of the conversation,” wrote Kendra in a blog post.

The idea was to paddle from Western Canada, all the way to the east, to raise awareness and funds for cystic fibrosis, a cause close to their hearts. Byway Babe Claire lives with CF, and was their inspiration for the trip.

They would leave from Vancouver on April 7, 2018, giving themselves plenty of time from autumn 2016 to plan and prepare for their 5,329 kilometre trip across Canada. Preparations began with weekly team meetings, where the Babes would write to-do lists, plan their route and build strength. They worked out and trained four times per week, including weekly paddles, to build the strength and endurance required for this ambitious feat. Wilderness training and cold water training were important elements to their preparation, helping them learn how to thrive (and survive) the elements. “Part of being prepared to deal with submersion is to know in advance how your body will react, which is accomplished by doing cold water training in a controlled environment,” said the Babes. This training came in handy during their journey.

And so, after a year and a half of preparation, the Babes set off from Vancouver and paddled the Fraser upstream to Hope, British Columbia in the first leg of their cross-country trip. They paddled and hiked their way across the mountains – as the Bow River was breaking up ice on the other side of the Rockies. They travelled down the Bow through Calgary to South Saskatchewan, right to Diefenbaker Dam. Here, a portion of water is siphoned off into the Qu'Appelle River, snaking them by Regina on their way to meet the Assiniboine River. The Assiniboine took the Babes to their home city of Winnipeg for some much needed, albeit brief, rest and to replace and repair gear.

Reflecting on the trip, Claire told the Winnipeg Free Press, "It was a lot easier than we thought it would be, in every aspect. We had prepared so much and prepared for the worst, it was kind of surprising how strong we were, fending for ourselves... It was pretty awesome."

Their rest was over before they knew it, and it was back to their beloved boat – their home for more than half of 2018. They resumed their trip up the Red River and skirted Lake Winnipeg to the Winnipeg River, where they played leapfrog with far too many dams into Ontario (or the Land of a Million Lakes, as they jokingly called it). Ontario was anticipated to be their biggest challenge in terms of navigation. Making their way through the many bodies of water between the Ontario-Manitoba border and Lake Superior was no small task.

But challenges – overcoming challenges, to be more specific – were nothing new to the Byway Babes. There were days Mother Nature had her own plans and the trio did not get on the water. Twice, their boat capsized. A terrifying experience for them all, but one for which they were well prepared for thanks to their training. Claire left the trip for three weeks for CF treatment – the irony of the intrusiveness of CF occurring during their journey was not lost on them. In fact, it kept them motivated. The Babes took in Canada's beautiful landscape and chatted up friendly strangers (now friends) they met along the way, even staying with a woman in Powerview-Pine Falls who heard about their trip on the radio and reached out to them.

Reflecting on the challenges and hiccups along their journey, it's easy to wonder why the Babes would agree to such a demanding and ambitious idea. But Claire's perspective offers some understanding: "With having CF, I know I don't have forever, so whenever an opportunity comes up, I jump on it."

After making their way along the north coast of Lake Superior to Sault Ste-Marie, the Babes passed into Lake Huron, and took the French River to Lake Nipissing, Pine Lake, Chant Plein Lake and to the Ottawa River. This trek brought the Babes to arrivals in Ottawa, Montréal and Quebec City in late September.

Rylea writes in a blog post dated October 9, 2018: "Six months is a long time. We paddled as the trees in Alberta began bare and cold just before the new leaves began to bud. At the time it felt like forever before the buds exploded into bursts of bright green and the new leaves unfolded in the warming sun. We paddled as the flowers along the river banks bloomed and the geese and ducks were pairing off before the first tiny fluff balls finally hatched. Baby moose, beavers, dear and loons were also spotted. We paddled as the spring fluff balls turned into awkward winged adolescents, and were learning to fly. We portaged through the dog days of summer and swam in the beautiful clear Ontario waters. We paddled as the leaves turned gold, red and copper and they're now beginning to fall."

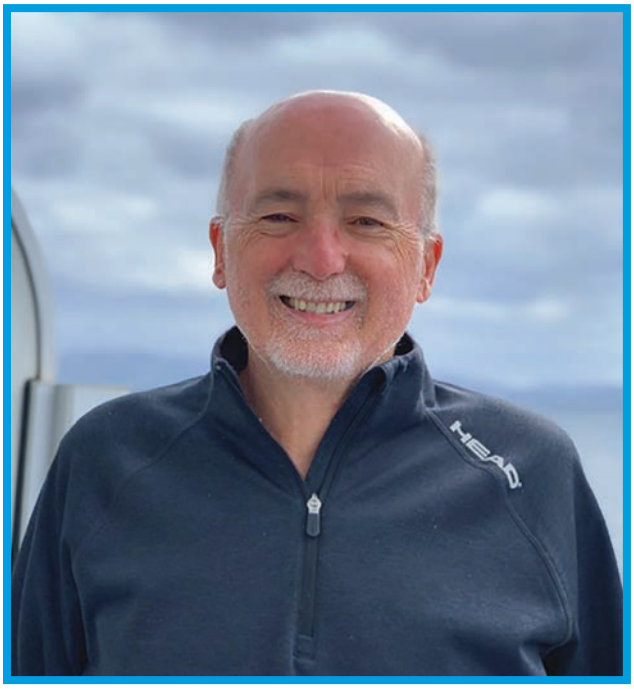
From Quebec, they zig-zagged their way down to Saint John, New Brunswick (via the Saint John River), allowing them to *finally* say they touched both oceans! **After six long months, enduring the elements, testing themselves both physically and emotionally, the Byway Babes achieved their goal of paddling across Canada, and raised an incredible $15,000 for Cystic Fibrosis Canada!**

Along the way, the Byway Babes made new friends, deepened their friendships with one another, were interviewed by Global News Winnipeg and Vancouver, and were even named three of the 100 most fascinating Manitobans of 2018 in a Winnipeg Free Press feature published in December!

Congratulations and thank you to the Byway Babes, for proving anything is possible, and for your incredible generosity and support. We hope you are getting some much deserved rest!

To follow the Byway Babes journey through their blog visit bywaybabes.com

JEAN'S STORY



Jean Carr at 65 years old

Jean Carr was born in Ottawa in 1953, the youngest of ten children. Having just reached 65 years of age, he is now officially a senior citizen living with cystic fibrosis.

Jean grew up in a time when little was known about cystic fibrosis, and he lived the majority of his life without a diagnosis. He attributes his longevity to his mother's instinctive understanding of how to care for her undiagnosed CF children, his active lifestyle, the support of the Ottawa CF clinic and the support of his wife.

Jean's parents lived through the intense heartbreak of losing six of their ten children. Five of the children passed between 1939 and 1952. Seven of the family's children are believed to have had CF – although Jean and his sister Lucille were the only children officially diagnosed in later years. Jean's three eldest living brothers do not show signs of the disease.

Sadly, the family lost twins shortly after birth in 1939, one year old George in 1941, Hélène aged six months in 1943, and most devastatingly Françoise age four years in 1952 and Lucille at 32 years in 1981.

When Jean was 18 months, he was hospitalized for an "unknown disease" and fell into a coma. Doctors miraculously installed tubes in his back to drain his lungs and administered a new antibiotic which ultimately saved his life. He bears the scars of this operation to this day.

Jean's mother noticed similar symptoms in many of her children and ultimately came to believe six passed away from CF related causes. Jean's mother knew instinctively than Lucille and Jean's health would be bettered by a determined effort to live a healthy active normal life in spite of obvious breathing issues. While at the time she did not know her children were dealing with cystic fibrosis, she identified lifestyle rules that would help Jean and Lucille live relatively healthy lives.

Jean's mom realized that clearing mucus by any means necessary was vital to her children's lives. She was a champion of clearing; determined, unrelenting, and instinctively believing this was a crucial part of her children's treatment. She also required that her children eat a variety of healthy foods, get up early every day, be physically active, pray for God's help continuously.

Jean's sister Lucille, in the center, graduated with the second highest average of her High School graduating class

Jean's older sister Lucille was diagnosed with CF at the age of 24 in 1973. As a result, Jean was tested repeatedly, but his sweat test always came back negative. Jean was diagnosed with cystic fibrosis through DNA testing at the age of 43 in 1997. Lucille was happily married to a wonderful supportive husband and gave birth to two children after her diagnosis, while fighting cystic fibrosis. At the time of her son's birth, the family was told that Lucille was the first in Canada to have done so with cystic fibrosis. Lucille fought the good fight, especially balancing her time in hospital with the kids riding on the I/V poles up and down the halls of the hospital.

While Jean notes that ignorance was bliss, he realizes that he has been lucky to have lived such a relatively healthy life. Living for so many years with undiagnosed cystic fibrosis, Jean attributes his longevity to his lifestyle rules his mother instilled in him.

ENCOURAGEMENT TO CLEAR

One of Jean's earliest childhood memories is of his mother giving him a cloth handkerchief or five tissues, with strict instructions to use them whenever he felt like coughing throughout the day. Jean only saw adults with cloth handkerchiefs, and was delighted to carry and use them. He felt like a grown-up. His mother would collect the soiled handkerchiefs and wash them, iron them, and replace them in his drawer. Over time, as he grew older and more aware of his surroundings, he began to notice that he coughed and cleared much more than other kids. At the time, he did not think he was odd or different, it was just the way things were.

WALKING THREE MILES A DAY

From grade one to grade eight; Jean would walk to and from school, a total of three miles per day. By grade eight, Jean could run the entire mile home in seven minutes. He believes that this regular activity helped to prolong his life.

GET OUTSIDE AND PLAY!

Jean remembers his mother instructing him to "Get out of the house and get some good clean air in your lungs," and in the winter, she would say "Get out of the house and get some good clean COLD air in your lungs." Television was not allowed during the summer months, instead Jean spent his time challenging neighbourhood kids to games of baseball, football, tennis and enjoying activities such as biking, swimming and canoeing.

NO SLEEPING IN – EVER, EVEN WITH A FEVER.

Growing up, Jean was never allowed sleep in on weekends or holidays and not even when he wasn't feeling well. His mother reasoned that getting up and moving around would increase circulation and help his body fight. Today, we know that movement inspires and facilitates clearing. To this day, Jean still makes a point of getting up and moving early, even on days when he doesn't feel like it or when not feeling well.

EATING A VARIETY OF FOODS

Jean's family had two steadfast practices concerning meals. One was eating at regular times and the second was eating a variety of foods. Jean fondly remembers his mother telling him that different foods contain different vitamins, and that he needed a variety of vitamins to be healthy. In the winter, she would supplement his diet with vitamins and cod liver oil. Again, Jean's mother's intuition was ahead of the medical industry. Today, it is known, a diet with a variety of vitamins is standard care for individuals with cystic fibrosis.

STAY HYDRATED

Jean's mother would instruct him to drink a glass of water during coughing fits. She would say that the water would help to liquefy whatever it was that was trying to get out. She would also encourage Jean to drink water regularly to stay hydrated.

SALTY AIR IS GOOD FOR THE LUNGS

Jeans family regularly vacationed in Florida for two or three weeks a year. Jean and Lucille realized they felt much better during those trips. Looking back, Jean notes that breathing salty air must have acted in a similar manner to a present day salt water nebulizer.

Jean at 31, before his CF diagnosis, with his wife on vacation in Freeport, Bahamas

BEING A SILLY KID

Jean recalls that when he was a youngster, he often played a game in which he would hang upside down, his hips and legs on his bed and his head on the ground. On his back face up, he would bounce a ball against the wall. On his stomach face down, he would also play a game alternating between breathing heavily and holding his breath for as long as he could. He remembers both of these games would often result in massive clearings. His lungs would feel tired afterwards, but his breathing much easier.

Jean's parents always tried to ensure that he was active, including chores at home and enrolling him in sports such as skiing. Jean and his siblings were always on the go. When Jean was 19, his summer job as a breakman at a paper company was in a hot, humid and steamy workplace. The summer of strenuous work in hot humid and steamy air resulted in lots of lung clearing likely contributing positively to his lung health.

As a young adult Jean continued his regular daily activity. From swimming, canoeing, waterskiing, biking and running long distances, he was always on the move. He also played hockey two evenings a week, ensuring his physical activity level was maintained during the winter months.

LIFE CHANGING DECISION

In his late 30's, he stopped most physical and sports activity as part of his daily life. He was transferred to jobs in California and then Paris, all the while living with undiagnosed CF. Progressively over this time he began to notice that something might be wrong. He thought he was just getting older and was out of shape.

When he moved back to Ottawa from Paris, his health had noticeably deteriorated. He could not, for example, waterski for even one minute. While mountain biking, he could no longer peddle up hill even in the lowest gear. He could no longer walk up hills of any steepness without stopping, and couldn't downhill ski without stopping to catch his breath every 30-60 seconds. Referred to a Respirologist, a DNA test was ordered. At 43 years old he was diagnosed with cystic fibrosis.

After the diagnosis his lung function continued a slow decline and he was evaluated for a lung transplant. He attributes the Canadian medical system and the Ottawa CF clinic for saving his life. Jean's medical team was tireless, passionate, compassionate, skilled, unrelenting and positive. He also recognizes the efforts of his supportive wife who, always with compassion, helps him maintain an active lifestyle, his therapy and healthy varied diet. His lung function stopped declining and in fact improved somewhat to the point that a transplant was no longer being considered. His lung function has been stable for over 15 years now. He says that his life expectancy is no longer short, but only if he takes care of himself.

Jean believes that his life-changing mistake of stopping his physical activity as part of his daily routine almost cost him his life. In a few short years, he went from playing hockey to barely being able to walk up a hill. 'Sitting is the new smoking', Jean likes to say, and it cannot be truer than for him as a CF patient.

Jean believes that he must exercise, and he must exercise more than the next person. In his experience, his early lifestyle of continuous, extreme sports and exercise masked his CF and the fact that his mother had figured out many aspects of CF.

JEAN'S ADVICE TO ANYONE LIVING WITH CYSTIC FIBROSIS?

Don't repeat my mistake of stopping an exercise oriented active and healthy lifestyle. In my case stopping was an involuntary mistake, but a mistake nonetheless. Never stop fitness training, sports and exercising. Damn the torpedoes! Choose and maintain a super active lifestyle.

TOUGH TALIA

Speaking with Talia D'Alessio feels like chatting with an old friend. Her warmth, ease, and openness is immediately apparent, and characteristic of a Nova Scotian. "I was diagnosed at nine months old," she says, cutting straight to the chase. "Mom and dad had no idea it was in the family. They had a son before me, my brother who passed in infancy, and it is likely he had CF as well," Talia recalls. "Mom said I was eating everything in sight, and I was breathing pretty heavy through the sinuses where sometimes it even seemed blocked." Talia's diagnosis led her to regular visits at IWK Health Centre with Dr. Gillespie, whose approach to medicine and care helped her build strong lungs and a strong immune system. "I didn't live in a bubble."

Talia's love for her parents, Andrea and Fred, and sister Jillian, is palpable. You can hear her smile through the phone when she talks about them. She credits them for her good health today and for establishing healthy lifestyle habits, "Had my parents not pushed me to stay in sports, I don't think I would have the enrichment and life that I do today. I know my parents made sacrifices for me and did everything to ensure I was healthy. The CF treatments can be long and enduring at times. However, I have so many fond memories."

Talia recalls summers spent at the 'downover,' and wonderful Christmas traditions; she speaks sweetly of her mom making up funny songs on a day home sick, and her dad never missing her sports events. "Dad used to take me 'truckin' to spend quality time together, and we would sing along to our favourite oldies songs. Unconditional love and support are my biggest takeaway from my parents."

Her sweet childhood memories are made sweeter by the relationship with her sister Jill. "She's my best friend. No matter where Jill and I are in our lives; whether she was off paddling and doing great things at the Olympics, or studying hard in law school, or when I was off coaching or building my career and family, we've always maintained our connection. Sisterly love is the best, if you know what I mean! And when it comes to my CF, she is the easiest person to talk to."

Talia found paddling as a method of exercise and therapy at a young age. For 10 years, Talia trained two times per day, sometimes for four hours at a time, leading her to competing at the Nationals. She loved the feeling of being on the water. Paddling became one of her first loves, offering her a form of therapy, an education in competition, and pushing her to become an elite athlete. Paddling is a hard sport that's strenuous on the body and lungs. While the deep breathing helped open up her airways, seeing other athletes make gains that she had to work twice as hard to achieve was very difficult. Frequently, Talia would have to take time away to be hospitalized, be on IV antibiotics or do CF physiotherapy treatments, "It was like having to restart and try and catch up each and every time."

At the end of high school, Talia's health took a turn and she got really sick. "CF can really settle in when it wants to. It's unpredictable, intrusive, and inserts itself into your life. I am so lucky that I have such a great support system." She remembers going to university and putting her treatment and health maintenance on the backburner. "I didn't want the "pity look" or people treating me differently," she recalls. She craved normalcy and as a result, sacrificed the health she had worked so hard during her younger years to build. "I was going down a really dark road. I remember thinking, how much time do I have?"

And then came “a godsend,” as Talia’s sister Jillian described it. At age 21, Talia discovered that she was pregnant. “I was told motherhood might not be in my plan.” The pregnancy rerouted her life in the best way possible, helping her get back on track to focusing on her health and giving her a sense of purpose. She knew her life was going to change, and she had to change with it. She had to set an example and wanted to be around for every pivotal point in her daughter’s life. “I wanted to make sure I was there for her wedding day.”

“My daughter Mia is 16 now, and we’re very close. In a way, I kind of think she’s my soulmate. She calms me, and when I’m feeling anxious or high-strung, she grounds me. Me having CF is the norm for her, she doesn’t see it as anything different. She’s so mature, sometimes she’s like “Mom, did you take your pills?’ I also have a six year old, Jacob. He’s beautiful. He’s magnetic and cuddly, and he definitely keeps me busy! Jacob doesn’t like when I am doing CF treatments and needs to be cuddled right in next to me doing my mask, but he is starting to learn more and sees it for the most part as the norm. I feel even more reason today to be here longer, which gives me even more drive and motivation.”

After completing her Dalhousie Arts degree, where she received full scholarship from the Terry Fox Humanitarian Award, Talia successfully completed an advanced Public Relations diploma. Since then, she has carved out a career in real estate, a job she’s grateful for as it gives her plenty of flexibility and balance to maintain her health. There have been times she’s been hospitalized and on IV, and while the uncertainty takes a toll, she’s always grateful she is employed somewhere she has the freedom to have that time or create a healthy balance.

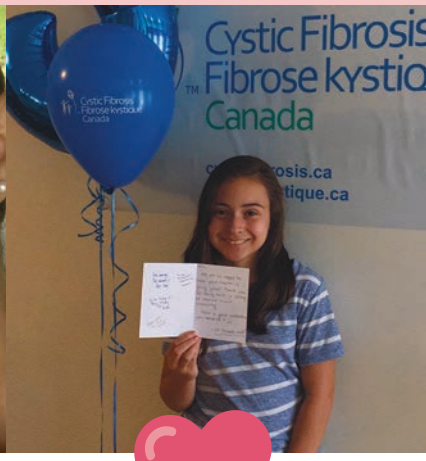
Though she gave up paddling, she returned to fitness throughout the years. Most recently, Talia has found a new passion: Crossfit. She began working out at a Crossfit gym over a year ago, and while she finds it challenging, she loves the sense of community and competing against herself.

She volunteers with the Scotia Chapter when time permits, participating in speaking engagements sharing her story and along with her sister collaborated and established the Kiwanis CF Dragon Boat festival. “I like giving back to the community in many ways, but sometimes being involved with the CF side of things is hard. It starts to consume me after a while. It hits close to home, so sometimes I need to take a step back.” Talia notes how CF is an invisible illness, and while she and others may sometimes look healthy, the true impact of the disease isn’t always visible and it’s important to treat everyone with kindness and compassion.

Talia and her family have truly settled into a routine, CF and otherwise and have also developed a love for travel. Each year they travel south, and they also live on a lake in Middle Sackville where they spend most of the summer where she kayaks with the kids, swims, paddleboards and water skis – her love for the water didn’t end with her paddling career. Last year, she went with her mom and sister to Spain, England and Scotland. “I want people to know that I am not missing out. I aspire to do many things, and I have, but I have priorities and these change depending on the status of my health.”

A lesson Talia has learned in her journey is staying true to herself and her needs. She’s learned and accepted that sometimes disappointing others is a part of doing what’s best for her. “While building my healthy lifestyle, it may look to someone as though I am missing out, but my decisions are always based on how I am truly feeling. I may be home taking antibiotics, doing my mask and physio and then choose to go for a workout. That may mean I miss out on a friend’s gathering, but I always have to take into account how I feel and what my long term goals are.”

“After years of trying so hard to keep up with friends and everything, I now know my body very well and I keep very in tune each day to it. I wake up each day and always take a few minutes for myself. I set my intentions and meditate each morning, some days need more time than others, but I always make time to do this. Along with having my children, it really has helped me to feel grateful for everything, for still being here and being able to share each day with the people love. My life is now so much more enriched with a real sense of being.”



MAMMA & MIA

Melissa Gaudenzi remembers the day her daughter Mia was born like it was yesterday. It was October 13, 2006 in Toronto, and her life changed forever when she welcomed Mia, her bundle of joy, to the world.

Mia was a healthy and happy infant. Suspecting that her daughter had cystic fibrosis was the last thing on Melissa's mind because Mia showed no signs of illness and was thriving. But that all changed when Mia was about three years old and started getting really sick.

There were lots of back and forth visits from the hospital. Doctors wondered if maybe Mia's new interaction with other kids at junior kindergarten was the culprit of the sudden change in her health. "Something doesn't seem right. Kids shouldn't just *get* pneumonia," Melissa remembers thinking.

Call it mother's intuition, but Melissa was certain something was serious, and knew she had to get to the bottom of it. Melissa started doing her own research and discovered the basic symptoms of cystic fibrosis. Something suddenly came to mind; Melissa remembered all the times that her own mother would kiss Mia and say, "You're so salty!"

Mia's birth date meant that they had just missed the implementation of newborn screening for CF, so Melissa called the closest CF clinic to explain her daughter's symptoms and arrange a test. After a rollercoaster of an experience over a year and a half, it was confirmed through a blood test that Mia did in fact have cystic fibrosis.

Over the next three years, Mia was in and out of the hospital. Admissions to SickKids became the norm, and a common cold would jeopardize any stability in her health. Melissa decided to begin homeschooling Mia, as it gave them more flexibility to maintain Mia's health and treatments, as well as her academics. "Mia wasn't born doing all the physio. What surprised me was how she just *took* to it. She doesn't ask questions when we change something, she's so accommodating. She never misses a day!" Melissa recalls.

Just after Mia turned seven, her health stabilized and began "clearing up." Her lung function is now at a whopping 91%, but that wasn't without plenty of admissions and continuous work. A special tradition that Melissa started for her daughter, is that each year Mia is admission-free, her family and friends have a celebration for her. Melissa thinks it's important to be reminded of how far they've come, how well they're doing with therapies, and to celebrate the little things.

"Every year that she passes one year, we do a little celebration! We order food and invite some family over. We recently celebrated her third year admission-free, so we decorated our home and ordered cupcakes! We had a movie night and made it a big celebration," says Melissa. "It may not always be three years admission-free like it is right now, so we need to celebrate where she's started to where she is now. We need to celebrate CF, even though it's taken so much from us."

With Mia's health currently stable, Melissa has hope for her daughter's future. She hopes that anything Mia wants to do in life, she does. Mia has dreams of going to Paris, and of one day becoming a nurse, so she can help others the way her healthcare teams have helped for her. "No matter what CF has taken from us, or no matter what CF brings us, I hope that she's still able to do what she wants to do," says Melissa. "I hope that someday, we get something that's close to a cure, so that life won't be so hard to her, for all the others with CF, and their families as well."

FAMOUS SEAMUS

My name is Amy Labonte, and I am a mom; a CF mom to be exact. So, I guess I am a lot of things. Depending on the day I am a doctor, or nurse, a pharmacist or a physiotherapist; a fundraiser, a homemaker and a chef, and a best friend and confidant – to my incredible eight-year-old son Seamus, *Famous Seamus*.

We live in Whitehorse in the beautiful Yukon Territory; home of the northern lights, the famous Dawson City, the world's smallest desert, the largest collection of stolen property in the world: The Signpost Forest in Watson Lake, and many selfless people who give their time to help us in our journey to a cure for cystic fibrosis. Though fairly small, and in the winter, very cold, life in the Yukon is special. The people are hospitable and fun, the vibe brings people from around the world, often leading visitors to make the Yukon their home; and the healthcare system, though in need of some touch ups, leaves me feeling grateful every month on medication pick up day.

I was born in Watson Lake, and though the last 31 years have brought me many places, the Yukon has always been my home, which is why, just over eight years ago I decided to have my son in the Whitehorse General Hospital. Surrounded by friends and family, Seamus came into the world at 7:00am, on Super Bowl Sunday, weighing almost eight pounds, and barring some unexpected complications, other than the fact that he was not the girl we had planned on him being, he was perfect.

Every day for 15 days after his birth I marvelled at how easy it all seemed; motherhood that is. He ate well, slept well, and other than being just a tiny bit yellow, I had no concerns. For 15 days I got to live a dream that before then, I didn't even know I had had.

Seamus was diagnosed with cystic fibrosis through the Newborn Screening Program, which had been implemented in the Yukon not long before he was born. That small drop of blood drawn shortly after he had been weighed, measured, and cleaned up changed our lives forever. The pamphlet the doctor shoved into my hand while muttering 'your baby has this' made me realize that those previous 15 days of perfection were all we were going to get.

Prior to Seamus' diagnosis I had only seen the commercials for "Drowning on the Inside" on TV. In addition, I had heard people talk about cystic fibrosis and I was sure that there was a CF connection in my hometown of Watson Lake; but the only thing I could remember with clarity was that it was fatal.

The six months following the diagnosis were a blur. We travelled to the Children's Hospital many times to have genetic testing done, sweat tests, blood work and a myriad of other tests so that the doctors could establish a baseline for his health status. Walking the halls of BCCH, and the streets of Vancouver, I felt powerless; I felt like we were at the mercy of cystic fibrosis and I

didn't have a clue on how to fight it or if I had strength enough.

Our fundraising efforts began in the summer of 2011. Seamus' aunt Shelagh and I started making handmade purple rose ribbons; we called it "Bring Around the Roses", and we raised almost $5000 selling them to family, friends, and on social media sites. The feeling of a lack of control powered our efforts, and we donated the initial funds raised to the CF clinic at BCCH. It was an amazing feeling, a sense that we were making a difference, feeling like maybe CF didn't have control over us after all. The following winter Seamus was ill often. He seemed to pick up every bug, virus and bacteria we happened across and my initial sense of purpose gave way to sleepless nights, hospital stays and learning to administer new treatments and therapies. Thoughts of fundraising escaped my mind, and it wasn't until early 2013 that Lauren Murphy, a friend and now avid CF Volunteer, came to me with Great Strides; a walk in support of cystic fibrosis research and care led by CF Canada, which happened every May all across the country.

I contacted Tracey who, at the time, was the Great Strides coordinator for CF Canada, and she gave us incredible information and support. In fact, everyone at CF Canada went above and beyond to ensure our walk was as successful as possible. And though neither Lauren or myself had ever held a major fundraising event before, we put our noses to the grindstone, rounded up as many more than willing volunteers as we could, and started putting the word out that Watson Lake would be host to their 1st Annual Great Strides walk that May. With online fundraising pages, door-to-door collecting, and selling our one-a-kind Yukon Great Strides tee-shirts, Watson Lake, our town of scarcely 900 people raised $12,000 that May! I remember sitting on my dad's couch that night after we had totalled up our numbers, crying. After two years of medications, taking in endless information, clinic trips, and holding down my baby while he screamed just so I could get his chest physio-therapy done, it finally I felt like we had taken a step forward. A step towards hope. A step towards a cure.

It was a beautiful thing, and our efforts did not go unnoticed. It didn't take long before Annie Markvoort, sister to Eva, found me on Twitter and sent me a direct message with her contact information at Cystic Fibrosis Canada. After a tear-filled conversation with Annie, I found myself agreeing to represent the Yukon at the upcoming, nation-wide Volunteer Engagement Conference (now called the Volunteer Leadership Forum) to begin discussing furthering our awareness and fundraising efforts. I left Toronto after that weekend feeling more inspired than ever. At the conference, I had been asked about our fundraising goal for the following year. I had replied, feeling confident with the number of volunteers, friends and family that had participated in our fledgling efforts, that we had decided we would reach for $25,000. Under the guidance of, and with the unwavering support provided by CF Canada staff, the Yukon was quickly deemed a National Chapter. We formed a Board with myself elected President, and then we were off running into our second year of fundraising. Late nights, hundreds of brainstorming sessions, and countless hours put in by our core volunteer group led us to what would be our highest fundraising year to date. That was the year we decided to hold not one CF walk, but two. One walk in Watson Lake headed by Lauren and my sister Erin, and one in Whitehorse, headed by my Whitehorse team. The walks were held on separate days, with many of our volunteers and supporters commuting to attend both. I don't think any of us had slept in a number of weeks leading up to our events, but our efforts paid off. The 2nd Annual Yukon Great Strides Walk, now the Walk to Make Cystic Fibrosis History 2014 was a success, bringing at least 200 participants in each location, and raising a total of $42,000!

Though our chapter has given me so many things to feel grateful for, my most treasured gift is the sense of community. When Seamus was diagnosed I felt so alone, so isolated; like there was no one out there who could ever understand. Part of me felt ashamed, like maybe I had done something to make him sick, and a part of me, a big part, felt like I had to be strong for Seamus, for everyone.

Every day he wakes up and he fights a battle that many people would be scared to face. He does it with grace and kindness, and an unwavering strength.

I suffered alone for a long time, not wanting to bother anyone with my worries, not wanting to look weak, not wanting to feel weak, but the time came when I knew I couldn't handle it all on my own, and so I reached out. I found a friend in Kelly Kearns, Watson Laker, mom to Avery who is also living with CF. She is the designer of our Yukon Great Strides t-shirts, and an all-around incredible soul. We bonded over our hatred for CF and our similar and morbid sense of humour. Just having someone who I didn't have to explain things to, who I could cry to, someone to just hold my hand when things were bad was a game-changer. I don't think she knows it, but she saved my life.

The support we have found within our CF community, as well as our local community has been nothing short of astounding.

Seamus just turned eight. Every day he wakes up and he fights a battle that many people would be scared to face. He does it with grace and kindness, and an unwavering strength. It's been almost two years since our last hospitalization and, other than a smattering of bugs here and there, this is the longest he's ever been this healthy. People always say how lucky we are; but luck has little to do with it. We work hard. HE works hard. He is aware and diligent, and faces CF head-on every single day with a strength I envy.

He poses for pictures and records radio ads and talks openly about his illness. "Anything to help get to cure," he says strongly. He's confident that he will see a cure in his lifetime, and once he sees that cure, he looks forward to spending time with Avery, and not having to do breathing treatments.

Now, with more hope than ever, we are looking forward to the future, and all the wonderful things it will bring us. Seamus is excited to grow up and pursue his dream to be a police officer, or a scientist, or an engineer who builds robots. Me, I want to see him graduate highschool, college and university - if that what he wants. I want to see him travel the world and chase his dreams; I want him to reach his full potential, but above all else, I want to see him happy.

We've come a long way in the past eight years, and we still have a long way to go. But with the unwavering support of our friends, and family, volunteers, and donors; we have hope.

ALEXANDRE LEVERT: **SPORTS AS THERAPY**

CF Canada: Hi Alexandre, can you introduce yourself briefly?

AL: My name is Alexandre Levert, I'm 15, I live in Montréal and I attend Beaubois College in Pierrefonds. I am very sporty, and I am very involved in everything I do. I love music; I have played piano since elementary school and clarinet since high school.

CF Canada: When were you diagnosed with cystic fibrosis?

AL: I was diagnosed shortly after my birth. I spent three weeks in the hospital when I was born.

CF Canada: What is life with CF like?

AL: In terms of treatments, I do not have many compared to others, but it becomes tiring in the long run. I have to do a treatment every morning when I wake up and take five enzymes with each meal. In the evening I do another treatment that is very similar to that of the morning. I also take a lot of vitamins, and every three months I have a checkup at the hospital.

Cystic fibrosis does not stop me from doing much. I have very good lung function. I am healthy. My lung function is so good that last summer I stopped being disciplined and diligent with my treatments. As a result, I was admitted to the hospital for seven days. This is when I learned something very important: if you see you're doing well, continue your treatments. That's what keeps me healthy. That, and sports.

CF Canada: What are your passions?

AL: Sports are my greatest passion, I have always moved a lot. When I was little, Dr. Lands from the Montréal Children's Hospital told my dad that swimming helped the lungs a lot - my variation of CF mainly affects the lungs. So I did all my juniors in swimming. I even did competition from eight to 12 years old.

Until recently, I was playing Water Polo in the Ahuntsic Camo team, which is a national team. In fact, two years ago, I took part in the Canadian championship. I am currently on the Espoir team in speed kayaking for Canoe Kayak Quebec. With school, kayaking and all the practice that it entails, I had to make a choice and I left the Water Polo team of which I was captain. In addition, during winter, I am also in the Mont-Tremblant acrobatic skiing team. I mostly do mogul skiing.

CF Canada: How have sports changed your life?

AL: I realize that to be as healthy as I am, sports are major. It is largely physical activity that keeps me healthy.

Two years ago, I had a concussion and had to stop sports for a month and a half. Well, at the end of this period my lung function had dropped. Not much, but still. I am sure that if I had stopped longer my lung functions would have continued to drop slowly.

Sports allow me to take away stress, pressure and think of something else. Besides, I'm good at school and I have a lot of concentration. It's also a way to see my friends and make new ones.

CF Canada: Which sporting achievement are you most proud of?

AL: What I am most proud of so far is my qualification on the Quebec kayak team. It's not easy, they only take the top five in each category. Last year I finished fourth in Quebec in my category and fifth in the category above.

Kayaking is what I like most! Next April, I'm going to Portugal for two weeks to train. My goal is to go to the Canadian championship. Last year, I missed the qualification by one hundredth of a second to go there. This year I want to succeed.

CF Canada: What would you like to say to people who support CF Canada?

AL: Thank you very much for the money you donate. This money goes to research and thanks to that, today, we have been able to develop incredible drugs that make people with cystic fibrosis live longer and as normally as possible.

CF Canada: And what would you like to say to teens like you who have CF?

AL: For me, the way to stay healthy is sports. Don't give up! We must accept that we live with the disease. When we accept it, it's a lot easier.

CARSTAR RAISES HIGHEST ANNUAL AMOUNT IN ITS HISTORY TO **HELP FIGHT CYSTIC FIBROSIS**

CARSTAR, North America's leading provider of premier collision repairs, exceeded its annual charitable goal by raising over $500,000 for cystic fibrosis research, care and advocacy.

The CARSTAR network, its vendor and insurance partners as well as the communities it serves have all helped the collision repairer surpass its goal. Car washes, ball hockey tournaments, gala events, golf tournaments, silent auctions, charity walks and car shows happen all year round with proceeds going to both Cystic Fibrosis Canada and the Cystic Fibrosis Foundation in the United States. Helping CARSTAR hit the monumental number this year was a significant showing of generosity at its annual North American Momentum conference.

"CARSTAR and its partners are a shining example of the impact that can be made through corporate philanthropy," said Kelly Grover, President and CEO, Cystic Fibrosis Canada. "In a single evening at its annual gala, CARSTAR raised an incredible $200,000 – this is in addition to CARSTAR's year-round unwavering commitment to ending cystic fibrosis. The funds raised by CARSTAR will help us get one step closer to finding a cure for this disease and on behalf of those living with cystic fibrosis, thank you for your generosity and dedication."

CARSTAR began fundraising for cystic fibrosis (CF) in Canada over 20 years ago, when a franchise partner's granddaughter received a cystic fibrosis diagnosis. Since then, the CARSTAR commitment to its charity of choice has only grown, as have the funds raised. CARSTAR has raised close to $3.7 million in Canada and looks to continue accelerating its fundraising momentum in the U.S.

"Our commitment to fundraising for cystic fibrosis research, care and advocacy runs deep within our corporate culture at CARSTAR, as many of us have heard touching stories from families and those affected by cystic fibrosis first hand," said Michael Macaluso, President, CARSTAR. "To say that these stories are motivating would be an understatement, because the strength demonstrated by these individuals is unimaginable and we want to do what we can to help make the fight against CF a little easier for them."

CARSTAR invites you to contact their franchise partners, to share your CF story and see how you can work together to grow their 2019 fundraising efforts. Visit CARSTAR.ca to find a CARSTAR location near you.

THYSSENKRUPP ELEVATOR CANADA

Blaine M. Coupal, President and CEO, thyssenkrupp Elevator (Canada) Limited

thyssenkrupp Elevator Canada and its branch managers celebrated the end of their 2018 fundraising campaign at their annual national meetings this past October in Vancouver. They certainly had a lot to celebrate, surpassing last year's goal in raising over $142,000. Additional festivities included bidding farewell and recognizing Ryan Wilson, former President and CEO, for his outstanding leadership in rallying employees, suppliers and customers to join him in raising awareness and funds for those living with CF.

Cystic Fibrosis Canada is pleased to welcome the new President and CEO of thyssenkrupp Elevator Canada, Blaine Coupal to the CF community.

"In October 2018, I became President and CEO of thyssenkrupp Elevator (Canada) Limited. One thing I knew for certain was thyssenkrupp needed to carry on the fight to find a cure for cystic fibrosis.

Our employees, customers, and vendors have stepped up time after time, breaking every fundraising goal we set, and remain committed to this cause by coming up with innovative ways to raise money. It is an empowering feeling knowing that you are making a difference in the lives of so many that suffer from this disease, as well as giving you a greater appreciation for your own good health.

I am so proud of the group of people I work alongside, and I look forward to seeing what we as a company will achieve this year. This fight isn't finished."

THE 2018 NORTH AMERICAN **CYSTIC FIBROSIS CONFERENCE**

Cystic Fibrosis Canada representations at NACFC 2018

The North American Cystic Fibrosis Conference (NACFC) is the largest event of its kind, bringing together physicians, nurses, researchers, multidisciplinary healthcare providers, and others connected to the delivery of care to those with cystic fibrosis. The NACFC took place from October 18-20, 2018, in Denver, Colorado, and was attended by over 5,000 delegates, the largest attendance in the Conference's 32-year history. With representation from over 40 countries, the scope of the Conference extends well beyond North America, demonstrating the international effort to combat this disease.

Cystic Fibrosis Canada's partners are committed to helping us realize our vision of a world without CF. It was invaluable to spend time with our colleagues from across the country and our dedicated sponsors Mylan, Vertex and Horizon Pharma helped to make it possible.

Mylan — Better Health for a Better World

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HORIZON THERAPEUTICS CANADA

With educational components, plenary sessions, workshops, poster presentations, and round-table discussions, the NACFC provides an opportunity to showcase the latest research findings, medications and treatment modalities, and it offers important networking opportunities for information exchange and sharing of best practices.

Along with the formal programming offered at the NACFC, Cystic Fibrosis Canada hosted additional meetings intended exclusively for the Canadian community of delegates. The purpose of these sessions was to support and promote the national network of CF caregivers and to provide education and information in an exclusively Canadian context.

The meeting of the Cystic Fibrosis Canada Nursing Advisory Group (CFCNAG) was attended by CF Clinic Nurses and Coordinators from across Canada. Presentations and discussion topics included CF and cancer; small colony variants; CFRD; along with presentations on the Canadian CF Registry's new *MyCFLifePortal*, and Cystic Fibrosis Canada's new transition program, CF S.T.E.P.

The Canadian Clinics Meeting is a highly-anticipated event, attended by clinicians and researchers from across the country. With the highest attendance yet, this year's meeting provided an unparalleled networking opportunity and a chance for CF Canada to connect with and demonstrate its support of all those who provide care to, or conduct research on behalf of those with CF. In addition to an introduction of Cystic Fibrosis Canada's Healthcare Advisory Council, presentations focussed on the Canadian CF Registry, and CF CanACT, Cystic Fibrosis Canada's clinical trials network. Case presentations in the categories of nursing, nutrition, and airway clearance generated much valuable discussion, all with an aim of exchanging ideas about ways to improve the health and quality of life for those with CF.

At NACFC, Cystic Fibrosis Canada met with our international peers focused on the care and treatment of CF, including organizations from the United States, Australia, the United Kingdom, and several European countries. These interchanges highlighted the collaborative ties that Cystic Fibrosis Canada has established internationally, for the intended benefit of those with CF in Canada and beyond.

By providing funding to each clinic, through the Clinic Incentive grant program, Cystic Fibrosis Canada is able to ensure that Canadian CF healthcare providers are able to attend this important conference, ensuring that knowledge remains current and focused and that all those who deliver care have access to the latest information about all aspects of CF care.

A special thank you to our sponsors Mylan, Vertex and Horizon Pharma, for their support of the Canadian delegates and meetings at the 2018 North American Cystic Fibrosis Conference.

AN INTERVIEW WITH **KIN CANADA'S NATIONAL PRESIDENT, ERIN THOMSON**

Kin Canada has been supporting Cystic Fibrosis Canada since 1964, working together to create a world without CF. These amazing Kinsmen and Kinettes work together with CF Canada's Chapter volunteers towards a vision of a world without cystic fibrosis (CF). They are also meeting the community's greatest need through community service, leadership and partnership.

One of these amazing CF supporters for many years is Erin Thomson, hailing from the Kinette Club of Timmins. Her passion for the CF cause is evident through the local, regional and national level initiatives she organized or supported through her local club, her District and in her current role as National President. This Kin member is unstoppable and an integral part of her #BeUnstoppable vision is to harness the power of enthusiastic initiative and creativity—to truly live *possibility thinking*. She inspires volunteers to see the possibilities in every situation and to put their passion into action for change in their community.

Erin is currently on her National President Tour of Canada, and we were able to catch up during her eventful schedule for a quick interview.

CF Canada: What's your involvement with CF Canada?

ET: I have been a Kin member for 15 years and have fostered a relationship with our local CF families and our National CF family through fundraising efforts locally, provincially, and nationally. As the current National President I am honoured and privileged to represent the thousands of Kin members who have made it their mission to find a cure or control for CF over the past 55 years.

CF Canada: What has been the greatest highlight of supporting CF Canada for you?

ET: In 2012 as a Service Director for District 8, my husband and I conceived of what many believed was a 'crazy idea' to celebrate two things that were happening at the same time: the 48th anniversary of the Kin/CF partnership coinciding with the 2011 registry median age of survival which was 48.5 years for our CF warriors. We pledged to kayak 480 km along the wilderness of the northern shore of Georgian Bay in late May to raise funds and awareness. We paddled every kilometer over 13 days. Sadly we fell short of our monetary goal, but in the end still raised $37,000 to end CF. In that endeavor, the training, the fundraising, the planning and logistics, with a few harrowing camping and paddling situations thrown in for excitement, we made many contacts within the Kin/CF family that we are blessed to call lifelong friends. We are wholly better humans because of this experience.

CF Canada: What does the 55 year partnership milestone between Kin Canada and Cystic Fibrosis Canada mean to you?

ET: I feel: amazed by the *possibility thinking* of Kin Bill Skelly and fellow Kin to see an opportunity for us to make a true difference in the lives of so many; impressed at the wisdom of Ian McClure and fellow Kin who put their passion into action and persevered to make CF Canada a Kin Canada National Partner; pride in the countless hours and $47 million raised by Kin who consistently choose positivity on the path in finding a cure or control; and a deep sense of commitment as a leader in Kin Canada to inspire, encourage, and build other leaders to continue the fight until we are victorious!

CF Canada: Why do you think it's important to support CF Canada?

ET: The hope we all feel as a result of the funds raised and the work done to date is tempered by the knowledge that we still lose CF angels well before we should; that families and CF warriors live with uncertainty and in fear of the next infection; that secondary medical issues plague our adult CF population due to the ravages of this disease. We are not done....YET!

CF Canada: What will #aworldwithoutCF mean to you?

ET: A celebration like no other knowing that the fear of this diagnosis will be eradicated; families will have hope in the future for their children; there will be athletes, and artists, and weddings, and babies – all without the fear that it will all be taken away because of CF. There will be the sigh of true relief in the knowledge that they will breathe easy forevermore!

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THE INITIATION OF A **BEAUTIFUL 55-YEAR PARTNERSHIP**: A BRIEF HISTORY

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The friendship between Kin Canada and Cystic Fibrosis Canada began out of a conversation in 1963 between Dr. Crozier, Director of the cystic fibrosis clinic at the Hospital for Sick Children, and Kinsman Bill Skelly. During their chance meeting at a Toronto pub, Dr. Crozier spoke to Bill about his young cystic fibrosis patients. This conversation left Bill interested in joining the fight against cystic fibrosis, and Dr. Crozier was invited to talk to the North York Kinsmen Club. Almost immediately, the North York Kinsmen enthusiastically backed the cystic fibrosis cause.

By the spring of 1964, at a District Executive meeting, Ian F. McClure and Bill Skelly from the Kinsmen Club of North York proposed that District 8 adopt Cystic Fibrosis Canada as its District Service Project. By this time, Dr. Crozier was recruited to speak at multiple Kin clubs, showing a very heart-wrenching video about the devastating effects of cystic fibrosis. The District Executive agreed that cystic fibrosis research was a deserving cause to whole-heartedly support and to promote awareness of in the District 8 community.

There was a proposal put forth to have CF as a National project at national convention that same year; however, unfortunately, the motion got rejected. Nevertheless, this did not stop a determined Ian. F. McClure from travelling the country from District to District to convince various Kin members to adopt CF as their District project. Kin Ian's commitment to creating awareness for CF across the eight districts was successful; over the years, district by district, they came on board. When all eight Districts came on board, a motion was put to national once again, and this time it was carried. In 1987, Kin Canada officially adopted cystic fibrosis as its National Service Project.

55 years later, the partnership is stronger than ever, and together, Cystic Fibrosis Canada and Kin Canada will continue the fight against this devastating disease.

Kin Ian McClure presents $50,000 from District Eight to CF patients Andrea and Kevin Taylor.

CF Chairman George Woodhead and Governor Jim Vair watch as Kevin and his sister Andrea Taylor, CF patients announce that District 8 raised $46,000 for research. The autumn issue of Candid Facts will have the full story by Chairman George.

At the semi-annual meeting of the Kinsmen's clubs of District 8 held at Toronto's Holiday Inn on October 24th, Union Carbide Canada Ltd. very kindly loaned for exhibition purposes one of their "Linde" L262 oxygen tents. In the photograph Mr. R. R. MacDonald, Product Manager of the Medical Products Division of Union Carbide is explaining the operation of the tent to a group of interested Kinsmen. Left to right: Jake Brown, co-ordinator of the District 8 Cystic Fibrosis project; District Governor Jim Gartshore; Bill Skelly of the North York club; Union Carbide's Bob MacDonald; and Allan Studholme, Eastern Ontario Regional Director of the Foundation.

THANK YOU KIN CANADA

Kin Canada is the longest standing partner and has raised more funds for Cystic Fibrosis Canada than any other organization. Throughout this 55-year relationship, our Kin Club partners have pioneered hundreds of fundraising initiatives and awareness campaigns in an effort to find a cure or effective control for cystic fibrosis. Since 1964, Kinsmen and Kinettes have raised more than $47 million in support of Cystic Fibrosis Canada that has benefited those individuals living with CF.

The power of Kin is unstoppable and Cystic Fibrosis Canada is truly grateful for their efforts in the fight. Thank you Kin Canada for 55 years of dedication and commitment to ending CF.

LA SOIRÉE DES GRANDS CRUS

LA SOIRÉE DES GRANDS CRUS

On November 8, 2018, the 18th edition of La Soirée des Grands Crus took place at Le Parlementaire restaurant in Quebec City. The evening brings together Quebec's business community over great food and wine in support of Cystic Fibrosis Canada. The event has been speerheaded by Louis d'Anjou since the start, and now his son Simon d'Anjou has joined him as an organizer. Respectively, Louis and Simon are President and Vice President and General Manager at Groupe Sani-Tech. Louis' contributions to CF Canada are in tribute to his two sisters who lost their battle with cystic fibrosis. Thank you to Louis, Simon and Honorary Chairman, Marie-Christine Laflamme (E-Commerce Manager, South Shore Furniture) for their dedication! This event raised $80,000 for cutting-edge CF research, critical care and advocacy!

MARITIME TIME FOR A CURE

On Friday, October 12, 2018, Maritime Time For a Cure, a kitchen party with a purpose, took place at Murphy's on the Water in Halifax, Nova Scotia. The evening was filled with East Coast indulgences, including traditional Maritime food, drink and entertainment. While guests sipped on signature cocktails and tried to outbid others at the silent auction, games of washer toss, blackjack, and more took place on the patio overlooking the beautiful Halifax waterfront. The evening ended with one lucky guest winning a trip for two from the Air Canada Foundation. Local CTV Morning Live host, Cyril Lunney, played Master of Ceremonies for the evening that **raised over $27,000! Congratulations to the Cystic Fibrosis Canada – Scotia Chapter.**

Thank you to the volunteer committee and sponsors for making the event such a success.

The 2018 Fusion Gala was held on October 20, 2018 at Angus Glen Golf Club in Aurora. This year's Shamrock Shenanigans theme was a huge hit, and featured a special performance by John McDermott, as well as a surprise appearance from O'Malley the Leprechaun! The 300+ guests enjoyed an evening filled with authentic Irish entertainment, delicious food and wine, exciting live and silent auctions, our Key to a Cure auction, and included the fantastic Hugo Straney returning as the Master of Ceremonies.

Through the generosity of the many sponsors, guests and donors, **over $300,000** was raised for cystic fibrosis research, advocacy and care! Over the last 17 years, the Fusion Gala has raised an incredible **$3.1 million** in support of Cystic Fibrosis Canada.

We would like to recognize Bonnie Griffin for all of the time, effort, and energy she's put into building and Co-Chairing the Fusion Gala over the past 17 years. Bonnie, alongside her husband Steve, and sons Clint and Shane, has been instrumental in making Fusion a success year after year. We'd like to thank the Griffin family, as well as all of the committee members, organizers, sponsors, donors, and guests who make this such a wonderful event!

The 18th annual 65 Roses Gala presented by B2Gold, took place on Saturday, November 2, 2018. It was a magical evening which included a silent and live auction, entertainment, a special presentation, dinner and so much more. The talented gala organizing committee, along with the tremendous help of Kimbo Design, created an "Enchanted Forest of Hope" theme - which included floral decor, and forest-themed attire. The evening's Masters of Ceremonies were CF Champion and Sickboy podcast host Jeremie Saunders and CBC Journalist Gloria Macarenko. We'd like to congratulate Gloria for her recent appointment to the Order of Canada. We are so grateful for her contributions to CF Canada over the last 17 years!

A huge thank you goes out to all of our generous supporters for helping to create another unforgettable night and raising **nearly $300,000!**

65 ROSES GALA

Shinerama

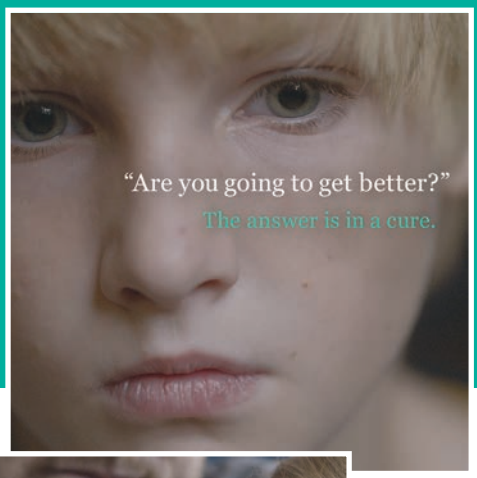
STUDENTS FIGHTING CYSTIC FIBROSIS

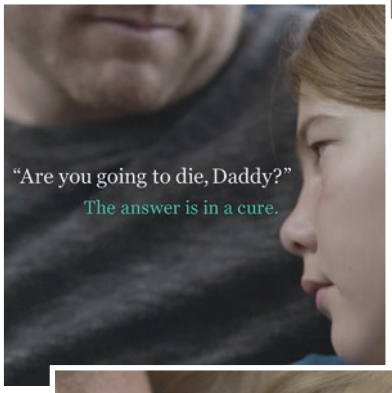
The 2018 Shinerama campaign was one to remember! Over 35,000 student volunteers from 39 Canadian universities and colleges across the country came together to make a difference in the lives of those battling cystic fibrosis (CF). Student volunteers all over Canada shined shoes, flipped burgers, washed cars, and even had an alpaca photo opportunity, to raise crucial funding for CF research and care. You'll notice the University of Saskatchewan's College of Rehabilitation had a special visitor at their Shine Day – **Prime Minister Justin Trudeau stopped by and said hello!**

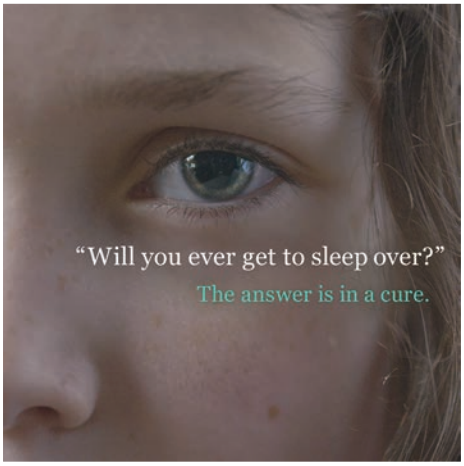
The 2018 campaign raised over $470,000 to drive CF Canada towards its goal of finding a cure of cystic fibrosis! The school with the **top fundraising amount was Wilfrid Laurier University – Waterloo Campus – the birthplace of the Shinerama campaign, raising over $100,000.**

Since 1964, Shinerama has raised approximately $28 million dollars for life-saving CF research and care. **2019 marks the 55th anniversary of Shinerama**, and the support we've received from the participating schools and students has been instrumental to advancing the battle against this devastating disease. We are so grateful to all past and present Shiners and will celebrate this milestone with an alumni reunion event in September. Stay tuned for more details!

CYSTIC FIBROSIS CANADA ASKS THE TOUGH QUESTIONS







On Tuesday, November 27, 2018, Cystic Fibrosis Canada launched its fully integrated holiday campaign: *Tough Questions*. The campaign featured questions that might seem simple, but the answers are complicated for people living with CF. The answers to the questions are in a cure.

"Having cystic fibrosis means more than health challenges," said Jennifer Nebesky, Chief Marketing, Communications and National Events Officer, Cystic Fibrosis Canada. "*Tough Questions* demonstrates the impact of the disease, the uncertainty it creates, and how a seemingly simple question is complicated when tomorrow isn't guaranteed. Our community doesn't live with the expectations of tomorrow; they take nothing for granted."

The fundraising campaign featured five Canadian families and individuals affected by CF. Ten-year-old Beckett Meyer wants to know if he's ever going to feel better. Anne-Sophie Barrette would love to have children one day, but doesn't know if she'll live long enough to realize that dream. Eight-year-old Ella McDougall hopes one day she'll get to say yes to a sleepover invite. Cindy Routhier takes pause when her three-year old daughter wants to know if she'll have to take pills when she's a grown-up. And 38-year old Jeremy Vosborough doesn't know how to answer when his daughter Daryn asks if he is going to die.

"Cystic Fibrosis Canada is at a critical moment in the fight to end this fatal disease," said Kelly Grover, President and Chief Executive Officer, Cystic Fibrosis Canada. "Through the generosity of our donors we have come so far, but too many questions still surround the complexities of cystic fibrosis. Support from our donors will help unravel the mysteries of this disease that we are determined to cure."

The campaign launched on Giving Tuesday, an international day of giving, and ran through January 2019. Donors experienced the campaign via a robust digital marketing, social media and direct mail strategy, and builds on the success of Cystic Fibrosis Canada's previous campaigns.

Thank you to everyone who supported the campaign and contributed to raising a grand total of almost $400,000 for CF research and care.

Cystic Fibrosis Canada
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