

# Connections

SUMMER/FALL 2017

▶ **JIM BEST**  
A 7000KM JOURNEY  
TO END CF

**INTRODUCING  
MITCH LEPAGE,  
CHAIR OF BOARD  
OF DIRECTORS**

**MAY AWARENESS:  
ADVOCATING  
FOR ACCESS**

**2015  
REGISTRY  
HIGHLIGHTS**



# TABLE OF CONTENTS

Message from the President and CEO .....	3
Introducing Mitch LePage, CF Canada Board Chair .....	4
Introducing the new CF Canada Board Members .....	5
<b>Hope Through Progress</b>	
Broken Arrow Conference Highlights .....	6
2015 Registry Highlights .....	7
New Research Impact Award Recognizes Cathleen Morrison .....	8
Introducing the New Jennifer and Robert Sturgess Fellowship .....	8
Study Finds Differences in Lifespan Between Canadians and Americans with Cystic Fibrosis .....	9
History is Made: Quebec Finally Implements CF Screening for Newborns .....	10
Access to New CF Medicines in Jeopardy .....	10
<b>Circle of Friends</b>	
Jim Best: A 7000km Journey to End CF .....	12
CF Strong Cup: Playing for Good .....	13
The Little Lemonade Stand That Could .....	14
Breathing Room .....	16
Transplants Require Organ Donors .....	18
Had We Only Known: The Jolin Family .....	20
The 24th Annual Mike Cassidy Legacy CF Golf Classic .....	22
#FUCF: The Hanna Family's Story .....	23
Dr. Patrick Daigneault, Placing the Patient at the Heart of his Practice .....	25
Lawn Summer Nights: Under The Stars and on The Green to Support CF .....	26
Fundraising Success .....	27
<b>Candid Facts</b>	
2017 Cystic Fibrosis Canada National Award Recipients .....	28
Celebrating 20 year Partnership with Siemens and CARSTAR .....	35
Kin Canada reaches the \$45 million milestone for Cystic Fibrosis Canada .....	36
CF Canada Welcomes a New National Partner: thyssenkrupp Elevator (Canada) Limited .....	37
Party City .....	37
The Decant Gala & Fine Wine Auction .....	38
Together we walked to Make Cystic Fibrosis History! .....	40
May Awareness: Advocating for Access .....	42



## MESSAGE FROM OUR PRESIDENT AND CEO, NORMA BEAUCHAMP



It's been a busy summer full of fundraising, advocating and researching. We are seeing the results of our community's efforts, and I am humbled and proud to represent an organization that is making a difference in the lives of Canadians living with cystic fibrosis (CF) and their families.

The season started with the news that Canadians with CF are living on average, 10 years longer than their U.S. counterparts. While there is still much work to be done, we celebrate this achievement and are encouraged by the news. We will continue to collaborate with the CF Foundation and our partners around the globe to share knowledge and research that will help us achieve the ultimate goal: a world without cystic fibrosis.

The release of the 2015 registry highlighted the progress we have made in diagnosing cystic fibrosis and treating it. While we have come so far, our progress is a reminder of how much further we must go. It is thanks to our clinics, researchers and the tireless efforts of our volunteers and staff that Canada has one of the highest median survival ages in the world for those living with CF.

During May, Cystic Fibrosis Awareness Month, we released a campaign that showed the heart of our community and advocated for accessible medication for all Canadians. We showed Canada real personal stories from the CF community, and how access to care and drugs is paramount for those living with CF to enjoy longer and better-quality lives.

Thousands of Canadians stepped up for a cure for CF at our Walk To Make Cystic Fibrosis History at over 65 locations across the country, raising more than \$3.6 million for innovative CF research and care. This event is truly an embodiment of the spirit and character of our community, and shows what we can accomplish when we come together.

The beginning of June marked an incredible milestone for Cystic Fibrosis Canada, with the announcement that Quebec will join the rest of North America by implementing newborn screening for CF. This is a feat that was 10 years in the making, and we are grateful to the government and Minister Barrette for taking action to better protect the health and wellbeing of children touched by CF.

As a result of this announcement, newborns will be diagnosed at birth, preventing irreversible consequences such as growth retardation and an increased risk of contracting pulmonary infections. It will also avoid numerous emergency visits and hospitalization, alleviating strain on Quebec's healthcare system. Congratulations!

I look forward to continuing to work with you, our CF community, including, partners, researchers, clinicians, volunteers, donors, Canadians with CF and their families. With your support and generosity, we will create a world without CF. I am encouraged by the progress made and I look forward to sustaining that momentum into the next season with Shinerama and our continued efforts to make CF history.

**Together we will create a world without cystic fibrosis.**

A handwritten signature in black ink that reads "N Beauchamp".

**Norma Beauchamp**  
President and CEO

# INTRODUCING OUR NEW CHAIR OF BOARD OF DIRECTORS: MITCH LEPAGE

## ? What has motivated you to be involved with Cystic Fibrosis Canada and ultimately, the board of directors?

My motivation began with the diagnosis of my son with cystic fibrosis when he was 11 months old. Over the following 22 years, I've witnessed, first hand, the incredible challenges that he, and others living with this terrible disease, face day in and day out and yet, despite these challenges, they display courage, dignity and maturity beyond their years. I'm also motivated by the many dedicated families and friends, volunteers, staff, donors, clinicians and researchers who share a common determination to find a cure or control for cystic fibrosis and who unselfishly give of themselves and their resources to achieve this objective. The great thing is that there is mutual energy between these stakeholders that maintains the momentum of progress.



My motivation for serving on the board reflects the fact that we all have a role to play in this fight and we each find our place in this mission according to our experience, abilities and interests. I get great satisfaction in being able to contribute my experience and personal familiarity with cystic fibrosis to a team of very committed board colleagues who collectively play their part in achieving a world without cystic fibrosis.

## ? What is your vision for the future of Cystic Fibrosis Canada and what do you hope to achieve?

My vision for the future of Cystic Fibrosis Canada is simply that we achieve our mission to end cystic fibrosis, and achieve our vision of a world without cystic fibrosis, using the tools provided in our values. We are now realizing some incredible gains in current treatments for segments of our CF population and we can't let our foot off the gas as we set our sights on accelerating these gains so that everyone living with cystic fibrosis can be a part of this success story.

## ? How will the Board of Directors support volunteer leaders, staff and partners in realizing a world without cystic fibrosis?

The members of Cystic Fibrosis Canada are all volunteers, including the board, and we are all dependent on each other for achieving a world without cystic fibrosis. Each membership group has a critical role to play. Chapter Presidents provide the local leadership that is vital in supporting fundraising activities while also acting as the local voice and helping hand for individuals and families living with CF. The Volunteer Advisory Committee is composed of volunteer leaders who provide advice to the board on matters impacting volunteers across the country.

The board supports our members, the staff and our partners, by providing governance oversight, especially in ensuring that our values of Excellence, Accountability, Teamwork and Caring guide everything that we do. To be honest, sticking to our values isn't always easy. It involves asking lots of questions, some difficult, taking positions that may be controversial and demonstrating vigilance in our advocacy efforts. As I said in my initial letter to all CF Canada members, the board will take on these responsibilities with "professionalism, disciplined focus and sound judgment" to ensure the clarity and accountability necessary for all volunteers, staff and partners to achieve our goals.

# INTRODUCING THE NEW CF CANADA BOARD MEMBERS

## PAMELA VALENTINE

Dr. Pamela Valentine, appointed by the Government of Alberta as Transition CEO, led the successful consolidation of the new Alberta Innovates organization. Prior to this role she served as the Interim CEO for Alberta Innovates – Health Solutions (AIHS). She was first recruited to AIHS in 2007 and held successively senior positions before taking the organization’s helm. Before joining AIHS, Pamela was an adjunct assistant professor in the Department of Clinical Neurosciences at the University of Calgary and a member of the Epilepsy and Brain Circuits Program at the Hotchkiss Brain Institute.

Pamela received her Ph.D., M.Sc., and B.Sc. in Psychology, from the University of Calgary. Dr. Valentine provides leadership in the health sector serving on several boards for international, national and provincial not-for-profit health and health research focused organizations.



### MESSAGE FROM PAMELA

**I am a mom of 3 fantastic kids, a 22 year old son who is a musician and 13 year old twins (boy and girl). I am a breast cancer survivor (ie. Warrior), and I love getting exercise... riding my bike, swimming, paddleboarding, running, walking. Being near water is my happy place. I love to host dinner and cook. I am a big gardener and have a beautiful perennial garden.**

### MESSAGE FROM BARBARA

**I have worked in the healthcare business for over 30 years and in chronic disease management for most of that time (end stage renal disease and children with hemophilia). The similarities in terms of care and clinical coordination opportunities are immense even though the disease and treatments are very different. I hope to be able to apply this specialized knowledge to make a valuable contribution to the CF community.**

## BARBARA M. HILL

Barbara Hill is President of The Grenview Group - a strategic global business advisory and executive coaching firm built on 30 years of extensive leadership and business management experience in healthcare. Previously, Barbara had a successful corporate career holding many senior positions including President and GM of Baxter Canada.

She has a Master of Business Administration (MBA) from University of British Columbia and an Honors Bachelor of Arts from University of Western Ontario. Barbara is also a member of the Institute of Corporate Directors (ICD) and has served as Chair and Board member in several associations and non-profit organizations ensuring role model governance and oversight.





# HOPE THROUGH PROGRESS

# BROKEN ARROW CONFERENCE

## BROKEN ARROW CONFERENCE 2017

### Clinical Trials & the Digital Health Revolution

On May 5 and 6 over 150 healthcare providers and researchers from around the world gathered at CF Canada's 16<sup>th</sup> Broken Arrow Conference to discuss the latest research and emerging topics in CF care. This year, the theme was **Clinical Trials and the Digital Health Revolution: Better Health for All Canadians with CF.**

Broken Arrow is an opportunity for donors, sponsors, people with CF and their families to celebrate advancements, and focus on emerging topics in research and care. In celebration of Canada's 150<sup>th</sup> birthday, success stories of Canadian CF research and care were shared, providing a uniquely Canadian perspective.



**ALMOST 4,200**  
 **CANADIANS**  
WITH CYSTIC FIBROSIS

 **52.1 YEARS**

THE ESTIMATED MEDIAN SURVIVAL AGE FOR CANADIANS WITH CYSTIC FIBROSIS, IS AMONG THE HIGHEST IN THE WORLD



**27.8%**



**17.5%**

27.8% OF FEMALE ADULTS AND 17.5% OF MALE ADULTS WITH CYSTIC FIBROSIS ARE CLASSIFIED AS UNDERWEIGHT

OF THE  
**47 CF PATIENTS**  
WHO DIED IN 2015,  
**HALF** WERE UNDER THE  
AGE OF 29.7 YEARS




**124**  
**NEW DIAGNOSES**  
INCLUDING 12 ADULTS



**85.4% OF CANADIANS**  
WITH CYSTIC FIBROSIS  
MUST TAKE PANCREATIC ENZYMES  
TO DIGEST FOOD AND  
ABSORB NUTRIENTS



 **59.2%**  
OF CF PATIENTS  
ARE DIAGNOSED WITHIN  
THEIR FIRST YEAR OF LIFE

**23.7%**   
OF ALL CF PATIENTS  
HAVE CF-RELATED DIABETES


THERE ARE MORE CF ADULTS  
THAN CF CHILDREN,

**60.5%** OF ALL  
PEOPLE WITH  
**CYSTIC FIBROSIS** IN  
CANADA ARE ADULTS




**42 CF CLINICS**  
ACROSS CANADA



CUMULATIVELY,  
CF PATIENTS SPENT OVER  
 **25,000 DAYS**  
IN HOSPITAL  
(OVER 68.5 YEARS)

**49** CF PATIENTS  
RECEIVED  
TRANSPLANTS



 **EVERY WEEK** IN CANADA,  
**1 BABY** IS DIAGNOSED  
WITH **CYSTIC FIBROSIS**  
THROUGH NEWBORN SCREENING



# NEW RESEARCH IMPACT AWARD RECOGNIZES CATHLEEN MORRISON

Cathleen Morrison was Cystic Fibrosis Canada's longest-serving Chief Executive Officer. Under her leadership from 1981 – 2011, the organization and its supporters grew nationwide and Cystic Fibrosis Canada-supported research produced remarkable advancements. Over this period, the estimated median age of survival for Canadians living with cystic fibrosis (CF) rose from 22.5 years to 47.9 years. To recognize her significant contributions to the cause, Cystic Fibrosis Canada is pleased to introduce the new Cathleen Morrison Research Impact Award.



The award recipient is selected specifically by the CF community stakeholder members who participate on Cystic Fibrosis Canada's Scientific Review Panel that reviews all research grant applications submitted to the annual competition. The community members play a key role on the Panel by sharing their unique perspectives on the relevance of the proposed research projects to the CF community. The applicant who earns the highest score in terms of relevance to the CF community, with the greatest potential to impact those living with CF, receives this award.

Cystic Fibrosis Canada is pleased to present the 2017 Cathleen Morrison Research Impact Award to Dr. Paul Linsdell at Dalhousie University. Dr. Linsdell will receive \$300,000 over three years, 2017-2020, to support his work on the structure of the cystic fibrosis transmembrane conductance regulator (CFTR), the protein defective in CF. Dr. Linsdell and his team are studying changes in the shape of the CFTR protein as it carries out its function, with the ultimate goal of developing improved CFTR-targeted drugs to address the underlying cause of CF.



Dr. Paul Linsdell is a faculty member in the Department of Physiology and Biophysics at Dalhousie University in Halifax. His research program focuses on understanding the structure and function of CFTR and he has received continuous research funding support from Cystic Fibrosis Canada since 1999. Over the years, a number of trainees in his lab have also been supported by fellowships, studentships, and summer studentships from Cystic Fibrosis Canada.

# INTRODUCING THE NEW JENNIFER AND ROBERT STURGESS FELLOWSHIP

Cystic Fibrosis Canada is pleased to announce a new research award, the Jennifer and Robert Sturgess Fellowship. After earning her doctorate in Pathology at the University of London in 1970, Dr. Jennifer Sturgess and her husband, Robert, moved to Toronto, where Dr. Sturgess pursued research at The Hospital for Sick Children. She focused on lung diseases, particularly cystic fibrosis (CF), and her research was supported, in part, by Cystic Fibrosis Canada. Following her tenure at The Hospital for Sick Children, Dr. Sturgess served as Associate Dean of Research at the University of Toronto and later as President of the Toronto Hospital Research Institute. She was a highly regarded thought leader in CF, served as a consultant to the World Health Organization and the National Institutes of Health, among others, and was a member of both the Medical Research Council and the Science Council of Canada.



To honour Dr. Sturgess' legacy in CF research, her family has made a generous donation to Cystic Fibrosis Canada which will be recognized by designating a CF research fellow each year for the next seven years. Cystic Fibrosis Canada sincerely thanks the Sturgess family for their support and wishes the first-ever Jennifer and Robert Sturgess Fellow, Dr. Patrick Stapleton, much success in his research.



Dr. Patrick Stapleton was named the 2017 Jennifer and Robert Sturgess Fellow. Dr. Stapleton is a medical microbiologist completing his specialization in pediatric microbiology at The Hospital for Sick Children. In his research fellowship, he will be working with Dr. Yvonne Yau to understand why some strains of *Pseudomonas aeruginosa* cause persistent infection in CF patients while others can be eradicated with antibiotic therapy. A second aim of his work is to investigate the possibility of cross-infection with *P. aeruginosa* between patients so that appropriate preventative measures may be taken at clinics in the future.



# STUDY FINDS DIFFERENCES IN LIFESPAN BETWEEN CANADIANS AND AMERICANS WITH CYSTIC FIBROSIS



**A study by Dr. Anne Stephenson of St. Michael's Hospital published in the *Annals of Internal Medicine* found that Canadians with cystic fibrosis are living on average, 10 years longer than their U.S. counterparts.**

The study, which was funded by the Cystic Fibrosis Foundation, is based on data in the Canadian Cystic Fibrosis Registry and the U.S. Cystic Fibrosis Registry from 1990 to 2013. Dr. Stephenson found that when specifically comparing the last five years (2009-2013) there was a difference of 10 years in the lifespan of Canadians and Americans with cystic fibrosis. Using Registry data from 2009 to 2013, the median age of survival for Canadians with CF was 50.9 compared to 40.6 in the U.S.

The goal of the study done by Dr. Stephenson and colleagues was to understand if there is a difference in the lifespan of Canadians and Americans with CF; it was not designed to find out why the difference exists. As such, there is no definitive reason for the survival gap, however, evidence suggests that Canada's implementation of the high fat diet with the goal of normal growth and nutrition from an early age may be playing a role. This approach to nutrition was implemented in Canada in the 1970s compared compared to the 1980s in the U.S. Other contributing factors identified in the study include lung transplantation and differences in our health care systems.

While over time there have been dramatic increases in CF survival in Canada (and the U.S.), there is still so much work to be done for Canadians with cystic fibrosis. Each year, there are still young Canadians dying or needing a lung transplant because of progressive lung damage – according to the 2015 data of Canadian patients who lost their battle to cystic fibrosis, half were under 29.7 years of age.

The fight against cystic fibrosis is a global one. We will continue to look to our neighbors in the U.S. and across the globe to share each other's knowledge and leverage resources and expertise that we can implement within our Canadian CF community and worldwide. For example, the Cystic Fibrosis Foundation (CF Foundation) was instrumental in the development of the first drugs that target the basic defect (ivacaftor), and continues to support a rich pipeline of therapeutics. Cystic Fibrosis Canada followed the CF Foundation's lead and started the Canadian Cystic Fibrosis Registry in the early 1970s (modeled after the U.S. Cystic Fibrosis Registry) so that we can better understand the population as a whole. Both the Canadian and U.S. Registries gather data on consented CF patients who receive care in accredited care centres and clinics, allowing for a comprehensive picture of the CF population in both countries. We will continue to collaborate with the CF Foundation and our partners around the globe to share knowledge and research that will help us achieve the ultimate goal: to ENDCF!

## HIGHLIGHTS OF THE STUDY INCLUDE:

- ✓ During the 2009 and 2013 the median age of survival for individuals with CF in Canada was 50.9 compared to 40.6 in the U.S.
- ✓ Canada began to experience a greater increase in survival around 1995 with an even more dramatic survival rate surge in 2005
- ✓ After adjusting for factors associated with severity of disease, the risk of death among people with CF was 34% lower in Canada than the U.S.
- ✓ There was no significant difference in risk of death between Americans with private health insurance compared to Canadians with universal healthcare
- ✓ Canadians had a 44% lower risk of death than Americans who who received continuous Medicare/Medicaid and Canadians had a 77% lower risk of death compared to Americans with unknown or no insurance

# HISTORY IS MADE: QUEBEC FINALLY IMPLEMENTS CF SCREENING FOR NEWBORNS

EVERY WEEK IN CANADA, 1 BABY IS DIAGNOSED WITH CYSTIC FIBROSIS THROUGH NEWBORN SCREENING



On June 8, 2017, Quebec's Ministry of Health and Social Services announced that it will implement a screening program for CF in newborns.

This is a huge win for the health and wellbeing of Quebec's children and is the culmination of years of work by CF Canada and the CF community in demonstrating how this will help Quebec babies with CF live longer and healthier lives.

"Since 2006, CF Canada has been calling for the implementation of a newborn screening program in Quebec. Now that this has been realized, our mission is to continue to support CF families and the clinics they depend on for essential care," said Yannick Brouillette, Regional Executive Director, CF Canada Quebec. "We would like to thank Minister Gaétan Barrette, as well as the entire CF community who have worked tirelessly in their efforts to improve the lives of Quebec newborns and their families, and will continue to do so until a cure is found."

Quebec was the only province in Canada and one of the rare places in the world that did not screen for CF in newborns. As a result of this announcement, children will be diagnosed earlier, preventing irreversible consequences such as growth retardation and an increased risk of contracting pulmonary infections. It will also avoid numerous emergency visits and hospitalization, alleviating strain on Quebec's healthcare system.

"My experience as a CF Clinic Medical Director shows me on a daily basis how important screening for CF in newborns is to improving babies' lives who are born with this dreadful disease. I am extremely pleased with this news and I hope that the program will be implemented quickly," adds Patrick Daigneault, MD, Pediatric respirologist at the Centre Mère-Enfant du CHUQ.

Cystic Fibrosis Canada applauds the Ministry for its life-changing decisions.

## ACCESS TO NEW CF MEDICINES IN JEOPARDY

It is both a good time and bad time in the history of CF medications. With two first-in-kind, disease modifying therapies on the market, Kalydeco (ivacaftor) and Orkambi (lumacaftor/ivacaftor), a new inhaled antibiotic (Quinsair), and **121 drugs in the development pipeline – 52 of which treat the basic defect in CF** – these drugs offer much hope that the progression of CF can be slowed and, potentially, reversed in the foreseeable future.

**The challenge lies in ensuring people can access them.**

Kalydeco is a prescription medicine for the treatment of CF in patients ages six and older who have specific mutations in the Cystic Fibrosis Transmembrane Regulator (CFTR) gene. Approximately 180 Canadians could benefit from Kalydeco, which improves lung function and other aspects of cystic fibrosis such as increasing weight.

In 2013 and 2014, the Canadian Agency for Drugs and Technologies in Health (CADTH) recommended Kalydeco be listed on the formularies of publicly funded drug plans for the treatment of cystic fibrosis in patients age six and older who have the mutations the drug is indicated for. Although it received a positive recommendation, provincial and territorial governments were slow – and in some cases hesitant – to make Kalydeco available to CF patients who could benefit from it.

Given the cost – approximately \$300,000 per patient per year – it is not surprising that governments took pause, but what is the price that governments put on their citizens' lives? It was only after a large-scale media campaign, extensive government relations activities, and mass protests that governments across the country made Kalydeco available to those who need it.

Enter Orkambi, the first drug to treat the basic defect in the largest population of people with CF, those with two copies of the delF508-CFTR mutation. There are approximately 1,550 patients in Canada aged 12 years and older who could benefit from Orkambi. The drug has been shown to improve lung function, reduce the rate of pulmonary exacerbations, which can lead to hospitalizations and accelerated lung disease, and improve nutritional status.

Although Orkambi showed similar lung function results to Kalydeco in clinical trials, CADTH made a negative recommendation to provinces, stating they should not make Orkambi available through public drug programs. Priced similarly to Kalydeco but indicated for a much larger population, CADTH cited a lack of effectiveness as the determining factor in its decision. This is in direct contrast to other international regulatory agencies that evaluated Orkambi, including Health Canada, which approved it for use in cystic fibrosis patients with two copies of the F508del -CFTR mutation aged six years and over.

When the manufacturer, Vertex, brought new evidence for re-consideration, CADTH stated that it would only accept evidence from randomized clinical trials. CADTH will not accept any other data, even real world data collected after people have been on the drug for some time. Cystic fibrosis is a rare disease with a small population; as such, meeting the CADTH data requirements is a challenge.

As a result of the CADTH recommendation, British Columbia stated it would not cover Orkambi, and no provinces have come forward to negotiate through the pan-Canadian Pharmaceutical Alliance (pCPA), the body our governments collectively negotiate prescription drug pricing. Increasingly, what used to be considered a recommendation from CADTH is now being taken as a directive by provinces. As citizens, we are losing the ability to work with our own provincial governments to determine how our public drug programs should work for us.

We are encouraging provinces to negotiate a fair price with Vertex. We believe provinces should enter innovative agreements with the manufacturer to make Orkambi available to their citizens who meet the conditions set by Health Canada and the clinical criteria established by Canadian CF clinicians. It is proving difficult to convince provinces to negotiate pricing for drug that received a negative recommendation from CADTH, especially given they haven't gotten around to negotiating price for drugs that have received positive recommendations.

Take the case of Quinsair, an inhaled antibiotic of a different antibiotic class than existing comparators, which has shown clinical benefits in adult patients with CF suffering from chronic *P. aeruginosa*. About 80% of CF patients are chronically infected with *P. aeruginosa* by adulthood. Due to intolerance, lack of efficacy and risk of resistance, other alternatives to existing therapies are required.

Quinsair received a positive recommendation from CADTH in November 2016. However, even with a recommendation to list on public drug program formularies, it took until June of 2017 for the province to begin negotiations with the manufacturer. That's nine months!

While some people can access Orkambi and Quinsair through private insurance, many can't and, in the case of Orkambi, those who can face the challenge of meeting their lifetime maximums within a year or two of coverage due to the price of the drug, which is approximately \$250,000 annually, pre-negotiation. Although we've come a long way in improving health outcomes for Canadians with CF, we have more to do. The median age at death for Canadians with CF in 2014 was 32 years of age. With so much hope in the pipeline, we need a system of drug approval and reimbursement that is accountable, transparent, effective and efficient, and we need to ensure that people with CF can get the medicines they need to live healthy and well.

So please, write to your local newspaper, contact your elected official, spread the word in your community. Don't take no for an answer. People's lives are in the balance.





# CIRCLE OF FRIENDS

## A 7000KM JOURNEY TO END CF

BY: JIM BEST

*Jim Best is a pharmacist and photographer living with CF from Centreville, Nova Scotia. This summer he hit the road in a coast-to-coast motorcycle ride to raise funds and awareness for CF Canada.*

The idea for the motorcycle-oriented fundraiser came from combining my passion for motorcycles and wanting to support CF Canada. Growing up I did some motocross and running the roads on two wheels was a natural progression.

Previously I completed a trip from Boston to San Francisco in 2014, and I drove the entire coast of Ireland in 2015. Both rides were to raise funds, awareness, and access to medications for Cystic Fibrosis Canada.

The Canadian coast-to-coast trip had been on my radar for the past 5 years and I was really excited to be able to do it this year. From June 26th to July 14 I travelled from Halifax, Nova Scotia to Vancouver, British Columbia on my 1997 YZF 600R motorcycle "Jenny".

Being 34 years old, there have been many of my friends with CF that have not had the same opportunities to attend university, get a job, and live an adult life. I feel very fortunate and driven to give back to help progress the awareness and research that goes on through Cystic Fibrosis Canada.

Coming into a trip like this, with approximately 7000km ahead of me, I needed to take many steps to prepare. I mapped out the route and balanced the time frame I had with the time I needed for rest and therapy for my CF. I wore a mask under my helmet to help filter out the fumes and dirt that came with riding long distances, and I tried to set time aside to rest after long days of travel. It's a taxing experience and while I still would like to do short runs and attend the Breath of Life drives, this may be my last long-distance ride.

The best part of travelling Canada was connecting with friends along the way and I am so appreciative of having such great support on the road. I think anyone who has done long distance travel on motorcycles can understand the physical and mental toll it takes. It's a pleasurable adventure, but there was a challenge to conquer there too.

For reasons I can't explain, travelling by motorcycle provides an ice-breaker on the road to strike up conversation. Whether it is fellow bikers or curious bystanders, it has been a great way to talk about the fundraiser when I am out on a motorcycle. I can easily talk about CF, the issues around its advancements and access to medications for people living with it, as well as the hurdles to treat and cure the disease.

Motorcycling provides a level of freedom that I seldom find anywhere else. I enjoy hiking, photography and playing sports (dodgeball, softball, volleyball) but being on two wheels gives me independence and control that is unmatched and sometimes isn't always available living with cystic fibrosis.

I think other people with CF can attest to battling and balancing the disease within their daily lives. For me, being out on the motorcycle gives me a temporary break from that thought process. When I'm out on these fundraisers, I feel accomplished. I carry with me the memory of those who are no longer with us, or the thoughts and well wishes of those supporting me really. Those positive thoughts really help the mental test of travelling long distances on these solo trips.

To learn more about Jim's motorcycle fundraiser, you can find him on **Facebook by searching CF Motorcycle**; on **Twitter @cfmotorcycle**; or on **Instagram @jhb主est**.



## CF STRONG CUP: PLAYING FOR GOOD

Shortly after she was born, Jenna and Tyler Dillon's daughter Georgia was diagnosed with cystic fibrosis (CF) through Alberta's newborn screening program. The family quickly familiarized themselves with their 'new normal' and when Georgia was only a few months old, the family became involved with Cystic Fibrosis Canada by participating in the Walk to Make Cystic Fibrosis History. Jenna had an urge to do more and she knew that one-year old Georgia's CF could consume her if she didn't find a way to keep busy.

Jenna was inspired through her eight year old son Seamus, an avid hockey player. She knew the local hockey community in Cochrane, Alberta was a hugely supportive group and decided that she would organize a novice, 3-on-3 youth hockey tournament in support of Cystic Fibrosis Canada. Jenna's goal was to raise awareness of cystic fibrosis as well as reach a lofty fundraising goal of \$10,000.

With support from the CF Canada team in Calgary, the Dillon's began looking for sponsors, and with help from Ducks on the Roof Cochrane and Spartan Hockey Development; they were able to buy the jerseys and book the ice time at Spray Lake Sawmills Family Sports Centre. Next, they needed players – and lots of them! Jenna posted ads in the local paper and with Seamus playing in both the winter and spring seasons, there was no shortage of support from the hockey community. Participants registered as individuals and Jenna set the teams: four teams each with 10 players. Bringing even more awareness about cystic fibrosis, each team was named after a child with CF in the local area.

The four team names were Georgia Peaches, Faith's Firecrackers, Nash's Nighthawks and Teagan's Tornados. The players knew they were playing and raising money to make a difference in another child's life. Nash's Nighthawks's were the tournament champs and the team generously signed a jersey and gave their trophy to their namesake, four year old Nash.

The Dillon's first take at organizing a fundraising event was a huge success! The players had a great time raising funds for a good cause and at the end of the three day event; the Dillon's not only raised a massive amount of awareness for CF, but raised \$13,470 for Cystic Fibrosis Canada!

Jenna also organized a raffle table with prizes donated by local businesses, the table helped tremendously towards the total amount raised.

The Dillon's were floored by the support they received from both the local and hockey community and the enthusiasm of all the volunteers. They have already begun thinking about the next event and hope to open the age group. The community has expressed interest in participating again and a few local businesses have already signed on to support!

Jenna's parting advice for others who want to host a fundraising event? Meet with your chapter first – they are full of knowledge and will be able to walk you through it. Make sure you ask for help, support and volunteers are essential.

CF Canada is so grateful for the tremendous contribution made by the Dillon family!



# THE LITTLE LEMONADE STAND THAT COULD



On October 17, 2012 Kimberly and her husband Jesse received the life-changing news that their four-year-old daughter Cassidy had cystic fibrosis (CF).

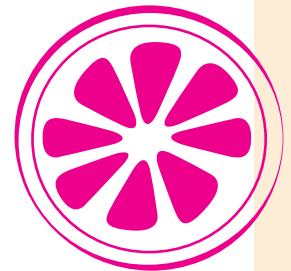
Since Cassidy was a newborn, Kimberly knew that something wasn't right – at first the family thought it was a digestive issue, so they ate a gluten-free diet and continued to take Cassidy for regular checkups, where doctors confirmed she was suffering from food allergies. But Kimberly's mothering instinct told her it was something more, and she pushed for additional testing and doctors eventually performed a sweat test to rule out CF. It came back positive. Born in 2008, Cassidy's CF went undetected at birth having just missed the introduction of newborn screening in January 2009.

Kimberly and Jesse welcomed their second daughter, Lucia, in February 2011. As Cassidy was the couple's first child, Kimberly and Jesse didn't realize how unusual some of the everyday occurrences with Cassidy were – when daughter Lucia came along, the differences were obvious.

Cassidy's diagnosis came as a shock. After a few months, the family decided to dive in. They knew that they could either look at Cassidy's CF as something that could break them, or as an opportunity to teach their daughters to be positive in the face of adversity. Kimberly started to write about Cassidy's journey on her blog, *The Kite Project*. Blogging was an outlet for Kimberly to update friends and family who began to ask how they could help, or donate to the cause.

It was then that Cassidy wanted to get involved too; she decided she would host a lemonade stand and donate the proceeds to Cystic Fibrosis Canada. That first year she was only five-years-old. The family lived in Saskatoon at the time and Cassidy set up a small table in their yard and spread the word to family, friends and neighbours. Cassidy raised \$100.00 and was thrilled with her not-so-small contribution!

The next year, Cassidy hosted her lemonade stand once again. Building on the momentum of year one, her grandfather built a small stand for her and she raised \$300.00.



*When all was said and done, Cassidy's little stand had raised over \$11,000.00*



Then, the family moved to Moose Jaw, SK. Cassidy wanted to continue her fundraising efforts and the family decided to give the stand a try in their new city. Cassidy's grandfather built her an adorable lemonade stand out of rustic pallets to get her started. They worried that the city was much smaller than Saskatoon and with both Kimberly and Jesse working from home; they did not have a large community of friends and family to reach out to. Living across from Cassidy's school, they decided to spread the word there. The family quickly learned that the community has a spectacular, rare quality. Moose Jaw has the mentality that if someone needs help, you support – no questions asked.

They hosted the lemonade stand one weekend on a Friday afternoon and Saturday. When Kimberly looked out her window at 3:30 p.m. on Friday, there was a lineup of about 150 people waiting to purchase lemonade. The lineups continued all weekend. Kimberly had to keep making runs to local stores to buy more supplies and to keep up with demand a friend brought reinforcements from Saskatoon. At the end of the weekend, Cassidy's small lemonade stand raised a whopping **\$7,200.00!**

Although the family thought that the massive amount of support they received the previous year was a fluke, for last years' stand (year 4) they prepared for an influx of people and purchased more supplies – just in case. It turns out it was not a fluke at all. Cassidy's stand was busier than the year before! A community member came in a vintage yellow truck to help draw more attention to the stand and donated \$1,500 - that's an expensive glass of lemonade! When all was said and done, Cassidy's little stand had raised over **\$11,000.00!**

Cassidy is already planning for the 2017 lemonade stand and has received many offers of help from members of the Moose Jaw community. A local renovation company is going to build her an impressive stand – complete with lemonade taps (courtesy of help from a local pub) and a local restaurant has offered to donate supplies for the lemonade. Her father, Jesse, has joined the local Kin group who has pledged to be on hand this year to support in any way they can.

Little sister Lucia is wise beyond her years and has helps with the lemonade stand any way that she can, she brings flyers to her friends at school and helps to fill the lemonade cups. She has taken on a caregiver role, often reminding Cassidy to take her enzymes.

The family is blown away by the incredible support of their community. The community has helped Cassidy to realize that something scary can also be something beautiful. She has learned that if she uses her energy for good instead of sadness, she can do anything she wants.

Cassidy's family is inspired by her strength and positivity. Since her diagnosis, Cassidy was put on enzymes and has been doing well, her height and weight are well within range. While she spends hours each day doing treatments, she stays positive and is happy, healthy and active. You can follow their journey through their blog [www.thekiteproject.com](http://www.thekiteproject.com) or on Facebook 'The Kite Project'.

 [www.thekiteproject.com](http://www.thekiteproject.com)

 [The Kite Project](#)



## BREATHING ROOM



Donovan and Beth

Beth and Laurier Gobeil were married after high school and their family soon grew, welcoming two daughters and two sons.

Beth knew that her husband's brother, Colin, had cystic fibrosis (CF) – but didn't know much about the disease – only that Colin seemed to have a bad cough. It wasn't until Beth and her husband were having their third child, Donovan, that her mother-in-law suggested she have the children tested for CF – only as a precaution.

Colin's health began to decline, and as his lung function plummeted he became dependent on oxygen. Just before Donovan's arrival, Colin was assessed and approved for transplant. He would have been only the second person in Canada to receive one.

Sadly, Colin passed away before he could receive his transplant. Shortly before Colin's passing, Donovan's sweat test came back positive, much to his parent's shock and dismay.

The family was left to grapple with the devastating loss of their loved one and the news that their young son might share the same fate. Beth and her husband clung to the hope that Donovan's health would take a different path than his uncle's had.

Donovan's health was in fairly good condition until his teen years when he began to have more frequent lung infections. During certain times in high school he was partially homeschooled due to frequent hospitalizations and at 15, he was granted a wish from The Children's Wish Foundation to see the Great Barrier Reef in Australia.

Donovan has a passion for photography and was admitted to a post-secondary program that would allow him to further explore his passion. Unfortunately, he realized he was not in good enough health to attend and had to decline. When he was 20, Donovan decided he was not going to let his CF stand in his way anymore. He committed to being a photographer at the summer camp he attended through his teen years and kept his commitment to the camp, despite being dependent on oxygen at night. Midway through the camp he called Beth to say he was sick, and although she wanted to come and get him, he was determined to finish the week.

### *Donovan decided he was not going to let his CF stand in his way anymore*

When he returned home, Donovan had never been in such poor health. The family immediately went to the ER where they learned he was in partial respiratory distress. After spending a week on I.V. antibiotics he returned home to finish his usual regime and recover, but this time it was different. He grew worse over the following week, so Beth and Laurier headed with Donovan to see a CF doctor in Saskatoon. On the way Donovan went into full respiratory distress for the first time. The family ignored all speed limits on the 1.5-hour drive and got Donovan to the hospital as soon as they could. After two days, they thought they might be out of the woods, but that night Beth and Laurier received a call that Donovan was coughing up blood. After that, they were unable to take him off of the respirator and were told that Donovan's only hope was transplant.

After eight days at Royal University Hospital, Donovan was airlifted to Edmonton where he spent the next five days sedated on a respirator in the ICU, and was not responding to IV antibiotics. The family clung to hope that his health would turn. Donovan was put on the lung transplant wait list and continued to decline, his lungs failing even with the aid of the respirator. It was an extremely emotional time for the family, knowing what had happened to Donovan's uncle Colin when he was placed on a transplant list. Finally, his family was told he may only have hours left to live, and would be placed on a heart-lung bypass machine, essentially life support, as his lungs were no longer able to filter oxygen properly. They were told he was dying, and may only have hours to live, even on the heart-lung bypass machine. However, the family's luck turned and only two hours after this devastating news, they received the call that there was a lung donor.

The doctors stressed that there would be no guarantees. In the 20 years of the transplant program at the University of Alberta they had performed over 300 transplants, but Donovan would be only the fourth patient to receive a double lung transplant while already on the heart-bypass machine.

On September 13, 2008, Donovan underwent the surgery.

### **He sailed through it.**

Eight years later, he has completed his post-secondary education and became a drug and alcohol addictions counselor. He has been happily married for the last three years and has run six half-marathons, and won several gold medals in the 2012 Transplant Games held in Calgary, AB.

His mother, Beth, has stayed busy as well. A longtime fan of journaling, she knew she needed an outlet to cope with her son's deteriorating health and the life he was missing out on. She took a creative writing class and poured herself into her writing. She also kept a blog to help update friends and family on Donovan's journey while in Edmonton.

**Breathing Room is available on Amazon and at many bookstores. Breathing Room can also be ordered through Beth's Facebook page, or by contacting her through email, [lbgobeil@gmail.com](mailto:lbgobeil@gmail.com).**

She was encouraged to submit some of her writing to CBC radio, which quickly accepted her work and purchased to be aired in a program which combines poetry and music. Beth's poetry aired several times, both provincially and nationally as an hour-long special about cystic fibrosis, transplant and Donovan's story.



*Breathing Room by Prince Albert author Beth Gobeil.*

An editor then suggested Beth submit her work to a publisher. She submitted the manuscript, *Breathing Room*, and much to her surprise it was accepted by Hagios Press. It was published in the fall of 2015, and last spring it was nominated for a Saskatchewan Book Award, a huge honour.

*Breathing Room* has not only helped Beth cope with her son's health, but it has served as a platform for others to open up about hardships, illness and transplants. A local cable channel has recorded a special documentary on Beth's family and her work, and a movie producer has reached out to the family with interest in their story and Donovan's journey.

Beth notes that any success of her writing does not come close to comparing to Donovan surviving. As well, it has been a true gift for Donovan's grandmother to see him triumph over the same disease that claimed her son Colin's life.

Today, Beth finds strength through her faith and Donovan's indomitable spirit. She explains that despite the hardships he has faced, Donovan has always stayed positive and determined. Beth is also a champion of organ donor awareness in Saskatchewan.

The book has been a great success, and went to a second printing. Beth generously donated her personal proceeds from *Breathing Room* to Cystic Fibrosis Canada and The Canadian Transplant Association.



# TRANSPLANTS REQUIRE ORGAN DONORS

**By: Wally Speckert**

My name is Wally Speckert. I am a 56-year-old 508deltaF CF adult. I was diagnosed at SickKids Hospital in May 1961. In December 2016, I underwent a double lung transplant at Toronto General Hospital (TGH).

When I was born, the life expectancy for CF was only 4 years of age. I was not expected to learn to spell my own name. However, I was blessed with parents that responded to my diagnosis by adopting a “never say die” attitude. Their example of dedication to my care, tenacity and perseverance in the face of obstacles has served me well.

I have been fortunate; I had the opportunity to get a good education, had a 25-year career at the Bank of Canada, owned a home, and raised two wonderful kids.

I have followed in my Mom’s footsteps, becoming a life-long volunteer for the CF cause from the age of five. Whether it is public speaking, raising funds or sitting on CF Chapter or National committees, I have always wanted to be a part of finding the cure of control for CF. Over the years through my involvement, I have been privileged to meet a wide variety of inspirational people in the CF community. The hardest part is to have become friends with so many amazing CF warriors who have passed on.

A double lung transplant has, for the time being, allowed me to avoid a similar fate.

My transplant journey began in the summer of 2013 when I was hit with a very bad infection and my lung function plummeted to 20%. I was in end-stage CF. In November 2014, I moved in with my transplant support persons, daughter Katy and her fiancé David in Cambridge, Ontario. I subsequently registered for TGH’s lung transplant program, which is recognized as one of the best in the world. The median expectancy for TGH’s lung patients is 5 to 8 years after transplant, and even a bit longer for CF patients given our younger average age and history of compliance.



However, shortages of donor lungs in combination with the fact that by working out three times a week I was in relatively good shape for a transplant patient, resulted in my wait for a call turning into a 25-month marathon! It is important to enjoy your journeys in life, not just the destinations! I lived each day to the fullest during my waiting period and enjoyed the pre-transplant experience for the most part.

Two false alarms later and my turn finally came. I’ve learned that everyone’s post-transplant experience is different. After a great start, I had several obstacles early on including hallucinations, speech impairment, atrial fibrillation, considerable pain and air leakage into my stomach. It was tough. Finally after 23 days I was able to leave the hospital and start my recovery in earnest as I travelled to and from TGH and Cambridge three times a week for workouts and a barrage of clinical tests and appointments.



*Wally's CF lungs, post-transplant*

My daughter Katy, who is also a registered nurse, was my advocate with the support of her fiancé David. My son Tom flew over from his home in Berlin, Germany for five weeks to help with my recovery. It was wonderful to have my adult children by my side! I consider myself very blessed! By the three-month mark, I had healed to the point where my lung function (FEV1) was over 2 ½ times what it had been pre-transplant. I could not have made it through so successfully without the support of family and friends! Support is so crucial when you undergo a transplant!

But lung transplantation is not a cure. It is a way to prolong life and to trade off one set of lethal problems for another set of critical constraints, but with a better expected quantity and quality of life. As well, treatment doesn't end after the transplant. Every 12 hours for the rest of their lives, patients must take immunosuppressants. This prevents their immune system from recognizing that they have someone else's lungs inside and trying to get rid of that foreign tissue. If we forget our immunosuppressant drugs, we risk setting off a rejection event which could prove fatal. Fortunately, people with CF have a lot of practice in taking pills. Since we are immunosuppressed, we must also take extra care to avoid contact with germs.

However, while there are challenges, uncertainty and economic and social hardships surrounding a transplant, I have yet to meet a lung transplant recipient who regrets their decision despite what they went through! There will always be new challenges, but anything life may throw at us certainly beats the alternative!

Transplantation truly makes a positive difference in the lives of those who receive one! For the first time in my adult life, I can now take a big deep breath. Without my transplant, I would not be able to play badminton without an oxygen tank. I would not be able to repay my aging Mom for caring for me so well all those years by being able to be there for her in her golden years. I would not be able to walk Katy down the aisle at her wedding this summer (at least not at normal speed and without an oxygen concentrator in tow). Nor would I ever have the opportunity to hold my grandchildren someday.

But transplants require organ donors. If we want friends and loved ones with CF who are on transplant lists to get compatible lungs in time from anonymous donors, we should be willing to sign up as donors ourselves and make sure that our loved-ones know and understand our decision to donate our organs.

The future I dream of for everyone with this disease is a world without cystic fibrosis! A world where even people born with two CF genes can look forward to living a normal, healthy life, and will no longer have to contemplate lung transplantation as the only option to extend their lives. For those reasons, my new lungs and I will continue to volunteer through Cystic Fibrosis Canada to help make that dream a reality.



## HAD WE ONLY KNOWN: THE JOLIN FAMILY

*Shortly after this article was written, Quebec's Ministry of Health and Social Services announced that it would finally implement a screening program for CF in newborns.*

It was a lovely, mild winter day when we visited Maude Côté Germain and Jonathan Jolin's family in the Gatineau area. The couple and their four beautiful children, Coralie, 8, Mikaël, 6, Isaak, 4, and Timoté, 3, were anxiously awaiting our arrival: they were about to invite us into their private lives to tell us about the difficult challenges that they had to overcome with two children suffering from cystic fibrosis. Troubled by a certain feeling of injustice due to the lack of neonatal screening for the disease in Quebec, these parents firmly believe that they would have done things differently had they only known.

Maude's first pregnancy was a dream, without any complications. Coralie was born on a beautiful day in August 2008 and showed all the signs of being a healthy baby. In the days following her birth, breastfeeding complications, gastric reflux problems and a lack of weight gain required the nurse to monitor her condition closely. As the days went by, Coralie slept more and more (sometimes nearly 20 hours a day!) and cried a lot during her short waking periods, most likely because she was hungry. When pimples appeared on her buttocks and thighs, along with certain sores, her mother knew that something was wrong and that she had to see a doctor immediately. In September 2008, Maude consulted a doctor who examined Coralie and decided to hospitalize her in order to better understand why she was not gaining weight. After a few days, Coralie was discharged from the hospital, and the family was told that their daughter would simply be a small baby.



Back at home, weeks went by, but the problems persisted. Maude knew that something was wrong. On December 4, 2008, the family went to the hospital where a doctor examined Coralie, asked several questions and decided to refer her to another pediatrician in the hospital. It was this meeting with Dr. Popa that was decisive. On December 8, after several tests, including the sweat test, the news hit the Jolin family hard: Coralie had cystic fibrosis. At the age of four months, weighing no more than a one-month-old, little Coralie was quite simply fighting for her life. Everyone agreed that, given her condition, it was a miracle that she was still alive.

“Had we known beforehand that Coralie had cystic fibrosis, we could have done so many things differently,” Coralie’s mother Maude recalls emotionally. When she was diagnosed, Coralie had to be hospitalized for more than three weeks and tube fed day and night for more than a year in order to make up for all the damage caused by her lack of weight gain since birth.

“Had we known much sooner, even when she was born, Coralie wouldn’t have suffered this much. That’s what upsets me most in my daughter’s whole story,” Maude points us. “We had to learn to insert her feeding tubes, which is not easy with a baby who always wants to pull them out. And because of her tubes and her very low weight for her age, we also had to deal with people’s stares and endless questions every time we left the house,” she remembers.

Quebec currently remains the only province in the country and one of the rare places in the world where neonatal screening for cystic fibrosis is still not included in the screening program already in place for newborns. “I think it’s totally unfair that we parents in Quebec cannot have this test performed like all the other parents in Canada. Our children with cystic fibrosis here in Quebec are entitled to be on equal footing with every other patient in terms of treatment!” Maude insists.

Throughout Coralie’s disease, the young parents, who always wanted to have a big family, sometimes hesitated before continuing down that path. However, the desire to expand the family was too strong. “After Coralie’s diagnosis, unlike Maude, I really questioned my desire to have a big family. But children are one of life’s gifts!” Jonathan says with emotion.

And life gave the Jolin family several more gifts with the arrival of three other wonderful children: Mikaël and Isaak, both of whom are completely healthy, and the youngest, Timoté, who also has cystic fibrosis. However, unlike Coralie, Timoté was diagnosed when he was only a few weeks old, and his parents were able to quickly manage his condition with the help of Dr. Popa’s team.

Given the situation, the parents have chosen to home school their four children in order to have a certain amount of flexibility with extended stays at the hospital in Rouyn Noranda, which is more than six hours away from their home by car. As Maude Côté Germain points out, “When you’re pregnant, it’s like magic. You don’t know what surprise is going to come out.” Nevertheless, she and her spouse are very happy to have a family united against the disease, a true example of fighting spirit and resilience on more difficult days. She also places a great deal of hope in research, which will one day lead to a cure for cystic fibrosis, and hopes that neonatal screening will very soon be available to all children in Quebec!

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*“Had we known beforehand that Coralie had cystic fibrosis, we could have done so many things differently,”*

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# THE 24<sup>TH</sup> ANNUAL MIKE CASSIDY LEGACY CF GOLF CLASSIC

On May 4, 2017, the 24<sup>th</sup> Annual Mike Cassidy CF Golf Classic attracted over 200 participants and raised over \$250,000 towards finding a cure for CF. After almost 25 years, the event is stronger than ever, and is a true testament to the impact Mike Cassidy had on the people around him.

The event is co-chaired by Mike's sister Colleen Gillis and his best friend Sid Keay, who have been there from the start. Thanks to their hard work, dedication and network of friends and colleagues, they have turned what used to be a small tournament into the largest privately generated source of funds for CF Canada in British Columbia – to date, the tournament has raised over \$5 million.

"Most people have said to me that this is the best tournament they have ever played in, and some of these people play in tons of charity events. Mike was a popular, charismatic person," says Colleen. "Some come to remember Mike – have a toast on his bench on the 12<sup>th</sup> tee – for some it is a networking opportunity, and others have a business connection to Sid and want to support him and all of his philanthropic efforts."

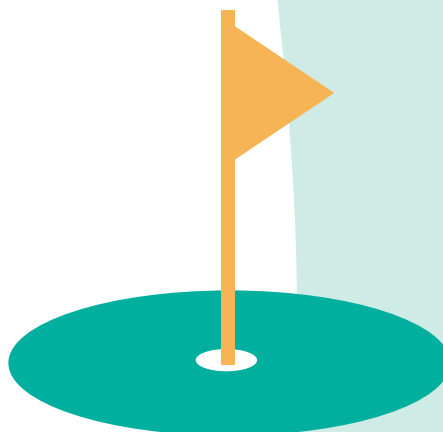
"Mike was a great person," says Sid. Mike lived "out loud" every day of his life, and chose to celebrate every single moment. He loved spending time with family and friends, and taught people not to take it all too seriously. Mike was born with CF and while he lived with it for his entire life, he never considered himself disabled by CF. He fought for the other people that had CF and was committed to making a difference.

And every year there are so many great moments and fond memories, says Colleen.

"I recall the year Eva Markvoort spoke to the room after dinner – a room full of top executives and/or heavy equipment and transportation people – mainly big tough men. After she spoke, there wasn't many in the room with dry eyes."

In terms of what the future holds for the event, both Colleen and Sid had the same response: that it ends, because a cure for CF has been found.

For more information on the 2018 Mike Cassidy Classic, visit: [www.michaelcassidylegacy.org](http://www.michaelcassidylegacy.org)





#FUCF

## THE HANNA FAMILY'S STORY

Every CF family has a story to share about the ups and down of caring for a child who has CF. The highs are high, and the lows can be low. But one thing that they all share is their tremendously positive outlook on life and never taking life's moments together for granted.

Connections caught up with one of those families, Julie and Kathleen Hanna, so that they could share their story.

### Can you share your early experiences with CF?

**Julie:** At 4 months of age, we were told that Kathleen had cystic fibrosis. Hearing those words brought such fear, anger, guilt and despair. We felt as if we were stuck in a nightmare.

**Kathleen:** I grew up having a relatively normal life, the oldest of 3 kids. I went to school and hung out with friends and played soccer since I was 4. Having CF meant I had to work hard to stay healthy, in order to do these activities.

### Julie, how did you overcome these emotions?

**J:** I learned a life lesson that day. As we all gathered at my mom's apartment, trying to absorb the news and deal with the shock of it all, my mother in all her wisdom took me by shoulders and said three words that have stuck with me since: NOW WE FIGHT! In that moment, those three simple words became our family's battle cry. Kathleen and Clayton will never be alone in their fight. Our battle cry is Fighting Until Cure Found (or #FUCF)!

### Kathleen, as you got older, how did CF impact your life?

**K:** As I mentioned earlier, I was managing the disease fairly well as a child. I would go into CHEO about every 3 years, for what they call a "tune-up" Basically, it was a 2 week stay to hook up to IV antibiotics, to clear the bug colonies out of my lungs.

This began to change around 16 years old for me. I was at war with the bugs in my lungs, and they were slowly beginning to win the battle, and they were taking over my lungs. My hospital stays began to become necessary every 3-4 months. I would continue my school work, and maintain my part-time job, all the while fighting this disease.

Around 18, I was really struggling to keep afloat. The hospital stays were now every month. My lung function dropped to anywhere between 30-40%, depending on infections. I was no longer able to keep up with my soccer team as running was too hard.

Despite all this, I was not going to let CF win! I always wanted to travel and see the world. So in the spring, when I was 20, I timed a backpacking trip to Europe. I knew that I would have a good 2 week window, right after an IV admission and that I could take my trip then, I would be home by the times the bugs took over, once again!! So with my backpack packed, 30% lung function left, I headed to London, Spain, Portugal and Scotland, for a whirlwind 2 weeks. And it was fantastic! As I predicted, the day after I got home, I was back in the hospital. This time, I was much weaker. The trip really took a toll on my body, but it was so much fun.



## And since then, how have things been for you?

**K:** It was at this point, the doctors began talking to me about my only option. I needed a double lung transplant. I couldn't believe it! I was scared, and really had no idea what this meant. My first tele-health meeting to discuss this option was on my 21<sup>st</sup> birthday.

In order to be accepted into the transplant program, I had to undergo a week of testing in Toronto. I had every scan imaginable, visits with many doctors, psychiatrist and social workers. After the week of testing, I was told that, other than my very sick lungs, I was a very healthy young woman, and would make an excellent candidate for transplant. I was then told to go home and get my affairs in order, and prepare for the move to Toronto.

How long I'd have to be in Toronto, was unknown. I had to be there to enter the pre-transplant physio program, which was 3 times a week in the gym, for an hour and a half. That's right, with only 17% lung function, and on oxygen, wheeled in on a wheelchair, I had to work out for an hour and a half.

Shortly after I returned to Ottawa to prepare, I crashed once again. This time my lungs were really struggling to function properly. I needed to be placed on a Bipap machine that did the work of cleaning CO2 out of my lungs.

This time last year, I was airlifted to Toronto to be listed right away. As I waited for my call, I had to stay on 2 IV antibiotics for good. My parents and I moved to a condo in Toronto, to work at regaining my strength, continue to fight the bugs in my lungs and wait for the call.

I was one of the lucky ones. My call came shortly before the 2 month listing date. I didn't have any false alarms, and my wait was short, compared to some. While one family was suffering the loss of their loved one, we were celebrating the start of my new life.

My surgery was a huge success, and I was up and walking the next day. I was out of hospital in 3 weeks. That is actually a shorter time than if I was admitted to fight infection. I stayed on in Toronto for 3 months after surgery. I had to be closely monitored and attend physiotherapy to get stronger.

I was able to move back home in early July. Today, things have changed drastically for me, for the better.

## That's fantastic! Can you tell me about the support you've had?

**J:** Living with CF in the family extends well beyond the walls of our home. We are blessed to have an amazing support group that has come to be known as #TeamHanna. Whether they be are our family, our friends, or our co-workers, they have always been at our side, providing a shoulder to cry on, a compassionate ear, filling up our freezer with meals, helping us juggle the children, **when we let them.** My husband Ken and I were not always able to just let everyone in. We wanted to be brave, strong and took on the attitude of **"We got this"**.

Thankfully a very wise friend of mine took me aside one day and said, "If you deny others the opportunity to step up and help you, you are denying God's helping hand." Wow! Who am I to stand in God's way?

Family and friends are often powerless to help in the day to day routines and struggles of CF life, but look what happens when we get out of their way and allow them in, and allow them to help in any way they can. I truly believe that in this past year, they have become more aware of what Clayton and Kathleen have been living with all their lives and that **we are where we are today because of their love and support.**

## Is there anything you would like to add?

**K:** Today, the medical challenge is about fighting rejection. I have to take 3 types of anti-rejection drugs, daily, for the rest of my life. Now the challenge becomes, protecting my liver and kidneys, as we try to keep my body from fighting the foreign organs. This is all worth it though, **I can breathe.**

With my new lungs, I am living my life like all 22 year olds should be, **well almost.** Thanks to the opportunity that my boss John Singlehurst provided me, I am back to work 3 days a week. **Thank you John for believing in me and giving me a chance.** I am taking 2 courses through Algonquin College, planning my next trip to New York, and best of all, going out with friends and not having to schedule all of this living, around IV treatments and hospital stays.

Connections would like to thank Julie and Kathleen for sharing their story with us, and hope that it inspires others to stay strong and optimistic in the face of adversity. In the words of Julie Hanna, you are all warriors!

# DR. PATRICK DAIGNEAULT, PLACING THE PATIENT AT THE HEART OF HIS PRACTICE

*Editor's note: This article was written prior to the announcement that Quebec would implement newborn screening for cystic fibrosis. Thanks to the hard work of people like Dr. Daigneault, this was made possible.*

With a stethoscope resting on his shoulders and a calm voice, Dr. Patrick Daigneault describes himself first and foremost as “a doctor like any other.” Although he is one of the rare pediatric pneumologists in Quebec, and manages the Cystic Fibrosis Clinic at the CHU de Québec’s Centre mère-enfant Soleil, he remains very humble. This is the portrait of a doctor who places the patient at the very heart of his practice.



“I take care of children’s lungs, but cystic fibrosis doesn’t affect these organs alone. It’s a disease that requires multidisciplinary management. That’s why I make sure I have all the support I need when I care for these children,” explains Dr. Daigneault, who specializes in the treatment of cystic fibrosis and pulmonary diseases in children. “Yes, I’m the Director of the clinic, but I’m also a member of the clinic like any other.”

Dr. Daigneault goes above and beyond to consider the reality of his patients, who must come in to the clinic for multiple consultations with specialists. In his opinion, cystic fibrosis does not affect only the children, but their families as well. For this reason, he has been working for nearly ten years to convince the provincial government to implement a newborn screening program for the disease for all children in Quebec.

“It’s very difficult for the families. They get the impression that their child’s illness is not serious enough to deserve attention.” He believes that early screening would prevent many complications for the children and their families. “Growth is extremely important during the first years of life. If the disease is diagnosed late, these children will face many more difficulties with their growth, which will lead to more long-term respiratory symptoms,” the specialist explains. When cystic fibrosis is diagnosed late, families often question why the disease could not be diagnosed earlier. The truth is that a simple test performed at birth is all that is needed to make an early diagnosis and improve living conditions for people with cystic fibrosis by reducing the consequences of the disease.

**Although Dr. Daigneault has been fighting for the cause of newborn screening for years, his patients remain his number one priority.**

Although Dr. Daigneault has been fighting for the cause of newborn screening for years, his patients remain his number one priority. However, this did not prevent him from conducting a study three years ago with the Quebec cystic fibrosis newborn screening team in order to ascertain the costs of implementing a screening program. “The hospitalizations and consultations required by parents seeking a diagnosis are definitely more expensive than a screening program,” he says. Based on the results of the study, a provincial screening program would cost only \$400,000 a year.

Convinced of the merit of a newborn screening program and the decrease in health costs for the population of Quebec, Dr. Daigneault continues his battle in the hope of better days to come for his patients with cystic fibrosis. He encourages them to take part in activities and even to start a family since there is little chance of affected parents passing the disease on to their children.

“In a different world, a world without cystic fibrosis, I could focus on the important aspects of my patients’ lives, like success at school or in sports,” Dr. Daigneault dares to dream. For him, his patients and their lives will always be more important than the disease.

# LAWN SUMMER NIGHTS: UNDER THE STARS AND ON THE GREEN TO SUPPORT CF

This summer in cities across the country, hundreds of people took to the green for an evening of fun and fundraising in support of friends and family with CF. Since its inception in 2009, Lawn Summer Nights has built a reputation as a standout event that attracts people from all walks of life who not only dress the part, but also give generously, all while enjoying a relaxed evening under the stars with acquaintances old and new.

Mark Heystee is Lawn Summer Nights' Chair, and is proud of the over \$2 million the event has raised. He sees great potential in the coming years for even bigger events in more cities. In 2016 alone, the event raised over \$500,000.

"I think a big part of our success is that we make a point of keeping it really simple and fun. We give people a chance to hit the greens on a summer night while enjoying a meal and a couple drinks with friends. When all that lines up, it's hard to have a bad time. Mix that with the fact that it's for a great cause and we've found people get hooked pretty quickly," says Mark.

"That being said, it's no question the biggest reason for our success is the amazing team of volunteers and partners that help put the events on across the country. The events would never happen without these people and we can't thank them enough. They are what make LSN the success it currently is."

Mark hopes that LSN can continue to build on what's in place while making sure to keep the roots of the event that originally made it so successful. He says they've found a formula that has worked really well and want to be careful to make sure they don't stray too far from that as they continue to grow.

The four pillars of LSN are fun, fundraising, awareness and legacy, and Mark says they are very conscious to keep those all in mind as they expand to new markets. Wherever the event goes in the next couple years, it will be done with those four pillars front of mind.

In terms of what makes LSN such a great event, Mark says it's hard to single out favourite moments because there have been so many special ones over the years.

"But one of the best is always the first night a city hosts an event. People work so hard to get ready for it and it's magic to watch it come to life for the first time. Every time we expand to a new city, I look forward to hearing how that first night goes. It never disappoints."

Of course, none of this would be possible without the hard work of volunteers who put their heart and soul, and a lot of sweat, into ensuring each event is a success.

"We've been so fortunate to have an amazing team of volunteers across the country since day one, and a community that continues to grow and expand every year. Without question, our biggest thank you has to go out to them. I hope they each appreciate how important they've been in making Lawn Summer Nights the success it's been. We really can't thank them enough. For those volunteers reading this – thank you."



LAWN SUMMER NIGHTS

"The four pillars of LSN are fun, fundraising, awareness and legacy."



Mark Heystee, LSN Chair



# FUNDRAISING SUCCESS



Team *JillyBean* is a Walk team in Vancouver, headed up by Travis and Melissa, whose daughter Jill lives with CF. Over the past 7 years they have raised over \$100,000 for CF research and care! The team includes friends, family and co-workers all committed to raising awareness and funds. Our sincere gratitude to Travis and Melissa for their support!



**JillyBean**



**Guardian Angels  
Catholic Elementary  
School**

The grade 3 students of Guardian Angels Catholic Elementary School in Waterdown, Ontario raised \$1,150 for CF Canada! The students worked with a community entrepreneur leadership program, and were immersed in the various roles needed in order to run a successful business. They organized a raffle, and advertised and sold tickets on Valentine's Day. Thank you so much to teachers Cristina Kinsella, Matilda Ciavarra and Lena Caprio, as well as the students!

Team *#CureCF4Avery* is from Bowmanville, Ontario and they participate in the Toronto Walk to Make CF History! Last year, their team of 11 registered walkers raised just over \$3000. This year, their team grew to an impressive 80 registered walkers and they raised of \$16,500 for CF research and care! A huge thanks to CF mom and dad Lisa and Gordon who work so hard to end CF for their daughter Avery and for all those living with CF!



**#CureCF4Avery**



**Mike Farwell**

Mike Farwell is a radio personality in Kitchener who started Farwell4Hire – a month long project where Mike offers his services for any odd jobs in exchange for a donation to CF Canada. The jobs Mike has done have included brewing beer, being a punching bag for self-defence classes, and cleaning the sheath of a horse! In its first 3 years, Farwell4Hire has raised almost \$95,000 for CF research! Mike fundraises in memory of his sisters Luanne and Sheri, who both lost to their battle with CF over 20 years ago. We thank Mike for his creative dedication to raising funds and awareness!



It is only through the commitment, courage and passion of our outstanding volunteers that we continue to improve the lives of Canadians living with cystic fibrosis (CF). Our volunteers take time from their busy lives to help make a difference in the CF community.

Congratulations to the 2017 national award recipients, together we are working towards a world without cystic fibrosis.

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The **Hall of Fame Award** is the organization's most prestigious award, presented to recipients who have contributed to the fight against cystic fibrosis for a minimum of 15 years and have demonstrated exemplary dedication to the mission of the organization.

### SUZANNE SPECKERT

Suzanne has devoted the past 40+ years to finding a cure or control for CF. She is responsible for helping to establish the Peterborough chapter, and for raising awareness of the disease in the community. She served two terms on the National Board of Directors, served as President for the Peterborough Chapter in the 1980s, and has organized countless fundraising events and initiatives.



Her influence has been especially profound to families who have recently learned of a CF diagnosis in their family. Suzanne offers one-on-one support and advice, and she has been a beacon of hope and strength for the many that rely on her. She inspires families to continue their fundraising and advocacy efforts, and to persevere and stay focused on the vision of a world without CF.

Suzanne's contribution to the cystic fibrosis community in Canada is immeasurable. Her dedication and commitment to finding a cure to help not only her son Wally, but all Canadians living with CF, is truly inspiring. Cystic Fibrosis Canada thanks Suzanne for her incredible contributions.

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The **Eva Markvoort Leadership Award** is designed to recognize an individual who has displayed outstanding leadership and made an exceptional, inspirational and/or motivational contribution to Cystic Fibrosis Canada.

### JEREMIE SAUNDERS

Jeremie is an active advocate for the CF community, and approaches his own struggle with CF with honesty, positivity and authenticity. He has promoted cystic fibrosis awareness and the work of Cystic Fibrosis Canada through his participation in special events as a guest speaker and agreeing to appear in a public service announcement that was shared in 2016. His enormous talent and presence as an effective speaker and personality made it possible for Cystic Fibrosis Canada to talk to strangers on the streets of downtown Toronto about cystic fibrosis and produce an excellent awareness piece. As of March 2017, the video has almost 150,000 views over 2,600 shares on Facebook. The launch of his podcast, *Sickboy*, demonstrated his initiative and entrepreneurial spirit. By choosing to create a voice and platform to talk about rare diseases, he also made a bigger space to talk about cystic fibrosis in Canada in a non-traditional way that has resonated with people across the country. CF Canada is honoured to have such a smart, unique and powerful voice in the chronic and rare disease conversation in Canada.



The **National Champion Award** recognizes service groups, corporations, companies and businesses that have provided exceptional leadership and/or financial support to the organization at a national level.

### LAWN SUMMER NIGHTS

Since its establishment in 2009, Lawn Summer Nights has grown into a national fundraising phenomenon that has raised over \$2,000,000 for Cystic Fibrosis Canada. By combining a unique social event with an important cause, LSN makes fundraising “fun”, all while introducing a group of young people to cystic fibrosis and the stories connected to it. The event inspires young professionals to get involved at a local level and volunteer, meet other individuals within their communities who share a passion for social change, and create an environment of positivity and continued hope towards a cure. We are grateful to all those volunteers that make Lawn Summer Nights happen every year.



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

### DR. ELIZABETH TULLIS

Dr. Tullis is an internationally recognized leader in adult CF care. It is largely due to Dr. Tullis' efforts that the adult CF clinic in Toronto has grown to be the respected service that it is, and her on-going work ensures that there continues to be new CF physician trainees, who can eventually care for adults with CF at clinics in other Canadian cities. Her dedication to the community is tireless, and she advocates for patients on a regular basis, through her work in Toronto, and nationally through the many Healthcare Programs that she volunteers her time to.



The **Volunteer Excellence Award** is bestowed to those who had made an exceptional national contribution to Cystic Fibrosis Canada for a minimum of 5 years.

### FRANCINE BERNIER

Francine has been a force to be reckoned with for the Montreal Chapter for over a decade. Demonstrating leadership and a commitment to the cause, Francine has made a positive impact on every aspect of the Montreal Chapter's activities and at the provincial and national levels. With the help of her team, Francine has been responsible for many successes such as the Halloween Coin Bank and Walk. She approaches her chapter with compassion, sharing her story as a CF grandmother, and motivates others to see brighter days to come. Thank you to Francine for her dedication and passion throughout the years.



### MITCH LEPAGE

When Mitch's son was diagnosed with CF in 1995, his first instinct was “how can I get involved and make a difference?” He immediately became an active member of the Durham Chapter, volunteering at events to raise funds and awareness. Shortly after, Mitch became the president of the Durham chapter. He used his inherent leadership skills to recruit new members, increase engagement and make the Durham CF chapter a force to be reckoned with within the community. Mitch selflessly continued to lead the Durham Chapter, while simultaneously taking on more national responsibilities and that has made a magnificent impact on the organization. Mitch now serves as Chair of the Board of Directors. He always gives 100% in the fight against CF and his impact is felt throughout the CF community; thank you for all you do Mitch.





### PAT MAGNAN

For over 10 years, Pat has tirelessly volunteered her time and talents in a variety of roles with the Edmonton & Northern Alberta Chapter. From remembering everyone's names and their stories, to saying hello and thanking every single person at events, Pat has been invaluable to her chapter. Never wanting any recognition for her contributions, Pat is caring, empathetic, and an outstanding exemplary volunteer and is continuously focused on working hard towards a world without CF. Thank you Pat for being such a dedicated and impactful volunteer.



The **Breath of Life® Award** recognizes outstanding and sustained contributions to a Cystic Fibrosis Canada chapter in a leadership capacity for a minimum of 3 years.

### BEV NICOL

Bev has volunteered with the HOPE chapter for over 12 years, and has been the main organizer of the Walk in the chapter. Bev has a “can-do” attitude, encouraging new volunteers to help or recruiting extra help when needed, fearlessly contacting local businesses for support, and even donating to reduce costs. Bev is a shining example of a volunteer.



### LISA LIVINGSTON

Lisa became involved with the Calgary and Southern Alberta Chapter in 2012 and quickly gained the trust and support of the team. She works behind the scenes at every event, and has applied her business and communications experience to completely advance the chapter's social media presence and align it with the national best practices. Because of Lisa's expertise, the chapter has experienced an increase in reach and exposure for both traditional and social media. We are grateful for Lisa's dedication and contribution in our goal to END CF.



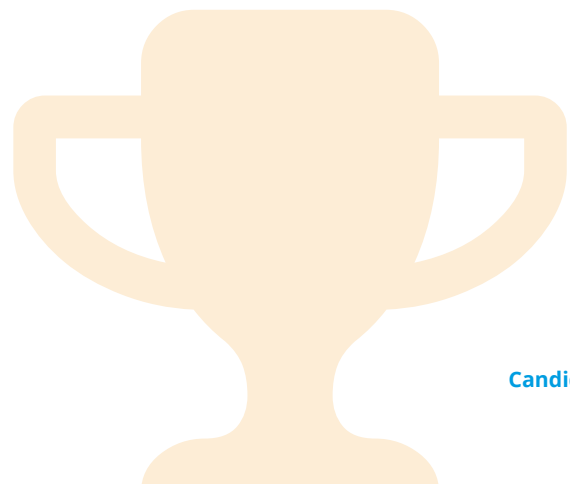
### SANDY STEVENS

Sandy is known for her energy and motivation among the members of the Edmonton and Northern Alberta Chapter. From organizing her own fundraising event “Tapas and Tunes” which raised over \$20,000 in 2016, to stepping up to help when needed, Sandy has a large impact on the chapter and the people within it. Sandy has, in one way or another been a part of nearly every event the chapter has offered, and gives her all to finding a cure or control. Thank you Sandy for all your hard work and dedication.



### SOPHIE GIRARD

Sophie has been the President of the Côte-Nord Chapter for the past eight years. As a restaurant-owner and busy mother of four, Sophie has impressed the whole team by always being available despite a busy schedule, and with her generosity of offering free meals to volunteers at her restaurant. Sophie is dedicated to committee meetings, which she chairs effectively and with flexibility. She is always willing to utilize her extensive network of business contacts to help create a world without CF. We thank Sophie for her passion and dedication in the fight to END CF.



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

### **MCKENZIE FAMILY**

For over three decades the McKenzie family has been incredibly active in the Kitchener-Waterloo Chapter. Karen, Ian and their three sons (one of who lives with CF) have dedicated their time to raising funds and awareness. Since Karen became the Chair of the Walk, the donations have increased substantially and she is always a force to be reckoned with when it comes to raising awareness and advocating for the cause. Ian is hands-on in his role as Event Site Coordinator for the walk and can always be counted on to get the job done. The McKenzie Family is a magnificent example of a family that embodies Cystic Fibrosis Canada's values of accountability, excellence, teamwork and caring.



### **PINSKY FAMILY**

Leona and Max Pinsky are considered to be pillars of the Vancouver Chapter. They have been supportive to the entire community, and transparent about their struggles with their daughter Rina's battle with CF. Their four children, have also made remarkable contributions, including lending their voices to speak at various events and Simon has led the Vancouver Lawn Summer Nights event for multiple years.



What makes the Pinsky family unique is the long term strategic impact that their family has had locally, regionally and nationally; from the Vancouver Chapter, the Vancouver 65 Roses Gala, GearUp4CF, Advocacy, scientific research, the Breathe Campaign, Chapter Board responsibilities, National Board duties and leading Lawn Summer Nights in Vancouver are just a few examples of what this family has been involved in. Thank you to Leona, Max, Simon, Tova, Rachael and Rina on demonstrating the qualities of exemplary volunteers for CF Canada.

### **WILCHUCK FAMILY**

The Wilchuck family has tirelessly spent decades contributing to the South Saskatchewan Chapter by giving their time to all chapter initiatives and by spearheading their own large events. Donna and Greg have greatly increased awareness of CF in Regina and the surrounding area through their events. The Ladies Night, the Ride for the Breath of Life and the Children's Royal Balls all draw in people not otherwise aligned with Cystic Fibrosis Canada. The Wilchuck family became involved in the fight when Donna's lifelong best friend Karen Lackey battled with cystic fibrosis. The impact her passing has had is what fuelled their passion to find a cure for all others impacted CF. We are thankful for everything that the Wilchuck family has done to support Cystic Fibrosis Canada over the years.



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**The Céline Award acknowledges a volunteer individual, couple or family who had made indispensable and sustained contribution to chapters at the "grassroots" level.**

### **ERICA VAN DORP**

Erica is an inspiring young adult with CF who is always ready to volunteer and share her story where she can. Her approachable and kind nature have motivated countless people who have met her, and she even goes so far to message other CFers to lift their spirits. For the past 15 years, Erica has volunteered in the Edmonton & Northern Alberta Chapter by sharing her story at events including Lawn Summer Nights and the Ride for the Breath of Life, connecting with medical students to explain the challenges of living with CF, and informing her peers about CF. Erica always has a smile on her face despite her hardships, and is never one to back away from a challenge. We thank Erica for her incredible service and for sharing her story to inspire others.



### JOANNE BREEZE

Joanne is invaluable to the team that organizes the Wrapping for a Cure fundraiser in Western Canada. Joanne joined the committee 7 years ago and became the Coordinator of Supplies within a few years. Her tireless devotion to the role - from finding volunteers, to returning unused supplies - has made the event the great success that it is. Joanne offers to fill shifts whenever extra hands are needed and is always prepared to do the heavy lifting. Cystic Fibrosis Canada is proud to recognize Joanne for her incredible efforts and contributions, and we are grateful for her commitment.



### RITA STEINER

Rita is considered to be the anchor of the South Saskatchewan Chapter. She has held almost every position available within the Chapter and has been actively involved in CF Canada for over 30 years. Rita is always the first person to connect with new families and volunteers and makes them feel welcome in joining the CF family. She is a constant presence in Regina and inspires others with her energy, passion and pragmatic disposition. For over 15 years Rita has organized a Jazzerthon, she has been the Chair of the Walk Committee for 9 years, and she is an incredible spokesperson for the organization. Rita is a passionate volunteer and we are grateful for her tremendous contributions.



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

### CHRISTINE BLACK

Christine has volunteered with Cystic Fibrosis Canada since 1983 and helped co-found the Campbell River Chapter after her daughter was diagnosed with CF that year. Since then, she has tirelessly worked for the cause educating the public about the disease. Most recently, in her role as the BC Provincial Advocate, Chris has helped motivate others across BC to become more active and engaged with advocacy efforts. She assists and encourages them to organize meetings with local MLAs, helps them prepare an agenda and speaking points for the meeting, and even travels from Campbell River to attend the meetings with community members to support them. Christine played a huge part in advocating for British Columbians to access Kalydeco, and she is currently working with the Government Relations and Advocacy Manager on developing a one day Government Relations and Advocacy Training. Cystic Fibrosis Canada thanks Christine for her tremendous contributions and for empowering the community.



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**The Julia Award is intended to acknowledge non-chapter groups or individuals who have made a sustained and ongoing financial contribution through third party events.**

### GROUPE SANI-TECH

Groupe Sani-Tech and the D'Anjou family are exceptional partners who provide essential support year after year to make the *Soirée des Grands Crus* possible. Without their constant support over the years, their boundless generosity with their time and their devotion to raising awareness about cystic fibrosis among their network, this flagship event in the Québec area would not be possible. Louis D'Anjou as well as his son Simon who is gradually taking the reins of the family business, constantly raise awareness of the cause among their company's suppliers and customers, and involve their staff in the event to ensure its success. We thank them for their support and generosity.





## THE KINSMEN CLUB OF WINNIPEG

Since 2000, The Kinsmen Club of Winnipeg has contributed over \$500,000 to the mission of finding a cure or control for CF. They have supported projects such as the Walk to End CF, The Ride for CF, and The Princess Ball. The Club also generously provides the chapter with a meeting space. Their incredible financial contribution has motivated the competitive streak in other Kinsmen clubs, inspiring others to attempt to surpass this incredible amount by increasing their fundraising efforts for CF. We are grateful to The Kinsmen Club of Winnipeg for their tremendous support.



## WAIWARD

For over 10 years, Waiward has supported Cystic Fibrosis Canada's Edmonton and Northern Alberta chapter through their annual golf tournament which has raised over \$15,000 annually. Each year, contributions have steadily grown and there are plans for this support to continue. Waiward employees are engaged in the cause, and the tournament is used as an opportunity to educate participants and advocate for those living with CF. The CF community is thankful for Waiward's contributions and support.



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**The [Communications Excellence Award](#) recognizes a chapter that has demonstrated overall excellence in the areas of advocacy and public awareness.**

## CYSTIC FIBROSIS CANADA QUEBEC CHAPTER

The Quebec Chapter has demonstrated an incredible amount of focus towards public awareness and has experienced increased media coverage as a result. Their major events are covered in local media, which has increased the visibility of their events. In addition, to raise public awareness of the cause of cystic fibrosis, the Québec Chapter regional committee created a new general Facebook page in 2016 in order to broaden its audience and relay the latest news to members in the area. The new Facebook page enables them to highlight the cause, the involvement of volunteers, the results of activities, the generosity of sponsors and partners, and to promote events. Thanks to its volunteers, the chapter was also able to recruit new sponsors and partners through awareness-raising activities during major events such as the Défibrose Mont-Sainte-Anne, the Soirée des Grands Crus, the Walk to Make Cystic Fibrosis History and the Défibrose – Rouler à pleins poumons.

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**The [Fundraising Excellence Award](#) recognizes a chapter that has demonstrated overall excellence in the area of fundraising.**

## CYSTIC FIBROSIS CANADA CALGARY & SOUTHERN ALBERTA CHAPTER

Despite a downturn in the Alberta economy, the Calgary & Southern Alberta Chapter exceeded their fundraising expectations exponentially. Securing sponsors and participants were expected to be a challenge, but the fundraising committees and office staff worked tirelessly to persevere. Wrapping for a Cure, 65 Roses Golf and The Princess Ball were all an incredible success and the chapter made a significant surplus of net income after operating expenses! We are thrilled to congratulate this incredible achievement and look forward to seeing the chapter build on their momentum.



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

### **CYSTIC FIBROSIS CANADA HAMILTON CHAPTER**

The Hamilton Chapter has been working hard on building a strong core volunteer leadership team over the past few years and this effort has been instrumental in the success of their Chapter. With only 5 Executive Committee members and a slew of volunteers for support they were able to raise over \$400,000 this past fiscal year. Their main event in 2016 – The Walk to Make Cystic Fibrosis History - involved over 60 volunteers and attracted over 800 participants and was the 2nd largest fundraising Walk in Canada raising over \$236,000.



Through personally connecting with each of the teams that joined their Walk, they were able to develop a sustainable relationship with a lot of the local families who are affected by cystic fibrosis. This past year the Chapter took on their first ever Princess Ball with a great group of volunteers organizing it. The co-chairs and committee members worked hard to build new relationships with businesses in the community and their hard work paid off when they sold out this event for 300 people in less than 36 hours! The Chapter has been able to raise awareness through local media, raise funds through successful fundraising, and raise political interest through past advocacy efforts. This group of passionate volunteers may be part of a small chapter but they are mighty and their level of accomplishment is exemplary to other chapters around the country.

*Congratulations to this  
year's recipients*



20th anniversary awards presented to CARSTAR and Siemens at the annual Decant Gala

Norma Beauchamp President & CEO, Cystic Fibrosis Canada, CARSTAR franchise partners, Stefaia and Frank Scottile, Bernice DiVito, Christine Martysiewicz Director Corporate Relations Cystic Fibrosis Canada, Faisal Kazi, Vice President Energy Management, Siemens and Jeff Beach Chief Executive Director Cystic Fibrosis Canada, Ontario.

## CELEBRATING 20 YEAR PARTNERSHIP WITH SIEMENS AND CARSTAR



# SIEMENS

In 1997, Prime Minister Jean Chrétien won a second majority, PEI's Confederation Bridge opened, Titanic hit the movie theatres and the Argos won the Grey Cup. It was also the year both Siemens and CARSTAR partnered with Cystic Fibrosis Canada for the very first time.

Siemens' first involvement was sponsoring the "Breath of Life" Ski Challenge founded by two time Olympian ski racer and Cystic Fibrosis Canada champion Ken Read. In fact it was Ken and the story of his nephew Andrew's fight with CF that first caught the attention of DL Leslie former corporate relations manager for Siemens.

CARSTAR became a proud supporter after learning that Victoria, a franchise owner's granddaughter, had been diagnosed with cystic fibrosis. That year, CARSTAR donated proceeds from their annual charity golf tournament to Cystic Fibrosis Canada's Hamilton Chapter.

In two decades, both Siemens, CARSTAR and their remarkable employees have supported our annual walk and held countless fundraising events, including the Siemens annual soccer tournament and corporate match program and CARSTAR'S signature shine month program featuring their Soaps It Up car wash.

The dedication and commitment of these partners to make a difference in the lives of those living with cystic fibrosis is evident in the success of their fundraising efforts. To date Siemens has raised \$1.74M and CARSTAR has just surpassed the \$3M milestone.

On behalf of Cystic Fibrosis Canada, our researchers, caregivers, patients and their families, thank you, Siemens and CARSTAR.

Thanks to you we are 20 years closer to a world without CF.





**Cystic Fibrosis  
Canada**



**Kin Canada**  
Kinsmen • Kinettes • Kin

*Together for life®*



## KIN CANADA REACHES THE \$45 MILLION MILESTONE FOR CYSTIC FIBROSIS CANADA

As Kin Canada and Cystic Fibrosis Canada celebrate 53 years of valued partnership, 2017 also marks another major milestone: \$45 million raised by Kin Canada to help Canadians living with cystic fibrosis.

The partnership between Cystic Fibrosis Canada and Kin Canada is unlike any other in the country. What started as a friendly conversation between Kin Bill Skelly and Dr. Douglas Crozier over drinks has blossomed into an incredible 53 year partnership that has reached the \$45 million milestone fundraised for Cystic Fibrosis Canada. This remarkable milestone was celebrated at the Kin Canada Convention in Halifax this August.

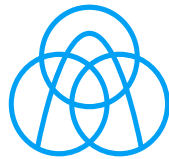
When Kinsmen and Kinettes first joined the fight against cystic fibrosis, most children with the disease did not survive long enough to attend kindergarten. Today, as a direct result of the advancement of research, the development of healthcare, and advocating for access to medication, Canadians living with CF are living into their 50s and beyond.

Year after year, the Kinsmen and Kinettes continue to lead with their hearts by organizing and participating in events in support of CF Canada, encouraging donations, raising awareness and supporting their local chapters. From golf tournaments, to Pub putts, to Radio-thons, to supporting the Walk To Make Cystic Fibrosis History; Kinsmen and Kinettes across Canada have been there every step of the way and have made a huge impact on the lives of those living with CF.

Kinsmen and Kinettes have been unwavering in their support and have set the standard not only for the cystic fibrosis community, but for the Canadian philanthropic community. We are so proud and grateful for an ongoing partnership that continues to improve the quality of life for Canadians living with CF.

Thanks to Kin Canada for their support for the past 53 years in creating a world without cystic fibrosis. We couldn't do it without them!

# CF CANADA WELCOMES A NEW NATIONAL PARTNER: THYSSENKRUPP ELEVATOR (CANADA) LIMITED



Earlier this year Cystic Fibrosis Canada had the pleasure of welcoming a new national partner thyssenkrupp Elevator (Canada) Limited.

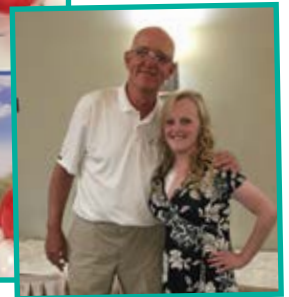
thyssenkrupp

thyssenkrupp is one of the world's leading elevator companies moving people in Canada for almost a half a century, with over 1800 employees in 24 branches from coast to coast. We are honoured to have been chosen as thyssenkrupp Elevator's first ever charity of choice.

Thanks to the remarkable leadership of Ryan Wilson, President and CEO, Meaghan MacRury, thyssenkrupp elevator's CF Ambassador, as well as all the branch managers and employees, they surpassed their original goal of a \$10,000 corporate match within just a few short months with all proceeds going to the Walk To Make Cystic Fibrosis History.

**To date they have raised over \$75,000** and have decided to continue to host fundraising events for the remainder of the year. There is certainly no shortage of creativity with this dynamic team whether it is curling, ping pong tournaments, tap your own maple syrup, children's art contests to win a spot in next year's company calendar, payroll deductions, bowling tournament, bake sales, 50/50, raffles and a t-shirt drive! We are excited to see what's coming next from this passionate team.

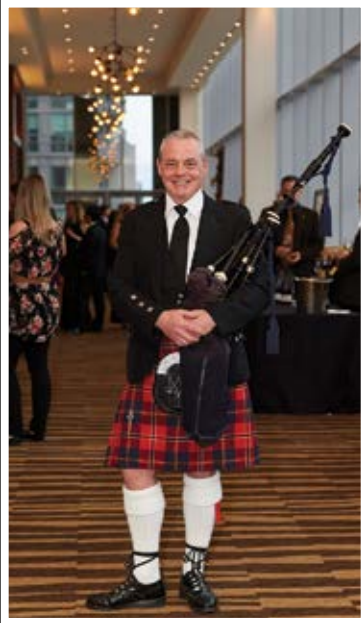
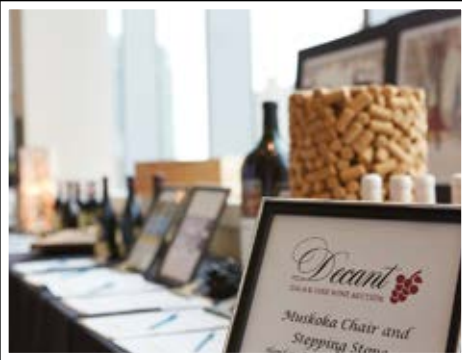
Thanks to everyone at thyssenkrupp Elevator Canada - it is because of supporters like you that we are closer than ever to finding a cure or control for cystic fibrosis.



Cystic Fibrosis Canada welcomed Party City Canada as a new national partner in 2016. Through the remarkable support and dedication of their regional and store management and their employees together they raised \$57,701 through their point of sale ask at cash program. We are thrilled to once again be included in Party City Canada's annual Party City Cares cause marketing campaign. The 2017 ask at cash for donations for cystic fibrosis which was extended for an additional month and took place April 1<sup>st</sup> - June 30<sup>th</sup>. We are very excited to share that Party City has more than doubled their fundraising efforts. As of print time the total was **\$157,000** and growing! A huge thank you to Party City.







# Decant

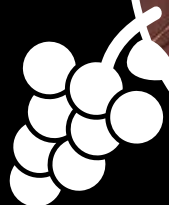
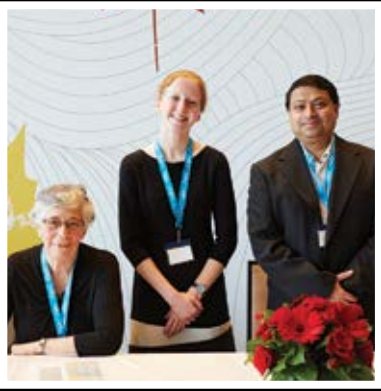
GALA & FINE WINE AUCTION

The Decant Gala & Fine Wine Auction took place on May 6, 2017 at the Delta Toronto Downtown. It was an incredible evening of dining, dancing, and fundraising that transported guests straight into the most famous wine regions of Canada. The Gala raised an incredible \$384,000 for cystic fibrosis research and care.

Cystic Fibrosis Canada was thrilled to host this event in celebration of Canada's 150<sup>th</sup> Anniversary. We were honoured to share in the pride of our great nation with a Canadian themed meal with sommelier inspired wine selections.









# WALK TO MAKE CYSTIC FIBROSIS HISTORY

## TOGETHER WE WALKED TO MAKE CYSTIC FIBROSIS HISTORY!

On May 28, thousands of participants in over 65 locations from coast to coast laced up and put their best foot forward in the fight to find a cure for cystic fibrosis. The Walk to Make Cystic Fibrosis History is CF Canada's largest fundraising event, raising vital funds for CF research, care and advocacy initiatives to help Canadians with cystic fibrosis live longer, healthier lives.

"This simple act went a long way. By joining the walk or sponsoring a participant, together we made great strides in making CF history," said Norma Beauchamp, President and CEO of CF Canada. "I would like to thank our fantastic volunteers for all the hard work they put into planning and organizing the walks. Without them, we would be nowhere near where we are today in terms of money raised and our investment in the future of the CF community."

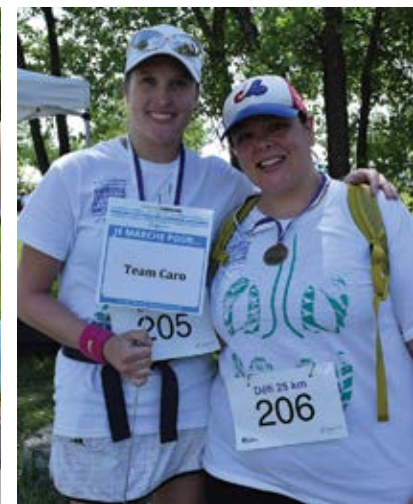
And for the first time, Walkers who couldn't get to a local Walk site were able to participate virtually! This meant that more people than ever were able to participate and show their support for the CF community.

The Walk raised a total of over \$3.6 million that will support world-class CF research and advocating for high-quality individualized CF care and access to medication programs funded by CF Canada.

Together we truly are making strides in finding a cure for CF. We are already looking forward to next year's event, and encourage you and your loved ones to join us!









# MAY AWARENESS: ADVOCATING FOR ACCESS

Every May is Cystic Fibrosis Awareness Month, and this year CF Canada wanted to focus on the work it is doing in advocating to provincial governments the importance of covering life-changing drugs under provincial health insurance plans.



The 2017 awareness campaign brought attention to the major challenges faced by the CF community around access to Orkambi. While provincial health insurance covers a number of other costly drugs to the benefit of their residents, Orkambi is not one of them, and this poses a major problem for the over 1,600 Canadians with CF who could benefit from the drug. It is CF Canada's position that if you are prescribed a drug that will improve your life, you should be able to access it – plain and simple.

CF Canada wanted Canadians to know that time is precious for people with CF, and quick and timely access to Orkambi is crucial. Things that most people take for granted can be impossible for someone with CF, such as going to work, school, and spending time with family or friends.

The campaign was launched online with a video of Cayden, who, like any seven-year-old, just wants to join his team on the field. But once again, a lung flare-up means he'll have to miss out. The right medication can change everything for him, making for less sick time and more game time. Also featured was Hunter, who was just about to leave for his prom. Unfortunately, due to a flare up, he was unable to attend. The only thing standing between him and one of the best moments of his life is not being able to afford the drug he's been prescribed.

CF Canada urged Canadians to sign a petition to ensure those who need access to Orkambi can get it, and to contact their provincial government officials to let them know why it is so important. There were **over 12,000 signatures** on the petition. Needless to say, this is a great start and will help bring attention to this important issue.

We are pleased with the success of the campaign, and to see that the CF community was highly engaged on social media. A number of print and broadcast outlets also covered the issue, including in an article appearing in the Globe and Mail and a segment on CTV news in London.

CF Canada continues to work on behalf of the CF community to advocate for access to life-changing drugs, support the fundraising efforts of our fantastic volunteers, and invest in innovative CF research and clinical care.



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WALK TO

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# MAKE CYSTIC FIBROSIS HISTORY

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Thanks to you, history has been made!

Over \$3.6 million was raised to target world-class research, and to support and advocate for high-quality individualized CF care!

See you next year!





[www.cysticfibrosis.ca](http://www.cysticfibrosis.ca)

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