Cystic Fibrosis Canada™

Connections

WINTER 2015

CYSTIC FIBROSIS CANADA AND **SICKKIDS** FOUNDATION **FORM NEW PARTNERSHIP**

2015 **CYSTIC FIBROSIS CANADA** *Award Winners*

TENILLE ARTS **USES MUSIC TO RAISE AWARENESS** FOR CYSTIC FIBROSIS

JEREMIE SAUNDERS **TEARING DOWN THE STIGMA** OF **LIVING** *WITH* **CHRONIC ILLNESS**

SICKBOY PODCAST MAKES ITUNES BEST OF 2015 LIST

Cystic Fibrosis Canada™

WALK WITH US ON

SUNDAY MAY 29, 2016

Walk with Cystic Fibrosis Canada on Sunday, May 29, 2016 and raise funds to make cystic fibrosis part of our history.

Please mark it on your calendars and start your fundraising.

Sign up at **cysticfibrosis.ca/walk** to be the first to know when registration for the 2016 walk is open.

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MESSAGE FROM OUR PRESIDENT AND CEO, NORMA BEAUCHAMP

It`s hard to believe how quickly my first year with Cystic Fibrosis Canada has gone by, and we have accomplished so many exciting milestones together. I have had the opportunity to connect with the CF community coast-to-coast from Vancouver to St. John. I've been deeply touched by the families and individuals who make our community so extraordinary.

2015 brought many milestones. We have developed a new strategic plan that will take us into the year 2020, as well as a new vision that I look forward to sharing with all of you in the coming months.

In May, Cystic Fibrosis (CF) Awareness Month, thousands stepped up for a cure or control for cystic fibrosis at CARSTAR's Great Strides Walk for Cystic Fibrosis Canada in 72 locations across the county, raising more than $3.5 million for innovative CF research and care.

This year also brought us an exciting partnership with the SickKids Foundation to establish the program for Individualized Cystic Fibrosis Therapy. Through a multi-year commitment to raise $7.5 million in support of CF research at the Peter Gilgan Centre for Research and Learning at SickKids, this centre will help researchers accelerate the discovery of new treatments and determine the most effective, personalized therapies for everyone living with CF.

We were also thrilled to be awarded with Imagine Canada's Standards Program accreditation and we join a growing community of organizations dedicated to operational excellence. The Standards Program is a Canada-wide set of shared standards for charities and non-profits designed to strengthen practices in five fundamental areas: board governance; financial accountability and transparency; fundraising; staff management; and volunteer involvement.

Most importantly, we have revitalized and maintained our commitment to individuals and families with cystic fibrosis through funding vital research and clinical care. These successes wouldn't have been possible without the support of our remarkable donors, partners and volunteers. There is a passion, a commitment and a power in the CF community that I have not experienced in any other sector or cause this far in my career. It is truly incredible how we have created a national and international network of people – families, clinicians, researchers, volunteers and donors – who work tirelessly together to build this Canadian CF success story.

Even with so much to celebrate, our job is far from over. We must continue to be innovative in all the work we do to remain a relevant and sustainable organization focused on our mission to END CF.

I hope you find the courageous stories in this issue of Connections as inspiring as I do.

Together we are creating a world without cystic fibrosis.

Norma Beauchamp
President and CEO

"We must continue to be innovative in all the work we do to remain a relevant and sustainable organization focused on our mission to END CF."

HOPE THROUGH PROGRESS

CYSTIC FIBROSIS CANADA AND SICKKIDS FOUNDATION PARTNER TO TRANSFORM THE FUTURE FOR PEOPLE LIVING WITH CYSTIC FIBROSIS

$7.5 MILLION COMMITMENT ESTABLISHES PROGRAM FOR INDIVIDUALIZED CYSTIC FIBROSIS THERAPY

Cystic Fibrosis Canada has formed a partnership with SickKids Foundation which sees the creation of the Program for Individualized Cystic Fibrosis (CF) Therapy. The partnership includes a multi-year commitment to raise $7.5 million in support of CF research conducted at the Peter Gilgan Centre for Research and Learning at SickKids. This generous support will help SickKids researchers accelerate the discovery of new treatments and determine the most effective, personalized therapies for CF patients.

Together, Cystic Fibrosis Canada and SickKids researchers are creating a national resource to rapidly develop effective, personalized treatments for every person living with CF. With more than two thousand different CF gene mutations, each patient is different. The Program for Individualized CF Therapy is the world's first resource dedicated to the discovery of more effective, personalized treatments for CF. Investments in this initiative will create the platform necessary to harness technological and scientific advances through:

STEM CELL COLLECTION
Tissue samples from CF patients who reflect the diversity of genetic mutations within the Canadian population are required to build a database of stem cells.

GENETIC ANALYSIS
Each patient's genetics will help researchers understand the factors affecting an individual's disease severity and response to therapy, and allow them to predict which therapies will work best for each patient;

PATIENT-SPECIFIC PRE-CLINICAL TRIALS
Researchers will be able to rapidly test new and existing drug compounds on multiple cell samples at the same time, predicting a drug's effectiveness before it is tested on patients;

CLINICAL TESTING
This will allow patients who might benefit from a specific therapy to receive treatment as soon as possible and rapidly bring new drugs to market;

COLLABORATION AND INNOVATION
The program will act as a hub for global collaboration and enable the world's most innovative ideas in CF to come to fruition

Cystic Fibrosis Canada and SickKids have driven a number of landmark discoveries in CF research, including identifying the gene responsible for CF in 1989. Through research supported by Cystic Fibrosis Canada, SickKids scientists were also the first to prove the disease is a defect of a chloride channel – the process by which salt is drawn to the surface of mucus membranes. These discoveries led to the development of Ivacaftor, the first drug that repairs the defective CF gene instead of relieving disease symptoms.

For more information about the partnership and to support the Program for Individualized Cystic Fibrosis Therapy, visit **cysticfibrosis.ca**.

"We've made tremendous progress in treating cystic fibrosis and many patients are now hopeful that CF will not define, or delimit, their lives. But with over two thousand known mutations, we still have work to do. With the successes we've seen over the years, no one should be left behind. This collaboration with SickKids will propel the field of personalized CF therapy and offer tremendous hope for ALL Canadians with cystic fibrosis."
- John Wallenburg, Chief Scientific Officer, Cystic Fibrosis Canada

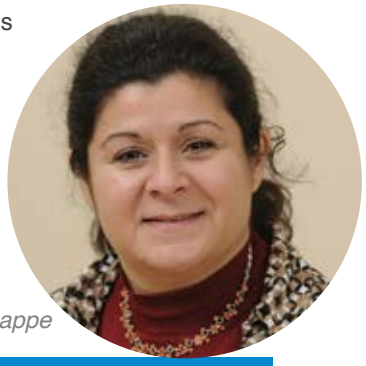
ABOUT THE PROGRAM FOR INDIVIDUALIZED CYSTIC FIBROSIS THERAPY

Drawing from leading programs and infrastructure in stem cells, genetics, and cystic fibrosis, SickKids is the world's most advanced centre for research into the genetic basis of CF and the use of stem cells to identify new treatments. Now, Cystic Fibrosis Canada and SickKids are bringing this work to the next level by establishing the Program for Individualized Cystic Fibrosis Therapy, a national resource dedicated to individualized CF drug discovery. With more than two thousand different CF gene mutations, each patient is different. The goal is to ensure every CF patient has access to the life-changing treatments that will work best for them, as quickly as possible.

"We have never been closer to being able to treat cystic fibrosis as a chronic, yet controllable illness with the development of new drugs that directly target the defects caused by mutation in the CF gene. It's clear that not all CF patients will respond well to the same drug so we need to be able to identify those people who will respond well to new therapies as they are developed. We will soon be able to compare multiple drugs in lung cells grown from stem cells to determine whether potential therapy will work for a particular individual with CF. Furthermore, new technology is allowing scientists a better understanding of complex genetic factors that affect an individual's response to treatment. Together, we will be positioned to provide precision medicine for CF patients, ensuring that each individual receives the best therapy based on knowledge gained from their genetic makeup and the behaviour of their own lung cells."
- Dr. Christine Bear, Senior Scientist, Molecular Structure & Function research program, SickKids

CORRECTING CFTR FUNCTION
Q & A WITH DR. VALERIE CHAPPE

Dr. Valerie Chappe is a Cystic Fibrosis Canada-funded researcher and Associate Professor in the Department of Physiology and Biophysics at Dalhousie University in Halifax, Nova Scotia. Her research is focused on better understanding CFTR dysfunction and how it can be corrected.



Dr. Valerie Chappe

Q. How did you become interested in cystic fibrosis research?

As a student, I was always interested in biomedical research that bridges fundamental knowledge with human disease and medicine. When I was a grad student I was fortunate enough to be in a lab that largely embraced that concept. Although I was working on a different topic (I was studying ion channels in thyroid cells), some members of our group were doing CF research. By interacting with them and listening to their presentations, I became very curious about this topic and wanted to learn more about the disease, how it affects people and what the research challenges were that needed to be resolved to find a cure. It was very inspiring and I guess they transmitted their passion to me. Since then, the high caliber of CF scientists, the challenges and progress of CF research over the years, the dedication of the healthcare teams and the involvement of CF families have been strong motivation for me to continue in this field and to inspire new students.

Q. Please tell us a bit about the research in your lab.

In my lab, we study multiple aspects of CF, mostly to better understand the molecular basis of the disease. Our goal is to understand what contributes to the misbehaviour of CFTR proteins in affected cells and tissues, in order to know what to target to correct the molecular basis of the disease. We are particularly interested in cellular & molecular mechanisms that make people sick by compromising CFTR protein function and stability at the surface of cells lining the airways and digestive tissues. Based on that knowledge, generated by us and by other CF research labs, we test different strategies that target key enzymes and proteins to correct mutant CFTR dysfunction. In my opinion, these aspects of CF research are critical issues that absolutely need to be addressed in order to develop effective, second generation corrector drugs.
Other research conducted in collaboration with CF nurses relates to the epidemiology of CF in the Maritimes, medication adherence and safety from the perspective of adults with CF, and disease progression in patients with rare mutations.

Q. What are some of the recent research highlights from your lab? What are the next steps?

In the last few years we have developed very exciting and promising research projects around the role and therapeutic potential of the neuropeptide Vasoactive Intestinal Peptide (VIP). This is a natural peptide in the body which is important to maintain healthy lungs and intestines, but that is thought to be deficient in CF. We started this project by providing some of the missing molecular knowledge about VIP and its relation to the CFTR protein and applied that to demonstrate that treating CF cells with VIP corrects CFTR proteins with the most common CF causing mutation, F508del. Although there is still a lot of fundamental knowledge that needs to be discovered on this topic, and we continue to devote research efforts to that, we are now at the very exiting step of pre-clinical studies of some engineered versions of VIP that have been developed by PhaseBio Pharmaceuticals Inc. (Malvern, PA, USA) that have very strong therapeutic potential. The data obtained so far are extremely encouraging and there is hope that they will lead to the production of a therapeutic drug for CF patients in the near future, so stay tuned!

Q. How will your findings impact the broader search for a cure or control for cystic fibrosis?

I am convinced that research from my lab has already contributed to further our knowledge of the CFTR protein which is the first step to finding a cure. I am sure that it will continue to do so by revealing new molecular targets for drug development, especially around the VIP peptide. The more knowledge obtained about the CFTR protein, the more molecular targets will be identified and the more therapeutic drugs will be developed for the benefit of all CF patients.

Hard at work in the Chappe lab.

CYSTIC FIBROSIS RESEARCH MAKING NEW STRIDES

Q & A WITH DR. BRADLEY QUON

Cystic Fibrosis Canada-funded researcher Dr. Bradley Quon is making new discoveries in a variety of areas related to cystic fibrosis (CF). Leading a diverse research program, Dr. Quon has identified markers in the blood that can predict lung infections in patients within 4 months. This helps CF patients to better predict and manage their lung infections. He has also found ways to use proteins to predict which patients will respond well to antibiotic treatment, which helps to guide treatment decisions.

In other research, Dr. Quon has examined factors associated with quality of life in adults with CF. Through a literature review, he found that lung function and lung infections had the biggest impact on health-related quality of life in CF.

Dr. Quon is co-leading an international study comparing survival and health outcomes for people with CF in Canada and the US. This research has resulted in an approach to measuring survival that aims to ensure consistent reporting across countries, enabling reliable international comparisons.

Q. How did you become interested in cystic fibrosis research?
As a respirologist, I was drawn to the field of cystic fibrosis by its youthful and engaged patient population. As a clinician-scientist, I felt there were many gaps in knowledge to perform clinical research that could either improve our understanding of the disease or enhance clinical care and decision-making.

Q. Please tell us a bit about the research in your lab.
We are using innovative technologies such as mass spectrometry and digital immunoassays to help identify and measure proteins in the blood (i.e. biomarkers) to detect CF lung infections earlier. We believe there's a danger signal circulating in the blood that precedes the onset of a lung infection flare-up.

Q. What are some of the recent research highlights from your lab? What are the next steps?
Using mass spectrometry, we identified a 6-protein blood signature that can predict lung infection flare-ups within 4 months of a routine CF clinic visit with good confidence. Our study findings were recently published in the journal *Thorax*. We are excited about our results and are in the process of fine-tuning the blood protein signature prior to evaluating it using blood samples collected from patients in the United Kingdom and United States.

Bradley S. Quon
MD, MSc, MBA, FRCPC.

Dr. Bradley Quon

Dr. Quon is a clinician-scientist with advanced training in biomarker research, epidemiology, health care management, and clinical respirology/cystic fibrosis. His research focuses on bridging discoveries in the basic laboratory into the clinic to improve patient outcomes. He is currently searching for novel biomarkers of inflammation and infection to improve disease monitoring in CF.

Currently, Dr. Quon is an Assistant Professor of Medicine and a Principal Investigator at Centre for Heart Lung Innovation (HLI) at St. Paul's Hospital. He is the Research Director of the St. Paul's Hospital Adult CF Clinic and co-director of the UBC Respirology Training Program Research Curriculum.

Q. What influenced your decision to work at St. Paul's Hospital?
My lab is located in the Centre for Heart Lung Innovation (HLI) at St. Paul's Hospital. This is a world-renowned research institute that was founded by Dr. Jim Hogg, one of the international giants in respiratory research. Furthermore, the Adult CF Clinic is located at St. Paul's Hospital, which provides an ideal environment for translational bench-to-bedside research.

Q. What is the most controversial question in your field right now?
Can tracking the body's inflammatory response in CF be used to predict disease activity (e.g., flare-ups) and help guide treatment decisions?

Q. If you could give one piece of advice to someone considering a research career, what would it be?
Research is highly competitive and therefore advanced training in your field of interest is critical to success. Having research mentors that are well connected within the broader scientific community is also important, as it will help you develop the collaborations necessary to complement or validate your research.

Q. How will your findings impact the broader search for a cure or control for cystic fibrosis?
Lung infection flare-ups have a profound impact on the quality of life and health of individuals living with CF. 1 in 5 children and 1 in 2 adults will require at least one course of intravenous antibiotics each year to treat these events. My ultimate goal is to develop a simple blood test that can be applied at the point-of-care by CF doctors so they can modify therapies to prevent lung infection flare-ups or treat them earlier to limit lung damage.

VIRTUAL EDUCATION PROGRAM FOR PATIENTS AND CAREGIVERS A SIX PART WEBINAR SERIES

Cystic Fibrosis Canada

SUPPORTED BY VERTEX

Cystic Fibrosis Canada received funding from Vertex Pharmaceuticals Inc. to host a six part educational webinar series for patients and caregivers. Topics were selected based on input from Cystic Fibrosis Canada's Healthcare Advisory Council, the Adult CF Advisory Committee and from the community via a Facebook poll. Delivering one webinar per month from April to September 2015, the series reached a total of 201 attendees, with a further 415 online views of the recorded sessions, thus far.

THE FOLLOWING IS A BRIEF SUMMARY OF EACH WEBINAR:

Webinar one, *Tips for Parenting a Child with CF*, was presented by Lisa Greene, author of three books on parenting children with health issues, certified Family Life Educator, and mother of two teenagers with CF. The engaging presentation included practical tools and skills to help deal with the everyday challenges of living with CF. During her presentation, Lisa stressed the importance of family relationships and emotional support on the health of family members.

Webinar two, *Depression and Anxiety in CF*, presented by Dr. Alexandra Quittner, provided an overview of mental health in CF and the recently developed guidelines for mental health screening in North America and Europe. Dr. Quittner noted that international guidelines suggest annual screening and ongoing education related to mental health for all CF patients beginning at age 12, along with offering screening to parents of children with CF from the time of the child's birth to 17 years of age.

Webinar three, *Collaborating with Your Clinic to Improve Your Healthcare* was presented by Kathy Sabadosa and Leila Khan Cruikshank. Kathy and Leila each provided a different perspective on the issue, with Kathy delivering an overview of the quality improvement initiatives in place at the US CF Foundation, and Leila talking about her own personal experiences as a spouse of a CF patient, working together with the St. Michael's Hospital Adult CF Clinic in Toronto.

Webinar four, *Transitioning from Pediatric to Adult Care*, was delivered by Anna Gravelle and Kristine Kerr. Anna talked from her perspective as a Cystic Fibrosis Nurse Clinician/ Care Coordinator at British Columbia's Children's Hospital (BCCH) and adjunct faculty member at the University of British Columbia School of Nursing. She shared helpful information on what parents may expect during the transitioning process and how they can help their youth prepare for the transition. Kristine shared her recent, personal experiences in successfully supporting her son, now 21, through transition to adult care.

Webinar five, *Cystic Fibrosis Treatment Adherence*, presented by Dr. Patrick Daigneault, provided an overview of current and future CF therapies and the therapeutic burden on patients' daily lives. He discussed the importance of therapeutic adherence, and why good adherence is so difficult to obtain. Lastly, he provided a case study from his CF clinic, demonstrating how adherence can be measured and how data can be used to help improve adherence. Following the presentation, Matthew, a young adult with CF, joined Dr. Daigneault during the Q&A session to share the patient perspective on adherence in response to audience questions.

Webinar six, *Cystic Fibrosis-Related Diabetes*, was presented by Dr. Yves Berthiaume and Paul Underhill. Dr. Berthiaume provided an overview of cystic fibrosis-related diabetes (CFRD), as well as information on how it presents in comparison to Type I and II diabetes, its relationship to lung disease and infection, and how it is diagnosed and treated. Paul Underhill, an adult living with CF and CFRD and co-founder of Rumble Drinks, shared his experiences living with CFRD, emphasizing the importance of healthy eating and living in managing his symptoms and staying well.

Cystic Fibrosis Canada is working to secure funding to continue this well-received webinar series in 2016. If you missed viewing the live webinars, you can watch the recorded sessions on our YouTube channel: youtube.com/user/CysticFibrosisCanada.

TEARING DOWN THE STIGMA OF LIVING WITH CHRONIC ILLNESS

BY JEREMIE SAUNDERS

My name is Jeremie Saunders. I am 27 years old, I live with Cystic Fibrosis (CF) and CF is the best thing that has ever happened to me. I know what you're thinking – "what the heck?! Who says that?" Let me explain a bit about myself first.

I was born in St. John's, Newfoundland in 1988 and according to my mom, I was the cutest little muffin-head around. Fast forward to 18 months old, and I was diagnosed with CF. As you can imagine, my parents were completely floored. In their late 20s they found out that their first child would live the rest of his life slowly but surely drowning in his own lungs, and more than likely wouldn't live beyond the age of 25.

It turned out out I have two of the best parents in existence. They did everything they could for me. As soon as I was able to walk on my own, they practically forced me to be very active. Sure, they knew that there was no cure, but they also knew that if my lungs were going to give out due to mucus build up and scarring, the least they could do to keep death off my doorstep was to put me into every sport you could imagine. So that was my life as a child, teen, and into my young adult life. You name it, I tried it. Soccer, baseball, basketball, tennis, swimming, track and field, sprint canoe/kayak. I did it all.

Because of my physically active lifestyle growing up, I was able to maintain a fairly solid lung function all the way up into my young adult life. I had a few "tune-up's" where I'd be admitted to the hospital for a couple of weeks, but those were very rare. More of my issues surfaced in the form of bowel obstructions. I was a sneaky little child and for some reason I figured I'd be better off if I just threw my digestive enzymes into the garbage, perhaps in a desperate attempt to be more "*normal*." Obviously that wasn't a great idea.

Jeremie Saunders and his two best friends Taylor and Brian, launched Sickboy Podcast which has made the iTunes Best of 2015 List.

I went into the hospital for the routine admittance which included IV fluids while undergoing enemas to clear me up, but this time the immense stomach pain never subsided. The doctor's soon realized what they were dealing with was anything but a regular bowel obstruction. This time, I had been diagnosed with something called Intussusception. My large intestine was essentially rolling my small intestine in on itself, kind of like how you roll up a pair of socks into one another (gross, right?) This experience was single handedly the scariest and the most embarrassing moment of my life.

As an actor/storyteller, I tend to view the good in all of the hardships in life. No matter how hard, scary or embarrassing things may be in the moment, there is always light to be found in every situation.

This brings in why I say CF is the best thing that has ever happened to me. There are two primary factors to this; the first is the fact that for most of my life, I've had time to come to terms with the fact that statistically speaking, I will not live nearly as long as most of my peers. Essentially, CF has given me the time to accept my own mortality. With that comes an extraordinary sense of freedom which has translated into choosing to live like nothing is unattainable.

"No matter how hard, scary or embarrassing things may be in the moment, there is always light to be found in every situation."

"The fear of death follows from the fear of life. A man who lives fully is prepared to die at any time." That's a quote from Mark Twain, it perfectly describes how I have been living my life. I have CF to thank for that.

The second reason for CF is the best thing that has ever happened to me is that, like the horribly embarrassing enema experience, CF gives me all of these incredible stories. Stories that are funny, scary, uplifting, inspiring and empowering. Knowing that I have an arsenal of stories worth sharing with the world I became inspired to create a way to share my stories and the stories of other people who are living with chronic or terminal illness. Enter *Sickboy Podcast*. *Sickboy* is a weekly podcast two of my best friends and I created, where we sit down and have an unapologetic, uncensored and humourous conversation about the absurdity of living life with illness. We take part in these conversations for: so we can tear down the stigma that comes with talking openly about illness, and to find the levity and humour in an otherwise dark place.

I have found laughter to be one of my all-time most effective forms of therapy. For me, it's just as important as the ventolin/hypertonic saline treatment meant to keep my lungs in check. With that in mind, we created this project and I am so proud to say that the response has been overwhelmingly positive.

Again, if it weren't for CF, I would never have come across this new passion for opening up a conversation with people from all over the world to hear their stories, and their experiences in living life with a chronic illness. I'd love for you – yes, YOU – to join in on the conversation and the laughs.

Check out Sickboy Podcast on iTunes. Follow along with what we are up to over at sickboypodcast.com, find us on Facebook and Twitter @sickboypodcast.

Jeremie Saunders was diagnosed with CF at 18-months-old.

STAYING POSITIVE

BY ALEXIS LAVOIE

Alexis Lavoie with Gaétan Frigon, former dragon on the show Dans l'œil du dragon.

My name is Alexis Lavoie and I live with cystic fibrosis (CF). I believe that in life, you have to take the negative things that are thrown at you to bring out the positive. With this mindset, I have fought cystic fibrosis daily for the last 26 years.

CF has its fair share of constraints and difficulties that impose on my daily life – the hospitalizations, the daily treatments and other physical challenges. I am reminded regularly of the severity of my disease, but I continue to fight and maintain a positive attitude.

Cystic fibrosis has helped me develop a strong character – I am a fighter. Despite having a very low lung function, I continue to fight for my dreams to become a successful entrepreneur. I also put my energy towards the company I founded, Lavron Solutions. Even with a very low lung function, I move forward with enthusiasm and hope.

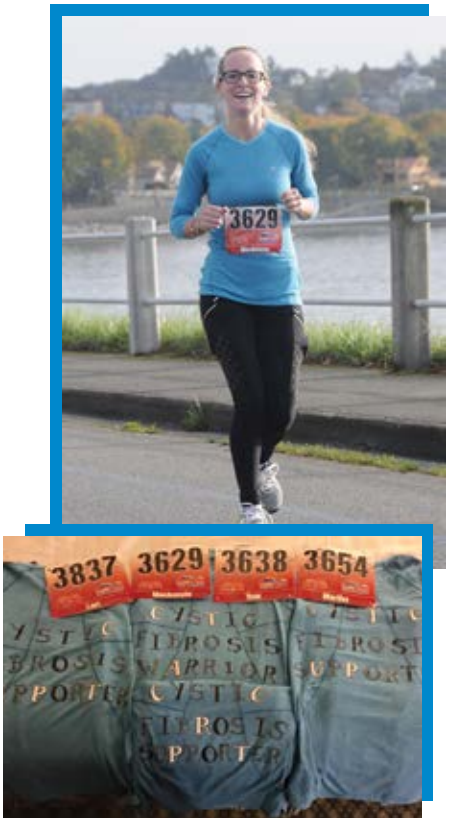
The advancement in CF research that continues to evolve also gives me hope for my future. My life would have been impossible 30 years ago without the progress CF research has seen and I am thankful to those who have invested in CF research. I have attached the same optimism to my own life and so I continue to fight.

MACKENZIE NORRIS DOESN'T LET CF SLOW HER DOWN

On Thanksgiving weekend, more than 9,000 runners met in Victoria, BC for the 36th annual Goodlife Fitness Victoria Marathon. The stunning half marathon route winds past historic government buildings, through Beacon Hill Park, and along the Pacific coast. For 24-year-old Mackenzie Norris, completing this 21 km run for the third time was particularly meaningful, because Mackenzie has cystic fibrosis (CF).

On race day, Mackenzie got up extra early to manage her CF, gear up, and walk in the dark to join the other runners for the 7:30 a.m. start. Running alongside her for support throughout the race were Mackenzie's mom, Tobi, her aunt Lori, and a friend. The four of them crossed the finish line together at 3:00.01, buoyed by the energy of other runners, spectators, and race organizers. For Mackenzie, the race had a few tough moments—her lungs felt pretty heavy at the beginning and some of those hills seemed incredibly long—but she showed her usual determination by digging deep and meeting the challenge head on. She didn't complain, kept a smile on her face, and even offered encouragement to other runners. In Mackenzie's words, "it was a day to show cystic fibrosis who was boss!"

Next year, Mackenzie's goal is to go one second faster and break the three hour mark.



Mackenzie Norris and her family run for CF at the Victoria Half Marathon.

STILL HERE, STILL TRYING TO **HELP MOVE THE CF 'EXPIRY DATE'** *FORWARD*

BY MAX MCGUIRE

Max McGuire speaks at Lawn Summer Nights in Ottawa, ON.

The day I was born, I was baptized immediately and five hours later was read my death rites. After being born seemingly healthy, I suddenly turned blue due to a diaphragmatic hernia, an occurrence that came with an 80-per-cent chance of death. Two years later, both my sister and I were diagnosed with cystic fibrosis.

At the time of my diagnosis, children with CF were only expected to live until the age of 13. Now, at 33, I'm still alive and doing relatively well. I'm lucky to have been born in an era of advanced medicine and into such an amazing, supportive family.

I'm luckier than the dozen or so CF kids my sister and I shared rooms with at the hospital: we are the only two fortunate enough to still be alive today. This says a lot about the wonderful care we've received over the years, along with the uncountable intangibles that our family provided in stability and love. Sadly, though, it says more about the inevitable devastating effects of this terminal illness.

It wasn't until Grade 8, when I had to read an article out loud about cystic fibrosis, that I was made aware of my own mortality. The article was filled with the usual medical terms about CF being a genetic illness that affects many of your organs and causes irreparable damage to your lungs. While reading it, I got trapped on a line that I had never heard before: "The average life expectancy for a cystic fibrosis patient is 33." I was forced to face the reality of my illness head on. Imagine at 13 believing that you only had 20 more years to live.

The following decades have been spent remembering to take my pills, doing my daily nebulizers and therapies, along with regular checkups and tests every three months. Every time I catch a cold, I hope it doesn't turn into a lung infection — inevitably, it always does. I then take weeks of heavy antibiotics, which wreak havoc on the rest of my body, while I try to prevent further lung damage. I also try to have a life.

Consciously or not, CF has been a part of every decision I've ever made. It's an internal curfew whether I like it or not; it's forced me to put down the extra drink or sleep the extra three hours when needed. It's also been the gift of awareness that inspires openness and honesty with friends, family and partners.

I know what it's like to have an expiry date or fear making long-term goals. In questioning life's purpose at an early age, I've been able to make choices to try to leave my mark on the world, which has inspired my chosen career in film.

After a decade of making mediocre movies and attempting to learn my craft, at 30 I finally tackled cystic fibrosis in a personal project, Foreverland. It is semi-autobiographical in content, if not in narrative, and has raised more than $200,000 for CF worldwide.

In 2013, I participated in the inaugural Lawn Summer Nights event in Ottawa. Lawn Summer Nights is a lawn bowling fundraiser that is held in cities across the country and benefits Cystic Fibrosis Canada. Founded in 2009, the event has helped raise more than one million dollars, generated awareness about cystic fibrosis and revived one of summertime's classic leisure sports: lawn bowling. Here in Ottawa, we've raised more than $80,000 in two years. This July, I will once again be lawn bowling in support of Cystic Fibrosis Canada. Joined by 40 other teams, I will be fundraising to help fund life-saving research for those living with CF.

I wasn't supposed to be here 20 years ago. Hell, I wasn't supposed to be here 33 years ago, but I am. I know I'm here because of the hard work and research that has been endlessly funded by fantastic events just like Lawn Summer Nights around Canada and the world, which have consistently allowed us to keep moving the "expiry date" forward.

Cary Feldstein, double-lung transplant recipient, Steveston, BC.

CARY'S GIFT OF LIFE

BY CARY FELDSTEIN

During the summer of 2014, I paused to look up at the sky while taking a long last breath of fresh air before entering Vancouver's St. Paul's hospital. At 36 years old, I had already lived longer than expected when my parents and I first learned about my cystic fibrosis (CF) diagnosis over 25 years earlier. I had entered St. Paul's and was quickly admitted to the ER. The doctor's initial assessment was not good – I was in septic shock.

I realized that this was not going to be another usual routine admission for a CF exacerbation. About eight years earlier I had received one of the most dreaded setbacks anyone with cystic fibrosis could get. My routine sputum sample had grown bacteria called *Burkholderia cepacia* complex (*B. cepacia*). Now with the onset of septic shock this likely indicated cepacia syndrome – an end stage complication of cystic fibrosis.

I knew that this day may come, but I had hoped for much more time. The next 24 hours were the scariest and toughest fight yet in his battle with cystic fibrosis, but thankfully they were not to be my last and the infection responded to antibiotics.

Life returned as normal as possible for me – an adult in end-stage cystic fibrosis lung disease. For me this meant spending more days in hospital or administering IV antibiotics at home. Sleeping about half the day, staring at my transplant pager and using supplemental oxygen to sit up or walk made up the rest of my time. I was also fighting a legal battle related to negligence of my employer in misrepresenting the degree of coverage I would receive for disability benefits. My wife and I made the tough decision to not relocate to Toronto to wait for a double-lung transplant due to financial reasons and the impact of taking everyone away from friends and family.

"My girls have their dad back, and I've got my donor and their family to thank."

Three months later, during a more routine hospitalization, it was a sunny afternoon. My wife and daughters had come by for lunch and they all had a fun and happy visit. Only a couple hours after they left, a nurse ran into the room and gave me the news I had been waiting for. A pair of lungs had been found for me!

The surgery was over ten hours and was successful. For everyone involved, the following days and weeks were an incredible fight for life and strength. The first several days after surgery, my new lungs were not working. I was kept alive by artificial life support and the family just waited. The weeks seemed like months, but I was happily home with my family just three weeks after transplant, in time to celebrate the holidays.

One year post transplant I continue to improve. I am significantly stronger than I was pre-transplant, and can take large breaths and be entirely free from coughing. Most importantly I've now had one entire extra year with my wife and daughters. One extra birthday, one extra summer vacation and so many new memories to share.

The help and support has overwhelmed me and my family. I often think about my donor every day and wonder about their story. The medical teams who have cared for me, advancements related to transplantation, cystic fibrosis and new medications all have been responsible for getting me this far and have kept my family together.

I now also volunteer to promote organ donation registration in BC and speak on behalf of cystic fibrosis. I was especially honoured to have the opportunity to share my story and directly thank Dr. Lap-Chee Tsui for his role in advancing cystic fibrosis research.

Cary with twin daughters Anna and Sophie.

ELIJAH'S STORY

BY: CHRIS FORDHAM

Seth and Elijah, BC.

We have two sons: Seth is 7 and Elijah is 5. Elijah was the first child in British Columbia (BC) to be diagnosed by the newborn screening process in Duncan, BC. Not long after the holidays, the year Elijah was born (2009), we received a phone call from our family doctor. We would not usually be too concerned except for the fact that the message was left over the holiday season and said we needed to call back to discuss some results as soon as possible but that we shouldn't worry.

As much as we tried not to worry, we did. We made contact with our doctor and she said that we needed to come in for a meeting and that she did not want to have this conversation over the phone. This led to more worry. Nothing could have prepared us for what came next.

"Elijah has cystic fibrosis." The statement hit hard and caused confusion. The questions and emotions came flooding. We felt as if we had just been struck by a tidal wave of epic proportions and we were in shock. The shock would last for many days, weeks and months (years, really) to come. Our world had instantly been flipped upside down, never to be the same again.

And so began our journey into the world of cystic fibrosis (CF).

Feeling quite helpless, we were introduced to the wonderful staff at the CF Clinic at Children's Hospital in Vancouver where it appeared we would be making many trips and visits in the days to come for tests, education, treatments and more. To say we were overwhelmed would be the understatement of the century. But so it went. We learned that we were able to join the CF Clinic in Victoria, and this was a huge provision as the ramifications of travelling with the kids to Vancouver each month or more would have been taxing on every level. At times, travelling to Victoria had been challenging enough.

Our first weeks and months were intense. They were filled with genetic tests, sweat tests, blood work, ultrasounds, x-rays and more. Shortly after the diagnosis of our son Elijah we were all tested so we could get a baseline and family history. My wife and I turned out, of course, to be carriers of the recessive gene for CF although neither of us have the disease. The doctor was trying to encourage us when he said "don't worry, the chances of Seth (our older son) having CF are slim. I wouldn't worry... it won't happen."

We waited and prayed and the results came back positive. Seth also had CF. We were trying to prepare ourselves for the possibility but holding out hope that it wouldn't be the case. Our world was rocked for the second time. We were trying desperately to figure out which way was up and what all this meant. Putting on brave faces and trying to cope, we were coming apart inside.

I threw myself into research. Determined to become an "expert" on cystic fibrosis and everything CF-related. What a process! It kept me occupied and somewhat allayed my feelings of complete and utter helplessness. At the same time I began to plan an event, The Elijah Project. The purpose was to educate, raise awareness, build community and support for Cystic Fibrosis Canada. The Elijah Project was a sponsor supported run, walk, or ride with family, friends, food and prizes. Almost 300 people came out to support and more than $10,000 was raised. This is something we hope to do again in the future.

CF has been a journey that has forever changed us. Our appreciation and thankfulness for life, health, family, friends and all of the most important things in life – relationships, has been exponentially compounded. We don't take as much for granted any more on any level and tend to try to make the most of every opportunity. Time with our kids is precious and treasured.

Both Seth and Elijah continue to enjoy very good health living with CF and have had very few incidents over the years.

Although the screening process brought us some of the hardest news we had ever received, newborn screening for cystic fibrosis is a vital tool to help slow the progression of this fatal genetic disease.

Early diagnosis for cystic fibrosis through newborn screening allows for immediate intervention and treatment. Without newborn screening, irreversible damage to the lungs and digestive system may occur.

MADI VANSTONE RECEIVES RARE CHAMPION OF HOPE AWARD

Advocacy Champion Madi Vanstone continues to turn heads for her outstanding work in raising her voice for Canadians with cystic fibrosis (CF). Global Genes™, one of the leading rare disease patient advocacy organizations in the world, honoured Madi with the *International Teen Advocacy Award* at the **4th Annual RARE Tribute to Champions of Hope** on September 26, 2015 in Huntington Beach, California.

At just 12-years-old, Madi successfully advocated for the funding of KALYDECO® in Ontario and was a key influencer in helping have the drug funded in other provinces across Canada. Now 14-years-old, Madi continues to impact the future for not only people living with CF, but all people living with a rare disease.

"I am both surprised and excited to be named this year's International Teen Champion of Hope. It is an incredible honour to be recognized for my efforts. I hope others my age will realize that their voices are loud enough to be heard as well," says Madi.

Over 300 individuals and organizations worldwide were nominated by their peers for a RARE Champion of Hope award for their notable efforts in rare disease advocacy, science, collaborative sciences, medical care and treatment. From the extraordinary list of nominees, members from the Global Genes Board of Directors, Medical and Science Advisory Board, and other key partners, selected the recipients.

TRIBUTE TO CHAMPIONS OF HOPE

Madi Vanstone is the 2015 RARE Champion of Hope in International Teen Advocacy

Past award honorees have included Dr. Elizabeth Neufeld – UCLA for her contributions in science related to Lysosomal Disorders, Henri Termeer – Genzyme for his Lifetime of Achievement in rare disease, Dr. Stephen Groft – for his lifetime achievement at the National Institutes of Health Office of Rare Diseases Research, Rick Guidotti – Positive Exposures, for his work in photography & rare disease, and Adam Nelson, three-time Olympic Athlete and Gold Medalist, for his commitment to raise awareness for rare disease.

Madi's remarkable work has also been acknowledged by the Canadian Organization for Rare Disorders (CORD) with a *Youth Leadership Award* which celebrates and recognizes contributions and achievements of young people in the rare disease community. Madi also received the Association for Fundraising Professionals (AFP) *Outstanding Youth in Philanthropy Award* for her noteworthy commitment to the community through her advocacy and fundraising work.

Congratulations Madi!

CYSTIC FIBROSIS CANADA ENVISIONS A WORLD WITHOUT CF

MAY AWARENESS MONTH 2015

A WORLD *without* CYSTIC FIBROSIS

PRESENTED BY Cystic Fibrosis Canada

Every year in May, Cystic Fibrosis Canada embarks on a month long campaign to raise awareness about cystic fibrosis (CF) and generate the crucial funding needed for life-saving CF research, care and advocacy initiatives to help improve the lives of the more than 4,000 Canadians battling this disease.

This year, we asked Canadians to imagine *A World Without CF*, inspiring the CF community to get involved online in the fight for a cure or control for this disease. We received many heartfelt responses on a microsite that was created to display all of the responses in one place. Canadians submitted their video, text and picture and messages describing what a world without CF would look like to them.

Our corporate partner CARSTAR Automotive Canada Inc. helped us raise even more awareness, most notably through social networks this year, with an agreement to donate $5 (up to $100,000) to Cystic Fibrosis Canada for every social tweet, retweet or share on Twitter or Facebook during the month of May that included the #AWorldWithoutCF hashtag. We were successful in exceeding this goal and CARSTAR donated $100,000.

We shared Public Service Announcements (PSA's) which included appearances by ETALK television host and Cystic Fibrosis Canada Celebrity Ambassador, Ben Mulroney; CF Champion, Madi Vanstone, and Toronto Football Club goal keeper, Joe Bendik. Ben, Madi and Joe raised their voices through short PSA's dedicated to raise awareness about CF and urged Canadians to get involved by joining CARSTAR's Great Strides™ Walk for Cystic Fibrosis Canada or volunteering for a local chapter.

Cystic Fibrosis Canada also published a captivating video on YouTube which featured Canadian living with CF and their caregivers talking about what a world without CF would look like to them. To watch the video, visit Cystic Fibrosis Canada's YouTube page: youtube.com/user/CysticFibrosisCanada.

After an incredibly successful May Awareness month this year, Cystic Fibrosis Canada is grateful to each and every person who was involved. Whether it was by sharing a tweet on Facebook or Twitter, or participating in a local Walk – you are helping us get closer to *A World Without CF*.

A NEW INITIATIVE **LIGHTS A SPARK** ON FUNDRAISING

This year, Winnipeg's own *Coal and Canary Candle Company* partnered with Cystic Fibrosis Canada to sell their *Always Keep Your Spark* scented candle – an amazing blend of Valencia orange, bergamot and chili pepper that was created to send a message of positivity and hope that reflects the unshakeable courage of all those fighting cystic fibrosis.

Each candle sells for $25, with $10 from every sale going to Cystic Fibrosis Canada.

Visit Coal and Canary's website to make a difference in the lives of Canadians living with cystic fibrosis and order your scented candle today!

www.coalandcanary.com

Tenille Arts uses her music to increase awareness of cystic fibrosis (Vanessa Lanktree Photography)

TENILLE ARTS USES MUSIC TO RAISE AWARENESS FOR CYSTIC FIBROSIS

BREATHE

Cystic fibrosis (CF) is a cause close to country singer-songwriter Tenille Arts' heart. Inspired by a CF fighter in her hometown of Weyburn, Saskatchewan, on April 14, 2015, Tenille released a song called *Breathe* on iTunes with 100 per cent of the proceeds going to Cystic Fibrosis Canada. The song was No. 6 on the iTunes country chart and No. 54 on the overall chart.

Tenille`s CF journey began when she was an assistant dance teacher in Weyburn and met five-year-old Teresa, who has CF. Tenille could not believe that a beautiful little girl could have such a devastating disease and the two developed a bond and from that bond came a strong personal desire for Tenille to help find a cure for CF. Ever since meeting Teresa, Tenille has performed at many events and fundraisers for cystic fibrosis in Weyburn and Regina, Saskatchewan.

"Music is so important to me because it connects people in ways that nothing else can..."

The song Breathe was co-written by Matt Scales and Barnaby Pinny about what it's like living with cystic fibrosis. Matt had CF and unfortunately lost his battle with the disease in 2007 at the young age of 27. Members of the CF community encouraged Tenille to re-release the song and Matt's dad graciously granted permission to share Matt's music with the world again. A fundraiser was held for the recording of the song at Teresa`s parents – Mike and Cara Weger's – 6th Annual Night Out for Cystic Fibrosis and at the end of 2014 and the song was recorded in Nashville, Tennessee.

"Music is so important to me because it connects people in ways that nothing else can and often says the words that people find hard to express. I've always said that my first song release would be something that I am so proud of, but I would have never thought it would be something so powerful and have the ability to change lives," says Tenille.

Download Breathe on iTunes at apple.co/1ROWmST or on Google Play at bit.ly/1MooUPo to help fund vital CF research and care for all those living with cystic fibrosis.

CHARITABLE CELEBRATIONS

HOW AN ECHOAGE PARTY CAN RAISE FUNDS FOR CYSTIC FIBROSIS

BY BONNIE LEVINE

Our family's journey with CF began in 1956 and has evolved from caregiving to fundraising. My mother Carol shares our story in her own words.

"Both my brother and infant sister passed away from cystic fibrosis (CF). My brother Jeffrey passed away in 1983 at the age of 27. He accomplished a great deal in his short life – he traveled, was independent, active and, most impressive, graduated posthumously from the Faculty of Dentistry at the Université de Montréal although, unfortunately, he never had the chance to practice. Our family started a fund – the Dr. Jeffrey Levine Memorial Fund in his memory and we became actively involved in fundraising for cystic fibrosis for many years, holding radio-thons and holiday gift wrapping events.

Enduring the loss of two children to this disease was a very hard burden to live with and something my father suffered with throughout his long life. I cared for my brother at our home in his last months, so I understand the day-to-day hardships that sufferers and families go through. My husband Allan, and daughters Bonnie and Doree, who were just 6 and 8 at the time had to grow up quickly as they were exposed to what CF looks like. When my father's 100th birthday was approaching our family started to brainstorm ways in which we could celebrate the man and his life, while at the same time making the milestone meaningful in a larger way. That's where ECHOage came into the mix.

Thanks to Bonnie and her work as an ECHOage Ambassador we saw this approach as a beautiful way to celebrate his 100th. While most people connect ECHOage with kid's parties, this worked out perfectly – after all, how many gifts does a 100-year-old need? My father was very happy with the result."

Louis Levine celebrates his 100th birthday with his family.

Louis Levine with his great-granddaughters.

ECHOAGE

What is ECHOage?

ECHOage, is an online birthday party/celebration website with a unique charitable twist! Reinventing the birthday party experience for the modern-day family, ECHOage gives parents all the tools they need to plan and manage an effortless celebration, while teaching their children about the value of giving at the same time. Whether it's a kid's birthday, milestone celebration, holiday party, baptism, retirement party, wedding or anniversary, you can ECHOage any event! Guests contribute funds securely online. The funds get split with a minimum of 50 per cent going toward the charity and the other portion going towards gifts if desired. A huge win for charities, parents, children and the environment! It's a better way to celebrate!

How was CF incorporated into your ECHOage party?

Guests were sent an invitation through ECHOage.com and asked to contribute to Louis' celebration in support of Cystic Fibrosis Canada rather than bringing gifts to the 100th birthday party. It was a way for our family and friends to recognize this important milestone in a meaningful and appropriate way. Giving back to a cause and charity that touched our family so closely made the celebration all the more special. Everyone felt great about recognizing my father's 100th birthday this way and giving back at the same time! The ease, convenience and tax receipt were added bonuses for our guests!

How can someone support Cystic Fibrosis Canada through ECHOage?

Whether you are planning on hosting a child's birthday celebration or any type of event simply visit the Cystic Fibrosis Canada profile page on the ECHOage website at **echoage.com/charities/cystic-fibrosis-canada** to get started. Pick your invitation design, enter in your party details, guest information and send off your invitations. It's as simple as that! Guests RSVP and contribute to your ECHOage gifts in just a few clicks. They even get a tax receipt for the charitable portion. It really makes gift giving a pleasure while raising funds for an important cause at the same time!

LSN Ottawa: Team "The Frenchies"

LSN Vancouver

LSN Ottawa

LAWN SUMMER NIGHTS

LSN Vancouver

Lawn Summer Nights is a unique summertime lawn bowling fundraiser held in 7 cities across Canada, benefiting Cystic Fibrosis Canada and raised over $460,000 this year. Since 2009, over $1 million has been raised through the events.

Lawn Summer Nights was inspired by Eva Markvoort, a friend of one of the founders in New Westminster, British Columbia. She was able to attend one event before she passed away on March 27, 2010 just before her 26th birthday. The event honours not only Eva but all those living with cystic fibrosis.

LSN Toronto

LSN Halifax: Team “Legally Bowled”

LSN Vancouver

LSN Ottawa

LSN Ottawa: Team “McGuires on Fire”

LSN Ottawa: Team “Greasy Grass Men”

LSN Vancouver

LSN Victoria

2015 CYSTIC FIBROSIS CANADA AWARD WINNERS

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 2015 award recipients, together we are working towards a world without cystic fibrosis.

The Volunteer Service Award is one of the highest award granted and is bestowed on an individual, couple or family who has made an exceptional contribution, of a national significance to the organization.

SID KEAY

Sid is one of the founding members and currently the Chairman of the highly successful Mike Cassidy Golf Classic that has raised more than $3 million for CF research and care over the last 21 years. Sid and his company – Ocean Trailer, also sponsor the 65 Roses Gala in Vancouver each year in addition to several other events organized by Chapters. Sid and his wife Leigh donated $25,000 as a matching gift for Key to a Cure in 2014 to inspire others to donate. Cystic Fibrosis Canada is honoured to have Sid as a supporter and benefactor.

DANIEL DETTMERS

Daniel has volunteered with Cystic Fibrosis Canada for over 30 years and has successfully organized, supervised, developed and supported a great number of fundraising initiatives. In 2015, Daniel surpassed the $1 million mark in donations from CARSTAR's Great StridesTM Walk for Cystic Fibrosis Canada in Montreal, an event he has been involved with since its very beginnings. Throughout the years, Daniel has shared his time, energy, friendship and love for the cause, and he continues to move forward day after day, tireless and relentless, until a cure for the disease is found.

BEVERLY VAN HORNE

Beverly has been involved with the Calgary and Southern Alberta Chapter for over 25 years, holding every position on the local board and volunteered hundreds of hours. Determined and dedicated to finding a cure, Bev has always been a positive force for Cystic Fibrosis Canada. A perfect example of a volunteer, Bev makes a difference in the lives of people with CF each and every day.

The Passion to Cure CF Award recognizes individuals who have significantly contributed to the mission including researchers, and clinicians. Recipients of this award, have moved beyond their professional association with cystic fibrosis to wholeheartedly embrace the CF cause.

ELIZABETH (BETTY) SHEPPARD

Betty has been a driving force behind the Newfoundland and Labrador Chapter for the last 15 years. As the Chapter's CF nurse coordinator, she has been a tremendous help to the Chapter in recruiting new families, sending out communications materials to the community and establishing a support group to help parents cope with life with cystic fibrosis. Betty gets the job done and makes sure everyone has fun while doing it.

The Breath of Life® Award recognizes outstanding and long-term contributions to a chapter in a leadership capacity by an individual, couple or family.

ABE VAN DORP

Abe first became involved with the Edmonton Chapter 17 years ago when his daughter was diagnosed with CF. He started a charity baseball tournament for Cystic Fibrosis Canada – an event that ran for 15 years. Abe has also been involved with the Ride for the Breath of Life and has helped to raise an incredible $191,000 over the last five years to help fund CF research and care.

JOAN LIDINGTON

Joan mobilized her efforts with the North Saskatchewan Chapter over 40 years ago after her son was diagnosed with CF. She has developed key partnerships with many major donors and businesses that would not have been possible without her instrumental involvement. Joan is propelled by a deep personal commitment to help those with CF not only survive, but thrive.

KAREN MCCULLOCH

Karen has been a member of the Kitchener-Waterloo & District Chapter after her son was diagnosed with CF in 1986. One of Karen's key accomplishments is growing the Great Strides™ Walk in Kitchener-Waterloo from raising $29,000 in 2007 with a group of 8 core volunteers and fewer than 100 walkers, to raising $235,000 with more than 900 walkers and a group of over 100 committed volunteers. Karen's determination to find a cure or control for CF is truly inspirational.

The Hall of Fame Award is the organization's most precious volunteers/supporters who have contributed over the long term. This prestigious award is presented to a nominee who has exhibited exemplary dedication to the mission of the organization.

WENDY AND GERRY UNDERHILL

Wendy and Gerry have been very active in our organization since the 1960s after their son was diagnosed with CF, and have left an everlasting mark on Cystic Fibrosis Canada. Gerry was a committed volunteer until his passing in December of last year. He held several executive positions within his chapter and region. On six different occasions he held the position of Regional Director or Director-at large covering more than 20 years. Gerry was the first Chair of the Stakeholder Council and just two months before passing away, Gerry had been in Victoria advocating the BC government for improved health care for patients. It was rare to see Gerry at a CF event without Wendy standing by his side. She was instrumental in the early years of the Victoria chapter, was a Board member of the BC Association for a few years and contributed so much right along with Gerry. The Underhill's epitomize what it means to care for a cause and will be forever remembered as making a difference.

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

KRISTINA JAKEMAN

Kristina's brother lives with CF and she began volunteering with the Calgary and Southern Alberta Chapter at the age of 12. Kristina is a talented artist and she has donated some of her paintings to the Chapter's silent auctions. She was also part of the *North Hill Centre Great Calgary Cake Off* contest that helped the Chapter win $10,000 in November, 2014. Her sustained contributions have not only made her an example for younger volunteers, but also an indispensable asset for the Chapter.

MARLENE MCKENZIE

A mother of two children living with CF, Marlene has been an active member with the Cape Breton Island Chapter since its inception over 8 years ago. Under Marlene's leadership, the Chapter started a second Great Strides™ Walk and is hoping to start more in three other communities. Marlene has been very successful in raising public awareness for cystic fibrosis through consistent local media coverage.

JUDY DERBOWKA

After her granddaughter was diagnosed with CF over 15 years ago, Judy began volunteering with the Calgary and Southern Alberta Chapter. Judy has been instrumental in leading Wrapping for a Cure, an event that has raised over $78,000 since its inception. Judy also sits on the Ladies 65 Roses Golf Committee. If help is needed at any time, Judy is always the first to offer.

The Chapter (Fred Blizzard) Award is designed to recognize chapters which have demonstrated either an overall excellence throughout the past year in the areas of fundraising, public awareness, volunteer development and partner support, or a particular strength in any one of these categories.

CALGARY & SOUTHERN ALBERTA CHAPTER

The Calgary & Southern Alberta Chapter successfully organized several outstanding events over the past year that have raised over $100,000 for vital CF research and care. The Chapter won the prestigious North Hill Calgary Cake Off, winning $10,000 for Cystic Fibrosis Canada. Through the hard work of many dedicated volunteers, the Chapter has also been highly successful in securing media coverage in their community.

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.

JOHN BENNETT

John started volunteering with the Newfoundland and Labrador Chapter after his son was diagnosed with CF. Not only has John kept engagement levels high at Chapter events, he has also inspired the Chapter to work harder, try new ideas and support each other through this journey. John was also a driving force behind the newborn screening campaign in Newfoundland and Labrador – he lobbied government, spoke to the media and encouraged everyone to sign the online petition. John's drive, commitment and enthusiasm for the CF cause is contagious.

The Summerhayes Award honours a person with cystic fibrosis who has demonstrated an exceptional commitment to the CF cause.

ALISON HAMILTON

Despite living with the challenges of CF herself, Alison is always willing to volunteer at events and share her inspiring story with others. Alison's involvement with Cystic Fibrosis Canada stems back to her childhood and as she grew up, so did her commitment. Since the Great Strides™ Walk started 10 years ago, Alison's team has raised almost $70,000.

ERICK BAUER

Erick Bauer, was diagnosed with cystic fibrosis at the age of six. Over the years, Erick has become a great contributor to the Toronto & District Chapter and Cystic Fibrosis Canada as a whole in various capacities. Erick started his own foundation – the Friends For Life Foundation (FFLF) in 2005 with his childhood friend (a cancer survivor) in support of Cystic Fibrosis Canada and the Oncology Unit at SickKids Hospital. The foundation raises awareness and funds for both causes through various fundraising initiatives and has raised more than $400,000 for CF research and treatment and childhood cancers since inception.

MICHAEL HAMILTON

Michael began his journey volunteering for Cystic Fibrosis Canada when he was diagnosed with cystic fibrosis at the age of 12. Michael has been involved with a number of events, including Gear Up for CF. Michael is completing a Masters degree in CF research and has volunteered in Dr. David Speert's research lab and completed a student internship in Toronto with CF researcher Dr. Christine Bear. Michael is a role model for other young people with CF and a wonderful inspiration.

TIM VALLILLEE

Tim was diagnosed with cystic fibrosis 47 years ago, and has been dedicated to Cystic Fibrosis Canada since the time of its founding. Over the past 20 years, he has raised thousands of dollars for Cystic Fibrosis Canada. He created the Squash CF Pumpkin Launch, which is held annually in Kingston, Nova Scotia. The event has grown to include Moncton and Ottawa, raising more than $10,000 in four years. In 2013, Tim gave countless hours of his time to the Champion for KALYDECO® campaign. He provided media coverage, conducted letter campaigns, and met several times with Nova Scotia's Health Minister in order to gain coverage and access for all those that would benefit from the medicine.

The Julia Award is intended to acknowledge non-chapter groups or individuals who have made a significant, on-going contribution to the organization through a chapter.

JORDAN AND MEGAN PARKER

Jordan and Megan have been dedicated volunteers with the Edmonton and Northern Alberta Chapter especially with their work through the annual Hockey Draft of Hope fundraiser – a National Hockey League (NHL) playoff event that has raised over $362,000 for the Chapter since 1988 and more than $100,000 in the last five years. Jordan and Megan have worked tirelessly to grow this event and increase revenue by expanding reach.

THE KINSMEN CLUB OF GREATER LONDON

The Kinsmen Club of Greater London has been by Cystic Fibrosis Canada's side for over 50 years and don't show any signs of letting up in the journey to find a cure or control for CF. The Kin volunteers are always there to lend a hand at fundraisers and other events. Not only do they relentlessly support the local Cystic Fibrosis Canada Chapter in their fundraising efforts, but they also have the initiative and passion to organize their own fundraisers to raise even more awareness and funds for cystic fibrosis research.

THE ROCK RIDERS MOTORCYCLE CLUB

Don't be fooled by their tough exterior, The Rock Riders Motorcycle Club have hearts of gold. After one of the club's founding members lost a niece to CF, they have been committed to the cause ever since. They helped establish the Calgary and Southern Alberta Chapter's first Ride for the Breath of Life in 2006. Over the years they have raised thousands of dollars for CF research and care and contributed over $11,000 through the Calgary Ride for the Breath of Life in the past two years alone.

CLAUDE PROVENCHER

A long-time volunteer and CF parent, Claude has greatly contributed to the Great StridesTM Walk in Montreal since its beginnings. In 2012, Claude exchanged his running shoes for pedals and the Juritour was born. The Juritour is a cycling event that brings together all the members of the legal field – notaries, lawyers, bailiffs, judges, court clerks, legal officers, paralegals, law students and professors, and raised $150,000 for CF research and care last Fall.

Kin representatives from the Bill Skelly Award winning clubs.

BILL SKELLY AWARD

The Bill Skelly Awards, presented by Cystic Fibrosis Canada, is an annual program that recognizes outstanding Kin Canada events that raise funds and awareness for Cystic Fibrosis Canada. The awards program is open to all Kinsmen, Kinette and Kin clubs from across Canada. One award is presented per district, annually.

2014-2015 WINNERS

District 1 – Kinette Club of Palmerston & District

District 2 – Kinette Club of Flin Flon

District 3 – Kinette Club of Lloydminster

District 4 – Kinsmen Club of Edmonton

District 6 – Kinette Club of Cornwall

District 8 – Kinsmen Club of Barrie

IAN F. MCCLURE AWARD

The Ian F. McClure award was introduced in 2014 in celebration of the 50th anniversary of the partnership between Kin Canada and Cystic Fibrosis Canada. It is awarded to a Kinsmen or Kinette in recognition of their exceptional skills coordinating and motivating groups of donors and volunteers for fundraising projects for the benefit of Cystic Fibrosis Canada and Canadians living with cystic fibrosis. There is only one award given out per year.

2014-2015 WINNER: Gerry Boehm

The Ian F. McClure award recipient, Gerry Boehm

15TH ANNUAL
65 ROSES GALA
CRYSTAL ANNIVERSARY

The 15th Annual 65 Roses Gala; presented by B2Gold Corp, is Cystic Fibrosis Canada - Vancouver Chapter's signature event. Over 300 guests gathered on November 7th at the Fairmont Waterfront Hotel to celebrate the Gala's "Crystal Anniversary." Guests enjoyed a silent and live auction filled with unique experiences, entertainment provided by *SideOne*, along with a special performance by vocalist Amanda Wood, and a multi course meal paired with wines from Haywire by Okanagan Crush Pad. Masters of Ceremonies included Gloria Macarenko from CBC and former two-time Grey Cup Champion, Angus Reid.

This year's Gala raised over $385,000 in support of cystic fibrosis research and clinical care. Since its inception in 2001, the event has raised over $3 million to help breathe hope into a future without cystic fibrosis.

LEAVING A LEGACY FOR CYSTIC FIBROSIS

Tammy Northam with son Zack.

For Tammy Northam, finding a cure or control for cystic fibrosis (CF) is extremely important to her. Tammy's 21-year-old son Zack has CF and she has been a Cystic Fibrosis Canada volunteer since her son's diagnosis 18 years ago.

"I have seen so much progress in research since Zack was diagnosed and the median age of survival has doubled from age 27 when Zack was diagnosed to well over 50 years of age today. But CF is still a hard disease to treat and takes lives every year. We have more work to do," says Tammy.

Tammy intends to leave a legacy gift to Cystic Fibrosis Canada and her generosity reminds us that anyone can make a difference in the lives of Canadians with cystic fibrosis. In Tammy's case it was extremely easy to add in a clause in her will that ensured she made a planned gift to Cystic Fibrosis Canada. "In my case, it did not cost any extra since I was changing my will anyways."

A planned gift is a donation made during your lifetime, but which Cystic Fibrosis Canada will not receive until sometime in the future. There are several different types of planed gifts – a bequest in your will, a gift of life insurance or a gift of securities – and make a lasting contribution in the fight against cystic fibrosis.

"After I pass away whether it's tomorrow or in 50 years, I want to see the important work that Cystic Fibrosis Canada does continue. It's critical that some of my life savings go back to the most important cause to me."

For more information about planned giving, visit **cysticfibrosis.ca/donate-today/planned-giving/**.

INAUGURAL GEARUP4CF PEI RIDE A SUCCESS

On June 26, 2015, the final day of GearUp4CF PEI Perimeter Ride, riders were left with feelings of accomplishment and determination to continue their fight against cystic fibrosis (CF).

Riders had three goals in completing this ride: to raise awareness of CF, to raise funds for CF research and care, and finally to complete their full ride – be it 65 km or 850 km. Inspired by the success of GearUp4CF Vancouver to Banff – a ride that organizers Paula Clark and Jan Meulenkamp have tackled twice, they were excited to welcome riders from across the country to experience the challenges of the PEI terrain.

Three seven-day PEI Perimeter Marathon Riders were joined by 12 kick-off century riders (a century ride means riding almost 170 km or more within 12 hours) and 65 km riders that raised over $32,000. While participants have reached their goals, the journey continues.

Paula Clark, mother of two teenagers living with CF, shared her thoughts on the event, “I have completed 850 km cycling along the coastline of Prince Edward Island, but my journey as a CF parent continues. It will not be complete until an effective control or a cure for cystic fibrosis is found and we can finally say CF stands for cure found.”

Thank you to each and every volunteer, sponsor, and supporter that helped make the inaugural GearUp4CF PEI Perimeter Ride a resounding success. The legendary warm welcome and wonderful hospitality of Prince Edward Islanders made this experience even more special.

Mark your calendars and start training for the 2016 GearUp4CF PEI Perimeter Ride, taking place over 8 days from June 18 – 25, 2016.

For more details and to register, visit: **www.850km.bikepei.com**.

TERRY FOSTER MAKES GREAT STRIDES FOR CF

Terry Foster receives Achievement Award from Cystic Fibrosis Canada

Terry Foster's story is one of courage, hope and determination that perfectly captures how the efforts of one person can inspire many.

Nearly 30 years ago, when a young family member was diagnosed with cystic fibrosis, Terry felt useless. As he watched his family cope with the realities of having a young child battle this devastating, fatal disease, he was inspired to take action to help find a cure or control for cystic fibrosis.

Initially inspired by the Zellers Moonwalk for CF and then later on by the Great Strides™ walk, Terry created his own fundraising walk to raise funds and awareness for cystic fibrosis research and care. In addition to walking in the Peterborough Great Strides™ walk, Terry for many years, took to the roads the weekend before in honour of all those who are unable to walk to find a cure.

"I have had many people tell me that they could never walk 10 km, even if it was for a good cause," Terry said. "I believe I represent all those who wish they could do more."

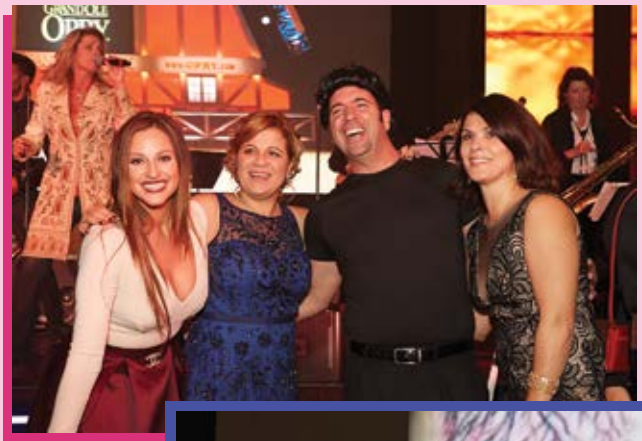
Several years ago, after years of fighting, Terry's family member lost her battle to cystic fibrosis at the age of 21. To honour her memory, and continue to fight cystic fibrosis, Terry relentlessly continues his walk year after year; he has now been walking for an astonishing 30 years.

Over the past 30 years, Terry has participated in a total of 91 – 10 km walks and has raised over $98,000 specifically for life-saving CF research and care. Terry has become a real celebrity within the Peterborough area; his inspiring story has been spread throughout the community and the local media.

It's because of the dedication of people like Terry, that we are making great strides to END CF.

WE WANT TO HEAR FROM YOU!

Do you have a great story you want to share with the CF community? Get in touch with us at public-relations@cysticfibrosis.ca.

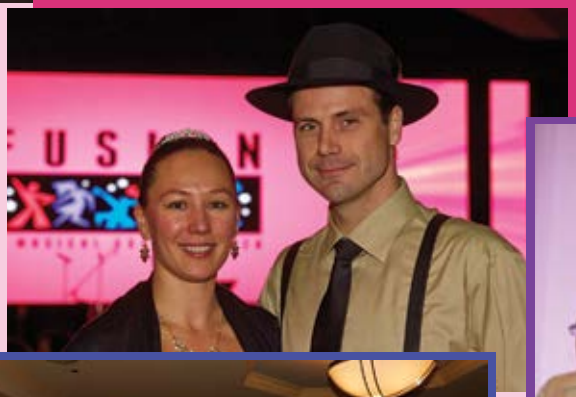


FUSION

A MUSICAL EXTRAVAGANZA

This year's Fusion Gala – ***A Musical Extravaganza***, brought together 320 guests on Saturday October 24th at the Angus Glen Golf Club in Markham, ON and raised $394,000! Guests enjoyed an incredible evening of dining, dancing, and live music from all of the great musical genres, including a special musical performance by Canadian country music star Tenille Arts, all while raising vital funds for Cystic Fibrosis Canada.

A special thank you to the Gala Committee, and its co-chairs Bonnie Griffin and Ron Anderson, who once again put together a spectacular evening of fun and fundraising. This year marked the 14th Fusion Gala, which has now raised over $2 million for Cystic Fibrosis Canada.



Thank you to this year's Presenting Sponsors: Team Industrial Services, Unifor, Restorer's Group, Century 21, Macdero Construction, The Giving Tree Foundation of Canada, The SPG Engineering Group, Vertex Pharmaceuticals (Canada) Inc., Apri Insurance, CG&B Group, BMO, Dentons, Highcourt Partners, Royalguard, Teslin Contractors and Weins Canada. We are so grateful for your partnership in the fight against cystic fibrosis.

HELPING THOSE WHO CAN'T BREATHE

There's nothing better than an event that honours those to whom the simple act of breathing is a challenge every day of their life. The following six events raised almost $300,000 for cystic fibrosis (CF) research and care in Quebec.

MAY 2, 2015

DÉFIBROSE SAINT-BRUNO, SAINT-BRUNO-DE-MONTARVILLE

500 runners of all levels from beginner to elite participated in a track event that included 1, 2, 5 and 10 km distances. Two young people with CF – Rosemarie (15) and Dylan (12) from Montarvillois, ran for fibrose kystique Quebec to support cystic fibrosis research in the province which raised nearly $22,000. Congratulations to Nancy Gauthier for making this event a reality.

MAY 24, 2015

IRONBEN, SHAWINIGAN

For the fourth year in a row, the IronBen event has raised $10,000 in the fight against cystic fibrosis. Almost 300 people took part in the 1,5 and 10 km races to support five-year-old Benjamin Pérusse, who lives with cystic fibrosis. Congratulations to Sylvain Pérusse for organizing this event.

SEPTEMBER 12, 2015

ROULER À PLEINS POUMONS, BEAUMONT

500 runners of all levels from beginner to elite participated in a track event that included 1, 2, 5 and 10 km distances. Two young people with CF – Rosemarie (15) and Dylan (12) from Montarvillois, ran for fibrose kystique Quebec to support cystic fibrosis research in the province which raised nearly $22,000. Congratulations to Nancy Gauthier for making this event a reality.

SEPTEMBER 13, 2015

JURITOUR, SAINT-MARC-SUR-RICHELIEU

Some 115 legal specialists including lawyers, judges, notaries, bailiffs, clerks and paralegals, cycled routes of 40 and 115 km along the Richelieu River at the 3rd edition of Juritour. Hats off to the organizer – Claude Provencher, who himself is a father of a daughter with cystic fibrosis. Thanks to Claude and his volunteers, this event united the legal community around a great cause that raised $95,000 for children and adults with CF to live long, healthy lives.

SEPTEMBER 19, 2015

LAC MEECH, GATINEAU

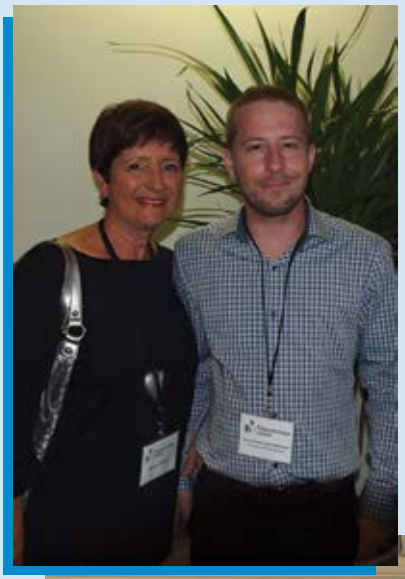
The very first *Défibrose du lac Meech* offered outdoor enthusiasts an unforgettable experience to excel and connect with nature by walking or running for 20 km. The event raised $35,000 and half was given to the Montreal Children's Hospital Foundation to fund clinical trials to test a new treatment for cystic fibrosis in collaboration with the Translational Research Center at the University cystic fibrosis McGill (CFTRc). Congratulations and thank you to Mario Gagnon and his regional committee of Gatineau.

OCTOBER 10, 2015

MON HIMALAYA, MONT-SAINTE-ANNE

The Défibrose *Mon Himalaya* challenged 400 runners and walkers to go up and down Mont-Sainte-Anne mountain as many times as possible between 7 a.m. and 3 p.m. Ex-olympian in cross-country skiing and Défibrose Mon Himalaya spokesperson Pierre Harvey, congratulated all donors and was impressed with the success of the seventh edition of this event which raised a record $96,500. Congratulations to the organizing committee of Quebec for this great achievement.

Earlier this Fall, Cystic Fibrosis Canada thanked its donors with an appreciation night in Toronto, Montreal and Ottawa. We are thankful for the commitment and support of our donors as we work towards a world without cystic fibrosis.



Thank You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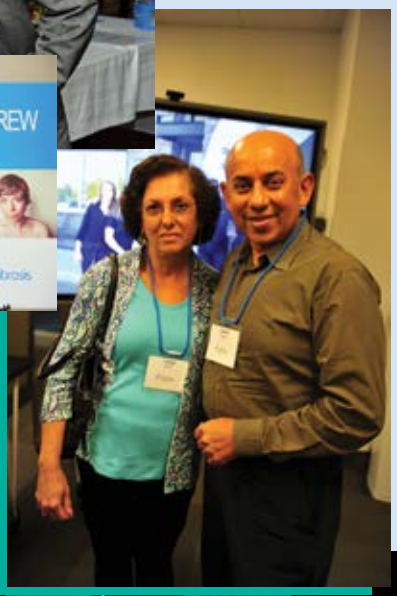


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