

# Connections

SUMMER/FALL 2018

► **THE WATSON SISTERS:  
IN THEIR OWN WORDS**

**FIVE REASONS TO  
PARTICIPATE IN A  
CLINICAL TRIAL**

**MEET OUR NEW  
PRESIDENT AND CEO:  
KELLY GROVER**

**ROBERT CLARK'S LEGACY**





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**MAKE CYSTIC FIBROSIS HISTORY**



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# MEET OUR NEW PRESIDENT AND CEO: KELLY GROVER



**In June, Cystic Fibrosis Canada welcomed Kelly Grover as President and Chief Executive Officer (CEO). Previously, Kelly served as Vice-President, National Programs and Partners at Ovarian Cancer Canada, where she led the organization in supportive care, advocacy, clinician partnerships and public education, while also providing leadership to the regional offices. With over 20 years of experience in a variety of health-based organizations in the charitable, public and research sectors, CF Canada is in extremely capable hands under Kelly's leadership and vision.**

In June 2018, I officially came on board as President and Chief Executive Officer (CEO) at Cystic Fibrosis Canada and what a great time it's been. I've been busy meeting the staff, Board and volunteers and learning about the extraordinary work you all do on behalf of those with cystic fibrosis. I am thrilled to be a part of this organization and to work side by side with you.

Cystic fibrosis is a disease I care about and one that is close to my heart, as I know people who have been affected. I remember a time when there wasn't a lot of hope for children with CF and it is so inspiring to witness the progress that has been made and to think about where we can go. I am excited to make a difference at Cystic Fibrosis Canada and with the advances in research, the disease is on the cusp of change. It's motivating to know that it is possible to change the outcome for people with CF – it is truly within our grasp.

I look forward to building on our success in research and advocacy and will continue to drive that forward to ensure that Cystic Fibrosis Canada makes the greatest impact possible for those diagnosed and living with CF. Finding a cure or control for CF is the ultimate goal; it motivates all of us to do the work we do. It is where we all want to be.

I look forward to being a part of the change for cystic fibrosis.

**Kelly Grover**  
President and CEO



# INTRODUCING CYSTIC FIBROSIS CANADA'S NEW BOARD OF DIRECTORS MEMBERS



L-R: Dr. Louise Desjardins, Dr. Hugh O'Brodovich and Dr. Kathryn Deuchars

## DR. LOUISE DESJARDINS

Dr. Louise Desjardins gained extensive experience serving the Networks of Centres of Excellence, the Canadian Institutes of Health Research and the Medical Research Council of Canada for 13 years in progressive senior management positions. She also served the Government of Canada as a team lead for key projects resulting in the Royal Assent of the CIHR Act. In her most recent roles, she has consulted for a number of health and science not-for-profit organizations including member-based associations. She supported and represented many of these public and private sector organizations on over 40 national and international boards and committees.

Dr. Desjardins received a B.Sc. Honours from Dalhousie University, an M.Sc. from the University of Guelph, a Ph.D. from the University of Western Ontario and an MBA from the University of Ottawa. She was a Post-doctoral fellow at University of Ottawa and a Research Associate at the National Research Council of Canada. She is the recipient of numerous academic and professional awards.

## DR. HUGH O'BRODOVICH

Hugh O'Brodovich MD, FRCP(C) spent his early years on a farm in Saskatchewan and then obtained his medical degree and training in pediatrics and pulmonology at the University of Manitoba. After further clinical and research training at Columbia University's College of Physicians and Surgeons he returned to Canada in 1981 to begin his career at McMaster University. In 1986 he moved to the Hospital for Sick Children (SickKids) in Toronto where he subsequently became a senior scientist, Division Chief of Respiratory Medicine and Head of the SickKids Research Institute's Division of Respiratory Research. As Chair of Paediatrics at University of Toronto and Paediatrician-in-Chief at SickKids (1996-2006) he participated in major initiatives to improve the coordination, integration and delivery of health care in Ontario, Canada, Ireland and Qatar. As Chair of Pediatrics at Stanford University and Physician in Chief at Lucile Packard Children's Hospital Stanford (2008-2016) he participated in health care and health care reform in the USA.

He has been a member of the Boards of leading children's hospitals and national and international medical societies. Until his retirement in 2016 he had an active research program and clinical practice in paediatric pulmonology. Throughout his medical career he has been directly and indirectly involved in the care of cystic fibrosis patients and their families. He is an elected Fellow of both the Canadian Academy of Health Sciences and American Association for the Advancement of Science. Dr. O'Brodovich is a Professor Emeritus at Stanford University, lives in Canada, and serves on the Scientific Advisory Board of AIT Therapeutics and Board of Directors of the Province of Ontario's Central West Local Health Integration Network (LHIN).

## DR. KATHRYN DEUCHARS

Dr. Deuchars is Senior Manager, Business Development and Research, at Ontario Genomics, where she works to facilitate genomic innovation in health care. Dr. Deuchars has over 20 years of experience in the field of biotechnology innovation, venture financing and health technology commercialization. She is also Director of the Ontario Personalized Medicine Network, a stakeholder volunteer group formed to enable the adoption of personalized medicine technologies in Ontario to improve health.

Previously Dr. Deuchars was President and CEO of Light Matter Interaction (formerly Attodyne Inc.), a Toronto start-up medical/industrial device company. Before that Dr. Deuchars focused on the venture financing of early-stage biomedical innovations as Chief Operating Officer of University Medical Discoveries as well as on later stage investment opportunities for Lumira Capital (formerly MDS Capital). Dr. Deuchars also spent six years in the biotechnology industrial sector as a research scientist at NPS Allelix Inc.

Dr. Deuchars earned her Master's and PhD degrees from the University of Toronto, and an Hon. B.Sc. from Western University.

## UNDERSTANDING WHAT TRIGGERS LUNG DISEASE IN PEOPLE WITH CYSTIC FIBROSIS

**Q&A WITH DR. JUAN IANOWSKI, ASSISTANT PROFESSOR AT THE UNIVERSITY OF SASKATCHEWAN**

### HI DR. IANOWSKI, CAN YOU TELL US A BIT ABOUT YOURSELF?

I was born in Buenos Aires, Argentina in 1970. Since an early age I was interested in biology, and spent most of my free time bird watching, collecting insects, and reading books on life sciences. After graduating from high school, I entered the School of Exact and Natural Sciences at the University of Buenos Aires to study biology and I graduated with an MSc equivalent degree in physiology.

In 1998, I left Argentina to join the graduate program at the Department of Biology at McMaster University in Hamilton, Ontario, where I graduated in 2004 with a PhD in epithelial physiology under the supervision of Dr. Mike O'Donnell. After graduation, I undertook five years of postdoctoral research. In 2009 (after 19 years of continuous university education as an undergraduate, a graduate, and a postgraduate!), I started my own research lab the University of Saskatchewan, in beautiful Saskatoon, as a tenure-track assistant professor in the Department of Physiology.

### HOW DID YOU GET INVOLVED IN CYSTIC FIBROSIS (CF) RESEARCH AND WHAT DO YOU ENJOY MOST ABOUT YOUR WORK?

CF is probably the best studied pathological condition of epithelial tissue. So as a graduate student, I developed a keen interest in CF, and after completion of my PhD, I was awarded a postdoctoral fellowship funded by Cystic Fibrosis Canada to study CF lung disease under the supervision of one of the best CF researchers in Canada, Dr. John Hanrahan. That was a very productive and enlightening time in my career, which propelled me into a successful path as a CF researcher.

What I enjoy the most about my work is the process of discovery - the design of experiments and the development of experimental techniques that allow us to advance our understanding of CF.

### WHAT ARE YOUR LATEST RESEARCH FINDINGS?

Our most recent findings, published in the journal *Nature Communications*, describe a previously unknown component of the innate immune defense against pathogens that one might breathe in, like *Pseudomonas aeruginosa*. Using piglets as a model, we showed that airways in healthy animals respond to inhaled pathogens by producing large volumes of airway liquid that is released by submucosal glands, at the site where the pathogen is located. This liquid traps, kills, and helps clear pathogens from the airway, which helps to



**Dr. Ianowski was awarded the 2018 Cystic Fibrosis Canada Senior Scientist Award for his impressive body of work in understanding the underlying causes of lung disease in CF.**

maintain lung health. In piglets without CFTR, however, this response is absent. Inhaled pathogens fail to trigger the airway liquid secretory response.

### WHAT DOES THIS MEAN FOR PEOPLE LIVING WITH CF?

Our results suggest that failure of CF airways to produce airway liquid would reduce the ability of the lung to kill, trap, and clear bacteria. As a result, bacteria would tend to remain longer in the airway, favoring infection and inflammation of the airway.

Another implication of our work is that it might be possible to improve lung health with treatments that may fix the issue with glandular fluid secretion. We are currently looking into this idea in collaboration with Dr. Julian Tam, Director of the adult CF clinic at the Royal University Hospital in Saskatoon.

### WHAT ARE THE NEXT STEPS?

We are very interested in studying where disease starts in the CF lung and how it progresses. We will also study what is different about those sites compared to healthier sites in the same CF lung. To this end, we developed a special computer tomography (CT) scan method that produces images with resolutions that are up to a 100 times better than standard medical devices.

We are also interested in studying to what extent bacterial infection is required to develop CF lung disease. We will house CF swine in sterile conditions, which means that they will have no microbes at all in their lungs. If infection is what causes lung disease, these animals with no microbes in their lungs should not develop lung disease.

Finally, we are interested in studying new complications that may emerge as CF patients live longer lives. In particular, we are interested in studying abnormalities of the peripheral nervous system. In collaboration with Dr. Verónica Campanucci, also at the University of Saskatchewan, we are studying how neuropathies may affect the gut and cardiovascular function as CF patients age.

# INTRODUCING THE TAYLOR NURSING AWARD FOR CONTINUING EDUCATION



Louise Taylor was the CF Clinic Nurse Coordinator at the Hospital for Sick Children for several decades, and served as a national authority on CF nursing care. The Taylor family has had a long history of involvement in the Canadian CF community, supporting fundraising and educational efforts in the healthcare setting.



Louise Taylor

The Taylor Family's support for those with CF is far-reaching, and through Louise's visionary contribution, the dedicated front-line nurses who provide care for the CF population in Canada will continue to benefit from her exemplary leadership and commitment well into the future.

As a champion for CF nurses, Louise continues to support the cultivation of education and knowledge exchange. *The Taylor Nursing Award for Continuing Education* will be awarded to one nurse each year who provides care on a regular basis through a recognized CF clinic in Canada. Offered through an annual competition, the Award is intended to support attendance at a CF-specific conference (the North American CF Conference or similar event).

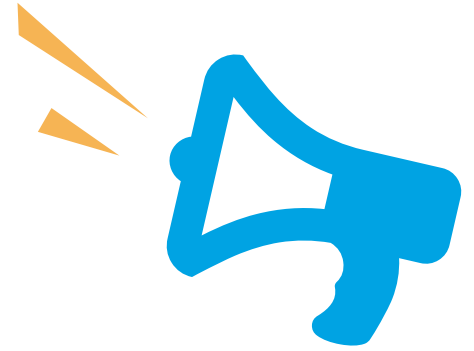
Applications will be adjudicated by senior leadership at Cystic Fibrosis Canada, in collaboration with Louise Taylor, based on demonstrated need, budget requirements and availability.

**THANK YOU TO OUR RESEARCH, HEALTHCARE, ADVOCACY & REGISTRY TEAM FOR ALL THE WORK THEY DO TO END CF!**



# INTRODUCING THE CYSTIC FIBROSIS CANADA NATIONAL ADVOCACY PROGRAM

What does it take to get medicines for cystic fibrosis (CF) covered in Canada? How can we ensure that Canadians with CF get the best possible care, community supports and services? Who can we turn to for public policy change that helps our community? These are all questions that Cystic Fibrosis Canada's National Advocacy Program works to address, and more.



Cystic Fibrosis Canada's National Advocacy Program is designed to help those with CF, and their families and friends engage with their local elected and non-elected officials to improve the lives and livelihoods of people with CF. The objectives of the program are to:

- ✓ Raise public awareness of CF and address key CF-related issues in Canada;
- ✓ Build relationships with officials and legislators to increase support for the programs, services and policies that can improve the quality of life for people with cystic fibrosis;
- ✓ Provide clear, consistent structure, training and support for our advocates and advocacy activities;
- ✓ Provide a voice for Canadians with CF locally, regionally and nationally.

"Advocacy is so important for people with cystic fibrosis and their families, because it allows opportunity for hope. Cystic fibrosis is a relentless disease and if no one is out there asking questions and taking strides to make it better, then a day won't come where we aren't battling this disease," said Kimberly Evans, Provincial Advocate, Saskatchewan. "Change only occurs when ideas are spoken about and brought forward. The more we can make the world aware of all the struggles that come along side having cystic fibrosis, the more opportunity there is to make a difference."

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Through the National Advocacy Program, Cystic Fibrosis Canada - and its over 100 advocates across the country - is advocating for better access to medicines and quality CF care, including mental health services and increased funding for clinics that have grown due to the increasing numbers of adults with CF.

Recent successes include extension of the Special Drug Program in Manitoba, a program the government planned to end with less than two months' notice before people had to join the general pharmacare program and pay a deductible. Our Manitoba advocacy team was able to get the timeline extended to six months and is still working to save the program. P.E.I. has announced coverage for Kalydeco for those with the G511D mutation, as well as coverage for Caysten and Pulmozyme. Moreover, just last year, Quebec was the final province to agree to implement newborn screening, but there is still more work to do.



## *“The progress of our efforts aligns with the progress of medicines and treatments for people with CF,”*

“The progress of our efforts aligns with the progress of medicines and treatments for people with CF,” noted Rob Burtch, Provincial Advocate, Ontario. “Those kinds of things can’t evolve if the rules by which the government decides on access don’t evolve. We can’t get new treatments to people unless we make sure that we’re constantly on top of access issues. Eventually, somewhere down the line when there’s a medication that provides a cure, we need to know the groundwork to access has been laid.”

Our National Advocacy Program provides training, support, mentoring and coaching for those who want to become advocates but may not have a background in government relations and advocacy. People join the program for many reasons.

## *“For me, having a daughter with cystic fibrosis, feels so out of my control. This is not what I would have chosen for her, but this is our reality. And because of that, I have made it my mission to do things that I can do to make a difference,”*

“For me, having a daughter with cystic fibrosis, feels so out of my control. This is not what I would have chosen for her, but this is our reality. And because of that, I have made it my mission to do things that I can do to make a difference,” said Kimberly. “Advocacy allows me to speak up, be heard and work together with the incredible Cystic Fibrosis Canada community to help create change.”

Advocacy is not always an easy undertaking, but it is a necessary one, even through difficult times. “When I had my transplant, there was a young woman who had a transplant at the same time. She had already had a liver transplant when she was young. She was 20 when she had her lung transplant and two years ago she passed away,” stated Robert. “On a regular basis I have a lot of friends on social media, people I’ve known over the years, some of whom have done really well and others who haven’t. Her death hit me really hard. I think at that point it kind of became more than just traveling and speaking and fundraising for me because I’m just really tired of seeing people who haven’t had a chance to live a life like I have.”

Kimberly continues: “Meetings that I have had with MLA’s and in the Provincial Legislative have all been really positive. The more vulnerable and real I am able to share our story, the greater the connection is made with the decision makers. It sometimes feels scary to be speaking about a topic that is so personal and has so much emotion attached to it, but it makes it so much more real for those that hear it. Patience is one of the virtues that I struggle with and in advocacy, patience is the name of the game because no decisions are made quickly. Seeing small victories and knowing that I’ve gotten to be a part of them makes it all worthwhile.”

In closing, Robert noted: “Advocacy is a long game and you have to know that going in. Know that going in that you are going to bring about change, but there will be roadblocks along the way. Advocacy is series of small wins that ultimately lead to bigger ones, but these things take time.”

**For more information on our National Advocacy Program please contact [advocacy@cysticfibrosis.ca](mailto:advocacy@cysticfibrosis.ca).**



## FIVE REASONS TO PARTICIPATE IN A CLINICAL TRIAL

A clinical trial, one type of a clinical study, tests the efficiency and safety of potential new interventions in real-life scenarios. Clinical trials are not only for new medications but also include new treatments, diets, physical therapy and devices. Each study has defined inclusion and exclusion criteria that a participant must meet to be eligible for the study. These criteria ensure the safety of participants and ensure the results from the study will be accurate and useful.

Here are five reasons why you should check out a clinical trial:



- 1. A clinical trial can help you take an active role in your healthcare and give you a better understanding of your diagnosis**
- 2. You'll help others living with the same conditions**
- 3. You'll gain access to new treatments not yet available to the public**
- 4. You can receive a treatment that may work better for you than current treatments**
- 5. Many research studies have shown that patients involved in clinical trials have better overall health outcomes, compared to patients who are not involved in trials**

Similar to starting any new medication or treatment, participants in a clinical trial may experience side effects or adverse reactions. It is important to note that participants can withdraw from a trial at any time, for any reason without affecting their clinical care, even if they have signed the consent form. A consent form is not a contract. For more information on clinical trials, please contact [clinicaltrials@cysticfibrosis.ca](mailto:clinicaltrials@cysticfibrosis.ca).

## THE CANADIAN CYSTIC FIBROSIS REGISTRY ANNUAL DATA REPORT

The Canadian CF Registry was created in the early 1970s with the goal of monitoring important clinical trends in the Canadian CF population. Since then, it has played an invaluable role in helping to improve the quality and length of life of people with cystic fibrosis. The data from these reports continue to show the incredible achievements made in CF care and research which would not be possible without the remarkable efforts of the CF clinic team members and the participation of CF individuals. Thank you to all involved and for your continued support of this amazing resource. The 2017 Canadian Cystic Fibrosis Registry will be available in Fall 2018. Stay tuned for more information!



Many of our community members have layers to their involvement. Volunteer, researcher, and CF sibling Nicole Filipow is one such person. We caught up with Nicole to chat about her involvement, research and hopes for the future!

## WHAT'S YOUR INVOLVEMENT WITH CF CANADA (ARE YOU A VOLUNTEER, DONOR, EVENT ORGANIZER, ETC.)?

I have volunteered with CF Canada over the past 20 years or so, at various events, in a multitude of roles. While completing my undergraduate degree at Carleton University, I was on the organizing committee for the Walk to Make CF History in Ottawa and became the Chair of the Walk Committee in 2017. Alongside my volunteering, I began my master's (also at Carleton University) in microbiology in 2016. Here my research thesis focused on the bacterium that is most seriously implicated in CF lung infections - *Pseudomonas aeruginosa*. Using experimental evolution, my thesis looked at how this bug can evolve and adapt to CF lungs, and what (if any) constraints there are on its ability to infect the lungs of people with CF. This was carried out in the hopes of creating better infection prevention guidelines, and better *Pseudomonas* eradication therapies. Given my research interests and volunteering experiences, I have also spoken at a number of CF events regarding the importance of fundraising and the real and major effect that donations have on bettering the lives of people with CF.



## WHAT IS YOUR CONNECTION TO CF?

My twin sister was diagnosed with CF when we were eight weeks old. Since then, I have grown up side by side her nebulizers, physio, hospitalizations, treatments, and diagnosis with CF-related diabetes. Since she must go through each day with her whole other world that is CF, I thought I could make some of my world researching the underlying causes of her lung infections. She is my inspiration for everything.

## WHAT HAS BEEN THE GREATEST HIGHLIGHT OF SUPPORTING CF CANADA FOR YOU?

Completing my master's recently was an incredible highlight. My thesis ended with some really cool results, and I was able to share these results with the Northern and Eastern Ontario CF staff at a public seminar. It was amazing to have all of their support throughout my degree, as well as the support of my family and friends who made my entire thesis on CF lung infections possible. I am really looking forward now to publishing the results and being able to further contribute to a world without CF.



## WHY DO YOU THINK IT'S IMPORTANT TO SUPPORT CF CANADA?

It's important to support CF Canada because CF is a horrible disease, with a very hopeful future. Statistics continuously show the improvement in life expectancy, and quality of life of individuals with CF even just over the past decade. CF researchers are constantly producing hopeful results, but this research is costly to come by. Any and all support is instrumental in the search for a better treatments and an eventual cure.



## WHAT WILL #AWORLDDWITHOUTCF MEAN TO YOU?

It will mean that my sister can wake up without saying "ugh, I feel so sick today."





*Amy and Allison Watson*

## THE WATSON SISTERS: IN THEIR OWN WORDS

We were both born and raised in Petitcodiac, NB. Amy is 36 and Allison is 31. We have a younger sibling, David, 29, who does not have CF.

Our family never knew anything about CF until Amy was born. She was diagnosed at birth due to meconium ileus and had to be rushed to the IWK hospital in Halifax to be operated on. Our parents then received a crash course in aerosols, physiotherapy, and digestive enzymes.

Allison was born four years later and our parents went through the entire experience again. Allison struggled with her weight from day one, and as a result spent much of her first four years in the hospital. She had a feeding tube inserted at 14 months to help with weight gain which was removed (finally!) when she was six and had stopped throwing up everything she ate. She was a feeding tube success story.

Our family did not let CF be the dominating factor in our lives. We had a very active childhood, with camping trips, hikes, and participating in sports. We all went on road trips, including across Canada in a minivan, for a month. Of course we still had our daily CF routine of aerosol masks twice a day, chest percussions, and leaving a trail of enzymes behind us everywhere we went.

We had a few hospitalizations as teenagers but overall were quite healthy and were able to do the things we enjoyed. Our parents always encouraged us to have autonomy over our own health. As such, we were confident going with our friends to sleepovers, overnight school trips, and summer camps. This independence helped when we went to university and were able to advocate for our health.



Mom and dad never hid the fact that we have CF and its implications for the future. As a result of this education, we have always been active participants in our own disease management. This has enabled us to have active and fulfilling lives without letting our disability become a barrier. We have been able to fulfill our love of travelling to places such as Europe, Egypt, New Zealand and many more. Allison and David were able to cycle across Canada in 2008 as an awareness campaign and fundraiser for CF Canada.

Our family has been active in the local CF Chapter. We have fundraised for the Walk to Make CF History since the Moonwalk days and have talked at various Shinerama and other fundraising events. Dad has been actively promoting awareness of CF since we were born. He did annual talks during elementary school to explain the disease to our classmates which helped them know why we were taking pills and coughing all the time. He was honoured to receive the Breath of Life award at the latest CF Canada Volunteer Leadership Forum.



Once we reached adulthood, the effects of CF had a detrimental impact on our lives. Allison was hospitalized many times for lung infections and had to stop working as a recreational therapist due to health. With her boyfriend, Isaiah, she moved to Toronto where she could be listed for a lung transplant in 2013.

During her time in Toronto, Allison felt the need to connect with people in the CF community who had also been through the transplant process. Neither Allison or Amy were very active in the online CF community because growing up as siblings with CF meant that we always had someone around with a shared lived experience to talk to whenever we need support. We were able to commiserate with each other about hospitalizations, lung failure, and other ordeals. Throughout Allison's transplant process, we both have made online CF friends within the community.

Allison received a life-saving double lung transplant in the fall of 2014. The recovery from the transplant was the most intense thing she's ever gone through in her life. It was challenging but worth the effort in the end. As a side-effect of the transplant, she has CF-related diabetes and was diagnosed with post-transplant lymphoproliferative disorder in 2015. After intensive chemotherapy, she is now two years cancer free and is again physically able to do the things she enjoys.



Amy was a NNICU nurse for over 10 years but has recently had to stop working due to declining health. She hopes to eventually receive a lung transplant but is currently unable to be listed due to the shortage of organ donors. She is working hard to remain stable by being as active as possible and always pushing at the edge of her physical limitations.

During our lifetime, we have seen a dramatic improvement in the quality and care for people living with CF. Having specialized CF clinics with a multi-disciplined team, improvements in medication, and the possibility of a transplant at the end of life have all been beneficial to our lives. This has all been possible through the work of CF Canada and their partners. We appreciate the work that CF Canada and their many volunteers have done in the past and continue to do to help enrich the lives of Canadians with CF.



# THE BREAKFAST OF CF CHAMPIONS

**They say breakfast is the most important meal of the day! Well, Lana Woulfe and her family prove it's also an incredible fundraiser!**

Lana and Derek Woulfe are from Marean Lake, Saskatchewan, and run the Marean Lake Valley Resort, about 150km northeast of Humboldt. Lana and Derek have three children, Hunter, 16, Jaden, 13, and Trey, 11. Each year the Woulfe family hosts two incredible fundraisers to help people like Hunter, who has cystic fibrosis, live long and healthy lives.

Hunter was diagnosed with CF when he was nine months old, but hasn't been in the hospital since he was two and a half years old. His steady health is an accomplishment that Lana credits to Hunter's activity – he loves hockey and lacrosse.

Lana and her family knew they wanted to organize an event that raised awareness about cystic fibrosis in their community, and that helped raise critical funds needed to help find a cure for CF. The idea to start a breakfast fundraiser came to them over coffee with some of their customers.

"When we started the pancake breakfast, we had 95 people show up and raised about \$500," says Lana. The event, which is in its 13<sup>th</sup> year, is hosted each July at the resort. The breakfast is \$6 for adults, and free for children, and includes live and silent auctions, 50/50 draws, live music, and bids for delicious homemade pies. It's a wonderful community event that brings together people for a great cause.

The event's humble beginnings in 2005 are far from what it's become. In 2017, the pancake breakfast raised an incredible \$23,000 for cystic fibrosis research, advocacy and care. That's a lot of pancakes! "It's grown so much... it's crazy! I think it's because of where we are, because of the community, people from all over come to support it." We are proud to announce that the 2018 Annual Pancake Breakfast for Cystic Fibrosis raised **over \$17,500 and fed more than 450 people!** Congratulations to the Woulfe family, and thank you!

The Woulfe family also hosts a second fundraiser each year, the Annual Hunter's Golf Tournament for Cystic Fibrosis. The event takes place each September at Greenwater Provincial Park. It's another fun community event that attracts golfers and sponsors, and is a great opportunity to raise awareness about CF. The 2017 tournament **raised over \$10,500!**

With two successful events that are a highlight for their community year after year, we had to know - what's the secret to their success? "It's the community," said Lana. "The community, the people have been completely generous. From my volunteers, right down to the supplies that are donated. Marean Lake is a very generous place to live."

Thank you to Lana, Derek and their incredible community for helping to create a world without cystic fibrosis!





In 2013, when their daughter Lucy was just two weeks old, Mary Sanagan and Aaron Mittler got a call that no parent ever wants to get. Their doctor informed them that Lucy had cystic fibrosis.

While receiving the news of Lucy's diagnosis was devastating, they immediately became exposed to the wealth of resources available to support Lucy and for them. "I will never forget that first visit to SickKids where we learned about how years ago children with CF didn't live to see kindergarten, but can now live long and productive lives," said Aaron. Mary and Aaron were eager to learn more about cystic fibrosis research, and the positive impact that research had in the lives of those with cystic fibrosis.

Mary and Aaron are so grateful to CF Canada advocates, who they credit with Lucy's early diagnosis: "We only knew about Lucy's diagnosis so early because advocates, supported by CF Canada, convinced the government to implement newborn screening of every child born in Ontario. This has given us a critical head start on a disease where prevention plays a huge role."

Inspired by the progress for Canadians with CF because of investments in research, clinical care and advocacy, Mary, Aaron and a group of their close friends (special shout out to Claire O'Shea) created Team Lucy, a group of CF Canada supporters and fundraisers.

The month following Lucy's diagnosis, Team Lucy founded *Lucky Lucy*, an annual fundraiser in Toronto named after the Queen of their hearts, Lucy. *Lucky Lucy* is a casino night with dinner, live music, casino games, and live and silent auctions. When asked why they started this group, Claire said: "We founded the fundraiser in the month following Lucy's diagnosis because we wanted to support Mary and Aaron with action that would have a meaningful impact for Lucy and all those with CF." Support they did, to date, **Lucky Lucy has raised over \$200,000 for Cystic Fibrosis Canada!**

*"It has been proven that with dedicated research, advocacy, and awareness a massive impact can be realized. Canada has amongst the best outcomes and life expectancies in the world for those with CF. That is a direct result of the hard work, dedication, and funds raised and invested by CF Canada," said Aaron.*

Mary and Aaron are hopeful that a cure or control for CF will come soon, so Lucy can spend less time on treatment and more time doing the things she loves like singing, dancing, and pretending to be a cat! "Every day I think about how I wish I could trade places with Lucy; to give her what I and so many others take for granted – our health!" Cystic Fibrosis Canada would like to thank Aaron, Mary and Team Lucy for their fundraising efforts, and for helping to create a world without CF for Lucy, and everyone living with cystic fibrosis.



To learn more about the 2018 *Lucky Lucy* event happening September 6<sup>th</sup>, 2018 and to purchase a ticket, go to [www.luckylucycasinonight.com](http://www.luckylucycasinonight.com)





 **YouTube**

[@MELLYBEAUTY026](https://www.youtube.com/@MELLYBEAUTY026)

Seventeen year old Melissa Powell is a dynamic, inspiring and resilient young member of our community. From Maple Ridge, British Columbia, Melissa produces, edits, and publishes a successful YouTube channel, sharing her CF journey (and fun beauty tips!) with almost 7,000 subscribers around the world.

When Melissa Powell was diagnosed with cystic fibrosis at five months old, her family's life changed forever. Melissa's mom Lisa, who is the Coordinator of the Pitt Meadows Walk to Make Cystic Fibrosis History, is eternally proud of her daughter, "She manages to face each struggle and hurdle with grace and positivity, never allowing self-pity to overshadow her blessings."

Since her diagnosis almost 17 years ago, Melissa has experienced many health challenges – in the past three years she has spent 27 weeks in hospital – yet Melissa maintains a balance of realism and optimism: "I could be better, and I could be worse," she says.

Melissa is wise beyond her years, an element of her personality she credits to the "blessing and curse" that is cystic fibrosis. Having CF has made Melissa more responsible she says, and has made her grow up and understand life from a different perspective. "When I think about my life without CF – everything would be different. It's both a curse and a blessing – a blessing in the sense that I have learned to appreciate life more, I have learned and experienced things that many people my age have not."

When she was in grade seven, Melissa began playing around on YouTube, teaching herself to shoot and edit short videos about beauty and fashion for a limited audience. Melissa gained a sense of purpose and enjoyment from her YouTube channel, "I can't control my health, but this is one thing that I can. It makes me happy, and I like putting myself out there and getting positive feedback." But that changed when she began high school - Melissa stopped posting videos, fearing what the "older kids" would think.

Come October 2017, Melissa's health posed challenges and she found herself in the hospital for an extended stay. Out of a need to keep busy, and with a growing confidence and apathy for what others thought, Melissa started up her YouTube videos again, but this time she posted about life with CF. A journey began.

Melissa's channel now has almost 7,000 subscribers and has become a resource for international youth with CF. She has over 80 videos that chronicle her days spent in the hospital, friends visiting, CF-related diabetes and her hospital discharge day. "People from all over, the US, UK, Australia and Hawaii have reached out," says Melissa. "Of course being at the hospital sucks, but it was motivating to connect with other people, and it almost puts my mind at ease in a way. Making the videos keeps me occupied, motivates me to get up, and takes my mind off things."



*“Melissa has been able to find strength and support in creating a YouTube channel which focuses on spreading awareness for CF, as well as awareness and understanding for her and others who struggle with chronic health issues,”*

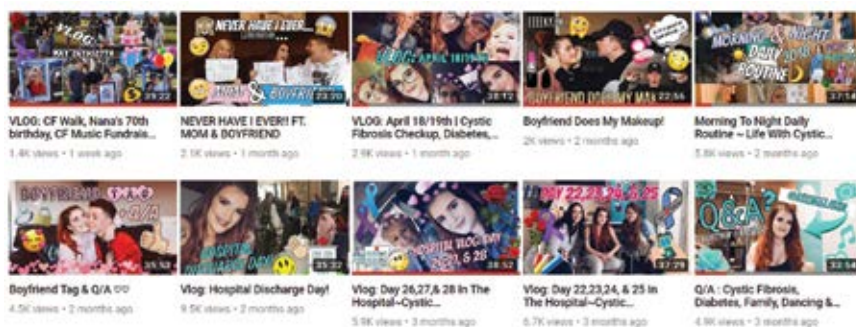
“Melissa has been able to find strength and support in creating a YouTube channel which focuses on spreading awareness for CF, as well as awareness and understanding for her and others who struggle with chronic health issues,” says Lisa. “This is not to deny that she doesn’t have those difficult days filled with emotion and anxiety, but overall she powers through persevering and gaining strength.”

The community of supporters that Melissa has gathered through her channel is inspiring. She has viewers who write to her that they are sharing her page with their other friends who have CF. Adults with CF write to Melissa to share their stable health as an inspiration, proving that her appeal as a “YouTuber” isn’t just for millennials. The connections she’s made as a result of her videos is something she finds most meaningful, “The worst part of CF is that you can’t really be around each other, unless you’re willing to risk your health. Because of how uncommon it is, the only people who truly understand what this is like are people with CF.”

Melissa acknowledges the demand of her channel, saying that she really only has the time to maintain the channel when she’s in the hospital, a situation she never wants to find herself in. Yet the idea that sharing her experience can benefit others who feel alone gives Melissa hope for her future and a direction for her ambitions, “I don’t want to spend my life doing something I don’t enjoy every day... My biggest hope is that CF will have a cure found. When I finally graduate, and one day move out, I hope my health will get better, and that my YouTube channel grows more – not only does it help me, I like hearing that it helps other people.”



**Make sure to subscribe to Melissa on YouTube @mellybeauty026**







## A CONVERSATION WITH LOUIS-PHILIPPE PESANT

*Louis-Philippe Pesant is a 36-year old member of our community, from Saint-Jérôme, Quebec. We talked to Louis about his experience with CF, his passion for cooking, and his hopes for the future!*

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### **WHAT WAS IT LIKE TO GROW UP WITH CF?**

I was diagnosed at birth, and it wasn't always easy. After I was born, I had to stay in the hospital for a long time. I was often sick as a child. I had many operations. I spent a lot of time in the hospital. I had H1N1. It was pretty difficult but I always came out all right.

It wasn't easy. Especially as a teenager, you go to school, you get sick, you spend two to three months in the hospital, you go back to school and have to start all over again.

There's no doubt that there were times when I was pretty sick and others when I didn't have to go to the hospital for a long time. In recent years, it has been a bit more fluctuating.

Last year, I was in the hospital for one month in May, and for three weeks in August and one month in December. It's not always clear how you can work. But that's life. No choice, you just have to keep going. But that has allowed me to see life differently, and get the maximum out of it, because I know I could get sick any time.

### **WHAT DO YOU DO FOR A LIVING?**

I'm a sous-chef and a pastry chef. I have plans for big challenges. And I am also a personal chef. I go to people's houses and prepare a 5-course gourmet menus for them.

### **WHAT HAPPENS WHEN YOU HAVE TO BE OFF WORK BECAUSE OF CF?**

I'm lucky because where I work, at the Groupe Maurice (owners of retirement residences), when I have to go to the hospital, or I have to have tests done, there is never a problem. I ask them and they make appropriate arrangements. In another restaurant, it would be more complicated but I try to get the most from this opportunity and I don't complain. In a previous job, I was told that my situation caused them problems because of the instability it created in the company. They talked about it, and I felt that there was a lot of unease about it and less confidence in me. Obviously, in the kitchen, confidence is really necessary, so I decided to quit. It was a big blow but it made me change directions. I worked at it and now I am much better off. But I have to say that nowadays it's not easy to work when you have CF. You have to go to the hospital a lot or have treatments and tests. Having a stable job is no easy feat.



### WHAT IS YOUR DAILY ROUTINE LIKE?

I get up around 6 a.m., to be at work around 8:30 or 9 am. I do my treatments religiously. It's the first thing I do when I wake up. I have three treatments that take me about an hour and a half, morning and night. Then I have protein shakes to keep my weight up. And I take my dog (a Labrador) out for a walk and get ready to go, and I will work the whole day.

There are times when I would like to stay in bed and bring the machine next me, to do the treatment while staying in bed.

Right now, things are okay. It takes me an hour and a half but not so long ago it took me about two and a half hours, morning and night, for my treatments, that's five hours a day. You can't keep that up. I try not to see it as an obligation because I do it to stay healthy, but it takes a lot of time.

Now it takes less time because after my most recent stay in the hospital, my lungs have regained a lot of capacity. So that has shortened my treatments. The doctors gave me a relatively new intravenous treatment. It often doesn't work, but it worked for me. When I went into the hospital, I had 21% lung capacity, and when I left, I was at 46%. Now I am at 28%.

This treatment is only given intravenously. It can't be given as a regular treatment, otherwise, even if it cost a fortune, I would try to pay for it to be able to stay at 46% lung capacity.

When the cold weather is coming, and with it comes temperature variations, hot inside, cold outside. I realize that this year, like every year, I will have bronchial spasms and other problems. Since our immune system is weaker, we are at greater risk of catching a virus, and when we get the flu, it has more serious consequences for us than for a healthy person. So I expect to have to up my treatment time.

### HOW DO YOU DEFINE LIVING WITH CF?

It's a fight every single day. Coughing is part of my regular routine. I have gotten to know myself well, to develop patience and to challenge myself regularly, especially during my stays in the hospital. But when I leave the hospital, I want to make the most of life, as if every day were my last one.

I know that everybody doesn't see life like that, but I remain positive and confident that in spite of the disease, it is possible to achieve something in life. Obstacles are part of life and the disease, but you have to stay positive.



Obviously, when you have been in the hospital for weeks at a time, it's harder to see the positive side. But when I leave, I am full of energy. I work a lot, 50 hours a week.

It's clear that I don't look ill. Even if I cough a lot, even in the kitchen. But for me, it's important to work, since it lets me lead a normal life and not spend all my time thinking about the disease.

### A CHILDHOOD MEMORY CONNECTED WITH CF?

When Céline Dion was very much involved with us, I went skiing with her, as a child. My father was president of Cystic Fibrosis Quebec for a long time, so I met Céline several times.



### WHAT IS THE SPECIAL LITTLE PLEASURE YOU ALLOW YOURSELF AND YOU REALLY LOOK FORWARD TO?

I appreciate everything in my day. When I left the hospital, I was feeling much better and I took the opportunity to go play golf, which is my passion. I couldn't do it before, because I was always out of breath. But I was really anxious to do it, because it was five years since I had last played golf. Small victory!

### WHAT IS YOUR BIGGEST CHALLENGE?

Beating the longevity records. I want to be the one who gets to be 65 or 70 years old and has had an incredible life (I'm 36 years old now, so I'm half-way there).



### WHAT WOULD A WORLD WITHOUT CF MEAN FOR YOU?

CF has enabled me to develop a taste for life, real patience and other things that I think characterize me today, and I would probably not be the same man without the disease. But having good health, a normal life, not to be always be gasping for air, that would be really something.

### IF A MAGIC WAND TOOK AWAY CF, WHAT WOULD BE THE FIRST YOU WOULD DO?

I would announce it! I would go to work as if nothing had happened but I would arrange my life to do more things, do more sports, like skiing, golfing, hockey and just go out more.



I would run with my dog, just for the pleasure of running. Because right now, I can't do that.

*Photo credit and special thanks: Allez-up Photographe*

## CANDID FACTS

### ROBERT'S CLARK'S LEGACY

*Cystic Fibrosis Canada would like to thank Robert W. Clark of Kingston, Ontario and the Clark family for their incredible support*

Say the name "Bob Clark" in Kingston, Ontario, and you'll likely be met with a smile of familiarity. Robert W. Clark was the owner and operator of the Aunt Lucy's Dinner House, St. Lawrence Cruise Lines, and the Worthington Park mobile home in Kingston's north end. His impact on the Kingston area reached far and wide, and his success was only exceeded by his kind heart and generosity. When he passed away in March 2016 at the age of 78, **Mr. Clark left an exceptional gift of \$2,000,000 to Cystic Fibrosis Canada in his estate.** This is the single largest donation ever received by Cystic Fibrosis Canada, and will have an impact on Canadians with cystic fibrosis for years to come.

Mr. Clark was predeceased by his wife, Myrna, in 2013, and although he had no children of his own, he was described as a family man through and through. Mr. Clark was very close to his nieces and nephews, namely his younger brother Jim's children, Jason and Shillane. Mr. Clark's connection to CF is his niece, Shillane Clark Labbett, a double-lung transplant recipient and cystic fibrosis champion. His nephew Jason Clark is now the President of St. Lawrence Cruise Lines, the company his late uncle humbly founded.

Mr. Clark's determination to help discover a cure for cystic fibrosis for people like his beloved niece Shillane is evident in his incredible generosity. Because of his bequest, and the generosity of other CF Canada donors, there are promising new therapies and a critical mass of researchers across Canada and around the world committed to improving the understanding of the disease and how to treat it, and genetic technologies that are opening the door to targeted treatments.



*Robert and Myrna Clark*

Mr. Clark is remembered as a business man with a heart, who cared deeply for his employees and always had a knack for recognizing potential. His employees felt like they were working *with* Bob, not *for* him. He supported local community events, and promoted Kingston, Ontario every chance he had. He brought that Kingston pride with him on his incredible international travels, including trips across Asia and South America.

Mr. Clark's unprecedented donation comes at a critical moment in the fight against CF, as we are now closer than ever to achieving our mission to end cystic fibrosis. This generous investment propels our researchers forward and provides hope for a brighter future for the families we serve. On behalf of our entire community, Cystic Fibrosis Canada would like to thank The Clark Family for the incredible legacy gift.

### THE SUMMERHAYES SOCIETY

Cystic Fibrosis Canada is pleased to announce the creation of *The Summerhayes Society*, a program designed to recognize donors who have made a significant impact on the organization through a legacy gift. The program is named after our founding members, Douglas and Donna Summerhayes.

In celebration and gratitude of his generous gift, **Cystic Fibrosis Canada is naming Robert W. Clark a Charter Member** of this very special group of donors. We are inspired by Robert's story and generosity, and know that his legacy will have an impact on generations to come.

Legacy giving, also known as planned giving, provides individuals and families the opportunity to make a special commitment to Cystic Fibrosis Canada. There are several options, with the most common being leaving a gift through one's will, naming Cystic Fibrosis Canada as a beneficiary

through a bequest gift. Other options include gifts of life insurance, annuities or a gift of retirement benefits. Legacy gifts allow certain tax incentives and advantages, and most importantly, provide for the future as we continue to strive towards a world without CF.

For more information on *The Summerhayes Society* and how you can help create a world without cystic fibrosis through your legacy gift, please visit [www.cysticfibrosis.ca/legacy](http://www.cysticfibrosis.ca/legacy); speak with your financial advisor; or call Molly Freeman, Manager, Annual & Planned Giving, at 1-800-378-2233 ext. 244.



**DOUGLAS & DONNA  
SUMMERHAYES SOCIETY**



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

It is hard to believe that it has been over 54 years since fate placed Dr. Crozier and Kin Bill Skelly at the same bar. And it is wonderful that in today's competitive charitable climate, our Kin members across Canada have managed to raise more than \$46 million in support of Cystic Fibrosis Canada.



*Tammie Corbett,  
Kin-CF Liaison Chair*

But a lot has changed in the past 54 years.

Although many believe that nothing in life can be truly static – I am starting to realize that Cystic Fibrosis Canada & Kin Canada do in fact have something in common that will never change. And that is, a commitment to finding a cure or effective control for cystic fibrosis (CF).

Following the Volunteer Leadership Forum (VLF) at the end of April in Toronto, I was thrilled to see how Cystic Fibrosis Canada volunteers and employees constantly embrace the Kinsmen and Kinettes as members of their own CF community. The VLF theme of “We Are Family” was very fitting as Kin members are considered part of the CF family and it was clear that we are all a cohesive unit working towards one goal.



*The Kin CF Liaison team for 2017/18 and the Kin CF Liaison team for 2018/19 at the Volunteer Leadership Forum*

I am also very proud of the outgoing Kin-CF Liaison team and would like to take this opportunity to thank the 2017/18 District Service Directors for doing a wonderful job this past year. The Districts were very well represented and Cystic Fibrosis Canada is very appreciative and celebrated the efforts of these wonderful individuals at the VLF this year.

Please join me in recognizing the following Service Directors who have made my first year as Kin-CF Liaison Chair an incredible one – Beatrice Crowley and Tim Natyshak (District 1), Pat Moldowan (District 2), Michelle Jandl (District 3), Rick Kuzyk (District 4), Anita Llewellyn (District 5), Monte Yancey (District 6), Terry Janes (District 7), and Cherie Anderson and Gary Newton (District 8). I thank you for your enthusiasm, leadership, and deep commitment to Cystic Fibrosis Canada.

As I embark on my second year as Chair, I am excited to work with the incoming Kin CF Liaison team; I am certain they will do a fabulous job. The 2018/ 2019 team is made up of some incredible Service Directors including: Tracy Spalding and Curtis Thoms (District 1), Hollee Babcock (District 2), Michelle Jandl (District 3), Dustin Bisson (District 4), Sandra Bowes (District 5), Sue Caron (District 6), Peggy Hefler (District 7), and Kathy McFarlane and Gilbert Boissonneault (District 8).

I look forward to another year of successful fundraising and raising awareness to make CF history. To the CF and Kin Community, I thank you all, for the memories and your continued commitment to the cause we share.

Working together we will end CF!

**Tammie Corbett,**  
Chair, Kin-CF Liaison Committee

Cystic Fibrosis Canada would like to thank Tammie Corbett, the 2017/18 Kin CF Liaison Committee and the 2018/19 Kin CF Liaison Team for their commitment and perseverance in helping us create a world without CF. Since 1964, Kin Canada has raised an incredible \$46 million for cystic fibrosis research and healthcare. The Canadian CF community is grateful for their outstanding contributions!



# CELEBRATING #LSN10

Lawn Summer Nights (LSN), a Cystic Fibrosis Canada national partner, began in 2009 with three friends who brought lawn bowling, a classic summer pass-time to Vancouver in support of their friend Eva Markvoort. Sadly, Eva lost her own fight with cystic fibrosis on March 27, 2010. She was 25 years old. LSN is proud to be a part of Eva’s legacy and the event will continue to accomplish what Eva championed the most – enjoying life and finding a cure for cystic fibrosis.

Since that first summer, LSN has expanded from one event to 18 events taking place across Canada from major cities to small, tight-knit towns – and they have raised more than \$2.7 million for Cystic Fibrosis Canada. Their success is due to the community they have built over the years – dedicated and passionate volunteers who organize and support Lawn Summer Nights #onthegreens.

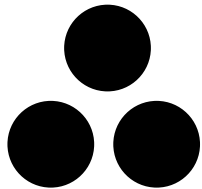
**This year they have an incredible milestone to celebrate - Welcome to #LSN10!** 2018 marks the tenth annual Lawn Summer Nights season, and the LSN community couldn’t be more excited. Over the past 10 years, they built a community of young professionals that continue to awe and inspire everyone they come in contact with. You can find out more about the event by visiting the new LSN website with refreshed branding at [www.lawnsummernights.com](http://www.lawnsummernights.com).

Cystic Fibrosis Canada is extremely grateful for all the support and commitment that Lawn Summer Nights has shown over the past 10 years. Thank you to an amazing organization and a dedicated group of hardworking volunteers!

# LAWN SUMMER NIGHTS.



**10 YEARS. 16 CITIES. 47 EVENTS. 5000 PARTICIPANTS.**





*“Fundraising doesn’t come easy, and it doesn’t always come naturally. When you sign up to bowl at Lawn Summer Nights, you’re joining a family of people who want more than just a good time; they want to be part of something bigger... they want to make a difference in their community.” - Mark Heystee, LSN Board Chair*



*“We believe in grassroots fundraising – in backyard BBQs and YouTube covers and yoga retreats and food fights, and all those millions of little things that set us apart from other fundraisers. We’re here for the ideas, no matter how big or small. Because after all, LSN began with one great idea...” - Ashley McAllister, LSN National Coordinator*



# CYSTIC FIBROSIS CANADA PARTNERS WITH NOGU

In June, Cystic Fibrosis Canada announced its national partnership with Canadian based jewelry company, NOGU. Mario and Luca Lavorato, founders of NOGU and both diagnosed with cystic fibrosis (CF) at birth, have pledged to donate 50 per cent of gross sales from the company's Kite Collection to CF Canada.

"Mario and Luca are living proof of the progress Canadians with cystic fibrosis are making as a result of advances in research and clinical care. We are so grateful for their generosity", said Jennifer Nebesky, Chief Marketing, Communications and National Events Officer at Cystic Fibrosis Canada.

NOGU's Crystal Kite Collection includes a crystal charm bracelet in eight variations; 18 karat gold, rose gold, silver, and gunmetal, each with the Cystic Fibrosis Canada kite logo as the charm.

"It has always been a dream of ours to give back to the CF community," said Mario and Luca Lavorato, founders of NOGU. "We are grateful that the strides made by Cystic Fibrosis Canada have afforded us the stability in our health to do what we love, support a cause that is so close to us, and to help create a world without cystic fibrosis."



NOGU Crystal Kite Collection bracelets



Luca and Mario Lavorato



**NOGU**

► The bracelets can be purchased at [www.nogu.ca/kite](http://www.nogu.ca/kite).

## CARSTAR PROVIDES TRAVEL AND ACCOMMODATIONS FOR CFIT STUDY PARTICIPANTS

CARSTAR will fund travel and accommodations for participants of the Cystic Fibrosis Individualized Therapy (CFIT) study. With CARSTAR's generous support, participants with cystic fibrosis (CF) from across Canada will travel to The Hospital for Sick Children in Toronto (SickKids) to take part in the ground-breaking study. With more than two thousand different CF gene mutations, each patient is different. The goal of the program is to ensure every CF patient has access to the life-changing treatments that will work best for them. To promote the study, CARSTAR produced a video to share with the Canadian CF community.

"We are delighted that CARSTAR is supporting CFIT, and is providing Canadians with cystic fibrosis from coast to coast the opportunity to participate in a world-class study," said Dr. John Wallenburg, Chief Scientific Officer at Cystic Fibrosis Canada.

"Our relationship with Cystic Fibrosis Canada started when a franchise partner's granddaughter was diagnosed with CF, so we hosted a small golf tournament to fundraise for the organization," says Michael Macaluso, CARSTAR President. "Over 20 years later, fighting cystic fibrosis has become our North American cause, with our franchise partners building longstanding relationships with their local chapters, and this charity being engrained in our networks culture."

The #RoadToResearch partnership is an exciting chapter in the Cystic Fibrosis Canada and CARSTAR 21-year partnership. Since 1997, Cystic Fibrosis Canada has been CARSTAR'S charity of choice. With over 270 locations across Canada, CARSTAR is the national leader of auto collision and auto glass services. Through various fundraising events including the CARSTAR North American Conference, golf tournaments, sports marketing promotions and the annual Soaps it Up National Car Wash, CARSTAR and its franchise partners have raised over \$3 million to date.

Thank you CARSTAR for your incredible commitment to end CF!



# SIEMENS

Siemens launched its END CF fundraising campaign at its Town Hall event on May 31<sup>st</sup>. Over 500 employees were in attendance, including Global CEO, Joe Kaeser and Canada's CEO, Faisal Kazi. The two CEOs officially kicked off the campaign and got the crowd excited by selling ice cream to all in attendance, employees also enjoyed the photo booth and 50/50 draw. The campaign was a great success with offices in Montréal, Quebec City, Ottawa, Calgary and Oakville participating in END CF. Siemens CF Ambassador Chloe Micallef, and her mom Tracy, joined in the campaign celebrations to give an update on Chloe's health and share the incredible progress Chloe has made with her G-tube. Tracy thanked the employees for all the great fundraising events which included bake sales, yoga classes and a re-gifting silent auction. Earlier this year Siemens Montréal hosted a hockey tournament and employees will flex their athletic skills once again at the annual soccer tournament in September. Siemens' unwavering commitment to CF Canada spans over 21 years and includes a corporate match of \$30,000!

Thank you to all of the employees at Siemens for your incredible commitment to improve the lives of those living with CF.



*Joe Kaeser, Siemens Global CEO joins Faisal Kazi Siemens Canada President and CEO selling ice cream at the Siemens Town hall event.*



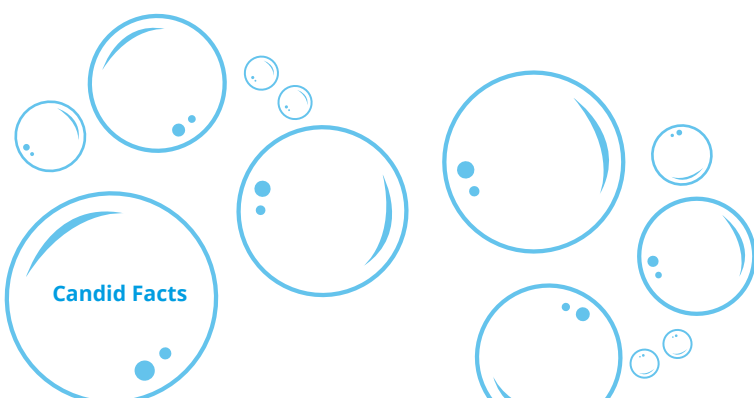
*Celebrating the wrap up of the Siemens CF fundraising campaign: L-R Tracy Micallef, Kate Milner, Christine Martysiewicz, Chloe Micallef and Faisal Kazi handing over a bucket load of cash from the 50/50 draw*

## PRO OIL CHANGE SOAPS IT UP!

This year marks the first year that Pro Oil Change raised funds for Cystic Fibrosis Canada. To support Shine month, Pro Oil Change Bracebridge cleaned and shined cars at its "Soaping it up" event and furthering their commitment to CF Canada, throughout the month of June Pro Oil Change Bracebridge asked for a donation with every oil change. CF Canada would like to thank Pro Oil Change for a successful first year of fundraising!



*The Pro Oil Change Bracebridge team*





# THYSSENKRUPP ELEVATOR CANADA

thyssenkrupp Elevator Canada shattered its 2018 fundraising goal in the first half of the year! Events such as the second annual curling bonspiel and bowling event in Ottawa were a huge success. In May thyssenkrupp hosted its inaugural hockey tournament PUCK CF, and two former Toronto Maple Leaf players, Wendel Clark and Kevin Maguire, were in attendance. Wendel and Kevin played with the teams, participated in many activities and truly made the event an unforgettable day. In total, the tournament **raised an incredible \$40,000 for Cystic Fibrosis Canada.**

Customers, suppliers, and thyssenkrupp Elevator Canada employees continue to come together to have some fun and raise significant funds for CF Canada.

The remarkable effort of this passionate group of individuals is incredible. thyssenkrupp CF Ambassador, Meaghan MacRury, leads all fundraising initiatives for CF Canada by engaging the branches from coast to coast. This year, Meaghan was recognized for her success at the Toronto Walk to Make Cystic Fibrosis History, placing in the top team category. Meaghan's team M&M celebrated its 10<sup>th</sup> anniversary and has **raised a total of \$117,643.24.**

Congratulations and thank you to everyone at thyssenkrupp Elevator Canada!



*PUCK CF: Christine Martysiewicz Director Corporate Partnerships, Cystic Fibrosis Canada, Meaghan MacRury, thyssenkrupp elevator Canada- CF Ambassador and Ryan Wilson, President and CEO thyssenkrupp Elevator Canada*



*PUCK Drop, thyssenkrupp elevator Team Captains*

## Party City

To kick off the Cystic Fibrosis campaign, which took place at Party City stores throughout April to June, six year old CF Ambassador Kaylee Chappell and her parents Alysia and Ron embarked on a road trip to Party City stores in Ontario. The Chappell family from London, Ontario, hit the road with stops at Ottawa area stores, Kingston, Belleville, Peterborough, Oshawa, Whitby and Ajax. With each store visit, Party City rolled out the welcome mat and hosted a unique themed activity for Kaylee.

Chantal Filion, Volunteer Chapter President & The CF Canada Sudbury Volunteer Team (Julie, Dale, Megan, Janessa & Shyanne) held a bake sale at the Sudbury store and **raised over \$500 and awareness for cystic fibrosis!** Party City stores in London and Windsor welcomed Cystic Fibrosis Canada into their stores to educate the community about CF and raise funds from balloon pulls for gift cards.

Congratulations to Party City Belleville who placed in the top spot for overall funds raised, with Windsor in second place and Newmarket securing third spot. A huge shout out to all the Party City store managers and employees for welcoming Cystic Fibrosis Canada into your stores and your hearts. **Congratulations on another outstanding campaign with a total of \$147,031 raised.** Thank you for all your support and hard work.



*Kaylee Chappell, Party City CF Canada Ambassador participates in a balloon pop fundraising event*



*L-R: Party City District Manager Kelli Dixon, Mike Cutting, Director Corporate Partnerships, Cystic Fibrosis Canada, Christine Martysiewicz, General Manager Kathy Marrisett, Samantha Pronovost and Linda MacMillan Director of Marketing, Party City Canada.*



# CYSTIC FIBROSIS CANADA NATIONAL AWARD RECIPIENTS 2018



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 2018 national award recipients, together we are working towards a world without cystic fibrosis.

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

## DR. LARRY LANDS

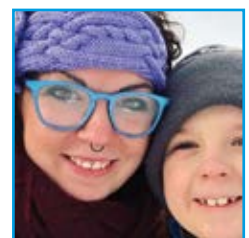
In addition to serving as the Director of a prominent CF clinic, Dr. Larry Lands provides medical liaison to the associated lung transplant program and clinical care in an outreach capacity. He has volunteered in many leadership roles over the years – working with equal dedication to both clinical care and research, including participating on the Scientific Review Panel, the Clinic Subcommittee, the Registry Review Panel, the advisory group for the development of the Canadian CF Clinical Trials Network and the Research Advisory Council. He was also integral in the efforts to ensure availability of newborn screening for CF in all provinces in Canada. Dr. Lands has been involved in Accreditation Site Visits across the country – from British Columbia to Newfoundland – helping to form policy and to ensure consistency of care nationally. Cystic Fibrosis Canada is very appreciative of his contributions over the years.



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

## AMY LABONTE

Amy is tenaciously dedicated to the CF cause. She was an integral part of Yukon's first Walk to Make Cystic Fibrosis History and since then, has coordinated every CF walk in Whitehorse. Despite the obstacles the Yukon Chapter has encountered due to vast distances between its communities, it has experienced numerous successes; including raising awareness about CF along the Alaska Highway and their very successful Walk each year. Thank you to Amy for her constant leadership and commitment.



## DAVID WATSON

David has been involved with the Moncton Chapter since 1980, when the first of his two daughters with CF was diagnosed. Thanks to David's efforts, the Moncton Chapter has not only grown its volunteer base, but it has introduced several new fundraising initiatives including the Ride for the Breath of Life, Squash CF Pumpkin Shoot, Sugar and Spice Ladies' Night Out, and the Vintage Fashion Show. Thank you to David for his dedication and passion throughout the years.



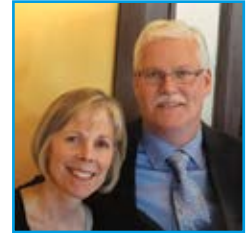
### **JEANNE STOPPARD**

Jeanne began volunteering immediately after her granddaughter was diagnosed with CF 13 years ago. Attending most meetings and Chapter fundraisers to ensure all appropriate financial practices are in place, she has been instrumental in safeguarding the accuracy of the Campbell River/Comox Valley Chapter's reporting. From organizing registration volunteers at the Walk, to fostering relationships with major sponsors, Jeanne is the model of a magnificent volunteer. Cystic Fibrosis Canada is thankful for Jeanne's outstanding leadership and support.



### **JEFF AND CHERYL SANDFORD**

Jeff and Cheryl are incredibly resourceful and creative volunteers. With Jeff taking on the role of Chapter Treasurer for the Nanaimo Chapter, and Cheryl managing many aspects of events and meetings, there are few Chapter activities that this power couple is not involved in. Jeff and Cheryl are at the root of the Nanaimo Chapter's success and the CF community is thankful for their contributions and support.



### **KATIE SCHULZ**

Katie is a natural leader. Being a mom to a child with CF, she is passionate about the CF cause and always makes herself available to spread awareness about the disease. Katie leads by example; taking on any task and helps others complete theirs. She is an advocate, an educator, a fundraiser extraordinaire, a dedicated mom and a tireless contributor. Katie's dedication to finding a cure to help not only her daughter, but all Canadians living with CF, is nothing short of inspirational; thank you Katie!



### **KIM BAIRD**

Kim is a one-woman dynamo for the Cornwall Chapter. She does so much for so many, and has truly dedicated her life to helping others. Kim is an incredibly valued member of the CF community, knowing many community members by name and maintaining relationships with sponsors, volunteers and families affected by CF for over 30 years. Thank you, Kim, for your dedication and for being an outstanding volunteer.



### **NERO FAMILY**

For over 20 years, The Nero Family and their 60+ employees in the Greater Sudbury area have been key supporters of Cystic Fibrosis Canada's Sudbury Chapter. Their time, dedication, generosity and continuous support are what drive the success of the Walk in the region. The Nero family's engagement as advocates for our mission to end CF is exemplary to other volunteers and business supporters. We are grateful for the Nero Family's teamwork and commitment.



### **STACY HIPKIN**

Stacy has been an active volunteer with the Edmonton & Northern Alberta Chapter for more than 12 years. First as Chapter Vice-President and then as President, Stacy assists with every fundraiser in one way or another. She is dedicated to effectively engaging with and organizing volunteers and is constantly working to help create a world without CF. Cystic Fibrosis Canada is very appreciative of Stacy's tremendous dedication and we thank her for her commitment in the fight to end CF.



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

### **ANDRE AND KAREN CHARTRAND**

Andre and Karen have volunteered with the Ottawa Chapter for over 15 years, and are largely responsible for the renewed stability and growth that the Chapter has experienced. They work tirelessly with volunteers and support groups, and speak from the heart whenever the opportunity to promote the CF cause presents itself. We are grateful for Andre and Karen’s dedication and contribution.



### **MARIE-LAURE BOUCHARD**

Marie-Laure is a model of resilience and hope for the Côte-Nord Chapter. Every year for the past 35 years, she has built new and existing relationships to secure funding. Although she is often working behind the scenes, Marie-Laure is also the first person out in the field to lend a helping hand. Cystic Fibrosis Canada is proud to recognize Marie-Laure for her successes as an exemplary volunteer.



### **SHAUN AND KATARINA NECHVATAL**

Shaun and Katarina are forces that energize and inspire the people around them. This couple is a fundraising powerhouse, running the annual event Hoops for Hope. Katarina is also the pediatric liaison for the North Saskatchewan Chapter, regularly reporting back with clinic updates and assisting with the organization and outreach for an annual CF education night. We thank Shaun and Katarina for being a source of motivation to all volunteers and for their remarkable contributions.



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**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. PATRICK DAIGNEAULT**

Dr. Daigneault is a healthcare professional who has been involved with Cystic Fibrosis Canada for many years. He supports the CF cause in various ways; participating in fundraising activities, speaking at gatherings and a steadfast advocate for Quebec’s newborn screening program. For all of the personal attention he offers those with living with CF, for the constant hard work within his professional life, for his loyalty to the cause; Cystic Fibrosis Canada would like to thank Dr. Daigneault for his dedication and support.



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**The Eva Markvoort Leadership Award is designed to recognize an individual (between the ages of 20 and 35 years of age) who has displayed outstanding leadership and made an exceptional, inspirational and/or motivational contribution to Cystic Fibrosis Canada.**

### **TARA BOURQUE**

Tara’s influence within the CF community is immeasurable. She has shared her struggle with CF with a determination to impact change in so many ways. Her dedication to Shinerama and work within the Sarnia-Lambton Chapter as President has inspired others to continue the fight against the disease. She participates in many interviews and videos to share her positive attitude and to provide hope to those affected by CF. Her presence is felt beyond any regional borders as she is often referred to as a source of information and inspiration, helping to increase fundraising initiatives and exposure year after year. We are thankful for everything that Tara has done and for sharing her story to inspire others.





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

### **CHRIS MACLEOD**

Chris has devoted his life to helping others; he carved a career out where he saw a need for help. He is driven by a deep-rooted sense of empathy, equity and justice, and is dedicated to fighting for drug coverage for those living with CF. Chris goes above and beyond to lift people up and shine a light on their stories to help create real and important change in our healthcare system; change that will benefit Canadians with CF now and for years to come. Cystic Fibrosis Canada thanks Chris for his outstanding and impactful contributions.



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

### **DETTMERS FAMILY**

The Dettmers family has spent over three decades dedicating their time and expertise to the Montréal Chapter. Daniel, Sylvie and their daughter Sarah (who lives with CF) have organized and supervised a large number of successful fundraising events. Sarah is an extraordinary spokesperson and Sylvie regularly supports event activities. The Dettmers family motivates members in their community to maintain momentum in the fight against cystic fibrosis. Daniel has also played a significant part in the development of the Chapter, the Montréal Walk and within Cystic Fibrosis Canada through his numerous roles in the organization throughout the years. Thank you to Sarah, Daniel and Sylvie for everything you have done to support Cystic Fibrosis Canada over the years.



### **HAGERTY FAMILY**

For almost two decades, the Hagerty family has been actively involved with the Newfoundland & Labrador Chapter. From organizing golf tournaments and hockey games to participating and volunteering in the Walk to Make Cystic Fibrosis History, the Ride for the Breath of Life, annual car shows and car washes; Greg, Stacey and their son Matthew are volunteer leaders. Their contributions are invaluable to their Chapter. Cystic Fibrosis Canada thanks the Hagerty family for their outstanding dedication and inspiration to the CF community.



### **WEGER FAMILY**

The Weger family joined the South Saskatchewan Chapter over 10 years ago and soon became role models in the CF community. They actively participate within the Chapter by running their annual Butter-tart Fundraiser and fundraising for the Walk to Make Cystic Fibrosis History in creative ways; including organizing a successful annual dinner. Mike also sits on the Chapter's Organizing Committee for the Ride for the Breath of Life. Mike and Cara's eldest daughter Teresa (who lives with CF) has become a spokesperson for those battling the disease, speaking at a number of events such as the Dream of a Diamond and Dream of a Cure Ladies Night. Cystic Fibrosis Canada thanks the Weger family for inspiring individuals and families to join and continue the fight against CF, and for their wonderful support throughout the years.



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

### **KPMG**

Since 2009, KPMG has set itself apart as a leader in supporting the growth of Lawn Summer Nights (LSN) and raising significant funds for Cystic Fibrosis Canada. KPMG sponsors LSN events in cities that their offices reside, and from a national level. There are many KPMG LSN teams setting and surpassing their fundraising goals. KPMG provides LSN day-of volunteers, and a number of their employees have joined LSN committees and the National LSN Board. KPMG is a leader in raising national awareness and funds for Canadians living with CF and Cystic Fibrosis Canada is grateful for their outstanding support.



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

### **JIM BEST**

Jim has spent over 15 years participating in local, regional and national fundraisers in support of Cystic Fibrosis Canada. He can often be found raising awareness for the CF cause by speaking at Shinerama events and with local newspapers while also engaging his coworkers to raise funds and participate in the Walk to Make Cystic Fibrosis History. Recently, Jim crossed Canada raising awareness and funds with his motorcycle ride from coast to coast. Thank you to Jim for his positive spirit and passion throughout the years.



### **MEAGHAN MACRURY**

Meaghan is an inspiring individual living with CF who demonstrates incredible leadership and fundraising abilities. In her position with thyssenkrupp Elevator Canada as the Cystic Fibrosis Ambassador, Meaghan has engaged thousands of employees from coast to coast. Meaghan has spearheaded many unique events including hockey tournaments, curling bonspiels, a children's art contest, bowling tournaments, bake sales, and is Team Captain for Team M&M for the Walk to Make Cystic Fibrosis History. We are grateful for Meaghan's dedication, strength and inspiration in the fight for all Canadians living with CF.



**The Volunteer Excellence Award is bestowed on an individual, couple or family who has made an exceptional sustained contribution of national impact to Cystic Fibrosis Canada for a minimum of five years.**

### **DANIEL LALONDE**

Daniel is an exceptional volunteer who has spearheaded a number of initiatives in the Quebec Region. He has held leadership positions on the committee for Quebec's Gala, obtains sponsorships from major donors, organizes evenings at golf clubs, and has recently joined the campaign cabinet for the Cystic Fibrosis Canada Campaign in Quebec. Daniel brings a high level of strategic development and philanthropy to the table to help Cystic Fibrosis Canada advance its mission to end CF. Thank you to Daniel for his leadership and dedication.



### **JO-ANN WALLIS**

Jo-Ann has volunteered with the Campbell River/Comox Valley Chapter for 34 years and has held many important roles within the organization. Her work ethic, empathy, enthusiasm and willingness to take on any challenge that the Chapter faces is inspiring and she always gets the job done. She has an amazing and unique skill for bringing various people in the community together to further Cystic Fibrosis Canada's mission. Cystic Fibrosis Canada thanks Jo-Ann for being a true representation of a volunteer leader.



### LISETTE TREMBLAY

Lisette has volunteered with the Mauricie/Centre-du-Québec Chapter for over 13 years and has carried out the duties of Chapter President with grace and skill for several years. She recognizes the importance of finding continuous sources of funding to ensure the advancement of research and the development of new treatments. Lisette has unique relationships with the Chapter's volunteers, regularly listening to their ideas and needs. Cystic Fibrosis Canada is grateful for Lisette's passion and leadership.



### LOVISA MCCALLUM

Lovisa McCallum began volunteering with Cystic Fibrosis Canada in 2004, after her son and niece were diagnosed with cystic fibrosis. Since then, Lovisa has made it her personal mission to do everything she can in the fight against CF. She is a strong leader and is a force to be reckoned with when it comes to her fundraising efforts; she is always one of the top fundraisers of the Walk to Make CF History. We are thankful for Lovisa's passion and commitment in our mutual goal to end CF.



### RON ANDERSON

For more than 15 years, Ron's leadership within the Toronto & District Chapter has directly contributed to its level of success. He can often be found organizing and supporting a number of initiatives in the CF community, such as golf tournaments, the Toronto Walk to Make Cystic Fibrosis History and various community events. Ron is instrumental in both the Fusion Gala and Decant Gala & Fine Wine Auction, which he co-created and continues to Co-Chair. He is an advocate for access to Orkambi and is currently one of the National Board of Directors at CF Canada working hard toward our mission to end CF. Cystic Fibrosis Canada is thankful for Ron's impact and contributions over the years.

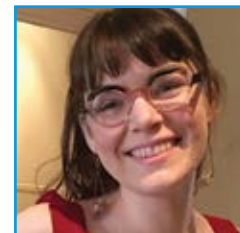


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**The Youth Impact Award is designed to recognize a young individual (19 years of age or under), who is a source of inspiration to others and has displayed leadership within the CF community on an ongoing basis.**

### ANNIE BARTLETT

Annie Bartlett was a youth artist, activist and speaker living with CF. She was granted a wish from Make-A-Wish Foundation and chose to speak in front of 20,000 youth at WE Day Vancouver to raise awareness for cystic fibrosis. Annie spoke to almost 3 million people at a variety of events, always discussing living with CF, the impact it has, and her hope for the future. Sadly, Annie passed away on August 8, 2018. We are grateful for Annie's exceptional work in raising awareness for the CF cause and for inspiring many others to take action.

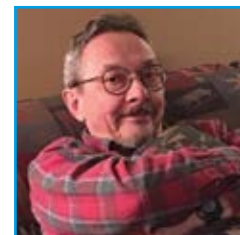


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**The Julia Award is intended to acknowledge non-chapter groups or individuals who have made a sustained and ongoing financial contribution through third party events.**

### CLAUDE UZELMAN AND 97 FOODS LTD.

Claude and 97 Foods/A&W are celebrating the 10<sup>th</sup> year of Breath of Life Day at A&W. Every year on this day, one dollar from every burger sold is donated to Cystic Fibrosis Canada. Thanks to Claude's outstanding leadership, this event has expanded across three Chapters - Okanagan, Kamloops, and Victoria - and there are now over 20 A&W restaurants that participate in the event. Cystic Fibrosis Canada would like to thank Claude and 97 Foods Ltd for their contributions.





### **CYSTIC FIBROSIS CANADA SOUTH SASKATCHEWAN ADVOCIS CHAPTER**

The South Saskatchewan Advocis Chapter has demonstrated a strong sense of volunteer engagement and leadership, having organized a golf tournament with volunteers who have been committed for several years. The Chapter also runs professional development days to promote CF, proving to be an unstoppable force in recruiting and retaining amazing volunteers. Cystic Fibrosis Canada is grateful for the devoted support that the South Saskatchewan Advocis Chapter provides in our mission to end CF.



### **SYLVAIN OUMET AND SYLVAIN YELLE**

Sylvain and Sylvain are unstoppable. For over 20 years, they have supported Cystic Fibrosis Canada by generously giving their time and expertise organizing the 'Lac-du-Cerf' rally to raise funds for CF research and care. In addition to organizing event logistics and ensuring participants are being looked after, they seek out sponsors and compile the results after the event. Cystic Fibrosis Canada thanks them both for their incredibly dedicated and enthusiastic 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 CAMPBELL RIVER/COMOX VALLEY CHAPTER**

Known as the "small but mighty" chapter, the Campbell River/Comox Valley Chapter has done an exceptional job in their public awareness efforts over the years. From their annual golf tournament to the Bowl for Breath event, volunteer participation, advocacy and CF awareness building are always at the forefront of the Chapter's activities. Cystic Fibrosis Canada thanks the Campbell River/ Comox Valley Chapter for their tremendous dedication and commitment in increasing awareness and advocating for access to medications.



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**The Fundraising Excellence Award** recognizes a Chapter that has demonstrated overall excellence in the area of fundraising.

### **CYSTIC FIBROSIS CANADA MAURICIE/CENTRE-DU-QUÉBEC CHAPTER**

The members of the Mauricie/Centre-du-Québec Chapter are active and passionate members of the CF community. They never hesitate to solicit companies or their contacts to help those who express interest in getting involved with fundraising initiatives. In addition to collecting sponsorships, their fundraising initiatives have raised public awareness of cystic fibrosis in their region. We thank the Mauricie/Centre-du-Québec Chapter for their tenacity, spirit and outstanding support.



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**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 QUEBEC CHAPTER**

The remarkable success of the Quebec Chapter is largely due to its volunteer committee's ability to recruit business partners in the Quebec City region. As a result of the connections within the community, the Chapter has access to many resources to build its presence and influence in the region of Quebec. The Chapter also utilizes media coverage and social media platforms to increase visibility of fundraising events, spread awareness about the disease as well as recognize the remarkable volunteers and the generosity of sponsors and partners. The volunteers of the Quebec Chapter are leaders in the CF community, and Cystic Fibrosis Canada is grateful for all that they do.



## CELEBRATING MILESTONES: JEAN GREGSON'S 75<sup>TH</sup> BIRTHDAY

Jean Gregson lives in Langley, British Columbia with her husband, Alan. In 1979, at age 35 – after many hospital stays, bouts of bronchitis and pneumonia and sinus surgeries, Jean was diagnosed with cystic fibrosis. Her diagnosis made medical history in B.C. because she and her two brothers were the first adults diagnosed with CF, at a time when there wasn't yet an adult clinic in B.C. In 1972, Jean graduated from UBC with a BA and went on to earn a Masters Degree in Library Science in 1974.

Jean worked as a librarian for the Langley School District for 33 years until the age of 65. Initially, she worked full-time, but frequent hospitalizations for lung infections led her to spend the last 20 working years part-time.

### On June 1, 2018, Jean celebrated her 75<sup>th</sup> birthday!

Cystic Fibrosis Canada would like to wish Jean a very happy (belated) birthday! She is an inspiration to the CF Canada community and her story motivates us to continue our important work so that all Canadians with CF can celebrate a birthday well into their 70s!

**Do you have a story you'd like to share? Email [public-relations@cysticfibrosis.ca](mailto:public-relations@cysticfibrosis.ca) for your chance to be featured!**



*Jean and her husband Alan celebrating her birthday with members of the Adult CF Clinic at St. Paul's Hospital*

*"I had a wonderful birthday celebration with over 160 guests including many of the staff from the CF clinic," said Jean. "My life is now more restricted, but I am still able to enjoy just being alive. My husband is a wonderful caregiver and I have tremendous support from my family, my friends and my church. All in all, life is pretty good."*

We wish Jean and her husband Alan many more years celebrating together!



## THE 2018 VOLUNTEER LEADERSHIP FORUM

On April 26-29, CF Canada hosted the Volunteer Leadership Forum (VLF) in Toronto. The purpose of the forum is to gather lead volunteers and motivate, inspire and educate. The volunteers can then go back to their chapters across the country and share their knowledge and skills with other members and volunteers of CF Canada. The VLF provides tools and training that are relevant to our volunteers and supports them in raising funds and awareness for people living with cystic fibrosis (CF).

During the VLF, volunteers attend a number of workshops and seminars, which are selected based on feedback from the volunteer engagement survey and important information CF Canada volunteers need to know. This year, the topics included a thorough walk-through of our

research, healthcare, registry and advocacy, succession planning for our chapters, leadership training and much more. A key feature of the VLF was the medical session, presented by doctors or clinicians in the field of CF care and research. This year Dr. Larry Lands and Dr. Valerie Waters joined us. Moderating their discussion was CF Canada's Chief Scientific Officer, Dr. John Wallenburg.

The VLF is always capped off with an evening of celebration during the Awards Gala dinner, followed by dancing. This is an opportunity to give recognition and thanks to our hardworking volunteers in front of their peers, who nominated and voted for them. This is an evening of celebration for all we have accomplished and a time to look forward with renewed enthusiasm for the year ahead.





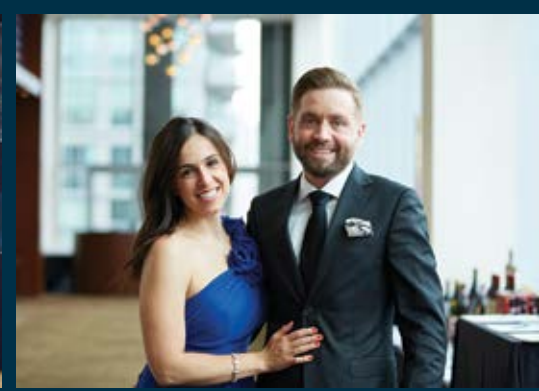


# Volunteer Leadership Forum

A big thank you to everyone that contributed to another successful event! We could not host the VLF without you. And a special thanks to you - our amazing volunteers for making time in your lives to come to this event and share your experience and knowledge with us!







# Decant

GALA & FINE WINE AUCTION

The Decant Gala and Fine Wine Auction took place on Saturday, May 5, 2018 at the Delta Toronto Downtown. This year's theme, An Evening in Italy, promised its guests a *bellissimo* time featuring the culture and culinary delights of Italy, sommelier paired Italian wines, an incredible selection of wine lots in the silent auction, exciting live auction items, and The Key to the Cure auction. Cystic Fibrosis Canada ambassador Ben Mulroney was the Master of Ceremonies of the evening, which raised **over \$415,000** for critical care, research and advocacy!

Congratulations and thank you to the committee and organizers for such a wonderful event!





# CYSTIC FIBROSIS CANADA LAUNCHES NEW MONTHLY DONOR PROGRAM: *MAKE IT 75*



What can you do in 25 years? How many more hugs would you give? How many new memories could you create? Since 1960, the median age for Canadians with cystic fibrosis has gone from 5 to over 50 years. We've come so far. But with your help, we can go even further.

Cystic Fibrosis Canada has launched a new monthly donor program: *Make it 75*. By joining this determined group of people, you are funding research and helping us fight for access to medication that could change lives.

The goal of the program is to encourage Canadians to sign up as monthly donors, so that one day the estimated median age of survival for CF is 75. To promote the program, CF Canada has developed a series of ads that showcase the humorous moments associated with aging, for example, wearing high-waisted pants or taking advantage of an early bird dinner special. While some Canadians might dread these moments in life, a person with cystic fibrosis dreams of living long enough to experience them.

As part of the program, you'll receive regular updates from members of the family – the Cystic Fibrosis Canada family, of course. You'll be part of celebrating our special moments and milestones, from research advancements to birthdays and marathons. The special moments and milestones made possible because you gave us the voice we needed to make it happen.

A quarter of a century worth of hand-holding, vacation-planning, daydreaming, memory-making, and life-living is worth fighting for. Let's do it on behalf of every Canadian with cystic fibrosis and everyone who loves them. Let's Make it 75. Then 76. Then 77. Then 78. Then let's make it the day when cystic fibrosis never limits lives again. Together, we can get there.

**Become a monthly donor today.**  
**Visit [www.makeit75.ca](http://www.makeit75.ca) here to register.**





On Sunday, May 27, 2018, thousands of participants across Canada united at local community walk sites during CF awareness month to celebrate their fundraising efforts, while imagining a world without CF.

10,000 supporters, including volunteers, donors, partners and participants supported Cystic Fibrosis Canada's mission: to end CF. **The 2018 Walk has raised over \$3 million** that continue to fund world-class CF research, advocacy and care.

We would like to thank all participants, partners, donors and our incredible volunteers for making this year's Walk such a success, and for making cystic fibrosis history!

Next year will mark the 15<sup>th</sup> anniversary of the Walk to Make Cystic Fibrosis History, and to celebrate CF Canada will host its first **international walk location with a trek to Machu Picchu in Peru**. The Walk to Machu Picchu will take place in May 2019, coinciding with the Walk happening across Canada on Sunday, May 26, 2019.

For more information about the Machu Picchu trek, or to register for the 2019 Walk, visit [www.cysticfibrosis.ca/walk](http://www.cysticfibrosis.ca/walk).

## WALK TO MAKE CYSTIC FIBROSIS HISTORY







# DONATE TODAY

Yes! I'll give a special gift to help create a world without cystic fibrosis.

Name \_\_\_\_\_

Address \_\_\_\_\_

City, Province \_\_\_\_\_

Postal Code \_\_\_\_\_

Phone Number \_\_\_\_\_

Email\* \_\_\_\_\_

## GIFT AMOUNT

\$250     \$100     \$75     \$50     Other \$ \_\_\_\_\_

or donate online at [www.cysticfibrosis.ca/donate](http://www.cysticfibrosis.ca/donate)

### Payment Options:

Cheque     Credit Card

Card number \_\_\_\_\_

Expiry date \_\_\_\_\_

Signature \_\_\_\_\_

I want to receive an e-receipt

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

Monthly giving     Planned giving     Tribute giving

Please send your completed donation form to:

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

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

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

**Charitable Registration No. 10684-5100 RR0001**



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

2323 Yonge Street, Suite 800  
Toronto, Ontario M4P 2C9

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