Cystic Fibrosis
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Canada

Connections

WINTER 2018

KIM WOOD
THE MOTHER OF ALL BLESSINGS

2016 REGISTRY HIGHLIGHTS

YEAR-END CAMPAIGN: 31 REASONS TO GIVE

CELEBRATING EXCELLENCE IN LUNG TRANSPLANT RESEARCH AND CARE

WALK TO MAKE CYSTIC FIBROSIS HISTORY

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Sunday, May 27, 2018

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WALK TO MAKE CYSTIC FIBROSIS HISTORY

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MESSAGE FROM MITCH LEPAGE, CHAIR OF THE BOARD OF DIRECTORS

On behalf of the Board of Directors, I'd like to take this opportunity to wish you a happy new year and reflect on our many recent accomplishments. Normally this message would be provided by our CEO, but because at the time of this writing we are in transition, I'm standing in for this issue of Connections. As we enter into the midway point of our strategic plan, I am confident that our organization is on the path to finding a cure or control for cystic fibrosis, and I thank all of you for your efforts to make our vision a reality.

The Canadian Cystic Fibrosis Registry provides a yearly opportunity for our CF community to identify cystic fibrosis care progress, and respond to the data collected. In November 2017, the 2016 data registry report was released. We are inspired that the median age of survival for Canadians living with CF has increased to 53.3 years. While this continued improvement demonstrates the positive impact on health outcomes for our CF community, we remain committed to continued improvement and ultimately, to a cure or control for cystic fibrosis. We are extremely grateful to the patients who volunteered this information, as well as the clinicians who dedicated their time to preparing this report.

Fundraising events like Shinerama united our communities over the past year and brought in critical revenues needed to support our 42 clinics across the country, as well as fund the research that helps us understand and treat the complexities of cystic fibrosis. As one example of this research, scientists at the University of Saskatchewan discovered why people with CF are prone to lung infections. Complex research and findings like this help us learn more about cystic fibrosis and how to treat it.

The *Sickboy* documentary on CBC, featuring Jeremie Saunders, gave Canadians a glimpse into what life is like for those living with chronic and/or fatal illness. With his candour and humour, Jeremie helped shed light on what so many living with CF experience daily, and increased awareness of cystic fibrosis for all the viewers.

The North American Cystic Fibrosis Conference was an opportunity for our team to meet with colleagues from south of the border. This conference unites more than 4,500 multidisciplinary leaders within the CF health care community: physicians, nurses, research scientists, respiratory therapists, physical therapists, nutritionists, social workers, and pharmacists. Our Canadian delegates learned strategies for improving the lives of people with cystic fibrosis, and shared our expertise and developments.

I would be remiss if I did not mention the departure Norma Beauchamp as President and CEO of Cystic Fibrosis Canada. Norma worked tirelessly throughout her tenure to lead CF Canada in its mission, and under her leadership, we have achieved significant milestones in the fight against cystic fibrosis. We are grateful to Norma for the lasting impact she has had and the legacy she leaves behind. Under the interim leadership of Jennifer Nebesky and Jeffrey Beach, CF Canada remains focused on our strategic plan, persistent advocacy for our cause, and continued support for our family and friends living with cystic fibrosis. The Board is diligently focused on recruiting a leader who will steer our team toward realizing our vision of a world without cystic fibrosis.

In April we will formally celebrate Norma's leadership and contributions at our Annual General Meeting. The Volunteer Leadership Forum will also be an opportunity to congratulate our volunteers who are so devoted to our shared cause, and inspire them to continue their incredible efforts at a grassroots level.

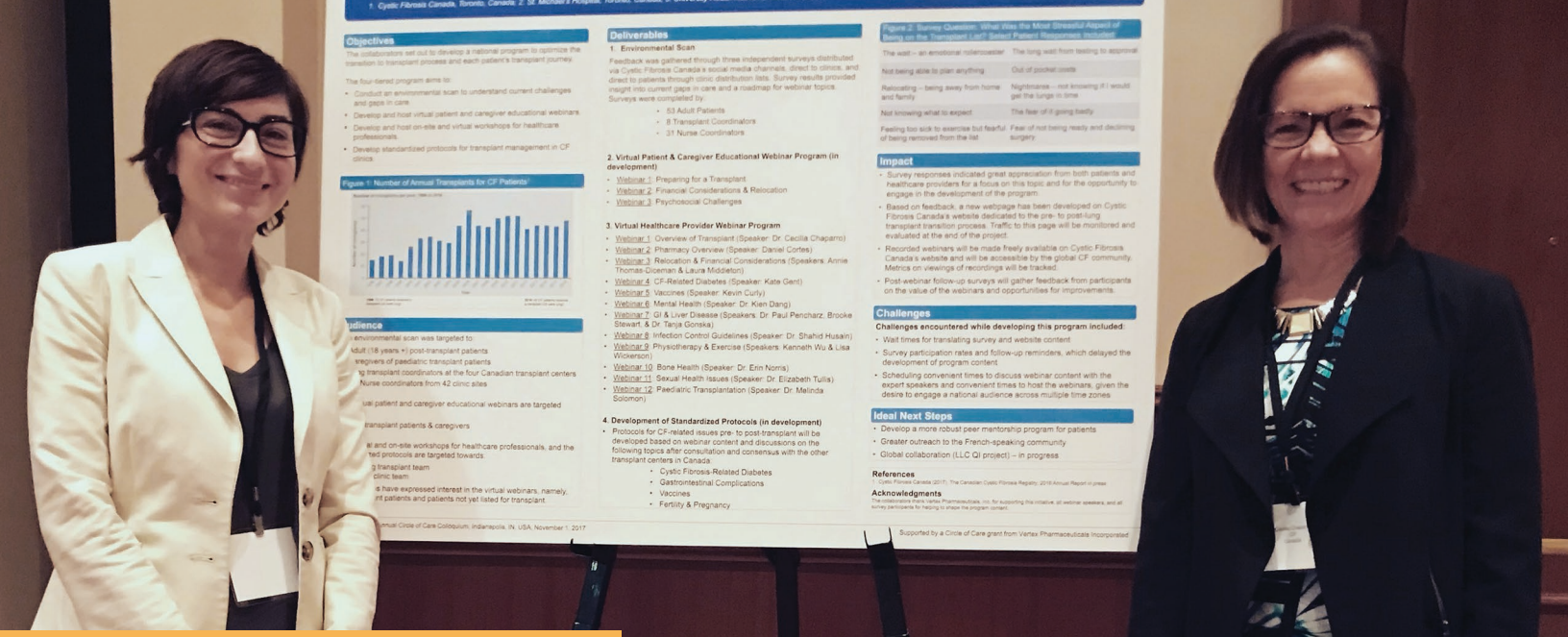
I thank all of you for your support. Together we will end CF.

Mitch LePage
Chair, Board of Directors

INTRODUCING OUR NEW CF CANADA BOARD MEMBER: FRANÇOYS LEVERT

François Levert is a Managing Director and Head of Global Markets with CIBC Capital Markets in Québec. He joined CIBC in 2011, and leads a team of 27 sales and trading professionals servicing institutional and corporate clients. He is responsible for developing and implementing CIBC Global Markets Strategy with the Québec client base. Prior to joining CIBC, Mr. Levert was Managing Director, Institutional Sales, and Head of Canadian Relationship Management at Manulife Asset Management, from 2009 to 2011. From 1996 to 2009, Mr. Levert held various key roles at State Street Bank and Trust, including Head of Canadian Institutional Foreign Exchange Sales.

François holds a Bachelor of Arts in Finance from HEC Montréal and the Chartered Financial Analyst (CFA) designation. François is a CF parent, and has been a member of the Committee of Honor for the Cystic Fibrosis Gala in Montréal for the past 14 years.



HOPE THROUGH PROGRESS

Joanna Valsamis, Chief Healthcare, Research & Advocacy Officer, CF Canada, and Dr. Cecilia Chaparro, presenting at the Vertex Circle of Care Colloquium at the 2017 North American CF Conference.

CELEBRATING EXCELLENCE IN LUNG TRANSPLANT RESEARCH AND CARE

Since the first successful lung transplant in 1983, Canada's world-renowned surgeons have pioneered new techniques now adopted internationally. They continually pursue ground-breaking research and innovate to achieve paradigm-shifting, world-first milestones. Today, funding from Cystic Fibrosis Canada continues to support improvements in transplantation processes and outcomes through its research and healthcare programs, a few of which are highlighted below.

TRANSPLANT CENTRE INCENTIVE GRANTS

Each year, Cystic Fibrosis Canada provides grants to support the four transplant centres located in Toronto, Montreal, Edmonton and Winnipeg. The Canadian CF Registry (CCFR) captures data on transplants and as of December 31, 2016, 694 Canadians with CF have received lung transplants.[1] Today the probability of surviving one year after lung transplant is almost 90 per cent and 10 years is 50 per cent.[2] Canada has one of the highest post-transplant survival rates in the world.

"It can be very frightening when your health gets to the point of needing a lung transplant," said Dr. Anne Stephenson, Medical Director, CCFR. "The positive news is that our research shows that survival rates following lung transplantation in Canadians with CF are high. In fact, on average, there is a 50 per cent chance of patients living beyond 10 years following lung transplantation."

VERTEX CIRCLE OF CARE GRANT: DEVELOPING NATIONAL STANDARDS IN CANADA TO SUCCESSFULLY TRANSITION TRANSPLANT PATIENTS WITH CYSTIC FIBROSIS.

In 2016, Cystic Fibrosis Canada successfully submitted a collaborative $100,000 proposal to the Vertex Circle of Care grant program. Joining forces with Dr. Cecilia Chaparro, transplant physician at the University Health Network-Toronto General Hospital, and Kate Gent, Nurse Co-ordinator at the Adult CF Clinic at St. Michael's Hospital, Toronto, the grantees are developing National Standards in Canada to Successfully Transition Transplant Patients with Cystic Fibrosis. Part of this initiative is to understand the current challenges and gaps in care as well as provide educational webinars for patients and caregivers, and training workshops for healthcare professionals. Further details can be found on CF Canada's website, under the "Healthcare" tab.

CANADIAN NATIONAL TRANSPLANT RESEARCH PROGRAM (CNTRP)

In 2013, CF Canada partnered with the Canadian Institutes for Health Research (CIHR) to support the Canadian National Transplant Research Program (CNTRP), comprising 86 researchers tackling seven projects, to increase access to transplantation and improve survival and quality of life post-transplant. The CNTRP is supported by $37 million from health charities, government agencies and industry partners. In 2017, CF Canada renewed its support of the CNTRP for an additional three years. In total, CF Canada is contributing $160,000 to this initiative.

Wally Speckert, surrounded by his collection of CF-related devices and medications no longer required following his successful double lung transplant

DR. SHAF KESHAVJEE'S RESEARCH PROGRAM, UNIVERSITY HEALTH NETWORK–TORONTO GENERAL HOSPITAL: TISSUE REMODELLING AND THE IMMUNE RESPONSE IN OBLITERATIVE BRONCHIOLITIS AFTER LUNG TRANSPLANTATION

To date, CF Canada has provided over $1.6 million in funding to Dr. Shaf Keshavjee's research program. His current grant focuses on reducing rejection in lung transplant recipients by modulating the levels of two important proteins involved in the immune response. Using a combination of gene therapy and a new drug to control this immune response, he hopes to develop a new approach to prevent and treat early and late lung failure after lung transplantation.

1. Canadian CF Registry.
2. Stephenson, A.L. *et al.* (2015) *J Heart Lung Transplant*. 34(9):1139-45.

NEWBORN RESOURCE KITS

In September 2017, a team of Cystic Fibrosis Canada staff and volunteers came together to assemble the Newborn Resource Kits.

This initiative began through the efforts of Helen Meinzinger, a CF parent, whose son Kaiden was diagnosed in 2009. Helen wanted to do something to help other newly diagnosed CF families, so in 2011 with funding from the Kin Canada Club of Russell, she created "Kaiden's Care Kits", which were assembled and distributed to new CF families in Ottawa.

In 2012, Helen approached Cystic Fibrosis Canada in hopes of partnering to distribute kits to all newly diagnosed families in Canada. The "Cystic Fibrosis Canada Resource Kit" was created following a pilot in 2013 that included feedback from nurses and families who received the Newborn Resource Kit.

The Newborn Resource Kits are designed to support families during the time of diagnosis, which many families report to be the most stressful and overwhelming point of their CF journey. Filled with reading materials on CF, as well as practical tools to help families care for their baby, the kit can help parents and caregivers to feel more confident caring for their child.

Parents and caregivers consistently give positive feedback on the Newborn Resource Kit, indicating that the kit helps them to feel less alone. One parent reported, "The kit was very helpful for our family. We are still using many of the components daily." Another parent commented, "I am extremely grateful for this kit. For someone to provide this for my family at a point where I felt devastated and overwhelmed by my newborn's diagnosis – it is a big blessing."

Cystic Fibrosis Canada would like to thank Mylan for sponsoring these kits, Johnson & Johnson for donating products to the kits, and our volunteers for assembling the kits.

HIGHLIGHTS FROM THE CANADIAN CF REGISTRY

Cystic Fibrosis Canada
Fibrose kystique Canada

OVER 4,200 CANADIANS
WITH CYSTIC FIBROSIS

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

122
NEW DIAGNOSES
INCLUDING 20 ADULTS

20.1% OF CF PATIENTS **TRAVELLED MORE THAN 250KM** TO RECEIVE CF CARE

OF THE
42 CF PATIENTS
WHO DIED IN 2016,
HALF WERE UNDER THE AGE OF 38.9 YEARS

84.8% OF CANADIANS
WITH CYSTIC FIBROSIS
MUST TAKE PANCREATIC ENZYMES
TO DIGEST FOOD AND ABSORB NUTRIENTS

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

59.1%
OF CF PATIENTS
ARE DIAGNOSED WITHIN THEIR **FIRST YEAR OF LIFE**

22.8%
OF ALL CF PATIENTS
HAVE **CF-RELATED DIABETES**

THERE ARE **MORE CF ADULTS** THAN **CF CHILDREN,**
60.8% OF ALL PEOPLE WITH **CYSTIC FIBROSIS** IN **CANADA** ARE **ADULTS**

45 CF PATIENTS
RECEIVED TRANSPLANTS WITH A
MEDIAN AGE OF 31.2 YEARS
AT THE TIME OF TRANSPLANT

HALF OF CANADIANS
WITH **CYSTIC FIBROSIS**
WHO HAVE **RECEIVED A LUNG TRANSPLANT**
SURVIVE BEYOND 10.2 YEARS FOLLOWING TRANSPLANTATION

CUMULATIVELY,
CF PATIENTS SPENT ALMOST
29,000 DAYS IN HOSPITAL
(ALMOST 80 YEARS)

Source: The Canadian CF Registry 2016 Annual Data Report

CANADA'S DRUG SYSTEM FAILS PEOPLE WITH CYSTIC FIBROSIS

This is an exciting time for people with CF. Currently, there are 143 drugs to treat CF under development; 60 are in clinical trials. Of the 143 drugs in development, approximately 45 target the basic defect in CF. Never have we seen a pipeline so promising.

This is also a scary time for people with CF. As a result of these innovative therapies, there will be a large volume of CF drugs going through the regulation and reimbursement processes in the next three to ten years; our pan-Canadian system is not ready for this.

Moreover, our system has shown us that it is not friendly to new medicines for CF, especially not medicines like Kalydeco and Orkambi that can alter the course of the disease. What these medicines offer to some is a control of the disease, and there is hope that the evolution of these types of medicines will ultimately lead to a cure.

But what good are these medicines if people can't access them? Our government subsidized provincial public drug programs typically cover Kalydeco for those who are six years old or older who have one of the many mutations Health Canada has indicated for, G511D. After two years of leaving these other mutations on the table for pricing negotiations, we learned in November of 2017 that our provincial governments will not negotiate pricing for said mutations.

The battle for another disease-modifying therapy, Orkambi, which helps people with two copies of the F508del mutation – the most common mutation in Canada – was approved by Health Canada in January, 2016 for those with this mutation who are 12 years of age and older. In April, 2017, Orkambi was approved for children between the ages of six years of age and older. Since the original Health Canada approval, Cystic Fibrosis Canada has been actively advocating for the provinces and the manufacturer to negotiate a deal on price so that people who need Orkambi now can access it.

But politics and process are at play. Indeed, some members of our community who have been on Orkambi and have subsequently lost their private insurance coverage have medical proof that it worked from them, yet still can't access it through provincial drug coverage because all provincial governments – except Quebec – have refused to cover the drug, citing a lack of evidence. This is despite the fact that we have real-world evidence of effectiveness in some of those who received Orkambi through private coverage.

Until November, 2017, the Canadian Agency for Drug and Technologies in Health (CADTH) – the body responsible for making recommendations to provincial drug managers on whether or not – required that any and all evidence provided by manufacturers for consideration of provincial coverage must be in the form of randomized controlled trial. CADTH would not accept any other evidence, not even real-world evidence, which is problematic for rare disease populations like CF where we don't always have enough sub-sets of people to run clinical trials.

After consultations, CADTH agreed that the requirement to produce new evidence through randomized controlled trials was onerous from a resubmission perspective, which is when a company receives a negative recommendation and is invited to "resubmit" new data.

This change opened the door for companies like Vertex, the manufacturer of Orkambi, to submit new data for review in January 2017. While CADTH's new guidelines are long-overdue and quite welcomed, we are concerned about the length of time it will take for companies to get through the new process and have asked for clarification from CADTH and have requested that provincial health ministers call for an expedited review. In the meantime, we have asked them to cover Orkambi for those who lost their private insurance coverage.

As it stands, only 60 per cent of treatments for rare disorders are ever approved in Canada and most get approved later than in the USA and Europe, by up to six years. That's not good enough for one of the world's wealthiest nations. Moreover, some CF medicines like Cotazym, Pulmozyme, Tobi Podhaler, and others, are only available through the Exceptional Access Programs in most provinces and many can't access them through public coverage as a result.

There is promise in our pipeline, but how do we pay for it? We are actively working to find new ways forward to ensure that Canadians with CF can get the medicines they need. To that end, we are building government relations and advocacy volunteer teams in provinces across the country to grow and strengthen our advocacy efforts in regions throughout Canada. **If you are interested in volunteering, please contact Kim Steele, Manager, Government Relations and Advocacy at ksteele@cysticfibrosis.ca or Eric Mariglia, Coordinator, Government Relations and Advocacy at emariglia@cysticfibrosis.ca.**

THE MOTHER OF ALL BLESSINGS

Kim Wood has never let living with cystic fibrosis get in the way of living her life to the fullest. Whether she's hauling her IV pull on a family trip, or is unwavering in her determination to become a mother, she continues to live a fulfilled life and recognizes all that she has to be grateful for.

Kim is a 36 year-old Campbell River resident, and is grateful for the perspective that having CF has given her. Kim credits CF with teaching her to be organized and how to deal with complications and setbacks in life. On one hand, CF pushes Kim to deal with things she'd rather not and to meticulously plan. But it's also the reason she's able to roll with the punches and embrace life's moments – especially the small ones.

Kim graduated from University of Victoria with a nursing degree in 2004 and worked for several years as a paediatric community health nurse in Vancouver. Kim was passionate about her job and disappointed when a decline in her health made taking a break from her job necessary.

GOLF TOURNAMENT

As a 12 year-old, Kim wrote a letter to NHL player Rod Brind'Amour. Rod was from Kim's hometown and she innocently reached out to seek his support for an event. Little did Kim know, this letter would be the starting point of what became the annual *Rod Brind'Amour Cystic Fibrosis Golf Classic Dinner* and Auction, which has raised close to $2 million over the years for Cystic Fibrosis Canada. Most importantly to Kim, it was the beginning of a lifelong friendship between her and Rod, and ignited Rod's ongoing commitment to fight cystic fibrosis. In 2006, Rod and his team members were each given a medal inscribed with the words, "Whatever it takes." They won the Stanley Cup which he brought home to a welcoming crowd in Campbell River. In a touching ceremony Rod presented his medal to Kim, saying she was the inspiration for his efforts.

Kim has described Rod as a true home-grown hero who keeps his feet firmly planted on the ground and his head squarely on his shoulders. She admires his work ethic for his sport, his commitment to his family, and the way he generously devotes his time to raising awareness for CF.

From left to right: Ryan Nugent-Hopkins; Kim, Charlie and James; Rod Brind'Amour

Five years ago, Edmonton Oilers NHL star Ryan Nugent-Hopkins attended the event. He was so inspired that he agreed to continue supporting the event and now the event is known as the *Brind'Amour/Nugent-Hopkins Cystic Fibrosis Golf Classic Dinner and Auction*. Kim describes Ryan as a young hockey star with a heart of gold. His head is in the right place, and lucky for the CF Canada community, so is his heart. Ryan's mother Deb and father Roger taught Ryan the importance of giving, and the CF Canada community is honoured to have him and his family join the event.

NEW CHAPTERS

Kim is a member of the St Paul's CF clinic patient advisory committee and of the CF Canada Adult committee. She keeps busy maintaining her health, blogging about her journey with CF, and helping with the golf tournament and other chapter events, but life just got a lot busier for her. On June 7, 2017, Kim became a mom for the first time to little Charlie. A very dear friend of Kim's gave her the most generous and beautiful gift – she was a surrogate for Kim and her husband James. Kim captured her excitement about becoming a mom and her endless gratitude in a blog post last Mother's Day:

"This woman is allowing me to become a Mom! She is going through the swollen feet, the nausea, the vomiting, the cravings, the sleepless nights, the heart burn, the all-encompassing agonizing pain and discomfort of labour and delivery. All because I want to be a Momma so badly and CF made it too unsafe for me to be pregnant. It's still hard for me to wrap my head around this. There are really no words that can even come close to expressing what is in my heart right now. But in an attempt to do so, I came across a quote that reads: 'To the world you may be one person, but to one person you may be the world'. Our surrogate, quite simply, means the whole world to us and I will forever and always be incredibly thankful to her."

HER GREATEST BLESSING

Becoming a mother has changed Kim in profound ways. For so long she wanted to become a mom and struggled, so when it finally happened it took a while to really grasp the immense amount of happiness it brought her. Kim says she has never experienced this kind of love before, and that there was this love deep in her heart that had been waiting to be released that was solely dedicated for her son.

Being a mom with CF has challenges of its own. Kim has never had to multitask like she does now. Kim has mastered a morning routine of doing physiotherapy, while feeding her son, while testing her blood-sugar levels, while having a bite of breakfast. Kim worried about how she would stay on top of her health while caring for a baby, but like all the other moms with CF told her, you just get it done! Kim has relied heavily on the support of her family and friends, and credits them with helping her manage. Her Campbell-River community has been amazing and she feels lucky that little Charlie will be raised among such incredible people.

Kim says that coping with CF takes strength and perseverance, but that being a mom with CF has given her so much more encouragement, inspiration and determination to find a cure or control. Charlie is Kim's biggest blessing, and the reason why she'll never stop fighting CF.

We wish Kim and her family all the best, and congratulate them on this exciting time in their lives.

Kim blogs about her life and CF at
www.livelovebreathebykim.blogspot.ca

THE FINNTASTIC DUO

"Big" Finn Murphy

"Little" Finn Sposito

Finn Murphy is a 13 year-old from Collingwood, Ontario. When he was diagnosed with CF at birth, his mom Kelly was shocked and overwhelmed. The first three months of Finn's life were spent at SickKids hospital under the care of the amazing doctors and nurses there, and the Murphys were relieved when they could finally bring little Finn home. Their friends and family rallied behind them and organized a slo-pitch tournament to help finance their travel to-and-from SickKids hospital. The first tournament raised $3,000, and over the next four years the tournament raised an average of $12,000 per year that was donated to CF Canada!

The slo-pitch tournament took a lot of planning, so the Murphys decided to end the tournament after 2008 and participate in the annual Walk to Make Cystic Fibrosis History instead. They knew they could raise just as much, if not more, for this event and began attending the Toronto walk location. Their first walk was in 2008, under the name "Jesse James Joggers", and in 2009 they were "Team Finn Classic". From 2010-2015 their walk team was "Team Finn" and they eventually started going to the Barrie walk – they love the location right by the waterfront. Through various fundraising efforts, "Team Finn" friends and family have raised more than $200,000 for Cystic Fibrosis Canada since Finn was born 13 years ago!

While registering for the 2016 walk, Kelly noticed that the name "Team Finn" was taken and was surprised to see a new "Team Finn" had been created and registered to attend the Barrie walk. At first she thought maybe one of her friends beat her to the punch, but it quickly became apparent it was a totally separate team. She registered as "Team Finn Murphy" for that year.

Through the SickKids clinic, Kelly had gotten word that there was a new Finn who had joined the CF tribe – Finnegan Sposito, a one year-old from Barrie, Ontario. Kelly wondered, "Could this be the Finn from the new "Team Finn"?"

It was at the 2016 Walk to Make CF History that the Murphy family and the Sposito family met for the first time. They realized the mix-up with the team names, and from that moment on a special friendship blossomed. Although the two Finns may not meet face-to-face for infection control purposes, big Finn (Murphy) has gotten to know baby Finn (Sposito) by following along his first year via social media.

The families have also become close, and have acted as support systems for each other. Kelly helped Camille and Matt Sposito adjust to the reality of having a newborn with CF. One time when baby Finn was at clinic, big Finn was admitted to SickKids upstairs at the same time for three weeks for a chest exacerbation, missing the start of grade eight. Camille and Matthew were kind enough to visit him and bring him homemade chocolate chip cookies on a day where Kelly had to leave him to work a shift in Collingwood.

Finn Murphy has grown up participating in every CF-related study he has been eligible for with the goal of contributing as much as possible to the science that will one day end CF. Big Finn is very proud when he is reminded that all of the CF studies he has participated in over the years will potentially improve the CF experience for baby Finn.

The two families decided to combine their Walk teams, and brainstormed different names. Among those ideas were "Team Finns" and "Team Finn2". They finally settled on a team name: "The FINNtastic Duo"! In their first year as a combined team at the 2017 walk in Barrie, **they raised almost $25,000 for clinical care and research for CF!**

"The FINNtastic Duo" is proof of something that our community proves time and time again – there is power in numbers! We wish the Murphy family and Sposito family all the best, and we'll see them at the Barrie walk this year!

KAYLA'S STORY

In Loving Memory of Kayla Mavretic, 1990-2017

By: Jennifer Mavretic

When Kayla was diagnosed with cystic fibrosis at five years old, Easter weekend of 1995, we knew nothing about CF. Life expectancy then was in her teens, but doctors reassured me they had found the gene and with scientific advances and research one day there could be a cure. Kayla was diagnosed late because there wasn't newborn screening like there is today. She was to spend three months at the Children's Hospital of Eastern Ontario (CHEO) to get healthier and learn everything about having CF, but her feisty self was out within one month and she was able to be a flower girl at her aunt and uncle's wedding! Kayla proved to be a go-getter at very early age, and I often wonder if this is part of all CF genetics. Bravery and resilience seems to be a common thread with every "CFer" I've come to know, and their parents. Kayla loved school, socializing, and church, and she was able to go on two Make-a-Wish vacations to Hawaii and Disney World Florida!

Kayla was diagnosed with liver disease due to CF, had a bowel resection due to intussusception at ten years old, and also required a liver transplant at 16. Luckily, my husband was a perfect match – call it fate. On Mother's Day, May 15, 2006, they both entered separate operating rooms and Mike was able to donate 60% of his liver to Kayla; it was a selfless act of love that saved her life! Kayla and Mike recovered remarkably well and were home within a few months. After the transplant, Kayla had the chance to be a teenager and learn to drive and travel again. She was also able to go back to school for grade 12 and graduate. Our biggest hurdle with CF was over and we assumed going forward it would be the occasional tune-up or antibiotics.

The unpredictability of CF reared its ugly head again when Kayla was 20 – her lung function was dropping. Instead of once a year for a tune up, it was every six months, then every three months. Within a few years, her health declined so much that she was always on home IVs or in the hospital and on oxygen full time. I became a full-time caregiver for Kayla. I always was, but this was 100 percent, 24-7. She went to physiotherapy three times a week for her strength training, as well as CF clinic and pre-transplant clinic. Kayla had blood clot issues, allergies to a lot of medications, and CO_2 issues that made her very sick, but she had a will to live and we would help her do it no matter what.

Kayla took to social media to share her fears and loves, started GoFundMe pages and found help getting her "Kayla's Medical Journey" Facebook group started. She was given tickets to hockey, soccer, and baseball games, concerts, and hotel stays. Lots of people did things to make her time waiting for new lungs a little better. She was lucky enough to have a friend-of-a-friend who knew someone at Universal Music. He took Kayla under his wing and tried to make her dreams come true. He managed to get us to a John Mayer and Phillip Phillips concert – we even had a meet and greet with Phillip Phillips! This person also came through and got Kayla VIP seating at the Much Music Video Awards. Kayla did all these things with an oxygen tank in tow.

Kayla's 24th birthday was on February 18, 2014, and on the morning of February 27 she got the call for lungs. We were in shock. We waited 18 and a half hours at the hospital to see if the lungs were viable; they were. The surgery took place on February 28. Kayla was not scared; in fact she was looking forward to recovery and life. We are so thankful for the family who chose to give another family the gift of life. There is no greater gift than seeing someone fight so hard to live and then seeing that dream come true. She recovered in record time, and we stayed in Toronto for three months post-transplant for recovery.

Kayla got a full-time position after moving as a nanny for a surgeon. She loved her job and it became her biggest passion in life. She bought her own car and started driving again. At 26-years-old she was ten years post liver transplant! Even though her pulmonary function tests started at 86 percent, they slowly declined over the next two years. Her lung tests showed that she had a typical CF bug, pseudomonas, in her lungs again.

As her health declined, Kayla wanted to do an online bucket list. In April, 2016 she raised enough money for a trip to Calgary! Kayla so badly wanted to see the west and our family that lived out there. We had luggage, oxygen concentrators, and bags of medication, but we did it! We were able to spend precious time with family, and go to Banff and Lake Louise! Kayla went to the Red Hot Chili Peppers concert in Ottawa with someone she met in lung rehab that needed a lung transplant. Both of them had their oxygen tanks in tow at the outdoor concert! Kayla also had dreams of hot-air-ballooning with her father and some amazing people helped make that dream come true... twice! There couldn't be anything more freeing than being able to go up in the balloon! Kayla also connected with a local business-owner who picked her up at the hospital once and took her for a Lamborghini ride.

In December 2016 we were told terrible news that she had rejection called Bronchiolitis Obliterans Syndrome, almost two years post-transplant. The transplant team decided that Kayla would not be a good candidate for a second transplant. It was the most devastating news ever. Kayla desperately wanted to be listed again, she had a taste of what life is really like, and she would do anything to have it back again. We left that meeting devastated, confused, hurt, and broken-hearted. We cried for days as a family, but pulled our socks up and decided to fight instead of dwell. Kayla's goal was to get herself as healthy as possible and revisit Toronto's decision. Ottawa recommended she attend a lung rehab facility and build strength. It was an eight week program and she rocked it, like everything else. Days after finishing the program she was admitted to the hospital.

Kayla's lung function was down to 18%, and she was put on a ventilator more than a few times that year due to CO_2 issues. A few times we had to call family in, terrified that she wouldn't come back and doctors prepared us. She spent a majority of 2016 in hospital, where I sat in a chair from morning to night talking to her, helping her when she was sick, and being her advocate. The days were long and stressful but we had been down this road before. Kayla was finally released for Christmas, and we knew this could possibly be her last Christmas with us but that there was always that possibility she could recover.

In January, she ended up back in hospital on life-support again, but she bounced back. Kayla decided this time that she had enough and told her team that she wanted to come home on palliative care. She did not want to see the inside of another hospital or be on a ventilator again. We all cried for days, but Kayla wanted to be in control of her fate. At-home palliative care explained that they would help to make her life more manageable and do what they can do without going to the hospital. Kayla was in a wheelchair and walker for a long time but she suddenly she built enough strength to not require that. We were able to hang out as a family in our home as opposed to a hospital setting. At first it was overwhelming with all these doctors and nurses at my home daily, but they soon became family. We had a hospital bed for Kayla in the living room, as she was unable to climb the stairs, so she could rest when she wanted and still be a part of everyday life. We had night nurses who watched over her so we could sleep at night and not worry about her coughing fits and junky lungs. With the help of palliative, her life improved and she was finally able to breathe better, rely less on oxygen tanks, and walk more. We were able to get rid of the hospital bed and night nurses, and Kayla became more independent, even climbing the stairs again.

She turned 27-years-old on February 18, 2017 and her three year "lungaversary" was on the 28th of February. If there was an occasion to celebrate, she was all about it! March came and her health improved even more. The steroids they put her on were making her eat non-stop and she had gained 20lbs! There were more good days than bad and she even had to cancel on her palliative team a few times as she was out and about. They would chuckle when she said, "Sorry I don't need palliative today, I'm at the mall and then going out for dinner." They told Kayla to start making regular doctors' appointments and check-ups, so she booked a CF clinic for May, four months after coming home on palliative. She was eager to show the clinic team how great she was doing, and she made it clear that she did not want palliative to leave her even though she was doing well. Her mind hadn't changed. They reassured her that she would have them no matter what. She never made that CF clinic appointment.

Kayla heard that the Juno Awards would be in Ottawa, so she contacted Universal Music again. Sure enough, she got tickets! Those few weeks were busy: her brother came from Sarnia to visit, she did an interview for the Ottawa Citizen, she received her Junos tickets, and they gave her meet-and-greets with musicians at the mall for the day before the show. She had the time of her life with her friend there.

Despite all the excitement, I found her to be quite tired during what would be the last few weeks of her life. She kept saying she was fine, but she became worried that she had a blood clot. Her palliative doctor recommended she get it checked out at emergency, and they found that it wasn't a clot but that her blood gases were high, which now explains her tiredness over those past weeks. She came home and I gave her all her anti-rejection medications, put her bipap on, and I spent the night by her side in her bed. The palliative doctor and nurses came in, and 15 hours after she got home from emergency she passed away. Peacefully. She was home in her bed, where she wanted to be, with no team of doctors and intervention. She is my hero.

There are no words to adequately describe our grief. Kayla passed away in May 2017, and we are empty without her. I always wanted to be much more involved in CF Canada and the community, but with the uncertainties surrounding Kayla I couldn't commit too much. She has taught me to go and live life to the fullest – like she would have loved to do. That is why I am slowly becoming more involved and sharing her story.

While we have come a long way in increasing the average lifespan for Canadian CFers, we still have far to go. I would have loved to watch my daughter get married and adopt kids, it would have been her final piece to her bucket list. We need to make more advances so hospital stays are shorter, transplants are fewer, and the lives of those living with CF are longer and healthier.

I wanted to share Kayla's story to honour her zest for life, her conviction in what she wanted, and to share how vibrant she was the week before her death. Kayla had a lot of complications and a lot of medical hurdles but that doesn't mean she didn't have an amazing life because she truly did. We just wish it was longer.

KEEPING ACTIVE AND STAYING HEALTHY

By: Jeremy Vosbourgh

My name is Jeremy Vosbourgh and I live in Winnipeg, Manitoba. I am 38 years old and I have been married to my wonderful wife Tara for 12 years. We have a seven year old daughter named Daryn, a dog named Ruby, and a cat named Sam.

I was diagnosed with cystic fibrosis when I was two years old. I have been told many times by my mother that prior to my diagnosis I ate a lot, much more than all of her friends' babies. Around age two, I stopped thriving and got very sick. I spent a few weeks in the hospital in London, Ontario near where we lived at the time, while the doctors tried to figure out what was wrong with me. Then, lo and behold, a keen-eyed doctor asked my mom if I tasted salty when she would kiss me.

From that moment on, once I was put on the right medication, I was quite healthy. I spent my childhood years very active playing baseball, soccer, running, and my most favourite sport, hockey. I was rarely sick and when I was, I was treated at home with antibiotics. I was only hospitalized one time from the age of three through 35 for pneumonia. I largely equate my generally good health to being so active and I continue to be active to this day, but more on that later.

I met Tara in 1998 and we dated until 2005 when we got married and moved to Winnipeg from Toronto. We were given the gift of our daughter Daryn in 2008 and our family was set. As Daryn gets older we explain CF more and more to her, including the challenges, medications, doctors' appointments, etc. She knows that daddy is sick but there are medications and ways for me to stay healthy. I always wanted to be a dad and I was lucky enough that it worked out for me.

One of my other dreams was to become a police officer. In 2007, I was accepted as a member of the Winnipeg Police Service. I was nervous about applying to be a police officer and having CF, but as it worked out, all they cared about was if I could do the physical tasks required. I'd spent my young adult life working out vigorously and pushing my limits almost daily as I was always at a disadvantage when it came to exercise. I could keep up with my peers but I could not excel past them. I passed the physical abilities testing with ease and began training to be a police officer. Going through the academy training was difficult. The academic portion required a lot of studying and the physical training put me through situations I had never experienced. I had to learn to fight through pure exhaustion and burning lungs to complete tasks. I spent the first four years of my career as a General Patrol member where I responded to emergency calls for service from the public. This time really opened my eyes to parts of our world I never fully knew existed. I spent the following seven years as a detective where I really learned how to put my investigative skills to the test. I enjoyed focusing my efforts on larger investigations and following through with them until then end.

Recently, I have been transferred back to General Patrol duties where now I am able to share my experience with younger members and put my new skills into action in a different environment. I am often asked how I deal with the physical daily demands of being a police officer. I will admit that I am a horrible runner but we have techniques and options available to us to avoid actually running after people for long distances. What most people don't realize is that being a police officer is very sedentary, but your heart rate can go from resting to maximum in the matter of seconds. It was because of this that I changed my workout routine many years ago.

In 2009, a good friend of mine and member of the RCMP introduced me to Crossfit. I have found that by training under the basic philosophies of Crossfit I have become better at everything in my life, but mainly I just feel better. The workouts work for me because many are set up with short work periods and short rest which allow me to catch my breath. I am able to work hard and fast but always at my own pace. With Crossfit there is a small amount of competition involved, which challenges me to work as hard, or harder, than my peers to keep up. Also, because I work out at a local affiliate I have coaching every time I exercise. I know others with CF find exercise incredibly difficult but any amount you can do will make you healthier, I firmly believe that's why I rarely see flare ups.

In the future, I hope to grow old with my wife and watch my daughter grow into a woman. I am confident that better and more cost-effective treatments will become available in my lifetime. I also know that my health and well-being are my responsibility, and I will continue to do everything I can to make sure I am as healthy as possible. Whether it's getting up at 5 a.m. to do my treatments before work, going to the gym even when I don't feel like it, admitting that I need to rest even when I don't want to, or meeting with my local Member of Parliament to discuss Orkambi, I will always fight as hard and as passionately as I can.

IRONBEN

Benjamin Pérusse was a small baby who weighed only six pounds, although he seemed very healthy. However, his parents, Isabelle Hallé and Sylvain Pérusse, had a feeling that something was wrong with his digestion because Isabelle had to breast-feed him almost constantly to satisfy his insatiable hunger. His abundant stools (16 to 20 a day) and frequent regurgitations also pointed to a health problem.

Despite a great deal of breast-feeding support and advice from several nurses, such as having Benjamin sleep on an inclined surface to ease digestion and avoid him choking on regurgitated milk, the situation did not improve. The couple could see that their son was growing, but knew that a medical examination was necessary because Benjamin was pale and was not gaining any weight. So they took him to the Trois Rivières hospital where several tests revealed a number of vitamin deficiencies. The medical team suspected Benjamin had cystic fibrosis, but the hospital was not equipped to perform the sweat test using the latest technology. They had to wrap Benjamin in a blanket to make him sweat and the test result, although unofficial, came back positive.

A DIAGNOSIS COMPOUNDED BY ALLERGIES

To have the test repeated with greater accuracy, the family headed to Quebec's University Hospital Center, where Benjamin was hospitalized. The diagnosis was delivered during his stay, when he was four and a half months old: Benjamin indeed had cystic fibrosis. To promote weight gain, his mother had to stop breast-feeding him in order to make way for fortified foods, medications and digestive enzymes. Preventative respiratory treatments were also administered in addition to his adapted diet. Luckily, Benjamin has not really suffered from respiratory problems to date. In his case, CF has mainly affected his digestive tract.

Later, other tests revealed that Benjamin had another health problem: an allergy to peanuts and shellfish. As a result, his diet must be constantly monitored because an allergic reaction could be catastrophic.

Today, Benjamin is doing well overall and seems quite content. CF and his allergies have made him very mature for his age and have forced him to be very careful and ask questions to ensure that his food is not contaminated. Just like his mother, he is drawn to art (he loves crafts!). He also participates in his parents' various sporting activities, although he does not share their passion for excelling at sports.

THE IRONBEN: A BEACON OF HOPE

Despite their separation when he was four years old, Benjamin's parents remain united to ensure their son's well-being. In fact, both of them are heavily involved in promoting the cause. Isabelle generously donates her time as a volunteer for the Mauricie/Centre-du-Québec Chapter of Cystic Fibrosis Quebec.

Benjamin's father Sylvain organizes the now famous IronBen, a family-oriented running event to raise funds for cystic fibrosis research and care. Participants are invited to cover a distance of one, two, five or eight kilometres at the Parc St Maurice in Shawinigan. The sixth edition of the IronBen was held on Saturday, May 20, 2017 where a record 430 participants helped beat the total of $11,600 raised the previous year. The enthusiasm for this event truly reflects people's desire to help advance research for CF, which affects 1 out of every 10,000 children in Québec.

IronBen was paired with the *Course du bonheur*, a race during which people in wheelchairs team up with partners. This event used to be held as part of the Shawinigan firemen's half-marathon. However, since the 2017 half-marathon was cancelled, the Course du bonheur was combined with the IronBen.

HIGHLY ANTICIPATED NEWS

On June 8, 2017, the Quebec Health Minister announced that the screening test for cystic fibrosis would be added to the Quebec Newborn Screening Program, news that Benjamin's parents greeted with great enthusiasm. Newborns will undergo this test starting in the spring of 2018.

Now every province in Canada screens for cystic fibrosis at birth. This important advance will put all children with cystic fibrosis, like Benjamin, on equal footing in terms of treatment and management.

LIFE IS LONG, DON'T MAKE IT SHORT

By: Tim Vallillee

My name is Tim Vallillee, I'm 50 years old and live in Wilmot, Nova Scotia with my wife, Agatha, and our 10 year old son, Isaiah.

For the first chunk of my life, I seemed to always be sick, malnourished, and had a grey tinge to my colour. I was seven months old when my mom mentioned to a doctor that I tasted salty when she kissed me on the forehead. She was quickly introduced to Dr. Terrence Gillespie who knew exactly what we were dealing with. He immediately had me tested and I was diagnosed with cystic fibrosis. Dr. Gillespie would be my doctor for the next 21 years of my life.

Growing up with CF has had its share of challenges and opportunities. As far back as I can remember, I never hid the fact that I had an illness. This made it very easy to get along with my teachers and friends at school. Everyone was usually kind to me with respect to the treatments I had to endure.

Every morning of my life started with my parents performing physiotherapy on me while my three siblings partook in regular school-prep childhood activities. I also had to take three aerosol masks a day and sleep in a "mist tent" for the first ten years of my life.

Other than the need to take pills to school, CF didn't affect my life too much until I got into my junior-high years when admissions to the IWK Hospital started to become more frequent. I first dealt with a couple bouts of pneumonia, nasal polyps and iron deficiencies.

I have fond memories of Camp Tidnish in the summer where I went to "CF Camp" with other friends who had CF – this was before the infection control policies. It was a time I wouldn't change for a million dollars. It was always difficult to hear of a friend who lost their battle to CF, but it also kept me fighting so that it wouldn't happen to me. I had too much to live for, and hopefully CF wouldn't keep me from doing it.

I grew up living by the motto: "life is short, make the best of it." Every day of life-living with CF is a gift that I wanted so much more of, but CF threw a big, dark cloud over that dream.

Every time I made a wish in a wishing-well or upon a shooting star, I had wished for the same thing: a cure or major control for CF. Even if it didn't work for me, I wanted it for kids who were diagnosed at a young age so they wouldn't have to go through the same fight for life that I have. When Kalydeco came out, I was blown away to hear that this new drug could be my new lease on a normal life. When my family and I realized that Kalydeco could treat me, we felt like we had won the life-lottery! Could this really be the answer I was looking for my whole life?

Even though I experienced incredible changes with my health, I wasn't prepared for the mental side of the coin. I knew how to be sick. I knew how to live in the moment and not look too far ahead. Kalydeco changed all of that and the reality I knew for my whole life. A few months after starting Kalydeco, I suffered a bad bout of depression because of the changes that came with this new lease on life. Depression was not what I expected to experience with such a wonderful new lease on life, but it still happened. Survival guilt is a nasty side effect of this gift, one that I have always had a bit of difficulty with. All I can do is keep fighting for everyone with CF so they can also feel the same relief that I feel. No words can express the gratitude I have for everyone in my life who gave their all towards this win! I have dealt with the depression, and I am learning to enjoy life to the fullest and to look ahead to the future.

Life is about the milestones we pass. As a child, all I

photo credit - James Skinner

knew was that it might be difficult to make it to the age of ten years old. Now at 50, I can proudly look back at many milestones that most people take for granted: I made to ten years old and well beyond, got my driver's license, graduated from high school, attended university, got married, divorced and re-married, held many jobs, had a child, and grew grey hair.

Living with CF doesn't typically let you look too far down the road, but what it has done is teach me how to enjoy the moment. Now the hard part is learning how to look forward, since most of my life I could not.

My beautiful wife Agatha has likely had the most difficult time fighting CF. We often forget about the team behind sick people. Without them the battle is unbeatable. Her faith in me to live is much more priceless than the impact of Kalydeco, and sadly goes unnoticed by most people. My parents brought me through the treacherous early years, and now I have lived long enough to survive adulthood thanks to my wife's diligence and love. A few angels in heaven have also kept me alive!

My new motto in life is: "life is long, don't make it short!" I will definitely be making the best out of it as often and as long as possible.

Ever since starting Kalydeco, I have had so many people in my life tell me, "now you can slow down." It's funny how others see life. It seems I have tried to fill my days and years with as much as possible. I have always had a shortlist of things on my to-do list, but now that I have a new lease on life, my list has grown ten-fold, so there is no slowing down.

I continue to advocate for cystic fibrosis, be it at a special event or sharing my story in person. My personal dream is to become a motivational speaker to help anyone looking for answers to become happier and driven in life. My story is long and complicated, but it is not unlike that of any other who has faced immeasurable challenges! I simply hope I can share my story to empower others to achieve their goals as well. I have learned dreams, and our wildest wishes, can come true – never give up!

A Northern taste for your face

Tilted Tower Broadcaster's Ale

$2,200

North Bay's KiSS 100.5 teamed up with local craft brewer, New Ontario Brewery, to create its very own beer "Tilted Tower Broadcaster's Ale" where $0.50 from every can sold was donated to the North Bay Chapter of Cystic Fibrosis Canada. Two days after the launch, the beer was completely sold out! The blueberry wheat ale raised a total of $2,200 and an invaluable amount of awareness for CF Canada and the North Bay Chapter! Special thanks to Kevin Oschefski and the rest of the KiSS 100.5 team, Mike Farwell, and Mike Harrison along with New Ontario Brewery for their support!

KISS CF Goodbye

$10,000 +

For the past three years, CF dad Paul Taskas has put his musical abilities to good use at *KISS CF Goodbye* – a tribute concert benefiting Cystic Fibrosis Canada. Paul and the rest of his band *Rock and Roll Over*, a KISS tribute band with the costumes to boot, played in Toronto in September at The Opera House along with U2 and Led Zeppelin cover bands. This year's benefit raised over $10,000! A huge thanks to Paul and the rest of the musicians, who work and play hard to find a cure or control for Paul's daughter Tori and the rest of then CF community. Paul's niece Chloe and her husband Mark held a BBQ fundraiser in honour of their son Logan who passed away from SIDS – the $3,300 that they raised was donated to KISS CF Goodbye. Thank you to the entire family and band for their generosity.

raise a glass TO MAKE CYSTIC FIBROSIS HISTORY

Raise a Glass

$13,000 +

James and Glenna Cummine launched *Raise a Glass* – a wine and beer tasting fundraising event – in April, 2017 at Breezy Bend Country Club in Winnipeg. The event was the first of its kind in Winnipeg, and the committee included about six members of the local CF Chapter. The goal of the inaugural event was to raise $5,000-$10,000, but thanks to the hard work of the committee and the attendance of more than 100 people, over $13,000 was raised for a cure or control for CF! A special thanks to the live band that played, the committee members, and Darin Amies of Eatz Enterprises (and local Moxie's restaurants). Darin has always stepped up whenever asked for support and had many of his supplier and industry colleagues help make the inaugural *Raise a Glass* a huge success.

THYSSENKRUPP ELEVATOR CANADA EMPLOYEES RAISE OVER $105,000 FOR CYSTIC FIBROSIS CANADA

Meaghan MacRury, CF Canada Ambassador at thyssenkkrupp Elevator

Building transportation leader thyssenkrupp Elevator Canada recently adopted Cystic Fibrosis Canada as its charity of choice, and set a first-year fundraising goal of $20,000. On October 25, 2017, thyssenkrupp presented a cheque to Cystic Fibrosis Canada, for $105,800, five times its original goal.

Meaghan MacRury, a thyssenkrupp Elevator employee living with cystic fibrosis, led thyssenkrupp's efforts as CF Canada ambassador, inspiring thyssenkrupp Elevator Canada's 2,000 employees to embrace a corporate fundraising campaign that included everything from bake sales and raffles to curling bonspiels and bowling events.

"Employees across the country embraced the new program and surpassed every goal we set," says MacRury. "This accomplishment speaks volumes about the employees here at thyssenkrupp Elevator Canada, and I am grateful to every single one of them that helped make this dream become a reality."

One of the unique fundraising initiatives that Meaghan spearheaded was an Art Contest involving thyssenkrupp Elevator Canada employees' siblings, children, grandchildren, nieces and nephews. The theme was Canada's 150th birthday and what it meant to the children to be Canadian. Entries poured in from coast to coast, and were featured at an art expo at the new Finchdene facility in Scarborough, Ontario. Three guest judges selected the winners, and each child's artwork is included in a 2018 calendar, and all money raised went toward the fight to end CF.

"Meaghan's spirit and strength is an inspiration to all of us, and we are very proud to stand with Meaghan and Cystic Fibrosis Canada to drive awareness and help those inflicted with this chronic disease," said Ryan Wilson, president and CEO of thyssenkrupp Elevator Canada.

A native of Oshawa, Ontario, MacRury was diagnosed with CF when she was seven months old. When she was 21, she went into respiratory failure due to CF and spent nearly three months in the hospital learning how to live again, 15 of those days were spent in a coma, including Christmas.

"It was during that time that I realized what my purpose on this Earth was, to raise as much funds and awareness as I could for CF research and care so that no child or family would ever have to go through what my family and I went through during those months," said MacRury. "CF Canada represents hope, and it is because of their research and advocacy that I am alive today."

WELCOMING OUR NEW PARTNER: PRO OIL CHANGE

Cystic Fibrosis Canada welcomes PRO OIL CHANGE as a new partner in the fight against CF!

PRO OIL CHANGE is a Canadian owned and operated retail franchise organization that started operations in 1996. A member of the Driven Brands family, the PRO OIL CHANGE team specializes in providing quick, professional, and convenient and value priced warranty approved services for all makes and models of vehicles. Currently, PRO OIL CHANGE has 36 stores operating in the provinces of Ontario, PEI, New Brunswick and British Columbia with plans for extensive growth in the next couple of years.

PRO OIL CHANGE plans to roll out their new fundraising platform in the spring, in tandem with CARSTAR Automotive Canada, which will include car washes, participation in the Walk to Make Cystic Fibrosis History, and point of sale opportunities for their franchisees.

CF Canada welcomes PRO OIL CHANGE to our family, we are proud to have them join our incredible partner community in helping us in the fight to end CF.

Cystic Fibrosis Canada
Fibrose kystique Canada

Kin Canada
Kinsmen • Kinettes • Kin

Together for life® Unis pour la vie℠

The Kin Canada and Cystic Fibrosis Canada partnership is a unique one. It was initiated at a bar over drinks in Toronto between Kin Bill Skelly and Dr. Douglas Crozier, then Director of the CF Clinic at The Hospital for Sick Children in Toronto. During this chance meeting, Dr. Crozier spoke to Bill about his young CF patients and his frustration with the lack of funds to support cystic fibrosis research as his patients were dying very young. This conversation left Bill interested in joining the fight against cystic fibrosis, and Dr. Crozier was invited to speak to the North York Kinsmen Club in District 8. Almost immediately, the North York Kinsmen enthusiastically backed the CF cause.

At the 1964 District Convention in Timmins, Ontario, the Kin members in District 8 formally adopted CF as their District Service Project. This commitment sparked the interest of other Districts and not long after, involvement spread Canada-wide throughout the Kin organization. Kin Ian F. McClure was influential in cementing the partnership by dedicating over 20 years to spreading awareness about cystic fibrosis to Kin clubs across Canada. His dedication to the cause resulted in a commitment from each Kin District to adopt Cystic Fibrosis Canada as their District Service Project, encouraging Kin Canada to make Cystic Fibrosis Canada its National Service Project in 1987.

Becoming Kin Canada's National Service Project was a monumental time for the partnership and it was around that time that the Kin CF Canada Liaison Committee was officially created.

Who is the Kin CF Canada Liaison Committee and what do they do?

The Kin CF Canada Liaison Committee is made up of Service Directors from all eight Districts, a National Service Director and the Chair. This dedicated committee leads the CF fundraising efforts for Kin Canada, continues to work with their Districts to spread awareness about CF in their communities, and raise funds for CF Canada towards the ultimate goal of a cure.

What is the role of the Kin CF Canada Liaison Committee's Service Directors?

The role of the Service Directors is a very important one to both CF Canada and Kin Canada's partnership. The Service Directors develop knowledge of cystic fibrosis and Cystic Fibrosis Canada during their Orientation and Development Weekend at the CF Canada office around March of every year. They are responsible for developing, communicating and providing updates to the rest of their districts throughout the year on Kin Canada and Cystic Fibrosis Canada initiatives. The Committee meets virtually on a monthly basis and twice a year in person (at the Orientation & Development weekend and at the CF Canada Volunteer Leadership Forum or Annual General Meeting). The team assists in maintaining the strong ties between Kin Clubs and Cystic Fibrosis Canada Chapters to ensure we are always collaborating on fundraising efforts where possible. These dedicated Service Directors also generate awareness about cystic fibrosis in their communities and help with the fundraising efforts that have meant so much to those living with CF. Thank you to all the Kinsmen and Kinettes who have served as a Service Director in the past; you have made a great difference in our mutual fight against CF.

What is the role of the Chair of the Kin CF Canada Liaison Committee?

The Chair of the Kin CF Canada Liaison Committee leads and motivates their team throughout their two year term to raise funds and awareness for CF Canada. Having completed the role of a Service Director before becoming a Chair, they are usually familiar with the roles and duties of their team and continuously work on assisting their team with their goals. They visit every district throughout their two year term, ensuring that the latest updates from CF Canada are communicated and to raise awareness about our unique partnership and the advancements we are taking to make CF history. The Chair also sits on Cystic Fibrosis Canada's Volunteer Advisory Committee (VAC) to ensure that Kin Canada is represented in the CF community since both organizations are so intertwined through their work at the local level within the chapters.

Thank you to the 2017/2018 Kin CF Canada Liaison Committee for their hard work this past year in our mutual fight to end CF.

Chair: Tammie Corbett
National Service Director: Penny Lees-Smith
District 1 Service Directors: Beatrice Crowley & Tim Natyshak
District 2 Service Director: Pat Moldowan
District 3 Service Director: Michelle Jaindl
District 4 Service Director: Rick Kuzyk
District 5 Service Director: Anita Llewellyn
District 6 Service Director: Monte Yancey
District 7 Service Director: Terry Janes
District 8 Service Directors: Cherie Anderson & Gary Newton

"The partnership between Kin Canada and Cystic Fibrosis Canada is unique and exceptional. It is rare to find long standing relationships of this kind, but for one to last 54 years is remarkable to say the least. The role of the Kin CF Liaison is multi-focused and involves sharing information in both directions. By travelling to the Kin Districts representing Cystic Fibrosis Canada, participating on the CF Volunteer Advisory Committee representing Kin Canada, and functioning in a lead and supportive role with the Kin CF Canada Liaison Committee provides opportunities to acknowledge what we have accomplished and formulates a plan for the future with one clear goal: A world without CF."

Tammie Corbett
Kin CF Canada Liaison Chair (2017-2019)

THANK YOU KIN CANADA

The hard work and support of Kin Canada is deeply appreciated by Canadians living with CF. Since 1964, Kin Canada and Cystic Fibrosis Canada have shared in many exciting accomplishments, including the discovery of the gene responsible for CF in 1989. The funding provided by Kin Canada was essential in making this discovery possible.

A 54 year partnership with Cystic Fibrosis Canada and $45 million fundraised dollars later, Kin Canada continues to be a force to be reckoned with when it comes to the fight to end CF. With friends like the Kinsmen and Kinettes, there is definite hope for the future of Canadians living with cystic fibrosis. Thank you, Kin Canada.

AN INTERVIEW WITH MARK MARAMIERI & STUART HODGE: CO-CHAIRS OF THE VOLUNTEER ADVISORY COMMITTEE (VAC)

Mark Maramieri *Stuart Hodge*

Cystic Fibrosis Canada's Volunteer Advisory Committee (VAC) does so much to drive the organization and our mission forward. We caught up with Mark Maramieri and Stuart Hodge, Co-Chairs of the VAC, to learn a bit more about their motivation to end CF and what the VAC is currently working on.

What has motivated you to get involved with Cystic Fibrosis Canada and ultimately, the Volunteer Advisory Committee?

Mark: The birth of my nephew Matthew and his diagnosis was my primary motivating factor for joining the CF Canada family. From day one, our family and friends have worked tirelessly to ensure Matthew and all CF patients alike are afforded the same opportunities and quality of life as non-CF patients.

I joined the VAC as I was highly impressed with the consultation work performed by Board members Mitch and Leona in laying the foundation and preliminary mandate for the group. The VAC is a highly engaged and collaborative group that, now with two years under its belt, is poised to make a greater and long-lasting impact. I look forward to continuing to meet new people in our community, sharing ideas, and providing assistance where possible.

Stuart: My Brother. His daughters both have CF which drives me to help find a cure or effective control as soon as we possibly can. Together we have worked with both the CF Foundation in the United States and CF Canada to do whatever is needed to make that happen, including mountain hiking 50km in one day wearing kilts.

I'm now in my fourth year as a member of the CF Canada Board and am proud to Co-Chair the VAC with Mark. As Board Liaison, I make sure that communication between the VAC, Board and all volunteers is open and transparent. I'm happy to talk to any volunteer, anytime, just email me at shodge@cysticfibrosis.ca and if I can help, I will.

What is the role of Volunteer Advisory Committee?

Stuart: Ultimately, the VAC members represent the interests of the Chapters. They liaise with the Regional Executive Directors for the betterment of the Chapters in their regions while supporting the implementation of the strategic directions of Cystic Fibrosis Canada. They also provide volunteer mentorship and leadership within their region to support fundraising and volunteer management activities for Cystic Fibrosis Canada.

What are some of the initiatives that the VAC is currently working on?

Mark: The VAC is currently tackling some of the issues that came out of the 2017 volunteer survey results; with a concentration on succession and retention of lead volunteers in Chapters. They will be working in collaboration with the Regional Executive Directors around the country to develop succession plans for Chapter and special event leaders.

The VAC is currently split into two subcommittees who are also working on two important initiatives; the Volunteer Leadership Forum (VLF) and the Volunteer National & Regional Awards program.

The 2018 Volunteer Leadership Forum (VLF) is an important initiative with a goal of inspiring and engaging the volunteer leaders with a special emphasis on collaboration. The VLF committee, chaired by Tim McKay, will shape the 2018 VLF that will take place following the Annual General Meeting in Toronto during the last weekend of April. The committee is providing input on workshops while ensuring that topics align with the results of the volunteer survey and the needs of the CF Canada volunteers.

The Volunteer Awards Committee, chaired by Jean-Sébastien Ferron, is another important initiative that is being worked on to ensure that supporters of CF Canada are being recognized at the regional and national level for their wonderful volunteer work. The Volunteer Awards call for nominations was announced on November 15, 2017 with a deadline of February 15, 2018. This subcommittee will administer and judge the nominations before presenting the awards at the Awards dinner at the Volunteer Leadership Forum on April 28, 2018.

What has been a highlight in the past year while with working with the VAC?

Mark: Being selected by my peers as Co-Chair and being afforded the opportunity to present the VAC's work and long and short term goals to the CF Board of Directors in this capacity. Through this engagement, the Board has made clear its desire to be in touch with grassroots volunteers and stakeholders. Both as a group and as individual lead volunteers, the VAC has proven to be an effective conduit and voice for both volunteers and CF Canada staff. It is the goal of both Stuart and I to ensure that through the work of the VAC that the views of both volunteers and CF Canada staff are heard and that there is positive collaboration occurring as we work towards an end to CF.

Stuart: Witnessing firsthand the professional way in which VAC members took on the task of reorganizing the awards process. The simplified process is making it easier to recognize the achievements of CF Canada's amazing volunteers and researchers.

Thank you to the VAC members who are working tirelessly towards our shared goal to end CF.

Stuart Hodge (VAC Co-Chair & Board member)
Mark Maramieri (VAC Co-Chair)
Aleka MacLellan
Debbie Carver
Helen Meinzinger
Jamie Ruth
Jean-Sebastien Ferron (Awards Committee Chair)
John Bennett
Lee Burry (Board member)
Sydney Hull (Shinerama Chair)
Tammie Corbett (Kin Canada Chair)
Tim McKay (Volunteer Leadership Forum Chair)

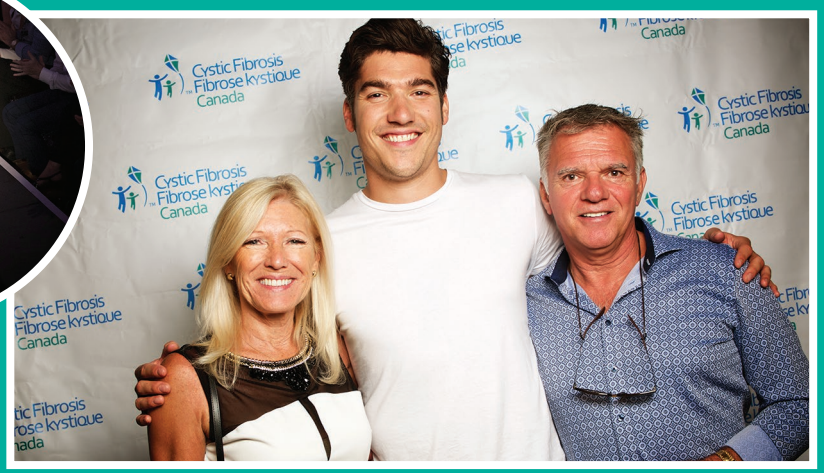
SHINERAMA RAISES OVER $600,000 FOR CF CANADA

This year, over 35,000 student volunteers from 43 Canadian universities and colleges across the country came together to make a difference in the lives of those battling cystic fibrosis (CF). Student volunteers all over Canada shined shoes, flipped burgers, and washed cars to raise crucial funding to fight cystic fibrosis. This national event puts the "fun" in fundraising!

Shinerama events this year raised a total of $600k at time of publication that will help fund critical care and research! This is an incredible accomplishment! The school with the top fundraising amount was Wilfrid Laurier University (Waterloo, ON) raising over $126,000.

Since 1964, Shinerama has raised approximately $27 million for life-saving CF research and care. We would like to extend our heartfelt gratitude to all past and present Shiners. The support from Shinerama schools and students over the past 54 years has been instrumental to advancing the battle against this devastating disease. The Shinerama 2017 program could not have been a success without our incredible partners! A special thank you to our Regional Partner Sun Life Financial; Regional Supply Sponsor Canadian Tire; Social Media Sponsor The Student Life Network, and generous donors The Morel Family Foundation.

Shinerama
STUDENTS FIGHTING CYSTIC FIBROSIS



FASHION *is in the air*

Fashion is in the Air, the inaugural fashion show for the Quebec region, took place on September 15, 2017 at Salon 1861 in Montréal. It was an incredible evening of style, featuring Montréal's most prominent personalities ranging from television hosts to athletes as the models. The event was emceed by Claudia Marques and CJ from The Beat 92.5, and over 15 local designers participated! A special thank you to all of the designers and models!

The fashion show raised an impressive $50,000 for cystic fibrosis research and care. Congratulations to the organizers on such a successful event, and for showing how fundraising for CF is never out of style!

Photography credit: Ferland Photo

Fusion

THE
GHOST & GOBLIN
BALL

On Saturday, October 21, 2017 Cystic Fibrosis Canada hosted its 16th annual Fusion Gala at the Angus Glen Golf Club in Markham, Ontario with a Ghost & Goblin Ball theme. This year's Fusion Gala raised a total of $409,000, and to date the Fusion Gala has raised over $2.5 million for cystic fibrosis research, clinical care and advocacy.

The evening transported guests to a world of witches, phantoms and creatures of the night! Throughout the night, guests participated in the live and silent auctions, including the Key to a Cure auction. Event sponsors included Team Solutions as Presenting Sponsor, Platinum Sponsor Unifor, and VIP Corporate Table Sponsor The Restorers Group, in addition to reception and corporate table sponsors.

EAST Meets WEST

A Quest for The Cure

On Saturday, November 4, 2017, the 17th annual 65 Roses Gala took place in Vancouver. This year's theme was "East Meets West". Hosted by CBC's Gloria Macarenko and Belle Puri, the event was attended by over 300 people at the beautiful Fairmont Waterfront Hotel. The 65 Roses Gala **raised over $320,000** in funds for critical care in research! Congratulations to the organizers and thank you for helping make CF history!

Beginning on Giving Tuesday, November 28, 2017, Cystic Fibrosis Canada launched its year-end giving campaign. The campaign, titled *31 Reasons to Give*, featured a different reason to donate to CF Canada for each day in the month of December.

"We are motivated by the stories from families and individuals affected by CF in our community and the moments that all of us, no matter our health, can identify with."

Though they're living with a chronic illness, people with CF are just like everyone else. Their days may include medical interventions, pills and doctor visits, but they're also filled with regular, everyday activities. They drop their children to school, volunteer at the local humane society, hang out with friends, dream about starring in their own rock band, go to work. They touch lives and change the world in unique and wonderful ways.

31 Reasons to Give demonstrated how a donation to CF Canada is a contribution to critical care and research, but also allows someone living with CF to have more of the moments that matter most to them.

"We are motivated by the stories from families and individuals affected by CF in our community and the moments that all of us, no matter our health, can identify with," said Jennifer Nebesky, Interim Co-CEO and Chief Marketing Officer, Cystic Fibrosis Canada. "Building on the success of our first-ever fully integrated campaign in 2016, our goal was to reach even more Canadians to help more people understand the impact of CF. Above all, we hope the personal stories from our community inspired Canadians to give. Every dollar counts as we are closer than ever to a cure."

The campaign was a success, generating new constituents for us to potentially steward, bringing in donations, capturing media attention, and raising awareness of CF.

Thank you to all those who participated in the campaign, especially the 19 families across the country who welcomed cameras into their homes and workplaces to share their stories!

Cystic Fibrosis Canada
Fibrose kystique Canada

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