Cystic Fibrosis
Fibrose kystique
Canada

Connections

WINTER 2016

CHARLOTTE GIROUX AND THE GIROUX FAMILY FIND HEALING THROUGH MUSIC

FIBROSE KYSTIQUE QUÉBEC CELEBRATES 35 YEARS

HOOPS FOR HOPE
RAISING FUNDS AND HAVING FUN

2016 CYSTIC FIBROSIS CANADA NATIONAL AWARD RECIPIENTS

NEWBORN SCREENING FOR CYSTIC FIBROSIS IN CANADA SHOWS BENEFITS

THE WALK TO MAKE CYSTIC FIBROSIS HISTORY

Register for the 2017 walk on Sunday May 28 and help make cystic fibrosis history! Visit www.cysticfibrosis.ca/walk to find a walk location near you to register, fundraise or donate to be part of history.

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MESSAGE FROM OUR PRESIDENT AND CEO, NORMA BEAUCHAMP

Welcome to our first e-edition of Connections magazine, I hope that you find inspiration in the stories in this issue.

It's hard to believe that 2016 is already coming to an end. However, it's true what they say – time flies when you're having fun; we walked, we shined, we rode, we biked and much, much more!

I am proud to say that the 2015 median survival age for Canadians living with cystic fibrosis is 52.1 years. This means that a child born with CF in Canada in 2015 will have a 50% chance of living beyond 52.1 years, based on current treatments, therapies and mortality rates. This is an increase from 2014 and an exciting milestone to be celebrated.

We know that our success would not be possible without the passion and dedication of our wonderful community – families, clinicians, researchers, donors, supporters and volunteers. I cannot thank each and every one of you enough for what you do. This is truly a shared success.

We ended this year with a celebration in Montreal to honour our progress in research and the 35th anniversary of Fibrose kystique Québec. Thank you to Denis Mouton for his outstanding leadership at Fibrose kystique Québec and to our sponsors and supporters in Quebec for their unwavering support. It has been a wonderfully successful 35 years and I thank you all for being a part of it. Since 1960; we have invested more than $235 million dollars in life-saving CF research and clinical care, nearly $50 million of this has been invested in research, health care and public education in Quebec.

While we have made great strides in the progress of research and improvement in care and treatments for Canadians with CF, we still have a long way to go to make CF history.

I am encouraged by the progress that 2016 brought us and look forward to sustaining that momentum in 2017 as we continue to work towards the goals in our 2020 strategic plan.

Together we will create a world without cystic fibrosis.

Norma Beauchamp
President and CEO

"As I look back on our achievements over the past year, I am honoured to represent such a wonderful organization. We strive to make a difference in the lives of Canadians living with cystic fibrosis and their families, and I truly believe that we are making that happen."

CIRCLE OF FRIENDS

AVA'S STORY

By: Jillian Dudar

If you saw our family walking down the street, we'd look just like your average young family. My husband Reid and I grew up in the same neighbourhood and have been together for 7 years. We have a hilarious five year old named Jaxson, who makes friends wherever he goes. We also have a beautiful, sassy, headstrong little (almost) two year old named Ava. We live in Toronto, and love being outside, adventuring around the city any chance we get.

What people don't always see is how complex our beautiful little girl is.

I had an easy, breezy pregnancy with Jaxson so I expected nothing less the second time around. My husband and I are young, active and (mostly) healthy. Toward the end of my second trimester with Ava, I noticed she was moving less and less. I mentioned this to my doctor, who quickly referred me for some testing to be sure everything, was all right. After three weeks of intensive testing, every parent's worst nightmare came true for my husband and I.

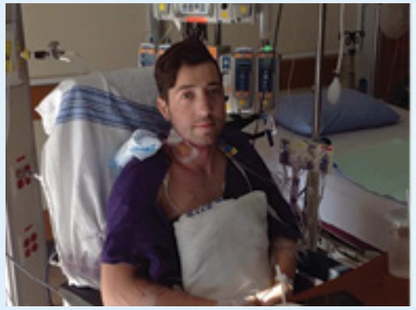
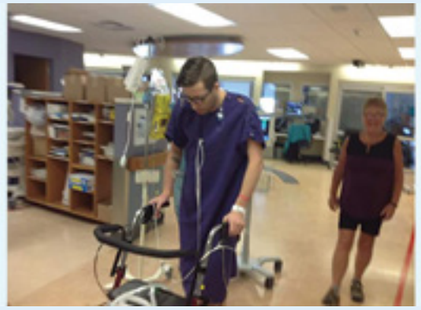
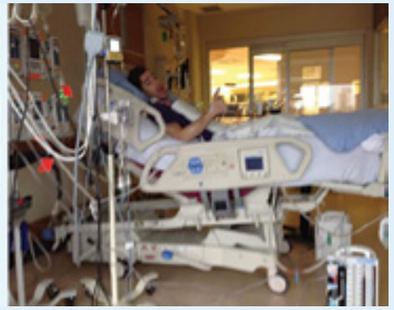
Everything was not all right. We were told that our unborn child had a disease called cystic fibrosis, a disease that neither one of us had any knowledge of whatsoever. We grieved and researched and tried to prepare ourselves as best we could for Ava's arrival. We were told by my high risk OBGYN that once Ava was born and stabilized she would be taken to The Hospital for Sick Children to have surgery. This surgery would attempt to repair her bowel, which had ruptured in utero. I had envisioned a bit of time in the hospital after surgery but little did we know she would spend the first 229 days of her life at SickKids. She would undergo another three surgeries (her first at only ten hours old), procedures, tests, studies and assessments before she was finally discharged. She was also given a secondary diagnosis of Short Bowel Syndrome just before she was two months old. The bowel rupture she had in utero caused her to lose about 85% of her small bowel.

Ava, almost two years old

We were lucky to have our baby cared for by some of the world's best surgeons, doctors, nurses and specialists at SickKids. We credit Sick Kids for why Ava is here today! It also gave us a wonderful opportunity to get to know the phenomenal health care team within the Cystic Fibrosis clinic.

It was wonderful to finally bring Ava home! But of course, being home posed a whole new set of challenges. Since her initial discharge, Ava has been admitted back into hospital another 4 times. We are on a good stretch – currently in month 5 without an admission! Ava was also given her first three month all clear from the CF clinic when we visited in July. That is a HUGE deal, considering post-discharge we were at the hospital three or four times per week! We had a wonderful summer and were able to travel to Montréal to visit friends and took a trip to Winnipeg to see our families. I am getting more comfortable managing Ava's care at home, as I gain new knowledge all of the time with regards to medication, treatment and managing this disease.

Today, we are overjoyed to have come to know the wonderful people at the amazing organization of Cystic Fibrosis Canada. They are some of the sweetest, loving, down to earth people we know. We are so grateful to have them in our corner. We have taken part in the fundraising walk for Cystic Fibrosis Canada the last two years, under the team name Ava's Angels. Our team members have been exactly that—our angels. In the last two years, we have raised almost $90,000 for the organization thanks to our amazing, generous team members. Last fall, we heard that the organization was looking for ambassadors and ambassador families – how could we not help? This cause is so near and dear to our hearts, and we want to be involved wherever possible. We hope that sharing Ava's story and our family's experience can give others hope and encourage people to join our fight.

NICK EWASIUK SHARES HIS TRANSPLANT STORY

1. Can you tell us a little bit about yourself and your journey with cystic fibrosis?

I was diagnosed with CF when I was five years old, grew up a "regular" kid. CF never really held me back. I played most sports that were offered in small town Manitoba, mainly hockey, baseball, and soccer, until junior high when I started playing more sports because they were offered through school. Around that time I also got into music, I bought my first guitar with birthday money when I was 13 years old.

Music has been a huge part of my life. Not only did it help me deal with things that were happening around me in my teens (between bullying and dealing with illness and coming to terms with that), but it also greatly affected my health and lung function. I see singing as one of the best forms of airway clearance because it forces you to focus on your breathing and push out great volumes of air when you're trying to hit or hold notes, not to mention it makes airway clearance a lot more fun.

As an adult I've worked full time since high school. I didn't go to college after high school because by the time I was in my late teens I started going into the hospital more often and was worried I would have to withdraw from school.

2. How did you come to find that a transplant was the next step in your treatment plan?

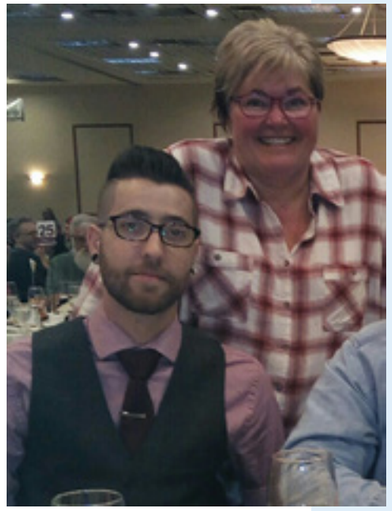
I had always been dead set against transplant. I had that mindset of "my lungs will never get that bad" and with the advancement in drugs like KALYDECO® I didn't think I would ever need a transplant. I was on KALYDECO® for the year pre-transplant and everything was going great; I hadn't been hospitalized once from October to June so I had decided I would apply to go back to school. I was accepted and started the nursing program in the fall. In mid-October I ended up with a chest infection and after a round of oral antibiotics that didn't work we decided it would be best for me to have a stay in the hospital which ended up being four weeks total.

This would prove to be a challenge as far as school went but I would pull through and pass my courses. At the beginning of the second semester— just before going back after winter break—I was hospitalized a second time, this time for six weeks. I had missed too much school and had to withdraw (my biggest fear when going back). **I knew at this point something had to change if I actually wanted to move on with and essentially LIVE my life, because I felt like I was more surviving life than actually living it**. I did my research and talked to my doctors and we decided to do the transplant assessment while I was in the hospital in January.

3. How long did you have to wait?

I was listed on the 4th of July while in the hospital for yet another chest infection. I was admitted the end of June, and was discharged on the 27th of July. I got the call to go to Edmonton on the 28th at 5:30 pm, got on the plane to Edmonton at 8 pm, and went into the OR at 3 pm on the 29th.

4. How have you been feeling post-transplant?



Nick with his mom, who supported him through his transplant process

Post-transplant I have been feeling pretty amazing, actually, aside from a few slight complications mainly due to the pain killers. Most recently my sugars have been all out of whack because of the Prednisone I am on but I knew going into it that this could be an issue.

Other than the few complications that I've experienced I have been doing awesome. At eight weeks, I decided to try and go for a run, which was quite successful. I ran a kilometer with only two small breaks – the funny thing about the breaks is that it wasn't my lungs that couldn't handle it, it was the fact that the rest of my body is so out of shape my legs couldn't keep up.

In this whole recovery process Monday has become my favorite day of the week. Its Pulmonary Function Test (PFT) day and I've been able to watch my FEV1 slowly go up from roughly 2.75L to 4.12L (last week's spiro) over the past six weeks which has just been amazing and it's still going up. It's crazy to think that I've come this far considering when I went into the hospital in December my FEV1 was roughly 1.2L with my old lungs.

5. What has been the hardest part of the transplant process?

You would think the hardest part of the process would be the surgery and initial recovery, but you'd be wrong. The hardest part in my opinion is learning to breathe again using muscles I haven't used to breathe in over 10 plus years – mainly my lower intercostal muscles which are finally starting to loosen up. The other thing that has been hard in regards to breathing is teaching myself proper breathing techniques for singing, which I'm starting to get the hang of.

It's been hard not working or being able to do much, aside from walking between six to 12 kilometers a day (because I'm bored and the rehab aspect of the walking and keeping my blood flowing). However, I'm now allowed to go back to the gym which will get me out of the apartment.

6. What do you have to do differently now to support your body and mind through the transplant recovery?

Honestly, not a lot has changed in my life since before transplant besides the fact that I am now on many more pills and I don't have any inhaled meds or chest physio which frees up a lot of time in my day. As far as my mind goes, I've been trying to keep occupied whether it be by playing guitar until my fingers can't take it anymore or finding new things to watch on Netflix and walks with my dog, Monster.

7. What are your personal hopes and goals, once you've fully recovered?

Once fully recovered I plan on reapplying for school and finishing up my nursing degree, now that I don't have to worry as much about my lungs bringing me down. I also plan on doing a bit of travelling as I have always been kind of afraid to travel, as I was always worried about coming down with a chest infection while away. Other than that, **I plan on actually living my life now that I have been given the opportunity to do so**.

The Giroux Family

IT'S AMAZING TO SEE CHARLOTTE DEAL WITH THE DISEASE

By: Julie Deschambault

In life, there are meetings that have a great impact on us, that move us deeply and that force us to realize just how lucky and blessed we are to be healthy.

It was on a mild fall morning in the Rosemount borough of Montreal that I had the privilege of meeting 12 year old Charlotte, who suffers from cystic fibrosis, and her wonderful family. We gathered at her home to film a short video that would later be used to tell her story and, most of all, to convey her message of hope.

Charlotte sits at the piano and starts playing the first notes of the score to the movie *Amélie*. Everyone in the room is astounded by her undeniable talent and by the beauty of this sweet melody. It must be said that Charlotte takes after her father, singer-songwriter Frédéric Giroux, member of the group Mes aïeux. "Music helps me work through the bad stuff and deal with my emotions," Charlotte says with self-assurance.

> ***"Music helps me work through the bad stuff and deal with my emotions,"***

On April 12, 2005, when Charlotte was a year old, her parents were told that she had cystic fibrosis. Her mother, Chantal, cannot help but become emotional as she talks about the day when their lives were turned upside down and changed forever. When the doctor called, she already knew what he was going to say. All the warning signs pointed to it: abnormal weight loss, considerably underdeveloped growth and salty sweat. "The shock was brutal, and our universe collapsed. It was the fear of the unknown. We didn't know what to expect. And, above all else, we immediately thought of the worst-case scenario, that our daughter was going to die," Chantal explains.

Once they had absorbed the shock and spent countless hours learning about cystic fibrosis, the couple rolled up their sleeves to manage Charlotte's disease. "We quickly learned to become home nurses," Frédéric recalls. The tube feeding every night, the clapping, the medication and the numerous visits to the hospitals soon became part of the family's daily routine. Given Charlotte's considerably stunted growth, the challenge was even greater. However, months and years passed, and Charlotte changed from a frail little girl into a young teenager filled with life and dreams for the future.

> ***"Had Charlotte's disease been diagnosed at birth, we could've stabilized her condition and avoided all the damage caused by her stunted growth,"***

"Had Charlotte's disease been diagnosed at birth, we could've stabilized her condition and avoided all the damage caused by her stunted growth," Frédéric points out. Incidentally, the couple reminds us that Quebec is the last province in Canada to not include cystic fibrosis in its neonatal screening program. Yet, an early diagnosis could limit the damage caused by the disease, damage that is sometimes irreversible. That's why, throughout their involvement with Cystic Fibrosis Canada over the past several years, the Giroux family has chosen to make this issue their main cause.

Today, Charlotte is doing well and manages her disease admirably on a day-to-day basis. Her parents encourage her to become more and more independent and are always nearby to support her during more trying times. The most difficult part is dealing with anxiety when Charlotte is not doing as well. The disease inevitably impacts family life, as well as Charlotte's younger sister, Juliette who is barely five years old. "Juliette notices that we pay a lot of attention to her older sister, especially when her condition deteriorates," Chantal explains. "This sometimes makes her react. She's even told us that she would like to have cystic fibrosis too!"

> ***"Juliette notices that we pay a lot of attention to her older sister, especially when her condition deteriorates," Chantal explains. "This sometimes makes her react. She's even told us that she would like to have cystic fibrosis too!"***

Chantal and Frédéric place a great deal of hope in research, which has led to great advances over the past 35 years in the search for new treatments. Some of these advances now make it possible to considerably improve Charlotte's day-to-day quality of life, as well as that of many other patients who suffer from the disease.

In fact, this young girl, who dreams of becoming a professional photographer in order to travel the world, is full of life! In addition to excelling at the piano, she regularly plays basketball, dances and goes downhill skiing with her family. Chantal and Frédéric also have great dreams for their Charlotte, particularly that of seeing her become a mother one day (if she wants to!) and, who knows, maybe even a grandmother. "Research allows us to believe and to cherish the hope that we'll be able to watch our daughter grow by our sides for as long as possible. Each time someone donates time or money to advance the cause, that person gives us a bit more hope," Frédéric explains.

Towards the end of the day of filming, Frédéric, accompanied by Charlotte, sang us a song from his first solo album *Le deuxième souffle* [the second wind], which was released in April 2016. The song entitled "T'es belle à voir aller" [you're amazing to see], written by Daniel Beaumont, describes Frédéric's admiration for his daughter and the struggle that she is waging. Charlotte is indeed amazing to see. And so is this beautiful family that, united in the face of the disease, gives us hope that we will one day find a cure!

HOOPS FOR HOPE

The 2016 Hoops for Hope winning team

Some of the action at Hoops for Hope

Organizing a charitable event is no easy task, as Katarina and Shaun Nechvatal know well. Along with Shaun's sister Sharlene, they've been organizing Hoops for Hope, an annual one-day basketball event in Saskatoon, since 2010. Through their efforts they have raised over $200,000 in support of Cystic Fibrosis Canada.

Katarina and Shaun have five children: Eva (12), who is now old enough to participate in the tournament; Anika (10), Dominic (8) and Benjamin (four months). Sadly, their middle son Jonathan passed away at six months from an undiagnosed metabolic disorder.

Their inspiration for the event comes from their sons, Dominic and Benjamin, who both have CF.

Shortly after Dominic's birth in 2008, the Nechvatals got a phone call from their local CF clinic in Saskatoon. Dominic had screened positive for CF. "That was a big shock to me," said Katarina. "Shaun and I didn't know we were carriers."

They learned that Saskatchewan would begin to implement newborn screening for CF in 2009, but somehow Dominic was lucky enough to have been tested before the screening officially began—he was the first infant to be screened, in fact, and the first CF newborn at the clinic. Very quickly, Katarina and Shaun were put at ease by the exceptional staff at the clinic.

When Dominic was a year old, Katarina attended her first chapter meeting and saw an opportunity for a different kind of fundraising event. "There wasn't anything really focused on being physically active," Katarina said, pointing out that incorporating a higher level of physical activity is one of the pillars of good CF care. Both Shaun and Sharlene played basketball as kids and played competitively on the University of Saskatchewan's Huskies, and coached. They decided that was a logical place to start. Katarina ran the idea of hosting a new event past the chapter members and they responded with enthusiastic support.

Like any good idea, it quickly grew.

Katarina started planning for a small event that she hoped would raise a few hundred dollars. However, within weeks she had secured a venue and several corporate sponsors and all of a sudden the event became larger than she had imagined, with eight basketball courts.

Katarina was all in. Once her youngest was in bed for the night, she would spend hours online researching, "I was thinking 'OK, how do you do a three-on-three basketball tournament?'" She laughs at the absurdity. "We didn't know anyone who had done anything like this before."

Fast-forward a few years and they've hosted their sixth tournament. Katarina, Sharlene and Shaun have the event down to an art: Players register online as teams of three or four and are guaranteed at least three games. Games take place on eight courts spanning a huge portion of the Market Mall parking lot. A live DJ provides the tunes, a barbecue raises additional funds, and there are bouncy houses for kids and three point contests. Dedicated volunteers and sponsors make the event possible year after year, and have contributed significantly to the fight against CF.

Winners of the divisions get their name on the trophy and a picture with it, but the real winners are the ones who bring in the most donations. Registration fees are kept low thanks to the substantial support from sponsors, which allow the event to be inclusive, something important to Katarina. Players are motivated to fundraise with the chance to win donated prizes such as entries into a draw for airline tickets, gift certificates, Huskies Basketball season tickets, and players also receive a Hoops for Hope swag bag filled with all kinds of goodies.

Unique to the Hoops for Hope event is the fact that very few participants have a direct connection with CF. Over the years the community has become committed to Hoops for Hope and have learned about CF through the event. One of their players who began as a 13 year old and now plays in the adult division claims that Hoops for Hope is his favourite day of the year!

There have been hard times, though. In 2014, the Nechvatals' son Jonathan passed away at 6 months from an undiagnosed metabolic disorder. Jonathan's disorder had no treatment and no cure. Katarina and Shaun knew they needed a break. They did not host the event that year but made a return in 2015. "What really helps me stick with organizing Hoops for Hope each year is knowing with certainty that CF is a disease we can do something about," said Katarina. "We've experienced positive changes in the eight short years since Dominic's diagnosis, and we expect to see many more."

Not too long ago Katarina was working on a video promoting Hoops for Hope, interviewed a doctor who had been in pediatric CF for decades. She asked him: What makes CF something that people should give their resources to? Without hesitation, he said two words:

We're winning.

HOOPS FOR HOPE BY THE NUMBERS:

- **44** teams played this year
- Over **50** people volunteered
- **2** University of Saskatchewan basketball teams volunteer to officiate
- As title sponsors, the POW City Kinsmen will donate **$10,000** per year on a three year commitment
- Over **$200,000** raised since 2010

Katarina and Shaun Nechvatal, organizers of Hoops for Hope

VIVIAN HILL'S LEGACY

Cystic Fibrosis Canada would like to thank Vivian Hill for her tremendous support.

Vivian was born in Toronto in 1929 and was an only child. Growing up, she loved spending summers at Lake Simcoe and enjoyed her pastime of sewing — she was known for making her own clothes. As a professional, she dedicated herself to her career as a legal secretary, which is how she came to know about cystic fibrosis.

Vivian worked for Bob Sutherland, who volunteered his services and was legal counsel and secretary for Cystic Fibrosis Canada for over 45 years. Bob volunteered much of his time to Cystic Fibrosis Canada and behind the scenes Vivian was very involved in Bob's CF work. Vivian worked for Bob for nearly 40 years and became very familiar with the plight of those with cystic fibrosis. While Vivian did not have a close family member or friend affected by cystic fibrosis, her involvement was made personal through her work with Bob Sutherland.

She was very charitable and supported many charities but generously left her estate to Cystic Fibrosis Canada, because of her involvement with the Sutherland family. While Vivian did not come from wealth, she was a savvy investor and was able to amount a significant estate.

Vivian passed away on September 19, 2014 at the age of 86. Through her incredible kindness, Vivian has **donated over $1.5 million to Cystic Fibrosis Canada**.

The legacy Vivian left at Cystic Fibrosis Canada will help to fund lifesaving research and care.

THE MOMENT WE KNEW

While more than 4,100 Canadians have cystic fibrosis, the number of Canadians affected by the disease is much greater than that. Cystic Fibrosis Canada wanted to highlight the stories of when loved ones found out that someone they care deeply for had cystic fibrosis. These stories are filled with unconditional love and we hope that they serve as inspiration to your family.

Thank you to the Eckensviller and Newell families for generously sharing their stories.

THE ECKENSVILLER

Charles and Meghan met during college and had an instant connection. As their relationship progressed, she told him about her cystic fibrosis. The revelation changed nothing about their relationship, Charles saw Meghan for Meghan and not her disease. The couple was married and went on to have three beautiful children. Sadly, Meghan passed away last winter at the age of 31 after a long, hard fight. Meghan's perseverance and positivity inspires Charles every day.

THE NEWELLS

Like any newlywed couple, Brandon and Rachel Newell fielded the "So when are you going to have kids?" question regularly. The couple tried for a child but, after a few years with no success, sought the help of a specialist. Through the help of a fertility clinic, the couple eventually conceived twins. Shortly after the birth, they were told their daughter Faith had cystic fibrosis. The family rallied around Faith. Brandon quit his job as a baseball scout and joined the Cystic Fibrosis Canada team. Today, they find strength in watching how courageous Faith is in her fight against cystic fibrosis.

POEM FROM MY LUNGS
Jehangir Saleh

mid afternoon the season changes

limbs sigh
trunk uprooted
leaves were, all along, full of blood

fished from a muddy stream
lungs compete to make larger
a wet sand pale
chest cavity

little wind

leaves fall
themselves

reuniting on the floor

a tiny furnace for decay
covers paths made through my body

was I here?

still breathing

the river manages a small tide.

wind labours down the sand pale.

two slimy fish rattle
violently.
perhaps this disease was around, 1918 Kerala
swollen dolls
animated
from the outside

how trust worthy, you think, our ancestors were
anticipating a mutation in the scriptures
building into our tradition so many years of foresight

cells instructed to produce a pus filled kingdom
for a nomadic, peaceful bacteria
now no longer homeless
now filling the branches of my bronchioles with nails
and making them rust

everyday, after praying, you would help me
mop the floor, sometimes
mop my body off the floor

POEM FROM MY LUNGS

Jehangir Saleh's family describe him as a curious and creative individual, an inspiration to those around him, not only through his capacity to find meaning in the challenging experience of living with a chronic illness, but also through his desire to encourage those around him to confront their own challenges and find meaning in their lives. To Jehangir, living with cystic fibrosis was just something he had, not something he was, but as his illness progressively became more difficult, writing, poetry, and studying philosophy became an outlet for him to understand and ultimately cope with his challenging reality.

Jehangir lost his life to cystic fibrosis in June 2013 at the age of 28. We are honoured to share a piece of Jehangir's poetry with you. Thank you to the Saleh family for allowing us to share his work.

Jehangir Saleh

The Mailly Family

LIVING WELL WITH CYSTIC FIBROSIS THANKS TO RESEARCH

By: Julie Deschambault

With her sparkling eyes, gentle smile and joie de vivre, Tamy often leaves others in disbelief when they find out that she has cystic fibrosis. The doctors were even more surprised to see the screening tests come back positive when she was barely two years old because the disease is extremely rare among Haitians. However, she must still follow a very strict routine every day in order to stay in shape.

We met with Tamy, as well as her mother Nadia and one of her older brothers, Andy, so that they could tell us how the disease turned their lives upside down.

HOW DID YOU REACT TO FINDING OUT THAT TAMY HAD CYSTIC FIBROSIS?

Nadia: It was a shock, but, at the same time, when you find out something like that, the adrenaline kicks in. The doctors told us it was unlikely because we were black, so they did the tests again. Tamy was almost two years old. She had the signs, but the doctors said I was worrying for nothing. Ouf! The emotions are all coming back! (*Nadia pauses to gather her thoughts.*) No one in the family had this disease. It's a known illness, but as long as it doesn't touch you, it doesn't concern you. It only concerns others.

ANDY, HOW DID YOU REACT TO FINDING OUT ABOUT THE DISEASE AND ITS PROGRESSION?

Andy: I was 11 years old. Adolescence is already a period of change and self-assertion, but, on top of that, we were moving from Longueuil to Saint Hilaire. We hadn't been in Longueuil very long, I was leaving all my friends and, at the same time, I found out my sister had cystic fibrosis. I didn't know anything about it, but I discovered it was a colossal disease. My sister had been around for barely two years, I was still getting to know her and then I found out that she had a fatal illness. All our lives changed at that point, and the news hit us hard.

At the time, we were three kids at home, but it was always Tamy, Tamy, Tamy. Thierry was six years old, and my mother told me that I had to pay a lot more attention to him. Thierry and I stuck together because we knew the situation was serious. It's the kind of situation that changes you and forces you to mature faster! (*Nadia nods in agreement with her oldest son.*)

TAMY, CAN YOU DESCRIBE YOUR DAILY ROUTINE WITH YOUR TREATMENTS?

Tamy: I get up and, while I'm having breakfast, I take enzymes that allow me to digest things that I normally can't. Then, I have to use a saline solution and apply cortisone in my nose twice a day because I have polyps. I do respiratory physiotherapy with a pump that helps to drain the mucus that blocks my bronchi to avoid getting pulmonary infections. When I have too much mucus in my lungs, I have trouble breathing and I cough a lot. I also take antibiotics using an inhaler, in the morning and at night. Afterwards, I exercise. It's good for my muscles and joints because I have cystic fibrosis-related arthritis. I take digestive enzymes, vitamins, antioxidants and antacids when I eat. Also, every morning, I drink shakes that contain protein, fibre and laxatives.

BUT YOU'RE STILL A YOUNG GIRL FULL OF PEP.

Tamy: Yes, cystic fibrosis is part of me, but I sometimes forget that I have it. It's something that I have to live with permanently. When I get up to go to school, I feel like a person who doesn't have a disease. I can do just as much as anyone else can. I go to parties. (*Tamy laughs*.) However, sometimes, I'm limited. When it comes to sports, I can't do everything. I have more trouble breathing, and cardio is very hard for me.

IF YOU COULD SEND A MESSAGE TO PEOPLE WHO DON'T KNOW THE DISEASE TO HELP THEM UNDERSTAND, WHAT WOULD YOU SAY?

Tamy: It's important to understand that it isn't a disease that shows. People often don't believe I have it. They minimize cystic fibrosis. They think it just causes lung problems, but it's much more than that. I have to eat more than others and make sure that my diet is rich in protein and high in calories to compensate for my dietary deficiencies. I also have to watch out for bacteria, for example, by not drinking tap water or using the hot tub, which would actually help my arthritis. I have treatments to administer every day, appointments at the hospital...

WHAT DO YOU MEAN BY "MINIMIZE"?

Tamy: For example, if we're running and I stop because I'm nauseous and feel like I'm about to throw up, some people think that it has nothing to do with cystic fibrosis. They think I just don't train enough. Also, even though I tell people I don't gain weight because of cystic fibrosis, they often say: "You eat and eat, but you never gain weight. You're so lucky!" Yes, I'm lucky with my bad luck, but I have trouble gaining weight.

WHAT DO YOU MEAN BY "LUCKY WITH YOUR BAD LUCK"?

Tamy: I've seen patients with more severe cases of cystic fibrosis than me who have to be fed intravenously. They end up in the hospital even more often. I'm lucky to be home. I go out with my friends, I go to restaurants, I work, I go to CEGEP and I can play sports, even though I'm limited.

IN QUEBEC, THERE'S NO NEONATAL SCREENING FOR CYSTIC FIBROSIS. WHAT DO YOU THINK ABOUT THAT?

Nadia: Neonatal screening is very important. It makes it possible to start the treatments as soon as possible. The earlier the treatments start (whether they're respiratory treatments or medications), the greater the chance of improving the patient's state of health. Dr. Lands, Tamy's pneumologist is very involved with this issue because the disease is quite common in Quebec. Many people carry it. In Lac-Saint-Jean, where I was born, 1 person out of every 15 is a carrier!

DO YOU HAVE A MESSAGE FOR PEOPLE WHO WOULD LIKE TO GET INVOLVED?

Tamy: When you give to the cause of cystic fibrosis, it allows me to live longer. The lifespan of a person with the disease is now 51 years. It helps with research and is a source of hope for every child with cystic fibrosis.

Andy: I remember a doctor telling us, "Every year of research is a year added to the life of a patient with cystic fibrosis." If we're able to raise as much money as possible every year to find new ways to treat this incurable disease, we can at least find solutions to help these people live a bit longer.

LIVING WITH CYSTIC FIBROSIS, ONE DAY AT A TIME

By: Julie Deschambault

Gatineau residents Daniel and Melyssa were living a perfect life with their little Émile when one day, everything changed, and their lives took a 180-degree turn. Émile's cystic fibrosis diagnosis hit the family like a ton of bricks and shattered their universe. However, once the shock had passed, this close-knit family banded together to face the disease. Today, they manage to live normally, or almost. This is the story of a family that deals with the disease one day at a time.

It was May 6, 2014. Émile, who was barely five weeks old, was hospitalized so that doctors could perform a battery of tests to determine the exact cause of the recurring symptoms that had been plaguing him since birth: abundant, foul-smelling stools, respiratory problems and weight loss. One final test–the sweat test– was performed, and doctors reached a diagnosis: Émile had cystic fibrosis. "The feeling I had when I heard the news, I still remember it like it was yesterday," says Émile's mother Melyssa, her voice choked with emotion. "It's like hitting a brick wall at 300 km an hour".

Melyssa's spouse Daniel uses the same comparison to describe what he felt when she told him the terrible news over the phone. Émile's father, who is a journalist at Ottawa newspaper *Le Droit*, was in his car when he got the call and admits that he does not remember his route or destination that day. "When I look back, I realize I was in shock, just like many people who experience a traumatic event," Daniel remembers with emotion.

In the days that followed, the couple rolled up their sleeves and faced everything that the disease would involve on a daily basis. Melyssa, a trained nurse, had some theoretical knowledge of the symptoms and treatments of cystic fibrosis, but admits that she had to learn about the disease just like any other parent whose child is diagnosed. Daniel, who knew practically nothing about cystic fibrosis, poured his heart and soul into learning about the disease and just about became an expert! "We always think this kind of thing only happens to other people. When it happened to us, we found out we both carried the defective gene. In Canada, one out of every 25 people is a carrier of the gene. That's a lot!" Melyssa points out.

One week after the diagnosis, the parents decided to look towards the future by becoming actively involved with the local Outaouais chapter of Cystic Fibrosis Quebec, including the annual walk. In just two weeks, Émile's team raised $3,300! Since then, the couple has never quit, and when fatigue and emotions start to get the best of them, they force themselves to remember the reasons that motivate them to move forward – improving Émile's quality of life and that of every other person suffering from cystic fibrosis.

Nevertheless, Melyssa and Daniel consider themselves lucky in spite of everything because the warning signs were detected quickly by alert, competent people, which led to Émile's relatively early diagnosis at five weeks. "If Émile had suffered more serious respiratory problems and had infection upon infection, the consequences would most likely have been more devastating," Melyssa insists. Neonatal screening still remains the best way to prevent the adverse effects of the disease and delay their appearance in a person's everyday life. For Daniel, it makes no sense that Quebec is the only province in Canada that does not offer the neonatal screening test for cystic fibrosis while several other tests are already performed. "The test would cost barely $5 per birth and could make a world of difference. Considering the cost of care and hospitalizations for the healthcare system, it's imperative that the government make this test available to families," Daniel points out.

However, the LeBlanc-Brisson family remain optimistic and place a great deal of hope in research, which has made huge advances in Quebec in the past years. The life expectancy of people with cystic fibrosis used to be 30 years; today, it is over 50 years. This suggests that little Émile, who is now two and a half years old, could far exceed this prognosis since research will continue to advance and will no doubt lead to a cure for the disease.

In the meantime, Émile continues to live his life one day at a time like any other child his age. He goes to daycare, plays with his friends and has fun playing with modeling clay and toy cars. The only difference is that Émile and his parents have to follow a daily routine that sometimes includes the administration of enzymes and inhaled antibiotics, periods of clapping and the use of inhalers. "What's hardest right now is that Émile has a lot of trouble sitting still during the treatment routines because of his age," Melyssa explains, her voice quavering. It is clear that this young mother wishes, more than anything, that she could let her son be just a carefree child instead of subjecting him to all this.

However, life also sometimes sends wonderful gifts. The family recently welcomed a second little boy, Maxandre, who is now nine months old. So Émile will have a little brother to play with in the next few years. Meanwhile, his parents continue to be involved with Cystic Fibrosis Canada and encourage everyone in Quebec to do the same. "With each fundraising event that's organized and each dollar that's donated to research, you allow us believe in a future filled with hope for our little Émile and the more than 4,000 Canadians, including more than 1,000 Quebecers, who suffer from cystic fibrosis," says Daniel.

HOPE THROUGH PROGRESS

NEWBORN SCREENING FOR CYSTIC FIBROSIS IN CANADA SHOWS BENEFITS

A recent study by a team including Cystic Fibrosis Canada's Dr. Denise Mak, Program Manager of Healthcare, examined the impact of newborn screening for cystic fibrosis (CF) in Canada. Newborn screening for CF involves testing a blood spot taken from the newborn during the first few days of life for common CF mutations. If the test is positive, the family is referred to one of the 42 CF clinics across Canada for further testing, and upon diagnostic confirmation, education and treatment begin, typically within the first six weeks of life. Newborn screening for CF is standard practice in several European countries, Australia, New Zealand and most of North America, with the exception of Quebec and Mexico. The authors hope that this study will provide further evidence to support advocacy efforts for newborn screening programs for CF.

The study involved a total of 303 children with CF over a six-year period, from 2008 to 2013. Researchers compared 201 children with CF from Alberta and Ontario who were screened as newborns, with 102 children with CF from Quebec who were not screened and were diagnosed only after showing symptoms of the disease.

They found that children who received newborn screening for CF had better overall growth in height and weight, which is linked to better long-term health. They also had fewer *Pseudomonas aeruginosa* and *Staphylococcus aureus* bacterial lung infections, fewer hospitalizations due to lung infection flare-ups, and shorter hospital stays. Children who were not screened as newborns had higher rates of pancreatic insufficiency, which causes difficulty in absorbing nutrients from food. They also attended fewer CF clinics.

Overall, the study showed that newborn screening for CF leads to better long-term health in people with CF in the first five years of life compared to those diagnosed clinically. Newborn screening is an important part of the clinical approach to improving health outcomes for people with CF.

To access the article abstract from the *Journal of Cystic Fibrosis*, please click here.

Amelia Ann Steeves from Victoria, BC, who was born in the fall of 2011 and diagnosed with CF by newborn screening, shown in the first picture as a baby, and in the second picture at age 4.

CYSTIC FIBROSIS CANADA'S HHR GUIDELINES PUBLISHED IN CANADIAN RESPIRATORY JOURNAL

For the first time, the work of Cystic Fibrosis Canada has been published in a peer reviewed academic journal. An article highlighting the Health Human Resources Guidelines (HHRG) developed and written by Ian McIntosh, Director, Healthcare, was published in Volume 2016 of the *Canadian Respiratory Journal*. The Health Human Resources Guidelines (HHRG) was developed in consultation with the 42 cystic fibrosis (CF) clinics across Canada.

CF is a multisystem disease that requires a multidisciplinary team approach to clinical care. For example, a person with CF ideally receives care from a CF doctor, nurse, dietician, physiotherapist, social worker, pharmacist, respiratory technician, and in some cases, a psychiatrist or psychologist. Other clinic professionals include a secretary or administrator. The HHRG guidelines specify the amounts of each of the above team members that are required for each CF clinic to meet the minimum human resource standards. The HHRG guidelines also describe each of these roles and how they work together.

The healthcare team at the Regina CF clinic during a September 2016 Accreditation Site Visit, with one visiting team member from each of the Saint John and Toronto CF clinics, and two representatives from CF Canada.

The HHRG guidelines provide a measurement tool for use during Cystic Fibrosis Canada's CF clinic Accreditation Site Visit program, which ensures that all CF clinics in Canada provide quality care. They are also intended as an advocacy tool to help obtain these resources.

To access the *Canadian Respiratory Journal* article, please click here.

IMPROVING THE LIVES OF PEOPLE DEPENDING ON TRANSPLANTS

For many people with cystic fibrosis (CF), lung transplantation offers hope for a second chance at life. CF is characterized by chronic lung infection and inflammation, which causes tissue damage over time. When the lungs have become damaged to the point that their function is severely reduced, lung transplant becomes the only option. Unfortunately, in Canada, the demand for viable donor lungs, and other organs, vastly outweighs the supply, with almost 4500 Canadians on transplant waiting lists (Canadian Organ Replacement Registry Annual Report, 2011).

A surgery setting using organs shipped in traditional containers on ice ready to be retrieved or transplanted.

In response to this need, the Canadian National Transplant Research Program (CNTRP; cntrp.ca) was created in 2013. This five-year program was formed after identifying that transplantation research and clinical applications would benefit from increased collaboration among the community. Led by Drs. Lori West at the Alberta Transplant Institute at the University of Alberta and Marie-Josée Hébert at the Université de Montréal, CNTRP brings together over 300 investigators, trainees, collaborators, patients and other partners at 29 sites throughout Canada to carry out research and develop resources to help Canadians waiting for transplants and to improve outcomes and quality of life after transplant.

The specific goals of the Canadian National Transplant Research Program (CNTRP) are to:

1. Increase the **number** of transplants
2. Extend the **lives** of transplant recipients
3. Improve the **quality of life** of transplant recipients
4. Develop and enhance the **pool of talent** in the transplant field
5. Integrate and coordinate **transplantation research** nationwide

Two years into the five-year program, CNTRP is on track to make a positive impact in each of its identified goal areas. A few of their accomplishments are listed below.

- They have brought **new technology** into operating rooms to enable surgeons to support and repair donated organs for transplantation that would have otherwise been discarded
- They are examining key factors relevant to **increasing organ and tissue donation**
- They are analyzing differences in **donation rates** across the country
- They are improving testing to more accurately determine **brain death**
- They are examining the expansion of **living kidney donation**
- They gathered evidence and published national guidelines for working with **organ donors at high risk of passing on infection**; Ontario Trillium Gift of Life Network produced a tool kit based on these guidelines to assist health care workers and administrators in decisions related to accepting organs from high risk donors
- They have explored **legal and policy issues** related to organ donation and produced a series of **Fast Facts** resources to inform policies and spark new research on topics such as consent for organ donation, potential benefits, impact and legality of incentives, organ trafficking and transplant tourism

DID YOU KNOW?

As of 2011, 30-40% of Canadians needing a transplant over their lifetime would not receive one. The Canadian National Transplant Research Program (CNTRP) is working to increase the chances of receiving a transplant.

DID YOU KNOW?

The Canadian National Transplant Research Program (CNTRP) is currently funded at a level of approximately $23 million, with $100,000 of that coming from Cystic Fibrosis Canada.

Dr. Markus Selzner from University Health Network's Toronto General Hospital with an OrganOx Metra device, which preserves organs outside the body by mimicking human physiological functions. Dr. Selzner successfully transplanted a deceased donor liver that was preserved using OrganOx Metra for almost 12 hours.

Dr. Jayan Nagendran (pictured left), is a CNTRP lung surgeon at the Alberta Transplant Institute in Edmonton who is working on improving portable ex vivo lung perfusion technology and investigating how to retrieve and repair lungs prior to transplant. Dr. Darren Freed (pictured right) is a CNTRP heart surgeon, also at the Alberta Transplant Institute.

Moving forward, the CNTRP aims to continue the work started in the first two years of the program, in addition to further integrating patients, families, caregivers and members of the public. They also aim to explore additional partnerships and collaborations, and build sustainability into the future by communicating the importance of the network to a wide range of stakeholders. Cystic Fibrosis Canada looks forward to continued involvement with CNTRP in the years to come, in recognition of positive benefits of the network for the cystic fibrosis community.

To access the Executive Summary of the network's Year Two Scientific Progress Report, click here.

Q&A WITH CYSTIC FIBROSIS CANADA RESEARCHER DR. ZHENYU CHENG

Recipient of Cystic Fibrosis Canada's 2016-2017 Marsha Morton Early Career Investigator Award, Dr. Zhenyu Cheng from Dalhousie University recently discussed his research in cystic fibrosis (CF) on CTV News Atlantic. Dr. Cheng is currently studying how Pseudomonas aeruginosa bacteria, a common cause of lung infections in people with CF, develop antibiotic resistance.

To view the clip, click here.

Cystic Fibrosis Canada recently asked Dr. Cheng a few questions about himself and his research. Here is what he said:

Q: What is your research background? How does this relate to CF?

I am a microbiologist who is interested in host-bacterial interactions. The bacterial pathogen that I study, *Pseudomonas aeruginosa*, causes lung infections in CF patients.

Q: What are you working on now?

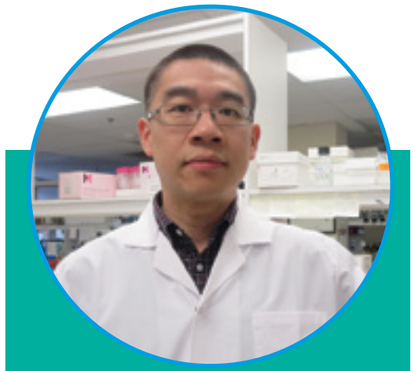
There are two lines of research in my lab. First, we are studying both host immune responses and bacterial virulence factors. Interestingly, my postdoctoral training in Dr. Frederick Ausubel's lab at Massachusetts General Hospital focused on plant-*P. aeruginosa* interactions. While the plant project is still part of my research, we are also trying to take what I found in plants and apply it to humans. In addition, my Cystic Fibrosis Canada-funded research is about trying to understand how *P. aeruginosa* survive antibiotics treatment.

Q: How will this positively impact the lives of people with CF?

If we can understand more about what makes *P. aeruginosa* bacteria harmful and how it causes damage to CF lungs, we can identify new ways to target the bacteria. On the other hand, we can also try to boost the immune system, which is important to the defense against *P. aeruginosa* infection. Similarly, knowing the reasons why *P. aeruginosa* tends to survive antibiotic treatment will help us to develop drugs that can enhance the effectiveness of existing antibiotics. If we have better drugs to treat this bacterial infection, it will also help to alleviate damaging inflammation in CF lungs.

Q: What part of this research are you most excited about?

It's fascinating that *P. aeruginosa* is almost everywhere in our environment and can cause diseases in both plants and animals. It is a tough pathogen to deal with, particularly for CF patients. We are really trying to come up with innovative approaches for intervention against this bacterial infection from all different angles.



Dr. Zhenyu Cheng is an Assistant Professor in the Department of Microbiology and Immunology in the Faculty of Medicine at Dalhousie University. Zhenyu completed his graduate studies at the University of Waterloo in Ontario, and after obtaining his PhD in 2010, he took a postdoctoral position in Boston, jointly appointed in the Department of Molecular Biology at Massachusetts General Hospital (MGH) and the Department of Genetics at Harvard Medical School. During his postdoctoral training, Dr. Cheng received a Natural Sciences and Engineering Research Council of Canada (NSERC) Postdoctoral Fellowship and a Banting Postdoctoral Fellowship from the Government of Canada, followed by a Tosteson Award from MGH. Dr. Cheng started his independent research lab at Dalhousie University in Nova Scotia in 2016 and he is a Cystic Fibrosis Canada Marsha Morton Early Career Investigator.

Brad Locke (seated), laboratory assistant in Dr. Speert's lab and recent graduate of University of British Columbia's medical school. Also pictured, James Zlosnik (standing), research associate in Dr. Speert's lab with a PhD in molecular microbiology from Imperial College London.

Q&A WITH FOUNDER AND DIRECTOR OF THE CANADIAN *BURKHOLDERIA CEPACIA* COMPLEX RESEARCH AND REFERRAL REPOSITORY, DR. DAVID SPEERT

Dr. David Speert has been a Cystic Fibrosis Canada funded researcher since 1980. He is also the Founder and Director of Cystic Fibrosis Canada's Core Facility, the Canadian Burkholderia cepacia Complex Research and Referral Repository (CBCCRRR), located at the University of British Columbia. The CBCCRRR is one of two core facilities funded by Cystic Fibrosis Canada, and is an important resource to cystic fibrosis (CF) clinics and research communities across Canada.

Cystic Fibrosis Canada recently asked Dr. Speert a few questions about himself and the CBCCRRR. Here is what he said:

Q: What is your research background? How does this relate to CF?

I am a Paediatric Infectious Diseases clinician-scientist with research funding from Cystic Fibrosis Canada (formerly the Canadian Cystic Fibrosis Foundation) since I was appointed to the University of British Columbia and British Columbia Children's Hospital over 35 years ago. Since 1980, I have studied lung infections in patients with CF. I have investigated the means by which both *Pseudomonas aeruginosa* and *Burkholderia cepacia* complex cause disease in CF and the means by which patients with CF defend against these infectious agents. These bacteria are the principal pathogens in patients with CF and they contribute to lung deterioration and death in the majority of patients.

Q: What is *Burkholderia cepacia* Complex? Why is it important to people with CF?

B. cepacia complex is a group of closely related bacterial organisms that have been shown since 1982 to infect patients with CF. The rate of infection varies dramatically from CF centre to centre, and there is now clear evidence that the bacteria can be spread from one patient to another. Infection with *B. cepacia* complex is associated with a worse clinical outcome than infection with other bacteria in CF.

Q: What does the CBCCRRR do?

The role of this facility is to evaluate isolates of *B. cepacia* complex from any CF clinic in Canada and to confirm and refine the identity. Once the bacteria are found to indeed be *B. cepacia* complex, they are further evaluated for species identity within the complex and then by using genetic "fingerprinting" they are further determined to be unique or the same as other isolates already evaluated at the facility.

Q: How does the CBCCRRR make a difference to the lives of people with CF?

The evaluations done in the facility allow us to determine if there is apparent spread of *B. cepacia* complex between or among patients with CF. If 2 or more patients are infected with the same strain, the assumption is made that the bacteria have been spread from one person to another. If such a situation is found, it is an indication that enhanced infection control precautions should be instituted.

Q: What do you think has been the CBCCRRR's biggest contribution?

Through evaluations of bacteria sent to the facility, we have been able to track all cases of apparent patient-to-patient transmission of *B. cepacia* complex in Canada. Because of these observations, new stringent infection control guidelines have been instituted which have almost eliminated transmission among patients. Most new acquisitions of these bacteria appear to be from the environment.

Dr. David Speert

Dr. David Speert is the Sauder Family Professor of Pediatric Infectious Diseases at the University of British Columbia. His research has concentrated on host-microbial interactions in the lung, focusing on pathobiology of cystic fibrosis lung infections. He is the recipient of numerous scientific awards, and his research trainees hold academic appointments in Europe, Asia, South America, Africa and Australia. Dr. Speert is author of over 200 primary publications.

Cynthia Gunarathan, summer student in Dr. Speert's lab and recent graduate of University of British Columbia's medical school.

CANDID FACTS

CARSTAR® WALK TO MAKE CYSTIC FIBROSIS HISTORY

Every year during May Awareness Month, Cystic Fibrosis Canada hosts a fundraising walk. On Sunday, May 26, 2016, The CARSTAR Walk to Make Cystic Fibrosis History hosted thousands of participants across Canada at local sites within their communities to celebrate our fundraising efforts and imagine a world without CF. This year, our walkers raised over $3.5 million and counting toward cystic fibrosis research, care and advocacy.

NATIONAL CHARITY SHOPPING NIGHT AT HOLT RENFREW

Thanks to an incredible partnership with Holt Renfrew, Cystic Fibrosis Canada was the recipient of funds from eight Holt Renfrew stores across Canada on Thursday September 22. Each store opened its doors and donated 10% of their sales from the evening to Cystic Fibrosis Canada. The National Charity Shopping Night was a huge success, creating relationships locally and raising an incredible $87,000 for cystic fibrosis research and care! Cystic Fibrosis Canada is grateful to the leaders and supporters who helped make this happen. We look forward to a long lasting future relationship.

Shinerama
STUDENTS FIGHTING CYSTIC FIBROSIS

Although the year is coming to an end, students from across Canada are still raising crucial funds for Cystic Fibrosis Canada. This year over 30,000 volunteers from 50 schools across Canada participated in Shinerama, rallying on the streets, hosting BBQs and washing cars to raise awareness for those affected by cystic fibrosis. For more than 50 years, dedicated students have come together to Shine, raising $26 million life-changing dollars and making an impact in their community. Thank you students!

Fusion
MOONLIGHT & THE MILKY WAY

Cystic Fibrosis Canada hosted its 15th annual Fusion Gala at the Angus Glen Golf Club on Saturday, October 22. The evening of Moonlight and the Milky Way raised a total of $330,000. To date, the Fusion Gala has raised over $2.8 million for cystic fibrosis research, patient care and advocacy. The enchanting evening transported guests to a world of romance, dreams and dancing in the moonlight – by way of spectacular dance and musical performances. Throughout the night, guests participated in the exciting live and silent auctions, including the Key to a Cure auction.

A special thank you to the Gala Committee and its co-chairs Bonnie Griffin and Ron Anderson who put on an outstanding event!

Thank you to event sponsors including, Team Solutions as Presenting Sponsor, Platinum Sponsor Unifor, and VIP Corporate Table Sponsor, The Restorers Group, in addition to Reception and Corporate Table Sponsors.

35 YEARS
OF FIGHTING AND HOPE

Cystic Fibrosis Canada is pleased to celebrate the 35th anniversary of Fibrose kystique Québec. Thank you to Denis Mouton for his outstanding leadership and the unwavering support and dedication of our sponsors and supporters in Quebec for a wonderfully successful 35 years.

Over the past 35 years, close to **50 million dollars** has been invested in cystic fibrosis (CF) research and care in Quebec.

- **$34,349,521** for research on the disease
- **$14,247,126** for improving CF-specialized clinics
- **$839,696** towards the Montreal University Hospital Centre (CHU) for lung transplants

Below is a spotlight on some of the exciting milestones of Fibrose kystique Québec.

The Québec Cystic Fibrosis Association (AQFK), now Fibrose kystique Québec, was created 35 years ago, in 1981 by Denis Mouton.

In 2004, among the 44 Canadians with cystic fibrosis who had a lung transplant, ten lived in Quebec.

In 2011, AQFK became Fibrose kystique Québec.

In 2013, the Quebec National Institute of Public Health tabled its final report: all participants agreed that newborn screening was necessary in Quebec and should be done in optimal conditions.

In 2015, a meeting with Minister Gaétan Barrette was held to discuss the newborn screening file.

In 2016, The benefits of newborn screening for cystic fibrosis: The Canadian experience, a study led by Dr. Larry Lands, was published.

Presently, Quebec remains the only province in Canada not to offer newborn screening to parents of a CF child.

Left to right: Denis Mouton, former AQFK president; Guy Wells, Esq, Justice of the Peace; Pierre-Paul Savard, former president of the Quebec Federation of Prevention against Cystic Fibrosis and new AQFK president, during the official signing.

The AQFK authorization certificate, produced in 1987, outlined the goals pursued jointly by the AQFK and the Canadian Cystic Fibrosis Foundation (CCFF), now Cystic Fibrosis Canada.

The first meeting of the presidents of the local regions of the AQFK took place in 1988.

In August 1989, Dr. Lap-Chee Tsui and Dr. Jack Riordan of the CCFF's first Research Development Program (PDR1) team, in collaboration with Dr. Francis Collins, marked a very important step when they announced the discovery of the gene responsible for cystic fibrosis. Studying the population of Saguenay/ Lac Saint Jean had greatly contributed to identifying the cystic fibrosis gene.

Cystic Fibrosis Canada national ambassador Céline Dion, with her niece Karine, who passed away in 1993. Céline participated in an awareness campaign in honour of her niece in 1994

First billboard for cystic fibrosis (with CF spokesperson Caroline Pazzy) on display, free of charge, for two years at the corner of Cathcart and Beaver Hall St., Montreal.

I-r: Micheline Martin of RBC Royal Bank and honourary campaign president, René Coutu, Chairman of the AQFK Board and Andrée Faucher, director of the RESPIRE campaign in Québec.

In 2004, the result of the RESPIRE research program – Innovative targets for the treatment of CF was unveiled after 14 months of campaigning. In Québec $1,835,000 was collected, more than 30% of the national objective.

In 1998, the main objective of the SPARX treatment and applied research special program was to update the new forms of treatment to resolve the root problem— lung infection and inflammation.

Ambassadors, Mila Mulroney and Céline Dion at the press conference to launch the SPARX fundraising campaign — one of the CCFF's biggest research projects to date.

2016 CYSTIC FIBROSIS CANADA NATIONAL AWARD RECIPIENTS

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 and we are enormously grateful for their contributions.

Congratulations to the 2016 award recipients; together we are working towards a world without cystic fibrosis!

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

CHRISTINE BLACK

Christine has volunteered with Cystic Fibrosis Canada since 1983 and helped co-found the Campbell River Chapter after her daughter was diagnosed with CF that year. Since then, she has tirelessly worked for the cause educating the public about the disease, supporting other families whose children have been diagnosed with CF as well as garnering support from the local community and raising funds for CF. She started out small, with bingos bringing in $93 a night, but has since progressed to running the premier fundraising event of the year: the Rod Brind'Amour Golf Classic, which has raised $1.5 million since its inception.

While the Chapter is in a small island community with a population of only 30,000, it manages to compete among Cystic Fibrosis Canada's top fundraisers. The members of the Chapter have said that Christine is the 'glue' that holds the group together and as a result of her leadership, still counts volunteers from 33 years ago as active members today. She is always looking for fresh, creative fundraising ideas to drive revenue not only for her Chapter, but for others as well. She assisted in resurrecting the Victoria Chapter when it was in danger of folding and continued to support the Chapter until it was running self-sufficiently. Christine has chaired the BC Association for eight years, was the Regional Director for BC for four years, was the Chair of the Stakeholder Council and has sat on the Executive Committee of Cystic Fibrosis Canada for ten years.

Christine's leadership and ability to build relationships has been instrumental in the success of the Campbell River Chapter. Her tenacity and determination have led to strong relationships with her local Kin clubs, school district, city council, media outlets, medical community and many corporate and community sponsors. Her involvement in the local community was noted in 2006 when she was named Campbell River Citizen of the Year, which speaks to her personal qualities and work ethic. Her dedication to the cause has also been evidenced through being awarded the Breath of Life Award in 1991 and a Volunteer Service Award in 2008. Christine is a true inspiration and her tremendous commitment, courage and passion will continue to improve the lives of Canadians living with cystic fibrosis. Cystic Fibrosis Canada thanks Christine for her tremendous contributions.

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

ANNE ARSENAULT

Anne has been a key supporter of CF Canada in the Durham Chapter since 1985—over three decades of volunteer work. What makes her service even more exceptional is the fact that she has no direct family connection to cystic fibrosis yet she has been involved in all major Durham Chapter events including The Walk, the Strokes for Life Golf Tournament and the Outrun CF 5k run. Anne was the Chapter Treasurer for over 10 years and continues to dedicate her wisdom and experience to the cause. Cystic Fibrosis Canada thanks Anne for her commitment.

DEBBIE LAVAL

Debbie joined the fight against cystic fibrosis in 1989 as a volunteer in the original Wrap for a Cure event, the Loonie Wrap. She went on to chair the 65 Roses Ladies' Golf Tournament and serve as the Volunteer Coordinator on the Calgary and Southern Alberta Chapter's board where she established the Chapter's social media program, giving the Chapter a strong social media presence. Debbie's efforts and dedication are truly appreciated by Cystic Fibrosis Canada and the CF Community.

KEITH & PAULETTE MCALLISTER

Keith and Paulette started volunteering with Cystic Fibrosis Canada's London Chapter over 20 years ago after their granddaughter was diagnosed with CF. They have attended nearly every meeting, run countless bingos, sold hundreds of raffle tickets, helped with The Walk and are involved with the 3-on-3 Road Hockey Tournament as well as the Tee Off Against CF Golf Tournament, which raises nearly $20,000 every year. They have dedicated their lives to the cause and after more than two decades, can still be found at nearly all CF fundraisers and events demonstrating their incredible dedication to the cause. Cystic Fibrosis Canada is proud to celebrate Keith and Paulette's accomplishments.

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

WALTER & LISA BRENNEN

Finding a cure for cystic fibrosis became the personal mission of Walter and Lisa after both of their daughters were diagnosed with CF, and their impact has been incredible. Lisa co-founded the Vancouver Chapter's 65 Roses Gala where she has been Chair several times. Walter has held many positions throughout the years at the Vancouver Chapter including President, Treasurer, Board Director, Gala Coordinator, and GearUp4CF Committee member. Their combined efforts and involvement with the GearUp4CF event and the Vancouver Gala have dramatically increased fundraising efforts for the chapter and have been pivotal in the success of Cystic Fibrosis Canada's Western Regional office. Lisa and Walter are phenomenal advocates in the mission to find a cure for cystic fibrosis and Cystic Fibrosis Canada is happy to celebrate their contributions to the CF community.

BRUCE LLOYD

Bruce has been a dedicated volunteer for over 40 years, beginning when his niece was diagnosed with cystic fibrosis in 1975. He has lead CF fundraisers in the Kitchener-Waterloo area, such as the JM Kropf Fall Classic Golf Tournament and the many wedding shows, and has helped to raise hundreds of thousands of dollars for CF research and care. Bruce also served as the National President of Kin Canada and Chair of the Kin-Cystic Fibrosis Canada Liaison committee, where he led the team to raise over $2 million over two years. Today he is a mentor for the many Kin Canada members he has involved in the fight against CF. Bruce Lloyd embodies Cystic Fibrosis Canada's values of accountability, excellence, teamwork and caring.

MARKVOORT FAMILY

Bill Markvoort, Janet Brine and their children Eva, Annie and Hunter, joined the fight against cystic fibrosis when Eva was diagnosed with CF at the age of one. Eva raised awareness through her well-known blog, 65_RedRoses, until she lost her battle with CF in 2010. The Markvoorts continued Eva's mission to find a cure for CF by starting several fundraisers, including the 65 Red Roses Painting Campaign and the 65 Red Roses Benefit Concert. They are part of many CF fundraisers and their efforts have resulted in over $600,000 raised for Cystic Fibrosis Canada. For Bill's 9-day GearUp4CF ride, he sought to raise $65,000 for his 65th birthday and surpassed his goal, raising over $100,000. We are thankful for everything that the Markvoort family has done to support Cystic Fibrosis Canada over the years.

BILL & EDNA WHITTON

Bill and Edna have been actively involved in the Moncton Chapter since 1970, after their daughter was diagnosed with cystic fibrosis at 18 months. Between them, they have chaired several fundraising events and served as both president and vice-president, a position they presently hold. They keep in close contact with several local CF families, writing letters of encouragement and sending 'get well' cards to those who have been hospitalized. They have volunteered at almost all of the Moncton walks and participated in many of the chapters fundraising events, built a room in their basement to host monthly Chapter meetings and are widely viewed as the driving force behind the Chapter. Their hard work and dedication is greatly appreciated by Cystic Fibrosis Canada and the CF Community.

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

T.J. BRODIE

T.J., of the Calgary Flames, has been instrumental in raising awareness about cystic fibrosis in Alberta. T.J. was inspired to support Cystic Fibrosis Canada as part of the Flames Foundation by his cousin who was diagnosed with CF as a child. T.J. helps with the Skate in Strides program, the Wrapping for a Cure event, the Ride for the Breath of Life motorcycle ride as well as the Catwalk for a Cure fashion show. T.J. has shown great commitment to Cystic Fibrosis Canada and the CF community is very thankful.

AKITA DRILLING LTD.

For the past 15 years, Akita Drilling Ltd. has hosted the Akita Drilling Ltd. Annual Charity Golf Tournament for Cystic Fibrosis, an event which grows in size and donations every year. Participants enjoy a great day of golf and can work on their swing while enriching the lives of people with CF. Since the tournaments inception in 2001, over $500,000 has been raised in support of people living with CF in Canada. Akita's Drilling support has been inspirational and the CF community is truly grateful.

KINSMEN CLUB OF HAMILTON

The Kinsmen Club of Hamilton has assisted The Hamilton Chapter with the Walk since 2011. They went from raising $5,000 at their first Walk to approximately $200,000 last year. The responsibilities and effort required to plan the Walk have matched its exponential growth and the Kinsmen have risen to the occasion year after year, setting an example for other Kin clubs in Canada. Without the efforts of the Kinsmen Club of Hamilton, The Walk would not be as huge of a success as it is today. We are proud to honour their dedication.

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

DR. MICHAEL SURETTE

Dr. Surette is a Professor of Medicine at McMaster University in Hamilton; his area of expertise is respiratory infections. He has volunteered for Cystic Fibrosis Canada for over 12 years. In 2004, he started as an external reviewer for fall research competitions, and he has provided valuable information to the scientific review panel. Dr. Surette was nominated to the Research Subcommittee of Cystic Fibrosis Canada's Medical Scientific Advisory Committee, now known as the Scientific Review Panel and the Research Advisory Council where he served as a reviewer from 2006 to 2010, on the Executive team from 2009 to 2012 and finally as Chair in 2012. During his three year term as Chair, Cystic Fibrosis Canada underwent significant restructuring, including the disbanding of the Medical Scientific Advisory Committee, and evolution of the Research Subcommittee into the Scientific Review Panel. Dr. Surette embraced these changes and assisted the organization in keeping the research community engaged, connected and supported. He received the Cystic Fibrosis Canada Senior Scientist Research Award in 2014 and has been invited to speak at CF conferences around the world. Nevertheless, he has always made himself available as a resource to the national office's research team, for media opportunities and for The Walk. The CF community is grateful to Dr. Surette for always going above and beyond the call of duty.

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

SANDRA SMITH

Sandra is a long-time volunteer with the Calgary and Southern Alberta Chapter. Despite receiving a double lung transplant in 2010, she has been a dedicated volunteer for the Gift Wrap fundraiser, The Walk and alongside her husband; Chairs the Albertan leg of GearUp4CF. When she isn't volunteering, she can be found participating in fundraisers, including the 65 Roses Golf Tournament and Lawn Summer Nights. She captains a large team at The Walk that raises a significant amount of donations and she participates in several third-party events. She is very active on social media and has an unstoppable spirit; she is an inspiration and role model to others with CF. Sandra has shown great dedication and Cystic Fibrosis Canada is very thankful.

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

SARAH-LYN COPELAND

Sarah is an amazing young adult with CF who has done great work raising awareness, funds and inspiring so many others to participate. Her Walk team, 'the Courageous Fighters', has raised over $31,000 across Ontario between 2012 and 2015 and with her family, she drove their Walk team's membership up to over 50 members. Sarah's leadership and motivational contribution through social media and online forums helps bring together CF patients and her impact is felt throughout the CF community. We are proud to recognize Sarah's outstanding contributions.

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

ROSS DRAKE

Ross has served as a Board Member, Regional Director and President, leading the Scotia Chapter's growth in both awareness and funds raised. He volunteers with The Walk committee, the Gallivan Golf Tournament; sells raffle tickets and sponsors many events. Ross participates in the EPIC Dartmouth triathlon and has recruited athletes with CF to participate in a triathlon as part of the CARSTAR Walk to Make Cystic Fibrosis History. He has personally raised over $80,000 for Cystic Fibrosis Canada, acts as an advisor for the Atlantic Region to help build strategic giving partnerships, and can always be counted on to give a speech at an event and attend every meeting. Ross' dedication to the cause is inspiring; we thank him for his support and commitment.

BRIAN KERR

As a parent to a son with CF, Brian has made a large impact over the years that he has been involved with Cystic Fibrosis Canada as a leader, donor and volunteer. He's served as Co-Chair of the Volunteer Advisory Committee, President of the Vancouver Chapter, President and Treasurer of the BC Association and Co-Chair of the GearUp4CF committee. He also trains and consults in website design and best practices, and has been an essential resource to the Western region for their contributions to the Vancouver Chapter website, GearUp4CF website and his current assistance with Cystic Fibrosis Canada's website. We thank Brian for his expertise and wide-reaching contributions, which have been invaluable to the cause.

HELEN MEINZINGER

Helen has lived and breathed the battle with cystic fibrosis every day since her son was diagnosed with CF. She has served as a Kin District 6 Service Director, supporting record-breaking fundraising efforts; she has been a guest speaker at countless events, and served as the Chapter President for Ottawa and is currently the Chair of the Kin-Cystic Fibrosis Canada Liaison Committee. Each year she mobilizes Team Kisses 4 Kaiden for The Walk, where she is often recognized as one of the top individual fundraisers at the Ottawa Walk where she also serves as the Chair. She started Kaiden's Care Kits, now known as the Cystic Fibrosis Canada Resource Kits, which are given to parents of newborns diagnosed with CF. She's started several fundraisers, participated in many interviews and gives 100% of her time and effort in all that she does for Cystic Fibrosis Canada. Helen is a true illustration of what leadership looks like and Cystic Fibrosis Canada is proud to recognize her accomplishments.

TAMMY NORTHAM

Tammy joined the Kitchener-Waterloo chapter in 1998 when her son was diagnosed with CF. She served as President of the Chapter for six years and Regional Director for an additional four. In addition to these positions she has managed the Chapter through a successful hiring process, secured sponsors for The Walk – and tripled it in size and donations raised over four years! Tammy is a passionate advocate for the cause and the CF community is grateful for her tremendous contributions.

The Chapter Awards are designed to recognize chapters which have demonstrated an overall excellence throughout the past year in the areas of fundraising, public awareness, volunteer development and partner support.

EXCELLENCE IN FUNDRAISING: ESSEX-KENT CHAPTER

Last year the Essex-Kent Chapter demonstrated excellence in fundraising by exponentially increasing the funds they raised through fundraising events. Their best-performing events included:

- Last year's CARSTAR Walk to Make Cystic Fibrosis History raised a net total of $87,780, which represented a 21 per cent increase from 2015
- A 2016 Princess Ball raised a net total of $55,925, nearly doubling its 2015 result of $27,680, welcomed 800 guests and secured several dozen sponsors.
- The 12th Annual Ride for the Breath of Life brought in a net total of $6,185

The Chapter raised an incredible amount of funds, engaged their volunteers and secured a large number of corporate sponsors. We are proud to celebrate their efforts with the Excellence in Fundraising Award.

EXCELLENCE IN PUBLIC AWARENESS: YUKON CHAPTER

The Yukon Chapter has been incredibly successful in promoting cystic fibrosis awareness throughout the community. Chapter President Amy Labonte often goes door-to-door to talk to local businesses about cystic fibrosis and her son Seamus' story, often receiving donations or sponsorships. Amy also works at a local radio station and uses her program and large social media following to promote CF awareness and Cystic Fibrosis Canada initiatives. The Chapter runs several events in local cities, engaging the communities and raising awareness about CF, such as the Paint the Town Purple, an annual St. Paddy's Day Party, a New Year's Eve Gala, Sing4CF and The Walk. The Yukon Chapter has successfully raised awareness about both CF and Cystic Fibrosis Canada in a relatively remote area. We are proud to recognize the Chapter's contributions.

EXCELLENCE IN VOLUNTEER DEVELOPMENT: CALGARY & SOUTH ALBERTA CHAPTER

The Calgary & South Alberta Chapter has served as an example of how to maintain volunteer participation. In late 2014 and early 2015, they held Leadership Development Workshops which covered important aspects of volunteering. The sessions brought clarity and created great dialogue between the presenters and board members/ committee chairs. The Chapter recognizes its volunteers with recognition awards presented to the volunteers at the event for which they were being awarded. The Chapter has demonstrated its ability to adapt to its volunteers needs and we are proud to recognize them for their efforts.

"KIN"GRATULATIONS TO THE 2016 BILL SKELLY AND IAN F. MCCLURE AWARDEES

Kin Canada is Cystic Fibrosis Canada's longest standing partner whose continued commitment has made a difference in the lives of Canadians with cystic fibrosis (CF). Since the start of the partnership 52 years ago, there have been many exciting advancements in the quality of life for Canadians living with cystic fibrosis and groundbreaking research that led to the discovery of the CF gene. These milestones would not have been possible without the dedicated and unwavering support from Kinsmen and Kinettes around the country.

Today, Kin Canada remains Cystic Fibrosis Canada's loyal partner as they continue to raise awareness and funds in support of crucial CF research and care. To learn more about our partnership with Kin Canada, click here.

KIN MIKE CROGHAN AWARDED THE 2016 IAN F. MCCLURE AWARD

A lifetime member of Kin Canada, Ian F. McClure is a pioneer in the fight against cystic fibrosis. In addition to serving as the President of Cystic Fibrosis Canada from 1976 to 1978, he was instrumental in forging a long-lasting partnership between Kin Canada and Cystic Fibrosis Canada.

As a tribute to Ian's outstanding commitment and dedication, Cystic Fibrosis Canada introduced the prestigious Ian F. McClure Award at Kin Canada's National Convention in 2014, during the 50-year milestone for the partnership. This year's winner, **Mike Croghan**, was announced in Edmonton during Kin Canada's National Convention in August. Mike was recognized for his exceptional skills in coordinating and motivating groups of donors and volunteers participating in fundraising projects supporting Cystic Fibrosis Canada and Canadians living with cystic fibrosis.

Congratulations Mike and thank you for everything you do every day in the fight to END CF!

2015-16 BILL SKELLY AWARD RECIPIENTS

The Bill Skelly Award is an annual program that recognizes outstanding Kin Canada events that raise funds and awareness for Cystic Fibrosis Canada. Kin Bill Skelly was in attendance at the National Convention this year in Edmonton and presented the awards.

The recipients of the 2015/2016 Bill Skelly Award are:
District 1: Kinsmen Club of Tilbury & District
District 2: Neepawa Kin Club
District 3: University of Regina Campus Kin Club
District 4: Innisfail Kinsmen Club
District 5: Kinette Club of Duncan
District 6: Kinsmen Club of Napanee
District 7: Kinsmen Club of Sackville
District 8: Kinsmen Club of Lindsay

Congratulations and thank you to all the award recipients!

CELEBRATING OUR PARTNERS

SIEMENS

Siemens Canada Caring Hands Employee Committee present their cheque from funds raised for the Walk to Make Cystic Fibrosis History to Christine Martysiewicz, Director Corporate Relations Cystic Fibrosis Canada.

One of the world's largest producers of energy-efficient, resource-saving technologies, Siemens is a leading supplier of gas and steam turbines for power generation, a major provider of power transmission solutions and a pioneer in infrastructure solutions and automation, drive and software solutions for industry. The company is also a foremost provider of medical imaging equipment and a leader in laboratory diagnostics.

Siemens and its 4,800 employees from coast to coast are long-time supporters of Cystic Fibrosis Canada. For almost 20 years, Siemens has shared a passion to help create a world where cystic fibrosis will no longer shorten lives and help to promote healthier communities.

Congratulations to Siemens Canada and its employees for another spectacular CF fundraising campaign raising **$138,097.70**. In addition to hosting a variety of fundraising events from coast to coast, Siemens Canada a national walk sponsor, matched funds raised by employees in support of the Walk to make Cystic Fibrosis History.

Team Siemens

Siemens passion to give back, have fun and sport healthy competiveness for CF continued in September with its annual soccer tournament. Now twelve teams strong, employees from across central Ontario participate in raising funds right up to the winning game on tournament day.

L-R Tracey Micallef Chloe's Mom, 8 year old Chloe Micallef CF Ambassador participating in the Siemens CF campaign launch with a visitor from the Toronto Zoo.

Samantha De Sousa, Patryk Korbut, employee's and organizers of the Siemens annual soccer tournament, Robert Hardt president and CEO Siemens and Christine Martysiewicz, Director Corporate Relations, Cystic Fibrosis Canada.

Faisal Kazi, Vice President, Energy Management Siemens Canada, Jeff Beach Chief Executive Director Ontario, Cystic Fibrosis Canada, Robert Hardt, President and CEO Siemens Canada.

fondation AIR CANADA foundation

This year Cystic Fibrosis Canada welcomed the Air Canada Foundation on a national level.

We are proud to partner with the Air Canada Foundation who generously provided Cystic Fibrosis Canada with maximum support of flight passes which are being used for fundraising opportunities for a variety of national and regional events from coast to coast. In addition to providing tickets for our walk to make cystic fibrosis history contest, tickets were also used to raise funds at many Galas, a BC lottery promotion and an NHL promotion in the Atlantic Provinces.

In addition, the new 2017 Air Canada Foundation –Cystic Fibrosis Canada Clinic Support Grant proposal was approved by the Air Canada Foundation Board of Directors. The much needed funds will be dedicated to the 25 pediatric CF clinics across Canada. With proper observance of infection control, protocols and cleaning, medical testing equipment can be brought directly to each CF patient, reducing their need to move throughout the institution to visit the requisite laboratories.

Thank you Air Canada Foundation for joining us in our mission to END CF.

(L to R) Christine Martysiewicz, Director Corporate Relations, Cystic Fibrosis Canada, Camille Gillcash-Sposit and husband Mathew, the lucky winners of two round trip Air Canada tickets accept the tickets from Cystic Fibrosis Canada President and CEO, Norma Beauchamp.

Party City

Cystic Fibrosis Canada welcomed Party City Canada as a new national partner earlier this year. Party City has over 50 stores across the country, including new locations opening in Sudbury and Kingston at the end of this year. The Party City CARES cause marketing campaign included a point of sale program that ran from April 1st through to May 31st. Customers had and option to make a $1, $2 or $5 donation to Cystic Fibrosis Canada.

Thanks to the remarkable support and dedication of the store management and staff at Party City, they raised an incredible **$57,701**.

Party City presents Cystic Fibrosis Canada a cheque for $57,701 at the Ancaster store: (L to R) Nathan Craig, GM Ancaster, Kaylee Chappell CF patient and Party City Ambassador, Linda MacMillan Director of Marketing Party City Canada, Norma Beauchamp President & CEO Cystic Fibrosis Canada, Christine Martysiewicz Director Corporate Relations, Cystic Fibrosis Canada, Neil Sparling, and Natasha Macdonald, Party City Ancaster.

Party City and their employees care deeply about their local communities and the children in them. They know that no celebration is complete without a child's smile, and that's why they partnered with Cystic Fibrosis Canada. We are honoured to be included in their Party City Cares program.

We are pleased to announce that Party City will include Cystic Fibrosis Canada in their 2017 campaign, and have extended their level of support for an additional month. The CF campaign will take place during the months April, May and June. Be sure to tell your family, friends and colleagues to visit Party City, make a donation or just thank an employee for their incredible efforts or a Party City customer for their generosity in raising funds for Cystic Fibrosis Canada!

CARSTAR® Collision & Glass Service

A partner since 1997, CARSTAR is a proud supporter of Cystic Fibrosis Canada. Woven into the fabric of the CARSTAR organization, CARSTAR continues to keep Cystic Fibrosis Canada in the forefront through their exceptional local fundraising and sport sponsorship marketing opportunities. Congratulations and thank you to CARSTAR Canada, store owners and all their great employees for another outstanding "Shine Month".

Through walk sponsorship and various fundraising events including the annual conference, golf tournament, the "Soaps it Up" national car wash, the "Skate in Strides" promotion with T.J. Brodie and the Calgary Flames Foundation and the "Catch for a Cure" promotion with the Edmonton Eskimos, CARSTAR Canada, its franchise partners and staff have donated close to $3 million since 1997.

Each year CARSTAR strives to create new fundraising opportunities. Thank you CARSTAR for joining us in helping end CF!

CARSTAR Mississauga 401, "Soaps it Up" car wash team.

CARSTAR Red Deer employees raise $7,200.00 during Shine Month.

left to right Dave Stretz(COO CARSTAR CMD Group), Craig Smith(Calgary Stampeders), Rachel Newell(CF Calgary Chapter Board President), Michael Piper(Regional Director CARSTAR Western Canada), Mark Stiles (Director Sponsorship Sales Calgary Flames)

CARSTAR London East & CARSTAR London West at the London Walk to Make Cystic Fibrosis History the CARSTAR team raised $5,150.00.

Thank you CARSTAR for the opportunity to participate and host individuals from the CF community in Calgary. L-R Norma Beauchamp, President and CEO Cystic Fibrosis Canada, Troy Dorchester, Brandon Newell, Fund Development Manager, Cystic Fibrosis Canada (Western Region) Matt Strathonikos, VP CMD Group CARSTAR, Scott Lavery, Operations Specialist Alberta CARSTAR.

L-R Mike Franco, Sr Director Business Operations Calgary Stampeders, Brandon Newell, Fund Development Manager Cystic Fibrosis Canada Western Canada, Dave Stretz—COO CMD Group, Matthew Stathonikos, VP CMD Group, Mark Kharfan, Carstar Franchisee, Michael Piper, Regional Director Western Canada Carstar, Scott Lavery, Operations Specialist Alberta Carstar

65 ROSES GALA CELEBRATION

Cystic Fibrosis Canada's Vancouver Chapter hosted its 16th annual 65 Roses Gala presented by B2Gold Corp. The chapter's signature event was held on Saturday, October 22nd at the Fairmont Waterfront Hotel and raised over **$385,000**. Since its inception in 2001, the event has raised close to **$4M** for important cystic fibrosis research, care and advocacy.

Over 300 guests enjoyed live entertainment, live and silent auctions and a multi course meal paired with wines from Narrative by Okanagan Crush Pad. The dazzling affair paid homage to the glitz and glamour of the roaring twenties and the Gatsby era. Flowing champagne, glamorous guests and stunning décor set the stage for a fundraising event like no other.

FUNDRAISING CELEBRATIONS

CAPE BRETON ISLAND CHAPTER CELEBRATES 3RD SUCCESSFUL LADIES NIGHT OUT

By: Kelly McMullin

Photo by the Cape Breton Post, l-r Sis Miller and Beverly Mozik

On Saturday November 5th, 400 ladies joined together to fight cystic fibrosis at the third annual **Ladies Night Out Christmas Gala** in Membertou, NS. Among attendees was Cape Breton Island Chapter President and event organizer, Marlene McKenzie.

"We wanted to do something fun, and we also wanted to engage our community. As the years have gone by, the community support has grown tremendously. We encourage businesses and the community to come together as a whole to support a fantastic cause, and we did that!" McKenzie explains.

The Cape Breton Island Chapter had three things in mind when planning began – raise awareness, raise money, and have fun doing it. They did just that with shopping, local entertainment, including hypnotist Carmen Giorno and an Elvis impersonator, live and silent auctions and tarot card readers – the event was a hit!

The event has inspired other chapters to begin their own ladies night out events, including a recent one held in the Moncton Chapter.

"The support has been wonderful, it's events like these that change the face of cystic fibrosis and give us hope for the future!" finishes McKenzie.

Thank you to everyone who has helped to make this event such a terrific success. The impact of the **Ladies Night Out Christmas Gala** and other events like it on cystic fibrosis is incredible. This event gives attendees something to look forward to each and every year!

QUEBEC CLOTHING STORE SOURIS MINI RAISES FUNDS FOR CF CANADA

Once again, Cystic Fibrosis Canada received tremendous support from Québec children's apparel store Souris Mini for Défibrose Mont-Sainte-Anne. Store owner, Annie Bellavance, was the Défibrose Mont-Sainte-Anne honorary president last year and as a grandmother to a child with CF, she is dedicated to the cause.

L-R Frédéric Imbert, Gilles Courchesnes et Annie Bellavance

Last year, the Souris Mini team raised more than $20,000, and this year they raised nearly $22,000! To raise funds, Souris Mini encouraged customers to donate $1 with their purchase for a period of time in September and set up a photo booth during the Défibrose Mont-Sainte-Anne event. Participants could enter to win a chance to model for Souris Mini and the winning family also received a Souris Mini gift certificate worth $500. All participants got to keep their photos, and all the money raised with the booth was donated to Cystic Fibrosis Canada.
Thank you, Souris Mini!

23 YEAR OLD RUNS FROM ORANGEVILLE TO TORONTO; AND UP CN TOWER TO ENDCF

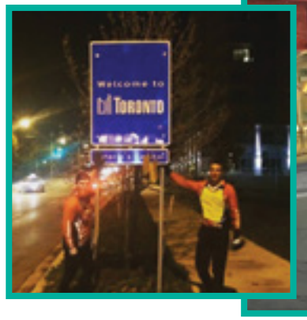
On Friday evening October 21, Orangeville native Nick Hann (23) started his run from Orangeville to Toronto and made his climb up the CN Tower on Saturday, October 22, in support of Cystic Fibrosis Canada. Nick ran a total of **82.12km** and **1,776 steps!**

Nick surpassed his fundraising goal of $10,000 and raised **$11,367.80!**

Nick has no personal connection to the disease, but was inspired to fundraise after hearing about Justin, a 26-year old that lost his life to cystic fibrosis. Nick is an avid runner and has participated in over 100 races (including full marathons, half marathons and ultra-marathons). At 22, he was the youngest to run and complete the 100 km Ultra Marathon in London, Ontario.

Thank you to Nick, for his inspirational effort to ENDCF!

Entering Toronto from Orangeville



Nick Hann, after running from Orangeville to Toronto and up the CN Tower

Team Nick before he set out to run to Toronto

Lawn Summer Nights celebrated its eighth year this summer, with events hosted in twelve cities across Canada. This year, LSN introduced a brand new event model called the **Pop Up** - a one day event that took place in Stratford, Montreal, and Ottawa. In addition to the Pop Up, Ottawa held its Classic event, and Toronto added another Classic event in the Beaches area. We were BOWLED away by the support we saw this summer! Over 3,000 donors, more than 1,500 participants, and since our inaugural event in 2009, LSN has officially raised over **$2 million** for **Cystic Fibrosis Canada!** Thank you bowlers!

LAWN SUMMER NIGHTS

Progress in Cystic Fibrosis Research

GALA 2016

On Thursday, December 1, Cystic Fibrosis Canada hosted its Progress in Cystic Fibrosis Research Gala at Windsor Station in Montreal. The event was an evening of celebration.

Cystic Fibrosis Canada welcomed guest of honour, Mrs. Mila Mulroney and her family to recognize her momentous contributions to CF in Canada which span over 30 years. Cystic Fibrosis Canada reflected on 35 years of Fibrose kystique Québec and celebrated the outstanding progress and milestones that have been made in cystic fibrosis research. A special video by Céline Dion played to recognize the leadership of Denis Mouton.

Ben Mulroney served as master of ceremonies and Juno nominated performer Nikki Yanofsky serenaded guests. Other performers included well known musician and parent to a child with cystic fibrosis, Frédéric Giroux, and young talents, Emma Cloutier and Emily Oulousian, the evening concluded with dancing courtesy of DJ Abeille.

A special thank you to the Gala Honorary Committee and its president, Sylvain Chrétien, who put on an unforgettable event!

Photography by Ferland Photo and Martin Alarie

Cystic Fibrosis Canada
Fibrose kystique Canada

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