Federated
Health Charities

Stories from Federated Health Charities' participants

Welcome to the Federated Health Charities Campaign!

This guide contains stories form the people living with these 21 illnesses and who access our charities services. You can use these stories during the campaign to let people in your ministry, agency or the OPP know how Federated Health Charities is helping the people of Ontario https://federatedhealth.ca/campaign-resources/.

Contents

Charity: ALS Society of Canada

Claudette's Story:

As part of ALS Canada's work to provide the community with current, credible ALS knowledge, awareness, and education, the Canadian ALS Learning Institute (CALI) was created.

Informed by and developed for people affected by ALS, the CALI provides attendees with an online, small group learning experience to better understand the Canadian ALS landscape, clinical research and therapy development, and how new therapies become approved and accessible to Canadians.

Participating in the CALI is an opportunity to learn more about the ALS research process and how to advocate effectively for access to Health Canada approved therapies.

Claudette Sturk, diagnosed with ALS in 2020, was able to find empowerment through the CALI, learning about research and how to effectively raise her voice for the ALS community.

"Advocating for the approval and drug access processes to be sped up is crucial," says Claudette. Funds raised for ALS Canada support programs like the CALI, which allows us to provide the ALS community with the tools they need to urge decision-makers to work together to remove barriers to access.

"With help from ALS Canada," Claudette says, "people living with ALS can become foot soldiers making real change."

Claudette says of the overall program, "The CALI was a fulfilling experience for me. I spoke with experts in the field, and I connected with other people living with ALS as well as their caregivers."

Charity: Alzheimer Society of Ontario

Kathleen’s Story:

For Kathleen, the Alzheimer Society was a lifeline.

Some moments can instantly change the course of your life. For Kathleen, this happened on an ordinary bus ride on her way home. “All of a sudden, I didn’t know where I was. I got off the bus, thinking I would recognize something, anything, but I didn’t. There was only confusion. I started to cry.”

A feeling of panic set in, so Kathleen called her husband Rob, now her primary care partner. “He talked to me and said, “Do you recognize the McDonald’s near our house? Do you know how to get home?’ I saw it, but I didn’t know how to get home. That’s when I realized there was a problem.”

Can you imagine those three haunting words: “You. Have. Dementia.” Kathleen was diagnosed with early-onset and vascular dementia at only 54 years old, and her life was changed forever. A dementia diagnosis will change the course of your life. It is not only scary - it can also be extremely isolating. The weight of a new diagnosis is suffocating, especially without a social support system in place.

“For about the first two weeks,” Kathleen said, “I didn’t want to get out of bed. I just wanted to give up and die.” But with the help of social recreation programs at the Alzheimer Society, things gradually got better. Her regular programs have allowed her the chance to get active in the comfort of her own home, meet new people in-person, get talking with others and laughing.

“The people I have met at these programs have become like a family,” Kathleen says, “they’re wonderful people … I felt so alone, but now I can laugh, exercise, and engage with others who truly matter… It’s a fantastic thing”.

Kathleen’s optimism is reminder that even in the face of adversity, even after a dementia diagnosis, life continues to hold moments of joy. “Just continue,” she says, “carry on. Dementia does not mean your life is over. You’re still very much alive.”

Read Kathleen’s full story here.

Charity: The Arthritis Society of Canada

Maddie’s Story:

Since she was a two-year-old, Maddie Watts has been skiing.

It’s what the Vancouverite has always done, and what she’s always loved to do. “It’s so freeing. You’re just zooming along, it’s beautiful, the air is fresh,” Maddie says. That’s why at age 17 her life went crashing off course with a diagnosis of facet joint syndrome, a severe form of osteoarthritis of the spine. This news arrived after an agonizing 18 months of tests, surgeries, and treatments. “Eighteen months of worry. Eighteen months of tears. And why? Because nobody thinks about arthritis,” says Maddie’s mom, Laura.

After being told her body would “buckle” under her, Maddie was forced to trade her cherished skis for walkers, wheelchairs, and canes. “It was just a lot of things going away very, very quickly,” says Maddie. “Being told I couldn’t ski anymore was certainly one of the defining moments in my journey. It kind of makes you disvalue yourself as a person because you’re not very effective to society. Everything was about my back, and it was the only thing anybody wanted to talk to me about. It just makes you feel like a problem and not a person.”

For millions of Canadians like Maddie, the fire of arthritis turns dreams and joys to ash. When Maddie learned of her diagnosis, she had a torrent of questions. She turned to Arthritis Society Canada for answers, just as 3.2 million other Canadians did in 2022-23.

Maddie’s story is brighter now as she has taken up adaptive skiing and has caught the attention of the Canadian Paralympic Committee. Rather than looking back on what her body could do, her eyes are fixed on the future – and a spot on the 2026 Canadian Paralympic Team.

Charity: Autism Ontario

Sally’s Story:

When my daughter was diagnosed with autism, I was scared!

I worried if I had the ability as her mom, to have the strength to help her while dealing with my own health issues. I cried a lot because I didn't know where to start.

I did a lot of searching online and I came across Autism Ontario, I found they had an online virtual meet-up with other moms. My first meeting, I was very shy and scared because of being judged so I listened as other mothers spoke, and group facilitator spoke about what Autism Ontario has to offer with events and supports. At the end of my first virtual meet up I felt not alone and understood and from then I haven't missed a virtual meet up unless an emergency occurred.

You never feel alone and always feel heard.

Charity: Canadian Cancer Society

Michael & Eli's Story:

When Michael Daykin's son, Eli, was diagnosed with leukemia, the COVID-19 pandemic was at its peak. Between the countless trips to the hospital, the emotional stress, and the exhausting task of taking care of a sick child, the Daykin family also had to go through the unique experience of maneuvering the healthcare system during lockdown.

"One of the biggest complicating factors was that we couldn't have our entire family in the same room," Michael says.

Eli went through three rounds of immunotherapy, each lasting 28 days, in addition to multiple rounds of conventional chemotherapy. Due to COVID-19 restrictions, Eli's sister, Katie, was not allowed in the hospital room for a large portion of Eli's treatment. During this time, Eli spent 139 days at the hospital in the span of a year, with Michael driving over 30,000 km in total to and from the BC Children's hospital in Vancouver, 900km from their hometown of Prince George.

"My wife and I had to make the difficult decision that I wouldn't remain at the hospital with them. The thing about this experience is that you need to think about the patient, but also about your whole family," he shares. "It was a very isolating experience for Katie and me."

An additional stressor for the family is that Eli has Down syndrome, which puts him at risk for further health complications during treatment. This factor fuels Michael's passionate support for research.

"People with Down syndrome have a slightly higher risk of leukemia. In 1980, the life expectancy for somebody with Down syndrome was in their 20s. Today it's in their 60s," Michael explains. "A lot of that comes back to that cancer treatment. And that research isn't only improving the outcomes, it's also shortening the amount of time that somebody needs to be in treatment."

Amidst all of this, the family needed a break. Camp Goodtimes, a medically supervised summer camp program funded by the Canadian Cancer Society, was able to offer that for them.

"I slept most of the first day, probably the first chance I'd had in a while," Michael shares, "for the first time, we weren't stressed about Eli's well-being because if anything happened, the doctor is right there."

Camp Goodtimes was not only an incredible place to rest for the Daykin parents, but also provided engaging activities and a supportive community for their children. Eli experienced archery for the first time, creating cherished memories, while Katie had the chance to bond with other siblings of cancer patients. The Daykin family also felt more relaxed when they were surrounded by people who understood what taking care of someone with cancer was like.

“You know parents here are also taking precautions, you know everybody is washing their hands,” Michael says, “The Camp Goodtimes team took great care of us in every regard, and it was just a really good experience. We look forward to going again.”

Eli has now returned to school full-time. The most intensive part of his treatment is behind them, and the family’s trips away from home are becoming less and less frequent. Michael remains thankful for the help they have received so far.

Charity: Canadian Liver Foundation

D.F.'s Story:

I contacted the Canadian Liver Foundation because I had an alarming experience being told that I may have autoimmune hepatitis. Desperate for information and support, I found the CLF Website.

I read up more about the disease, but I felt that nothing would compare to speaking to someone about how anxious I was about potentially having to live with this rare disease. The CLF staff seemed to have picked up on my anxiety with the email I sent them, and they contacted me within a day! I wasn't expecting such a quick response, but I was so glad they did! They even stayed later than usual to speak to me on the phone because of our time difference. They did not seem rushed, and they really spent the time explaining what autoimmune hepatitis was and what the next steps are. They calmed me down and encouraged me to make positive dietary and lifestyle changes. The staff member checked up on me after my liver biopsy and shared my huge relief to find out that I tested negative for autoimmune hepatitis.

I was diagnosed with fatty liver disease, and they were still very supportive and positive that with the proper diet and exercise, I would be able to reverse it.

The CLF was an absolute pleasure to speak with, and they had such a friendly and reassuring tone. I'm so thankful that they answered my call and was always positive and informative during every conversation. I hope the CLF continues the great work that they do to help more people and to support them throughout their own journeys.

Charity: Crohn’s and Colitis Canada

Andrew’s Story:

I have had Crohn’s disease since I was nine years old and my IBD stats are 33 colonoscopies, 12 different medications, 2 surgeries and 6 extended hospital stays.

My Diagnosis

The world of inflammatory bowel disease, is leaps and bounds away from when I was officially diagnosed back in 2006, which plays a role as to why it was like moving mountains to try and figure out what was wrong with me.

The eight months before doctors gave me the word of my condition, I had several other doctors tell me I was overly-stressed, had an eating disorder, or my favourite... faking it and looking for attention.

How or why an eight-year-old would “fake” going to the bathroom 10+ times a day, lie on the bathroom floor to endure stomach pains or throw-up anything they ate... is beyond me.

What a lot of people don’t understand when talking to someone with a chronic illness, is how much they are forced to grow up and mature quicker than their peers. Before my symptoms first started, my parents were going through a divorce and I had a front row seat to a lot of the ugliness that came with it. That experience, coupled with living with Crohn’s disease, led to me growing up at a very young age.

I knew what it was doing to my family, seeing me suffer every day, so I did my best to hide a lot of my symptoms or “episodes” so that I could at least pretend and not have to worry about seeing my mom cry because she couldn’t fix me.

It was March 2006 when, I finally started to act like a ‘normal’ young kid again. Crohn’s disease took away my social life as a child, it took away my extra-curriculars like hockey and soccer and it took away the joy I was supposed to be having as someone who still didn’t have all their adult teeth in yet but the magic of western medicine had me kicking ass on the ice, pitch and making friends again... there was finally a light at the end of this, so I thought.

1 Treatment, 2 Treatment, 3 Treatment... OK We’re Running Out of Options

When I finally started my treatment, it was rocky, I was put on steroids and couldn’t handle them orally which led to a whole ordeal where I had to accept them through intravenous. (Fun.)

As great as my first round of treatments seemed to work, they weren’t permanent, which meant trial and error with other possible medications to try and keep me healthy.

I was a VERY GOOD student… even throughout the eight months of hell… like I got straight As without even trying, the idea of failing a test or assignment was completely unheard of to me. So, when my doctors were telling me I was failing drug after drug, I was incredibly distraught.

Every medication failed to work – it was beyond frustrating and left us at a complete loss for words. At one point, I was taking upwards of nine pills a day. It wasn't until I was 11 (two years later) where we finally found a treatment that would stick.

Finally, a period of time where Andrew was Andrew for more than two weeks at a time.

Before all this nonsense entered my life, I was known as the funny kid who was smart, could play the odd sport and keep a smile on not only my face, but everyone else's… life was looking up and I was ready to finally be me again.

You Plan… God Laughs

Entering high school, I was stoked. It meant growing up, new friends, maybe a couple girlfriends, everything a teenager dreamed of. But very quickly into freshman year my Crohn's disease decided to give me a metaphorical double middle-finger and say "Ya, so you thought."

I lost 30lbs in a month and could barely stay awake in class. I tried soldiering on and managed to keep up with good grades and playing hockey when I could but when my new doctor at McMaster took one look at me he said, "We need to act, and we need to act fast."

That is when Andy Mac (my nickname in high school) learned how to incorporate his braces and NG Feeding Tube into his school uniform. For three months, I was tube fed because my intestines were so inflamed and sick, they couldn't digest food without slowly killing me.

This was the lowest I had ever been. How was I going to get a girlfriend when I had a tube up my nose? How was I going to be normal when my meals consisted of me being tied to an IV pole? Why won't this damn disease just leave me alone?

Even after my tenure with my tube feeding ended… it didn't work and I was forced to go under the knife for the first time. Three feet of my digestive track gone, thrown into a biomedical waste heap and I was now off to start a new chapter in my life – I began injection-based treatments to keep my Crohn's in check and ended up having a pretty awesome remaining three years of high school.

So… Now What's Up?

So… now I am 26 and still not really in a remission.

As a lot of us with IBD know, we constantly have ups and downs and that's how I've lived my life. Since high school, I've had a second resection surgery to remove some more gut and then went on and got my degree as well as a graduate degree.

I battled through some flare ups along the way but trucked along just as I've taught myself to do.

With all things considered, I am very thankful with where things are at. I have my hiccups for sure, will have to be careful with what I eat every day but with everything this disease has thrown at me, I ended up on the other side. I refuse to stay down and have continued to return the double middle-finger back at my Crohn's at every occasion.

I'm me again… which is weird to say because I feel like this disease has made me a different "me."

If you were to now ask me who I am, I would tell you I am a very laidback, goofy individual that knows when to get serious and look at things maturely – I've merged my two sides kind of like having the best of both worlds – but I'm not defined by my disease, I'm defined by how I've gotten up each time after being knocked down.

I'm not here without my support group – my friends who I made before, during and after the "tube phase," my family, or my incredible team at McMaster Hospital.

My mantra with this disease is: "I have Crohn's disease; Crohn's disease doesn't have me" and I'll live by those words until I no longer have to.

Andrew (Andy) Mac Isaac

Charity: Cystic Fibrosis Canada

Hilary's Story:

From the early days of my diagnosis at six months old, CF has been a constant companion in my thirty years of life. As I navigated the challenges and uncertainties, I discovered an unstoppable spirit within myself. Despite the grim prognosis given to my parents—that I might only live until my teens or early twenties—I remained determined to make the most of every moment. With unwavering support from my loved ones, I found strength and embarked on a journey filled with hope and resilience.

My life changed dramatically when I started taking Trikafta in January 2022. Before Trikafta, my health was deteriorating, and hospital visits became alarmingly frequent. I battled double pneumonia, kidney stones, and debilitating muscle injuries. Exhausted, underweight and struggling to breathe, I found myself isolated in a hospital room during a global pandemic. Homecare became my new reality, as I managed my own treatments, needles, and medications, desperate to survive.

But then, in October 2021, a ray of hope emerged. Like many others who have started this ground-breaking medication, my life took a 180-degree turn. No longer plagued by incessant coughing, I experienced restful nights, improved digestion, and a regained sense of vitality.

My hopes for the future of CF research, care and access to medicines are multifaceted. Firstly, I yearn for a day when CF stands for "Cure Found." We must continue to push the boundaries of scientific research to uncover breakthrough treatments and, ultimately, find a cure.

Living with cystic fibrosis has shaped me into the resilient, hopeful and strong individual I am today. Trikafta has unlocked a world of possibilities, allowing me to thrive and dream of a future that was once uncertain. However, our journey is far from over. We must continue to advocate for those who have yet to benefit from new treatments, pushing the boundaries of research, and expanding access to life-changing medications.

Charity: Diabetes Canada

Amber’s Story:

Amber Lopes knows a lot about the highs and lows of living with diabetes—and not just in terms of her blood sugar levels. The lows include near-death experiences and fears that she would never live a “normal” life; the highs include becoming a mother and sharing her happiness and hopes with other people who have diabetes.

Amber was just 12 years old when she fell into a diabetic coma one night just after Christmas in 1995. She survived only because her father heard her fall out of bed and rushed her to hospital, where she was diagnosed with type 1 diabetes and treated for diabetic ketoacidosis, a life-threatening condition in which the body does not have enough insulin to process blood sugar (glucose)—see FYI below for more information. Although she miraculously survived a 48-hour diabetic coma, it was a blow for the preteen to learn that she had diabetes and would have to give herself insulin injections for the rest of her life.

“My whole life turned upside down. I couldn’t do what my friends were doing,” she remembers.

Many of my friends wouldn’t even hang out with me because they were scared something might happen to me. It was very hard and hurtful.

Teenage struggles

For several years, Amber struggled to manage rapidly see-sawing and unpredictable blood sugar levels. Fruit could send her blood sugar soaring, while a cold—or even strong emotions, like being upset or excited—could plunge them so low she had to be hospitalized. One afternoon when she was in university, tired from classes and eager to be heading home for a visit, her blood sugar crashed (known as hypoglycemia, causing her to pass out and fall to the ground in front of a gas station. “I had fallen a couple of times and I had dirt in my hair, so some people thought I was drunk or on drugs. If the people at the gas station hadn’t called an ambulance to take me to hospital, I wouldn’t have survived,” she says.

It wasn’t until she got an insulin pump in her 20s that her diabetes became easier to manage. The pump dispenses the right amount of insulin at the right time, which reduces the risk of low or high blood sugar levels. “Getting an insulin pump was a life-changing experience,” says Amber, who is now 40 and living in Ontario.

Growing confidence

The pump not only improved Amber’s blood sugar management, it also gave her newfound freedom and flexibility. Still, she worried that some people might feel uncomfortable seeing a medical device) attached to her body. That changed a few years ago when a 12-year-old girl saw Amber wearing a bikini with her pump in full view. The girl, who also has type 1 diabetes, told Amber that she had been embarrassed by her pump, but Amber's example helped her wear it with confidence. "That was the best moment," says Amber.

The experience led her to start sharing her diabetes story with more people, including through Diabetes Canada campaigns and events. She is hopeful that fundraising and research will eventually lead to a cure. "We're getting closer every day", but in the meantime, she focuses on living her best life with her husband, Philip, and their two young children.

"Yes, I still have challenges and frustrations living with diabetes," she says. "But each morning I wake up with a positive mindset, and I tell myself, 'Today is a good day. I got this!'"

Charity: Heart and Stroke

Garima’s Story:

‘They told me it was a sinus infection.’ Garima Dwivedi was having a stroke.

The stroke had impacted the part of her brain that affects language, so she began her recovery relearning how to write. She was put on blood-thinning medication, which impacted her periods. The constant bleeding meant she had to have several transfusions because her iron was so low. A low-grade headache permeated most of her days.

Nine years later, Garima is mostly back to her normal self, except for what she describes as a few little things: missing words when she’s tired and trouble remembering names in her first and third language, Hindi and French, which she did not use much during the early days and months of recovery.
Aside from the occasional struggle while talking, Garima believes that she’s doing better and feels fortunate to have recovered so far. “It could have been a lot worse,” she reflects.

An indispensable part of her recovery journey was a promise she made to herself to get involved and raise awareness of stroke to help other women “I made a decision after I had the stroke that I would give my time and make a difference.”

Garima spoke at a conference mere months after her stroke and has been a part of the organization’s community advisory group. “I want women to know the signs of stroke, and I want them to be aware that it’s not just men and it’s not just when you’re older.”

“Seeing yourself in someone else’s story can make all the difference,” she says. “As women, we get so busy that sometimes we don’t have time to tell our stories. But it’s important we do.”

Research is key
It’s a fact that 2/3 of heart and stroke clinical research has been based on men. Garima wants to see that change. “If there was more research on stroke in women, maybe they would find that women present differently,” she says. “And we could help more women earlier.”

In hindsight, Garima isn’t sure anyone could have identified she was having a stroke. In the beginning, she was not showing any of the **most common signs** we are aware of today; she was able to drive, talk, and lift both arms.

She didn’t have any history of stroke; a sinus infection was a plausible diagnosis. “You’re dependent on the system,” she says. “You know, you just believe."

But she wonders. With more research and more awareness, could her stroke have been diagnosed on Monday instead of Tuesday? Would she have been taken straight to the stroke centre instead of being transferred later?

Whatever the implications for her own story, she believes more research will make a difference in the lives of women.

Full story available here: https://www.heartandstroke.ca/articles/misdiagnosed-stroke-they-told-me-it-was-a-sinus-infection.

Garima with her daughter Ila

Charity: Hemophilia Ontario

Landon's Story:

The Importance of Camps

I am a 12-year-old boy with severe Hemophilia B.

I started attending Wanakita camp when I was 7 years old. Before attending camp, I felt like I was the only one with hemophilia, as I did not have others close to me. While at camp I was able to do things I would never have been able to where I live but with the safety of hemophilia nurses there to support me if I was injured. I had the chance to make friends with other kids that have hemophilia. Making these new friends at camp, I no longer felt like I was the only one fighting this battle.

My first year at camp, I had a councillor named Luke who was also a hemophiliac. Before I attended camp Wanakita I hated needles and I feared having infusions but with the help of the nurses and Luke at my side motivating me, I came home knowing how to mix my own factor and helping hold the needle with a nurse or my mom when we infuse. Having Luke as a role model encouraged me to take interest in my own infusion.

By the time, I went back next summer I was hitting my own veins at home. When I returned to camp, I was excited to see my friends from the previous summer and show the nurses my accomplishment. My second year, I would go with my friends to the Bayer den even when I didn't need my needle I would go to support and encourage my friends to do their infusions.

This camp has given me a place to feel normal, have friends with the same battle, and learn new activities and survival skills. If I never had the opportunity to attend this camp, I think I would have struggled with confidence for my infusion and continue feeling isolated. I look forward to returning each year to see the friends I have made as well as the hemophilia nurses. This camp has provided me with lasting friendships, fond memories as well as confidence and independence in my treatments.

Thank you for providing support so kids like me can attend camp.

Charity: Institute for Advancements in Mental Health (IAM)

My nightmare began in university, a time when I was beginning to realize my dreams. My dream was to become an expert. I had so many high hopes and dreams. I entered university with a very high average, a full scholarship, and in my dream field.

Then, it happened. I failed. For the first time in my life ever. My dear parents sent me to a psychiatrist, and he was reluctant to say that I had schizophrenia, instead, he said I was depressed. I returned to university part-time and somehow managed to graduate, however, it took me three more years than the majority of students. Following university, I was unable to hold a job. I was fired several times even before my probation period ended. Concerned, my parents sent me to an in-patient program at the hospital. There, I officially became "schizophrenic".

Years passed. Getting jobs. Losing jobs. Delusions. Psychosis.

Somehow, I got an amazing job in another university where I could study for free. It reignited my passion for intellectual pursuits. I decided to try a master's degree and was accepted - something I thought it would never happen. This was my first inkling of my recovery. Slowly and gradually, I improved. Academically, I did so well that today I am doing a PhD which was impossible. It wasn't just education that saved my sanity, it was also the excellent support I got from the hospital and from IAM. They pulled me from the depths of despair.

I learned life-changing skills through the hospital and IAM - CBT, Mindfulness, and the Arts. Plus, most importantly, I participated in one-on-one counselling with a very knowledgeable, talented, and compassionate member of the IAM team who helped me become the person I am today. She helped me extensively with her deep knowledge of schizophrenia and helped me cope with my symptoms. Because of this, I am moving my life forward.

I am experiencing a new beginning. I have spent twenty years of my life debilitatingly delusional and psychotic. Years wasted - unyieldingly festering in my delusions. Today, more and more, I am in the present and building my future. I feel free. Life is wonderful and getting better day after day. Although I may never get rid of my delusions and psychosis completely, I know how to cope and manage. I know that I do have a bright future.

Today, my dream is to finish my PhD. Although I still live with my psychosis, slowly and surely, I am recovering. Dreams that seemed impossible, are becoming true. After all, tomorrow is a brand-new day with no mistakes.

Charity: The Kidney Foundation

Kristin’s Story:

Every year my son asks for two Easters. One Easter with his friends. One Easter with our family. My 14-year-old son does not focus on his little sister’s illness. Or the trips to the ER. Or what life feels like when your seven-year-old sister is too sick to hunt for eggs, eat chocolate and hug bunnies.

For Foster, Easter means independence, spontaneity and the kindness of friends and family. For me and my husband, our daughter’s kidney disease (FSGS) means kidney transplants, hospital stays, stressful days, sleepless nights. The first Easter our family was split apart comes back to me in snapshots. There was the pain of not celebrating Easter with our son. Watching him scooped up by loving friends who promptly gifted him a “spare” chocolate bunny. I remember smiling at my son’s easy joy, wondering when my daughter would be so fortunate to be in the company of good friends, good food and good luck.

Our little girl was not just swollen and exhausted. She was struggling to walk, struggling to eat. Any relief my husband and I felt seeing a specialist visit Lily in the ER was quickly eclipsed by panic. The doctor had been summoned on a holiday weekend. And he was alarmed enough to come see our sick little girl.

As Lily visits the ER more and more frequently, my son is invited out for more and more meals with family and friends; my husband and I are rarely home. Foster’s little sister is just so sick. She will spend more than three months in hospital, all of us helpless as a rare type of kidney disease permanently damages and scars her kidneys.

Easter gives way to summer. Lily remains in hospital, a team of doctors buzzing around her like honeybees. A tube in Lily’s nose because her stomach is so swollen from kidney disease. A tube in Lily’s chest to help with blood treatments that we hope can save her kidneys. A tube in Lily’s stomach so my baby girl receives food and medication.

Our son Foster continues to thrive in the outside world. Our daughter Lily fights to survive. My husband and I… we watch. And we hope. And we continue to thank our friends, family, volunteers, and strangers over and over again. Because they keep showing up, they keep taking care of our son and showing us – all four of us – that we are not alone.

Charity: Lung Health Foundation

Chris's Story:

Chris Leaman's COPD diagnosis came as a bit of a surprise. But he was becoming increasingly short of breath while working in construction and roofing.

When he signed up to participate in a clinical study that involved a once-a-week breathing test, he was immediately disqualified on the basis that "his lung function is too far gone". Here are some of the hard-won insights that Chris has picked up as he deals with lung disease.

1. Shortness of breath does not fall into the same category as wrinkles.
Despite his history of smoking, Chris thought his breathlessness was just part and parcel of getting older. He was wrong. By the time he was diagnosed with COPD, as often happens, the disease was already quite severe. In a cruel twist, his breathing deteriorated dramatically as soon as he started work in construction.

2. There's no place like hope.
When a lung transplant became one of the possible treatment options, Chris made the difficult decision to move from his hometown of Kingston to his daughter Chelsea's apartment in Toronto. It just made sense to live closer to his specialists, to Toronto Western Hospital's rehabilitation program, and most importantly to Toronto General Hospital's Lung Transplant Clinic where he felt he could be "heard and seen" by his medical doctors.

3. Learn to roll with the punches.
Chris would have been on the lung transplant list a lot sooner (he eventually did), but he developed another lung disease – Mycobacterium avium complex (MAC). MAC is an opportunistic infection that takes advantage of a weakened immune system. To make things even worse, he was affected by tuberculosis (TB) and suffered two heart attacks, further complicating his chances to get on the lung transplant list.

4. Focus on what you can do instead of what you can't.
While the avid athlete can no longer play sports himself, he derives a great deal of satisfaction from watching hockey, basketball, volleyball, and football. Between helping his daughter, walking the dog, going to the rehabilitation program three days a week, and attending various doctor's appointments, Chris refuses to just sit on the sidelines.

5. Make a difference with every breath.
Chris feels a keen sense of responsibility to advise people to better understand COPD and related risks of smoking. Which is why he helped found the Lung Issues

Support Toronto Western Hospital, so everyone could share their experiences and support each other with advice and compassion. He also attends the COPD support group put on by The Lung Association, which offers people a way to share their experiences and hear from others, allowing them not to feel alone in their journey. As a Lung Health Ambassador team member, Chris wanted to get involved with advocacy right away, signing petitions for Bill 41, the Lung Health Act.

Charity: MS Canada

Melanie's Story:

Melanie Bennett has seen firsthand the benefits of MS Canada's work.

Melanie was diagnosed with multiple sclerosis 17 years ago, at age 30. She experienced aggressive symptoms that clouded her ability to maintain hope, until she received the support she needed. "My story is why I believe in MS Canada. The funds raised go to research that helps create drugs that help people affected by MS."

Melanie has lived with MS for nearly 18 years. First diagnosed at 30, she experienced a very aggressive variation of the disease, affecting her eyesight and the use of her limbs. Through the support of MS Canada and thanks to the various drug modified therapies (DMTs) available she was able to find a medication that worked well for her, fully funded. She was then able to go into remission and regained the use of her limbs, she was able to run her first marathon in 2019!

In 2016 she began volunteering with MS Canada. Melanie and her close network of friends have put on a scrapbooking event to raise funds. Which has grown from 10 women to 100 women. 100 women raised over 10K. A way of giving back and doing something for the rest of the MS community.

Melanie spoke about her experience and her work with MS Canada with Global News Nova Scotia ahead of the MS Bike Annapolis Valley event in 2023.

Karen's Story:

Karen received her diagnosis shortly before COVID-19 and learned to adapt fundraising efforts to achieve positive impact. "Volunteering has had a huge impact on my life. It reminds me that my contributions, however big or small, do make a difference. I can't control my disease, but I can control the effort I make to fundraise, educate, and contribute. I want to do as much as I can, in the ways that I can, for as long as I can!"

Karen began her volunteer work with MS Canada shortly after her diagnosis in January 2020, just weeks before the world was introduced to COVID-19.

"During the pandemic, all our in-person efforts were put on hold and fundraising was critical. Limited to online connection we found new, creative ways to raise awareness, funds, and solicit support. Personally, I reached out to my local MP., reconnected with former business colleagues and strengthened my relationships with my community. Together, our combined efforts made an impact!

From the beginning, MS Canada knew that the key to a cure was knowledge. That pursuit of knowledge has led to major discoveries – things that have given people like me choices and some control over how we live with this disease."

Charity: Ontario AIDS Network

Brittany's Story:

My name is Brittany. I am 28 years old and have been HIV positive for almost 8 years. I am also a full-time student of social service work, a small business owner and a mother of three beautiful children. This is my testimonial on how the wonderful leadership training that I received from the Ontario AIDS Network changed my life.

Before I attended leadership development, I knew that I was passionate about creating change, but I didn't feel that I had the power to do so because I had no formal training in leadership skills. I live in a rural community with very few opportunities to better educate myself about HIV.

When I attended the leadership training, I really didn't know what to expect. My only expectation at the time was to go and come back in one piece, potentially empowered to continue making a difference in my community as someone living with HIV. Little did I know the training that I received would set the foundation for me to go back to school and solidify the decision to work for social services. The training is invaluable, and the skills gained help me in my day-to-day life. I was able to find my voice, envision the future, search for opportunities to change, grow and improve, strengthen others by sharing my experiences, and celebrate my values and victories by creating a sense of community.

Your support has added value and purpose to my life, and it is because of the training I have received that I continue my passion of advocacy for those living with HIV, myself included. As I finish up with my final semester of school and I go on into the workplace I often reflect on the leadership skills I learned with gratitude.

Charity: Ontario Federation for Cerebral Palsy

Adam's Story:

Project Relate is a project by Google to help people with disability-related speech impairments or speech differences use Android phones and tablets by letting them dictate to the device using a particular voice profile that takes the unique speech patterns of your disability into account and allows you to dictate a lot smoother and quicker with fewer mistakes. It has enriched my life.

To use tools like Project Relate though, you have to have the appropriate devices, and they have to be of good enough quality for the tools to work effectively. The Ontario Federated for Cerebral Palsy (OFCP) provided me support to ensure I had the devices I needed. I thank OFCP for giving me a leaf grant to purchase my new Samsung tablet. It let's me effectively communicate quicker and easier because it runs my project Relate voice to text system from Google much faster than my previous tablet.

Why this support is so important is that the Google Relate system allows me to communicate freely and engage more in my community. It also helps me with my work as both a professional artist and technology tester. Because I'm freelance, I'm not eligible for workplace equipment, so this support was tremendously important, so I was able to work. Also, using Project Relate and the project relay keyboard made communicating with friends, family, and colleagues much easier. Assistance to allow me to have the best technology available impacts so many areas of my life.

Charity: Osteoporosis Canada

Juanita’s Story:

Juanita Gledhill had just celebrated her 50th birthday. During her annual physical, she asked her doctor for a bone density test. Juanita’s mom lives with osteoporosis and given her mother’s diagnosis; Juanita worked hard to reduce her risk of getting the disease. She ensured she got enough calcium and protein in her diet and stayed active. Then the doctor called with the results. Juanita had the onset of osteoporosis. She was stunned. She had done everything in her power to avoid getting the same diagnosis as her mother. However, it was also because of her experience that she knew just what to do next.

Juanita’s story began before her own diagnosis. She cared for her mom for many years helping her manage her own condition. However, even though Juanita was proactive with her daily nutrition intake, vitamin D supplementation and exercise for healthy bones, she was diagnosed with osteoporosis.

Juanita has thankfully not experienced any fractures. She has learned how to be very aware of her surroundings and has made the necessary changes in her lifestyle to decrease her risk of falls. Juanita feels strongly that her diagnosis was not as advanced, because she was proactively working to keep her bones strong and healthy. Today, Juanita and her mom are each other’s “best support partner” as they live a full and healthy life with osteoporosis.

Charity: Parkinson Canada

Margot & John's Story:

"I wish you could meet my wife, Margot. We've been married for 34 years and—I know I'm biased—she's the most wonderful woman I've ever met."

John Parkhurst knows all too well what it means to be a care partner. His wife, Margot Bartlett, has lived with Parkinson's for over 30 years. As a registered nurse, Margot thought she may have Parkinson's. Still, the day they heard the diagnosis was gut-wrenching. It felt like a loss that could never be replaced. Margot was just 42 then. Their daughter was only four years old.

Parkinson's doesn't just affect the person diagnosed; it changes the lives of all those around them—spouses, children, friends, and their caregivers.

Margot is the kind of person who'd get up bright and early, work all day as a Registered Nurse, then teach piano until 9 or 10 at night. Her energy was boundless!

But as her Parkinson's progressed it took all of that away – and more.

John became her primary caregiver. It shattered the hopes and dreams they shared for a life together. It set them on a different path, and yet it never tore them apart.

"For me, being a caregiver is as rewarding as it is challenging."

From the day they met, Margot and John have been a team. Since her diagnosis he has helped her have the best life she can. Margot worked for 12 years after she was diagnosed. She'd often be tired so John supported her, however he could. He ran the household and when she travelled for work, John went with her. There were high out-of-pocket expenses, and his career certainly was affected. John often says it's like switching over to "alternate programming." It's not what he expected, and it is still an adventure.

"We are a pretty good pair, but we wanted to grow our 'care team.' We began a Parkinson's Support Group, which continues to this day. As a caregiver it's important that you have a network of people you can call upon for practical help and moral support. Sometimes, when Margot isn't doing well, I just need someone else to talk to so I can find my hope again," says John.

Their lives were enriched when they found Parkinson Canada. Both Margot and John have served on the Parkinson Canada Board of Directors. Drawing on their lived experience, John has been a strong advocate for caregivers, and that's why he is delighted with the release of the new publication, *Care Partnering: Managing Parkinson's Disease Together,* a book made possible through the generous support of donors across Canada.

This practical, insightful book is an invaluable resource. It delivers supportive, accurate information to caregivers, and references to other resources that are a big help when navigating a Parkinson's journey. John sincerely wishes there was something like it back when Margot was first diagnosed.

Life as a caregiver can be gratifying, and it's very important to take care of you, too.

"I'm lucky. Margot is very supportive and makes sure I have a life outside caregiving. In the summer I sail with our daughter. I also love photography and music—even if I spend just five minutes a day playing guitar or ukulele, I find it improves my mindset."

John knows every day is a gift, and with it comes new research, new treatments and therapies that are making life better for people living with Parkinson's. Donor generosity helps Parkinson Canada fund incredible research so one day, there will be a cure, and no one will have to switch to "alternate programming."

For your complimentary copy of *Care Partnering: Managing Parkinson's Disease Together*, email info@parkinson.ca or call 1 800 565 3000.

Charity: Sickle Cell Awareness Group of Ontario

Jelesa’s story

My journey started quite uniquely because I did not find out I had sickle cell anemia until I was thirteen. When I had an arm crisis before the diagnosis, healthcare providers thought I was being abused and they put me in a cast when I was actually having a sickle cell crisis. One year, close to the holiday season, I went to the hospital with gallstones and had my bloodwork done, which is when they discovered that I had sickle cell anemia. My mom has always suspected that I had more than just the sickle cell trait due to serious symptoms I would have, but it was still shocking and emotional for her when this was confirmed on Christmas Day. Honestly, my life completely changed after that diagnosis. I feel lucky to have a great support system around me, including my family, friends, healthcare team, and the sickle cell support group in Hamilton.

Elementary school was a challenge for me, especially since sickle cell disease kept me out of the classroom for a week or two at a time due to hospitalizations, causing me to fall behind on my schoolwork. I am someone who likes keeping on top of my work, so catching up on my schoolwork after missing weeks of class was incredibly difficult. It would be easier for children with sickle cell disease if teachers would send work home so that the student does not fall behind, especially in those primary school grades, where learning to read and write is so important. Having that extra work to do in the hospital rather than watching television or playing video games would help students stay on top of their schoolwork and excel at school. Nowadays at work, I face similar struggles when it comes to having to miss work and catching up afterwards. Unlike my experience at school, I have incredible support from my colleagues and supervisors, who check on me every single day and want to make sure that I am okay first. I have also realized that though I think about working on those days when I am unable to work, I also need to take care of myself first before I can go back to work.

In the emergency department and my interactions with healthcare providers, my experiences have been very positive. Some of my best experiences occurred at Mackenzie Health in Richmond Hill – the absolute best hospital for sickle cell anemia patients, in my opinion. The waiting time was extremely low, they gave oxygen right away, the providers were very knowledgeable, and I never had such great healthcare service at a hospital. It is important to me that physicians and nurses understand what the first steps are in my care. My experience is improved knowing that they want to make me feel comfortable, even when I am squirming in pain. Clear communication is also valued: right now, I could email my nurse and she would get back to me quickly with detailed information about my situation.

To view video: https://youtu.be/LruqrVxUd44

Charity: Spinal Cord Injury Ontario

Carolyn & Mike's Story:

Last Christmas Carolyn found Mike at the bottom of their stairs with no vital signs. Paramedics were able to revive him, but he lost vital signs again on the way to the hospital, but they were able to revive him once more. Mike and Carolyn would soon learn that Mike had sustained a spinal cord injury and their lives would be changed forever.

Carolyn said, "The early days were quite a blur for us, I was dealing with the emotions of such a devastating accident and Mike was not really aware of details … he was only periodically coherent … I wasn't sure what the future held and couldn't imagine a future without him by my side."

In those early days Stephanie Bolton reached out to Mike and Carolyn to assure them that she and Spinal Cord Injury Ontario were there for them and would help them navigate the healthcare system and their support options. Stephanie talked to Mike and Catherine about their goals and how she and Spinal Cord Injury Ontario could help them build towards them.

Carolyn explains: "Stephanie has many connections and people she can reach out to. And she told us that she would help us connect the dots to where we want to go." Spinal Cord Injury Ontario Regional Service Coordinators like Stephanie help people from the time they sustain a spinal cord injury through recovery and rehab to building a life of independence and choice.

Stephanie: "For example, sometimes when I meet people, they've already been given assistive technology supports. But Mike had been told it would be a year or two. I knew we could do better than that and got moving on setting up his assessments."

Mike is now equipped with speech input software and an eye tracking input device that he can use to direct a mouse pointer. The assistive technology has helped him reclaim some independence and boosted his outlook. He can email family and friends and research on the internet. Another small blessing is that the equipment allows Mike to again pursue his love of reading. He now can pass some of the long hours in hospital reading independently without the assistance of others.

Mike's goal was always to get back home. "I wanted to go home, but the resources and care needed for me to be on a ventilator at home were prohibitive," says Mike. "So, getting off the vent was my first step."

To support this step, Stephanie connected Mike and Carolyn with a previous SCIO client who has successfully come off a ventilator, so they could learn from his experience. This young man had undergone a rare surgery to implant a diaphragm pacing system designed to help normal breathing by electronically stimulating the diaphragm muscles and nerves.

Mike went ahead with the surgery and went through a ‘weaning’ process to get him off the ventilator. He went from being able to be off the ventilator for only minutes to being able to be off it for four hours twice a day. He continues to work towards being “vent free”.

“This is not the future we had planned, but we’re now changing the plan,” say Mike and Carolyn “With Mike’s hard work and determination, we are pushing forward to make it the best we can make it. We’re looking forward to what the New Year will bring and are hoping for a brighter future.”