Federated
Health
Charities

Charity Client Stories

These stories can be used in their entirety or you can pull snippets from them to use in your promotional material for the campaign.

They provide a clear picture of the reality people living with these diseases face and the impact of our donor dollars.

ALS Society of Canada

Kristine's Story

In 2012, Kristine fell inexplicably and broke her ankle. As someone who admits to having always had a propensity for losing her balance, she wasn't too concerned at the time. However, within four months, she started developing drop foot, an abnormality in a person's gait due to weakness in the muscles, and her symptoms became progressively worse.

Subsequent falls lead to a broken sternum, broken ribs, stitches, and countless bruises, prompting Kristine to visit a neurologist. After receiving various diagnoses, such as hereditary spastic paraplegia and primary lateral sclerosis, her diagnosis of upper motor neuron predominant ALS was confirmed in July 2016.

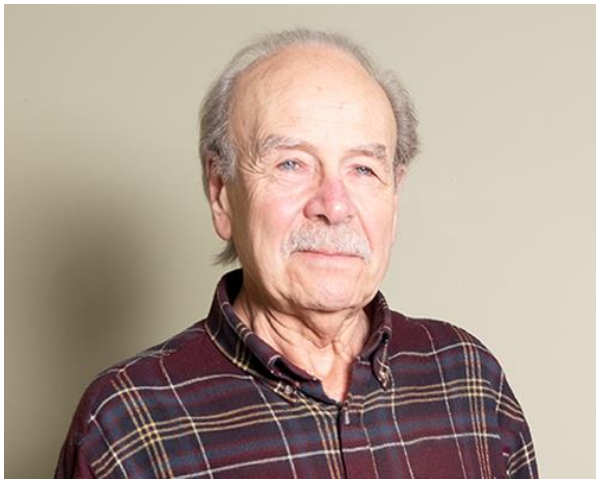
Living with ALS has forced Kristine and her family to make some adjustments. For example, they had to move from their family home because she could no longer walk up and down the stairs. Everyday tasks such as getting dressed, taking a shower, and getting in and out of bed now require helping hands, which Kristine is fortunate to have.

"I've been loaned lots of equipment from ALS Canada during the various stages I've gone through," she recalls. "For example, a scooter, several bath transfer chairs, a transport chair, a tilting bath/commode chair, a hospital bed, a mattress, and most recently a Hoyer lift."
https://www.als.ca/blogs/kristine-lee-making-adjustments-along-way/

Additional Client Stories
https://www.als.ca/blogs/carol-living-loving-laughing-today/
https://www.als.ca/blogs/much-physical-abilities/
https://www.als.ca/blogs/don/

Alzheimer Society of Ontario

Bill's Story



I was diagnosed in January 2000 when I was 59 years old.

I have often said that my initial reaction to my diagnosis was like receiving a kick in the teeth. All my future plans seemed to go out the window. I was told that with an early diagnosis and being put on medication that I may expect up to five good years before I would need full-time care. Basically, I was told to go home and get my affairs in order.

Now at 77, my doctors are telling me to do whatever it is I'm doing because they don't know why I have continued to do this well for this length of time.

When I was diagnosed, my family was very supportive. They reacted with love and care. Some of my friends were surprised to hear the news, perhaps because I was relatively young, but I never felt like I was abandoned by anyone.

I wouldn't say I have experienced stigma and I try to get involved in whatever is going on provided I'm interested.

The Arthritis Society

Steff's Story

Steff Ivory Conover had an active childhood—skiing as soon as she could stand, with dreams of becoming a competitive gymnast. But all that changed with ongoing chronic pain, and an eventual diagnosis of **osteoarthritis** by age 15. But the disease took its course, and it took her dream. Gymnastics soon became untenable, so Steff pursued a career as a singer, actor, and dancer instead. But by 25, she was again in pain, walking with a four-pronged cane and accepting the reality of two additional diagnoses: **psoriatic** arthritis and **sacroiliitis**. Multiple diagnoses are heartbreakingly common, but a child with chronic pain today faces much better odds--a faster diagnosis, quicker treatments, and better health outcomes.

Steff is aware of the Arthritis Society's role in her life, from the well-thumbed copy of the Arthritis Society Medication Reference Guide in her doctor's office to the frontline research which informed her treatment decisions. Today, with the help of a healthy diet, regular exercise and support from her health team, Steff is almost as active as she was as a child, returning recently from a trip to Iceland where she hiked volcanic mountains at 14,000 feet—a feat she once thought would be insurmountable.

Steff is an active volunteer with the Arthritis Society.

"The Arthritis Society was there for me. It helped give me back control of my life."

- Steff Ivory Conover

Autism Ontario

The McCreary's Story

"No man is an island."

This expression is a quotation from **John Donne's** Devotions (1624): "No man is an Island, entire of itself; every man is a piece of the Continent, a part of the main."

What is the meaning behind this phrase? The phrase expresses the idea that human beings do poorly when isolated from others and *need to be part of a community to thrive.*

For 46 years, Autism Ontario and its Chapters across Ontario have strived to be such a community for people on the autism spectrum and their families. But we cannot do it alone, and families like the McCrearys are at the heart of living our vision and mission.

Meet the McCreary family – Susan and Doug, and their children, Andrew, Michael, and Matthew, who sadly passed away in 2018. This family has been woven into the life of Autism Ontario for over 20 years through their volunteer efforts where they live, in Chapters, in the community, and with the provincial organization.

When Susan and Doug were told about their children's diagnoses they sought out as much information as possible about autism, which brought them in contact with Autism Ontario. Autism Ontario was in their community and offered opportunities to engage with other parents who also understood the complexities, and the delights, of being a parent of a child, or children, on the spectrum. Having support from other families, who similarly experienced at times the lack of understanding and the judgement from others when they engaged in public activities. or their children attended school and extracurricular programs, was so important. In short order, the McCreary family was helping others too, by actively involving themselves in their local Chapter. Susan and Doug continue to support and give back to individuals and families in so many ways, and their community is stronger for it.

"Autism Ontario stands up for those across Ontario', says Doug. And in doing so, Autism Ontario seeks to enable parents to be their child's champion through informative webinars with experts in the field, providing educational kits for schools, advocating on behalf of thousands to the Ministries for the appropriate services and funding for all ages, and by being part of local communities through 25 Chapter offices across Ontario.

Not only did Susan and Doug become advocates, their commitment and determination to find the best path for answers led to their son Andrew being blessed by opportunities for involvement that shaped him into the person he is today.

Finding ways to ensure that loved ones in your family and community achieve quality of life as a respected member of society impacts the entire family in ways that are often unseen at the start of the journey. Autism Ontario, with its vast network of volunteers and staff, provide inclusive and welcoming arms for everyone.

Need to learn more about autism and what Autism Ontario does? Check out this video

https://www.youtube.com/watch?v=ubR7VLw8gq0

Think of the possibilities and potential you can help unlock.

Canadian Cancer Society

Heidi's Story

On February 29th, 2008, I was diagnosed with ALL, Acute Lymphoblastic Leukemia. You never forget the moment when you are told that you have cancer. For me, I was nine years old, sitting in a hospital room with this horrible wallpaper around me and my doctor came in, sat down, and said to me "Heidi you have Leukemia, you have cancer." Within a matter of seconds, I went from a child without a care in the world, to fighting for my life. I was admitted that night and started chemo two days after that. My protocol involved just under three years of intense chemotherapy. The easiest part of my treatment involved chemo every night, chemo in my port-a-cath every two weeks, bloodwork every two weeks, steroids five days a month, and chemo that was injected into my spine every month. I am very lucky and privileged to say that on Mother's Day in 2010 I finished all my treatments, and to this day I have been in complete remission. I think it is important to state that although I have lived through childhood leukemia, the chemotherapy I endured as a child has left long term side effects that I deal with everyday such as, heart damage, brain damage, bone damage, I will not be able to have children and I will have another cancer by the end of my life. The truth is, I am living with cancer. It is the first thing I think about when I wake up and the last thing I think about when I go to bed. However, I wouldn't change it for the world. People call me crazy when I say this, but I think cancer is a beautiful thing. Cancer is a thing that brings out the kindness, beauty, and courage in every person it affects. I know the pain and the loss that cancer brings, I feel it every day, I've lost family members and to many friends to cancer. However, I am still thankful I had cancer because I would not be where I am today with the experiences that have come it. Now as a twenty-year-old student at Trent University, I use my experiences with cancer to make a difference in the world. I have worked with the Canadian Cancer Society as an inspirational speaker sharing my story across the province to show people that change is happening. I can tell my story today because of donors like you and organizations like the Canadian Cancer Society.

Cystic Fibrosis Canada

Melissa's Story

Melissa Gaudenzi remembers the day her daughter Mia was born like it was yesterday. It was October 13, 2006 in Toronto, and her life changed forever when she welcomed Mia, her bundle of joy, to the world.

Mia was a healthy and happy infant. Suspecting that her daughter had cystic fibrosis was the last thing on Melissa's mind because Mia showed no signs of illness and was thriving. But that all changed when Mia was about three years old and started getting really sick.

There were lots of back and forth visits from the hospital. Doctors wondered if maybe Mia's new interaction with other kids at junior kindergarten was the culprit of the sudden change in her health. "Something doesn't seem right. Kids shouldn't just *get* pneumonia," Melissa remembers thinking.

Call it mother's intuition, but Melissa was certain something was serious, and knew she had to get to the bottom of it. Melissa started doing her own research and discovered the basic symptoms of cystic fibrosis. Something suddenly came to mind; Melissa remembered all the times that her own mother would kiss Mia and say, "You're so salty!"

Mia's birth date meant that they had just missed the implementation of newborn screening for CF, so Melissa called the closest CF clinic to explain her daughter's symptoms and arrange a test. After a rollercoaster of an experience over a year and a half, it was confirmed through a blood test that Mia did in fact have cystic fibrosis.

Over the next three years, Mia was in and out of the hospital. Admissions to SickKids became the norm, and a common cold would jeopardize any stability in her health. Melissa decided to begin homeschooling Mia, as it gave them more flexibility to maintain Mia's health and treatments, as well as her academics. "Mia wasn't born doing all the physio. What surprised me was how she just *took* to it. She doesn't ask questions when we change something, she's so accommodating. She never misses a day!" Melissa recalls.

Just after Mia turned seven, her health stabilized and began "clearing up." Her lung function is now at a whopping 91%, but that wasn't without plenty of admissions and continuous work. A special tradition that Melissa started for her daughter, is that each year Mia is admission-free, her family and friends have a celebration for her. Melissa thinks it's important to be reminded of how far they've come, how well they're doing with therapies, and to celebrate the little things.

"Every year that she passes one year, we do a little celebration! We order food and invite some family over. We recently celebrated her third-year admission-free, so we decorated our home and ordered cupcakes! We had a movie night and made it a big celebration," says Melissa. "It may not always be three years admission-free like it is right now, so we need to celebrate where she's started to where she is now. We need to celebrate CF, even though it's taken so much from us."

With Mia's health currently stable, Melissa has hope for her daughter's future. She hopes that anything Mia wants to do in life, she does. Mia has dreams of going to Paris, and of one day becoming a nurse, so she can help others the way her healthcare teams have helped for her. "No matter what CF has taken from us, or no matter what CF brings us, I hope that she's still able to do what she wants to do," says Melissa. "I hope that someday, we get something that's close to a cure, so that life won't be so hard to her, for all the others with CF, and their families as well."

Canadian Liver Foundation

Shirley's Story

Shirley and her husband were like most new parents after welcoming in a new baby girl named Selene—excited, nervous, and always wondering whether their daughter was eating and sleeping as she should. But as the days turned into weeks, their biggest worry became why their baby was getting more and more yellow (jaundiced). What they couldn't have seen was that Selene's liver was getting increasingly damaged—so damaged that she would end up needing a liver transplant to save her life.

Selene was two months old when doctors diagnosed her with biliary atresia, a disease with no known cause or cure that is the leading cause of liver failure in newborns and children. She underwent a surgical procedure called the Kasai to try and re-establish bile flow. When the surgery failed, Selene's life was in danger. Without a liver transplant, Selene may not have lived beyond the age of two.

For Shirley, there was no question that she would protect her daughter at all costs—even if that meant physically giving a part of herself to save Selene's life.

At five-months-old, Selene underwent an intense surgery to receive a part of her mother's liver. Thankfully, it was successful with minimal complications.

Fast forward to 2018, Selene started Junior Kindergarten. She is very engaged, active, and enjoying life to the fullest. While the liver transplant saved her life, Selene will need to take aggressive medications to suppress her immune system and keep her body from rejecting her liver potentially for the rest of her life. These drugs are hard on the body and will make her more susceptible to viruses and illnesses since her defence system is weakened.

Research provided Selene's doctors with the knowledge and tools required to save her life, but much more is still needed. The Canadian Liver Foundation funds lifesaving research projects exploring how to prevent, diagnose, treat, and cure all forms of liver disease in children and adults.

Spinal Cord Injury Ontario

Mike's Story

Last Christmas Carolyn found Mike at the bottom of their stairs with no vital signs. Paramedics were able to revive him, 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 Woodward: "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 … Mike was 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 is to get back home. “I want to go home, but the resources and care needed for me to be on a ventilator at home would be prohibitive,” says Mike. “So, getting off the vent is 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 in July and has since been going through a ‘weaning’ process to get him off the ventilator. He has gone from being able to be off the ventilator for only minutes to recently 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 2019.”

“Stephanie has added to our support network. She is another friend who is part of Mike’s journey and someone I can rely on. She has truly been a bright light at the end of a dark tunnel, helping us to navigate, always with a smile on her face and a funny story to share.”

Mike, Carolyn, and their family are still on their journey and Stephanie and Spinal Cord Injury Ontario are there for them.

Each day in Ontario someone like Mike begins one of the world’s most challenging journeys. You can make a lasting impact in their life and the lives of their family by making certain they have help in their time of need.

Crohn’s & Colitis Canada

Kolby’s Story

Kolby was diagnosed with ulcerative colitis at the age of 15. Using personal fundraising pages Kolby and his mom Kimberly found a fun and easy way to run their own fundraising campaign to help Make it Stop. For Life.

At the young age of 16 Kolby has had to make a lot of adult decisions. Having been diagnosed with ulcerative colitis and finding that a variety of medications were not enough, he was faced with a total colonetomy. For 4 months he lived with an ileostomy and followed by another surgery to have a J pouch constructed.

Resilient and upbeat Kolby is adjusting to his new normal and looking for ways to assist those around him. He donated his unused ileostomy supplies to those who are struggling with the cost and started to think of other ways to make a difference.

That’s when his mom, Kimberly, got involved. She created a personal fundraising page to share Kolby’s story while raising money to help others who are living with Crohn’s and ulcerative colitis. Kimberly was already thinking of donating her long blonde hair to a local cancer charity, so this seemed like the ideal time to motivate people to donate.

By letting people know that she would shave her head if she reached the goal of $2,000, Kimberly received an overwhelming response. She surpassed her goal in no time at all! Knowing she could do more she raised the goal to $5,000 and has passed that goal as well.

“I have to say that I am so happy with the support we have received. The awareness has been amazing. Everywhere we go people bump into Kolby or me and they have a story for us. It's been great! I am shocked by the amount of people that suffer or know someone who has Crohn's or Colitis. It has been so good for Kolby as well. As a 16-year-old going through this he feels very alone but this has made him realize that he is not alone.” – Kimberly

Congratulations to Kimberly and Kolby for their hard work and amazing success!

Canadian Diabetes Association

Siva’s Story

As a chef and owner of Chezsiva Cooking School, Siva Swaminathan enjoys talking about good nutrition and good food. As a person living with type 1 diabetes and co-founder of Diabetes Canada’s South Asian diabetes chapter, she is even more passionate about sharing her message with others in her community who are living with the disease. With good reason: People of South Asian descent are one of the populations at a higher risk of developing type 2 diabetes.

It is a huge task, given that the Greater Toronto Area includes people from Sri Lanka, India, Pakistan, and Bangladesh—with many languages, such as Hindi, Punjabi, Urdu, Gujarati, Bengali, and Tamil. “India in itself, I call it a mini Europe!” says Swaminathan, originally from India herself.

Because of this “incredible diversity,” she says, “one solution is not going to fit all. We really need to have community members who will voice their opinion” on materials and presentations from Diabetes Canada to ensure the information represents their culture and lifestyle correctly. “Otherwise people will just put it through the shredder because it won’t be taken seriously.”

In 2005, Swaminathan was diagnosed with type 1 diabetes at the age of 40. One of her first projects for Diabetes Canada involved working on the nutrition committee to review a pamphlet about diabetes and food, and she helped ensure the meal suggestions were appropriate for the South Asian audience and were available in a variety of languages.

The message that lifestyle matters when it comes to good diabetes management and prevention also needs to be tailored to South Asian audiences, many of whom attend Diabetes Canada information sessions and diabetes expos. “Maybe [people] have recently immigrated or they are working two jobs just to keep up in terms of all the things they want to give their children—because they came here for a better life. So, they’re stressed and don’t have time to think about food,” says Swaminathan, executive chair of the chapter. “We need to connect the dots about how the food is going to affect their blood sugar and how their lifestyle—in terms of getting off the sofa relaxing after a long day, and exercising—is also going to affect their blood sugar.” In November 2018, the South Asian Diabetes Chapter and Diabetes Canada held a successful 11th annual expo.

Swaminathan has also volunteered on Diabetes Canada’s National Advocacy Committee and Ontario Advocacy Committee. For Diabetes Awareness Month in 2016, the committee went to the provincial legislature to talk to Members of Provincial Parliament about the need for a province-wide policy for children with type 1 diabetes in schools, and for “offloading devices” that shift weight from injured or sensitive parts of the feet in order to help avoid dangerous foot ulcers and amputations. Says Swaminathan, “For me, it’s all about helping people with diabetes, from getting funding to live healthy lives, to creating diabetes awareness and education among those with or at risk for the disease.”

Heart & Stroke

Robin's Story

Robin Paradis's father, Mark, was showing her how to apply a final coat of paint to the family's dining room walls amid home renovations one-night last summer. Suddenly, Mark staggered and fell to his hands and knees.

"He was making gurgling sounds like he couldn't breathe at all," says Robin, 31.

She shouted for her mother to call 9-1-1. Then Robin started CPR. "I could see that his lips were starting to turn blue."

Cardiopulmonary resuscitation, CPR for short, is an emergency procedure that restores blood flow when someone's heart stops beating. Anyone can do CPR. It can keep a person in cardiac arrest alive until advanced medical care is available.

From training to real life

Robin, newly graduated as a registered nurse, had learned CPR as part of her training. Her father had a history of heart issues, but she never imagined that the first time she'd use CPR in a real situation would be to save her dad's life.

"I felt a moment of panic when he first fell to the ground, but then (my CPR training) took over. I almost felt like a robot just doing what I knew I needed to do."

It was only when paramedics arrived that Robin processed what was happening. "Then I panicked and cried and couldn't function."

In the hospital, Robin and her family learned that 62-year-old Mark's cardiac arrest was triggered by ventricular fibrillation, a condition where the lower chambers of the heart can pump little or no blood to the body. Not only did CPR save Mark's life, but his doctors say his daughter's quick actions prevented serious long-term complications.

The power of CPR

When a cardiac arrest occurs at home or in a public place, only about one in 10 people survive. Doing CPR and using a defibrillator if one is available can more than double the chances of survival.

Heart & Stroke leads CPR education in Canada. In 2017 Heart & Stroke trained more than half a million people – including many everyday Canadians learning CPR for the first time as well as health professionals and first responders upgrading their skills.

"I didn't realize how important it was to take CPR until I came across a situation with my own loved one," Robin says. "If you're waiting for a 9-1-1 dispatcher to tell you what to do, those lost minutes can make the biggest difference to the outcome," she says.

Four months after Mark Paradis' ordeal – including nine weeks in hospital – Robin says her dad is mostly back to normal. But her family will never forget. "My aunt kept telling me that I'm a hero because he wouldn't be here without me. And my dad is very proud of me." She laughs. "I'm definitely his favourite child now."

Hemophilia Ontario

Chad's Story

"No matter what happens to you, it doesn't have to define who you are or who you want to become." This is what 44-year-old Chad White wants others with Hemophilia and other inherited bleeding disorders to know. Chad's journey has been nearly unbearable at times, but he is using his battle to inspire others.

He was diagnosed with Mild Hemophilia A as a child, a bleeding disorder which makes it difficult for his blood to clot. This can mean that a little bump against the kitchen table on the way to work can quickly become a trip to the hospital if intravenous clotting factor is not administered quickly. This can make life difficult and painful on a physical level, but also mentally exhausting as energy is spent every day on awareness and control of your body. Hemophilia is a rare genetic condition passed through the family line, the most famous example of which is Queen Victoria's family and her great grandson, Alexei, the son, and heir to Tsar Nicholas II of Russia. Chad's diagnosis on the other hand, came as a shock to his family because it was a random mutation, and they were not prepared for the impact it would have on their lives.

Chad was active throughout his life in sports and always strived to be the best in every aspect of his life despite his Hemophilia. He used sports as an outlet for his anger at his condition and felt that if he ignored the pain he could push his way through it – this lead him to make decisions that had a negative impact on his life and he convinced himself that he could outrun his problem and not admit that he was different. Thankfully, Chad had the support of his Hemophilia Treatment Centre throughout his journey to accept and learn to live with his Hemophilia. It is through the tireless advocacy efforts of Hemophilia Ontario and its sister organizations throughout Canada that people with bleeding disorders have access to a dedicated healthcare and social support network. The Canadian Hemophilia society has worked with government and with the health care system to make sure that all people with bleeding disorders have access to a full complement of haematologists, nurses, physiotherapists, and social workers. These dedicated clinicians ensure that when a person with a bleeding disorder falls, they have the care and support they need to get back up again.

In 2009, Chad was faced with a major health decision. He was diagnosed with a stomach cancer gene that would cause him to develop cancer soon, so he made the hard decision to have his stomach removed. Cancer was found during the surgery, and Chad knew then that he had made the right decision and was able to continue without the need for chemotherapy or radiation. His physical recovery was hard, but his mental recovery was just beginning; he knew something had to change. Chad has four amazing kids and is married to a remarkable woman named Jocelyn, who embraced his journey and his kids. As part of his recovery, Chad began bodybuilding and pushing himself physically, but he still struggled with accepting his Hemophilia. He experienced significant mental health challenges as a result and eventually made the courageous decision to seek treatment. Through treatment he found out he was suffering from PTSD because of his bleeding disorder, and that though he found ways to cope, he had been “afraid of his story”. He was embarrassed by his journey and his trials but realized the thing that he was afraid of was the same thing that could give courage to others.

Chad was able to access the bleeding disorders community through Hemophilia Ontario and began sharing his story with people going through the same things he was. Through this experience he saw how other people were inspired by how he had managed to overcome so many obstacles, and to finally come to terms with his Hemophilia. He discovered that inspiring others through his story brought purpose to his pain. Hemophilia Ontario aspires to give people like Chad a platform to share their experiences and to access the support they need to lead active and healthy lives. By speaking about his experiences, he is hoping to open a frank and honest conversation about the mental health impact of living with a chronic illness.

Chad is currently playing competitive soccer and competing in bodybuilding shows. He has linked up with #HemoLife and wants to tell others not to give up, no matter how hard their struggle may be. He wants to share his story with as many people as possible and hopes to one day speak at the World Hemophilia Conference. His favorite motto is: “I couldn’t control the waves, so I had to learn how to surf”.

Institute for Advancements in Mental Health

Dimitri's Story

When Dimitri first found out he had schizophrenia, he felt like shutting himself off from the rest of the world. It was incredibly scary for him to discover that his life had changed forever.

Just before he was diagnosed, Dimitri began having a difficult time at university. "My classes weren't going well. I'd lost my part-time job and was finding it hard to cope with many aspects of my life. Finally, I had to drop out of school and return home." Dimitri wanted to retreat from everything and everyone. But thankfully, he was never truly alone. His parents reached out to the Institute for Advancements in Mental Health (IAM) for help.

"My parents always did their best to understand what I was going through. And behind them was IAM, giving my family the tools, they needed to help me navigate my new life. With my parents' support, I started to get involved in activities outside my home. I volunteered as a tutor, spent time with close friends and eventually returned to school."
Today Dimitri is a PhD Candidate at Trent University.

"I know that my success wouldn't have been possible without the help my family received from IAM. My parents learned so much about what I was going through. I also participated in activities that gave me a chance to meet other people with the same challenges. That was very reassuring."

We cannot give up on those living with schizophrenia and other psychotic illnesses. Each one of them has the potential to live productive and fulfilling lives.

The Kidney Foundation of Canada

Cathy's Story

At twenty years old, Cathy thought she was invincible. Her diagnosis of kidney disease seemed like nothing more than a bad dream. A rare form of glomerulonephritis was a disease for old people, not a young woman. It wasn't until she became pregnant at twenty-five that the realities of chronic kidney disease became Cathy's reality. During her first pregnancy, Cathy's kidneys began to fail, and she was induced at twenty-eight weeks. While her son, was born healthy, doctors told Cathy it would be dangerous to have another child, so, Cathy's sister-in-law offered to carry her second child. The medications from the process, however, left Cathy in complete kidney failure. By the time her new daughter was two months old, Cathy was on dialysis.

"I know I'm not the youngest person to go on dialysis, but I was young, and I had young kids and to accept that this was going to be for the rest of my life was the hardest part. For me to try and feel like I'm normal and for my kids to feel that they are not growing up in a house where it is all about mom being sick…it's a challenge."

Undeterred, Cathy's family again stood strong by her side as she came to terms with her illness. In 2006, Cathy's identical twin sister was tested and donated her kidney. For five years, Cathy lived with her identical sister's kidney without the fear of rejection or anti-rejection drugs. The disease that had taken her own kidneys, however, struck at her sister's kidney and Cathy found herself back on dialysis. A year later, Cathy received a deceased donor kidney and unfortunately, the disease reoccurred and now, Cathy lives on home hemodialysis.

"I'd be lying to say that it's been easy from the beginning and we haven't had our struggles. But, [kidney disease] has made our family that much closer. It has helped me to realize that I'm a much stronger person than I realized."

Part of Cathy’s strength lies within the support of her family, and her drive to give her children a normal family life that does not revolve around her chronic kidney disease. To create memories outside of her illness, Cathy and her husband try each summer to take their family to Lion’s Camp Dorset.

Located in the Muskoka’s and supported by The Kidney Foundation, Camp Dorset is a family camp equipped with dialysis facilities and trained staff on site. The camp allows families like Cathy’s to “be a normal family” and go on vacation. With day programming and activities like canoeing and tennis, it’s a chance to get away from the realities of kidney disease while being connected to a reliable medical team. For Cathy, going to Camp Dorset is easy and her entire family can go together without being controlled by her dialysis schedule.

“It’s convenient and, thankfully, The Kidney Foundation supports it. Because it’s not just getting away, it is the financial aspect of taking a vacation while on dialysis. I am on disability and am not able to work which impacts our finances. But the Kidney Foundation is there to help and have made it possible for us to go away and have these experiences together.”

“My kids and my family, they just love it there. To be able to go away on a summer trip that usually we couldn’t go on because of my dialysis, it’s simple but it has a huge impact on our family.”

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, Chris 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.

MS Society of Canada

Sogol’s Story

Being diagnosed with MS can be a frightening experience. It can be even more so when you’re far away from somewhere you’ve always called home.

Sogol’s MS diagnosis (in 2010) brought on a sense of loneliness, and after her marriage ended, she fell into a deep depression. She knew she needed a fresh start, so without knowing a soul, she moved to Canada from Iran. The move to a new country intensified her feelings of isolation, and that’s when she turned to the MS Society for support.

After connecting with MS Society staff, Sogol wanted to take an active role in helping others living with the disease. She envisioned a safe space where recently diagnosed newcomers to Canada could share their experiences with MS. She started an MS support group for people who spoke Farsi - a confidential group with a focus on educating and supporting new immigrants who live with MS.

“Living with a chronic disease in an English-speaking country when English isn’t your first language can be extremely isolating. For people who don’t have family or friends in Canada, this support group helps create a sense of community. Many of us have experienced similar MS symptoms such as depression and mood swings, and this group has given us the means to talk about it. With our new family, we can share our experiences, relate to one another, and truly feel understood.

At first, my diagnosis felt like a wave of confusion, sadness, and loneliness because it took away my health and happiness. Now, I see it as a blessing in disguise. It changed my perspective on life for the better. Throughout the years, I have met people with inspiring stories of perseverance, and they have helped me live with my new reality. My goal was to help people, but in return, they saved me."

Parkinson Canada

John & Margo'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.

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.

Ontario Federation for Cerebral Palsy

Daniel's Story

When Daniel Mustapha became a member of the Ontario Federation for Cerebral Palsy, he was looking for support in pursuing activities that interested him. One of his passions is Karate, but he unfortunately did not have the funds to participate in tournaments. This is the type of situation where programs that the OFCP offers can really make a difference. Through our Life Enriching Activity Fund assistance, Daniel was able to participate in local tournaments, and last year he won a gold medal at the PARA National Karate Tournament in Halifax. He is planning on competing in the National Tournament once again this year, as well as internationally. Daniel is a wonderful example of what our programs can provide for people with cerebral palsy all over the province of Ontario, creating opportunities for our members to live the most meaningful, fulfilling, and enriched life possible.

Osteoporosis Canada

Christine's Story

Every Mother's Day, I'm reminded of the most devastating time of my life.

It's hard to talk about, even now. But if telling my story will prevent even one person from experiencing the same kind of pain, it's worth it.

I got married when I was 39. My husband Gerry and I immediately wanted to start a family. I wanted so badly to hold a child in my arms, to be the kind of loving mother my own mom had been. But three miscarriages later, I started to lose hope.

Then something wonderful happened—I gave birth to our daughter Chanel. It was a high-risk pregnancy because of my earlier miscarriages, but I followed my doctor's instructions to the letter. I went on eight weeks of bed rest and blood thinners. I was determined to do whatever it would take to hold my baby.

When we brought Chanel home from the hospital, Gerry and I could hardly contain our happiness. We were so excited to start this new phase of life together as a family.

Two weeks later, I was standing beside Chanel's crib, watching her sleep. She was so angelic, so peaceful. I bent down to pick her up … and then pain ripped through my body, more excruciating than anything I had ever felt before.

I didn't realize it at the time, but I was suffering from severe osteoporosis. And bending over to pick up my baby had literally broken my back.

Osteoporosis is a disease that slowly, quietly weakens bones. It often goes undiagnosed, even when it breaks your bones.

After this traumatic event, I spent the next several weeks in excruciating pain, undergoing all kinds of tests and exams to try to figure out what was causing it. A month later, my doctor called me with the devastating news.

She said, “Christine, I don’t know how to tell you, but you have five spinal fractures and severe osteoporosis.”

With those words, my life was changed forever.

Even now, years later, my heart aches when I remember that time in my life. I’d wanted to be a mother so badly. But the pain of osteoporosis robbed me of that precious first year of motherhood.

I couldn’t even hold my baby. I couldn’t breastfeed her, or bathe her, or take her for walks around the neighbourhood.

I couldn’t even look after myself, let alone an infant. I was as helpless as she was. Gerry had to help me bathe and dress. I couldn’t do laundry, cook, or drive to my many, many medical appointments.

Eventually, we required a homecare assistant. I’m so grateful for her help—and goodness knows we needed it. But it was heartbreaking to watch my baby bond with her, and not me.

I tell you this story because osteoporosis is a misunderstood disease. I’ve heard people say, “It’s an old women’s disease” or “All it does is curve your spine” or “It’s a normal part of aging.” These myths are simply not true.

The truth is osteoporosis can be what I call “3D”—devastating, debilitating, and depressing. It’s more than just a curved spine or a broken bone. One false move, one fall on a slippery sidewalk, even one sneeze can change your life forever.

It’s not just the physical effects that are debilitating. The emotional impact can be overwhelming.

After my shocking diagnosis, I spiraled into a deep and dark depression. All I wanted to do was lie horizontal in bed, where it was the least painful. I was terrified of moving around in case I fell and broke more bones. I felt lost and incredibly alone.

That’s when I found Osteoporosis Canada—and I’m so glad I did. The support I received saved my life.

For me, they were a lifeline.

Through Osteoporosis Canada, I met people who had experienced similar pain and trauma, who really understood how I was feeling. I was inspired by others who had been able to move forward and manage the disease, and not let it dictate their life

I'm so grateful I got the support and care I needed. It was a long road back, but eventually I was able to manage my pain and the disease. But every day I know something as simple as a sneeze could cause a devastating setback.

Now, when Mother's Day comes around, I make sure to hold my daughter close, even though she's now 16 years old! Osteoporosis can be genetic—my own mother and her sisters also had osteoporosis (although at the time everyone just thought their rounded backs were due to aging). So, I keep a very close eye on Chanel and make sure she gets enough calcium, Vitamin D, and exercise.

Sickle Cell Awareness Group of Ontario

Lynella's Story

I was diagnosed with Sickle Cell Disease (SCD) in Guyana, South America, when I was three years old. As I got older, SCD began to affect virtually all aspect of my life. I began presenting frequently in hospitals with numerous medical issues and various severities. For the sake of my well-being, close relatives and friends began to advise my parents that Guyana may not the most medically advanced to support my care efficiently.

Thus, in 1995 my family migrated to Canada and during the winter months, I experienced my first Canadian sickle cell crisis. As I was rushed to St. Joseph Hospital in Hamilton, we were all confident I would receive the best medical treatment from Canadian doctors whom we assumed to be well-trained and knowledgeable on SCD. My family was mortified to realize the physicians and nurses who cared for me knew very little about my disease. As a result, I was hospitalized for three weeks during which I felt like a laboratory rat.

I've always had a strong family support system which I am grateful for, but when I was introduced to the Sickle Cell Awareness Group of Ontario (SCAGO) five years ago, it was a life-changing experience for me. A nurse I was seeing in clinic that day asked if I would like to share my story at an awareness event held by SCAGO in Hamilton - and I said yes!

I was thirty-three years old when I first spoke about what it is like living with SCD. Until then, no one had asked me. But there I was, for the first time telling my story to a room full of strangers during that particular SCAGO event.

For nineteen years of living in Canada, I knew of no one else with SCD nor of any support groups for people with SCD. So, when through SCAGO, I met other people living with SCD and heard their stories, I was comforted that I wasn't the only one with this disease! I am particularly grateful for SCAGO's programs connecting families with SCD together and supporting knowledge translation among care providers, to ensure patients with SCD receive optimal care in Ontario hospitals.

SCAGO supports clinical and psycho-social research and trains patients and their care givers to be effective advocates.

Personally, it was because of the training provided by SCAGO that I was empowered to become not only a confident advocate but also the founding coordinator of the Hamilton-Wentworth chapter of the SCAGO which I am grateful for.