# IMPACT STORY: SHANNON

## “I was an otherwise healthy 46-year-old woman living a normal life. Married, with a grown son, and enjoying my dream job. Then, out of nowhere, I had a stroke.”

Alone at the cottage, I suddenly felt my left side wasn’t working. Though the possibility of a stroke crossed my mind, I dismissed it, thinking I must have slept funny. I seemed fine: walking, talking, just feeling a bit off with some tingling on my left side. Hours later, as my whole left side became paralyzed, the reality set in.

I spent weeks in hospital and in a rehabilitation facility where I learned to reuse my left side: retrain my brain and relearn the easiest of tasks from walking to writing, which was especially hard as I am left-handed. Unfortunately, I’ve had several strokes and seizures since the first one. People look at me today and can’t believe that I have had strokes. I worked long and hard to get to where I am now, and I still work hard every day.

Health charities like HealthPartners and Heart & Stroke have been my lifelines. Sharing my story and advocating for survivors has given me a renewed sense of purpose and has allowed me to spread awareness that stroke can happen to anyone at any age and no sign should go untreated.

My advice to others is to start with Heart & Stroke. Although no two strokes are the same, the journey may be parallel and there are resources available to help you and your loved ones.

HEALTHPARTNERS PARTENAIRESANTÉ

HSC

## “My experience with Huntington Disease (HD) is a deeply personal one. I’ve lost three of my four siblings and my mother to this relentless disease.”

HD is a rare genetic disorder, affecting about 1 in 7,000 Canadians, with symptoms that combine the worst aspects of Alzheimer’s, Parkinson’s, and ALS. For families like mine, there is a 50% chance of inheriting the gene from a parent which casts a constant, daunting shadow.

However, I’ve found hope through my work with the Huntington Society of Canada and HealthPartners. I’ve been able to passionately share my family’s story, advocating for greater awareness and research funding. My volunteer work with the Huntington Society of Canada helps give my life purpose and helps me to honour the family members I lost to Huntington Disease.

My career with the federal government has given me a unique perspective on the importance of workplace giving campaigns. I deeply appreciate these initiatives and the donations that make a profound difference to those in need.

I also value the sense of community and belonging health charities provide. In the past 15 years, I’ve helped raise over $250,000 for Huntington Society of Canada, served as a volunteer treasurer and amaryllis coordinator for the Ottawa Chapter, and participated in numerous fundraising events. Every year the emotions hit hard as I think about my sisters and brother who died from Huntington Disease.

Ongoing human drug trials give us substantive hope that a treatment is possible. This hope propels me to continue championing medical research and science. Together, we can create a future free from the devastating grip of Huntington Disease.

# IMPACT STORY: BROCK

HEALTHPARTNERS PARTENAIRESANTÉ

Parkinson Canada

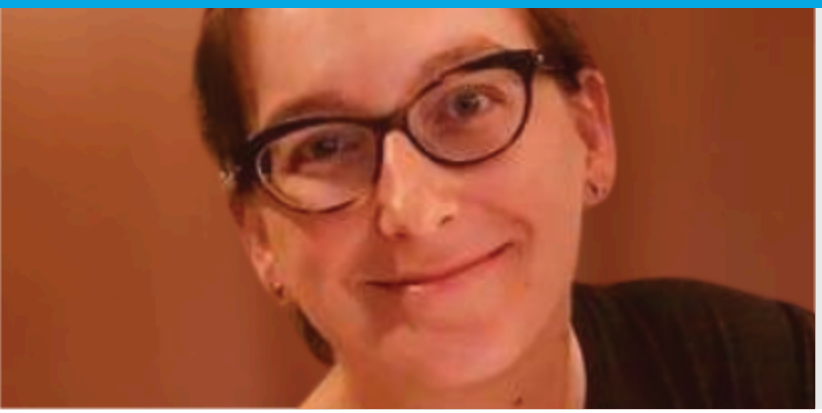
"When I had to tell my family about my Parkinson's diagnosis, it was one of the hardest moments of my life. I rehearsed how I would reveal this to my wife and kids, but in the end I just blurted it out amidst some tears."

The days that followed were filled with worry and fear. My wife and I worried about our future and our adventures. She worried about losing her autonomy and sense of purpose. Our kids, too, were shocked, but showed up strong, loving and supportive.

Living with Parkinson's has been a journey of adaptation, becoming aware of my new and evolving limitations and pushing myself where I can. This journey has also revealed unexpected sources of strength and community.

Organizations like Parkinson Canada and HealthPartners have been a lifeline. I look to them for knowledge, community, and ways to contribute —key elements in building resilience and continuing a life of purpose. Parkinson Canada's Every Victory Counts provides invaluable information about the disease and emerging research. Support groups connect me with others facing similar challenges, creating a network of understanding and support.

Parkinson Canada has also been there for my wife, helping her manage her fears. Their caregiver support services have helped her navigate this journey. Some advice to anyone newly diagnosed: accept the diagnosis and find ways to sustain the activities that brought you joy before. Be kind to yourself. Stay active – exercise has helped me manage my symptoms. And lastly, remember, you are not alone.



HEALTHPARTNERS PARTENAIRESANTÉ

HSC

## “It wasn’t until my grandfather passed away that we learned he had been living with Huntington disease – and that we might all have it too.”

Huntington is a neurodegenerative disease passed down through genetics. After a family discussion, my mother went for predictive genetic testing since she was exhibiting some memory loss.

The test results confirmed our fears – my mother had the disease. I was deeply concerned for her and anxious about my own future, knowing that children of those with Huntington Disease have a 50% chance of inheriting it. Slowly, I began to prepare myself for this seemingly inevitable fate.

I reached out to my local chapter of the Huntington Society of Canada to get tested. The result came back in my favor: I did not have Huntington Disease. However, out of my mom and her seven siblings, five tested positive and many of my cousins did too. Since then, I’m trying to help them as much as possible.

Attending information sessions and caregiver meetings hosted by the Huntington Society of Canada, has given me invaluable insights about the disease and how to help my family manage it. The regional organization, Huntington Society of Quebec, arranged for my mom to attend a speciality summer camp, giving my father a welldeserved break from his caregiving duties.

It’s heartbreaking to watch the disease slowly take away the ones you love. However, I am thankful for the support we’ve received from health charities and the hope they give other families like mine.

# IMPACT STORY: JEFF

"When I was 10 months old, I was diagnosed with Spinal Muscular Atrophy Type 1. I can't begin to imagine the devastation my parents felt when they were told that their baby might not live past two years old."

Back then, medical equipment like wheelchairs were very basic, information was lagging, and people with disabilities had to fight to get into the public school system. On top of that, rehabilitation was not a priority, and many supports were not in place for families.

But thanks to the tireless efforts of organizations like Muscular Dystrophy Canada, things have changed. Jump ahead 47 years, and there's no slowing me down!

Today, my wheelchair is custom-made, allowing me to change positions, control my computer, and operate various home appliances. I have a great career, I'm married, I built my own house, and I love to travel. I'm actively involved in my community and get to help others.

I have now begun a new treatment called Risdiplam. The improvements, though minor, have been life-changing for me.

Over the years, my family and I have received immense support from Muscular Dystrophy Canada, including medical equipment, support from staff when it came to making life altering decisions, and education to improve my quality of life. My wife has attended caregiver retreats and received support and friendship from our local chapter network.

Your donations to health charities like HealthPartners and Muscular Dystrophy Canada truly make a difference in people's lives.

# IMPACT STORY: THE TREUSCHES

## At age 2, Patricia and Andrew's young son was diagnosed with kidney damage. By his teenage years, he became dependent on regular dialysis treatment. His family hoped for a kidney transplant.

Andrew, a perfect donor match, gave his kidney, but the transplant failed. Their son returned to dialysis five days a week, spending over seven hours at the hospital and travelling. Through all this, Patricia and Andrew were his unwavering caregivers, supporting him through a demanding and relentless schedule while also making sacrifices of their own.

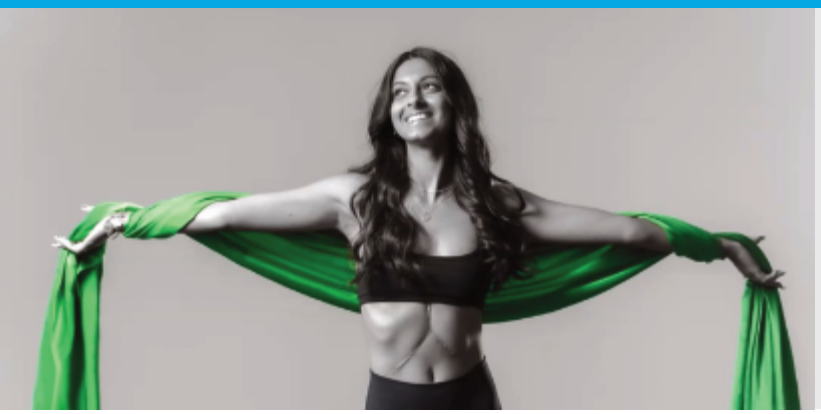
Two years later, Patricia became an eligible donor match, and her kidney brought hope with a successful transplant.

Unfortunately, a successful transplant is not a cure, and complications are expected in those with kidney failure. The Treusches' son developed diabetes, Crohn's disease, and high blood pressure. The emotional toll was heavy, with mental health struggles shadowing their journey. In 2019, another setback struck—his kidney failed again. Fortunately, he received a third organ donation and has been resilient since then, showcasing the crucial importance of organ donors.

Kidney disease affects 1 in 10 people in Canada. Health charities like The Kidney Foundation of Canada have been a lifeline for the Treusch family, providing support and funding for critical research. For families with limited resources, the Foundation offers services like transportation to dialysis, food, warm blankets during treatment, and gifts for children on Christmas Day whose treatment can't take a break.

Your donation to HealthPartners brings support, research, and hope to families coping with kidney disease.

# IMPACT STORY: AFSANA LALLANI



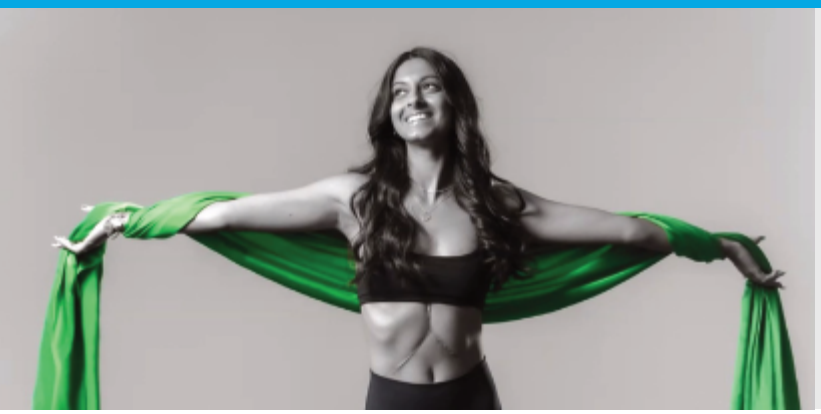
HEALTHPARTNERS PARTENAIRESANTÉ

"I've always been one to look on the bright side and to walk through life smiling because being alive is simply a gift in itself. That's the reason I feel grateful every day and motivated to continue facing my health adversities with such bravery."

At just 16 years old, Afsana Lallani was diagnosed with primary sclerosing cholangitis (PSC), a rare and chronic autoimmune liver condition that gradually damages bile ducts and can lead to liver failure. Unfortunately, there is no cure for PSC except for the eventual need for liver transplantation. By 2021, her condition had progressed to liver failure and she was officially placed on the transplant waitlist. The process was challenging, as she needed to maximize her nutrition, so she advocated for herself to receive an NG tube to ensure her body could meet the demands of the operation and recovery, all while juggling internal bleeds, extreme pain and itch, brain fog, and other uncontrolled liver failure symptoms.

Because Afsana did not have any blood type matches in her family, she couldn't ask any relatives to be evaluated as potential living donors. Undeterred, she launched a public campaign called Afsana Lallani Needs a Living Liver Donor, sharing her story openly on social media to reach a wider audience and raise awareness about PSC and living organ donation. Reflecting on the experience, she says, "It was a vulnerable experience to be so open about something so personal, especially since I consider myself a private person! But I knew it was my best shot at finding a living donor and saving my life, so I had to be brave."

After nine long months of searching and enduring PSC's most difficult symptoms, an anonymous donor came forward. Following a transplant surgery that lasted more than 10 hours, Afsana's procedure was successful, and her donor was recovering well. Afsana spent the following month recovering in the hospital, then completed the remainder of her six-month recovery at home. Today, four years post-transplant, she is thriving and no longer experiences liver failure symptoms. While she now lives with post-transplant challenges, she continues to embrace life with resilience and hope.



HEALTHPARTNERS PARTENAIRESANTÉ

Afsana's story doesn't end there. Inspired by her journey, she now supports others in need of a living donor, especially those who, like her, don't have a blood type match within their family or close circle. She creates and manages social media campaigns to share their stories and reach potential donors. She has been successful in helping several people find donors this way!

Alongside this advocacy, Afsana completed her university degree and is now a fully licensed registered nurse working in palliative care. She was inspired to pursue this field through her personal health experiences, having been so close to becoming palliative herself, and is grateful to her donor for giving her the gift of life, allowing her to turn this dream a reality.

Continuing her journey, Afsana actively supports others in the transplant and PSC community. She serves on the Volunteer Advisory Council for the Centre for Living Organ Donation at the University Health Network (UHN), where she also received her transplant. She contributes to peer support initiatives through PSC Partners Canada, including facilitating monthly group calls for teens living with PSC. Through all of this, she remains committed to raising awareness, fostering community, and encouraging those awaiting transplants to stay hopeful, while also helping to inform potential donors about the different pathways to donation, whether through living donation programs via hospital transplant centres and Canadian Blood Services, or by registering their wishes for deceased organ donation through the Trillium Gift of Life Network (Ontario Health).

Her journey is perhaps best captured in her own words:

**"This experience taught me the power of community and generosity, but also the importance of patience while waiting on the transplant list, and of holding onto hope, resilience, and bravery. I wouldn't be here without my support team and my family, or the incredible person who gave me the gift of life."**