

MS[®] PROGRESS Report

Living Beyond the Stigma: How Susan Reshaped her MS Journey

Susan was only 21 when she first started noticing that something was off. After a week of unexplained numbness in her right hand, she finally saw a general practitioner at a walk-in clinic, who recognized the early signs of MS. Susan was referred to a neurologist right away.

“For me, my first MRI was traumatic,” recalls Susan. “Not because of claustrophobia, or the loud noises of the MRI that sound like you’re connecting to dial-up internet, but because of the vulnerability – the possibility of being diagnosed with a chronic, incurable disease.”

When the doctor called to tell Susan she had MS, her heart dropped. All she had ever heard about MS was that it was a terrible disease that could put you in a wheelchair. She also had misconceptions that MS only affected the elderly and always led to restricted mobility.

“I went home and decided I would tell no one,” says Susan. “And I didn’t. Those were my darkest days. I lived in secrecy, hiding from the stigma of the disease.”

Over the next couple years, Susan would endure MS relapses that usually took form in a tingling sensation and numbness in her hands and legs – but in 2013, Susan went blind in her right eye due to optic neuritis. Still, she told no one.

It wasn’t until she found the MS Society of Canada that her attitude towards her diagnosis started to change.

When Susan arrived as a first-time volunteer at the Jayman BUILT MS Walk, she was greeted by a community of people whose lives had been touched by MS. They were holding signs and wearing bibs that read “I walk because I have MS” or “I walk for my aunt” – they were proclaiming their connection to MS for all the world to see. Susan was moved.

“My MS Walk experience helped me to realize that sharing my story could lead me to people who love and support me,” says Susan. “It could lead to my loved ones walking with bibs reading ‘I walk for my daughter,’ ‘I walk for my wife’ and one day, ‘I walk for my Mom.’”



“My experience with the MS Society exposed me to knowledge on the progress in MS research, which gave me hope for the future”

Susan’s first MS Walk experience inspired her to start telling people in her life about her diagnosis; soon after, she was invited to share her story at MS events, with some audiences as large as 1,500 MS Walk participants.

“My experience with the MS Society exposed me to knowledge on the progress in MS research, which gave me hope for the future,” says Susan. Now, she is proud to share that hope with her family and friends who all know about her diagnosis.

After years of anxiety and depression – feeling like she had to keep her MS a secret –

Susan can now finally live free from the stigma. “I now know that I can make a difference in the lives of others by sharing my experiences and in doing so, I will find a community of people who want to be there for me.”

Your generosity makes it possible for the MS Society to support Canadians like Susan. On behalf of every Canadian living with MS, thank you for your loyal support.



A Message from the President

Dr. Pamela Valentine

There's no denying that the COVID-19 pandemic has made this a difficult year for all. Yet, even in these challenging times, there is incredible work

being done to help create a world free of MS. As President and Chief Executive Officer of the Multiple Sclerosis Society of Canada, I see it in every corner of the country – dedicated researchers, volunteers, and donors like you that have stepped up and made our progress possible, despite so many obstacles.

As Canadians, creating a world free from MS is a cause that's especially close to us. Since on average 11 Canadians are diagnosed with MS every day, most of us have some sort of connection to this devastating disease – whether it be our sibling, spouse, parent, friend or neighbour. I believe these personal connections will ultimately inspire and empower us to continue working towards our vision: a world free of MS.

The impact of the novel coronavirus will be felt by our community for years – and still, we are working tirelessly to fully understand the scope of that impact. We've enacted global initiatives to help provide insights on the effects of COVID-19 on people with MS and other demyelinating diseases. And every day, we continue to ensure that vital support services and resources are still available in a virtual setting to Canadians living with MS and their caregivers.

The COVID-19 pandemic also threatens our ability to invest in promising research projects – but with contributions from people like you, I know we can keep the wheels of our research efforts in motion, now and well into the future. As you'll see in this issue of Progress Report, your efforts have already made a profound difference for the tens of thousands of Canadians living with MS.

Together, we will get through this – and help create a bright future for the MS community. Thank you again for your generosity, and for making such outstanding progress possible.

Sincerely,

Dr. Pamela Valentine
President and Chief Executive Officer
Multiple Sclerosis Society of Canada



RESEARCH SPOTLIGHT:

Dr. Tremlett



What if – using physical cues and carefully documented symptoms – we could uncover who is likely to develop MS years before they're ever diagnosed? That's precisely what Dr. Helen Tremlett and her team are doing.

According to Dr. Tremlett's findings, in the five years before people develop the first clinically recognized signs of MS, they are up to four times more likely to be treated for nervous system disorders such as pain or sleep problems – and are 50 percent more likely to visit a psychiatrist.

Because the symptoms of MS are so varied, often associated with other disorders, and can be unpredictable, diagnosing MS can be a challenge.

But Dr. Tremlett and her team recently published a groundbreaking study in *Multiple Sclerosis Journal*, providing evidence that MS can be preceded by early symptoms—known as a prodrome.

“The existence of such ‘warning signs’ are well-accepted for Alzheimer’s disease and Parkinson’s disease, but there has been little investigation into a similar pattern for MS,” said Dr. Tremlett, a Canada Research Chair in Neuroepidemiology and Multiple Sclerosis at the University of British Columbia. “We now need to delve deeper into this phenomenon, perhaps using data-mining techniques. We want to see if there are discernible patterns related to sex, age, or the ‘type’ of MS they eventually develop.”

Dr. Tremlett's work has enormous potential to help the MS community get ahead of future diagnosis and treatment. We are so grateful to our generous donors for bringing hope to countless Canadians living with MS through high-quality research like this.

Visit mssociety.ca/research to learn more.

MS Breakthroughs: New treatments and new insights

The MS Society of Canada is thrilled to share that Health Canada has approved Mayzent™ (siponimod) as a treatment for adults with secondary progressive multiple sclerosis (SPMS). This new treatment option is designed to delay the progression of physical disability. Mayzent™ is the first oral treatment approved for people living with SPMS with active disease, and the first treatment approved for SPMS with active disease in almost 15 years – so **this announcement brings hope to thousands of people around the world**.

We are also excited to announce that through a COVID-19 & MS global data sharing initiative, researchers are capturing and sharing data to understand the effect of COVID-19 on people with MS and other demyelinating diseases. Healthcare professionals and people living with MS urgently need this data to make evidence-informed decisions on how to best manage and treat MS



during the pandemic. This initiative aims to rapidly provide insights on the impact of COVID-19 on people with MS – and aims to understand how factors such as age, comorbidities (co-existing health conditions), and treatments are associated with COVID-19 outcomes.

These breakthroughs prove that progress IS possible through research, thanks to friends like you.

COVID-19 and the MS Society of Canada

Due to COVID-19, many people in the MS community are facing extreme feelings of isolation and the loss of important support systems. That's why we've ensured that critical resources like our MS Knowledge Network and the 1:1 Peer Support Program are still available to anyone experiencing an MS-related challenge during these especially difficult times.

To help stop the spread of COVID-19 and reinforce the need for physical distancing, we've had to pivot our in-person fundraising events to virtual solutions. Since the MS Society of Canada receives minimal government funding, this has put a huge strain on our fundraising revenue – at a time when people living with MS need us most.

Your support is more crucial than ever. Please help people living with MS today.



Create a legacy of progress.

Help fund future research breakthroughs that can rid the world of MS.

Consider becoming a legacy donor with a bequest to the MS Society of Canada today. Your legacy gift will help generations of Canadians living with MS and support future research in search of new treatments and therapies.

Learn more at mssociety.ca/legacygiving

Investing in groundbreaking MS research

The MS Society of Canada supports MS research with the potential to improve the lives of those with MS – and to one day, create a world free from this devastating disease. With help from donors like you, we hope to continue funding promising research opportunities like the AI & MS Discovery Grant.

This exciting opportunity aims to improve treatment and prognosis of people living with multiple sclerosis using artificial intelligence (AI). Our researchers are seeking transformative ideas that leverage existing clinical and patient data and the power of AI methodologies to develop a clinical decision support tool capable of optimizing and informing treatment plans for Canadians living with MS.

Clinical decision-support tools powered by AI have the potential to learn and benefit from the wealth of existing data on treatment responses to various disease-modifying therapies. Using this technology, it can then be used to predict an appropriate treatment path.

This is an incredible opportunity to derive meaningful insights from vast amounts of data to inform clinical practice and improve the health outcomes for Canadians living with MS.

In the future, research opportunities like the AI & MS Discovery Grant will help us make real progress in the fight to create a world free of MS. And with your support, the MS Society of Canada will continue our efforts to improve the health and lives of Canadians living with MS.

To learn more about what our research grants will fund, visit us online at mssociety.ca/2020funding



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