

MS[®] PROGRESS Report

Thanks to a breakthrough clinical trial, Heather lives a life free from MS!

It was not that long ago we heard about the results from the groundbreaking Canadian Bone Marrow Transplantation (BMT) clinical trial conducted at the Ottawa Hospital Research Institute and funded by the Multiple Sclerosis Society of Canada and its affiliated Multiple Sclerosis Scientific Research Foundation (MSSRF). BMT uses intense chemotherapy to effectively eliminate the patient's immune system, which is then "regrown" using their own stem cells, which must be harvested before the procedure. While this procedure is risky and only individuals with aggressive relapsing-remitting MS (RRMS) are eligible, we are still hearing about the positive impact this treatment has on the lives of those that participated in the clinical trial.

Today we share the story of Heather Harris, a woman whose life was forever changed by her participation in this clinical trial – made possible by generous people like you. Heather was 24 when she first experienced numbness in her right foot. By the end of the day, the numbness had claimed the entire right side of her body. Shortly thereafter, Heather met with neurologist Dr. Mark Freedman, one of the leaders of the BMT clinical trial. After an MRI – and just weeks before her wedding – Heather learned she had MS.

Heather had heard of the BMT clinical trial, but Dr. Freedman initially advised against it. This type of aggressive chemotherapy has serious potential side effects – including sterility. Only patients with extremely poor MS prognoses were considered eligible.

But Heather's illness progressed with terrifying speed. Soon after her diagnosis, Heather could no longer drive her manual transmission car ... then, she struggled to walk. When Dr. Freedman predicted she'd be in a wheelchair within just five years, it became clear that the BMT trial was Heather's best chance at the life she wanted.

After the trial, Heather's symptoms slowly began to reverse. Twelve years later, she can now walk, run – she can even ski. She also enjoys a fulfilling career, working full-time as a



“After the treatment, I never had another attack. I just started to feel better, and totally recovered.”

– Heather Harris, on her 2006 stem cell transplant

school principal. “I really feel like I'm cured,” Heather says.

Heather hasn't experienced another MS relapse since the clinical trial. And after undergoing fertility treatments, Heather and her husband welcomed a second miracle into their lives – a daughter named Zoe.

“I am so lucky and incredibly grateful,” said Heather. Despite the clinical trial's risks, doctors are optimistic about the results and the future. Currently, more than 50 Canadians living with MS have undergone the same treatment as Heather, with all of them experiencing a halt in progression.

Without generous supporters like you, breakthrough research like this simply wouldn't be possible. Please help us continue to fund vital research that significantly improves the lives of Canadians living with MS.



A Message from the President

Dr. Pamela Valentine

When I joined the Multiple Sclerosis Society of Canada, I felt humbled and honoured to become a part of such an effective organization. Months later, I remain energized, grateful, and proud. I'm simply in awe of the people I work with each day, and of all the progress we are making with your help.

As Canadians, we have a special stake in this fight. We have one of the highest MS rates in the world. The landscape of MS research is changing rapidly – and thanks to your support, the MS Society of Canada is leading the way. Last year, we were able to fund dozens of promising MS research studies, each with the potential to change the trajectory of this mysterious and unpredictable disease.

If we are to defeat MS and care for those who live with it, we must advance vital research and public policy efforts. At the MS Society's recent Day on the Hill, we met with government leaders to urge them to make MS a national priority. We're working towards increased research investments, better patient care, and more accessibility. And as you'll see in this issue of Progress Report, we are making a difference. Together.

I recently met a young woman who reminded me why our fight is so important. She's a working mom with MS, and the fatigue, challenges and setbacks she faces each day are often invisible to the rest of the world. For me, her story drove home the need to advocate for care, employment and income support structures that recognize the unique – and sometimes even invisible – nature of MS.

With your help, we're improving lives and getting closer to new research breakthroughs. Thank you for your generosity, and for making all our important work possible.

Sincerely,

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



Dr. Rebecca Spain

Dr. Rebecca Spain of Oregon Health & Science University in Portland, Oregon, conducted a pilot study that analyzed the impact of lipoic acid on people diagnosed with secondary progressive MS (SPMS). Lipoic acid is an antioxidant produced naturally in our own bodies. Dr. Spain's pilot study showed that a lipoic acid supplement reduced the rate of brain volume loss by 68% compared to the placebo group, and had other positive effects on MS as well.

With funding from the MS Society of Canada and support from the Centre for Drug Research and Development, Dr. Spain's current research is focused on fine-tuning this lipoic acid treatment. Her initial study discovered that not every patient absorbed lipoic acid equally, and some even experienced unpleasant side effects.



Now, Dr. Spain hopes to study whether a new formulation of this supplement is an effective treatment for people with SPMS, a type of MS that has no approved therapies.

"Lipoic acid may not turn out to be the best treatment for progressive MS," Dr. Spain explains. "However, by the process of learning how it treats MS, we can understand the underlying mechanisms of disease in progressive MS and go back to the lab to develop the next treatments."

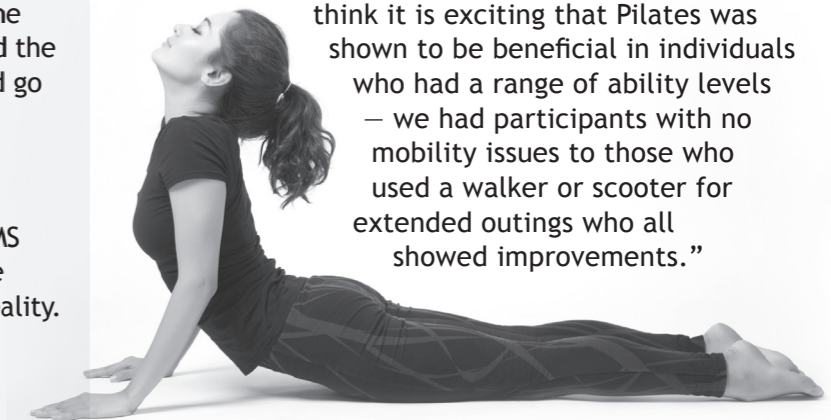
Dr. Spain's goals include finding effective ways to treat different types of MS, and helping the MS community understand more about this complicated disease. The MS Society celebrates Dr. Spain's accomplishments, and we sincerely thank our donors for making her research a reality.

Learn more at mssociety.ca/research.

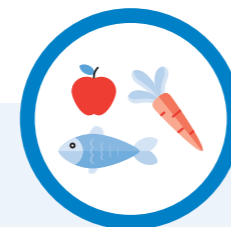
New study shows Pilates benefits people living with MS

As research advances medical treatments for MS, interest in wellness solutions also continues to grow. The Hermès Canada | MS Society Wellness Research Innovation Grant was created to foster the development of innovative wellness solutions for people affected by MS. One of the first grant recipients was Dr. Charity Evans from the University of Saskatchewan, whose team studied the impact of Pilates on people with MS.

The study found that people who did Pilates showed improved walking performance and functional ability. Dr. Evans says, "Specifically, I think it is exciting that Pilates was shown to be beneficial in individuals who had a range of ability levels – we had participants with no mobility issues to those who used a walker or scooter for extended outings who all showed improvements."



Modern Milestones in MS Research



1949-1981

1949 MS Society of Canada awards its first research grant to Dr. Roy Swank.

1981 Magnetic resonance imaging (MRI) pictures of an MS-affected brain revolutionize MS diagnosis.



1995-1996

1995 Betaseron is approved for use in Canada, making it the first-ever disease-modifying therapy (DMT) for relapsing-remitting MS (RRMS).

1996 First published evidence that exercise improves quality of life with MS.



2000-2004

2000 Canadian Bone Marrow Transplantation (BMT) trial is launched with funding from the MS Society and the MS Scientific Research Foundation (MSSRF) to gain insight into the mechanisms of the disease and determine whether wiping out, then rebuilding, a patient's immune system using transplanted stem cells is effective in treating MS.

2001 McDonald Criteria for diagnosing MS are established, incorporating both clinical and imaging measures for the first time.

2004 Link between higher vitamin D intake and reduced MS risk is identified.



2008

2008 MS Society hosts the first-ever endMS conference, and partners with the MSSRF to launch \$20M endMS Research and Training Network to attract, train and retain the world's best and brightest MS researchers.



2012-2014

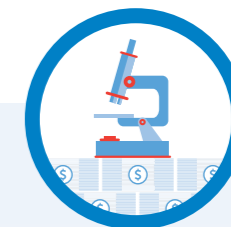
2012 MS Society becomes a founding member of the new International Progressive MS Alliance, a group of organizations committed to collaboratively accelerating global research and treatments for progressive MS.

2014 MS Society and the MSSRF fund \$3.6M in research to understand the role of the B cell in MS



2016

2016 Launch of the Hermès Canada | MS Society Wellness Research Innovation Grant, funding aimed at translating research findings into wellness solutions to improve health and quality of life and the Canadian BMT Trial results are published, showing no new disease activity following treatment of patients with aggressive, highly inflammatory RRMS.



2017

2017 In cooperation with Biogen Canada and Brain Canada, MS Society launches the \$7M+ Canadian Progression Cohort, the first large-scale Canadian study aimed at decoding the mysteries of MS progression. And additional MS Society-funded clinical trials demonstrate that common antibiotic Minocycline may delay or prevent MS onset in people who display early signs of the disease.



2018

2018 Ocrevus™ (ocrelizumab) is conditionally approved as the first drug therapy for adults with early primary progressive MS.

Investing in groundbreaking MS research

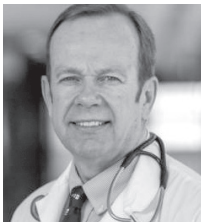
The MS Society of Canada is committed to supporting research that aims to improve lives and change the future of MS. With help from supporters like you, we fund several researchers every year through our annual competition. After reviewing dozens of applications for the 2018-2019 Annual Research Competition, we are pleased to award over \$4.5 million in grants to 13 new Canadian research projects, including:

“It’s a fungal world: the microbiome in pediatric MS”



Dr. Helen Tremett, University of British Columbia
Our gut microbiomes are comprised of all the living microorganisms that populate the digestive tract, including bacteria and fungi. This study seeks to understand the microbiome’s role in pediatric MS by assessing the gut fungi of children with and without MS to determine whether there are associations between MS risk and disease course. MS is rare in children, so this study represents an important opportunity to examine the disease very close to its actual onset.

“Inflammasome activation in the central nervous system: determinants and outcomes in progressive MS”



Dr. Christopher Power, University of Alberta
Inflammasomes are groups of interactive proteins in the immune system that contribute to inflammation and brain injury. Dr. Power’s research team has identified bacterial proteins in the brain that may contribute to inflammasome activation. To gain a better understanding of progression and potential treatment applications, this project will examine the effects of these bacterial molecules in human brains, studying their impact on inflammasomes and damage to brain tissue.

“Targeting DICAM, a novel mediator of neuroinflammation, to treat MS”



Dr. Alexandre Prat, Centre de Recherche du Centre de Hospitalier de l’Université de Montréal
The blood-brain barrier (BBB) is a network of cells that prevents potentially harmful substances from entering the central nervous system (CNS). In MS, the BBB becomes leaky, allowing white blood cells from the immune system to pass through and damage the CNS, leading to the formation of brain lesions. In a previous grant also funded by the MS Society, Dr. Prat identified a molecule, called DICAM, that regulates the migration of cells across the BBB – and found that people with MS have increased levels of DICAM. In this project, Dr. Prat hopes to advance our understanding of how pathogenic immune cells enter the CNS and cause damage with the goal of developing new therapeutic options.



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In the coming years, these and other researchers will study many different aspects of MS in order to understand and more effectively treat it. And with your help, the MS Society of Canada will continue working to improve the health and quality of life of those living with MS. To learn more about the 2018-2019 research grant recipients and their research, visit us online at mssociety.ca/2018funding