MS® Research

Fall 2019

FEATURE STORY

Restoring cognitive loss: A global study on MS's most invisible symptom

LIVING UNAPOLOGETICALLY: 5
VITAMIN D AND MS 6
DID YOU KNOW? 7

contents

Fall 2019

RESTORING COGNITIVE LOSS: *A global study on MS's most invisible symptom* 3

LIVING UNAPOLOGETICALLY: *How a clinical trial has helped Brooke run again* 5

VITAMIN D AND MS *Recommendations for people living with MS and those at risk of developing MS* 6

DID YOU KNOW? *Noteworthy advancements* 7

@DrPamV

Acts of greatness. This means actions, big and small, that are making an impact for Canadians living with or affected by MS.

Acts of greatness are all around us. As you'll read in the issue, we announced the launch of a groundbreaking clinical trial led by Dr. Anthony Feinstein. It's really the first of its kind – a team that spans the globe, all trying to understand the link between cognitive rehabilitation and aerobic exercise in improving cognition in people with progressive MS. This trial has the potential to change the lives of millions in Canada and beyond.

At a personal level, Brooke shares her story about her unique journey with MS and the everyday acts that changed *her* life. With many ups and downs, it centres around her incredible results from a stem cell trial. Now, she is unapologetically living a life full of these small acts, some as simple as going for a run on the beach. In this issue you'll also read about recommendations for vitamin D – looking at it as a modifiable risk factor in understanding disease prevention.

From clinical trials with global teams, to progress made at a personal level, we are celebrating acts of greatness. Acts of greatness that take us from research, to tangible results for the person affected by MS. This is progress. Thanks to your support, this is making a difference for Canadians, so that one day we can hope for a world free of multiple sclerosis.

Sincerely,

Pamela Valentine

Pamela Valentine
President and Chief Executive Officer
MS Society of Canada

Multiple Sclerosis Society of Canada

Published by the Multiple Sclerosis Society of Canada
Suite 500, 250 Dundas Street West, Toronto, Ontario M5T 2Z5
T 416-922-6065 **F** 416-922-7538
Toll free 1-866-922-6065
mssociety.ca

Charitable Registration no. 10774 6174 RR0001
Contact: Gordon Moir, development officer, major gifts:
gordon.moir@mssociety.ca
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Progression
& therapies

Restoring cognitive loss:

A global study on MS's most invisible symptom

> *"Research like this is crucial. It will allow people living with MS a better quality of life and to make MS the subtext to how they live each day."*

Thanks to the generosity of an anonymous donor, the Multiple Sclerosis Society of Canada announced last fall a $5 million grant in support of a game changing clinical trial. It will be the first, international, multi-centre clinical trial to investigate cognitive rehabilitation and aerobic exercise in improving cognition in people with progressive multiple sclerosis.

The study is led by renowned scientist Dr. Anthony Feinstein, Neuropsychiatrist and Associate Scientist at Sunnybrook Health Sciences Centre and a Professor of Psychiatry at the University of Toronto, and a group of international MS rehabilitation specialists. It has the potential to dramatically change day-to-day life for people with progressive MS affected by cognitive difficulties such as attention, processing speed, or memory.

Cognitive dysfunction is considered an "invisible" symptom that can affect up to 70 per cent of people with progressive MS. This can have a serious impact on employment, relationships, and day-to-day activities. Currently, there are no effective disease-modifying therapies for adults with early secondary progressive MS who no longer experience relapses. There is only one therapy that is conditionally approved in Canada for early primary-progressive MS. The global research team will test whether cognitive rehabilitation, exercise, or a combination of both improves cognitive function in individuals living with progressive MS. The study is unprecedented in size. It will enroll 360 people with progressive MS from 11 clinical centres across six countries, with treatment spanning 12 weeks.

"Cognition is central to improving the quality of life for people living with MS," says Dr. Feinstein. "The research community understands the need to further develop options for all stages of MS but there's a large group of individuals with progressive MS who often feel left behind. This clinical trial addresses their needs in a substantial way. We're looking at combined interventions and results that will be applicable across countries and cultures."

Brain imaging using magnetic resonance imaging (MRI) will also be conducted in a subgroup of 120 participants to see whether cognitive improvement is also linked to changes in lesions and brain atrophy and improved regional brain activation during the performance of a cognitive task.

"While we're all desperately seeking a cure, the reality is, there is time before then," says Beverley MacAdam, who lives with MS and volunteers as a community member of the MS Society's research review panel. "Research like this is crucial. It will allow people living with MS a better quality of life and to make MS the subtext to how they live each day."

DR. ANTHONY FEINSTEIN

is a Neuropsychiatrist and Associate Scientist at Sunnybrook Health Sciences Centre and a Professor of Psychiatry at the University of Toronto. Dr. Feinstein has researched behavioral disorders in people with MS for 26 years and runs a busy clinical practice in which over 80 per cent of the patients have MS. Dr. Feinstein's studies entail detailed neuropsychological testing, brain imaging (both structural and functional) and quantification of mood symptoms. More recently, Dr. Feinstein has also begun a series of studies looking at how cannabis might affect cognition and brain imaging in people with MS. Currently, the Society is supporting two projects led by Dr. Feinstein, one is the clinical trial for improving cognition and another which is evaluating the effects of cannabis on cognition.

To read more, visit **https://mssociety.ca/resources/news/article/ms-society-of-canada-supports-international-multicenter-clinical-trial-to-improve-cognition-in-progressive-multiple-sclerosis**

Living unapologetically:

How a clinical trial has helped Brooke run again

> ***“The fact that I was staring down living the rest of my life in a wheelchair makes me appreciate the fact that I can drive three hours to my parents’ home on my own. Those years before the treatment are now a tiny blip in my story.”***

“If I ever write a book, it’s going to be called *Unapologetic* because that is what MS has taught me to be,” Brooke Robinson says. “I don’t need to apologize because I rushed out of a meeting to go to the bathroom. If it takes me forever to get down the stairs, then so be it. This is my life now.”

Brooke’s MS story starts in 2015. She was in the throes of a successful career in communications — young, healthy, and extremely active. The first signs of multiple sclerosis (MS) began with symptoms related to bowel and bladder incontinence. Her doctor assured her it was Irritable Bowel Syndrome (IBS). She was a 26-year-old woman and she was running to the bathroom with legs that were failing her.

“My story was very much like everyone else,” Brooke explains. “I spent my childhood playing competitive sports and graduated from Western University with an honours degree in History. Then I was diagnosed with MS and I had to change my path in life.”

Diagnosed in April 2015, her disease rapidly progressed, and by October she was walking with a cane.

A chance encounter in June 2016, changed the course of Brooke’s disease. While walking down the street, cane in hand, she passed a man on a scooter. He looked at her cane and asked, “Is that permanent?” Brooke says, “Most people just assume I’ve had hip surgery. I told him that I actually had MS and he said, ‘Me too!’

We stood there for almost 40 minutes talking, and he told me about a revolutionary stem-cell trial that was taking place in Ottawa, called the Bone Marrow Transplantation (BMT) trial. Drs. Mark Freedman and Harold Atkins were using chemotherapy to wipe out patients’ immune systems, and then successfully rebuilding them with their own healthy stem cells.”

Dr. Freedman is an expert neurologist in MS who approved Brooke as a candidate for the treatment and referred her to Dr. Atkins. This procedure is for individuals that are progressing in their MS incredibly fast, and feel this treatment is their very last option while still being healthy enough to recover from such an intense procedure.

So, in October 2016, a year and a half after her initial diagnosis, Brooke started the trial.

Brooke lost all of her gorgeous, long blond hair two weeks after her first dose of chemotherapy. After the completion of chemotherapy, Brooke made a trip to the hospital each day to be monitored. If platelets were down, new platelets would be given to her to ensure that her body was functioning until the immune system had a chance to rebuild. The worst that Brooke felt was like she had a bad case of the flu. She experienced a few bad days and slept a great deal. As the fatigue wore off and weeks wore on, she found she didn't need her cane anymore.

Today Brooke is back home and getting better each day. With her husband's encouragement, she has returned to the gym and just last week did something she never thought she would be able to do again: she ran at full speed on the beach near their home.

Before the trial, Brooke was a 6.5 on the Expanded Disability Status Scale (EDSS) – requiring walking aids, and only a few months away from life in a wheelchair. Now she's a 2 on the scale – living with minimal disability. Last summer, Brooke met up with the man she met on the street, the one she credits with saving her life. Though his own condition had deteriorated, he was happy to see her healing. Even though he couldn't participate in the trial, it symbolized hope.

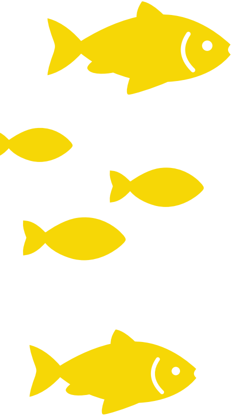
Brooke says that this trial has changed her attitude on life and given her more than just a new outlook on her MS.

"The fact that I was staring down living the rest of my life in a wheelchair makes me appreciate the fact that I can drive three hours to my parents' home on my own. Those years before the treatment are now a tiny blip in my story," Brooke says.

Vitamin D and MS

Recommendations for people living with MS

The Multiple Sclerosis Society of Canada has released evidence-based recommendations on vitamin D that can help people affected by MS make informed decisions about their health.



WHY IS VITAMIN D SO IMPORTANT? Vitamin D is an essential nutrient to the human body. Vitamin D maintains strong bones and may have a role in the body's immune system, heart and brain health, and how sugars are broken down in the body.

WHERE CAN YOU GET VITAMIN D? Safe exposure to sunlight, food sources, and supplements.

WHAT DO THE VITAMIN D RECOMMENDATIONS ENTAIL? For people at risk of developing MS (individuals with a sibling, parent, or child with MS and those that smoke or are obese), getting enough vitamin D may help decrease their chances of developing MS. For individuals living with MS, keeping vitamin D levels within the optimal range may also prevent their MS from getting worse. The recommendations provide the daily vitamin D intake and blood vitamin D levels that should be maintained for individuals with or at risk of MS.

These recommendations also highlight comorbid conditions and toxicity associated with vitamin D supplementation.

Vitamin D alone is not an effective treatment for MS, and too much vitamin D can be harmful.

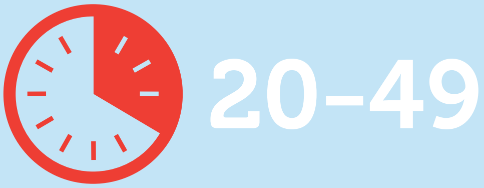
TALK TO YOUR DOCTOR! Blood tests provide you information on your vitamin D levels so that you can make sure you are getting enough vitamin D.

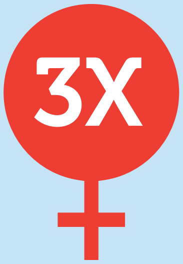
↘ *For more information on these recommendations, visit* ***https://mssociety.ca/hot-topics/vitamin-d***

Did you know?

Canada has one of the highest rates of MS in the world

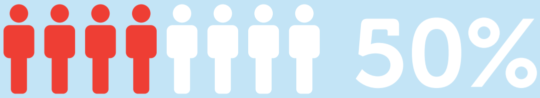
The onset of MS is typically between the ages of 20-49





Women are 3x more likely to be diagnosed with MS than men

Within 10–20 years of being diagnosed with relapsing-remitting MS ~50% of people develop secondary progressive MS



Total annual health sector costs for MS are expected to reach $2.0 billion by 2031

Fundraising goal for the Acts of Greatness campaign to help end MS: $75 million

On average, 11 Canadians are diagnosed with MS every day

↘ *For more information, visit* ***ActsofGreatness.ca***

↘ *Read the full story at:* ***https://blog.mssociety.ca/2019/02/love-conquers-all/***

At some point in their lives, nearly half of Canadians aged 15 and older have provided care to a family member or friend with a long-term health condition, disability, or aging need. Libby and Grant Sanderson have been married for 36 years and are no exception.

When Libby was diagnosed with multiple sclerosis (MS) in 1990, their world turned upside down. Grant is now Libby's caregiver and helps her with everyday activities as well and runs a support group at the MS Society of Canada. Today, Libby and Grant are stronger than ever, and persevere through daily acts of greatness.

MS® Multiple Sclerosis Society of Canada

Acts of Greatness

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