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@Dr_KarenLee

Some of the most promising research discoveries come from thinking outside the box. Approaching complex problems with an unconventional perspective can carve a path to new insights and solutions. Multiple sclerosis is a complex disease. The cause of MS is unknown, and it is difficult to explain why people experience different courses and have different responses to treatments. The unpredictable nature of MS lends an opportunity to researchers to think outside the box when designing and carrying out their studies.

The recently published minocycline clinical trial, supported by the MS Society of Canada and affiliated MS Scientific Research Foundation,

is an example of thinking outside the box. You will read about how one scientist at the University of Calgary uncovered an interesting property of minocycline – a common and inexpensive acne medication – that he tested further in mice with MS-like disease, and which launched a human MS clinical trial led by MS neurologist Dr. Luanne Metz.

This issue also features the Canadian MS Progression Cohort, a first-of-its-kind initiative formed by the MS Society of Canada in partnership with Biogen and Brain Canada. The Canadian MS Progression Cohort is an opportunity to bring together the brightest scientists and clinicians in the country to investigate why people with MS experience progression, how treatments impact progression, if there are biological changes that can be measured and used to predict progression, and to determine the cost of progression to the individual, their community and the country. These fundamental questions require an out of the box approach and a new way of viewing progression, and this innovative project will tell us new things about why progression occurs and how it can be stopped or reversed.

Finally, you will read about an MS Society funded study led by world-renowned rehabilitation expert Dr. Marcia Finlayson. With multiple MS publications under her belt, and the esteemed title of Vice Dean of Health Sciences at Queen's University, Dr. Finlayson is leading a project that will determine if an interactive resource she developed with a team of Canadian researchers can help reduce fatigue among people with MS.

I encourage you to think of ways the MS community – people affected by MS, health care professionals, researchers, the MS Society, and policy makers – can work together and think outside the box to tackle major challenges and knowledge gaps in MS. If you want to learn more about research funded by the MS Society, or want more information on the initiatives I described above, visit my blog at **DrKarenLee.ca** or follow me on Twitter **@Dr_KarenLee**

Sincerely, **Dr. Karen Lee Vice-president, research**







A Canadian MS research success story

Safe, affordable treatment uncovered for people with early-onset MS



are very encouraging and position minocycline as a viable treatment option for people with early signs of MS given its availability, established safety profile and cost. 22

An important breakthrough in multiple sclerosis research was announced this spring when Dr. Luanne Metz's study was published in the New England Journal of Medicine. The promising results show that minocycline – a drug that's been around for decades – has the potential to reduce the risk of developing MS in individuals with early signs of the disease.

Dr. Metz, an MS neurologist and professor at the University of Calgary, began her work with minocycline in 2008 when she launched a phase III, double-blind, randomized, placebo-controlled clinical trial with funding from the Multiple Sclerosis Scientific Research Foundation (MSSRF). The candidate drug? Minocycline – an antibiotic that's most

commonly known for treating bacterial infections such as acne. Early discovery research done by Dr. Metz's University of Calgary colleague, Dr. Wee Young, showed that minocycline had anti-inflammatory and neuroprotective properties. This work, also funded by the MSSRF, eventually propelled Dr. Metz into leading a clinical trial to see if minocycline could reduce the chance that people who experienced symptoms suggestive of MS (clinically isolated syndrome) would progress to a diagnosis of MS.

The clinical trial consisted of 142 participants from 12 Canadian MS clinics, who were randomly selected to receive either 100mg of minocycline twice a day or placebo for up to 24 months. Jill, a participant from Calgary, shares her experience



Jill, phase III trial participant

☑ Read the Minocycline FAQ for more information about the trial and what it means for people living with MS: mssociety.ca/minocycline

and results from participating in the trial, "From the time I started taking minocycline seven years ago, I haven't had any other MS-related symptoms. I feel that this drug has really helped me from progressing to a MS diagnosis." She continues, "The rate of people going from CIS (clinically isolated syndrome) to MS is very high, and I'm so fortunate that this drug seems to have stopped any further progression in its tracks. I'm still undiagnosed and I strongly believe that it's because of this drug."

The exciting results of this clinical trial show that minocycline reduces the risk of developing MS in individuals with early signs of the disease. It also shows that treating MS or early events predictive of MS as early as possible with a readily available, affordable treatment like minocycline is essential. In Canada, the generic form of minocycline costs around \$1 per dose. Based on two doses a day, this works out to around \$500-600/year, which is considerably cheaper compared to other treatments that are available.

The results from the trial are very encouraging and position minocycline as a viable treatment option for people with early signs of MS given its availability, established safety profile and cost. In addition, the study will help inform decisions made by neurologists and people with MS around early treatment and whether minocycline can be considered as part of one's treatment plan.

The journey of minocycline is a successful example of "bench to bedside", where researchers translate findings from early laboratory studies into clinical applications. This unique Canadian research study was designed and conducted by Canadian researchers and involved Canadian patients. The MS Society of Canada and MSSRF have been behind this work from start to finish, by funding the initial basic science conducted by Dr. Yong to the clinical trials led by Dr. Metz. The results of these efforts will help to mobilize more options for people living with MS, and contribute to the growing movement to treat as early in the disease as possible.

Canadian MS Progression Cohort study

Multi-million-dollar initiative launched to study the progression of MS





This past March, the Multiple Sclerosis Society of Canada announced something that could change the way we understand, diagnose, treat and ultimately cure MS – a \$7+ million study will be launched within a year, to study progression in Canadians with MS over time.

The study will begin in early 2018 and will be conducted by a team of selected researchers from across Canada. They will establish a cohort of people living with MS in Canada, who will be studied over a period of time spanning at least 5 years. The MS Society is partnering on the project with Biogen Canada and Brain Canada who are each contributing more than \$2 million to the project. This work would also not be possible without the remarkable contributions of over \$2 million from PCL Construction and Bennett Jones LLP. With this funding, the team will have the resources to build infrastructure that will allow them to study progression from biological, lifestyle, and real-world perspectives.

This project marks a major milestone for the Canadian MS research and medical communities, as it's the first of its kind in the country that will address why certain people with MS progress in their disease and others do not, or why the rate of progression is faster for certain individuals and how that progression impacts them, their family

and communities. The research team will investigate biological changes that occur during progression, the effects of treatments on disease progression, real-world health outcomes, socioeconomic impacts, and many other factors. This initiative will not only generate one of the most comprehensive MS databases, but will also encourage coordinated and collaborative research efforts across Canada, engage the voice of people living with MS, and build an open resource that will not only benefi the Canadian MS research community but also researchers who look at other neurological diseases.

Chantal Milne (diagnosed with MS in 2012) profoundly moved the crowd when she shared her inspiring words at the announcement of the initiative. "With some of the world's best MS clinicians and researchers involved in this study, maybe by the time my daughter can ask me about what MS is and how it will impact me – maybe, just maybe – I will have the answer. That is where I want my MS journey to go, and the MS Progression study is giving me a road map to get there," says Chantal.

Ultimately, this project could impact how we treat MS, how we diagnose MS, how people live with MS, and change how we talk about MS progression altogether – this is a significant pursuit of knowledge, one that could dramatically change the landscape about what we know about MS.

≥ To find answers to any questions you might have about the trial, take a look at our Canadian MS Progression Cohort study: mssociety.ca/msprogressioncohort



MS Society funded project addresses fatigue in multiple sclerosis



Dr. Marcia Finlayson

An important goal of the MS Society is to fund projects that will improve the management of symptoms and quality of life for individuals with MS. Currently, we fund eight operating grants totaling nearly \$2 million in this research area. Dr. Marcia Finlayson, Vice-Dean (Health Sciences) and Director of the School of Rehabilitation Therapy at Queen's University, recently received approximately \$300,000 for her research targeting fatigue in MS. An occupational therapist by training, Dr. Finlayson knows firsthand the importance of effective interventions and lifestyle behaviours that help individuals with MS cope with the physical and mental challenges they face each day.

Her current project centers on a fatigue management resource called MS-INFoRm. Designed by Nadine Akbar and Karen Turpin as part of the MS Society's Scholar Program for Researchers IN Training (SPRINT) program, MS-INFoRm is a tool that enables people with MS to take a personalized approach to managing fatigue by focusing on factors such as sleep, exercise, mental exertion, depression and more. It allows them to establish goals and promote self-efficacy and reflection, while providing examples of how others have managed their fatigue and ways to manage stress and anxiety when performing fatiguing tasks. "There's strong evidence already that fatigue management education is effective for reducing the impact of fatigue," says Dr. Finlayson.

Nearly two-thirds of people with MS experience fatigue, making it one of the most commonly experienced symptoms. Fatigue has many consequences for individuals with MS, impacting employment, social relationships, and ability to engage in daily activities. The 200-person study led by Dr. Finlayson, in collaboration with the trainees who worked on developing MS-INFoRm, will look at changes in fatigue in people who've used the resource for three and six months, and compare the findings to those who used alternative resources. "We hope that the use of MS INFoRm will enable people with MS to take a more active approach to managing their fatigue so that fatigue has less impact on their daily lives," says Dr. Finlayson.

Trending in MS Research

Noteworthy advancements

Canada has the highest rate of multiple sclerosis in the world. It's because of our donors, event participants, and volunteers that we are able to fund some of the best MS research in the world, right here in Canada. To read more about the studies mentioned below and the latest in MS research, visit mssociety.ca/research-news, and follow @Dr_KarenLee & @MSSocietyCanada on Twitter.

MS_®

MS Society of Canada @MSSocietyCanada June 2

MSSOC and Centre for Drug Research and Development launches collaborative translational project on progressive MS focusing on ion channels in the brain & neurodegeneration.

#endMS

MS_®

MS Society of Canada @MSSocietyCanada · May 31

Study funded by MS Scientific Research Foundation finds that oral treatment minocycline reduces risk of converting to MS.

#ResearchBreakthrough

MS.

MS Society of Canada @MSSocietyCanada · May 11

Together MS Society & Fast Forward announce research project targeting the neurodegenerative process that contributes to progression in #MS.

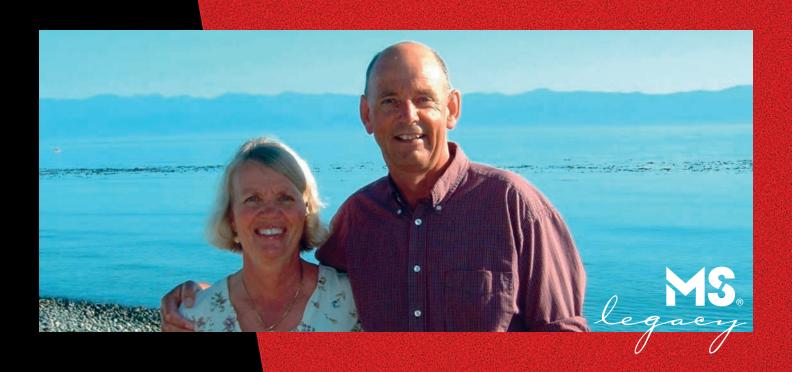
MS_®

MS Society of Canada @MSSocietyCanada · April 18

MS Society funded researchers explore the potential of antioxidant compound TEMPOL to limit disease progression in with MS-like disease! #MSresearch

"I'M BENEFITING FROM MS RESEARCH NOW, AND HOPE OUR ESTATE CAN HELP CANADIANS DOWN THE ROAD."

-Marion and Martin, British Columbia



Add a gift in your will to support Canadians living with multiple sclerosis, and help create a future free of MS.

Please contact Eli Clarke, senior development officer, major gifts at 416-922-6065 x3119, or eli.clarke@mssociety.ca