Vol 33 | SPRING 2021

MS PROGRESS Report

A match made in heaven

Mari-Lynn finds connection through our 1:1 peer support program

Mari-Lynn has always loved to connect with people. After reluctantly leaving her teaching career because of her multiple sclerosis diagnosis, Mari-Lynn looked for other places to belong. Over the last 18 years, she's volunteered with several organizations in various roles, searching for the right fit.

"I wanted to do something different. I was looking for a volunteer position that was flexible, and that I could do from home since I don't drive anymore."

Through a friend, she was introduced to the 1:1 Peer Support Program. After 3 years in the program, she's on her 10th match.

"I have great relationships with all of my peers — we are truly like friends. Even the matches that have officially come to an end, I am still in contact with on a friendship basis."

The 1:1 Peer Support Program is currently offered for individuals living with MS, and caregivers of individuals with MS.

The 1:1 Peer Support Program is a telephone and internet-based program for individuals living with MS and for loved ones of people with MS. The program matches a peer with a volunteer — someone who can provide a non-judgmental, understanding, and empathetic listening ear. The pair connects through whichever methods they prefer, and discussion topics are open to whatever they are both comfortable with. Volunteers often find themselves sharing their first-hand experiences with symptom management, or sharing programs, tools, and resources that worked for them.

And at a time when the COVID-19 pandemic has thrown so many communities into a state of isolation and fear, our 1:1 Peer Support Program is more important than ever for Canadians living with MS and their loved ones. The program helps people maintain a sense of community and connection when it's needed most — and offers personalized support through these difficult times.

While the benefits are clear for the person receiving support, Mari-Lynn also finds personal benefits from conversations with her peers.

"As humans, we are better together rather than separate, and we can always learn things from one another. I learn about things from my peers all the time!"

MESSAGE FROM THE PRESIDENT

Dr. Pamela Valentine

As we look ahead to another spring, I can't help but take a moment to look back and thank you for your generous support during one of the most challenging years we've seen as a community and country.

The COVID-19 pandemic upended lives across the nation — but for Canadians living with MS, the need has never been greater. More than ever, it's been crucial to have friends like you by our side, helping us to provide vital support services to the Canadian MS community and to ensure that we don't lose precious momentum in our research efforts to treat and cure this unpredictable disease.

To continue moving forward, we must keep our foot on the gas pedal. We must work together to continue funding important initiatives like the ones included in your MS Progress Report. As you'll read inside, your support advances groundbreaking research studies like the one led by Dr. Ruth Ann Marrie, or the efforts to accelerate treatments made possible by the International Progressive MS Alliance. With your help, we're also maintaining critical resources like our 1:1 Peer Support Program that has provided families across Canada with a much-needed sense of community and connection.

As a fellow Canadian, I'm sure I don't need to explain to you the power of community and connection. I trust you feel it every day — and I sincerely thank you for helping bring the power of it to your family, friends and neighbours living with MS. Together, with your ongoing support, we can build a world free of MS. Thank you in advance for your loyalty and commitment.

Sincerely,

Pamela Valentine

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

RESEARCH SPOTLIGHT:

Dr. Ruth Ann Marrie, PhD

> *"Research helps me to address questions that arise during my clinical work — and in turn, I hope will improve the care that we can deliver to people with MS."*
>
> — Dr. Ruth Ann Marrie

As a Professor of Medicine and Community Health Sciences at the University of Manitoba — and the current holder of the Waugh Family Chair in multiple sclerosis — Dr. Ruth Ann Marrie's research makes a life-changing difference for the MS community every day. Her current focus is on understanding the risks of comorbid diseases for people living with MS, like heart disease and cancer, to understand how to optimize clinical care for people living with MS for improved prevention, diagnosis and treatments.

The comorbid disease she's currently studying? Heart disease. **MS may be associated with an elevated risk of ischemic heart disease — and Dr. Marrie wants to know why.**

Her research will aim to determine whether premature subclinical atherosclerosis occurs in people with MS who do not have any strong risk factors for heart disease. This work will also aim to understand if the relationship between risk factors and atherosclerosis is the same in people with and without MS. The researchers will conduct a pilot study that will enroll 108 people with MS. As part of this study, participants will complete questionnaires, undergo physical and cognitive assessments, carotid ultrasound, and provide blood samples.

To help the Canadian MS community, it is crucial to know whether people with MS have an increased risk of heart disease. A better understanding of the reasons and risk factors for heart disease will guide future efforts to prevent, screen and treat heart disease designed specifically for people living with MS.

MS in the NEWS

Accelerating treatments for progressive MS

A new biomarker is on the horizon

The International Progressive MS Alliance (also known as "the Alliance") convened an expert panel, including people affected by MS, researchers, and clinicians to focus on biomarkers for progressive MS.

A biomarker is a "biological marker" — a material naturally found in the body that is the product of a disease. Its levels can be measured and are indicative or predictive of disease — and can be used to help determine the effect of treatment.

In order to help the MS community, biomarkers are crucial. Discovering a biomarker that can effectively and accurately measure progression is instrumental to accelerating the development of new treatments that can stop disease worsening for progressive MS.

In the September, 8, 2020 issue of *Neurology,* the Alliance's expert panel published their first paper, highlighting evidence for one of the most promising biomarkers for progressive MS called 'neurofilament light (NfL)', an important component of nerve cells that is released into the blood stream following damage or as a result of neurodegeneration.

Recent clinical trials in MS have demonstrated that NfL levels are a possible indicator of treatment effect in both relapsing and progressive forms of MS. NfL levels are able to predict relapse rates, brain tissue loss, disability progression and can be used as indicators of treatment response. NfL is also detected in healthy individuals, and its concentrations can increase with age.

In the publication, the expert panel outlined recommendations for additional research needed to overcome the current challenges in using NfL as a biomarker. These challenges include the development of standardized procedures for sample collection and analysis, understanding the differences in NfL levels for active inflammation versus disease progression, and the effect of age and comorbid conditions (e.g. effect on NfL levels from other neurological diseases such as Alzheimer's disease). Additionally, the Alliance is seeking to have drug regulators, like the FDA, recognize NfL as a measure of treatment response so that it can be used as a biomarker in clinical trials for new therapies.

Thanks to this publication — and the ongoing work from the Alliance — researchers are closer than ever to their longstanding goal of accelerating new treatments for people living with progressive MS.

The effects of COVID-19 on the MS community

This past fall, Dr. Steve Simpson-Yap of the University of Melbourne presented the first results of the COVID-19 & MS global data sharing initiative. This initiative was assembled by the MS International Federation, MS Data Alliance, and other data partners to inform MS clinical management during the COVID-19 pandemic. **In his presentation, Dr. Simpson-Yap indicated that older age, progressive MS, and higher disability are associated with higher frequencies of severe COVID-19 outcomes.**

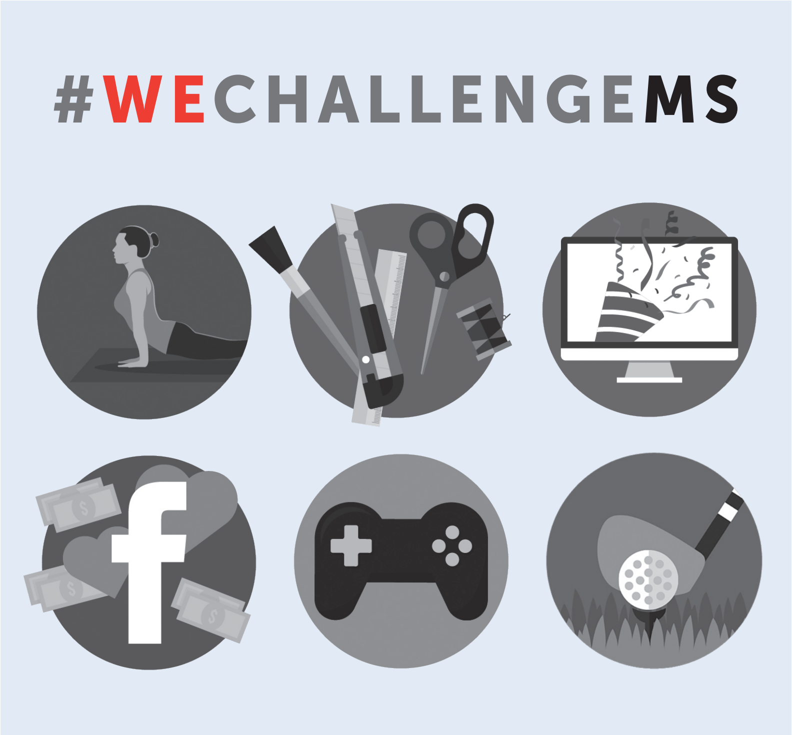
Dr. Amber Salter, professor at the Washington University School of Medicine in St. Louis, also presented initial results from COViMS, which is the North American initiative that captures clinical information and outcomes of people with MS who have developed COVID-19. **The initial analysis assessed COVID-19 outcomes in minority groups with MS. Data within the COViMS registry suggest that Black/African American MS patients were younger and more likely to have comorbidities (such as hypertension and morbid obesity) compared to White MS patients.** Furthermore, Black MS patients showed an increased risk for poorer COVID-19 outcomes (such as mortality, ICU admission and/or hospitalization) compared to White MS patients.

We will continue to share updates on our website as more research on COVID-19 and MS emerges.

Join the #WeChallengeMS movement

Achieving a world free of multiple sclerosis takes more than one person — and there isn't just one way to accomplish it. We Challenge MS is a nationwide movement turning people's ordinary hobbies and passions into extraordinary actions. Whether you choose to create, stream, write, bake, game, craft, walk, share, cycle, run, however you choose to challenge MS, know that, #WeChallengeMS together.

Sign up for ways to be part of the #WeChallengeMS movement at mssociety.ca



Leave a legacy of hope for Canadians living with MS

You can invest in a world free of MS and leave a legacy of hope with a bequest to the MS Society of Canada. Your legacy gift will help generations of Canadians living with MS and support research searching for new treatments and therapies.

For more information about legacy giving, please call Karine Trudel at 1-800-268-7582.

Build connections this World MS Day on May 30, 2021

Join members of the international MS community for World MS Day 2021, as we work to combat the disease and challenge the barriers it can create — barriers that too often leave those who live with MS feeling lonely and isolated. That's why our goals are to help people build community connections, foster self-connection and make the right connections to the health care they need and deserve.

Join the conversation when you post your own **#MSConnections**

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See you online!