



RESEARCH PRIORITIES DISCUSSION

The history of the Multiple Sclerosis Society of Canada is deeply rooted in a number of individuals from different backgrounds and places who realized the need to learn more about the disease. It was the actions of Sylvia Lawry whose brother had been diagnosed with MS that set everything in motion with a simple advertisement in the New York Times. Her advertisement also attracted the attention of Dr. Colin Russel, a neurologist and Evelyn Opal and Harry Bell, both whom lived with MS. All three had different backgrounds but it was through their desire to know more about MS, that the MS Society of Canada was created.

To this day, the varying stakeholders who make up the MS Society -- the person living with MS, the caregiver of their loved one with MS, the cyclist riding sixty kilometers for research, or the researcher trying to study the complexities of the disease, -- are all aiming for one thing: to further understand MS so that one day we can end MS.

Since 1948 the MS Society of Canada has contributed \$140 million towards MS research. This investment of funding has enabled Canada to create a pipeline of exceptional MS researchers and has become a leading contributor to discovery in the field of MS.

However, significant questions remain unanswered with regard to the cause, prevention and cure of MS.

To aid the MS Society in mapping out research priorities for the next 10 years, a series of discussions took place across the country with the intent of understanding varying experiences and perspectives. Seven full-day live and interactive discussions were held, bringing together both the research community and people affected by MS. Two key questions were asked: What does MS research mean to you? What are your research priorities?

WHAT DOES MS RESEARCH MEAN TO YOU?

In roundtable discussions around the country, people living with MS, people affected by MS, donors, young researchers/clinicians and MS Society staff discussed what MS research meant to them. The sessions allowed for open discussion of everyone's perspective, from the person living with MS stating that research gives us the ability to unlock doors to new treatments for MS and other diseases; to researchers stating that MS research means trying to live up to the expectation and hopes of the MS community. Although participants came from diverse backgrounds, it was clear that communication about research is crucial

as is the need to increase knowledge. The end result is increased hope, the common denominator that keeps research activities moving forward.

Hope

The most significant theme emerging from the discussions about what research meant to those participating in the dialogue was **hope**. Hope in MS research meant different things to different people, but at the foundation of this notion was simply that research provided both optimism and expectation of what the future could bring in relation to finding the cause and cure of MS.

“Hope to find a cause and cure.” Atlantic participant

“Hope, maybe not for now but for the future.” Alberta participant

“Hope for the future, a healthier future.” Manitoba participant

“To me, MS research represents hope – it is most powerful morale booster to someone living with MS. Knowing that MS research is on a promising trajectory has a powerful psychological effects of someone living with a chronic condition.” Ontario participant

“Hope for all people dealing with all aspects of MS.” Saskatchewan participant

“Promise of a brighter future.” British Columbia participant

For some, hope equated to research resulting in a cure. For others, research to provide for a healthier, more manageable future in living with MS was also important. The notion that research could also improve one’s quality of life was as important as research for a cure.

Communication

Another important aspect of the discussion in answering the question of what research meant to participants was the importance of **communication**. There are several facets to this theme. One facet was acknowledgement from both those who conducted the research, and from those who lived with MS, that

greater engagement with each other was required. A researcher understanding what it meant to live with MS on a daily basis would benefit as much as a person living with MS understanding research outcomes in layperson terms. The two-way dialogue, between people living with MS and the researcher, could be a powerful tool in understanding disease-related issues and translating them into critical, underlying information in a research setting. In the same fashion, a person living with MS, hearing directly from a researcher about their work, provides a powerful tool of hope, of better understanding of what the future could promise through research.

“Hearing both the good and the bad results of research. Continual communication to stakeholders is important.” Atlantic participant

“More communication between researchers and the person they are hoping to impact.” Alberta participant

“Support and clarity in communication.” Manitoba participant

“Most importantly, MS research needs to be effectively communicated to all groups in the MS community. The most promising research in the world becomes meaningless to a lay person if it is impossible to understand.” Ontario participant

“Communication to lay persons that creates engagement and interest in research.” Saskatchewan participant

“Knowing that people are listening to what we are experiencing and trying to find answers to why it affects everyone differently.” British Columbia participant

Knowledge

A third critical theme that emerged from the discussion related to what research meant to participants was **knowledge**. Not only are there many unanswered questions related to MS research, the recent worldwide interest in CCSVI also emphatically highlighted the need for clear translation of research into understandable, meaningful terms. At the end of the day, the knowledge gained from research should be distilled to answer the key question a person living with MS might pose: “What does it mean for me?” Translating research into

understandable and meaningful language can empower the person living with MS to make informed decisions about their own treatment and care.

A second important aspect related to the discussion of knowledge is the actual translation of research into outcomes that can be applied in day-to-day living. The term “bench to bedside” is most commonly used in this context, but the notion is inherent to the hope a person living with MS might have in research. This is again, where dialogue between researchers and people living with MS is critical. What does “bedside” mean for the person with MS? In other words, in the vast amount of research that needs to be translated from bench to bedside, what are the priorities? Knowledge sharing can also uncover gaps or information that may have been overlooked leading to further discovery and analysis.

“Translation of how research is applied is important, it needs to be practical and accessible to people” Atlantic participant

“Research is a long and complex process, we need to move towards researchers better communication of what they do, this is a building block.” Alberta participant

“Outcomes that translate to practical quality of life increases on a day to day basis connecting the science with the lived experience of MS.” Manitoba participant

“In the long term, this question means understanding how my research fits in with the broad spectrum of MS research. Also, understanding the needs of the MS community with respect to how I can prioritize my research, contribute to revealing the cause of MS and ensure that my research is relevant and can be translated one day.” Ontario participant

“To bring more knowledge to people with MS, caregivers and the general public.” Saskatchewan participant

Hope. Knowledge. Research. Now.

A critical aspect in engaging people living with MS directly in our research process has uncovered a priority that should be explored further. We learned through our discussions during these nationwide research priorities sessions that research knowledge made an impactful contribution to the hope of people living with MS. However, not only did they express research into a cause, cure and treatments as critical to sustaining their day-to-day hope, it was also important to acknowledge that this work needed to be done now. It is known that research and the processes related to research take time, resulting in the accepted notion that people would be patient while research ran its course. It has become increasingly evident, though, that this notion should not be accepted nor is it sufficient. The need to speed up that process of research to find a cure here and now needed to occur. Decisions related to directed research, involving people with MS as laypersons in granting processes, and understanding the need for exploring ways to invest in the traditionally underinvested area of translational research – these are some of the things that can be improved to challenge the view that research takes time. Accelerating the pace of research is just as critical to the hope of people living with MS as the research itself.

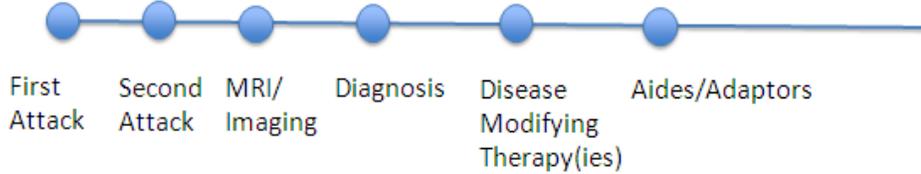
“I am tired of living in a perpetual state of ignorance about how my MS occurred, why it progressed the way it did, why I am better, and what I need to do to stay well.” BC participant

“Research takes time!” Alberta participant

“Knowing that MS research is on a promising trajectory has a powerful psychological effect on someone living with a chronic condition.” Ontario participant

MS PROGRESSION TIMELINE

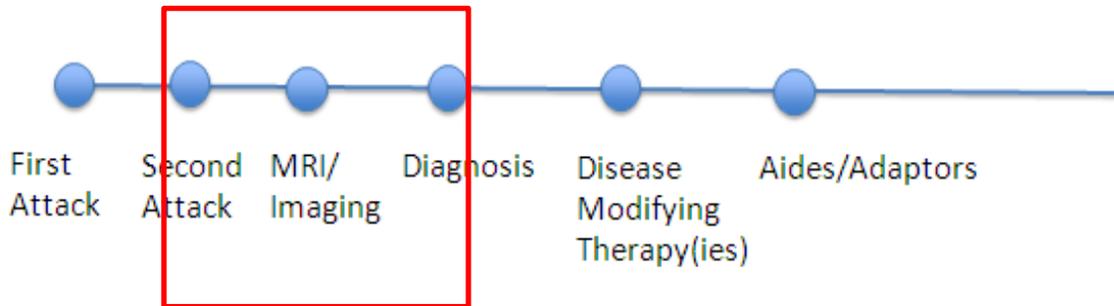
The participants were asked to provide insights on the MS progression timeline (see below), that outlines specific milestones in one's journey with MS (see



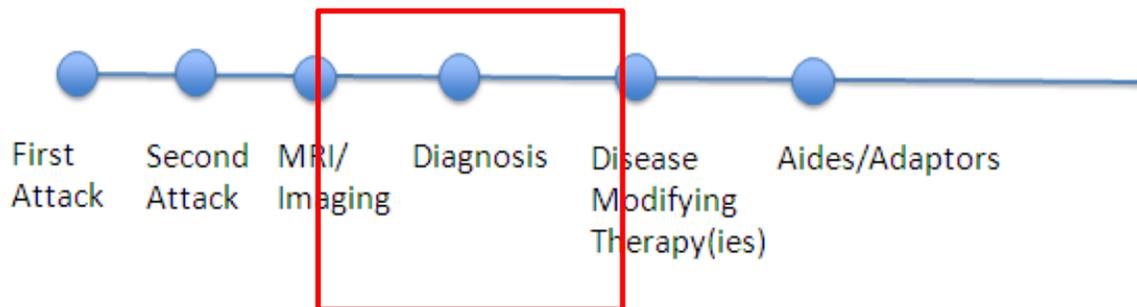
Appendix for further descriptions). It should be noted that the MS progression timeline was designed to spur discussion and does not necessarily reflect how an individual's MS progresses. For MS researchers, we requested that they highlight areas where we have made advances and areas that required more work. Through this activity, each stakeholder was able to better appreciate the other's perspective and most importantly, we were able to develop the research priorities from these discussions. The following common answers and themes were generated from this exercise.



Person affected by MS	Researcher/Clinician
<ul style="list-style-type: none"> Anxiety Uncertainty and fear Worry over diagnosis Appearance of first subtle symptoms <p>★ The star indicates earlier events which occur before the first attack, for example genetic and lifestyle factors which may contribute to a predisposition to MS</p>	<ul style="list-style-type: none"> Symptom recognition and management Preventing progression Observing inflammation

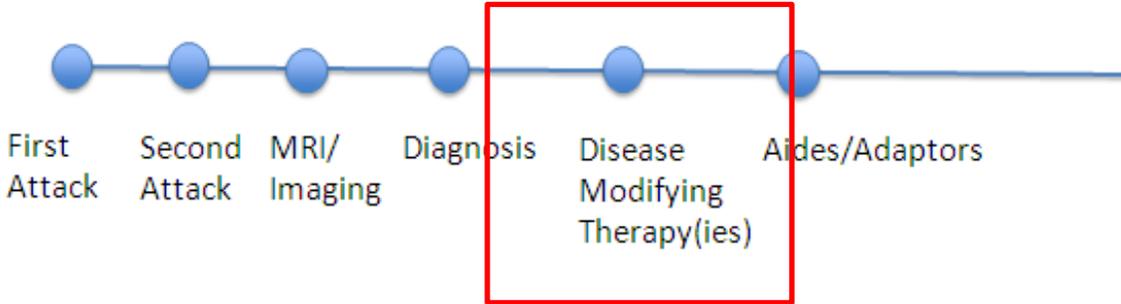


Person affected by MS	Researcher/Clinician
<ul style="list-style-type: none"> • Limited access to neurologists and MRI scan technology • Long wait times for scans and in between scans • Extended wait time between scan and diagnosis • Seeking information on imaging and evaluating other screening modalities • Concern over misdiagnosis 	<ul style="list-style-type: none"> • Developing more accurate methods of early detection • Examining linkage of MS with other diseases • Improving identification of lesions • Determining mechanisms responsible for remission and remyelination

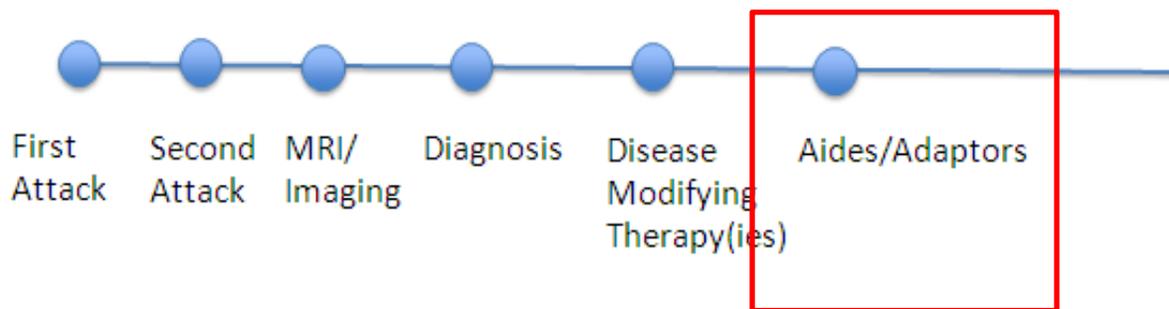


Person affected by MS	Researcher/Clinician
<ul style="list-style-type: none"> • Shock, fear, grief, and pity • Eventual acceptance • Personal research (i.e. Google), self-education • Seeking information from MS Society • Advocacy work, volunteering • Involvement in support groups 	<ul style="list-style-type: none"> • Standardizing criteria for diagnosis • Identifying and monitoring symptoms as reflected by the MRI • Observing severity of lesions • Evaluating correlation between lesions and disability

<ul style="list-style-type: none"> • Effect of disease progression on relationships and social interactions (personal, work) 	
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Person affected by MS	Researcher/Clinician
<ul style="list-style-type: none"> • Frequent clinic visits • Questions about treatment options • Transitioning between therapies • Eligibility criteria for and affordability of therapies • Managing symptoms and side effects • Lifestyle changes: diet, exercise, stress management, sleep • Investigating potential complementary and alternative therapies • Frustration over lack of therapies for progressive MS • Understanding why some drugs work and others do not 	<ul style="list-style-type: none"> • Consistent communication with patients following diagnosis • Markers for RRMS vs PMS • Dose, side effects and target population for DMTs • Markers for progression • Increasing speed of drug screening and validation • Examining impact of DMTs on pediatric patients • Assessing alternative therapies • Current treatments do not focus on repair or how to rebuild myelin



Person affected by MS	Researcher/Clinician
<ul style="list-style-type: none"> • Home modifications • Adapting to accessibility barriers • Difficulties with mobility and transportation • Anxiety over seeking assistance • Engaging in rehabilitation • Concerns over cost for aides • Acceptance of using assistive devices 	<ul style="list-style-type: none"> • Assessing accessibility and efficiency of aides • Developing tools for long-term patient monitoring • Monitoring repair/remyelination

Some groups wondered about the order of events across the timeline, noting that given the complexity of the disease and the variance of disease courses amongst individuals, the events in the timeline do not always occur in that order and often overlap.

Many of the groups drew arrows across the timeline to signify events which take place over a much longer time course. Statements such as “information gathering”, “general decline”, “denial of diagnosis”, “symptom management”, and “awareness and advocacy” were marked on the timelines as events which occur throughout a lifetime for someone with MS.

It was through the discussions of the MS progression timeline that participants in every Division identified and created a list of areas that they felt were areas of MS research that needed further work. Many of the lists contained over 20 topics that participants felt warranted further research. Each participant was given an opportunity to prioritize the list, resulting in a top 5 research priority list from each Division.

Using a point system (see appendix) a consolidated list of the top 5 research priorities was created as follows:

- 1) Cause
- 2) Repair/Remyelination
- 3) Life Modifying Therapies (Exercise, Diet , Quality of Life)
- 4) Progressive MS (tie)
- 4) Diagnosis (Tie)
- 5) Cognition and Mental Health

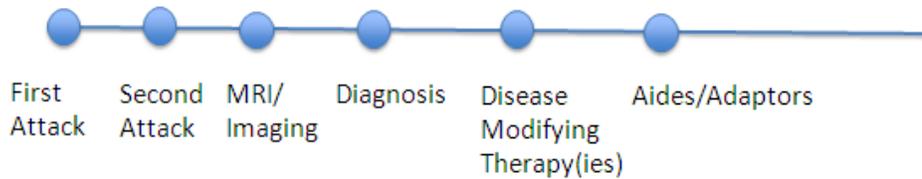
The next step is for the MS Society to develop strategies that consider the expressions of these stakeholders.

It is interesting to note that when we embarked on this process, we truly believed that the priorities between the various stakeholders would be very different. However, as the discussion has revealed, priorities are very much aligned across perspectives – even with the different stakeholder groups taking part in the discussions.

As we move forward with further refining our research priorities moving into the future, the MS Society will continue to consult our core stakeholders: those living with or affected by MS, donors, staff and the researcher/clinician communities. We thank all participants for their involvement in these important discussions and welcome continued feedback. These discussions have helped foster discussion, collaboration and partnership – important elements as we continue in our efforts to end MS.

Contact info:
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Appendix



There is no typical case of MS, but we are providing some context around the identified milestones that were used for the MS progression timeline. It should be noted that the MS progression timeline was designed to spur discussion and does not necessarily reflect how an individual's MS progresses.

First Attack: the first symptom of MS is typically loss of vision in one eye or numbness of the limbs. This can also be referred to as Clinically Isolate Syndrome (CIS)

Second Attack: Symptoms similar to the first attack, however, further attacks follow and recovery may be incomplete

MRI/Imaging: MRI is the preferred method of detecting MS.

Diagnosis: confirmation of MS requires diagnostic test (MRI, evoked potential, spinal fluid examination, CT scan), full history review of current symptoms, past symptoms, previous illness, use of medication and family history of neurological diseases. Multiple abnormalities in time and space including the diagnostic test is what a neurologist needs to consider in making a judgment on MS diagnosis.

Disease Modifying Therapy(ies): there are several disease modifying therapies that are available, a person living with MS has a choice of which treatment option to try.

Aides/Adaptors: difficulty walking is a problem in MS. The ability to be mobile is perceived to play an important role in the quality of life. There are different aides that help those living with MS to stay mobile and independent.

The Top 5 Research Priorities by Division

<u>DIVISION</u>	<u>TOP RESEARCH PRIORITIES</u>
Ontario	<ol style="list-style-type: none"> 1. Treatment options for progressive MS 2. Cause 3. Regeneration and repair 4. Biomarkers for MS 5. Stem cell therapy
Quebec	<ol style="list-style-type: none"> 1. Biomarkers for MS 2. Physical exercise 3. Remyelination 4. Stem cells 5. Cause/Progressive MS (tie)
Manitoba	<ol style="list-style-type: none"> 1. Cause 2. Progressive MS 3. Quality of life – day to day 4. Remyelination and repair 5. Symptom management
Atlantic	<ol style="list-style-type: none"> 1. Exercise 2. Cognition 3. Repair and remyelination 4. Immunology and inflammation 5. Cause/alternative therapies/burden of disease – economics, social/progressive MS (tie)
Saskatchewan	<ol style="list-style-type: none"> 1. Cause 2. Repair and remyelination 3. Progressive MS 4. Prevention 5. Progress of disease
British Columbia and Yukon	<ol style="list-style-type: none"> 1. Disease management/healthy living (exercise, diet, vitamins) 2. Cause 3. Speed and accuracy of diagnosis/prevention of progression (symptom management) (tie) 4. Progressive MS/Cognition (tie) 5. Neonatal
Alberta and North West Territories	<ol style="list-style-type: none"> 1. Repair 2. Cause 3. Biomarkers 4. Life modifying therapies 5. Cognition and mental health

The top 5 research priorities for each Division were tabulated by a research list that was created through the discussions of the MS progression timeline. Through the discussions the moderator wrote down the various research areas that were being highlighted by the participants. At the end of the discussion, each participant was given 5 stickers (votes), and they were asked to place a sticker next to the research area they felt was a priority to further conduct research. All participants were free to place a sticker next to a research area more than once. The moderator tallied the votes and created the top 5 research priorities for each Division.

The overall top 5 research priorities were created by giving each Divisional top 5 research priorities points depending on their ranking.

Ranking 1= 5 points
Ranking 2 = 4 points
Ranking 3= 3 points
Ranking 4 = 2 points
Ranking 5 = 1 point

In the end, the points for each research area was added and led to the overall top 5 research priorities.