



2019 Impact Report

# Building on the Momentum



## Our Vision

A world free of multiple sclerosis.

## Our Mission

To connect and empower the MS community to create positive change.



Our efforts to create a world free of MS and our progress towards that vision is made possible every day with the collective support of our MS community.

**We'd like to thank you, our donors, partners, volunteers, and all those who contribute, for your generosity.**

Your investment of time, money, and energy means we can provide the crucial support services that our community needs, while investing in promising research projects aimed at ending this disease once and for all. Together, with your support, we can mobilize a nation to accelerate the pace of MS breakthroughs — and to empower Canadians affected by MS to live their fullest lives.

“*Canadians affected by MS are the heart and soul of our organization. Because of you, we can continue to support world-class groundbreaking MS research, while providing programs and essential support for the thousands of Canadians affected by the disease. It will take the global community to create a world free of MS, and by working together, we will get there faster.*” – **Pamela Valentine, President and CEO, MS Society of Canada**

“*Our new strategic plan has built upon the work of the entire MS community, and empowered us to move closer to our vision — a world free of MS. We're making real progress and gaining momentum each day thanks to your support. Without you, it would be impossible to envision a future free of MS.*” – **Valerie Hussey, Chair, Board of Directors, MS Society of Canada**

“*Thank you for your outstanding commitment to ensuring Canadians living with MS, and their families, can participate fully in all aspects of life. Your unwavering leadership in countless communities across the country is what drives our ability to deliver on our mission — to connect and empower the MS community to create positive change. Working together, we can help improve the lives of tens of thousands of Canadians affected by MS.*” – **Nancy Love, Chair, MS Scientific Research Foundation, MS Society of Canada**

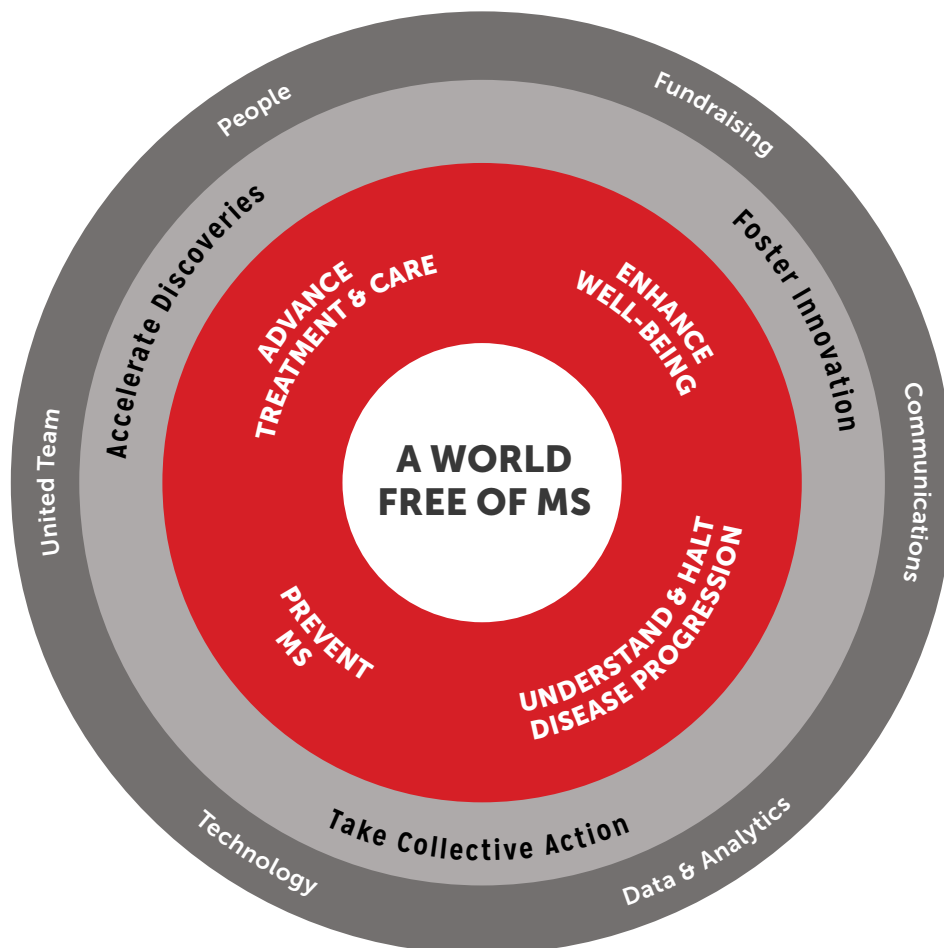
“*Being involved with the MS Society programs has provided me with a sense of belonging and community, which I often feel I have lost since being diagnosed. The relationships I have made through these programs have been the motivation I need to turn a devastating diagnosis into a meaningful and purposeful life. Thank you for supporting the MS Society — knowing I have their support reinforces that I am not alone in this fight against MS.*” – **Amanda Simms, living with MS**

“*When my sister was diagnosed with MS during my undergrad, I knew I wanted to contribute to the field of MS in order to try to make a difference. The investments you make to the MS Society help to further our understanding of MS and allow PhD students like myself to develop necessary skills to grow as scientists. Thank you for your continued support and together, one day, we can hopefully see a world free of MS.*” – **Yodit Tesfagiorgis, BMSc, PhD Candidate, Microbiology and Immunology, University of Western Ontario**

# Discover. Innovate. Act. Our Strategic Plan

This year we launched Discover. Innovate. Act., a bold and ambitious strategy that sets a new chapter in our journey with a mission to connect and empower the MS community to create positive change. It builds on the momentum of the work already done and sets us on the path to achieving our vision.

Our strategy focuses on four impact goals that will have long-term health, social, and economic impacts on the MS community and beyond. We will assess and track our progress towards these goals over time using a robust impact measurement framework, one that reflects the collective efforts of the MS community.



## The Power of the MS Community

Fundraisers  
 Health care providers  
 Caregivers  
**People with MS**  
 Family  
 Advocates  
 Policy-makers  
 MS Society staff  
 Researcher  
 Partner organizations  
 Employers  
 Volunteers  
 Friends  
 Allied communities  
 Donors

Our journey towards a world free of MS is fueled by the collective action of the MS community, here and around the globe. By working together with this diversity of perspectives and strengths, we can drive change, accelerate research, tackle challenges, and achieve the outcomes needed by Canadians affected by MS.

# 2019 Your Impact at a Glance

## Fostering capacity

 **RAISED \$52,194,000**  
from generous donors

 **LEVERAGED \$1,167,451**  
in partnered research funding

 **SUPPORTED 332**  
MS researchers & trainees\*

 **ENGAGED 424**  
trained volunteers to deliver programs

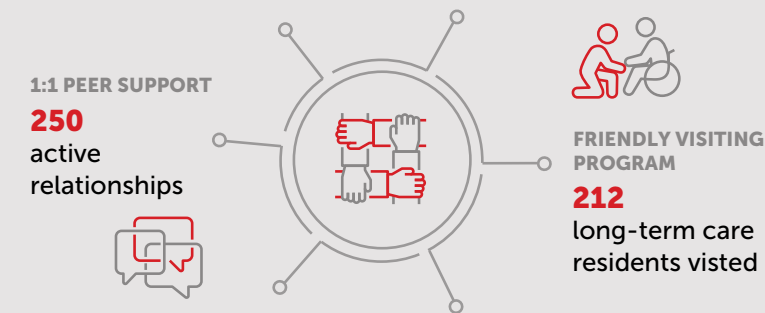
 **LAUNCHED**  
the Community Engagement Model to empower leadership volunteers

 **HELD 1<sup>ST</sup> NATIONAL YOUNG ADULT SUMMIT**  
80 participants

## Providing support

 **KNOWLEDGE NETWORK**  
**6,107** people affected by MS supported by an MS Navigator

**QUALITY OF LIFE EQUIPMENT GRANTS**  
**1,603** people received funding assistance for medical equipment (Total value over \$1M)




**SUPPORT GROUPS**  
**227** support groups met from coast to coast

**VOLUNTEER LEGAL ASSISTANCE PROGRAM**  
**319** people received assistance with a **90% success rate** on income support applications

## Expanding connections

**80** government meetings held during Day on the Hill, advocating to improve #LifeWithMS



 **36,930** participants came together in solidarity at **154 MS Walk and MS Bike events** across the country supported by **1,768** volunteers



**340** people involved in an **I Challenge MS** event



## Advancing MS knowledge

 **\$9,512,135** invested in research\*

**end MS**  
Hosted largest Canadian scientific conference focused on MS, attracting **300 attendees**



**160** in-person and virtual education events held across the country with **4,500** people reached



**NEW!**  
Bilingual MS resource for healthcare professionals

**NEW!**  
Women's Health & MS webpage in partnership with the LOVE YOU by Shoppers Drug Mart™ program




## Informing decisions and empowering action


 **20,000** #MakeMSMatter letters sent by supporters to influence federal election candidates

 **82%** surveyed said they'd take action after being served by an MS Navigator

 **69,938** followers across our social media channels

 **1,696+** mentions in the media to help us reach the MS community

**1,500** people attended Women Against MS (WAMS) galas in six cities across Canada



We're **1 of 48** organizations coordinating globally through the MS International Federation

We're **1 of 6** managing members leading the International Progressive MS Alliance to tackle progressive MS

\* Note: research is funded by the MS Society of Canada and the MS Scientific Research Foundation.

## Advance Treatment and Care

Having access to a variety of effective treatment and care options for symptom management, wellness, and self-care will help people on their unique MS journey. We support a broad portfolio of research that leads to better understanding and new and more effective treatments, we advocate for access to medicine, and provide programs and services that support those living with MS to live their fullest lives.



## Increasing Treatment Options

In the last 20 years in Canada, we have seen incredible progress in understanding and treating MS. Available treatment options have grown from three disease-modifying therapies to 15, with more treatments currently in development. This extraordinary rate of progress in such a short period of time is a direct result of the collaborative efforts of the MS community.

Your support means that we can continue to invest in this research to transform disease management and improve the lives of people living with MS.



“Only two decades ago, there were very limited treatment options for people with MS. Much of the time, we would tell people that we had nothing to stop their disease. Now, we have hope and treatment options, even for some people who have progressive forms of MS. **As a clinician, I’m able to help more people with MS live healthier and fuller lives because I can target their MS better – offering more options that fit their MS journey, personalizing their treatments and wellness.** Continuing to fund this kind of research is critical to reaching our ultimate goal – that we could predict and personalize MS care, and maybe even prevent MS from occurring altogether.”

– Penny Smyth, MD, FRCPC



## Exploring the Next Leaps in Science

We invest in research to explore the latest, innovative treatment options for MS. This year we partnered with industry and other research organizations to launch studies that examined a spectrum of new treatments, from using cannabis to manage MS symptoms, to understanding bio-mechanisms that slow progression, to applying artificial intelligence to predict the right treatment paths for patients.

One of these studies [showed](#) that blocking ALCAM (a molecule in our blood that carries immune cells into the brain and spinal cord) can slow progression and reduce disease severity in human cells and mice. Early results from studies like this show promise for new treatments.

## Ensuring Canadians Have Access to MS Medicines

Patient input is critical to informing the review of new drugs and in making recommendations to publicly funded health plans for reimbursement of MS medications. We continue to work with patients and patient groups to gather this important information that ultimately results in the availability of more treatment options for all types of MS.

## A Holistic Approach to Care

Helping people with MS live their fullest life goes beyond medicine, encompassing all aspects of care. We continue to deliver a wide range of programs and support for people affected by MS in communities across the country, assisting over 10,000 people in 2019.

“*I was only 20 years old when I was diagnosed with MS and it was a complete shock to me. I had no idea what MS was, and it was terrifying to have to go through this huge change in my life alone. **The Peer Support Program made me feel comfortable in my own skin again.** It gave me back the confidence I lost after my diagnosis and allowed me to [develop a friendship](#) that I will cherish forever.” – Jessie, living with MS*



# Enhance Well-Being

We are helping remove physical and social barriers within communities to ensure access to opportunities and supports for people affected by MS.



## You Helped Make Canadian History!

In this historic moment, [“An Act to ensure a barrier-free Canada”](#) was adopted by both Houses in Parliament. Known as the Accessible Canada Act, this is the first-ever piece of federal legislation aimed at improving accessibility for people with disabilities. Through the advocacy efforts of the MS community, the Act includes the term “episodic” in the definition of disability – a huge, and historic step in recognizing the nature of many diseases, including multiple sclerosis.

This new law will help identify, remove, and prevent accessibility barriers that people living with MS face daily across the country – in the workplace and in other areas that fall under federal jurisdiction.

“Some of the greatest obstacles, when dealing with MS, have to do with the invisibility of the disease. When I was newly diagnosed, I quickly learned that my employer did not understand the episodic nature of MS and couldn’t provide the support I needed. I was forced to leave the organization.

Now, in my volunteer advocacy work with the MS Society, ***I’ve seen the inclusion of episodic illness in the definition of disability, which is such an important mind shift for all Canadians and employers.*** Having things you’ve worked on, and advocated for, come full circle is a great feeling.”

– Julia Stewart, living with MS



## Looking Beyond the Disease

Investing in research to better understand how different factors (or social determinants of health) affect people living with MS is crucial to advocating for change in the health system, influencing policy and equalizing care for everyone. For example, a [recently funded study](#) found that lower socioeconomic status and education levels are associated with a higher risk of disability progression in MS.

## Advocating for Policy Change

At 15 weeks, Canada has one of the shortest periods of sickness protection among industrialized countries. A large consortium of stakeholders came together in a roundtable discussion to examine how to extend EI Sickness Benefits to 26 weeks, [resulting in a report](#) to guide government policy-makers.

“*The uncertainty of life with an episodic disability can be one of the most debilitating aspects. With that often comes stigma, and even the inability to sustain meaningful employment. People with MS don't know when a relapse may happen or how long it will last. **Having support through EI sickness benefits would create some form of predictability in a life that is incredibly unpredictable.** Knowing you can work and be supported if and when you need it would completely change the lives of people living with MS.*” – Patricia Rzechowka, living with MS

## Easing Access to Existing Supports

We provide programs to assist people living with MS to access financial and other supports available to them. In 2019, over 300 people used our Volunteer Legal Assistance Program (VLAP) for professional advice to help them apply for income support. Ninety per cent of these applications were successful, with up to \$1,600 a month in direct financial aid.



“*There is no possible way I could manage getting the information expected of me without help. The forms provided a lot of stress for me and were impossible to fill out as my cognition is worsening, but then I was introduced to VLAP and they made sense of everything. **I am very grateful for the VLAP service as they made it easier for me to fill out my forms correctly and to access Long-Term Disability and Disability Tax Credit.** Thank you so much VLAP for allowing me to be part of society again.*” – Cameron Campo, living with MS

## Understand and Halt Disease Progression

Understanding the complexities of MS progression will help effectively stop MS in its tracks. We continue to invest in research and support world-wide efforts to better understand how and why MS progresses.



## CanProCo, a Canadian Collaboration Continues

A significant portion of individuals initially diagnosed with relapsing-remitting MS will go on to develop [secondary progressive MS](#). Progression is a challenging reality, and despite major advances in research to delay progression, it is not fully understood.

The Canadian Prospective Cohort Study to Understand Progression in Multiple Sclerosis (CanProCo) is an unprecedented [multidisciplinary](#) and pan-Canadian effort directed at understanding progression in MS drawing on the expertise of nearly 50 researchers at sites across Canada.

This unique study will collect a broad range of data from 1,000 patients to help deepen our understanding of progression, leading to improved diagnosis, treatment, long-term monitoring, prediction, and identification of those likely to progress, and potential strategies to prevent progression in MS.

This year, [additional investment](#) from government and industry brought the total to more than \$10 million for the project. Since its inception, we have leveraged our initial investment by over four-fold through our partnerships with government, industry and not-for-profit organizations to support CanProCo.



“*It is my hope that this study will allow for a better understanding and more accurate depiction of what life with MS is really all about. It has the potential to be a [game changer](#) because a lot of information is being collected over a duration of time. The results could be very powerful and make an impact in influencing positive change in people’s lives.”* – Heidi Pylypjuk, living with MS

## Unravelling MS at the Molecular Level

Identifying the underlying factors involved in disease progression could mean that people with secondary progressive MS would have more treatment options that would slow, halt, or even repair the damage from their disease.

This year we continued to support research aimed at understanding the fundamental (molecular) causes of MS, including \$1M project that looks at the role of [microglial cells](#) (immune cells in the brain and spinal cord) in progressive MS.

Researchers have discovered a specific immune cell in the gut that can travel to the brain to reduce inflammation in mice with MS. The research found a lower level of these cells in the guts of people living with MS as well, showing that these cells may be 'recruited' to the brain to help fight MS. [This key finding](#), published in the renowned journal, *Cell*, raises questions about the importance of lifestyle, specific foods, or therapies that could create an optimal gut environment that allows these immune cells to flourish.

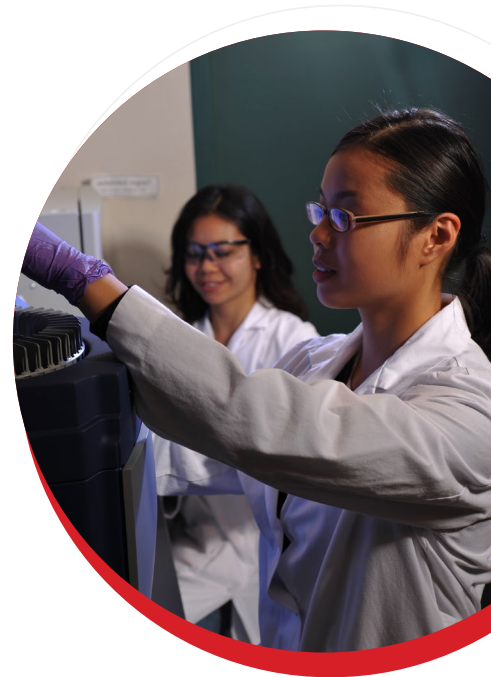
## Bringing the World Together to Study MS Progression

There is an urgent, unmet, worldwide need for life-changing solutions for people affected by progressive MS. The [International Progressive MS Alliance](#) is working to answer this need, rallying the global community in an unprecedented collaboration of MS organizations, researchers, healthcare professionals, pharmaceutical companies, trusts, foundations, donors, and people affected by MS. As a founding partner and executive member of the Alliance, we're driving the research agenda in progressive MS and bringing together the brightest minds in the world.

By working collectively across many disciplines, the Alliance can accelerate research in ways not possible by one country alone. Like collecting large numbers of MRI images to look for biomarkers for progression, creating a rich pipeline for potential molecules for drug development, and creating a global clinical trial platform that helps move molecules to treatment faster.

“*Research is key, it's fundamental, and is absolutely critical when you've got a complex problem. And understanding progression is about as complicated as it gets in multiple sclerosis. **So, collaboration is essential, bringing the best brains of the world together to focus on this issue.***”

– Dr. Alan Thompson, Chair of the Alliance's Scientific Steering Committee and Dean of University College London Faculty of Brain Sciences



## Prevent MS

Stopping MS before it starts will reduce the number of people who develop the disease. We continue to invest in research that examines the factors that could lead to MS and how people might shape their lives to reduce their risk of getting the disease.





## “Imagine if we could prevent even one person from getting MS?”

What if we could identify the causes of MS? What if we knew which factors contributed to someone being at risk for developing the disease?

We know that there are risk factors that contribute to someone getting MS. Risk factors are exposures in a person’s life cycle that increase the chances of that person developing MS. Some are in our control; some are not. We already know about some factors that increase a person’s risk of getting MS – such as smoking and exposure to second-hand smoke, childhood and adolescent obesity, vitamin D insufficiency, and genetics.

We continue to fund research focused on risk factors, including [nutrition](#) and [immune system infection](#), and their connection to MS. Investing in this important research means that we can make sure those living with MS, their families, and the public have the knowledge they need to make conscious decisions about shaping their lifestyle and health.



“For me to be able to have an open discussion with my kids – to say, here’s the evidence-based research that shows because I have MS, here’s how likely you are to have MS but **here’s what you can do to potentially prevent it – that’s priceless**. When the MS Society came out with vitamin D recommendations in 2018, this was a huge step in educating the public on what they could do for themselves to help combat MS.”

– Kent Kirkpatrick, diagnosed with MS in 1998

# Bringing the MS Community Together

To reach our vision of a world free of MS, it is critical that we provide opportunities for our community to connect, share knowledge, and ultimately, take action.

## endMS Conference (December 8-11, 2019)

The [endMS Conference](#) is the largest MS scientific conference in Canada showcasing the latest in MS research. We brought together over 250 MS researchers, trainees, health professionals, policy makers, and other members of the MS community from across the country to create a strong, connected MS network and accelerate research in MS. Participants learned more about the mechanisms of MS, shared information about new treatments, and explored how research can be translated into programs and policy.

The theme of the conference aligned with our new strategic impact goals: advance treatment and care, enhance well-being, understand and halt disease progression, and prevent MS.

### “The Top 10 Things I Learned (as a Lay person) at the Conference”

1. Always true – earlier diagnosis and treatment is better.
2. Mental toughness – find the positive in every negative situation.
3. Brain – build your cognitive reserve.
4. Eat better, exercise more.
5. The future is personalized care and treatment.
6. Vitamin D – the full value of taking it isn't clear – but it can't hurt – so take it!
7. There is a business case to solve MS puzzle and find a cure.
8. Drugs don't work for people that don't take them.
9. Importance of bio-markers – you need them to recognize and measure progress or you won't know if you are getting there.
10. Therapies – need holistic approach to managing.

– Beverley MacAdam, conference participant living with MS

“The endMS Conference is the occasion in which all of us come together and get excited about all the things we're hearing. It is also about inspiring the next generation, and it is inspiring for all of us – it motivates us to aspire to greater heights in light of all the wonderful progress that has been happening.” – Dr. V. Wee Yong, Hotchkiss Brain Institute, University of Calgary

**189**  
delegates

**120**  
trainee  
delegates

**37**  
speakers

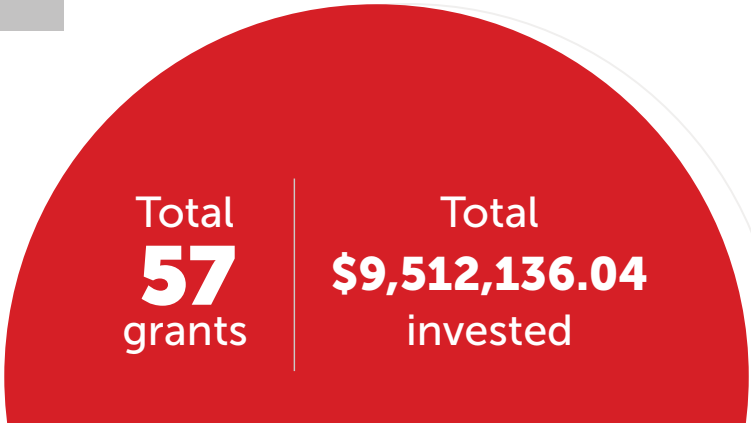
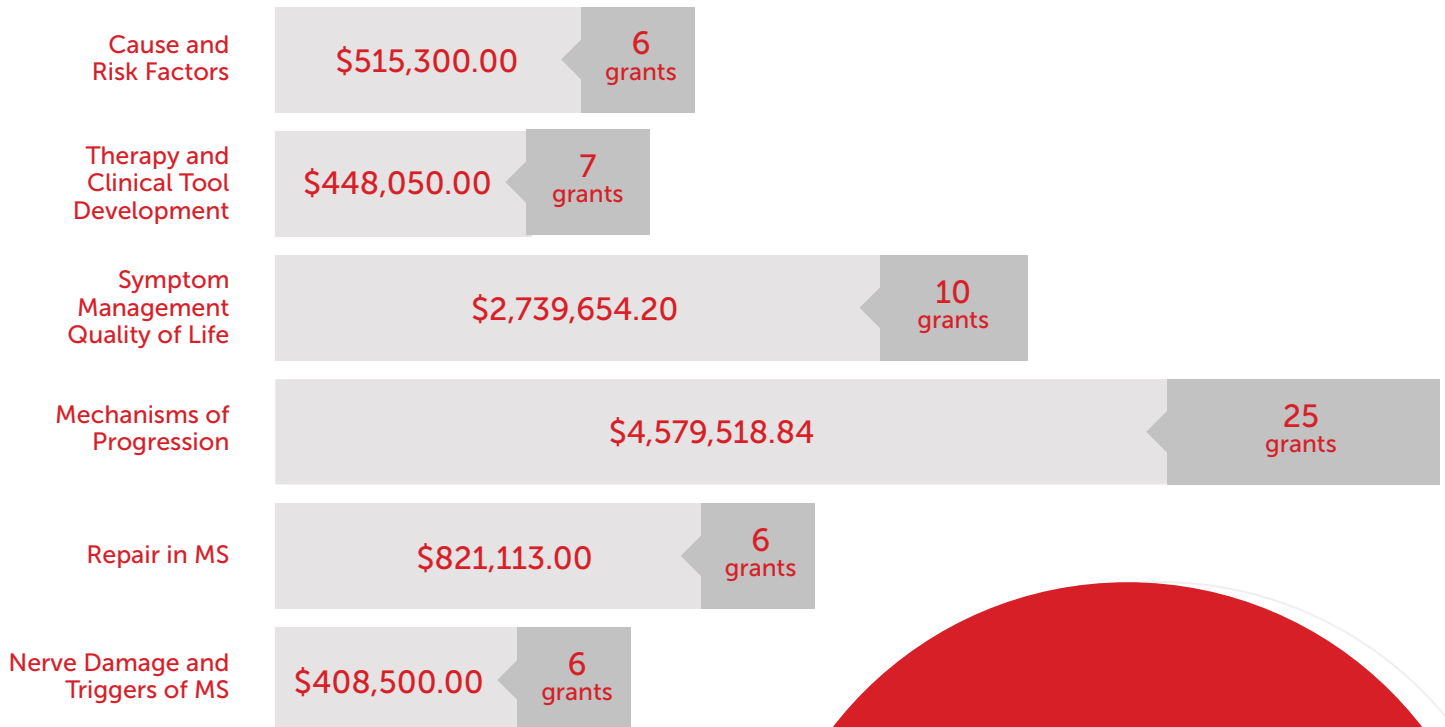
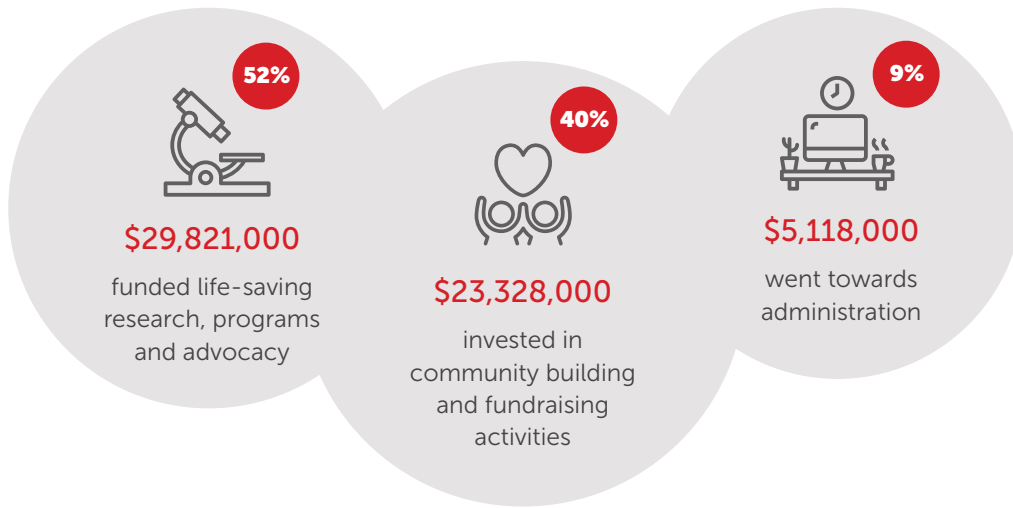
**100+**  
posters





# Financial Highlights – Your Dollars at Work

Of the **\$57,160,000** raised in 2019:



\* The financial highlights include both the MS Society of Canada and the MS Scientific Research Foundation.\*

## With your support, the possibilities are endless.

“For the Joseph and Westman Families, MS is our disease. My grandmother had MS, I have MS, and my daughter also lives with MS. My grandmother was determined to live long enough to see a cure for this disease. While her wish is getting closer, it was not achieved in her lifetime. Both my daughter and myself, along with many others from around the world have benefited greatly from the many advances and successes in treatments, specifically as an outcome of the amazing research being conducted right here in Canada, however, we still have a long way to go. As third and fourth generation volunteers and donors, we have been personally impacted and seen the value of research, fundraising, and community outreach in our lives. I am determined to fulfill my grandmothers wish and live long enough to see a world free of MS, for both myself and my daughter.” – **Diana Joseph, President, Westman Charitable Foundation**

“I became a donor and volunteer in 2004 because my daughter lives with MS. I want her to live life to the fullest – without the fear and uncertainty that MS often brings. The MS Society funds the most innovative research and works with global experts to make healthy futures possible for my daughter and everyone who lives with MS.” – **Joe Randell, President and CEO, Chorus Aviation Inc.**

“As someone who’s been living with the challenges of MS for over 25 years, I feel I have a great life! MS research helped make that possible. I’m excited to support the next wave of cutting-edge research that will bring more treatments and one day a cure.” – **Janet Ames, retired lawyer**

### Thank you

To see a list of the donors that helped make 2019 a successful year, visit [mssociety.ca/donors](https://mssociety.ca/donors).





With your dollars and efforts, we continue to  
build on creating a world free of MS.

**Thank you!**