2018 Impact Report

LIVING WELL WITH MS

The last 20 years of ***multiple sclerosis research*** have generated many ***breakthroughs*** and as a result more people with MS are ***living better*** than ever before. This progress is incredible given the diversity and variability of symptoms that individuals deal with day-to-day or even episodically. While it's true we've seen ***an increase of disease modifying therapies*** in the past two decades, we've also learned that managing MS requires an array of different approaches. For some, this means combining ***medication*** with ***physiotherapy***, ***exercise*** and ***nutrition,*** giving many greater control of their own care plan and enhancing overall wellness.

Jessica and her service dog Nutella.

Jessica FROM ALBERTA

Jessica is thriving. From the outside looking in, you wouldn't know that this 26-year-old has been living with MS for 11 years. "Those who know me, know I personally refuse to let MS have a hold on me." says Jessica. Through the support of her community, including those she met as a participant of MS Summer Camp, and as a staff member of the MS Society of Canada, Jessica has found motivation to take control of her life.

Thanks to your support we've made incredible research progress over the last 20 years.

In addition to having 14 disease modifying therapies, research is showing that exercise plays an important role in the overall management of MS symptoms.

Visit **mssociety.ca/physicalactivity** for tips.

MS has given her the passion for health and fitness that she never had before. With a collaborative approach to health and wellness, Jessica developed her own personal team of experts and trainers to make sure she gets the best overall treatment possible for her personal goals.

When Jessica was in university, she used a cane for five months. Since she began boxing and working with a personal trainer, she has only needed her cane once and says her balance and mobility have improved immensely.

Jessica not only works for the MS Society supporting our peer support and youth programs, but also helps organize the MS Walk in Calgary and is proud to be taking action to help raise funds to end MS. With her service dog in training, Nutella, by her side, she approaches MS with more strength and perseverance than ever before.

Blake and his mother Neva. (Photo by Berni Wood/Reel Media)

Blake FROM PEI

Blake's mother, Neva, has lived with progressive MS for more than 21 years. She uses a wheelchair and now lives in a long-term care home. Despite these challenges, she maintains a positive attitude which inspires him every day. "Not many people could go through what she has and still wake up with a smile on her face. But she does."

> ***I Challenge MS is our name for a do-it-yourself fundraiser.***
>
> Whether you run a bake sale, a fitness challenge or a party, your acts of greatness through I Challenge MS contributes to a future free of MS.
>
> Learn more at: **ichallengems.ca**

Her journey with MS motivated Blake to take action to help his mom and others living with MS. He created an athleisure wear line called Push & Pull Athletix and donates 10 per cent of his proceeds to the MS Society.

Blake also hosted the first annual Push & Pull 4 MS as an I Challenge MS event to raise funds for research. It was such a success his team held another event more recently, called Lift 4 MS. He credits their success to their fervent desire to help find a cure for MS.

Blake has recently taken on a new role as a MS Walk ambassador for Atlantic Canada. In this role, and through his other fundraising, he's confident he'll make a difference for his mom, and encourage other people who have loved ones with MS to become part of a community taking action to end MS.

Sara and her family. (Photo by Stéphanie Chassé)

Sara FROM QUEBEC

In 2009, Sara was diagnosed with MS at the age of 28. The diagnosis turned her world upside down. Given her challenges, she was forced to end her career when she was 35. Through photography, she is expressing herself while dealing with her diagnosis.

Sara sought support from a self-help group organized by the MS Society in Rimouski. Talking to other people with MS and learning what has helped them has made a big difference. Today, Sara is focused on climbing Mount Ernest Laforce in Gaspésie National Park as part of her first I Challenge MS fundraiser. Since she has difficulties with her right leg, this challenge is an important one for her.

For Sara, accepting her illness means living fully in the moment and accepting that some days are more difficult than others. She also feels it's important to recognize the support of her partner and daughter, "Sometimes we forget to thank those who make it easier for us to manage living with this disease." With her family, her support group and the MS Society by her side, Sara maintains a positive attitude and believes resilience is the key to learning to live with MS.

WE'VE MADE REAL PROGRESS THANKS TO YOUR ACTS OF GREATNESS

Donors across the country are making significant gifts to better the lives of people affected by multiple sclerosis.

Philanthropy drives important change – we see this now more than ever as we edge closer to new breakthroughs as we work to understand and halt disease progression in MS. In 2018 we announced the incredible cross-Canada research team for Canadian Prospective Cohort Study to Understand Progression in MS (CanProCo) – an important study looking at progression in MS. We put a spotlight on symptom management at the International Progressive MS Alliance Scientific Congress which we hosted in Toronto in May. In September, we announced an anonymous gift of $5 million in support of Dr. Anthony Feinstein's research to shed light on the role of exercise on cognition in MS. In the fall we launched our recommendations on vitamin D, which are fostering important discussions among families and raising greater awareness about modifiable risk factors. We're making real progress and gaining momentum each day thanks to your support.

Acceleration is also at the core of our $75 million Acts of Greatness campaign which launched publicly last November. This campaign will drive our bold new strategic plan that focuses on advancing treatment and care, enhancing well-being, understanding and halting disease progression and preventing MS through discoveries, innovation and collective action.

Through this report we highlight your many acts of greatness that are making an important difference. Dramatic change is within reach and only possible with your generosity and passion.

Thank you.

Dr. Pamela Valentine
President and CEO, MS Society of Canada

Valerie Hussey, C.M.
Chair, Board of Directors, MS Society of Canada









THANKS TO YOU THE MS KNOWLEDGE NETWORK IS EXPANDING TO REACH MORE CANADIANS

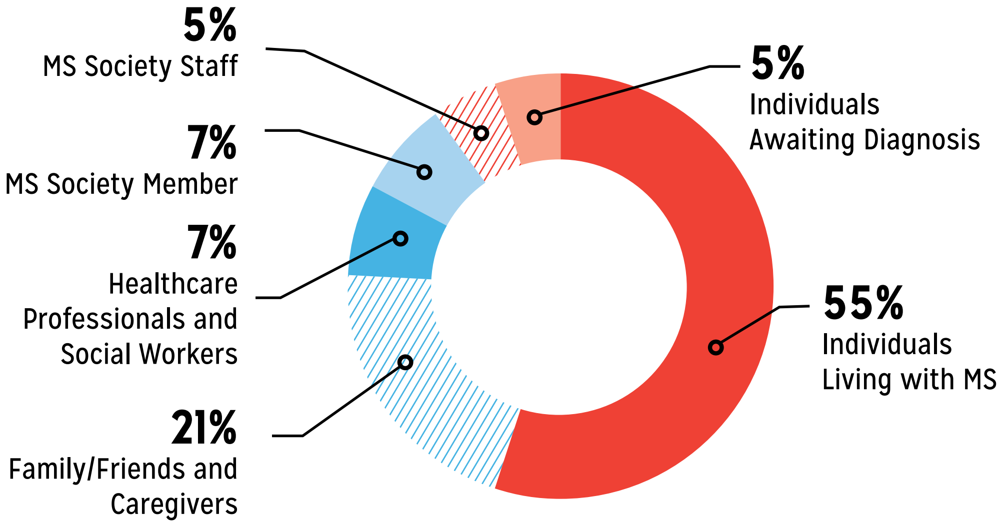
Top five areas of support

MS Navigators provide information, support and referral in the areas of:

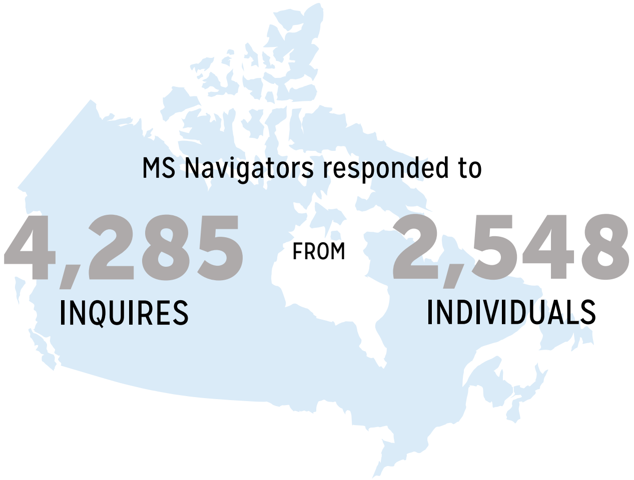
1. MS Information
2. MS Society of Canada Information
3. Treatment Options
4. Income Support Inquiries
5. Access to Professional Health Services

We heard from ***Canadians living with multiple sclerosis*** that navigating their MS journey was one of the most challenging aspects in their day-to-day lives – particularly with the inaccurate and limitless amounts of MS information available, and the complexities of health care and other support systems. The MS Knowledge Network and its hub of navigators provide ***reliable, high-quality MS information*** and ***support for Canadians***. Via phone, email and live chat, ***MS Navigators*** provide ***trusted information*** on different aspects of life with MS tailored to the ***unique needs of each individual***, including symptom management, treatment options, peer support, access to professional health services, income support, current research and navigating community resources.

Who is connecting with us?



Serving more Canadians in a variety of ways



MS Navigators responded to

4,285 INQUIRES FROM **2,548** INDIVIDUALS

Feedback from MS Knowledge Network users

87% of respondents were **very satisfied or satisfied** with their overall experience connecting with an MS Navigator.

84% of respondents stated that they would **recommend the service** to someone else affected by MS.

80% of respondents stated they intend to **take action** based on the information they received from an MS Navigator.

> *I am really **happy** this resource exists, the response to my questions included **well curated links** to **smart information** and an invitation to **connect** to the **community** further.*

> *I was **very impressed** with the service I received. I emailed a **question** regarding a new medication and **within 20 min** had received a reply from an MS Navigator. The MS Navigator sent me **information** and the **most recent study** associated to the medication I was inquiring about.*

MS Navigators are available from 8 a.m. to 8 p.m. ET.

Phone: 1-844-859-6789
Email: msnavigators@mssociety.ca
Live Chat: visit **mssociety.ca** and click *MS Information* or *Support and Services*.

GLOBAL COLLABORATION IS KEY TO ADVANCEMENT IN PROGRESSIVE MS RESEARCH

The International Progressive MS Alliance is a global collaboration of multiple sclerosis organizations, researchers, clinicians, industry partners and people living with progressive MS who share the same goal of advancing research and aiding those living with progressive MS.

In an era where boundaries are increasingly blurred, the Alliance recognizes that removing geographic borders and collaborating globally is key to fast-tracking new treatments for progressive MS. The Alliance achieves three critically important things: brings together the brightest minds; elevates awareness of progressive MS on a global scale; and accelerates the development of new breakthrough treatments.

In six short years, the Alliance has funded several grants including €12 million for three Collaborative Network awards involving 40 leading investigators from 21 institutions in nine countries. Today, thanks to your support, we're on the cusp of several new breakthroughs. In May 2019 the Collaborative Network research teams uncovered their initial findings, revealing these global projects are making significant headway. One of those projects is being led by Dr. Doug Arnold of the Montreal Neurological Institute at McGill University.

Dr. Arnold and his team of researchers across the globe are trying to accelerate clinical trials by exploring a progression biomarker. His team is studying magnetic resonance imaging (MRI) markers that signal disease progression and adapting these for use in early clinical trials of progressive MS treatments. Dr. Arnold's theory is that disease progression in MS is detectable by MRI prior to its physical manifestation or identification by a clinician.

Researchers like Dr. Arnold know how important it is to collaborate not only across the globe but across disciplines if we hope to solve the mysteries of progressive MS. "Thanks to your generous support, the work of the Alliance in forging collaboration and funding ground-breaking research brings hope for advances in progressive MS."

LIVING WITH MS AND INFLUENCING WORLD-CLASS RESEARCH TO CHANGE LIVES

Heidi FROM MANITOBA

People affected by multiple sclerosis play a crucial role as community representatives in reviewing innovative research grant applications. Community representatives comment on how research could influence their daily lives and what breakthroughs could mean to them and the MS community.

Heidi, a community representative for two years (2018-2019) from Winnipeg, was diagnosed with MS over 18 years ago and has struggled through nearly every major event of her life. She thinks about the possible triggers for MS progression believing that factors like the environment, lifestyle and socio-economic status could play a role and was excited to learn about the Canadian Prospective Cohort Study to Understand Progression in MS (CanProCo).

CanProCo, led by Dr. Jiwon Oh, a neurologist from St. Michael's Hospital and assistant professor of medicine at University of Toronto, and her team of nearly 50 leading MS researchers, will observe a large group of people living with MS from Canada over several years. CanProCo will collect specific information to help identify features of progression in MS and understand why and how it occurs.

Heidi explains that typically there is only an annual snapshot of data collection at yearly appointments to monitor progression. CanProCo will collect information, including non-clinical factors (health and socio-economic impact, etc.), over a five-year period and the data will not only be collected at the clinic but also through mobile apps that can collect data from anywhere.

The CanProCo study is the first Canadian collaboration of its kind focused on data collection with researchers, clinicians, industry partners and people with MS. It is made possible by the generosity of our donors and funding partners. Heidi believes it has real potential to uncover the cause of MS progression and change the lives of millions at home and around the world.

How are research projects selected?

The MS Society uses a gold standard review process to select and fund projects of the highest scientific merit. Through rigorous scrutiny, research and clinical experts determine whether proposed projects will advance knowledge and improve health and quality of life. Community representatives review applications to ensure that research projects are relevant and impactful to people affected by MS. They challenge researchers to communicate their work in easy to understand ways.

Did You Know?

CanProCo is the first project of its kind in Canada to help unravel the unpredictable nature of disease progression. Progression is a challenging reality faced by many, and despite major advances in MS research, it is not fully understood. The multidisciplinary research team will study hundreds of patients across Canada over several years to learn about the mechanisms of progression and ways to stop it. This important study is possible with support from Brain Canada Foundation, Biogen Canada and Hoffmann-La Roche Limited (Roche Canada). The MS Society is grateful to lead donors, PCL Construction and Bennett Jones LLP for their generous support.

The CanProCo research team from left to right: Drs. Larry Lynd, Anthony Traboulsee, Alexandre Prat, Scott Patten, Jiwon Oh, Roger Tam, Shannon Kolind.

Wilbur and Erin MacLean, assistant coach for Pearl Gloves.

FIGHTING MS HEAD ON

Wilbur FROM ONTARIO

In 2015 Wilbur began to experience blurry vision, short-term memory loss, fatigue and issues with balance. As the symptoms advanced, he had to use a wheelchair. The following year, at age 34, Wilbur was diagnosed with multiple sclerosis.

> ***What's in your care plan?***
>
> For some people living with MS, drug therapy is part of their care plan. Diet and exercise also matter, and Vitamin D could help too—particularly for those with MS, and those at greater risk of getting MS.

Despite the obstacles, he persevered to regain his strength and balance. In March 2018 he started Ocrevus, just one month following the announced approval by Health Canada of the first treatment for people with early primary progressive MS. He also changed his diet and walked every day until eventually, he was able to run.

Within a few months, he participated in a five kilometre run. Soon after, he discovered the benefits of physical activity for people living with MS, so he joined a boxing club. "Over time, I could sense myself getting better. My eyes got better, my balance got better and I got stronger. This pushed me to work even harder."

In 2018 Wilbur joined an annual charity boxing fundraiser in Niagara, Ontario, called Pearl Gloves, to help fight MS. In taking care of his own health, he found an outlet to help others.

> ***Thank you Pearl Gloves for your generous support to fight MS!***

Wilbur participating in charity boxing fundraiser Pearl Gloves.

Three days after the fight, Wilbur's partner gave birth to a beautiful baby girl, Kyrie.

Wilbur continues to focus on his health and is currently training for a 10 kilometre run with Kyrie in her running stroller: "I want to give myself the best shot possible to maintain my physical and mental well-being. I also want to minimize the impact MS has on Kyrie and do whatever I can to prevent her from getting it too."

VITAMIN D AND MS:
Evidence-informed recommendations released in 2018 for people with MS and those at risk

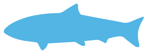
The MS Society has released evidence-based recommendations on vitamin D supplementation that can help people affected by multiple sclerosis make informed decisions about their health.

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?

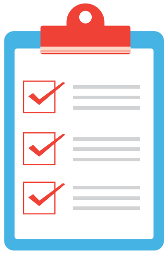
Safe Exposure to Sunlight



Food Sources

Supplements

What do the vitamin D recommendations entail?



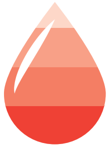
For people at higher risk of developing MS (individuals with a sibling, parent or child with MS, and those that smoke or are obese), getting enough vitamin D may help decrease their chances of developing MS. For individuals living with MS, keeping vitamin D levels within the optimal range may also help 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 developing 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 information on your vitamin D levels so that you can make sure you are getting the correct amount.



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

ACTS OF GREATNESS: *Fueling progress and change for people affected by MS*

Whether you're living with multiple sclerosis, on the front lines of research or someone who understands how life can turn on a dime, your acts of greatness make a difference. In November 2018 we launched Acts of Greatness, a campaign to raise $75 million to ensure researchers have the resources to find answers and new treatments, particularly for those with progressive MS.

Every act of greatness is a moment of victory. Thanks to your support, we will stop disease progression, empower more people to live their best lives and mobilize a nationwide movement to drive change.

Join us. Learn more at **actsofgreatness.ca**.

Christine Sinclair, Honorary Chair, Acts of Greatness.
(Photo by Canada Soccer/Nora Stankovic)

COLLECTIVE ACTION TO IMPROVE #LIFEWITHMS FOR CANADIANS WITH MS

Living with multiple sclerosis can feel like living in a body that doesn't listen to you. The episodic nature of MS poses many challenges including securing employment, income and disability supports.

On May 30, 2018, Member of Parliament, David Yurdiga, put forth a Private Member's motion (M-192) on episodic disabilities. This motion calls for a review and recommendations for federal legislation, policy and programs to be inclusive of people with episodic disabilities.

Patrycia before her testimony to support M-192.

Witnesses who testified in support of M-192 from left to right: Deborah Lovagi, Patricycia Rzechowka, Michael Prince, Deanna Groetzinger, John Stapleton, Lembi Buchanan.

In the fall of 2018 over 5,200 letters were sent to MPs across this country in support of M-192 and improvements to #LifeWithMS. This incredible collective action led to Patrycia Rzechowka appearing before the parliamentary committee where she shared her experience of living with MS. Her compelling words painted a clear picture of what is at stake for Canadians living with episodic disabilities:

"You may wonder what gets me up. It's knowing that I have somewhere to be, knowing that I have responsibilities and that I have purpose. I can't imagine if my ability to work were taken away, all because I might need a little extra support."

Episodic disability: conditions or diseases where levels of disability vary through out an individual's lifetime.

Another way Patrycia fights MS is by being an ambassador for MS Bike.

Thanks to Patrycia's act of greatness, and that of thousands of other Canadians speaking up to improve #LifeWithMS, Motion M-192 was passed and a full report from the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities was released in 2019.

"I'm not only fighting for myself, but for all the people I've met who're affected by MS."

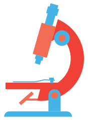
Patrycia takes collective action to heart when it comes to fighting MS. Since her diagnosis in 2012, she's led the MS Bike team MS'd with the Wrong Girl, has served as an MS ambassador and makes time for anyone who wants to talk about MS.

To hear or read Patryicia's full testimony to the Parliamentary committee visit **bit.ly/motion192**.

FINANCIAL HIGHLIGHTS

Your vital support stimulates innovation in ***research***, ***treatment*** and ***support***. The rapid pace of MS research at home, and around the globe, is driving us closer to important ***new breakthroughs*** for people affected by MS. None of this is possible without you. More than hope, you've funded ***real progress for Canadians affected by MS***.

Of the $54 million raised in 2018:

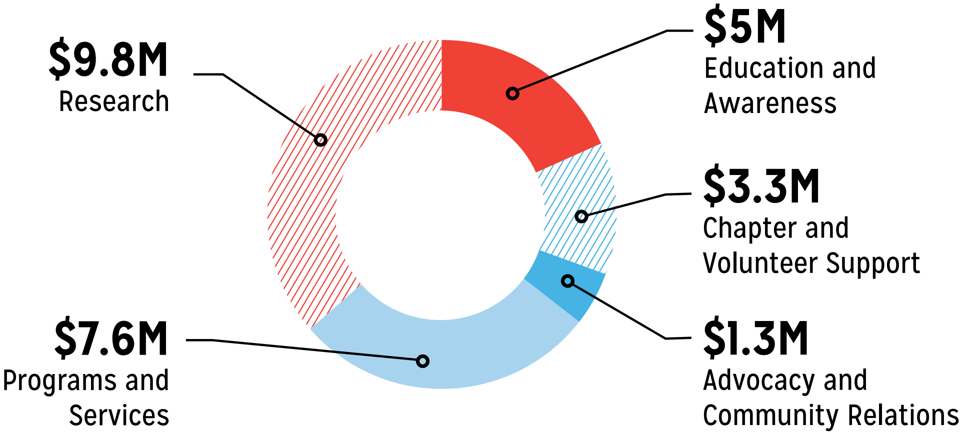


50% funded life-saving research, programs and services, and advocacy.

41% was invested in community fundraising activities like MS Walk and MS Bike, allowing us to fund breakthrough research, and grassroots programs that directly support people living with MS in communities across the country.

9% went towards our administrative and operational costs.

Of the $27 million we spent on mission, we invested:



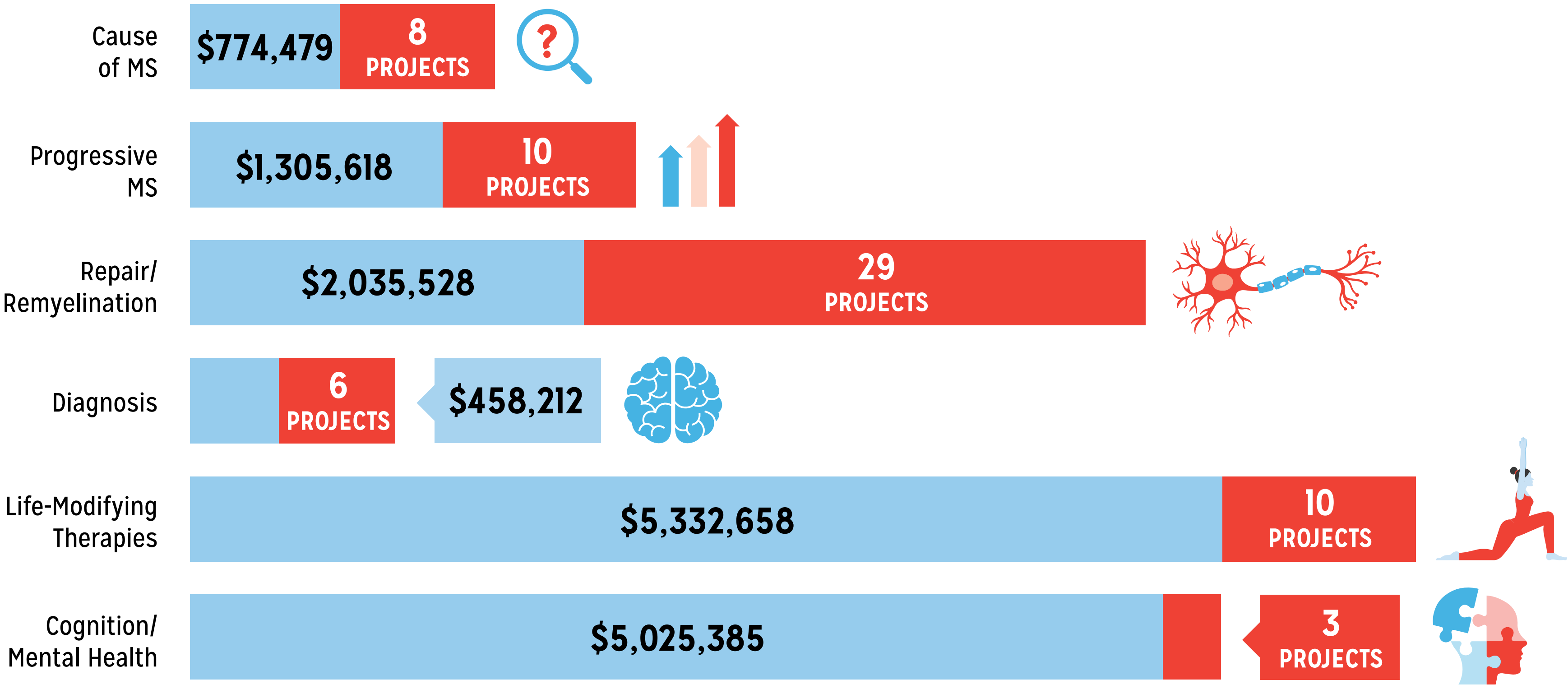
Thank You

To see a list of the donors that helped make 2018 a successful year, visit **mssociety.ca/donors**.

We are grateful to our board of directors for their leadership and commitment to our work.

To see a list of current board members, visit **mssociety.ca/about-us/governance/ms-society-board-of-directors**.

Thanks to your generous support, the MS Society committed $14.9 million in new research in 2018.



Thank you for continuing to make life better for ***Canadians living with MS***. Your support is truly an ***act of greatness***.

Multiple Sclerosis Society of Canada

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mssociety.ca

Front cover photo of Sara by Annick Michaud.