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# Chair's message

"To hope is to gamble. ... Hope [just] means another world might be possible, not promised, not guaranteed. Hope calls for action; action is impossible without hope."

-Rebecca Solnit, Hope in the Dark

MS can be an unpredictable and isolating disease. In conversations with people across the country, I've heard that MS means different things to different people, and I frequently hear people speak of an ever-deepening fear of the future. What is common to everyone with whom I speak is their need for hope. Our goal at the MS Society is to turn fear into hope, and hope into action.

The work of the MS Society — including research, advocacy, programs and services — helps people impacted by MS enhance their quality of life and not lose hope. We all want a future free of MS.

People affected by MS are at the centre of everything we do. In 2016, our MS Knowledge Network extended and enhanced the services that we provide to Canadians affected by MS. Our Network may be the first point of connection with the MS Society for someone newly diagnosed. Or, a lifeline for someone experiencing a relapse or needing to identify support within their community. Our Knowledge Network is just one of the recent developments in programs and services. (see page 6).

We participated in a series of consultations initiated by the federal government aimed at improving accessibility legislation. The consultation aligned with our focus on independence. Government supports should allow people living with episodic disabilities to remain in the workforce longer, which

is an important factor in maintaining independence and quality of life. MS Awareness month in May places these ideas at the forefront of our advocacy efforts. Our government relations team met with parliamentarians from across the country to advocate for more flexible income and employment supports.

It has also been an exciting year for breakthroughs in MS research. The promising results of the Canadian Bone Marrow Transplantation (BMT) trial were published, describing how some people living with severe MS-related disabilities had experienced substantial long-term recovery. The achieved gains contribute to what we think may be possible with MS and BMT. For a more comprehensive overview of the trials results, visit drkarenlee.ca.

For 10 years, Yves Savoie was an exceptional president and CEO to the MS Society. Yves brought a wealth of experience, knowledge, and skill to his role, and an unwavering dedication to our common cause. Yves was recently appointed CEO of Heart & Stroke Foundation of Canada. He will be greatly missed. Join me in wishing Yves tremendous success in the next chapter of his career, and a heartfelt thank you for his tenure with the MS Society of Canada. Merci, Yves.

I ask you to join me in the journey to end Canada's disease. A future free of MS is within our reach; let's turn our hope into action and together we will end MS.



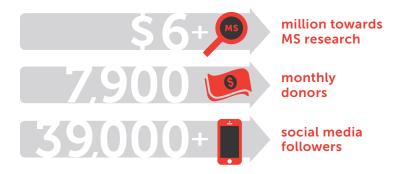
Valerie Hussey
Chair

# **Expenditures overview**

With your help, we are working toward the largest possible breakthrough for people living with multiple sclerosis: a cure. As we work toward that goal, your support continues to have an impact on people's daily quality of life.

In 2016, your donations allowed the MS Society to commit \$6 million toward Canadian MS research.

Thank you, from the bottom of our hearts. We couldn't do it without you!



Have you subscribed to our blog? Visit blog.mssociety.ca to read stories from people living with MS, gain insight into living with MS, and find out how you can help push our governments to support people affected by the disease.

Share our content using the hashtag **#endMS** to add your voice to the community.











# TOGETHER WE ARE **#STONGERTHANMS**

Canada has the highest rate of multiple sclerosis in the world. MS affects people's lives in many different ways. Family members become caregivers supporting a loved one who lives with MS; students with a parent who lives with MS are inspired to apply for scholarships to contribute to the future of MS research; and people living with MS feel the loss – be it sudden or gradual – of their independence with every new symptom or relapse. MS is Canada's disease, and Canadians are coming together and working hard to end it, and to improve life with MS for everyone affected.

The MS Society of Canada enables Canadians affected by MS to live well with:

# RESEARCH



# **STEM CELLS:**

# Unlocking their potential



Jennifer Molson was diagnosed with MS at age 21. She received IAHSCT (stem cell therapy) at The Ottawa Hospital.

66 But now, here I am: walking, skiing, kayaking. Independent, working full time, married after having danced at my wedding."

"I won't sugar coat this: the trial was hell. For three years, between 2002 and 2005, my life was a series of questions, tough decisions, and uncertainties. My body didn't feel like my own. At one point I was taking 129 pills a day, and my stomach lining was so eroded that I couldn't keep food down for a year. Destroying your immune system is no easy feat.

But now, here I am: walking, skiing, kayaking. Independent, working full-time, married after having danced at my wedding. I have been living relapse-free for 14 years, and it's because of the Canadian Bone Marrow Transplantation (BMT) trial conducted by Dr. Mark Freedman and Dr. Harry Atkins at The Ottawa Hospital.

The BMT trial is responsible for a new immunoablation and autologous hematopoietic stem cell transplantation (IAHSCT) option for people with an early, aggressive form of multiple sclerosis, like the type I was living with in my early 20s. Five years after being diagnosed with MS at age 21, I had declined so rapidly that I was living at The Ottawa Hospital Rehabilitation Centre under constant care. Dr. Mark Freedman, my neurologist and lead investigator of the

BMT trial, told me my MRI scan looked like a cheese grater – there were so many lesions on my brain that my nervous system looked like it had been shredded by MS.

A year after I completed the trial, I started to see improvements: first I was able to walk without a cane, then get through the day without a nap, then make plans with my friends without needing to cancel. Finally, in 2006, I had regained complete ability, was able to return to work full-time and feel more independent than I had in years.

I'm currently living relapse-free, but I'm also living with the after-effects of extreme chemotherapy. My husband and I have had to accept that we will never have children, as the treatment triggered early menopause in my body. I've had to get most of my childhood vaccines again, but I need to live without the Measles, Mumps, Rubella (MMR) vaccination. I am very prone to infection, and I developed a blood infection, shingles, and bladder infections after the treatment.

But when I'm asked if it was all worth it, I answer without hesitation: yes."



To follow our progress and get the inside story on MS research, visit **DrKarenLee.ca** or follow @**Dr\_KarenLee** on Twitter.

# Canadian BMT Trial

Ongoing research is helping to expand the arsenal of treatment options for MS, while placing greater emphasis on a more personalized approach to treating the disease.

Immunoablation and autologous hematopoietic stem-cell transplantation (IAHSCT) adds to the growing list of options that are available for aggressive forms of relapsing-remitting MS (RRMS), which is a positive step towards preventing disease progression.

The findings from the Canadian BMT trial represent an important breakthrough in research exploring cell-based therapies for MS. The trial is the only one of its kind in Canada, although there are a number of other stem cell trials using similar techniques conducted abroad, the Canadian BMT trial has the longest follow-up period for this procedure for MS to date, providing a clear window into the long-term benefits of this procedure.

The study was funded by the MS Society of Canada and its affiliated Multiple Sclerosis Scientific Research Foundation (MSSRF) to identify a potential treatment for MS involving stem cells.

#### **END MS CONFERENCE:**

It's worth celebrating the MS Society of Canada's 2016 endMS Conference for its capacity to bring together so many of the great minds that have embarked on tackling the many unresolved questions about MS. We set out to bring researchers from Canada and abroad – who represent different fields of research and academic levels – together in one room to forge new collaborations and enrich each other and the field of MS research as a whole.

One of the highlights of the endMS Conference was the Hope and Engagement through Accelerating Research in Multiple Sclerosis (HEAR MS) day, which was dedicated to building and strengthening connections between research trainees and people affected by MS. Conversations and activities throughout the day allowed researchers to gain a better understanding of MS at a personal level, and at the same time people affected by MS had a chance to learn about the various studies being led by promising young investigators. HEAR MS day succeeded at fostering dialogue between two communities, which will ultimately enrich the way research is conducted and translated into meaningful outcomes for people affected by MS.

# HERMÈS CANADA | MS SOCIETY WELLNESS RESEARCH INNOVATION GRANT (WRIG):

To help address the need for more information around wellness in MS, we launched the Hermès Canada | MS Society Wellness Research Innovation Grant (WRIG), with a goal of translating research findings into innovative wellness solutions that will improve health and quality of life for people with MS.

Three teams were awarded funding:

- **1.** Impact of a Pilates program in multiple sclerosis. Dr. Charity Evans, University of Saskatchewan.
- 2. Web-based physiotherapy in moderate to severe MS. Dr. Katherine Knox, University of Saskatchewan.
- 3. Development of a mobile app to increase activity levels in youth with MS. Dr. Ann Yeh, University of Toronto.



For more Canadian research updates, visit mssociety.ca/research

# **MS KNOWLEDGE NETWORK:**

# The many kinds of support

In the fall of 2016, the MS Society launched a marquis support program, the MS Knowledge Network, the first phase of which was the implementation of our MS Navigator service. Anyone in Canada who needs help finding answers to questions about multiple sclerosis can easily connect with an MS Navigator.

MS Navigators represent the MS Society's commitment to providing the best possible quality service for people affected by MS. One phone call or email links a person to an MS Navigator, who can provide carefully curated information on topics such as medication, healthcare, symptom management, and MS research. The service is available during business hours, with multiple navigators working together to ensure full coverage across the country.

The idea was born out of the MS Society's Listening to People Affected by MS initiative, which collected perspectives from thousands of Canadians affected by MS. The message was clear: there is a need for reliable access to quality information about MS and assistance to navigate the web of medical, community, and government supports available.

MS is unpredictable, and its effects can ripple to various areas of a person's life. The MS Navigator's role is to readily assist Canadians on whatever path MS takes them, and to help provide clarity to individuals living with a complex disease.

#### MS NAVIGATOR SERVICE BY THE NUMBERS



Average number of telephone inquiries received per month since the service launched.



Average number of email inquiries received per month since the service launched.



Hours per day MS Navigators take phone calls or answer emails (9 a.m. to 5 p.m.), no matter what time zone.



Number of hours of training the MS Navigators receive before they begin taking inquiries.



Number of days in which the majority of inquiries are handled and resolved by MS Navigators.

#### PEOPLE ASK THE MS NAVIGATORS ABOUT...





1-844-859-6789 | msnavigators@mssociety.ca.

# MS 1:1 Peer Support Program

Another branch of the MS Knowledge Network is the MS 1:1 Peer Support Program which completed its first full year of service matching volunteers living with MS with individuals looking for support. The service is offered by phone and email. Participants may be newly diagnosed, may have a specific question, or may be dealing with an issue related to their MS. Sometimes the best person to talk to is someone who also has MS. Volunteers from across Canada are provided with extensive training to ensure they have the skills to best support individuals who reach out for support.

### MS 1:1 PEER SUPPORT PROGRAM BY THE NUMBERS



Number of trained volunteers nationwide.



Number of matches between volunteers and people seeking support.



To learn more about the MS Knowledge Network, please visit mssociety.ca/ support-services/ms-knowledge-network.

66 Working one-on-one with someone for six months, you get to become this interesting part of their life. The majority of the people I speak with are newly diagnosed and don't want to burden the people that they love with the day-to-day of what MS can bring. When I initiate a conversation with a peer, I put myself into that headspace and make sure they understand that I'm here to listen. That they can tell me anything. I know what it's like and I can hear it in their voices, they're internalizing it, they're depressed, they're angry."

-Trish Eastman lives with MS and volunteers her time with the 1:1 Peer Support Program

# **MAKING OUR VOICES HEARD:**

# Mobilizing Canadians to effect real change



Coriann Berry was diagnosed with MS in 2015.

"One of the challenges of living and working with MS is the episodic nature of the disease. Relapses come and go with no warning, making it difficult, if not impossible, to abide by a rigid schedule. A few months ago I had a relapse that lasted nearly two weeks. Not only were my feet and hands numb, I was also numb from the waist down. All my muscles tightened and it was difficult to walk. It was tough walking from the CTrain to the office. I told one of my supervisors about my relapse and he told me to take it easy. He offered some extra help if I needed

it. I was also experiencing neck pain at the time and was able to adjust my office furniture so it didn't put so much strain on my neck."

"The flexibility and accommodations offered by my employer have been so central to my well-being and quality of life. I know that my story does not reflect reality for so many others who are affected by MS.

I wish other employers could see how easy it is to offer support to their employees the way my employer has supported me.

There is value in valuing your employees.

My story is an example of that."

#### **GOVERNMENT RELATIONS:**

Mobilize and equip
MS volunteers
to reach out to
governments
to hold them to
account and meet
their obligations

Make governments aware of MS research potential and outcomes, and request they dedicate increased funding Influence governments to fund adequate income and programs for people with disabilities



A key vehicle to position the person with MS at the centre of our work Raising awareness about MS is crucial to effecting change. In 2016, our focus was on making sure the voices of Canadians affected by MS were heard regarding what they need to live the best lives possible.

On May 24, the Conference Board of Canada released a report entitled; Multiple Sclerosis in the Workplace: Supporting Successful Employment Experiences. In their press release, the group states, "While Canada has the highest rate of multiple sclerosis (MS) in the world, we may not be doing enough in terms of providing appropriate workplace accommodations and income supports for this population and their caregivers."

Key findings from the report are very much in line with the Institute for Research on Public Policy's (IRPP) report titled Leaving Some Behind: What Happens When Workers Get Sick; and ACTION on MS from the MS Society's Listening to People Affected by MS initiative. This report outlines some key actions that can be taken by employers, governments, and other stakeholder groups, including the following:

- Positive employer attitudes and accommodations for employees with MS
- Early use of interventions and disease management strategies
- Better and more coordinated employer and government supports

So what does this mean? It means we have one more piece of concrete evidence to take to our governments to raise awareness and effect change. It means we have more tools to advocate for crucial changes that will have a real impact on the working lives and financial future of people living with MS and their caregivers.

System-wide change starts with assessing where we are now, so that we are fully informed when pushing for progress. We are working to make sure our voices are heard through our annual Day on the Hill and Carnation Pinning Ceremony, and through our participation in the federal government's 2016 accessibility consultations.

# 2016 ACCESSIBILITY CONSULTATIONS:

The federal government championed by Minister of Sport and Persons with Disabilities, Carla Qualtrough conducted a series of public consultations throughout 2016.

We participated in the accessibility legislation consultations in person as well as prepared a written submission with our recommendations.

With these recommendations, we hope to make Canada a more fully inclusive place for people living with MS.



To read the reports mentioned here in full and learn more about our advocacy activities, visit blog.mssociety.ca/category/advocacy

# THE POWER OF ONE

# I Challenge MS



When Ahmed moved here from Egypt, he learned that Canada has the highest rate of MS in the world and he decided to be part of finding a cure. He recently won the MS National award of merit, non-member.

Starting along the Atlantic coast of France and ending just shy of the Black Sea in Romania, longtime MS Bike participant, Ahmed Nassrat, took to his bike on his own journey to end MS. He cycled **4,500 kilometers**, through eight countries, over **55 days** with a goal of raising **\$1 for every kilometer** he rode.

The MS Society's I Challenge MS program is about empowering you to raise money for Canadians living with MS in a way that is meaningful to you. When you create an I Challenge MS campaign, you are given access to a wealth of resources to make the process of sharing updates and collecting donations simple and easy. Help make a difference in your own creative way. For more information, visit **ichallengems.ca**.

"This ride was an opportunity to spread the word that Canada has the highest rate of MS in the world, and to raise funds for MS research. As a Canadian, it's my place to help end our country's disease and I hope to inspire others to join me."

Ahmed had never been on a long distance cycling trip before. Nor had he ever travelled by himself, let alone in a series of countries where he doesn't speak the language. His reasons for going on this ride were three-fold:

as a means of self-discovery; to spread awareness about MS and raise funds to help find a cure for the disease; and to inspire others to take action for the causes close to their hearts.

"I raced against cruise ships on the canal, I raced against tractors on the ground, and I even raced against a 70-year-old man I met along the way," he explains on his YouTube channel. "The truth is, I was afraid of being lonely, but I never once felt alone."

In his final video from abroad, Ahmed thanks the long list of people who took him in and made him feel welcome along his journey. He describes a night spent in a total stranger's house, something he never would have thought of doing prior to this trip.

"What started as a personal challenge, became a truly eye-opening experience for me," says Ahmed. His advice to others: "Get out of your comfort zone, you will be rewarded. I met amazing people and learned about so many countries. I also learned that despite all of our differences, we are all seeking the same things: a happy life surrounded by people we love. I'm proud that I was able to raise awareness about Canada's disease in places so far away."

# A&W: Burgers to Beat MS



Thanks to Canadians like you in communities across the country, 2016 was our most successful A&W campaign to date. In 2016, Burgers to Beat MS (formerly known as Cruisin' to end MS) focused heavily on raising awareness about the fact that Canada has the highest rate of MS in the world. With the help of MS Ambassador and A&W Champion's Tour all-star, Juan Garrido, the campaign successfully raised a record-breaking \$1.6 million. Thank you!

A&W continues to be the MS Society's largest cause marketing partner, with an annual campaign that has raised more than \$9 million in eight years for research and improving life with MS for Canadians affected by multiple sclerosis. Through a \$1 donation from every Teen Burger® sold, to local fundraising initiatives, more than 850 A&W restaurants across the country were able to make an impact in their communities, and nationwide.



I'm going to do as much as I can today because I'm not sure what I'll be able to do tomorrow. So today, I'm going to work my two jobs, and volunteer with the MS Society and be looking for my next opportunity because I can do that. If anything, MS has pushed me to take advantage of my abilities and get the most out of life."

-Juan Garrido, A&W Champion



To learn more about our corporate partnerships, please contact Brian Lim at brian.lim@mssociety.ca.

## LEADERSHIP DONORS

The MS Society is pleased to thank and recognize the following donors who made a significant and meaningful gift or commitment in 2016 in support of Canadians affected by MS.

#### \$100.000 - \$249.999

Slaight Family Foundation

#### \$50.000 - \$99.999

Vancouver Foundation

#### \$25,000 - \$49,999

Innovative Medicines Canada In honour of Bill & Isabel Kelley KIN Canada District 7 Atlantic The Lawrason Foundation Elizabeth Malcolm

The Catherine and Maxwell Meighen Foundation

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Douglas Wright

Raymond Yong Anonymous (7)

The Multiple Sclerosis Society of Canada would also like to thank the United Way of Canada.

## endMS: WHATEVER IT TAKES CAMPAIGN DONORS

The MS Society is grateful to the following donors who made a generous gift commitment in 2016 to the endMS: Whatever It Takes campaign, which funds the most promising research in Canada and around the world to find better treatments, improve quality of life, and enable people living with MS to lead the best life possible.

#### \$1,000,000 +

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#### \$500,000 - \$999,999

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#### \$100,000 - \$499,999

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#### \$1,000 - \$9,999

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From I to r: Yves Savoie, President and CEO, MS Society of Canada, Bill McFarland, CEO and Senior Partner, PwC Canada, Paul Mantini, Partner, Bennett Jones, Jon Love, CEO, KingSett Capital, Nancy Love, Chair, MS Scientific Research Foundation, Hugh MacKinnon, Chairman and CEO, Bennett Jones, Dave Filipchuk, President and CEO, PCL, Jim Dougan, President, Eastern Canadian Buildings and Civil Infrastructure, PCL



If you are interested in learning more about how you can make a significant gift to help end MS, please contact Cheryl Hanson at cheryl.hanson@mssociety.ca

## **TOP EVENT DONORS**

Our fundraising events enable us to fund cuttingedge Canadian MS research as well as programs and services for people living with MS across the country. We are delighted to recognize the following donors who made a gift in support of the MS Society's 2016 fundraising events.

#### \$50,000+

Medavie Blue Cross RBC Financial Group, through the RBC Foundation Sanofi Genzyme

#### \$25,000 - \$49,999

North American Produce Buyers Ltd. Novartis Pharmaceuticals Canada Inc. Scotiabank

#### \$10,000 - \$24,999

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David Wilton

#### \$5,000 - \$9,999

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NAV Canada

Oliver Wyman Inc.

David G Palmer

Karen Penrice

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## RESEARCH PARTNERS

Research partners are a special community of individuals, foundations, and corporations from across the country who are committed to supporting research into the cause of and cure for MS. The MS Society of Canada is grateful to the following research partners who made a gift in 2016.

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James & Glenna Christie Doug & Joanne Ellenor Agnes Faraci Peter O' Sullivan Roy Robbins

#### \$5,000 - \$9,999 R F Blair

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## **TeamMS TOP TEAMS**

TeamMS encourages MS Walk and MS Bike participants to form teams with their families, friends, and co-workers for fun and camaraderie. Thank you to the following teams for their outstanding fundraising contributions in 2016.

#### \$100,000+

Happy Fillmores AB Les Pédaliers de l'Avenir ac

#### \$75,000 - \$99,999

Doug and Marion's MS Erasers on Muck Yeah! on Team LAH oc Team United Cycle AB Woop de Woo BC

\$50,000 - \$74,999

Doug and Marion's MS Erasers on eSPrit SPortif oc Gregor Bombs AB

Lespérance oc Libro Freewheelers on Muck Yeah! on PD Slow Riders AB

Smokin' Embers AB

Solutions Partagées oc Sus Scrofas AB

Team Bleiwas on

Team Cowbell (formerly Sparling's Propane) ON

Team LAH QC Team United Cycle AB Woop de Woo BC

#### \$25,000 - \$49,999

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London Life Cycles ON Maple Reinders AB Mastronardi Produce on Menstrual Cycles AB Midland in Motion MR Millennium Stars Self-Help Group BC Misterleaou ac Mr. Lube AB MS AIN'T PURDY AB MvButts-Eh-King sk On the Run AB PCL Construction AB Rockingham Riders NS SG Front Forks AB Shifting Rears AB Slow Spokes NB Steps for the Cure on Team Framosa ON Team Nervous AB Team Rehabilitation AB The Brotherhood Team ON The Heartbrakers AB The Remyelinators sk The Spokespeople AB Tour de Ands AB VIA Rail oc Vol-au-vent oc

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Stellas and Glens and Bikes oh my on

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Team Chris AR

Team ML oc
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The Rear Guard BC
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We are proud to honour our nationwide corporate sponsors, cause marketing, and promotional partners who have demonstrated leadership in supporting the MS Society's fundraising events and overall mission.

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Named for the founder of the MS Society, the Evelyn Opal Society recognizes donors who share a commitment to helping end MS and giving those living with MS a better future. The following generous donors have made a designated gift through their estate plans. Respectfully, many donors wish to remain anonymous. Those who granted permission to be recognized as members are listed below.

Gayelene Bonenfant Bob and Pat Decker Valerie Hussey Kent Kirkpatrick Betty-Lou Northway We are grateful to many individuals who designated a legacy gift to the MS Society of Canada as part of their estate. Through their careful planning and consideration, we realized these gifts, either in part or in whole, in 2016. We are grateful to each of them and acknowledge their generosity and its lasting impact.

#### \$100.000 - \$249.999

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# MULTIPLE SCLEROSIS SOCIETY OF CANADA Combined Statement of Revenue and Expenditures

For the year ended December 31, 2016 (in thousands of dollars)

To view our full audited financial statements, please visit **mssociety.ca/financial** 

\* In addition to our staple research funding program, we invested more than \$3.9 million in MS research through the Multiple Sclerosis Scientific Research Foundation (MSSRF). The MSSRF is a legal entity separate from the MS Society of Canada, and we generate separate financial statements for the MSSRF. The MSSRF's T3010 is available on the CRA website.

	2016	2015
Revenue	·	
Leadership giving activity Bequests	2,194	3,725
endMS Research and Training Network	292	432
endMS: Whatever It Takes	2,140	573
Corporate giving and major donors	2,140	2,159
Grants from governments	1,218	1,159
Grants from pharmaceutical companies	460	636 732
Other grants	707 9,151	9,416
Company with a good free dwaring a growth	19,813	21,402
Community based fundraising events Individual giving and direct marketing	19,613	13,314
Dinners, tournaments, and third party events	7,164	6,392
Gaming	1,419	1,495
United Way and Health Partners	1,608	1,676
Public awareness activities	657	721
Sale of goods Miscellaneous	249 350	286 233
Memberships	52	34
Investment income	455	493
	52,995	55,462
Fundraising expenditures		
Leadership giving	1,852	1,988
Community based fundraising events	7,117	8,461
Individual giving and direct marketing	7,271	7,663
Dinners, tournaments, and third party events Indirect fundraising	2,351 2,264	2,065 1,940
Gaming	189	219
Cost of goods sold	174	164
	21,218	22,500
Program and administration expenditures		
Client services	7,921	8,851
Research*	6,257	6,404
Research – endMS Research and Training Network Research – Whatever It Takes	292 2,330	754 965
Public education and awareness	4,844	5,765
Chapter and volunteer support and development	3,472	3,821
Government and community relations	1,521	1,719
MS Clinics	106	249
Administration	5,112	4,148
	31,855	32,676
	53,073	55,176
(Deficiency) surplus of revenue over expenditures before the	(70)	206
undernoted	(78)	286
Fair value change in investments	31	(92)
(Deficiency) surplus of revenue over expenditures for the year	(47)	194



## 1-800-268-7582

# info@mssociety.ca

# mssociety.ca

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