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 MS Society in-depth: Priorities and operations

Chair and president's message

Our country has the highest rate of multiple sclerosis in the world. A startling reality, and a fact all Canadians should be aware of. Together, we need to support Canadians touched by MS and show our family, friends and communities that this disease is not something we can ignore.

In an effort to acknowledge and improve the lives of people touched by MS, over the past 18 months we developed the Listening to People Affected by MS initiative. One of the goals of this initiative was to find out what impacts quality of life for people with MS and their loved ones. More than 6,000 people affected by MS engaged with us and expressed what good quality of life means to them: maintaining independence, financial freedom and support systems that provide coordinated, quality lifelong care. As the leader in advocating for Canadians affected by MS, the MS Society of Canada is calling on federal, provincial and territorial governments to improve supports in these and other areas. As Canadians, we cannot ignore the realities of living with MS and we must advocate for change.

Our commitment to honouring the voices of people with MS continues to flow through the Renewal Initiative outcomes, which inspired Canadawide research priority discussions between researchers and people affected by MS. Through these discussions, we witnessed a powerful yearning for more speed in the development of therapies to help treat and manage MS symptoms. For decades the MS Society has funded innovative research that has led to insights about MS and novel therapies for the disease. Through our recent collaboration

with the Centre for Drug Research and Development (CDRD), we will accelerate translation of these insights to expedite the development of effective treatments, and ultimately a cure for MS. We are optimistic that this partnership will breed positive outcomes for all people living with MS.

Financial results for 2013 reveal continuing economic challenges in many regions of the country. Against this backdrop, the efforts of participants at MS Walk and MS Bike events across the country are all the more deserving of praise and recognition. We are always moved by the dedication of our most valued supporters, and by the hope that is inspired at each of these events for a future free of MS.

The decline in revenue this past year fuels the need to re-invest in our core events and seek new streams of revenue to support people living with MS. We are building on the success of Totale Bouette, an event inaugurated by our Quebec City and Region Chapter that attracted 2,500 new supporters to the MS cause in a romp through mud and obstacles. Totale Bouette has now been expanded, and will have its Muck MS counterpart launching events in Ontario and British Columbia this summer.

On behalf of people living with MS, I'd like to extend warm thanks to all MS Society volunteers, donors and participants. Canada may have the highest rate of MS in the world today, but this present-day reality does not have to be part of our future. In fact, Canada and Canadians have an opportunity to play a leadership role in building a world free of MS.

Thank you for being part of the journey to end MS.



Yves SavoiePresident and chief executive officer



Chuck Ford
Chair

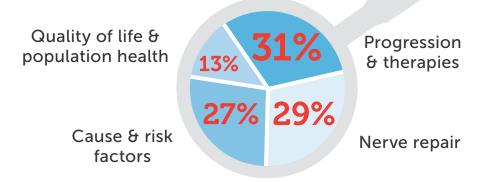
YEAR IN REVIEW

Multiple sclerosis is Canada's disease – 100,000 Canadians have MS, and Canada has the highest rate of MS in the world. As the country's advocate for people with MS, we're proud to fund some of the best research in the world and programs and services that help people with MS live well. In 2013, we funded \$8 million in Canadian MS research, \$9 million in programs and services for people affected

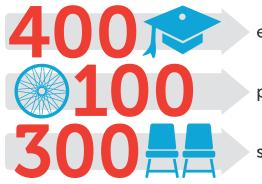
by MS, \$6 million in public education and awareness, \$2 million in government and community relations and \$4 million in volunteer and chapter development.

It is because of our supporters across the country that the MS Society of Canada continues to help Canadians with MS and push for better treatments and a cure for this disease. Thank you.

Research funding



Programs and services*



education events

physical activity programs

self-help groups

Engagement volunteers who raise funds across the country letters/emails sent to Members of Parliament *The MS Society provides a range of programs and services that offer information, supports and recreational activities that help enhance the quality of life of people affected by MS. For a comprehensive list, visit mssociety.ca/services

66 New work in stem cells has moved my disease out of permanent disability and into a life where I can fully participate as a physician, friend and active member of my community.

FASTER PATHS TO MS RESEARCH

With a refreshed commitment to hearing the voices of people affected by MS via the Renewal Initiative in 2012, the MS Society of Canada facilitated seven research priorities discussions, which brought together Canadians affected by MS and researchers to discuss the future of MS research.

During these discussions, we heard clearly that accelerating the pace of research is just as important as research itself. Taking action, the MS Society established a \$1 million fund with the Centre for Drug Research and Development (CDRD). Through this collaboration, the MS Society and CDRD will leverage resources to identify promising scientific discoveries and speed up their development into effective treatments, and ultimately a cure, for MS. Visit mssociety.ca/research for more information on the partnership.

The MS Society continues to support a diverse portfolio of research areas, such as repair, cause, progression and therapies. In 2013, we celebrated new discoveries in stem cell research and myelin repair.

Advances in stem cell research

Alex was a 24-year-old medical student when he was diagnosed with an advancing form of multiple sclerosis. "As my disabilities became more permanent, I realized my chosen therapy wasn't working," Alex says. "I knew I needed a more aggressive option to slow down my progression."

In the year 2000, the Multiple Sclerosis Scientific Research Foundation funded a pioneering stem cell clinical trial led by Drs. Mark Freedman and Harry Atkins at the Ottawa Hospital Research Institute. Alex was one of 24 participants with aggressive MS who were not responding to standard treatment. Each person received chemotherapy to eliminate their immune systems, followed by the introduction of their own bone marrow stem cells to re-boot the immune system. After several years, researchers noticed dramatic improvements in some participants, including Alex.

Bone marrow transplantation bears serious risks, in which some people can experience severe adverse effects, but the trial outcomes have changed the landscape of stem cell work in MS and provide researchers with the opportunity to develop safer, more targeted therapies for more people with MS.

Successes in myelin repair: Preventing MS progression

It's an exciting time for MS research in myelin repair – in 2013, MS Society funded researchers Dr. Jack Antel, Dr. Rashmi Kothary and Dr. Veronique Miron achieved success in learning about cells that may stimulate myelin regeneration after an MS relapse.

Myelin repair is vital to preventing the neurological damage that often leads to progressive MS. *Visit* **mssociety.ca/msupdates** for details on advances in this exciting field of research.



To follow our progress on this work and get the inside story on MS research, visit DrKarenLee.ca or follow @Dr_KarenLee on Twitter.

66 My wife Teresa takes time off work to drive me to medical appointments and be there for many rounds of treatment. She is the rock of the family.

LISTENING TO PEOPLE AFFECTED BY MS: calls to action

Over the past 18 months, more than 6,000 Canadians affected by MS responded to the Listening to People Affected by MS initiative, allowing us to better understand the impact of multiple sclerosis on quality of life needs and barriers.

When asked to describe what a good quality of life means to them, participants from across the country spoke of maintaining independence without being a burden on family and friends, the financial freedom to make choices and the need for a navigation service to sort through the maze of information and services for MS.

Canadians affected by MS look to the MS Society of Canada as an important leader, positioning the organization to play an important role in improving and advocating for better quality of life of Canadians affected by MS.

The MS Society plans to build on existing information and referral services to create a nation-wide MS information and support service that will allow people affected by MS to connect by phone and online to a team of information and referral navigators. Additionally, the MS Society is asking federal, provincial and territorial levels of government to take action in four areas that are crucial to improving the lives of Canadians living with MS.

For more information about the Listening to People Affected by MS initiative and the calls to action, visit **mslistening.ca**

1

Support secure jobs and income for people affected by MS

The federal government needs to take leadership with provinces and territories to improve job retention and better coordinate income and disability benefits for people impacted by MS.

2

Care for the caregiver

The federal government should initiate the development of a National Caregiver Action Plan working with provinces, territories, caregivers, employers and organizations to: reduce financial burden, improve access to resources, create flexible workplace environments, and recognize caregivers' vital roles.



Coordinate quality lifelong care and support for people with MS

It's time to help people get the care they need, when they need it, throughout their lives. Provincial and territorial governments play the leading role in delivering supports and services and they must lead the development of MS strategies that better coordinate lifelong care and support for people affected by MS.

The federal government must do its part and harness the forthcoming report of the National Population Health Study of Neurological Conditions to deliver an action plan for all Canadians living with diseases of the brain including MS.



Accelerate progressive MS research

Develop therapies for people living with progressive MS within the next 8 years.

66 Alberta has one of the highest rates of MS in Canada, and we have a responsibility to reduce barriers for Albertans with MS. I'm proud to have contributed to bringing The Way Forward to life.

Judy Gordon, former mayor of Lacombe and Alberta MLA, diagnosed in 1998



THE WAY FORWARD: Enhancing care and support

In 2013, after five years of sector collaboration, the Government of Alberta announced The Way Forward: its commitment to providing Albertans affected by MS with streamlined access to a comprehensive system of care, services and support.

Through partnerships and better communication between provincial agencies and community organizations, The Way Forward will create an integrated system of support for Albertans living with MS that includes family and friends, healthcare providers, community supports and specialized services.

The Way Forward initiative is a framework that:

- provides a better road map for Albertans with MS looking for a wide array of services and supports
- coordinates government policies with disability supports
- supports empowerment and selfmanagement
- develops education and awareness within systems serving Albertans with MS
- advances MS research and evaluation

The Way Forward is the first initiative of its kind in Canada, and the MS Society is calling on other provincial and territorial governments to develop similar models of integration.

For more information on The Way
Forward, visit http://bit.ly/1dUXQJM

Access to medications in New Brunswick and Prince Edward Island

In the past, people living with MS in New Brunswick and Prince Edward Island without private insurance paid for expensive MS medications out of pocket or went without disease-modifying treatments, which have been proven effective for people with relapsing-remitting MS. In 2013, the MS Society of Canada led major accomplishments in establishing catastrophic drug coverage plans in the two remaining provinces in Canada that did not have coverage plans.

In October 2013, Prince Edward Island began offering drug coverage for those whose prescription drug costs were affecting their household's ability to maintain life essentials. In December, New Brunswick announced the first phase of a drug program to begin on May 1, 2014, with premiums depending on income levels.

The success of each initiative has empowered people living with MS to make choices about their treatment with greater funding supports from the government.

Advocacy priorities and successes across Canada





INVESTMENT & GROWTH: To serve Canadians better

In 2013, the MS Society refocused its investments in core fundraising events to enhance sustainability of critical local fund development activities.

To ensure that we continue to innovate within Canada's competitive fundraising environment, we established new sources of revenue through events like Totale Bouette while re-investing in our MS Walk program to improve long-term capacity to support research, programs and services in communities across Canada.

Through a diverse fundraising portfolio, MS Society initiatives engage with members of the community who ensure that support for MS research and programs continues to grow.



Investing in MS Walk

Every year, organizations across Canada sponsor MS Walk events in their home province. In an increasingly competitive fundraising environment, these partnerships are vital to supporting MS Walk events so that even more funds raised by participants can go directly to programs and services for people living with MS in their region, as well as research into treatments and a cure for MS.

In 2013, more than 40,000 participants in more than 160 communities across Canada gathered at the MS Walk. We are grateful to the following title sponsors for ensuring that MS Walk fundraising continues to support Canadians living with MS.

MS. WALK Sponsors

EVERY STEP MATTERS.

Canada-wide: Student Works Painting and Brinks

British Columbia: Scotiabank

Alberta: Enerflex



Music 4 MS

Where popular bands in my community donate their talent to entertain 250 music lovers. The event is my way of taking action against my disease, which I'm fighting off every day. Music 4 MS has raised more than \$30,000 to support people in Saskatchewan with MS. I am so happy to be able to help people in my community, just like I was helped when I was first diagnosed with this very confusing disease. \$9

Sharon, diagnosed in 2001

Saskatchewan: Saskatchewan Blue Cross Manitoba: Manitoba Liquor & Lotteries

Ontario: Mandarin Restaurants
Atlantic: Medavie Blue Cross



A&W Cruisin' for a Cause

In 2013, A&W Cruisin' for a Cause reached a milestone: the campaign raised more than \$5 million in five years for Canadians affected by multiple sclerosis.

On August 22, 2013, A&W and the MS Society of Canada raised \$1.45 million through customer contributions, events and donations of \$1 from every Teen Burger® sold. The MS Society is grateful for the partnership with A&W.



Patrycia Rzechowka, who lives with MS, enjoys an A&W root beer with Naheed Nenshi, mayor of Calgary

LEADERSHIP DONORS

The MS Society of Canada is delighted to recognize the following individuals, corporations and foundations that made a gift commitment in 2013 in support of the 100,000 Canadians living with MS.

\$1,000,000 +

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\$500.000 - \$999.999

Anonymous (2)

\$250,000 - \$499,999

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"I believe researchers will find a cure for multiple sclerosis for me, for everybody, in my lifetime. Supporting research is an expression of hope, my expression of hope."

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

\$115.000+

Jasper H-Core Rockhoppers Graham Metzger AB-NWT

\$100.000 - \$114.999

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Shifting Rears Karin Nelson AB-NWT

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Team Unagi Shaianne Kotlar sk

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Team BASF Scott Hodgins on

Team DiBattista Judy Gane on

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EVELYN OPAL SOCIETY & LEGACY GIFTS

The following individuals have confirmed a legacy gift to the MS Society in the past year, and we are privileged to welcome them as the newest members of the Evelyn Opal Society:

Jim & Diane Butlin Sylvie Choquette Yves Savoie Jennifer Sweeney & Daniel Ouellet Garry Wheeler & Jennifer Steber Anonymous

And a special thank you to Gayelene Bonenfant, a current Evelyn Opal Society member who created a second legacy gift in support of the MS Society in 2013.

We also recognize the following Evelyn Opal Society members for their generous support through their legacy gift in 2013:

\$1,000 - \$4,999

Estate of Bill & Sammy Tiner

We are humbled by the generosity of our donors and the extraordinary commitment they show to the fight to end MS. We are honoured to recognize the contributions of the following estates in 2013.

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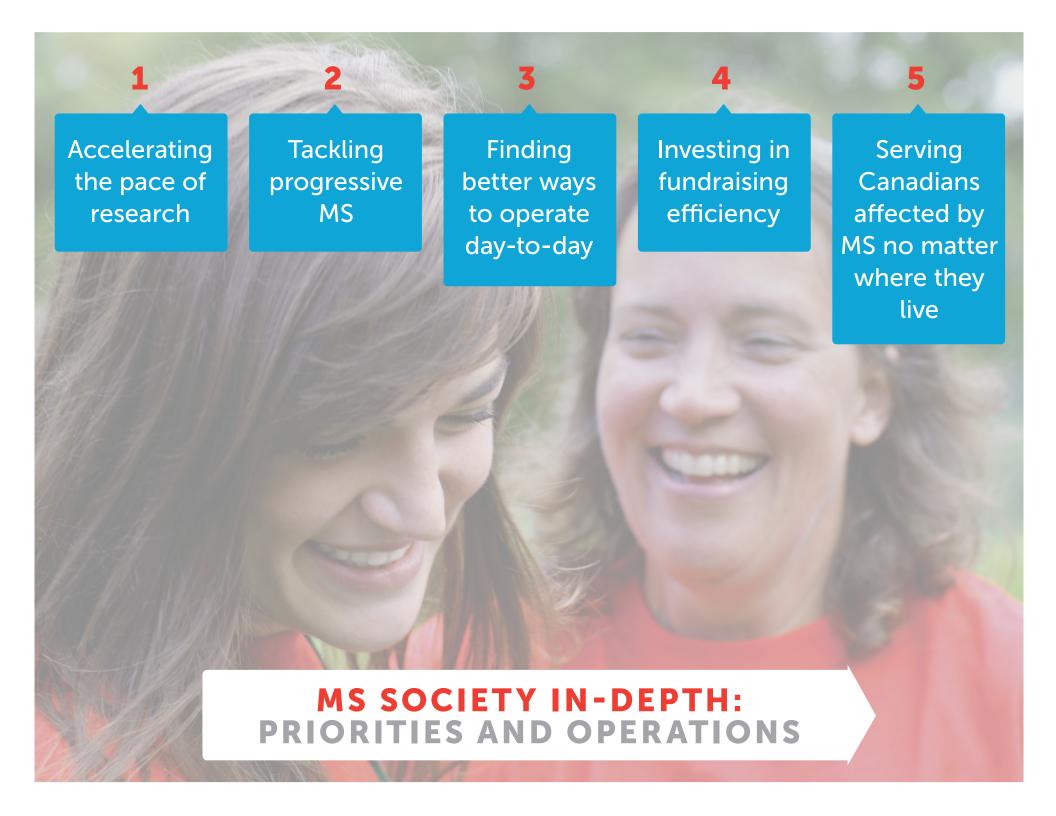
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MULTIPLE SCLEROSIS SOCIETY OF CANADA Combined Statement of Revenue and Expenditures

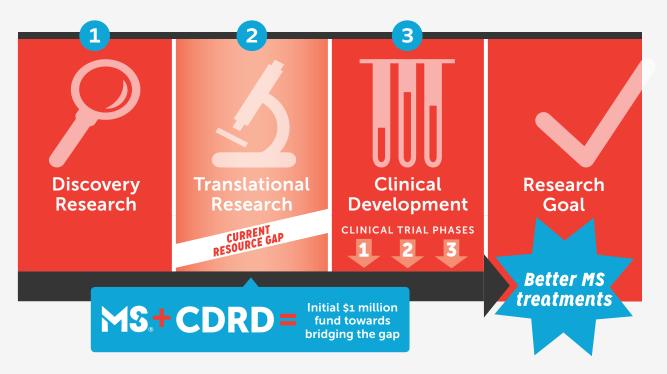
For the year ended December 31, 2013 (in thousands of dollars)

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

Davis	2013	2012 \$
Revenue Leadership giving activity Bequests endMS Research & Training Network	2,487 1,232	2,798 1,919
Corporate giving and major donors Grants from governments Grants from pharmaceutical companies Other grants	2,043 1,348 767 825	1,659 1,337 743 636
3	8,702	9,092
Community based fundraising events Individual giving and direct marketing Dinners, tournaments and third party events Gaming Sale of goods United Way and HealthPartners Public awareness activities Miscellaneous Memberships Investment income	22,554 13,815 6,383 1,467 277 1,661 1,007 253 73 615 56,807	23,668 14,649 5,607 1,599 314 1,840 1,025 286 81 475 58,636
Fundraising expenditures Leadership giving Community based fundraising events Individual giving and direct marketing Dinners, tournaments and third party events Gaming Cost of goods sold Indirect fundraising	1,936 8,590 8,436 1,967 247 160 1,851 23,187	1,541 8,930 8,473 1,761 410 194 1,959 23,268
Program and administration expenditures Client services Research Research — endMS Research & Training Network Public education and awareness Chapter and volunteer support and development Government and community relations MS Clinics Administration	9,223 6,653 1,457 6,453 4,152 1,893 1,030 4,234 35,095 58,282	9,393 7,202 1,800 6,225 3,719 1,707 1,017 3,962 35,025 58,293
(Deficiency) excess of revenue over expenditures before the undernoted	(1,475)	343
Fair value change in investments	526	288
(Deficiency) excess of revenue over expenditures for the year	(949)	631



ACCELERATING THE PACE OF RESEARCH



When you're living with multiple sclerosis, it can be difficult to wait for research to yield results that will have a real-life impact on quality of life. We recognize the importance of propelling research forward to accelerate the development of therapies for people living with MS. Much of this acceleration requires that we invest in translational research — those steps between discovery research and the commercial availability of treatments.

Significant breakthroughs in treatment begin in the lab. They start with an idea, or observation, that is tested under controlled conditions. This is the basis of discovery research, which takes place in universities and hospitals around the world. Discovery research

is the foundation from which treatments for multiple sclerosis are developed.

There are, however, many steps along the research continuum — from the lab to benefiting a person living with MS. Discovery research produces biological knowledge that requires exhaustive testing to ensure that treatments are safe, beneficial and tolerable in humans. These additional steps require expertise, time and financial resources that are often beyond the scope of non-profit and academic funding agencies.

In 2013 the MS Society collaborated with the Centre for Drug Research and Development (CDRD) to boost its capacity for supporting translational research. As a

first step of this collaboration, the MS Society established an initial \$1 million fund with CDRD to identify promising therapeutic agents and develop them into safe and effective treatments for people living with MS. The fund aims to accelerate general treatment development while facilitating the discovery and development of treatments for progressive forms of MS.

The collaboration has already seen activity with the first call for research proposals focusing on progressive MS targets. The competition invited researchers to submit innovative and novel ideas on progressive MS that can be further developed into treatments. For more information, visit **cdrd.ca**.

TACKLING PROGRESSIVE MS

Progressive MS research funding

Advances in treatments for relapsing-remitting MS over the past decade have been remarkable, and people affected by MS would like to see the same for progressive forms of MS. Currently, there are no disease-modifying therapies for progressive MS. The following graphic highlights the number of MS Society operating grants that seek to benefit people living with progressive MS.

2013 BREAKDOWN OF OPERATING GRANTS FOCUSED ON PROGRESSIVE MS



WHY IS RESEARCH IN MYELIN REPAIR AND NEUROPROTECTION IMPORTANT?

During or after a relapse in multiple sclerosis, the central nervous system will attempt to recover or work harder to perform basic functions. In either case, this exerted effort can lead to further, irreversible injury that often leads to disease progression and disability.

Effective and timely repair of myelin – the insulation in the central nervous system that is damaged during a relapse – is critical to avoiding exhaustion of nerve cells and further damage to tissue. The development of treatments that have neuroprotective effects, such as the ability to keep neurons healthy, alive and functioning, are an important step towards tackling progression in MS.

Major research in progressive MS

With the support of a \$3.8 million Multiple Sclerosis Scientific Research Foundation collaborative grant, Dr. Peter Stys and colleagues at the University of Calgary are working to better understand the neurodegenerative component of multiple sclerosis.

Dr. Stys' team proposes that early degenerative events in the central nervous system result in activation of immune cells that cause further damage. This unconventional view of what triggers MS is based on a number of scientific observations that Dr. Stys is studying more closely in the lab.

The goal of Dr. Stys' research is to understand MS progression and disability by identifying which cells are contributing to nerve injury and how the injury is disseminated throughout the central nervous system.

FINDING BETTER WAYS TO OPERATE DAY-TO-DAY

Toronto office servicing National Office, Ontario & Nunavut Division and Toronto Chapter

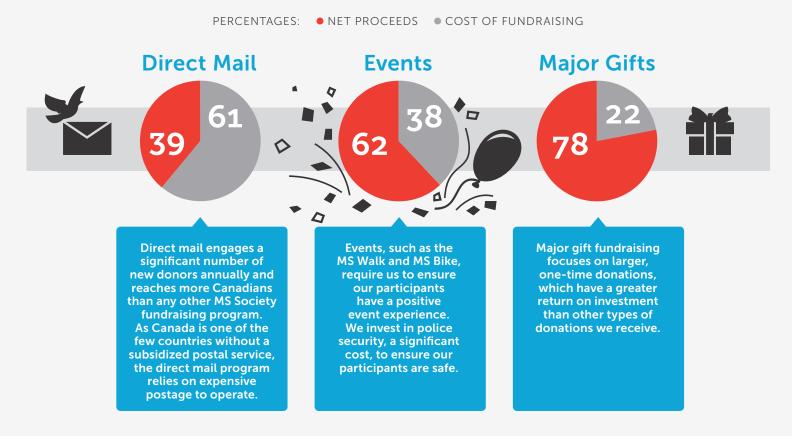


Feedback from volunteers, donors and staff reveals that our presence in the MS community is vital to the people we serve. As part of the Renewal Initiative, the MS Society is committed to using our real estate as efficiently as possible. In 2013 we achieved greater efficiency with our office space to ensure that it is used to its fullest potential within each community.

In some smaller communities, we transferred staff resources to home offices and have begun delivering programs in partnership with other organizations such as the YMCA. For our largest office in Toronto, which serves the National Office, Ontario & Nunavut Division and Toronto Chapter, we negotiated an early termination to our office lease to reduce space and long-term real estate expenses.

Some staff were moved into chapter offices, and we have expanded our work-fromhome policy to allow personnel to work from home one or two days per week. This has allowed the MS Society to eliminate private offices in Toronto and move to a 100 per cent open concept office design, where staff share desks depending on those days they will be present in the office.

INVESTING IN FUNDRAISING EFFICIENCY



How you can help us be more efficient

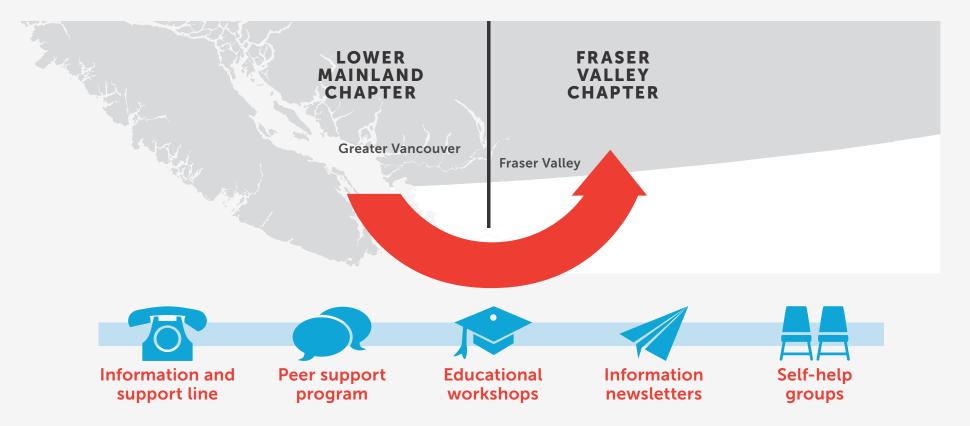
When we continue to invest in activities that donors and event participants consistently engage with, we discover more efficient ways to fundraise. We continue to focus on expanding fundraising programs that have the lowest cost of fundraising, including more efforts in major gifts and planned giving.

Please help us become more efficient by making your contributions online. Online fundraising is highly efficient; in 2013, our online fundraising increased by eight per cent over 2012. We've increased our online engagement through "do-it-yourself" and third-party fundraisers, and by partnering with community members who wish to fundraise for the MS Society on their own time and in their own way.

While there is no simple way to increase fundraising efficiency for any charitable organization, there is a high commitment from our volunteer leadership to ensure the MS Society is raising funds as efficiently as we can. In 2010, the national board of directors passed a motion to reduce the cost of fundraising and continues to provide oversight in this organization endeavour today.

SERVING CANADIANS AFFECTED BY MS NO MATTER WHERE THEY LIVE

Sharing of programs & services



As one example of our efficient service to Canadians affected by MS in British Columbia, the Lower Mainland Chapter (LMC) began sharing its staff and volunteer resources with the Fraser Valley Chapter (FVC).

Last year, the Lower Mainland Chapter and the Fraser Valley Chapter engaged in collaborative discussion on how to best utilize staff and volunteer resources. Dialogue focused on how to most effectively provide client services, avoid service duplication and ensure best practices while maintaining the local voice of each region. After much discussion, a partnership was created and resources were shared. People living with MS in the FVC area now have access to all client services that were previously only available to people in the LMC area.

Boards of directors continue to play an integral role in representing both communities. This representation ensures that each chapter

continues to leverage its strengths and that the needs of each community are not lost. By sharing the resources of one of BC's largest chapters, the partnership has effectively helped the MS Society deliver programming to more clients, regardless of where they live.

We continue to look for ways to share services across communities in other areas of the country.

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