



Multiple
Sclerosis
Society of
Canada

Société
canadienne
de la sclérose
en plaques



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MULTIPLE SCLEROSIS SOCIETY OF CANADA FACT SHEET

What multiple sclerosis is

Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system (brain and spinal cord). It is the most common neurological disease of young adults in Canada. An estimated 50,000 Canadians have MS. Prevalence rates range from one MS case per 500 population to one per 1,000 across the country. The MS Society estimates, based on current prevalence rates, that there are approximately 1,000 new cases of MS diagnosed each year. This means that three more people are diagnosed with MS every day in Canada.

MS attacks the protective myelin covering of the brain and spinal cord, causing inflammation and often destroying the myelin in patches and, at times, the nerve fibres (axons) themselves. When this happens, the natural flow of nerve impulses is interrupted. The result may be vision problems, numbness, loss of balance, extreme fatigue, tremors, even paralysis.

The most common form of MS has well defined attacks (relapses) followed by periods of recovery (remissions). This pattern of attacks and recovery can continue for months or years. The unpredictable attacks can cause additional symptoms and disability. As yet, the cause and cure are unknown, but drugs to reduce the frequency and severity of MS attacks are available for the most common form of MS. In addition, almost all MS symptoms can be helped by medications and therapy.

Multiple sclerosis is usually diagnosed between the ages of 15 to 40 although it can occur at any age including in childhood. MS is more than twice as likely to occur in women as in men and is seen most commonly in people of northern European background. It is more common in countries that are further away from the equator, like Canada. Epidemiological studies have shown that Canada has one of the highest prevalence rates of MS in the world.

Cost of multiple sclerosis

Multiple sclerosis is a costly disease, both emotionally and financially. The unpredictable, potentially disabling nature of MS impacts people with MS and their families. An estimated 80 percent of people with MS are eventually unable to work full time because of the severity and unpredictability of MS symptoms. While studies vary, it is estimated that within ten years of diagnosis, one-half of all people with MS are unable to work with the largest drop occurring in the first five years after symptom onset. In addition to the indirect costs associated with the loss of productivity and the day-to-day activities of life, MS has an economic impact on the health care system because of increased visits to a doctor or hospital and longer stays in hospital. It is estimated that the lifetime cost of the disease is \$1.6 million per person. This means that the annual cost of MS to Canadian society today may be more than one billion dollars.

Multiple Sclerosis Society of Canada

Founded in 1948, the Multiple Sclerosis Society of Canada has a membership of 28,000. It is Canada's foremost leader in MS research, education and the provision of services to people with MS and their families and caregivers. The MS Society is governed by a National Board of Directors comprised of 27 volunteer members who are elected annually. The seven regional divisions and nearly 120 chapters are also governed by elected volunteer boards of directors.

Some 1,500 volunteers serve on MS Society national, division and chapter boards and committees. An estimated 13,500 women and men are volunteers for service programs, fundraising events, public awareness campaigns and government relations activities. Along with these committed volunteers, more than 120 Canadians participate in MS Society fundraising events, and more than one million donors support the MS cause. The head office of the Multiple Sclerosis Society is located in Toronto, Ontario. Division offices are located in Dartmouth, Montreal, Toronto, Winnipeg, Regina, Edmonton and Burnaby.

Eighty-two percent of MS Society net revenue is devoted to program areas: MS research, services for people with MS and their families, MS clinics, government relations and social action, public education and chapter development. Administration and fundraising costs are just 18 percent.

Our Mission

The mission of the Multiple Sclerosis Society of Canada is:

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

Goals

We will have achieved our mission when:

1. The cause and cure for multiple sclerosis are identified in the shortest possible time.
2. People with MS have the opportunity to participate fully in all aspects of life.
3. The Canadian public is fully aware of MS, the MS Society and what it does.
4. All necessary activities of the MS Society are adequately funded.
5. The volunteers and staff of the chapters, divisions and national organization are working together effectively towards our common mission.

Research and MS Scientific Research Foundation

Much research into MS is based on the idea that MS is probably an autoimmune disease. This means that MS is the result of an overly active immune system attacking the protective myelin covering of nerve fibres in the central nervous system. There is good evidence that genetic factors may determine a predisposition to multiple sclerosis and that environmental factors, such as viruses, may be part of the cause as well.

The Multiple Sclerosis Society of Canada is a leader in the search to find a cure for MS. It has funded medical research into multiple sclerosis since the first grant of \$10,000 was approved in 1949. Today, the MS Society funds a research program totalling about \$6 million

annually. The total investment in research since its founding is more than \$98 million. In addition, the related MS Scientific Research Foundation funds large cooperative multi-disciplinary research projects. Together, they are the largest funders of MS research in Canada. (See below for more information about the Foundation.)

Many researchers and people with MS alike are talking of a new era in MS research. This new era is the result of unprecedented and ongoing research collaboration, much of it led by the MS Society of Canada and the MS Scientific Research Foundation.

Research funded by the MS Society and the Foundation focuses primarily on:

- Repair of damaged brain and spinal cord tissue including myelin, the cells that make myelin and nerve fibres
- Blocking the immune system attack on the brain and spinal cord including a study of the use of bone marrow transplantation as a treatment
- Genetic susceptibility to MS and potential environmental factors
- Use of MRI to provide a “window” into the brain and spinal cord
- Studies of health and treatment effects

Since 1995, four medications have been approved by Health Canada for the treatment of relapsing-remitting MS (interferon beta-1a, Avonex® and Rebif®; interferon beta-1b, Betaseron®; glatiramer acetate, Copaxone®). One is approved for secondary-progressive MS (interferon beta-1b, Betaseron), and one is approved for people at high risk of developing MS and for secondary-progressive MS with relapses (interferon beta-1a, Avonex). The treatments have been shown in clinical trials to actually modify the course of the disease. They decrease the frequency and severity of MS attacks, reduce the number of MS lesions in the brain and several have been shown to slow the progression of disability. Treatment early in the disease is recommended because of recent studies showing the presence of early nerve fibre (axonal) damage. Also important are therapies which are available to help MS symptoms such as spasticity, bladder problems, depression, pain and fatigue.

Numerous clinical trials of other potential MS treatments are underway in Canada and other countries. Researchers are using magnetic resonance imaging (MRI) to analyze the results of such treatments on the living brain, thus speeding the progress of clinical trials. Another promising area of research is in myelin repair using experimental techniques to either stimulate the body to produce new myelin-producing cells or transplant myelin producing cells into the body.

MS Scientific Research Foundation

The MS Scientific Research Foundation was established in 1973 with an initial investment of \$1,000. Over the years with financial support primarily from donors to the MS Society of Canada, the Foundation has become the largest fund in the world dedicated strictly to MS research.

The goal for the Foundation today is two-tiered: to support large cooperative, multi-disciplinary research projects beyond the scope of the MS Society of Canada’s regular granting program and to plan for and fund future needs and opportunities. The Foundation encourages projects where significant collaboration of scientists from more than one institution and more than one

discipline produce better treatments and discoveries. The Foundation also funds small pilot research projects which allow investigators to pursue innovative approaches in MS research.

The quality of research funded by the Foundation has led to measurable progress and the potential for major discoveries is a reality of today. Currently, the Foundation is funding four flagship, multi-million dollar collaborative initiatives including the unique study of the development of MS in children, the Canadian collaborative study of genetic susceptibility to MS, the definitive clinical trial of whether bone marrow transplantation can stop MS progression and the examination of myelin repair using the body's own stem cells. The innovative projects supported by the Foundation represent some of the most significant advances in recent MS research. All four Foundation-funded projects are recognized globally as providing unparalleled opportunities in the search for the cause and cure of MS.

Client Services

Client services assist individuals with MS, their families and caregivers and people awaiting a diagnosis of MS by providing information and referral, education, support, individual advocacy and funding. Within these major activities, volunteers and staff provide the following services:

- Information and referral
- MS Society publications
- Research updates
- National Information Resource Centre
- Lending libraries
- Conferences and workshops
- Support and self-help groups
- Recreation and social programs
- Supportive counselling
- Individual advocacy
- Equipment purchase and loan
- Special financial assistance

Services offered vary depending upon existing provincial and community programs and financial resources available in the divisions and chapters. The MS Society does not duplicate services available through other sources.

MS Awareness Month / Other Awareness Activities

The MS Society has been committed since its early days to informing Canadians about MS and how they can join the fight against MS. May is MS Awareness Month at which time many public education activities take place. MS Awareness Month began in the late 1970s. The national office coordinates an overall public awareness campaign which is complemented by division and chapter activities.

Government Relations / Social Action

The Multiple Sclerosis Society of Canada works with people who have MS to ensure they have the opportunity to participate fully in all aspects of life. Volunteers across the country endeavour to change government policies at all levels, private industry practices and public attitudes in ways that will positively benefit people with MS.

Fundraising

The Multiple Sclerosis Society of Canada is an almost entirely self-funded organization with support from community, corporate and foundation partners. In 2005, it had consolidated net revenues of \$26.5 million. The funds are used to support research, client services, public education, government relations and volunteer resources. Most of this income comes from public donations, bequests and special fundraising projects conducted by the MS Society. The major fundraising programs are the MS Carnation Campaign, the RONA MS Bike Tour, the MS Read-A-Thon, the Super Cities WALK for MS, the direct marketing program and major gifts/planned giving.

History

A small group of dedicated volunteers in Montreal founded the Multiple Sclerosis Society of Canada in 1948 after contact with the newly established National MS Society (USA). Support of MS research began in 1949.

Headquarters for the Society remained in Montreal until the mid-1960s when the offices were moved to Toronto. Other advances came with the establishment of regional divisions; there are now seven divisions across Canada, from coast to coast. The Multiple Sclerosis International Federation, of which the Canadian Society is a charter member, was established in 1967.

Multiple Sclerosis International Federation (MSIF)

The Multiple Sclerosis International Federation (MSIF) was established in 1967 with the Canadian Society as one of the founding members. The aims and purposes of MSIF are to: stimulate scientific research on a global scale; distribute information internationally; assist in the development of national MS societies; and encourage the integration and participation of people affected by multiple sclerosis. ~~DELETE the following in green --~~ The MS Society of Canada helps fund the new Sylvia Lawry Centre for MS Research based in Munich. The Centre's first objective is the development of the most complete database on MS, which will be invaluable for future studies of MS therapies.

The Federation includes the following national societies: Argentina, Australia, Austria, Belgium, Brazil, Canada, Chile, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Great Britain and Northern Ireland, Greece, Hungary, Iceland, India, Iran, Ireland, Israel, Italy, Japan, Korea, Latvia, Luxembourg, Malta, Mexico, the Netherlands, New Zealand, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Switzerland, Turkey, the United States and Zimbabwe. The MSIF is an official member of the World Health Organization and is a consultative organization with the United Nations Education and Scientific Council.

Toll free to MS Society division offices: 1-800-268-7582

Web site: www.mssociety.ca

Multiple Sclerosis Society of Canada FUNDRAISING PROGRAMS

Direct Marketing

The Direct Marketing Program is the MS Society's largest single fundraiser. It offers individuals and corporations the opportunity to make contributions directly and simply through the mail several times during the year. Direct marketing became a national program in 1984. Since then it has raised more than \$70 million in support of world calibre MS research thanks to generous gifts from committed donors.

Major Gifts/Planned Giving

Major and planned gifts are a significant part of the MS Society's annual revenue. Individuals, corporations and public/private foundations across the country support Canadians affected by MS through their gifts of \$1,000 and more to MS research and services. More and more, Canadians are also including gifts through their estate plans (such as bequests, life insurance policies, annuities, etc.) to support future MS services and research. The MS Society ensures that all donations adhere to the wishes of the donor while aligning with the priorities of the MS Society. In 2005, donors made major and planned gifts of \$6.3 million to the MS Society.

FUNDRAISING SPECIAL EVENTS

MS Carnation Campaign

The MS Carnation Campaign is a national fundraising campaign held on Mother's Day weekend to raise money and public awareness to help fight multiple sclerosis. Since becoming the first national fundraising program of the Multiple Sclerosis Society of Canada in 1976, the MS Carnation Campaign has raised more than \$45 million. During the MS Carnation Campaign, more than 6,000 volunteers in over 280 communities across the country offer fresh flowers and/or carnation symbols to the public for a donation to the Society, raising \$1.5 million annually.

MS Read-A-Thon

The MS Read-A-Thon has proven itself to be an excellent motivational tool for children to learn the importance of reading while raising funds to support MS research and services. The MS Read-A-Thon program has been endorsed since 1978 by thousands of educators across Canada. Every year, approximately 150,000 elementary school children learn about multiple sclerosis, read half a million books and raise \$1.5 million annually for MS research and services.

RONA MS Bike Tour

The RONA MS Bike Tour challenges cyclists on routes of up to 170 km while raising funds for MS services and research. This national event series provides an opportunity for cyclists to have a one or two-day leisurely ride through rural areas, city parks and mountains. The first MS Bike Tour was held in August 1989. The event now raises \$6.5 million annually and draws 10,000 enthusiastic riders from coast to coast. This year, there will be 21 tours.

The Super Cities WALK for MS

The Super Cities WALK for MS is the largest national fundraising event for the MS Society of Canada. The one-day 5, 10 and 15 km walks began in Canada in 1991 with successful events in Edmonton, Alta., St. John's, Nfld., and Kingston, Ont. The event attracts 70,000 people from all walks of life and raises \$11 million annually. The Super Cities WALK takes place in more than 160 communities across Canada.

MS Global Dinner Party

The MS Global Dinner Party is an entertaining fundraiser where participants host a party for friends and family. Instead of bringing a gift for the host, the guests are asked to make a donation to the MS Society of Canada. Hosts and guests are part of a global initiative, as countries around the world participate on the same day. The event typically takes place on the last Saturday in February.

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