

MULTIPLE SCLEROSIS SOCIETY OF CANADA FACT SHEET 2002

What multiple sclerosis is

Multiple sclerosis (MS) is the most common disease of the central nervous system affecting 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.

The disease attacks the protective myelin covering of the central nervous system, causing inflammation and often destroying the myelin in patches. 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.

Spontaneous recovery from symptoms can occur and last for several months or years. Unpredictable attacks can cause additional symptoms and disability. Multiple sclerosis is often progressive over time. As yet, the cause and cure are unknown, but drugs to reduce the frequency and severity of MS attacks have become available for certain types of MS. In addition, many MS symptoms can be helped by medications and therapy.

Multiple sclerosis affects more women than men -- almost two to one -- and usually strikes people who are between ages 20 to 40. 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.

Multiple Sclerosis Society of Canada

Founded in 1948, the Multiple Sclerosis Society of Canada has a membership of 28,000. It is the only national voluntary organization in Canada that supports both MS research and services for people with MS and their families. 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, fund raising events, public awareness campaigns and social action activities. 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 Vancouver.

Eighty percent of MS Society net revenue is devoted to program areas: MS research, services for people with MS and their families, MS clinics, social action, public education and chapter development. Administration and fund raising costs are just 20 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

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 totaling \$6 million annually and is the largest funder of MS research in Canada. Total investment in research since the beginning of the program is more than \$74 million.

Of the research projects currently funded, almost 50 percent are targeted at myelin biology and repair. Particular attention is focused on finding ways to stimulate central nervous system cells to produce new myelin. Other significant areas of MS research are immunology, 33 percent, and MRI studies, 11 percent. In addition, the MS Scientific Research Foundation is funding extensive studies on bone marrow transplantation, myelin gene regulation, genetic susceptibility to MS and myelin repair. The Foundation is related to the MS Society, its primary funding source.

The positive outcomes of a number of clinical trials have resulted in four treatments for relapsing-remitting MS. Avonex™, Betaseron® and Rebif® are types of recombinant beta interferon and have been proven in clinical trials to reduce the frequency of attacks in relapsing-remitting MS. Copaxone™ (glatiramer acetate, formerly known as copolymer-1) has also been shown in clinical trials to reduce the number of attacks in relapsing-remitting MS. Betaseron is approved as well for use in secondary-progressive MS.

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.

Individual and Family Services

Individual and Family Services assists individuals by providing information, funding and support. Within these major service areas, volunteers and staff provide the following core services:

- MS Society publications
- ASK MS Information Resource Centre
- Publications and videos
- Conferences and workshops
- Equipment purchase and loan
- Special assistance
- Individual advocacy

- Support counselling
- Referral to community resources
- Support and self-help groups
- Recreation and social programs

Services offered vary depending upon existing provincial and community programs and financial resources available in the divisions and chapters.

Public Education

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. The national office coordinates an overall public awareness campaign which is complemented by division and chapter activities. The current campaign emphasizes how the often devastating effects of MS touch people with the disease, their families and many others. It reminds Canadians: “MS lives here.”

Social Action

The Multiple Sclerosis Society 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.

Fund Raising

The Multiple Sclerosis Society of Canada had net revenues of \$24.8 million in 2001. The funds are used to support research, individual and family services, public education, social action and volunteer resources. Most of this income comes from public donations, bequests and special fund raising projects conducted by the MS Society. The major fund raising programs are the MS Carnation Campaign, the MS Bike Tour, the MS Read-A-Thon, the Super Cities WALK for Multiple Sclerosis, gaming activities, 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 International Federation's aims and purposes 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. 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, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Great Britain and Northern Ireland, Greece, Hungary, Iceland, India, Ireland, Israel, Italy, Japan, Latvia, Luxembourg, Malta, Mexico, the Netherlands, New Zealand, Norway, Poland, Portugal, Slovakia, Slovenia, South Africa, Spain, Sweden, 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 FUND RAISING PROGRAMS

Direct Marketing

The Direct Marketing Program is the MS Society's largest single fund raiser. 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 almost \$70 million in support of world calibre MS research thanks to generous gifts from committed donors.

Major Gifts/Planned Giving

Individual Canadians in every province are contributing high-level gifts in support of MS research and services. More and more, Canadians are also creating gifts through their estate plans to support future MS services and research. MS staff across the country ensure large donations match the goals of the donor and the work of the MS Society. Staff have resources available for tax questions and questions regarding different types of gifts (such as securities, annuities, bequests, trusts, life insurance policies, etc.)

FUND RAISING SPECIAL EVENTS

MS Carnation Campaign

The MS Carnation Campaign is a national fund raising campaign held just before Mother's Day to raise money and public awareness to help fight multiple sclerosis. Since becoming the first national fund raising program of the Multiple Sclerosis Society of Canada in 1976, the MS Carnation Campaign has raised more than \$36 million. During the MS Carnation Campaign, more than 6,000 volunteers across the country offer fresh flowers and/or carnation symbols to the public for a donation to the Society, raising \$600,000 annually.

MS Read-A-Thon

The MS Read-A-Thon has proven itself to be an excellent motivational tool for children to discover recreational 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 200,000 elementary school children learn about multiple sclerosis, read half a million books and raise \$1 million annually for MS research and services.

MS Bike Tour

The MS Bike Tour combines recreational cycling and fund raising. The national event provides an opportunity for cyclists to have a one or two day leisurely ride through rural areas or city parks to raise funds to help fight MS. The first MS Bike Tour was held in August 1989. The event now raises over \$2 million annually and draws 7,500 enthusiastic riders from coast to coast. This year, there will be 20 MS Bike Tours.

The Super Cities WALK for Multiple Sclerosis

The Super Cities WALK for MS is the newest and fastest growing national fund raising special project 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 now attracts 60,000 people annually, making it the MS Society's single largest fund raising event. The Super Cities WALK takes place in more than 135 communities across Canada.

Gaming Activities

Over \$1.8 million in net revenue is raised annually, primarily from volunteer co-ordinated bingo events across the country and through Ontario Nevada break open lottery tickets.