

# With Passion and Commitment



## The Continued History of the Multiple Sclerosis Society of Canada

*By Deanna Groetzing*

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Multiple Sclerosis Society of Canada

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Multiple Sclerosis Society of Canada

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250 Dundas Street West, Suite 500  
Toronto, Ontario M5T 2Z5  
1-866-922-6065  
ISBN-978-1- 926803-07-4

## **About multiple sclerosis and the MS Society**

An estimated 100,000 Canadians have multiple sclerosis. Multiple sclerosis is a complex disease of the central nervous system. While it is most often diagnosed in young adults, aged 15 to 40, we know that it affects children, some as young as two years old. The impact is felt by family, friends and by the community. MS is unpredictable, affecting vision, hearing, memory, balance and mobility. Its effects are physical, emotional, financial, and last a lifetime. There is no cure.

The Multiple Sclerosis Society of Canada is here to help. No one needs to face MS alone. In communities across Canada, volunteers and staff provide information, support, educational events and other resources for people with MS and their families. Researchers funded by the MS Society are working to develop new and better treatments. The ultimate goal is to end MS.

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## ► Foreword

In the last year of her nearly 40 years of exemplary service to the MS Society of Canada and to people with MS, Deanna Groetzinger accepted the invitation to author the history of the last 25 years of the MS Society. *With Passion and Commitment: The Continued History of the Multiple Sclerosis Society of Canada* now becomes the companion to *Volunteers in Action* which earlier had traced the history of the MS Society from its earliest beginnings. Trained as a journalist, Deanna was uniquely placed to interview key individuals who marked indelibly the recent history of the MS Society in Canada. Their accounts are found in these pages and bring life to the recent history of the MS Society.

Deanna writes compellingly about a period during which the MS Society experienced remarkable growth in the range and ambitiousness of its programs and its fundraising revenues. These past decades were also marked by an explosion in the speed and ease with which people with MS can easily gain access to a wealth of information about MS. This has transformed the MS Society and its role in supporting people with MS to live the best lives possible. The translation of decades of research efforts into the first disease-modifying therapies that reduce the number of attacks and slow the disease for those with relapsing-remitting MS will probably be remembered as the key turning point in the last decades, an important harbinger of hope that MS could one day be eradicated.

It is this hope that one day we will live in a world free of MS which animates all who are involved in the work of the MS Society. Today, as we look to the future with passion and commitment, volunteers and staff are

bringing renewed focus and determination to accelerate the development of therapeutics that will halt or slow the more debilitating forms of progressive MS. We have also redoubled efforts to ensure that the important work that we do to improve the quality of life of people affected by MS reaches all Canadians impacted by MS, young or old, independent of where they live.

People with MS, caregivers, volunteers, researchers, health professionals and staff have all played important roles in shaping the MS Society which we know today. I salute their efforts and invite you in these pages to celebrate what we have achieved together.

Yves Savoie  
President and CEO  
Multiple Sclerosis Society of Canada

## ► Introduction

The story of any organization is the story of people. This short history of the Multiple Sclerosis Society of Canada is an account of what people who are passionate about a cause can accomplish by working together.

Success was by no means guaranteed when the MS Society was founded in 1948 by a small group of volunteers in Montreal. Their challenges and their successes are well described in Robert Fraser's book *Volunteers in Action*, published by the MS Society in 1986. *With Passion and Commitment: The Continued History of the Multiple Sclerosis Society of Canada* continues the story by focusing on the men and women who continued to build the MS Society and to make it the dynamic organization it is today.

There have been significant changes since the early 1980s both within the MS Society, in MS research and in society as a whole. Most significantly for people living with relapsing-remitting MS was the introduction of disease-modifying therapies in the mid-1990s. For the first time, MS was a treatable disease. That fact electrified the MS community, and confirmed that research was yielding results that could make a difference in people's lives. Unfortunately, it was not all good news. The therapies only benefitted people with relapsing-remitting MS and not those with more progressive forms of the disease. As well, many with the "right" kind of MS could not afford them. This quickly propelled the MS Society into its largest and most sustained advocacy campaign, as it sought to persuade provincial governments to fund expensive MS therapies for those who didn't have extended health benefits or could not pay for the therapies themselves.

Another major change has been how people communicate with each other and the MS Society. Speedy communication in the 1980s meant using the telephone or a new device called the fax machine. Most communication was by mail. The MS Society started using email in the 1990s and created its first website in 1995 as a new way of providing information to people affected by MS and engaging the public in fundraising and ongoing awareness. As more and more people living with MS used email, were connected to the Internet and embraced social media tools like Facebook and Twitter, the pace of communications grew at a frenzied pace. People could be connected to each other and the MS Society almost instantaneously, bringing many advantages but also demands on the MS Society to communicate and act quickly.

Many of the issues the MS Society faced prior to the 1980s continued into the following decades. The question of how much the organization should spend on its research and client services programs was considered in meeting after meeting of the MS Society board of directors. The agreed-upon solution was for “balanced spending” between the two programs; however, at subsequent board meetings, directors continued to grapple with how to make that a reality.

Another major issue was how to make the MS Society a more efficient organization without losing its grassroots base. In the early 1980s, the organization was decentralized with a small national office, seven divisions and more than 100 chapters. Over time and through many discussions, the MS Society became a more deliberately collaborative organization with common goals and objectives. In November 1992, following extensive consultations, the MS Society board approved the organization’s first formal strategic plan, *The Way Forward*. The drive toward collaboration culminated in a significant reorganization in 2013, resulting in a single MS Society (national) governance board and written agreements between the MS Society and its seven divisions spelling out their respective responsibilities. The following year, divisions and their chapters started working on similar agreements.

A constant throughout the decades - and indeed from the time of the founding of the MS Society - has been the commitment of volunteers and staff alike to ensuring that Canadians affected by MS are at the centre of the Society’s work and that its mission is fulfilled: To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

## ► Chapter one: Focus on finances and cohesion in the 1980s

In 1981, Alistair (Al) M. Fraser became executive director of the MS Society. He drew on his successful career in sales and marketing for Armstrong Canada to solve an immediate problem:

“The most pressing issue [in 1981], was the Society’s weakness in its finances - spending was outstripping revenues - before anything else could be done, I had to remedy that. When I joined the MS Society, it was highly decentralized. The national office had no revenue stream of its own. But the Society had a solid base; there was a stable national staff, and I had the backing of key volunteers to make investments where they were needed. We started the direct marketing program quickly since the Society was the only major charity that didn’t have one at that time. The direct marketing program not only raised funds but gave us a presence everywhere in Canada - it made us known.

“Event fundraising was important in raising both funds and awareness. The MS Read-A-Thon was a great program. It educated an entire generation about MS and raised money from people outside the immediate MS Society community. The MS Carnation Campaign was already underway when I came on board. All of these extended our support base and our reach across the country. It was important to put the MS Society on a sound financial footing with the help of a board of directors who were dedicated to the cause. Increasingly, the Society was able to attract topnotch volunteers when it needed them. The

next step was to establish a major gifts program. It was important the Society was ready to go when the major transfer of wealth began.”

Becoming a national health charity executive director (the title changed to “president and chief executive officer” in 1997) was a natural progression for Al Fraser. While at Armstrong, he was a loaned executive to the United Way of Montreal which he said “opened my eyes to the work of the [charitable] sector.” In 1976, he transferred to Toronto and became head of the Easter Seals of Ontario. Attracted by the opportunity to work for a national organization, he moved to the MS Society in 1981.

Alexander R. (Sandy) Aird became president (title changed to “chair” in 1997) of the MS Society board in December 1985, following his leadership of the Ontario Division board of directors. He brought significant business experience to the organization as well as personal knowledge of MS since his mother had lived with the disease for many years.

“When I became chair of the MS Society board, it was clear we had to increase revenues and control costs. Working with Alistair Fraser, we led the consolidation of the staff of the national office and Ontario Division with Al being executive director (now called president and CEO) of both. Jeremy Arnold, who was treasurer, led significant cost reductions.

“Toward the end of my tenure as board chair, we were able to convince Jack Sinclair, who was head of Bell Canada in Ontario, to join the board. I asked him and Wally MacGillivray (board director from PEI) to set up a corporate campaign with the aim of raising \$500,000 from the corporate community. With David Torrey (board

director and prominent Montreal businessman) as chair, the campaign was successful, and as a result of that, major gift fundraising became part of the MS Society's fundraising approach."

Fundraising, which had always been important to the MS Society since it did not receive major ongoing funding from governments, became even more significant under Al Fraser's leadership. The 1985-86 fiscal year saw a record year for fundraising with dramatic growth in revenue of \$2 million over the previous year, thanks largely to the direct marketing campaign. In addition, the MS Carnation Campaign raised \$2.1 million and funds from the MS Read-A-Thon also increased. The Society achieved its objective of balanced spending on services and research for the 1986-87 fiscal year thanks to increased revenues. And fundraising was about to get much bigger. In 1989, the MS Society introduced the MS Bike Tour to Canada, adapting it from the National MS Society (USA). The first-ever Canadian Bike Tour was held in Ontario in August, with 600 cyclists raising \$443,000. In 1992, under the leadership of Wendy Gibbs, national fundraising director, and Kenneth O. Macgowan, board director and former board chair, the Society launched the Super Cities Walk for MS (now called the MS Walk) at 13 sites across Canada, again adapted from a similar event in the US.

Al Fraser recalls another major step forward for the MS Society. "In reviewing files and records, I learned the MS Society had established the Multiple Sclerosis Scientific Research Foundation during the 1970s. There was only \$1,000 in it, but it was obvious to me and to Sandy Aird that we had to activate it because that would allow us to put money aside for MS research and not have to expend it immediately. We knew that to make a difference in MS

research, the Foundation had to be able to accumulate significant amounts of funds. We worked together with others on the board and with legal counsel to put the case to the federal government that the Foundation should be able to accumulate \$5 million plus accrued interest before being required to spend it. We received permission for that and a few years later went back again to have the amount raised to \$10 million plus accrued interest.”

Sandy Aird became chair of the Foundation with David Torrey as vice-chair. Sandy Aird remembers, “We built the board intentionally to involve people who had the ability to attract money from the corporate community. For the first few years, the focus was on growing the money by ensuring we had the right investment advice and by attracting good directors to the board.”

Another issue Al Fraser and the MS Society board needed to tackle was how to make the organization more cohesive and financially accountable. While legally one organization – with the exception of Quebec Division which was incorporated in 1969 and was permitted to use the name of the MS Society of Canada – at times the divisions and chapters acted in ways that were not aligned with each other or were contrary to the wishes of the MS Society board. The first step toward more collaboration was the MS Society board decision that one professional services firm, starting with the 1986-87 fiscal year, would conduct all of the audits of the national office and divisions to ensure more accountability and standardization in financial reporting. In June 1990, the board approved a centralized cash management system to simplify the work of chapter treasurers; as a result, funds were pooled centrally for purposes of treasury and cash flow management with chapters retaining control over

their expenditures. This change enabled the Society to generate additional investment income from excess cash.

The early 1990s were also notable for the development of the MS Society's first strategic plan. Under the leadership of board director J.E. (Jack) Sinclair, volunteers and staff gathered to provide input into the plan. The board approved it in November 1992. Mr. Sinclair became president of the board at that meeting as well. Called *The Way Forward*, the plan, as well as outlining objectives for the Society to achieve, also spelled out the organization's mission for the first time: "To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life." Members at all levels of the Society soon adopted the mission as their own.

- ▶ In September 1983, the MS Society hosted the MS World Conference in Vancouver with 400 in attendance.
- ▶ 1986 was the year of MS champions - London-based Canadian Laurie Dennett, whose mother had MS, walked via an ancient pilgrimage route from northern France to Spain raising \$28,000 and public awareness through weekly broadcasts on Toronto radio station CFRB; Richard Beecroft, a Canadian, who lived with MS, completed his MS World Tour by cycling 40,000 kilometers in 16 countries in 35 months. Ms. Dennett went on to complete two more walks - to Rome and Jerusalem - raising funds and awareness of MS wherever she walked.

## ► Chapter two: Evolution of the MS research program

By 1998, the MS Society had provided nearly \$64 million in research funding since the beginning of the program in the late 1940s. The Society sought confirmation that its investments in training awards and fellowships were making a difference. The audit of the research postdoctoral fellowship and studentship program confirmed that the majority of grantees pursued careers in MS research; this was especially notable for young researchers who had received postdoctoral grants. It also found the Society led all other granting sources in Canada in funding research projects and scholarships related to MS.

Leading MS researchers and clinicians recall how the program changed and grew over the years. Dr. Jack Antel, past chair of the Medical Advisory Committee and an MS clinician and researcher at McGill University, notes MS Society research grants were enormously important to developing a robust MS research community in Canada. "What impressed me was the goal of the MS Society to fund all research projects judged by its grant review committee to be scientifically worthwhile and relevant to MS. The MS Society has established a highly responsible and effective process whereby its medical advisory committee and its grants review panel recommends funding for such research projects, as well as funding for graduate students and postdoctoral fellows."

Dr. T.J. (Jock) Murray, past director of the Dalhousie MS Research Unit, retired dean of the Faculty of Medicine, and professor emeritus at Dalhousie University, has been

involved with the Society since the early 1970s. "It has been interesting to watch the success of the MS Society from about \$250,000 being invested in research to all the activity that is happening now. The Society has been able to develop a committed community of MS clinicians and scientists. You don't have that by happenstance. In the 1970s, there were just a few MS researchers. Now if you go to MS meetings, there is a whole community of people because of the support and strength of the MS Society."

Dr. Murray credits his being asked to serve on the MS Society's Medical Advisory Committee in 1972 for his long career as an MS neurologist and clinical researcher. "Being on the committee got me interested in MS. I did a study on a cluster of people with MS in a rural part of Nova Scotia called the Falls. There were only 150 people, but 15 had MS. Over the next two years, I examined them, looked at well water, their eating habits and their backgrounds. Some didn't have MS, including members of a family with both a mother and a son who had been diagnosed with MS. I found the mother had myasthenia gravis, which is treatable. But there were still 11 people with MS, a lot for a small population. I found much of the MS could be explained from a genetic point of view. I also found that all of them felt abandoned. Their family doctors and neurologists had said there was no treatment, so good-bye. I decided people with MS needed to be followed carefully so I designed a clinic called the Dalhousie MS Research Unit, where we provided patient care, conducted research and ensured careful documentation through a system I asked my daughter Suellen to design. We are still using it today."

Fortunately, the experience of “diagnose and adios” came to an end for most people living with MS with the development of a robust MS clinic network across Canada and the introduction of the disease-modifying therapies.

Dr. Samuel Ludwin, former chair of the Medical Advisory Committee and a long-time MS researcher at Queen’s University, observes, “In terms of where research is today, we have a much clearer definition of the pathological process underlying MS and are able to translate that into meaningful therapies. When I began working as a researcher, there was little a neurologist could offer for treatment. The overall advance has been the development of meaningful therapies. We still don’t really know the ultimate cause, and so we don’t have the ultimate cure. One of things the MS Society has done, and continues to do correctly, is provide funds for both research and services for people with MS. We have to do both. The MS clinics that provide researchers, data and materials, together with outstanding clinical care have been a wonderful resource to achieve this. The clinic network has been a major source of research projects and good clinical care in Canada.”

Dr. William J. McIlroy, who served as MS Society national medical advisor from 1982 to 2007 and was chair of the International Federation Medical Advisory Board beginning in 1989, also credits the MS clinics as being hugely important in advancing research and clinical care. “In the 1970s, we started talking about the establishment of MS research clinics. (Dr. Donald) Don Paty set up a clinic in London at the University of Western Ontario which served as a model for the establishment of other clinics across

the country. One key requirement was that the clinic had to be affiliated with a university and to do research to be recognized.” With a modest amount of funding and assistance with coordination, the MS Society encouraged the development of MS research clinics from coast-to-coast. They became key partners when clinical trials were implemented to confirm the efficacy and safety of disease-modifying therapies.

Dr. Murray adds, “The first important change was increased interest in the neurological community in MS and caring for MS patients - that happened even before we had new treatments. The second major change was the advent of therapies that altered the outcome of MS. It was a big change in the sense of providing hope – maybe MS isn’t an incurable disease. We were now in a therapeutic era. The other change was the increasing role of the randomized clinical trial in which everyone was blinded (neither participants, doctors, nurses nor technicians knew who was receiving active treatment) which provided increased sophistication in determining whether a therapy worked or not. We got increasingly good at doing clinical trials, which was a very important advance. What is not getting enough attention is the other side of MS care, which is helping people maintain their health and providing rehabilitation. We have to get better at that.”

The Society’s efforts to accumulate funds in the MS Scientific Research Foundation paid off in 1993 when it issued its first research grant of \$2.2 million over three years to Dr. George Ebers, then at the University of Western Ontario, and Dr. Dessa Sadovnick, University of

British Columbia, and their collaborators in the MS Clinic Network to examine the genetic susceptibility of MS.

The MS Society funded a major MS symposium in Vancouver in June 1987 to foster research collaboration among Canadian researchers. Among the topics discussed was the potential of research into genetics. Dr. Ebers had just published results that found identical twins more likely to both develop MS than fraternal twins; this provided evidence that genetics was somehow involved in the development of MS, a new concept at the time.

Sandy Aird describes how the first grant was awarded: "The first research project funded by the Foundation was led by Dr. George Ebers and Dr. Dessa Sadovnick investigating genetic susceptibility in MS. We used the MS Society Medical Advisory Committee to review the grants that met the ground rules. The projects had to be collaborative and take place at more than one research centre as well as being of high quality and relevant to MS. I believe the way we set up this funding model was ground breaking. It set the precedent in how the Foundation would fund collaborative research projects in the future."

Dr. Samuel Ludwin recalls the unique approach to collaborative research begun by the Foundation in the 1990s mentioning again the work of the late Don Paty. "There is no way one can talk about this without acknowledging the contribution of Dr. Don Paty in pulling the country together. He founded the MS clinic in London at the University of Western Ontario and then another at the University of British Columbia. He reached out to other neurologists across the country to work together. Don created an MS database and encouraged its use at

the other MS clinics. Those individual clinics became a network thanks to his work and some funding from the MS Society.

“The Foundation’s approach to research funding was remarkable in terms of MS research at the time. Instead of small, individually-held grants, the Foundation enabled researchers to think about how they could work together with broad programmatic grants. The MS Society and the Foundation were nimble and actualized this faster than other national MS societies.”

The genetic study quickly produced more evidence of genetic involvement. In 1995, it was reported that individuals who had been adopted do not have increased risk of MS while being raised in a family with MS in the household. In 1996, the researchers reported MS susceptibility is related to a number of genes, not a single one. By this point, more than 15,000 people with MS at 14 MS clinics across the country were involved in the study. Drs. Ebers, Sadovnick and colleagues received funding from the Foundation for several more phases of the genetic susceptibility study over the next few years. This enabled them to advance scientific knowledge about MS and genetics at an unprecedented rate.

In August 1999, the Foundation, following the model established with the genetic susceptibility project, funded two additional collaborative, multi-centre research projects. One, led by Dr. Alan Peterson, McGill University, focused on how to trigger the repair of myelin, the crucial covering of the brain in the central nervous system that is damaged by MS attacks. The second led by Drs. Mark Freedman and Harold Atkins, University of Ottawa,

examined whether bone marrow transplantation could stop the disease in people who had rapidly advancing MS. The procedure has been shown to be successful for a number of people with this type of MS. To date, the Foundation has funded nine collaborative, multi-centre research projects. In 2008, it launched the unique endMS Research and Training Network (More information about the Network is in chapter five.)

- ▶ In 1997, the Medical Advisory Committee and the MS Society board agreed to launch a separate health research grant program after hearing from people affected by MS as well as scientists that the MS Society should increase its funding of projects that dealt with clinical, population health and quality of life research.
- ▶ In October 1999, the first MS clinic for children with MS opened at the Hospital for Sick Children. The Toronto Chapter was involved in advocating for its establishment.

## ► Chapter three: Client services, individual activism and advocacy in the 1990s

In the 1990s, individuals living with MS pushed the MS Society to be more inclusive, to develop more programs and services that would directly benefit people affected by MS and to demand governments respond to the needs of people affected by MS. Prominent among these activists was Reid Nicholson of Sydney, NS.

"I was in the navy and developed some weird symptoms – I couldn't feel the deck underfoot. I was not yet 39 and otherwise very physically fit. I was medically discharged in 1978, which left me a very angry person. My wife Evie, who was working as a nurse at the local hospital, convinced me to go to an MS Society chapter meeting. It was horrible for someone who was newly diagnosed - most people were in their seventies and very disabled. I left saying to myself I wouldn't have anything to do with the Society.

"But I received a phone call asking for help with the chapter's financial books. Actually, there were no books, just a box of unorganized bills and receipts. I agreed to organize the expenses and was then made treasurer in 1979. Within a year or so, I became chapter president and started attending Atlantic Division board meetings. I was also trying to finish a degree in history at the then Cape Breton College of St. Francis Xavier.

"In 1981, at a meeting in Moncton, I met with Al Fraser and shared some ideas. I worked with Al and others to pitch the national Kinsmen organization to make the

MS Society of Canada a national project, as the Atlantic Kinsmen had done with the Atlantic Division. While we weren't successful, I did get to know Al and others at the national level.

"I became involved nationally beginning in 1989 when I was asked by Audrey Macgowan, who was then the Canadian representative to the MS International Federation Persons with MS Advisory Committee, to take on that role. I attended my first international meeting in Dublin and two years later became chair of the committee. I contacted Beverley Brown (national director - later vice-president - of client services) and Al and told them I was gung-ho to take on the job but needed a way to get input from Canadians with MS. We formed the Canadian Persons with MS Network with great people like Suzette McMaster-Clement in Quebec, Denise Atkins in Ontario and Lynn McDonald in British Columbia. The Network was extremely helpful when we were working on the international employment project, *Working Together: MS in the Workplace.*"

Marie-Josée Comtois of Ste-Julie, Quebec, knew firsthand what services the Society should offer and, as the result of her involvement, became a voice for people affected by MS in Quebec.

"A year after my diagnosis in 1990, I started volunteering with the MS Carnation Campaign; I worked on the campaign for five years. I started by selling carnations, and then I organized a team with family and friends to make bunches of carnations for sale throughout the Montérégie area south of Montreal. We had success and multiplied sales by three times. I was working at the same time as a

dental hygienist and taking care of my baby, who was born five weeks before my MS began.

“Magali Plante, who was then head of services in Quebec, asked me to help organize a local chapter. There were about 600 people with MS in the area but no activities or services. I worked with Magali and Mikos Fulop (then executive director of the Quebec Division) to develop the chapter and then served as chair. I knew there was a real need for good information. We organized a conference with Dr. Pierre Duquette (director of the MS Clinic at Notre Dame Hospital, Montreal), and I thought we might have 50 people attend. Instead, we had 250 people at the conference.

“I agreed to join the division’s client services committee in the mid-1990s. I had seen at the chapter the needs that clients have; I asked the division to work on more information for spouses, teenagers, children, doctors and other health-care professionals. We also organized a meeting with a representative from each chapter in Quebec to exchange ideas and to provide tools and training. We created a program for people with MS who were newly diagnosed. I am really proud of that program. When the neurologist says you have to live with MS, you feel really bad. When you have good information about MS and your treatment, it gives you power.”

In the early 1990s, board director and chair of the services committee Gail Cook-Bennett and Beverley Brown led the development of policies and guidelines to assist in the standardization of services delivery across the country so people affected by MS could receive similar information and services regardless of where they lived. This objective

was assisted greatly by the increased use of electronic communication, including the launch of the first MS Society website in 1995. Initially, the site consisted of just information about MS posted by the national office, but soon expanded by connecting division and then individual chapter sites to the single web address. To help people with MS obtain accurate information about the disease, the National Individual and Family Services Department (as it was called then) launched the ASK MS Information System with 400 articles about all aspects of MS. In the early 1990s, the Society received the first of a number of grants from the McConnell Family Foundation which allowed it to examine more closely issues of importance to people living with MS, and to then develop support programs and educational material. Issues researched included alternatives to institutional care, the impact of MS on children and teens who have a parent with MS and the impact of MS on caregivers.

- ▶ The board approved in 1987 the recommendation from the services committee the name of the department and program be changed from “patient services” to “individual and family services” reflecting usage by the MS International Federation. In 2002, the name was changed to “client services”.

The National Client Services Department and divisions worked together to develop educational materials. A unique project led by the Quebec Division developed

resources for families including a booklet for children, *Myelin is Getting on My Nerves* was a unique resource. The Society was also involved in the international employment project and produced a Canadian publication *An Employers Guide to MS in the Workplace* as part of its outreach to employers.

The MS Society began to focus more on the needs of caregivers and developed a publication *Taking Care: A Guide for Well Partners* and then, with funding from the McConnell Family Foundation, took on three pilot projects in Saskatchewan, Manitoba and Atlantic Divisions to determine the best approach to caregiver support. Separately, Ontario Division held the first workshop for men who are caregivers, "Daring Men to be Caring Men". The session was selected as a poster presentation at the Consortium of MS Centres meeting in Halifax in 2000.

Individual activism coupled with MS Society advocacy came together with the approval in Canada of the first disease-modifying therapy in 1995. For the first time, there was actually a treatment for at least one form of MS. But the excitement about an approved therapy was tempered by the concern that its cost was almost \$20,000 a year, and there were no government-funded programs to help people pay for the therapy.

The MS Society board had laid the groundwork for a more visible advocacy program with the establishment of the National Social Action Committee. In December 1987, Gary Bray, board director from Ottawa, was appointed the first chair of the committee, and Deanna Groetzinger (director of communications and later vice-president of government relations and policy), provided staff support.

The advocacy work became even more focused and professional when Susan Murray of Toronto and head of a government relations firm joined the MS Society's board and provided her expertise as chair of the committee from 1999 to 2005.

The committee's first major action was to back a case brought by Nigel Brown of Newmarket, Ontario, on behalf of his wife Mary. When filing his federal taxes, he claimed the cost of an air conditioner as a medical expense since Mary needed - as supported by her doctor - to be in a cooled environment because of MS. A legal aid clinic specializing in disability issues assisted with the legal issues, and the MS Society led the advocacy push including a letter writing campaign in 1989 directed at Minister of Finance Michael Wilson and Members of Parliament. The campaign received a boost when Beryl Gaffney, MP, Nepean, Ontario, developed a private member's bill to allow the cost of air conditioning as a medical expense. The issue was finally decided in the Browns' favour when the Federal Court ruled in December 1994 that the cost of an air conditioner could be considered a legitimate medical expense.

This experience was useful for Society volunteers and staff when they needed to join forces for an even bigger campaign: to convince provincial governments to pay for expensive MS therapies. Some of the lessons learned were to keep advocacy respectful, engage all stakeholders, connect with allies and above all - never give up.

The MS Society had been monitoring closely the progress of clinical trials of the first disease-modifying therapies and had established a Subcommittee on National Drug Cost

Reimbursement to create a strategy for the MS Society to use given the anticipated approval of Betaseron and other MS therapies.

In 1995, the federal government approved Betaseron, the first disease-modifying therapy for relapsing-remitting MS. Copaxone was approved in September 1997, also to treat relapsing-remitting MS and in 1998 two more treatments, Avonex and Rebif, were approved, making Canada the only country to have approved all four available treatments. While this was exciting progress, there were concerns about who would pay for the therapies, which ranged in cost from \$17,000 to \$25,000 a year. Some people were fortunate to have employer drug plans, but others didn't have drug benefits or were no longer working. Drawing on the work of the subcommittee, the MS Society board reviewed various options. It agreed the MS Society could not afford to help fund the therapies, and that its role should be to press governments to help pay for the approved therapies. The advocacy work paid off: by the end of 1997, Quebec, Ontario, British Columbia and Saskatchewan had established special drug programs to help people cover the cost of these important therapies.

Marie-Josée Comtois recalls the advocacy work in Quebec: "Another important event in 1996 was to convince the government to include Betaseron in the new provincial drug insurance program. We weren't sure it was going to happen, so we needed to convince the minister of health. We rented buses and invited persons with MS and families to travel to Montreal for a demonstration in front of the minister of health's office in Montreal. About 300 people took part. And we were successful. When

the insurance program started, the first MS therapy was included on the list!”

Another activist who helped the MS Society convince provincial governments to reimburse expensive disease-modifying therapies was Suzanne Deschamps of Cold Lake, Alberta.

“I was diagnosed in 1992. I had never heard of MS at all, so I contacted the MS Society and found there was a support group in Cold Lake. Later, I became president of the local Lakeland Chapter, as it was called then. My biggest overall involvement has been as spokesperson for the Mountain MS Bike Tour. While I can’t ride anymore, I still raise money and cheer everyone else. But I was also involved in advocacy.

“When I was diagnosed, the only thing doctors could offer was prednisone; I gained 27 pounds on that. With the first disease-modifying therapy, Betaseron, the cost was high. I was able to pay for it because I had a drug plan, but many people couldn’t afford it. In June 1998, the Alberta Division asked me to join the fight to persuade the government to pay for it. A group of about 20 people with MS had held a protest at the legislature, and the division organized a petition drive. I walked up the steps of the legislature with half of the petitions with 33,000 signatures; my share was about a foot high. With the division executive director, I presented the petitions to Minister of Health Halvar Jonson. In September, he called me and let me know the government would pay for the approved therapies through a special insurance program. I am still really proud of this work; it helped a lot of people.”

- ▶ In 1998, the MS Society commemorated its fiftieth year by presenting Pioneering Spirit Medallions to 50 outstanding volunteers as well as to original pioneers Evelyn Opal, one of the MS Society founders, and Sylvia Lawry, founder of the National MS Society (USA).
- ▶ By 2000, the MS Society is one organization coast-to-coast with the former Victoria and Vancouver Island MS Society becoming the Capital Region Chapter of the BC Division.
- ▶ Two Canadians living with MS were honoured for their outstanding achievements as persons with MS. In 1990, Lynn Meredith, Vancouver volunteer, received the Wolfensohn Award at the MS International Federation meeting in Amsterdam, the first Canadian to receive the award; Anne Belohorec of Sherwood Park, Alberta received the Wolfensohn International Award at the MS International Federation meeting in Jerusalem in 1995.

## ► Chapter four: Change and transition during the Millennium decade

The MS Society entered the new millennium with another record-setting year in fundraising. The next 10 years would see the development of the first research fundraising campaign and the growth of new programs and new ways to involve people affected by MS.

At the end of the decade, the Society would face an unexpected challenge when an unproven but appealing way to treat MS was proposed by Dr. Paolo Zamboni in Italy. In 2007, two of the Society's long-time leaders - Alistair M. Fraser, president and CEO, and Dr. William J. McIlroy, national medical advisor - retired after decades of service, and the organization welcomed Yves Savoie as its new president and CEO. Savoie was the first bilingual CEO of the MS Society. He brought to the Society years of experience in major gift fundraising and as an advocate for the inclusion of people with disabilities in his work as the head of both Family Service Toronto and Muscular Dystrophy Canada.

The 2005-2006 annual report saluted Mr. Fraser: "When Alistair Fraser joined the MS Society in August, 1981, total revenues were less than \$6 million and there was virtually nothing available except treatments for some multiple sclerosis symptoms. In February 2007, Mr. Fraser retires from his position as president and chief executive following our best year ever. He goes with the gratitude of thousands of people living with MS who have benefited, and stand to benefit, from 25 years of outstanding research and client services. He goes with the appreciation

of all staff and volunteers who have made important contributions under his guidance and acumen. And he goes with the respect of all who have witnessed the many life-changing advancements that keen leadership can inspire.”

Dr. McIlroy was honoured in the 2006-2007 annual report: “For the past 35 years, Dr. McIlroy has been the public face of MS in Canada, interpreting what’s happening medically and scientifically in the MS world, in his capacity as national medical advisor to the MS Society... From this vantage point, he can say with assurance that Canadian MS researchers are among the best in the field and that the MS Society is on the right track, venturing into large collaborative multi-centre research projects funded by the MS Scientific Research Foundation... Now, there is a wide sharing of MS-related research information on a worldwide basis. That’s encouraging because it will speed up the pace of finding the path to end MS.”

Reid Nicholson, chair of the National Client Services Committee, remembered the decade as a time of building a more cohesive approach throughout the organization. In services, he worked with the national committee and the divisions to examine what services the MS Society should provide. “We developed a single national voice on services and what we would offer. As a result, the Society started to move toward more sophisticated services for people affected by MS, delivering information, funding and support.”

Ensuring that information about MS was useful and accurate was made more of a reality thanks to support from corporate donors, including the pharmaceutical

companies that had developed the disease-modifying therapies. In 2001, the MS Society under the leadership of Reid Nicholson and Jon Temme, new vice-president of client services, initiated the first of a series of educational programs for people affected by MS. For the first time, people received the same program content delivered by experts in a number of large cities in various regions of the country. The first series, Living Well with MS, attracted people with MS, their families and caregivers. Over the next few years, the national education series delivered programs on topics including accessing reliable health information, managing fatigue, dealing with emotional issues and managing pain. Several of the programs were broadcast to sites in northern and rural areas, thus extending their reach beyond urban areas.

Using the Society's new consolidated, single-entry website (launched in 2000), the National Client Services Department initiated an online forum called Ask the Expert in 2006 to allow people with MS, families and caregivers to connect with leading North American MS health professionals and researchers. Some of the online education sessions addressed sensitive issues and garnered an overwhelming positive response from clients who said the programs helped improve their quality of life and independence.

Client services staff and volunteers also focused on evaluating services programs in an effort to determine where time and resources should be spent. A grant from Health Canada enabled the MS Society to conduct a study called Growing Up Strong to examine the needs of children whose parents had MS and to develop new

programs if required. The MS Society and the National MS Society (USA) also partnered on a Young Persons with MS Network. In 2004, the Society conducted its first-ever survey of people living with MS, using the national publication *MS Canada*. A total of 10,550 people responded and said that timely, credible and relevant information was the most valued service followed by personal support from volunteers and staff at divisions and chapters. Following the national survey, the Atlantic, British Columbia and Manitoba Divisions and Toronto and Calgary Chapters teamed up to do a survey on the impact of equipment and special assistance programs. Those surveyed praised the programs for improving their mobility and independence.

In 2007, the MS Society introduced two new programs that targeted young people. The first-ever scholarship program for university and college students was launched in 2007 thanks to Aaron Solowoniuk, drummer with the band Billy Talent, who has lived with MS for more than 10 years. He approached the MS Society looking for a creative way to assist youth impacted by multiple sclerosis. The scholarship program assisted students up to age 25 who have MS, or who have a parent who lives with the disease. Sixty-one scholarships valued at \$60,000 in total were given out for the 2007-2008 school year. The scholarship program was phased out after several years of successful operation.

Recognizing that younger children are also touched by MS, in summer 2007 the MS Society introduced two camps in Perth, Ontario and Val Morin, Quebec, for children and teens impacted by MS. The Ontario

camp was the result of collaboration between the MS Society and Easter Seals Camp Merrywood and was also supported by Toronto's Hospital for Sick Children's Pediatric MS Clinic. In Val Morin, the Quebec Division initiated a camp for children with parents living with MS to share their experiences freely. A highlight for the children at the Ontario camp was meeting Aaron Solowoniuk.

- Communications staff at the national office and divisions worked together to develop and launch a new MS Society logo in 2004. It used the familiar broken MS/SP letters and combines them with the organization's name in a dynamic new presentation.

The National Government Relations Committee (which had a name change from National Social Action Committee) in 2004 turned its focus on advocating to the federal government for better income support for people disabled because of MS and other conditions and for recognition of the episodic nature of MS. Working closely with client services volunteers and staff, the committee identified as major problems the fact that many people with MS could no longer stay employed after an MS diagnosis and then had problems in accessing government programs such as Canada Pension Plan disability (CCP) benefits and the Disability Tax Credit (DTC) because the symptoms of MS often come and go. Working with other organizations, the MS Society gained significant improvements to the DTC application form,

which made it somewhat easier for people with MS to qualify for the credit. In recognition of the MS Society's growing influence with the federal government, Deanna Groetzing, vice-president of government relations and policy, was appointed to the new Disability Tax Credit Advisory Committee in 2005.

Andrea Butcher-Milne, a person living with MS from Barrie, Ontario, describes how she became involved as an MS Society advocate at all levels of the organization and especially in pressing for changes to CPP disability benefits.

"My mother was diagnosed with MS in 1984, and right away I wanted more information. I had done the MS Read-A-Thon as a child but didn't know many details. I phoned the MS Society for information about research studies. Then I became involved in fundraising, initially for the MS Carnation Campaign. That was special for my mother and me. Every year I gave her silk carnations from the campaign. When the MS Walks developed, I did the MS Walk in 1996. Within a year, I was also diagnosed with MS.

"I was attending MS exercise classes in Barrie (organized by the MS Society) and was recruited to the chapter board in 1998. The only position open was social action so I took that on and then moved into an education position on the board. I have always felt education and social action walked hand and hand. First you realize the things that needed to be done and then you go out and try to change them.

"Between 1997-2001, my disease was really active, and I had problems with walking and balance. I had regular attacks every three months. My body became completely paralyzed for short periods of time. Because I couldn't

work, in 1998 I applied for CPP disability benefits. I was turned down, appealed that, was turned down again and appealed to the CPP tribunal. I phoned the MS Society for help. It turned out the Society was pushing for changes to the CPP disability benefits program so more people with MS could qualify, and they asked to use my case as an example. Of course I said yes.

"Improvements to CPP were very important. What I do a lot of is reading the fine print and the details. Sometimes those details are what impact people the most. We had to educate CPP officials about episodic disabilities. It's better but it's not perfect - we have to keep on our toes. I also became involved with the Ontario Division and eventually the division government relations committee."

Members of the National Government Relations Committee became much more active in taking these issues directly to the federal government and Members of Parliament, holding its first-ever reception for MPs and officials on Parliament Hill in April 2005 under the leadership of Susan Murray, board director and chair of the National Government Relations Committee. In 2007, the Society held its first MS Society Day on the Hill to enable committee members to meet one-to-one with MPs and Senators.

Working with other organizations and coalitions became more important. The MS Society was one of the founding members of Neurological Health Charities Canada (NHCC). This coalition of neurological health charities came together because they all needed more information about the extent, impact and cost of their individual conditions. Meetings with MPs and Senators in June 2008 ended successfully with a federal government

pledge in October to provide \$15 million for a population health study of neurological conditions. Study results and a major report on the findings were made public in September 2014.

In the divisions, advocating to provincial governments for people with MS to have access to disease-modifying therapies continued to be a major focus. In 2007, the Atlantic Division concluded successful advocacy for a government program to help people pay for MS therapies in Newfoundland and Labrador. Volunteers and staff used a variety of attention-grabbing methods to win support from the public, news media and, eventually, provincial politicians for the establishment of a drug program. Humour was mixed with good policy analysis: on Valentine`s Day 2007, the MS Society sent then Premier Danny Williams a giant cookie bearing the message “Premier, have a heart”. As a result of the division`s efforts, the government announced an expansion to its prescription drug program so that all people with high drug costs - not just people living with MS - would receive assistance.

Also in 2007, the Alberta Division created the MS Ambassador Program to increase visibility of the MS Society in the province and to provide a new way for people affected by MS to become involved in important initiatives. The first priority for the ambassadors was to meet with and educate members of the provincial legislature about the new endMS campaign and what the province could do to support it. (See chapter five for details about the endMS campaign and the endMS Research and Training Network.) As a result, the Alberta Government committed \$1.5 million to the endMS

campaign, a huge success for the ambassadors' initial effort. MS Ambassadors in Alberta continue to be active in government relations, client services and fund development.

Inspired by the success of Alberta's initiative, the Ontario Division launched its own MS Ambassador Program in May 2008, focusing mostly on provincial government relations activities. Other divisions have since established MS Ambassador programs to harness the experience and commitment of people affected by MS from coast-to-coast, again demonstrating the power of MS Society volunteers when they work together.

The first decade of the new millennium also brought about a global recession the magnitude of which had not been seen since the Great Depression. While Canada's economy withstood the shocks of the recession better than many of its counterparts, the impact on employment levels and consumer confidence would take many years to subside. Since the recession triggered by the bankruptcy of Lehman Brothers in September 2008, Canada's economy has enjoyed growth since the recession but that growth has been fueled by Canada's resource-rich provinces which continue to account for most of the wealth and employment creation.

## ► Chapter five: endMS Campaign and Network - new concepts in fundraising and research

The MS Society had built a solid reputation with its research program. It supported the best research projects and young scientist trainees and steadily increased its contributions to MS research. Its fundraising efforts continued to grow thanks to local fundraising as well as established events such as the MS Walk, MS Bike Tour, MS Read-A-Thon and the MS Carnation Campaign. The efforts to secure major gifts from individuals and corporations started to pay off. A highlight was the Society's first-ever million dollar donation. It was made in 2000 by Doug Bergeron, a now Silicon Valley, California-based businessman in honour of his father George who lived with MS and was active with the MS Society chapter in Windsor, Ontario serving as the chapter chair for many years.

This was a great step forward, and underlined the thinking by MS Society leaders - both lay people and scientists - beginning in the 1990s that it was vital for the MS Society to attract large donations from both individuals and corporations to support innovative MS research.

Former MS Society chair and MS Scientific Research Foundation chair A.R. (Sandy) Aird recalls early discussions: "In the mid-to-late 1990s, we started to talk about raising funds directly for the Foundation. Previously, the funds had come largely from MS Society revenue that was not needed for the MS Society research program. We started to add directors who could and would be fundraisers in the corporate community. They included, Dick (Richard)

Thomson (former CEO and chair of the TD Bank Group), Purdy Crawford (former chair, president and CEO of Imasco Limited) and Helen Kearns (president and CEO of Bell Kearns & Associates).

“Ken Mayhew, then director of fundraising, started to explore a corporate campaign with a preliminary goal of \$5 million. Through Helen Kearns’ connections, we were able to recruit Bank of Nova Scotia CEO Rick Waugh as honorary chair of the campaign. Our rule throughout this process was to take the time to get the right people. Al Fraser had the campaign approach vetted by external experts and was told \$5 million was about the upper limit for our campaign in terms of the portion which would be generated incrementally from major gifts. In spite of that, and with the encouragement of Rick Waugh, we settled on an incremental target of \$20 million within a \$60 million comprehensive campaign.

“It is important to emphasize the contributions of Al, who was so supportive of developing such a thrust, and that of Ken, who pushed hard to increase the quality and success of the program. Both were strong contributors to the creation of the endMS Campaign.”

Sandy Aird continues: “While the fundraising side was being put into place, I was also working with the research community and especially Dr. Samuel Ludwin, prominent researcher and chair of the Medical Advisory Committee. I asked him what was the most important aspect of research the Foundation could fund. After consulting the Medical Advisory Committee, he said what was needed was to develop a new cadre of top young MS researchers since many current researchers were approaching

retirement. That was the beginning of the development of the endMS Research and Training Network.”

Dr. Ludwin recalls: “One of the most satisfying things in my involvement with the MS Society was the development of the Network. Sandy Aird, as chair of the Foundation, put a challenge to the Medical Advisory Committee. He said, ‘if the Foundation could raise the money, to what best use would the research community put it?’ I played a role in recognizing that current MS research leaders were aging, and that it was important to attract young scientists to MS research to continue this wonderful Canadian strength. We recommended the money should be used to form a national training network to increase person power and to create a national feeling of community.

“This was a unique venture. People bought into the idea immediately, worked hard to make it happen and made it a great success. I have no doubt that those who were involved in the Network will stay in MS research and the MS research community. Of course, there had to be and there were serious discussions between the Society, the Foundation and the researchers about how best to achieve these goals and how to best use resources. Through it all, there was good will and the desire to see research and training proceed.”

The \$60 million endMS campaign launched officially in 2008 during the sixtieth anniversary of the founding of the MS Society to accelerate Canada’s contribution to the pace of MS research worldwide. The Foundation committed to raise \$20 million through major gifts, and \$40 million was to come from the MS Society’s existing fundraising events and sources. Rick Waugh, Scotiabank

president and CEO, was the campaign's honorary chair, and Foundation chair Alexander (Sandy) R. Aird, was chair. The launch was supported by a public awareness campaign with donated advertising space for TV and print, which enabled the Society to get the message of excitement and hope on network television and on billboards across the country. Astral Media donated advertising space worth \$3 million to support the endMS campaign launch while Canwest Global donated a further \$1 million worth of advertising. Combined, the \$4 million in advertising propelled the MS Society into the national spotlight making for the most comprehensive public exposure it had ever received.

Shortly after the launch, the Alberta government announced a \$1.5 million contribution to the endMS campaign, thanks to the great efforts in promoting the value of the new Network by the campaign leaders and by volunteers and staff in the Alberta Division - including the new volunteer MS Ambassadors. With the campaign committee and MS Society fundraisers hard at work, funds started to flow to the endMS Research and Training Network. Dr. Jack Antel was appointed to serve as its scientific director while the MS Society assumed the leadership of administrative aspects of the complex Network with Jon Temme initially serving as managing director succeeded by Dr. Karen Lee. The Network was ably guided by a steering committee of eminent clinician-scientists and researchers from across the country among whom were the directors of each of the Network's Regional Research and Training Centres (RRTCs).

The core purpose of the Network was to recruit, train, support and retain the next generation of MS researchers

in Canada so the cure for MS could be found in the shortest possible time. The vehicle was the endMS Research and Training Network. The funds raised were not to be spent on building new classrooms or laboratories but were targeted at creating ways for young scientists to learn from established mentors and from each other in a variety of locations and situations.

Key innovations included the endMS SPRINT (Scholar Program for Researchers IN Training), an annual intensive endMS Summer School and five endMS Regional Research and Training Centres. The Network also provided generous scholarships and awards, including the endMS Transitional Career Development Award program, to support outstanding postdoctoral and clinical fellows conducting research in an area related to MS. The coveted \$500,000 award provided Canadian researchers with the means to establish a strong base for their MS-focused independent research career at a Canadian research institution. These awards were made possible by gifts of \$500,000 for each award from individuals and corporations, a reflection of the maturation of the Society's major gift fundraising efforts.

Three endMS conferences were crucial in fostering knowledge exchange on MS research and collaboration among researchers and trainees. The three-day event of lectures, workshops, poster sessions and networking allowed all involved in the Network to be linked even more closely so they could collaborate fully on working toward the cure for MS.

The endMS campaign reached its goal in 2012 by surpassing its \$60 million target. Thanks to all donors -

large and small - who were inspired by the opportunity to help end MS, more than \$60 million was raised for the endMS Research and Training Network and for ongoing MS research. The endMS Network brought together more than 1,000 experienced researchers and trainees from more than 65 Canadian academic and health institutions in a variety of collaborations. The endMS Network attracted, trained and retained talented medical and research professionals at varying stages of their careers. Thanks to the endMS campaign, more researchers are involved in MS research in Canada than ever before.

During this time, the MS Society was also able to grow its regular research program. The MS Society and the Multiple Sclerosis Scientific Research Foundation continued to invest \$8 to \$10 million annually on research to find the cause of MS, treat symptoms and improve quality of life, and ultimately discover a cure for the disease. Funding was directed at promising avenues of research including the cause of MS, imaging, myelin repair, and stem cell research. Another important step forward was the decision to include people affected by MS as full members of the research grant review committees. This meant the views of people most impacted by MS were included throughout the research adjudication process.

Reflecting back to the beginning of both the endMS campaign and the Network, Sandy Aird says: "What I am most proud of is that we learned to be innovative and to be creative and bold. Personally, I am proud of chairing a cabinet of highly talented fundraisers that reached its objectives. I am also proud of having chaired the Foundation and moving it into a major research funding

body. I have really enjoyed the calibre of the people within the MS Society. The Society is blessed with strong leadership who are well qualified to do their jobs. The boards are dedicated, as are the committees such as the Medical Advisory Committee and the research review committees. This is a tribute to the MS Society having worked hard to have good relationships with the research and medical community.”

## ► Chapter six: The challenge of CCSVI

People living with MS, their families and caregivers were excited by reports in the news media in November 2009 that there may be an association between blocked veins and MS. Canadians affected by MS were especially eager to learn more because of a CTV news program that reported unblocking veins could alleviate MS symptoms and perhaps reverse the impact of the disease. CTV's treatment of the news was sensationalist and caused many to believe that Dr. Zamboni's exploratory story was in fact conclusive.

The news media were reporting the findings of Italian researcher Dr. Paola Zamboni that the veins of people with MS were more often blocked than those of people who did not have MS. According to this theory, blocked or narrowed veins lead to the venous system not being able to efficiently remove blood from the central nervous system. Calling the blockage chronic cerebrospinal venous insufficiency (CCSVI), Dr. Zamboni also suggested that opening blocked veins through a process called angioplasty could alleviate the symptoms of MS.

Reaction in the MS community was mixed. Some people with MS were anxious to find out if their veins might be blocked, and if they were, to have the obstruction removed as soon as possible. Others were more cautious, wanting more information and more research. Most MS neurologists and researchers were also cautious. Some had seen other potential treatments being welcomed with much excitement, only to have the initial promise fade following further investigations. Others were

keen to include this new research challenge into their work. Most agreed, as Dr. Zamboni concluded in his preliminary papers, that more research needed to be done immediately and with more robust study designs including control groups.

In late November 2009, the MS Society issued a request for research proposals to study the relationship between CCSVI and MS. This was the first time in the MS Society's history that it had issued a call for specific research proposals. Very quickly, the Society and the National MS Society (USA) agreed to work together on the research competition, with both organizations providing funding and conducting joint reviews to address the questions as quickly as possible.

But for many people affected by MS, funding research into CCSVI was not enough. They called and emailed the MS Society demanding that it pressure physicians and governments to make both the diagnostic test for CCSVI used by Dr. Zamboni and the angioplasty procedure available right away. Some suggested the MS Society help fund the procedure for individuals. Many people were angry and frustrated at what they considered the Society's lack of response to something they were convinced would help right away. They put pressure on the MS Society as well as the federal and provincial governments to make the treatment available immediately. Many hundreds travelled to clinics outside of Canada for diagnosis and treatment, paying thousands of dollars. Some reported dramatic improvements, others noted an easing of fatigue and balance problems, while still others had no improvements at all. Most said it was important to try it.

Lynn Hunter, who was chair of the British Columbia Division board and a director of the MS Society board, recalled the Society board meeting in November 2009: "I was at a Society board meeting right after the CTV program aired. During the discussion, it was clear the scientists were very skeptical; others on the board were unsure. But no one knew how divisive this would be. The news media grabbed it as the miracle cure. I was dubious about that, and others worried about vulnerable people being manipulated by false hope. I see it as a sad chapter for the organization because it diverted energy and funds from a more stable approach.

"Personally, I don't think the cure will come the way that the CCSVI theory describes. I remain skeptical. However, my daughter, who has MS, and I went to southern California where she had the procedure. I was supportive of my daughter's decision, and fortunately, her friends rallied and raised the money for the procedure and related costs. My daughter does feel the procedure did help by improving the circulation in her legs. She no longer has severe and painful spasms in her legs - an improvement which came after the CCSVI treatment.

"In terms of impact on the MS Society, I think there was a dip in fundraising at that time, because people were tapped out. What was most harmful, and infuriating to me, was that some people believed the MS Society didn't want a cure."

MS Society leaders including CEO Yves Savoie and then chair of the board Linda Lumsden recognized that differences of opinion about CCSVI and how to approach it were becoming divisive both within the organization

and externally. The MS Society had immediately launched a research competition but still needed to develop ways to meet the ongoing information and support needs related to CCSVI of people living with MS, their families, volunteers, members and staff.

By July 1, 2010, funds were flowing to seven research projects - four in Canada and three in the US - focused at determining the best methods to screen for blocked veins and the relationship between CCSVI and MS. By the usual research competition timelines, this was lightning speed. To people who wanted immediate access to a method to diagnose and to open blocked veins, however, the funding timelines seemed frustratingly slow.

The June 2010 MS Society annual general meeting illustrated the significant divisions that the CCSVI issue had developed in the MS community. Many people living with MS and their families felt the Society was not doing enough to speed up CCSVI research. They also wanted the Society to push governments to make the diagnosis and treatment for narrowed veins available immediately.

For the first time, the annual general meeting - usually a sedate affair at which the appointment of auditors and the election of directors happened quickly and without opposition - was one with challenges from the membership, and a hard-fought election for the vacant positions on the board. In the end, the challenges did not succeed, but there were important criticisms that the board of directors took seriously and led to changes for subsequent meetings. For example, several members pointed out the Society did not make information such as the audited financial statements and other

key governance documents available ahead of time so members could vote in an informed way. These documents are now made available prior to MS Society annual general meetings.

In July 2010, the MS Society established the CCSVI Working Group, chaired by Linda Lumsden, to bring together individuals who were advocating for the CCSVI treatment, medical experts in neurology and the venous system, and directors from the MS Society board. The group met for the first time in September 2010 and continued to meet - mostly by teleconference - until mid-2013. Including CCSVI advocates and medical experts as well as directors in the working group allowed the MS Society board to hear quickly and directly the issues that were important in both communities.

Linda Lumsden recalls the impact of the CCSVI Working Group: "What we accomplished...was a deeper appreciation on all sides of the issues and concerns. The MS Society learned that it needed to communicate more and to reach out and have people more involved. The CCSVI advocates understood better that the MS Society's heart was in the right place, and that the scientists were not trying to protect their labs and work. The scientists came away with a better understanding of why the MS Society might go in one direction and not another.

"CCSVI took over our agenda for a period of time. We had to respond. Although this was a stressful time, we learned from it. Could we have avoided it? I doubt it. Maybe if we hadn't had the heated media coverage, things might have been different. We didn't have any choice but to go in the direction that we did. We needed to put money into

research studies and had to put resources into responding to the issue.”

In September 2010, the MS Society board took another major step forward by approving the allocation of \$1 million for CCSVI and MS pan-Canadian therapeutic clinical trials. The funding was set aside to ensure funds were available if and when a trial was developed and approved. At the same time, the MS Society pressed federal and provincial governments for action on three issues: first, to commit funding for an eventual CCSVI clinical trial; second, to establish monitoring systems or registries to track the outcome from people who choose to have treatment for narrowed veins outside of Canada; and third, to ensure that people who had treatment outside of Canada had appropriate follow-up care once they returned home.

By mid-2011, most governments had responded to CCSVI advocates and the MS Society in a variety of ways. The government of Saskatchewan in October 2010 said it would provide money for a therapeutic clinical trial. The Saskatchewan Health Research Foundation invited researchers to submit applications for funding, however, there were no successful applicants. In January 2012, the Saskatchewan government said it would use \$2.2 million of the money it had committed to allow people with MS in Saskatchewan to take part in a CCSVI treatment clinical trial in Albany, NY. That clinical trial was halted in September 2013 because of a lack of qualified participants. Meanwhile, in March 2011 the Government of Canada announced the creation of a national MS monitoring system to capture information including

long-term outcomes of treatments including the CCSVI procedure, and in June 2011, the federal minister of health announced it would support, through the Canadian Institutes of Health Research (CIHR), a phase one/two clinical trial of the procedure to unblock veins. The MS Society committed funds to the clinical trial as did the governments of British Columbia, Quebec and Manitoba (which had previously committed \$5 million for a clinical trial on CCSVI and MS). The CIHR-led study is currently underway. The government of New Brunswick provided matching funding to help people who travelled outside of Canada pay for the treatment. The government of Ontario developed guidelines for physicians to follow when providing medical care for people who had received treatment for narrowed veins outside of Canada.

The MS Society also had to look at the way it was communicating and make changes. By the end of 2010, it was using Facebook, Twitter and the organization's website to relay frequent, credible and relevant information about CCSVI. It stated it would not be judgemental of an individual's decision regarding CCSVI treatment. As the volume of information and conversation related to CCSVI swelled over the course of the year, it became apparent that creating a separate space for CCSVI content would make it easier for individuals to find the answers they were seeking. The MS Society launched a website ([ccsvi.ca](http://ccsvi.ca)) in the spring of 2011 to meet this need and to also enable people to ask questions and share their personal stories.

Numerous research projects have been undertaken or are underway. Five of the seven diagnostic studies funded

in 2013 by the MS Society of Canada and the National MS Society reported negative results by mid-2013 - none found people with MS had blocked veins more frequently than did healthy controls or people with other neurological conditions; two studies were still underway by mid-2014. A large (1,767 participants) Italian study found there was no significant difference in the occurrence of blocked veins among people with MS, people with other neurological conditions and health controls.

While we now understand from the definitive anatomical studies that CCSVI is not a causal factor involved in the etiology of MS, we await the results of the pan-Canadian phase one-two interventional trial to discover whether CCSVI treatment may have a beneficial impact on symptoms often associated with MS such as fatigue and brain fog.

The CCSVI issue was a challenging one for the MS Society for several years. Some people with MS and their families felt the organization was blocking their access to a potential treatment. Some in the medical community believed the MS Society was putting scarce research dollars in studies that would not yield promising results. The debate provided opportunity for the MS Society to reflect on its ultimate responsibility. The board of the MS Society confirmed its resolve that people living with MS was its top priority. The role of the MS Society as the go-to source for definitive, timely and relevant information about developments in research and treatments of MS was also reaffirmed through this arduous debate, a role that the Society has now reinvented as supporting the person with MS in making their own choices.

## ► Chapter seven: Organizational renewal

During the 1980s and 1990s, the MS Society functioned as a decentralized organization even though it had been and still was one corporate entity for decades with a few exceptions. The exceptions were the Quebec Division and most of its chapters, which is separately incorporated. However, within the MS Society, the boards of directors of each of the seven divisions and the approximately 100 chapters had significant authority in hiring and managing staff, making decisions about real estate and determining annual budgets.

Beginning in the late 1980s, volunteers and staff, especially at the national level, realized the Society needed to bring in better financial controls for the entire organization and ease the administrative burden for divisions and chapters. As described in chapter one, these changes brought about more cohesion and collaboration as did the development and adoption of the Society's first strategic plan in the early 1990s.

However, the MS Society board remained limited in its authority and relied heavily on persuasion and good will to solve the Society's continuing issues, including how to achieve balanced spending on research and services activities. In 1998, the Society board was once again grappling with the question of how much the organization should spend on research and services. The question of "balanced spending" was one the board had returned to again and again since the natural tendency for local levels of the MS Society was to spend as much as they could

to serve local clients and provide “left over funds” to the national research program. In June 1993, after consulting division boards, the MS Society board established a spending formula so the organization could balance its spending on services and research overall. But by 1998, services expenditures were once again disproportionately related to client services. For every \$100 available, less than \$40 was going to the research program.

The board turned to Reid Nicholson to head a special task force. Besides being a member of the board and the National Executive Committee, he was chair of the International Persons with MS Advisory Committee and of its Canadian equivalent. He was joined by other directors: Barry Cavanaugh of Vancouver, Jennifer Rodgers of Edmonton, Jake Doherty of Owen Sound, Ontario, and Daniel Larouche of Montreal.

The task force asked the question: “How can we share our expenses between research and member services?” Eighty per cent of those who responded said the balanced spending formula was correct and that for each dollar donated to research, another dollar should go to services. The task force reported back to the board with this input, and the MS Society board renewed the commitment to balanced spending on research and services. Because of increased fundraising revenues, the decision was made in early 2003 to invest 17 per cent more funds in MS research. By the 2005-2006 fiscal year, the Society had achieved the fifty-fifty balance in spending on research and services, with \$9 million expended on each of those crucial program areas.

Then secretary-treasurer Daniel Larouche wrote in the summer 2007 issue of *MS Canada*: "The 2006 fiscal year was a real financial success. The Society's income exhibited the highest increase in its history, growing from 26.6 to 30.1 million dollars. If this had been the only highlight, we would already be quite satisfied. But there is more. After several years of ongoing group efforts, we now have reached a balance between services and research, providing each with \$9 million dollars."

He described the approach to achieving balanced spending: "... it was out of the question to cut down on contributions provided to services in order to reach this goal. Balance had to be achieved by increasing the total revenues generated and use this growth wisely to benefit research... In 2003, the board of directors decided that balance needed to be reached by year-end 2007. Since this happened by year-end 2006, we are one year ahead of schedule. This performance was made possible thanks to the leadership of the boards of directors and division and chapter executives. We must also acknowledge the commitment of the 13,500 volunteers and employees at the Society, at every level of the organization and throughout the Canadian regions. You all deserve a warm round of applause! But it would be a mistake to stop now. Finances are somewhat like walking on a high wire: it's not all to achieve balance; the key is to keep it! We know now we can do it!"

In addition to the issue of balanced spending, some MS Society board directors were concerned the MS Society's organizational structure kept it from reaching its maximum potential. In March 2004, the board authorized a small task

force led by then board chair David L. Knight to review the operating structure and to make recommendations. Other task force members were Barry J. Cavanaugh, past chair of the Alberta Division; L.G. Thomas Epp, then chair of the Ontario Division; Daniel Larouche, board director and member of the National Executive Committee; and CEO Alistair Fraser. The task force delivered its report to the board in September.

The overall direction of the task force's recommendations was that the MS Society better coordinate its activities at all levels of the organization. Key among the suggested changes were: strengthening accountability between the national president and CEO and division presidents; decreasing the size of the MS Society board of directors and increasing the frequency of its meetings to enhance its decision-making ability; and creating a Leadership Advisory Council of past board directors and other MS Society leaders to increase their involvement.

Al Fraser moved immediately to increase communication and accountability with division presidents by including them in more decision-making meetings. Realizing as well that more information was needed about how and by whom decisions are made within the Society, he initiated a "responsibility mapping" process that resulted in visual depictions of existing lines of responsibility within the increasingly complex organization. Other task force recommendations were not implemented until the MS Society made other organizational changes under the leadership of Yves Savoie who became president and CEO in February 2007.

During his first months with the Society, Yves Savoie combined travelling to meet volunteers and staff across

the country with attending numerous consultations on the development of the new strategic plan, a process he initiated shortly after his arrival. During the consultations, participants considered four questions: How do we create value for our stakeholders? At what processes must we excel? Financially, what is most critical to us? How do we grow and change to meet ongoing demands?

He describes the consultations: "What impressed me, wherever I travelled and whoever I met, was the exceptional commitment to make a great organization even better."

By October 2007, the first draft of *Momentum 2015* was made available to various stakeholders for final input. The MS Society board approved the strategic plan in March 2008, and work began to make it operational by September, the start of the next fiscal year. By coincidence, 2008 was also the sixtieth anniversary of the Society's founding.

Yves Savoie describes *Momentum 2015* as: "a guide to planning and decision-making at all levels of the Society over the next seven years. At the start of our new fiscal year in September 2008, this plan will lead us both in charting a course for the future and in adapting to unexpected changes in the field. *Momentum 2015* also is the launch of an ambitious framework for measurement and accountability. It will be an important building block in the development of annual plans and budgets."

While work was underway on the development of the strategic plan, another important process was launched. The board launched a governance review in September 2007. By June 2008, the process resulted in

recommendations for changes to the Society's national by-law. The most significant change was the reduction in the size of the MS Society board of directors from 27 to 14 directors and the change in role of the Executive Committee which no longer meet on a standing basis. Another amendment was the change of the fiscal year end from August 31 to December 31 beginning in 2010. The current organizational structure of the MS Society of Canada (chapters, divisions and national office) was maintained. The revised by-laws were approved at the Society annual general meeting in November 2008. With these changes, more of the recommendations from the 2004 task force were now in place.

Linda Lumsden became chair of the MS Society board in November 2008 and led the MS Society for the next three years as it moved forward with a new focus on accountability and realizing the commitments in *Momentum 2015*.

She describes how she became involved in the MS Society. "I was recently widowed. I had retired three years before as a business executive and had spent three years as a caregiver to my husband. After he passed away, I needed to do something that was mentally stimulating. I wanted to do volunteer work, but not with any of the organizations related to his illnesses because I felt I would have a hard time being objective. I saw an ad in the local Ottawa newspaper asking for people to join the MS Society chapter board. I knew a little about MS and felt I could contribute and be objective.

"I joined the Ottawa Chapter board in September 2000. The chapter board was very business-like. From that perspective I thought it was doing well. While I didn't know

much about Ontario Division or the national level, I did understand there was tension between the different levels and too much protection of turf.

"I had just moved to past chair of the chapter, when I was recruited to join the Ontario Division board. I became vice chair and then chair in 2007. I left that position early to go to the MS Society board as a member-at-large. I think what kept me involved was that I felt my background would allow me to find ways to help the Society to become stronger. I had begun my career with a provincial telephone company and ended up working for a national company. All of my projects involved trying to resolve tensions between the different companies. My strength has been on the people side in getting people to work together. I felt that was where we needed to go as an MS Society."

### **MS Society divisions**

While people affected by MS living in the 10 provinces were served by an MS Society division or one of its chapters for many years, until 2009 those living in the three territories did not have an official connection. They are now specifically linked to the appropriate division.

Atlantic Division (covers the four Atlantic provinces)

Quebec Division

Ontario and Nunavut Division

Manitoba Division

Saskatchewan Division

Alberta and Northwest Territories Division

British Columbia and Yukon Division

In September 2011, the board announced the creation of the Renewal Initiative. A task force was established to examine all aspects of the MS Society including its internal structure, roles and responsibilities to determine if there are ways to more effectively and efficiently deliver on the mission. Membership on the task force included people living with MS, volunteers, members of the research and clinical community and staff. Work began in September 2011.

Over the next year, the task force listened to stakeholders and sifted through submissions made by individuals and by informally constituted groups as well as boards and committees. It issued three consultation papers that stakeholders could react to and improve upon. By September 2012, the final report went to the board of directors. The task force provided 38 recommendations to the board covering four key areas: Increasing revenue and reducing costs and duplication; increasing organizational alignment; strengthening client services programs; and examining research avenues with greatest potential to advance progress.

The board approved the Renewal Initiative Report and the recommendations in September 2012, under the leadership of Jim Casey, who had become chair in June.

Linda Lumsden welcomed the direction the report took the Society. "To operate as a team you need a structure in place to allow you do to that. Everyone at every level believed in the mission, but there was a lack of trust between the levels because people didn't understand the roles and responsibilities and the commitment of people at every level. So it was a matter of trying to strengthen

the understanding and knowledge and making sure everyone understood that everybody cared about the same mission and vision and goal. When I first became involved, we weren't taking advantage, for example, of the skills of chapter executive directors. Now we had a great opportunity for the organization to become stronger and leaner and tighter."

Ms. Lumsden was tapped to lead a key working group to put the renewal initiative decisions into place. The Memorandum of Agreement (MoA) Working Group was created to develop standard memoranda of agreement between the different levels of the organization, i.e., divisions with the national level and chapters with divisions. The MoAs were to clearly spell out roles, mandate and authorities at each level.

Beginning its work in January 2013, the working group, made up of volunteers and staff from chapters, divisions and the national level, developed a draft division charter template (the name was changed from MoA), consulted with affected divisions and presented a final draft to the MS Society board in June 2013 where it was approved. With the division charter template finalized, the working group turned to developing the chapter charter template and an affiliation agreement between the MS Society and the Quebec Division. A separate affiliation agreement was required because the division is legally incorporated unlike the other divisions. A robust consultation process in late summer and fall 2013 resulted in a charter template that was flexible enough to encompass the differences between large and small chapters but still provided a standard framework for all to work within. The MS Society

board approved both the chapter charter template and the Quebec Division affiliation agreement in December 2013.

Reflecting on her work with the MS Society, Ms. Lumsden says: "I think one of our biggest accomplishments is the work we have done with the Renewal Initiative. Looking at the work we did on the charters for the divisions and chapters, we involved people on the working group who were not necessarily historically pro-division or pro-national. We came away from that exercise with quality products and with support across the country. To me, that was a signal that we had turned a corner, and we were working together as a Society. I appreciate having an opportunity to work with that team. To see how well they worked together, made me feel the time I have spent with the MS Society was well spent. The organization has moved in the direction that I wanted it go when I first joined."

There was one more change the MS Society had to accomplish in terms of governance. The MS Society had to transition its incorporation from the Canada Corporations Act to the Canada Not-for-Profit Corporations Act by October 2014. A key requirement was that members directly elect all of the directors on the MS Society board of directors. This meant that none of the directors could be appointed by divisions, which had been the practice in the past. The MS Society also took the opportunity to adjust other parts of its by-law that resulted from the Renewal Initiative. Members approved the new by-law in June 2013.

The approval of the Renewal Initiative report and the new by-law finalized numerous improvements that had begun in the 1980s. A modest first step to standardize some accounting practices was followed by other changes that ultimately culminated in an organizational structure that was more unified but still valued the uniqueness of the divisions and chapters. And throughout all the changes, the MS Society continued to follow its mission and to keep people affected by MS at the centre of everything it did.

## ► Epilogue - Building for the future

While it is indeed foolhardy to attempt to predict the future, as the MS Society moves closer to its seventieth anniversary in 2018, the organization is on course to maintain its grassroots character balanced by better organizational alignment and accountability. A key initiative called *Listening to People Affected by MS*, launched in 2012 provided the Society with input from more than 6,000 Canadians affected by MS that is being used to guide program, services and advocacy work at all levels. In addition, people living with MS are valued and active members of the Society's research grant review committees.

Like other charities and non-profit organizations in Canada, the MS Society is facing the challenge of raising funds in a highly competitive, post-recession environment, and older fundraising events such as the MS Carnation Campaign and the MS Read-A-Thon that began in the 1970s and 1980s are no longer significant money raisers. The Society is increasingly and successfully looking toward innovative partnerships such as the one with A&W's Cruisin' to end MS event which began in 2009 and has raised more than \$5 million by 2013.

Listening, caring and innovating are concepts the MS Society is increasingly living by as it moves forward.

## ► Appendix One: MS Society presidents/ chairs - 1985 to 2014.

The list of MS Society presidents from 1948 to 1984 is included in *Volunteers in Action*. In 1997, the MS Society board of directors changed the terminology for its chief volunteer from president to chair. In 2010, the MS Society changed its fiscal year to the calendar year.

1985-1988 - Alexander R. (Sandy) Aird, Toronto, Ontario

1988-1991 - David L. Torrey, Montreal, Quebec

1991-1994 - J.E. (Jack) Sinclair, Toronto, Ontario

1994-1997 - Bruce R. Richmond, CA, Toronto, Ontario

1997-1999 - Sarah E. Pepall, Toronto, Ontario

1999-2000 - Norman Latowsky, Toronto, Ontario

2000-2003 - Louis P. Desmarais, Montreal, Quebec

2003-2005 - David L. Knight, FCA, Toronto, Ontario

2005-2007- Lou J. Maroun, Halifax, Nova Scotia, and Toronto, Ontario

2007-2009 - Daniel Larouche, Montreal, Quebec

2009-2011- Linda Lumsden, Ottawa and Brockville, Ontario

2011-2013 - James Casey, Edmonton, Alberta

2013 - Charles (Chuck) Ford, Halifax, Nova Scotia

## ► Appendix Two: MS Scientific Research Foundation Research Grants

The Multiple Sclerosis Scientific Research Foundation was established in 1973 by the MS Society of Canada. With funding from the MS Society, the Foundation has supported large collaborative research projects since 1993.

**Canadian Collaborative Study on Genetic Susceptibility**, five phases, initial funding approved 1993. Principal investigators: A. Dessa Sadovnick, PhD, University of British Columbia; and George Ebers, MD, initially University of Western Ontario, then University of Oxford.

**Canadian Collaborative Study on Myelin Gene Regulation**, funding approved 1999. Principal investigator: Alan Peterson, PhD, McGill University.

**Long Term Outcomes Following Immunoablative Therapy and Autologous Stem Cell Transplant for Poor Prognosis MS**, two phases, initial funding approved 1999. Principal investigators: Harold Atkins, MD; and Mark Freedman, MD, Ottawa Hospital.

**Remyelination in Multiple Sclerosis: Neural Precursor-Based Repair**, two phases, initial funding approved 2001. Principal investigators: Jack Antel, MD, McGill University; Samuel Weiss, PhD, Hotchkiss Brain Institute and University of Calgary; and Moses Rodriguez, MD, Mayo Clinic, Rochester, Minn.

**Prospective Study of the Clinical Epidemiology, Pathobiology and Neuroimaging Features of Canadian Children with Acquired Demyelinating Syndromes,**

funding approved 2004. Principal Investigators: Brenda Banwell, MD, Hospital for Sick Children, Toronto; Douglas Arnold, MD, Montreal Neurological Institute; Amit Bar-Or, MD, Montreal Neurological Institute; A. Dessa Sadovnick, PhD, University of British Columbia; and Ruth Ann Marrie, MD, PhD, University of Manitoba.

**Randomized, Controlled Phase III Trial of Minocycline in Clinically Isolated Syndrome,**

funding approved 2006. Principal Investigator: Luanne Metz, MD, University of Calgary.

**Molecular Genetics of Multiple Sclerosis,**

funding approved 2008. Principal investigators: George Ebers, MD; University of Oxford; Julian Knight, MD, PhD, University of Oxford; A. Dessa Sadovnick, PhD, University of British Columbia; and Alexandre Monpetit, PhD, McGill University.

**Pathobiology of MS: Complex Interplay Between Degeneration and Inflammation in Progressive MS,**

funding approved 2011. Principal investigators: Peter Stys, MD, University of Calgary; Jeroen Geurts, PhD, VU University Medical Centre, Amsterdam; Jan Van Minnen, PhD, University of Calgary; Serge Rivest, PhD, Laval University; Wayne Moore, MD, University of British Columbia; and V. Wee Yong, PhD, University of Calgary.

**B cells and MS: Who, What, When and Where?,**

(funding approved 2013. Principal investigators: Amit Bar-Or, MD, McGill University; Alexandre Prat, MD, University of Montreal; and Jennifer Gommerman, MD, University of Toronto.

