MS Society Announces $3.8 Million to Study Progressive Forms of Multiple Sclerosis

Progressive MS is a devastating diagnosis for anyone. That’s why the MS Society of Canada and the MS Scientific Research Foundation have announced a $3.8 million grant that will have a special impact on those with progressive forms of MS.

The grant funds a collaborative study led by Dr. Peter Stys from the University of Calgary’s Hotchkiss Brain Institute that will investigate damage that occurs in MS prior to inflammation.

“If we can understand more about the earliest triggers in the disease processes in MS, we might learn how to intervene and prevent the damage that occurs prior to an inflammatory response,” says Dr. Stys.

While there are seven disease-modifying treatments approved for relapsing forms of MS in Canada, little progress has been made in the disease management of progressive MS.

This research may change that, and of progressive MS.

The research will investigate damage that occurs in MS prior to inflammation.

What advice would you give to someone who has just been diagnosed with MS?

Most of us were taught from childhood that we should see to the needs of others before fulfilling our own needs. The problem is that when you have MS, putting yourself last will just about guarantee that you’ll be perpetually burning the candle at both ends and never able to achieve an optimal level of health.

If there was one thing I could wish for all those newly diagnosed, it would be for them to discover early on just how important it is to listen to your body. Learning when to push through the symptoms and when to rest is a vital and empowering lesson.

What has been the most fulfilling part of being a volunteer for the MS Society, and why?

The most fulfilling part of being a volunteer? Wow, the list is just so long!

It would have to be the self-esteem that I was able to recover after having lost my job and my first career to this disease. When we have to leave the workforce due to our health, one’s confidence can be shattered. Volunteering allowed me to transfer many of my skills from one field to an entirely new field and evolve them in a new direction.

It is not enough for me to simply feel better. I want to be productive and helpful, so I look to create opportunities to do both.

Why do you think it is important to support the MS Society of Canada?

There’s no way to fully convey the positive impact that the MS Society of Canada can have on the life of a person with MS. Between funding programs and the various support programs available, anyone with MS can benefit. I’ve seen people transformed from emotional paralysis after diagnosis to fully participating in their communities for the first time in their lives. The MS Society gives people the opportunity to make that happen.

To read profiles of more Canadians with MS, go to mssociety.ca/en/information/msprofiles.htm.

Progress Report

An Important Message from President Yves Savoie

You can help endMS

Four years ago, the Multiple Sclerosis Society of Canada launched one of the world’s most innovative – and momentous – campaigns ever to make the end of multiple sclerosis a reality. We called it the endMS campaign.

Our goal? To raise $60 million to recruit, train, support and retain the next generation of MS researchers in Canada, and to accelerate their research activities to find a cure and improved treatments for MS.

Today, thanks to our many supporters, individuals, corporations and foundations from across Canada, we are close to our fundraising goal. But we still need nearly $2 million in order to capitalize on this extraordinary opportunity.

The time has come to turn to friends and supporters like you, and ask you to lend your support to the endMS campaign.

A research revolution

The success of the endMS campaign will revolutionize the way the MS medical community will collaborate. To researchers and doctors, it will ensure that our progress towards a cure will continue. To people living with MS, it will enhance hope that a future free from MS is an achievable goal.

Here is how the endMS Campaign works:

The flagship initiative of the campaign is the $20 million endMS Research and Training Network, which now involves more than 950 MS researchers from more than 65 academic and health institutions across Canada. The network will:

• Attract and retain trainees and researchers to pursue long term careers in MS research
• Foster collaboration and provide education and training that will increase knowledge and skill in MS research
• Increase the opportunity to conduct MS-focused research in Canada.

The time to end MS is now

For the estimated 55,000 to 75,000 Canadians who live with MS, nothing could be more important. Your gift can put us over the top – and help raise the remaining $2 million we need to reach our campaign goal.

To make a gift online, please go to www.endms.ca. Or return the enclosed reply slip with your donation.

I hope that we can count on your generous support.
Engaging Children and Youth with MS:
A forward-thinking strategy for Canada’s youth

Is the MS Society of Canada successfully engaging Canadian youth living with MS? The answer, we learned a few years ago, is that we could be doing more.

Following a research project in 2009, we determined that our traditional service delivery model did not fully capture or support young people in an age-appropriate way. So we set out to deliver information, help and hope in a way that young people could relate to.

Our first task was to convene a National MS Youth Advisory Group comprised of young adults impacted by MS. One of its recommendations? Develop an online youth community; one in which young adults could express themselves freely, and receive advice, counsel and support from people just like themselves.

A website devoted to Canada’s youth: Someoneilikeme.ca

“This is a place to be yourself!” is one of the first things you’ll read when you click on someoneilikeme.ca. Adults with MS can certainly come and take a look, (but this website is not designed for them.)

It was developed exclusively by and for young adults with MS, and those with a personal connection to MS. It also serves as a brilliant resource for youth who have a loved one with MS or are supporting an individual who is living with MS.

On someoneilikeme.ca, young Canadians can share their stories, along with their advice on how to cope with the many challenges of living with MS.

A comprehensive toolbox, forums, blogs and posts tackle a variety of topics that include ways to manage the physical and emotional challenges of MS. Young adults have a variety of ways to get involved including telling their own personal stories and joining the National Youth Advisory Group.

“I’m not even sure how to describe how helpful it has been to be able to talk to other people who understand, not only what the physical side of all this feels like, but also how it feels emotionally. The wealth of information in the “toolbox” portion of the site has been instrumental in helping me understand a lot of the things I’ve been going through. I can’t say enough good things about someoneilikeme.”

Post on someoneilikeme.ca

The National MS Youth Advisory group

The National MS Youth Advisory Group is comprised of youth and young adults impacted by MS who share these common goals:

• To bring the voice of youth and young adults to the organization

• To create a forum for young Canadians living with MS to work in a youth friendly environment that respects and values their opinions and input

• To involve young Canadians living with MS in aspects of decision making for youth initiatives developed by the MS Society of Canada

Introducing our MS Youth Ambassador

Aaron Salowionik, the drummer from the band Billy Talent, is a philanthropist, fundraiser and agent of social change who is passionate about the MS cause. He also happens to live with relapsing remitting MS.

Aaron has supported young Canadians living with MS by raising funds and building awareness through his involvement in art shows, golf tournaments and rock concerts around the world. And he’s an active blogger on someoneilikeme.ca.

MS Summer Camp

“[My child] still talks about her camp experience like it was the best time for her since all this MS started!”

— A parent

The MS Summer Camp is an opportunity for children and teens with MS to meet at the banks of the beautiful Big Rideau Lake for a weeklong adventure! It’s full of fun activities, new friends and gives kids an opportunity to escape the daily stresses associated with MS in a safe, supportive environment.

If you know someone who would like to attend the MS Summer Camp, let us know. They can sign up for an information package at mssoociety.ca/en/helplcamp.htm. Or call us toll-free at 1-800-268-7582.

MS Bike Tour.
Coming to a town near you!
The MS Bike Tour is one of the nation’s largest fundraising events on behalf of the MS Society. To find out where and when your local bike tour will take place, go to http://mssoociety.ca/mbsiketours. Or call 1-800-268-7582.

Reading raises millions for MS research.
In 2011, the school-based MS Read-A-Thon raised $1.7-million in support of the MS Society’s work.

Call us at 1-800-268-7582 or email rat@mssoociety.ca to learn how you or your school can become involved.

Show your support – Wear a carnation.
This May, volunteers across Canada are showing their dedication to finding a cure by selling carnations on street corners, malls and other public spaces. Help raise awareness about multiple sclerosis by purchasing a carnation and together we will help end MS.

Spring Events

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Help lead the way toward a cure.

Become one of our Partners in Progress.

By becoming one of our Partners in Progress monthly supporters, you can play a leadership role in the search for an MS cure.

The facts is, 92 per cent of our funding comes from private donations from friends like you. So the monthly donations that we receive from Partners in Progress provides steady, reliable funding that we can count on for new research projects, scholarships, and training.

There are so many advantages:

• It’s flexible. You choose how you would like to give — via credit card or through your bank account. You select the amount you’d like to give. And you have the ability to adjust or even opt out of monthly giving any time you wish by contacting us at 1-800-361-2985.

• It’s effortless. No more cheque writing or searching for your receipts at tax time.

• It’s rewarding. Our monthly donors are kept up to date on the progress our MS Society supported researchers are making and you’ll receive invitations to annual research teleconferences.

The benefits of joining us as one of our Partners in Progress include:

• MS Canada Magazine, a quarterly, full color publication, will give you insight into many of the issues related to MS.

• Published bi-annually, the Progress Report highlights research advances in MS along with timely news about the activities of the MS Society.

• All of your monthly donations are tax-deductible to the full extent allowed by law. The MS Society will provide you with an annual statement outlining your donations for the year.

• From time to time, we’ll send you name and address labels as well as notepads to say “thank you” for your ongoing support.

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While there are seven disease-modifying treatments approved for relapsing forms of MS in Canada, little progress has been made in the disease management of progressive MS.

This research may change that, and it is only made possible thanks to the generosity of MS Society supporters and donors like you.

For more information on this research grant and the hope it provides to Canadians with MS, go to www.mssociety.ca/news.

MS Society Announces
$3.8 Million to Study
Progressive Forms of
Multiple Sclerosis

Portrait of a Volunteer:
Trish Robichaud

Minimizing her own MS symptoms through profound lifestyle changes, self-awareness, proper treatment and conflict and stress management, Trish has lived a joyful and rewarding life despite her lifelong battle with depression. She has inspired admiration, hope, courage and strength in others since being diagnosed with multiple sclerosis in 1993, and has served the MS Society as a volunteer in many capacities.

We asked her what her experience has taught her – and why she supports the MS Society.

What advice would you give to someone who has just been diagnosed with MS?

Most of us were taught from childhood that we should see to the needs of others before fulfilling our own needs. The problem is that when you have MS, putting yourself last will just about guarantee that you’ll be perpetually burning the candle at both ends and never able to achieve an optimal level of health.

If there was one thing I could wish for all those newly diagnosed, it would be for them to discover early on just how important it is to listen to your body. Learning when to push through the symptoms and when to rest is a vital and empowering lesson.

What has been the most fulfilling part of being a volunteer for the MS Society, and why?

The most fulfilling part of being a volunteer? Wow, the list is just so long!

It would have to be the self-esteem that I was able to recover after having lost my job and my first career to this disease. When we have to leave the workplace due to our health, one’s confidence can be shattered. Volunteering allowed me to transfer many of my skills from one field to an entirely new field and evolve them in a new direction. Had I not chosen to step up to volunteering for the MS Society shortly after my diagnosis, I’m not sure that I would have found my way to eventually becoming self-employed as a coach and helping others walk the path that I’ve already charted with chronic illness.

Why do you think it is important to support the MS Society of Canada?

There’s no way to fully convey the positive impact that the MS Society of Canada has on the life of a person with MS. Between funding programs and the various support programs available, anyone with MS can benefit. I’ve seen people transformed from emotional paralysis after diagnosis to fully participating in their communities for the first time in their lives. The MS Society gives people the opportunity to make that happen.

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April 9, 2012

Dear Friend,

Like many people who support our fight, I have a personal relationship with multiple sclerosis.

My mother had MS during a time in Canada when no drugs existed that could help diminish the symptoms of the disease, and there was no specialized care to be found. I was witness to how MS impacted her life and the lives of everyone who loved her.

Years later, after I had established myself in my career and I had the opportunity to give something back, I chose to play an active role in supporting the MS Society of Canada. My hope and dream is to see the day when MS is cured.

I think many supporters of the MS Society of Canada feel the same.

That is why, when I was asked to take on the role of chairman of the endMS Campaign, I didn’t hesitate. While I knew that raising $60 million would be an enormous challenge, I also understood that it was an unprecedented opportunity to attract and retain the caliber of research talent that we need to beat this disease.

Let me tell you why I think that this campaign is critically important to the future of MS research in Canada and why I wholeheartedly believe that your participation will help end MS.

What makes the endMS Campaign different than any other fundraising effort we’ve ever launched is the fact that it is driven by the researchers themselves. When we asked medical experts to tell us what their research “dream” was, they came back with a vision of a cross-Canadian network of key MS centers; a network that would attract and retain brilliant young researchers who would dedicate their research to ending MS.

That conversation took place five years ago. Back then, I could not have imagined where we would be right now.

(over, please)
Today, the MS Society of Canada has five coast-to-coast research and training centres, involving more than 65 healthcare institutions and 950 researchers across a broad range of disciplines.

This network offers students and researchers positions in the world of MS research that are increasingly difficult to find in today’s competitive marketplace. We have developed a unique curriculum that allows them to gain knowledge with more speed and fluency than they might have done otherwise.

It provides young researchers with experienced mentors, and ensures that they have some of the finest minds in the field to help them learn, grow, and develop their expertise.

Perhaps most importantly, this highly collaborative network model creates an environment that allows researchers to blossom in a way that they could not do anywhere else in the world.

In this way, we are ensuring that MS research moves forward. In fact, this internationally unique model accelerates the pace of research discoveries so that we will get to where we need to be sooner, rather than later.

At the end of the day, regardless of what your experience with MS is, in the hearts of all Canadians, there’s only answer – a cure. If we can all get behind this network and support the research projects that come from these talented scientists, we are going to reach our goal.

It’s as simple as that.

On behalf of everyone involved in the endMS Campaign, I urge you to support us in fulfilling this important initiative.

Gratefully,

Sandy Aird
Chairman, endMS Campaign