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VOLUME 24 ISSUE 4

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LEAD

MS Multiple Sclerosis Society of Canada
www.mssociety.ca

LEAD



The past year has been one of unwavering commitment and steadfast determination for the Ontario Division of the MS Society of Canada. In changing and sometimes uncertain times, we nevertheless celebrate great achievements as we pursue our mission to find a cure for MS and enable Ontarians living with MS to enhance their quality of life.

In the year since the launch of the endMS campaign, more than two thirds of our \$60 million goal has already been contributed by generous donors. This year also saw the creation of five Regional Research and Training Centres, as well as a number of educational programs aimed at MS researchers and trainees.

We take pride in the involvement of various MS Society representatives in the development of accessibility standards in support of the Accessibility for Ontarians with Disabilities Act. The standards that will be implemented over the next few years will allow our clients to continue striving for access to various opportunities to participate fully in their communities.

And most recently, we celebrate the announcement that Tysabri (natalizumab), used to treat relapsing-remitting MS, has been approved for reimbursement under the Ontario Public Drug Programs' Exceptional Access Program. This decision will positively impact the life of many Ontarians with MS.

Our commitment to people living with MS has never been stronger. We thank all of our supporters who share our vision of a future free of multiple sclerosis. You are a part of the certainty with which we face the future. With your involvement, we will end MS.



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

Chair: Linda Lumsden
President: Yves Savoie
Editor-in-chief: Lisa McDonald
Managing editor: Carol Kim
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Linda Lumsden
Chair, Ontario Division
Board of directors

Yves Savoie
President and chief executive officer
President, Ontario Division

MS ambassadors help improve access to medications

People with MS may benefit from early treatment with drugs that can reduce frequency and severity of attacks and slow progression of disability. However, disease-modifying drugs can cost between \$17,000 and \$40,000 per year, and many cannot afford them without help from provincial drug programs.

Tysabri, a new disease-modifying therapy, was approved by Health Canada in 2006, but the Government of Ontario would not reimburse it despite many other jurisdictions doing so, including Quebec and very recently Alberta and Saskatchewan.

This past year, Ontario Division's MS ambassadors – a team of government relations volunteers – met with MPPs in communities across the province and at Queen's Park to champion this issue. Their efforts paid off: Ontario recently decided to reimburse Tysabri under the province's Exceptional Access Program for individuals who meet specific criteria.

"This is a testament that a collective, consistent and coordinated advocacy effort can make a difference in people's lives," says MS ambassador Lynda DaSilva of Lindsay. "I'm so happy to have been a part of it."

Enhanced quality of life through information, referral and support

For a person living with MS, accessing up-to-date, reliable information, receiving supportive counselling and connecting to community supports is vital. With health situations often being complex and needing time and effort to resolve, it is not always easy to find answers, especially when many issues are at play and resources for an individual or family may be limited.

The MS Society's client services team provides support and information to persons living with MS, as well as their family, friends and caregivers. Inquiries from clients into Ontario Division numbered over a thousand in the past year. Thousands of other calls and emails were answered from volunteers and staff in communities across Ontario. For many of the callers, access to a reliable source of information also provides them with an opportunity to connect with an individual who can listen and provide support when it's most needed.

Living with MS brings all kinds of challenges. Access to information, referral and support enables those living with MS to make important, educated decisions about their health and strive for a better quality of life.

"I have MS. That's why I walk"

Historically, there has not been a visual way for MS Walk participants to identify themselves at the event as someone living with MS.

The 2009 MS Walks saw many changes, including the opportunity for MS Walkers who live with multiple sclerosis to self-identify at events in Ontario. This spring, new red walker bibs that state, "I have MS. That's why I walk" were made available on walk day as an alternative to the standard walker bib.

Wearing the bibs allowed people living with multiple sclerosis to inspire and encourage other participants as they fundraised and walked to end MS, demonstrating their commitment and dedication to the cause, despite the challenges the disease may present.



Premier Dalton McGuinty with MS ambassador Yassemin Cohanim at the MS Society's Day at Queen's Park.



MS Walk participants proudly wearing their "I have MS. That's why I walk" bibs.

This year the MS Walk saw over 29,000 Walkers, raising \$6.2 million across Ontario in support of MS research and services for those living with MS.

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“We are honoured to bring the voice of the MS community to the table and we are fortunate to have tremendous support from the [MS] Society in our efforts.

Joan Gallagher-Bell



Champions of change: Joan Gallagher-Bell and Cathy Topping

Together, we will build an accessible Ontario. Mark my words.”

Cathy Topping

Funding programs for clients

For many living with MS and their families, it is not always financially feasible to access services or purchase the essential equipment necessary to help increase independence and enhance their quality of life.

Equipment Program

The Equipment Program helps those in financial need, who are living with MS, acquire funding for the purchase, loan or repair of medical equipment. As well, the program provides an opportunity for people to donate clean, safe and reliable medical equipment that is no longer required. This past year, the MS Society provided to clients living in a non-chapter area, the purchase or repair of over a hundred pieces of equipment. As well, 18 pieces were recycled from existing inventory and 19 clients were provided with monthly/yearly funding for incontinence/catheter supplies at an average cost of \$700/year.

The funding provided to clients living in a non-chapter area, through the equipment program, enables them to access their community, attend social outings, create a safer living environment and continue or regain a certain level of independence, while enhancing their physical well-being.

Special Assistance Program

The MS Society’s Special Assistance Program assists people with MS to purchase services that will help increase independence and enhance their quality of life. The Special Assistance Program may provide funding towards the cost of services such as housekeeping, respite, grass cutting, child care or transportation. This past year, a total of 115 clients living in a non-chapter area received funding, 27 of which were new to the program.

For many, the MS Society is the only resource for financial assistance to purchase equipment and/or services they would otherwise not be able to obtain. This program provides an important service for clients to maintain their role as homemakers, supplement attendant care, allow for family respite and provide some means of travel or transportation to appointments and attend community and/or family functions.

Champions of change

Approximately 1.85 million Ontarians – 15.5% of the province’s population – face barriers to work, to information and communications, and to getting around and receiving services in their communities. These are people living with disabilities, and among them are the many people with multiple sclerosis.

MS Society volunteers Joan Gallagher-Bell and Cathy Topping have worked tirelessly to advance Ontario’s accessibility agenda and through their hard work and dedication helped bring about the Accessibility for Ontarians with Disabilities Act (AODA) in 2005. The first act of its kind in Canada, the AODA requires Ontario to become fully accessible by 2025 through the implementation of accessibility standards.

Cathy and Joan each sit on committees that have developed these standards and are working to ensure accessibility and equal opportunities to all Ontarians with disabilities, including those living with MS. It’s up to all of us to enact these hard won standards and to provide equal opportunity for Ontarians.

endMS - A year in review

MS researchers across Canada have made incredible advances in the knowledge and treatment of multiple sclerosis, at times overcoming the adversity associated with sharing knowledge among colleagues scattered across the country. Leading Canadian researchers identified this challenge and the declining number of young scientists selecting MS for their professional focus as potential impediments towards the accelerated progress necessary to end MS.

In January 2009, the Ontario endMS campaign cabinet was launched under the leadership of chair David Garton. Combined with the generosity of endMS campaign donors, five Regional Research and Training Centres were established across Canada this year, including one for Manitoba-Ontario. This centre brings together MS researchers and trainees from 16 health research institutions in the two provinces to undertake national activities and regional programs that address the specific needs and opportunities of health science communities in those provinces.

The activities of this training centre are greatly complemented by the fact that directors Drs. Brenda Banwell and Ruth-Anne Marrie are also co-investigators in the Canadian Paediatric Demyelinating Disease Study, the world's most comprehensive study of MS symptoms in children and adolescents. The study links 50 clinicians and scientists from 30 Canadian paediatric health institutions to increase the likelihood of earlier diagnosis and intervention.

Thanks to the leadership of the Ontario endMS cabinet and all donors across Ontario, the results of this and other funded studies will further strengthen Canada's already significant reputation as the global leader in MS research. The opportunity for exposure to the study's activities will also help attract new researchers and trainees to the network from across Canada and encourage them to pursue specialization in MS.



Dr. Brenda Banwell



Dr. Ruth-Anne Marrie.



Dr. Paul O'Connor

The Manitoba-Ontario Research and Training centre is being co-led by Dr. Brenda Banwell of the Hospital for Sick Children in Toronto, Dr. Ruth-Anne Marrie of the University of Manitoba and Winnipeg Health Sciences Centre and Dr. Paul O'Connor of St. Michael's Hospital in Toronto.

Leading the way for the next generation of volunteers

As experienced chapter/unit board volunteers contemplate retirement from positions they have held for some time, the need for a succession plan becomes apparent.

The MS Society, Simcoe County Chapter has grown substantially over the past few years and does not want to lessen their pace when welcoming new chapter leaders. Their solution? Create a transition plan to document volunteer roles, processes and procedures, so everyone has a sense of the chapter's direction and methodology.

This strategy served the chapter well this year, when three long-term board members resigned. As a result of their succession plan, the chapter had no trouble filling the positions while maintaining their momentum, a measure that has helped everyone cope with the transition.

“Our chapter has always held our volunteers in high regard, making sure to nurture and maintain an environment of mutual respect; taking a team approach...”

Chapter chair Jeanette Elliott



A Simcoe County volunteer raises awareness and discusses volunteer opportunities.

LEAD

Ontario leadership giving donors

We are proud to recognize the following donors for their generous gift of \$1000 or more in support of the valuable work of the MS Society of Canada, Ontario Division:

\$25,000 +

Anonymous (1)
The Estate of Helen Butler
The Estate of David Housby
IBM Employees' Charitable Fund
The Estate of Nelson Johnson
The Catherine & Maxwell Meighen Foundation
The Estate of Reginald Morianti
National Logistics Services (2006) Inc.
The Ontario Trillium Foundation

\$10,000 - \$24,999

Anonymous (2)
Robert Edgar Arnold
Biogen Idec Canada Inc.
The Estate of Rosemary Deleo
Noble Trade (a RONA related company)
The Estate of Helen Peters
Pfizer Canada Inc.
RBC Foundation
The Estate of Charles Watters

\$5,000 - \$9,999

The Lloyd Carr-Harris Foundation
The Arthur and Audrey Cutten Foundation
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Rogan Foundation
Shandex Group
United Way of Ottawa
The Estate of Sylvia Van Der Hout

\$1,000 - \$4,999

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TELUS
United Way of Peel Region
Welded Tube of Canada Limited

endMS donors

We are proud to recognize the following early Ontario donors who made pledges and gifts to the endMS campaign up to August 31, 2009:

\$500,000 +

Anonymous (1)
CIBC
Garrett Herman
Louis J. Maroun
Scotiabank
The Waugh Family Foundation

\$499,999 - \$100,000

Anonymous (2)
Bob Decker
Ian and Kiki Delaney
Deloitte & Touche Foundation Canada
The Goodman Family and the Dundee Group of Companies
Susan A. Murray
PricewaterhouseCoopers
Richard and Heather Thomson

\$99,999 - \$50,000

Sandy and Margot Aird
Purdy and Bea Crawford
John Feld and Phyllis Yaffe
Alistair M. Fraser
Kenneth Macgowan
Osler, Hoskin & Harcourt LLP
Bruce and Sylvia Richmond
Mark & Sarah Wellings

\$49,999 - \$10,000

Anonymous (1)
Paul Atkinson
Michael Bernstein & Nadini DasGupta
Stewart Busbridge
Frances Carmichael & Jack Cashman
John F. Clifford
Cuddy Farms Corporation in memory of A.M. Cuddy
Elan Pharmaceuticals
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\$9,999 - \$5,000

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Yolanda Bronstein
Mike den Haan and Family
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Mike McClintock
Sarah Pepall

\$4,999 - \$1,000

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Chris Breen
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Ian Fraser
Jeff & Sandra Goldstein
Rohit & Aimee Gupta
Kathleen Murphy
Irene Russell
Sassafras
Allen Stern
Mark Whitmore
Waterloo Chapter - Fall Fashion Fantasy Show

(We apologize for any errors or omissions).

Multiple Sclerosis Society of Canada, Ontario Division Financial summary (unaudited)

Statement of Revenue and Expenditures for the year ended August 31

Below is an unaudited summary of revenue and expenditures for the year ended August 31, 2009. It combines the activities of chapters and the divisional office. The financial results of Ontario and all other divisions are examined by PricewaterhouseCoopers in order for them to express an audit opinion on the results of the MS Society of Canada's financial statements.

	Division	Chapters	2009 Total	2008 Total
REVENUE				
Donations and special fundraising projects (net of related expenditures)	4,357,437	4,169,713	8,527,150	8,575,117
Direct Mail & corporate campaign	1,205,089	-	1,205,089	1,639,651
endMS Research Network	653,264	-	653,264	218,919
Allocations from United Way	-	539,617	539,617	531,992
Grants	(258,429)	695,586	437,157	548,634
Memberships	760	51,919	52,679	55,624
Investment Income	14,724	10,933	25,657	71,775
Miscellaneous Income	-	2,495	2,495	110,300
Total Revenue	5,972,845	5,470,263	11,443,108	11,752,012
EXPENDITURES				
Program services				
Funds remitted to National for research	1,126,868	1,385,825	2,512,693	3,521,558
Funds remitted to National for endMS Research Network	691,833	-	691,833	218,919
Funds remitted to National for programs and services	1,011,310	-	1,011,310	663,731
Client Services	636,017	2,974,215	3,610,232	3,719,060
Public Education	420,784	526,098	946,882	894,317
Chapter Resources	714,537	213,051	927,588	1,039,673
MS Clinics	673,093	-	673,093	643,124
Government Relations	156,022	69,580	225,602	193,348
	5,430,464	5,168,769	10,599,233	10,893,730
Support services				
Administration	411,799	292,345	704,144	715,204
Fundraising	130,582	35,644	166,226	142,962
	542,381	327,989	870,370	858,166
Total Expenditure	5,972,845	5,496,758	11,469,603	11,751,896
EXCESS OF REVENUE OVER EXPENDITURES FOR THE YEAR	-	(26,495)	(26,495)	116

Complete financial statements are available upon request.

Ontario board of directors

- | | | |
|------------------------------------|--------------------------|---------------------------------|
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Ontario chapters and units

- | | | |
|--|---|---------------------------|
| Brampton and Caledon Chapter | London-Middlesex Chapter | Simcoe County Chapter |
| Brant County Chapter | Mississauga Chapter | Simcoe-Norfolk Unit |
| Bruce County Unit | Muskoka Unit | Stratford-Perth Unit |
| Cambridge Unit | Niagara Peninsula Chapter of Hope | Sudbury Chapter |
| Chatham-Kent Chapter | North Bay and District Unit | Thunder Bay Chapter |
| Cornwall and District Chapter | North Bruce and Grey Unit (<i>dissolved Sept. 2009</i>) | Timmins Chapter |
| Durham Regional Chapter | Northumberland County Chapter | Toronto Chapter |
| Elgin County Chapter | Ottawa Chapter | Waterloo District Chapter |
| Frontenac, Lennox and Addington (Kingston) Chapter | Oxford County Chapter | Wellington County Chapter |
| Haldimand-Norfolk Unit | Peterborough Chapter | Windsor-Essex Chapter |
| Halton Regional Chapter | Prince Edward County Unit | York East Chapter |
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This issue of MS Ontario is a reproduction of the Ontario Division 2008-2009 annual report.



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