



Multiple
Sclerosis
Society of
Canada

Société
canadienne
de la sclérose
en plaques



Ontario Division

175 Bloor Street East
Suite 700, North Tower
Toronto, Ontario M4W 3R8
Telephone: 416-922-6065
Fax: 416-922-7538
Toll Free: 1-800-268-7582
www.mssociety.ca

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Distribution:

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Government Relations/ Social Action Workshop

Making a Difference Today was the theme of the first-ever Ontario government relations/ social action training workshop for chapters held in Toronto in late April. Almost 40 participants gathered to learn from experts and from each other about how to influence governments and to bring about change in their local communities. A highlight was the presentation by two seasoned former policy advisors Chris Breen and Chuck Rachlis who told the audience how it really works at Queen's Park. They emphasized that mayors, city councillors, MPPs and ministers are approachable but you have to be organized, focused and provide workable solutions for the issues.

Volunteers Cathy Topping of St. Thomas and Carole Ward of Burlington inspired participants with their presentations about how they have made a difference in their local communities. Cathy explained how she and other volunteers created a successful Thumbs Up accessibility program, and Carole described how she identified a problem (the lack of accessible dental services) and developed a solution with the help of community partners.

Volunteer Ian Greaves of Niagara Falls provided practical ways to work with local politicians by involving them in MS Society activities and events (the WALK is a great way to involve people you want to influence, he noted.) Fran Chesney, executive director, Hamilton Chapter, described both the initial successes and challenges in making age-appropriate long-term care a reality in Hamilton.

Workshop participants also rated highly the presentations about the new Local Health Integration Network (LHIN) and how to work with them. A detailed presentation about changes to the human rights system, an update on the Accessibility for Ontarians with Disabilities Act and the building code provided everyone with the latest information to use and share. Information sharing was a major benefit of the workshop, according to the post-event survey. One person said, "Seeing how active other chapters and units...gave me some ideas on how to get the 'fire' burning with our members. There is so much we can learn from each other and just attending helped open up the communication link."

Workshop presentations and photos will be posted on the MS Society website in the near future.

Patient Members for Committee to Evaluate Drugs

An announcement is expected within the next few weeks about who has been selected to fill the two patient member positions on the Committee to Evaluate Drugs (CED). Several people associated with the MS Society applied for these newly positions. The CED provides advice to the Ontario Ministry of Health and Long-Term Care on drug-related matters, including providing recommendations as to which drugs should be listed on the provincial drug formularies for reimbursement. This is the first time that the CED will include people who are not health care professionals.

New AODA Standards Committees to be Selected

The members of two more AODA standards committees will be announced shortly. The two committees are the Accessible Built Environment Standards Development Committee and the Employment Accessibility Standards Committee. Several people associated with the MS Society have applied for both committees. More information will be provided when it is available.

New Accessibility Website

A new website called Accessibility News provides weekly updates about accessibility issues around Ontario. To sign up, just go to www.accessibilitynews.ca and follow the links.

Survey – Ontario Human Rights Commission

In preparation for its new role within the human rights system, the Ontario Human Rights Commission is conducting a strategic planning process via a survey and local consultations. The Commission says it wants to have input on what Ontarians see as the most pressing human rights issues, which are the most under-served communities and ways in which the Commission can use its new mandate most effectively. The survey deadline is June 15.

The survey is available on the Commission's website:

www.ohrc.on.ca/en/resources/news/priorities

Information about its new mission and vision can be found at: www.ohrc.on.ca

CCAC Issues Added to Long-Term Care Action Line

People who receive home care through their local Community Care Access Centre (CCAC) will be able to use the existing Long-Term Care Action Line to provide a complaint or concern about service. The government of Ontario announced the expansion on May 1 and said it was one of the recommendations in the report on home care by Elinor Caplan last year. The action telephone number is 1-866-876-7658 or TTY 1-800-387-5559.

Tysabri Recommendation and Ontario

Health Canada approved Tysabri, a new disease-modifying therapy, in September 2006. The next step in determining whether provincial governments will pay for Tysabri was a review by a joint federal/provincial/ territorial agency called the Common Drug Review (CDR). On April 30, CDR recommended to provincial governments that Tysabri not be listed on their drug formularies. This recommendation is not binding on provincial governments, and each will determine whether to include Tysabri on drug formularies or special programs for reimbursement.

The MS Society national office stated: The Multiple Sclerosis Society of Canada is disappointed that Tysabri did not receive a positive recommendation from the Common Drug Review (CDR). The MS Society urges provincial governments to include Tysabri among the MS therapies that can be reimbursed. The MS Society suggests the question of who should take Tysabri is something that should be answered through discussions between an individual and his or her neurologist.

Within Ontario, the MS Society will be working with government officials to have Tysabri reimbursed within the current provincial MS program.

Access to Implantable Pumps for Pain

The MS Society continues to work with the Neuromodulation Coalition to improve access to devices that can help people who have severe spasticity (implantable baclofen pump) or movement problems such as occur with Parkinson's disease. Recently Yves Savoie, president and chief executive; president, Ontario Division, wrote to Minister of Health George Smitherman pointing out the need for an integrated provincial strategy for neuromodulation in Ontario. Currently, access in Ontario is among the worst in Canada.

Ontario Election – Preparation for October 10

Keep this date – the next provincial election will be October 10. This is the first fixed election date in Ontario, and the positioning amongst the politicians and the parties is already underway. The MS Society is working on a brief election paper to assist chapters and volunteers of bringing our priority issues to the forefront during the campaign. It will be distributed to chapters and units

Government Relations and Social Action E-Alerts Online

The Government Relations and Social Action Alert newsletter is available online. Just go to www.mssociety.ca/ontario and click on Government Relations & Social Action/ Social Action Alert.

Deanna Groetzinger
Vice-President, Government Relations
& Policy

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