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**September 14, 2006**

**VIA E-Mail and Chapter Mail**

**Distribution:**

Chapter/ Unit Chairs & Executive Directors  
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Ontario Government and Community Social Action Committee  
Ontario Executive Committee & Board  
Government Relations & Social Action E-Network  
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*(Please forward to other interested members)*

**Government Relations and Social Action E-Alert**

- **New Coalition Pushing for Pumps for Spasticity**
- **Update on Human Rights System Reform**
- **Finding My Place: Age-appropriate long-term care**
- **Abilities Magazine**
- **Government Relations and Social Action E-Alerts Online**

**New Coalition Pushing for Pumps for Spasticity**

The MS Society has become involved with a new group, the Neuromodulation Coalition, that is advocating for better access to neuromodulation therapy. This includes implantable pumps to treat severe spasticity, experienced by a number of people with MS and spinal cord injury and deep brain stimulation to treat Parkinson's disease. **You can become involved as well.**

Earlier this year, the MS Society learned that a hospital program in Hamilton that serves people who use implantable pumps was to be closed because of a lack of resources. The physician in charge said he could no longer manage the program without additional support – both financial and staffing. After much pressure from the MS Society, individuals, and physicians, the hospital allowed the program to continue. At this point the only stable program appears to be in London, and it is not accepting patients outside of its area. There is no program in Toronto or eastern Ontario and the one in Windsor is under threat.

Moving forward, two hospitals (Hamilton Health Sciences Centre and the University Health Network in Toronto) have presented a business plan to the Ministry of Health and Long-Term Care. The strategy is intended to establish on-going, stable programs with funding directly from the Ministry. The program should benefit people with MS, spinal cord injury, Parkinson's disease, dystonia and chronic pain related to certain injuries and diseases.

The MS Society, along with several other voluntary health organizations, has joined the Neuromodulation Coalition to put pressure on the Ontario government to fund the proposal in its 2007-08 budget. The plan as presented by the two hospitals has a significant chance to succeed. The need of Ontarians with MS who have severe spasticity for this type of program is well supported by neurologists and nurses at the MS clinics. The initiative is being led by a professional public affairs and public relations company, Counsel Public Relations with funding from Medtronic of Canada.

**How you can help.** It is important to put a face on the issue. Please contact Deanna Groetzing, if you would like to become involved. The coalition is looking for stories from a variety of people: those who are successfully using an implantable pump to treat their spasticity; and those whose doctors who have recommended an implantable pump for severe spasticity but haven't been able to have it implanted. Please contact Deanna at: [Deanna.groetzing@mssociety.ca](mailto:Deanna.groetzing@mssociety.ca) or at 1-800-268-7582, ext. 3007.

In addition, for people in the Toronto and Hamilton areas, the Neuromodulation Coalition is holding two roundtable discussions about the issue. The Toronto event will be Thursday, September 28, 6:30-9 p.m., InterContinental Hotel, 225 Front St., W., Kingsway Room. The Hamilton event will be Thursday, October 5, 6:30-9 p.m., Ramada Plaza Hotel, 150 King St. E., Pavillion A. If you wish to attend, please contact Emma Jowett at 416-961-5898, ext. 217, or [ejowett@counselpr.ca](mailto:ejowett@counselpr.ca)

## **Human Rights Legislation**

On August 9, Yassemin Cohanim, member of the Ontario Government and Community Social Action Committee (OSAC), did a terrific job in presenting the MS Society concerns about the proposed human rights legislation (Bill 107) and our recommendations to improve it. She reported the presentation to the Standing Committee on Justice Policy went well and that many other presenters echoed our concerns. Later in the month, the MS Society was asked specifically by Attorney General Michael Bryant to let him know what improvements we have. We quickly responded by letter with specific suggestions. There should be another opportunity this fall to let MPPs know about the shortcomings in the proposed legislation with the continuation of the public hearings in Toronto by the Standing Committee on Justice Policy.

**You can get involved as well.** During the next few weeks, please contact your local MPP(s) and tell them about the MS Society's concerns regarding the proposed human rights legislation and our suggestions to help the government get it right. Remember, most MPPs are in their local constituency offices on Fridays and Saturdays once the legislative session gets underway. For more information, please see the brief that was presented during the public hearings in Ottawa. It is posted on the MS Society website in both English and French at the following links. <http://www.mssociety.ca/ontario/rights.htm>  
<http://www.mssociety.ca/ontario/rightsFr.htm>

## **Finding My Place: Age-appropriate long-term care**

In June, all chapters received suggestions about how to use locally *Finding My Place*, the new position paper on age-appropriate long-term care for younger adults with MS. If you

have some progress to report or if you would like to receive the information again, please contact Deanna at: [Deanna.groetzinger@mssociety.ca](mailto:Deanna.groetzinger@mssociety.ca) or at 1-800-268-7582, ext. 3007.

### **Abilities Magazine**

In the mailed version of this E-Alert, chapters will receive a copy of *Abilities* magazine, which is the premier magazine in Canada for persons with disabilities. The MS Society of Canada nationally has a page in *Abilities* in the forum section to let readers know about various initiatives and programs. The MS Society article in the fall issue of *abilities* is on page 54 and focuses on caregivers. If you wish to subscribe to *Abilities*, you can find information at [www.abilities.ca](http://www.abilities.ca) or write to Canadian Abilities Foundation, 340 College St., Suite 401, Toronto ON M5T3A9. A subscription is \$14 a year.

### **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](http://www.mssociety.ca/ontario) and click on Government Relations & Social Action/ Social Action Alert.

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