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Government Relations and Social Action E-Alert

- **MS Society Reception at Queen's Park**
- **Ontario Government Tables Bill to Reform Drug System**
- **Human Rights Legislation**
- **Home Care Funding**
- **Federal Budget Highlights**
- **Staffing Changes**

This issue will be longer than usual since the past six weeks have been extraordinarily busy both in government policy developments and within the MS Society.

MS Society Reception at Queen's Park

The first-ever MS Society, Ontario Division, reception at the Ontario Legislature April 19 provided a terrific opportunity to raise awareness of MS and the profile of the MS Society among MPPs and government officials on the eve of MS Awareness Month in May. Tad Brown, Chair of the Ontario Division Board of Directors, Alistair Fraser, President and Chief Executive, and Deanna Groetzinger, Vice-President, Government Relations and Policy, were able to engage George Smitherman, Minister of Health and Long-Term Care, and Michael Bryant, Attorney General, in discussions about the implementation of the Local Health Integration Networks (LHINs) and changes to the human rights system. Ian Greaves, member of the Ontario Government and Community Social Action Committee (OSAC), was also able to have a detailed discussion with Attorney General Bryant about some of the concerns people with disabilities have about the changes to the human rights system. Both ministers noted they had family members and friends with MS and said they were aware of the many issues of importance to Ontarians with MS.

Formal remarks by Tad Brown, Alistair Fraser and Dr. Brenda Banwell reminded attendees of the critical role the MS Society plays in funding services and research in Ontario and the progress being made toward ending MS. They also thanked MPPs for their leadership on

the Accessibility for Ontarians with Disabilities Act. Dr. Banwell is director of the Pediatric MS Clinic at the Hospital for Sick Children and leads the cross-Canada study of the development of MS in children, funded by the MS Scientific Research Foundation, related to the MS Society.

To note just a few of the MS Society attendees: Ontario Division Board of Directors – Tad Brown, John Clifford, Sean Foran, Niranjana Vivekanandan, John O'Dwyer, Colin Rickards and Karen Torrie-Racine. OSAC – Daniella Bernard, Ian Greaves, Kris McDonald, and Mike Roche.

The awareness reception was made possible thanks to educational grants from Bayer HealthCare, Biogen Idec Canada and Serono Canada. The MS Society, Ontario Division, is grateful for their support.

Ontario Government Tables Bill to Reform Drug System

In mid April, Minister of Health and Long-Term Care George Smitherman introduced Bill 102, legislation that will make significant changes to the drug system in Ontario. Called the Transparent Drug System for Patients Act, 2006, the intent of the legislation is to improve the existing system in five key areas: 1. Ensure better value for money; 2. Improve patient access to drugs; 3. Promote the appropriate use of medications; 4. Invest in innovative health system research; and 5. Strengthen drug system transparency and accountability.

The question, of course, is whether the legislation will improve access to medications, as promised or whether, as some have suggested, it will control costs by reducing patient and physician choice. The issue is confusing, possibly because there seems to be a disconnect between the policy goals as announced by the minister and detailed further by Helen Stevenson, Executive Lead of the Ontario Drug System Secretariat, and the actual legislation. In essence, Bill 102 amends two existing acts that govern the drug system.

On the plus side, the government has said the changes will eliminate the Section 8 process (also called Individual Clinical Review) and Limited Use. Instead, it provides a Conditional Listing category that would allow people to access new drugs while they are being evaluated for a formal listing. In addition, the government will create an Exceptional Access process, which is to allow access to drugs that are not available in any other way. And, it promises rapid funding decisions on breakthrough drugs for life-threatening conditions. Government officials have also said that there will be no changes for people who currently receive drug benefits.

This is all good news. The MS Society recommended during the consultation process last year that the Section 8 process be eliminated or reformed and MS disease modifying therapies that people currently access under Section 8 be put on the full formulary. It is unclear right now into which category the MS drugs will fall under the new legislation and if they would be put on the drug formulary. (Being listed means that people who need to have drugs paid for by the province either through the Trillium Drug Program or the Ontario Drug Benefit program would have automatic access.) We also recommended that the government provide more information about the process of listing drugs on the formulary, which is promised under the reform.

Other positive steps as announced by Minister Smitherman and Ms. Stevenson are the inclusion of “patients” as voting members on the committee which recommends which drugs should be listed or delisted on the drug formulary; the creation of a Citizens Council to provide overall advice vis-à-vis Ontario drug policy; more transparency by providing the reasons why drugs are listed or delisted to the public. Minister Smitherman has said in the legislature that moving the power to list and delist drugs to the executive officer will speed up the decision-making process and make the decisions more accessible to the public – something not possible today because of official Cabinet secrecy. However, some of these are not provided for in Bill 102; we will have to await the regulations to see whether the government’s delivery matches its stated intentions.

Concerns with Bill 102

Power of the executive officer – Some of the changes appear to be problematic, and criticism of the bill is coming from several sectors. A number of health charities and patient advocate groups including the MS Society have met in recent days to scrutinize Bill 102 in detail. One concern is the power of executive officer, who will have the power to list and delist drugs on the provincial drug formulary. There is no appeal process external to the executive officer. The review process proposed will be conducted by the executive officer who made the initial decision. Currently, decisions to list and delist drugs are made by Cabinet on the recommendation of the Minister of Health; there is no formal appeal process. The publication *Inside Queen’s Park* (April 26, 2006) noted “The greatest potential for mischief could be the sweeping powers for the drug czar (or czarina) under the governance changes. Delegated to this functionary will be the power to add and remove drugs on the Formulary, determine which products are interchangeable, deal completely – and largely without appeal – with any breach...”

Expansion of drug interchangeability – Another concern being discussed by health charities is the expansion of drug interchangeability. Currently, interchangeability is limited to drugs that have the same active ingredients in the same dosage. (Interchangeability means the ability of the pharmacist to substitute another drug for the one prescribed -- usually it would be the substitution of a cheaper generic drug for the brand name one.) Under Bill 102, the pharmacist would be able to substitute for the prescribed drug one that has “similar” ingredients and dosages. Many people with chronic conditions who need drugs on a long-term basis are worried this change would mean they will not get the medication that is best for them. It should be noted that the physician would still – it appears at this point – be able to write “no substitution” when prescribing.

MS Society staff and volunteers will continue to be involved in this issue. Deanna Groetzing is participating in a meeting with Ministry staff on May 11 and will raise questions about these important issues. Updates and possible future activity by chapters/units and individuals will be sent through upcoming E-Alerts. To read the description of the changes as outlined by the government, go to the Ministry of Health website:

<http://www.health.gov.on.ca/index.html>

Human Rights Legislation

On April 26, the Ontario government introduced legislation to amend the Ontario Human Rights Code. The legislation, if passed, will significantly change the process people use to bring human rights complaints forward. Attorney General Michael Bryant said the reforms

will modernize the human rights system by allowing the Ontario Human Rights Commission to focus on preventing discrimination and the Human Rights Tribunal of Ontario on resolving individual disputes quickly and effectively. Some disability groups have said the changes will actually curtail access to the human rights system for people with disabilities.

Essentially, the changes are:

- The Ontario Human Rights Commission (OHRC) will focus on education, public advocacy, research and analysis to counter discrimination. The Commission will work to address systemic issues that have a broad impact on communities and groups, and attempt to resolve them.
- Two new secretariats will be established within the OHRC, an anti-racism secretariat and a disability rights secretariat.
- Individuals with human rights complaints will make them directly to the Human Rights Tribunal of Ontario. (Currently complaints go first to the OHRC, which investigates and determines whether the complaints should go to the Tribunal.) The Tribunal will have enhanced statutory powers to determine its own practices and procedures to manage its caseload efficiently and effectively, and to provide alternative dispute resolution mechanisms.
- A new Human Rights Legal Support Centre will be created.

The MS Society, along with other organizations in Ontario, has criticized the painfully slow process of review and litigation within the current Ontario Human Rights Commission. We are also been concerned that the proposed changes may limit opportunities for people with disabilities to pursue human rights complaints since many are not able to afford legal counsel. The creation of a Human Rights Legal Support Centre might alleviate this concern. A backgrounder from the Ministry of the Attorney General says “a new Human Rights Legal Support Centre ...would provide information, support, advice, assistance and legal representation for those seeking a remedy before the tribunal.” However, establishing the Human Rights Legal Support Centre is not part of the government’s legislation, and there are no details about what services it will offer. Again, check against delivery.

The AODA Alliance has criticized the legislation for removing the OHRC’s role in bringing cases to the Tribunal, which could negatively impact AODA enforcement. The Alliance also makes a number of important, related suggestions for change. See the AODA Alliance website: www.aodaalliance.org. The AODA Alliance is the successor to the ODA Committee. To receive updates from the AODA Alliance, just send an e-mail to the following address and asked to be added to the list-serve: mlumgair@chs.ca.

The Legislature began second reading debate (approval in principle) on the proposed legislation on May 8. The next step should be committee hearings in which the MS Society plans to participate to bring forward the voice of Ontarians with MS. Background about the legislation is posted on the website of the Ministry of the Attorney General (just scroll down to April 26 announcements): <http://www.attorneygeneral.jus.gov.on.ca/>

Home Care Funding

On May 1, the Ontario government announced funding of \$117.8 million for home care and community support services. It also announced that it will accept 68 of the 70 recommendations in the report by Elinor Caplan on Community Care Access Centres

(CCAC) provider issues and that \$30 million of the funding will go to implement the recommendations. Minimum wages for personal support workers will increase, travel time and mileage will be compensated, and CCAC contracts with home care service providers will be extended up to nine years. The MS Society provided input to Ms. Caplan during her consultation based on a survey of chapters and units.

Also funded were: \$35 million to CCACs for acute home care services; \$26.7 million for end-of-life care; \$12.7 million for in-home rehabilitation services for post hip and knee replacements; \$13.1 million for community services.

Federal Budget Highlights

The May 2 federal budget contained two measures that should impact people with MS and the MS Society. It increased the maximum amount of the refundable medical expense supplement to \$1,000 from \$767 for the 2006 tax year. This supplement improves work incentives by helping to offset the loss of coverage for medical and disability-related expenses under social assistance when recipients move into the labour force.

The budget eliminates the capital gains tax on donations of publicly-traded securities (stocks) to charities, effective immediately. The MS Society advocated for this change since it should encourage larger donations of this type in the future.

Staffing Changes

Deanna Groetzinger's title has changed to Vice-President, Government Relations and Policy following the realignment of the Marketing and Communications groups into one department. She will focus on government relations/ social action activities for Ontario Division and the national organization and on internal policy issues.

Government Relations and Social Action E-Alerts Online

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