

Multiple Sclerosis Society of Canada

CADA Presentation May 4, 2011











MS Society's Mission

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



Governance & Funding

- Volunteer-led health charity
 - National Board of Directors
 - Division Boards of Directors
 - Chapter/Unit Boards of Directors

- Primarily self-funded through fundraising activities such as:
- Special events major philanthropic giving
- Direct marketing corporate partnerships



Where We Are

- National Office Toronto
- British Columbia & Yukon
- Alberta Division & Northwest Territories
- Saskatchewan
- Manitoba
- Ontario
- Quebec
- Atlantic (NS, NB, PE, NL)
- 120 Chapters/Units



What is Multiple Sclerosis?

 "MS is an unpredictable and sometimes disabling disease of the central nervous system."

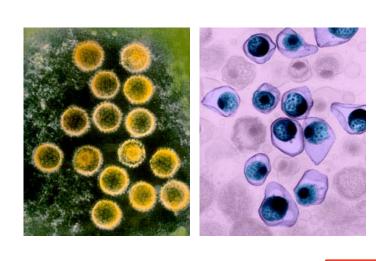
55,000 – 75,000 Canadians have MS

Female: male ratio is 3:1

 It is the largest cause of disability in young Canadians



Potential Triggers for Multiple Sclerosis









Environmental factors

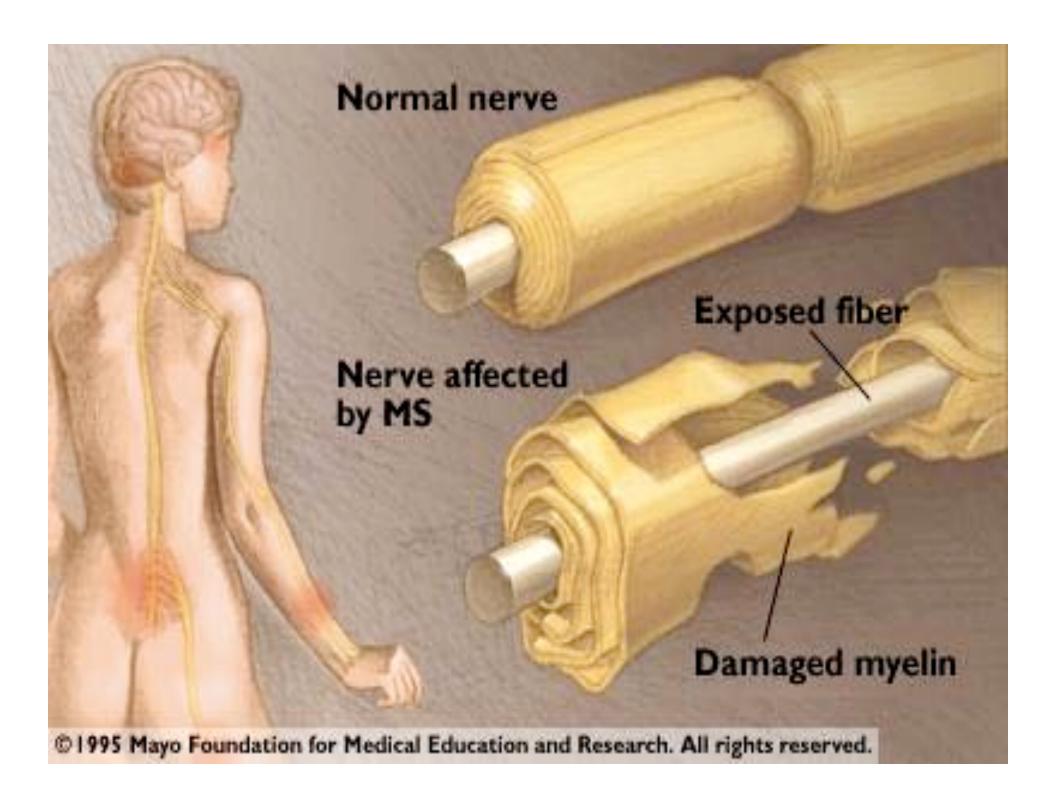
Infectious agent







Gilden et al. Lancet Neurol. 2005;4:195; Noseworthy et al. N Engl J Med. 2000;343:938.





Types of MS

Relapsing Remitting MS

Primary Progressive MS

Secondary Progressive MS

Progressive Relapsing MS



COMMON SYMPTOMS

- Fatigue
- Sensory
- Balance & Coordination
- Depression
- Pain
- Vertigo

- Vision change
- Motor function
- Bowel & Bladder
- Cognitive ability
- Sexual function



MS Treatments

Disease Modifying Therapies

- injections
- oral therapy released in March 2011

Symptom Management

- steroids, muscle relaxants,
- antidepressants, anticonvulsants
- physiotherapy



MS Society's Research Commitment

- Major funder of MS research:
 - MS Society supported first research grant in 1949 for \$10,000
 - Currently 10 million to research programs annually
 - MS Scientific Research Foundation currently about \$4 million to research projects annually
 - endMS Research and Training Network



Government Relations

- Ensure people with MS have opportunity to participate fully in all aspects of life.
- Advocate for change that will enhance the quality of life of people affected by MS.
- Respond to issues that may impact on MS research or services programs.



Current GR Issues

- Improved income security
- Increased funding of health research
- Reimbursement for approved therapies
- Accessible communities
- Improved home care, housing, long-term care
- Better support for caregivers
- Ontario Brain Strategy



National Coalition Work

- Episodic Disabilities Network
 - Income security issues
- Health Charities Coalition of Canada
 - Research funding
 - Access to therapies
- Neurological Health Charities Canada
 - Brain strategy



Dr. Zamboni

Cerebrospinal venous insufficiency in patients with multiple sclerosis.



CCSVI Theory

Blocked veins (stenosis)

Increased back pressure

Development of collateral circulation

Leakage

Concentration of iron in brain tissue

Activation of immune response





Treatment Decisions

We reflect the position and needs of all Canadians living with MS.

The MS Society honours the right of personal choice. We recognize that the decision to seek any kind of treatment is personal and we respect these decisions.



MS Society's Response

- announced a special CCSVI research competition Dec 2009
- announced \$2.4 million for 7 research projects – diagnostic approaches, in collaboration with the US MS Society
- Pledged \$1 million for therapeutic trials, if/when approved
- Government Relations working with federal and all provincial governments
- ccsvi.ca website



Client Services Goal

To provide programs and services to those affected by multiple sclerosis to achieve the highest possible quality of life while living with the daily challenges that MS presents.



Client Services

- Information and referral
- Education
- Individual advocacy
- Supportive counselling
- Self Help Groups
- Funding programs



Funding Programs

Equipment

Special Assistance Program



Funding Program Criteria

- Diagnosis of MS
- Lives within the region/chapter area
- HCP assessment
- Completed application
- Other funding sources
- Available funds
- Approved list



Equipment Funded

- Mobility Devices
- Bathroom Aids
- Transfer Aids
- Hospital Beds
- Incontinence/Catheter supplies
- Air Conditioning
- Vehicle adaptations
- Portable Ramps
- Repairs
- Other (feeding utensils, computers with adaptions)



MS Equipment Inventory & Repairs

- No means testing
- Donations
- Returned equipment
- Equipment repairs



MS Society Contact Information

Ontario Division Client Services

MS Society Ontario Division 700-175 Bloor St. East

Toronto ON M4W 3R8

1-800-268-7582