



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY

THE CENTRAL NEW ENGLAND CHAPTER

MS MATTERS

Legislative and Community Update

MS ADVOCATES ... Turn out for Beacon Hill Day

From Springfield to Yarmouthport, more than 100 advocates joined the staff of the Central New England Chapter at the State House on April 9th for "MS Day on Beacon Hill". The event offered a unique opportunity for people with MS, their families, and community professionals to unite in a common goal of increasing awareness of MS within the Legislature. Many attendees not active in advocacy have since joined the *Action Alert Network*.

The event was marked by the presentation of a Senate Resolution to Chapter President Arlyn White, designating the week of April 7-13 as "MS Week in the Commonwealth".

The nine legislative sponsors addressed the attendees and applauded their efforts for participating in the legislative process. Lead event sponsors Senator Montigny (D-New Bedford) and Representative Casey (D-Winchester) highlighted the state's fiscal crisis and the challenging budget process ahead. Dr. Matthew Gold, President of the Massachusetts Neurological Association unified the role of the physician and patient in advocacy. Marge Van Houten, a board of trustee member

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Accessibility

"One Person's Access Is Another's Barrier"

Know Your Rights.

It has been more than ten years since Congress passed the Americans with Disabilities Act (ADA). Many accessibility improvements have been made for people with disabilities, but more remains to be done.

How many times have you encountered a door that is too hard to open or found the aisles in a department store clogged with clothes racks?

If you have experienced problems with access in any public accommodation (hotels, stores, theaters, schools, etc.) now is a good time to utilize your advocacy skills. One can tackle barriers to accessibility using different approaches.

First, try to talk to the person in charge without being confrontational. Many times a friendly conversation is all it takes. If this is not practical, write a letter describing your experience and the changes you think are needed. Point out in your letter that the changes you are seek-

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MS Advocates turn out for Hill Day

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and former Chair of the Government Relations Committee spoke poignantly about her daughter with MS and the need for increased services for independent living.

Following the rally, advocates visited with their Senators or Representatives to advocate for 1) MS budget funding 2) improved community based services such as home care, respite care, transportation 3) increased awareness of the impact of MS on the individual and their family. MS Day on Beacon Hill also provided the opportunity for advocates from the same region to meet and network.

The measure of the day's success was later demonstrated by the action of the eighteen representatives, who by their own initiative, signed an amendment to reintroduce the MS

line-item funding into the House budget. Although the final House budget did not include funds for line-item 4523-1115(funding the Department of Public Health's MS program) The Senate reintroduced the MS funding at the FY'02 level.



The Chapter is already planning of next year's Day on Beacon Hill for early April. We will notify you as soon as a date is chosen and hope that many of you unable to attend this year will mark your calendars early. The Chapter appreciate the time and effort of those

who did attend. Feedback on how to improve next year's event is always welcome.

Accessibility

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ing are mandated by Title III of the ADA. The Title III section pertains to accommodations in public buildings, etc. The general public is frequently unaware of the difficulties for persons with disabilities, but is often willing to make changes when educated. Sometimes you will face resistance to change, and the resources listed below should prove helpful.

Take Action.

Determine if the city or town where you have encountered a problem has a Commission on Disability. If so, contact them about your issue. The Commission monitors complaints, intervenes when appropriate and advises about other courses of action.

If the city or town does not have a Commission On Disability, The Massachusetts Office On Disability is a state agency that is

ready to offer assistance in all matters pertaining to the disabled. They can be reached at: One Ashburton Place, Room 1305 Boston, MA 02108 (617) 727-7440 (800) 322-2020.

You should also notify the Architectural Access Board and file a complaint. The Board oversees access to all public buildings in the state. They can be reached at One Ashburton Place, Room 1310 Boston, MA 02108 (617) 727-0660 (800) 828-7222

As a last resource, or if you feel your rights have been violated, contact the Attorney General's Disability Right's Project (617) 727-2200.

Remember that **you** have it in your power to solve problems with access. Advocate for yourself as well as others with MS.

Maneuvering Forward to Improve Access for MS

From the Berkshires to the Merrimack Valley to the Cape Cod Shores, public transportation has been identified as a major obstacle for the Chapter's Self-Help Groups visited this past year. People with MS often face daily challenges and commuting from point A to point B is one of the greatest. This is particularly true for those with mobility issues.

In Dracut, a person has no public means of seeing a doctor outside the city limits. In Stockbridge, there is no public transit system. Unless you can afford to pay for private options, you're pretty much homebound. The difficulties with the *MBTA Ride* that services residents of Eastern Massachusetts with disabilities are well documented. Nightmarish scenarios, ranging from late cancellations by the "RIDE", advance reservation requests and waiting on a corner for a transfer pick-up is plentiful.

Addressing issues of a complex, bureaucratic system is not easy. Targeting specific problems with innovative approaches is one solution. The Chapter's Government Relations Committee has begun to gather data on transportation problems, so as to determine the best strategies to effect change for those we serve. A collaborative approach, involving the Chapter, its members and state government will be essential to achieve results

The Pennsylvania-CAN Chapters of the National MS Society and the State Department of Transportation conducted a survey of peo-

ple with disabilities. This resulted in new options in eight rural counties. The Central New England Chapter is distributing a questionnaire to members to gather data on the problems in the public transportation system. Your timely response to the questionnaire will ensure you have a voice in guiding the Chapter's focus on this issue.

As the state strives to implement the *Olmstead decision* to improve community-based services for people with chronic illnesses and disabilities, transportation will be a key component in increasing one's independence and participation in community life. As more people re-enter the work force through the *Ticket To Work* program, an expanded, accessible transit system will ensure that those who want to work are given every opportunity to do so.

An improved system will not only benefit the individual, but will strengthen the state's distressed economy.

The need for improved access is also reflected in this recent message from Chapter President Arlyn White. "Each of us is part of the global community. And everyone has the right to participate in and contribute to the life of that community. When obstacles to that full membership arise, it means that an individual has been excluded, through no fault of their own. Those of us at the National MS Society will continue to be active advocates to breakdown society's barriers and restore full



Attention Advocates

Help us keep you informed !

The Chapter wants to ensure you receive timely advocacy e-mails and mailings. If your contact information has changed, or if you have comments or suggestions for future articles please call Michelle Dickson at 1-800-493-9255 ext 146 or michelle.dickson@mam.nmss.org

Upcoming Events

MS Advocacy: Getting Involved

Michelle Dickson, Advocacy Coordinator, Central New England Chapter of the National Multiple Sclerosis Society will be the guest speaker on Monday July 29, 2002 from 5:30-7:30 pm at the MS Support Group, Sturdy Memorial Hospital-Attleboro. Attendance is open to all people with MS and their family members. For more information, please contact Cheryl Thompson RN, MSN, CS at 1-508-236-7170

Boston Advocacy Training

The second regional Chapter Advocacy Training is being planned for an upcoming Saturday morning in September. Date and location to be determined. More details to follow.

MS MATTERS

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