



ADVOCACY

January 13, 2012

CC: Programs & Services

Sample of FY 2010 State Legislative Priorities and Successes

Original NewsSheet posted: December 10, 2010

Advocacy campaigns unite the voices of people who want to do something about MS NOW, and enhance quality of life for those affected by it, until its cure is discovered. FY 2010 state and local advocacy priorities and successes encompassed: Long Term Care; Access to Health Care; Quality Health Care; and Disability Rights. For an overview of FY 2010 state and local priorities and legislative successes, [click here](#).

A sample of state legislative and administrative victories included measures to:

- ✓ Prohibit **NY** regulated health insurance companies from imposing drug tiers based upon expense or disease categories and charging cost-sharing percentages for prescription medication.
- ✓ Preserve \$75,000 in **MA** state funds for the Greater New England Chapter Care Management Program.
- ✓ Delay electricity disconnection and provide easier access to payment plans during the summer months with the **TX** Public Utility Commission.
- ✓ Establish an MS check-off on **OK** and **LA** state income tax returns.
- ✓ Fund the first MS specific **NJ** housing development, with 30 barrier free one and two bedroom apartments.
- ✓ Preserve \$720,000 for the **CT** Home Care Program for Disabled Adults in FY 2010 and 2011 state budgets.
- ✓ Create a **PA** Adult Protective Services Program.
- ✓ Preserve a **MO** state income tax credit for accessible home modifications.
- ✓ Require **CA** pharmaceutical manufacturers dispensing self-injection medications to administer the safe collection and proper disposal of these waste devices.



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January 13, 2011	CC: Programs & Services
<u>Sample of FY 2011 State Legislative Priorities and Successes</u>	
Original NewsSheet posted: October 28, 2011	

Advocacy campaigns unite and engage the voices of people who want to do something about MS NOW, and enhance quality of life for those affected by it, until its cure is discovered. FY 2011 state and local advocacy priorities and successes encompassed: Access to Health Care; Disability Rights; Long-Term Care; Quality Health Care and Research. For an overview of FY 2011 state and local priorities and legislative successes, [click here](#).

A sample of state victories included these measures:

- ✓ **Louisiana** and **Texas** contain the cost of MS disease modifying therapies during a contract and require transparency in pricing, while **Virginia** and **West Virginia** assess implications between increasing costs and lack of patient access to these treatments. **Vermont** and **Delaware** prohibit co-insurance pricing for one-year, while **Delaware** will also investigate lack of patient access due to cost of treatments.
- ✓ **Texas** bans “discretionary clauses,” or contract language that gives an insurance company the ability to unfairly deny benefits.
- ✓ **Colorado** authorizes the public utilities commission to adopt rules creating an exemption from tiered electricity rate plans based on a customer’s medical condition, or use of an essential life support device.
- ✓ **Oregon** establishes standards for accessible pathways to *Cluster Mail Box Units* for private development.
- ✓ **Illinois** strengthens penalties for accessible parking violations, while **Missouri** establishes minimum number of spaces designated for vans.
- ✓ **Washington** permits foreign educated, U.S. trained neurologists to treat people with MS, while also maintaining strict proficiency standards.



CHAPTER PRESIDENTS

January 13, 2012	CC: ALL
<u>Eastern North Carolina and Mid Atlantic Chapters Join Together to Form the Greater Carolinas Chapter</u>	

Effective January 1, 2012, the Eastern North Carolina and Mid Atlantic Chapters joined together to form the Greater Carolinas Chapter of the National Multiple Sclerosis Society, serving a combined total of 13,500 individuals and families who are affected by MS.

By consolidating administrative functions and combining the talents of boards, staff, and volunteers, these chapters can streamline operations, increase fundraising effectiveness, and expand programs, services and advocacy for those affected by MS.

The Raleigh, NC, Charlotte, NC and Columbia, SC offices will remain open to serve people affected by MS throughout the chapter territory.

The combined strengths of Eastern North Carolina, Western North Carolina and South Carolina will move us closer to the ultimate goal that we all share—whatever the name of our state or chapter—a world free of MS.

If you have questions, please visit www.nationalMSSociety.org/nct for the most current information and Frequently Asked Questions regarding this transition. If you have additional questions, please contact jennifer.gawler@nmss.org.



DEVELOPMENT

January 13, 2012	CC: Marketing
2012 Bike MS Strategy Calls	

As part of our networking and sharing opportunities for 2012, we're pleased to announce the format and timing of our Bike MS Strategy calls.

The goal of this year's calls will be to provide support to Chapters as you begin to implement the components of the "Extraordinary Rides" checklist. Each call will review specific "extraordinary" items to help provide guidance on how each of these should be executed. The calls will be held in three series of 4 calls each, according to the date of our events, and will focus on a set of topics related to what event managers will likely be focusing on at the time.

All calls have the same dial-in number: 866-504-5571 passcode: 7253724110.

Series #1: April – May Rides:

Call Dates: January 25, February 22, March 28 and April 25
9 am pacific, 10 am mountain, 11 am central, 12 pm eastern

Series #2: June – August Rides:

Call Dates: February 22, March 28, April 25, May 23
11 am pacific, 12 pm mountain, 1 pm central, 2 pm eastern

Series #3: September – November Rides:

Call Dates: May 23, June 27, July 25, August 22
9 am pacific, 10 am mountain, 11 am central, 12 pm eastern

Topics:

- Call 1: Plan of Operations/Pre-Planning, Volunteer Planning
- Call 2: Day Of Planning – Logistics
- Call 3: Day Of Planning – Experience/Incentives
- Call 4: Post Event, Next Year Prep

Please add these calls to your calendars!

If you have questions, please contact: Sarah Klein at sarah.klein@nmss.org or 303-698-6100 x15170 or your Bike MS Work Team Regional Liaison:

West Region: Becky Woolley – becky.woolley@nmss.org

South Central:

Midwest Region: Elle Ullum – elle.ullum@nmss.org

Southeast Region: Ailena Parramore – ailena.parramore@nmss.org

East Region: Jeff Brody – jeff.brody@nmss.org

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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

January 9, 2011

Study Offers Insight on How Epstein-Barr Virus May Play a Role in MS

An international team has identified clues that may help explain how Epstein-Barr virus, which has been linked to multiple sclerosis, may contribute to the brain inflammation experienced by people who have MS. In active brain lesions (spots of disease activity) in people who had MS in their lifetimes, the researchers found high levels of an inflammation-stimulating chemical (interferon alpha) that helps the body fight viruses, and nearby, immune B cells latently (inactively) infected by Epstein-Barr virus. They did not find signs of active viral infection. The findings may point to a possible mechanism for how the virus might indirectly stimulate MS disease activity. Dr. U.-C. Meier (Queen Mary University of London, UK) and colleagues published their study in the journal Neurology (January 3, 2012 vol. 78 no. 1 15-23 <http://www.neurology.org/content/78/1/15.abstract>).

The team examined brain specimens from seven people who had had MS, and eleven people who had had other disorders or neurological diseases. They found suggestions of latent Epstein-Barr virus infection in all samples of active MS lesions from the specimens, and also in cases of stroke and central nervous system lymphoma (both of which are conditions involving inflammation), but not in other specimens. The authors outlined additional research needed to confirm and expand these findings and their implications.

An accompanying editorial by Epstein-Barr virus expert Dr. Jan D. Lünemann (University of Zurich) notes that although there have been conflicting studies as to the involvement of this virus in MS, this study is intriguing because it suggests a mechanism by which a latent virus, rather than active viral infection, might indirectly stimulate or maintain central nervous system inflammation in MS.

Read more about viruses as a possible trigger of MS

<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/what-causes-ms/viruses/index.aspx>