National Multiple Sclerosis Society
News Sheets

ADVOCACY

October 28, 2011	CC:
	Programs & Services
Sample of FY 2011 State Legislative Priorities and Successes	
Action Requested/Deadline: NA	

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.

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PROGRAMS & SERVICES

October 28, 2011	**CC:**
	Chapter Presidents
Program and Services Staff Email Group	
Action Requested/Deadline: N/A	

In October 2005, the Programs and Services Department launched the Programs and Services List-Serve. There are currently close to 200 chapter and home office staff members from both the National MS Society and the MS Society of Canada registered.

The goal of the list-serve is to develop networking and sharing opportunities for Programs and Services staff. The list-serve is for exchanging information on best practices, programming, community resources and managing client issues. The home office also occasionally uses the list serve to share certain information relevant to programs and services. Topics of recent conversations include:

- Staff certification programs
- Best practices for managing equipment loan closets
- Care management

You can post questions, seek opinions and/or ask for assistance from programs and services colleagues from across the country and Canada. Messages are delivered as individual posts or in a digest format. The benefit of the list-serve concept is that you do not need to go to a separate site to view posts —all posts are delivered directly to your email inbox.

To register, please send your name and email address to Kim Koch at Kimberly.koch@nmss.org. Upon confirmation, instructions on how to use the list-serve will be provided and you can begin posting. Please note – if you believe you are a registered member but have not received posts over the past several months, contact me to confirm your email address. The non-receipt of messages could be related to a change in your email address.

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

October 28, 2011

Positive results announced from a second Phase III Trial of oral BG-12 in relapsing MS

Biogen Idec announced that the experimental oral therapy BG-12 significantly reduced the average number of annual MS relapses in a two-year, Phase III clinical trial of more than 1400 people with relapsing-remitting MS. Although its exact mode of action is not known, BG-12 is thought to inhibit immune cells and molecules involved in MS attacks on the brain and spinal cord. The results of the CONFIRM study were announced in an October 26 press release. Data analysis is ongoing and the company expects to provide a full report at an upcoming medical meeting. Positive results from another Phase 3 trial of BG-12 were also announced this year, paving the way for a potential application for marketing approval.

Background: Multiple sclerosis involves immune system attacks against brain and spinal cord tissues. Although its exact mechanism of action is not known, BG-12, an oral drug, is thought to inhibit immune cells and molecules and may be protective against damage to the brain and spinal cord. In an earlier phase II study, compared to inactive placebo, the highest tested BG-12 dose led to a 69% reduction in gadolinium-enhanced (a contrast agent) disease activity on MRI scans from weeks 12 to 24. Earlier in 2011, Biogen Idec announced positive results in another phase III study, the DEFINE trial (http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=4903). Further details on these results were presented at the joint meeting of the European and Americas Committee for Treatment and Research in MS (ECTRIMS/ACTRIMS) last week.

This Study: The primary goal of the CONFIRM study was to determine whether BG-12 could reduce the average annual MS relapse rate at two years. Secondary objectives included assessing BG-12's effects on the proportion of people who had relapses, disability progression, and disease activity detected by MRI. Safety and tolerability were also assessed.

Participants were randomly assigned to one of two treatment groups receiving different oral doses (240 mg twice each day and 240 mg three times each day), a group receiving glatiramer acetate (Copaxone®, Teva Pharmaceutical Industries, an approved, injected therapy for MS) or a group receiving placebo. Both BG-12 groups and Copaxone were compared to the placebo groups, but not to each other.

According to the press release, in both groups taking BG-12, the primary endpoint was met; the average number of MS relapses in a year was reduced by 44% versus placebo in the lower-dose group, 51% in the higher-dose group, and 29% in the Copaxone group. Disease activity on MRI and the proportion of patients experiencing relapses also were reduced significantly more in the BG-12 groups versus placebo. Disability progression was not reduced significantly more in the BG-12 groups than in the placebo group. According to the press release, the most common adverse events in the BG-12 groups were flushing and gastrointestinal events.

Comment: Full details and evaluation of this study should help to define further the safety and promise of BG-12 as a potential therapy for relapsing MS. According to the company press release, these positive results set the stage for upcoming filings for marketing approval from drug regulatory agencies.