



CHAPTER PRESIDENTS

September 21, 2012	CC: All
<u>2012 Society Leadership Conference Registration Now Open</u>	
Action Requested/Deadline: Hotel – Oct. 18/Conference Registration – Oct. 26	



A SHARED PROMISE
2012 SOCIETY LEADERSHIP CONFERENCE

Each November, leaders across the MS movement gather together to celebrate progress, learn from each other, and strengthen our commitment to have even greater impact.

Registration for the 2012 Society Leadership Conference is now open. [Register Now!](#) Join us in Dallas, November 8-10 at the Hyatt Regency, Dallas Fort Worth Airport and please remember, this year's conference begins on THURSDAY the 8th and concludes on SATURDAY the 10th.

Important Notes:

- The hotel cut-off date is **October 18** [Book your room today!](#)
- The conference registration deadline is **October 26**
- The conference website is your best source for the most current information on speakers, schedules and more. Bookmark:
www.NationalMSSociety.org/2012LeadershipConference

Who should you invite?

The Society Leadership Conference is for leaders of all kinds – volunteer and staff.

- Any volunteer leader – governance or otherwise – who helps drive us toward the vision we all share – a world free of MS.
- Volunteer and staff MS Activists who relentlessly advocate for federal, state, and community policies and programs to improve the lives of people affected by MS.

- Leaders who address the challenges of everyone affected by MS through development and delivery of programs, services and enhanced clinical care.
- Fundraising movers and shakers – those who qualified through your Tour of Champions, team captains representing your most influential teams, and volunteers who are using Do It Yourself events to help fuel the mission.
- Research champions who drive research forward, fund this fundamental piece of our mission, and create awareness about research opportunities – all helping us STOP MS in its tracks, RESTORE function lost to MS, and END the disease forever.

**As individuals, our contributions to the MS movement are many.
Together, we're keeping A Shared Promise.**

Chapter Presidents: Please forward this to appropriate chapter staff, volunteers and staff leaders.

The 2012 Society Leadership Conference Team



PROGRAMS & SERVICES

September 21, 2012

CC: All

National Customer Service Week Oct. 1-5, 2012

Action Requested: Participate!

Celebrate National Customer Service Week, October 1 – 5, 2012! Started by the International Customer Service Association in 1984 and always held the first week in October, this has become a national event as proclaimed by the U.S. Congress. In 1992, then President Bush issued a proclamation to establish this important form of recognition.

http://www.csweek.com/customer_service_week_proclamation.php

Each year, thousands of businesses and organizations around the world celebrate Customer Service Week in an event devoted to recognizing the importance of customer service.

Purpose:

- Boost morale, motivation and teamwork.
- Raise organization wide awareness of the importance of customer service.
- Raise awareness of the role of customer service to help us achieve our mission.

All staff members are invited to engage in a couple of special events planned for this week. One such opportunity will be a Society specific customer service trivia contest. See how well you can make the connection to understanding how colleagues around the country are providing service to people living with MS, to donors, to volunteers, and with all constituents. Fabulous (and donated) prizes will be awarded to winners including a Nikon Coolpix S9300 and an Amazon Kindle Fire! Watch your email the morning of Monday, October 1st to participate in this fun and informative contest.

A second all Society offering is through the Help Desk Institute (HDI) with a free three-part webinar series on Wednesday, October 3rd. This program is filled with discussion starters and team-building activities that include case study presentations (*Fanatical Support at Rackspace* with Rob La Gesse and *Service the Zappos Way* with Jon Wolske) and a keynote presentation on *The Customer of the Future: Creating True Customer and Employee Loyalty* with Cindy Solomon. Click here to register for the event and participate as much or as little as you choose.

<http://www.thinkhdi.com/topics/library/webinars/2012/october-3.aspx>

All are encouraged to create your own program or activity to recognize and celebrate good principles and delivery of customer service. Organize a potluck; treat each other to a pizza party or ice cream social, and/or share examples of great customer service experiences to increase our own recognition of contributions made by colleagues across the Society and how we can support those efforts.

For questions or other great ideas on ideas on celebrating National Customer Service Week contact Lisa Custy, lisa.custy@nmss.org or Carol Sloper, carol.sloper@nmss.org.



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

September 19, 2012

Results published of successful phase III trials of oral BG-12 for relapsing MS

Published results from two large, phase III clinical trials of BG-12 capsules (dimethyl fumarate, Biogen Idec) in people with relapsing-remitting MS (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/index.aspx>) suggest that this experimental therapy significantly reduced relapses and disease activity as detected by MRI. In one trial, BG-12 also reduced disability progression. These results were previously reported at medical meetings, and lead authors Ralf Gold, MD (Ruhr-University Bochum) and Robert J. Fox, MD (Cleveland Clinic) and colleagues have now published complete results in *The New England Journal of Medicine* (2012; 367: 1087-97 <http://www.nejm.org/doi/full/10.1056/NEJMoa1206328> &1098-107 <http://www.nejm.org/doi/full/10.1056/NEJMoa1114287>). The U.S. Food and Drug Administration is currently reviewing an application for marketing approval for BG-12.

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. A chemically related compound, called Fumaderm (dimethyl fumarate and fumeric acid esters), has been used for decades in Germany to treat psoriasis. Two large-scale phase III studies of the BG-12 capsule, called DEFINE and CONFIRM, were conducted in people with relapsing-remitting MS.

DEFINE Trial: The DEFINE trial involved more than 1200 people and was designed to determine whether BG-12 could decrease the proportion of participants experiencing relapses compared to inactive placebo, and also looked its safety and tolerability. A total of 952 people completed the study. Secondary outcomes included the effects on the frequency of relapses, progression of disability, and disease activity detected by MRI.

Participants were randomly assigned to one of two treatment groups receiving different doses (240 mg twice each day and 240 mg three times each day), or a group receiving placebo. For

both groups taking BG-12, the primary endpoint was met, meaning that there was a significant reduction in the proportion of people who experienced relapses at 2 years, compared with the placebo group (26% and 27% of those on BG-12, versus 46% on placebo, representing a 49% and 50% reduction in the risk of relapse versus placebo). All secondary endpoints were met as well in these groups, including significant reductions in annualized relapse rate (0.17 and 0.19 for BG-12 groups versus 0.36 for placebo, representing relative reductions of 48% and 53%), and reduction in the risk of confirmed progression of disability as detected by the EDSS, a standard scale that measures disability. The proportion of those who progressed over two years was 16% and 18% for BG-12 and 27% for placebo, representing a reduction of risk of disability of 38% (twice daily) and 34% (thrice daily) versus placebo. Both treatment groups also showed significantly fewer new, enlarging, or active (enhancing) MS lesions on MRI scans than those on placebo.

CONFIRM Trial: The primary goal of the CONFIRM study, which involved more than 1400 people, was to determine whether BG-12 could reduce the average annual MS relapse rate at two years. Secondary objectives included assessing 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 the study was not designed to compare BG-12 and Copaxone.

Results showed that the primary endpoint was met; the average number of MS relapses in a year was reduced by 44% versus placebo in the twice daily group, 51% in the thrice daily group, and 29% in the Copaxone group (annual rates of relapses per year were 0.22 for the twice-daily group, 0.20 for thrice-daily group, 0.29 for Copaxone, and 0.40 for placebo). Results in secondary endpoints included significant reductions in disease activity on MRI and the proportion of patients experiencing relapses in the BG-12 groups versus placebo. Disability progression was not reduced significantly in the BG-12 groups compared to the placebo group.

Safety During BG-12 Trials: The most common adverse events in the BG-12 groups were flushing and gastrointestinal events (such as diarrhea, nausea, and upper abdominal pain). BG-12 reduced blood lymphocyte (white blood cell) counts but no opportunistic infections were reported. Liver enzyme tests were elevated in the DEFINE study, but there were no reports of significant liver injury or liver failure.

Comment: Based on these positive studies, Biogen Idec has submitted an application to the U.S. FDA for marketing approval of BG-12 as a treatment for relapsing MS. The FDA's review of these results and other data should help define the safety and promise of this as a

potential new oral therapy for relapsing MS. A decision by the FDA is expected before the end of 2012.

Copaxone is a registered trademark of Teva Pharmaceutical Industries.