



## CHAPTER PRESIDENTS

<b>October 7, 2011</b>	<b>CC:</b>
<b><u>2012 Certification Standards</u></b>	

The final 2012 Certification Standards including the tools and resources available to help chapters and regions meet the standards and including the compliance determination process have been posted to Share Point under Chapter Management, Organizational Policies/Procedures. Changes from the 2011 Standards are indicated in **BOLDFACE**. They have been aligned with the objectives in the Society’s Strategic Response 2011-2015 and the 2012 implementation strategies identified by the Goal Steering Committees.

As a reminder, the Chapter Relations Committee, National Board of Directors approved the recommendation from the Certification Task Force on the fiscal year 2012 Chapter Certification Standards at their meeting on July 21.

A task force comprised of volunteers and staff representatives from each region and the home office developed the 2012 standards over a series of 2 in-person and 5 conference call meetings. They reflect the Society’s expectations that each chapter and each region bears responsibility for meeting Society-wide standards.

### TASK FORCE MEMBERS

**Bill Monahan**, Chair, National Board of Directors & Greater Delaware Valley Chapter Board of Trustees

**Pat Abruzzo**, Manager, Special Projects, Field Operations

**Cindy Bean**, Executive Vice President, West Region

**Peter Galligan**, National Board of Directors & Greater New England Board of Trustees

**Jeff Gentry**, Executive Vice President & CFO, South Central Chapter

**Lisa Gerrol**, Connecticut Chapter, President

**Julie Kaufer**, National Board of Directors and Southern California & Nevada Board of Trustees

**Craig Lynch**, National Board of Directors & Mid Atlantic Chapter Board of Trustees

**Dick Moore**, Northwestern Ohio Board of Trustees

**Dean Munger**, Midwest Volunteer Leadership Council Co-Chair & Michigan Board of Trustees

**Phyllis Robsham**, Gateway Area Chapter, President

**John Sheller**, Kentucky/NE Indiana Board of Trustees  
Julie Kaufer, National Board of Directors and Southern California & Nevada  
**Corrina Steiger**, North Florida Chapter, President  
**Craig Weber**, Vice President, Chapter Operations  
**Cyndi Zagieboylo**, President & CEO

Prior to sending the final recommendation to the Chapter Relations Committee, Chapter Presidents were provided an opportunity to comment during a series of three conference calls and a two-week comment period via Survey Monkey. Those comments resulted in some modifications that have been incorporated into this final report.

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## CHAPTER PRESIDENTS

<b>October 7, 2011</b>	<b>CC: Development</b>
	Marketing
	Programs & Services
<b><u>Estate and Financial Planning for those living with Multiple Sclerosis</u></b>	

Please join and invite donors, clients, and care givers to the free 60 minute webinar **Estate Planning for those Living with Multiple Sclerosis**. Martin M. Shenkman, CPA, JD, and tireless advocate for people living with MS is presenting the program with Dr. Nicholas G. LaRocca, MS Society VP, Health Care Delivery and Policy Research. The program is taking place during National Estate Planning Awareness Week.

Reserve your webinar seat now through the link below  
<https://www3.gotomeeting.com/register/126203022>

Date: Monday, October 17, 2011

Time: 12:30 to 1:30 ET

Login: <https://www3.gotomeeting.com/register/126203022>

Recordings of the webinar, accompanying PowerPoint slides and articles will be posted on <https://www.rv4thecause.org> to access at a later date.

Attorney Martin Shenkman has donated hundreds of hours of his professional time to the Society. His passion for educating people on Estate Planning for Those Living With Chronic Illness is born out of firsthand experience when his wife, Patti, was diagnosed with multiple sclerosis in 2006 and he realized that her diagnosis had triggered changes that forever affected their lives and plans for the future. Marty applied his estate planning strategies to accommodate for Patti's chronic illness and the unique unpredictable elements of living with MS. Marty realized that other families living with MS or other chronic illnesses could benefit from this type of specific estate planning advice.

October 17 - 23, 2011 has been named National Estate Planning Awareness Week. It is estimated that over 120,000,000 Americans do not have up-to-date estate plans to protect themselves or their families from an unexpected occurrence. The purpose of Estate Planning Awareness Week is an educational endeavor to encourage consumers to consider an estate plan.



## CHAPTER PRESIDENTS

<b>October 7, 2011</b>	<b>CC: All</b>
<b>National MS Society Blog</b>	

The Society has a strong commitment to engage people affected by MS how, where and when they want to connect. One of our most important strategies to fulfill that commitment is to increase opportunities for people to come together in a secure online environment to learn, share, meet and move their lives forward.

The Society is working to expand our online community experience by creating a number of opportunities to make our website more interactive and reflect the diversity of people in the MS movement. This evolving strategy is the result of our experiences, the perspectives of several industry experts and input from our constituents. It is also an ongoing process as the environment changes and we are presented with new opportunities.

A crucial component is to more deeply engage MS experts and key online influencers. We are pleased to announce our initiating a Society Blog Pilot launching at the upcoming European and American Congress on MS Research and Treatment (ECTRIMS) in October, one of the most important MS research meetings held.

### **Our Next Steps:**

Julie Stachowiak, a professional media blogger on About.com who is living with MS, will blog from ECTRIMS on the Society's behalf in late October; our multi-channel promotions will make our constituents aware of her personal and educated blog updates on worldwide MS research. Leveraging this event provides a unique opportunity to launch the Society Blog Pilot – as the first phase of our online community expansion during FY12.

A blog is an online journal or diary with regular entries that often includes interactive elements to engage readers. The Society Blog will help raise awareness about multiple sclerosis, offer another avenue for the MS community to connect with the Society online (where and when they want to connect), and importantly provide a channel for us to connect MS experts and online influencers with our online community through guest blog posts.

**Content:**

The Society blog content will focus on the most popular MS-related topics online (based on our listening and constituent feedback), centering on living well with MS and including such topics as: symptoms, management, treatment, research, coping, and caregiving. We'll be closely evaluating activity and engagement to help further refine next steps in our blog strategy.

We'll also be eager to hear your feedback and advice on how to fully develop this important communication tool.

If you have questions, please contact Maura Dunn, Social Media Manager at [maura.dunn@nmss.org](mailto:maura.dunn@nmss.org) or 303-698-6100 x15185.



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## RESEARCH/CLINICAL UPDATE

cc: Chapter Presidents, Programs, Development

October 5, 2011

### **Results of successful phase III trial of oral teriflunomide for relapsing MS** **– reduced relapses, MRI disease activity, and higher dose reduced disability progression**

Oral teriflunomide (Sanofi-Aventis) reduced the average number of MS relapses in a year significantly more than inactive placebo in a study of 796 people with relapsing forms (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/index.aspx>) of MS. The therapy also reduced the volume of tissue damage and active areas of damage in those who were taking teriflunomide compared to placebo at the end of the two-year trial. These TEMSO study results were previously reported at medical meetings, and Paul O'Connor, MD (University of Toronto) and colleagues have now published the complete results in *The New England Journal of Medicine* (2011;365:1293-303 <http://www.nejm.org/doi/full/10.1056/NEJMoa1014656>). The study was sponsored by Sanofi-Aventis.

**Background:** Multiple sclerosis occurs when the immune system attacks the brain and spinal cord. Teriflunomide is a novel oral compound that inhibits the function of specific immune cells. Other phase 3 studies of teriflunomide are ongoing, including the TOWER study of 1110 people with relapsing forms of MS; the TOPIC study in 780 people at high risk for developing MS; and studies of teriflunomide in combination with approved disease-modifying therapies.

**The Study:** In the TEMSO trial, 1088 people with relapsing MS were randomly assigned to receive 7 mg teriflunomide, 14 mg teriflunomide, or inactive placebo for 108 weeks; 796 (73.2%) completed the study. The primary endpoint measured was the average number of relapses in a year, and secondary endpoints included disability progression using the EDSS disease activity scale, disease activity on MRI scans, and measures of fatigue.

**Results:** After two years, both doses of teriflunomide significantly reduced the average number of relapses in a year by as much as 31.5% over placebo. Fewer of those on the higher dose (14mg) experienced progression of disability compared with those on placebo (20.2%

progressed on therapy vs. 27.3% on placebo); there was a trend toward less progression in those at the lower dose but it was not statistically significant. On imaging scans, the total volume of tissue damage and active areas of damage were reduced significantly more in both teriflunomide groups than in the placebo group. No significant differences were reported in brain tissue volume changes, or in fatigue.

**Safety:** No serious infections were observed in participants, and no deaths occurred. Three cases of serious kidney infection occurred in the 14-mg group, with one resulting in discontinuation of study medication. The most common side effects experienced by those on teriflunomide were nausea, diarrhea, mildly elevated liver enzymes and thinning of the hair. Reductions in white blood cells were slightly higher in the 14-mg teriflunomide group than the other groups, and stabilized over time. Increased blood pressure was higher in the teriflunomide groups than in the placebo group, but no patient discontinued treatment because of blood pressure issues.

**Comment:** These positive results are the first phase III results of oral teriflunomide for treating relapsing forms of MS. These and results from additional phase III studies of teriflunomide now underway should help define the short-term safety and promise of teriflunomide as a potential new therapy for relapsing MS. The long-term impacts, benefits, and potential adverse events of teriflunomide and other emerging therapies are still to be determined.

-- Research Programs department