



## ADVOCACY

<b>December 17, 2010</b>	<b>CC: Chapter Presidents</b>
	<b>Programs &amp; Services</b>
<b><u>'Special' GR Roundtable on State Advocacy Initiatives Re: Healthcare Reform 1/13/11</u></b>	

The Society's Healthcare Reform Implementation Team will sponsor a WebEx on "Engaging in Healthcare Reform Implementation at the State Level: Priorities for People with MS and Their Advocates" on Thursday, January 13<sup>th</sup> from 3:00 -- 4:30 EST. Chapter-based advocacy staff and interested others are encouraged to hold this date and time, and to watch for future details about accessing the WebEx. No advance registration will be required, and a recorded version will be available for later viewing by any interested but unavailable on January 13<sup>th</sup>. The purpose of this training and discussion is to provide information, resources and guidance to advocacy staff and interested others about state legislation and/or regulation to assure they meet the requirements of the Affordable Care Act.

Because state lawmakers have choices to make about how to adopt or adapt their existing state health insurance laws and regulations, chapter advocacy staff and their coalition partners are encouraged to consider engaging them to advocate for approaches that will best serve people with chronic illnesses or disabilities. WebEx participants will learn more about the health insurance exchanges (the planned coverage marketplaces outlined in the Affordable Care Act), and the Society's recommended provisions for their establishment and operation. Resources from the Society, as well as other voluntary health and consumer organizations with whom the Society collaborates will be reviewed and described, and open discussion and brainstorming will be encouraged.

Plans for the previously-scheduled GR Roundtable, to be held Thursday January 6<sup>th</sup>, remain unchanged. This 'special' roundtable has been added to the schedule in preparation for the anticipated introduction of reform-related legislation in many states after the New Year.

For additional information, contact Kim Calder ([Kim.Calder@nmss.org](mailto:Kim.Calder@nmss.org))



## CHAPTER PRESIDENTS

<b>December 17, 2010</b>	<b>CC:</b>
<b>2009 Transparency Report</b>	

The FY2009 Transparency Report has been posted on SharePoint under Chapter Management, Strategic Planning.

The report includes two parts.

Part I presents information on how the National Multiple Sclerosis Society uses its financial resources, both at the home office and the entire Society. Using the FY09 audited financial results the information is presented both in percentage terms and in dollar terms.

Part II presents information on how the National Multiple Sclerosis Society compares with 10 other voluntary health agencies using the FY09 audited financial results, with prior year comparisons, from each of those agencies. Information provided includes total revenue raised, total expenses, support of research and other programs in percentage terms, one-year and two-year revenue growth rates, populations served, and revenue raised per capita served.

Craig Weber  
VP, Chapter Programs  
303-698-6116  
[Craig.weber@nmss.org](mailto:Craig.weber@nmss.org)



## CHAPTER PRESIDENTS

December 17, 2010	CC:
<b><u>2010 National Conference – Workshop Information</u></b>	

The Society's [Website](#) now has the conference workshop presentations available for download. You can also view all of the General Session video recordings from this site. Feel free to share all of this great information with your Society colleagues and volunteer leaders, both those who attended this year's conference, and those that did not.

Also available by request is the National Conference Contact List. The list includes individuals that chose to opt-in to the list during the registration process. The list is for personal use only. If you have a volunteer that would like to receive the list please contact [Sandra.Genova@nmss.org](mailto:Sandra.Genova@nmss.org)

.  
Thank you!



## CHAPTER PRESIDENTS

<b>December 17, 2010</b>	
<b><u>Blue Ribbon Panel Update: Reserves Work Group To Reconvene In 2011</u></b>	
<b>Action Requested/Deadline: January 5, 2011</b>	

We are pleased to announce the Blue Ribbon Panel is getting re-organized to begin its work on Society reserves. This topic was deferred in 2009 due to the adverse economic conditions and the lack of financial stability in chapters and the Society as a whole. The Panel focused on remittances, developing a new sharing formula and calculation of national program expense, along with a number of recommendations designed to simplify our internal processes, eliminate billings and redundancies, provide greater incentives to raise research-specific gifts, and ultimately increase focus and resources on our mission.

Thanks to the good work of the Panel we have experienced our first year of Blue Ribbon Panel recommendations – including convening the inaugural Budget Review Committee and using our simplified formula to calculate national program expense for 2011.

When the Blue Ribbon Panel recommendations were approved in January 2010 it was with the understanding that the Panel would reconvene to consider the issue of Society reserves when: conditions were more favorable; the Society was financially more stable; and there was greater organizational readiness to address this important topic. We believe sufficient time has passed, and that there is greater organizational readiness to discuss this important issue. While there is still uncertainty in the economy, this past year has been far more stable than the two previous years, and we currently project modest growth in 2010 and in 2011 as well.

We are pleased to announce Peter Galligan will continue to serve in capacity as Chair, and will be joined by the Society's CFO, Lisa Risi, as the staff lead and Peter's Co-chair. I will serve on the Reserves work group and provide oversight to the process and communications as necessary.

The following volunteer members of the Blue Ribbon Panel have already indicated their interest in serving on the Reserves work group.

Peter Galligan, Blue Ribbon Panel Chair, NBOD, Greater New England Chapter Board  
Peter Porrino, Connecticut Chapter Board

Tom Muller, Upstate New York Chapter Board  
Chris Serocke, Pacific South Coast Chapter Board  
Jim Tidwell, NBOD, South Central Board  
Mal Wattman, NBOD, New York City - Southern NY Chapter Board  
Jeff Wessel, NBOD, Greater Illinois Chapter Board

All other Panel members – 30 members in total, including staff and volunteers representing broad and diverse perspectives throughout the Society -- will review the Reserves work group's deliberations and recommendations. The full Panel will then present recommendations to the Delegate Assembly for feedback, and to the National Board of Directors for its consideration and approval.

While we are comfortable with the talent and diversity in perspective of the existing Blue Ribbon Panel members, we welcome additional members to the Reserves work group. Given the passage of time – the Blue Ribbon Panel was convened nearly two years ago – and the nature of the Reserves topic, we want the process to be as inclusive as possible. We welcome staff and volunteer leaders, with interest and expertise in financial management and analysis, and the ability to evaluate a wide range of options objectively, in the best interests of the Society and those we serve. Those joining will be fully functioning members of the Reserves work group, and will participate on the full Blue Ribbon Panel in reaching consensus on a set of recommendations.

We will meet primarily via a series of conference calls in 2011, and may schedule an in-person meeting, possibly in Washington, DC during the Public Policy Conference. We will keep you apprised of the progress and timeline of the group's work, and welcome you to email Lisa Risi, no later than January 5<sup>th</sup>, 2011, if you would like to propose a member to join the Reserves work group of the Blue Ribbon Panel. Please provide a brief description of your nominee's background and qualifications and be sure to include contact information (email and phone) to expedite the process.

Thanks for your continued support of this important work, and please contact me ([Paul.Weiss@nmss.org](mailto:Paul.Weiss@nmss.org); 212-476-0406) or Lisa Risi ([Lisa.Risi@nmss.org](mailto:Lisa.Risi@nmss.org); 212-476-0424) with your comments or questions.

From: Paul Weiss  
Chief Operating Officer



## CHAPTER PRESIDENTS

<b>December 17, 2010</b>	<b>CC: Development</b>
<b><u>Class of 2011 MS Clinical Care Physician Fellows Recommended: Funding From Regions, Chapters and Donors Needed</u></b>	

As a result of surveying over 10,000 individuals touched by MS to inform the Society’s 2011-2015 Strategic Response, we know that one of the major themes expressed was a call for the Society to attract, train and retain the next generation of MS scientists and clinicians. The number of neurologists and physiatrists with specialized focus in MS clinical care is currently inadequate. This shortage of specialists results in delayed diagnoses and inadequate or less optimal treatment for many people with MS. The quality of life experienced by people with MS and quite possibly their future prognosis depends on the medical care that is available.

The Multiple Sclerosis Clinical Care Physician Fellowship program was initiated in 2003 to address this critical shortage of neurologists and physiatrists with the special knowledge and skills needed to provide the care so integral to the quality of life of people with MS. For 2011, 12 highly-qualified physicians have been approved for awards. We cannot, however, commit to these awards until funding is secured. All funds to support these fellows must be raised through gifts from individuals, corporations, chapters or regions. The total amount needed to fund all fellows is \$900,000.

This year-long program for board eligible/certified neurologists or physiatrists provides fellows with the opportunity to perform new patient consultations and follow-up evaluations under the supervision of an MS specialist physician. They also participate in multidisciplinary team activities, lectures and professional meetings leading to the acquisition of skills and knowledge necessary to provide quality care to individuals with MS.

**The Class of 2011 Fellows Includes:**

- A candidate inspired to become a master in comprehensive MS care after seeing the profound impact that an MS specialist had on her mother’s diagnosis and treatment. .
- Applicants with interest in pediatric MS and its unique treatment for this underserved patient population.
- Several candidates drawn to the complexities of treating MS and the impact of comprehensive care on a patient’s quality of life.

- Candidates who ultimately wish to pursue academic careers, dividing their time between clinical practice, research and teaching. These candidates desire to join or establish MS centers and to contribute to the training of even more MS specialists.
- Applicants who have completed residencies in physical medicine and rehabilitation who desire to leverage that knowledge to expand treatment options for patients with MS.

### **The Class of 2011 Fellows Training Locations:**

- University of California, San Francisco, California
- Cleveland Clinic Foundation, Cleveland, Ohio
- University of Washington, Seattle, Washington
- Children's Hospital, Boston, Massachusetts
- Corrine Goldsmith Dickinson Center for MS, New York, New York
- University of Utah, Salt Lake City, Utah
- UT Southwestern Medical Center, Dallas, Texas
- Stanford University Hospital and Clinics, Stanford, California
- University of Colorado, Denver, Colorado
- Ohio State University, Columbus, Ohio
- The University of Chicago, Chicago, Illinois
- Kaiser Permanente Southern California, Los Angeles, California

The Class of 2011 Fellows will conduct their fellowships at some of the most prestigious MS training sites around the country. Based on a survey of past fellows, we know that almost all fellows remain in the field of MS care, and many will practice in various states of the country during their career.

The training of these fellows benefits all living with MS, regardless of location, and every region and chapter can have a part in fulfilling the Society's promise to train the next generation of MS scientists and clinicians, thus improving the lives of people living with MS for generations to come. The Society can only meet our funding goal through donations from regions, chapters or donors, either to support a specific fellow or to support the program in general.

### **Questions or More Information Needed?**

If you have questions about the Clinical Fellows Program or how you or a donor can ensure the entire class of 2011 receives funding, please contact Carrie Radant at 303.698.6139 or [carrie.radant@nmss.org](mailto:carrie.radant@nmss.org) or Mary Milgrom at 303.698.6103 or [mary.milgrom@nmss.org](mailto:mary.milgrom@nmss.org).



## HUMAN RESOURCES

<b>December 17, 2010</b>	<b>CC: ALL</b>
<b><u>Employee Handbook</u></b>	

Over the next several months, the Human Resource Department will facilitate the development of a comprehensive Employee Handbook for the entire Society. While we recognize that there will be policies, state and local regulations, and benefits that are specific to your chapter or location, it is a healthy and important risk management strategy to function with one Employee Handbook. To capture chapter variations and other differences an appendix by location will be part of the Employee Handbook.

Based on the way our liability insurance policy is structured our carrier has advised us to develop one Employee Handbook that is applicable to all Society employees in time for our 2011 insurance renewal. From a legal liability perspective it is advantageous as an organization to maintain consistency in policies and procedures. We have been advised that in the event we face issues of liability, having one Employee Handbook places the Society in a much stronger position “defensibly”.

This project will require a significant effort, necessitating coordination among staff throughout the Society. A plan for the collection of required information is being developed and we will be providing specifics, as well as a detailed timeline, shortly after the first of the year. We anticipate completion of the Employee Handbook by mid-summer 2011.

In the meantime, should you have questions or comments please contact Lisa Goldfarb (212-476-0467) or Carolyn Hayes-Gulston (212-476-0432).



## PROGRAMS & SERVICES

December 17, 2010	CC:
<b>2011 Trainings for New Self-Help Group Leaders</b>	

Based on feedback received from you and your self-help group leaders, the Society will move to a coach-based approach to training new self-help group leaders beginning in January 2011. This new approach will maintain the integrity of the existing training curriculum, but will allow for more personal attention, in-depth discussions, customization of the curriculum to the volunteers' needs, small group activities and time for skills-based practice. A National MS Society staff member or consultant, and a veteran self-help group leader (when available) will facilitate the training calls. (Please note: This training is for **new** self-help group leaders only. Additional teletrainings for **all** self-help group leaders are offered throughout the year.)

The teletrainings are offered at no charge. Also new in 2011 is a change in the registration process. Registrations will be managed on a rolling basis, with classes beginning when a minimum number is met. Class size is limited to 5-7 volunteers, and the group will meet for 1 ½ hours/week for four weeks.

The registration form is available on SharePoint at Programs and Services>Social Connections and Support Resources>Self-help Group Materials. Please direct any new leader training questions to Julie Gibson at (253) 921-2027 or [Julie.Gibson@nmss.org](mailto:Julie.Gibson@nmss.org). Julie is a project consultant for the Programs and Services Department and is providing support to this project. She will work with you and your volunteers on scheduling and related training issues.

Additional questions can be directed to Kim Koch at (303) 698-6100, ext. 15158 or [kimberly.koch@nmss.org](mailto:kimberly.koch@nmss.org).



**National Multiple Sclerosis Society**  
733 Third Avenue  
New York, New York 10017-3288  
Tel +1 212.986.3240  
Fax +1 212.986.7981  
E-mail [nat@nmss.org](mailto:nat@nmss.org)  
[Nationalmssociety.org](http://Nationalmssociety.org)

## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

**December 17, 2010**

### **Society Convenes Think Tank on Progressive MS**

*-- Cross-sector participants outline research needed to understand what drives disease worsening and to develop new therapies*

The hopes of most people who have MS today rest on finding a way to stop disease worsening and reverse the damage to restore lost functions. MS progression can be slow or it can be fast, but most agree that it occurs in the majority of those who have the disease, even those successfully treated for relapses. A think tank recently convened in Boston by the National MS Society and its commercial drug development entity, Fast Forward ([www.fastforward.org](http://www.fastforward.org)), brought together MS investigators, research funding agencies and industry representatives to map out next steps to move the field toward better understanding of factors underlying MS progression and to increase the number and quality of clinical trials in progressive MS.

### **Why Now?**

In opening remarks, Society President and CEO Joyce Nelson noted that there's been a great deal of progress in treating relapsing forms of MS, with many FDA-approved therapies. But for every new therapy approved for relapsing forms of MS, people with progressive MS, for whom there are few significant treatment options, feel left behind.

Ms. Nelson commented that progressive MS is the centerpiece of the Society's Strategic Response (<http://www.nationalmssociety.org/about-the-society/our-strategic-response/index.aspx>) for the next five years, with a research focus on understanding mechanisms that lead to progression, finding ways to repair damage to the nervous system, and accelerating development of new therapies. This think tank was very timely and critical to developing next steps.

A few of the knowledge gaps about progressive MS discussed by participants include:

- What are the underlying mechanisms that influence why some people have very slow progression while others worsen quickly? Knowing these should point to new therapeutic targets.
- What factors influence the transition from relapsing MS to the secondary-progressive stage of MS? Understanding these factors should make it possible to interfere and stop progression.
- What causes nerve degeneration in MS? Finding ways to stop the loss of nerve tissue, and to repair the loss, is crucial to restoring function.
- How similar or different are progressive forms of MS? The differences and similarities will help inform future research and clinical trials.

### **About Progressive MS**

During her presentation epidemiologist Helen Tremlett, PhD (University of British Columbia) outlined some basics. There are two main types of progressive MS. The most prevalent type occurs after people who initially experience relapses and remissions of symptoms transition into a second stage in which there are fewer or no relapses at all, but gradual worsening. This is referred to as secondary-progressive MS (SPMS), and can occur from one to three decades after initial onset of relapsing MS. People who have the second main type of progressive MS, called primary-progressive MS (PPMS), start with gradual worsening at onset without ever experiencing relapses or remissions.

Dr. Tremlett explained general ways that the two types are different, based on large population studies, but individuals show a wide variation in their own experience of progressive MS. Here are a few key differences:

<b>Primary-Progressive MS</b>	<b>Secondary-Progressive MS</b>
Younger at onset of progression	Older at onset of progression
More likely in men	More likely in women
Generally takes longer to diagnose than relapsing MS	Is diagnosed well after transition from relapsing to SPMS has already occurred

The question of differences becomes especially important when trying to determine who to include in a clinical trial of a therapy to treat progressive MS. Too much variation in participants may skew results and possibly lead to failure a trial of a potentially beneficial therapy.

CONTINUED...

Read complete summary and view video on Website:

<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=4322>



**National Multiple Sclerosis Society**  
733 Third Avenue  
New York, New York 10017-3288  
Tel +1 212.986.3240  
Fax +1 212.986.7981  
E-mail [nat@nmss.org](mailto:nat@nmss.org)  
[Nationalmssociety.org](http://Nationalmssociety.org)

## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

**December 17, 2010**

### **Pediatric Centers of Excellence Publish Findings on Children with MS**

Researchers from the Network of Pediatric MS Centers of Excellence established by the National Multiple Sclerosis Society (<http://nationalmssociety.org/about-multiple-sclerosis/pediatric-ms/pediatric-ms-centers-of-excellence/index.aspx>) have published new findings on MS in children and adolescents. The Society has been funding the sites for the past five years, as part of its Promise 2010 campaign which is winding down. The centers are leveraging collaborations made possible by the funds into further research efforts.

When one therapy fails in kids with MS: There is no disease-modifying therapy specifically approved for children who have MS, so gathering and sharing treatment experience is an important task of the centers. E. Ann Yeh, MD (State University of New York, Buffalo) and colleagues at all six centers reviewed the records of 258 children with MS who had been treated with disease-modifying therapies. ([http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/index.aspx#disease\\_course](http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/index.aspx#disease_course)) Of these children, 144 (58%) stayed on their first therapy; 65 (25.2%) were switched to one other therapy, 29 (11.2%) were switched twice, and 20 (7.8%) were switched three times. Most switched to other first-line disease-modifying drugs such as interferons or glatiramer acetate. In 55 children (21.3%), however, treatments included corticosteroids, mitoxantrone, cyclophosphamide, natalizumab, or daclizumab. The investigators noted that Hispanic children were significantly more likely to experience “breakthrough” disease activity while receiving first-line disease-modifying therapies.

The authors highlight the relatively frequent use of second-line therapies, noting that the long-term safety of these is not yet known in children. They acknowledge the study’s limitations; a retrospective review may not capture all of the relapses that occurred, or what socioeconomic factors might be associated with disease activity or treatment choices. They conclude that further studies should evaluate the safety and effectiveness of MS drugs in children, as well as

the mechanisms (socioeconomic, psychological, or biological) that contribute to breakthrough disease activity. This report was published online on December 13 in the *Archives of Neurology* (<http://archneur.ama-assn.org/cgi/content/short/archneurol.2010.325>).

Exploring associations with cognitive problems in kids: In a small study, Kelly Ross, MA, and colleagues at the National MS Society-supported Center for Pediatric-Onset Demyelinating Disease, at the Children's Hospital of Alabama, administered a battery of neuropsychological tests to 20 African American and 22 Caucasian American kids with MS. On average, the African American children with MS performed significantly worse on tests of language and complex attention. An accompanying editorial notes that further studies in this area should consider ethnicity, as well as social factors and treatment status, to better understand how cognitive problems impact different segments of children with MS. This study (<http://www.neurology.org/content/75/23/2097.abstract>) appears in the December 7 issue of *Neurology*. Read more (<http://www.medbioworld.com/news.php?topic=0&article=20101213clin009.xml>) (Reuters).

Over the past five years, the Pediatric Network has developed several resources to help parents and school personnel deal with the effects of cognitive problems on kids with MS; the earlier such issues are addressed, the better. A key resource is the network's handbook (PDF), "Students with MS & the Academic Setting: A Handbook for School Personnel" (<http://nationalmssociety.org/about-multiple-sclerosis/pediatric-ms/pediatric-ms-centers-of-excellence/download.aspx?id=16356>).

Comment: These studies highlight the importance of teasing out the effects of MS in children. While the initial grants to the Pediatric Network Centers of Excellence are soon ending, there is funding for the next two years to support a data coordination and analysis center so the Network can continue to collect data and study Pediatric MS and related disorders. Over the past five years, the Network as a whole has published two original research papers, and many review papers. Additionally there have been over 150 papers, posters and presentations made by Network sites on pediatric MS, and network members are the lead authors of a textbook on Pediatric MS that will be available in early 2011 from Cambridge Press. They and the Society are now working on ways to leverage this stellar collaboration and data collection into continued care and further research to benefit children and adolescents with MS.

In one example of these efforts, the network was recently awarded a five-year grant from the National Institutes of Health to study the genetic and environmental risk factors, and their interactions, in pediatric MS. This federal grant will provide \$3.2 million to help this talented team understand more about how MS begins in children, knowledge that can eventually be applied to more common, adult forms of MS.

Read more (<http://nationalmssociety.org/about-multiple-sclerosis/pediatric-ms/index.aspx>) about pediatric MS.