



CHAPTER PRESIDENTS

July 6, 2012	CC:
<u>Interim Executive Vice President, East Region: Andrea Maloney</u>	

The East Region Management Team and leadership volunteers have concentrated much of the last 6 months on planning for the long range direction of the region. Now, a team of volunteer leaders from the region are working to deliver a recommendation to the Region Volunteer Leadership Council, Chapter Boards of Trustees and Presidents at the National Conference in Dallas in November.

In our volunteer leadership meetings in February and May, we spoke about how it must remain a priority focus and that the search for a new Region Executive Vice President is premature as we focus on that priority. In the meantime, we will have an interim structure.

There is still work that must continue in the region and while I focus on my role as Chief Field Services Officer, Andrea Maloney will serve as Interim Executive Vice President for the East Region through December 2012 while the region volunteer leadership and staff continue work on long range planning. Andrea currently serves as Vice President of Organizational Development and Interim Management; leading the team that provides interim management in chapters during times of transition.

In this interim role, Andrea will provide leadership to the activities in the East Region, including the Region Management Team and the Region Volunteer Leadership Council. She will oversee the daily operation and initiatives, planning and budgeting. She will participate, with other Region Executive Vice Presidents, as a member of the Senior Leadership Team; ensuring that East Region perspectives are represented during discussions and decision-making.

Andrea has 25 years of experience with the Society. She began her career with the Greater New England Chapter and then moved to positions of increasing responsibility in the Society Field Operations Department. Her extensive experience includes development, management and execution of operational and strategic plans and budgets, creating and sustaining strong relationships with corporate, community and national partners and demonstrated success in building teams from different disciplines and geographical

territories. Andrea has served as Interim Chapter President in 8 Chapters ranging from \$1M - \$10M. Andrea can be reached at: andrea.maloney@nmss.org or at (978) 369-4463.

If you have questions, please feel free to contact me at: john.scott@nmss.org or 303-698-8800. Please join me in welcoming Andrea to this new role in the East Region.

Thank you,

John Scott
Chief Field Service Officer
John.Scott@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
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

July 6, 2012

Small Study Suggests Botox Injections Improve Arm Tremor in People with MS – Larger trial needed to confirm and expand findings

Botox[®] (onabotulinumtoxin A, Allergan, Inc.) reduced arm tremor (uncontrollable shaking) and improved arm and fine hand movements and function significantly more than inactive placebo in a study of 23 people with MS. If confirmed in a larger study, this research may yield a new strategy to address this common and disabling symptom of MS, which is often resistant to treatment. Anneke Van Der Walt, MBChB, and colleagues (University of Melbourne, Melbourne, Australia) report their findings in *Neurology* (2012;79:92-99, <http://www.neurology.org/content/79/1/92.abstract>). The study was supported by the Box Hill MS Research Fund and The Royal Melbourne Hospital Neuroscience Foundation.

Background: Many people with MS experience some degree of tremor, or uncontrollable shaking. It can occur in various parts of the body. Tremor occurs because there are damaged areas along the complex nerve pathways that are responsible for coordination of movements. To date, there have been no reports of consistently effective medical or exercise treatments for tremor; it is considered by physicians and other health professionals to be one of the most difficult symptoms of MS to treat.

Botox is a powerful neurotoxin that temporarily blocks connections between the nerves and muscles, resulting in short-term relaxation of the targeted muscle. The FDA has approved Botox for treating upper limb muscle spasticity (extreme tightness) and bladder muscle dysfunction in people with MS and other disorders. Botox has shown some benefit in treating tremor in other disorders.

The study: The investigators recruited 23 people with MS who had arm tremor, and randomly assigned them to receive either Botox or inactive placebo (saline) injections for 12 weeks. Each group was then switched to the other treatment for an additional 12 weeks. Before injections

began, the investigators assessed tremor patterns to determine the specific arm muscle to inject. Before and after treatment, tremor severity and writing and drawing ability were measured. Participants underwent video assessments as well.

Tremor severity was reduced significantly more with Botox than placebo injections, and writing/drawing ability improved significantly more with Botox as well. Video assessments by an independent observer also revealed significant improvements with Botox treatment.

Mild to moderate arm weakness occurred in 14 people treated with Botox, compared with two receiving placebo. Weakness resolved within two weeks.

Comment: The authors conclude that these results provide the framework for a larger, phase III study to confirm the findings. If confirmed, this research may yield a new strategy for addressing an often disabling and treatment-resistant symptom of MS.

Read more about MS-related tremor (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/symptoms/tremor/index.aspx>).

Botox is a registered trademark of Allergan, Inc.



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
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

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Italian Researchers Find that MS Disease-Modifying Therapies Reduce the Risk of Future MS Progression

Researchers used novel statistical methods to study outcomes for 1178 people with MS from three MS centers in Italy, and concluded that using disease-modifying therapies significantly reduced the risk of progressing from relapsing-remitting (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/relapsing-remitting-ms-rrms/index.aspx>) to secondary-progressive (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/secondary-progressive-ms-spms/index.aspx>) MS. Roberto Bergamaschi, MD (Neurological Institute C. Mondino, Pavia, Italy) and colleagues report their findings in *MS Journal* (2012 May 31. [Epub ahead of print], <http://www.ncbi.nlm.nih.gov/pubmed/22653657>). This novel, investigator-initiated study adds to the body of evidence suggesting that MS therapies improve future outcomes for people with MS.

Background: Multiple sclerosis occurs when the immune system attacks the brain and spinal cord. Several treatments, called disease-modifying therapies (DMDs -- <http://nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/index.aspx>), are available that can reduce the inflammation associated with the immune attack and reduce disease activity.

The effect of these therapies on damage to nerve fibers is not well understood, and it is unknown to what extent they reduce the progression of MS, which is associated with nerve fiber damage, beyond what is reported from relatively short-term clinical trials. Some of the difficulties involved in answering this question using traditional, randomized clinical trials include that it would take a long time to observe effects on progression, and that the conditions of a trial do not necessarily reflect how the 'real world' affects disease progression.

The study: These researchers took a novel approach to analyze data and outcomes related to 1178 people who had MS for 10 or more years and were examined at one of three MS centers in Italy. Of these, 478 had received no prior MS treatment; 700 had been treated with disease-modifying therapies of any type, including 606 who had taken interferons or glatiramer acetate. The researchers focused many of their comparisons on this group rather than the smaller number who had been on other therapies such as natalizumab, mitoxantrone or fingolimod.

The researchers used a measure of how many people shifted from relapsing-remitting MS to secondary-progressive MS. Following an initial period of relapsing-remitting MS, many people develop a secondary-progressive disease course in which the disease worsens more steadily, with or without occasional flare-ups, minor recoveries (remissions), or plateaus. In this study, secondary-progressive MS was considered to have begun after an individual experienced continuing deterioration without a relapse or remission, for at least one year, severe enough to lead to an increase of at least one point on the EDSS disability scale.

Results: The investigators found that those who had received treatment were significantly less likely to have shifted to secondary-progressive MS. At 10 years, 382 out of 478 (79.9%) who had not been treated still had RR MS, and 96/478 (20.1%) had developed SP MS. Of those treated with interferons or glatiramer acetate, 585/606 (97%) still had RR MS and 21/606 (3%) had developed SP MS.

The team designed a novel statistical method that incorporated clinical factors collected within the first year of disease. These factors indicated whether people were at high risk or low risk for progressing from relapsing-remitting to secondary-progressive MS. In evaluating these factors, the risk of progression to secondary-progressive MS was reduced in people who took DMDs – both in people at high risk and at low risk for progression.

Comment: This novel study adds to the body of evidence suggesting that MS therapies improve future outcomes for people with MS, having a positive effect not only on inflammation but also on the damage to nerve tissues that causes progression of disability over time. The study requires further confirmation, but it indicates the value of pursuing every novel avenue to answer the tricky questions posed by MS.