



## CHAPTER PRESIDENTS

May 18, 2012	CC: All
<b>All Society Staff Call on May 2 – Recording Available</b>	

The All Society Conference Call held on Wednesday, May 2 was recorded and can be downloaded on SharePoint under the HR Section < Announcements.

The quarterly All Society Call is for ALL National MS Society Staff and is an opportunity for the entire organization to join together to celebrate our progress, learn how our organizational priorities have real impact for our constituents, and look ahead to important work that moves us closer to a world free of MS.

On this call, Cyndi Zagieboylo and Lisa Goldfarb discussed some timely, important ongoing work across the organization; Tim Coetzee shared some breaking research news from AAN; and we heard from Robin McGraw, Corrina Steiger and Dr. Robin Miskimins about how critical research is and how essential it is to create opportunities for those who want to drive research forward.

**All Society calls scheduled for the rest of the year are as follows:**

June 20 (Wed) at 1 pm Eastern

Sept 20 (Thurs) 1 pm Eastern

Dec 19 (Wed) 1 pm Eastern

Chris Yankee

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## DEVELOPMENT

May 18, 2012	CC: Chapter Presidents
<b><u>New Golden Circle Print and E-Newsletter Templates</u></b>	

Updated templates for Golden Circle print and e-newsletters are now available to help you provide ongoing communication with prospects and donors, promote Golden Circle activities and inform donors of opportunities to deepen their engagement with the MS Society. Please utilize these resources as an integral part of your donor cultivation plans and ongoing communication with top chapter donors and Golden Circle members and prospects.

The art files for the Golden Circle print newsletter template are available on the FTP site by going to:

Materials > Major Gifts > Golden Circle > GoldenCircleNewsletter\_Final Folder

The email header for use on Outlook is available on the FTP site by going to: Materials > Major Gifts > Golden Circle > GoldenCircleNewsletterEmailHeader\_Final.jpg

The new Golden Circle stationary for sending e-newsletters through Convio is available at: Convio > Email > Stationery > (search for) Golden Circle

Detailed instructions for accessing files on the FTP server using Internet Explorer 7.0 and 8.0 are posted on SharePoint. For additional information on Golden Circle resources contact [susan.goldsmith@nmss.org](mailto:susan.goldsmith@nmss.org) 303-6986100 x15102.



## PROGRAMS & SERVICES

May 25, 2012	CC: Chapter Presidents
	Development
	Marketing
<b>African Americans and Multiple Sclerosis Brochure</b>	

We are pleased to announce a new brochure about [African Americans and MS](#) to use for community engagement and outreach.

To Order: E-mail your request to [chapterorders@nmss.org](mailto:chapterorders@nmss.org) or fax a chapter order form to Chapter Supplies at 212-986-3911.

Item # BR0085, Minimum Order Quantity (MOQ) 50. The brochures are free but you will be invoiced for shipping and handling.

This community engagement tool is part of the Society's public awareness campaign to more fully engage the African American community in the MS movement. The campaign aims to shatter the myth that African Americans do not get MS, and to better engage the community with programs and resources to support optimal care and living well with MS.

This tool can be used at health fairs, church events, community festivals and Society fund-raising events. Also consider distributing the brochure to health care professionals for dissemination to their patients, and for use in developing relationships with community based organizations targeting the African American community. For more information on community engagement, resources, and strategies please reference the [Society's Community Resources Engagement Toolkit](#).

If you have questions about the campaign or reaching culturally diverse communities, please contact Craig Wesley at 212-986-3240, ext 64044. For more information about the Society's National African American Advisory Council please visit: [www.nationalMSSociety.org/AfricanAmericansandMS](http://www.nationalMSSociety.org/AfricanAmericansandMS)



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## RESEARCH/CLINICAL UPDATE

[Do Not Post on NMSS.org](#)

cc: Chapter President, Programs, Development, PR specialists

May 15, 2012

### **Latest results about emerging MS therapies, risk factors, disease mechanisms, rehabilitation, CCSVI, and much more presented at AAN Meeting**

#### **EXECUTIVE SUMMARY**

Nearly 12,000 neurologists and investigators convened in New Orleans in April to present findings at the American Academy of Neurology's annual meeting. Over 500 scientific presentations and display posters focused on research to stop MS, restore function, and end MS forever. The MS sessions were often standing-room only, and appear to get bigger every year. Among these were the latest results from pivotal clinical trials of emerging MS therapies, possible risk factors, underlying disease mechanisms, rehabilitation approaches, CCSVI, and much more. For free access to the conference abstracts (brief summaries), go to the American Academy of Neurology's Website: <http://www.abstracts2view.com/aan/>

In most cases, studies presented are considered preliminary. Many of the results will be analyzed more thoroughly, and usually published in peer-reviewed science and medical journals. Confidence in a study's findings grows when it is repeated by others, with similar results.

- **STOPPING:** Among studies reported were these first results from late-phase clinical trials. If these treatments are found to be safe and beneficial, some of them may come on the market in 2012 and 2013. Other studies focused on understanding benefits, risks and modes of action of available and emerging therapies.
- **RESTORING:** Rehabilitation to address cognitive changes was explored. In addition, several presentations focused on imaging techniques and pathology findings related to Chronic Cerebrospinal Vascular Insufficiency and MS.
- **ENDING:** Understanding risk factors that influence who gets MS, and also what course their MS will take, is crucial for finding ways to prevent MS and progression of symptoms. Among the presentations were studies that looked at interactions of genes, gender, and vitamin D levels.

## Highlights:

### RESEARCH TOWARD STOPPING MS IN ITS TRACKS

Among studies reported were these first results from late-phase clinical trials. If these treatments are found to be safe and beneficial, some of them may come on the market in 2012 and 2013. Other studies focused on understanding benefits, risks and modes of action of available and emerging therapies.

- **BG-12** (Biogen Idec) – The phase III CONFIRM trial of this oral therapy in 1430 people with relapsing-remitting MS – tested at two or three times a day against placebo over two years – achieved statistical significance on the primary endpoint of reducing average annual relapses by 44 to 51% over placebo. Both BG-12 groups and a group given glatiramer acetate (Copaxone<sup>®</sup>, Teva Pharmaceutical Industries) were compared to the placebo groups, but not to each other. Both doses of BG-12 reduced disease activity on MRI. Disability progression was not reduced significantly by BG-12. The most common adverse events in the BG-12 groups were flushing and gastrointestinal events. (Abstract S01.003) A small study in 56 healthy volunteers treated with BG-12 showed that pretreatment with aspirin (325 mg for 4 days) decreased the incidence and severity of flushing, without increasing gastrointestinal upset. Whether long-term use of aspirin with BG-12, if approved, in people with MS will be as effective and well tolerated is not known. (Abstract P04.136) Biogen Idec has applied to the FDA for marketing approval of BG-12 for MS.
- **Alemtuzumab** (Genzyme/Sanofi) – The two-year CARE-MS II phase III trial compared intravenous alemtuzumab against standard dosing of Rebif<sup>®</sup> (interferon beta-1a, EMD Serono Inc. and Pfizer) in 840 people with relapsing-remitting MS who had relapsed while on prior therapy. Alemtuzumab was infused once each year, on five consecutive days the first year, and on three consecutive days the second year. The relapse rate was reduced by 49% compared to Rebif, and the risk of disability progression was reduced by 42%. Several aspects of MRI-detected disease activity also showed benefit, and alemtuzumab reduced brain atrophy. Adverse events of alemtuzumab included autoimmune thyroid-related problems in 15.9%, ITP (a rare blood disorder) in 0.9%, and infusion-related reactions. The most common infections were upper respiratory and urinary tract infections, sinusitis and herpes simplex infections; serious infections occurred in 3.7% of the alemtuzumab group and 1.5% of the Rebif group. (Abstract S01.004) Genzyme has publicized plans to file for FDA approval of alemtuzumab in the second quarter of 2012.

CONTINUED... ON SHAREPOINT:

[http://intranet.nmss.org/Topics/cr/Pages/Latest MS Research Presented at AAN Meeting.docx](http://intranet.nmss.org/Topics/cr/Pages/Latest_MS_Research_Presented_at_AAN_Meeting.docx)

ON THE WEB: <http://nationalmssociety.org/news/news-detail/index.aspx?nid=6377>



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## RESEARCH/CLINICAL UPDATE

[Do Not Post on NMSS.org](#) | cc: Chapter President, Programs, Development

May 14, 2012

### **Small Study Reports Benefit of Marijuana on MS Spasticity**

A small clinical trial by California investigators found some benefit of smoked marijuana against spasticity (muscle tightness and spasms) and pain in people with MS. Participants also experienced significantly reduced thinking ability after smoking marijuana, highlighting the need for research on cannabis products or other treatments that can more selectively reduce painful symptoms without producing adverse effects on cognitive function. Additional research examining the effects of marijuana on spasticity in MS is being supported by the National MS Society and others. The current study was published online on May 14, 2012 in the Canadian Medical Association Journal (<http://www.cmaj.ca/content/early/2012/05/14/cmaj.110837>).

**Background:** For many people with MS, spasticity (muscle tightness and spasms -- <http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/symptoms/spasticity/index.aspx>) is a painful and disabling symptom that can have a significant negative effect on quality of life. Since the currently available medications do not entirely work for everyone, people with MS are searching for solutions to help with their spasticity. The search for more effective treatments for spasticity and other symptoms related to MS is an important research priority for the National MS Society.

The Society is currently supporting a clinical trial of different forms of cannabis products to test their ability to relieve spasticity in people with MS. This California-based trial is currently recruiting participants (<http://clinicaltrials.gov/ct2/show/NCT00682929>).

**The study:** Jody Corey-Bloom, MD, PhD (University of California, Davis) and colleagues conducted a placebo-controlled clinical trial involving 37 people with MS whose spasticity was resistant to standard medications. In the first 3-day treatment phase, half of the participants smoked marijuana once a day, and half smoked a placebo, and all underwent testing. After

waiting 11 days, the groups were switched so that those originally in the marijuana group were in the placebo group and those originally in the placebo group were in the marijuana group, and all tests were repeated. Thirty people completed this trial.

Compared to those on placebo, the investigators found significant improvement in spasticity according to a clinical measure called the modified Ashworth scale in those who smoked marijuana. They also reported improvement in patient-reported pain in those on marijuana. However, using a measure of information processing speed and accuracy called the Paced Auditory Serial Addition Test, the researchers found that after smoking marijuana, participants experienced significantly reduced thinking ability, compared to placebo. Limitations of this study include the small number of participants, the fact that many participants knew when they were smoking marijuana versus placebo, and that many participants had a history of marijuana use.

**Comment:** There is an unmet need for better ways to treat MS spasticity, which can have significant negative effect on quality of life. This study points to the potential of cannabis or cannabinoids for reducing spasticity and pain, but also highlights the need for more research to develop treatments that can selectively reduce spasticity without compromising cognition.

The search for more effective treatments for spasticity and other symptoms related to MS is an important research priority for the National MS Society, and the Society is currently supporting a clinical trial of different forms of cannabis products to test their ability to relieve spasticity in people with MS. The Society is also supporting research on non-pharmacologic treatments for spasticity, such as muscle-targeted exercise.



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

May 11, 2012

### **Speeding Clinical Trials for People with Progressive MS: Outcomes Published from an International Workshop on MS Disability Measurement Tools**

Disease progression, or gradual worsening, experienced by people who have multiple sclerosis usually occurs over many years, and it is difficult to track with the standard clinical measurement scales used by doctors to assess disease activity. An international meeting was convened to determine how to improve clinical measures so that MS progression can be better tracked, especially during clinical trials of experimental therapies aimed at stopping progression. Better ways of measuring changes in disability will help to speed the development of new therapies for MS, in particular for progressive forms of the disease.

The meeting was organized by the International Advisory Committee on Clinical Trials in MS, an international group of MS experts jointly sponsored by the National MS Society and the European Committee for Treatment and Research in MS (ECTRIMS).<sup>\*</sup> A summary of this meeting has now been published in *Lancet Neurology* (2012 May;11(5):467-476, <http://www.ncbi.nlm.nih.gov/pubmed/22516081>). The Society is responding to the group's recommendations, and sponsoring a collaborative effort to revise one clinical measure for primary use as a means of measuring disability in MS studies.

The Meeting: The “International Conference on Disability Outcomes in MS” was held in Washington, D.C. in 2011. Over 70 experts in MS and clinical trial design from around the world – including academic physicians and scientists, representatives of companies pursuing new therapies in MS and regulators from the U.S., Europe and Canada – gathered to discuss the measures currently used to measure MS disability, including the Expanded Disability Status Scale (EDSS), and the MS Functional Composite (MSFC). They agreed that these measures do not adequately measure the changes in MS progression that occur over time, or the patients’ own perceptions of their health and quality of life.

The group reviewed disability rating methods that show promise but require more study, such as “composite” endpoints that combine several measures, and innovative tools such as smart phones and other instruments that may offer better ways of tracking a person’s mobility.

Imaging, such as sophisticated MRI techniques used to examine changes in MS in the brain and spinal cord, and techniques to assess changes in the visual system over time (such as optical coherence tomography, OCT), were also discussed in terms of their abilities to objectively track signs of disease progression.

Meeting participants also reviewed a variety of “patient reported outcomes” being explored in MS clinical trials. These are surveys of clinical trial participants’ perspectives of their own health status and response to therapies, and are increasingly incorporated into clinical trials in MS and many other disorders. These subjective measures can add a dimension of clinical relevance to the objective measurements used by physicians to assess disability and the effectiveness of therapies.

The attendees made recommendations for improving upon current measures. In the case of the EDSS, they recommended developing a standard interview script so that all clinicians would administer this scale similarly, and simplifying the complex scoring rules. In the case of the MSFC, the group recommended that the MSFC could be improved by the addition of a test that measures change in visual function over time, by replacing the currently used method of assessing cognitive function, and by developing alternative scoring methods.

Following the meeting, these recommendations were discussed by the National MS Society’s senior research advisors, who concluded that the Society should sponsor an effort to revise the MSFC. The advisors appointed an interdisciplinary group of people with expertise in the clinical trials arena, from academia, industry, regulatory agencies and patient advocacy groups. This team is shepherding the process of revising the MSFC scale for use as a primary disability outcome in MS clinical trials.

The goal is to speed clinical trials of promising therapies aimed at stopping progression or restoring function. “We can’t afford to wait years to determine whether a therapy is working against MS progression,” noted Timothy Coetzee, PhD, Chief Research Officer of the Society.

\*Additional support for the meeting was provided by the Americas Committee for Treatment and Research in MS, MS International Federation, MS Society of Canada, Bayer Healthcare Pharmaceuticals, Inc., Biogen Idec, Inc., F Hoffmann-LaRoche Ltd., Genzyme Corporation, Novartis Corporation, Sanofi-Aventis SA, and Teva Pharmaceutical Industries Ltd.