



CHAPTER PRESIDENTS

October 9, 2009

CC: All

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Jan Bell –New Chapter President for Alabama-Mississippi Chapter

We are very pleased to announce that Jan Bell has accepted an offer to become the Chapter President for the newly merged Alabama-Mississippi Chapter and will begin her new position on October 13. The Alabama Chapter and the Mississippi Division of the All America Chapter merged effective October 1.

The Search Committee conducted an extensive search and is extremely pleased that Jan has decided to take her talents to the National MS Society. Jan brings to us an outstanding background in non profit leadership and has held a variety of positions at the local, regional and national levels. She began her career as the President of the Greater Birmingham Habitat for Humanity, and since then has worked with both the Juvenile Diabetes Research Foundation (JDRF) and the National Arthritis Foundation. At JDRF, she served as the Executive Director of the local chapter and then was promoted within the organization to the role of National Manager of Major Donor Relations. She then served as the Executive Director at the National Arthritis Foundation and later assumed the position as a National VP of Field Relations. Most recently, Jan served as the VP of Philanthropy at the Community Foundation of Greater Birmingham

Jan will be in attendance at the next Executive Management Team meeting in Chicago. Please take a moment to welcome her to the chapter and the Society.

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CHAPTER PRESIDENTS

October 9, 2009

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National Research Call on Nervous System Repair & Protection Featuring Dr. Gavin Giovannoni to be Held October 15th

What if we could actually reverse the damage that MS causes, restoring function to those who have been living with the disease for years? Recognizing that this dream could be advanced more quickly through collaborative, multidisciplinary research, the Society committed in 2005 to raise funds to support the work of four expert investigative teams focusing on nervous system repair and protection as part of the *Promise: 2010 Campaign*. These teams are making significant progress, developing non-invasive tools and models for monitoring results and paving the way for clinical testing by 2010 to restore function in people with MS.

Join us for a **special research conference call focusing on the Nervous System Repair and Protection (NSRP) Initiative, to be held Thursday, October 15th at 3:00 PM Eastern**. The 60 minute call features Dr. Gavin Giovannoni and will be moderated by Dr. Patricia O’Looney, the Society’s Vice President of Biomedical Research.

Dr. Gavin Giovannoni (Queen Mary University of London, UK) is the principal investigator of a team attempting to turn cells into vehicles that will deliver repair molecules to sites of injury in the brain, and screening molecules for their protective properties as a prelude to clinical trials.

National research calls are a great way for donors, donor prospects, staff and volunteer leaders to remain abreast of the many avenues by which the Society is advancing discovery into the cause and cure of MS and to hear directly from some of the world’s leading MS researchers about the most progressive science.

Participation in national research calls is growing, as staff has embraced spreading research knowledge to various Society supporters who are critical to increasing awareness and funding of MS research. **We hope you will identify and invite participants in each of the following groups:** major donors or prospects, major gift officers, chapter presidents, additional Society staff members, board members, significant event check writers, top event fundraisers, and research advocates. The number of donors/prospects/volunteers that you invite should be consistent with your ability to make personal contact with participants after the call as suggested below.

****ADVANCE REGISTRATION IS NO LONGER REQUIRED: Dial-in directly at 877.860.4996, Conference ID 24353962. Please share these numbers with donors, staff and volunteers who intend to participate.** If there are multiple participants dialing-in from your chapter offices, please help us manage the costs associated with the calls by calling in from one phone line.

How You Can Cultivate Supporters through National Research Calls:

Identify constituents in the groups outlined above, especially those who have expressed an interest in MS research. Anyone who can get to a phone, whether in an office, home, city or rural area is able to participate. Also consider inviting prospects to join you and others for the call at the chapter office to provide greater participation and cultivation opportunities.

We suggest extending invitations via a conversation over the phone or in person, or via email. **The dial-in information may be provided directly to the participant, as registration for the call is no longer necessary.** If you would like a template email or letter invitation, please contact Carrie Radant.

After the call, maximize this cultivation opportunity by speaking with participants about their call experience and exploring their interest in supporting research. The call will be recorded and one CD will be available to each chapter for duplication. Chapters may give the CDs to call participants, donors/prospects unable to participate and future prospects/donors and/or staff. Calls are also now available under the Research section of the national website at <http://www.nationalmssociety.org/research/research-news/ConversationswithMSResearchers/index.aspx>. The CDs and weblink will be available approximately two weeks after the call; CDs must be requested.

For additional information, an invitation template, or to request a CD recording of the call, please contact me at the number or email listed below:

Carrie Radant

National Director, Donor Development
303.698.6100 x 15165, carrie.radant@nmss.org



CHAPTER PRESIDENTS

Date: Oct 9, 2009	
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Region B Activity Update	

The Regional Management Team (the Chapter President from each chapter in the region and the Regional Executive Vice President), along with more than 60 senior staff members from the region have been involved in region formation meetings and conference calls.

The purpose of these meetings were: to discuss and agree on the collaborative culture; to clarify the roles and responsibilities of the Regional Management Team and the Regional Executive Vice President, to understand the strengths, challenges and goals of each chapter. The team discussed opportunities to leverage talent and expertise in the region; achieve efficiencies through the new economies of scale and increase overall effectiveness through collaboration.

A comprehensive update on the activities in Region B has been posted as a document in the “Region Information” landing page of Sharepoint and will be posted this week to the www.msmovingforwardtogether.org website. In it, you will find information about:

- The purpose and objectives of the regions;
- The four phases in the region formation process;
- The region goals;
- The process for moving from strategy into operation;
- The formation of workgroups;
- A description of the first two groups to launch;
- The role and formation of the Regional Leadership Committee; and
- A list of a few of the early successes.

If you have questions or would like more information, please do not hesitate to contact me or any one of the Regional Management Team.

John Scott
Regional Executive Vice President
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PROGRAMS & SERVICES

October 9, 2009

CC: Chapter Presidents

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Clinical Affiliation Program – Web Site Updates

The clinical affiliation process is now underway and we are pleased to report that 6 chapters have had profiles reviewed to date by the Clinical Affiliation Review Committee. This represents 21 clinical sites.

- 13 centers have been recommended to be “affiliated centers for MS comprehensive care”.
- 2 sites were felt to have not met the defined comprehensive and coordinated care elements. These two sites are exemplary in many ways and are providing critical clinical services to patients; the chapters are looking at ways to acknowledge these sites outside of the affiliation program.

In 6 cases, the clinical affiliation review committee requested additional clarifying information in order to make an informed decision. Here is what we’ve learned:

- 1) The profile worksheets must stand alone to tell the story of how the site responds to patient needs. This is the document the review committee sees. All of the discussion topics outlined in the profile need responses. The bullets that say “we will discuss” need written responses. (What were the outcomes of that discussion?)
 - A. It is important to describe how services are coordinated, how patients access services, and the nurse role in patient care.
 - B. It is important to clearly define the relationship between the site and the chapter.

A sample profile worksheet is on SharePoint along with 16 other documents.

The committee is currently meeting monthly and will continue to do so as needed.

Affiliation Review Committee Meetings	Dates profiles must be submitted to the Home Office (cristina.lipka@nmss.org deborah.hertz@nmss.org)
Oct. 13, 2009	They have 7 profiles to review (3 chapters)
November 3, 2009	Oct. 16 th (we already have 4 profiles in hand)
December 3, 2009	Nov. 16 th

Dates for 2010 will be determined shortly.

IMPORTANT NOTE: While there are 13 sites that have now been recommended for affiliation, these affiliations are not considered final until the written agreements are in place. We are still working on the details of this. It will be available mid November. Until then, while you can certainly congratulate the sites – please hold off announcing the affiliations publicly until the agreements are signed. When we distribute the agreement template we will also provide a sample press release and more information about recognition plaques.

WEB SITE (ACTION)

The Home Office has made changes to the national web site to reflect the new clinical affiliation program. We have removed the clinic listings and have replaced them with a description of the new program, which can be found at:

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/affiliated-centers-for-comprehensive-care/index.aspx>. This Web page, which currently does not list specific centers, will be modified in the coming months as more centers are approved. Once we have affiliated centers in at least 25 states, the page will include a full state listing, with contact information. In the meantime, the page refers users to the IRC, where they can learn about our affiliated center program and specific information about affiliated centers (as they are formalized) and other providers for referral purposes.

We are asking you to do the same. **Please remove information you currently have posted about centers and provide a link to the above noted national page. Note that the previous treatment locations page has been removed from the national site so any links to that page or supporting state based pages will need to be updated locally on chapter sites.**

We have ensured that all the providers listed in the previous listing on the national Web site are in Altair, and will be accessible to the IRC specialists.

The next bi-weekly support call is October 20, 1:00 PM Eastern time. The call in number is 973-935-8602 and use pass code 15122898#.

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RESEARCH/CLINICAL UPDATE

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

October 9, 2009

PreCISe Study Results – Showing Benefit of Copaxone® in People at High Risk for MS – Published

Results of the PreCISe Study – which showed that early treatment with Copaxone® (glatiramer acetate, Teva Pharmaceutical Industries) delayed the development of definite multiple sclerosis – have now been published. Dr. Giancarlo Comi (Scientific Institute San Raffaele, Milan) and colleagues presented results of this study at the Annual Meeting of the American Academy of Neurology in 2008, and based on these results, the U.S. Food and Drug Administration (FDA) extended the labeling of Copaxone to include people with MS who have experienced a first clinical episode and have MRI features consistent with MS. The team’s report has now been published in the *Lancet* (published online October 7, 2009).

Background: The diagnosis of clinically definite MS requires two neurological events suggesting demyelination (loss of nerve-fiber insulation) in the brain and spinal cord separated in time and in location in the nervous system. Studies have shown that individuals who experience a clinically isolated syndrome (a single occurrence of a sign or symptom of demyelination) and multiple clinically “silent” MRI-detected brain lesions are at high risk for developing clinically definite MS within several years. Individuals who have similar neurologic problems but no evidence of MRI-detected lesions are at relatively low risk for developing MS over the same time period.

The PreCISe Study: A total of 481 people with CIS with lesions typical of MS on brain MRIs were randomly assigned to receive either Copaxone (given by daily under-the-skin injections) or inactive placebo for up to 36 months. The primary outcome measure was the time it took individuals to experience a second attack that would confirm the diagnosis of definite MS.

Results showed that in those who took Copaxone, the risk of developing clinically definite MS was reduced by 45% versus placebo, and the time to development of definite MS was delayed by 386 days more than in the placebo group. The proportion of individuals who developed MS

was 43% in the placebo group versus 25% in the Copaxone group. At a pre-planned interim analysis, the Data Monitoring Committee recommended that all people in the placebo-controlled group be offered Copaxone treatment.

In a post-study analysis based on all patients who completed two years of the study without developing MS, there was a significant reduction in new “T2” lesions in those who took Copaxone versus those who took placebo, by 43% during the first year and by 52% over the entire two years. (T2-weighted MRI scans are used to provide information about the total amount of tissue damage in the brain or spinal cord.)

The most common adverse events were consistent with those known to be associated with Copaxone use: injection-site reactions (56% in the Copaxone group and 24% in the placebo group) and immediate post-injection reactions (19% in the Copaxone group and 5% in the placebo group). Fourteen people in the Copaxone group and four in the placebo group withdrew from the study because of adverse events.

Based on the PreCISe results, the U.S. FDA extended the labeling of Copaxone to include people with MS who have experienced a first clinical episode and have MRI features consistent with MS.

Comment: Research suggests that damage to brain and spinal cord tissues can occur early in the disease course of multiple sclerosis, and that early use of disease-modifying therapies can delay onset and forestall to some extent future disability. The PreCISe study results – and the subsequent FDA approval of expanded labeling for the use of Copaxone in people who have had a single attack and MRI scan suggestive of MS – add another option for early treatment, and should send a signal to physicians and third-party insurers that this is an appropriate treatment for individuals with this condition. In addition to Copaxone, both Avonex[®] (interferon beta-1a, Biogen Idec) and Betaseron[®] (interferon beta-1b, Bayer Healthcare Pharmaceuticals) are approved to treat relapsing MS as well as a first clinical episode with MRI findings consistent with MS.

Individuals interested in the use of Copaxone for earliest demyelinating event suggestive of MS should contact their personal physicians. Additional information about Copaxone can be obtained through the Copaxone support program, Shared Solutions[™], 1-800-887-8100, or www.copaxone.com.

[Read more](#) about “pre-diagnosed” MS.

-- Research and Clinical Programs Department

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Avonex is a registered trademark of Biogen Idec.

Betaseron is a registered trademark of Bayer Healthcare Pharmaceuticals.

Shared Solutions is a trademark of Teva Pharmaceutical Industries



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RESEARCH/CLINICAL UPDATE

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October 9, 2009

Research into Blood Flow in the Brain and Venous Insufficiency, or CCSVI, in Multiple Sclerosis

A few recent reports have revived ages-old speculation about a possible dysfunction of brain blood flow and/or drainage in individuals who have MS. For example, one study involving 65 people with different types of MS compared with 235 people who were healthy or had other neurological disorders, a strong relationship was found between MS and signs of venous insufficiency – suggesting that blood drainage by veins may be blocked, causing or contributing to nerve tissue damage. This study, by Paulo Zamboni, MD (University of Ferrara - Ferrara, Italy) and colleagues, was published in the June 2009 (J Neurol Neurosurg Psychiatry 2009; 80:392-399 <http://jnnp.bmj.com/cgi/content/abstract/80/4/392>). If confirmed, these findings may open up new research avenues into the underlying pathology of MS. Further research is now underway.

The idea that MS may involve a problem in blood circulation was an early idea that was eventually dismissed as more research suggested that immune-system attacks and inflammation played a pivotal role in the damage to nervous system tissues. A few recent studies have posed the idea that lower blood flow in the brain might contribute to nervous system damage.

In the recent study by Dr. Zamboni and colleagues, they screened for abnormalities of blood outflow in major veins draining from the brain to the heart in 65 people with different types of MS, compared with 235 people who were either healthy or who had other neurological disorders. They used sophisticated sonography techniques to detect abnormalities of vein drainage. The investigators found significant evidence of slowed and obstructed drainage in the veins draining the brain in many of those with MS. They also found evidence of the opening of “substitute circles” – where the flow is deviated to smaller vessels to bypass obstructions, and these were often found to have reverse flow (reflux) of blood back into the brain.

The investigators called this venous obstruction “chronic cerebrospinal venous insufficiency,” or CCSVI. The treatment status of the people with MS did not appear to influence whether they showed signs of CCSVI. The authors speculate that the reverse flow of blood back into

the brain might set off the inflammation and immune-mediated damage that has been well described in MS.

If confirmed, these findings may open up new research avenues into the underlying pathology of MS, and further research is now underway. One study getting underway was described at the 2009ECTRIMS meeting in September. It involves a collaboration between researchers in Italy, Buffalo (NY) and Birmingham (AL) who are attempting to treat venous obstruction in 16 individuals using balloon dilation such as has been used for many years to treat blocked arteries.

Many questions remain about how and when this phenomenon might play a role in nervous system damage seen in MS, and at the present time there is insufficient evidence to suggest that this phenomenon is the cause of MS.

Frequently Asked Questions About CCSVI and MS

Q: Do these reports of a possible association between insufficient vein drainage and MS mean that MS is caused by venous insufficiency?

A: No. Based on results published about these findings to date, there is not enough evidence to say that obstruction of veins causes MS, or to determine when this obstruction may occur in the course of disease.

Q: If CCSVI turns out to be important in MS, can it be treated?

A: No one knows yet. At least one small study is testing the effects of balloon dilation inside an obstructed vein to determine whether that procedure would be beneficial.

Q: I have MS. Should I be tested for signs of CCSVI?

A: No, unless you are involved in a research study exploring this phenomenon, since at this time there is no proven therapy to resolve any abnormalities that might be observed, and it is still not clear whether relieving venous obstructions would be beneficial.

Q: Does CCSVI make the standard treatments of MS meaningless?

A: No. There is ample evidence proving that the FDA-approved therapies for MS provide benefit for people with most forms of MS.

Q: Will the National MS Society fund research into CCSVI in MS?

A: The National MS Society welcomes research proposals from any qualified investigators whose research questions are relevant to multiple sclerosis. All proposals received are thoroughly evaluated for their relevance and excellence by our volunteer scientific peer review panels. At the present time, we have not been approached for funding any projects related to CCSVI. If we receive a proposal related to CCSVI that is found to be outstanding and relevant to MS, we would likely commit to fund such a study.

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