



## CHAPTER PRESIDENTS

**Date:** April 1, 2010

**CC:** All

**Live Webcast Forum on CCSVI from the American Academy of Neurology Meeting on Wednesday, April 14, 12 pm ET – 1:30 pm ET**

The topic of CCSVI (chronic cerebrospinal venous insufficiency) and what it could mean to the future of people living with MS has generated significant interest within the international MS community over the past several months.

CCSVI will be a topic of focus at the upcoming American Academy of Neurology (AAN) meeting in Toronto the week of April 12 with at least two data presentations being released. In order to maximize the opportunity of what we believe will be heightened interest in CCSVI research and the wealth of expertise on site, the Society and AAN will be hosting a live 90-minute webcast for journalists and the general public on CCSVI. The event will cover what is currently known about CCSVI and what yet needs to be determined in order to establish what its relationship to the MS disease process might be and whether surgical intervention can improve the disease course.

Panelists include Dr. Paolo Zamboni from the University of Ferrara in Italy, whose research has been at the center of the heightened interest in this topic, as well as Dr. Robert Zivadinov from the University of Buffalo, who is conducting a clinical study of CCSVI, and Dr. Aaron Miller, from Mt. Sinai and the Society's Chief Medical Officer

The live webcast will be held onsite at the AAN. Journalists registered for the AAN proceedings can attend in person. All other participants will be able to join the live event online where they can watch the forum and ask questions in real time. The webcast can be viewed from the Society's dedicated CCSVI web page at [www.nationalMSSociety.org/ccsvi](http://www.nationalMSSociety.org/ccsvi)

For people who can not participate in real time, we will post the recorded version with transcript for viewing shortly after the event.

### **Webcast details**

**When:** April 14, 2010 from 12:00 p.m. to 1:30 p.m. ET

**Where:** Online with the opportunity to post questions for the panelists on line in real time.

**Panel:** Includes --

**Dr. Paolo Zamboni**, Director, Vascular Diseases Center, University of Ferrara, Italy

**Dr. Robert Zivadinov**, Associate Professor of Neurology at the University at Buffalo, State University of New York

**Dr. Aaron Miller**, Professor of Neurology and Director of the MS Center at Mount Sinai, New York, member of the AAN Board of Directors, Chief Medical Officer of the National MS Society

**Register:** To register for the webcast visit: [www.nationalMSSociety.org/ccsvi](http://www.nationalMSSociety.org/ccsvi) **NOTE:**  
**REGISTRATION WILL BE LIVE THE WEEK OF APRIL 5**

### **Marketing components:**

The Society is promoting this opportunity through several channels including:

- ✓ Society home page flash panel – timing: April 2-14
- ✓ Social media outreach including on our national Facebook page, Twitter feed and to select bloggers – timing: April 2-14
- ✓ Chapter flash panel – posted April 1 to the chapter CMS
  - Go to Content Management System; search for “CCSVI Chapter Flash Panel”
  - Headline thru April 13 – April 14: A live discussion about CCSVI potentials
  - Headline as of April 14 – Watch the CCSVI webcast today
  - Text for link – Register Now (link to: [www.nationalmssociety.org/ccsvi](http://www.nationalmssociety.org/ccsvi))
- ✓ Inclusion in April National MS eNEWS, distributed April 12
- ✓ A pre-event press release PR Newswire, PR Web and the Society’s Vocus health/science list – the week of April 5
- ✓ Distribution through AAN press channels beginning week of March 29

### **Marketing the webcast through local channels:**

- ✓ We recommend posting the flash panel on your site through April 14
- ✓ We also recommend highlighting this webcast through your social media channels – by closely imitating posts on our national Facebook page and Twitter feed. Contact Beth Clark [Beth.Clark@nmss.org](mailto:Beth.Clark@nmss.org) with questions.

### **CCSVI background and talking points:**

All information regarding CCSVI including our position statement and frequently asked questions can be found at: [www.nationalmssociety.org/ccsvi](http://www.nationalmssociety.org/ccsvi)

### **Questions?**

Contact Arney Rosenblat [Arney.Rosenblat@nmss.org](mailto:Arney.Rosenblat@nmss.org) or Becca Kornfeld [Becca.Kornfeld@nmss.org](mailto:Becca.Kornfeld@nmss.org)



## CHAPTER PRESIDENTS

<b>April 1, 2010</b>	<b>CC: Development</b>
<b><u>Promise 2010 Update: Calls Planned to Discuss Next Steps</u></b>	

There will be series of calls to update Chapter Presidents and staff on the Promise 2010 campaign. Calls will be hosted by Graham McReynolds and Mary Milgrom and will take place on:

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|-----------------------|--|
| <b>April 19, 2010</b> | <b>3:00 pm EDT, 2:00 pm CDT, 1:00 pm MDT, 12:00 pm PDT</b>   |
| <b>April 21, 2010</b> | <b>1:00 pm EDT, 12:00 pm CDT, 11:00 am MDT, 10:00 am PDT</b> |
| <b>April 23, 2010</b> | <b>11:00 am EDT, 10:00 am CDT, 9:00 am MDT, 8:00 am PDT</b>  |

**Topics include:**

- Where we stand with the overall Campaign - now that we are on the home stretch
- How to bring closure to this initiative
- Plans beyond Promise 2010

Chapter Presidents and chapter staff who are operationally responsible for raising money for the Promise 2010 Campaign and other research initiatives should plan to join the call.

Lisa Risi and Dr. Patricia O’Looney will also be available for questions.

Nearly six years ago the Society made a bold promise: Beginning in 2005, we would raise \$32 million over five years to support four research initiatives that would seek to improve the care, treatment and understanding of multiple sclerosis. **Promise: 2010** proved to be a challenge and an inspiration—a promise that is not only being kept, but one that has profoundly impacted MS research as it moves forward. We look forward to sharing how close we really are to making this \$32 Million goal a reality.

You must register for these calls in advance. Registration information will be sent out shortly. Please allow 60 minutes for this call.

If you have any questions or need any additional information regarding the Promise 2010 Campaign, please contact **Carrie Radant at 303-698-6100 ext. 15165** or [carrie.radant@nmss.org](mailto:carrie.radant@nmss.org).

From: Myrna Mulholland - AVP of Individual Giving, Advancing the Regions Team  
303-698-6138



## DEVELOPMENT

<b>April 1, 2010</b>	<b>CC: Chapter Presidents</b>
<b><u>BikeMS Committee Chair Networking Calls</u></b>	
<b>Action Requested/Deadline: April 14, 2010</b>	

Back by popular demand! We are gearing up for our 2010 Bike MS Committee Chair Networking Calls, and we need your help! The goal of this initiative is to facilitate networking and develop strong Committee Chairs and committees throughout the nation. Make sure your Committee Chair has the opportunity to be involved!

Because these calls are so beneficial, we want to ensure each chapter and region has the opportunity to be involved. If you do not have a Chair for your committee, we encourage you to identify a lead volunteer to be a part of this networking group.

The calls will occur the second Tuesday of each of the following months: May, July, September and November, at 4PM Pacific, 5PM Mountain, 6PM Central and 7PM Eastern.

Please submit the following contact information for your Bike MS Committee Chair, potential Committee Chair or lead volunteer to Doug Suggitt at [doug.suggitt@nmss.org](mailto:doug.suggitt@nmss.org) by April 14, 2010:

- Chapter Name / Region
- Ride Name
- Committee Chair First and Last Name
- Committee Chair Email Address
- Committee Chair Phone Number

Thanks for your partnership as we move Bike MS forward in 2010!

For more information, please contact Doug Suggitt at [doug.suggitt@nmss.org](mailto:doug.suggitt@nmss.org) or 281-576-9397.



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<b>RESEARCH/CLINICAL UPDATE</b>
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	cc: Chapter President, Programs
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**April 1, 2010**

**Email You May Have Received Recruiting for a Survey**

In the past couple of weeks, many chapters were contacted by Margot Goldblum from the company DKBmed, who was seeking the Society's help to recruit people with MS to answer an online survey. The survey was being conducted to help DKBmed develop physician education programs for its clients. Since they reached out nationwide, we asked the company for further information so that we could review this survey per our recruitment policies. In their response, they did not supply additional information and also noted that they now believed they had sufficient information and did not need to recruit further. Therefore, we will not be posting a link to the survey on the national Website and request that chapters refrain from posting it or recruiting for this survey as well.

Please read more about study and survey recruitment policies on the Intranet at [http://intranet.nmss.org/Topics/cr/Lists/Critical%20Info/Attachments/7/Study\\_Survey\\_Recruitment\\_Policies.pdf](http://intranet.nmss.org/Topics/cr/Lists/Critical%20Info/Attachments/7/Study_Survey_Recruitment_Policies.pdf).

Questions? Please contact Sara Bernstein, Manager, Research Information  
[sara.bernstein@nmss.org](mailto:sara.bernstein@nmss.org); 212-476-0419

-- Research and Clinical Programs Department



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

**March 29, 2010**

### **Study Fuels Progress Toward Predicting An Individual's Response to MS Therapy**

Why do some people respond to MS disease-modifying therapies and others do not? This is the basic question underlying a newly published study that, with further research, could lead to tools to predict who would do best on which therapy and usher in the beginning of personalized medicine for people with MS. The study, funded in part by the National MS Society, is by a collaboration led by Lawrence Steinman, MD (Stanford University) and Chander Raman, PhD (University of Alabama at Birmingham). It was published online on March 28, 2010 in **Nature Medicine**

(<http://www.nature.com/nm/journal/vaop/ncurrent/abs/nm.2110.html>).

**Background:** Multiple sclerosis involves immune attacks that target areas of the brain and spinal cord and cause a variety of neurological symptoms. There are seven FDA-approved disease-modifying therapies (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/index.aspx>) for people with MS that can reduce the immune attacks and reduce disease activity. Four of these therapies are interferons.

For reasons that are not clear, a significant proportion of individuals with MS do not “respond to,” or benefit from, interferon therapy, but it can take many months or even years to figure that out. Since earlier treatment has been linked to better outcomes, having a way to predict whether a person’s MS would respond to interferon or other therapy could save months or even years of guesswork and potentially improve outcomes.

**This Study:** In a series of lab investigations, the collaborators tested the idea that response to interferons might depend on which types of immune messengers, called cytokines, were leading the immune attacks typical of MS. They transferred two different types of disease-causing immune T cells into mice, and both were able to produce the MS-like disease EAE. (The two types of T cells are called T helper 1 cells and T helper 17 cells, and each type causes a different pattern of cytokines to become activated.)

Then they tested whether there was any difference in the response of the mice to interferon. They found that interferon reduced EAE symptoms in mice whose disease had been induced by T helper 1 cells, but it worsened disease that had been induced by T helper 17 cells. They also identified which immune messengers were influencing the different responses.

To further explore this phenomenon in human MS, the team examined the profiles of immune messengers apparent in serum samples taken from 26 people with MS before and after they had received interferon therapy, without knowing in advance who had responded to therapy. They found that they could differentiate between those who did not respond to interferon and those who did, based on patterns of cytokines. Those who did not respond had high levels of a cytokine associated with T helper 17 cells (interleukin-17F), and those who did respond had very low levels of this cytokine.

Larger clinical studies will be needed to confirm and expand on these findings and to identify additional potential predictors of therapeutic response not just for interferons but for other MS therapies as well. Nevertheless, this work represents progress toward a future of personalized medicine for people with MS, where doctors would be able to use simple tests to predict optimal treatment regimens for individual patients.

Support for this study included grants from the National Institutes of Health and the National MS Society, especially a postdoctoral fellowship to first author Robert Axtell, PhD, and a Collaborative MS Research Center award to Dr. Steinman, without which, he stated, “this study would never have happened.”

Read more about the Society’s efforts to fuel collaborative research

(<http://www.nationalmssociety.org/research/research-we-fund/collab-research-centers/index.aspx>)

-- Research and Clinical Programs Department