



## CHAPTER PRESIDENTS

January 8, 2010

CC: All

### **New Volunteer Module in Altair Set to Launch February 18, 2010!**

It is with great excitement we announce the new Volunteer Management Module in Altair will be available Society wide beginning February 18, 2010!

The new module began in limited release on October 9, 2009. We ran a successful pilot of the new volunteer functionality from October 19, 2009 – November 20, 2009, and our pilot participants included Southern California, Georgia, New York City, Michigan, Minnesota, Eastern North Carolina, Gateway, Central Pennsylvania and Wisconsin Chapters as well as our Home Office Advocacy and National Board support teams.

With the conclusion of the pilot program, we have been working with our development partner, Epsilon, to implement functionality enhancements identified during the pilot. These changes will go a long way to ensuring strong user adoption once the new system is accessible to everyone.

Additionally, because the new volunteer module has so much functionality, we are developing training based on a modularized approach. Overall course materials will be broken down into individual recorded classes available on the LMS. Society employees will be able to sign up for and take each class on-demand at their own convenience. Each training class will provide in-depth coverage of one of the key feature sets available in the new Volunteer Management Module. The main feature sets include, Individual Volunteer Profile, Group Volunteer Profile, Volunteer Positions, Volunteer Assignments and Reporting. Training for all Society employees will be available on the LMS starting the week of February 8, 2010.

In preparation for our big launch, it is time to start thinking about the different members in your Chapter who will require training and who will need to be knowledgeable about this new tool. This list may include team members from advocacy, events, programs and services, as well as any other staff members or volunteers who assist in the volunteer engagement process.

Stay tuned for more project announcements in the coming weeks. For more information about the new Volunteer Management Module, please contact Sid Wittenberg at [sidney.wittenberg@nmss.org](mailto:sidney.wittenberg@nmss.org) or Leigh Anne Cade at [leighanne.cade@nmss.org](mailto:leighanne.cade@nmss.org).

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### MS Service Day Training and Networking Call

Chapter volunteers and staff are invited to: What a Difference a Day Makes! MS Service Day training and networking call.

Date: Thursday, February 4, 2010

Time: 1:00 ET, 12:00 CT, 11:00 MT, 10:00 PT

On the call, participants will learn MS Service Day best practices from volunteers who launched the Mid Atlantic Chapter volunteer pilot project. Whether you are planning a future MS Service Day for your chapter or you have completed a similar project, it will be an opportunity to learn from the folks who started it all and network with other staff and volunteers.

Topics will include volunteer recruitment, project logistics, background checks, data entry, media opportunities and more.

To join the call:

Go to <https://nmss.webex.com/nmss/k2/j.php?ED=131351337&UID=1025618717>

Dial 800-910-3597 conference code 57448188#

If you have questions, please contact:

Sid Wittenberg

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## DEVELOPMENT

January 8, 2010	CC: Marketing
<b>Bicycling Magazine Ad Kicks Off Partnership With Specialized</b>	

We are excited to let you know that the March issue of *Bicycling* magazine will feature a four-page ad which opens off the front cover (known as a “gatefold”) highlighting Bike MS and driving readers to BikeMS.org through a contest in partnership with Specialized bikes.

- *Bicycling* subscribers will begin to receive the magazine the week of January 25 and it hits news stands on February 2.
- In anticipation of a surge in visitors to BikeMS.org, exciting enhancements to the ride finder are underway creating a more powerful and dynamic marketing site including video.
- Chapters will receive several copies of the magazine featuring our ad. Please share this highly visible marketing piece with key sponsors, top fundraisers, team captains, etc.
- Click here for a sneak preview of the creative  
<http://intranet.nmss.org/Topics/marketing/Documents/BicyclingMagazineAdvetorialComp.pdf>
- **In preparation for the ad, please make sure your event appears on BikeMS.org and that registration is open.** (Chapters should have completed training on creating events on BikeMS.org – please complete a Track-It ticket if you need help.)

### ***Specialized contest kicks off national partnership for Bike MS season***

The ad also serves as the kick-off to a new national partnership with Specialized bikes. We are very excited about the opportunity to associate the Bike MS brand with Specialized and to initiate this relationship for the upcoming Bike MS season.

- The ad promotes a contest for readers to enter and win one of 20 Specialized bikes.
- The bikes are carbon frame mid to elite level styles.
- The contest runs February through April.

- Specialized will handle fulfillment for the winners.
- Chapters will be informed if they have a winner.
- Additional elements of the partnership include visibility through Specialized national email, online and social marketing channels to encourage rider participation.
- The partnership will also focus on local dealer/chapter engagement in select markets including a toolkit for dealers about working with chapters which may include in-store promotions to drive additional Bike MS registration.

We will continue to update you as we move this relationship forward. Questions?

Bicycling magazine ad and contest, contact Rachael Nuwash,  
303-698-6100 x 15136 [rachael.nuwash@nmss.org](mailto:rachael.nuwash@nmss.org)  
Specialized partnership, contact Becca Kornfeld,  
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## RESEARCH/CLINICAL UPDATE

January 8, 2009

### **MS Trial Alert:**

### **Investigators in Buffalo Recruiting for Research Study on Venous Insufficiency, or CCSVI, in People with MS and Others**

**Summary:** Investigators at the University of Buffalo are recruiting 1600 adults and 100 children for a research study investigating the frequency of CCSVI (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2206>) in people with MS when compared to healthy controls and controls with other neurological disorders. The University's Buffalo Neuroimaging Analysis Center of the Jacobs Neurological Institute is funding the study. CCSVI is also the subject of a recently released "Requests for Applications" released by the National MS Society (USA) and the MS Society of Canada seeking grant applications to pursue this potentially important lead.

**Please note: This is not a clinical trial of a therapy. This study is evaluating the prevalence of venous obstruction in people with MS, and does not involve treatment of obstructions. Participants must be able to travel to Buffalo, NY to complete testing.**

**Rationale:** Recent reports are calling attention to the idea that a phenomenon called chronic cerebrospinal venous insufficiency (CCSVI), a dysfunction of brain blood flow and/or blood drainage, may contribute to nervous system damage in MS. A recent study of 65 people with MS compared with 235 controls without MS reported significant evidence of slowed and obstructed drainage in the veins draining the brain and spinal cord in many of those with MS (J Neurol Neurosurgery Psychiatry 2009; 80:392-399). If this hypothesis is confirmed, it may open up new research avenues into the underlying pathology of MS and new treatment approaches to therapy.

Read more about CCSVI: <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2206>

**Eligibility and Details:** Participants should be an adult or child with confirmed MS of any type. The study is also recruiting individuals with neuromyelitis optica, other neurological disorders, and healthy individuals. All participants must have normal kidney function. Participants must not be in active MS relapse or have had steroid treatment in the past 30 days. Conditions that would prevent participation include, among others, vascular or heart problems, severe cognitive impairment/dysfunction, or a history of drug or alcohol abuse.

The study procedures include doppler/ultrasound testing, blood collection, a clinical examination and completion of a questionnaire. Interested participants can also have an MRI (magnetic resonance imaging) scan performed. A subset of these individuals will also undergo an MRI of the neck veins.

**Contact:** To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please call 716-859-1396 or email [ctevd@bnac.net](mailto:ctevd@bnac.net). Please visit [http://www.bnac.net/?page\\_id=517](http://www.bnac.net/?page_id=517) for more information.

[Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial \(PDF\).](#)

-- Research and Clinical Programs Department



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## RESEARCH/CLINICAL UPDATE

January 8, 2010

### **MS Trial Alert:**

### **Investigators in Ohio Recruiting 24 People for Study of Autologous Mesenchymal Stem Cell Transplantation**

**Summary:** Investigators in Ohio are recruiting 24 people with relapsing forms of MS for a study of the safety and tolerability of transplanting one's own mesenchymal stem cells (derived from bone marrow). The study is being conducted at Cleveland Clinic Mellen MS Center, University Hospitals Case Medical Center, and the National Center for Stem Cell and Regenerative Medicine, all in Cleveland. This study is supported by the Congressionally Directed Medical Research Programs, a program funded through the Defense Department, thanks in large part to the tireless work of MS activists across the country who helped to secure the funding. ***Please note: This study involves numerous visits to the study site.***

**Rationale:** There are many types of stem cells, and varying degrees of research and knowledge about different types of stem cells and their potential usefulness for treating MS. At present, there has been no proven therapy for MS that uses stem cells. Read more about stem cells in MS (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=791>).

One type of procedure that has been explored for several years in MS is called "autologous hematopoietic (blood cell-producing) stem cell transplantation." This procedure has been used in attempts to "reboot" the immune system. These stem cells (derived from the bone marrow or blood) are stored, and the rest of the individual's immune cells are destroyed by chemotherapy or radiation or both. Then the stored stem cells are reintroduced by injection. Eventually they grow and repopulate the body with immune cells. The hope of that as yet experimental procedure is that the new immune cells will no longer attack myelin or other brain tissue, so that the person has perhaps a completely new immune system.

Another line of stem cell research in MS relates to efforts to repair nervous system damage. This research is in its infancy, and there is no evidence yet that any types of stem cells can

reverse MS damage or restore function. There are a few known research studies being conducted by researchers who are attempting in a controlled fashion to safely test the ability of mesenchymal stem cells to treat MS damage.

Mesenchymal stem cells, which are present in many tissues of the body, potentially have the ability both to treat immune disorders and promote tissue repair. This phase I clinical trial in Cleveland is testing the ability of an individual's own mesenchymal stem cells isolated from the bone marrow to both inhibit immune mechanisms and to augment intrinsic tissue repair processes in people with relapsing forms of MS. Unlike previous bone marrow transplant studies, in this study the person's immune cells are not destroyed before the stem cells are infused.

**Eligibility and Details:** Participants should be ages 18 to 55, and have a diagnosis of relapsing MS, with active disease during the previous 24 months. This study involves numerous criteria for including or excluding participants. Further details can be obtained from <http://clinicaltrials.gov> (search for study# NCT00813969) or the contacts below.

The treatment involves a single intravenous infusion of mesenchymal stem cells that have been previously removed from the participant's bone marrow and expanded in the laboratory. The study involves several safety assessments, blood tests, neurologic assessments, MRI scans and others tests over six months.

The primary goal of the study is to determine the feasibility, safety and tolerability of the procedure. Secondary goals include assessing the effects on MS disease activity and severity, as measured by clinical, MRI, and other testing.

**Contact:** To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please contact:

Sarah Planchon Pope, PhD  
Program Manager  
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[Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial \(PDF\).](#)

-- Research and Clinical Programs Department



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

Updated January 7, 2010

### **UPDATE: Blood Flow in the Brain and Venous Insufficiency, or CCSVI, in Multiple Sclerosis – Letters of Intent Received from Request for Research Applications Released Worldwide**

**Summary:** Recent reports are calling attention to the idea that a phenomenon called CCSVI, a reported abnormality in blood drainage from the brain and spinal cord, may contribute to nervous system damage in MS. This hypothesis has been put forth by Dr. Paulo Zamboni from the University of Ferrara in Italy. Based on the results of his initial preliminary findings, Dr. Zamboni states that this pilot study warrants a subsequent larger and better controlled study to definitively evaluate the possible impact of CCSVI on the disease process in MS.

It has been proposed by Dr. Zamboni, but not yet proven, that CCSVI may be corrected through endovascular surgery, which involves inserting a tiny balloon or stent into blocked veins in order to permit the flow of blood out of the brain and spinal cord, a procedure that has been called “liberation therapy” in some reports.

UPDATE: The National MS Society is undertaking the funding of new research on CCSVI in MS and has invited investigators worldwide to apply for grants that would explore this lead. In response to a January 6 deadline, the National MS Society and the MS Society of Canada received numerous letters of intent from investigators from seven countries. These letters of intent, which briefly describe the proposed research, will be reviewed and those that meet grant guidelines will be invited to submit full research proposals.

#### **CCSVI Research Funding Timeline**

January 12, 2010 – Investigators whose letter of intent meet guidelines are invited to submit full research proposals with a deadline of February 9, 2010.

May 2010 – International panel of experts conducts an expedited review of all applications received through this special request for applications.

June 2010 – Funding decisions announced.

July 1, 2010 – Anticipated start date for funding of any successful research applications.

The applications will undergo an accelerated review process by an international panel being convened in cooperation with other MS Societies to ensure an expedited, coordinated response. If this hypothesis is confirmed, it may open up new research avenues into the underlying pathology of MS and new treatment approaches to therapy.

**Background:** In a recent study by Dr. Zamboni and colleagues, the team evaluated abnormalities of blood outflow in major veins draining from the brain and spinal cord 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 venous drainage. The investigators reported evidence of slowed and obstructed drainage in the veins draining the brain and spinal cord 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 call this venous obstruction “chronic cerebrospinal venous insufficiency,” or CCSVI. The treatment status of the people with MS (i.e., whether or not they were on an MS disease modifying drug) did not appear to influence whether they showed signs of CCSVI. The authors speculated 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. This study was published in June 2009 (J Neurol Neurosurg Psychiatry 2009; 80:392-399 <http://jnnp.bmj.com/cgi/content/abstract/80/4/392>).

It is proposed, but not yet proven, that CCSVI may be corrected through endovascular surgery. This surgery is being called “liberation therapy” in some reports. 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.

In a small, open-label study by Dr. Zamboni and colleagues published in December, the team evaluated the safety and preliminary outcomes of vascular surgery (percutaneous transluminal angioplasty) in 35 individuals with relapsing-remitting MS, 20 with secondary-progressive MS, and 10 with primary-progressive MS. (J Vasc Surg 2009; 50:1348-1358 [http://www.jvascsurg.org/article/S0741-5214\(09\)01568-7/abstract](http://www.jvascsurg.org/article/S0741-5214(09)01568-7/abstract)) They reported some positive impacts and suggested that controlled trials were necessary to better determine potential safety and benefits of this procedure.

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