CHAPTER PRESIDENTS

Date: 12/18/09	CC:
	Development
2010 Major Giving Winter Meeting	
Action Requested: Save the Date	

Save the dates and make plans to attend the 2010 Major Giving Winter Meeting. You can attend this annual major gift training opportunity in person or virtually.

When: February 18 - 19, 2010
(All day Thursday and ½ day Friday)

Who should attend: Major Gift Officers
Golden Circle Program Managers
Staff responsible for major giving
Staff responsible for Golden Circle

Where: Denver, Colorado

Registration, agenda and accommodations information will be available early in January.

CHAPTER PRESIDENTS

December 18, 2009	**CC:** Development
	Programs and Services
Low Cost/High Impact Program and Service Initiatives Document Now Available	

The document, *Low Cost/High Impact Program and Service Initiatives*, is now available for your use. This resource was developed for the session on "Influencing the Quality of Life for People Living with MS" at the Executive Management Team meeting in November 2009.

In light of tough economic times, this document is an invaluable resource. Chapters have shared information on a wide variety of innovative programs and initiatives that are highly impactful and delivered in a cost-effective manner. Of particular note are the exciting volunteer-driven and community partnership initiatives going on across the country.

Low Cost/High Impact Program and Service Initiatives is available on Sharepoint at Programs and Services>Department Management, Committee and Accessibility Resources.

Thank you to all of the Chapter Presidents who participated in the call for submissions. You and your staffs are doing remarkable and creative work in tough times to move us towards a world free of MS. The document will be updated periodically, and we look forward to reporting on and sharing new and innovative strategies.

Please direct any questions about this document to Heather Webb, Programs & Services Associate Specialist, at heather.webb@nmss.org or 303-698-6100, ext. 15176.

CHAPTER PRESIDENTS

Date: 12/18/2009	
Treatment of Offers to Donate to Chronic Cerebrospinal Venous Insufficiency (CCSVI) Research	

Significant international media attention has focused on whether chronic cerebrospinal venous insufficiency (CCSVI), a dysfunction of brain blood flow and/or blood drainage, may contribute to nervous system damage in MS. We are hopeful that this exciting avenue may lead to promising therapeutic approaches for people living with MS A summary of this topic can be accessed at http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2206. As a result of these news stories, a number of constituents have inquired about the possibility of contributing to research focusing on CCSVI.

Because of the timing issues described below, we ask that you refrain from proactively promoting contributions at this time. However, we expect that donors may approach us to make restricted gifts for CCSVI research.

Should you speak with a donor with this interest, you should understand and share the following information.

1) Requirement of Recommendation through Scientific Peer Review. We are the only MS organization in the nation that is driving an effort to support further research in CCSVI. As you know, the Society's research process requires that Society funds be distributed only to projects that have been reviewed and recommended for funding by our scientific peer review panels. This core tenet of our program ensures that we support the most promising science worldwide. In the case of CCSVI, applications will be reviewed by an international scientific peer review panel. The MS Societies of the US and Canada are taking primary responsibility for convening this panel, and other MS societies that are a part of the international community may participate as well. This is the first time a joint panel has been convened for review of projects on a single topic area, and will ensure that an appropriate range of issues is addressed. We are excited about this new collaborative approach to quickly, effectively and competently analyze and rate submitted projects.

2) Status of CCSVI Project Review. Research applications on CCSVI are due in February with the review to take place later in the spring. The Society will be in a position to distribute funds to CCSVI research when one or more projects are approved at that time.

3) Treatment of Current Donations to CCSVI Research. Donors should know that contributions received cannot be distributed until a project is approved through our peer review process. Any gifts received will be held in a separate account pending the decision of the peer review panel. If a project is approved (and we believe that one or more are likely to be), the contribution will be distributed and the donor will receive an IRS acknowledgment at that time. In the very unlikely event that no projects are approved, we will talk with donors about refunding or redirecting their gifts.

While we do not typically accept and hold donations for projects pending review and approval, we are doing so in this case because of the special circumstances attendant to interest generated by significant media exposure. If you are approached by a donor who is considering a gift, please call Mary Milgrom or Carrie Radant to discuss more detailed considerations.

In addition, it is **essential that gifts directed to CCSVI research be coded in the following manner to facilitate proper tracking**. Please code the gift as usual using the 200 fund code to designate as research. When submitting the monthly remittance report, please indicate the amount for CCSVI. We will track these funds separately at the home office.

Should you have questions about donations for CCSVI, please contact Mary Milgrom at 303.698.6103 (mary.milgrom@nmss.org) or Lisa Risi at 21.476.0424 (lisa.risi@mss.org).

DEVELOPMENT

Date: December 18, 2009	CC:
	Chapter Presidents
Stair Climb Events – Opportunity to Learn More	

If you are planning a stair climb event in 2010 or just want to learn more, mark your calendar now for a 60 minute WebEx call on January 20th at 10:00 a.m. PT, 11:00 a.m. MT, 12:00 p.m. CT and 1:00 p.m. ET. The call will be recorded in case you are not available.

The call, facilitated by our New York City-Southern New York Chapter and Greater Illinois Chapter, will include an overview on events currently produced by other organizations, background on the Society's experience with this event, as well as important logistics, marketing and fundraising tips.

Further details about the call will be coming early next month.

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs

December 18, 2009

Crucial Evidence Supports Autoimmune Nature of Neuromyelitis Optica, an MS Mimic

Two newly published studies lend credence to the idea that neuromyelitis optica (NMO), a disease closely related to multiple sclerosis, is an autoimmune disease that targets one or more specific proteins in the brain, and provide a rationale for new treatment approaches that could also have implications for treating MS. The separate studies, by Jeffrey Bennett, MD, PhD (University of Colorado Denver School of Medicine) and Monika Bradl, PhD (Medical University Vienna, Center for Brain Research) and international colleagues are published in the November issue of *Annals of Neurology* (Ann Neurol 2009;66:617-629 and Ann Neurol 2009;66:630-643).

Background: NMO (also known as Devic's disease) is a disorder that until recently was often considered a variant of MS. It mainly attacks the optic (eye) nerves and spinal cord. As with MS, nerve-protecting myelin is destroyed in NMO by an immune system attack. Although antibodies (proteins made by immune system cells that "recognize" specific parts of cells or other substances) are thought to play a role in MS, their important role in causing nervous system damage in NMO now appears more certain. In addition, treatment for NMO focuses on reducing circulating antibodies such as by using plasma exchange, so finding better ways to distinguish between the two disorders early in the clinical course is one goal of research in these diseases.

A breakthrough in the disease occurred in 2005, when Dr. Vanda Lennon and others at Mayo Clinic identified an antibody that is found in the blood of 70 to 75% of those with NMO and the presence of this antibody is now used as a diagnostic test. However, there is no apparent clinical difference between those people with NMO who have the antibody and those who do not.

The antibody attaches to and flags for destruction a tiny protein, called aquaporin-4, that regulates the flow of water in brain cells known as astrocytes. Astrocytes help support and maintain other cells in the brain and spinal cord. Up to now it has not been clear whether the anti-aquaporin-4 antibodies play a direct role in the disease pathology or are merely bystanders.

New Studies: In two new studies, researchers conducted a series of experiments that help establish the role of anti-aquaporin-4 antibodies in the disease. In the first, Dr. Bennett and colleagues investigated antibodies present in the spinal fluid of an individual who had recently experienced a first attack of NMO and whose blood showed the presence of anti-aquaporin antibodies. The team explored how reactive the antibodies were toward human aquaporin-4 in lab dishes, and found that most attached to aquaporin-4. They also found that a specific anti-aquaporin-4 antibody could produce changes in disease when injected into rats with the MS-like disease EAE, and could also alter the underlying pathology such that the tissue destruction resembled that in NMO. This study was funded by the National Multiple Sclerosis Society, MS Society of Canada, NIH and other supporters.

The second study by Dr. Bradl and team compared the ability of antibodies taken from the blood of people with NMO, MS, other neurological diseases, or healthy controls to alter the course of EAE in rats. Like Dr. Bennett's team, this team found that antibodies from NMO patients whose blood was positive for aquaporin antibodies were able to alter EAE into an NMO-like disease. This study was funded by the European Union, government institutions of Japan, and Innsbruck Medical University.

In an accompanying editorial, Moses Rodriguez, MD (Mayo Clinic College of Medicine) states that both studies "strengthen the argument that NMO is an immune-mediated autoimmune disease process." NMO now becomes the only autoimmune demyelinating disease for which the protein target ("antigen") is known with near-certainty. This opens up the possibilities for learning how to treat demyelinating diseases in an "antigen-specific"manner. This approach carries the potential for stopping the autoimmune disease process without predisposing patients to complications of immune suppression, such as PML or cancer. This has strong implications for the development of future treatments for MS, which is also demyelinating and believed to be autoimmune in nature.

To follow up this work, the National MS Society recently launched a new study by Dr. Bennett identifying other antibodies found in people with NMO, to determine their precise targets and, by testing their impact on a mouse model of MS, exploring their contributions to tissue damage and the possibility that some may play a role in MS.

-- Research and Clinical Programs Department

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs

Updated December 16, 2009

UPDATE: Blood Flow in the Brain and Venous Insufficiency, or CCSVI, in Multiple Sclerosis – *Request for Research Applications Released to Investigators 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.

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. These 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 2009 ECTRIMS 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) They reported some positive impacts and suggested that controlled trials were necessary to better determine potential safety and benefits of this procedure.

Next Steps: The National MS Society has prompted communications between MS Societies worldwide and leveraged resources to ensure an open exchange of information and a coordinated and expedited approach to conducting and evaluating additional research on CCSVI. On December 16, 2009, the Society released a worldwide Request for Applications to the scientific community to explore CCSVI, and is collaborating with the MS Society of Canada and possibly other societies to convene an international panel of experts to conduct an accelerated review of proposals. We are also working with our sister MS Societies around the world to assure that our research strategies are coordinated.

According to the Buffalo Neuroimaging Analysis Center, although 500 subjects have already been selected for their initial combined transcranial and extracranial venous doppler evaluation study, they are still seeking participants for a larger-scale clinical study (http://www.bnac.net/?page_id=517) with the aim of evaluating the prevalence of venous obstruction in people with MS. This study does not involve treatment of obstructions.

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