



CHAPTER PRESIDENTS

11/13/2009

CC: Development

National Research Call on a Rehabilitation Fellowship & the Research it Will Advance Featuring Dr. Fay Horak to be Held November 17th

Rehabilitation in MS is offering promising new leads on ways to restore function and improve quality of life in people with MS. To support this research, the Society offers a mentor-based postdoctoral fellowship in rehabilitation research. This fellowship provides a multi-year award for a well-established mentor to attract young clinician scientists to the field of MS and to train them to conduct MS-specific rehabilitation research.

Join us for a **special research conference call on a recent rehabilitation fellowship award and the important research the fellowship will advance on Tuesday, November 17th at 3:00 PM Eastern.** The 60 minute call features Dr. Fay Horak, recipient of a five-year award to mentor postdoctoral fellows to better understand how MS impacts control of balance and gait in order to design improved rehabilitations programs to improve mobility. The call will be moderated by Dr. Nicholas LaRocca, the Society's Vice President of Health Care Delivery & Policy Research.

Fay Horak, PhD, PT (Oregon Health & Science University, Professor of Neurology) is an internationally-renowned expert on the neuroscience of postural control and the rehabilitations of neurologic disorders affecting gait and balance. She serves as primary mentor over five years to develop a better understanding of gait and balance problems in MS and how to improve them through rehabilitation. Each year she will mentor a new fellow to help advance this research and to continue in the field of MS research and care.

The Society offers a broad range of fellowships to attract scientists and clinicians to the field of MS research and care. Read more about the variety of fellowships offered and their specific goals on the Society's national website at: <http://www.nationalmssociety.org/professionals/researchers/get-funding/index.aspx>.

National research calls are a great way for donors, donor prospects – including Golden Circle 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, research advocates and Golden Circle members or prospects. 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 38910768. 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
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CHAPTER PRESIDENTS

November 13, 2009	CC:
	All
<u>Region Formation Update</u>	

The Region Formation Update presented at the November 5, 2009 Delegate Assembly meeting is posted on the Intranet:
http://intranet.nmss.org/Topics/regional_information/Pages/Formation_of_Regions.aspx

It is also posted on the website www.msmovingforwardtogether.org along with other updates on Charting Our Future recommendations progress.

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DEVELOPMENT

November 13, 2009	CC: Chapter Presidents
<input type="checkbox"/> Do Not Post on NMSS.org	Information Technology (IT)
	System Administrators
Event Redesign Update #4 – New Participant Center 2.0 Available	

We continue to make great progress since our last event redesign update and wanted to share with you the latest. Again, we know that many of you have already set-up your 2010 events but you may want to consider these enhancements. In 2011, they will be a part of the event site set-up so will not be optional.

Available Now:

New Participant Center 2.0 Available (PC2) - The new Participant Center is now available for use. This is a great new tool and we recommend that you use it for your 2010 events. You should consider that it may be confusing for participants who have already logged in to see a different interface when they go back to their Participant Center. Make sure to prepare messaging to let them know that the look and feel will be changing, however, there are many new enhancements that make fundraising and recruitment even easier.

Please read the IT News Sheet titled [New Participant Center 2.0 is Now Available](#) for instructions on how to enable this new feature.

Left Hand Navigation - Through usability testing, we have created some guidance based on feedback for effective left hand navigation. Here is an outline of how to best map your event navigation to make it easier on your participants to find what is important to them and us:

- (In order)
- Home
- My Account
- Register
- Donate
- Volunteer
- Event Details
- Fundraising
- Teams

Contact Us

An important change to note is the use of 'My Account' instead of 'My Participant Center' to follow common web practice.

For a visual of this left hand navigation and how it differs from before, there are two resource documents to reference: [Current vs. Updated Left Navigation Titles](#) and [2010 Event Site Structure](#).

CMS Content Pages - When setting up the 2010 marketing landing page in the CMS, please include the following key information. Numbers 1 - 4 should be above the fold (the area on the Web site that is displayed when the user lands on the page before any action is taken).

1. Name of the Event
2. Event date(s)
3. Registration links (participate, volunteer) and Donate link
4. Event location
5. Event description
6. Event photos

We have created the following 'mock' CMS marketing landing pages (where people will be directed when they click on the event link from WalkMS.org or BikeMS.org) are as visual aid to help you see how your page should look. Click on the links below or copy and paste the URL into a new browser window:

Bike: <http://staging.nationalmssociety.org/chapters/event-redesign-mock-site/fundraising/bike-ms/index.aspx>

Walk: <http://staging.nationalmssociety.org/chapters/event-redesign-mock-site/fundraising/walk-ms/index.aspx>

Coming later this month (November):

- Updated Event Wrappers for Convio Pages – we have new branding for the Convio event wrappers that matches the 2010 Walk MS, Bike MS and Challenge Walk core marketing materials.
- Ability to create child pages when using the new wrappers (sub links under the main left hand navigation link). Training information will be provided soon.

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Duanyelle West, Senior Analyst; 303-698-6100 x 15145

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INFORMATION TECHNOLOGY (IT)

Date: 11-16-09	CC:
<input type="checkbox"/> <u>Do Not Post on NMSS.org</u>	X
	X
	X
	X
<u>New Participant Center 2 Is Now Available</u>	
Action Requested/Deadline:	

The New Participant Center 2.0 (PC2) is now available. PC2 has been completely redesigned and re-architected to a more easy-to-learn and easy-to-use fundraising tool for Team Raiser (TR) participants.

Can I turn on PC2 and turn it off again?

Yes, you can enable PC2 for a published event. You can turn it off again, but any Email Drafts that have been saved may appear as Suggested Message Templates, and new features (Groups and Sent Messages) will no longer be available.

If the TR event is already open, please consider that it may be confusing for participants who have already logged in to see a different interface when they go back to their Participant Center.

How do I enable PC2?

There are only a few steps to enable PC2. Please click on the links below to access the instructions needed to enable and configure PC2 for your TR.

- [Enabling PC2 on Convio TR](#) – Use this document to update the TR
- [PC2 Changes](#) – Example (screen shots) of the changes made to PC2 that the participant will see. **Please note:** The PC2 Changes document will not be ready until Monday, November 16, 2009.

Both documents are located on SharePoint within Information Technology, Applications, under User Documents.

If you have any questions, please submit a Track It ticket at <http://support/selfservice> (on Society infrastructure) or <http://support.nmss.org> (not yet on Society infrastructure)



PROGRAMS & SERVICES

November 13, 2009	CC:
	Chapter Presidents
	Development
Grant Search Resource	

Chapter and home office staff are invited to become authorized users of the *Foundation Center's Directory Online Platinum*. Since starting the subscription in 2003, over 100 program and development staff members from chapters and the home office have registered. Users report a high level of satisfaction with the service. Comments indicate that the directory is easy to use and enhances the grant search process.

The Foundation Directory Online Platinum offers complete profiles of 98,000 grantmakers and over 1,200 corporate giving programs. The different search fields allow users to search among trustees, officers, and donor names. This service also includes detailed descriptions of over 1.8 million grants, searchable by zip code, congressional district, and more. The online directory is updated on a regular basis, thus offering the most current information available on grant funding sources.

This service is offered at no cost. Current users can continue to use the same access information. There are some restrictions imposed by the type of subscription we have, specifically there is a limit to the number of users logged on at any one time. In the event that you are prohibited from logging in, please try again at a later time.

If you are interested in becoming an authorized user or for more information, please contact me (contact information below).

From:
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PROGRAMS & SERVICES

11/13/09	CC: Advocacy
	Chapter Presidents
Medicare Rx Plan Enrollment 2009	

→ The Annual Coordinated Election Period for Medicare Prescription Drug Plans for 2010 begins Monday, November 15 and ends Thursday, December 31st.

For most Medicare beneficiaries, this six-week period is the only time of year to enroll in or switch drug plans. For that reason, it is important to remind Medicare beneficiaries and their caregivers to carefully review their plan options, with help from the Society or other resources, before committing to a drug plan for the upcoming year. People currently enrolled in a drug plan who do nothing will continue with their same plan in 2010, but all drug plan participants will see some out-of-pocket costs go up. In addition to cost increases, other changes that drug plans can impose for the upcoming plan year include changes to their formulary (drugs covered by the plan), as well as requirements for prior authorization or step therapy, quantity limits and more. All current plan enrollees should have received a letter from their plan in October detailing any changes likely to effect them in 2010, and extensive details on all drug plan options can be reviewed at www.medicare.gov.

The IRC Staff in Denver is available to help any clients or caregivers review drug plan options and help them make best use of information and benefits. Additionally, information about Medicare Prescription Drug Plans, including up-to-date cost information for 2010, is available in the 'Living with MS' > 'Money Matters and Insurance' section of the national website. Reminder notices are once again included in Fall 2009 edition of Core Pages. Finally, background and resource materials about Medicare Prescription Drug Plans, also known as Medicare Part D plans, is available for new staff, volunteers or interested others on SharePoint. (See Medicare Part D under Programs & Services, Employment & Insurance Resources)

For additional information, contact Kim Calder (kim.calder@nmss.org) or Kris.Erickson (kris.erickson@nmss.org). ←



PROGRAMS & SERVICES

November 13, 2009	CC: Chapter Presidents
<input type="checkbox"/> <u>Do Not Post on NMSS.org</u>	Development
	Marketing
<u>The Heuga Center for Multiple Sclerosis Changes Name to Can Do Multiple Sclerosis</u>	

The National MS Society and The Heuga Center for Multiple Sclerosis have collaborated on a wide variety of initiatives in recent years. Encouraged by the success of these efforts and the Society’s continuing commitment to effective partnerships, our organizations have been working more and more closely over the past 6-12 months. We expect to announce a formal partnership between the Society and The Heuga Center for Multiple Sclerosis – largely centered on programs & services and marketing – in the coming months. In the meantime, please be aware of the following changes taking place The Heuga Center for Multiple Sclerosis.

The Heuga Center for Multiple Sclerosis recently announced that the organization’s new name is Can Do Multiple Sclerosis. The organization’s leadership believes the new name best reflects the organization’s core beliefs, builds a stronger brand and creates new national collaborative opportunities with outside organizations.

“Twenty-five years ago our organization’s founder, Jimmie Heuga, introduced a pioneering philosophy of active self-care that inspired people to act on the belief that they are more than their MS,” said Kim Sharkey, CEO, Can Do MS. “Our new name and brand reflect our growing role as a unique educator that uses health, wellness and lifestyle principles to empower people with the knowledge, skills, tools and confidence to realize their power to create well-being and transform their lives. Our CAN DO, CAN DO 2 and JUMPSTART programs have helped thousands of people living with MS reclaim a sense of dignity, control and freedom by teaching them how to take charge of their MS and tailor lifestyle strategies to help them live their best lives.”

Can Do MS connects the expertise of industry professionals from across the field of MS care management, including neurologists, psychologists, occupational and physical therapists, speech and language pathologists, registered nurses, physicians and nutritionists. It offers programs that address the needs, concerns and challenges of support partners, such as family members or friends. The programs allow support partners to be acknowledged, understood, accepted and respected by a community of peers and health professionals. The organization

also works collaboratively with MS care providers and organizations to support the journey to more empowered living.

Stay tuned for more information about the Society's partnership with Can Do MS.

For more information, please contact Kim Koch, Programs and Services Department (303-698-6100, ext. 15158 or kimberly.koch@nmss.org) or Chris Yankee, Marketing and Development Department (303-698-6100, ext. 15161 or chris.yankee@nmss.org).



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RESEARCH/CLINICAL UPDATE

November 13, 2009

MS Trial Alert:

Recruiting Nationwide for Study of Copaxone in Patients with First Episode of Acute Optic Neuritis

Summary: Investigators at sites throughout the United States are recruiting 200 people who have experienced one episode of acute optic neuritis, to determine whether nerve fiber loss can be minimized with administration of glatiramer acetate (Teva Pharmaceutical Industries) treatment. Optic neuritis is an inflammation of the optic nerve, and often is the first symptom of multiple sclerosis. The study is funded by Teva Pharmaceutical Industries.

Rationale: Glatiramer acetate is a synthetic protein that simulates myelin basic protein, a component of the myelin sheath that insulates nerve fibers in the brain and spinal cord. This drug seems to block myelin-damaging T-cells through a mechanism that is not completely understood. Glatiramer acetate is approved by the U.S. Food and Drug Administration to treat patients with relapsing-remitting MS and individuals who have experienced a first clinical episode (clinically-isolated syndrome) and have MRI features that are consistent with MS.

In animal models, glatiramer acetate has shown some ability to reduce nerve fiber loss. In the current study, investigators are studying whether the drug can protect against thinning of the optic nerve (indicative of nerve fiber degeneration) in people who experience a first episode of optic neuritis. Often, these people go on to develop MS.

Eligibility and Details: Participants will be aged 18 to 45, and will have experienced first episode of acute optic neuritis. Participants must be enrolled in the study no more than 9 days after the onset of visual disturbance. A diagnosis of MS will exclude people from participating in this study.

Participants will receive either glatiramer acetate (20 mg) or placebo daily delivered via injection under the skin) for six months. The primary endpoint is to compare changes in retinal nerve fiber layer thickness. Secondary endpoints include measures of visual function.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please visit <http://www.tevaclinicaltrials.com/Acute-Optic-Neuritis/default.aspx>. Sites are located in the following cities:

Durham, NC
Atlanta, GA
Baltimore, MD (2 sites)
St. Petersburg, FL
Berkeley, CA
Richmond, VA
Rochester, NY
Newark, NJ
Seattle, WA
Peoria, IL
Charlotte, NC
New York, NY
New Brunswick, NJ
Tallahassee, FL
Syracuse, NY
Buffalo, NY
Fort Collins, CO
Oklahoma City, OK
Glenview, IL
Philadelphia, PA
La Jolla, CA
Charlottesville, VA
Missoula, MT
Salt Lake City, UT
Minneapolis, MN
Miami, FL
Pompano Beach, FL
Albany, NY
Aurora, CO
Grand Rapids, MI
Golden Valley, MN
Houston, TX
St. Louis, MO
Prairie Village, KS
Milwaukee, WI

[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

November 13, 2009

Minimally Invasive Radiosurgery May Improve MS Facial Pain that Does Not Respond to Drugs

Researchers report that minimally invasive surgery using precision radiation (known as gamma knife radiosurgery) relieved facial pain known as trigeminal neuralgia in a group of 37 people who had not fully responded to standard treatments. Dr. Douglas S. Kondziolka (Peter J. Jannetta Professor of Neurological Surgery, University of Pittsburgh School of Medicine) and colleagues report their findings in *Neurology* ([2009;73:1149-1154](#)).

Background: Pain syndromes are common in MS. Trigeminal neuralgia is a stabbing pain in the face. It can occur as an initial symptom of MS. While it can be confused with dental pain, this pain is neuropathic (caused by damage to the trigeminal nerve) in origin. It can usually be treated with medications such as the anticonvulsants carbamazepine (Tegretol[®], Novartis Corp.) or phenytoin (Dilantin[®], Warner-Lambert Co.), and some types of surgery have also been used with mixed success.

Gamma knife radiosurgery has been suggested as an alternative approach for MS-related trigeminal neuralgia that is not controlled by medication. This surgery does not involve incisions, but is performed by applying intersecting beams of radiation precisely focused on the area in the brain thought to be causing the pain. Gamma knife radiosurgery has been used extensively for the treatment of tumors, and it has been used for treating trigeminal neuralgia caused by other conditions. Its usefulness for treating MS trigeminal neuralgia has not been well studied.

The Study: The team reviewed the cases of 37 people with MS and trigeminal neuralgia who had been treated over a 12-year period. All patients had undergone treatment with various medications for this syndrome, and 78% had undergone prior surgery without adequate relief. The patients were followed for a mean of 56.7 months. Pain relief was assessed using the

Barrow Neurological Institute scale, with categories ranging from pain-free to no pain relief whatsoever.

Complete pain relief after radiosurgery was noted by 23 patients (62.1%) and reasonable pain control – categorized as complete, occasional or some pain improvement – was noted by 36 people (97.3%) at some point during follow-up, and was maintained in 82.6%, 73.9%, and 54% of patients after 1, 3, and 5 years. Fourteen people (37.8%) underwent a second procedure for residual or recurrent pain. After surgery, two people had facial sensory dysfunction, but it was not disabling, and none reported worsening of MS symptoms.

Comment: The authors comment that a definitive study would require a randomized comparison with medication, but that this type of surgery may be an attractive approach to managing trigeminal neuralgia in people with MS who do not respond to medication, because it has a low rate of complications and can be repeated if necessary.

[Read more](#) about managing MS-related pain.

-- Research and Clinical Programs Department

Dilantin is a registered trademark of Warner-Lambert Co.
Tegretol is a registered trademark of Novartis Corp.



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

November 13, 2009

Harvard Study Links Teen Obesity in Girls to Increased Risk of Developing MS

A study of more than 200,000 female nurses suggests that those who were obese at the age of 18 were twice as likely to develop MS later in life. Obesity during earlier childhood or in adulthood was not associated with increased MS risk. Based on this study in women, it is not clear whether the same would hold true for teenaged boys. Kassandra L. Munger, ScD, Alberto Ascherio, MD, DrPH, and colleagues (Harvard School of Public Health, Boston) report their findings in *Neurology* ([2009;73:1543-1550](https://doi.org/10.12149.2009.73.1543-1550)).

Background: While MS is not contagious or directly inherited, epidemiologists—the scientists who study patterns of disease—have identified factors in the distribution of MS around the world that may eventually help determine what causes the disease. These factors include gender, genetics, age, geography, and ethnic background. This study explores whether weight is a factor that affects MS risk.

The Study: The Harvard team collected information from women aged 25 to 42 who enrolled in the Nurses' Health Study (a cohort of 121,700 female registered nurses) and Nurses' Health Study II (116,671 female nurses). During the course of the study, women reported their height and weight currently, and at age 18, and if there was a diagnosis of MS. Also, women selected a silhouette that described their body size at ages 5, 10, and 20. The investigators computed the body mass index (BMI), a measure of body fat based on height and weight. A BMI greater than or equal to 30 (kg/m²) is considered obese. Over the course of 40 years of follow-up, 444 cases of definite MS and 149 cases of probable MS developed among the nurses.

Women who had a BMI of more than 30 at age 18 were more than twice as likely to develop MS. Having a large body size (based on silhouettes) at age 5 or 10 was **not** associated with an increased MS risk, but a large body size at age 20 was associated with a 96% increase in MS risk. Adult BMI was not associated with increased MS risk.

Comment: Based on this study in women, it is not clear whether the same would hold true for teenaged boys. The authors comment that while a strength of this study is the large sample size, the reliance on “self-report” is a limitation. They hypothesize that if an association between teen obesity and MS is confirmed, a possible biologic mechanism might be the lower levels of vitamin D associated with obesity. Growing evidence indicates that vitamin D may help protect against the development of MS.

[Read more](#) about healthy living with MS.

-- Research and Clinical Programs Department