National
Multiple Sclerosis
Society
News Sheet

ADVOCACY

Date:	CC:
November 2, 2009	Chapter Presidents
	Advocacy
	Programs
Nomination for US Representative, Senator and Governor of the Year	

Time to Acknowledge
Your U.S. Representative, U.S. Senator, and Governor

- Award Nominations due **before Friday December 18, 2009** -

While many in Washington and across the country are focused on finishing the business of the 1st session in the 111th Congress, now is the time to take a moment and recognize those who have helped us during 2009. What have your elected officials done to move us closer to a world free of MS? How have they joined the movement? Maybe your U.S. representative helped champion funding for MS research within the CDMRP or was a leader in the introduction of some of the legislation we worked on. Did your governor support funding for prescription drug assistance programs or boost programs for people with disabilities? Is your U.S. senator someone who is a key player and supports MS issues? It's time to identify those decision makers who have supported public policies or encouraged changes in the past year that benefited people living with MS.

We are calling for your nominations to acknowledge and award the National MS Society's annual U.S. Representative of the Year, U.S. Senator of the Year, and Governor of the Year. **The deadline for 2009 nominations is December 18, 2009.**

This award can be a strong relationship builder for your chapter. It helps bring attention to the Society and raises awareness for the needs of people with MS. It also can create a loyalty toward MS issues that could help us overcome future challenges. Most importantly, it says, thank you for joining the movement.

NOMINEE QUALIFICATIONS

- A record of advocacy and support for benefits, programs, and services that help people with MS — including biomedical research, quality and affordable health care, long-term care, health insurance, employment related assistance, physical accessibility, or prevention of discrimination.
- Visibility or recognition in your state as a champion for any of those issues.
- A history of involvement with the Society or one/more chapters.

SELECTION PROCESS

- The Public Policy Office will review all nominations and make recommendations to the National Board of Directors. The Board will make the final selection.
- 2009 winners will be invited to speak at the 2010 Public Policy Conference in Washington, D.C.

INSTRUCTIONS

- In one page, please describe your nominee's leadership and accomplishments in health and disability policy, in public awareness about related issues, and in terms of the qualifications above.
- Tell us how your nominee has moved us closer to a world free of MS.
- Include specific examples of legislation, action, publicity, and Society involvement.
- Add photos. Name drop. Be creative.
- Include your name, chapter, and contact information.
- For consideration e-mail or fax your nomination to Shawn O'Neail before December 18, 2009. shawn.oneail@nmss.org or fax 202-408-0696.

CHAPTER PRESIDENTS

11/6/2009	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/for-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
303.698.6100 x 15165, carrie.radant@nmss.org

National
Multiple Sclerosis
Society
News Sheet

DEVELOPMENT

Date: 11/06/09	CC:
	Chapter Presidents

TrainingPeaks Training Software for Bike MS 2010

Based on the success of our pilot project, we're please to announce that TrainingPeaks will be available to ALL Bike MS participants in 2010.

An email went out to Bike MS staff on Monday, November 2nd with information about the program and how to roll it out to participants in the upcoming event season. A summary of this information is included below.

TrainingPeaks.com is the "Official Training Software" of BikeMS. TrainingPeaks gives our participants access to customized Bike MS training plans as well as the ability to map their rides, keep a food diary and workout log, and track their heart rate, power, speed and much more either manually or by uploading exercise data from one of more than 80 popular training devices.

Joe Friel, endurance coach, author of the *Cyclist's Training Bible* and owner of the coaching company TrainingBible Coaching is now the "Official Coach" of Bike MS. Joe has developed a range of training plans for our cyclists that are available on the TrainingPeaks software to provide Bike MS participants with the motivation and skills necessary to arrive well-prepared for their Bike MS experience, allowing them to finish their event eager to return for the following year.

The support available through Training Peaks will ensure that all Bike MS participants have access to the training and tools they need to meet their own personal challenge and enjoy the ride – regardless of their level of experience. Bike MS riders bring millions of dollars to the MS cause, so we want to honor their extraordinary efforts by providing the very best tools available to support their training and ride experience.

BikeMS event participants will have their choice of 6 cycling plans designed by Joe Friel for various route lengths -- from 50 miles to 150 miles, and ability levels -- from the beginner to the experienced rider. Participants will receive daily email workout reminders and they can

track their progress as they move toward the day of the event in either a free Basic Personal Edition or in a Premium Personal Edition TrainingPeaks account for a monthly subscription fee.

A special thank you to our Pilot chapters: Central New England, Greater Delaware Valley, Lone Star, Mid Atlantic, New York City, and North Florida

For questions about TrainingPeaks, please contact Sarah Klein at sarah.klein@nmss.org or 518-952-4153.

National Multiple Sclerosis Society
733 Third Avenue
New York, New York 10017-3288
Tel +1 212.986.3240
Fax +1 212.986.7981
E-mail nat@nmss.org
Nationalmssociety.org

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 glatirmamer 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
Charlottesvile, 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

National Multiple Sclerosis Society
733 Third Avenue
New York, New York 10017-3288
Tel +1 212.986.3240
Fax +1 212.986.7981
E-mail nat@nmss.org
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

November 6, 2009

Fast Forward Think Tank Explores Personalized Medicine and the Translation of High-Tech Lab Discoveries to Improving Treatment of MS

How do we take the explosion of information coming from high-tech MS studies and ultimately develop simple lab tests that would enable a doctor to quickly diagnose MS, to predict the disease course in any individual, and to predict which therapy would work best?

Progress and roadblocks to this dream of "personalized medicine" for people with MS were themes of a mid-October Think Tank held by Fast Forward, the drug development subsidiary of the National Multiple Sclerosis Society. Some 50 leaders from academic institutions, biotech and pharmaceutical companies, and voluntary health agencies came together to share data and engage in lively discussions during the meeting, hosted by the David H. Murdock Research Institute at the North Caroline Research Campus in Kannapolis.

Information Explosion: Advances in biotechnology are permitting complex experiments to be completed in hours or days rather than the weeks or months they would have taken a decade ago. But the advances are not just about speed. These high-tech genomic, proteomic and other "omic" studies are producing millions of data points – "an avalanche of information," as it was called by presenter Stephen Sawcer, PhD (University of Cambridge). This avalanche -- requiring super-powered computing and analysis to begin to reveal connections and biological interactions – is already changing the face of biomedical research in general, and MS research in particular.

With this tech explosion comes the possibility of uncovering not only the genes that make people susceptible to MS and may control other aspects of the disease, but also the possibility of finding "biomarkers" – the signature presence of substances or traits that will translate into tests that can consistently predict disease onset, disease progression, or response to treatment. Beyond personalized medicine, many experts also agree that having reliable MS biomarkers would also enable quicker results from clinical trials of new therapies.

This point was stressed in the introductory remarks by National MS Society Executive Vice President for Research and Clinical Programs John R. Richert, MD, when he described the critical importance of identifying MS biomarkers, combined with better outcome measures, that could speed clinical trials and reduce the number of trial participants needed to test new therapies.

Genetics: Several members of the National MS Society-funded International MS Genetics Consortium and others presented current data on the dozen or so gene variations that have been confirmed as being linked to susceptibility (and resistance) to MS. Dr. Sawcer called the variations identified thus far the "tip of the genetics iceberg" of unknown proportions. (The largest whole-genome scan ever undertaken in MS, now being done by the Consortium with funds from the Wellcome Trust, the National MS Society and other funding agencies, will ultimately involve 20,000 patients and should identify many more common variations that play roles in MS susceptibility.)

Think Tank co-chair Jorge Oksenberg, PhD (University of California, San Francisco) reminded participants of the variability of MS, and he detailed some of the ways his team is investigating how gene variations come together to produce MS "phenotypes," or observable characteristics of the disease. Investigators have been looking at how specific gene profiles might influence, for example, a person's response to interferons. Dr. Oksenberg said that the MS trait that so far has the strongest evidence of genetic influence is age at disease onset. He and others stressed the importance of digging into the functions of the genes identified thus far, many of which relate to immune function, and how they influence other molecules and functions. "We need to look at pathways and networks, not just genes," he commented.

Along those lines, Philip De Jager, MD, PhD (Harvard's Brigham and Women's Hospital, Boston) described his work dissecting the functional consequences of a specific gene variant. With funding from a Harry Weaver Neuroscience Scholar Award from the National MS Society, his team has been studying the gene variant on chromosome 1 called "CD58," which actually appears to reduce the risk of MS in people who carry this variant. The variant appears to produce immune-system changes that increase the production of CD58, and his team has also found that this gene's "expression" – how active it is – is lower in people who have MS and in particular in people during MS relapses. This is just one example of how digging down to understand MS gene variations may provide substantial leads to what's going wrong in MS and how to fix it.

Additional ways to alter gene expression were discussed by Simon Gregory, PhD (Duke University and the David H. Murdock Research Institute), also a co-chair of the Think Tank. He described several other factors that can control genes, regulate the amount of gene activity, and even silence them... (Continued...) Download a PDF of the entire article http://www.nationalmssociety.org/fast-forward/fast-forward-news/download.aspx?id=15949

National Multiple Sclerosis Society
733 Third Avenue
New York, New York 10017-3288
Tel +1 212.986.3240
Fax +1 212.986.7981
E-mail nat@nmss.org
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs

November 6, 2009

Society-Funded Researchers Show that Early Relapses Link to MS Progression

A group funded by the National MS Society reports that more relapses early in the course of MS were associated with increased disease progression in a study of 2,477 people with MS, but that this effect diminishes over time. Helen Tremlett, PhD, and colleagues (University of British Columbia, Vancouver) report these results in *Neurology* (2009;73:1616-23).

Background: The course of MS can involve both relapses – exacerbations or flare-ups that involve new symptoms or worsening of old symptoms – and disease progression (persistent worsening of neurologic symptoms, and development of sustained disability). Although we have some clues, we don't yet fully understand what triggers relapses or what causes MS to progress. The disease progression rate, severity, and specific symptoms of MS are unpredictable and vary from one person to another. In light of these uncertainties, Dr. Tremlett aimed to study the impact of both early and later disease relapses on disease progression over time.

The Study: Dr. Tremlett's team retrospectively reviewed the histories of 2,477 people with MS selected from the British Columbia MS database. Cases were included if MS had a relapsing onset (as opposed to immediately progressive) and if diagnosis occurred before July 1988. The cases had been followed for an average of 20.6 years.

The group looked at the impact of relapses at different time periods on disease progression, which for this study was defined as progression to an EDSS score of 6 or the onset of secondary-progressive phase of disease. (The EDSS is a scale that measures MS disease severity. A score of 6 is assigned when the individual requires the use of a cane for walking. Secondary-progressive MS is a course of steadily worsening disease with or without occasional flare-ups, which often follows an initial period of relapsing-remitting MS.)

They focused on the relationship between relapses during the first five years of MS, years 5 to 10, and after more than 10 years, and progression. People who had more relapses within the first five years of disease were more likely to reach an EDSS of 6. Relapses during this period had the most impact on early disease progression. However the association between early relapses and progression decreased over time, so that people with early relapses who did not experience significant progression early in the course of their disease (did not require a cane to walk by year 10 or did not transition to secondary-progressive disease) were only slightly more likely to at longer-term follow-up.

Dr. Tremlett also found that relapses in people under the age of 25 had a more enduring impact on disability compared to those 35 years of age and older. This underscores the importance of early treatment to prevent relapses and hopefully, future disability.

Comment: In an accompanying editorial, Ruth Ann Marrie, PhD (University of Manitoba, Winnipeg, Canada) and Gary Cutter, PhD (University of Alabama, Birmingham) comment that teasing out the role of relapses is important because disease-modifying drugs that are approved to treat MS clearly reduce relapse frequency but have shown only moderate effects on disability progression in the limited duration of most clinical trials. However, they caution against underestimating the role of relapses, despite the fact that Dr. Tremlett's team found a diminishing effect of relapses on disability progression over time.

"The financial cost of a single severe relapse is estimated at more than $10,000," write Drs. Marrie and Cutter. "The emotional costs—including anxiety and anger—and social costs are also high. While moderate or severe gait dysfunction is inherently important and more easily measured than other domains, domains such as vision, cognition, and hand function are also important."

More research is needed to understand the full effects of relapses on disability progression, and how disease-modifying drugs impact the long-term course of MS.

Read more about coping with exacerbations and progression in MS.

-- Research and Clinical Programs Department

National Multiple Sclerosis Society
733 Third Avenue
New York, New York 10017-3288
Tel +1 212.986.3240
Fax +1 212.986.7981
E-mail nat@nmss.org
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs

November 6, 2009

Results Published from Rituximab Study in Primary-Progressive MS

Primary Endpoint Not Reached but Subgroup Analysis Shows Evidence of Benefit in Younger Patients with Active Disease

A study of intravenous rituximab (Rituxan®, Genentech and Biogen Idec) in 439 people with primary-progressive MS* has shown that the drug did not slow disease progression when compared with inactive placebo, the primary endpoint of the study. However, MRI scans suggested some benefit, and an analysis of subgroups within the study showed significant delays in patients younger than age 51 and with active disease observed on MRI scans. Early results from this OLYMPUS study were originally reported in a press release in 2008, and at the American Academy of Neurology Annual Meeting in 2009, and now Kathleen Hawker, MD (The Ohio State University Medical Center, Columbus) and colleagues have published their complete findings in *Annals of Neurology* (2009;66[4]:460-471)

Background: Rituximab binds to a molecule (CD20) on the surface of B cells and depletes them from the circulation for an average of 9 months. B cells are immune cells that make antibodies and may play a role in the immune attack on brain and spinal cord tissues in multiple sclerosis. Rituximab is approved for treating some forms of cancer. Researchers reported earlier this year that in a phase 2 study, one intravenous course of rituximab reduced disease activity and relapses for 48 weeks in people with relapsing-remitting MS** (*The New England Journal of Medicine* 2008 Feb 14;358[7]:676-88). The current study evaluated the safety and effectiveness of rituximab in people with primary-progressive MS, a course of MS for which no specific treatments are currently on the market.

The Study: The study enrolled 439 subjects at 60 sites in the United States and Canada. Participants were age 18-65 years, had primary-progressive MS, and had had MS for at least one year. Patients were randomly assigned to receive either four intravenous doses of Rituxan or inactive placebo every six months for 96 weeks. Brain MRI scans were conducted before

treatment, and at weeks 6, 48, 96 and 122. The primary outcome measured was the time to confirmed disease progression.

Rituximab did not reduce the time to disease progression, as compared with placebo. However, in a secondary endpoint, those on therapy had significantly less increase in brain lesion volume on MRI scans after 96 weeks. In addition, the study was designed to tease out effects in subgroups of patients. These further analyses showed that disease progression was significantly delayed in participants who were less than 51 years of age and in those whose pre-treatment MRIs showed signs of active (gadolinium-enhanced) brain lesions indicative of inflammation. This benefit was more pronounced in people younger than 51 with active brain lesions. The investigators conclude that these results will inform the design of future trials involving people with primary-progressive MS.

Serious adverse events occurred more often (16.1%) in the rituximab arm than in the placebo group (13.6%), with serious infections occurring more often in the rituximab group (4.5% vs. less than 1%) as well. There were more infusion-related reactions with rituximab, mostly mild to moderate in severity.

Comment: In an accompanying editorial, Hans-Peter Hartung, MD, and Orhan Aktas, MD (Heinrich-Heine-Universität Düsseldorf, Germany), comment: "The important and undoubtedly encouraging findings from the OLYMPUS trial presented here would suggest that PPMS anti-inflammatory and/or immunomodulatory therapy may be beneficial in younger patients with more rapid progression… Therefore further trials with rituximab or other CD20-directed monoclonal antibodies such as ocrelizumab or ofatumumab are definitely warranted in this particular patient population." (A phase II study of ocrelizumab and a dose-finding study of ofatumumab are ongoing in people with relapsing-remitting MS, but not in primary-progressive MS. These trials are listed on clinicaltrials.gov.)

Read more about living with primary-progressive and other progressive courses of MS.

-- Research and Clinical Programs Department

*Primary-progressive MS is a course of MS characterized by a slow but nearly continuous worsening of disease from the onset.

**Relapsing-remitting MS is a course of MS characterized by clearly defined flare-ups followed by partial or complete recovery periods (remissions) free of disease progression between attacks.