



CHAPTER PRESIDENTS

January 29, 2010	CC: Development
National Research Call on the State of Society and MS Research to be Held Feb. 8th	

A special research conference call on the **State of Society and MS Research** is being held Monday, **February 8th at 2-3 PM Eastern**. This 60 minute call will feature Dr. John Richert and Dr. Richard Rudick. They will discuss the most important MS research milestones, recent research accomplishments, and their views of the research areas and anticipated findings that will be most important in 2010. The last 20-25 minutes of the call will be reserved for questions from call participants.

Dr. John Richert is the Society's Executive Vice President for Research and Clinical Programs. He heads the world's leading MS biomedical, clinical and healthcare policy research initiatives and oversees the Society's extensive professional information and education programs. Dr. Richert has been at the Society since 2005 and under his leadership, the Society has launched bold new strategic efforts to increase its role as a driving force in MS research.

Dr. Richard Rudick is both Director of the Mellen Center for MS Treatment and Research and Vice Chairman of Research and Development at the Neurological Institute at the Cleveland Clinic. Dr. Rudick is also Chair of the Society's Research Programs Advisory Committee. He has played key roles in several pivotal MS clinical trials, continues studies on immunologic changes in MS patients, and has led development of new clinical and imaging measures for MS trials. In addition, he continues to see MS patients at the Mellen Center.

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 53580453. 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



CHAPTER PRESIDENTS

January 29, 2010	CC: All
Save the date! 2010 November Leadership Meeting	

The dates for the 2010 meeting are slightly different than prior years, so please mark your calendars now. Our goal continues to be to provide motivation, celebration, and educational opportunities that enable each attendee to not only personally remain engaged and committed to the MS movement, but to network and share ways in which we all can move others.

When: November 10-12, 2010

Where: Sheraton Chicago Hotel & Towers, Chicago, IL

Key Activities Anticipated: Executive Management Team Meeting, National Board of Directors Meeting, New Board Chair Orientation, Delegate Assembly, Team Captain Rally and Tour of Champions

More information will be forthcoming – including meeting schedules and open registration, which is anticipated for September. We look forward to seeing you in Chicago!



DEVELOPMENT

January 29, 2010	CC: Chapter Presidents
<u>2010 Individual Giving Winter Meeting</u>	
Action Requested: Confirm Participation by 2/8/10	

All staff members responsible for major giving and/or the Golden Circle program are encouraged to participate in the 2010 Individual Giving Winter Meeting either by attending the meeting in person or virtually via conference and WebEx.

- When: February 18 - 19, 2010
(All day Thursday and ½ day Friday)
- Where: National MS Society Training and Resource Center
Denver, Colorado
- Cost: Attendees are responsible for their own travel and accommodations. There are no registration fees. Meals are included at the meeting.
Value of training and networking – it's priceless!
- Accommodations: Single/double room rate of \$135/night hotel reservation information will be provided when you confirm your attendance.
- Key Topics: Assessing Your Fundraising Readiness; Building Donor Relationships; Identifying and Developing Personal Plans for Top Prospects; Refining Golden Circle for 2011; Disney's Customer Service as a Model
- Confirmation: Please confirm how you plan to participate (in person or virtually) in the Individual Giving Winter Meeting via email to Susan Goldsmith at susan.goldsmith@nmss.org



DEVELOPMENT

January 29, 2010

CC: Marketing

Specialized Bike Sweepstakes Kicks Off

As we reported earlier in the January 8th newssheets, the March issue of *Bicycling* magazine features a four-page ad which opens off the front cover (known as a “gatefold”) highlighting Bike MS and driving readers to BikeMS.org.

Bicycling subscribers have started to receive the issue this week and it hits news stands on February 2. The ad also 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 January 25 - April 30.
- Specialized will handle fulfillment for the winners.
- Chapters will be informed if they have a winner.
- Once the contest is complete, chapters will receive email addresses of potential riders by zip code.

In addition to the March gatefold ad, we’ll have another full page ad in the April issue promoting Bike MS and the Specialized contest.

Please include the following information and link in all rider communication and on your Bike MS webpage through April 30: *Enter today to win one of 20 Specialized® bikes! We are raffling off five Pro level bikes valued at \$4,400 each and 15 Elite level bikes valued at \$2,200 each.*

http://www.nationalmssociety.org/forms/bikems/specialized_contest.aspx

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. More information on this is forthcoming.

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

Specialized partnership, contact Becca Kornfeld, 212-476-0484 becca.kornfeld@nmss.org



PROGRAMS & SERVICES

January 29, 2010	CC: Chapter Presidents
	Development
	Individual Giving
2010 Scholarship Timeline	

It's time to start gearing up for the 2010 program and make a note of some important dates and guidelines. The deadline for accepting scholarship applications has passed (January 15th).

If you haven't already done so, please make sure you review the Scholarship Manual, which can be found on SharePoint under Programs and Services > Scholarship Information. This document includes program guidelines (such as fees for applications, reviewer materials and guidelines, FAQs, and a program timeline). Even if you'd read it before, it's good to refamiliarize yourself with the process.

Here are some upcoming deadlines to note and be prepared for:

Starting now – Print timeline from the Scholarship Manual and keep at your fingertips. I will inform you if any of the dates change.

Continue solicitation of donors. See SharePoint for template and scholarship manual for details. Susan Goldsmith in the Development Department is available for consultation around donor funding of the scholarship program. Please contact her at susan.goldsmith@nmss.org for 303-698-6100, ext. 15102.

Recruit and determine your application review committee. Applications will be sent to chapters on March 30th.

February 6 – Home office will notify chapters of the number of applications received by ACT in their chapter area.

February 13 – Chapters notify the home office of how many eligible applications they want to review. [Minimum of 3 family member applications and all “student with MS” applications] Fees apply: Applications from students with MS are free. For all others, the chapter will be billed \$150 per application.

March – Prepare review materials (letter, guidelines, scoring sheets, etc.). Templates can be found in the scholarship manual. Due to the short turnaround time for reviewers, it's

a good idea to get your review materials and processes ready so you can send to reviewers as soon as you receive the applications.

End of March – ACT will forward transcripts to the chapters. The application (in PDF format) includes GPA, class rank, SAT/ACT test scores, etc. as entered by the applicant. It is the chapter's prerogative to cross check the transcript with the application as you and your selection committee deem appropriate. The language of the online application and requirement to send documentation should discourage any falsification of information. If you should discover significant discrepancies, please notify Wenda Carlson.

March 30 – Applications will be provided in PDF format. Please do *not* contact the student applicants at this time.

April 10 – Chapters notify home office of any students to be considered for top scholar awards. Further details will be provided as we approach this deadline.

April 20 – Chapters notify home office of recipients and award amounts. Do not contact recipients. They will be notified by ACT in mid-May, at which time you can contact recipients directly to do press releases.

Some information on 2010 application stats:

We have received 789 applications. We have been receiving an average of 1000 applications for the past few years, so this is about a 20% reduction from previous years. The drop in applications appears to be nationwide and does not apply to any one particular chapter. As you know, we did change scholarship companies this year and used an online application. We have not heard many concerns from applicants and in fact most seem to have found the process user friendly. We are a little mystified as to why there is a drop in applications. The IRC did not receive notable complaints, but if you have heard any feedback from your clients, please let us know. We did have some students who completed the process but were missing the required recommendation. Just in case there is a glitch in our system we aren't aware of, we have decided not to eliminate these students who completed and submitted the application on time but whose recommenders did not respond. We are giving those students a chance to get the recommendations in via email. We will be conducting a follow-up survey to evaluate the new system, so that we can make any necessary improvements for next year.

If you have further questions, you may contact me.

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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

January 29, 2010

Australian Study Questions Established Concepts of Early Disease Events In MS

Investigators at the University of Sydney have published a study suggesting that the earliest activity seen in the brain in MS is the destruction of cells that make myelin (oligodendrocytes), occurring before the onset of immune activity usually blamed for triggering the disease. This provocative study, co-funded by many sources including the National MS Society, opens up new possibilities for finding the cause of the disease and developing new treatments. The study is authored by Drs. John W. Prineas, Andrew P.D. Henderson and colleagues, and is published in the December issue of *Annals of Neurology* (2009;66:739–753; <http://www3.interscience.wiley.com/journal/122511223/abstract>).

Background: Multiple sclerosis has long been thought to be triggered by immune attacks in the brain and spinal cord, causing a spectrum of neurological symptoms. Extensive research has been underway to better understand what triggers the immune attacks and which immune cells are involved, and to better understand the damage to the central nervous system that occurs during the course of MS. In addition to studies of immune activity underlying what has been considered an autoimmune process, another important approach has centered on pathology studies involving microscopic explorations of MS lesions (damaged areas, also called plaques) in the brains of people with MS.

The lead author of the current study, John W. Prineas, MB, BS, FRCP, was the 2001 winner of the John Dystel Prize for MS Research (<http://www.nationalmssociety.org/for-professionals/researchers/get-funding/john-dystel-prize/index.aspx>), an award given jointly by the National MS Society and the American Academy of Neurology. He was recognized for being the investigator who first described how myelin, the substance that insulates nerve fibers, is broken down in MS, and he was the first to demonstrate that myelin repair occurs during the course of MS through the body's natural repair processes.

Current Study: For this study, the team used brain specimens from 11 people who had died early in the course of their MS, and the team also used comparison specimens from people with other disorders including stroke. Some of the tests focused on subsets of specimens from seven people who had lesions showing active myelin destruction. To get a sense of immune cell activity in the brain and at what stage it was occurring, the team examined newly active and resolved lesions, as well as nearby blood vessels, surrounding areas showing some disease activity and surrounding areas that appeared normal, and areas that were farther away from the lesions of interest.

Results: In tissues surrounding newly forming lesions, the investigators found evidence of the loss of oligodendrocytes with an absence of immune T or B cells that would normally be held responsible for launching the immune attack against oligodendrocytes and the myelin they produce. These and other immune cells, including scavenger cells (macrophages and microglia), were more numerous in lesions and surrounding tissues at apparently later stages of destruction and sometimes in lesions that were in the process of repair. In specimens from two very early cases of clinical onset of disease, they found few immune cells within the lesions and no evidence of activation of scavenger cells.

These and other unexpected findings from this study led the investigators to propose that the early immune activity seen in active lesions is that of macrophages and microglia, whose job it is to clean up and remove damaged myelin. They propose that lesion formation is caused by something other than destructive immune activity led by inflammatory cells against a component of myelin or oligodendrocytes.

Comment: This study is a significant addition to a small but growing body of evidence that highlights the question of what triggers MS and whether there is something other than, or in addition to, the immune attacks that lead to tissue damage in the brain and spinal cord of people with MS. Further research, which is ongoing by investigators around the world, should shed further light on this question and may offer novel treatment approaches.

Note: The availability of donor brain specimens was crucial to this and other studies focusing on disease pathology: Learn about how to participate in an MS brain bank (<http://www.nationalmssociety.org/research/researchers-need-you/donate-to-tissue-banks/index.aspx>)

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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

January 22, 2010 **UPDATED January 26, 2010**

FDA Approves Fampridine SR, Now Called Ampyra, to Improve Walking for People with All Types of MS

The U.S. Food and Drug Administration has approved the marketing of Ampyra™ (dalfampridine, formerly known as fampridine SR, from Acorda Therapeutics) for its ability to improve walking in people with any type of multiple sclerosis. This is the first therapy specifically approved to treat a symptom of MS, and it represents a big step forward for the many people who may benefit.

Comment: “The FDA’s approval of Ampyra is wonderful news for many people with MS who experience problems with walking,” said John R. Richert, MD, Executive Vice President for Research & Clinical Programs at the National MS Society. “This brings a welcome symptomatic therapy that may restore some function and make a real difference in quality of life for a large number of people with different types of MS.” Further study and clinical practice may help determine the extent to which the drug may impact other functions not measured in the clinical trials, and provide hints as to which individuals are most likely to respond.

UPDATE: Acorda has established a phone line that individuals may call for information: 1-888-881-1918. The full label with prescribing and patient information guide is now available on the FDA’s Website: http://www.accessdata.fda.gov/drugsatfda_docs/label/2010/022250s000lbl.pdf

Q. What is Ampyra? (pronounced amPEERah)

A. Ampyra, formerly known as fampridine SR, is a tablet containing a sustained-release formula of 4-aminopyridine, which blocks tiny pores, or potassium channels, on the surface of nerve fibers. This blocking ability may improve the conduction of nerve signals in nerve fibers whose insulating myelin coating has been damaged by MS. The first studies of this potassium-blocking approach in people with MS were supported by the National MS Society.

Q. How is a “symptomatic therapy” different from the approved [disease-modifying therapies](#) for MS?

A. A symptomatic therapy is usually a drug that addresses a particular aspect of a disease, but taking it does not change the underlying course of the disease or limit the damage caused by the disease. There are many medications taken by people with MS to manage specific [symptoms](http://www.nationalmssociety.org/about-multiple-sclerosis/symptoms/index.aspx), such as spasticity, fatigue or depression (<http://www.nationalmssociety.org/about-multiple-sclerosis/symptoms/index.aspx>). While there are FDA-approved disease-modifying therapies (<http://www.nationalmssociety.org/about-multiple-sclerosis/treatments/index.aspx>) that are partially effective against some forms of the disease, as well as rehabilitation and symptomatic treatments for some symptoms, until now there was no pharmacologic treatment available for MS-related difficulty walking.

Q. How common are walking problems among people with MS?

A. A recent survey among more than 1,000 individuals with MS and many of their family members examined the impact of difficulty walking on quality of life among people with MS and their families. Some two-thirds of patients reported difficulty walking and of these, 70% reported that such difficulty was the most challenging part of their MS, and most reported that difficulty walking restricts their daily activities significantly, including their ability to travel. (Read more about survey results <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=199>)

Q. How Effective is Ampyra?

A. Two phase III clinical trials of the drug were sponsored by Acorda Therapeutics. In the first, involving 301 people with any type of MS, walking speed increased by 25% compared with placebo. Results of this study have been published (February 28, 2009 issue of **The Lancet** (2009 373;732-738 ([http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(09\)60442-6/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(09)60442-6/abstract)), summarized here: <http://www.nationalmssociety.org/research/research-news/news-detail/index.aspx?nid=951>). Results from a later, second phase III study involving 240 people with MS (<http://www.nationalmssociety.org/research/research-news/news-detail/index.aspx?nid=237>), announced in 2008, confirmed the benefits seen in the first, finding that a significantly greater proportion of people on the therapy had a consistent improvement in walking speed compared to those who took placebo. Among those taking Ampyra who improved in walking speed, there was a statistically significant improvement in leg strength.

Q. What are the potential side effects of Ampyra?

A. In the first phase III study, common adverse events (side effects) experienced more often by those on active treatment included back pain, dizziness, insomnia, fatigue, nausea and balance disorder. Two serious adverse events led participants to discontinue taking the drug (one case of anxiety and one seizure in a person who developed sepsis from a urinary tract infection). In the second phase III study, additional common adverse events in those on therapy included urinary tract infection, falls, and headache.

CONTINUED...

On Sharepoint:

http://intranet.nmss.org/Topics/cr/Pages/FDA_Approves_Fampridine_Now_Called_AMPYRA_To_Improve_Walking_for_MS.pdf

On Website: <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2586>



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

January 29, 2010

National MS Society Seeks Proposals for a Study on Risk Factors Influencing MS Progression

The question of what factors influence the course and progression of multiple sclerosis is the focus of a new research initiative of the National MS Society, recently launched with the worldwide release of a Request for Applications. The goal of this first step is to award a pilot grant to a consortium of investigators, who would test the feasibility of a longitudinal study to determine why some people with MS have mild courses while others experience serious worsening of symptoms over time. Such a study could offer avenues for predicting who may experience progression, and ways to prevent and stop progression.

Background: The biggest question surrounding MS is what causes it. Getting the answer should provide a very clear path to ending this disease forever. A recent international workshop <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=991> convened by the Society explored the concept of long-term studies needed to identify factors that cause the onset of MS, as well as factors that influence whether individuals will develop progressive disability. Workshop participants recommended that we first tackle the feasibility of a study of risk factors for MS progression. Designing such a pilot should lay the groundwork for the more ambitious study on risk factors for disease onset.

Thanks to extra funding provided by the Society's **Greater Delaware Valley Chapter**, we released a Request for Applications to the international scientific community in mid January. The successful applicant would receive a two-year grant starting October 2010 for up to \$650,000 to design the study, standardize measurement tools, determine which type of patients would be most informative, help frame and validate the methodology, and seek other potential funding sources that would be needed for a full-scale study to identify risk factors that influence MS progression.

The deadline for proposals is March 12, 2010. Download the RFA (.PDF):
<http://www.nationalmssociety.org/for-professionals/researchers/download.aspx?id=17878>

Read about [who](#) gets MS

<http://www.nationalmssociety.org/about-multiple-sclerosis/who-gets-ms/index.aspx>

Read about progressive MS <http://www.nationalmssociety.org/about-multiple-sclerosis/progressive-ms/index.aspx>

-- Research and Clinical Programs Department