



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
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CHAPTER PRESIDENTS

2/5/2010

CC: Development

National Research Call on Fast Forward to be Held Feb. 23rd at 1-2 PM Eastern

Have you been curious about the new research initiative at the National MS Society called Fast Forward? *What is it? How does it work? How does it fit in with the Society's other funded research? How does the organization partner with for-profit corporations?*

We will address these and many more questions in a 60-minute interview and lively discussion with Dr. Tim Coetzee, President of Fast Forward and Mr. Michael Richman, President and CEO, Amplimmune, Inc. Leadership volunteer for the Fast Forward fundraising campaign, Mr. Jamey Power, will interview these two partners in the mission of Fast Forward, raising questions and soliciting answers. The last 20-25 minutes of the call will be reserved for your questions and those of other participants.

Dr. Timothy Coetzee is President of Fast Forward, LLC. He is responsible for the Society's strategic funding of biotechnology and pharmaceutical companies as well as partnerships with the financial and business communities. Prior to assuming his current position, Dr. Coetzee led the Society's translational research initiatives on nervous system repair and protection in MS as well as the Society's programs to recruit and train physicians and scientists in MS research.

Mr. Michael Richman is President & Chief Executive Officer of Amplimmune, Inc. and has over 24 years of experience working in research, intellectual property and business development capacities in companies such as Chiron Corporation (now Novartis) and MedImmune, Inc. (now Astra Zeneca), where he was Senior Vice President Corporate Development.

Jamey Power is the former Senior Vice President and Strategic Advisor at J.D. Power and Associates. Since overseeing the transition of the private business to the McGraw Hill Companies, he has been working on a number of new business activities and philanthropic interests for the Power family. He was recently elected to the Board of Trustees of the Southern California Chapter of the National Multiple Sclerosis Society and serves as Campaign Co-Chair for the Fast Forward Campaign.

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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.

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****ADVANCE REGISTRATION IS NO LONGER REQUIRED: Dial-in directly at 877.860.4996, Conference ID 53582858. 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.

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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

January 22, 2010 **UPDATED February 3, 2010**

Update: FDA Approves Fampridine SR, Now Called Ampyra, to Improve Walking for People with All Types of MS – Wholesale price announced, new Webcast available from Society

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. **Update: A new National MS Society Webcast on Ampyra is now available, and additional frequently asked questions are provided below, including newly released cost information.**

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.

- A new National MS Society video webcast/podcast from MS Learn Online that discusses Ampyra is now available: <http://www.nationalmssociety.org/multimedia-library/webcasts--podcasts/ampyra-a-new-medication-to-improve-walking/index.aspx>
- 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

FREQUENTLY ASKED QUESTIONS

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](#), 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>)

CONTINUED...

On Sharepoint:

[http://intranet.nmss.org/Topics/cr/Pages/UPDATE%20FDA Approves Fampridine Now Called AMPYRA To Improve Walking for MS.pdf](http://intranet.nmss.org/Topics/cr/Pages/UPDATE%20FDA%20Approves%20Fampridine%20Now%20Called%20AMPYRA%20To%20Improve%20Walking%20for%20MS.pdf)

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