



CHAPTER PRESIDENTS

2/12/2010

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.

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 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.

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



DEVELOPMENT

February 12, 2010	CC: Information Technology
	Programs & Services
<u>“Contact Us” Web Inquiries for Bike MS and Walk MS</u>	

As we finalize the migration of WalkMS.org, BikeMS.org and ChallengeWalk.org to the national webpage, we are making changes to the content on each of these pages. One update is that we are adding a link to the new pages that allows users to contact us for more information. When someone requests more information about these events from one of the sites, their contact information and comments (which they will submit through the National Contact Us form) will go directly to your chapter via email. It will be sent to your designated contact for chapter inquiries that has already been determined by your chapter. Note that this new process replaces the list of Bike prospects previously sent to you by Michelle Larsen.

If you don't know who this person is at your chapter, please find out to ensure that the mailbox is being checked regularly and that a communication plan is in place for Bike MS Walk MS and Challenge Walk inquiries.



MARKETING

February 12, 2010

CC: All

Convio Update

In order to better safeguard our data, we will enable CAPTCHA for our Convio eCard and Tell-A-Friend features on Thursday, February 18.

CAPTCHA is a “challenge-response” test that ensures a response is manual and not computer-generated:

A screenshot of a web form titled "Guest Book". The form contains a text input field for "Your Name" and a larger text area for "Your Message". Below these fields is a CAPTCHA challenge. The challenge consists of a small input box for the code, a blue accessibility icon, and the word "making" in a stylized, lowercase font. A red rounded rectangle highlights the CAPTCHA input area. At the bottom of the form are two buttons: "Sign Guest Book" and "Cancel".

For questions about this enhancement – or the Society’s online marketing strategy in general – please contact Rich at rich.sarko@nmss.org or 303-698-6100 x15171.



MARKETING

February 12, 2010

CC: All

February-April 2010: E-communications Update

February National MS eNews

Send date: 2/17/10

Audience: Full List

The February National MS eNews will be sent on Wednesday, February 17. Due to the President's Day holiday, the send date was moved back one day. Content includes a feature about the FDA approval of Ampyra (fampradine-SR), as well as information regarding promising results of oral MS disease-modifying drugs, CCSVI updates, a We Keep Moving announcement, and more.

March E-fundraising Campaign

Updated send dates: 3/25, 3/29, 3/31 and 4/1

The send dates have been changed to optimize the recipient experience and take into account Good Friday. The fourth e-mail (scheduled on 4/1) will only be sent if the campaign goal is unmet as of midnight on 3/31. Standard exclusions apply (see Notes below), and further details regarding this campaign will be provided later this month.

Notes

Individuals with a 'no email' classification on their Altair accounts will be suppressed, along with standard Direct Marketing Program excludes/suppressions. If you would like to review the updated Direct Marketing Program excludes, please visit the new Intranet: Development → FY09_Direct_Marketing_Overview_CD_Master_Exclude_Document.

The current Constituent Communications Calendar is also on the new Intranet: Marketing → Constituent_Communications_Calendar_FY10.

Contact Information

For editorial questions or suggestions regarding our National MS eNews, please contact Martha at martha.king@nmss.org or 212-476-0539.

For questions about our online fundraising campaigns, please contact Katharine at katharine.grant@nmss.org or 303-698-6100 x15139.

For questions about our national e-communications strategy, please contact Rich at rich.sarko@nmss.org or 303-698-6100 x15171.



MARKETING

February 12, 2009	CC: Development
<u>Title of News Sheet: MSAW Special Merchandise Offers from Society Store</u>	
<u>Action Requested/Deadline: Order MS Awareness Week Kits by Feb 22</u>	

In honor of MS Awareness Week, March 8-14th, the Society Store is lowering prices 20% on every single item through March 31.

As an extra incentive to chapters, enter the code name CURE at checkout to receive an additional 15% discount on purchases now through May 2010.

We encourage everyone to take advantage of this tremendous offer and "gear up" with custom branded MS clothing and accessories for MS Awareness week. The store is offering a special MSAW package that will include Society branded items including a custom LED keychain, Frisbee, lenticular clip, post-it pad, and MS pen all for \$9.99 per set. Chapters can pre-order kits (minimum 2) up until Feb 18 and receive free shipping. To pre-order kits contact sales@internationalprint.com

We encourage you to also think ahead to the Walk MS and Bike MS events and purchase items now for sale at your events. All of the Society Store items are custom branded and high quality.

To place your orders and for more information, please log onto www.msstore.org. For customer service, please call 1-800-570-0358.

To receive merchandise in time for your MS Awareness events order merchandise by Feb 22.

Or Sandra.Genova@nmss.org
303 698-6100 Ext 15172



MARKETING

Date: February 12, 2010	CC: Chapter Presidents
	Development
	Programs & Services
UPDATE: “We Keep Moving” launches – start spreading the word!	

We are excited to announce that the We Keep Moving site and request for story submissions is up and running! Please visit www.wekeepmoving.org and start to spread the word that we are accepting story submissions through February 26. Don't forget to take advantage of the chapter toolkit materials, located on Sharepoint. Please note we have updated the toolkit this week to include some suggested Facebook and Twitter post language. The toolkit is available at the following link:

<http://intranet.nmss.org/TOPICS/MARKETING/Pages/marketing.aspx>

You can post the chapter flash panel and on your chapter home page, spread the word through Facebook and Twitter, and more!

A national press release was distributed on February 11 along with a targeted email and a flash panel on our national home page.

Background: We Keep Moving project launch and key dates

The official project launch was **February 11**. On the 11th, the site - www.wekeepmoving.org – went live to collect submissions from people who want their story told. Story submissions will be accepted until **February 26 at noon MT**.

Beginning MS Awareness Week (March 8) people will be asked vote on whose story will be filmed and shared with the world, and each week for the subsequent 10 weeks, people will be able to vote on the next story subject and location. The project wraps the week of World MS Day – May 26 – in New York City.

To support the project launch, a national press release/call for stories was issued on PR newswire on February 11 and a series of online, email and social media promotion kicked off as well. During MS Awareness Week, a national press release to kick-off voting will be released and supported by a satellite media tour on March 9.

We encourage you to spread the word by re-posting and re-tweeting information that will be pushed out about this exciting and unique nationwide campaign.

This initiative is supported in part by Novartis Pharmaceuticals Corporation and we thank them for their partnership and support.

We Keep Moving Background:

- *We Keep Moving* will tell the stories of people living with and affected by MS through a cross-country trip that a “road crew” - a trio of artists living with MS - will lead us through beginning MS Awareness Week and concluding World MS Day.
- Stories will be captured via video and highlighted on our national site as well as through various social media channels.
- Stories from across the country are needed! The story selection process will involve people impacted by MS from around the country submitting their stories online, with ongoing opportunity for community engagement through website voting to select each location that the road crew will go.
- The site opens on February 11 and will accept story submissions through February 26. Then, beginning MS Awareness Week, the online community will be asked to select where the road crew goes next, and each week, will be asked to vote on the next story and location.
- The ability to generate awareness for the MS movement is nothing short of exceptional, and we need your participation to maximize engagement from all corners of the country!

For more information, please contact: Todd Culter, online marketing,
Todd.Culter@nmss.org



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

Updated February 9, 2010

UPDATE: CCSVI or Blood Flow in the Brain and Venous Insufficiency in MS – Society Leaders Meet with Dr. Zamboni Today. Research Proposals Received from Around the World on February 9th Grant Request Deadline.

Summary: Recent preliminary studies indicate that a phenomenon called CCSVI, a reported abnormality in blood drainage from the brain and spinal cord, may contribute to nervous system damage in MS. This hypothesis has been put forth by Dr. Paulo Zamboni from the University of Ferrara in Italy. Based on the results of his initial preliminary findings, Dr. Zamboni states that this pilot study warrants a subsequent larger and better controlled study to definitively evaluate the possible impact of CCSVI on the disease process in MS.

It has been proposed by Dr. Zamboni for further study that CCSVI may be corrected through endovascular surgery, which involves inserting a tiny balloon or stent into blocked veins in order to permit the flow of blood out of the brain and spinal cord, a procedure that has been called “liberation therapy” in some reports.

The National MS Society is pursuing this potential MS lead by undertaking the funding of new research on CCSVI in MS and has invited investigators worldwide to apply for grants on this topic. In response to a January 6 deadline, the National MS Society and the MS Society of Canada received numerous letters of intent from investigators from seven countries. Those letters of intent that met grant guidelines were invited to submit full research proposals, which are due February 9, 2010. The full planned funding timeline is below.

UPDATE: National MS Society leaders met with Dr. Zamboni today in advance of his invited lecture at New York University’s MS Center of Excellence. In meetings and during today’s presentation, Dr. Zamboni suggested that if further evidence supports the link between MS and CCSVI, that its treatment may ultimately add to the arsenal of therapies available for MS. He emphasized the need for more research on his hypothesis, and noted that it is still not proven whether CCSVI is a cause of MS or possibly a product of MS. Dr. Zamboni also noted that people with MS should remain on their immunomodulatory therapies as has his wife after her endovascular surgery.

The Society shares in the public urgency to expeditiously advance any lead that has the potential of stopping, repairing or preventing MS.

CCSVI Research Funding Timeline

January 12, 2010 – Investigators whose letter of intent meet guidelines are invited to submit full research proposals

February 9, 2010 -- Deadline for proposals

May 2010 – International panel of experts conducts an expedited review of all applications received through this special request for applications

June 2010 – Funding decisions announced

July 1, 2010 – Anticipated start date for funding of any successful research applications

Taking advantage of the organizations' international scope, the applications will undergo an accelerated review process by an international panel being convened in cooperation with other MS Societies to ensure an expedited, coordinated response. If this hypothesis is confirmed, it could open up new research avenues into the underlying pathology of MS and new approaches to therapy.

Background: In a recent study by Dr. Zamboni and colleagues, the team evaluated abnormalities of blood outflow in major veins draining from the brain and spinal cord to the heart in 65 people with different types of MS, compared with 235 people who were either healthy or who had other neurological disorders. They used sophisticated sonography techniques to detect abnormalities of venous drainage. The investigators reported evidence of slowed and obstructed drainage in the veins draining the brain and spinal cord in many of those with MS. They also reported evidence of the opening of “substitute circles” – where the flow is deviated to smaller vessels to bypass obstructions, and these were often found to have reverse flow (reflux) of blood back into the brain.

The investigators call this venous obstruction “chronic cerebrospinal venous insufficiency,” or CCSVI. The treatment status of the people with MS (i.e., whether or not they were on an MS disease modifying drug) did not appear to influence whether they showed signs of CCSVI. The authors speculated that the reverse flow of blood back into the brain might set off the inflammation and immune-mediated damage that has been well described in MS. This study was published in June 2009 (J Neurol Neurosurg Psychiatry 2009; 80:392-399 <http://jnnp.bmj.com/cgi/content/abstract/80/4/392>).

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<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2206>

or download the PDF on Sharepoint

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