



CHAPTER PRESIDENTS

June 18, 2010	CC: Development
	Marketing
<u>Text-to-Give Pilot Opportunity</u>	
Action Requested/Deadline: June 28, 2010	

We are pleased to announce a nationally-organized text-to-give pilot program. The goal is to test effectiveness of text-to-give response from new/external audiences – and understand the fundraising potential for mobile-savvy donors outside of our constituency.

The program will consist of 3-5 pilots. Each pilot will include at least one chapter, which will plan, implement and pay for (if necessary) the promotion of the text-to-give call to action. This promotion could be a professional sports game, outdoor advertising campaign, or any effort to reach new donors. The following requirements have been designed to ensure we have adequate vendor support, budget and time to execute a successful pilot program.

- Chapter-led promotional opportunity to external audience completed by November 30, 2010
- Designated chapter text-to-give contact who will work with the home office on pilot execution

The home office infrastructure will cover the text-to-give short code and keyword costs; the chapter(s) in each pilot will receive the related revenue. Weekly revenue reports will indicate the number of donors by date, however revenue will not be received until 90-120 days post-donation. As with previous text-to-give efforts, we are unable to capture donor demographic or contact information – eliminating the opportunity for future messaging to respondents.

If your chapter meets the above qualifications and is interested in becoming a part of the pilot program, please submit your responses to the following questions (one page maximum):

1. Title and brief summary of your promotional opportunity(s) including all channels
2. Date(s) of your promotional opportunity(s)
3. Target audience of your promotional opportunity(s), including number of impressions, demographics, etc.
4. Estimated expense for your promotional opportunity(s)
5. Contact information for chapter text-to-give representative who will work with the home office on pilot execution

Prior to submitting your response, please reference the recent [mobile update](#) on SharePoint (Marketing → Online Marketing → **Mobile Update: The Society and Mobile Technology**). Pilot participants will be chosen based on responses to the questions above (opportunity, date, reach and expense); multiple chapters are encouraged to work together and submit a joint pilot program response – whether single or multiple promotion(s).

Responses should be sent via email to Beth Clark, beth.clark@nmss.org, by July 16. Pilot participants will be notified by July 21. Specific pilot details (including promotion, schedule and keyword for each chapter) will be announced via newsheet on July 23. Feel free to email or call Beth Clark with questions, 303-698-6100 x 15126.



MARKETING

June 18, 2010	CC: All
<u>Reminder and Updates: June 30 Live Webcast on “What’s new in MS research and treatment”</u>	

REMINDER – Live research webcast:

On June 30, join Dr. Patricia O’Looney, Vice President of Biomedical Research at the National MS Society, as she moderates a panel of experts during a live discussion about “What’s new in MS research and treatment,” focusing on new leads in stopping, reversing and preventing MS.

Webcast details:

When: June 30, 2010 from 1:00 to 2:30 p.m. ET

Where: Online with the opportunity to submit questions for the panelists in real-time

Register:

To register for the webcast visit: www.nationalMSSociety.org/june30webcast

UPDATED – Marketing components:

- ✓ Chapter flash panel – currently available to chapters in the content management system
 - Go to Content Management System; search for “june30webcast Chapter Flash Panel”
 - **REVISED** – “Nav Area Headline” (thru June 29): June 30: Live webcast on MS research and treatment
 - **REVISED** – “Nav Area Headline” (as of June 30): Today: Live webcast on MS research and treatment
 - **REVISED** – “Link Text” (throughout): [Learn more and register now](#)
 - Link: www.nationalMSSociety.org/june30webcast

Questions?

Contact Arney Rosenblat Arney.Rosenblat@nmss.org or Becca Kornfeld Becca.Kornfeld@nmss.org



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

June 18, 2010

Over \$2.4 Million Committed to Support 7 Initial CCSVI Grants to Determine the Role of CCSVI (Venous Insufficiency) in Multiple Sclerosis Disease Process
-- Expedited international review and new Rapid Response Fund facilitates July 1 launch of CCSVI research projects

Over \$2.4 million has been committed by the National MS Society (USA) and the MS Society of Canada to support 7 new research projects focusing on the role of [CCSVI \(chronic cerebrospinal venous insufficiency – http://nationalmssociety.org/ccsvi\)](http://nationalmssociety.org/ccsvi) in MS.

All research applications underwent a rigorous expedited review process by an [international review panel \(http://nationalmssociety.org/news/news-detail/index.aspx?nid=2866\)](http://nationalmssociety.org/news/news-detail/index.aspx?nid=2866) that included experts drawn from all key relevant disciplines including radiology, vascular surgery and neurology. The U.S. National MS Society and the MS Society of Canada worked collaboratively to assemble the reviewers who considered scientific merit, responsiveness to the Request for Applications, experimental design, likelihood of producing definitive data, and the experience of the applicant teams in making their recommendations.

These new studies are necessary because we don't yet know whether, or if so how, CCSVI contributes to MS disease activity. They will achieve several important goals. First, the new studies will carry out significant steps needed to confirm the phenomenon originally described by Dr. Paolo Zamboni who reported abnormalities in the veins draining the brain and spinal cord in people with MS and resolve the questions raised by him and others as to whether CCSVI is a cause of MS or related to MS in some other manner. Second, these studies will resolve conflicting data from previous research, such as how frequently CCSVI occurs in MS, and how often it occurs in people who do not have MS. Third, if blockages are found, the findings will speed the way to determining whether therapeutic trials to correct them will be helpful in improving or altering MS disease process.

The new projects take a comprehensive look at the structure and function of the veins draining the brain and spinal cord in people representing a spectrum of MS types, severities and durations, and compare them to structure and function of veins in people with other diseases and healthy volunteers. The studies incorporate accepted high standards of experimental blinding and controls designed to provide unbiased results. They also use a variety of imaging technologies including the Doppler ultrasound technology originally used by Dr. Paolo Zamboni and his team.

Together, these studies aim to further understand the role of CCSVI in MS and identify optimal methods for screening for the condition, which would be necessary to determine the next steps required in advancing this CCSVI lead. They will also be of value in designing protocols for possible exploratory therapeutic trials that might be independently undertaken in North America or abroad.

Although there were a number of promising submissions, for this initial round of grants, the international review panel recommended studies they agreed combined the strongest science with the research goals necessary to most quickly determine the scope and meaning of reported abnormalities in blood drainage from the brain and spinal cord in MS. It is hoped these findings will provide clarity regarding the need for next-step therapeutic trials to correct such blockages as Societies around the world pursue. The two-year grants will begin July 1, 2010.

Read complete bulletin and other details on our Website:

Full bulletin: <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=3339>

FAQs about new CCSVI grants: <http://www.nationalmssociety.org/research/intriguing-leads-on-the-horizon/ccsvi/faqs-about-new-ccsvi-grants/index.aspx>

Download from Sharepoint:

Talking points on new CCSVI grants for internal use only, **updated June 12:**
http://intranet.nmss.org/Topics/cr/Pages/CCSVI_grants_talking_points_internal_use_only.doc



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

June 18, 2010

FDA Agrees to Fast Track Status for Drug Being Tested for MS

It was announced by the drug maker Genzyme Corporation (Cambridge, MA) that intravenous alemtuzumab has been designated by the U.S. Food and Drug Administration as a “Fast Track Product.” This designation should expedite its future review by the FDA after the sponsor submits results of current phase 3 trials that are underway (these studies have completed enrollment but are not yet completed).

Multiple sclerosis occurs when the immune system mistakenly attacks the brain and spinal cord. Alemtuzumab is a humanized monoclonal antibody directed at CD52 (a protein on the surface of immune cells) that is currently approved by the FDA as a single agent for treatment of patients with B-cell chronic lymphocytic leukemia. Its ability to target immune cells led to its testing as a possible treatment for relapsing-remitting MS.

Earlier [Phase 2 studies](http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=431) (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=431>) showed that treatment with alemtuzumab reduced the accumulation of disability and the frequency of relapses in people with early [relapsing-remitting MS](http://www.nationalmssociety.org/about-multiple-sclerosis/what-is-ms/index.aspx) (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-is-ms/index.aspx>), compared to [Rebif®](http://www.nationalmssociety.org/about-multiple-sclerosis/treatments/medications/interferon-beta-1a-rebif/index.aspx) (<http://www.nationalmssociety.org/about-multiple-sclerosis/treatments/medications/interferon-beta-1a-rebif/index.aspx>, interferon beta-1a, EMD Serono, Inc. and Pfizer, Inc.). (*New England Journal of Medicine* 2008 359;17:30-45)

--Research and Clinical Programs

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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

June 18, 2010

Collection of Milestone MS Research Papers Now Online **-- Free Access Sponsored by National MS Society/Fast Forward**

A collection of pivotal MS papers – featuring guidelines on stem cell transplantation research, pediatric MS, and other topics – is now online in a “Web Focus” feature from Nature Publishing Group, a publisher of high impact scientific and medical information (<http://www.nature.com/nrneurol/focus/ms/index.html>). The National MS Society and its drug development subsidiary [Fast Forward](http://www.fastforward.org) (www.fastforward.org) sponsored this collection to ensure three months of free access to these papers, and it is being further promoted with a full page advertisement in the July issue of *Nature Reviews Neurology*. This access enables broader dissemination of this information to increase awareness of the significant progress made in these research areas and their potential for propelling the field forward.

The collection highlights these publications:

Stem cell transplantation in multiple sclerosis: current status and future prospects

Gianvito Martino, Robin J. M. Franklin, Anne Baron Van Evercooren, Douglas A. Kerr & the Stem Cells in Multiple Sclerosis (STEMS) Consensus Group

[Nature Reviews Neurology 6, 247-255 \(2010\)](http://www.nature.com/nrneurol/journal/v6/n5/full/nrneurol.2010.35.html)

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In brief: These guidelines, developed by an international panel of MS experts with input from MS Societies around the world, pave the way for more coordinated global research efforts and potentially better, and quicker, patient access to stem cell trials. [Read more](#) about this effort.

Environmental factors and their timing in adult-onset multiple sclerosis

Adam E. Handel, Gavin Giovannoni, George C. Ebers & Sreeram V. Ramagopalan

[Nature Reviews Neurology 6, 156-166 \(2010\)](http://www.nature.com/nrneurol/journal/v6/n3/full/nrneurol.2010.1.html)

(<http://www.nature.com/nrneurol/journal/v6/n3/full/nrneurol.2010.1.html>)

In brief: The authors review three risk factors that have been linked to MS – vitamin D, Epstein Barr virus infection, and smoking – and investigate how timing of exposure to these factors (for example, before or after MS onset, during childhood or adulthood) may influence the development of MS. [Read more](#) about research on environmental factors and MS.

Pediatric multiple sclerosis

E. Ann Yeh, Tanuja Chitnis, Lauren Krupp, Jayne Ness, Dorothée Chabas, Nancy Kuntz & Emmanuelle Waubant

[Nature Reviews Neurology 5, 621-631 \(2009\)](#)

(<http://www.nature.com/nrneuro/journal/v5/n11/full/nrneuro.2009.158.html>)

In brief: This review covers the latest findings on children and adolescents with MS, including information on diagnosis and treatment. The authors are investigators from each of six Pediatric MS Centers of Excellence funded through the National MS Society's Promise:2010 Campaign. Physicians can earn CME credits through the paper. [Read more](#) about pediatric MS.

Imaging outcomes for neuroprotection and repair in multiple sclerosis trials

Frederik Barkhof, Peter A. Calabresi, David H. Miller & Stephen C. Reingold

[Nature Reviews Neurology 5, 256-266 \(2009\)](#)

(<http://www.nature.com/nrneuro/journal/v5/n5/full/nrneuro.2009.41.html>)

In brief: The question of how to detect nervous system protection and repair in people with MS – without having to wait possibly years to observe a person's disease progression – was the theme of a workshop convened by the Society's International Advisory Committee on Clinical Trials. This paper sums up these discussions, and the authors rate available imaging techniques on several criteria to determine the most promising options for use in nerve repair and protection studies. [Read more](#) about this workshop.

Genome-wide association study identifies new multiple sclerosis susceptibility loci on chromosomes 12 and 20

The Australia and New Zealand Multiple Sclerosis Genetics Consortium (ANZgene)

[Nature Genetics 41, 824-828 \(2009\)](#)

(<http://www.nature.com/ng/journal/v41/n7/full/ng.396.html>)

In brief: MS researchers in Australia and New Zealand report the results of a genome-wide scan for MS genes in 1,618 people with MS and 3,413 controls. The results identify two new genes that have been associated with other autoimmune diseases and pinpoint a gene related to vitamin D, which is being increasingly highlighted as a factor in MS development. [Read more](#) about MS genetics research.

These papers reflect a genuine “team effort” in the MS research community today. Each is the result of a network, collaboration, or workshop that brings together experts in the field. Such efforts can exponentially speed us toward our three research goals of stopping MS, reversing the damage, and ending MS forever.

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