National
Multiple Sclerosis
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News Sheets

DEVELOPMENT

7/15/11	**CC:** Chapter Presidents
Society Chosen for State Farm & Major League Baseball Nationwide "Go To Bat" Program	

For a second year, State Farm has partnered with Major League Baseball (MLB) to sponsor the "Go To Bat" program, giving fans a chance to "Go To Bat" for the cause that matters most to them. Based on requests from fans last year, the National MS Society was selected to participate in this nationwide campaign for 2011.

Program Details:
Fans are encouraged to go online to register to play a simple online game for the chance to help win a weekly donation of $18,000 for their chosen charity and a personal trip to the 2011 World Series. Each week the charity that has the highest batting average for that week will receive a donation from State Farm for $18,000.

How to "Go To Bat" for the Society:
Step up to the plate for the National MS Society by going to: www.statefarm.com/gotobat
Once registered, you can play up to three times per day. Remember, the charity with the best batting average **for that week** will be awarded $18,000 from State Farm (10-week campaign), so swing hard and swing often!

We will periodically be promoting this exciting program through our national social media channels and we encourage everyone to share these exciting program details and "Go To Bat" for the National MS Society. If you have any questions or comments regarding this program, please contact Julie Stone Hurley at julie.stone.hurley@nmss.org.

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MARKETING

July 15, 2011	**CC:** Chapter Presidents
	Programs & Services
	Information & Resources
	Development
Momentum Fall 2011 Issue	

The fall issue of **Momentum** will reach readers in your area by mail beginning August 1, 2011. The fully interactive **digital** edition will be posted ahead of the mail date. The digital edition includes all content from the print edition, including advertisements, and allows readers to click on live links, comment on articles, download articles as PDFs, print pages and share articles via email, links or by posting to social networks.

The cover story features "Amazing Race" host, MS Ambassador and the first MS NOW Research Champion Phil Koeghan and introduces MS NOW: An MS Research Revolution. The feature story focuses on single life with MS, describing personal experiences, challenges, problem-solving strategies and suggestions for creating strong support networks.

Other articles include a special report on Society President and CEO Joyce Nelson's retirement, the Society's new fall prevention program, social life and low vision, the role of drugs or surgery to maintain mobility, how to avoid fast food, telling children about MS, palliative care, DIY fundraising events, and more.

If you anticipate needing additional copies of this issue for your chapter, please e-mail **Gary Sullivan** at **gary.sullivan@nmss.org**.

This issue may prompt readers to ask for information about or referrals to the following:

- NOW: An MS Research Revolution and becoming a Champion for MS research
- An MS Navigator®
- Low-vision specialists
- Your state's department of vocational rehabilitation
- The Society's scholarship program
- The Society's Financial Education Partners program
- The Society's MSFriends program

- Starting a Bike MS or Walk MS team
- The Society's "Free from Falls" DVD and program
- Hosting a DIY community fundraiser
- Support groups
- Palliative care teams

The issue mentions these books that you may want to consider for your chapter library:

Living with Progressive Multiple Sclerosis: Overcoming Challenges, by Patricia K. Coyle, MD, and June Halper, APN-C, MSRN, FAAN

It's Not All in Your Head: Anxiety, Depression, Mood Swings and Multiple Sclerosis, by Patricia Farrell, PhD

Facing the Cognitive Challenges of Multiple Sclerosis, 2nd Edition, by Jeffrey Gingold

We hope this is helpful. Please let me know any feedback you receive.

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National Multiple Sclerosis Society News Sheets

PROGRAMS & SERVICES

July 15, 2011	**CC:** Chapter Presidents
Update: Possible Funding Opportunity to Support Continuation of the Relationship Matters Program	

In late-June, the Society learned that the Administration for Children and Families (ACF) is accepting applications for Community-Centered Healthy Marriage and Relationship Grants. ACF is the funding entity for the grant that currently supports the *Relationship Matters* program. The grants provide for one-year of funding, with subsequent funding (for years two and three) awarded through a non-competitive grant process and available monies.

Based on the overwhelming success of the program in addressing the challenges faced by couples living with MS, and the role the program has played in our programming for couples, we are submitting a grant proposal under this new opportunity. The core program will remain the same (in-person workshops and teleclasses using the *8 Hours to a Lifetime of Relationship Satisfaction* curriculum, with a new component added which is specific to employment coaching/counseling for interested program participants. Our goal is to serve over 500 couples through both the in-person and teleclass programs. For more information on the grant announcement please go to http://www.acf.hhs.gov/grants/open/foa/office/ofa.

If funded, we anticipate supporting 45 in-person workshops during FY 2012. Funding levels for the workshops will remain the same ($2,500 for a one-day and $4,100 for a two-day), as will the suggested workshop format and number of participants. So as to assist in our readiness to launch the program in October, chapters interested in hosting a workshop are asked to contact Jessica Roeder (contact information below). You will be notified upon receipt of the award announcement (on or around September 29, 2011).

Please direct all questions and requests to Jessica Roeder at Jessica.Roeder@nmss.org or 303-698-6100, ext. 15217. Thank you for your ongoing support of the program.

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

July 15, 2011

Positive Results Announced from First Phase III Study of Alemtuzumab in MS

Sanofi and its subsidiary Genzyme have announced that the experimental intravenous therapy alemtuzumab (with a proposed brand name Lemtrada,™) met one of two primary endpoints by significantly reducing relapse rates in a two-year study comparing two annual cycles of alemtuzumab against standard subcutaneous dosing of Rebif (interferon beta-1a, EMD Serono Inc. and Pfizer). The study, called CARE-MS I, involved 581 people with early relapsing-remitting MS. The study did not meet its second primary endpoint of slowing disease progression compared to Rebif. The results were announced in July 11 press release. Data analysis is ongoing and the company expects to provide a full report at an upcoming medical meeting. Another trial of alemtuzumab, called CARE-MS-II, is currently underway.

Background: Multiple sclerosis involves immune system attacks against brain and spinal cord tissues. Alemtuzumab is a humanized monoclonal antibody directed at CD52 (a protein on the surface of immune cells) that is currently approved by the U.S. FDA for the treatment of B-cell chronic lymphocytic leukemia. Its ability to target immune cells led investigators to test its potential as a treatment for relapsing-remitting MS. An earlier phase II study compared two dose levels of alemtuzumab with Rebif in 334 subjects with relapsing-remitting MS who had never taken any other disease-modifying therapies. Those taking alemtuzumab had a 74% reduction in the risk of MS relapse compared with those on Rebif, and a 71% reduction in the risk for sustained accumulation of disability (*New England Journal of Medicine* 2008 359;17: 30-45).

Dosing was temporarily suspended in the Phase II study due to the occurrence of immune thrombocytopenic purpura (ITP), a rare condition in which low blood platelet counts can lead to abnormal bleeding. After the first cases of ITP occurred, one of which was fatal, Genzyme implemented a patient safety monitoring program which includes patient and physician education and regular contacts with patients. Two phase III studies comparing alemtuzumab with Rebif were then launched.

In June 2010, it was announced that alemtuzumab had 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 company submits results of the phase III trials. The press release stated that the company expects to file for regulatory approval of alemtuzumab for MS in early 2012.

This Study: In the CARE-MS I study, approximately 581 people with early, active relapsing-remitting MS, who had never received disease-modifying therapy to treat their MS, were randomly assigned to receive alemtuzumab or Rebif. Alemtuzumab was given by intravenous infusion for 5 days initially and for 3 days one year later. Those on Rebif received the standard dose of 3-times weekly subcutaneous injections. According to the company press release, after two years the relapse rate of those on alemtuzumab was reduced by 55 percent compared to those on Rebif. After two years, 8 percent of those on alemtuzumab had an increase in their EDSS score (a standard scale of physical disability) compared to 11 percent on Rebif – a difference that was not statistically significant.

According to the press release, the most common adverse event associated with alemtuzumab in the CARE-MS I study included reactions associated with infusions (such as headache, rash, fever, flushing, hives and chills). There were more infections in those taking alemtuzumab, predominantly mild to moderate, and there were no fatal infections. Less than 20 percent on alemtuzumab developed autoimmune thyroid-related problems and less than one percent developed ITP.

In the ongoing CARE-MS II study, approximately 1200 subjects at over 250 study sites have been randomly assigned to receive one of two alemtuzumab treatment regimens, or Rebif.

Comment: These positive results are the first reported from this Phase III study of alemtuzumab. Full details and evaluation of this study, and from another Phase III study now underway, should help define the safety and promise of alemtuzumab as a potential new therapy for relapsing MS.

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

July 15, 2011

Study: Bone Health is a Concern in Early MS

Researchers report that low bone mass was more prevalent among people newly diagnosed with MS, or those with clinically isolated syndrome (CIS, a first episode of MS-like symptoms), than among controls without MS. The risk of bone loss had been known for people with MS, but this study shows that it can occur very early, even before MS has been diagnosed. Stine Marit Moen, MD, and colleagues at Oslo University Hospital report their findings in *Neurology* (2011;77:151-157, http://www.neurology.org/content/77/2/151.abstract).

The team measured bone density in several areas and the total body in 99 people newly diagnosed with MS, or those with clinically isolated syndrome (CIS, a first episode of MS-like symptoms), compared to 159 controls without MS. They also administered a questionnaire concerning risk factors for osteoporosis (a disease that causes bones to thin). More than half of the people with MS or CIS had low bone mass, compared with 37.1% of controls, and low bone mass remained significantly lower in the spine and hip even after adjusting for other possible risk factors.

The authors conclude that this study "calls for an active approach to optimize bone health in early stages of MS."

Read more details of this study in a press release from the American Academy of Neurology (http://www.aan.com/press/index.cfm?fuseaction=release.view&release=966).

Read more about osteoporosis and MS (http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/osteoporosis/index.aspx) and how you can build bone health (http://www.nationalmssociety.org/living-with-multiple-sclerosis/you-can/build-healthier-bones/index.aspx).

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

EMBARGOED UNTIL JULY 14, 2011, 4PM EASTERN TIME

Research Teams Report First Year's Progress From MS Societies' Initial Studies on CCSVI and MS

The first-year progress reports from seven multi-disciplinary teams investigating CCSVI (chronic cerebrospinal venous insufficiency) in MS (http://www.nationalmssociety.org/ccsvi) indicate that they are on track to provide essential data and critical analysis as these two-year projects move toward their completion. These studies were launched on July 1, 2010 with a more than $ 2.4 million commitment from the MS Society of Canada and the National MS Society (USA).

The research teams have already recruited a broad spectrum of people with MS and others to build understanding of who may be affected by CCSVI. In addition they are refining CCSVI imaging methods for accuracy and consistency in order to reliably validate the occurrence of CCSVI and understand its implications in the MS disease process.

Representatives of each of the seven funded teams are part of the Canadian Institutes of Health Research (CIHR)'s Scientific Expert Working Group. Following a meeting of the working group in June 2011, the Canadian Federal Minister of Health, the Honourable Leona Aglukkaq, announced a Phase I/II interventional clinical trial on CCSVI (http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/_2011/2011_87-eng.php). The working group will provide leadership and advice in the drafting of the terms of reference for the Phase I/II clinical trials in Canada, and will continue to monitor and analyze the data from the seven studies and other studies related to CCSVI and MS around the world.

Regarding the seven funded teams, all have received approval for their studies from the required Institutional Review Boards in the U.S. or the Research Ethics Board in Canada, a first step established by regulatory authorities to protect human subjects involved in research projects. (Read more http://www.nationalmssociety.org/research/intriguing-leads-on-the-horizon/ccsvi/steps-involved-in-launching-clinical-research/index.aspx about steps involved in conducting clinical research.)

Already more than 486 people have undergone scanning with various imaging technologies being used by the studies, including the Doppler ultrasound technology originally used by Dr. Paolo Zamboni and his collaborators, as well as magnetic resonance studies of the veins (MR venography), catheter venography, MRI scans of the brain, and clinical measures.

Because the studies employ rigorous blinding and controls designed to collect objective and comprehensive data, the full results of the ongoing research will be available only after completion of the studies which will involve more than 1300 people representing a spectrum of MS types, severities and durations, as well as individuals with other disease types and healthy controls. In the meantime, several teams are planning to present preliminary results at medical meetings later this year.

"We are pleased that this important work investigating the link between CCSVI and MS is advancing quickly," notes Dr. Tim Coetzee, chief research officer at the National MS Society. "Results from these comprehensive studies will help inform important next steps."

Yves Savoie, President and chief executive officer of the MS Society of Canada concurs, "The CIHR's Scientific Expert Working Group, who will provide leadership and advice in the drafting of the terms of reference for the Phase I/II clinical trials in Canada, will continue to monitor and analyze the data from these studies and other studies related to CCSVI and MS around the world. We are heartened to be moving closer to more definitive answers about CCSVI and MS."

Details: The funded investigators, who are drawn from a broad range of disciplines ranging from MS neurology, vascular surgery and interventional radiology, report progress in establishing standardized protocols, recruiting and scanning participants and in the development of plans for sharing their findings, as summarized below.

READ FULL SUMMARY ON THE WEBSITE (after 4pm Eastern, July 14, 2011):
http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=5261