



ADVOCACY

March 25, 2011	CC: Marketing
2011 Public Policy Photos Now Available	

Photographs from the 2011 Public Policy Conference are now available and filed by Region on the FTP site. To access the FTP site, follow these [steps](#). Additional and select high quality images are also on the Society Asset Management System (SAMS): <http://nmss.emotion.com>. These are located under Photos>Advocacy>2011 Public Policy Conference.

Use these images to heighten awareness of MS to facilitate understanding, engagement and action to fuel the movement. Here are some ideas:

- Pitch to the media — Now is the time to send a photo of your group to your local daily, weekly, or community newspaper. It's not too late. Use this [template](#).
- Post online or print in your chapter newsletter.
- Share with major gift officers, volunteers, marketing staff, and others to demonstrate the power of advocacy in giving voice to the many people who want to do something about MS and in shaping key policies.
- Illustrate MS activists in action ... in an MS Action Alert or an Advocacy E-letter.

Thank participants — Send to your MS activists who attended the PPC ... or those who weren't able to attend.



MARKETING

March 25, 2011	CC: All
<u>March 2011: E-communications Update</u>	

March National MS eNEWS

Send date: ~~3/22/11~~ 3/23/11

Audience: Full List

The March National MS eNEWS was sent on Wednesday, March 23 – a day’s delay due to important late breaking news. Content included a feature about new treatment options in the Spring 2011 issue of Momentum; a Walk MS call-to-action; and information about additional funding for Canbex Therapeutics as a result of initial support from Fast Forward.

Many staff create integrated communications plans taking into account the Society’s national e-communications program. Although last minute changes to this program are rare, they clearly impact these plans. Going forward, the following protocol will be used to communicate unexpected delays or changes: (1) email to the ‘brandchampions’ and ‘prlist’ groups and (2) issue a news sheet announcement. If you wish to be added to one or both of the above email groups, please submit a Track-It ticket. Thank you for your efforts and understanding.

Notes

Individuals with a ‘no email’ classification on their Altair accounts will be suppressed, along with standard Direct Marketing Program excludes/suppressions.

The FY 2011 Society Constituent Communications Calendar and Schedule is available on SharePoint at:

http://intranet.nmss.org/Topics/marketing/Documents/Society_Constituent_Communications_Calendar_and_Schedule_FY2011.xls

Contact Information

For editorial questions or suggestions regarding our National MS eNEWS, please contact Gary at gary.sullivan@nmss.org or 212-476-0538.

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



MARKETING

March 23, 2011	CC: Chapter Presidents
	Development
	Information & Resources
	Programs & Services
<u>Momentum now available for iPhone and iPad</u>	

A fully interactive edition of **Momentum** is now available for use on the iPhone and iPad. Users can download the Spring 2011 issue—and all issues going forward—at <http://itunes.apple.com/us/app/momentum-magazine-by-national/id422081258?mt=8> or by searching for “Momentum magazine” in the Apple Apps Store on the user’s device.

Momentum for iPhone and iPad includes all editorial content from the print edition. It also offers RSS feeds to all the News Bulletins on the Society’s home page, our live Twitter feed, and every video on our YouTube channel.

It also allows readers to:

- E-mail articles to others
- Post links to articles on Facebook and Twitter
- Post personal comments or questions to the articles
- Zoom in and out to increase readability

Future issues of **Momentum** for the iPhone and iPad will be available in the Apps Store in advance of the print edition’s ship date. (E.g., the Summer edition will be available mid-April; print copies will ship out on May 2nd.)

If you have any questions about the iPhone/iPad edition, please e-mail Gary Sullivan at gary.sullivan@nmss.org.

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MARKETING

March 25, 2011	CC: Chapter Presidents
	Development
	Information & Resources
	Programs & Services
<u>Momentum Summer 2011 Issue</u>	

The summer issue of **Momentum** will reach readers in your area by mail beginning May 2, 2011. NEW: The fully interactive **digital** edition will be posted April 18. 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 e-mail, links or by posting to social networks.

This issue of **Momentum** includes a feature on progressive MS, ranging over current research, personal experiences, how diagnosis is made, risk factor connections and finding treatments. The cover and the second feature focus on Bike MS. Other articles include a low-vision alert on workplace solutions, aquatic exercise, the latest on vitamin D, a personal story on getting back into the workforce, readers' comments on parenting with MS, and dating challenges.

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:

- An MS Navigator®
- The Americans with Disabilities Act
- Employment or job retraining services
- Educational programs
- Your state's department of vocational rehabilitation
- Aquatics programs
- Becoming an MS Activist
- Bike MS events
- Support groups for parents with MS

Readers may ask for copies of these Society publications:

Low Vision Alert, Spring 2011 (Momentum article)

Timmy's Journey to Understanding MS (DVD)

Keep S'myelin (newsletter)

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

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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

March 25, 2011

Small, Uncontrolled Study Looks at Long-Term Effects of Bone Marrow Stem Cell Transplantation for MS

In a small uncontrolled study, 35 people with MS underwent bone marrow stem cell transplantation aimed at “rebooting” the immune system, and were followed for two to 15 years. Two deaths occurred which were attributed to the treatment, and three other patients died over the follow-up period, two of which were attributed to complications of their MS. The treatment showed the most benefit in people considered to have aggressive disease. This procedure is experimental, and is the subject of ongoing clinical trials to determine its benefits and risks in people with MS. Drs. A. Fassas, Vasilios K. Kimiskidis, and colleagues (Aristotle University of Thessaloniki Medical School, Greece) report their findings in *Neurology* (March 22, 2011 76:1066-1070, <http://www.neurology.org/content/76/12/1066.abstract>).

Bone marrow transplantation is a lifesaving treatment for certain cancers. It is variously called “hematopoietic stem cell therapy” and “autologous stem cell transplantation.” People are given infusions of their own bone marrow stem cells, which are first extracted and treated. Chemotherapy and sometimes whole-body radiation are used to wipe out the person’s immune system before the bone marrow cells are reintroduced by injection. The hope is that the new immune cells will no longer attack myelin or other brain tissue, so that the person develops a new more tolerant immune system.

This procedure is strictly investigational. In clinical trials over the years, it has produced some good results in MS, usually for younger, less disabled people, however, others have seen their MS return, and experienced more progression. And, sadly, a few have died. The National MS Society’s list of Clinical Trials in MS 2010 lists three ongoing studies in the U.S. and Canada using this approach; read more (<http://www.nationalmssociety.org/research/clinical-trials/participate-in-clinical-trials/download.aspx?id=224>) about these trials.

The team from Greece conducted 35 transplants from June 1995 until May 2001 in people whose MS symptoms had progressed in the year preceding treatment. Two people died from transplant-related complications at two months and 2.5 years after the procedure, and three others died over the follow-up period, two of which were attributed to complications of their MS. Sixteen people improved on the EDSS scale measuring disability, with improvements lasting for a median of 2 years. Two of the individuals stabilized and remained improved over 7 and 8 years, respectively. Seven worsened during follow-up but remained better than their disability level at baseline, while seven others worsened compared to their disability level at baseline. The results appeared to be most beneficial in those who had evidence of active areas of disease activity (“gadolinium-enhancing lesions”) on MRI scans at the time of the transplant.

The most impressive results in this series were observed in very active “aggressive” MS cases, but whether bone marrow transplantation is superior to conventional treatments cannot be answered on the basis of this study, note the authors, because of the methods used. This was an uncontrolled and unblinded study, meaning that no other treatment or sham procedure was used for comparison, and all participants and clinicians knew what therapy was being administered (blinding is used to control bias). Furthermore, the duration of follow-up varied widely, and many individuals who initially improved following treatment worsened to varying degrees during follow-up. The treatment-related deaths, which occurred in 6% of the study population, are of concern, and warrant caution in pursuing such experimental therapy outside of a clinical trial setting.

Read more (<http://www.nationalmssociety.org/about-multiple-sclerosis/progressive-ms/can-progressive-ms-be-treated/index.aspx>) about treatments for progressive MS.

Research Programs Department