



CHAPTER PRESIDENTS

May 6, 2011	CC: All
<u>May 2011: E-communications Update</u>	

May National MS eNEWS

Send date: 5/14/11

Audience: Full List

The May National MS eNEWS will be sent on Saturday, May 14. Content includes a feature about BG12 and Laquinimod, as well as information about the Summer 2011 issue of **Momentum**, the May 24 live webcast “Working Toward Your Best Life: Advances in Quality of Life Research”, and the May 2011 Matching Gift E-fundraising Campaign.

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.



CHAPTER PRESIDENTS

May 6, 2011

CC: All

May 2011: E-fundraising Update

May Matching Gift E-fundraising Campaign

Send dates: 5/10, 5/12, 5/17 and 5/18

Audience: ~850,000

Objectives: (1) The e-fundraising campaign goal for the four part email series and promotions implemented on the national website will be \$150,000. (2) This campaign represents a continued focus on integrating our online/offline efforts, leveraging the Pure Protein matching gift campaign that is also running in the mail at this time.

The theme of this four part email series is a matching gift campaign. The deadline for donations to be made toward this campaign (via the specific email series and national website promotions) is May 18 at midnight. Please note that this special matching gift opportunity only applies to gifts received in response to this specific campaign. Other fundraising efforts — including Bike MS and Walk MS — do not apply.

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Contact Information

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.



CHAPTER PRESIDENTS

May 6, 2011	
Rural Healthcare Strategic Work Group	

As we prepare to move forward our strategic priority of increasing access to specialized MS care in rural areas and for others who are underserved, a work group of Society staff and healthcare leaders with experience and expertise in the rural healthcare field is being convened in Kansas City, Missouri May 16-17. This group will provide insight and guidance on how we can leverage our internal resources and engage in fruitful partnerships to enhance access to quality MS care in rural areas. They will define access issues, identify potential partners, and analyze needs. They will develop a framework for moving forward along with realistic outcomes for 2012 and beyond.

The group will include representation from the six regions, as well as experts from a variety of perspectives who share a commitment to expanding access to quality rural healthcare. Participants of this meeting are as follows:

- Denise Bell, MPH, Dept. of Public Health Education, N.C. Central University
- Lisa Custy, MSCIR, Associate Vice President, Information Resource Center
- Debra Frankel, MS, OTR, Associate Vice President, Programs/Services, ART team
- Kathleen Fuchs, PhD, ABPP, University of Virginia Health System
- Debbie Garrison, Executive Vice President, Mission Advancement, Central PA. Chapter
- Amy Goldstein, MSW, Director of Programs, Mid-America Chapter
- Kaye Gooch, MSW, Executive Vice President, Services & Volunteers, Eastern N.C. Chapter
- Jennifer Kline, Chapter President, North Central States Chapter

- Dorothy Northrop, MSW, Vice President of Clinical Operations, Home Office
- Erin Poznanski, MA, Executive Vice President, Programs & Services, Gtr. Northwest Chapter
- Linda Redford, RN, PhD, Director, Central Plains Geriatric Education Center
- Mary Roberts, Associate Vice President, Programs & Services, South Central Region
- Carrie Lyn Sammarco, Dr. NP, FNP-C, MSCN, Nurse Practitioner, Multiple Sclerosis Care Center, NYU School of Medicine
- Lisa Taylor Skutnik, PT, MA, MA Executive Vice President, Clinical Programs, Home Office
- Brock Slabach, MPH, FACHE, Sr. VP of Member Services, National Rural Health Association
- Amber Stalker, MEd, Program Director, Community Programs, Greater New England Chapter
- Robert Stiles, Director, State Primary Care Office, Kansas Bureau of Local & Rural Health
- Renee Vandlik, MA, Director, State & Local Government Relations, Public Policy Office
- Amy Vieth, PT, MBA, Director of Therapy Operations, Rusk Rehabilitation Center
- Mitchell Wallin, MD, MPH, VA MS Center of Excellence-East

Considerable interest and energy has been generated throughout the Society about access to quality MS care in rural areas. We anticipate that this work group will be very helpful in determining where to best direct our efforts and resources, particularly where a Society-wide consistent approach will be important. Therefore we will make sure that this input helps to guide chapter, region and Society-wide initiatives in this area. A written report will come from this meeting that will be made available across the organization and should prove helpful as we engage in our strategic thinking and planning.



PROGRAMS AND SERVICES

May 6, 2011	CC:
June Telelearning Opportunity for Society Connection Program Volunteers	
Action Requested by June 15, 2011	

The second telelearning for fiscal year 2011 for all Society connection program volunteers (self-help group leaders, peer support and MSFriends volunteers) is scheduled for June 2011. The topic is *Using a Strengths Perspective in Peer-to-Peer Relationships*.

This training will provide an overview of solution focused-conversations, to include a discussion of a variety of techniques volunteers can use in their peer-to-peer relationships in the group setting or one-on-one. Motivation to make positive changes is based on fostering strengths, not dwelling on weaknesses. Solution-focused support emphasizes success. When successes are identified and celebrated, confidence and motivation increases. Every environment, no matter how impoverished, is full of resources that can be used for positive change.

Our presenters are Julie Gibson and LuAnn Pierce, both consultants are with the Society.

This learning opportunity is open to all Society self-help group leaders, peer support and MSFriends volunteers. Due to the complexity of the topic the calls are scheduled for 90 minutes, not the typical one-hour call.

SCHEDULE

Three calls are scheduled. It is the same agenda offered at three different times.

- Call 1 is Tuesday, June 21, 2011 from 7-8:30 pm ET (6 pm CT, 5pm MT, 4 pm PT)
- Call 2 is Wednesday, June 22, 2011 from 1-2:30 pm ET (12 pm CT, 11 am MT, 10 am PT)
- Call 3 is Thursday, June 23, 2011 from 10-11:30 pm ET (9 pm CT, 8 pm MT, 7 pm PT)

The call will be recorded for those who miss it or would like to listen again. A playback number will be provided for you to share with your volunteers. The recording and associated handout will also

be available for download on the self-help group leaders' resource page on the Society's website (<http://www.nationalmssociety.org/selfhelpgroupleaders>.)

COST

There is no cost for this telelearning opportunity.

REGISTRATION AND CANCELLATION INFORMATION

The registration form and marketing handout are available on SharePoint: Programs and Services>Social Connections and Support Resources>Self Help Group Materials. For registration purposes you can customize the marketing handout with your chapter contact's name, phone number and email address.

Due to numerous factors, including the need to reserve lines with the conference call company, charges for unused lines, and the distribution of call information and handouts, registration and cancellation deadlines have been established. The **registration deadline** is **Wednesday, June 15th**. Chapters needing to **cancel a registration** should do so no later than **Monday, June 20th**. Please send all registrations and change notifications to Selfhelpgroupleaderregistrations@nmss.org.

The Programs and Services Department will e-mail the training handouts to all volunteers registered on or before the registration deadline. Hard copies will be mailed to volunteers without an email address. For registrations received after the June 15, 2011 deadline, chapters will be responsible for distributing the training-related handouts to those registrants.

Please address any registration-related questions to Heather Webb-Jones in the Programs and Services Department at 303-698-6100, ext. 15176 or heather.webb@nmss.org.

Topics and dates for future telelearnings will be announced in upcoming news sheets.

Additional questions or suggestions for FY 2011 telelearning topics can be directed to Kim Koch at (303) 698-6100, ext. 15158 or kimberly.koch@nmss.org.



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

May 6, 2011

MS Trial Alert:

Study of Oral Teriflunomide (HMR1726) Added on to Interferon Beta Recruiting People with Relapsing Forms of MS Worldwide

Summary: Investigators in the United States and others around the world are recruiting 1455 people with relapsing multiple sclerosis for a study comparing two doses of oral teriflunomide (HMR1726), an investigational medication, or inactive placebo, in people taking any type of approved interferon beta. The study is sponsored by Sanofi-Aventis.

Rationale: Multiple sclerosis occurs when the immune system attacks the brain and spinal cord. Teriflunomide is a novel oral compound that inhibits the function of specific immune cells. Results from a two-year, phase III trial in 1,088 people with relapsing MS (the TEMSO trial), comparing two doses against placebo, showed that both doses significantly reduced the rate of MS relapses by up to 31.5% relative to placebo. The most common side effects were nausea, diarrhea, mildly elevated liver enzymes and thinning of the hair. Combining this experimental oral therapy with a moderately effective standard therapy may boost therapeutic benefits. Other studies of teriflunomide in MS are ongoing.

Eligibility and Details: People eligible for participation include individuals 18-55 years of age with relapsing forms of MS. Participants must have received a stable dose of any approved type of interferon beta for at least six months, and have had disease activity in the previous 12 months, sometime after the first three months of interferon treatment.

Participants will be randomly assigned to receive – in addition to interferon – either 7 mg teriflunomide, 14 mg teriflunomide, or placebo once daily for 24 weeks. The main goal of the study is to determine the effectiveness of this combination on reducing the relapse rate. Other goals include evaluating disease activity as observed on MRI, safety and tolerability, and measures of fatigue and quality of life.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please refer to the site listing and contact information on clinicaltrials.gov: <http://clinicaltrials.gov/ct2/show/NCT01252355>.

Sites are to be enrolling in the following cities:

Phoenix, Arizona

Oceanside, California

Ormond Beach, Florida

St. Petersburg, Florida

Tampa, Florida

Ft Wayne, Indiana

Indianapolis, Indiana

Louisville, Kentucky

Missoula, Montana

Charlotte, North Carolina

Bismark, North Dakota

Vienna, Virginia

[Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial \(PDF\).](#)