



CHAPTER PRESIDENTS

July 27, 2012	CC: All
<u>Updated Organizational MS Awareness Metrics Report</u>	

The organizational MS awareness metrics report – a key organizational milestone identified in the Society’s 2012 Awareness Plan – is now available on SharePoint:

http://intranet.nmss.org/Topics/marketing/Documents/OrganizationalAwarenessMetricsCY2012_Q1-2.pdf

The 2012 Organizational Awareness Plan is being thoughtfully implemented across the Society. As a key step in evaluating the effectiveness our awareness efforts, this important metrics report benchmarks organization-wide activity levels on the web, in social media, and in traditional media. Moving forward, the Society-wide Marketing Work Team will continue to enhance the report and work across the organization to ensure the information it contains is fully leveraged in organization-wide planning.

One example of enhancements to come is inclusion of MSconnection.org key metrics:

Number of new users	Number of Pageviews
March 2012: 3,693	March 2012: 26,180
April 2012: 1,349	April 2012: 78,920
May 2012: 1,356	May 2012: 93,520
June 2012: 1,135	June 2012: 104,738
	Average: 75,840

The report is being announced to all Society social media, marketing, and communications lists, as well as to Regional Executive Vice Presidents, Chapter Presidents and the Senior Management Team. If you have questions about the report and how it can be leveraged to support awareness planning, please feel free to contact Chris.Yankee@nmss.org or any member of the Society-wide Marketing Work Team, listed below. Upcoming report publication is planned for October 26th.

Please also feel welcome to review the 2012 Awareness Implementation Plan as a refresher on the key organization-wide milestones for 2012.

http://intranet.nmss.org/Topics/marketing/Documents/2012%20Awareness%20Implementation%20Plan_Approved.pdf

The Society-wide Marketing Work Team includes: Sherri Giger, Holly Anderson, Beth Clark, Marni Deckter, Meghan Finn, Kevin Moffitt, Debbie Pope, Arney Rosenblat, Corrina Steiger, Ericka Tavares, and Chris Yankee.



PROGRAMS & SERVICES

July 23, 2012	CC:
Telelearning Opportunity for Society Connection Program Volunteers	
Action Requested by: August 15, 2012	

The fourth and final telelearning for fiscal year 2012 for all Society connection program volunteers (self-help group leaders, peer support and MSFriends) is scheduled for Thursday August 23 and Friday August 24. The topic is: *Powering the National MS Society's Research Investments: The Peer Review Process.*

Presented by Erica de Klerk, Director of Donor & Volunteer Relations. Erica has been on staff with the Society since 2005 and currently is supporting fundraising and volunteer engagement for the No Opportunity Wasted (NOW) campaign.

Participation in this call will increase your volunteer's understanding of the Society's research funding decision process and build their confidence that the Society is pursuing all promising solutions for people impacted by MS.

This learning opportunity is open to all Society self-help group leaders, peer support and MSFriends volunteers.

SCHEDULE

This one hour call will be repeated on two different dates and times:

- Thursday August 23 at 7 p.m. ET (6 p.m. CT, 5 p.m. MDT and 4 p.m. PT)
- Friday, August 24 at 1 p.m. ET (12:00 p.m. CT, 11 a.m. MDT, 10 a.m. 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/living-with-multiple-sclerosis/connection-programs/resources-and-support-for-self-help-group-leaders/index.aspx>)

Call participants will be invited to submit questions prior to the call. Participants will also be provided instructions on how to submit questions after the call, whether they listen to it live or the recording.

COST

There is no cost to chapters or participants 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, August 15, 2012.** Chapters needing to **cancel a registration** should do so no later than **Friday, August 17.** Please send all registrations and change notifications to Selfhelpgroupleaderregistrations@nmss.org.

The Programs and Services Team 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 August 15, 2012 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.jones@nmss.org.

Additional questions or suggestions for FY 2013 telelearning topics can be directed to Monica Aden at (303) 698-6100, ext. 15169 or monica.aden@nmss.org.



PROGRAMS & SERVICES

July 27, 2012	CC: Advocacy
	Chapter Presidents
	Development
	Programs & Services
	Volunteer Management
<u>MS Ambassador Training Materials Distribution</u>	

We are pleased to announce that new resources for training MS Ambassadors will be posted next week on SharePoint in the Volunteer Engagement section. These materials provide basic MS Ambassador training as well as guidance about supplemental instruction for the various roles that Ambassadors might play-- Research Advocates, Community Health Volunteers, Speakers to Community Groups, Activism Ambassadors, Event Champions, Health Fair representatives, etc. By using these common training materials, we can take a more consistent approach to preparing volunteers to represent the National MS Society to various audiences.

Two Saba webinars are scheduled to review these materials and discuss the various roles that fall under the MS Ambassador umbrella. No pre-registration is required (The webinar is repeated—it is only necessary to attend only one.) The target audience includes: Volunteer Engagement Professionals, Programs and Services staff, Advocacy staff, Event staff and others who may recruit, train and work with volunteers who represent the Society.

This call will be repeated on two different dates and times:

Date/Time: Tuesday, August 14, 2012; 2-3:30pm ET (1-2:30pm CT, 12-1:30pm MT, 11am-12:30pm PT)

Dial in number: Dial in number: 888-279-3775 (15100); 8001#

Link <http://mt211.centra.com/GA/main/00000137d7c900000137a7af7a68a2f6>

Date/Time: Thursday, August 23, 2012; 2-3:30pm ET (1-2:30pm CT, 12-1:30pm MT, 11am-12:30pm PT)

Dial in number: 888-279-3775 (15100); 8001#

Link <http://mt211.centra.com/GA/main/00000137d7c900000137a7af7a68a2fb>

Please join us for one of these calls to learn more about how this important program has been enhanced to embrace all types of volunteers who represent the Society to the public.

Questions? Please contact:

Sid Wittenberg (Sidney.wittenberg@nmss.org)

Michele Groden (Michele.Groden@nmss.org)

Debra Frankel (debra.frankel@nmss.org)

Debby Bennett (debby.bennett@nmss.org)



PROGRAMS & SERVICES

July 27, 2012	CC:
New Training Materials for Vocational Rehabilitation Professionals	

New training materials for vocational rehabilitation professionals are now available on SharePoint: Programs & Services/Employment & Insurance Resources/Employment Programs.

The materials consist of:

- A slide deck offering an overview of MS
- A slide deck addressing the employment challenges and vocational needs often generated by MS
- A “Tip” sheet with information about implementation and additional case examples

These training materials were developed by Barbara McKeon (NYC/Southern NY Chapter) and Steve Nissen (National Capital Chapter). Reviewers included Phil Rumrill (Kent State University) and Rick Roessler (University of Arkansas), along with Society staff.

Using these materials when you conduct in-service training for vocational rehabilitation counselors will assure that you are providing the most up-to-date and relevant information, and in a manner that is consistent across the Society.

Please join us for a discussion and review of the materials on:

Date/Time: October 18, 2012 at 3-4pm ET (2-3pm CT; 1-2pm MT; 12-1pm PT)

Phone Number: 888-279-3775 or 15100; 5286#

Link: <http://mt211.centra.com/GA/main/00000026efd30000013850828b568362>

Questions? Please contact Barbara McKeon, Steve Nissen, or Kris Graham.



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

July 23, 2012

FDA Updates Prescribing Info for Ampyra to Address Risk of Seizure in Those with Reduced Kidney Function

The U.S. Food and Drug Administration (FDA) released a Drug Safety Communication (<http://www.fda.gov/Drugs/DrugSafety/ucm312846.htm>) to address the risk of seizures in people with MS who are starting Ampyra[®] (dalfampridine, Acorda Therapeutics). Ampyra was approved in January 2010 to improve walking in people with MS. Seizures are a known side effect of Ampyra, and seizure risk increases with higher blood levels of the drug. Based on its evaluation of post-marketing reports of seizures occurring in people with MS on the therapy, the agency is updating prescribing information for Ampyra to advise that kidney function should be checked before starting Ampyra, and monitored at least annually, because impaired kidney function can result in high blood levels of the drug.

The FDA also emphasizes that patients who miss a dose should not take extra doses, since an extra dose of Ampyra can increase seizure risk. In its evaluation of adverse event reports, most of the seizures happened within days to weeks after starting the recommended dose and occurred in patients having no history of seizures. Most of those who experienced seizure were at least 50 years old and were at risk for mild, age-related kidney impairment.

The FDA communication notes that “The potential benefits of Ampyra treatment must therefore be carefully considered against the potential risk of seizures before using Ampyra in patients with mild renal impairment.”

Read the FDA Communication: <http://www.fda.gov/Drugs/DrugSafety/ucm312846.htm>

AMPYRA is a registered trademark of Acorda Therapeutics