



## ADVOCACY

March 16, 2012

CC: Development

### **Walk MS and MS Activism – Photo Booths**

One aspect of the We are Activists Strategic Response Implementation Plan is to develop a more consistent process that is utilized throughout the organization to recruit and engage volunteer activists. One way to do this is by tapping into the momentum created by participants at Walk MS. Chapters have found successes staging an MS Activism Photo Booth at these events to raise awareness and engage participants in MS activism. Artwork for photo props to support this common tactic is now available. Materials are located on the FTP site, in the folder: Activist Self Identification at Walk MS.

To fully realize the benefits of this tactic at your Walk MS events, please plan adequate training for those staffing this booth, and identify measurable outcomes you aim to achieve by engaging walkers with this concept. For instance, measurable outcomes to gauge progress could include:

- An increase in Facebook Fans, Twitter followers or numbers of volunteers registered for the MS Activism Network;
- Votes cast to rank policy issues for people with MS and those that care about them;
- Signatures collected for a petition drive to move a policy or legislative priority forward;
- Personal testimonials collected to illustrate the need for policy reform related to a current advocacy priority.

Refer to these tools: [Advocacy at Walk MS – Easy to Understand Next Steps](#) and [Advocacy at Walk MS 2012 Society MS Activism Results](#) to further identify measurable outcomes and train volunteers to staff the booth, using this power point filed on Share Point > Advocacy > Advocacy Training, Basics and Tools > Advocacy at Walk MS to guide your training. Click [here](#) for easy-to-understand directions to create photo props locally. Instructions to access the FTP site can be found [here](#).

To order stickers and/or buttons with the “I’m an MS ACTIVIST” logo to support this tactic, please contact Liz Dodge at Darter Specialties at 203-699-9805. Stickers must be ordered in quantities of 500 and are \$125 per roll; buttons can be ordered individually and are .50 each. Questions regarding this tactic can be directed to Renee Vandlik at [Renee.Vandlik@nmss.org](mailto:Renee.Vandlik@nmss.org) or 202-408-8112.



## DEVELOPMENT

March 16, 2012

CC: Chapter Presidents

### **2012 Bike MS Post Event / Demographic Survey**

As a part of the “100 Extraordinary Rides” program, we are developing a national post-event Bike MS survey which will help us gather consistent feedback and demographic information from all of our participants nationwide.

In the coming weeks, we will be sending out an email which should be forwarded to all 2012 Bike MS participants after your ride(s). The e-mail will include an introductory paragraph and a link to the survey on SurveyMonkey. The purpose of this survey is to update our participant demographic information, which is used in marketing the event, pitching the event to potential sponsors and establishing key audiences, as well as soliciting feedback for your event in particular. Our hope is that this survey will replace any post-event survey you generally send out, so we’re not asking participants to complete more than one survey.

We are asking each chapter to send this survey out to all of your local Bike MS participants (a person is considered a participant if they have either raised at least \$1, or that they are marked as attended by the use of the attended flag in Altair). This survey should be sent only to participants of completed 2012 Bike MS events. You can send the survey, along with the introductory paragraph, in a scheduled e-mail to participants or you can send it out on its own. **The survey will remain open until November 30, 2012.**

Final results will be compiled shortly after the survey is closed and posted to SharePoint. We will alert you via news sheet when final results are available. Results will be compiled on a National basis and a state of residence basis, and will also be sorted on a chapter by chapter basis. If you would like to see your local event results prior to December, we can accommodate a weekly report.

Thank you for your help with this important project! If you have questions about the survey please contact:

Paula Eichholz at 303-698-6100 x16197 or [paula.eichholz@nmss.org](mailto:paula.eichholz@nmss.org)

Sarah Klein at 303-698-6100 x15170 or [sarah.klein@nmss.org](mailto:sarah.klein@nmss.org)



## MARKETING

March 16, 2012	CC: All
<b><u>March 2012: E-communications Update</u></b>	

### **February National MS eNEWS**

**Send date: 3/21/12**

**Audience: Full List**

The March National MS eNEWS will be sent on Wednesday, March 21. Content will include a feature on a new oral therapy, BG-12, which was just submitted to the FDA, as well as a push to the Society's new online community at **MSConnection.org**, a wrap-up of the Public Policy Conference, a link to a profile of 2012 John Dystel Award for MS Research winner Dr. Richard Ransohoff, and a push to **BeaMShero.org**.

### **Contact Information**

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

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



## MARKETING

<b>March 16, 2012</b>	<b>CC: Chapter Presidents</b>
	Development
	Information & Resources
	Programs & Services
<b><u>Momentum Summer 2012 Issue</u></b>	

The summer issue of **Momentum** will reach readers in your area by mail beginning May 1, 2012. The fully interactive **digital** and **smartphone** editions 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, download articles as PDFs, print pages and share articles via email, links or by posting to social networks.

This issue of **Momentum** includes a feature on traveling with MS that includes: personal experiences, accessible destinations, getting there, using travel agents, practical tips, accessibility laws, medical travel needs and more. Other articles include a story on the Bike MS-Raleigh partnership, a highlight on the “three faces” of fatigue, a profile of comic book creator Mark Millar, a personal account of adaptive bicycling, an activism success story and more.

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

- Travel and recreation resources
- Bike MS events
- Fatigue management
- Adaptive bicycling
- Becoming an MS activist

Readers may ask for copies of these Society publications:

**Travel and Recreation** (website page)

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

**Everyone’s Universe: A Guide to Accessible Astronomy Places**, by Noreen Grice

**The Disability Law Handbook**, published by the DBTAC Southwest ADA Center

**Multiple Sclerosis: 300 Tips for Making Life Easier**, by Shelley Peterman Schwarz

**What Nurses Know ... Multiple Sclerosis**, by Carol Saunders, BA, BSN, MSCN

**Multiple Sclerosis: The Questions You Have, The Answers You Need**, by Rosalind  
Kalb, PhD

If you anticipate needing additional copies of this issue for your chapter, please email me or phone me at the number below. We hope this is helpful. Please let me know any feedback you receive.

Gary Sullivan  
Managing Editor  
212-476-0538  
[gary.sullivan@nmss.org](mailto:gary.sullivan@nmss.org)



## PROGRAMS & SERVICES

<b>March 16, 2012</b>	<b>CC: Chapter Presidents</b>
	Development
<b><u>Coached Courses on LMS</u></b>	

As part of the Society’s commitment to ongoing professional development opportunities we offer the following coached courses for Programs and Services staff:

- Employment and MS
- Solution Focused Conversations
- Grantsmanship: Keys to Success
- Service Management

These courses will be offered on a rolling basis, contingent upon registration. The courses are currently accessible through the Society’s Learning Management System, and will eventually move to Saba once that migration is complete. A future communication will go out related to registering for the courses on Saba.

The courses are only available to National MS Society staff. There is no cost to chapters for the courses. Participants must have worked for the Society a **minimum of five months** by the start of the course. This requirement helps to ensure basic job familiarity in addition to providing the necessary background on Society resources, information and referral procedures, etc.

The LMS allows participants access to the course materials 24 hours a day, seven days a week. Participants will be assigned an experienced coach to work with them (typically on a weekly basis) through the course modules. Each course has coaches with recognized expertise and experience in the subject area. For more information on the registration process and course descriptions please go to:

[http://intranet.nmss.org/Topics/programs\\_services/Pages/StaffDevelopmentOpportunities.aspx](http://intranet.nmss.org/Topics/programs_services/Pages/StaffDevelopmentOpportunities.aspx)

If you have any questions or need additional information please contact Kim Koch at [kimberly.koch@nmss.org](mailto:kimberly.koch@nmss.org) or 303-698-6100, ext. 15158.



## PROGRAMS & SERVICES

<b>March 16, 2012</b>	<b>CC: Chapter Presidents</b>
<b>MSSMC Certifications February 2012</b>	

The following individuals earned the Multiple Sclerosis Service Management Certification (MSSMC) in February 2012. We are pleased to congratulate:

- Melissa Bruno, Greater Delaware Valley
- Heather Donegan, Indiana
- Anastatia Fabris, New York City/Southern NY
- Barbara Goettsch, Greater Carolinas
- Robyn Hirsch, Hampton Roads
- Amy Keller, Pacific South Coast
- Janell Marshall, Pacific South Coast
- Todd Robertson, Maryland
- Andrew Rose, Northern California
- Jennifer Tauchman, Colorado/Wyoming
- Julia Vallelunga, National Capital
- Kathryn Zapach, Central Virginia

Chapter certification requirements for 2012 note that, “The chapter has at least ONE service manager who has achieved Certification through the MSSMC test by 9/30/12, or has a relationship with another chapter in the region to provide access to a certified Service Manager for clients in need of Tier 2 services.” The next MSSMC test dates are August 11 – August 25, 2012 with a deadline to register of June 29<sup>th</sup>. Please go to [www.ptcny.com](http://www.ptcny.com) to register and for reference materials. Contact Janis Pluss, 303- 698-6100, ext. 15284 or [Janis.pluss@nmss.org](mailto:Janis.pluss@nmss.org) for additional information



## PROGRAMS & SERVICES

<b>March 16, 2012</b>	<b>CC: Chapter Presidents</b>
<b><u>2012 North American Education Programs</u></b>	

This year's North American Education Program (NAEP) will profile leading medical professionals and researchers in the field of pain and sleep disorders. Pain and sleep disorders are two common symptoms of MS that can be challenging to report and treat. Over 60% of those diagnosed with MS experience pain. For people living with MS, sleep disorders affect their health and quality of life. The DVD and program booklet will highlight the causes of pain and sleep disorders in MS, provide insight into on-going research, and ultimately provide tools to discuss managing pain and sleeplessness with doctors.

We are able to once again offer this program at no cost. Chapters will receive five DVDs and 100 program booklets. Additional program books and DVDs are available upon request. Self-help Group "meeting in a box" tool kits will be shipped directly to self-help group leaders. Each kit will include a cover letter, facilitator's guide, (1) DVD, and (15) program booklets. Group leaders in need of additional program materials will be instructed to contact their chapter liaison with those requests. Instructions on coding in Altair for the shipping of the tool kits will be communicated in a future news sheet.

Program materials will ship in mid-August. As you begin planning for FY2013, please consider including this turnkey program in your plans.

For more information please contact Doris Lill at (303) 698-6167 or via email at [Doris.Lill@nmss.org](mailto:Doris.Lill@nmss.org).



**National Multiple Sclerosis Society**  
733 Third Avenue  
New York, New York 10017-3288  
Tel +1 212.986.3240  
Fax +1 212.986.7981  
E-mail [nat@nmss.org](mailto:nat@nmss.org)  
[Nationalmssociety.org](http://Nationalmssociety.org)

## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

**March 16, 2012**

### **Study Suggests Need for Further Research on Understanding the MS Experience of Hispanics/Latinos**

Findings from a study of Hispanics/Latinos with MS call attention to the need to better understand unique characteristics of MS in this population and the need for more accessible and culturally relevant mental health and social services. Researchers found that a sample of Hispanics/Latinos with MS reported more pain, fatigue, cognitive problems, mental health problems, and dissatisfaction with their access to mental health care than the general MS population, when approximate comparisons were made reviewing data from the Sonya Slifka Longitudinal MS Study. This study by Robert J. Buchanan, PhD, (Mississippi State University) and collaborators was supported by a Pilot Research Award from the National MS Society, and was published in the *Journal of Social Work in Disability & Rehabilitation* (2011;10:211-231, <http://www.tandfonline.com/doi/abs/10.1080/1536710X.2011.622959>).

**Background:** While MS is more common in countries at northern latitudes and in Caucasians with northern European ancestry, MS affects most ethnic groups, including Hispanic and Latino populations. (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/who-gets-ms/index.aspx>) Ensuring that Hispanics/Latinos with MS receive culturally competent care and access to necessary services requires understanding how the disease is experienced in this population. Previous studies found that ethnic minorities are at greater risk for depression and poor mental health, and less likely to receive adequate care for these problems. Investigations like this study are necessary so that Hispanics/Latinos with MS can get care and support services targeted to their specific needs.

**The Study:** Recruitment letters were sent to 686 Hispanics/Latinos who were enrolled in the North American Research Committee on MS patient registry. A total of 99 Hispanics/Latinos with MS agreed to participate in a telephone interview including questions on demographics; symptoms and disease characteristics; physician services; mental health status; MS-related feelings and experiences; and a standard Health-related Quality of Life survey. Researchers compared these findings to similar data from 2000 people with MS who enrolled in the Sonya

Slifka Longitudinal MS Study (<http://www.nationalmssociety.org/research/research-we-fund/targeted-research/sonya-slifka-study/index.aspx>).

In several areas, results from this pilot study matched those from the Slifka Study. The demographics of the two groups were similar, including gender ratios, average age, education, and marital status. Fewer Hispanic/Latino respondents were employed; 33% compared to 44% in the Slifka Study. The type of MS was similar in both groups, although Hispanics/Latinos were younger at disease onset and at diagnosis.

There also appears to be disparities in symptoms. For instance, 94% of the Hispanics/Latinos in the pilot study said fatigue had an impact on their daily activities, while 83% of the Slifka Study respondents reported fatigue as a symptom. Hispanics/Latinos also reported experiencing more pain (73% vs. 54%) and cognitive problems (83% vs. 56%).

Other differences between the two groups involved emotional and mood problems, access to mental health care, and quality of life factors. Depressive symptoms were reported by 44% of the Hispanic/Latino respondents, somewhat higher than the 38% incidence of emotional or mood problems in the Slifka Study. (Note: questions in the two studies were asked differently so these are approximate comparisons.) However, while 98% of participants in the Slifka Study had no difficulty accessing mental health care, only 61% of Hispanics/Latinos with MS were highly satisfied with their access to this kind of care. In contrast, 76% of the Hispanics/Latinos surveyed were highly satisfied with their access to other MS care.

Investigators compared Health-Related Quality of Life scores from this study with a sample of the general U.S. population that had been reported in a previous study. Hispanics/Latinos demonstrated worse scores related to physical function, pain, and general health. The degree to which physical and emotional problems limited the ability of these Hispanics/Latinos to function socially and to perform daily activities and roles was also greater than the general U.S. population.

**Comment:** Providing adequate MS care across the cultural and socioeconomic spectrum means understanding how each group experiences and perceives the disease and identifying the factors that limit access to care. This study points out important factors that warrant further study, since, compared to a broad national sample of people with MS, the Latinos in the study reported more pain, fatigue, cognitive problems, mental health problems, and dissatisfaction with their access to mental health care. The authors recommend more support for vocational and social skills to improve function and quality of life in these areas.

The National MS Society's Hispanic/Latino Advisory Council advises the Society on strategies and programs to overcome cultural barriers and make resources more available to this community. Read more (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/hispanic-latino-advisory-council/index.aspx>) about this council and about Hispanics/Latinos with MS.