



## MARKETING

January 15, 2010

CC: All

### Constituent Communications Calendar (FY 2010) – Updated

The FY 2010 Society Constituent Communications Calendar has been updated to include Home Office communications through September 2010 (please note entries are subject to change). The Calendar is on the new Intranet at:

Marketing → Constituent\_Communications\_Calendar\_FY10

Please note that certain Home Office e-communications are labeled “HOM-Exclusive Send”, which indicates a nationwide target audience. Consequently, Home Office and Chapter managers are requested to not e-mail anyone on the target list on the indicated days.

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



## PROGRAMS AND SERVICES

January 15, 2010	CC: Chapter Presidents
<b><i>Keep S'myelin</i>® Issue #10</b>	
<b>Action Requested/Deadline: Information only</b>	

Issue #10 of *Keep S'myelin*® will be arriving at your chapter and in subscribers' mailboxes in late January. This issue is titled *Treating MS*. The issue contains fun activities for children and families, reader-submitted materials, and important information for parents. *Keep S'myelin* is a newsletter for children (ages 5-12) who have a parent or loved one with MS.

To assist chapters in maintaining and growing their *Keep S'myelin* mailing lists, the Programs and Services Department developed a centralized distribution system, modeled after the successful *Knowledge is Power*® system. For chapters contracted with the IRC, the IRC specialists are now registering children for the newsletter in Altair. Chapters not yet on the IRC are responsible for coding their *Keep S'myelin* clients in Altair. For more information on the Altair registration process please contact Heather Webb at [heather.webb@nmss.org](mailto:heather.webb@nmss.org). Chapters will continue to receive newsletters for chapter use.

The materials in *Keep S'myelin* are not dated, so they have a long "shelf-life." Please make every effort to distribute this valuable resource as widely as possible to families in your area.

- Distribute *Keep S'myelin* at chapter programs and events, including your fundraising events. *Keep S'myelin* makes a great stuffer for the MS Walk goodie bags.
- Make sure branch offices have an adequate supply to distribute locally. Branch offices can request additional copies from their chapter office.
- Conduct targeted mailings and distribution to MS clinics, physicians and other health provider offices, libraries, schools, self-help groups, etc. *Keep S'myelin* also is a great addition to newly diagnosed packets.
- Advertise *Keep S'myelin* in your chapter's newsletter and website.

As always, we welcome your suggestions and comments about *Keep S'myelin* and hope it is a valuable resource to your chapter. We are interested in finding out how you grow your distribution lists. If you would like to share your strategies, please e-mail them to me (contact information is below).

All 24 issues of the newsletter are available on the National MS Society website as both a downloadable PDF and interactive versions.

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## PROGRAMS & SERVICES

January 15, 2010

CC: Chapter Presidents

### **Exciting Research Opportunity for NMSS Self-Help Group Leaders**

**Action Requested/Deadline: February 1, 2010**

National MS Society self-help group leaders are invited to participate in an exciting research opportunity. Leslie Krongold, a doctoral student at the University of San Francisco, is conducting a survey of support group facilitators as part of her dissertation. The purpose of her research study is to describe support group facilitators' role perceptions, goals, and strategies used to achieve social support goals and self-management behaviors in the group setting. The study will look at both professional and volunteer-lead groups. Ms. Krongold contacted the Society and asked that we partner with her on her outreach and recruitment efforts. The survey instrument, study protocol and related materials have been reviewed and approved by Society staff. Copies are available upon request.

Currently there is very little research about support groups for people with chronic health conditions and even less about support group facilitators. By participating in this voluntary research study, self-help group leaders have the opportunity to contribute to a neglected, but very important area of research. Interested leaders can participate in two ways – either through an online survey or by completing the hard copy version. Data collected from both versions of the survey instrument will be anonymous – name, address and phone number of the responders will not be connected with their responses.

The Programs and Services team is coordinating the outreach and recruitment efforts. Chapters are asked to submit an Excel spreadsheet with leaders' names and email addresses, or mailing address if there is no email address, to my attention (contact information below). The survey closes in mid-to-late February, so we are asking that the contact lists be submitted no later than Monday, February 1, 2010. Information on the survey will also be posted to the Society's list-serve for self-help group leaders.

Thank you in advance for your assistance and participation. Ms. Krongold has agreed to share her final report with the Society, and a future news sheet will announce its availability.

For more information please contact Kimberly Koch at 303-698-6100, ext. 15158 or [Kimberly.koch@nmss.org](mailto:Kimberly.koch@nmss.org).



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs & Services

January 15, 2010

### **MS Research Banks Need Participants**

People living with MS may hold the key to curing this disease. There are several ways to help move research forward, including participating in the following ongoing studies and collection banks. Without the participation of people who have MS, this research would come to a standstill.

**[Participate in Genetic Studies](http://www.nationalmssociety.org/research/researchers-need-you/participate-in-ms-genetic-studies/index.aspx)** (<http://www.nationalmssociety.org/research/researchers-need-you/participate-in-ms-genetic-studies/index.aspx>)

Researchers around the world are collaborating to find the genes that make people susceptible to developing MS and other autoimmune diseases. These studies are fed by the participation of people with MS and their family members who donate blood samples from which DNA is derived.

### **What is involved?**

Participants will be asked to fill out a family information form, sign a form to release medical records (only people with MS), read and sign a consent and authorization form, and donate a blood sample (approximately five tablespoons). If you are interested in participating, please contact:

#### **Clinical Coordinator**

UCSF Department of Neurology

San Francisco, CA

Phone: 1(866) MS-GENES or 1(866) 674-3637

Website: <http://neurology.ucsf.edu/msdb/index.html>

**[Donate to Specimen Banks](http://www.nationalmssociety.org/research/researchers-need-you/donate-to-tissue-banks/index.aspx)** (<http://www.nationalmssociety.org/research/researchers-need-you/donate-to-tissue-banks/index.aspx>)

You can make a difference by arranging in advance to donate your brain and spinal cord tissues for research. The National MS Society supports three MS tissue banks, which are storage facilities that provide tissue samples to researchers studying MS. These studies generally focus on the pathology of MS — its nature, cause, and effects on the brain — and they are extremely important. Tissue samples are preserved very soon after the death of the

donor. The banked tissues are carefully catalogued with information about the each donor's medical history.

### **What is involved?**

For those considering donating tissue, planning ahead is essential, as is involving one or more family members who can help carry out your plan. Brain tissue must be prepared within hours after death to be of use in research. (This donation need not interfere with funeral arrangements.) Those interested in the possibility of tissue donation may contact these banks:

#### **Human Brain and Spinal Fluid Resource Center**

West Los Angeles Health Care Center

Los Angeles, CA; Phone: (310) 268-3536; 24-hour pager: (310) 636-5199;

Web site: [www.loni.ucla.edu/uclabrainbank](http://www.loni.ucla.edu/uclabrainbank)

#### **Rocky Mountain MS Center Tissue Bank**

Englewood, CO; Phone: (303) 788-4030; Web site: [www.mscenter.org](http://www.mscenter.org)

#### **Multiple Sclerosis Tissue Repository at University of Illinois at Chicago**

Chicago, IL; Phone: (312) 996-5763; Web site: [www.mstissuebank.uic.edu](http://www.mstissuebank.uic.edu)

### **[Donate to MS Blood Repository of the Accelerated Cure Project](http://www.acceleratedcure.org/repository/)**

(<http://www.acceleratedcure.org/repository/>)

This repository -- not funded by the National MS Society -- also has been established to provide the scientific community with biological samples and data from people with MS and other demyelinating diseases such as neuromyelitis optica, ADEM (acute disseminated encephalomyelitis), optic neuritis and transverse myelitis. This project also enrolls any first degree relative (parents, siblings, children) as controls, but an individual is not required to enroll with a control. Five of the sites also have the capability of enrolling pediatric subjects (case and control) in addition to adults.

### **What is involved?**

At the initial visit, the study coordinator will collect a blood sample and also gather information about health and family history, residences, past and current employment, etc., and data gleaned from a review of medical records. This study is longitudinal, meaning that they hope to encourage people to return for follow-up visits every 1-2 years to provide additional blood samples and data. Committing to a follow-up visit is not required, however. For information about participating, contact Sara Loud at 781-487-0032;

Web site: [www.acceleratedcure.org/repository/](http://www.acceleratedcure.org/repository/)

#### **Current collection sites:**

Worcester, MA (University of Massachusetts Worcester MS Center); Baltimore, MD (Johns Hopkins University); Dallas, TX (University of Texas Southwestern MS Clinic); Atlanta, GA (Shepherd Center); New York, NY (MS Research Center of NY); Phoenix, AZ (Barrow Neurological Institute); Columbus, OH (The Ohio State University Medical Center); Boston, MA (Beth Israel Deaconess Medical Center) Denver, CO (The Rocky Mountain MS Center)