



DEVELOPMENT

March 5, 2011	CC: Chapter Presidents
	Financial Management
	Information & Resources
	Programs & Services
FY11 Direct Marketing March Mailings	

FY11 March Acquisition Mailing

Project: FY11 March Acquisition
 Drop Week: **3/7/2011**
 In-Home Week: **3/21/2011**

This mailing will be the sixth acquisition campaign of fiscal year 2011 and the third in the calendar year. Here are the objectives for this mailing:

March Acquisition	Outside Exchange and Rental Lists	Internal Altair & Lapsed Direct Mail Lists	Total Campaign Projections
Mailed	500,000	656,507	1,156,507
Gifts	7,662	7,308	14,970
Revenue	\$89,016	\$175,280	\$264,296
Percent Response	1.08%	1.4 %	1.29%
Average Gift	\$16.49	\$20.80	\$17.66

The control offer is the 2011 Annual Fund Drive. There are two copy tests. 1) a Volunteer Drive, call to action, will be retested to database names. The message “please join the Society’s Volunteer Drive today. If you don’t have the time, would you consider sending a gift instead?” offer yielded a 91% lift in response rate. Thus, we will retest to larger quantity to see if these response rates hold true.

As with any new or expanded test, please note that we anticipate feedback. Here are two possible questions and responses for you to use.

I just volunteered for Helping Hands? – Wonderful, we appreciate your efforts. Please know this is just another opportunity and no obligation.

I'm doing Walk MS this year – why did I get this letter? Let's check and make sure we have your registration. It may be that this mailing was in process during the time you registered and must have overlapped in the mail. Thank you for your support and work for everyone living with MS.

FY11 March Renewal Mailings

Project:	FY11 March Annual Fund #3	Control
Project:	FY11 Local Donor Drive	Control
Project:	FY11 How Your Money Helps	Re-Test
Project:	FY11 Every Step, Every Gift	Test
Drop Week:	3/7/2011	
In-Home Week:	3/21/2011	

The schedule for March reflects our work to deliver the right package to the right audience. While it looks like four mailings, we're actually splitting delivery based on where a donor is in terms of both their recent gift value and relationship with the Society.

We learned over the past two years that the standard Annual Fund messages brings the most revenue and response from our higher valued audience segments, whereas lower dollar donors and those just coming on the file tend to respond better to our Local Donor Drive copy. We will be re-testing the How Your Money Helps in a March timeslot and trying out a new message called, "How Your Money Helps" to demonstrate to donors that every accomplishment, every gift is a step toward a much bigger goal of stopping MS.

What's our objective? The FY11 March Annual Fund #3/Local Donor budget calls for this campaign to raise \$630k in gross revenue and \$494k in net revenue.

Who are we talking to? The final audience for this campaign will be DM only donors. The audience will consist of current 0-12 month donors, lapsed 13-24 month and lapsed 25+ month donors.

We are NOT mailing March renewals to Golden Circle in DM lite.

An electronic copy of this mailing will be posted to the Direct Marketing section of the Society Intranet in March for your reference.

Please email or call Katharine Grant at katharine.grant@nmss.org, 303-698-6100 x15139 with questions or concerns regarding our programs.



INFORMATION TECHNOLOGY (IT)

March 4, 2011	CC:
Data Management Team Update 3/4/11	

The Data Management team, a Strategic Work team of the Society, started the new year by welcoming Mike Jones to our team as project manager. The team is operating in two week sprints with planning sessions and project demos for each sprint.

Team Delivery – Sprint 1, 2011:

During our first two week sprint of 2011, we reviewed all data entry standards on SharePoint and ensured that all standards established by the Society and released by the data management team in 2010 are easily accessible.

The standards can be found on SharePoint by navigating to the Information Technology page. Click on Documents in the left hand navigation, and then go to the documents listed under the heading of Data Management. Or you may click [here](#).

We have also welcomed representatives from each region to our team. The representatives are Denise Wallace, West Region; Lisa Klaus, Midwest Region, Catie Bickers and Jim Fussell, South Central Region, David Hulnick, East Region; Barbara Davis, Northeast Region and Debbie Hoffman, Southeast Region.

If you have any questions about the work of the data management team please contact Jo Hennessy James, product owner at Jolene.hennessy@nmss.org or (303) 698-6100, x 15127.



PROGRAMS & SERVICES

March 4, 2011	CC:
<u>Fall Prevention Program Training-Consortium Annual Meeting</u>	

The National MS Society is developing a new fall prevention program-- a multi-session curriculum, designed for people living with MS who are ambulatory but who may be at risk for falling. Discussion, exercise, group and individual activities are elements of this engaging format where participants will learn about: fall risks, tips and strategies to reduce risk for falling and exercises to enhance balance and safety. A supportive group atmosphere and expert instructors in the field of rehabilitation, health and wellness will help each participant develop a personal plan to maximize safety. We will be distributing program materials and supporting implementation of the program (including providing funding to offer the program) this summer.

At the annual Consortium of MS Centers meeting in Montreal in June, we will present a pre-meeting workshop about this new program. It will take place on Wednesday morning, June 1 from 8:30-11:30am at the CMSC meeting venue in Montreal (The CMSC meeting begins at noon)—at no charge to participants. The workshop will describe and demonstrate the components of the program and is targeted to potential program coordinators/sponsors and instructors, e.g., rehabilitation, health and wellness professionals. Workshop participants will each obtain a copy of the facilitator and participant materials and, via demonstration and discussion, will be prepared to offer the program, in partnership with the MS Society, to people with MS in their communities.

We need your help to publicize the workshop at the CMSC!

- Please send the e-mail invitation below to health care professionals on your mailing list—or include in any e-news you send to health care professionals.
- Consider subsidizing the cost of attending (perhaps pay the CMSC registration fee or airfare?) for a health care professional with whom you could collaborate to offer the falls program in your community.
- Bring the workshop invitation postcard to any professional education meetings you have planned over the next few months, your CAC meetings, your affiliated clinics, etc.

(Contact Shawna Golden at Shawna.golden@nmss.org) to let us know how many postcards to send you.)

- Attend the free workshop yourself!

As mentioned above, the Society will have some financial subsidies to offer chapters and/or Partners in MS Care to pilot this important program in FY 2012. You will receive more information about fall prevention initiatives and how to implement it in your communities, including information about a packaged program for Self-Help Groups that will help raise awareness about fall risk and prevention. Attending the pre-CMSC workshop yourself, and/or inviting MS health care professionals who might partner with you to offer the program will facilitate our implementing this fall prevention program across the Society.

Questions? Contact Debra Frankel, AVP Programs, Services and Clinical Activities 617-795-7002; debra.frankel@nmss.org

E-Mail Blurb

The National MS Society has developed a new fall prevention program-- a multi-session curriculum, designed for people living with MS who are ambulatory but who may be at risk for falling. Discussion, exercise, group and individual activities are elements of this engaging format where participants will learn about: risks, tips and strategies to reduce risk for falling and exercises to enhance balance and safety. A supportive group atmosphere and expert instructors in the field of rehabilitation, health and wellness will help each participant develop a personal plan to maximize safety.

The Society will present a pre-CMSC meeting workshop about this new program on Wednesday morning, June 1 from 8:30-11:30am at the CMSC Meeting venue (The CMSC meeting begins at noon)—at no charge to participants. The workshop will describe and demonstrate the components of the program and is targeted to potential program coordinators/ sponsors and instructors, e.g., rehabilitation, health and wellness professionals. Funds will be available to implement several pilot programs across the country and all workshop participants will be able to apply. Workshop participants will each obtain a copy of the facilitator and participant materials and, via demonstration and discussion, will be prepared to offer the program to people with MS in their communities.

To register for this program please send an e-mail to: heather.webb@nmss.org. Include your name, professional affiliation, address, phone number and e-mail address. You will receive a confirmation with further details. (The development of this Fall Prevention program is funded by unrestricted grants from Acorda Therapeutics, Teva Pharmaceutical Industries, Genentech Inc. and Biogen-Idec.)



PROGRAMS & SERVICES

March 4, 2011	CC: Chapter Presidents
<u>The Great Escape: Getaway for Teens with MS</u>	
Action Requested/Deadline: May 31, 2011	

As part of the Society's ongoing efforts to address the psychosocial needs of children and teens with MS, the Southern California & Nevada Chapter is hosting their second annual camp for teens with MS, *The Great Escape: Getaway for Teens with MS*. The getaway is open to children and teens ages 10-18 and is scheduled for June 20-23, 2011 at Pali Mountain in Running Springs, California (www.palimountain.com). The cost is \$75 per camper, which includes lodging, all meals and activities. Airfare is not provided, however the chapter will provide transportation to/from the airport and the camp.

For more information or to request an application packet please contact Tiffany Jordan, Programs Manager, Community Development and Public Education, Southern California & Nevada Chapter at 310-479-4456 ext. 130 or tiffany.jordan@nmss.org.

Thank you to the Southern California & Nevada Chapter for recognizing a need and being so generous in their response, reaching well beyond their chapter borders to engage and connect these young people with MS.



PROGRAMS & SERVICES

March 4, 2011	CC:
<u>Department of Veteran Affairs Caregiver Initiatives</u>	

The Department of Veteran Affairs (VA) recently launched two new exciting initiatives for caregivers of Veterans, with one specifically for caregivers of Veterans with MS. The first is the National Caregivers Support Line, a telephone-based information line for family members and loved ones who provide care for Veterans who are living with the effects of war, disability, chronic illness, or aging. Licensed clinical social workers are available to answer questions, listen to concerns and link callers to the Caregiver Support Coordinator at their local VA Medical Center. The support line is open Monday-Friday 8:00 am to 11:00 pm Eastern Time, and Saturday from 10:30 am to 6:00 pm Eastern Time. For more information call 1-855-260-3274 or visit www.caregiver.va.gov.

The second initiative is a monthly support and education conference call for caregivers of Veterans with MS, where caregivers can connect and share their experiences. In addition to time for networking, educational topics and resources will also be discussed. The group meets the fourth Monday of every month from 8-9 pm ET (7-8 pm CT, 6-7 pm MT, 5-6 pm PT). The call-in number is 1-800-767-1750, access code 43157#. For more information on this monthly support group please contact the group's facilitator, Maggie Kazmierski, LCSW-C at 1-800-464-6295, ext. 6095/410-605-7000, ext. 6095 or email Margaret.Kazmierski@va.gov.

Questions about these resources can be directed to Kim Koch at 303-698-6100, ext. 15158 or Kimberly.koch@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
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs & Services

March 2, 2011

FDA Sends Letter Stating that the Application to Market Oral Cladribine for MS is Not Ready for Approval

-- Outlines Need for Additional Data

The U.S. Food and Drug Administration has issued a “Complete Response Letter” to EMD Serono indicating that the company’s application to market oral Cladribine to treat relapsing forms of multiple sclerosis is not ready for approval in its current form, and outlining requirements for additional information. At this point it is difficult to predict when the company might address the agency’s requirements.

According to a company press release, the FDA requested that the company provide an improved understanding of safety risks and the overall benefit-risk profile either through additional analyses or by additional studies. In the release, EMD Serono affirmed its commitment to bringing new therapies to people with MS and outlined plans to request a meeting with the FDA to review additional requirements listed in the letter.

Background: Cladribine can interfere with the activity of lymphocytes, a subset of white blood cells that underlie the immune attacks that cause the unpredictable symptoms of MS. Injectable Cladribine is used to treat hairy cell leukemia. The phase III trial of oral Cladribine (EMD Serono), known as the CLARITY study, showed that the drug reduced relapse rates significantly more than inactive placebo in a study involving 1,326 people with relapsing-remitting MS. The results were published in the *New England Journal of Medicine* (2010; 362:416-426, <http://www.nejm.org/doi/full/10.1056/NEJMoa0902533>). Read more (<http://nationalmssociety.org/news/news-detail/index.aspx?nid=2569>) about the CLARITY results.

In November 2009, EMD Serono announced that it had received a “refuse to file” letter from the FDA, indicating that its application requesting approval of Cladribine for MS was

incomplete. On June 8, 2010, the company announced that it had resubmitted its application to the FDA for approval of Cladribine, and on July 28, the agency granted Priority Review status to the application, which was to have shortened the review period with an expected decision by the end of November. At that time, the review process was extended by the FDA to provide more time for a full review of additional information provided by the company. Oral Cladribine was approved for MS in Russia and Australia, but it was not approved by the European Medicines Agency.

In addition to a two-year extension study of CLARITY, other ongoing studies of oral Cladribine funded by EMD Serono include the ONWARD study, an investigation of the safety and effectiveness of adding high or low doses of oral Cladribine to interferons in a trial in people with relapsing forms of MS; and the ORACLE MS study, designed to evaluate oral Cladribine in people who have experienced a neurological episode that puts them at risk for developing MS. Both are ongoing, and according to the company, top-line results from the ORACLE MS study and CLARITY extension study are expected by the end of 2011, and from the ONWARD study in the first half of 2012.

Read information about currently available treatments for MS at:

www.nationalMSSociety.org/treatments

Additional oral and infrequent-dose therapies are making their way through clinical trials.

Download a list of current clinical trials in MS (.pdf)

<http://www.nationalmssociety.org/research/clinical-trials/download.aspx?id=224>