



## CHAPTER PRESIDENTS

July 11, 2011	
<b><u>Year End Report Addendum – Research Awareness Report</u></b>	
<b>Action Requested/Deadline: October 14, 2011</b>	

With the exclusion of the Excellence in Delivery Report from the Year End Report – Parts I & II this year, we realized after its publication that we would also be eliminating information previously obtained in this section on research awareness activities. This information is shared in the Research Promotion newsletter to chapters and Research Advocates. Since this information is a valuable resource to the organization, I am providing a Research Awareness Activities Addendum to be completed by October 14, 2011 and to be submitted with the rest of the chapter's Year End Report information.

You can find the Research Awareness Activities Addendum on SharePoint, under Chapter Management, Announcements.

From: Pat Abruzzo, Project Manager  
Field Operations Department  
TRC – Denver



## CHAPTER PRESIDENTS

<b>July 22, 2011</b>	<b>CC:</b>
	<b>Development</b>
	<b>Programs and Services</b>
	<b>Advocacy</b>
<b>Simple Ways to Cross-Market Advocacy at Walk MS</b>	

This year at Walk MS events, legislators met their constituents and advocacy was cross-marketed in simple ways. Check-out some of this year’s success stories on Share Point at [Advocacy > State and Local Advocacy > 2011 Advocacy at Walk MS Success Stories](#).

### **Highlights include:**

- Photo booths drew long-lines and an opportunity to recruit new MS Activists.
- Filmed videos captured the personal stories of those affected by MS.
- Petition drives collected hundreds of signatures to support specific state legislation or state legislative agendas.
- Advocacy themes such as, “MS Activists Spark Change,” “Step up for MS Activism,” and “Spring into Action,” attracted new MS Activists.



## PROGRAMS & SERVICES

July 22, 2011	
<b>Comfort of Homes Books</b>	

In 2006, the Society collaborated with Maria Meyer (CareTrust Publications) on the book, *The Comfort of Home™: An Illustrated Step-by-Step Guide for Multiple Sclerosis Caregivers. The Comfort of Home: Multiple Sclerosis Edition* reviews caregiving options and discusses the financial and legal decisions family caregivers may encounter.

Ms. Meyer recently donated over 2,000 copies of the book to the Society for use throughout the organization. Starting July 18, 2011 the books are being mailed to chapters (US Postal Service -Media Mail) at no cost to you. The number of boxes being shipped varies by chapter size (16 books per box; 1-4 boxes shipped). To request additional copies please contact Heather Webb Jones at [heatherwebb.jones@nmss.org](mailto:heatherwebb.jones@nmss.org) or 303-698-6100, ext. 15176.

Possible uses for the books may include:

- As giveaways/thank you gifts during National Family Caregivers Month
- An addition to your chapter lending or local library
- Door prizes at a carepartners self-help group
- As part of a carepartners book club or self-help group meeting
- A targeted mailing and distribution to MS clinics, physicians, other healthcare providers or care managers

The book continues to be an excellent resource, guiding readers through every caregiving stage from making the decision to provide home care, to preparing the home for comfort and safety, to assisting with activities of daily living, to strategies to avoid burnout. Other important topics covered include financial management, purchasing equipment, travel and therapies. Chapters are filled with special notes and tips that alert both people with MS and their carepartners to important issues that make life easier for all concerned.

Please direct any questions to Kim Koch at [Kimberly.koch@nmss.org](mailto:Kimberly.koch@nmss.org) or 303-698-6100, ext. 15158.



## PROGRAMS & SERVICES

July 22, 2011	
<b>Update: Society-Wide Service Providers Standard Practices</b>	

As a reminder, a work team in the Northeast Region, along with members of the IRC and with input from service managers across the Society, has been developing a standard practices manual regarding the development and maintenance of a quality service provider database in Altair.

This manual contains information and guidance about: identifying relevant service providers (health care providers and community service providers), collecting data from those providers, the vetting process, data entry standardization and data maintenance.

The manual describes our revised approach to developing a service provider database—*focusing on the categories and provider types about which clients most frequently inquire and collecting and entering data in a consistent, efficient manner.*

We will be finalizing the manual and **conducting Society-wide trainings this fall.** You will not be expected to re-create existing provider records, but as you update providers and identify new ones, we will all use the same processes. This consistent approach will yield more accurate, complete and relevant information that is provided to our clients.

We are exploring the feasibility and cost associated with an option for electronic data entry, i.e. information about the provider could be collected via an on-line form, and after vetting by the chapter, the data could be uploaded to Altair electronically, reducing or eliminating the need for manual data entry. While we are excited by the possibility, please don't count on this as an option yet! We will keep you informed.

We are providing this update so you can build maintenance of your service provider data into your 2012 annual plan and so that you will be on the lookout for a future news sheet announcing dissemination of the standard practices manual and training dates.

For more information contact Debra Frankel, AVP Programs and Services and Clinical Activities ([debra.frankel@nmss.org](mailto:debra.frankel@nmss.org) or 617-795-7002).



## PROGRAMS & SERVICES

July 22, 2011

### Exciting Research Opportunity for Carepartners of People with MS

**Action Requested/Deadline: August 12, 2011**

The National MS Society, in partnership with the National Alliance for Caregiving and SIR Research, is recruiting caregivers to participate in an online survey to gather input on the issues related to caring for someone with MS and the needs of the person providing care. SIR Research is a third-party marketing research company hired for this project.

For the purposes of this research study, caregivers are defined as family or friends, not professionally-paid caregivers. The survey takes approximately 20 minutes to complete and is completely anonymous and confidential. The survey is open until August 11, 2011.

The study will look into topics such as:

- The demographic profile of the caregiver.
- When caregiver involvement is the highest.
- The impact progression of MS has on the caregiver.

The survey instrument and study protocol have been reviewed and approved by Society staff. The survey questions are available on SharePoint: Programs and Services>Family and Youth Resources>Family Programs>2011 Caregiver Survey Questionnaire. The survey will be promoted through a variety of nationally-facilitated channels. If you are interested in engaging in local recruitment efforts, sample email text is available on SharePoint: Programs and Services>Family and Youth Resources>Family Programs >2011 Caregiver Survey Invitation.

The results of the survey will be an invaluable resource as we move forward with the FY' 2012 strategy: *Accelerate and expand engagement and support of families living with all forms of MS across the spectrum of the disease to strengthen the family unit, promote communication, and facilitate access to resources critical to the maintenance of optimal family functioning*. A date for the final report has not yet been determined, although it is expected to be released before the end of 2011. Availability of the final report will be announced in a future news sheet.

This project is made possible through support from Sanofi-Aventis to the National Alliance for Caregiving.

Please direct all questions to Kim Koch at [Kimberly.koch@nmss.org](mailto:Kimberly.koch@nmss.org) or 303-698-6100, ext. 15158.



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

July 22, 2011

### **MS Trial Alert:**

### **Recruiting for a Nationwide Study of an Investigational New Treatment for Spasticity**

**Summary:** Investigators nationwide are recruiting 200 people with any type of MS for a study comparing several doses of an investigational study drug, arbaclofen placarbil (AP), which is similar to a currently approved medication, baclofen, with inactive placebo. The study is funded by Xenoport, Inc.

**Rationale:** Spasticity refers to feelings of muscle stiffness, tightness, and involuntary muscle spasms (sustained muscle contractions or sudden movements). It is one of the more common symptoms for people with MS. Baclofen is the most commonly used drug to treat spasticity and is a muscle relaxant. AP is a new drug that has the same mechanism as baclofen. Baclofen has 2 components (R- and S-baclofen) and only one of these (R-baclofen) is responsible for improving spasticity. AP is a prodrug of R-baclofen, meaning after AP is taken orally your body changes it to R-baclofen. In a study in spinal cord injury (SCI) patients with spasticity, AP showed a significant and sustained anti-spasticity effect when AP was taken twice daily, therefore it is believed that AP may result in less frequent daily dosing (Nance PW, Huff FJ, Martinez-Arizala A, et al. Efficacy and safety study of Arbaclofen Placarbil in patients with spasticity due to SCI. Spinal Cord 2011).

**Eligibility and Details:** Participants must be aged 18 to 70, with definite MS and spasticity. If participants are taking a disease-modifying MS treatment, the dosage, frequency, and route of administration must be stable for at least 30 days before screening and are expected to be stable throughout the study. Further details on enrollment criteria are available via the contact information below.

Participants are being randomly assigned to receive three tablets, twice each day, containing either 15 mg, 30 mg, or 45 mg of AP, or inactive placebo, for 13 weeks. The primary outcomes

being measured are improvement on the Ashworth scale, (which measures spasticity), and improvement on the patient's impression of change. Secondary outcomes being measured include improvement of PRISM score, severity of pain associated with muscle spasm, and sleep quality.

**Contact:** To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please visit [www.CommandTrial.com](http://www.CommandTrial.com), or the study listing on the National MS Society Web site (<http://www.nationalmssociety.org/research/clinical-trials/participate-in-clinical-trials/clinical-trial-details/index.aspx?eid=2115>).

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



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

**July 20, 2011**

### **New Study on Cost Effectiveness of MS Therapies**

A new study co-funded by the National MS Society, the National Institutes of Health and the University of Rochester examined the cost-effectiveness of therapies to treat MS, and finds that the cost for improving the quality of life for people with MS in the U.S. is high. The study in no way suggests that anyone appropriate for these treatments should not be on them, and it found that the earlier disease-modifying therapies were used, the more cost-effective they were, adding to growing evidence suggesting that treating MS early and consistently is the best way to ward off future disease activity. Katia Noyes, PhD, MPH, and colleagues (University of Rochester, NY) report their findings in *Neurology* (published online July 20, 2011).

Background: The management of MS has been substantially advanced by the availability of the disease-modifying agents. The first was approved in 1993, and over the ensuing years, evidence from clinical trials and prescription use has shown their effectiveness in reducing the number and severity of MS attacks and slowing disease progression. Although they do not work for everyone, for many individuals they have profoundly enhanced their ability to stay active and productive.

In 2004 the National MS Society released a request for proposals with the goal of developing a way to analyze the cost-effectiveness of disease-modifying therapies used in the U.S. The goal of cost-effectiveness research is to determine what it actually costs to produce a given amount of increment in quality of life. In the U.S., there is no standard or official threshold for what is considered “cost effective” therapy, as it is extremely difficult to put a price on what enhanced quality of life can mean to individuals living with a chronic illness.

After a competitive peer review process that engaged experts nationwide, a contract was awarded to Dr. Noyes, a health services researcher at the University of Rochester. This contract focused on the four approved disease-modifying therapies in the U.S. available for

treating MS at the time: interferon beta-1a (intramuscular and subcutaneous forms); interferon beta-1b; and glatiramer acetate. Read more about currently approved MS therapies (<http://nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-mhs/treatments/index.aspx>).

The Study: The team developed and tested an experimental statistical model of cost-effectiveness using data from the National MS Society's Sonya Slifka Longitudinal MS Study, a national sampling of people who have MS. The team gathered data on subsets of participants, looking at health care costs, lost work time, and other factors, and their use of disease-modifying MS therapies. The team used a 4-year window to estimate disease outcomes, costs and cost savings over 10 years. The group determined how treatment affected quality-adjusted life years, which measure the number of years that would be added by using a drug and the quality of life during those years.

The investigators found that under current prescribing and pricing conditions in the U.S., the disease-modifying therapies help people with MS, but that the extent of improvement in quality-adjusted life appears to be modest compared to the high costs of these therapies, when based on the study's analytic model. They also found that starting treatment earlier was associated with a more favorable cost-effectiveness ratio compared to initiating treatment at any phase of the disease. This study was not a clinical trial and did not measure whether these therapies altered disease progression that can lead to severe disability.

READ FULL SUMMARY ON THE WEBSITE (after 4pm Eastern, July 20, 2011):  
<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=5294>



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<b>RESEARCH/CLINICAL UPDATE</b>
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<b>July 22, 2011</b>	cc: Programs and Services
<b>FDA Issues Warning about Medications Containing Oxybutynin</b>	

Some of medications (Ditropan<sup>®</sup>, Ditropan XL<sup>®</sup>, Gelnique<sup>®</sup> gel, Oxytrol<sup>®</sup> transdermal patch) used to treat urinary problems in people with MS contain oxybutynin. The FDA has added a warning to the labeling of these medications stating that angioedema (a swelling similar to hives that occurs under the skin) of the face, lips, tongue and/or larynx has been reported with oxybutynin taken orally. In some cases, angioedema occurred after the first dose; in other cases it occurred with later doses. The swelling was severe enough in some individuals to interfere with breathing and required hospitalization and emergency treatment. Although this reaction appears to be relatively rare, given the many years that oxybutynin has been used safely and successfully by people with MS and others, any person taking a medication containing oxybutynin who experiences swelling of the tongue or throat or difficulty breathing should stop the medication and seek immediate medical attention. Individuals who have questions or concerns about this medication should discuss them with their physician.

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