



## CHAPTER PRESIDENTS

September 11, 2009	CC: Advocacy
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	Marketing
	Programs & Services
<b><u>Guidelines for Communicating New Drug Information</u></b>	

With so many potential new drugs in the pipeline coming to market over the next 12-24 months, we wanted to make sure that everyone across the Society has our guidelines regarding communicating information when new MS therapies come to market. This document has also been shared with our pharmaceutical partners at a national level. This document is saved on Sharepoint in the marketing section. Questions?

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### **National MS Society guidelines for communicating information regarding new drugs before and after they are approved by the FDA for market**

The National MS Society prides itself on communicating unbiased, relevant and timely information to all those in the MS movement – including people with MS and the professional healthcare community. This is important when a new product to treat MS is both in development and brought to market.

When a new product launches, the Society does everything possible to work through the correct channels within companies and within the larger research and clinical community to communicate the facts about this MS breakthrough to its constituents.

Below is the process the Society follows when deemed appropriate to communicate information quickly and effectively to its constituents concerning breakthroughs in MS research and treatment:

- Regarding therapies that are in various stages of development, the Society will post information for its constituents as appropriate on research results, favoring data published in peer reviewed journals or reported at major national conferences. The Society, however, does not report out financial or marketing data on products.
- Information is posted on the Society’s website in several sections including a new medication sheet added to the Medications Used in MS page; Research and Clinical Update posted in the Research News section and an announcement on the home page that links to the update; further, a description is added to relevant pages in the About MS and Press Room sections.
- All existing Society publications that contain information on MS treatments are updated via an addendum. When the publication is reprinted, updated information is incorporated in all relevant sections.

- Information may be communicated with suggested talking points and promotional ideas to chapters via emails and internal news sheets – a standard communication channel used to impart news broadly across the organization; chapters will typically use this information to communicate with local constituents including local healthcare professionals, people with MS, the media and on local chapter sites. The Society will also communicate updates as appropriate regarding the various phases of a drug in development, including information resulting from FDA panel hearings.
- As a patient advocacy organization, it is important that the Society have a public voice to address the unmet needs of patients when a new drug is coming to market or a drug currently on market is being reviewed. If deemed appropriate, Society staff and volunteers may be present at FDA hearings to testify about the unmet needs addressed by potential therapies. This decision is made by key Society leaders across the organization and on a case-by-case basis.
- Because the information we provide to chapters, healthcare professionals and others is always vetted to ensure its suitability for us, we need to review all proposed materials from our pharmaceutical partners prior to its distribution at Society venues, and to suggest changes should they be appropriate.
- Information is emailed to a list of healthcare professionals – both clinicians and researchers – who have requested MS research and treatment updates from the Society. Information is also emailed to chapter volunteers known as research advocates, who are conduits for research information and are both professionals and non-professionals. And, depending on the topic, select research news is distributed to Society members through monthly e-newsletters.
- The Society may work both independently and in cooperation with the pharmaceutical company marketing the new drug in story development. Story development may include identifying people with MS who can serve as possible spokespeople and providing them with talking points (both nationally and in local markets).
- If the information is relevant and appropriate, the Society will inform chapters and our national Information Resource Center of pharmaceutical educational programs such as webinars, related to a new treatment. These programs must be comprehensive symptom management or treatment programs rather than promotional regarding the new product and its benefits.
- To help ensure access for people with MS to breakthrough medical therapies, the Society's advocacy team will work with MS activists across the country to reach out to legislators and appropriate decision makers with information about the new approved therapies and unmet needs in the MS community.
- As an unbiased resource for the entire MS community, the National MS Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendations or prescriptions. For specific information and advice, the Society always recommends that individuals consult a qualified physician.

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**DEVELOPMENT**

<b>09/11/09</b>	<b>CC: Chapter Presidents</b>
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<b><u>FY10 Direct Marketing Program Update –Track B, allowing exclusions for Event Participants, Discontinued</u></b>	

The issue of how, if and when to include event participant names in direct marketing has been of concern across the organization for sometime. Previously, there was little or no data to support the standard industry practice of introducing event participant names within approximately six weeks following the event date. However, a rigorous, two-year study conducted by the National MS Society and Merkle (the Society direct marketing vendor) has demonstrated that direct marketing contact does not harm event fundraising and actually may increase event retention and fundraising.

The direct marketing team enlisted an advisory committee consisting of National MS Society chapter presidents and senior management to help build and analyze this study. This advisory committee and executive leadership have endorsed the recommendation that the National MS Society discontinue the ‘Track B’ option for event participants within the Direct Marketing Program and move to a single, uniform process for integrating event names into direct marketing contact beginning in fiscal year 2010. The following information outlines the history, process and data that resulted in this action:

**The Issue –**

Bike MS and Walk MS events are a major source of the National MS Society’s revenue nation wide. In order to maximize the National MS Society’s integrated fundraising strategy, Society leadership knew it was important to understand how integrating Walk MS and Bike MS names into the direct marketing channel impacts relationships, event revenue and overall Society fundraising. It was essential to learn whether or not direct marketing was harming the event fundraising channel. Until we could measure the impact of direct marketing on Walk MS and Bike MS, chapter staff have had the ability to select how engaged their event participants would be in the direct marketing program through ‘Track A’ or ‘Track B’ options since FY07. Track B was provided as a more conservative option and would exclude event participants from direct marketing contact for as long as the participant was active with the event. Track A and Track B were established to provide event participant / direct marketing

integration options until enough data could be analyzed to provide recommendations for a Society-wide integration plan.

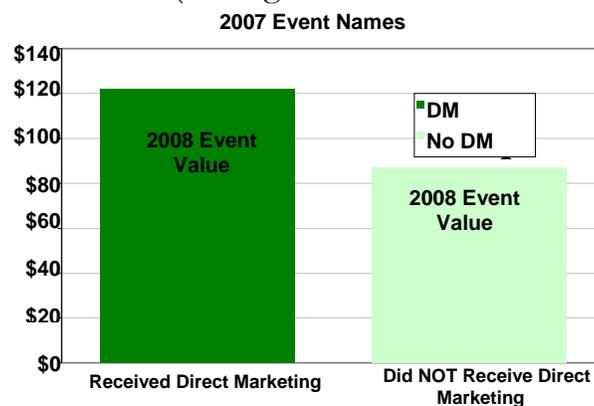
It is also clear that event names are important to the direct marketing program. Event names are an excellent source of lower cost donor acquisition and generate more than \$3 million in direct marketing revenue each year.

**The Study and the Results** – Test groups were established for more than 27,000 event participants in direct marketing (DM) for the A Track and B Track chapters. A third ‘control’ hold out group of 5,000 participants was set up and received no DM contact. Event participant and donor behavior were monitored in FY07 and FY08. Initial results showed that DM contact had no negative impact on event participant retention. In fact, the A track group that received DM more quickly post-event, showed slightly higher event retention. The test was run for an additional 12 months with no change in results. The study shows that incorporating event names into the direct marketing program has a positive impact on event retention and event fundraising. As a result, we can remove Track A and Track B options and create a single track or process for incorporating event names into direct marketing.

### **Results – Increased Event Revenue Follows Direct Marketing (DM) Contact**

Graph below shows event names with first National MS Society gift in 2007 Walk MS or Bike MS Event – and their value to the event the following year in 2008

- Dark green=2008 event giving from event names -- after receiving DM contact
- Light green = 2008 event giving from event names -- did NOT receive DM
- After receiving DM contact – event names increased giving in 2008 event – regardless of response to DM
- Event names that received DM had about 25% increase in following year event value compared to event names with no DM contact
- Selection for direct marketing may be indicator for higher value event name
- 2007 event value = \$72 (for segment of event donors that came back in 2008)



## **Next Steps – One Track for Event Names in Direct Marketing**

- **Event Participant Name** – will be suppressed from direct marketing from the first file pulled after their event registration and will not receive direct marketing contact until 6 weeks after the event.
  - Participant eligible for direct marketing contact 6 weeks after their event.
  - Process applies to participants with or without direct marketing history.
- **Bike MS \$1000+ Participants & Donors** - Continue process for \$1000+ Bike MS participants /donors (0-18 months)
  - Suppress these participants and their donors (as noted in Altair) if they are not direct marketing donors until lapse from Bike MS for 18 months.
  - If they are direct marketing donors within 36 months, they will be suppressed from current registration through 6 weeks post event.
- **Event Donors** - Walk MS and other Bike MS event donors will be eligible for contact in the direct marketing channel all year.
- **Other Event Participants / Donors** – participants and donors from other events like Challenge Walk, lunches and dinners will continue to be suppressed from the direct marketing program unless they have prior direct marketing giving history.

**Thanks are extended to the entire Direct Marketing Program Advisory Committee for their leadership, guidance and input on this process.**

Maureen Reeder, Chapter President – Minnesota Chapter  
Jennifer Lee, Chapter President – North Florida Chapter  
Lisa Gerrol, Chapter President – Greater Connecticut Chapter  
Lori Espino, Vice President Resource Development – Central New England Chapter  
Rich Israel, Chapter President – Pacific South Coast Chapter  
Sheryl Keeme, Chapter President – Arizona Chapter  
Sharon Grossman, Chapter President – Hampton Roads Chapter  
Graham McReynolds, Executive Vice President – National MS Society  
Nancy Law, Executive Vice President – National MS Society  
Betty Ross, Associate Vice President – National MS Society  
Pat Scheiber, Associate Vice President – National MS Society  
Susan Goldsmith, Director – National MS Society  
Rich Sarko, Director – National MS Society  
Jolene Hennessey James, Senior Analyst – National MS Society  
Katharine Grant – Senior Manager – National MS Society  
Ceola McCaney – High Level Specialist – National MS Society  
Krista Byers – Senior Director – National MS Society

**Questions** – The FY10 Direct Marketing Program Strategy Overview contains additional detail on the event name integration analysis and is available on SharePoint. If you have additional questions, please contact Krista Byers at 303.698.6100 x15118 or [krista.byers@nmss.org](mailto:krista.byers@nmss.org).



## PROGRAMS & SERVICES

September 11, 2009	CC: Chapter Presidents
<input type="checkbox"/> <u><a href="#">Do Not Post on NMSS.org</a></u>	
<b>MS Next Step® Now Available for Order</b>	

### **Order Information**

The new *MS Next Step*® is now available for order from chapter supply. To order, send an e-mail to [chapterorders@nmss.org](mailto:chapterorders@nmss.org). The item number is BR0058; the cost to chapters is \$1.50 each. They will be shrink-wrapped in pre-packs of 5, so the cost per pre-pack is \$7.50. To get your order in before the end of this fiscal year, please place your order ASAP – you can place your order even if the product is not yet in stock. The product is currently en route to the warehouse and if it arrives and is received into inventory before September 19<sup>th</sup>, the warehouse will be able to ship and your chapter will be invoiced in this year.

### **Information about *MS Next Step*®: Information for People Newly Diagnosed**

This piece provides a unique opportunity to communicate with health care providers (HCPs), especially neurologists and others involved in the diagnosis of MS. It also provides opportunities to engage more quickly and effectively with the newly diagnosed.

What should you know about the new *MS Next Step*®?

- Distribution was previously exclusively through HCPs, with a focus on neurologists. The new package is designed to be distributed both through HCPs *and* directly to individuals who have been diagnosed with MS. This means the new *MS Next Step*® can be used as a tool for outreach to HCPs *and* for engagement with the newly diagnosed.
- The overall message and content is similar to the previous version, though it has been thoroughly reviewed and updated; it is an introduction to MS and the Society’s resources for people living with MS. It is designed to be the very first information a person receives following a diagnosis, including the information someone should know about topics that are most important during the days and weeks after a diagnosis.
- As before, content is provided in booklet format. But the new *MS Next Step*®, packaged much like an audio CD, also includes a DVD with video content, electronic versions of the booklet and video transcripts, plus Spanish translations of all the content.
- *MS Next Step*® focuses on engaging those who have been newly diagnosed in specific ways: to work with their doctor closely to take control of their MS; to participate in Knowledge is Power; to get accurate information, which they can do by exploring Society resources; and to “Join the Movement” in a way that makes sense for them.

- Remember that *MS Next Step*® is designed for someone who has JUST been diagnosed. A person who has been living with MS for some time will likely not benefit from this piece; a person who has lived with the diagnosis for several months or more will likely get much more out of Knowledge is Power or another targeted program.
- Because the content is more accessible and direct distribution is planned, promotion and use of this piece is expected to be much more widespread. In addition to including in your strategy for outreach to neurologists and HCPs, you will probably want to integrate this piece into your plans for engagement with the newly diagnosed.
- The IRC will provide *MS Next Step*® to constituents when appropriate. The charge to chapters will be \$1.50. If it is included with other materials in a packet, as it is likely to be, there will not be an additional \$1.50 charge.
- *MS Next Step*® content is not available online, though an information page will be available on the national site in the coming weeks.

Comments or questions about *MS Next Step*®? Contact [Nancy.Law@nmss.org](mailto:Nancy.Law@nmss.org) or [Chris.Yankee@nmss.org](mailto:Chris.Yankee@nmss.org).

### **Outreach to Neurologists and other HCPs**

Chapter program staff should now have access to two new communication pieces to support outreach to neurologists and HCPs – *MS Next Step*® and *The National MS Society Resource Guide for Clinicians*. These pieces are quite distinct from one another but chapter strategies to leverage these tools should be coordinated so the opportunity to communicate with and support HCPs in your area is maximized.

As a reminder, *The National MS Society Resource Guide for Clinicians* is designed to inform HCPs about the wide range of products and services the Society makes available to support their clinical and research activities. It includes descriptions of all of the core products and services the Society offers to clinicians, as well as a listing of topics and/or content summaries for each type of publication or service. This summary guide is appropriate for distribution to any HCP who supports people with MS and can be used as a centerpiece of outreach to HCPs.

Copies of *The National MS Society Resource Guide for Clinicians* were shipped to each chapter in June. Copies will also be distributed directly to HCPs who request it from the Professional Resource Center (PRC). Also, the PRC is maintaining a limited inventory that can be sent to chapters who require additional copies. Chapters may request additional copies by e-mailing a request to the PRC at [HealthProf\\_Info@nmss.org](mailto:HealthProf_Info@nmss.org) or calling 1-866-678-7328.

If you have comments or questions about *The National MS Society Resource Guide for Clinicians* or its distribution, please contact [Rosalind.Kalb@nmss.org](mailto:Rosalind.Kalb@nmss.org) or [Chris.Yankee@nmss.org](mailto:Chris.Yankee@nmss.org). You can view the guide at: <http://www.nationalmssociety.org/for-professionals/healthcare-professionals/download.aspx?id=11268>. It is available on the PRC pages of the Web site, at [www.nationalmssociety.org/PRC](http://www.nationalmssociety.org/PRC).