



ADVOCACY

October 16, 2009	CC: Chapter Presidents
<input checked="" type="checkbox"/> <i>Do Not Post on NMSS.org</i>	
2010 MS Public Policy Conference Poster Session	
Action Requested/Deadline: Dec 18, 2009	

The Public Policy Office is collecting your best case studies and success stories for the 2010 MS Public Policy Conference poster session.

This past year, we highlighted the award-winning chapter advocacy programs with a poster session. In 2010, the poster session will showcase the top chapter advocacy case studies and success stories. All entries also will be used on the Intranet and as examples to other chapters throughout the year.

We invite you submit your best case study or success story in any of the following areas. Or feel free to submit one on your own topic.

- Case study of your work to successfully pass legislation
- Case study of a successful effort toward a legislative goal (even if it did not pass)
- Case study of your work to change a regulation or government program
- Case study of effective work with a coalition
- Success story of MS activist recruitment and/or MS activist mobilization efforts
- Success story of advocacy in your Walk MS and Bike MS events this year
- Success story of a new or growing legislator relationship
- Success story of a virtual or unique MS advocacy or policy day at your state capitol

Use the “Advocacy Template for Case Studies and Success Stories” on the Intranet > Advocacy > Advocacy Basics and Tools. Send your final entry to tara.raeber@nmss.org by Friday, December 18.



CHAPTER PRESIDENTS

October 16, 2009

CC: Development

[Do Not Post on NMSS.org](#)

Mud Run Pilot Chapters Selected

Given the success of the North Florida Chapter's Mud Run held last January and the exciting opportunity to explore the potential of a new special event, there was great interest expressed by chapters in the 2010 pilot.

How did we identify the pool of potential pilots?

- Informational calls were conducted providing chapters with the opportunity to learn more about the event from the North Florida Chapter
- The North Florida Chapter and Home Office fielded questions from chapters following the call
- Chapters confirmed ongoing interest in the pilot following informational calls through an online survey

As with any new event, we believed it was necessary to limit the number of pilot markets to insure the best learning possible. Given the event is owned by a third party, Two Circles, we also had to consider their capacity for expansion. Therefore, four chapters have been chosen to participate in the pilot in addition to the North Florida Chapter who will host their second annual Mud Run in March. They include:

- Colorado
- Gateway Area
- Greater Delaware Valley
- Minnesota

How did we select the pilot chapters?

Two Circles was a key partner in determining pilot chapters for 2010. We relied heavily on their expertise in selecting markets with the greatest potential for success given the nature of this event.

In addition, we considered the following:

- Market potential for growth in the future – is there a strong population base to draw from in subsequent years?

- Chapter capacity to support a new event with adequate financial, staff and volunteer resources
- Ability of a chapter to focus on a new campaign while still supporting the Society's priority campaigns – Walk MS and Bike MS
- Chapters with a proven track record of growth in core events
- Timing of and commitment to other chapter events
- Experience in rolling out new events
- Staff tenure
- Geographic diversity and weather

While we know some of you will be disappointed at not being able to add this event in 2010, we hope you can appreciate our plans to be strategic in this pilot creating a strong foundation for future success. It is also important to understand that Two Circles is at the core of our growth plan for Mud Run and our contract prohibits chapters from replicating this event outside the scope of our contractual relationship with them.

Next steps:

- We are working with Two Circles negotiating the final contract and once that is complete we will get it to pilot chapters for signatures
- We will also be formalizing the pilots' commitment through a letter of agreement with the Home Office stipulating what each pilot needs to provide as part of the pilot process
- We will host an introductory conference call with Two Circles and the pilots to identify immediate next steps and begin implementation plans
- Pilot chapters will be attending a Mud Run event in Dallas on November 7th as part of their orientation

Thank you all for your interest and support!

We look forward to a successful event providing the opportunity for rapid expansion in the future. We will be sharing progress reports and results as they become available. Meanwhile, please feel free to contact Sarah Klein if you have any questions.

Sarah Klein, Sr. Manager, Bike MS

sarah.klein@nmss.org

(518) 952-4153



**National
Multiple Sclerosis
Society
News Sheet**

FINANCIAL MANAGEMENT

October 16, 2009	CC:
	Chapter Presidents
<u>JOINT COST ALLOCATION FOR BIKE MS BROCHURE</u>	
Action Requested/Deadline: None	

We have analyzed the sample Bike MS brochure for Fiscal 2009 in an effort to assist chapters in allocating Joint Costs for this brochure in accordance with SOP 98-2 issued by the American Institute of Certified Public Accounts (AICPA). This SOP became effective on October 1, 1999 and has been employed by the Society since fiscal year 2000.

All chapters should have received the sample 6 panel brochure from the national vendor. This discussion is based upon the presentation and verbiage of this sample brochure with the understanding that the wording may be changed by individual chapters, and if so, these recommendations may or may not apply.

In the 6-panel brochure, we would recommend excluding 17% of the brochure content for allocation purposes. The reason for exclusion of 1 panel (cover) is that it is neutral in character and should not affect the allocation percentage.

By our interpretation **one-third** of the panel titled “team up for more fun!” qualifies for classification as Public Education under Joint Cost Allocation methodology. In our view this section (starting with the title “create a world free of MS”) provides a clear public education message that meets the required criteria of purpose, audience and content. There is a necessary call to action under the purpose and content criteria which further support joint cost allocation. Therefore, we believe it would be appropriate to allocate the costs of the 6-panel brochure at 93% to Fund Raising and 7% to Public Education.

We wish to emphasize that these are only guidelines and that all chapters are encouraged to review SOP 98-2. Chapters are further encouraged to discuss these individual approaches with their respective auditors, who will ultimately judge the soundness of this application.

From: David Lee, Associate Vice President, Finance
(212) 476-0502
e-mail: david.lee@nmss.org



**National
Multiple Sclerosis
Society
News Sheet**

FINANCIAL MANAGEMENT

October 16, 2009	CC:
	Chapter Presidents
<u>JOINT COST ALLOCATION FOR CHALLENGE WALK BROCHURE</u>	
Action Requested/Deadline: None	

We have analyzed the sample Challenge Walk brochure for Fiscal 2009 in an effort to assist chapters in allocating Joint Costs for this brochure in accordance with SOP 98-2 issued by the American Institute of Certified Public Accounts (AICPA). This SOP became effective on October 1, 1999 and has been employed by the Society since fiscal year 2000.

All chapters should have received the sample 6 panel brochure from the national vendor. This discussion is based upon the presentation and verbiage of this sample brochure with the understanding that the wording may be changed by individual chapters, and if so, these recommendations may or may not apply.

In the 6-panel brochure, we would recommend excluding 17% of the brochure content for allocation purposes. The reason for exclusion of 1 panel (cover) is that it is neutral in character and should not affect the allocation percentage.

By our interpretation **one-third** of the panel titled “team up for more fun!” qualifies for classification as Public Education under Joint Cost Allocation methodology. In our view this section (titled “create a world free of MS”) provides a clear public education message that meets the required criteria of purpose, audience and content. There is a necessary call to action under the purpose and content criteria which further support joint cost allocation. Therefore, we believe it would be appropriate to allocate the costs of the 6-panel brochure at 93% to Fund Raising and 7% to Public Education.

We wish to emphasize that these are only guidelines and that all chapters are encouraged to review SOP 98-2. Chapters are further encouraged to discuss these individual approaches with their respective auditors, who will ultimately judge the soundness of this application.

From: David Lee, Associate Vice President, Finance
(212) 476-0502
e-mail: david.lee@nmss.org



**National
Multiple Sclerosis
Society
News Sheet**

FINANCIAL MANAGEMENT

October 16, 2009	CC:
	Chapter Presidents
<u>JOINT COST ALLOCATION FOR WALK MS BROCHURE</u>	
Action Requested/Deadline: None	

We have analyzed the sample Walk MS brochure for Fiscal 2009 in an effort to assist chapters in allocating Joint Costs for this brochure in accordance with SOP 98-2 issued by the American Institute of Certified Public Accounts (AICPA). This SOP became effective on October 1, 1999 and has been employed by the Society since fiscal year 2000.

All chapters should have received the sample 6 panel brochure from the national vendor. This discussion is based upon the presentation and verbiage of this sample brochure with the understanding that the wording may be changed by individual chapters, and if so, these recommendations may or may not apply.

In the 6-panel brochure, we would recommend excluding 17% of the brochure content for allocation purposes. The reason for exclusion of 1 panel (cover) is that it is neutral in character and should not affect the allocation percentage.

By our interpretation **one-third** of the panel titled “team up for more fun!” qualifies for classification as Public Education under Joint Cost Allocation methodology. In our view this section (titled “how your fundraising \$ helps”) provides a clear public education message that meets the required criteria of purpose, audience and content. There is a necessary call to action under the purpose and content criteria which further support joint cost allocation. Therefore, we believe it would be appropriate to allocate the costs of the 6-panel brochure at 93% to Fund Raising and 7% to Public Education.

We wish to emphasize that these are only guidelines and that all chapters are encouraged to review SOP 98-2. Chapters are further encouraged to discuss these individual approaches with their respective auditors, who will ultimately judge the soundness of this application.

From: David Lee, Associate Vice President, Finance
(212) 476-0502
e-mail: david.lee@nmss.org



MARKETING

10/16/09

CC: All

[Do Not Post on NMSS.org](#)

End of Year All Society Call Recording Available

The End of Fiscal Year Society Call recording is available to download on SharePoint in the Human Resources Section under Announcements.

<http://intranet.nmss.org/Topics/hr/Lists/Human%20Resource%20Announcements/DispForm.aspx?ID=12&Source=http%3A%2F%2Fintranet%2Enmss%2Eorg%2FTopics%2Fhr%2FPages%2FHumanResource%2Easpx>

The call agenda included updates from Joyce Nelson, keynote address from National Board Chair Weyman Johnson and a research update.

Questions: Shawna.golden@nmss.org



MARKETING

October 16, 2009

CC: ALL

[Do Not Post on NMSS.org](#)

MS Awareness Week 2010 Chapter Roundtable Calls & Updates

As we're all gearing up for MS Awareness Week March 8-14, 2010, please take advantage of two opportunities to idea share and network around how we all plan to "Move it!" for this important awareness campaign. Please plan to join us for one of the two opportunities:

November 11th: noon-1 pm MT; 11 am-noon PT; 1-2 pm CT; 2-3 pm ET

<https://nmss.webex.com/nmss/j.php?ED=128330077&UID=0>

Call in #: (866) 528-9737, Conference Code: 353506

November 18th: 11 am-noon MT; 10-11 am PT; noon-1 pm CT; 1-2 ET

<https://nmss.webex.com/nmss/j.php?ED=128330092&UID=0>

Call in #: (866) 528-9737, Conference Code: 353506

In addition, Phase I toolkit materials including an updated logo, style guide, electronic letterhead and PowerPoint template are currently available. Phase II toolkit deliverables will be available by mid-November which will include:

- Topline messaging by audience
- Web banners
- Web downloadable page
 - Banners
 - Badges
 - Icons
 - Wallpaper
- Ecard
- Print ads in various formats
- Email template
- Postcard/flyer template

Questions? Contact:

Shawna.Golden@nmss.org

Becca.Kornfeld@nmss.org



MARKETING & DEVELOPMENT

10/16/09	ALL DISTRIBUTION LISTS
<input type="checkbox"/> <i>Do Not Post on NMSS.org</i>	
National Email Program – FAQs	

Over the past two years the national email program has performed well and exceeded expectations in many areas, such as fundraising, even in the midst of our current economic challenges. As the program moves into its third year, exciting opportunities and challenges will continue. Society-wide collaboration to monitor and balance the volume and types of all constituent communications –email messaging in particular – is more important than ever.

The program has had many accomplishments made possible by the partnership and efforts of many Society staff – from chapters and the home office. For continued success, the program needs much – and perhaps even more – of the same teamwork, creativity and idea sharing.

To help ensure all Society staff are aware of the national email program, below are some frequently asked questions. This list is not comprehensive and is an initial resource for those who wish to more fully understand the program.

For questions or suggestions please contact:

Rich Sarko
Director, Online Marketing
rich.sarko@nmss.org
303-698-6100 x15171

National Email Program – FAQs

When did the national email program start?

The program launched in November 2007 in partnership with M+R Strategic Services, our former online strategic partner. As of November 2009 the program will be managed in house by home office staff.

Who is on the national email file?

All Society constituents with an email address comprise the file. As of October 2009 there are nearly 1.6 million users with a **valid** email address. Due to considerations such as direct

marketing excludes and duplicate email addresses, the approximate final file size for our monthly national e-newsletter is 1 million recipients.

How are people added to the national email file?

People are added to the file in a variety of ways, including but not limited to:

- New event participants (Convio registration page)
- New event participant sponsors (Convio donation page). **Important: only those who complete the donation/event participant sponsorship process are added – those who receive solicitations from event participants are NOT added unless a donation is completed.**
- New donors (Convio donation page – or – data sync from Altair)
- New activists (Convio action alert page – or – data sync from Altair)
- Self-registration via www.nationalMSSociety.org/SignUp or www.nationalMSSociety.org/ContactUS, etc.
- IRC (data sync from Altair)

Where can I find FY 2010 national program email dates?

[Intranet - Home → Marketing → Constituent Communications Calendar FY10](#)

How do the program's e-fundraising exclusions work?

The 'Track B' option for event participants within the Direct Marketing Program – which includes e-fundraising – will be discontinued as of FY 2010. We will move to a single, uniform process for integrating event names into the direct marketing channel. Event participants will be suppressed from the first file pulled after their event registration and will not receive direct marketing contact until 6 weeks after the event. Walk MS and Bike MS event donors – except those who sponsor \$1,000+ Bike MS Participants – will be eligible for contact all year. For more information please refer to the September 11, 2009 news sheet from Krista Byers (Topic: Development).

What changes were made to Convio email interest categories?

In short, more than 40 categories were consolidated to 8. Details of this project are available in the June 26, 2009 and July 17, 2009 news sheets ([Intranet - Home → News Sheets](#)).

What's next with regard to Convio email interest categories?

Phase 2 of this project includes an inventory of all the ways we acquire online constituent information and a review of what types of information is collected. Upon completion of the audit, steps will be taken to improve this process.

Are a constituent's email interests passed from Convio to Altair?

No, this system enhancement is in the planning phase with a target implementation date in 2010/2011.



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 Presidents, Programs

October 16, 2009

Case report: Person treated with Tysabri for MS develops brain cancer (primary central nervous system lymphoma)

A case report of brain cancer (primary central nervous system lymphoma) developing in a person being treated with [Tysabri](#)[®] (natalizumab, Biogen Idec and Elan Pharmaceuticals) has been published. Achim Berthele, MD (Technische Universitate Munchen, Germany) and colleagues report the case early online in *Annals of Neurology* (<http://www3.interscience.wiley.com/journal/122466435/abstract>). Based on this single report, it cannot be confirmed that Tysabri caused (or predisposed to) the lymphoma. However, the authors suggest that any development of new or unusual neurological signs or symptoms in a person taking Tysabri should prompt a diagnostic workup for possible complications. Such monitoring is required in people enrolled in the TOUCH risk management program in the U.S.

Background: Tysabri is a laboratory-produced monoclonal antibody that is approved for patients with relapsing forms of MS to delay the accumulation of physical disability and reduce the frequency of clinical exacerbations. It is designed to hamper movement of potentially damaging immune cells from the bloodstream, across the “blood-brain barrier” into the brain and spinal cord.

In the general population, primary central nervous system lymphoma, or PCNSL, is most often diagnosed in the elderly and in individuals whose immune systems have been suppressed by medications or disease. There is no reported increase of PCNSL in individuals who have multiple sclerosis.

Details: A 40-year old man from Germany with relapsing-remitting MS had been treated previously with interferon beta and azathioprine. A previous brain biopsy had shown no signs of lymphoma. He developed partial loss of sensation (hypoesthesia) on his right side after having received 21 doses of Tysabri. MRI-detected lesions were not typical of multiple sclerosis, prompting tests that led to the diagnosis of primary central nervous system lymphoma.

The authors tested the lymphoma, a high-grade B-cell non-Hodgkin lymphoma, for the presence of Epstein-Barr virus, since this virus has been associated with PCNSL when it develops in immune-suppressed individuals. They found no evidence of the virus in the lymphoma tissues, somewhat reducing the likelihood that the tumor was related to Tysabri-induced immunosuppression.

Comment: “This report underscores the importance of carefully tracking patients on powerful medications like Tysabri and remaining vigilant for new neurologic signs in people on this medication,” said Dr. John R. Richert, executive vice president of research and clinical programs at the National MS Society. It cannot be confirmed from this single report that there is a causal link between Tysabri administration and the occurrence of primary central nervous system lymphoma. However, careful monitoring for new or unusual neurological signs and symptoms in those taking Tysabri, which is required in those enrolled in the TOUCH risk management program in the U.S., should be adequate for detecting possible signs of brain lymphoma.

-- Research and Clinical Programs Department

Tysabri is a registered trademark of Biogen Idec and Elan.



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

[Do Not Post on NMSS.org](#) | cc: Chapter President, Programs

October 14, 2009

Panel Recommends that FDA Approve Fampridine-SR (proposed name Amaya) for Symptomatic Treatment of MS

-- Found to improve walking speed for people with all types of multiple sclerosis

A U.S. Food and Drug Administration advisory committee today recommended that the agency approve marketing of Fampridine-SR (Acorda Therapeutics, with a proposed name change to Amaya) for its ability to improve walking speed in people with any type of multiple sclerosis. While the FDA is not required to follow the recommendations of its advisory committees, it usually does. The agency is expected to make a final decision about whether to approve the drug for market on or before the target date of October 22, 2009.

During an all-day meeting held October 14, 2009, the FDA advisory committee considered Acorda Therapeutics' application for approval of Fampridine-SR, reviewing data about the drug's effectiveness and safety. The committee also heard public testimony from individuals and patient advocacy groups, including the National MS Society, which testified to the unmet need for therapies to improve walking for people with MS.

Among its discussions, the advisory committee recommended that the FDA require the sponsor to evaluate the effects of doses lower than originally studied, but that these studies would not be required to be done prior to the drug's marketing approval. In addition, the FDA is likely to require a plan to mitigate potential risks. During its presentation to the committee, Acorda representatives outlined such a plan -- the Risk Evaluation Mitigation Strategies (REMS).

Background on Unmet Need: Problems with [gait \(difficulty in walking\)](#) are among the most common limitations in MS. While there are six FDA-approved [disease-modifying therapies](#) that are at least partially effective against some forms of the disease, as well as rehabilitation and symptomatic treatments for some symptoms, at present there is no pharmacologic

treatment specifically available for MS-related difficulty walking. This disability has wide-ranging effects on people's lives, even in its milder manifestations.

A recent survey among more than 1,000 individuals with MS and many of their family members examined the impact of mobility issues, such as difficulty walking, on quality of life among patients with MS and their families. Some two-thirds of patients reported difficulty walking and of these, 70% reported that such difficulty was the most challenging part of their MS, and most reported that difficulty walking restricts their daily activities significantly, including their ability to travel. (Read more about survey results <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=199>)

About the Drug: Fampridine-SR is a sustained-release formula of 4-aminopyridine, which blocks tiny pores, or potassium channels, on the surface of nerve fibers. This blocking ability may improve the conduction of nerve signals in nerve fibers whose insulating myelin coating has been damaged by MS. The first studies of this potassium-blocking approach in people with MS were supported by the National MS Society.

What Clinical Trials Found: Acorda Therapeutics sponsored two phase 3 clinical trials of the drug. In the first, involving 301 people with any type of MS, walking speed increased by 25%. Results of this study have been published (February 28, 2009 issue of *The Lancet* (2009 373;732-738 ([http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(09\)60442-6/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(09)60442-6/abstract)), summarized here: <http://www.nationalmssociety.org/research/research-news/news-detail/index.aspx?nid=951>). Results from a later, second phase 3 study (<http://www.nationalmssociety.org/research/research-news/news-detail/index.aspx?nid=237>) involving 240 people with MS confirmed the benefits seen in the first, finding that a significantly greater proportion of people on the therapy had a consistent improvement in walking speed compared to those who took placebo. Among those taking Fampridine-SR who improved in walking speed, there was a statistically significant improvement in leg strength.

In the first study, common adverse events (side effects) experienced more often by those on active treatment included back pain, dizziness, insomnia, fatigue, nausea and balance disorder. Two serious adverse events led participants to discontinue taking the drug (one case of anxiety and one seizure in a person who developed sepsis from a urinary tract infection). In the second study, additional common adverse events in those on therapy included urinary tract infection, falls, and headache.

Comment: “The clinical trial results suggest that for a substantial percentage of people with MS, Fampridine has the potential to restore some significant function and make a real difference in people's quality of life,” said John R. Richert, MD, Executive Vice President of Research & Clinical Programs for the National MS Society. “If the FDA agrees that Fampridine is safe and effective, this would bring a welcome symptomatic therapy that has potential utility for a large number of people with different types of MS.”

Further study and clinical practice may help determine the extent to which the drug may impact other functions not measured in the clinical trials, and provide hints as to which patients are most likely to respond.

-- Research and Clinical Programs Department