National
Multiple Sclerosis
Society
News Sheet

CHAPTER PRESIDENTS

Oct. 30, 2009	**CC:** Development
	Marketing

Unique fundraising and awareness opportunity through best-selling author, Wally Lamb

We are excited to let you know about a national fundraising and awareness opportunity brought to the Society via the Connecticut Chapter.

Wally Lamb is an accomplished best-selling author (*She's Come Undone, I Know This Much Is True, The First Hour I Believed*), who has had two of his novels selected for Oprah's book club. At the end of each of his books Mr. Lamb typically asks readers to contribute to selected charities. He has a new novel coming out in November titled *Wishin' and Hopin'* and in this novel the National MS Society is listed the charity that he recommends supporting.

The language in the book suggests making a donation to the National MS Society through one of three channels – calling the Society's 800 number; sending a check to our national office; or going online to a special web page.

Mr. Lamb has requested that funds received (net of credit card and Convio fees) be divided as follows: 40% directed to research and 60% directed to the donor's local chapter. We have set up a special URL and landing page on the national site web page so we can easily track donations. The URL is: nationalMSsociety.org/wallylamb.

We can not predict how much revenue this will generate, however know this will be a great awareness opportunity for the Society.

Special thanks to Lisa Gerrol, CT chapter president, for shepherding this relationship.

Questions? Contact:
Becca.Kornfeld@nmss.org

DEVELOPMENT

Date: 10/28/09	CC:
	Chapter Presidents
	System Administrators
Event Redesign Update #3	

We have made great progress since our last event redesign update and wanted to share with you the latest. We know that many of you have already set-up your 2010 events but you may want to consider these enhancements. In 2011, they will be a part of the event site set-up so will not be optional.

Available Now:

Left Hand Navigation - Through usability testing, we have created some guidance based on feedback for effective left hand navigation. Here is an outline of how to best map your event navigation to make it easier on your participants to find what is important to them and us:

(In order)
Home
My Account (this replaces My Participant Center)
Register
Donate
Volunteer
Event Details
Fundraising
Teams

An important change to note is the use of 'My Account' instead of 'My Participant Center' to follow common web practice.

CMS Content Pages - When setting up the 2010 marketing landing page in the CMS, please include the following key information. Numbers 1 - 4 should be above the fold (the area on the Web site that is displayed when the user lands on the page before any action is taken).

1. Name of the Event
2. Event date(s)
3. Registration links (participate, volunteer) and Donate link
4. Event location

5. Event description
6. Event photos

We have created the following 'mock' CMS marketing landing pages (where people will be directed when they click on the event link from WalkMS.org or BikeMS.org) are as visual aid to help you see how your page should look. Click on the links below or copy and paste the URL into a new browser window:

Bike
http://staging.nationalmssociety.org/chapters/event-redesign-mock-site/fundraising/bike-ms/index.aspx

Walk
http://staging.nationalmssociety.org/chapters/event-redesign-mock-site/fundraising/walk-ms/index.aspx

Coming in November:

- New PC2 (Participant Center) - as you know it's already available but testing is just wrapping up. Look for a newssheet in a few weeks with instructions on how to turn this great new interface on for your participants!
- Updated Event Wrappers for Convio Pages – we have new branding for the Convio event wrappers that matches the 2010 Walk MS, Bike MS and Challenge Walk core marketing materials.
- Ability to create child pages (sub links under the main left hand navigation link). Training information will be provided soon.

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DEVELOPMENT

October 30, 2009	**CC:** Information Technology (IT)
	Marketing

Use of TeamMS Infringement on Trademark

Two years ago, the Society ceased using the name "TeamMS" as we believed its use as a stand alone brand was confusing to our constituents. While teams continued to be at the core of our growth strategies for Walk MS and Bike MS, we changed our language from "join TeamMS" to "form or join a team."

Since that time, all event materials developed by the Home Office reflected this change and we asked all chapters to do the same – from print materials to websites to staff titles.

We have recently learned that "Team MS" is registered by a non profit organization in Wisconsin who helps others living with multiple sclerosis. We are taking this opportunity to remind everyone that TeamMS should **not be used** in any context by the Society and, in fact, is a violation of an existing trademark held by another party.

Please review all materials (print and electronic) to insure TeamMS has been properly removed. If you have any questions, please contact Betty Ross or Sherri Giger.

FINANCIAL MANAGEMENT

October 30, 2009	**CC:** Chapter Presidents
Chapter FRx Audit Schedules	

The following FRx Chapter Audit reports have been released for general chapter use:

Schedule of Special Events and New Campaigns
Schedule of Memberships and Contributions
Schedule of Due to National MS Society
Statement of Functional Expenses
Statement of Activities (Income Statement)

These reports have been loaded into each chapter's FRx spec set. Specific instructions to use these reports have been e-mailed out to all Chapter Finance staff and are posted on Share point.

We hope to have the Statement of Financial Position (Balance Sheet) and Statement of Cash Flows available shortly.

The home office finance support team for questions about using these reports is Melissa Perlin and David Lee. Please e-mail them any questions or feedback you have.

From: David Lee
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MARKETING & DEVELOPMENT

10/30/09	ALL DISTRIBUTION LISTS
Convio Email Updates	

Background
Over the last few months a number of important Convio email changes have been made to improve the experience of our email recipients as well as the efficiency of Society email administrators. Some of these include an improved Email Campaign training program, a new Convio software release (Shasta), improved opt-in opt-out language on our Convio forms, and enhancements to our Society-wide email interest categories. (For more information on these changes, please refer to the respective news sheets.)

Risk Management – Feedback Process
In order to reduce the risk of errant emails, the IT team solicited input from a number of chapter email users, including but not limited to: Central New England, Central North Carolina, Georgia, Greater Washington, Lone Star, Michigan, Mid Florida, Northwestern Ohio, Ohio Buckeye, and Oklahoma. A number of home office staff provided input as well.

New Email Requirements and Improvements – Effective Immediately
Thanks to the great feedback, the following changes are effective immediately:

Convio Email Campaign Training and Certification
Every Convio Email Administrator is required to take the revised "Convio: Email Campaigns" and pass a certification test. The revised class was introduced in July 2009. Regardless of other internal or Convio-led classes taken, every Convio Email Administrator must take this revamped course and become certified by 12/17.

- Register via the LMS (www.nmsslearning.org)
- Four classes available: 11/4, 11/12, 11/18 and 12/10
- **Deadline to complete and pass certification: 12/17**

Important: If a user's training and certification is not completed by 12/17, her or his Convio Email Campaign security access will be put on hold. Beginning the week of 11/2, weekly reminders will be sent to all users who have not met the requirements.

Continued Improvements to our Email Campaigns Documentation
In addition to the excellent online resources offered by Convio, the IT Training Team will continually update the Society-specific Email Campaigns Training Guide. This is a living document and will be enhanced whenever necessary. User feedback will continue to be a critical driver of training program improvements. To review the most current Training Guide, please visit the new Intranet: Information Technology → Convio_Email_Campaigns_Training

Added Tips and Warnings to the Convio Email Campaigns Module
Enhancements are scheduled for early November and will continue as appropriate. As with training, user feedback will be a critical driver of these improvements.

Contact Information
For questions about these updates – or the Society's online marketing strategy in general – please contact Rich Sarko at rich.sarko@nmss.org or 303-698-6100 x15171. For questions about Convio Email Campaign Training, please contact Dana Gelotte at dana.gelotte@nmss.org or 603-974-2006.

National
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MARKETING & DEVELOPMENT

10/30/09	ALL DISTRIBUTION LISTS
***MS Connection* Delivery Considerations**	

Background
Targeted constituent communications are integral to engage people in the MS movement, and the Society should always consider how to provide the information people want, when they want it, and in the way they want to receive it. Given the need to steward and maximize our resources, particularly in the current economic environment, staff across the organization (chapter and national) have been discussing "how" it's best to send communications, including the opportunity to transition certain Society communications from a print to a digital format. The following recommendations are the result of this work to date.

Recommendations
Based on feedback from many chapters, as well as from their constituents, many *MSConnection* recipients still prefer to receive it in print. Consequently, it is recommended that print continues to be the primary medium for this communication.

Additionally, development of a digital (email or electronic) option is strongly recommended to support those who prefer to receive their information online. However, the digital solution should be specifically designed for email delivery – not simply a PDF, Word, or other document linked to (or included within) a Convio email message.

It is recommended that *MSConnection* recipients be invited to **opt out** of print and **opt in** to digital once an appropriate digital version and process are ready. It is important that we empower our constituents with the decision to determine "how" they receive their Society communications.

Overall, the Society should continue to request, capture and maintain constituent email addresses. There are a number of organizational initiatives that seek to accomplish this, including but not limited to: email appends for people living with MS and for donors (an email append is the process of adding an email address to an existing database record – a third-party, permission-based database is used to find and "append" the correct email address), Convio email interest categories to mitigate opt outs, an analysis of our online acquisition channels (events, donations, advocacy actions, surveys, etc.) to optimize email

capture while in no way hindering the user objective, and IRC request for a caller's email address.

All chapters are encouraged to participate in Society-wide email acquisition initiatives whenever possible and to pursue their independent acquisition efforts as well. These efforts may include letters, phone calls, social media driven campaigns, etc. – many of which could be volunteer led or facilitated. Additionally, an organizational informational insert, often referred to as a buckslip, is under development. Buckslips are a convenient mechanism that can be included in publications such as *Momentum* and chapter newsletters, as well as in local initiatives to key audiences. More about this project will be communicated by November 30.

With regard to *MSConnection* specifically, chapters are encouraged to reach out to recipients directly and request them to **opt out** of print and **opt in** to digital (email). Language for these requests should be carefully selected, and chapters may consider the talking points below:

- Our goal is to deliver people what they want, when they want it, and how they want it.
- We desire to maximize resources, which "going digital" supports.
- Wherever possible, we are in pursuit of "going green".

In addition, messaging may include language akin to the following:

> Providing timely and relevant information is of utmost importance to the Society. In order to keep you as up to date as possible about what is happening in our area, we will begin issuing *MSConnection* electronically (by email) on << date >>. We invite and encourage you to help us maximize resources and connect with you more readily by providing us with your email address.

Requirements

2010 Certification Standards require that chapters issue *MSConnection* a minimum of two times per year, with a good-faith effort to reach as many of their constituents as possible. The communication may be in print, in digital, or a combination of both.

Contact Information

For questions regarding the delivery of *MSConnection*, please contact Rich Sarko at rich.sarko@nmss.org or 303-698-6100 x15171. For questions regarding Chapter Certification Standards, please contact Craig Weber at craig.weber@nmss.org or 303-698-6116.

PROGRAMS & SERVICES

10/30/09	**CC:** Advocacy
	Chapter Presidents
	Research & Clinical Programs

Health Insurance Appeal Letters: A Toolkit For Clinicians 2nd Edition Now Available

We are pleased to announce the publication of the second edition of 'Health Insurance Appeal Letters: A Toolkit for Clinicians'.

The Toolkit provides health care professionals with model letters of appeal to support the clinicians' first choice for treating MS or its symptoms. The expanded, second edition includes 22 model letters with citations from peer-reviewed medical journals, abstracts from studies and Society Expert Opinion Papers or Clincial Bulletins cited in each letter. Concise guidance on consumers' rights to appeal denials or restrictions on benefits from health plans have been updated and include step-by-step procedures for requesting an exception to Medicare prescription drug plan rules or denials. Hard copies of the toolkit include a CD to simplify the process of customizing any of the sample letters for busy health care professionals or their clinical staff.

The Toolkit is available in hard copy with the accompanying CD, and in pdf format in the 'For Professionals' section of the national website (http://www.nationalmssociety.org/for-professionals/healthcare-professionals/resources-for-clinicians/index.aspx). One complimentary, sample copy including the CD will be shipped to each chapter. We hope chapter staff will inform clinicians in their communities about the expanded Toolkit through their Clinical Advisory Committees, professional education forums and other programs involving local MS specialists.

Although production costs for the expanded edition require that we charge chapters $3.25 per piece to offset the total costs for this project, the availability of the toolkit online offers free access to the entire contents.

For additional information contact Kim Calder, kim.calder@nmss.org, 0r 212-476-0450.

To Order:
E-mail a chapter order form to chapterorders@nmss.org, or fax it to Chapter Supplies at 212-986-3911.

Item# BR0065
Price: $3.25 each

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RESEARCH/CLINICAL UPDATE

Keyword:	Interferon therapy
Section:	TREATMENTS, APPROVED

October 30, 2009

New Data Support Early Interferon Treatment for Multiple Sclerosis

In a study of 2,570 people with MS, early treatment with interferon therapy was associated with a significant reduction in the risk of MS progression. Maria Trojano, MD (University of Bari, Italy) and colleagues from 14 other Italian centers report their findings in *Annals of Neurology*. (2009 May 28;66(4):513-520)

Background: Currently six therapies are approved by the U.S. Food and Drug Administration for the treatment of MS. These agents can reduce future disease activity for many individuals with relapsing forms of MS, including those with secondary progressive disease who continue to have relapses. The National MS Society's Medical Advisory Board recommends that initiating MS therapy with an immunomodulating drug (such as FDA-approved interferons or glatiramer acetate) should be considered as soon as possible following a definite diagnosis of MS with a relapsing course, and for selected patients with a first attack who are at high risk for MS. Some clinicians disagree, however, choosing to defer treatment until the extent of disease activity is more clearly established.

The Study: Dr. Trojano and colleagues at 15 Italian MS centers followed a group of 2,570 people with relapsing-remitting MS who were being treated with any type of interferon beta for up to seven years. Treatments included one of two dosing regimens of Rebif® (interferon beta-1a, EMD Serono, Inc. and Pfizer, Inc.), Avonex® (interferon beta-1a, Biogen Idec), and Betaferon® (European brand of Betaseron, interferon beta-1b, Bayer Schering Pharma AG).

The investigators recorded the dates of MS onset and treatment, and tracked disease progression every six months using the EDSS scale, which measures physical disability on a

rating scale of 0 to 10. Early treatment was defined as less than or equal to one year from disease onset, and delayed treatment was defined as more than one year from MS onset.

After following individuals for a median of 4.5 years, and using statistical methods aimed at adjusting for potential biases, the investigators found that early treatment significantly reduced the risk of progressing one point on the EDSS scale compared to those whose treatment was delayed. Early treatment also reduced, by about 40%, the risk of progressing to an EDSS score of 4. (An EDSS score of 4 is defined as fully ambulatory and self-sufficient, despite severe disability in one system, such as visual or sensory systems, or less severe disability in a combination of systems). The interferons were not rated separately, so it is not known if one worked better than another.

Comment: "This large-scale study adds significant support to considering MS treatment as soon as possible following a diagnosis of probable or definite MS," commented John R. Richert, MD, who heads research and clinical programs at the National MS Society.

There are many strategies available to modify the disease course, treat relapses, manage symptoms, and improve function and quality of life for people who have MS. Determining the best treatment options is a complex decision best made in collaboration between the person with MS and his or her neurologist. Read more about treatment options and the information and support available for people who are newly diagnosed with MS.

-- Research and Clinical Programs Department

The National MS Society is proud to be a source of information about MS. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

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RESEARCH/CLINICAL UPDATE

	cc: Chapter Presidents, Programs

October 29, 2009

Update on Tysabri and PML: Company Releases Details of Cases and Risks

According to information released yesterday by Biogen Idec, there have been 24 confirmed cases of progressive multifocal leukoencephalopathy (PML, a viral infection of the brain that usually leads to death or severe disability) among people who have used Tysabri® (natalizumab, Biogen Idec and Elan Pharmaceuticals) after it became available for prescription in July 2006.

As of the end of September 2009, 60,700 people have used Tysabri worldwide. Although the absolute risk for PML in patients treated with Tysabri cannot be precisely determined, the sponsor has now released data suggesting that the risk increases with increasing time on therapy, starting out lower than the one-in-one thousand level that was estimated at the time of Tysabri's re-approval in 2006, and rising after two years of infusions to about one in one thousand. There is insufficient information to determine the risk of PML in those who have been on therapy for three years or more. Right now only 2,000 people have been on the therapy for over three years.

This release followed an October 23 announcement (http://www.emea.europa.eu/pdfs/human/press/pr/67119009en.pdf) from the EMEA, the European equivalent of the U.S. FDA, indicating that one of its advisory committees was launching a review of the risks and benefits of Tysabri in light of the increasing number of new cases of PML.

Signs of PML: Typical symptoms associated with PML progress quickly over days to weeks, and can include:

- personality or behavioral changes
- changes in thinking, memory, and orientation leading to confusion
- onset of seizures, clumsiness or progressive weakness on one side of the body
- disturbances of vision

If individuals taking Tysabri experience new, unusual symptoms, they should contact their prescribing physician immediately. Physicians who need guidelines on the protocol to follow when they have a patient on Tysabri who experiences unusual symptoms should contact Biogen Idec.

Details of Cases: According to the company, the 24 cases of PML have occurred in both men and women who had been given infusions of Tysabri every four weeks for a duration ranging from one year to three and a half years, with an average of two years.

- 16 of the cases occurred in Europe, and 8 in the United States
- 4 of the 24 died
- The degree of disability in the 20 survivors is a wide spectrum: at the milder end, some have recovered enough to return to work, and at the other extreme, some are confined to bed, requiring extensive assistance with activities of daily living, and others were in between this range. Further details of their condition were not provided.
- It appears that when PML is detected and treated early, it generally improves outcomes. It is important that individuals taking this drug and their doctors be vigilant in monitoring for any occurrence of new, unusual symptoms that might indicate PML.
- Based on these cases, the sponsor stressed that, contrary to prior information, the presence of gadolinium-enhancing lesions on MRI **does not** exclude the possibility of PML. Likewise, the absence of JC virus DNA in the spinal fluid **does not** exclude PML.
- There has been no characteristic among those who have developed PML that would give substantial clues to who might be more likely to develop it, except that half of the cases had prior histories of having been on immunosuppresive therapies, such as mitoxantrone, and less commonly, azathioprine and methotrexate.
- Right now there is no test that can predict who is more likely at risk for developing PML while using Tysabri; in a large company-sponsored study, testing of blood cells, plasma, serum and urine for the causative JC virus in people before and after 48 weeks of Tysabri therapy (Rudick et al, ECTRIMS 2009 http://registration.akm.ch/einsicht.php?XNABSTRACT_ID=97270&XNSPRACHE_ID=2&XNKONGRESS_ID=106&XNMASKEN_ID=900) did not show any differences in the presence of the virus in those fluids. The results of these studies, performed at the U.S. National Instituties of Health, differ somewhat from an earlier study (N. Engl. J. Med. 361:1067, 2009 http://content.nejm.org/cgi/content/abstract/361/11/1067) suggesting higher virus levels after treatment.
- When PML was suspected, Tysabri infusions were halted. There is no specific therapy to treat PML, but the best hope is to reconstitute a person's immune responses. In most of the 24 cases, once PML was confirmed, Tysabri was removed from their systems with the blood-cleansing treatments of either plasma exchange or immunoadsorption.
- During the aftermath of PML, as the immune system begins to recover, a condition called IRIS (immune reconstitution inflammatory syndrome) usually occurs about 4 weeks after the removal of Tysabri from the system. The sponsors suggested that some of the treating physicians found that prompt use of intravenous steroids to treat this brain inflammation led to improvement.

The FDA provides post-marketing safety warnings on Tysabri at this link, although the updated information above is not currently provided:
http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm107198.htm

-- Research and Clinical Programs Department