



CHAPTER PRESIDENTS

September 25, 2009	CC: Development
<input type="checkbox"/> <u>Do Not Post on NMSS.org</u>	Marketing
Special MS-focused supplement in September 26 issue of the Wall St. Journal	

We are pleased to announce that there will be a special six-page color pullout supplement section focusing on MS – research, treatment and living well with MS – in the September 26 issue of the Wall St. Journal. The supplement will be available in the East Coast edition of the paper (circulation: 780,000).

The Society has worked closely with the publisher of this supplement – MediaPlanet – to ensure content is accurate. The supplement is funded by several of our pharmaceutical and biotech partners and we are grateful for their support.

Articles include a foreword by Joyce Nelson, What Is MS, Treating MS, Symptom Management, Research in Progress, Fast Forward, Moving Forward after an MS Diagnosis, Getting Involved, and Financial Planning.

Each chapter will receive 50 copies of the supplement and divisions will receive 15 copies. These can be used as a great handout to provide to major donors, team captains and more. The papers will be delivered to the attention of chapter presidents in each chapter and to the appropriate division office contact. We will also place a PDF version of the pullout on the national site and will post on Sharepoint upon receipt.

Please let us know if you have any questions.

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MARKETING

September 25, 2009	CC: ALL
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Rescheduled – Sept 30 - Design Training for 2010 Event Core Materials	
See Dates Below	

Due to the All Society call on September 30 the first of 3 design training sessions on September 30 at 11am MST has been rescheduled to October 30 at 11am MST.

As a reminder, there are 3 sessions available for Core Materials Design Training. Info below.

- Customizing event logos in Adobe Illustrator
- Customizing event brochures and other materials in Adobe InDesign
- Exporting event logos in different formats
- Creating PDFs of brochures for review
- Packaging files for print

Below are dates, times, and Webex info for the 3 sessions.
No need to sign up, just show up for the offerings!

Tuesday, October 6. 11:00am – 12:30pm MST

Go to <https://nmss.webex.com/nmss/j.php?ED=126673212=1017015002>

Tuesday, October 8. 11:00am – 12:30pm MST

Go to <https://nmss.webex.com/nmss/j.php?ED=126672212&UID=1017013927>

Tuesday, October 13. 11:00am – 12:30pm MST

Go to <https://nmss.webex.com/nmss/j.php?ED=126673347=1017015167>

If you have trouble with the above links, just go to <http://nmss.webex.com> and look for the 2010 Core Event Materials Design Training and click JOIN.

Any questions, please contact Mark Serratori at mark.serratori@nmss.org



PROGRAMS AND SERVICES

09/25/09		CC:
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<u>October Staff Teletraining</u>		
Action Requested/Deadline: October 14th		

OCTOBER STAFF TELETRAINING

This news sheet contains information on the teletraining calls being offered for chapter Programs and Services staff for the month of October

The topics for the this August teletraining is:

Cost-Benefit Approach to Homecare Vendor Partnerships (Thursday, October 15, 1 p.m. ET)

For the complete agenda, details, and presenter information for each training,

The details are also accessible on the intranet at:

Programs & Services> Staff Development Opportunities> 09-25-09

October_Staff_Teletraining_News_Sheet_Attachment.

IMPORTANT INFORMATION

Registration Information

Registration for the staff teletrainings is managed through the Society's **Learning Management System (LMS)**. **To register:**

- 1) Log on to the LMS at https://www.nmsslearning.org/MaestroC/dsp_login.cfm
If you have never logged on to the LMS, your username is your first name initial, followed by your last name and then the last four digits of your social security number, e.g. cterakura5678. The password will be **welcome** unless you have already logged on to the LMS. If you have logged on to the LMS previously, it will have prompted you to change your password.
- 2) Click on the **Course Catalog** tab, then click on **Catalog**.
- 3) Type in **teletraining** into the search field box.
- 4) The two August teletraining courses will appear.

- 5) Click on the teletraining for which you would like to register.
- 6) Click on the **Preview Schedule** button at the bottom.
- 7) Within the table, locate the teletraining for which you are registering, and under the **Options** column on the far right, click on **Register**.
- 8) Once you are registered, the top of the screen should read, **Class Registered** in red and you will receive an e-mail confirmation in your Outlook mailbox.
- 9) To view the agenda and additional information regarding your teletraining, click on **Online Resources**, under the **Options** column on the far right.

On the day of the teletraining, approximately 15 minutes before the teletraining time is to begin, log-on to the LMS, click on the “My Courses” tab in the upper right orange menu bar, then click on “Instructor-Led Courses” to start the WebEx, and get the call information.

This year’s teletrainings will be using a toll-free number. There is no charge for this teletraining. Participants are encouraged to dial into the conference center at least five minutes before the scheduled start time so all lines are connected before the teletraining begins.

Note: If you have any difficulties with the LMS, please contact Sarah Gauthier at sarah.gauthier@nmss.org or 802-863-9699. Sarah is the LMS administrator and will be able to assist you.

Thank you all for taking the time to register on the LMS.

Cancellation Information

To cancel your registration, please log on to the LMS, click on the “My Courses” tab, “Instructor-Led Courses,” locate the teletraining and click on “Drop Class.”

Questions should be addressed to John Aden (john.aden@nmss.org).

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RESEARCH/CLINICAL UPDATE

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September 25, 2009

Therapeutic Strategies for MS and More Highlighted at ECTRIMS Conference

Hundreds of multiple sclerosis clinicians and investigators convened to present findings and develop collaborations at one of the top MS-focused conferences in the world. The 25th Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) was held September 9-12, 2009, in Dusseldorf, Germany. Here is just a sample of these presentations, full details of which are available online at <http://www.akm.ch/ectrims2009/>.

Latest on Oral Drugs in the Pipeline

As several oral treatments wrap up phase III studies and prepare to submit data to the FDA, investigators reported on additional safety and effectiveness data from phase II and III studies:

- Dr. Gavin Giovannoni and colleagues analyzed data from the CLARITY study, a phase III trial of oral cladribine (EMD Serono). **Cladribine** – a drug that interferes with the immune cells that underlie the attack in MS – as reported previously reduced the relapse rate significantly more than inactive placebo in 1,326 people with relapsing-remitting MS (RR MS). Now the team reports that treatment with cladribine resulted in a greater proportion of people with no new disease activity (44.3% on a higher dose, 43% on a lower dose) than inactive placebo (16%). The company plans to submit to the FDA for approval of cladribine to treat MS in 2009. (#P471)
- Dr. Mark Freedman and colleagues reported on phase II results of a study in which two doses of oral **teriflunomide** (sanofi-aventis), an immune modulator, or placebo, were added to ongoing interferon beta-1a therapy in 116 people with RR MS. Disease activity as observed on MRI scans was reduced by 56% over placebo in the lower dose group, and by 81% over placebo in the higher dose group. Phase III studies of teriflunomide are underway in [relapsing](#) MS and in people [at high risk](#) for MS. (#P878)

- Dr. Frederik Barkhof and colleagues presented MRI findings from the TRANSFORMS study that compared two different doses of oral **fingolimod** (FTY720) with Avonex[®] (interferon beta-1a, Biogen Idec) over only one year. Previous results reported significant reductions in relapse rates with the study treatment; now the team reports as well that fingolimod reduced active areas of tissue damage observed on imaging scans. Phase III studies are ongoing. (#89)
- Dr. Giancarlo Comi and colleagues reported on a long-term extension of the phase II study of **laquinimod** (Teva Pharmaceutical Industries), an oral immune modulator now in phase III trials. Laquinimod reduced disease activity by 40.4% compared with placebo in a study of 306 people with RR MS treated for 18 months; 155 of 209 patients who entered the extension have been treated for an additional 24 months. The “annualized” relapse rate for this group is 0.46, compared with 0.53 in the original study; 10.5% of participants have shown progression on the EDSS disability scale, compared with 14.8% during the first 18 months; and 61% have not had new active areas of tissue damage on MRI scans. The most common side effects include nasopharyngitis (25.8%) back pain (12.4%) and headache (8.1%). (#P443)

Read more ECTRIMS highlights on SharePoint at

http://intranet.nmss.org/Topics/cr/Pages/MS_Research_at_ECTRIMS.pdf, or on the Web site at <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2117>.

-- Research and Clinical Programs Department

Avonex is a registered trademark of Biogen Idec



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cc: Chapter Presidents, Programs & Services

September 25, 2009

Update on Tysabri and PML

According to the U.S. Food and Drug Administration, there have been 13 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. Although the absolute risk for PML in patients treated with Tysabri cannot be precisely determined, the frequency to date remains less than the one-in-one thousand risk that was estimated at the time of Tysabri's re-approval in 2006.

The latest post-marketing safety warnings provided by the FDA on Tysabri can be found at this link:

<http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm107198.htm>

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.

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

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

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.

There is no specific therapy to treat PML, but the best hope is to reconstitute a person's immune responses. Based on small-scale studies supported by Biogen Idec, plasma exchange, a blood-cleansing treatment, has been used to clear the bloodstream of Tysabri. There is insufficient evidence to determine whether plasma exchange can reduce PML symptoms.

-- Research and Clinical Programs Department

Tysabri is a registered trademark of Biogen Idec and Elan.