



DEVELOPMENT

November 5, 2010	CC: Chapter Presidents
	Marketing
Virtual December Walk MS and Bike MS New Staff Training – Save the dates!	

The December Mass Market Workshop will be offered virtually again this winter in order to make training more accessible to all chapters by minimizing budget impact. The training will highlight the latest “how-to’s” for creating an exceptional event experience, strategies for more effectively utilizing our newest tools to cultivate participants and raise more money, key risk management info, team strategies, and event research findings. Attendees will walk away with a big picture understanding of the National MS Society and our signature events: Walk MS and Bike MS. Although hosted virtually, this will be a highly interactive training for all participants and will provide a great networking opportunity.

This workshop is designed primarily for new Development staff who have not previously attended a regional mass market workshop, but veteran staff who would like a refresher on event core strategies are welcome to attend as well.

Participants will take part in seven seventy-five minute calls which will take place over the course of two weeks. All trainings will start at 11 am PST, Noon MST, 1 pm CST and 2 pm EST. The dates of the trainings are: December 6, 7, 8, 9, 13th, 14th and 16th. Staff who register for the trainings are committing to all seven of the workshop sessions.

The training series fee is only \$30 for telecom changes.

Registration will be open soon and the link will be sent in a forthcoming newsheet.

If you have questions, please contact Rachael Nuwash at 303-698-6100 x 15136.



MARKETING

November 5, 2010	CC: All
Updated Brand Guidelines Training Schedule	

The Society's Brand Guidelines have been modified to include the following updates:

1. The Society's Boiler Plate language
2. Use of Alternate Marks on the logo
3. Corporate Achievers Logo now carries a registered trademark
4. MS Navigator is trademarked
5. Language Style Guide is now included within the Brand Guidelines

The revised guidelines have been posted on The Society Asset Management System (<http://nmss.emotion.com>), Sharepoint (<http://intranet.nmss.org/>) and the 'Materials' FTP site.

Training Sessions will be held on the following dates and will include a WebEx presentation:

Tuesday, November 30. 10:00AM – 11:00 AM MST

<https://nmss.webex.com/nmss/j.php?ED=143200157&UID=1050478222&RT=MiMxMQ%3D%3D>

Thursday, December 2. 10:00 AM – 11:00 AM MST

<https://nmss.webex.com/nmss/j.php?ED=143200587&UID=1050478427&RT=MiMxMQ%3D%3D>

Please join us!

Please contact mark.serratori@nmss.org or shawna.golden@nmss.org if you have questions.



MARKETING

November 5, 2010

CC: All

NEW! – Live Streaming at National Conference, November 10-12. TIMING CHANGES

The national conference, November 10-12, is a unique opportunity for everyone who is part of the movement to share, celebrate and be inspired. Now, for the first time ever, each general session at the national conference will be streamed live on our national website. This means anyone who is unable to attend in person can still join us for the general sessions. Anyone affected by MS, Society staff, team captains, fundraising champions and donors are encouraged to tune-in to these exciting sessions – which can be viewed live while they are happening, or accessed later via a recorded version. Below are dates, times, and session information. All sessions can be viewed live by visiting:

Timing changes are highlighted below

NationalMSSociety.org/nationalconference at the scheduled time.

Schedule

Wednesday, November 10, 4:00 – 5:30 pm CT

Opening Afternoon Session

Highlights: We are UNSTOPPABLE – everyone in the movement will be on their feet for this inspirational and motivational session, during which we meet the We Keep Moving team (www.wekeepmoving.org).

Thursday, November 11, 8:30 -9:30 am CT

Morning Session

Highlights: Celebrate our nationwide event fundraisers at the Team Captain rally, and hear from Society CEO Joyce Nelson during her keynote address.

Thursday, November 11, 12:20 – 1:30 pm CT

Mid-day Session

Highlights: Help recognize corporations who support the MS movement and hear from Jamey Power, a committed volunteer leader, and co-author of *SATISFACTION: How Every Great Company Listens to the Voice of the Customer*.

Thursday, November 11, 6:30 – 8:00 pm CT

Evening Session

Highlights: Hear directly from experts in MS Research through a panel discussion, acknowledge the dedication of volunteers across the MS movement and celebrate our completion of the Promise 2010 campaign.

Friday, November 12, 11:50 am- 1:30 pm CT

Closing Mid-day Session

Highlights: Our final session will inspire everyone as we meet Andrei Floroiu, who will be completing his flight around the world raising awareness for MS. We are truly UNSTOPPABLE as we move forward together toward a world free of MS.

All sessions will also be available as recordings after the conference and can be viewed at Livestream.com/nationalmssociety.

For more information contact:

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PROGRAMS & SERVICES

November 5, 2010

CC: Chapter Presidents

New Online Resource for Society Self-Help Group Leaders

The Society recognizes the valuable role self-help groups play in addressing the informational, emotional and social support needs of our members. We also recognize that well trained self-help group leaders are key to the ongoing delivery of this core program, and are committed to their development through the provision of ongoing learning and networking opportunities.

To assist in addressing these needs, a webpage designed specifically for self-help group leaders was recently launched on the Society's website (Living with MS>Society Programs and Services>Connection Programs>Resources and Support). By visiting this webpage, this key group of volunteers can access tools and resources related to their leadership role. Leaders can access and download recording and handouts from past telelearnings and learn about upcoming opportunities. Visitors can also access meeting in a box tool kits, as well as *Best Practices for Managing and Leading Self-Help Groups: A Manual for National MS Society Self-Help Group Leaders*. The webpage will be updated as new information becomes available, such as the release of a new tool kit or when a telelearning is scheduled.

You may want to take this opportunity to reconnect with your self-help group leaders to share this resource with them. Information on the webpage will also be posted to the Society's list-serve group for self-help group leaders.

We look forward to your and your leaders' comments. Please contact Kim Koch, Programs and Services (303-698-6100, ext. 15158 or Kimberly.koch@nmss.org) with questions and feedback.



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

November 5, 2010

FDA Approves Nuedexta™ to Treat Episodes of Uncontrollable Laughing or Crying, a Symptom That Can Occur in People with MS and Other Disorders

The first drug specifically developed to treat uncontrollable laughing or crying, also called pseudobulbar affect, or PBA, has been approved by the U.S. Food and Drug Administration. Nuedexta™ (dextromethorphan hydrobromide and quinidine sulfate, formerly called AVP-923, Avanir Pharmaceuticals) is an oral therapy shown in clinical trials to significantly reduce episodes in people with MS, ALS and other disorders. The company expects that the drug will be available by prescription by sometime in the first quarter of 2011.

Comment: “This FDA approval represents a significant step forward for people who live with the debilitating effects of pseudobulbar affect,” said Dr. Nicholas LaRocca, Vice President of Healthcare Delivery and Policy Research at the National MS Society. “For people who experience unexplained bouts of inappropriate laughing or crying, this new therapy has the potential to substantially help both them and their families.”

Background: It is currently estimated that approximately 10% of persons with MS experience episodes of uncontrollable laughing and/or crying that are unpredictable and seem to have little or no relationship to actual events or the individual’s actual feelings. This condition, which also affects people with other neurological conditions, is thought to result from lesions – damaged areas – in emotional pathways in the brain. It is important for family members and caregivers to know this, and realize that people who experience these episodes may not always be able to control their expression of emotions. Until now, no medication was approved specifically to treat this condition.

Avanir Pharmaceuticals has been conducting trials of Nuedexta in its current and earlier formulations for several years as a treatment for pseudobulbar affect in a number of disorders, including MS and ALS. Nuedexta is a patented, orally-administered combination of

dextromethorphan and an enzyme inhibitor known as quinidine. Quinidine slows down the breakdown of dextromethorphan in the body, which results in a sustained elevation of dextromethorphan in the brain. In 2006, Avanir received a letter from the FDA indicating that the drug was “approvable” and requesting that additional studies be conducted, leading to the phase III study that was recently published. (*Annals of Neurology*, published online September 13, 2010, <http://onlinelibrary.wiley.com/doi/10.1002/ana.22093/abstract>). Results of that study suggested that the drug significantly reduced the rate of episodes of pseudobulbar affect by about 47-49 percent compared to placebo. Secondary outcomes, including patient diaries and episode-free days, also suggested significant benefit among groups taking Nuedexta. **Read more** (<http://www.nationalmssociety.org/research/research-news/news-detail/index.aspx?nid=3945>)

Safety: According to the approved prescribing information, Nuedexta may cause serious side effects including changes in heart rhythm, and is not recommended (contraindicated) for people who have certain types of heart conditions unless they have an implanted pacemaker. The most common adverse reactions in patients taking Nuedexta capsules are diarrhea, dizziness, cough, vomiting, weakness, swelling of feet and ankles, urinary tract infection, flu, elevated liver enzymes, and flatulence. Since Nuedexta may cause dizziness, precautions to reduce the risk of falls should be taken, particularly for those with motor impairment affecting gait or a history of falls.

Drug Interactions: Nuedexta can interact with other medications causing significant changes in blood levels of those medications and/or Nuedexta. Nuedexta is contraindicated in patients receiving drugs that both prolong QT interval (part of heart function) and are metabolized by CYP2D6 (e.g., thioridazine and pimozide) and should not be used concomitantly with other drugs containing quinidine, quinine, or mefloquine. Nuedexta is contraindicated in patients taking monoamine oxidase inhibitors (MAOIs – a class of antidepressant drugs such as Marplan, Nardil or Parnate) or in patients who have taken MAOIs within the preceding 14 days.

For additional important about the use and safety about Nuedexta, please see the full Prescribing Information at <http://www.nuedexta.com>.

Read more (<http://www.nationalmssociety.org/about-multiple-sclerosis/symptoms/emotional-changes/index.aspx>) about MS and emotional changes.

A Clinical Bulletin for physicians, providing details about pseudobulbar affect and its treatment in MS (<http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/clinical-bulletins/download.aspx?id=143>), is available on the National MS Society’s Professional Resource Center.



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

November 2, 2010

MS Researchers Share Progress at AnnualECTRIMS Conference

More than 5,500 neurologists and other investigators from around the world convened in Gothenburg, Sweden on October 13-16 to present findings at the annualECTRIMS (European Committee for Treatment and Research in Multiple Sclerosis) conference. More than 900 scientific presentations and display posters covered virtually every aspect of research to stop MS, restore function, and end MS forever. Among these were the latest results from pivotal clinical trials of emerging MS therapies, possible risk factors, underlying disease mechanisms, rehabilitation approaches, CCSVI, and much more.

Here are highlights. For free access to the conference abstracts, go to theECTRIMS 2010 Website:

http://registration.akm.ch/einsicht.php?XNKONGRESS_ID=126&XNSPRACHE_ID=2

RESEARCH TOWARD STOPPING MS

-- Experimental Treatments in the Pipeline

Among studies reported atECTRIMS were these first results from newly completed trials:

- Teriflunomide (sanofi-aventis) is a novel oral compound that inhibits the function of specific immune cells. Dr. Paul O'Connor, of the University of Toronto, representing the international group of investigators involved, presented positive results from a two-year, phase III trial in 1,088 people with relapsing MS, comparing two doses of teriflunomide against inactive placebo (the TEMSO trial). Both doses significantly reduced the rate of MS relapses ("annualized relapse rates") by up to 31.5% relative to placebo, and the higher dose was found to reduce the risk of disability progression by 29.8% compared to placebo. (Abstract 79) A separate poster by lead author Dr. Jerry Wolinsky of the University, of Texas Health Science Center in Houston, showed that the therapy also reduced the risk of new MS lesions seen on MRI, and reduced disease activity in a range of other MRI measures. (Abstract P982) Risk of adverse events was the same across all groups, and the most common side effects for active

treatment were nausea, diarrhea, mildly elevated liver enzymes and thinning of the hair. Additional clinical trials of teriflunomide are underway.

- Positive results of a phase II safety and effectiveness trial of an oral compound called finategrast (Glaxo Smith Kline) involving 343 people with relapsing-remitting MS were presented by Dr. David Miller of the UCL Institute of Neurology in London. Similar in approach to the approved infused therapy natalizumab, oral finategrast interferes with movement of immune cells into the central nervous system by blocking the molecule known as alpha 4-integrin. Different doses or placebo were taken for 6 months. The primary outcome measure was the cumulative number of active (“enhancing”) new MS brain lesions, detected with MRI scans. The highest dose caused a significant decrease (49%) in the average rate of new lesions. The drug was well tolerated. (Abstract 113)
- Dr. Ludwig Kappos, of University Hospital in Basel, presented positive results of a phase II safety and effectiveness trial of ocrelizumab (Roche and Biogen Idec) involving 220 people with relapsing-remitting MS. Ocrelizumab is a “humanized” version of rituximab, targeting and killing immune B cells. In this 24-week trial, different doses or placebo were given by two infusions on day 1 and day 15. The primary outcome measure was total number of active (“enhancing”) new MS brain lesions, detected with MRI scans, at weeks 12, 16, 20 and 24. Both doses showed significant benefit at each time point, with a relative reduction of new lesions by at least 89% over placebo. The most common side effect was infusion-related reactions, mostly at the first infusion. One person died from a systemic inflammatory response syndrome, which Dr. Kappos explained could possibly be related to therapy but that it wasn’t yet clear. (Abstract 114)
- Dr. Per Soelberg Sorensen of Copenhagen University Hospital Rigshospitalet presented negative results of a large phase II clinical trial testing the safety and effectiveness of adding the cholesterol-lowering treatment simvastatin or placebo to standard therapy with Avonex® (interferon beta-1a, Biogen Idec) for one to three years in people with relapsing-remitting MS. Previous evidence of the potential benefits of statins in MS has been mixed. The results showed no benefit of adding simvastatin to Avonex, and there was some suggestion that this statin might antagonize the benefits of Avonex. (Abstract 134)
- In a platform session related to “Hot Topics” Dr. Antonio Uccelli of the University of Genoa described new attempts to stop MS progression using infusions of an individual’s own bone marrow or blood stem cells, called mesenchymal cells, which has been used safely in people with some blood disorders and to a limited extent in people with MS. In 2009 international consensus was developed on using these cells in clinical trials....

CONTINUED...

Download entire summary on SharePoint:

http://intranet.nmss.org/Topics/cr/Pages/Researchers_Share_Progress_atECTRIMS_Conference.doc

Also on the Web: <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=4057>