



## CHAPTER PRESIDENTS

October 23, 2009

CC: All

### November Leadership Meeting - Schedule of Events

We are looking forward to seeing all of you in Chicago in a couple weeks. This overview lists all meetings, times and rooms. Please refer to the final program that you'll receive when checking in to ensure you have the most up to date information. ***It's not too late to [register!](#)*** The registration deadline is October 30<sup>th</sup>. If you have not made your hotel [registration](#), please do so by October 28<sup>th</sup>.

#### **Tuesday, November 3<sup>rd</sup>**

Noon–5:00 pm | Colorado and Arkansas Rooms

Advancing the Regions and Organizational Development and Interim Management Team Meetings - *Invitation Only*

Noon–6:00 pm | Ohio

Fast Forward Team Meeting - *Invitation Only*

5:30-8:30 pm | Mayfair

Region B Team Dinner Meeting - *Invitation Only*

6:00-9:00 pm | Mississippi

Fast Forward Campaign Committee Dinner - *Invitation Only*

#### **Wednesday, November 4<sup>th</sup>**

7:30–8:45 am | Arkansas

Executive Management Team Council - *Invitation Only*

7:30–11:30 am | Mississippi

Fast Forward Campaign Committee Breakfast - *Invitation Only*

9:00 am - Noon | Parlor D

Fast Forward Project Team Meeting - *Invitation Only*

9:00 am–3:30 pm | Michigan A & B

Executive Management Team Meeting - *Invitation Only*

## **Wednesday, November 4<sup>th</sup> (cont'd)**

12:00–6:00 pm | Registration Desk Open

4:00–5:30 pm | Sheraton Ballroom

Opening General Session

Tribute to Weyman and Keynote from Phil Keoghan – please join us!

6:00–9:00 pm | Chicago 6 & 7

Welcome Reception & Carnival

7:00–9:00 pm | Arkansas

Governance Committee of National Board of Directors - *Invitation Only*

7:00–9:00 pm | Colorado

Chapter Relations Committee of National Board of Directors - *Invitation Only*

7:00– 9:00 pm | Mississippi

Finance Committee of National Board of Directors - *Invitation Only*

## **Thursday, November 5<sup>th</sup>**

7:00–8:15 am | Mississippi

Chairs Advisory Council - *Invitation Only*

7:30–8:30 am | Sheraton Ballroom

Continental breakfast

7:30–9:30 am - Region Meetings

Region B | Illinois boardroom

Region C | Parlor E

Region D | Parlor F

Region E | Parlor G

Region F & G | Colorado

*Invitation Only*

8:00 am–6:00 pm | Registration Desk

Registration open

8:30–9:30 am | Sheraton Ballroom

General Session for Team Captains & Tour of Champions

**Thursday, November 5<sup>th</sup> (cont'd)**

8:00–11:45 am | Parlor C

National Board of Directors Meeting - *Invitation Only*

9:30–11:30 am - Region Meetings

Region A | Parlor B - *Invitation Only*

9:30 am–12:15 pm | Columbus A & B

New Chapter Chair Orientation -*Invitation Only*

10:00–11:30 am - Team Captains & Tour of Champions' Workshops

Social Networking | Arkansas

Creative Fundraising | Michigan A

Recruitment & Retention | Colorado

MS & the family | Missouri

11:30 am–12:45 pm | Ohio

Strategic Response Committee - *Invitation Only*

11:45 am–12:45 pm | Parlor C

Delegate Assembly Lunch - *Invitation Only*

12:00 –1:15 pm | Sheraton Ballroom

General Session & Luncheon for Team Captains & Tour of Champions

1:00–5:15 pm | Chicago 8, 9 & 10

62nd Annual Meeting — Delegate Assembly of the NMSS -*Invitation Only*

1:30–3:00 pm - Team Captains & Tour of Champions' Workshops

Social Networking | Arkansas

Mission Possible | Michigan A

Communicating Effectively with MS | Missouri

Fundraising & Retention | Colorado

It's not just for grown-ups | Michigan B

6:00–10:00 pm | Sheraton Ballroom

General Session for All & Celebration Dinner with Clay Walker Concert

**Friday, November 6th**

8:00–9:30 am | Sheraton Ballroom  
Continental Breakfast

8:00 am–11:45 am | Michigan B  
New National Board Member Orientation - *Invitation Only*

9:00–10:30 am - Team Captains & Tour of Champions' Workshops  
Cognitive Changes in MS | Missouri  
Charting the Course | Michigan A  
How far does a pledge for MS go? | Colorado  
Keeping Things Fresh | Arkansas

11:45 am–1:15 pm | Sheraton Ballroom  
Closing General Session & Luncheon for Team Captains & Tour of Champions

1:15 –4:15 pm | Mississippi  
All America Chapter Board Meeting - *Invitation Only*

If you have questions, please contact the appropriate meeting organizer:

Craig Weber – Chapter Board  
[Craig.weber@nmss.org](mailto:Craig.weber@nmss.org)

Denise Paul - All America Chapter Board Meeting  
[Denise.paul@nmss.org](mailto:Denise.paul@nmss.org)

Jan Johnson – Regional Meetings and Executive Management Team  
[Janet.johnson@nmss.org](mailto:Janet.johnson@nmss.org)

Pattie Bean – National Board and Delegate Assembly  
[Pattie.bean@nmss.org](mailto:Pattie.bean@nmss.org)

Rachael Nuwash – Team Captains and Tour of Champions  
[Rachael.nuwash@nmss.org](mailto:Rachael.nuwash@nmss.org)



## DEVELOPMENT

10/23/09

CC: Marketing

### *boundless* Fundraising for 2010 Events

#### ***boundless* Fundraising™ Facebook Application for All Events in 2010**

Developed by our partner Charity Dynamics, *boundless* Fundraising is an application (“app”) that uses Facebook as a channel for event fundraising and acquisition. The app syncs seamlessly with Convio and facilitates real-time donations and participant profile updates.

Based on the remarkable success of our 2009 *boundless* Fundraising pilot, we will be incorporating the tool in all Bike MS, Walk MS, and Challenge Walk events nationwide in calendar year 2010. It will also be available for 2<sup>nd</sup> tier events such as Stair Climbs, Mud Runs, etc. We have received excellent feedback from both our participants and our Chapters who’ve used the program, and we’re excited to make the tool available to all event participants in the upcoming year.

Special thanks to the pilot chapters: Colorado, Greater Delaware Valley, Greater Illinois, Mid Atlantic, Mid Florida, Minnesota, Southern California, and Utah State.

Our partners at Charity Dynamics will begin installing *boundless* Fundraising in all 2010 events beginning the week of November 2<sup>nd</sup>.

For those of you who have not used this app, we will be hosting a WebEx presentation explaining the program and how to use it on Monday, November 9<sup>th</sup>. Below is the call information:

Topic: Boundless Fundraising

Date: Monday, November 9, 2009

Time: 2:00 pm, Mountain Standard Time (GMT -07:00, Denver)

Meeting Number: 482 529 073

Meeting Password: (This meeting does not require a password.)

1. Go to <https://nmss.webex.com/nmss/j.php?ED=128662032&UID=0>
2. Enter your name and email address.
3. Enter the meeting password: (This meeting does not require a password.)
4. Click "Join Now".

As a reminder, the cost for this tool is \$135 per TeamRaiser

Support for this tool is multi-faceted: there is a 'Help' function on the component for end users, an FAQ document will be posted on the Intranet, and for any technical questions or issues that you may have, you can submit a Track-It ticket for support.

Also, we've encountered some questions about the difference between the Facebook Connect feature on the new Shasta release of Convio and the *boundless* Fundraising tool. Just to clarify:

**Facebook Connect** is a Convio tool which allows users to log into their Facebook Account from Convio and take action to publish or share "stories" about the site to their Facebook wall and to their friends' Facebook feeds. The intention of this feature is to enable our constituents to share information about us on Facebook, increasing awareness about the organization and our fundraising and/or advocacy efforts.

***boundless Fundraising***<sup>TM</sup> is a Facebook application that enables participants to extend their fundraising efforts beyond their TeamRaiser Participant Center. Participants first register for an event and, once registered, are given the option to add *boundless* Fundraising to their Facebook page. Once participants have added the app to Facebook, their **fundraising progress** is displayed on their Facebook page where their **friends can check their progress and donate to their efforts**. The tool communicates with Convio regularly to provide up-to-date data on fundraising progress. In addition, *boundless* Fundraising provides automatic Newsfeeds (messages to Facebook friends) and Notifications (messages to the participant via Facebook) giving updates on progress to date and encouragement to donate.

We look forward to another successful event season and are pleased to be able to offer our participants another channel for their fundraising and acquisition efforts!

For questions about *boundless* Fundraising, please contact Sarah Klein at [sarah.klein@nmss.org](mailto:sarah.klein@nmss.org) or 518-952-4153

For questions about social networking — or the Society's online marketing strategy in general — please contact Rich Sarko at [rich.sarko@nmss.org](mailto:rich.sarko@nmss.org) or 303-698-6100 x15171.



## DEVELOPMENT

October 23, 2009

CC: Information Technology (IT)

### Change in Process for Updating Google Maps for Events

**Action Requested/Deadline: December 1, 2009**

Exciting development plans are underway that will bring improvements to the BikeMS.org, WalkMS.org and ChallengeWalk.org websites which feature Google mapping functionality. The sites are moving from micro sites to our Content Management System (CMS) creating a stronger, more compelling landing page for national marketing efforts. We also hope to improve the map view by using a US map vs. a map of North America and new markers that will make it easier to identify event locations. Moving these national event sites to CMS also provides an opportunity for more dynamic content on these landing pages providing opportunities to feature national promotions and partners.

This change also eliminates the need for chapters to send the Home Office information to create events on the map. Instead, chapters will have the tools and training needed to do this locally. In order to prepare for this change, **training is required**. Please see the information at the end of this News Sheet to register.

These websites are core to national event marketing. Don't miss the opportunity to benefit from traffic to these sites. The Home Office has already committed to an advertising buy in ***Bicycling*** magazine that will drive readers to BikeMS.org thanks to the success of the GNC in-store fundraising campaign earlier this year. The 4-page gatefold ad off the magazine cover will appear in their March issue and on the streets in early February. **Please insure all 2010 events are uploaded by December 1 including Bike MS, Walk MS and Challenge Walk to get maximum exposure from marketing efforts in the coming months.**

### Training schedule and registration

- All sessions are presented via WebEx.
- To register for a session email [Duanyelle.West@nmss.org](mailto:Duanyelle.West@nmss.org) 24 hours in advance. All session times are eastern.
- The same conference number will be used for all training sessions:  
1-866-528-9689 ID 52163560#
- You may also go to WebEx, log in and access the session.
- **If you have any questions about training, please contact Duanyelle West via email.**

**October 28<sup>th</sup>: 2:30 – 3:30pm ET**

.ORG Admin Training #1

Go to <https://nmss.webex.com/nmss/j.php?ED=128336847&UID=0>

**Conference # 1-866-528-9689 ID 52163560#**

**October 29<sup>th</sup>: 2:00 – 3:00pm ET**

.ORG Admin Training #2

Go to <https://nmss.webex.com/nmss/j.php?ED=128336877&UID=0>

**Conference # 1-866-528-9689 ID 52163560#**

**October 30<sup>th</sup>: 1:30 – 2:30pm ET**

.ORG Admin Training #3

Go to <https://nmss.webex.com/nmss/j.php?ED=128336722&UID=0>

**Conference # 1-866-528-9689 ID 52163560#**

**November 3<sup>rd</sup>: 3:30 – 4:30pm ET**

.ORG Admin Training #4

Go to <https://nmss.webex.com/nmss/j.php?ED=128336772&UID=0>

**Conference # 1-866-528-9689 ID 52163560#**

**November 4<sup>th</sup>: 3:30 – 4:30pm ET**

.ORG Admin Training #5

Go to <https://nmss.webex.com/nmss/j.php?ED=128513287&UID=0>

**Conference # 1-866-528-9689 ID 52163560#**

Betty Ross

[Betty.ross@nmss.org](mailto:Betty.ross@nmss.org)



## DEVELOPMENT

October 23, 2009

CC: Chapter Presidents

**December Walk MS and Bike MS New Staff Training Going Virtual**

**Action Requested/Deadline: Register by December 1**

We are pleased to announce that the December Walk MS and Bike MS New Staff Training (formerly known as Mass Market Workshop) will be offered virtually this year in order to make training more accessible 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, event research findings and provide a great networking opportunity for all attendees. Finally, 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.

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 six 90 minute calls which will take place over the course of two weeks. All trainings will start at 1 pm eastern, 12 pm central, 11 am mountain, 10 am pacific. The dates of the trainings are:

- December 8
- December 9
- December 10
- December 15
- December 16
- December 17

Staff who register for the trainings are committing to all six of the workshop sessions. The training series fee is only \$30.

To register for the Walk MS and Bike MS New Staff Training please go to <https://meetings.nmss.org/attendee/event/massmarketworkshop.wv>

The registration deadline is **December 1**.

If you have further questions about the Walk and Bike Virtual Training please contact Ellen Penrod at [ellen.penrod@nmss.org](mailto:ellen.penrod@nmss.org) or 303-698-6100 x15104.



## DEVELOPMENT

<b>October 23, 2009</b>	<b>CC: Chapter Presidents</b>
<b><u>2010 Hoovers Subscriptions</u></b>	

Hoover's online is now offering chapters a special subscription deal for 2010. For those of you unfamiliar with the Hoovers website, Hoovers provides detailed information on thousands of companies, including locations, leadership staff and top competitors. This powerful tool can provide extensive corporate background information to help staff with sponsorship and corporate team cultivation. Chapters will receive a year long subscription (November 1, 2009 to October 31, 2010) for the deeply discounted rate of \$950.

Chapters who want to take advantage of this offer need to sign-up by **Friday, Oct 30**.

Below is an informational sheet from Hoovers about the subscription and how to sign-up.

Because chapters will now be able to directly pay Hoovers for their subscription, the Home Office is keeping their individual Hoovers account but discontinuing the group subscription to Hoovers. All chapters that are currently on the group plan who wish to continue their Hoover's service will need to contract directly through Hoovers. The National subscription will stop on November 1.

If you have further questions about Hoovers please contact Ellen Penrod at [ellen.penrod@nmss.org](mailto:ellen.penrod@nmss.org) or 303-698-6100 x15104.

### **HOOVER'S SPECIAL OFFER FOR THE NATIONAL MULTIPLE SCLEROSIS SOCIETY**

#### **WHY HOOVER'S**

The economic climate is very challenging today – but you still need tools to help you identify new donors and partners. Hoover's is the business information tool that can help you meet your fundraising goals. If you haven't used Hoover's in the past – it is a very intuitive, easy-to-use tool – go ahead and take a Free Test Drive Now – you will have access through Wednesday, 10/28/2009.

Free Login:

<http://access.hoovers.com/hvweb/webintegration/WebIntegrationServlet?call=LoginWeblet>

Username: [tryme@hoovers.com](mailto:tryme@hoovers.com)

Password: trymefree

**Self Guided Tutorials** (how to use Hoover's). Each takes less than 5 minutes. Flash 8 is required. [Get it here.](#)

- [How To Search For Information With Hoover's](#) (Flash 8)
- [How To Build A List With Hoover's](#) (Flash 8)
- [A Quick Start To Using Hoover's](#) (Flash 8)
- [Using Hoover's In Sales & Marketing](#) (Flash 8)
- [Build Better Lead Lists](#) (PDF Format)

### **SUBSCRIPTION DETAILS:**

Access for your branch for 1 Year

Hoover's Relationship Manager

- Access to over 60 million worldwide companies and 70 million people
- Family Tree Access – understand corporate linkage on over 1 million companies – great for expanding relationships with the companies that you work with
- Build a List – build a prospect list of companies or people and download into Excel or your CRM

Annual Cost is only \$950 for the year

Payable with Credit Card

Offer good through Friday, 10/30/2009

### **HOW DO I SIGN UP?**

Contact your Account Manager, Debbie Long for an Order Form and further details

512-374-4684

[dlong@hoovers.com](mailto:dlong@hoovers.com)



**National  
Multiple Sclerosis  
Society  
News Sheet**

## DEVELOPMENT

10/23/09

CC: Marketing

### *Mission Possible* Artwork Submissions Requested for 2010 Award Plaque

We are now accepting submissions of artwork for the 2010 Mission Possible Award.

Artwork should be created by someone connected to (but not employed by) the National MS Society and should reflect the Society's positive messages of hope, empowerment, and movement.

Please send your submissions electronically to Sarah Klein at [sarah.klein@nmss.org](mailto:sarah.klein@nmss.org) by November 30<sup>th</sup>. The winner will be chosen by a committee and will be notified by December 11<sup>th</sup>.

As you know, "Mission Possible" provides chapters the opportunity to recognize the outstanding fund raising efforts of their top donors. Most chapters market Mission Possible to event participants and position it as a mission-focused award that can be easily attained by raising \$1 for every client served locally.

If you have questions regarding this valuable donor recognition strategy, contact Sarah Klein, at 518.952.4153 or [sarah.klein@nmss.org](mailto:sarah.klein@nmss.org).



## MARKETING & DEVELOPMENT

October 23, 2009	CC: All
FY 2010: E-communications Updates	

### November National MS eNews

**Send date: 11/12/09**

**Audience: Full List**

The November 2009 National MS eNews (formerly known as the Nationwide E-newsletter) will be sent on Thursday, November 12. You may have noticed a new look and feel to the October issue. We are very excited to have rolled out a number of changes to the eNews, including a new editorial process and refreshed design. The goal is to deliver an online newsletter that is as fresh and engaging as possible.

### November E-mail Campaign

**Send dates: 11/16/09 and 11/30/09**

**Audience: ~450,000**

An e-mail series is currently in the planning stages that would begin in November and be sent to people living with MS and their family and friends. More details regarding this campaign will be communicated within one-two weeks.

### Additional notes

For all national e-communications, individuals with a 'no email' classification on their Altair accounts will be suppressed, along with standard Direct Marketing Program excludes / suppressions. If you would like to review the updated Direct Marketing Program excludes, please visit the new Intranet: Development → FY09\_Direct\_Marketing\_Overview\_CD\_Master\_Exclude\_Document

As we approach FY 2010, we continue to optimize the FY 2010 National E-mail Program. To review the most current national e-mail program send dates, please visit the new Intranet: Marketing → Constituent\_Communications\_Calendar\_FY10

For questions about national e-communications, please contact Rich Sarko at [rich.sarko@nmss.org](mailto:rich.sarko@nmss.org) or 303-698-6100 x15171.



## MARKETING & DEVELOPMENT

October 23, 2009

CC: All

### 2009 Customer Satisfaction Surveys

Significant changes in the Society's communications have occurred since our last user surveys in 2006. In particular, in March of 2007 we re-launched the national Web site, and in the winter of 2007 we re-launched our flagship print publication as *Momentum* magazine.

For the current surveys, our goal is to revisit customer satisfaction for these two significant communication channels – *Momentum* and [www.nationalMSSociety.org](http://www.nationalMSSociety.org). We will reassess core audiences and determine the changes that have occurred since 2006. In addition, we hope to better understand our overall customer attitude toward – and preferences regarding – offline versus online communications.

Importantly, the print and Web surveys have been designed so that we can benchmark current survey responses to those of 2006. Survey results will be completed in December.

For questions please contact:

Print

Gary Sullivan  
Managing Editor, Publications  
[gary.sullivan@nmss.org](mailto:gary.sullivan@nmss.org)  
212-476-0538

Web

Rich Sarko  
Director, Online Marketing  
[rich.sarko@nmss.org](mailto:rich.sarko@nmss.org)  
303-698-6100 x15171



## PROGRAMS & SERVICES

Date: October 23, 2009

CC: Advocacy

### **REMOVING A MAJOR BARRIER TO NECESSARY CARE: the Medicare "Improvement Standard" Advocacy & Education Initiative**

The Society has been working on the advocacy front with the Center for Medicare Advocacy on the issue of the Medicare Improvement Standard. We recently coordinated a call with the Centers for Medicare and Medicaid Services (CMS) which included the Center for Medicare Advocacy on this issue. We were pleased with the positive response we received from the Medicare Ombudsman to our request for him to review the inappropriate utilization of the improvement standard in denying people with Medicare access to necessary care in the form of on-going physical therapy. We anticipate a response to our meeting within the next month with an outline of possible next steps by CMS.

The following announcement by the Center for Medicare Advocacy ties to this effort by the Society:

*The Center for Medicare Advocacy is launching a new advocacy and education initiative to eliminate the Medicare "Improvement Standard," which requires that Medicare beneficiaries be able to improve in order to qualify for coverage. The insistence that people must be able to get better unfairly restricts access to Medicare coverage and necessary health care.*

*Although the Improvement Standard conflicts with the law, it has become deeply ingrained in the system and ardently followed by those who provide care and those who make coverage determinations throughout the health care continuum. Beneficiaries are told Medicare coverage is not available if their underlying condition will not improve, if they have "plateaued," are not likely to improve, or if they need "maintenance care only". As a result it keeps people with debilitating, chronic conditions from receiving the care they need. This practice persists although the Medicare Act does not require improvement as a precondition to coverage for illness or injury. Further, the federal regulations state that "restoration is not to be the deciding factor" in making Medicare coverage determinations.*

*Everyday the Improvement Standard blocks access to Medicare and health care for real people. The people most affected by this barrier include people with Multiple Sclerosis, Alzheimer's disease, ALS (Lou Gehrig's disease), spinal cord injuries, diabetes, Parkinson's disease, hypertension, arthritis, heart disease, and stroke. Further, the erroneous standard disproportionately affects people who have*

*low-incomes, as well as African-Americans and Hispanics.*

*With support from The Atlantic Philanthropies, the Center for Medicare Advocacy will begin a focused, collaborative effort to eliminate the Improvement Standard in Medicare policy and practice. This effort will include advocacy with the administration, litigation if needed, and a multi-faceted education campaign.*

*For decades, the Improvement Standard has been among the most significant obstacles facing the Center's clients, as well as the millions of other people with Medicare who have no legal representation. By removing this obstacle, we will open doors to needed medical and rehabilitative care for people with long term conditions and injuries. This is the goal of the proposed project.*

The Society will continue to work with the Center for Medicare Advocacy to advance this issue according to the priority strategies of the Society. If you are working with or know of someone who is facing issues regarding the “improvement standard” contact the Center for Medicare Advocacy at: [improvement@medicareadvocacy.org](mailto:improvement@medicareadvocacy.org).

**Shawn O’Neil**

VP, Federal Government Relations  
Advocacy

**Kris Erickson, MSCIR, MSSMC**

Health Insurance Manager  
IRC / Programs & Services Department

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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

October 23, 2009

### **Researchers Show How Immune Attack May Directly Damage Nerve Fibers in MS**

Researchers report on a protein that may engage the immune attack to target nerve fibers in MS; studies suggest that damage to nerve fibers may be the root cause of long-term disability in MS. Edgar Meinl, MD (Max Planck Institute of Neurobiology, Martinsried, Germany) and colleagues reported their findings in *Proceedings of the National Academy of Sciences USA*, ([2009 May 19;106\(20\):8302-7](#)). This study was funded by the MS Society of Great Britain and Northern Ireland, among others.

**Background:** Multiple sclerosis occurs when the immune system attacks and damages the brain and spinal cord, with a major target being the myelin that ensheathes nerve fibers. Recent research indicates that damage to nerve fibers themselves may occur early and contributes to long-term disability in people with MS. But it is not clear how nerve fibers are damaged in the course of the immune attack, or whether they are directly targeted by the immune system.

**The Study:** First, Dr. Meinl's team used proteomics – technology that scans thousands of proteins at once – to identify antibodies (immune proteins that target specific molecules) in brain tissue from people with MS that react to nerve fiber components. This process highlighted a protein called “contactin-2/TAG-1” (transiently expressed axonal glycoprotein 1). Contactin-2/TAG-1 is active on nerve cells, in the region where myelin connects with the nerve fibers.

They then compared the reactivity of immune T cells from individuals with MS and other disorders by exposing their T cells to Contactin-2/TAG-1. They found that T cells from people with MS showed signs of “recognizing” and mounting immune responses to this molecule, and also found evidence of antibodies in MS spinal fluid that reacted to this molecule.

To determine the potential significance of these T cells, the group administered immune cells that showed reactivity to contactin-2/TAG-1 to lab rats, and they developed a mild form of EAE, an MS-like disease. In a further experiment, the investigators followed up the administration of T cells by administering antibody targeting a myelin protein. In this so-called “two-hit” model, the EAE was much more severe, resulting in widespread damage to gray matter, that is, areas of the brain where nerve cell bodies and their nerve fibers are not covered by myelin.

The results suggest that contactin-2/TAG-1 is a possible target for the immune attack in MS, and that the attack may cause direct damage to nerve fibers. In a related article, Drs. Richard Rudick and Bruce Trapp (Cleveland Clinic Foundation) note that Dr. Meinl’s two-hit model is a good one to use when teasing out why nerve fibers are damaged in MS, and for developing therapeutic approaches that target damage to nerve fibers – a key need in the treatment of MS. (*The New England Journal of Medicine* [2009;361\(15\):1505-1506](#)).

-- Research and Clinical Programs Department



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

**UPDATED October 22, 2009**

**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. According to the sponsor, the agency is expected to make a final decision about whether to approve the drug for market on or before January 22, 2010.

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