



## DEVELOPMENT

September 14, 2012	CC: Marketing
<b>All Event Staff Call, Tuesday, September 18, 2012</b>	

Our next All Event Staff Call is scheduled for September 18, 2012 when we will be presenting an industry update on social media. We will also provide a tour of the Society's most important chapter resources- SharePoint, and the Society's FTP and SAMS sites.

Call details:

1 pm eastern, 12 pm central, 11 am mountain, 10 am pacific. Dial in number is 15100, passcode 15123 if using a cell phone or calling from a non-society line call in number is 888-279-3775; passcode 15123. SABA link,  
<http://mt211.sabameeting.com/GA/main/000000e79eb30000013975e2588a8392>

If you have further questions about the special event calls, please contact:

Amy Boulas, [amy.boulas@nmss.org](mailto:amy.boulas@nmss.org)  
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## PROGRAMS & SERVICES

September 14, 2012

CC: Marketing

### Author-submitted Book Review Process

The Society receives a large number of requests by authors asking to have their books included in the Books section of our online Multimedia Library and promoted through a variety of channels. A work team comprised of Society staff and key volunteers have developed guidelines and procedures for submitting books for review to the Society.

Books to be considered for inclusion in the Society's online Multimedia Library should align with the Society's organizational values of inspiring hope and addressing the challenges of living with MS with an overall positive theme. The complete book submission guidelines and review procedures are posted on [SharePoint/Programs and Services](#), as well as at [www.nationalMSSociety.org/multimedialibrary](http://www.nationalMSSociety.org/multimedialibrary).

If you have books to be reviewed for inclusion in the Multimedia Library, please refer to the posted guidelines. Books that fall within the scope of review can be sent to:

Heather Webb Jones  
National MS Society  
Broadway Station  
900 S. Broadway 2nd Floor  
Denver, CO 80209

Please make sure to include any corresponding materials received with the books and contact information for the authors. If you have questions about how to handle publications you've already received, please contact Doris Lill. Please note- these guidelines only apply to the online Multimedia Library and do not apply to book reviews done by the Momentum editorial staff.

For more information please contact Doris Lill at (303) 698-6167 or via email at [Doris.Lill@nmss.org](mailto:Doris.Lill@nmss.org).



## PROGRAMS & SERVICES

September 14, 2012

CC: Chapter Presidents

### MSSMC Certifications September 2012

Congratulations to the following individuals who earned the designation of Multiple Sclerosis Service Management Certification (MSSMC) in September 2012!

Kerri Bowes, Gateway Area

Kimberly Burkett, Northwestern Ohio

Jackie Carrino, North Florida

Pat Chuck, Mid Florida

Lynette Coleman, Connecticut

Pam Dixon, Western Pennsylvania

Amanda Gelter, Ohio Valley

Lisa Gordon, New Jersey Metro

Susan Guinter, Central Pennsylvania

Mary Ann Holm, Southern California

Mary Lee Jackson, Western Pennsylvania

Jennifer Koeller, Arizona

David LaRue, Home Office

Katie Maclean, Gateway Area

Maureen Mohny, Northwestern Ohio

Susan Raimondo, Connecticut

Stephanie Shapiro, Georgia

Meredith Sheehan, Rhode Island

Angela Taylor, Home Office

Robin Unangst, Central Pennsylvania

April Wolfe, Ohio Buckeye

This exam is a rigorous test of one's knowledge of service management principles and practical application. These individuals are to be commended for this achievement. A complete list of all MSSMC certified staff throughout the Society can be found on SharePoint:

[http://intranet.nmss.org/Topics/programs\\_services/Pages/StaffDevelopmentOpportunities.aspx](http://intranet.nmss.org/Topics/programs_services/Pages/StaffDevelopmentOpportunities.aspx)

The 2013 MSSMC testing dates have not been established, but should be similar to this year's dates of February and August. An announcement will be made in the newssheets as soon as the dates are identified. You can also visit the Professional Testing Corporation's website at [www.ptcny.com](http://www.ptcny.com) for the dates as well as registration and reference materials. We will again be offering the series of study materials and conference calls.

Contact Janis Pluss, 303 698-6100, ext 15284 or [janis.pluss@nmss.org](mailto:janis.pluss@nmss.org) for additional information.



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## RESEARCH/CLINICAL UPDATE

cc: All staff

September 12, 2012

### **FDA Approves Oral Teriflunomide – Brand Name Aubagio® – as Disease-Modifying Therapy for Relapsing MS**

The U.S. Food and Drug Administration has approved teriflunomide once-daily pills (Aubagio,® Genzyme, a Sanofi company) to treat relapsing forms of MS. This is the second oral disease-modifying therapy approved for the treatment of multiple sclerosis. The therapy is expected to be available for prescription by October 1, 2012 in the U.S. The company has also applied for regulatory approval in other parts of the world.

“We are greatly encouraged to see a new oral therapeutic option become available to people living with MS,” advised Bruce A. Cohen, MD, Professor, Davee Department of Neurology and Clinical Neurosciences at Northwestern University’s Feinberg School of Medicine, and incoming Chair of the National MS Society’s National Medical Advisory Committee. “As with any new therapy, the long-term safety of Aubagio will need to be carefully monitored,” he added. Dr. Timothy Coetzee, Chief Research Officer at the National MS Society agreed. “With the collaborative research underway around the world today, this is an extremely hopeful time for anyone who is diagnosed with MS.”

Read the FDA’s press release:

<http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm319277.htm>

About Teriflunomide/Aubagio: Multiple sclerosis involves immune system attacks on the brain and spinal cord. Aubagio (pronounced **oh-BAH-gee-oh**) is a novel oral compound that inhibits the function of specific immune cells that have been implicated in MS. It is related to leflunomide, a drug used to treat arthritis. Aubagio can inhibit a key enzyme required by white blood cells (lymphocytes), reducing the proliferation of T and B immune cells active in MS and also inhibiting the production of immune messenger chemicals by T cells. It is not thought to

affect resting immune cells that are not in an activated state. Two doses (7mg and 14 mg) have been approved.

Potential benefits: Three large clinical trials of Aubagio have been completed, and at least two more are ongoing. In the phase III TEMSO study, Aubagio reduced the average number of MS relapses and disease activity on MRI scans significantly more than inactive placebo in 796 people with relapsing forms of MS. Read more (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=5577>) about this study.

In a recently completed phase III TOWER study involving 1,169 people with relapsing-remitting MS, oral Aubagio reduced relapses compared with placebo over at least 48 weeks, according to a company press release. Of two different doses tested during the TOWER trial (7 mg and 14 mg), the higher dose also slowed progression of disability. Read more (<http://nationalmssociety.org/news/news-detail/index.aspx?nid=6456>) about this study.

In another study, called TENERE, Aubagio was compared with Rebif<sup>®</sup> (interferon beta-1a, EMD Serono and Pfizer) in relapsing MS, and did not reach its primary endpoint (the main question posed by the study) -- the “risk of failure,” meaning the first occurrence of a relapse, or permanent discontinuation of the study treatment, whichever came first. There was no significant difference in the numbers of participants who experienced events defined as treatment failure among the Aubagio and Rebif groups.

Potential risks and screenings: In trials to date, Aubagio was generally safe and well tolerated. The most common side effects experienced by participants in clinical trials include diarrhea, abnormal liver tests, nausea, flu, and hair thinning.

The prescribing information includes a boxed warning related to the potential for liver damage in persons taking Aubagio. There is also a warning that Aubagio is not indicated for women who are pregnant or women with childbearing potential who are not using reliable contraception. The prescribing information also contains information on how to clear Aubagio from the system in case that is required.

Before people begin taking Aubagio, they should have a blood test, or have had one within six months, to detect levels of liver enzymes and levels of blood cells (Complete Blood Count). They should also have their blood pressure checked, and have a screening test for tuberculosis (tuberculin skin test). It should be verified in women of childbearing potential that they are not pregnant before taking Aubagio.

After starting Aubagio, blood tests to detect liver enzymes should be done at least monthly for the first six months, and then patients should be monitored for signs of liver damage. Patients should also be monitored for signs of infection, and blood pressure should be checked periodically.

Taking a disease-modifying therapy is currently the best way to reduce MS disease activity and future deterioration. Selecting an MS therapy should be done by people with MS in collaboration with their MS doctors, taking into account a variety of factors, including the effectiveness of any therapy they are currently using, and weighing potential risks and benefits, costs and lifestyle factors.

Physicians and people with MS can contact Genzyme for information about Aubagio and patient support programs by calling: 1-855-676-6326

Download the Prescribing Information and Medication Guide (.pdf)

<http://products.sanofi.us/aubagio/aubagio.pdf>

Read more about disease-modifying therapies and other treatments for MS and MS symptoms:

<http://nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/index.aspx>

Read about National MS Society efforts to speed research in progressive MS:

<http://nationalmssociety.org/research/research-we-fund/research-in-progressive-ms/index.aspx>

CONTINUED... FIND FAQs and any future updates of this information at this link:

<http://nationalmssociety.org/news/news-detail/index.aspx?nid=6864>

Aubagio is a registered trademark of Genzyme, a Sanofi company

Rebif is a registered trademark of EMD Serono and Pfizer.



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development



**Stop MS**

**September 10, 2012**

### **MS Societies Worldwide Collaborate to Stop MS Progression**

*International Collaborative on Progressive MS Publishes Research Agenda – “The time is right for concerted action”*

Despite significant progress in the development of treatments for people with relapsing forms of multiple sclerosis, there are few treatment options for people with progressive forms of MS. The newly formed International Collaborative on Progressive MS has published an opinion paper outlining challenges in developing therapies for progressive MS and identifying key research priorities to propel efforts to stop MS progression. The Collaborative is the greatest effort to date aiming at speeding research on progressive MS, and is formed of the MS Societies of Canada, Italy, Netherlands, the UK and the US, and the MS International Federation. The paper, by lead author Robert J. Fox, MD (Mellen Center for Multiple Sclerosis, Neurological Institute, and Lerner College of Medicine, Cleveland Clinic) and colleagues, identifies five key priority areas for research, and was published in the *Multiple Sclerosis Journal* (Online First, August 23, 2012

<http://msj.sagepub.com/content/early/2012/08/22/1352458512458169.full>).

“Overcoming the challenges of progressive MS is a key objective of the Society’s Strategic Response to MS,” says Timothy Coetzee, PhD, Chief Research Officer of the National MS Society and member of the Collaborative. “This is just one of the ways we’re collaborating worldwide to speed clinical trials in progressive MS.”

**Background:** The hopes of most people who have MS today rest on finding a way to stop disease worsening and reverse the damage to restore lost functions. MS progression can be slow or it can be fast, but most agree that it occurs in the majority of those who have the disease, even those successfully treated for relapses.

There's been a great deal of progress in treating relapsing forms of MS, with many FDA-approved therapies. But for every new therapy approved for relapsing forms of MS, people with progressive MS, for whom there are few significant treatment options, feel left behind. Virtually every therapy approved for relapsing MS has been tested, or is now in testing, in people with progressive forms of the disease. Up to now, clinical trials involving people with relapsing MS often rely on counting relapses or doing MRI scans to detect immune activity. The fact that there is no easy way to detect progression quickly is one reason why drug development for progressive MS is behind.

The mission of the International Collaborative on Progressive MS is to expedite the development of effective disease modifying and symptom management therapies for progressive forms of MS. To do so, research efforts are needed on several fronts to lay the groundwork needed to identify possible therapeutic targets and conduct clinical trials aimed at stopping progression of the disease.

The Research Agenda: Through a series of meetings, the collaborative has identified five key research priorities for progressive MS.

- Experimental Models – There is an urgent need for animal models that more clearly reproduce the clinical symptoms and underlying tissue damage seen in progressive MS.
- Identification and Validation of Targets and Repurposing Opportunities for progressive MS – Insights for identifying new targets may come from advances in MS genetics, or from re-evaluating drugs that are approved for other indications.
- Proof-of-Concept Clinical Trial Strategies – New clinical trial strategies are likely to involve biomarkers that measure important events in nerve fiber injury [which contributes to the progression of disability] and correlate with disability, and trial designs that minimize trial size and duration.
- Clinical Outcome Measures - The ideal measurement would be sensitive to change over time, and predictive of future change. The authors note an effort already underway to revise the MS Functional Composite – read more (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=6777>).
- Symptom Management and Rehabilitation – More well controlled trials are needed to evaluate symptomatic therapies and rehabilitation methods, particularly cognitive rehabilitation interventions.

Comment: “Tackling these issues will require an integrated, multi-disciplinary approach to enable effective translation of research into therapies,” wrote the authors. “The time is right for concerted action.”

The Collaborative commissioned five working groups to identify strategies and potential lines of research within each area. An international meeting is set for February 2013, where plans will continue for moving this research forward.

Read more (<http://www.nationalmssociety.org/research/research-we-fund/research-in-progressive-ms/index.aspx>) about research on progressive MS.