



ADVOCACY

November 11, 2011

CC: Programs and Services

Rural Health Care Fact Sheet

The third in a series of Society Fact Sheets, "[Rural Health](#)," is now available for chapter reference and as a resource to advance the Strategic Response, "We develop, deliver and leverage resources to enhance care for people with MS and quality of life for all those affected by the disease." Studies cited within it can provide relevant research findings to bolster efforts to, "Increase the number of MS specialists and access to specialized care in rural areas for others who are underserved."

The Rural Health Fact Sheet, filed on Share Point under Advocacy > Advocacy Training, Basics and Tools, is a useful resource for:

- ✓ grant applications
- ✓ program development
- ✓ education outreach efforts
- ✓ advocacy campaigns
- ✓ and, more

To learn more about these National MS Society research findings and their application in support of the 2011-2015 Strategic Response, join us for a:

Government Relations Roundtable Discussion

Thursday December 1, 2011

3:00 pm ET/2:00 pm CT/1:00 pm MT/12:00 pm PT

with Dr. Nicholas LaRocca.

1-866-417-3327

Pass code 7865563#

Questions regarding these findings and their potential uses can be directed to:

Nicholas.LaRocca@nmss.org or Renee.Vandlik@nmss.org



CHAPTER PRESIDENTS

November 11, 2011	CC: All
Update: The Society & Mobile Technology	

Nearly 303 million people in the U.S. are wireless subscribers – that’s 98% of the population (ctia.org, Dec. 2010). As such, mobile technology is appealing to marketers and has quickly become an important tool for organizations worldwide.

To learn more about mobile technology and its potential to grow the MS movement, the Society began a nationwide effort, investing in several key areas beginning in 2009. As with many new media and technologies, elements of mobile technology have great potential to further our strategic response and the MS movement. Examples include tools to keep our constituents informed, enhance the event experience and increase fundraising, empower activists and much, much more.

Please review this [three-page update](#) about current and upcoming pilot projects and areas of interest, including:

- Update on text messaging pilots and mobile applications
- Thoughts on QR (quick response) codes
- Findings / lessons learned as well as what we’ve yet to learn

If your chapter is utilizing mobile technology if you have questions, concerns or ideas about the Society and mobile technology, please share your experience, learnings and thoughts – contact Beth Clark, Online Marketing Manager, at beth.clark@nmss.org or 303-698-6100 x15126.



PROGRAMS & SERVICES

November 11, 2011	CC:
Fall Prevention Resources Available	

Next week, each chapter will receive several copies of the new *Free From Falls* DVD, along with multiple copies of the Society’s new Client Educational brochure, entitled: *Minimizing Your Risk of Falling: A Guide for People with MS*. These materials were created to:

- Increase awareness of fall risk factors
- Offer tips and strategies to minimize risk
- Encourage participation in a fall prevention program

At the same time, a copy of the *Free From Falls* DVD, along with a Discussion Guide and 15 copies of the brochure, will be sent to self-help group leaders as part of a ‘meeting in a box’ tool kit.

The DVD is also posted on the Society web-site and clients can contact the IRC to obtain their own copy. (Please note that this DVD is a stand-alone awareness/educational tool and is not part of the 8-week Free From Falls curriculum.)

Some suggestions for using these materials include:

- Share with local MS Clinics and Partners in MS Care
- Share with rehabilitation facilities or individual therapists and encourage them to share with their patients with MS
- Share with co-sponsors of the Free From Falls program
- Incorporate into client/family education programs about mobility, safety and independence

We are confident that these new resources will be of benefit to people with MS and their families. You may order additional copies of the brochure (at no cost) from chapter supply.

For more information please contact Debra Frankel, Associate VP, Programs and Services at debra.frankel@nmss.org or at 617-795-7002.



PROGRAMS & SERVICES

November 11, 2011	CC: Chapter Presidents
<u>SERVICE MANAGEMENT CERTIFICATION STANDARD 2012/MSSMC TEST DATES 2012</u>	
Action Requested/Deadline: Registration Deadlines	

The FY 2012 Certification Standards establishes a new requirement that “certified service management staff provides service management (tier 2 services) for complex client needs”. The compliance measurement reads: “The chapter has at least ONE service manager who has achieved Certification through the MSSMC test by 9/30/12, or has a relationship with another chapter in the region to provide access to a certified Service Manager for clients in need of Tier 2 services”. The Multiple Sclerosis Service Management Certification (MSSMC) test is offered twice a year through the Professional Testing Corporation.

MSSMC Test Information

- The two year eligibility requirement has been eliminated. A Bachelor’s degree is still required.
- **2012 Test Dates:** Test dates have been moved up to accommodate the 9/30/12 deadline:
 - 1st test option: 2/11/12 – 2/25/12; registration deadline December 30, 2011
 - 2nd test option: 8/11/12 – 8/25/12; registration deadline June 29, 2012
- The cost for registration is \$300.00
- For those who are nearing the five year requirement for MSSMC recertification, alternative options for meeting this requirement are under consideration and will be announced in the 2nd quarter of FY ’12.

MSSMC Test Preparation

Reference materials are located on the Professional Testing Corporation website at www.ptcny.com with the course content outline, sample questions, and reference materials. Additionally, the LMS Service Management course is also available to build and enhance knowledge of service management practices and resources. To register for the MSSMC test, please visit the PTC website at www.ptcny.com.

For more information, please contact Janis Pluss at janis.pluss@nmss.org.



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RESEARCH/CLINICAL UPDATE

November 11, 2011

CC: Programs and Services

Emerging Therapies Collaborative – Important Update

The Emerging Therapies Collaborative (www.ms-coalition.org/EmergingTherapies) continues to expand its content.

- Information about BOTOX (onabotulinumtoxinA), a medication recently approved by the FDA for the treatment of urinary incontinence (leakage) in neurologic conditions such as multiple sclerosis (MS) or spinal cord injury, has been posted for clinicians and for people affected by MS. The urinary incontinence in these conditions is caused by an overactive bladder detrusor muscle. BOTOX is also approved to treat spasticity in the upper limbs.

To date, the Collaborative has also created information sheets for Gilenya (fingolimod – the first oral disease-modifying therapy approved for MS), Ampyra (dalfampridine – a medication to improve walking in MS), and Nuedexta (dextromethorphan + quinidine – a medication to treat pseudobulbar affect (uncontrollable episodes of crying and or laughing)).

Participants in the Collaborative include:

- The Multiple Sclerosis Coalition
 - Accelerated Cure Project
 - Can Do Multiple Sclerosis
 - Consortium of Multiple Sclerosis Centers
 - International Organization of MS Nurses
 - Multiple Sclerosis Association of America
 - Multiple Sclerosis Foundation
 - National Multiple Sclerosis Society

- United Spinal Association
- American Academy of Neurology
- VA Multiple Sclerosis Centers of Excellence – East and West
- Americas Committee for Treatment and Research in Multiple Sclerosis

We still have a small supply of promotional postcards for the Emerging Therapies Collaborative. If you are interested in receiving more to share with clients and healthcare professionals, we would be happy to send them to you. Please email your request to the Professional Resource Center at healthprof_info@nmss.org.

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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development, PR specialists

November 11, 2011

Global MS Research Efforts Shared at ECTRIMS/ACTRIMS Meeting

EXECUTIVE SUMMARY

More than 7,000 investigators convened in Amsterdam on October 19-22, 2011 to present findings at a joint congress of ECTRIMS (European Committee for Treatment and Research in MS) and ACTRIMS (Americas Committee for Treatment and Research in MS). Over 1100 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.

Below are highlights and a more extensive summary. For free access to the conference abstracts, go to the ECTRIMS/ACTRIMS 2011 Congress Website:

http://registration.akm.ch/einsicht.php?XNKONGRESS_ID=150&XNSPRACHE_ID=2 On-site commentary was provided on the National MS Society's Blog (<http://blog.nationalmssociety.org/>) and video of select researchers can be found on the Society's You Tube page (<http://www.youtube.com/playlist?list=PLC6EC283DA0067B78>).

Highlights:

STOPPING MS

- First results from late-phase clinical trials of new agents, some of which, if found to be safe and beneficial, may come on the market in 2012 and 2013.
- Progress toward more individualized approaches to treating MS, or “personalized medicine” was evident, including efforts to find non-invasive signals or biomarkers that may be predictive of treatment response and disease course and may speed up clinical trials.

RESTORING

- The full potential of a variety of rehabilitation and exercise regimens to help restore function to people with MS were presented, including approaches to address troubling symptoms including pain, cognitive issues, fatigue and tremor. In addition, 19 presentations focused on Chronic Cerebrospinal Vascular Insufficiency and MS. Many reported on the prevalence of CCSVI in people with MS compared to controls, with conflicting results. Others reported new findings related to imaging techniques and pathology findings.

ENDING

- Genes that make people susceptible to MS contribute only about 30% of the risk – the remainder may be contributed by factors in the environment. Results on possible risk factors – and protective factors – were featured, including new information about how our intestines influence immune activity, as well as levels of vitamin D in the bloodstream. New studies are getting under way to identify risk factors in children with MS and to test whether vitamin D supplements added to ongoing therapy can reduce MS severity.

Summary:

RESEARCH TOWARD STOPPING MS IN ITS TRACKS

-- Experimental Treatments in the Pipeline

Among studies reported were these first results from late-phase clinical trials. If these treatments are found to be safe and beneficial, some of them may come on the market in 2012 and 2013. The more that ongoing studies reveal about the modes of action as well as potential benefits and risks of these and other emerging therapies, the clearer it should become regarding how they might be used either alone or in combination, if and when they are approved for use.

- BG-12 (Biogen Idec) – Results from the DEFINE phase III trial of this oral therapy in relapsing MS, tested at two or three times a day against placebo over two years, achieved statistical significance on all primary and secondary outcomes measured, including reducing the proportion of patients who experienced relapse after two years (as low as 26% in treated groups versus 46% of those on placebo -- a reduction of up to 50%), reducing the risk of disease progression (by up to 38% over placebo), and reducing disease activity seen on MRI. The most common adverse events were flushing (in about 35% of those on BG-12) and bowel problems such as diarrhea and cramping (2 to 3% on BG-12) (Abstract 95).

CONTINUED...

Read full version on Sharepoint:

[http://intranet.nmss.org/Topics/cr/Pages/Global MS Research Efforts Shared at ECTRI MS ACTRIMS Meeting.doc](http://intranet.nmss.org/Topics/cr/Pages/Global_MS_Research_Efforts_Shared_at_ECTRI_MS_ACTRIMS_Meeting.doc)

Or the Website: <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=5695>



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

November 11, 2011

Phase II results published of clinical trial of ocrelizumab in relapsing MS

The experimental monoclonal antibody ocrelizumab (Genentech), given intravenously, significantly reduced disease activity as measured by MRI (magnetic resonance imaging) scans in a phase II study of 218 people with relapsing-remitting MS. One person on the higher dose died due to brain edema; the relation of this death to the study medication is unclear. Since this is a phase II study, additional research will be needed to further determine this therapy's safety and benefits. The results were originally announced in a press release in 2009 and have now been published in the Lancet (published online November 1, [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)61133-1/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61133-1/abstract)).

Background: Ocrelizumab binds to a molecule (CD20) on the surface of B cells and depletes them from the circulation. B cells are immune cells that make antibodies and may play a role in the immune attack on brain and spinal cord tissues in multiple sclerosis. The drug is a humanized version of rituximab, a mouse antibody to CD20 that has previously shown benefit in people with relapsing-remitting MS.

The Study: Participants were randomly assigned to receive intravenous low-dose ocrelizumab (600 mg), high-dose ocrelizumab (2000 mg), or inactive placebo, or intramuscular injections of Avonex[®] (interferon beta-1a, Biogen Idec). The main objective of this study was to determine whether ocrelizumab was effective in reducing MS disease activity (number of gadolinium-enhancing lesions) compared with placebo, as observed on MRI at 12, 16, 20, and 24 weeks. Other secondary objectives included assessing relapses. After 24 weeks, participants were switched to ocrelizumab and followed out to 48 weeks. (An uncontrolled extension of this study evaluated safety in participants for up to 96 weeks; results were not included in this published paper.)

Results: The results show that disease activity on MRI scans was 89% lower than placebo in the low-dose ocrelizumab group, and 96% lower in the high-dose group. Among secondary endpoints, the average number of relapses per year was reduced by 80% over placebo in the low-dose group and by 73% in the high-dose group. Comparisons to Avonex (which were done as tertiary, or third endpoints) showed benefit for the ocrelizumab groups.

One person in the high-dose group died due to brain edema (swelling), after the occurrence of systemic inflammatory response syndrome with multi-organ failure. The association of this event to the study medication is unclear. At first infusion, more people in the ocrelizumab groups (35%, 44%) had infusion-related adverse events than did those in the placebo group (9%). In phase-III rheumatoid arthritis trials of ocrelizumab, high rates of opportunistic infections were seen with ocrelizumab treatment, but none were noted in this study.

At a recent medical meeting (ECTRIMS), results of the 96-week open-label extension study from this trial were announced. The benefits and safety of ocrelizumab were maintained out to 96 weeks, according to a Genentech press release.

Comment: Since this is a phase II study, additional research will be needed to further determine this drug's safety and benefits. Two Phase III studies have begun in people with relapsing-remitting MS, and one involving people with primary-progressive MS.