



## CHAPTER PRESIDENTS

<b>July 1, 2011</b>	<b>CC:</b>
<b><u>Year End Report Part I &amp; Part II Available on SharePoint</u></b>	
<b>Action Requested/Deadline: August 15, 2011 &amp; October 14, 2011</b>	

Each year we have asked chapters to report on year end information for the purpose of organizational benchmarking and Certification monitoring. We are continuing to review the Year End Report – Parts I & II to look at ways to reduce the need for self-reporting and ensure that we are not asking chapters to duplicate information already provided in another manner. We have also identified the expected outcomes that can be derived from this information. We have made significant progress in these areas:

- Trustee and Employer Information form deleted – and will be captured in the Volunteer Module
- Excellence in Mission Delivery Report – deleted and will be re-evaluated next year
- Advocacy report has been streamlined – An advocacy report is generated to share within the organization and chapters.
- Volunteer Verification – We have included a checkbox for those chapters that have inputted their volunteer information into the Volunteer Module. Those chapters will not be required to provide this data in the Year End Report. The information will be directly pulled from the Volunteer Module. For those chapters that have not inputted the volunteer information into the Volunteer Module, they will be required to fill out the Year End Report. The strategic response on volunteerism necessitates the establishment of a baseline of volunteer information against which we can monitor progress in coming years.
- The Marketing Department continues to review the materials that chapters submit. This information provides an opportunity to share the best work across the organization and will inform the Marketing work teams as they facilitate cross-organizational planning and implementation of marketing and awareness plans.
- Certification Standards – Self-report standards have been scaled back. Only those standards that the Home Office is unable to receive by other means are included in the Year End Report. This information is used to determine

chapter compliance to standards. Please refer to the 2011 Certification Guidebook for more information about verification activities.

- Corporate Sponsorship – This information is used to identify potential sponsors and/or partners.

The Year End Report – Parts I & II is now available on SharePoint under Chapter Management, Announcements. Part I is due from chapters by August 15 and Part II is due by October 14, 2011.

When submitting your Year End Reports, please fill out the Year End Report Inventory Sheet located in the Year End Report – Part I. When the information has been ***received and processed***, you will get an acknowledgement confirming receipt. Please email your information to: [patricia.abruzzo@nmss.org](mailto:patricia.abruzzo@nmss.org).

If you have any questions, you may contact me either through email at [patricia.Abruzzo@nmss.org](mailto:patricia.Abruzzo@nmss.org) or call 303-698-6100 ext. 15131. Since I get so many e-mails during this time from chapters with their Year End Report submissions, please indicate in your e-mail title that you have a question. That will allow me to be more responsive to your question instead of gradually working my way through all the emails. Thanks for your help.

From: Pat Abruzzo, Project Manager  
Field Operations Department  
TRC – Denver



## CHAPTER PRESIDENTS

July 1, 2011	CC: All
<b><u>Update: The Society and Mobile Technology</u></b>	

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.

**We recently completed a thorough RFP process, including region review and approval, resulting in a new Society-wide partnership with industry-leading mobile technology provider, Mobile Commons ([www.mobilecommons.com](http://www.mobilecommons.com)).**

[Please review this two-page update](#) about what the Society has studied so far, including:

- Update on text-to-give and text messaging pilots
- Findings / lessons learned
- Thoughts on QR (quick response) codes
- Next steps and what we’ve yet to learn

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



## PROGRAMS & SERVICES

<b>July 1, 2011</b>	<b>CC: Chapter Presidents</b>
<b><u>Free From Falls Program-Pilot Funding Available; WebEx Dates</u></b>	
<b>Action Requested/Deadline: September 15, 2011 for pilot funding</b>	

The Society has developed new comprehensive fall prevention program for people with MS—“Free From Falls”. This 8-week curriculum is designed for people living with MS who are able to walk (alone or with one cane, walking stick or crutch) but who may be at risk of falling.

Each week’s 2-hour program will have two parts; a discussion component focused on awareness of issues related to falls and an exercise component directed to improving postural alignment, balance, endurance and mobility.

The participants in the course will:

- Increase awareness of the prevalence of falls among people with MS and the risk factors that may contribute to falls.
- Identify strategies that can be employed to prevent falls and develop a fall prevention action plan.
- Engage in and develop a home fitness plan that addresses balance, endurance, and strength, aimed at reducing fall risk.
- Increase their confidence in minimizing fall risk and in managing falls if they do occur.
- Identify additional community resources to implement a fall prevention action plan.

### **Funding Available for Pilot Programs**

We are fortunate to have received educational grants from several sources to develop the program. (Our thanks go to Acorda Therapeutics, Biogen Idec, Genentech, and Teva Neuroscience for their generous educational grants.) As a result of this support, funds are available to pilot the program in a number of locations across the country. The amount of

funding that can be provided for each program is \$4,000. These funds would be used to cover expenses such as publicity, professional fees for facilitators, printing, etc.

The requirements for being a pilot are as follows:

- The program must be implemented through a collaboration between the chapter and a clinical practice, facility or community organization (e.g. comprehensive and coordinated MS center; rehabilitation hospital, PT practice).
- The curriculum must be used as is, with no modifications.
- The pre and post assessments must be completed as described and the data submitted for analysis.
- Provide an accounting for expenses.
- Agree to follow up with participants several months after the program with a brief survey.

To submit a request to be considered a pilot program, please [complete the application](#) and submit to: Heather Webb Jones ([heather.webb.jones@nmss.org](mailto:heather.webb.jones@nmss.org)) by September 15.

Even if you are not selected as a pilot program, we hope you will consider offering this program in your area in 2012. The program did appear in the budget package but the cost was not included. We anticipate the costs to be about \$4,000-\$5,000 for the 8-week program.

### **WebEx Training Calls:**

We have scheduled Web-ex trainings this summer to further describe the program and discuss implementation logistics. Please register for one of these calls.

- Tuesday, July 26; 1-2:30pm ET, noon-1:30pm CT, 11am,-12:30pm, 10-11:30am PT  
<https://nmss.webex.com/nmss/j.php?ED=153002687&RG=1&UID=0&RT=MiM2>
- Thursday, August 11; 3-4:30pm ET, 2-3:30pm CT, 1-2:30pm MT, noon-1:30pm PT  
<https://nmss.webex.com/nmss/j.php?ED=153003032&RG=1&UID=0&RT=MiM2>

Additionally, the Society has produced a 25 minute video, also entitled “Free From Falls”. This video is an introduction to fall prevention and is an awareness-raising and educational tool. It is not part of the 8-week curriculum, but rather a resource that will be shared soon with chapters and self-help group leaders. We encourage you to share it with your local MS care centers and other clinical partners and it will also be posted on the Society’s web site.

Many thanks to Denise Nowack (Southern California Chapter) and our volunteer committee of rehabilitation experts from across the country for their significant role in developing this important program. We look forward to your participation.

Debra Frankel, MS, OTR, Associate VP-Programs, Services and Clinical Activities  
617-795-7002; [debra.frankel@nmss.org](mailto:debra.frankel@nmss.org)



**PROGRAMS AND SERVICES**

<b>July 1, 2011</b>	<b>CC: Chapter Presidents</b>
<b>ORDERING INFORMATION: NORTH AMERICAN EDUCATION PROGRAM</b>	
<b>Research – Progressive MS</b>	
<b>Action Requested/Deadline: August 1, 2011</b>	

This year’s North American Education Program (NAEP) focuses on the research efforts for progressive multiple sclerosis (program title to be determined). The program will highlight the different areas of research in progressive MS, challenges to researchers, and new and exciting ways that researchers are studying progressive MS. Thanks to robust funding we are able to once again offer this year’s NAEP to chapters and self-help groups at no cost.

You will be provided five DVDs and 100 program booklets to use in chapter programming. Additional program books and DVDs are available upon request, and depending on the size of the order there may be a nominal charge. Please contact John Aden (contact information below) with these requests.

Meeting kits will be mailed directly to self-help group leaders and will be coordinated through a mailing house. The meeting kit will include a cover letter, facilitator’s guide, one DVD, and 15 program booklets. Group leaders in need of additional program materials will be instructed to contact their chapter liaison with those requests.

Different this year is the way in which self-help group leaders’ names and addresses will be gathered for the mailing. Rather than submitting an order form as has been done previously, names and addresses will be pulled from data entered in the Altair Volunteer Module. In order to meet the shipping deadline, group leaders should be coded in the Volunteer Module by August 1, 2011. Prior to submitting the final mailing list to the mailing house, you will have the opportunity to review the list for accuracy.

When coding self-help group leaders in the Volunteer Module please use the following position title to identify the primary leader of the group:

Self-Help Group Leader Primary \_\_\_\_ 2011. You may further identify the group by filling in the blank. Please note – only one meeting kit will be provided per group, so only one group leader should be identified as the primary leader for any one group.

In those instances where there is more than one leader, best practice suggests these leaders be coded with the position title, Self Help Group Leader \_\_\_\_ 2011 with the blank filled in with your own identifier. For more information please go to Share Point>Volunteer Engagement>Altair Volunteer Module>Business Practices Document.

The program DVD and booklets will be shipped starting September 1<sup>st</sup>. Chapters and self-help groups should plan to host NAEP meetings no earlier than September 15<sup>th</sup>.

Funding for this project is made possible through support from Biogen Idec, Genentech, Genzyme, Novartis Pharmaceuticals and Teva Neuroscience. Thank you to the Pharmaceutical Relations Team and the Marketing and Development Department for their hard work and relentless pursuit in securing the funding for this very important and educational program, and to the Research and Clinical Teams for their contributions to the content review and approval process.

Please direct any program questions to John Aden at (303) 698-6100 x15143 or [john.aden@nmss.org](mailto:john.aden@nmss.org).



## PROGRAMS & SERVICES

<b>July 1, 2011</b>	<b>CC: Chapter Presidents</b>
<b><u>Online Peer Connections Program Launching Fall 2011</u></b>	

The Society is launching a new nationwide peer support program in the Fall 2011 (actual launch date TBD). The Online Peer Connections program adds an element to the variety of ways that people living with MS can connect with their peers through the National MS Society.

Participants seeking a peer can search through online profiles of trained peer support volunteers via a dedicated site in the house community. Profiles will be searchable by demographic information including age, mobility status, etc. Once the person identifies a volunteer of interest, he/she completes the program application and the matching process begins. Once the match is confirmed, communication between the person and the peer is managed by phone, by email or both.

The Online Peer Connections program is structured similarly to traditional chapter-based peer support programs. The conversations are confidential, one-on-one and are centered on a mutually agreed upon goal. The length of the relationship will depend on the goal of the participant. The difference is that the person looking for a peer can identify and select their peer on their own; staff persons are not involved in the match selection process. People are also not limited to connecting with peers in their geographic area, but will have access to volunteers from across the country.

Online Peer Connections volunteers are trained in peer support similarly to chapter peer support volunteers, with additional training specific to managing email relationships. Volunteers have National MS Society email addresses and are trained and supervised by a staff person on the Programs & Services team in Denver.

As part of the final stage of development prior to launch, the Online Peer Connections program team is actively recruiting volunteers. During this first phase of recruitment the team is looking to recruit from the Society's pool of existing trained peer support volunteers. These could be volunteers who are underutilized in their present peer support role or those looking for an additional opportunity. For more information please contact Monica Aden (contact information below).

Two informational calls are scheduled for staff interested in learning more about the program:

- Wednesday, July 20 at 12-1 pm ET (11 am CT, 10 am MT, 9 am PT)
- Wednesday, July 27 at 4-5 pm ET (3 pm CT, 2 pm MT, 1 pm PT)

Pre-registration is not required. The call-in number is 1-877-875-7564, passcode 977052#.

This project is made possible through the support of Novartis Pharmaceuticals. Special thanks to the Programs and Services staff and volunteers in the West Region and the National Capital Chapter for their assistance in developing the Online Peer Connections program.

If you have peer support volunteers interested in volunteering for this program, or if you have questions, please contact Monica Aden at 303-698-6100 ext. 15192 or [Monica.Aden@nmss.org](mailto:Monica.Aden@nmss.org).



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

July 1, 2011

### **Researchers Funded by Promise:2010 Find Possible Regulator of Myelin Repair**

Researchers report that a molecule – called “Axin2” – may be essential to regulating the repair of nerve fiber-insulating myelin, and may be a good target for future therapies aimed at regenerating myelin that has been damaged by the MS disease process. (Myelin is the substance that nourishes and insulates nerve fibers and is damaged in MS). Stephen Fancy, DVM, PhD, David Rowitch, MD, PhD (University of California, San Francisco) and colleagues report on a study co-funded by the National MS Society’s Promise:2010 initiative, the MS Society of the United Kingdom and Northern Ireland, and other funders, in *Nature Neuroscience* (published online June 26, 2011,

<http://www.nature.com/neuro/journal/vaop/ncurrent/full/nn.2855.html>). This study furthers the Society’s goal of restoring function that has been lost to people with MS, by identifying a possible target for nervous system repair strategies.

Background: The symptoms of MS are caused by faulty nerve signals that are the result of damage to myelin, the material that insulates and protects nerve fibers, and to the nerve fibers themselves. In the brain and spinal cord, myelin is made and maintained by cells known as oligodendrocytes, which are also damaged in MS. Oligodendrocytes develop from progenitor cells, or OPCs; for unknown reasons, these cells often fail to maintain their capacity for myelin repair in people with MS. One goal of MS research is to find ways to stimulate OPCs to make new oligodendrocytes that will repair the damaged myelin.

Previous work by team members has helped to unravel the complex interactions that occur in normal brain development and that may play a role in the repair of myelin that has been damaged by MS (Read more about these studies, here, <http://nationalmssociety.org/news/news-detail/index.aspx?nid=1780>, and here, <http://nationalmssociety.org/news/news-detail/index.aspx?nid=4319>.) In this study, the team

investigated the specific role of Axin2, a key control mechanism of the Wnt pathway, a pathway implicated in myelin repair in their previous work.

The Study: The researchers conducted a series of experiments in mice, as well as in tissue samples isolated via autopsy from human newborns with brain injuries, and from adults with MS. They compared activity levels of the gene Axin2, and found that the gene was active in oligodendrocytes in newborns with brain injury, but not in normal newborn brain tissue. They also found that the Axin2 gene was active in oligodendrocytes in areas of inflammation in people with MS, but not in tissue that appeared normal.

Mice genetically engineered lacking the Axin2 gene showed a delay in both developmental myelin formation and myelin repair after injury as adults, and Axin2 seemed to be important in controlling the timing of oligodendrocyte maturation during these processes. The group also found evidence that a chemical called XAV939 could increase the levels of Axin2 in oligodendrocytes, by preventing it from degrading, and this led to an acceleration of myelin repair in mice.

Comment: These findings, co-funded through the National MS Society's Promise:2010 Nervous System Repair and Protection Initiative, point out a potential target for the development of a therapy that may reverse MS myelin damage and restore function. As noted by the authors, further research is needed to confirm the findings and to determine the safety and effectiveness of agents such as XAV939 in stabilizing Axin2 and promoting myelin repair.

Read more about the Promise:2010 Nervous System Repair and Protection Initiative (<http://www.nationalmssociety.org/research/research-we-fund/targeted-research/nervous-system-repair/index.aspx>) that co-funded this study.



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

July 1, 2011

### **Study Suggests Most Women with MS Have Normal Pregnancies, Deliveries and Birth Outcomes**

Adverse pregnancy or birth outcomes did not differ among more than 400 women with MS, when compared with more than 2,000 women without the disease, according to a new study of women in British Columbia, Canada. Mia L. van der Kop, MSc, Helen Tremlett, PhD and colleagues (University of British Columbia, Vancouver) report their findings in [Annals of Neurology](http://onlinelibrary.wiley.com/doi/10.1002/ana.22483/abstract) (published online: June 27, 2011, <http://onlinelibrary.wiley.com/doi/10.1002/ana.22483/abstract>).

**Background:** MS often occurs in women of childbearing age. When young women receive a diagnosis of MS, they frequently have questions about the effects of the disease on childbearing—and vice versa. Studies undertaken over the past several decades allow health professionals to provide answers to many of these questions. Read more about pregnancy and reproduction issues in MS: <http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/pregnancy/index.aspx>

There is no evidence that MS impairs fertility or leads to an increased number of spontaneous abortions, stillbirths or congenital malformations. Several studies of large numbers of women have repeatedly demonstrated that pregnancy, labor, delivery and the incidence of fetal complications are no different in women who have MS than in control groups without the disease.

**The Study:** With funding from the Canadian Institute of Health Research, investigators gathered data from the British Columbia MS Clinics' database and the British Columbia Perinatal Database Registry, which captures nearly all births in the province. They analyzed 432 births to women with MS and 2975 births to women without MS from 1998 to 2009, looking at gestational age, birth weight, assisted vaginal delivery, and Caesarean section. Thanks to

having access to both databases, this unique study was able to explore clinical factors in the women with MS, examining age at MS onset, disease duration, disability levels and other factors.

The results show that overall, women with MS did not differ in pregnancy outcomes from women who did not have MS. The mean birth weight and gestational age of babies did not differ, and women with MS were not at a greater risk of adverse deliveries, including Caesarean section and assisted vaginal delivery.

There was a slightly elevated risk of adverse delivery outcomes among women with MS and greater levels of disability, but this difference was not statistically significant. The authors comment that further study is needed to determine whether women with greater disability require closer monitoring during pregnancy.

This study differed from similar efforts, in that the investigators were able to control for “confounding factors” that might affect pregnancy and birth outcomes, such as gestational hypertension, diabetes, obstetrical history, and body mass index. In fact, the results show that mothers who had MS were more often overweight or obese. Because a high body mass index is associated with adverse pregnancy and birth outcomes in general, the authors suggest that women with MS should be counseled to optimize their weight when planning a pregnancy.

Read more (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/pregnancy/index.aspx>) about pregnancy and MS.