



CHAPTER PRESIDENTS

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| July 30, 2010 | | CC: |
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| Year End Report Part I & Part II Available on SharePoint | | |
| Action Requested/Deadline: August 16 & October 15, 2010 | | |

Each year we consolidate the Home Office's requests for information from chapters by providing the Year End Report as a reporting tool for chapters to respond. The Year End Report – Parts I & II is now available on SharePoint under Chapter Management, Announcements. Part I is due from chapters by August 16, Part II is due by October 15, 2010.

The Certification section of the Year End Report in Part II has been reformatted this year using a Certification Verification Checklist. There are several items that chapters do not need to self report and those are indicated in the column that indicates “No Response Required”. Compliance for these items will be determined by the Home Office. The Certification Verification Checklist provides Chapter Presidents with an opportunity to self-report on which certification standards they achieved. Please see the 2010 Certification Guidebook for more information about verification activities.

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.

In light of the email challenges we have been having and the wealth of information that each chapter sends me, I am requesting that those chapters that have access to the Home office infrastructure to please place your information on the pdrive, publicuse, field operations, 2010 Year End Report. The link to the pdrive is: <\\nyfs\NYC Public>
When naming your documents, please include your chapter's name (i.e. Colorado - Year End Report, Colorado - advocacy information, etc.) For those chapters that do not have access to the pdrive, please email your information to: patricia.abruzzo@nmss.org.

If you have any questions, you may contact me either through email at Patricia.Abruzzo@nmss.org or call 303-698-6100 ext. 15131. Since I get so many emails during this time from chapters with the Year End Report submissions, please indicate in your email 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
ODIM Department
TRC – Denver



MARKETING

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| July 27, 2010 | CC: Chapter Presidents |
| | Information & Resources |
| <u>MSConnection and Certification Guidelines</u> | |

Print vs. Web issues

In a recent study conducted at City University, London, researchers reported that Europe’s first newspaper to make a complete transformation from in-print to online-only publication had a lower rise in online traffic than papers that continued to publish both print and electronic versions.

Articles on the trend in the **Wall Street Journal**, **PoynterOnline** and elsewhere tell a similar story: Readers report being “happy with both [Web and print], though in different ways,” and that reaching out via both media tends to result in greater engagement.

From our own data

We have seen this trend in action at the Society. In a 2010 survey of **Momentum** readers and National MS Society Web site visitors, readers who reported the greatest engagement with the magazine were also more likely to visit our Web site frequently—and vice versa. And many who receive the magazine do not frequent our Web site. Moreover, some have no access to the Internet.

This summer we asked chapters to tell us about their **MSConnection** publishing practices and how those practices have impacted budgets and constituent engagement. Following are some highlights of what was shared:

- Most chapters have cut back on the frequency of issues published on paper and mailed out—about a third went from 4 to 2 issues per year.
- More than half of the chapters said that, other than cost savings, no positive results had been seen by going from print to online. Positive results cited were less staff time needed to prepare an online-only issue and a renewed focus on Web content by readers.

- Nearly half of the chapters reported negative consequences, including low open rates of e-mailed newsletters, a stated preference for hard copy by some readers, and a lack of client e-mail addresses. (The Society does not have e-mail addresses for approximately 275,000 of the nearly 400,000 people with MS who are in Altair.)

New recommendations and requirements

Based on these responses and on what we're seeing as a larger trend, the National MS Society will be changing our newsletter publishing requirements regarding chapter certification guidelines to maximize client engagement with our publications, the Society and the MS movement.

Beginning in FY11, all chapters will be required to publish 4 issues of **MSConnection** per year. It is recommended that all 4 issues are published in print, but only 2 print issues per year will be a requirement for certification.

Beginning in FY12, all chapters will be required to print 4 paper copy issues of **MS Connection** each year. Making the newsletter available online **as well** is strongly recommended. Readers can be encouraged to opt in for an e-mailed version.

Many of you may remember that this was the requirement prior to FY09, after which the requirements were loosened due to budget challenges and to see what the uptake online might be.

The publications team will continue to provide ongoing content for chapters through the free **MSConnection** story bank on **SAMS**, which is updated each quarter.

Graham McReynolds
Executive Vice President of Marketing and Development

Craig Weber
Vice President, Chapter Operations

Nancy Law
Executive Vice President, Programs & Services



PROGRAMS & SERVICES

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| July 30, 2010 | CC: Chapter Presidents |
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| <u>What's New In MS Research And Treatment DVD Available</u> | |

Due to continued interest in the June 2010 webcast program, *What's New in MS Research and Treatment*, the Programs and Services team is mailing chapters one DVD of the program. Based on feedback from chapters, we know self-help groups are interested in watching the broadcast together and the DVD format will make this easier for a group program.

You are welcome to make as many copies as you would like to distribute to self-help groups, interested individuals, or for other program needs. Interested individuals who do not have easy access to the archived web program can request a DVD by contacting the IRC.

Thank you to the Marketing Team for making this possible.

Additional questions can be directed to Heather Webb Jones at heather.webb@nmss.org or 303-698-6100, ext. 15176.



PROGRAMS & SERVICES

July 30, 2010

CC: Marketing

Online Communities of Support

The National MS Society has collaborative partnerships with two organizations whose sole missions are to reduce the feelings of isolation families living with MS may experience during times of medical crisis.

Lotsa Helping Hands (www.lotsahelpinghands.com) is a free web-based service that allows family, friends, neighbors, and colleagues – the community circle of a person with MS – to more easily assist with household tasks that can become a burden during times of medical crisis. It's an easy-to-use, private group calendar, specifically designed for organizing helpers, where everyone can pitch in with meals delivery, rides, and other tasks necessary for life to run smoothly during times of medical crisis, or family caregiver exhaustion. It is also a place to keep these 'circles of community' informed with status updates, photo galleries, message boards, and more.

CaringBridge (www.caringbridge.org/nationalmssociety) is a free one-stop shop that connects and updates communities of support on a person's ongoing health status, treatment, surgeries, progress in therapies and recovery. A personalized CaringBridge website helps keep others informed during difficult times. In return, family and friends give support through guestbook messages.

Every personalized CaringBridge website includes:

- Patient care journal
- Guestbook for messages
- Photo gallery
- Free online support for using the service

Both of these services are effective and efficient means of maintaining communication during stressful times. You are encouraged to share these resources with your constituents. You may wish to link from your chapter's website to the Society's website Communities of Support webpage (Living with MS>Relationships>Carepartners>Communities of Support). Additional means of promoting these resources include articles in MS Connection or as part of your chapter's e-communication strategy. Sample promotional materials are available upon request.

For more information on these partnerships or to request sample promotional materials, please contact Kim Koch (kimberly.koch@nmss.org or 303-698-6100, ext. 15158) or Shawna Golden (shawna.golden@nmss.org or 303-698-6100, ext. 15168).



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

July 30, 2010

FDA Gives Priority Review Status to Application for Oral Cladribine to Treat Relapsing Multiple Sclerosis

EMD Serono has announced that the U.S. Food and Drug Administration has accepted and given Priority Review to its application seeking approval to market cladribine as an oral disease-modifying therapy for relapsing forms of MS. A Priority Review means that the FDA will review the drug in less than the usual amount of time. This designation is given to drugs that offer major advances in treatment, or provide a treatment where no adequate therapy exists. The goal for completing a Priority Review is six months from when the application is submitted, meaning that the agency's approval decision could happen in December 2010, but it might take longer.

In a large-scale phase 3 clinical trial, cladribine tablets significantly reduced relapse rates and other disease activity in people with relapsing-remitting MS. Read more about this study (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2569>).

In November 2009, EMD Serono announced that it had received a "refuse to file" letter from the FDA for its original cladribine application submitted in late September, which usually means that the agency deems the application incomplete. On June 8, 2010, EMD Serono announced that it resubmitted its application to the FDA for approval of cladribine.

Another oral therapy for MS, fingolimod (Novartis International AG), is currently undergoing final review by the FDA after an FDA advisory committee recommended (<http://www.nationalmssociety.org/research/research-news/news-detail/index.aspx?nid=3338>) that it be approved. The agency's approval decision for fingolimod is expected in September 2010.