



## CHAPTER PRESIDENTS

December 4, 2009

CC:

CEO Update on our Strategic Response to MS August, 2009 – November, 2009

### CEO Update on our Strategic Response to MS August – November 2009

*We are a driving force of MS research, relentlessly pursuing prevention, treatment, and cure.*

1. On October 14th, an FDA advisory committee reviewed clinical trial data and recommended the approval of Acorda Therapeutics' symptomatic therapy Fampridine SR (with a proposed name of Amaya). Society staff and volunteers provided oral testimonies about the unmet need for therapies to improve walking ability during the committee meeting. The FDA is expected to make an approval decision on or before January 22, 2010.
2. EMD Serono applied to the FDA seeking approval to market oral cladribine for relapsing forms of MS. In a large-scale clinical trial, cladribine tablets significantly reduced relapse rates and other disease activity in people with relapsing-remitting MS. If the FDA application is successful, it would be the first approved oral disease-modifying therapy for MS.
3. Novartis International AG announced that oral FTY720(fingolimod) significantly reduced relapse rates and slowed disability progression over two years in a large-scale, phase 3 trial in relapsing-remitting MS. According to the company, safety data confirmed a positive benefit-risk profile, and the company plans to seek marketing approval at the end of calendar year 2009.
4. Fast Forward entered into an agreement with Amplimmune, Inc to support the company's lead MS program, AMP-110. Fast Forward will provide up to \$500,000 to support the company's preclinical studies. Fast Forward will receive warrants for purchase of equity in the company at a later date.
5. Fast Forward entered into a collaborative partnership with the Accelerated Cure Project (ACP) for MS. Fast Forward will provide strategic planning support to ACP to ensure that its tissue repository addresses needs of biotechnology and pharmaceutical companies.

6. Fast Forward received 47 proposals in response to a 'Request for Proposals' issued under the terms EMD Serono Collaboration Agreement. 23 of these were selected for a full review which will conclude in December 2009.
7. Plans are underway for the 2010 Tykeson Fellows Conference, to be held in conjunction with the Consortium of MS Centers (CMSC) and the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) in San Antonio June 2-5, 2010.
8. Fast Forward held a one-day think tank in partnership with the David H. Murdock Research Institute. Nearly 50 participants from academia, industry, and venture capital met to discuss genetics, biomarkers, and the future of personalized medicine in MS.
9. Fast Forward presented at the ACI Financing for Life Sciences conference, the BIO Investor Conference, the Life Sciences Business Development Roundtable, the BioPharm 2009 Conference, and the MassBio Annual Meeting.
10. A process to develop messaging and materials for the Society's research program is well underway. This process will assure that we talk about the Society's research initiatives in relevant and consistent ways regardless of the audience and communication channels.
11. Dr. O'Looney is serving on the Integration Review Panel for the Department of Defense's MS Research Program where \$5m will be awarded.
12. Three new clinical trial bulletins were released to assist in recruiting patients for trials of new or existing MS treatments, and the trials were added to our Website database designed for those seeking to participate in trials.

***We address the challenges of each person whose life is affected by MS.***

1. A common approach to providing financial assistance, including overarching operating principles, application and cover letter, minimum covered items and services, and marketing messages was developed effective October 1.
2. The North American Education Program: Clinical Trials – Solving One Piece of the MS Puzzle was delivered to chapters of the National MS Society and the MS Society of Canada, as well as over 1,200 self-help groups in the United States.
3. MS Learn Online featured webcasts on primary-progressive MS. The series included interviews with Drs. John Richert and Rosalind Kalb, as well as Shelley Peterman Schwarz who shared her Everyday Tips When Living with Primary-Progressive MS. The series was sponsored by Genentech.
4. MS Learn Online will begin to transition its webcasts to YouTube and other social networking websites in order to tap into a potential larger viewership. Short clips placed as a pilot have had more than 10 thousand views.
5. The newly re-designed MS Next Step®: Information for Newly Diagnosed is now available for distribution. The package includes an informative booklet and DVD featuring Meredith Vieira, with Spanish translations.
6. The Society entered into a partnership with Hire Disability Solutions to help people with MS nationwide who want to work find employment possibilities, including part time and

work at home options. Leadership in the New Jersey Metro Chapter facilitated this partnership.

7. The Society's 2010 scholarship program opens October 1, 2009 and ends on January 15, 2010 ([www.nationalmssociety.org/scholarship](http://www.nationalmssociety.org/scholarship).)
8. The Society developed two new educational pieces about children and teens with MS: Pediatric MS: Understanding for Today, Hope for Tomorrow, a DVD that provides a general overview of pediatric MS and Student with MS & the Academic Setting: A Guide for School Personnel, a handbook for school staff.
9. The Society's federally funded program, Relationship Matters: A Program for Couples Living with MS, has been re-approved for \$489,481. The program recently completed a successful third year, exceeding the stated goal of serving 480 couples in fiscal year 2009, by 108 couples (total served 588).
10. The Stepping Stones fund provided \$122,949.49 and leveraged another \$108,900.54 in community resources to provide direct assistance to people living with MS for the FY '09.
11. The IRC now processes registrations for all client programs, both offline and online, through the Convio system. Constituents who prefer to access information online are able to view and register local programs at their convenience. This process also simplifies the Chapter statistical reporting.
12. Unprecedented pharmaceutical grant funding of \$318,000 for the 2009 North American Education Program facilitated materials distribution to all chapters at a significantly reduced cost – less than half the cost of prior years.
13. 35-40 nurses from 19 nursing homes that provide specialized programming or wings for residents with MS attended an intensive course on MS clinical care at the Boston Home. This meeting was supported by the John Dystel Nursing Fund.
14. In a collaborative effort with the Heuga program, we now offer information and video clips describing the role of each member of the MS Treatment Team, as well as the role of each team member in the care of people with primary-progressive MS. We are utilizing YouTube to bring this video content to an audience that extends far beyond our own Web site.
15. The Society has maintained up-to-date information about the H1N1 flu and its vaccine on our website for professionals and clients.
16. The Society's national Facebook page has nearly doubled since the last report to 17,000 members. A majority of those members live with MS and connect through this channel to share information and provide support.
17. Real Talk Real Answers successfully taped 2009 programming for people with MS in their 20's and 30's – resulting webcasts will be available at [realtalkrealanswers.com](http://realtalkrealanswers.com) in November.
18. The Society met with leadership from The Heuga Center for Multiple Sclerosis, and is reviewing the resulting written agreement to finalize a formal partnership.
19. On September 30, 2009 the following two chapter mergers were completed:
  - The Vermont office of the All America Chapter will be merged with the Central New England Chapter.

- The Southern New York Chapter will be merged with the New York City Chapter.
20. On November 1, 2009 the following mergers will take place:
    - Louisiana will be merged with the Lonestar Chapter.
    - The Mississippi office of the All America Chapter will be merged with the Alabama Chapter.
  21. On January 1st, 2010 the West Virginia office of the All America Chapter will merge with the Blue Ridge Chapter.
  22. The National website was updated to support video content providing for many more options for sharing information with our constituents.
  23. The software integration between two major Society computing systems, Convio and Altair, was enhanced to provide the most timely constituent and event information to our Chapters.

***We mobilize the talents and resources of the millions of people who want to do something about MS.***

1. A three day virtual summit was held for all Society staff with three high profile volunteer keynote speakers and over a dozen breakout sessions covering Engaging the MS Community, Social Networking and Volunteer Engagement.
2. Eight Chapters (Southern California, Georgia, New York City, Michigan, Minnesota, Eastern North Carolina, Gateway Area and Central Pennsylvania) begin testing the volunteer engagement database which will launch January, 2010.
3. Chapter walk committee chairs who have exhibited exceptional leadership were recruited to serve as trainers for other walk committee chairs throughout the Society
4. More than half of chapters are planning to adopt one of the volunteer engagement pilot projects (17 Chapters are adopting MS Service Day) and the other chapters are designing or expanding a program of their own.
5. Region B met to discuss organizational change; chapter visits by the REVP to staff and board of trustees members in the region and conference calls with chapter presidents in the region continued.
6. Region B goals have been developed in the areas of: increasing participation in client programs through new delivery methods and shared expertise across the region; increasing net income through the development of new revenue streams; reducing expenses through shared purchasing; and improving accuracy and timeliness of database information and consistency of entry processes as a foundation for improving shared services.
7. The Region B Regional Volunteer Leadership Committee is being formed. The primary role of this committee will be to ensure that chapter and region goals are aligned with Society strategy. A full update of Region B activities and goals has been posted to the [www.msmovingforwardtogether.org](http://www.msmovingforwardtogether.org) website and a region formation update will take place at the Delegate Assembly.

8. Region E was launched officially with the hiring of Mark Neagli as the Regional Executive Vice President.
9. Regional Executive Vice Presidents have been identified for Regions A and D. They will start their positions and launch those regions January 1. Region A's REVP will be Mike Elkow, current chapter president of the New Jersey Metro Chapter, and Region D's REVP will be Maureen Reeder, current chapter president of the Minnesota Chapter.
10. Ongoing trainings and engagement opportunities were made available to Society self-help group leaders. Forty-one volunteers completed the training for new leaders, and an additional 220 leaders attended a tele-training.
11. Cristina Espinosa, M.A., bilingual IRC Specialist, represented the Society at the Fourth Annual National Mexican MS Conference from 10/2-10/4/09 in Puebla Mexico, serving as the opening keynote speaker for the conference.
12. The Society formed a Steering Committee of nearly 30 staff and volunteers to provide leadership in developing our 2011-2015 strategic response. Over 9,000 individuals responded through on-line and in-person surveys. The results have been placed into a white paper for review and deliberation by the Strategic Response Steering Committee.
13. As a follow up to the Charting our Future recommendations, a Blue Ribbon Panel of 32 Society volunteer and staff leaders has been meeting since January to address the Society's reserves policy and the remittance and sharing formula. It issued its report to member of the Delegate Assembly who will be asked to provide feedback for the National Board.
14. The new Volunteer Management computer system provides the Society with improved processes for identifying, tracking and matching volunteers, conducting background checks and reporting on volunteer activities.
15. The Fast Forward Campaign Cabinet will hold its kickoff meeting in Chicago conjunction with the National Leadership Meeting. The campaign cabinet, chaired by c-chaired by Christian and Liliane Haub and Weyman Johnson, is composed of leadership volunteers who will provide strategic direction and assistance for the planning and execution of the fundraising campaign for Fast Forward.

***We are activists.***

1. The Society was featured in a special supplement to the Wall Street Journal's east coast run (780,000 people). Funding was provided by the Society's pharmaceutical partners.
2. Engagement of the Obama administration has moved forward with meetings to discuss a proposed summit focused on caregiving for adults living with chronic disease.
3. A significant response to a nationwide email requesting action related to health care reform in August has demonstrated the power of this communications channel.
4. 64,000+ MS Activists have opted to receive email alerts about advocacy issues through Convio. Through outreach at Walk MS, Bike MS, and other events, chapters have significantly increased their activist numbers.

5. MS activists participated in advocacy days, rallies, or coalition events at 32 state capitols in 2009.
6. People with MS and their care-givers in Connecticut and Texas will receive enhanced services in the community due to MS activism led by the Connecticut Chapter and Lone Star Chapter. The Connecticut Home Care Program for the Disabled serves 41 people, and saved the state \$2,089,524 in Medicaid expense last year, while the state of Texas has set aside \$1 million for respite services for family care-givers in a pilot program.
7. Chapters engaged in 47 state and local policy issues to create broader access to quality health care for those that live with MS. Priorities ranged from successfully eliminating insurance caps on maintenance physical therapy for people with MS (Greater Illinois Chapter) to preservation of the Catastrophic Insurance Fund and coverage for MS (Central New England Chapter).
8. The Society worked closely with prominent legislators in both chambers of Congress to get legislation introduced that would lower the out of pocket costs for individuals impacted by prescription drug tiering schemes. The legislation is named the Affordable Access to Prescription Medications Act.
9. The Society hosted a town hall reception recognizing Rep. John Murtha for his support in establishing the new research funding program within the CDMRP. The reception was done in cooperation with several veterans' organizations and lead by the Western PA Chapter.
10. The Society hosted a Congressional briefing inside the US Capitol to provide Members and staff an overview of MS. The briefing attracted bi-partisan attendance including 3 Members who spoke on behalf of people living with MS and the Society's work.
11. The Society helped develop language and identified a Member of Congress to introduce legislation that will allow people with Medicare Part D to appeal for coverage of drugs prescribed "off label" (such as Provigil) by referring to major drug compendia, authoritative medical literature and/or accepted standards of medical practice.
12. The Society's Federal Activism Council evaluated the Society advocacy goals mid-session and discussed opportunities to influence current health care legislation.
13. The Society hosted a health care reform conference call that was open to Society volunteers and leadership. The speakers on the call included the Society's CEO, the NBOD chairman, Society volunteers, a neurologist and Congressional staff who work with the Senate Finance Committee.
14. The Society has worked closely with policy staff from the American Academy of Neurology to influence health care reform legislation to recognize neurologists as eligible for 5-10 percent bonuses for providing primary care services.

***We will raise a total of \$1.25 billion by the end of 2010 to be used in the fight against multiple sclerosis.***

1. Conference calls were held with chapter audit committee chairs. 43 volunteers from 37 chapters participated.

2. Conference calls were held with chapter auditors and finance directors with 35 auditors and finance staff from 32 chapters.
3. Fast Forward received a \$200,000 gift from a donor in the South Florida Chapter
4. Commitment to sponsor the 2010 Tykesons' Fellows Conference has been secured from Teva Neuroscience and Genzyme Corporation.
5. Pharmaceutical revenues for calendar year 2009 are on track to deliver nearly \$7.3 million – representing a \$3 million increase over 2008.
6. The Golden Circle campaign, a new program designed to build relationships and increase individual giving among donors making outright gifts in excess of \$1,000 annually, was launched in October with 31 chapters participating in a year-long pilot.
7. The Society will host top team captains and top fundraisers from across the country at the November Leadership Meeting in Chicago. Attendees will be recognized for their efforts, and enjoy hearing from Phil Keoghan, host of the Emmy award winning show The Amazing Race, and country music star Clay Walker.
8. The Society received \$621,807 in bequest income, representing 29 bequests in 21 chapters between August and October.
9. 2009 special event revenue is projected to be \$155 million – down 10% overall from 2008's total. Bike MS experienced the smallest decrease over FY08 – about 5%; Walk MS was down nearly 15%; Dinners, Leadership Events and other Special Events were down 20% - attributed primarily to cutbacks in corporate support and ticketed event sales decline.
10. An in-depth phase II external analysis of Bike MS was completed and provided vital insight and direction in the development and delivery of 2010 core event marketing materials. The analysis included interview finding with Bike MS riders, staff members, and a survey to 3,000 Bicycling Magazine subscribers.
11. The Society is piloting the MS Mud Run in several markets in 2010 to evaluate new trends and opportunities in special events. This boot camp-style obstacle course event was introduced by the North Florida Chapter last year.
12. Momentum Magazine continues to demonstrate effectiveness as an ancillary fundraising vehicle – garnering \$90,000 through the centerfold donation envelope during 09.
13. Information Technology is in the process of rolling out Boundless Fundraising for our 2010 events. The Boundless Fundraising application allows users of Facebook to raise money directly through their wide network of friends while integrating results seamlessly into Convio.
14. We deployed a Voice over IP (VoIP) solution to the Northern California chapter. This telephone over the Society's infrastructure solution reduces the operations budget of the chapter.
15. Thirty-four donors attended the Fast Forward think tank on October 12th in Kannapolis, NC. In addition to observing the proceedings that focused on MS genetics, they toured the lab at the David Murdock Research Center and interacted with scientists, Society leadership and other chapter donors.



## CHAPTER PRESIDENTS

12/04/2009

CC: Development

**National Research Call on a Rehabilitation Fellowship & the Research it Will Advance Featuring Dr. Fay Horak to be Held December 14<sup>th</sup>**

A special research conference call on **Pediatric MS** will be held **December, 14 at 10:00 AM Eastern**. The 60 minute will be moderated by Deborah Hertz, Associate Vice President of Medical Programs at the Society and will feature Dr. Ann Yeh of the Pediatric MS Center of Excellence at SUNY Buffalo, and Kathy and Mike Flaherty whose young daughter Claire is a patient of Dr. Yeh.

This unique call offers an opportunity to hear first-hand updates on the progress already being made by the Centers in speeding MS diagnosis in children, educating the medical and educational communities about pediatric MS and its impacts, and developing methods for conducting critical research – to benefit all people with MS – based on the Centers’ work. You will hear the perspective of Dr. Yeh who treats many children with pediatric MS and also conducts research, and you will also hear about the experience of the Flaherty family in finding correct diagnosis for their daughter and managing her care through the Pediatric MS Center of Excellence.

**Dr. Ann Yeh is Co-Director of the Pediatric MS and Demyelinating Disorders Center of Excellence at SUNY Buffalo**, where she also co-directs the Child Neurology residency training program. She is a pediatric neurologist specializing in Pediatric Multiple Sclerosis. Her clinical research interests focus on therapies and outcomes in pediatric demyelinating disorders. She received her Pediatric training at McMaster University and her Child Neurology training at SUNY Buffalo. She received her undergraduate degree from Harvard University, master’s degree from McGill University, and MD from McMaster University.

**The Flaherty family** has been navigating the complexities of pediatric MS since their young daughter first became ill in July of 2006. They became patients of Dr. Yeh in April of 2007. I hope you can join us for this unique opportunity to hear directly from some of the world’s leading MS researchers seeking to better treat the youngest MS patients and to unravel the mysteries of MS.

National research calls are a great way for donors, donor prospects – including Golden Circle prospects – staff and volunteer leaders to remain abreast of the many avenues by which the

Society is advancing discovery into the cause and cure of MS and to hear directly from some of the world's leading MS researchers about the most progressive science.

Participation in national research calls is growing, as staff has embraced spreading research knowledge to various Society supporters who are critical to increasing awareness and funding of MS research. **We hope you will identify and invite participants in each of the following groups:** major donors or prospects, major gift officers, chapter presidents, additional Society staff members, board members, significant event check writers, top event fundraisers, research advocates and Golden Circle members or prospects. The number of donors/prospects/volunteers that you invite should be consistent with your ability to make personal contact with participants after the call as suggested below.

**\*\*ADVANCE REGISTRATION IS NO LONGER REQUIRED: Dial-in directly at 877.860.4996, Conference ID 42689424. Please share these numbers with donors, staff and volunteers who intend to participate.** If there are multiple participants dialing-in from your chapter offices, please help us manage the costs associated with the calls by calling in from one phone line.

### **How You Can Cultivate Supporters through National Research Calls:**

Identify constituents in the groups outlined above, especially those who have expressed an interest in MS research. Anyone who can get to a phone, whether in an office, home, city or rural area is able to participate. Also consider inviting prospects to join you and others for the call at the chapter office to provide greater participation and cultivation opportunities.

We suggest extending invitations via a conversation over the phone or in person, or via email. **The dial-in information may be provided directly to the participant, as registration for the call is no longer necessary.** If you would like a template email or letter invitation, please contact Carrie Radant.

After the call, maximize this cultivation opportunity by speaking with participants about their call experience and exploring their interest in supporting research. The call will be recorded and one CD will be available to each chapter for duplication. Chapters may give the CDs to call participants, donors/prospects unable to participate and future prospects/donors and/or staff. Calls are also now available under the Research section of the national website at <http://www.nationalmssociety.org/research/research-news/ConversationswithMSResearchers/index.aspx>. The CDs and weblink will be available approximately two weeks after the call; CDs must be requested.

For additional information, an invitation template, or to request a CD recording of the call, please contact me at the number or email listed below:

### **Carrie Radant**

National Director, Donor Development  
303.698.6100 x 15165, [carrie.radant@nmss.org](mailto:carrie.radant@nmss.org)



## CHAPTER PRESIDENTS

December 4, 2009

CC:

### Operational Audit Findings

Fifteen chapters had Operational Audit site-visits in FY2009. Eleven were scheduled due to Chapter President and/or Finance Directors changes; 6 of 11 occurred in less than the normal three-year cycle due to staff changes. One was conducted due to a merger of two chapters. While the goal is to visit all chapters at least once over a three-year period, leadership transitions and emergency situations are accommodated. Thus, due to budget limitations some chapters have not been visited for 4-5 years.

The key objectives of the Operational Audits include:

- Managing risk
- Compliance with Society policies and GAAP presentations
- Communicate and share operating practices that are succeeding
- Recommend improvements, where applicable

Typically the Operational Audit covers the following areas:

- Financial Management including Financial Statement review, Budgeting, Forecasting & Cash Management and Internal Control Procedures
- Board Governance
- Human Resources
- Risk Management
- Delivering the Mission

### 2009 Results:

Frequent findings, found in two or more chapters, and critical findings, in just one chapter are posted on Share Point under Chapter Management.

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Chapter Operations Vice President  
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## DEVELOPMENT

December 4, 2009	CC: Chapter Presidents
	Information Technology (IT)
<b>Additional Training Sessions for Updating Google Maps (.ORG Training)</b>	

Exciting development plans are underway that will bring improvements to the BikeMS.org, WalkMS.org and ChallengeWalk.org websites which feature Google mapping functionality. Read more about these changes and original communication by clicking [here](#) link to the October 23<sup>rd</sup> News Sheet.

This change 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**. Training information is below:

**These are the last 'live' training sessions.** Both sessions are presented via WebEx. Click on one of the meeting links below and select '**Add to Calendar**' to register for the session. You must register at least 1 hour before the session to ensure you receive the class materials.

### Wednesday, December 9<sup>th</sup>

1:30 – 2:30pm ET <https://nmss.webex.com/nmss/j.php?ED=130170652&UID=0>

3:00 – 4:00pm ET <https://nmss.webex.com/nmss/j.php?ED=130170967&UID=0>

**If you have any questions about training, please contact Duanyelle West via email.**



## MARKETING & DEVELOPMENT

December 4, 2009	CC: ALL
Convio Email Campaign Training – Update	

### Background

Over the last few months a number of important Convio email changes have been made to improve the experience of our email recipients, as well as the efficiency of Society email administrators. Some of these include an improved Email Campaign training program, a new Convio software release (Shasta), improved opt-in opt-out language on our Convio forms, and enhancements to our Society-wide email interest categories. (For more information on these changes, please refer to the respective news sheets.)

### Enhanced Convio Email Campaign Training

Every Convio Email Administrator is required to take the revised “Convio: Email Campaigns” and pass a certification test. The revised class was introduced in July 2009. Regardless of other internal or Convio-led classes taken, every Convio Email Administrator must take this revamped course and become certified by 12/17.

- Register via the LMS ([www.nmsslearning.org](http://www.nmsslearning.org))
- Live classe available: 12/10
- **Deadline to complete and pass certification: 12/17**

**Update:** The “Convio: Email Campaigns” class – including certification instructions – is now recorded and available on the LMS ([www.nmsslearning.org](http://www.nmsslearning.org)).

**Important:** If a user’s training and certification is not completed by 12/17, her or his Convio Email Campaign security access will be put on hold. An email reminder will be sent to all users who have not met the requirements.

### Continued Improvements to our Email Campaigns Documentation

In addition to the excellent online resources offered by Convio, the IT Training Team will continually update the Society-specific Email Campaigns Training Guide. This is a living document and will be enhanced whenever necessary. User feedback will continue to be a critical driver of training program improvements. To review the most current Training Guide,

please visit the new Intranet (SharePoint): Information Technology →  
Convio\_Email\_Campaigns\_Training

#### Added Tips and Warnings to the Convio Email Campaigns Module

Enhancements were made to the Convio platform in November and feature reminders for users to “Always calculate the audience before sending the email.” We seek to continually improve the user experience for both the Convio platform, as well as our training classes. Your feedback will continue to be a critical driver of such improvements.

#### Contact Information

For questions about these updates – 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. For questions about Convio Email Campaign Training, please contact Dana Gelotte at [dana.gelotte@nmss.org](mailto:dana.gelotte@nmss.org) or 603-974-2006.



## PROGRAMS & SERVICES

<b>December 4, 2009</b>	<b>CC: Chapter Presidents</b>
<b>Financial Assistance Program – Brochure and Flyer Templates Available</b>	

Please note that a tri-fold brochure and one page flyer template are now available to help you promote the Financial Assistance Program in your area. These pieces share similar photos, language, and overall look and feel. Both pieces provide standard language about the program that is derived from the language used on the national Web page. In addition, both pieces offer customizable space which can be used for local information, testimonials, success stories and other content that will make the pieces more compelling to your audience.

These pieces can be found on the FTP site at:

<ftp://ftp.nmss.org>

**Programs & Services Materials  
Financial Assistance 2009-10**

Remember that you can use the customizable spaces to build versions for different audiences (one to promote the program to clients, one to appeal to potential donors, etc.). You can also utilize the creative elements and language to develop additional pieces if your efforts require additional formats (bi-fold brochure, display card, postcard, etc.).

### **Reminder - National Web Page Live**

The home office has developed a Financial Assistance Program Web page on the national site. It was developed using core program messages, with some slight modifications appropriate for use on our site, as well as some additional opportunities for related information through use of sidebars. You can find the page at [www.nationalMSSociety.org/FinancialAssistance](http://www.nationalMSSociety.org/FinancialAssistance).

There are several paths a chapter may choose when creating a chapter Web page for the Financial Assistance Program.

1. Chapters may refer to the national page to “borrow” language, style and layout ideas for a unique chapter page. Chapters may make modifications and additions of chapter-specific information as long as those changes are within the guidelines of the program:
  - The name of the program is the National MS Society Financial Assistance Program. Once referred to initially, it may also be called “the Financial Assistance Program” or “the program” as appropriate.
  - There is one, common application process.
  - The program is designed to engage people to find solutions together – not just to apply for financial support.
  - Minimum covered categories must be honored, though chapter-specific details may vary.
2. Chapters may simply link to the national page instead of, or in addition, to a chapter page that is created primarily to address chapter-specific issues (specifics on covered items, etc.). This option may take a variety of shapes but it is fine to lean on the national page to provide full program details while the chapter page focuses on local aspects. The national page is intentionally not specific about covered items since this varies by chapter.

### **Financial Assistance Program: Recap**

A workgroup including representatives from more than 20 chapters developed common elements for the Society’s financial assistance program.

The workgroup’s proposal for the following common elements was approved by the NPRC and is being rolled out.

1. Common name (“Financial Assistance Program”)
2. Overarching society-wide principles
3. Application process (including common cover letter and common application and IRC protocol)
4. Minimum covered items
5. Common marketing messages (for web page, publicity materials)

It is expected that chapters are adopting these new processes and materials ; use of these common elements is a certification requirement in FY 2010.

Full details on the Financial Assistance Program and the core messages supporting this program can be found on the intranet under Programs and Services/Financial Assistance Resources

If you have additional questions, please contact [Debra.Frankel@nmss.org](mailto:Debra.Frankel@nmss.org) about program details or [Chris.Yankee@nmss.org](mailto:Chris.Yankee@nmss.org) about marketing and Web aspects.



## PROGRAMS & SERVICES

<b>December 4, 2009</b>	<b>CC: Chapter Presidents</b>
	Development
	Marketing
<b><u>New Pediatric MS Resources for Families</u></b>	

The Society announces the availability of two new resources for families with a child or teen with MS: *Pediatric MS: Understanding for Today, Hope for Tomorrow*, and *Student with MS & the Academic Setting: A Handbook for School Personnel*.

*Pediatric MS: Understanding for Today, Hope for Tomorrow* is a 20+ minute DVD that provides an overview of pediatric MS and how the Society is addressing the needs through programs and services and the Network of Pediatric MS Centers of Excellence. The piece includes interviews with three families with a child with MS, healthcare professionals from the six Pediatric MS Centers of Excellence, and Society staff and volunteers. The DVD is hosted by Society volunteer Channing Barker, a young adult who was diagnosed with MS in her teens. The stories shared by the families and healthcare professionals are compelling and offer tremendous insight into what it is like to be a family with a child with MS, making the DVD not only a valuable resource to share with families, but an excellent tool to use as part of your fundraising and awareness activities.

*Student with MS & the Academic Setting: A Handbook for School Personnel* is a 32-page guide for school staff working with children and teens with MS. The handbook includes sections on the issues children and teens with MS may face, recommended accommodations and modifications in the school setting, transition issues, and basic information on MS. The handbook is a collaborative project of the Society and the Network of Pediatric MS Centers of Excellence. The handbook is available in hard copy and on the Society's website ([www.nationalMSSociety.org](http://www.nationalMSSociety.org) and go to About MS>Who Gets MS>Pediatric MS>Pediatric MS Support Group.)

Both of these resources were made possible through a Program Honor Roll gift from the Greater Delaware Valley chapter.

Five copies of the handbook and DVD will be mailed to chapters in early December. Additional copies can be requested by contacting me at [Kimberly.koch@nmss.org](mailto:Kimberly.koch@nmss.org). There is no charge for the handbooks or DVDs. The Programs and Services Department will be mailing a packet with the handbook and DVD to families registered with the Network for Children and Teens with MS and their Families. We will also be sending copies to the pediatric MS centers. If you are planning to do a mailing to families in your area, please contact me to confirm if your families received the materials as part of the Department's mailing.

From:

Kimberly Koch, MPA

Associate Vice President, Family and Support Programs

(303) 698-6100, ext. 15158

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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Marketing

November 30, 2009

### **Sponsor Receives “Refuse to File” Letter from the FDA for its Application Seeking Approval for Oral Cladribine**

***-- Usually means agency deems application incomplete***

EMD Serono announced that it has received a “refuse to file” letter from the U.S. Food and Drug Administration for the application it submitted in late September requesting approval of cladribine tablets for the treatment of relapsing MS. This action by the FDA usually means that it deems the application incomplete. According to a company press release, the sponsor plans to request a meeting with the FDA to determine what would be required for the application to be accepted for review. Once an application is accepted, a decision about its approval could take six to ten months, depending on the priority status assigned to it by the agency.

Read more about cladribine in MS:

<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2162>

-- Research and Clinical Programs Department



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

**December 1, 2009**

### **UPDATE: Research into Blood Flow in the Brain and Venous Insufficiency, or CCSVI, in Multiple Sclerosis**

Recent reports have suggested that a dysfunction of brain blood flow and/or blood drainage may be involved in MS. For example, in one study involving 65 people with different types of MS compared with 235 people who were healthy or had other neurological disorders, a strong relationship was found between MS and signs of venous insufficiency – suggesting that blood drainage by veins may be blocked, causing or contributing to nerve tissue damage. This study, by Paulo Zamboni, MD (University of Ferrara - Ferrara, Italy) and colleagues, was published in June 2009 (J Neurol Neurosurg Psychiatry 2009; 80:392-399 <http://jnnp.bmj.com/cgi/content/abstract/80/4/392>). If confirmed, these findings may open up new research avenues into the underlying pathology of MS as well as potential new approaches to therapy. Further research is now underway. The National MS Society has invited research proposals to investigate this lead.

The idea that MS may involve a problem in blood circulation was an early theory that was eventually dismissed as research suggested that immune-system attacks and inflammation played a pivotal role in the damage to the nervous system. However, some recent studies have suggested that abnormal blood flow in the brain might also contribute to nervous system damage.

In the recent study by Dr. Zamboni and colleagues, they screened for abnormalities of blood outflow in major veins draining from the brain to the heart in 65 people with different types of MS, compared with 235 people who were either healthy or who had other neurological disorders. They used sophisticated sonography techniques to detect abnormalities of venous drainage. The investigators found significant evidence of slowed and obstructed drainage in the veins draining the brain in many of those with MS. They also found evidence of the opening of “substitute circles” – where the flow is deviated to smaller vessels to bypass obstructions, and these were often found to have reverse flow (reflux) of blood back into the brain.

The investigators call this venous obstruction “chronic cerebrospinal venous insufficiency,” or CCSVI. The treatment status of the people with MS (whether or not they were on an MS

disease modifying drug) did not appear to influence whether they showed signs of CCSVI. The authors speculate that the reverse flow of blood back into the brain might set off the inflammation and immune-mediated damage that has been well described in MS.

If confirmed, these findings may open up new research avenues into the underlying pathology of MS, and further research is now in progress. One study getting underway was described at the 2009 ECTRIMS meeting in September. It involves a collaboration between researchers in Italy, Buffalo (NY) and Birmingham (AL) who are attempting to treat venous obstruction in 16 individuals using balloon dilation such as has been used for many years to treat blocked arteries. A larger-scale clinical study is also getting underway in Buffalo ([http://www.bnac.net/?page\\_id=517](http://www.bnac.net/?page_id=517)) with the aim of evaluating the prevalence of venous obstruction in people with MS. This study does not involve treatment of obstructions.

There have been anecdotal reports of surgical attempts to treat CCSVI in people with MS. The details and outcomes of these attempts have not been published, so it is not possible to fully evaluate the value or safety of this procedure. However, one death following surgery has been reported.

Many questions remain about how and when this phenomenon might play a role in nervous system damage seen in MS, and at the present time there is insufficient evidence to prove that this phenomenon is the cause of MS.

### Frequently Asked Questions About CCSVI and MS

**Q: Do these reports of a possible association between insufficient vein drainage and MS mean that MS is caused by venous insufficiency?**

A: No. Based on results published about these findings to date, there is not enough evidence to say that obstruction of veins causes MS, or to determine when this obstruction may occur in the course of disease.

**Q: If CCSVI turns out to be important in MS, can it be treated?**

A: No one knows yet. Surgical procedures for CCSVI in MS are still experimental and should be undertaken only as part of formal clinical trials that include all of the standard safeguards that are followed in such trials. At least one small clinical trial is getting underway, with the aim of evaluating benefits and risks of treating venous obstruction in people with MS.

**Q: I have MS. Should I be tested for signs of CCSVI?**

A: No, unless you are involved in a research study exploring this phenomenon, since at this time there is no proven therapy to resolve any abnormalities that might be observed, and it is still not clear whether relieving venous obstructions would be beneficial.

CONTINUED – Read complete bulletin on Sharepoint ([http://intranet.nmss.org/Topics/cr/Pages/10-20%20UPDATE\\_Research\\_on\\_Venous\\_Insufficiency\\_or\\_CCSVI\\_in\\_MS.pdf](http://intranet.nmss.org/Topics/cr/Pages/10-20%20UPDATE_Research_on_Venous_Insufficiency_or_CCSVI_in_MS.pdf)) OR Website: <http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2206>