



CHAPTER PRESIDENTS

April 20, 2012	CC:
<u>NPE Policy Changes Approved by the CRC</u>	

The NPE Policy Review Committee met on March 4 and 5, 2012 and reviewed 30 questions, concerns and issues that had been identified by staff and/or volunteers across the Society. Many of the issues were similar in nature and were grouped into larger categories. The Committee discussed all of the issues and proposed four changes. In addition the Committee concluded that in many instances, the issues reflected misunderstandings and/or confusion about the portion of the home office budget that is covered by income received from chapters (NPE) and the mechanics of the NPE allocation process. The Committee is in the process of providing responses to the 30 questions, concerns and issues which were brought to its attention.

The Committee recommended four changes to the NPE policy with respect to how NPE is allocated among chapters. They were approved by the Chapter Relations Committee at its March 29, 2012 meeting.

Current Policy: National Program Expense (NPE) is the portion of the home office budget that is covered by budgeted payments allocated to chapters. The total home office budget is determined through an inclusive budget planning process led by a Budget Review Committee that provides input to the CEO. The Budget Review Committee is comprised of members of the Senior Leadership Team, members of the National Board of Directors and a representative from each of the regional volunteer leadership councils. Once the total home office budget and the portion of it to be designated as NPE is finalized, the budget is presented to the Finance Committee of the National Board and, ultimately, to the National Board of Directors for approval.

Once the home office budget and total NPE has been approved by the National Board, NPE is allocated to chapters utilizing the allocation process built into the NPE policy. Each chapter's allocation is based on its average gross revenue (including benefit to donor but excluding in-kind donations and investment income) over the past two years of audited results. A revenue scale with progressively higher percentages is used in the allocation process. In addition to NPE, the chapter's Annual Invoice may include licensing and shared fees.

There is currently one exception to the use of actual average gross revenues from the prior two years that a chapter may elect to utilize that will impact its share of allocated NPE. It involves the treatment of large gifts and currently states:

Treatment of Large Gifts: For any single donor gift exceeding \$100,000 the chapter has the following options:

- Treat the gift in the same manner as all other gifts. The current year remittance would not be adjusted and the chapter would apply the gift to offset its NPE in the current year. The gift would be included in the average revenue formula for future years in accordance with the remittance allocation process. In this option the chapter must anticipate a higher NPE in future years (but would also have the opportunity to use the funds otherwise budgeted to be paid as NPE in the current year).
- Make an Honor Roll contribution of the gift amount above \$100,000 in the year it is received. In this case the gift amount above \$100,000 would be excluded from the average gross revenue calculation in future years. The first \$100,000 is included in actual gross revenue in the year the gift is received. It is used to satisfy the chapter's NPE obligation that year, and becomes part of the chapter's revenue base in future years.

NPE Exception Review Process:

The Chapter Relations Committee (CRC) is responsible for approving exceptions to chapter policies. Although the NPE allocation process is simple and straightforward, special circumstances may occur from time to time. Chapters should seek CRC review to determine if unique circumstances warrant an exception. Instances of financial hardship are addressed through a separate review process.

NPE Policy modifications approved by the CRC on March 29, 2012

- 1) **Treatment of Large Gifts:** For any single donor gift exceeding \$100,000 the chapter has the following options:
 - Treat the gift in the same manner as all other gifts as noted above in the current policy.
 - Make an Honor Roll contribution of any portion of the gift up to the entire amount of the gift. The portion that is an Honor Roll contribution would be excluded from the average gross revenue calculation for purposes of determining the NPE allocation in future years. (No longer would Honor Roll contributions be limited to amounts above a \$100,000 threshold).
- 2) **Research-restricted campaigns:** A chapter may wish to initiate a specific one-time research-restricted campaign and may treat the aggregate total of gifts received as an honor roll gift and thereby have the campaign gifts excluded from gross income for purposes of determining its NPE allocation in future years. This assumes that many if not all of the gifts would be below the \$100K threshold for treatment of large gifts and that the honor roll gift would be in addition to the chapter's regular NPE allocation. A chapter would be required to receive prior approval by the CRC in order to treat the campaign income as an exception. A

proposal should first be discussed with the REVP and Chief Research Officer to determine whether it warrants further consideration.

3) Locally Restricted campaigns: A chapter may request an “NPE exception from the CRC to exclude locally restricted campaign income from future NPE calculations. The request will be considered within the NPE exception review process. Factors to be considered include, but are not limited to: 1) is the locally restricted funding from one source significantly higher than the average locally restricted funding of all chapters, 2) is the locally-restricted funding a material amount of the chapter’s budgeted income, 3) is the funding covering a program that is budgeted for each year, or does it cover a new, unbudgeted program with the expectation that the program will become part of the normal budget process in future years, and 4) is the restricted program in alignment with the priorities of the strategic response. An exception request should first be discussed with the REVP to determine whether it warrants further consideration.

4) Rental Income: Chapters may request an “NPE Exception” from the CRC to exclude rental income, realized from sub-leasing excess space, from average gross revenue for purposes of determining future NPE allocations. If approved, the NPE Exception would be effective for the remaining term of the lease or for as long as the sub-lease exists.

NPE Policy Review Committee

22 Participants included individuals from each region:

3 Chapter Presidents: Tami Caesar, Colleen Kalt, Annette Royle-Mitchell

7 Chapter Board of Trustee members: Jack Betkowski, Don Burton, Carl Hertrich, Ernest Johnson, Dean Munger, Cynthia Perrazo, Arthur Schramm (note that those members who were selected by the Region Volunteer Leadership Councils will act as liaisons for communication to each council and will assist chapter leadership in their understanding of NPE)

4 National Board of Directors Members (who are also Chapter Board of Trustee members): Jim Cantalupo, Peter Galligan, Dick Knutson, Jim Tidwell

8 Home Office staff: Pat Abruzzo, Loretta Buckman, Mike Elkow, Melissa Perlin, Lisa Risi, John Scott, Craig Weber, Paul Weiss

Facilitator: John Paul



DEVELOPMENT

April 20, 2012	CC: Marketing
<u>Special Bike MS Recruitment Strategy Calls</u>	

As part of our support for chapters around Bike MS recruitment efforts, and in recognition of National Bike Month, we will be hosting four recruitment-focused strategy calls in the month of May. These calls will feature a guest speaker or two from chapters experiencing recent recruitment success and will also provide ample time for idea sharing, questions and answers, and networking around the topic of cyclist recruitment. Calls are open to all chapters and regions – please choose the day that works best for you (and you may attend as many calls as you like!).

Call Dates:

- Monday, May 7
- Wednesday, May 9
- Tuesday, May 22
- Thursday, May 24

Time: 10 am pacific, 11 am mountain, 12 pm central, 1 pm eastern

All calls will have the same dial-in number: 866-417-3327, passcode: 7253724110.

If you have questions, please contact: Sarah Klein at sarah.klein@nmss.org or Paula Eichholz at paula.eichholz@nmss.org.



MARKETING

April 20, 2012	CC: All
April-May 2012: E-communications Update	

April National MS eNEWS

Sent date: 4/17/12

Audience: Full List

The April National MS eNEWS was sent on Tuesday, April 17. Content included a feature on a Society-funded study on heat and MS, as well as information about a new MS Learn Online feature presentation on fatigue, a push to the online community **MSconnection.org**, a “MEET” about the Morgan family and their gift to the NOW initiative, and a “SAVE THE DATE” announcement of an upcoming May 23 webcast on progressive MS.

May National MS eNEWS

Sent date: 5/19/12 (originally 5/17/12)

Audience: Full List

The May National MS eNEWS will be sent on Saturday, May 19. Content is in development, but will include an invitation to sign up for the May 23 webcast “The Next Frontier: Understanding and Treating Progressive MS” (to immediately learn more and register now, please visit: www.nationalMSSociety.org/may23webcast). More information regarding the May eNEWS content will be shared next month.

Contact Information

For editorial questions or suggestions regarding our National MS eNEWS, please contact Gary at gary.sullivan@nmss.org or 212-476-0538.

For questions about our national e-communications strategy, please contact Rich at rich.sarko@nmss.org or 303-698-6100 x15171.



PROGRAMS & SERVICES

April 20, 2012	CC: Chapter Presidents
2012 Scholarship Program Awards and other news	

Thanks for your participation in the 2012 scholarship program.

Applicants have been reviewed and finalists selected. Notification letters were mailed to all recipients and non-recipients on April 13th. Please do not contact students or publicize scholarship recipients until end of April when notifications have been received.

Stats: Nationwide we received 839 eligible applications and awarded 409 new scholarships. In addition, 236 renewals were granted. New awards total \$698,675 and renewals total \$437,500 for a grand total of \$1,136,175.

Thanks: In addition to your support, we would like to acknowledge the outstanding support of Teva Neuroscience, the O'Donnell Family Foundation, Golden Corral, Diversified Developers Realty, and the Modestus Bauer Foundation—and all of the many donors and event participants nationwide who make this program possible and who change so many lives with their contributions.

Publicity: All recipients will be listed by state/chapter/recipient name on our national web site by end of May. The top scholars will also include brief bios and photos. All recipients are asked to email a digital photo to Wenda Carlson by May 14th and then the photos will be forwarded to you. You can publicize your recipients via your chapter website, newsletters, e-communications and press releases. Please use your website to recognize and honor your scholarship recipients. We have found that families are very proud to see their scholar recognized in this way, and this can be a good way to drive traffic to your site. You may also want to use your site as a reference for donors as you develop relationships for future funding. A press release template is posted on SharePoint under Programs and Services/Scholarship Information.

Altair: Please wait to enter the scholars and awards into Altair. Detailed instructions will be provided in May.

Top Scholars: The home office will recognize 16 top scholars this year. The Kathryn Dailey Scholarship is a one-time award.

2012 TOP SCHOLAR RECOGNITION

Presidential Scholar

Caterina Fedyk – Gateway Area

Mike Dugan Scholar

Sandra Paola Medrano – Connecticut

Nicholas Polonski – Greater Carolinas
Harry Wagenhein – Greater Delaware Valley
Christina Marshall – Greater Northwest
Ezra Kawika – Hawaii
Apurva Shah – Maryland
Jacqueline Schneider – Mid Florida

Kooper Dessecker – Ohio Buckeye
Leah Wilson – Ohio Buckeye
Autumn Howell – South Central
Taylor Aldridge – South Central
Cari Logston – Southern California & Nevada
Jessica Blosberg – Upper Midwest
Reyne Mullins – Wisconsin

Honorable Mention – (Ruth Leverton Scholarship)

Mara Klecker – Upper Midwest

Recipients of Kathryn Dailey Scholarship – One-time awards

Mccall Heaton – Utah-Southern Idaho
Lindsey Oates – Ohio Valley

Scholar Engagement: It is important to keep your scholarship recipients involved and engaged in the work of the Society. These young scholars have an important connection to the Society and may someday become valued volunteers and donors. They can also inspire and motivate more people to give to the scholarship program by simply sharing their story. Please read the section on “Keeping Your Students Involved” in the [Scholarship Manual](#), which is posted on SharePoint under Programs & Services> Scholarship Program.

Please join us for our next scholarship conference call, **“Enhancing Your Scholarship Program: Taking it to the Next Level”** on June 22nd. See the April 13th news sheet titled, [“Programs and Services Staff Training”](#) for more information.

If you have questions, please contact Wenda Carlson at 303-698-6100, ext. 15152 or wenda.carlson@nmss.org.



National Multiple Sclerosis Society
733 Third Avenue
New York, New York 10017-3288
Tel +1 212.986.3240
Fax +1 212.986.7981
E-mail nat@nmss.org
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

April 18, 2012

Update: Canadian Government Chooses Research Team to Conduct Clinical Trial to Treat CCSVI

The Canadian Institutes of Health Research (CIHR) announced (<http://www.cihr.ca/e/45249.html>) that after a rigorous peer review process, a research team has been chosen to conduct a phase I/II clinical trial to determine the safety of venous angioplasty and obtain evidence on patient outcomes in people with MS. The CIHR has indicated that the names and location of the chosen Canadian team will be announced after the researchers obtain [their required](#) ethics approval from relevant institutional research ethics board(s) (<http://www.nationalmssociety.org/research/intriguing-leads-on-the-horizon/ccsvi/steps-involved-in-launching-clinical-research/index.aspx>).

The selection of the clinical trial research team follows the CIHR's release of a Request for Proposals that sought grant applications from researchers to conduct an early-phase clinical trial in Canada to test the ability of a surgical procedure called balloon venoplasty to improve blood drainage in individuals with MS who have been identified as having CCSVI (chronic cerebrospinal venous insufficiency – <http://www.nationalmssociety.org/ccsvi>). This announced clinical trial is a collaborative initiative between the CIHR and the MS Society of Canada.

Currently, there have been conflicting reports about whether and to what extent CCSVI impacts MS disease activity. Although some individuals who have MS have undergone this surgical procedure, there has not yet been a controlled trial to determine its effectiveness or safety.

The National MS Society shares in the public urgency to advance the understanding of CCSVI as quickly as possible. To build understanding of CCSVI, seven studies (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=3339>) were launched on July 1,

2010 with a more than \$ 2.4 million commitment from the MS Society of Canada and the U.S. National MS Society.

“Our funded CCSVI researchers have been serving on the scientific working group that is advising the CIHR on CCSVI and on aspects of the design of the clinical trial,” noted Dr. Timothy Coetzee, Chief Research Officer of the U.S. National MS Society. “The findings from the seven projects, and what we expect to be a well-designed clinical trial, will help determine next steps.”

Read the 18-month progress reports from the seven multi-disciplinary teams investigating CCSVI in MS (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=5261>).



National Multiple Sclerosis Society
733 Third Avenue
New York, New York 10017-3288
Tel +1 212.986.3240
Fax +1 212.986.7981
E-mail nat@nmss.org
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

April 20, 2012

MS Trial Alert:

Trial of Vitamin D Supplementation Recruiting People with Relapsing-Remitting MS

Summary: Investigators at several centers nationwide are recruiting 172 people with relapsing-remitting MS to compare the effectiveness of the current recommended amount of vitamin D supplementation versus high dose vitamin D supplementation at reducing MS disease activity, when added to standard therapy with glatiramer acetate (Copaxone[®], Teva Pharmaceutical Industries). The principal investigator is Ellen Mowry, MD, MCR (Johns Hopkins University, Baltimore) and the study is funded by a research grant from the National MS Society.

Rationale: A number of genetic and environmental factors influence whether a person will get MS. These factors may also impact the severity of the disease. Research is increasingly pointing to a reduced level of vitamin D in the blood as a risk factor for developing MS. In lab mice, vitamin D can reduce the effects of EAE, an MS-like disease, and growing evidence suggests it is time to test whether vitamin D can provide benefits to people who have MS.

Eligibility and Details: Participants should be between the ages of 18 and 50, and diagnosed with relapsing-remitting MS. Participants must be willing to stop taking additional supplemental vitamin D, except as part of a multivitamin, and must be willing to not take cod liver oil. More details on the enrollment criteria are available from the website and contacts below.

Participants will begin standard Copaxone treatment daily and will be randomly assigned to take either 600 IU (the current recommended daily allowance) or 5000 IU of vitamin D. The primary goal of the study is to determine the effects on reducing the proportion of people who experience a relapse. Other outcomes being studied include relapse rate, quality of life, brain tissue volume, disability progression, and excess calcium levels in the blood (a possible side effect of high doses of vitamin D).

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please see: <http://www.clinicaltrials.gov/ct2/show/NCT01490502>, or e-mail vitamindtrialms@jhmi.edu.

Sites are active in the following cities, and more may be added; please refer to the above link to the clinicaltrials.gov listing for the latest information:

San Francisco, California

Baltimore, Maryland

St. Louis, Missouri

Portland, Oregon

[Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial \(PDF\).](#)

Copaxone is a registered trademark of Teva Pharmaceutical Industries.