



DEVELOPMENT

January 10, 2013	CC: Chapter Presidents
<u>Help Donors Understand Their Opportunities To Make Tax-Free Gifts!</u>	
Action Requested/Deadline: Feb 1, 2013 to qualify for 2012	

Donors have **3 WEEKS FROM TODAY** to take advantage of the 2012 Charitable IRA Rollover Extension. Details and a downloadable eBrochure are available on our website in the Planned Giving section: [The IRA Charitable Rollover is Back for 2012 and 2013!](#)

The charitable IRA rollover legislation allows a donor to transfer lifetime gifts up to \$100,000 using funds from his/her individual retirement account (IRA) without undesirable tax effects.

Individuals may contribute funds this way if they:

- Are age 70½ or older at the time of the gift.
- Made a qualified charitable distribution of any amount up to \$100,000 in 2012 or make a qualified charitable distribution before Feb. 1, 2013, which may count retroactively for 2012.
- Make a qualified charitable distribution of any amount up to \$100,000 on or before Dec. 31, 2013, to qualify for 2013.
- Transfer funds directly from an IRA.
- Transfer the gifts outright to one or more qualified charities, but not to supporting organizations, or for gift annuities, charitable trusts, donor advised funds or any gift from which they receive a personal benefit.

Encourage donors to consult with a tax professional if they are contemplating a charitable gift under the extended law. Please feel free to contact Lane Malone, Planned Giving Specialist, at 303-698-6100, x 15112 or lane.malone@nmss.org with any questions you may have.



PROGRAMS & SERVICES

January 10, 2013	CC:
February 2013 Telelearning Opportunity for Society Connection Program Volunteers	
Action Requested by February 4, 2013	

The second telelearning for fiscal year 2013 for all Society connection program volunteers is scheduled for Tuesday, February 12 and Wednesday, February 13, 2013. The topic is:

“Managing Difficult Behaviors in Peer Relationships”

This telelearning is facilitated by Nancy Law, Executive Vice President of Programs and Services for the National MS Society. Nancy has been employed by the Society since 1986 and has led the Society’s efforts to achieve high quality programs for people with MS and their families nationwide.

This learning opportunity is open to all Society self-help group leaders, peer support and MSFriends volunteers. There is no fee to chapters or participants for this telelearning opportunity.

SCHEDULE

This one hour call will be repeated on two different dates and times. Volunteers only need to attend one call:

- Tuesday, February 12, 2013 from 7-8 pm ET (6pm CT, 5pm MST, 4pm PT)
- Wednesday, February 13, 2013 from 2-3 pm ET (1pm CT, 12pm MST, 11am PT)

The call will be recorded for those who miss it or would like to listen again. The recording and associated handout will also be available for download on the self-help group leaders’ resource page on the Society’s website (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/connection-programs/resources-and-support-for-self-help-group-leaders/index.aspx>).

Call participants will be invited to submit questions during the call. Participants will also be provided instructions on how to submit questions after the call, whether they listen to it live

or the recording. Within two weeks of the calls, the P&S team will code all volunteers who participated in the live training in Altair with the program code and mark as attended.

REGISTRATION AND CANCELLATION INFORMATION

Volunteers registered for the centralized notification of telelearnings will receive registration information via email or mail the week of January 7 and will be directed to their chapter liaison to register. It would be beneficial to follow up with your volunteers prior to the registration deadline to make sure they received the telelearning notification and know how to register and attend.

The registration form and marketing handout are available on SharePoint: Programs and Services>Social Connections and Support Resources>Self Help Group Materials. For registration purposes you can customize the marketing handout with your chapter contact's name, phone number and email address.

Due to numerous factors, including the need to reserve lines with the conference call company, charges for unused lines, and the distribution of call information and handouts, registration and cancellation deadlines have been established. The Programs and Services Team will e-mail the training handouts to all volunteers registered on or before the **registration deadline of Monday, February 4, 2013**. Hard copies will be mailed to volunteers without an email address. Registrations will still be accepted after the February 4, 2013 deadline, but chapters will be responsible for distributing the training-related handouts to those registrants. Please send all registrations and change notifications to Selfhelpgroupleaderregistrations@nmss.org.

Please address any registration-related questions to Heather Webb Jones in the Programs and Services Department at 303-698-6100, ext. 15176 or heather.webb.jones@nmss.org. Cancellations can also be sent to Heather until the morning of the telelearnings.

Additional questions can be directed to Monica Aden at (303) 698-6100, ext. 15169 or monica.aden@nmss.org.



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RESEARCH/CLINICAL UPDATE

January 10, 2013

MS Trial Alert: **Investigators Recruiting for Study of Generic Glatiramer Acetate**

Summary: Investigators are recruiting 750 people with relapsing-remitting MS at 175 sites worldwide, for a study comparing GTR (generic glatiramer acetate, Synthon BV) with Copaxone[®] (glatiramer acetate, Teva Pharmaceutical Industries Ltd) and placebo.

Rationale: Glatiramer acetate is a synthetic compound that simulates myelin basic protein, a component of the myelin that insulates nerve fibers in the brain and spinal cord. This therapy seems to block myelin-damaging T-cells through a mechanism that is not completely understood. Copaxone is approved by the U.S. Food and Drug Administration to reduce the frequency of relapses in patients with relapsing-remitting MS and for use in individuals who have experienced a first clinical episode (clinically-isolated syndrome) and have MRI features that are consistent with MS. This study is comparing a generic form of glatiramer acetate with Copaxone.

Eligibility and Details: Participants are ages 18 to 55 and are diagnosed with relapsing-remitting MS and have not previously been treated with Copaxone (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/relapsing-remitting-ms-rrms/index.aspx>). Further details on enrollment criteria are available from the contact below.

Participants are being randomly assigned to receive GTR (20 mg/day injected under the skin), Copaxone (20 mg/day injected under the skin), or inactive placebo (injected daily under the skin) for nine months. Approximately, 1 out of 10 subjects will receive placebo. In a second, open-label phase to study long-term effectiveness, participants who complete the first 9 months are being treated with GTR (20 mg/day) for 15 months.

The primary goal of the study is to compare the effectiveness of the study arms at reducing disease activity on MRI scans. Other objectives include comparing effectiveness at reducing the relapse rate, improving scores on clinical scales, and safety.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please contact Dr. Binu J. Alexander, PSI Project Manager, 267-464-2526, binu.alexander@psi-cro.com.

Sites are going to be enrolling in the following cities:

Charlotte, NC
Charlottesville, VA
Dayton, OH
Downey, CA
Elk Grove Village, IL
Fairfield, CT
Franklin, TN
Gilbert, AZ
Indiana, PA
Long Beach, CA
Louisville, KY
Maitland, FL
New London, CT
Northbrook, IL
Port Charlotte, FL
Raleigh, NC
Sunrise, FL
Tampa, FL

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



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RESEARCH/CLINICAL UPDATE

January 10, 2013

Study Suggests Eyes Offer Unique Window to MS Damage and Repair

- May represent new way to track benefits of therapy during clinical trials in progressive MS

A team of researchers scanned the eyes of a group of people with MS over nearly two years, and also did MRI scans and regular clinical exams. The researchers, from Johns Hopkins University and other institutions across the country, found that thinning of the back layer of the eye may represent a window to global damage occurring in the nervous system, and suggest that this tool may be useful for tracking nerve protection in clinical trials involving people with MS. The study, by John Ratchford, MD, Peter Calabresi, MD, and colleagues, was funded in part by the National MS Society's Promise: 2010 Nervous System Repair and Protection initiative. It was published in the January 2013 issue of *Neurology* (<http://www.neurology.org/content/80/1/47>).

Background: In MS, the immune system damages the brain and spinal cord. However, damage to nerve fibers and cells, which send messages and allow normal nervous system function, also occurs even when inflammation is controlled. Finding better ways to more quickly measure nervous system damage and progression would speed clinical trials focusing on trying to protect the nervous system and stop MS progression.

The back part of the eye, called the retina, is affected in MS and is damaged even in people with MS who do not have visual symptoms. The use of a simple, non-invasive technique called optical coherence tomography (OCT) has been shown by members of the study team and several other groups to be an effective way to examine the retina to track MS damage. The new study uses a more powerful technique called OCT segmentation, which allows a finer quantification of the thickness of various layers of the retina. For this study, the team set out to see how thinning of another layer of the retina, called the ganglion cell and inner plexiform layer (GCIP), may link to MS disease activity such as relapses and lesions seen on MRI scans. They also wanted to track changes to the GCIP over time to determine whether it would be a sensitive measure of nerve protection in clinical trials.

The study: Dr. Ratchford and colleagues examined a link between changes in the retina and changes in the brain and nervous system function in people with MS. Over a period of 21.1 months, they studied 164 people with relapsing or progressive disease, as well as 59 healthy control participants. They used OCT scans every six months to measure the thickness of the GCIP layer, which contains cells whose nerve fibers are damaged in MS. GCIP thinning is known to occur in the eyes of people with MS, regardless of vision problems. Participants also underwent traditional brain MRI imaging and neurological assessments to see how changes in the retina seen with OCT correlated with other manifestations of disease activity.

Results showed that the GCIP layer was thinner in people with MS than in healthy controls. Faster rates of GCIP thinning occurred in people with MS who experienced non-visual relapses, who had new brain lesions (as seen with other types of imaging), who showed disability progression, and who had an MS disease duration of less than 5 years compared to people with MS who did not show these types of progression. Thus, changes in the retina in MS were linked to global changes in the brain.

Comment: An unmet need for finding therapies for progressive forms of MS revolves around finding better tools to quickly measure the ability of treatments to protect or repair the nervous system. Until now, researchers have had to rely on more expensive and more difficult MRI to look at progression of MS damage. This study, funded in part through the National MS Society's Nervous System Repair and Protection initiative, provides the first longer-term evidence that tracking a specific portion of the retina offers a window to global nervous system damage. If further research verifies these findings, OCT may provide a way to indirectly measure nervous system damage or protection and speed clinical trials in progressive MS.