



ADVOCACY

February 4, 2011	CC: Chapter Presidents
	Programs & Services
<u>Healthcare Reform Team Launches New Working Group On State Implementation</u>	

The Society’s Healthcare Reform Implementation Team is pleased to announce a new and ongoing opportunity for Society Government Relations staff to participate in a working group on healthcare reform implementation and advocacy issues in the states. The intent of these monthly conference call meetings is to enable GR staff and interested others to share information, resources and support related to healthcare reform implementation and advocacy activities in their states. Additionally, these discussions will help the Implementation Team identify staff needs and interests.

The first of these calls is scheduled for Thursday, February 17th at 3:00 EST (2:00 CST, 1:00 MT, 12:00 PT). Future dates and times will be determined by those interested in participating. There is no advance registration required for this call. Simply dial-in to: 1-877-366-0246, followed by code number 6042086.

Several members of the Healthcare Reform Team will participate to help lead the discussion, offer resources and guidance. Participation is voluntary and the format will be informal. The initial hour long discussion will focus on the following:

- What is the general attitude among your state’s lawmakers regarding healthcare reform and the establishment of health insurance exchanges? (e.g., pro, con, mixed, don’t know yet)
- Has your state determined whether your state will establish its own health insurance exchange or plan to allow the federal government to establish one?

- Do you know how your state leaders are utilizing their exchange planning grant funds, and how they are assuring consumer input into the planning process? (e.g., advisory group, public forums, hearings, other)

- Has legislation been introduced in your state to establish an exchange? Has your chapter commented on it, or considering doing so?

For additional information about this new working group prior to February 17, please contact Kim Calder or Bari Talente of the Implementation Team.



CHAPTER PRESIDENTS

February 4, 2011	CC: All
<u>Announcement regarding Joyce Nelson's retirement as President and CEO of the National MS Society</u>	

Following is the announcement from national board chair Tom Kuhn, sent to volunteer leaders Society-wide regarding Joyce Nelson's retirement, effective October 1, 2011. Also included is Joyce Nelson's letter announcing her retirement to staff and volunteers.

If you have any questions or need further communications support, please contact Graham McReynolds at graham.mcreynolds@nmss.org

TO: Members of the National Board of Directors. Chapter Chairs, Chairs Advisory Council members

FROM: Thomas Kuhn, Chair of the National Board

SUBJECT: Joyce Nelson's Retirement

Joyce Nelson, our President and CEO, has decided to set her retirement date, effective October 1, 2011.

I am happy for Joyce and John as they make retirement plans for their future, but saddened for the Society and the loss of her leadership.

Joyce began her career at the National MS Society in 1983 as a READaTHON coordinator in the Northern California Chapter. She went on to provide leadership in a wide range of areas, including as chapter president in the Mid America Chapter, vice president of the national field operations and development departments, and of course, as the Society's President and CEO since 2004.

Under Joyce's leadership the Society launched a range of new initiatives including: our "Join the Movement" brand messaging; the Promise 2010 initiative; our 2007-2010 and

2011-2015 strategic responses to MS; establishment of local and national direct financial support programs for families most severely impacted by MS; establishment of regions; restructuring our remittance processes; establishment of Fast Forward; support for high cost research efforts like the MS genetics project and clinical trials of estriol, and much more.

Joyce leaves the Society in a position of strength. We have survived the challenges of the recent recession and expect to fund all approved research projects, fellowships, pilot grants and research meetings in 2011. The unanimous approval of our 2011-2015 strategic response provides clear direction for the future and the Society's professional staff - locally, regionally and nationally - are the best in the industry.

The process to identify Joyce's successor will begin later this month. Eli Rubenstein, Chair of the Society's Governance Committee, will head the CEO search committee and members of the committee will be recruited shortly.

There will be time to celebrate Joyce's accomplishments in the months ahead. In the meantime, I know you join me in wishing her and her family all the best as they enter this new phase of their lives.

Letter from Joyce Nelson, CEO and President



CHAPTER PRESIDENTS

February 4, 2011	CC: All
<u>National MS Society House Community</u>	
Action Requested/Deadline: February 15, 2011	

As part of our commitment to connect with our constituents how, where and when *they* want to connect, and to increase opportunities for people to come together in a secure online environment to learn, share, meet and move their lives forward, the Society is developing a “house community.” This house community will include several exciting new features and services to help ensure that we are the best possible online resource and community for those we serve – and to make our valuable website (national and chapter pages) a better-utilized, interactive resource to which people will return again and again.

This NewsSheet provides an overview of our house community. We feel it is important that all staff is informed of this initiative; the only recommended action at this time is to attend one of the following information sessions:

Tuesday, February 15, 10:30 AM Mountain. Call: 1-866 417 3327, Conf Code: 862 801 9268
WebEx: <https://nmss.webex.com/nmss/j.php?ED=146623537&UID=483195797&RT=MiM2>

Thursday, February 17, 2:00 PM Mountain. Call: 1-866 417 3327, Conf Code: 862 801 9268
WebEx: <https://nmss.webex.com/nmss/j.php?ED=146623572&UID=483195797&RT=MiM2>

Key next steps are outlined in the [Frequently Asked Questions](#) document available on SharePoint and will be reviewed in the information sessions.

What is a house community?

A house community is an online community that lives within an organization’s website (e.g. the Society’s website) – where people can gather and connect in a trusted environment and interact with the organization and its resources. Examples:

- Christopher and Dana Reeve Foundation (<http://www.spinalcordinjury-paralysis.org>)
- American Diabetes Association (<http://connect.diabetes.org>)
- Sierra Club (<http://connect.sierraclub.org/ActivistNetwork/home>)

- Image for visualization purposes only – not indicative of final community design:

Why build a house community?

Many people affected by MS use the Internet as a way of accessing information and connecting with one another. In order to provide a safe and reliable online environment – a hub for the MS movement – and to ensure that people have access to accurate information and support – the Society needs to enable constituents to more easily navigate the online /social media realm. The Society house community will provide an opportunity to connect people involved in the MS movement with one another, with the Society’s web content (in an interactive way), with Society activities (fundraising events, advocacy, etc.), and with Society resources such as peer support volunteers, MS Navigators, MS experts and personalities.

- Over 77% of Americans (US) use the internet – nearly 240 million users (internetworldstats.com Jun 2010)
- Facebook has over 500 million users worldwide, about 30% of which are in the US – or nearly 48% of the US population (Facebook Dec 2010)
- Neurology patients are most likely to search the web and visit online support groups – patients with MS are among the most active neurology patients online (Neurology Today Dec 2003)
- MS patients are five times as likely to participate in forums or chat sessions as other patients with chronic disease (Neurology Today Dec 2003)
- According to a Society web survey, people with MS are nearly 50% more likely as the general population to engage in social media (Dec 2009)

A survey conducted on the Society's national Facebook page indicated that 97% of 1,832 respondents would participate in a private community hosted by the Society (Aug 2010). Members won't have to navigate multiple online resources in order to find support, access accurate information and interact. In contrast to users of Facebook and other external communities, Society house community members will have the assurance of safety – user-friendly privacy settings, secure data storage, no selling of personal information – and easy connection with others who care about the MS movement in one place. The community will also provide constituents with connectivity to more easily consume and share resources, information and support through existing online communities and conversation channels such as Facebook, Twitter, YouTube, LinkedIn, Flickr and more.

How will the Society house community work?

Members will create a personal profile in which they may store and share posts/updates, blogs, photos, videos and links. Members may view profiles and community-related activities of other members and search for other members by demographics, shared interests and more. Members can “friend” other members, comment on and “bookmark” the Society's web pages (including chapter pages), online publications and other content, as well as read and contribute to general or targeted (topic, geography, etc.) discussions and join member groups.

When and how will I learn more?

1. Answers to [Frequently Asked Questions](#) are available on SharePoint
2. Join an information session (see page 1 of this NewsSheet
3. Upcoming NewsSheets will highlight the progress of the Society house community

If you have questions or would like to get involved, please contact Maura Dunn, Online Information Specialist at maura.dunn@nmss.org or 303-698-6100 x15185.



DEVELOPMENT

February 4, 2011	CC: Chapter Presidents
<u>Preparing for the Research Initiative – Relationship Building Skill Practice (Virtual Training)</u>	
Action Requested/Deadline: Register by 2/11/2011	

All Staff members responsible for Major Gifts and/or the Golden Circle Program are encouraged to participate in the “Preparing for the Research Initiative – Relationship Building Skill Practice” virtual trainings on February 15th and 16th. **Registration is required.**

Here is the agenda for the training:

When: Tuesday, Feb. 15th and Wednesday, Feb. 16th
(11:30am EST – 4pm EST each day)

Key topics: “Getting the Appointment” (Day 1)

- Gaining the Prospect’s/Donor’s Attention by Building Connections
- What to say during Cultivation/Donor Events to build connections
- Using “30-Second spots” to get appointments on the phone
- Skills Practice (Triad Calls)

“Conducting Effective 1-on-1 Meetings with Donors” (Day 2)

- Moves Management Fundamentals
- Donor Meeting Objectives
- Opening the Meeting
- Probing and Listening to build interest
- Skills Practice (Triad Calls)

Guest Speaker/Presenter: Carol Moreland

Registration Information:

Tuesday, Feb. 15, 2011

Topic: Individual Giving Winter Meeting “Getting the Appointment”

Date: Tuesday, February 15, 2011

Time: 9:30 am, Mountain Standard Time (Denver, GMT-07:00)

Meeting Number: 484 487 174

Meeting Password: (This meeting does not require a password.)

To start or join the online meeting

Go to

<https://nmss.webex.com/nmss/j.php?ED=146053457&UID=482412807&RT=MiM2>

Teleconference information

Provide your phone number when you join the meeting to receive a call back.

Alternatively, you can call:

Call-in toll-free number: 1-(866) 417-3327 (US)

Call-in number: 1-(404) 665-9186 (US)

Leader PIN: 482145

Conference Code: 734 718 4220

Wednesday, Feb. 16, 2011

Topic: Individual Giving Winter Meeting “Conducting Effective 1-on-1 Meetings with Donors”

Date: Wednesday, February 16, 2011

Time: 9:30 am, Mountain Standard Time (Denver, GMT-07:00)

Meeting Number: 483 323 233

Meeting Password: (This meeting does not require a password.)

To start or join the online meeting

Go to

<https://nmss.webex.com/nmss/j.php?ED=146053827&UID=482412807&RT=MiM2>

Teleconference information

Provide your phone number when you join the meeting to receive a call back.

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Call-in number: 1-(404) 665-9186 (US)

Leader PIN: 482145

Conference Code: 734 718 4220

If you have any questions or need any additional information, please call or email Myrna Mulholland at 303-698-6138 or myrna.mulholland@nmss.org



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

February 4, 2011

MS Trial Alert:
Investigators Recruiting for Study Comparing Exercise Programs to Improve Depression

Summary: Investigators at the University of Washington, Seattle, are recruiting 108 people with all types of MS or spinal cord injury nationwide for a study comparing the effects on depression of two telephone-coordinated exercise programs. The study, also called the inMotion study, is funded by the National Institutes on Disability and Rehabilitation Research.

Rationale: Depression is common during the course of multiple sclerosis. In fact, studies have suggested that clinical depression, the severest form of depression, is more frequent among people with MS than it is in the general population or in persons with other chronic, disabling conditions. Some research has indicated that exercise can improve depression in people with MS.

Eligibility and Details: Participants should be at least 45 years old, have MS or spinal cord injury, and should meet the criteria for Major Depressive Disorder or chronic depression. Further details on enrollment criteria are available from the contact below.

After several baseline phone calls, and wearing an accelerometer (a device that measures physical activity, similar to a pedometer) for seven days, participants will be randomly assigned to one of two groups. In Group A, a research study counselor will help participants to develop a personalized exercise program, based on individual motivation and need. The counselor also will provide six to eight follow-up phone counseling sessions, helping participants to raise motivation, track progress, problem solve, and make changes to the exercise program as needed.

In Group B, participants will receive one 60-minute phone session during which a counselor will review how to exercise safely and provide extra information on how to find exercises that suit individual needs. No follow-up counselor calls will be made to Group B. Both groups will receive three more questionnaire calls at Weeks 6, 12, and 24 of the study period.

Participants will be reimbursed for their time and for phone expenses up to \$120.

The primary goal of this study is to determine how each of these exercise strategies affects depression, as measured by a specific clinical scale. A secondary goal is to determine the effectiveness of each program in increasing physical activity, according to a questionnaire.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please contact:

The inMotion Study
University of Washington
Box 356490
Seattle, WA 98195
1-866-928-2114
agerrtc@uw.edu

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