



ADVOCACY

September 23, 2011	CC: Chapter Presidents
	Programs and Services
Medicare's REVISED Fall Open Enrollment Period is Now October 15 to December 7	

BACKGROUND: Every year, Medicare beneficiaries have a chance to make changes to their Medicare Prescription Drug (aka, Part D) and Medicare Advantage coverage. Beneficiaries are strongly encouraged to take advantage of this opportunity to review their coverage choices and change plans if another option better suits their needs. Part D/Medicare Advantage plan members that are happy with their coverage are urged to review any 2012 changes to their current plan to make sure that it is not drastically different for the upcoming year. Changes made to health plans will be effective on January 1, 2012 and remain in effect for the year. Current enrollees should receive an Annual Notice of Change (ANOC) from their plan highlighting any scheduled changes to the premium and other out-of-pocket expenses for plan enrollees. The ANOC will also review any changes to the formulary scheduled for 2012. Copies of these notices may also be requested directly from the plan.

WHAT'S NEW THIS YEAR? As of this year, the Annual Election period will be longer, but the timeframe will be pushed up for enrollees to make changes to their plans. The Open Enrollment period for Part D and Medicare Advantage Plans will begin on October 15th and end on December 7th. *This is the only time Part D enrollees can switch plans during the calendar year without a financial penalty unless they qualify for a special enrollment opportunity.*

HOW DOES THIS IMPACT PEOPLE WITH MS? Roughly one quarter of all people in the US living with MS rely on Medicare for their health care coverage. Many are able to minimize their costs by combining and coordinating their Medicare benefits with coverage from other sources, such as an employer's plan, the VA, or Medicaid. Understanding the many options, decisions and necessary steps can be challenging, and costly mistakes can be devastating. One-to-one phone counseling and support is available through the Society's Information Resource Center, and helpful information and resources appear on the national website.

HOW YOU CAN HELP: Society staff and volunteers can help their Medicare clients with reminders about the Annual Open Enrollment Period, alerting them to the new dates, and referring individuals and caregivers to 1-800- FIGHT MS. Chapter offices could also post

this flyer (<https://www.shiptalk.org/ShipTalkInfoLib/misc/OpenEnrollPosterFinal.pdf>) where clients are likely to see it.

Finally, watch for news of other Medicare enrollment periods later in the year.

Use the following link to see additional information from Medicare

(<http://www.medicare.gov/Publications/Search/Results.asp?PubID=11219&Type=PubID&Language=English>)



CHAPTER PRESIDENTS

September 21, 2011	CC: All
<u>Anne Mageras Named Chapter President – Western Pennsylvania Chapter</u>	

We are pleased to announce that, in partnership with the Chapter Board of Trustees; Anne Mageras has been selected for the position of Chapter President for the Western Pennsylvania Chapter (effective October 1st).

Hired in 1993 as the Programs and Services Director, Anne brought with her the background and experience of creating inter-disciplinary teams in providing health and human services. As chapter Vice President, she provided leadership for the chapter activism; launched the WAMS (now: Women on the Move) and initiated the chapter's relationship-building strategies with key community constituents and donors. Anne has served as a Chapter consultant and on numerous clinical work teams for Society initiatives.

We look forward to Anne's work in the East Region as a new member of the Region Management Team. Please take a moment to join me in congratulating Anne on her new role with the Society.

John Scott
Executive Vice President
East Region
National Multiple Sclerosis Society
215-480-4406



CHAPTER PRESIDENTS

September 23, 2011	CC: All
<u>Midwest Realignment Announcements</u>	

Two chapter territory realignments are underway in the Midwest Region:

The **Mid America and Nebraska Chapters** are joining together to form a new chapter, serving a combined total of 11,000 people with MS and their families in Kansas, Nebraska, Western Missouri, and Pottawatomie County, Iowa. Board members from both chapters favored the name Mid America Chapter and will use it for the new chapter.

The **Minnesota and North Central States Chapters** are joining together to create a new chapter, serving more than 17,000 people with multiple sclerosis and their families in Iowa, Minnesota, North Dakota and South Dakota, as well as several counties in Nebraska and western Wisconsin. The name of this new chapter will be identified in the next few weeks.

This realignment of chapter territories is positive news for people affected by MS in all the states listed above.

By combining the talents of staff teams, boards and volunteers, these chapters expect to streamline operations, increase fundraising effectiveness and commitment to research, mobilize more volunteers, reduce costs, and expand programs, services and advocacy for people living with MS and their families and friends

The new Mid America Chapter officially comes into being on October 1, 2011, and Kay Julian will serve as Chapter President.

The new chapter that will serve the Minnesota and North Central States territory will launch its realignment on October 1, 2011, and Holly Anderson will serve as Chapter President. Jennifer Kline, former North Central States Chapter President, has accepted a position within the National MS Society as Senior Vice President of Strategic Initiatives, with a focus on rural and underserved MS populations.

Congratulations to the staff and volunteers at all four chapters for their vision and leadership to combine their strengths and develop a long term strategy to deliver our mission throughout their chapter territories.

Maureen Reeder
Executive Vice President, Midwest Region
Maureen.reeder@nmss.org

Tami Greenberg
Senior Director, Organizational
Development & Interim Management



CHAPTER PRESIDENTS

September 23, 2011	CC: All
<u>Reminder Strategic Response Goal Steering Teams 2012 Nomination Process</u>	
Action Requested/Deadline: September 30, 2011	

Strategic Response Goal Steering Teams: 2012 Nomination Process

This is a reminder that all nominations are due by Friday, September 30th.

Please use the following link to review the goal specific competencies and to submit your nominations: [Goal Steering Team Nominations](#)

To read the original news sheet announcing the Strategic Response Goal Steering Teams 2012 Nomination Process from September 16th [click here](#).

Thank you for your continued participation in the implementation of our strategic response.

Bonnie Higgins
Paul Weiss
Strategic Response implementation Co-leads



DEVELOPMENT

September 23, 2011	CC: Chapter Presidents
<u>Workplace Giving Campaign Kick-Off</u>	
Action Requested/Deadline: Immediate Attention	

Are you ready for the 2011 Combined Federal Campaign? Beginning in a few weeks, millions of public and private sector employees will designate their charitable contributions to non-profit organizations nationwide through workplace giving campaigns, such as the Combined Federal Campaign (CFC). Unfortunately, not all campaigns are easy for the donor to navigate and there are many sound-alike organizations. In order to help our donors, it is important that we act now to educate them on how to designate their workplace giving gift to the National MS Society.

In most workplace giving campaigns, including the Combined Federal Campaign, participating charities are listed by federation. Instruct your donors to look for the National MS Society listed under Community Health Charities. If an individual works for the federal government or a branch of the military and participates in the Combined Federal Campaign, they can simply use the Society’s CFC designation code number: 11409. (If your chapter has a local listing in the Combined Federal Campaign, you may also direct your donors to your local CFC designation code.)

Workplace giving is primarily a local level initiative. As a result, the best way to impact this campaign is through chapter activities. Just a few simple steps can have significant results. In the next few weeks, chapters are strongly encouraged to:

- Contact your state affiliate director of Community Health Charities for information on local health fairs and kick-off events
- Designate a volunteer or staff to participate in local events by hosting a public education booth
- Review and customize the workplace giving webpage on your chapter website. If you haven’t recently updated your chapter website, please review the national webpage on workplace giving and update your local webpage accordingly. (Be sure that your webpage includes the current national designation number, the CHC logo, and all local designation numbers. (The national page is: www.nationalmssociety.org/donate/workplace-giving/index.aspx)

- Feature workplace giving on your chapter homepage from September through December. Be sure to include the Community Health Charities logo and the CFC donor designation number: 11409 (The CHC and CFC logos are posted on SharePoint.)
- For the next few months, be sure your chapter's CFC designation number is listed in special event mailings, board mailings and educational mailings
- Distribute information on CFC designation or corporate workplace giving campaigns to support group leaders and appropriate team captains
- For additional activities and marketing templates, visit SharePoint.

To support local efforts, the home office will promote our CFC designation number on the homepage of the website in October; through the e-newsletter in November; and on Facebook. We have placed a half page ad in the fall issue of Momentum and the September issue of MS Connection (available on the Society Asset Management System). We will also be purchasing advertisements in Military Times and Federal Times Magazines.

For questions related to workplace giving campaigns in your state, please contact your Community Health Charities state affiliate director. (A listing is posted on SharePoint.) For additional questions, contact Laura Uzzle (email: luzzle@msn.com or phone: 303-895-6797.)

The National MS Society's national designation code for the Combined Federal Campaign is CFC# 11409.



PROGRAMS & SERVICES

September 23, 2011	CC:
<u>FY 2012 Café con Leche: Conversation and Support for Native Spanish Speakers Living with MS</u>	

Entering into its fourth year, the Society will again be offering the Café con Leche telephone-based self-help group for native Spanish speakers. The group meets once a month for 90 minutes through June, 2012 with subsequent dates to be determined. The first group meets Tuesday, October 11, 2011. Topics will focus on areas of interest to people living with MS. Additionally; experts from different areas of specialization in MS will join the group to speak about important topics in MS care.

Interested participants can register by calling 1-800-344-4867 and selecting Option 3 (Spanish dedicated phone line). The group features rolling admission and new members are welcome to join at any time.

Promotional fliers are available on SharePoint at Programs and Services>Social Connections and Support Resources>Self Help Group Materials. The program also will be promoted on the Spanish pages of the Society’s website.

For more information about the Café con Leche group, please contact Moyra Rondon, LCSW, Director of Education and Hispanic Outreach, New York City-Southern New York Chapter at 212-453-3237 or mrondon@msnyc.org.

This program is made possible through an educational grant from the Medtronic Foundation. A special thank you is offered to the New York City-Southern New York chapter for their ongoing management of this project.



PROGRAMS & SERVICES

September 23, 2011	CC:
October Telelearning Opportunity for Society Connection Program Volunteers	
Action Requested by October 19, 2011	

The first telelearning for fiscal year 2012 for all Society connection program volunteers (self-help group leaders, peer support and MSFriends) is scheduled for Tuesday, October 25, 2011. The topic is *An Overview of the Programs and Services of the National MS Society and Our Partners*.

We know that finding answers and making decisions relies on having the right information at the right time. During this telelearning volunteers will learn more about the variety of programs, services and resources available to people with MS and their families at all levels of the organization, as well as how to access these resources – valuable information they can share with their group members and peers. During the call we will discuss not only those programs and services offered by the Society, but also those of our partners.

Our presenters are Cathy Castor and Kim Koch. Ms. Castor is the Information Resource Center's Training Director. She began her career with National MS Society almost 10 years ago when she was hired as one of the first Information and Referral Specialists. She has a Master's degree in Audiology and clinical experience in providing diagnostic testing for MS. Ms. Koch began her career with the Society in 2003 and is currently Vice President, Programs and Services. She oversees nationwide initiatives in the areas of client education, family support and connection programs.

This learning opportunity is open to all Society self-help group leaders, peer support and MSFriends volunteers. This training is sponsored in part by CaringBridge.

SCHEDULE

Two calls are scheduled. It is the same agenda offered at two different times.

- Call 1 is Tuesday, October 25, 2011 from 1-2:00 pm ET (12 pm CT, 11 am MT, 10 am PT)
- Call 2 is Tuesday, October 25, 2011 from 8-9:00 pm ET (7 pm CT, 6pm MT, 5 pm PT)

The call will be recorded for those who miss it or would like to listen again. A playback number will be provided for you to share with your volunteers. 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/selfhelpgroupleaders>.)

COST

There is no cost for this telelearning opportunity.

REGISTRATION AND CANCELLATION INFORMATION

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 **registration deadline** is **Wednesday, October 19th** (2 pm ET, 1pm CT, 12 pm MT, 11 am PT). Chapters needing to **cancel a registration** should do so no later than **Monday, October 24th**. Please send all registrations and change notifications to Selfhelpgroupleaderregistrations@nmss.org.

The Programs and Services Department will e-mail the training handouts to all volunteers registered on or before the registration deadline. Hard copies will be mailed to volunteers without an email address. For registrations received after the **October 19, 2011** deadline, chapters will be responsible for distributing the training-related handouts to those registrants.

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@nmss.org.

Topics and dates for future telelearnings will be announced in upcoming news sheets.

Additional questions or suggestions for FY 2012 telelearning topics can be directed to Kim Koch at (303) 698-6100, ext. 15158 or kimberly.koch@nmss.org.



PROGRAMS & SERVICES

September 23, 2011

CC: Chapter Presidents

Partners in MS Care Initiative – Training Calls in October

The Partners in MS Care workgroup is pleased to offer a series of staff training calls for anyone involved in relationships with health care professionals, including chapter presidents.

Prior to the calls, (by October 12th) we will post the tools and supportive resources for the *Partners in MS Care* program on SharePoint, including a chapter guide, materials for collecting information about potential partners, reviewer forms and instructions for your clinical advisory committee.

You only need to sign up for one call, as the agenda will be the same for all of the calls. Following the calls, the *Partners in MS Care* Workgroup will offer bi-weekly Q&A calls for chapter staff. Additionally your workgroup liaison is also available to support your on-going efforts.

Monday, **October 17th** 10-11:30 AM Pacific time/11 AM – 12:30 PM Mountain time/12 – 1:30 PM Central time/ 1 -2:30 PM Eastern time

Wednesday, **October 19th**: 10-11:30 AM Pacific time/11 AM – 12:30 PM Mountain time/12 – 1:30 PM Central time/ 1 -2:30 PM Eastern time

Tuesday, **October 25th** 1-2:30 PM Pacific time/2-3:30 PM Mountain time/ 3-4:40 PM Central time/ 4-5:30 PM Eastern time

Thursday, **October 27th** 11 AM -12:30 PM Pacific time/ 12-1:30 PM Mountain time/ 1-2:30 PM Central time/ 2-3:30 PM Eastern time.

Call in number: 1-877-875-7554; code 26669000# . Web-X details, including how to register are forthcoming. But please save the dates!

On another note, the Centers for Comprehensive MS Care that have been reviewed and approved by the Comprehensive Care Review Committee (and for which we have signed written agreements) are posted on the Society's web-site. We will continue to add names of centers as new agreements are completed. <http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/index.aspx>. In early calendar year 2012 we will be launching a web page for all *Partners in MS Care*. This page will be able to pull information directly from Altair and will be specifically designed to assist people affected by MS to search for *Partners* – in all categories, including centers for comprehensive care. The new page will replace what is currently on the web-site.

If you have questions, please contact a member of the workgroup:

Sarah Clark, Information Resource Center Technology Manager

Lisa Custy, Associate VP, IRC, Programs & Services, (Home Office)

Debra Frankel, Associate VP: Programs, Services and Clinical Activities, ART Team

Colleen Friedman, Vice President, Programs, Greater Illinois Chapter, Midwest Region

Debbie Garrison, Executive VP, Mission Advancement, Central PA Chapter, East Region

Sherri Giger, Vice President, Marketing

Linda Guiod, EVP, Chap Pgrms, Svcs, & Advocacy Greater New England Chapter, Northeast Region

Debbie Hertz, Associate VP, Medical Programs, (Home office)

Audra Hindes, Director, Clinical Programs, Southern California Chapter, West Region

Karen Hooper, Vice President, Programs and Services, Pacific South Coast Chapter, West Region

James (Jim) O'Brien, Director of Programs and Services, Mid-Florida Chapter Southeast Region

Sharon O'Hara, Vice President Programs and Services, Colorado Chapter, West Region

Ray Owens, Vice President, Clinical Programs South Central Region

Lisa Skutnik, Executive Vice President, Clinical Programs

Craig Wesley, Manager, Diversity and Outreach initiatives, Clinical Programs



PROGRAMS & SERVICES

September 23, 2011	CC: Chapter Presidents
	Development
	Marketing
<u>2012 Scholarship Program</u>	

The start of the 2012 scholarship program is just around the corner. See the bullet points below to prepare your chapter for the upcoming season.

Gearing up for the 2011 program

- If you have not already done so, be sure to include a link on your chapter’s website to the national scholarship web page at www.nationalMSSociety.org/scholarship. The 2012 application will be available there starting on October 1 and will remain posted until the January 13, 2012 deadline.
- Continue publicizing the program in future issues of MS Connection.
- Continue solicitation of donors.
- As a reminder, scholarship brochures (item code BR3005) are available at no cost from chapterorders@nmss.org.
- The Scholarship Program Manual is posted on SharePoint under Topics>Programs and Services>Scholarship Information. The manual includes:
 - Home office and chapter procedures
 - Annual timeline
 - Frequently Asked Questions
 - Application review process and materials
 - Ideas for “Developing a Local Presence”
 - How to “Approach and Engage Donors”
 - How to “Keep your Students Involved”

For more information, please contact Wenda Carlson at 303-698-6100, ext. 15152 or wenda.carlson@nmss.org.



PROGRAMS & SERVICES

September 23, 2011	CC: Advocacy
	Chapter Presidents
Veterans With MS Update	

The Society is closely aligned with the two federally-funded VA MS Centers of Excellence (MSCoE). These centers have four mission elements: provision of quality MS clinical services to veterans, research into causes and treatments for MS, informatics (which includes a focus on telemedicine to better serve rural and underserved areas), and education of veterans, caregivers and VA health care providers.

Geographically, the MSCoE East serves veterans east of the Mississippi River, and the MSCoE West serves veterans with MS west of Mississippi. Besides the two main funded coordinating centers (the West shared between Portland, Oregon and Seattle, WA; and the East in Baltimore, MD), there are VA hospitals across the country designated as ‘MS hubs’. (Please refer to a map of the USA, with the locations of the VA MS clinical programs on SharePoint (Research & Clinical Programs/collaborative partnerships)

[http://intranet.nmss.org/Topics/cr/Clinical%20Document%20Libraries%20and%20Links/VA MS Centers Of Excellence Map.pdf](http://intranet.nmss.org/Topics/cr/Clinical%20Document%20Libraries%20and%20Links/VA%20MS%20Centers%20Of%20Excellence%20Map.pdf).

There are over 20,000 veterans with MS receiving regular care through the VA, but there are thousands more who are not receiving on-going MS care through the VA system.

Collaborative Opportunities:

- 1) A web-page in the Living with MS section of our website <http://nationalMSSociety.org/veteransMS> has been launched in an effort to engage veterans with both the Society and the VA MS Centers of Excellence. Post cards describing this website connection have been printed and are available for distribution. **Post cards may be ordered through chapter supplies at no cost.** View the post card at <http://intranet.nmss.org/Topics/cr/Clinical%20Document%20Libraries%20and%20Links/Postcard.pdf>

- 2) The Society (including staff from the Mid Florida Chapter and the Home Office) supported a booth at the recent Paralyzed Veterans of America (PVA) Summit in Orlando, Florida (September 17-19). This conference included health care professionals within the VA and focused on MS and spinal cord injury. Society materials were quickly taken, and there was a real thirst for more information about MS for themselves and for the veterans they serve.
- 3) The Society is represented on the Advisory Boards of both the East Coast and West Coast VA MS Center of Excellence.
- 4) We have a tremendous opportunity to collaborate with the VA clinical centers across the country in serving people affected by MS. Developing strong alliances is directly in line with our strategic response to enhance quality of care and access to care for people living in rural and underserved communities. Many chapters have already developed strong relationships with their local VA centers. Here are some ideas to enhance those relationships and/or to develop new ones.
 - Contact your local VA facilities (some of the MS programs are within neurology units and others are within spinal cord injury units at the VA hospital)
 - Visit a VA hospital with an MS program and learn more about the patients with MS they serve, the needs of the health care professionals, and how they are attempting to reach veterans in rural communities.
 - Explore ways to collaborate on service delivery to veterans with MS
 - Invite VA staff to professional education programs, and/or offer resources or possibly an in-service training to VA staff.
 - Ask the VA facilities to promote information to patients with MS about our Navigator program, client/family education, social programs and advocacy activities.
 - Offer the services of the Society's Professional Resource Center
 - Distribute the post card (see above) about the Society's web page for veterans
 - Explore interest in targeted support groups, and care giver activities for veterans with MS and their families
 - Distribute chapter brochures and MS Navigator brochures to the VA hospitals where MS is seen and diagnosed.
 - Consider inviting a representative of the VA onto your Clinical Advisory Committee.
 - Explore regional opportunities

Please don't hesitate to contact me with questions or comments.

Debbie Hertz, Clinical Programs Department
Tel: 212-476-0468/ deborah.hertz@nmss.org



PROGRAMS & SERVICES

September 23, 2011	CC:
	Chapter Presidents
Working Toward Your Best Life DVD	

Due to continued interest in the June 2011 webcast program *Working Toward Your Best Life: Advances in Quality of Life Research*, the Programs and Services team is mailing chapters one DVD of the program. Based on feedback, 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 copies 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: <http://www.nationalmssociety.org/multimedia-library/webcasts--podcasts/index.aspx>, can request a DVD by contacting an MS Navigator at 1-800-344-4867, option 1.

Thank you to the Marketing Team for making this possible.

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



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

September 23, 2011

MS Trial Alert:

Investigators Recruiting for Study Comparing Telephone-Delivered Self-Management Programs to Improve MS Symptoms

Summary: Investigators at the University of Washington, Seattle, are recruiting up to 200 people with all types of MS nationwide for a study comparing the effects of two telephone-delivered self-management programs targeting pain, fatigue, and depression. The study, also called Take Charge, is funded by the National Institutes on Disability and Rehabilitation Research (NIDRR) as part of the Rehabilitation Research and Training Center for Multiple Sclerosis (MSRRTC) at the University of Washington.

Rationale:

Pain, fatigue, and depression are some of the most common symptoms of MS. Self-management approaches – programs and strategies that enable people to monitor and manage their disease, its symptoms, and its consequences – have been shown to help people with other chronic conditions reduce similar symptoms. The purpose of this study is to see if these treatments, when delivered by telephone, can help reduce pain, depressed mood, or fatigue in people with MS, and reduce the negative consequences that these problems may cause in terms of a person’s mood, daily activities, and quality of life.

Eligibility and Details: Participants should be at least 18 years old, be diagnosed with MS, and must have at least one of three symptoms (fatigue, pain, depression) that is currently interfering with daily life. People currently participating in regularly scheduled psychotherapy are excluded. Further details on enrollment criteria are available from the contact below.

Participants are being randomly assigned to one of two “self-management” approaches, both involving eight phone treatment sessions delivered by clinical psychologists or social workers. Both treatments involve educating participants about pain, fatigue, and depressed mood, and

teaching different ways of managing these problems in hopes of reducing them and their impact on daily life. Every participant will receive eight weekly therapy sessions (lasting 60-75 minutes) and five phone surveys (lasting 60 minutes). Participation in the study will last 13 months. Participants will be compensated up to \$120 for time and effort.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please contact Laura Henderson at (206) 221-5642, 1-888-634-6778 (toll-free), or via email, at: msrrtc@uw.edu.

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