



SIGNATURE

NEWSLETTER OF THE VA SPECIAL INTEREST GROUP OF THE CONSORTIUM OF MS CENTERS

Volume 7, Number 4, Fall 2009

WELCOME TO OUR LATEST EDITION

Our goal is to provide a medium for VA MS professionals to share expertise and improve care for MS patients. We welcome your thoughts, comments, and participation. Please pass this issue along. If you know someone who wishes to be included on the electronic distribution list, forward the email address to the editor.

A LETTER FROM THE VA-SIG CHAIR

Dear Colleagues,

This summer many of you attended the annual Consortium of Multiple Sclerosis Centers (CMSC) meeting in Atlanta. The meeting was highly successful and marked the onset of a few changes that we plan to continue. Early in the conference we had a social event to introduce newcomers to all the organizations and to collaborate with colleagues. A schedule of VA events was handed out and participants were made aware of special meetings that were to be held in the hospitality suite.

Later in the conference we held a joint meeting with both Multiple Sclerosis Centers of Excellence, East and West, and the VA-SIG. This reduced schedule conflicts and duplication. The *VA Signature* newsletter will continue to be a conduit for information and will add sections for scholarships, fellowships, and other educational opportunities for both funding and collaboration in research. Upon review, we noted that everyone was appreciative of the changes in travel reimbursement. Transportation and reimbursement was a smooth process.

We thank PVA for their generosity in assisting VA providers in obtaining the education that allows us to provide the best to our veterans.

Sincerely,

Peggy A. Coffey, MD
VA-SIG Chair

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NOVEMBER IS NATIONAL FAMILY CAREGIVER MONTH...

Let's plan ahead and do something special at our facilities. In this newsletter, read Laural Traylor's article on caregivers for inspiration!

SCHOLARSHIP AND EDUCATION CLEARINGHOUSE

National Multiple Sclerosis Society Scholarship Program

Audience: Students with MS or who have a parent with MS

Application available Oct. 15, 2009, and due prior to Jan 15, 2010.

Link:

<http://www.nationalmssociety.org/get-involved/programs-and-services/scholarship/index.aspx>

National Multiple Sclerosis Society Scholarship Program

Application available Nov. 1, 2009.

You can support this fund by shopping with various retailers who donate up to 5 percent.

Link:

www.myspace.com/elainememorial

Research Opportunities

Grantor: Genentech and IOMSN

Audience: Nurses who are members of IOMSN

Up to \$5,000 for research

Link:

http://www.iomsn.org/research_grant.htm

Contact: Eileen Scheid
(Eileen_Scheid@URMC.Rochester.edu)
or
Suzanne Smeltzer
(Suzanne.smeltzer@villanova.edu)

IOMSN
P.O. Box 450
Teaneck, NJ 07666
Phone: (201) 487-1050
Fax: (201) 678-2291
Email: info@iomsn.org

ABOUT THE VA-SIG

The VA-SIG is a grassroots organization consisting of VA health-care professionals who care for patients with multiple sclerosis. We care for approximately 28,000 veterans with MS from coast to coast. We are unique due to the complexities of the patients we treat and a multidisciplinary approach to care. We have the luxury of having two MS Centers of Excellence, one on each coast. These centers provide a wealth of information for both patients and staff; however, the bulk of MS care is provided in the field. We have regional hub sites, based on population density and these hub sites have local spokes. Our members are from the centers, hubs, and spokes. It is our joint efforts that have made a significant impact.

MULTIPLE SCLEROSIS HEALTHCARE PROFESSIONALS SHAREPOINT SITE

PAUL GUTIERREZ, MD

The VA-SIG (Special Interest Group) for Multiple Sclerosis wants to remind you of an important resource for VA staff who are involved in the care of patients with multiple sclerosis (MS): the "Multiple Sclerosis Healthcare Professionals" SharePoint Site. This site was established to enhance communication between colleagues in VA who are treating veterans with MS. You can access this site at http://vawww.portal.va.gov/National_Sites/Other/Multiple%20Sclerosis%20Healthcare%20Professionals/default.aspx.

Useful features of the SharePoint Site include a calendar section that lists educational and other events of the VA-SIG and MSCOE's and a "shared documents" section that contains past newsletters, forms for patients on natalizumab or mitoxantrone, and other pertinent documents. In addition, the "People and Groups" section is a directory of VA staff involved in the care of veterans with MS.

We encourage you to review the information in this directory, and please notify us of anyone who needs to be added to the directory. We are working with the Office of Information Technology to modify the site to enable the updating of contact information (currently simply pulled from your Outlook profile) and addition of digital pictures so we can connect a face with a name.

We are also open to suggestions for modifications to the MSHP SharePoint Site to meet the needs of the providers. Please send any suggestions, events, or documents to be posted, or names of members to be added to the directory, to paul.gutierrez@va.gov.

VA FAMILY CAREGIVERS: PARTNERS IN QUALITY VETERAN CARE

LAURAL TRAYLOR, MSW

Caregivers are your friends, family, and neighbors, people you that you love, people that you know and, just maybe, *you* are a caregiver. Former First Lady Rosalynn Carter stated in her book, *Helping Yourself Help Others*, that “there are only four kinds of people in the world—those who are caregivers, those who were caregivers, those who will be caregivers, and those who will need care.”

If you aren't a caregiver now, there is a good chance you will be a caregiver at some point in your future.

AARP's Public Policy Institute (Valuing the Invaluable, 2006) reported there are approximately 34 million family and informal caregivers in the United States who support someone who is ill or disabled (approximately 11 percent of the population). Economist Peter Arno reported at the 2006 Veterans Affairs Care Coordination and Caregiving Forum, that the “value of the services family caregivers provide for ‘free’ is estimated to be \$306 billion a year.” The National Family Caregiver Organization points out that this amount is “almost twice as much as is annually spent on homecare and nursing home services combined (\$158 billion).” Based on this information, one VA Care Coordination article estimated the unpaid value of caregivers in Veterans Affairs to be roughly \$46 billion per year. In any event, we know that families and others provide critical support systems for veterans, whether through intrinsic altruism or a sense of duty or loyalty.

In 2005 a general survey queried VA staff about what they perceive to be gaps in service for caregivers both

inside VA and in the community. Staff identified the greatest needs in the areas of transportation, medication management education, communication with medical staff, individual emotional support, assistance with personal care, stress management, case management and service coordination, management of challenging behavior, caregiver self-care education, and social care and emotional support. Another survey was done in 2005 evaluating caregiver stress and burden in the general veteran population in Veterans Integrated Service Networks 10, 19, and 22. Caregivers' responses indicated that a significant number of VA caregivers experience stress and burden. Significant physical and mental health challenges can also result from the physical and emotional strain of caregiving.

November is National Family Caregiver Month! We salute all of the caregivers who provide unconditional support and care to veterans with multiple sclerosis. Thank you for all that you do!

People caring for someone with multiple sclerosis also face the unpredictability of this progressive disease. In one survey that examined family caregivers of MS patients it was reported that top needs included knowing that doctors and team members were interested and supportive and that the caregiver was made to feel valued. Caregivers also had a need for news and information from the MS clinic. (Koopman, Bendbow and Vanderboort, 2008). In another study, MS caregivers reported needs related to the functioning of their roles (education about caregiving tasks), diet and meal preparation, assistance with finances, child care, and house-

hold duties. Sato, Ricks, and Watkins (1996).

VA's staff has put great effort into keeping veterans living where they most prefer to be—at home and in non-institutional care. Family caregivers and others who provide ongoing, often life-long care to veterans are critical to keeping veterans in their home. VA recognizes that caregivers have their own needs and that if caregivers are to contribute quality care for veterans, they must be mentally and physically healthy. Unfortunately, sometimes caregivers don't understand the problems that they are facing, and even if they do, they often don't know where to go or how to ask for help. This is where VA staff can play an important role. There are resources in VA and the community that are not widely utilized and, therefore, go untapped. Veterans, caregivers, and VA staff being well informed about these resources can lead to better ways and alternative methods to keep our veterans and their caregivers healthy, happy, and at home. You are encouraged to contact your local VA and speak with a social worker regarding VA and community resources/programs that could make a positive difference.

There are a number of projects under way in VA that focus on caregivers. This year VA awarded \$4.7 million to support caregiver assistance pilot programs to eight VA sites across the United States. For further information, see <http://www1.va.gov/opa/pressrel/pressrelease.cfm?id=1428>.

[11] Metlife Juggling Act Study, Balancing Caregiving with Work and the Costs of Caregiving. Met Life Mature Market Institute, November 1999

VA-SIG STEERING COMMITTEE

Peggy Coffey, MD
Chair, Acting Editor
peggy.coffey@va.gov

Edward Daly, MD
Vice Chair
edward.daly@va.gov

Paul Gutierrez, MD
Membership
paul.gutierrez@va.gov

Sandra Williamson, NP
Clinical Care
sandra.Williamson@va.gov

Rachel Palmieri, RN
Past Chair
rachael.palmieri@va.gov

CALL FOR SPEAKERS

The centers are recruiting speakers who are involved with MS clinical trials—veterans with MS or who may have an interesting case study that they would like to share for one of the upcoming education conference calls for the following dates:

Oct. 13 or 14 @ 4 ET

Nov. 4 @ 4 ET

Dec. 8 or 9 @ 4 ET

Please contact Angela.Young4@va.gov to volunteer.

FOR THIS NEWSLETTER:

What would you like to see here?
Please SUBMIT:

- Forum topics
- Clinical questions
- Research topics
- Ongoing MS projects
- QI issues
- Outcome measurements
- Team initiatives
- Announcements

Please contact the *VA-SIG* editor Peggy Coffey at peggy.coffey@va.gov or assistant editor Angela Young at angela.young@va.gov.

A WORD FROM THE CENTERS

ANNUAL MEETINGS

The MS Center of Excellence–East will be having the Directors' and Coordinators' Annual Meeting September 13–15, in Baltimore. The MSCOE–West will be meeting in Portland October 16–17. Watch for a special VA-SIG report on these meetings in the next VA Signature Newsletter!

The 2009 Congress on Spinal Cord Medicine and Rehabilitation will be held September 23–26 in Dallas. For more information see <http://www.pva.org/site/News2?page=NewsArticle&id=10567>.

CAREGIVERS' CONFERENCES

November 4

21st Annual Caregiver's Conference
Seattle, WA

This conference, located at the Seattle facility, will provide information, education, support and a chance to meet others facing similar challenges as caregivers. It is targeted toward the needs of family members, friends and health-care professionals in the community caring for adults with chronic illness and/or disability.

November 5

8th Annual Caregiver's Conference
American Lake, WA

This conference will provide information, education, support and a chance to meet others facing similar challenges as caregivers. It is targeted toward the needs of family members, friends and health care professionals in the community caring for adults with chronic illness and/or disability.

TYSABRI

The information you provide on patients prescribed Tysabri is very important for patient care. Please complete the "initial" form for your new patients and don't forget to complete "annual" forms for all patients. Your participation is appreciated. Send both types of forms to Alicia.Sloan@VA.gov.

These forms are available on the Sharepoint Site, as discussed on p. 2, or the MSCOE website, www.va.gov/ms.

MITOZANTRONE

Do you have a list of patients treated with Mitozantrone at your facility? If not, contact Joel.Culpepper@VA.gov. These patients need follow-up on a regular basis. Want clinical advice on treating patients who have had Mitozantrone? Contact Ruth.Whitham@VA.gov (West), or Mitch.Wallin@VA.gov (East).

PATIENT RESOURCES

Does your facility receive VA Centers of Excellence *MS VETERAN*? Do you receive enough copies? If your facility needs copies, please contact Jane.Stolte@va.gov (East) or Drew.Blazey@va.gov (West)

Do Your Patients Know About the Available Education Calls?

Date: 2nd Monday of Every Month Time: 8–9 p.m., ET

Topic: A New Topic Every Month

To Participate: (800) 767-1750 (Access Code 43157#)

For a list of topics, contact Angela.Young4@va.gov.