

A Letter from the VA-SIG Chair

Dear Colleagues,

After many years of tireless service, our editor, Deborah Downey, has decided to pursue other interests. The steering committee would like to thank Debbie for her dedicated efforts in preparing the *VA SIGNature*. Her contributions have been greatly appreciated and we wish her success in future endeavors. If you are interested in editing the newsletter, please contact any of the steering committee members. And, of course, we are always looking for articles. The newsletter is our primary source of communication between the annual CMSC meetings.

The VA-SIG is very fortunate to continue to work with Thomas Stripling and Vivian Beyda, DrPh, both representing PVA. As our organization grew, we were “moved” within PVA from Research and Education to Medical Services, where we worked with Jim Dudley. We had only a very short time with Jim, and we appreciate his eagerness to help us reach our goals for participation in the annual meeting. We congratulate Jim on his retirement and thank him for his efforts and enthusiasm. And, Thomas, we thank you for taking us back. We also appreciate the support of United Spinal Association.

The VA-SIG is your organization and your contributions lead to its success. I encourage each of you to participate this year. As we start this new year, I thought a review of some of the important issues was in order. This entire newsletter serves as an update from the chair with information on many of the areas of importance to the VA-SIG. I hope this review will provide inspiration.

Sincerely,

Peggy A. Coffey, MD
VA-SIG Chair

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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*nature* editor, Peggy Coffey: peggy.coffey@va.gov.

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.

CMSC

The annual Consortium of Multiple Sclerosis Centers meeting will be jointly held with ACTRIMS (Americas Committee for Treatment and Research in Multiple Sclerosis), in Atlanta, Georgia, May 27–30. The economy has been plummeting, and we have been striving to improve financing for our members to attend this meeting. Hopefully, we can continue to have representation from most VA facilities. Watch the CMSC website, www.msca.org, for further details.

All VA employees and associates of the VA SIG / Multiple Sclerosis Centers of Excellence are invited to a “meet and greet” on Wednesday May 27, 2009 at 9 pm to 10:30. This relaxing, after dinner event promises to be very low key and ideal for new members to meet others and find out about the various organizations. If this is your first meeting, please come. For others, this is an ideal time to “catch up” with colleagues and make plans to meet during the rest of the CMSC conference. The “meet and greet” will be held in our hospitality suite. This year, we will use the hospitality suite to hold smaller group meetings on specific topics. Please stop by...stay for the rest of the evening to relax or just for a few minutes!

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Please see page 5 for a schedule of meetings and educational events sponsored by the VA-SIG/Multiple Sclerosis Centers of Excellence

Centers of Excellence

The Multiple Sclerosis Centers of Excellence (MSCOE) are a valued resource for all VA professionals caring for patients with MS. The MSCOEs have provided CDs of previous lectures, which are available by request. Please visit the MSCOE website, www.va.gov/ms. Topics available are as follows:

- Nursing Care for Patients with Multiple Sclerosis
- MRI Guidelines for Diagnosing and Managing MS
- Pain and Palliative Care in MS
- Advances in Treating Multiple Sclerosis
- Sexual Intimacy and Multiple Sclerosis
- Treating Multiple Sclerosis:
- Making a Difference in Veterans' Lives
- Fatigue and the Cognitive Effects of Multiple Sclerosis

Also, the MSCOEs have received positive patient feedback from the patient newsletter. If your patients do not receive this newsletter at your facility, please notify the MSCOE–West. If your patient has an inspiring story, please encourage him or her to submit it to the patient newsletter. We encourage you to write an article for the newsletter as well.

Most of us have had opportunities to review and comment on the MS Handbook, and now we would like to see facilities try the guidelines and provide feedback.

MSCOE–East Highlights

The MSCOE–East meeting was held in Baltimore last September. This meeting gave us a better under-

standing of the administrative organization of VA and opened the door for discussion on some of our issues pertaining to the annual meeting and supporting research.

Timothy O'Leary, MD, PhD, discussed how to navigate the research process and gave hints on career development. In talking about the review process for the Cooperative Studies Program, he cited poor methodology as a common reason for rejection. He listed Biomedical and Laboratory Research and Development as favorable source for funding, as this VA branch is responsible for research involving etiology, pathogenesis, diagnosis and treatment for diseases common to veterans. This branch supports research that is investigator-initiated, and the training of clinicians in basic and clinical research. He discussed the Merit Review Program, which is a principal mechanism to fund investigator-initiated research by VA scientists.

O'Leary also spoke about the Career Development Program, which offers protected research time for up to three years, and the VA Cooperative Studies Program (CSP), a group of experienced professionals who help researchers submit applications for their ideas. The employee submits a letter of intent to the CSP, which reviews submissions and approves appropriate projects for planning support. A planning committee convenes and develops a study protocol. A face-to-face review occurs and then a funding decision is made. One benefit of using this branch

is the shortened process for the researcher, who files a letter of intent instead of the entire application that could be required by, for example, the National Institutes of Health. Where to start? Dr. O'Leary recommends starting with a good question. The following website is helpful: <http://www1.va.gov/resdev/>.

Chris Jankosky, MD, MPH, CDR, MC, U.S. Navy, spoke about multiple sclerosis in the active duty population. Dr. Jankosky shared data on the number of cases per branch of service, gender, age at diagnosis, and race. He discussed his military experience, the opportunity to use the information available from the DoD's Silver Spring Serum Repository and reminded conference participants that military physicians are eager to collaborate with VA colleagues.

Michael C. Levin, MD, discussed infection and viruses associated with Gulf War veterans. He reminded all participants that JC virus, the cause PML, is present in everyone and a screening IgG titer is not helpful. He reviewed a "report card" for each of the typical viruses often associated with MS and questioned if persistence of a virus in the body is related to autoimmune disease, and, in particular, noted the sudden increase of MS in women living in Kuwait.

Walter Royal III, MD, also discussed infections and viruses implicated in Gulf War veterans. He discussed genetic distribution and incidence in Kuwaitis and listed Alshubaili AF, et al. *Eur neurol*, 2005 as a reference.

Centers of Excellence *continued*

Continued from page 3

He concluded that it is difficult to prove that infections cause MS.

There is no evidence to demonstrate that an endogenous infectious agent in Iraq is the likely cause of MS in Gulf War veterans. Gulf War veterans may have encountered agents in Iraq that are more commonly associated with MS in Western countries. He concluded that mechanisms triggered by other exposures in the Gulf region may be what causes MS.

William J. Culpepper II, PhD, MA, gave a report on the epidemiologic description of the VA Multiple Sclerosis Surveillance Registry. Please watch for these surveys and participate. Also, the MSCOE–East encourages VA sites to join the longitudinal study.

A panel discussion and debate on oral steroids versus intravenous steroids was held. As expected, the optic neuritis study from the '80s was mentioned, and many were concerned that a low dose of steroids was worse than no steroids. Others reported that they avoid oral dosing because of the large number of pills that have to be swallowed for adequate dosing. Bob Shin vividly illustrated this point by offering a cup of 64 M&Ms. Some members of the audience were receptive to the M&Ms analogy; however, general consensus was that patients prefer IV dosing. Various preparations, dosing, and duration of treatment were discussed. Watch for more discussion on oral steroids.

Robert Zivadinov, MD, PhD, gave an exciting lecture on advances in imag-

ing techniques. He also discussed a potential role of iron in the disease process.

MSCOE–West Highlights

The MSCOE–West met in Portland at the end of September. Highlights from the first day included breakout sessions to discuss the educational needs of providers and patients. Discussion focused on more extensive departmental collaboration among SCI/D, Neurology, PM&R, and Radiology departments. Some participants were concerned about having adequate resources to fulfill handbook suggestions. The suggestion of a coordinator position was mentioned. Others discussed patient access to all clinics.

The importance of proper Veterans Equitable Resource Allocation (VERA) assignment arose in discussion. Multiple sclerosis patients are classified as groups 4 and 5, depending on DMT supply. Some patients are class 8 or 10 for paraplegia/tetraplegia. Proper coding helps your facility obtain the support that both you and the patient need. Please speak to your local coding staff if you are unclear about the necessary documentation.

The topic of Tysabri continues to be of interest. At the time of the meeting, worldwide, 31,800 patients were taking this medication. We are all familiar with the three cases prompting the FDA to start the TOUCH (Tysabri Outreach Unified Commitment to Health) program. These three patients were also exposed to immune modulating drugs. Now we have two cases

of PML in Europe on single therapy. Please participate in the clinical monitoring project. Forms can be faxed to Alicia Sloan in Seattle. Also, the MSCOEs remind us to send the patient to a screening dermatology appointment to evaluate for melanoma and an eye exam to check for ocular nevus. We have not had any serious adverse events on Tysabri in VA to date. In the monitoring of patients on mitozantrone, these patients will require a Muga scan before each dose *and* annually thereafter. Remember, early treatment of CHF improves outcome.

Flu Shots

On another clinical note, please remember the flu shots are indicated for patients with multiple sclerosis. These patients are often at risk for respiratory complications. The vaccine does not cause exacerbations; however, influenza can cause an exacerbation. If the patient is currently having an exacerbation, a delay in vaccine is recommended. Avoid the nasal spray and follow the typical contraindications as indicated for all patients.

Site Visits

Thomas Stripling, our Paralyzed Veterans of America representative, discussed plans for site visits to all spoke facilities. Paralyzed Veterans is interested in the organization of MS care in each facility and plans to progress to concepts outlined in the MS Handbook in the future. The visit would be directed to problem solving with practical approaches.

Multiple Sclerosis Healthcare Professionals SharePoint Site

The VA-SIG for Multiple Sclerosis is pleased to announce the establishment of a SharePoint site for VA Staff involved in the care of patients with multiple sclerosis. We expect this site will markedly enhance communication among colleagues in VA who are treating veterans with MS. The site is called “Multiple Sclerosis Healthcare Professionals” and can be accessed at http://vaww.portal.va.gov/National_Sites/Other/Multiple%20Sclerosis%20Healthcare%20Professionals/default.aspx.

One of the important features of the site will be a directory of VA staff involved in the care of veterans with MS. I encourage you to review your information in this directory. It is also requested that you send a digital picture of yourself to include in your profile.

If you know of other people who are not currently included in the directory, but should be, please have them contact Paul Gutierrez at paul.gutierrez@va.gov.

This site will still need to undergo some modifications to meet the needs of the providers and thus will be a work-in-progress for the foreseeable future. Please send any suggestions or updates to Paul at the email address above.

CONTINUING EDUCATION ACTIVITIES

The following is a list of meetings and educational events sponsored by the VA-SIG/ Multiple Sclerosis Centers of Excellence.

Please note, the combine VA-SIG/ Multiple Sclerosis CoE meeting on Thursday, May 28 at 4:30- 6:00 pm is required for all scholarship participants.

Christopher Bever, MD, MBA, is directing a hands-on symposium on “Measurement Outcomes in Clinical Trials” from 9 a.m. to noon on Thursday, May 28. The program is as follows:

EDSS and Other Scored Neurological Examinations – Mitchell Wallin, MD, MPH
MS Functional Composite – Kerry Naunton, RN, BSN, MSCN, CCRC
Neuropsychological Outcomes – Aaron Turner, PhD
Neuro-ophthalmologic Outcomes – Robert Shin, MD
QOL and Other Patient Reported Outcomes – Heidi Maloni, RN, PhD

Thursday May 28, 1–4 p.m.

Advance Practice Nursing in MS by Kathleen Costello, MS, CRNP, MSCN
TBA–Robert Shin MD

Jodie Haselkorn, MD, MPH is directing a symposium on “Multiple Sclerosis and Mobility” from 9 a.m. to noon on Friday, May 29. The program is as follows:

Mobility in Multiple Sclerosis – Michelle Cameron, MD, PT
Making It Work: Doing What Matters at Home and On the Road – Janet Powell, PhD, OTR/L
Fitness, Exercise, and Assistive Technology – Patricia, Provance, PT, MSCS
Beds and Mobility: Functional Activities, and Preventions of Complications – Richard Buhner, MD, ARNP, MSCN
Rehabilitation through Sports and Leisure – Daniel Scott, MD

Saturday May 30 7–8 a.m.

Round Table

MS Veteran

The VA Multiple Sclerosis Centers of Excellence are proud to present their spring 2009 issue of the veteran newsletter "MS Veteran." The newsletter was recently mailed to 17,400 veterans throughout the United States. To meet the MSCOE's goal of reaching out to every veteran diagnosed with MS, 50 copies of the "MS Veteran" was mailed to each MSCOE network facility. If you would like to display the newsletter in your clinic area to help us ensure that every veteran with MS is reached, please contact: Jaimie Henry, MPA, at 503-220-8262, ext. 53296, or 1-800-949-1004, ext. 53296, or Jaimie.Henry@va.gov

Directory

We have been working on a directory to facilitate direct contact between members. Please see Paul Gutierrez' article in this edition. Remember, use of the directory is restricted to VA employees; however, non-VA employees can be listed.

Learn More About MS!

MS Centers of Excellence (MSCOE) produced and recorded DVD's from their live educational programs. They are a great way for clinicians and patients to learn more about MS.

- MRI Guidelines for Diagnosing and Managing MS
- Pain and Palliative Care in MS
- Advances in Treating MS: An Update on Dmts
- Sexual Intimacy and MS
- Treating MS: Making a Difference in Veterans' Lives
- Fatigue and Cognitive Effects of MS
- Mobility for People with Early/Transitional MS: A new DVD coming out at the end of May 2009. The VA satellite broadcast is scheduled for May 5, 2009. Interested in receiving free DVD's? Contact: Jaimie Henry, MPA, Ph: 503-220-8262, x 53296, Jaimie.Henry@va.gov

Veterans with MS: Patient Education Conference Calls

Learn first hand about Multiple Sclerosis (MS) from MS experts and other health care professionals.

Date: 2nd Monday of Every Month

Time: 8–9 p.m. ET, 7–8 p.m. CT, 6–7 p.m. MT, 5–6 p.m. PT

Topic: Different Topic Every Month

To Participate: Dial 1-800-767-1750, Access Code 43157#

Participation is free. Callers are anonymous. Questions can be asked as time permits. For questions about the call or topic for the month, contact Angela Young at 1-800-463-6295, ext. 7133 or send email to Angela.Young4@va.gov.

Please check with your medical director for information pertaining to the invitations for attending the CMSC meeting in May 2009.