

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

Hello Everyone,

I hope that this letter finds you all enjoying your summer.

As my first year as chair comes to a close, I can only hope my second year will be as exciting and challenging as the past one. Approximately 78 VA-SIG clinicians attended the 2003 Consortium of MS Centers (CMSC) meeting, which is phenomenal considering we only funded 45 clinicians. This shows our VA clinicians' commitment to the care of MS patients.

As you all know, we have established our MS Centers of Excellence—East, under the direction of Christopher Bever, MD, and —West under the joint direction of Jodie Haselkorn, MD, and Dennis Bourdette, MD. I am working closely with both centers to establish an ongoing link between our SIG and the centers. SIG committee liaisons will actively participate in the centers' educational and research programs. This collaborative opportunity will significantly improve MS care throughout VA.

For those not able to attend the CMSC meeting in San Diego, the SIG program was used to showcase the centers. The presentation by both centers was thorough and dynamic. It was exciting to see VA innovations in telecommunications. Further CoE development will be fertile ground for all types of research, and it is hoped that emphasis will be placed on allied health professional research as well as ongoing medical research projects.

Plans for the 2004 CMSC meeting are beginning. I would like to ask everyone for symposium ideas. I will need to bring the plans for the 2004 symposium to the CMSC board meeting in November, so if you have ideas, please email them to me.

I again want to encourage you to start, or in some cases continue, to serve as VA ambassadors in your local communities. I continue to give public education programs for our local MS society, and I'm scheduled to present on MS and the CoEs to our medical and house staff.

In closing, I would like to say how much I enjoyed seeing all of you in San Diego and meeting our new members. If any questions or problems arise during the year, please do not hesitate to contact me by phone or email.

Please stay safe and healthy,
Rachel Palmieri

“The Spectrum of Multiple Sclerosis Care”: A Conference Overview

This year’s annual meeting of the Consortium of Multiple Sclerosis Centers (CMSC), held in San Diego May 28–June 1, focused on “The Spectrum of Multiple Sclerosis Care.” The consortium consists of 108 member centers, including 53 Department of Veterans Affairs centers. More than 800 participants, both VA and non-VA, from the United States, Canada, and Latin America attended. The Paralyzed Veterans of America’s Research and Education program, together with the Eastern Paralyzed Veterans Association, supported the travel, registration fees, and accommodations for 45 VA clinicians to attend. In addition, another 33 VA clinicians attended. In total, VA representation included 78 clinicians from 45 VA medical centers, a remarkable turnout.

Saturday’s sessions were of particular interest to VA participants. Dr. Robert Roswell, VA under secretary for health, had agreed to keynote the morning session—demonstrating VA’s commitment to MS issues—but then was unable to attend. Mindy Aisen, MD, VA deputy chief research and development officer, substituted ably, giving an overview on the two new VA Centers of Excellence in MS, the VA-Special Interest Group on MS (a recognized section of CMSC), and VA’s research program on MS.

Dr. Aisen also spoke about the remarkable career of Dr. John W. Kurtzke, neurologist and epidemiologist, whose work spans nearly 45

years at the Washington, DC, VA Medical Center. Dr. Kurtzke was the recipient of this year’s CMSC Lifetime Achievement Award. In addition to his clinical work as an attending neurologist, Dr. Kurtzke’s research includes contributions on epilepsy, spinal cord injury, and MS. His landmark research work, which he presented at the conference, was a longitudinal study of three MS epidemics in the Faroe Islands between the 1940s and 1960s, following British occupation during World War II. Dr. Kurtzke’s conclusions suggest that the cause of MS may be a viral agent that triggers susceptibility in genetically predisposed populations. While further research is needed, Dr. Kurtzke’s work exemplifies the vast clinical knowledge and scientific expertise residing within VA.

The VA-SIG received presentations on the two newly designated VA MS Centers of Excellence. The two centers form a national partnership, serving as a hub to provide core clinical, educational, research, and informatics resources to support MS care at VA centers throughout the country.

These centers represent the results of five years of Paralyzed Veterans of America (PVA) program building and legislative advocacy, stemming from a PVA Board of Directors resolution six years ago. PVA can be proud of its efforts, which culminated in the establishment of these two centers in December 2002. For additional information on the centers, check out the web site www.va.gov/ms.

By Thomas E. Stripling, director of Research, Education & Clinical Practice Guidelines, Paralyzed Veterans of America

Announcement: First John N. Whitaker Memorial Lecture

**Monday, September 29, 2003
Baltimore VAMC**

The first annual John N. Whitaker Memorial lecture will be given by Henry McFarland, MD, clinical director, National Institute of Neurological Diseases and Stroke, on Monday, September 29, 2003, at the Baltimore VAMC. The memorial lecture will serve as the keynote address of the inaugural symposium for the MS Center of Excellence–East. The daylong symposium will include state-of-the-science sessions on neurodegeneration and neuroprotection in MS in the morning and on neuroplasticity in the afternoon. For additional information, contact Christine Martin, PhD, associate director for Education and Training, MS Center of Excellence–East at (410) 605-7060.

CMSC Research Interest Groups Meeting

The purpose of the newly created Multiple Sclerosis Clinical Study Group (MSCSG), recently announced by the Consortium of MS Centers (CMSC), is to develop highly meritorious clinical study proposals that will be submitted for competitive funding. A key part of the structure of the MSCSG is a series of research interest groups (RIGs), which are charged with the responsibility of generating ideas for clinical studies. A preliminary list of RIGs with the co-organizing members is given below. Memberships in

the RIGs are open to CMSC members. The first organizing meeting of the RIGs and MSCSG steering committee was held in Boston August 17–18. Ten to 12 representatives of each RIG attended this initial meeting. Individuals interested in joining RIGs should contact one of the co-organizing members:

Proposed Research Interest Groups (RIGs)

Psychosocial

Frederick Foley, PhD

ffoley1@aol.com

Deborah Miller, PhD, LISW

millerd@ccf.org

Rehabilitation

Susan Bennett, PT, EdD, NCS

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Ben Thrower, MD

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Immunology

Steven Kamin, MD

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Kottil Rammohan, MD

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Epidemiology

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A. Dessa Sadovnik, PhD

sadovnik@infeinet.net

Symptom Management

Francois Bethoux, MD

bethouf@ccf.org

Eileen Scheid, RN

escheid@mail.neurology.rochester.edu

Boston, Buffalo, Charleston, Cleveland, Jackson, New York, Philadelphia, Richmond, Tampa, and Washington, DC. Also attending was Dr. Jodie Haselkorn, representing the MS CoE–West.

The Regional MS Program

Concept: The mandate of the MS CoE initiative is to develop a network of regional “hub” programs that are staffed by providers with expertise in the care of MS patients who will oversee and coordinate the care of MS patients being seen in facilities in their region that lack MS subspecialists. The plan of the MS CoE–East is to have at least one hub center in each of VISNs 1–11. The purpose of the organizing meeting was to gather the leadership of the regional hub programs identified thus far to review hub center functions in research, education, and clinical areas.

Research: The MS CoE is mandated to promote research throughout the network. The use of the network to support a long-term longitudinal study of MS outcomes was presented by Dr. Christopher Bever. The longitudinal study will utilize established clinical measures, including the Kurtzke EDSS and the MS functional composite (MSFC). Workshops were held reviewing scoring procedures. In addition, Dr. Robert Kane, associate director for Communications, CoE–East, presented advances in web-based neuropsychological testing that are available for application.

The study will include automated segmentation analysis of yearly cranial MRI scans, which was discussed by Dr. Joseph Frank, NINDS. Dr. Suhayl Dhib-Jalbut, research associate director, CoE–East, dis-

cussed immunological studies that will be included in the longitudinal study as potential predictors of long-term outcome. The goal of the longitudinal study is to enroll 200 patients over the next 12 months to generate preliminary data that would be used to support a cooperative studies application for extended funding. Dr. Paul Hoffman discussed other opportunities for research funding from VA, NIH, and NMSS. Dr. Jodie Haselkorn discussed opportunities in rehabilitation research. Current MS-related research projects from Baltimore, Cleveland, and Tampa were presented and discussed.

Education: Regional MS centers will promote patient, family, and provider education. The program included discussion of traditional educational approaches as well as academic detailing. In the latter, the program coordinator would travel to providers who are caring for MS patients at regional facilities that lack MS subspecialists to meet with them and discuss issues of MS management based on existing clinical practice guidelines and evidence-based management approaches. The program also presented educational approaches made possible by advances in informatics such as web-based educational programs and educational materials embedded in the computerized patient record system of VA.

Clinical Care: The regional MS programs will work within the network to promote a uniform, high level of care for MS patients regardless of the site of their care. This would be promoted by the use of standards of care, such as clinical practice guidelines (CPG). Existing

VA MS Center of Excellence–East: Update

The first meeting of the MS regional program directors and coordinators of the MS CoE–East was held at the Baltimore VAMC June 20 and 21. Represented were the following VA programs: Albany,

CPGs for spasticity, bladder dysfunction, fatigue, and disease-modifying therapies were discussed. Working groups to update CPGs and adapt them to the VA system will be developed and outcomes will be identified that can be tracked in the VISTA database to determine whether their implementation alters outcomes. To allow for centralized planning and resource allocation for MS-related clinical programs, an MS case registry was mandated as part of the MS CoE initiative. The registry was presented and the key role of the regional hub centers in case verification was discussed.

By Christopher Bever, MD, director, MS Center of Excellence–East

VA MS Center of Excellence–West: Update on Clinical Care Initiatives

The recent Consortium of MS Centers annual meeting in San Diego in May provided a great opportunity for us to share our initial vision for the clinical care programs for the VA MS Centers of Excellence and to meet face-to-face with clinicians involved in providing care to veterans with MS. There is much work to be done and much enthusiasm from members of the VA-SIG.

The Portland/Seattle VA MS Center of Excellence–West is working on a number of clinical care initiatives, with our top priorities largely determined by initial feedback from VA MS clinic directors in VISNs 12–23 and from primary care providers within our own

VISN 20. We will also be working closely with the VA-SIG Clinical Care Committee and coordinating our activities with those of the MS Center of Excellence–East. Highlights of our work and a preview of future plans are outlined below:

- A survey of MS clinic directors in VISNs 12–23 was completed. Responses for VISNs 12, 16, 17, 19, and 20 indicate that (1) these VISNs have one or more MS clinics; (2) MS clinics are commonly directed by a neurologist; (3) essentially all MS clinics offer standard diagnostic tests, such as MRI and CSF exam, rehabilitation services, urological services, and neuro-ophthalmology or ophthalmology services; and (4) some, but not all, MS clinics offer a clinical trials program, a spasticity/baclofen pump program, or a spinal cord injury program.
- A review of MS clinic visits at the Portland VAMC over the past two years indicates that 90 percent of the clinical activity is for ongoing care of MS and that 10 percent of the visits are for MS veterans new to the facility. This suggests that clinical activities targeted at meeting the ongoing care needs for veterans with established MS and their providers will be important. We also need to determine if newly diagnosed veterans with MS are being promptly referred to a VA MS clinic.
- A **toll-free number** for VA health care providers in VISNs 12–23 to access VA MS CoE–West clinicians 24/7 will be available in September.

- The MS CoE–West will host a regional MS meeting **September 25 and 26** for MS clinic directors from VISNs 12–23, with at least one representative from each VISN. The agenda will include clinical and research topics.
- Enhancements in CPRS are being developed, such as progress note templates, easy orders, and links to clinical practice guidelines, that should make it easier to provide consistent, high-quality care. We are piloting the use of a template in the Portland VA MS Clinic, and we will be able to export it to interested VA providers in the near future.
- Recruitment for a postresidency fellow in multiple sclerosis has begun. Candidates from neurology, physical medicine and rehabilitation, or internal medicine are encouraged to apply for July 2004 admission (contact ruth.whitham@med.va.gov or jodi.haselkorn@med.va.gov). The first MS CoE–West fellow, Jesus Lovera, MD, began his fellowship in July 2003. Lovera completed a three-year neurology residency at Tulane University, where he was the neurology chief resident. He is also completing a master of science in public health. Lovera is based at the Portland VAMC; he plans a two-year Research and Clinical MS Fellowship.
- We will implement pilot telemedicine initiatives to maximize our outreach to veterans with MS and to enhance clinicians' abilities to consult with each other and to obtain CME. Please contact us if you would like more information or want to get involved.

- A training program for VA physical therapists and occupational therapists will be developed by Cinda Hugos, MS, PT, and Lois Copperman, PhD, OTR, in conjunction with VA MS CoE–West clinicians.
- Web-based resources for providers will be available at <http://www.va.gov/ms>.

Thanks to all MS clinic directors and/or chiefs of neurology or PM&R in VISNs 12–23 who completed the questionnaire regarding their MS clinics. Many of you also included helpful suggestions for the MS Centers of Excellence and expressed willingness to participate in the VA Council of MS Clinic Directors. Please email us if you are a MS clinic director in VISNs 12–23 and did not receive our introductory questionnaire, and we will resend it. We also welcome suggestions and comments from the VA-SIG membership.

By Ruth Whitham, MD, associate director for Clinical Care of the VA MS CoE–West, ruth.whitham@med.va.gov

VA MS Provider Assessment Survey—A Brief Snapshot of Results

Sincere thanks to all of those who completed our “Provider Assessment” survey at the CMSC meeting in San Diego. The goals of the survey were to (1) assess current educational needs, (2) assess current standards of practice, and (3) identify contact persons to develop a network of providers with an interest in caring for persons with MS. In addition to distributing the surveys at the

CMSC meeting, we are planning to send them to other providers in VHA facilities who are identified as providing care to MS patients. If you haven’t taken the survey and wish to do so, it can be accessed at the MS CoE web site: www.va.gov/ms. Just click on “Please fill out an MS provider survey.”

Here is a brief snapshot of our results to date. One hundred and fifty-two providers completed the survey at CMSC, of which 58 (38 percent) were from the VHA. Among total providers, approximately 24 percent were physicians, 34 percent were nurses, and 7 percent were physical therapists. The remaining 35 percent of responses were obtained from a wide variety of professionals, including occupational therapists, pharmacists, physician assistants, psychologists, social workers, and speech and language pathologists. Providers were asked to identify areas in which they were interested in receiving continuing education in the future; the most common response was cognition (13.5 percent), followed by fatigue (11.5 percent), disease-modifying therapies (10 percent), spasticity (8.8 percent), pain (8.6 percent), and sexuality (7.6 percent). When asked to identify areas on which they would most appreciate consultation, providers identified almost exactly the same areas.

These results are in agreement with veteran-identified priorities for more education, assessed by MS CoE–West in a 2000 needs assessment. Specifically, veterans identified fatigue as the subject on which they would most appreciate more information and education. Other

identified priority areas were, in order, cognition, vision, pain management, mobility, bowel care, and bladder management.

We look forward to gaining feedback from additional providers and anticipate submitting a more complete summary of our data in the near future. Special thanks to the VA Employee Education System for collaborating with the MS centers to create our survey.

By Aaron Turner, PhD, MS Center of Excellence–West, Education & Training staff

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Centers of Excellence— Education Program Report

The Education Core of the MS Centers of Excellence has published the following goals:

The education and training core will improve veterans' health and quality of care by increasing provider and patient knowledge, self-efficacy, and access to resources. Our collaborative and comprehensive programs will be designed to:

- Address the educational needs of veterans, their caregivers, and providers;
- Build collaborations between VHA and other facilities;
- Increase veterans' and providers' knowledge of best practices guidelines;
- Empower veterans and their caregivers to participate actively in their health care;
- Broaden the educational and research experience of health-care providers through continuing education, mentoring, consultation, and preprofessional training;
- Target across provider audiences: physicians, nurses, therapists, and allied health professionals.

Our strategies for delivery include:

- To disseminate clinical practice guidelines for care of veterans with MS to providers using innovative and accessible technology;
- To develop tailored educational resources for patients, caregivers, and family members;
- To develop discipline specific pre-professional training program

materials related to MS, for dissemination throughout the VHA.

VA-SIG members meeting during the Education roundtable discussion at the MS Consortium in San Diego concurred in their discussion with these published goals of the Education Core. VA-SIG members Donna Healy, from the Iowa City VA, and Vidya Jayawardena, from the Richmond VA, offered to act as liaisons to the MS CoE's Education Committee.

At a recent meeting, the MS CoE–West Education Committee finalized educational goals for year one (ending Oct '03) as follows:

1. Distribute MS provider survey feedback;
2. Continue MS CoE web site development—link to existing approved guidelines.

By Lynne Walker, CRRN, MS Center of Excellence–West, Puget Sound Health Care, Seattle Division

SIG Research Roundtable

The VASIG research committee met in roundtable discussion at the CMSC meeting in San Diego May 31. Several ideas for cooperative studies within the VA were discussed:

- A multicenter, prospective, cross-sectional study of the immunomodulatory drugs currently available for MS: Copaxone, Rebif, Avonex, and Betaseron. The plan is to study both naive patients and patients up to EDSS 5 already on treatment. They would be followed with certain measures of efficacy, includ-

ing EDSS, MS functional composite (MSFC), and annual MRI, using the consortium guidelines for MRI in MS to measure lesion load, enhancing lesions, and cerebral atrophy.

The primary outcome measures would be MSFC and the MRI. Some discussion was made about adding certain tests to the MSFC to increase its sensitivity and measure other aspects of the MS condition, such as a contrast sensitivity visual test and the oral form of the Symbol Digit Modalities Test. Also, the addition of double-dose, twice-a-week Avonex patients to the study would be of interest. A standard for drug failure must be developed as a definite endpoint for this study, at which time the patients may be switched to another drug or a drug may be added. Since the May meeting, Dr. Robert Herndon has drafted a protocol for this study for review. This was presented at the meeting of the VA membership of the MS CoE–East in Boston June 21–22. Contact me at robert.baumhefner@med.va.gov for the draft protocol.

- Also proposed at the roundtable was a study of add-on drugs with secondary progressive MS patients who have failed immunomodulatory therapy. The drugs used would have a track record of some benefit in MS, including, but perhaps not limited to, azathioprine, mitoxantrone, cyclophosphamide, methotrexate, and pulse corticosteroids. Dr. Christopher Bever, director of the MS Center of Excellence–East, is working on a protocol for this type of study.

- Other ideas for studies discussed included pilot trials of Cellcept, 5-fluorouracil, and twice-a-week Avonex.
- Studies of symptomatic therapy also were discussed. One proposal was a comparison trial of drugs for fatigue, perhaps in a crossover study design.

The updated membership of the VASIG research committee is as follows:

Robert Baumhefner, Nancy Adams, John Bachman, Christopher Bever, Donna Jo Blake, Dennis Bourdette, Ed Daly, Irene Estores, Alan Forte, Smaranda Galis, Jodie Haselkorn, Robert Herndon, Richard Kazel, Kyuha Lee, Albert Lo, Joseph Nicolas, Salome Perez, Sunil Sabharwal, Rita Shapiro, Bill Tyor, and Sally Zachariah.

By Robert Baumhefner, MD, neurologist, West Los Angeles VA Medical Center

Call for All MS Social Workers

We are seeking contact information for all of the social workers currently employed in the MS field. If you are, or work for, a member of the Consortium of MS Centers, let us know how we may contact you directly. We are developing a list of social workers who are interested in becoming involved with the work we do for the CMSC web site. Send us your name, work address, phone number and email address. I will get back to you and tell you about our activities. Contact Teri Jiwa, RN, MSW, CMSC web site project leader for social work: tjiwa@vanhosp.bc.ca.

Call for VA Research Papers for 2004 Consortium of MS Centers Symposium

We are soliciting ideas for specific topics that can be presented at next year's symposium. I would like to hear from our VA MS providers by October 1 if you have a research topic or paper you would like to present. Again, please contact me by October 1! Thank you.

By Rachel Palmieri, chair, VA-SIG, rachel.palmieri@med.va.gov

Guide to Nursing Home Care for Individuals with MS Available

The Professional Resource Center of the National Multiple Sclerosis Society has recently published a new document to assist nursing homes in providing the targeted, specialized care that residents with MS require. Titled *Nursing Home Care of Individuals with Multiple Sclerosis: Guidelines and Recommendations for Quality Care*, this publication provides information that is both practical and easily referenced. The guidelines address nursing and daily care, rehabilitation, psychosocial needs, and cognitive issues. To obtain a copy, contact Alicia Soto at (212) 476-0457 or alicia.soto@nmss.org.

PVA 2002 Research Program Report Available

The Paralyzed Veterans of America recently released the 2002 annual report for its Research, Education & Practice Guidelines program. The report covers the activities of PVA's Spinal Cord Research Foundation, Education and Training Foundation, and the Consortium for Spinal Cord Medicine (which PVA administers), as well as other special projects of the department, over the past fiscal year. The report is available free of charge. For copies, please contact Elinor Tucker, PVA associate director of Research and Education, at (202) 416-7651 or elinort@pva.org; or download a copy from the PVA web site at www.pva.org.

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 VA-SIGNature Editor at deborah.livingstone@med.va.gov

Thank you!