

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 time of year finds you all in good health and not too harried.

With the end of the calendar year fast approaching, it is a good time to assess our progress with multiple sclerosis. For VA it was a monumental year with the MS Centers of Excellence—East (CoE—East) and —West (CoE—West) up and running and their staff working hard to develop programs. As many of you know, both centers presented a fine overview at the Consortium of Multiple Sclerosis Centers (CMSC) VA-SIG symposium in June. We look forward to their symposium at the CMSC conference in June 2004.

As chair, I had the privilege of representing the VA-SIG at the CoE—East strategic planning conference, which was very well planned. The VA-SIG will continue to play an integral role in helping both centers develop. In addition, the VA-SIG continues to be a major contributor to the CMSC with VA attendees representing the largest percentage of members that attend the yearly conference. Also of interest, I participated in a conference call with the PADRECS to assist them in developing a VA Special Interest Group.

The VA-SIG will have elections for new officers at the CMSC June meeting. Offices to be filled are chair, vice chair, and chairs for the membership, research, education, newsletter, and clinical care committees. I urge everyone to give these offices consideration; we need new blood to infuse these offices with energy. Each position requires a two-year commitment to serve and comes with the expectation that each officer will accomplish his or her respective goals. Many of you would do a great job in these positions, and I look forward to seeing your names nominated.

As the CoEs develop, the VA-SIG will look at how to effectively integrate into this MS network to enhance their efforts. The groundwork is being laid as I write. This is a work in progress.

I hope that the new year will bring peace, good health, and prosperity to all of you.

Sincerely,
Rachel Palmieri

VA-SIG Inaugural Symposium Synopsis

The Multiple Sclerosis Center of Excellence–East (CoE–East) recently held its inaugural symposium at the VA Medical Center in Baltimore, Maryland. Attended by local and regional clinicians and researchers, as well as several MS CoE–East hub directors and clinical coordinators, the symposium featured the first John N. Whitaker VHA Distinguished Lecture in Multiple Sclerosis, which was awarded to Henry McFarland, MD, director, Clinical Neurosciences Program, National Institute of Neurological Disorders and Stroke.

The Whitaker Lectureship alternates annually between the MS CoEs and celebrates the many contributions Dr. Whitaker made both in understanding MS and to holistic care of veterans with multiple sclerosis. Serving as a VA staff neurologist in Minneapolis, Memphis, and Birmingham, he won both clinical and medical investigator awards for his research on the interaction of myelin basic protein and MS, and he participated actively in both clinical and research at local and national levels. Dr. Whitaker helped frame the concept of the two national VA MS Centers of Excellence and contributed to the description of their function to improve MS veterans’ care. President W. Ann Reynolds of the University of Alabama at Birmingham remarked upon his passing: “It is fitting that the VA MS Centers of Excellence should recognize and honor Dr. Whitaker for the monumental contributions he made both in our understanding of MS and his lead-

ership in the improvement of care for MS veterans across the United States.”

Mrs. Elaine Whitaker and son Jeff were guests of honor for the day-long symposium, which included discussions of (1) recent research advances regarding the pathogenesis and treatment of MS; (2) evidence of neurodegeneration and the role of neuroprotective agents in MS; and (3) the investigation of neuroplasticity and the potential for its application in the rehabilitation of patients with MS. Mrs. Whitaker addressed the audience and candidly expressed her thoughts on how her husband would have appreciated the dedication of the center and lectureship in his honor. Her moving and heartfelt commentary was warmly received by the people in attendance.

Dr. McFarland’s keynote address focused on mechanisms involved in the acute brain lesion and the relationship of the acute lesion to the mechanisms that contribute to the progression of MS. The relationship between disability, inflammation, and degeneration over time were shown for varying courses of the disease. Discussion regarding varying hypotheses and evidence of progression from several noted studies ensued. Dr. McFarland noted that the past two decades have seen much progress in both our understanding and ability to treat MS. The combination of innovative clinical trials of new therapies done with careful MRI measures of disease activity and immunologic and genetic assessment of the effects of the therapy should continue to provide improved understanding of the disease and hopefully new therapies. A truly effective therapy will need

to target both the inflammatory component of the lesions as well as the processes that contribute to axonal loss.

Joseph Frank, MD, chief of Experimental Neuroimaging in Diagnostic Radiology Research at National Institutes of Health, began the morning session on neurodegeneration and neuroprotection, discussing the techniques and measures of MRI as predictors of MS, and reviewing the evidence from MRI studies of neuronal and axonal loss. T1 black holes may be useful in this regard but most enhancing

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lesions appear hypointense on uncontrasted T1 scans, later recovering and appearing isointense. New or total enhancing lesions indicate 5 to 10 times more activity than clinical disease with the associated burst of activity correlated to exacerbations in the course of MS.

Advanced techniques used to monitor these lesions include magnetization transfer imaging, diffusion weighted imaging, magnetic resonance spectroscopy (MRS), and magnetic resonance spectroscopy to monitor cerebral atrophy.

In discussing potential targets for neuroprotection, Gary Fiskum, PhD, Department of Anesthesiology, University of Maryland School of Medicine (UMSoM), defined the necrotic and apoptotic mechanisms of neuronal and oligodendrocyte cell death as major contributors to the pathophysiology of MS. Since multiple genes, proteins, and pathways are involved in cell death and survival, the knowledge of the cellular death mechanism provides potential investigative targets for neuroprotection.

Paul S. Fishman, MD, PhD, professor of neurology at UMSoM presented clinical evidence of neuroprotective agents in several neurodegenerative diseases including ALS, Parkinson's, and Alzheimer's Disease. These diseases share common aspects, such as age-related incidence, possible diagnosis prior to disability, and region-specific cell loss. The merits and drawbacks of several neuroprotective trials were discussed for each disorder.

Suhayl Dhib-Jalbut, MD, professor and chairman at the Robert Wood Johnson Medical School, spoke on the dual nature of inflammation in MS as having both detri-

mental and beneficial effects. From a neuroprotective perspective, glatiramer acetate (GA) therapy has been shown to induce Th2 cells with anti-inflammatory and neuroprotective properties. Additionally, GA-reactive T-cells produce brain-derived neurotrophic factor (BDNF), which relates to the ability of GA to reduce the proportion of new lesions evolving into permanent black holes. Dr. Dhib-Jalbut presented evidence that neurotrophic factors such as BDNF can be delivered into the brain using bone marrow cells as a vehicle. This could have potential therapeutic implications for the treatment of neurodegeneration in MS.

The afternoon session on neuroplasticity and neurorehabilitation began with Christopher Bever, MD, MS CoE–East director, who discussed the potential of neuroplasticity in MS patients by presenting evidence of cases that have included compensatory neuroplastic cortical change and functional reorganization in response to disease activity.

Daniel Hanley, MD, PhD, Division of Brain Injury Outcomes, Johns Hopkins Medical School, discussed an animal model of neuroplasticity. In this model, motor learning occurred in stages across different time frames and was protein synthesis dependent. The implication is that interventions will probably need to be synchronized to motor learning stages.

Jill Whitall, PhD, Department of Physical Therapy, UMSoM, presented imaging evidence of neuroplasticity after chronic stroke rehabilitation and emphasized the application of rehabilitation techniques known to induce neuroplasticity. Her clinical

data were based on studies using bilateral arm training with rhythmic auditory cueing. Neuroplastic changes were demonstrated both through changes in functional MRI and transcranial magnetic stimulation.

Richard Macko, MD, associate director of Research, Baltimore VA GRECC, is currently investigating task-oriented exercise following stroke and presented rationale for a similar study to be developed for MS patients. Citing several studies, Dr. Macko presented evidence that adaptive brain plasticity present in MS appears to be characterized by increased ipsilateral cortical activation during motor tasks.

Patricia Coyle, MD, acting chair of the Department of Neurology, SUNY Stony Brook, ended the day by providing critical commentary of the days' activities, suggesting direction for future research and collaboration in the field of MS.

By Christine Martin, PhD, assistant professor, associate director of Education and Training, MS CoE–East at the VA Maryland Health Care System–Baltimore, christine.martin@med.va.gov

USE TOLL-FREE NUMBER FOR MS CONSULTATION

Health care providers in VISNs 12–23 now can access the MS Center of Excellence West's VA MS Consultation Service via a toll-free telephone number. Consultation is available from VA clinicians of the MS CoE–West. If no one is available to take your call immediately, you may leave a voice message, and someone will attempt to return your call within 30 to 60 minutes.

The telephone number is (866) 76-MS CoE (766-7263).

This number is intended for use by VA health care providers. Providers should feel free to share this number with other VA providers within VISNs 12–23. However, please provide this number only to VA providers and not to patients.

We already have begun to receive calls at this number, and we look forward to speaking with you about issues related to individuals with MS or about MS in general. If you use the consultation service, please provide feedback on its helpfulness or suggested improvements. If you have trouble reaching us using the toll-free number, please notify us via email at ruth.whitham@med.va.gov.

VA MS Web Site Is Up

The MS Centers of Excellence (MS CoE) have launched a new web site devoted to clinicians, veterans with multiple sclerosis, and their caregivers. The MS CoE web site (www.va.gov/ms) focuses on providing guidance and answers to frequently asked questions from both a clinician's and veteran's perspective.

Current Functionality

- guidance for providers and veterans with MS and their caregivers;
- frequently asked questions;
- disability response questionnaire for future development of the web site;
- feedback;
- enrollment of email address for mailing list; and
- "About MS-CoE," providing description of the mission and organization of the MS Centers.

While some topics are covered in the initial launch, web site visitors are encouraged to submit new questions and topics related to MS and care at VA. Selected submissions will be reviewed and answered by MS experts and posted to the site. MS CoE has established an editorial review board that will solicit specialists in MS to write content on MS-related or VA-related issues. The editorial review board is composed of a physiatrist, two neurologists, an MS nurse specialist, a rehabilitation psychologist, and a technical communications specialist.

With the site, the MS COEs seek to develop an evolving inventory of peer-reviewed information that meets the interests and needs of the VA communities they serve.

Responses will be posted in indexed form so that they can be found both by category and using a search feature. The web site will also feature recent news and important events that will be posted on the front page for immediate viewing.

Visitors will also be able to provide feedback on their experience at the web site and, should they choose, provide an email address so that they may be notified when significant content is added or major features released. All content will be reviewed by the editorial review board and dated. The web site is currently under development, and feedback on current functionality or new features that you would like is encouraged.

By Michael Hatzakis, MD, associate director for Information Technology and Communications, MS CoE–West

MS COE–West Regional Meeting Summary

On September 24–26, 2003, the MS Center of Excellence–West held its first regional meeting in Portland, Oregon. In attendance were representatives from VISNs 12–23 and special guests John Booss, MD, chief of Neurology, VA Central Office; Vivian Beyda, DrPH, Eastern Paralyzed Veterans Association; Jack Simon, MD, PhD, Radiology Department, University of Colorado; Steve Berkowitz, PhD, from the VA Central Office; and Christopher Bever, Jr., MD, director, MS CoE–East.

The following summary outlines the general outcomes of the meeting and goals for the upcoming year.

RESEARCH

1. Dr. Dennis Bourdette, codirector, MS CoE–West, reviewed the special nature of the veteran population with MS and the unique opportunities available for MS-related research within VHA.

2. Dr. Steven Berkowitz provided an overview of the reorganization of VA Research and Development and then discussed the process for applying for a VA cooperative studies grant.

3. There was a general discussion of potential studies that might be proposed for VA cooperative studies. At the conclusion of this discussion, there was a general agreement that a natural history study of MS with specific hypothesis to be tested would be an excellent VA cooperative study proposal.

Key hypothesis that could be tested include the following:

- Early initiation of DMT will delay progression to an EDSS of 6.0.
- Comorbidities, such as post-traumatic stress disorder, cigarette smoking, and risk factors for atherosclerotic disease, increase the rate of progression.
- Male gender is associated with a greater risk of progression among patients with relapsing MS.
- Drs. Bourdette and Haselkorn will hold a teleconference with Dr. Bever to discuss a possible natural history study on MS to be submitted to VA Cooperative Studies.
- A CPRS clinical reminder, which will pop up when a disease modifying therapy (DMT) is ordered in CPRS, is being developed by Dr. Michael Hatzakis. The clinical reminder will capture MS disease subtypes (RRMS, SPMS, PPMS) so that it can be linked to a national VA database.
- Discussion is continuing regarding final selection of a motor disability measure that can be easily scored by non-MS specialists and MS specialist providers, to be used in the DMT Clinical Reminder for linkage to a VA Database. EDSS and the Disease Steps Score were both proposed and discussed.
- Other CPRS enhancements, such as automatic linkage to laboratory orders for interferon prescriptions and linkage to physical therapy order menus, are planned.

- The five available Multiple Sclerosis Council CPGs (Disease Modifying Therapies, Fatigue, Immunizations, Urinary Dysfunction, and Spasticity Management) will be posted on the MS CoE web site in a user-friendly, searchable format.
- Additional “MS Clinical Management Strategies” will be developed with content and advisory input from the MS CoE–West Council.

CLINICAL

1. 800 Number for MS Consultation: *(Editor’s Note: Please see related article in this issue.)*

- An email contact for an MS clinic director in the caller’s VISN will be provided when appropriate, to arrange follow-up consultation locally.
- A list of VA MS clinic resources in each VISN will be developed, e.g., availability of intrathecal baclofen pump placement and refills.

2. CPRS MS Templates and Enhancements

- Gordon Campbell, FNP, is developing a New MS Outpatient Evaluation Template. The goal is to export a template to other VISNs by the end of the calendar year.
- A standardized VA interfacility MS Consult request form will be developed by MS CoE–West and shared with other VISNs.

3. MS CoE–West Network/Western Council of VA MS Clinic Directors

- There was significant interest in the development of an MS CoE–West Council of VA MS Clinic Directors, representing VISNs 12–23, serving an advisory and information exchange function for MS CoE–West.
- Annual spring and fall meetings of the council will be held, with EPVA and PVA representation on the council.
- Council activities will be coordinated with VA MS CoE–East and the VA-SIG.

4. MS Clinical Practice Guidelines (CPG) and MS Clinical Management Strategies for VA.

MRI and MS

1. Dr. Jack Simon presented a summary of the MS Consortium MRI Protocol for the Diagnosis and Follow-up of MS, which will be linked to the MS CoE web site.
2. MS CoE–West will explore with VA Neuroradiology Faculty in VISN 20 the feasibility of standardizing MRI in MS in VISN 20, in preparation for a possible later proposal to standardize MRI in MS in all VISNs.
3. Regional meeting attendees were generally enthusiastic about standardizing MRI in MS and doing so under the auspices of the VA MS CoE–West Council. Concerns were expressed about possible local obstacles to implementation.

EDUCATION

1. One of the education core goals is to develop materials that reflect provider and veteran priorities and needs. To this end, we are formally assessing the needs of providers in two ways.
 - First we designed a survey to (1) measure current practice, per-

ceived needs, and resources and (2) identify contact persons nationwide.

- To identify providers who treat veterans with MS, but who do not identify themselves as MS experts or attend MS-specific meetings, we plan to identify veterans with MS using the nationwide patient record database in Austin and then identify their providers and contact them to find out how we might best assist them. We will also check the feasibility of contacting facility chiefs and directors and ask them to identify persons who treat veterans with MS in their facilities.

2. Another major topic was development of web site content. An editorial board (Drs. Bowen, Williams, Hatzakis, Bever, Martin, and Lynne Walker) will coordinate the review of all materials to be posted on the web site. Members of the MS councils in both the East and West will be reviewers, as well as contributors, to the web site. Meeting participants were supportive of this proposed process and requested formalization of this process to ensure a consistent peer review format.

3. The third major topic was development of teaching guidelines, which are comprehensive and organized systems based on best clinical practice guidelines. Meeting participants expressed a preference for products and tools that would be available quickly, such as handouts for veterans that could be downloaded from the Web at the point of care. Education core will discuss this feedback and revise plans as indicated.

4. Finally, we discussed several other educational initiatives, such as the postdoctoral fellowship and the development of a manual and course to teach providers how to plan and implement group-based psychosocial interventions.

ELECTRONIC MEDICAL RECORD

1. An interfacility consultation process was established for VISN 20 and other non-VISN 20 sites. We began a network of referrals such that a contact would be designated for each facility to facilitate easy communication.

2. Encounter template: We received consensus on the initial patient evaluation template in VISN 20, which will undergo final review and implementation by spring.

3. Clinical reminders: A conceptual reminder to be used to improve prescription rates for DMT agents was demonstrated. A beta test in several VISN 20 sites is planned for later this calendar year.

4. Links to clinical guidance: Support was obtained for continued development of the linkage of electronic record with training info on the VA MS web page.

REGISTRY

1. Broad support and enthusiasm was achieved for the registry project that could represent data to providers including, but not limited to, geographic mapping, summarized data (analogous to the Advanced Health Management system in VISN 20), and direct access using SQL (structured query language queries).

2. We discussed methods to populate the registry with prospective data. Consensus was not reached as to the most effective method to accomplish this or the exact data to be populated. There was broad support for a subtype designation but not for disability level.

TELEMEDICINE

1. We plan to develop a formal survey of experience and capacity and send it out by the end of the calendar year; we have solicited input on planned pilots and offered equipment loan option to those wanting to try pilots.

2. We established interest in quarterly videoconference for providers.

3. We also solicited valuable feedback regarding the types of applications, limitations and scenarios providers felt would be most effective.

WORLD WIDE WEB

1. Current web site concepts were demonstrated and broad support for use of the web as a utility for providers and patients was received.

2. There was interest in web-based messaging with veterans. Many had been using email, and in the future web messaging may be the only viable alternative for compliance with the Health Insurance Portability and Accountability Act (HIPAA) in communicating with veterans.

By Jodie Haselkorn, MD, MPH, director, MS CoE–West and Dennis Bourdette, MD, codirector, MS CoE–West

Clinical Research Fellowship in Multiple Sclerosis Available

Yale University School of Medicine is accepting applications for a clinical research fellowship in multiple sclerosis. The purpose of this one-year fellowship, with an option to continue a second year, is to guide and develop the MS Clinical Research Fellow to ultimately become a specialist in clinical neuroimmunologic disease and an expert in multiple sclerosis treatment and research. For a general description, description of clinical duties, and research and educational opportunities, please contact:

Yale Center for MS Treatment and Research
Department of Neurology, Yale University School of Medicine
40 Temple Street, Suite 6-C
New Haven, CT 06510
Telephone: (203) 764-4280
Facsimile: (203) 764-4288

Candidates for the MS fellowship should forward a letter of interest, curriculum vitae, and names/contact information for three references to:

Marco A. Rizzo, MD, PhD
Yale Center for Multiple Sclerosis Treatment and Research
Yale University School of Medicine
40 Temple Street, Suite 6-C
New Haven, CT 06510

A Success Story—MS Support Group at New Orleans VAMC

In response to strong patient interest, an MS support group meeting was established at the VAMC, New Orleans in 1996. Initially we

met once a month, but because attendance lagged during summer months, about two years ago we made the meeting quarterly. These meetings now take place on the second Friday of March, June, September, and December at 11:30 a.m. and last about two hours.

During the most recent meeting, I presented an overview of the MS Consortium meeting in San Diego in June 2003. At the next meeting, a sales representative from Pfizer/Serono will talk about Rebif, which we just started prescribing.

Meetings usually feature an invited speaker; otherwise, we have a free discussion with patients. In the past, Dr. Stazio from Tulane Medical Center has given talks about various treatments and general background about MS. In addition, an occupational therapist has discussed various assistive devices. Future discussion topics include alternative medicine, the role of tai chi, and other nontraditional methods of treatment.

On average, we have about 25 people in attendance. In addition, a neurologist, a representative from the physical therapy department, a social worker, PVA member, clinic nurse, and neurology office staff (who help arrange the meeting) attend. About 30 patients live in and around New Orleans, and some bring family members to meetings. Our public relations department assists by making fliers and mailing them to patients.

Patients look forward to these meetings. They have established camaraderie and friendship. PVA actively participates in our endeavor to help the patients and provides information on what VA can offer.

By Dr. Sarala Palliyath, chief of Neurology, VAMC New Orleans

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!