

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 e-mail address to the editor.

A Letter from the VA-SIG Chair

Hello Everyone,

As you all know, the VA budget proposal is quite fiscally “tight.” I would like to encourage all of you to continue your hard work with your patients and continue to make their VA experience as good as it can be.

On a more pleasant note, our annual Consortium of Multiple Sclerosis Centers (CMSC) annual conference is scheduled for June 1–5 in Orlando. Because monies are tight, please try to find alternative funding. It never hurts to apply for funding from your facility or to ask your local chapter of PVA. The MS Centers of Excellence (CoE) have set up a dynamic VA symposium again for this conference on the topic “Neuroprotection and Neurogeneration: New Avenues in the Treatment of MS.” I know everyone will be very interested in the information that will be presented.

The CMSC meeting also provides the setting for the annual VA SIG business meeting. This is an important part of keeping our organization vital: This is your chance to discuss issues and problems you are facing in caring for your MS veterans and your opportunity to become more involved in our work. We need as many people as possible to make this successful.

Please make your reservations as soon as possible for the CMSC conference hotel as spaces fill up fast.

I look forward to seeing you all at our CSMC conference in June.

Sincerely,

Rachel L. Palmieri
VA-SIG Chair

VA-SIG STEERING COMMITTEE MEMBERS:

Rachel Palmieri, RN
rachel.palmieri@med.va.gov
Chair

Christine Martin, PhD
christine.martin@med.va.gov
Vice Chair

Peggy Coffey, MD
peggy.coffey@med.va.gov
Chair, Clinical Care Committee

Elizabeth Auld, PA-C
elizabeth.auld@med.va.gov
Chair, Membership Committee
Editor, *VA Signature*

Albert Lo, MD albert.lo@med.va.gov
Chair, Research Committee

Lynne Walker, RN, CRRN
lynne.walker@med.va.gov
Chair, Education Committee

UPDATE ON TYSABRI (natalizumab)*

On February 28, 2005, Biogen Idec and Elan Corporation, the companies that make Tysabri, announced a voluntary suspension in the marketing of this promising new treatment for multiple sclerosis (MS).

This decision is based on very recent reports of two serious adverse events that have occurred in patients treated with Tysabri in combination with Avonex® (Interferon beta-1a) in clinical trials. These events involve two con-

international studies that showed the efficacy of natalizumab. One of these studies (the AFFIRM trial) compared natalizumab against placebo. This study showed that natalizumab reduced relapses of MS by 66 percent compared to placebo after one year of treatment and also dramatically reduced new MS lesions within the brain detected by MRI. The other study (the SENTINEL study) compared interferon-beta 1-a (Avonex) given with natalizumab to interferon-

natalizumab in clinical trials prior to their cessation.

In teleconference, Dr. Herndon stressed that these two cases of adverse reaction occurred in patients who received both Avonex and Tysabri for more than two years. There have been no other major adverse events in the more than 2,800 other patients who have received Tysabri. Dr. Herndon believes the combination of the two medicines led to the development of the fatal disease.

**NATALIZUMAB IS A HUMANIZED MONOCLONAL ANTIBODY
AND IS THE FIRST SELECTIVE ADHESION MOLECULE (SAM) INHIBITOR
DRUG TO BE RELEASED BY THE FDA. NATALIZUMAB REPRESENTS
A NEW CLASS OF DRUG FOR THE TREATMENT OF MS.**

firmed cases of progressive multifocal leukoencephalopathy (PML), a rare and frequently fatal, demyelinating disease of the central nervous system. Both patients received more than two years of Tysabri therapy in combination with Avonex.

The companies will work with clinical investigators to evaluate Tysabri-treated patients and will consult with leading experts to better understand the possible risk of PML. The outcome of these evaluations will be used to determine possible reinitiation of dosing in clinical trials and future commercial availability.

Tysabri was approved at the end of 2004 based on the results of two

beta 1-a given with placebo. This study also showed a dramatic decrease in relapses after one year of therapy in people receiving natalizumab.

Natalizumab is a humanized monoclonal antibody and is the first selective adhesion molecule (SAM) inhibitor drug to be released by the FDA. It represents a new class of drug for the treatment of MS. Natalizumab binds to white blood cells and prevents them from entering into the brain and spinal cord. The drug is given by monthly infusion in a doctor's office or hospital-based clinic and is generally well tolerated. More than 2,800 patients had received

He further speculated on how Tysabri combined with Avonex may have led to the development of PML. PML is an opportunistic viral infection of the central nervous system that is mediated by T cells. It had been extremely rare until the advent of HIV-AIDS with concomitant depletion of T cells. Avonex affects the number and activity of T cells. Tysabri prevents T cell migration into the CNS. When taken together, Avonex and Tysabri may, in some cases, result in depletion of T cells within the CNS that are essential for preventing the onset of PML. Dr. Herndon cautioned that the same may be true for the combination of Copaxone and Tysabri.

Understanding the concern of clinicians and patients, he gave assurances that once stopped, Tysabri will have been fully metabolized and eliminated from patients within five to six weeks of their last dose.

The diagnosis of PML is most commonly based on MRI; the patients in the combination trials will all be screened with MRIs. If they are normal and Tysabri has been stopped, there is very little chance that the virus will be able to take hold and develop into PML.

Very few patients in the VA system had received this medication prior to the cessation, so the risk of PML to veterans is very small.

There is much more to be learned about the patients exposed to the combination medications in the trials and about the future of natalizumab. The second-year clinical trial results are due to be presented at the upcoming meeting of the American Academy of Neurology. Dr. Herndon predicted it will again be made available for use in the treatment of multiple sclerosis—but with a black box warning—and that it will be used with caution for carefully screened patients.

Submitted by Elizabeth Auld, PA-C

* Information in this story comes from the VA MS Center of Excellence Web site, www.va.gov/ms, and from Robert Herndon, MD, during a teleconference sponsored by the Consortium of MS Centers, March 8, 2005.

MEMBERSHIP UPDATE

Help Needed

If you work at one of the VA facilities listed below, please contact Elizabeth Auld, PA-C, in West Haven: Elizabeth.auld@med.va.gov.

Alexandria VAMC
Atlanta VAMC
Chillicothe VAMC
Dallas VAMC
East Orange VAMC
Little Rock VAMC
North Chicago VAMC
Palo Alto VAMC
Prescott VAMC
Topeka VAMC
Tuscaloosa VAMC
Tuskegee VAMC

NEWS FROM MS CENTERS OF EXCELLENCE

Multiple Sclerosis Fellowship

The MSCoE–East is pleased to offer a one- or two-year post-residency fellowship in multiple sclerosis care and research.

The fellowship will include customized learning experiences to enable fellows to prepare themselves for a range of professional paths, including clinical care, clinical research, laboratory research, and medical education.

The fellowship program will emphasize opportunities in three main areas—clinical, research, and education—and will consist of five interrelated components: practice and care for patients with multiple sclerosis; design and implementation of

clinical trials; basic laboratory research as well as MRI-based research; formal course work in statistics, epidemiology, and design of clinical trials; and educational opportunities to include educator-training, competence in the use of telemedicine technology, and individualized mentoring tailored to each fellow.

The fellowship will be based in the MS Center of Excellence at the Baltimore VAMC with the option of locating training experiences at other VA facilities with established MS programs in VISNs 1 to 11. The fellowship includes salary and other benefits. Fellowship candidates must be eligible for employment by the Department of Veterans Affairs.

For more information contact:

Christopher T. Bever, Jr., MD
Director, MS COE–East
UMH, Room N4W46
22 South Greene Street
Baltimore, MD 21201
410-605-7060
Christopher.Bever@med.va.gov

IOMSN Produces Educational DVD

Over the past four years the CMSC has conducted a workshop at the annual meeting titled “Neurology for the Non-neurologist.” Several MS physicians, advanced practice nurses, and a physical therapist have participated as faculty. During the workshop the principles of history taking, differential diagnosis, and neurological exam findings pertinent to MS have been discussed. To summarize the workshop information, a normal neurological exam was demonstrated. Attendees suggested that the information would be useful in daily

practice if it was more accessible to the provider and included abnormal findings common in MS.

In response to the stated need, Kathleen Costello, MS, MSCN, and Linda Morgante, MS, MSCN, of the International Organization of MS Nurses (IOMSN), with an educational grant from Teva-neuroscience, produced a 20-minute DVD that discusses and demonstrated the neurological exam as it pertains to MS.

Robert Shin, MD, an MS specialist physician from the University of Maryland and the Baltimore VA MS Center of Excellence, served as narrator for the video. Costello and Morgante served as the examining practitioners.

Patricia Provance, a nationally known MS physical therapist, provided her expertise for the examination of gait and use of assistive devices. It is hoped that this video will help the new practitioner develop skills and have greater confidence in neurological assessment for multiple sclerosis.

The DVD is available without charge to all members of the IOMSN. The cost for nonmembers is \$25 made payable to IOMSN.

*by Kathleen Costello,
University of Maryland Center for MS;
Baltimore MS Center of Excellence*

Save the Date: April 28

Satellite Broadcast Seminar: Fatigue and the Cognitive Effects in Multiple Sclerosis

Two leading experts on fatigue and MS will lead an upcoming satellite broadcast seminar, providing information on quality-of-life issues as they relate to fatigue and people with MS. The Multiple Sclerosis Center of Excellence–West, the

Multiple Sclerosis Center of Excellence–East, and the Department of Veterans Affairs Employee Education System will sponsor the April 28 broadcast.

The two-hour presentation will be given by Lauren Krupp, MD, and Cinda Hugos, MS, PT. Dr. Krupp will focus on the neurological effects of MS fatigue, and Hugos will present medical management of MS fatigue. Continuing educational units will be available for physicians, physical therapists, nurses, occupational therapists, and social workers.

Dr. Krupp is a professor of neurology and psychology at the State University of New York at Stony Brook Medical Center; she specializes in multiple sclerosis. She is director of the Pediatric MS Center at Stony Brook (the first and only Pediatric MS Center in the United States), codirects the adult MS Center at Stony Brook, and directs a research program that covers the relations between fatigue, mood disturbance, and cognitive dysfunction in MS within the Department of Neurology. She is recognized internationally as a noted authority on multiple sclerosis and has published more

than 100 original articles and chapters. Other areas of expertise include Lyme disease, headache, and behavioral neurology.

Hugos is an instructor in the Department of Neurology at Oregon Health and Science University. She has extensive experience with complex issues surrounding people with multiple sclerosis. She developed the curriculum and participated in the “Fatigue and MS” video-based series on fatigue management, sponsored and produced by the National Multiple Sclerosis Society. She is active in developing Clinical Practice Guidelines for the American Physical Therapy Association, MS Council sponsored by American Academy of Neurology, Consortium of MS Centers, Paralyzed Veterans of America, National MS Society, and other health-care professional organizations. Her areas of research include the effects of body temperature and exercise, yoga and its effects on attention in aging and MS, and changes in functional performance of stroke patients.

*by Marsha H. Tarver, PhD,
Education Coordinator, CoE–West*

Volunteers Needed for VA SIGnature

The primary goal of this newsletter is to share information across the VA system. We need a few interested people from around the country to join an editorial committee. The main task would be to research and report on interesting developments (as well as possible problems that the VA SIG could help resolve) in the VA Facilities near them. There will be a specific meeting in Orlando to establish this editorial committee. If you are interested but cannot be in Orlando, please contact Elizabeth.Auld@med.va.gov.



CPRS MS TEMPLATE UPDATE

The following is a letter sent to VA MS providers announcing the template.

Dear Fellow VA MS Provider:

The Multiple Sclerosis Centers of Excellence East (Baltimore) and West (Portland and Seattle) invite you to use our new CPRS enhancements, developed in a coordinated effort by our Clinical Care and Informatics Committees. Thank you for your patience as you waited for their distribution! As many of you already know, we designed these templates to help you and your staff as they compose new patient and follow-up clinic evaluations of veterans with MS, and as they write orders for DMTs. We hope these CPRS enhancements will help you perform these tasks:

- With more efficiency (click boxes and drop-down menus and bundled order sets);*
- With more guidance from our clinical experts (links to our MSCoE Web site);*
- With more standardized assessment measures (validated disability scales, McDonald diagnostic criteria, MS fatigue severity scales);*
- With easier access to patient education tools (support group information, educational handouts, and Web sites for national groups).*

In a separate email through our VISTA system, a clinical applications coordinator (CAC), Tom Brenk at the Portland VA Medical Center, is exporting the templates to a CAC at your VA. We welcome your feedback on these tools, as we expect to modify and improve them with time. We will send out an email survey to you in several months to see how the templates work for you, and to your CAC to see how well they import. In the meantime, if you have specific concerns, please contact Gordon Campbell, FNP of the Portland VA Medical Center (gordon.campbell@med.va.gov).

Christopher Bever, Jr., MD, director of the MSCoE-East

Jodie Haselkorn, MD, MPH, director of the MSCoE-West

Dennis Bourdette, MD, codirector of the MSCoE West and associate director for Research & Development

Ruth Whitham, MD, associate director of Clinical Care of the MSCoE West

EDUCATIONAL OPPORTUNITY

The Multiple Sclerosis Comprehensive Treatment Training Program offers a two-and-a-half day preceptorship at the University of Texas Southwestern Medical Center at Dallas. Fourteen sessions will be offered in 2005; each is limited to 10 participants. All costs are covered. Neurologists, neurology residents, and qualified allied health-care professionals (e.g., physician assistants, nurse practitioners, or nurses with advanced clinical training) are encouraged to apply. For more information call (214) 648-9559 or send email to mstraining@utsouthwestern.edu.

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

Contact the editor at
elizabeth.auld@med.va.gov

*See Calendar of Events,
page 6*

DATES TO REMEMBER

April 25

Satellite Educational Broadcast: Fatigue and the Cognitive Effects of Multiple Sclerosis

8 a.m. to 10 a.m. (Pacific Time)

Contact Jennifer Jett at Jennifer.Jett@med.va.gov for more information.

June 1–5

Navigating the World of Multiple Sclerosis, the 19th Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) Centers

Orlando, Florida

June 2

VA SIG Business Meeting

5 p.m.

June 3

Caring for People with Advanced MS

A workshop by Jodie Haselkorn, MD, MPH, Chair; David Gruenewald, MD; James Bowen, MD; and Christopher Bever, MD

Afternoon

June 4

Neuroprotection and Neuroregeneration: New Avenues in the Treatment of MS

Panel presentation chaired by Dennis Bourdette, MD

9 a.m.–noon

Information: www.mscares.org.

September 6–8

Annual Meetings of American Paraplegia Society, the American Association of Spinal Cord Injury Nurses, Social Workers, Psychologists

Las Vegas

October 13

Center of Excellence–East Coordinators meeting

Baltimore

October 14–15

Third Annual John N. Whitaker Memorial Lecture

Baltimore