

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 would like to share a few thoughts with you on the retirement of Dr. John Booss as neurology chief at the VA Central Office. Without him, the VA-SIG would not be where it is today. He was the guiding force behind its very existence, rallying good people to assist our organization's inception.

In 1997 at the Calgary Consortium of MS Centers (CMSC) conference, Dr. Booss, along with John Carswell and Thomas Stripling from the Paralyzed Veterans of America, Vivian Beyda from United Spinal Association (then EPVA), and some 40 VA MS providers discussed the need for an organization to give MS providers in the VA a way to address issues and problems specifically related to their work in the VA system. In January 1998, Dr. Booss and his group then convened to discuss the feasibility and set up the structure and goals for what became the VA Special Interest Group of MS Providers (VA-SIG). Dr. Booss has continued as our "guidance counselor" as we have grown to our present structure and size. He has been a tremendous support to me in my role as chair and to our VA-SIG.

Dr. Booss was also instrumental in the creation of the MS Centers of Excellence (East and West). I would personally like to thank him for all his support and assistance. I feel privileged to have had the opportunity to work with him and would like to use this letter to personally thank him and to wish him all the best with his future endeavors.

On a totally different note, I would like to extend my thoughts and prayers to all who have been victims of Katrina and Rita, especially to our colleagues living in the affected areas. My hopes and prayers are with all of you and your families; may you find the strength that you all will need in the weeks to come to rebuild your lives and go on.

Finally, I wish you all a very happy, healthy, and safe holiday season and 2006!

Rachel Palmieri
VA-SIG Chair

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Editor's Note: *Much of this issue of VASIGNature is dedicated to John Booss, MD, on his retirement as director of neurology, VA Central Office. We hope you enjoy reading the following articles about his contributions to the field of research in multiple sclerosis and especially to the care of veterans with MS.*

A Career Honored

In reviewing the career and accomplishments of Dr. John Booss, three words come to mind: focus, productivity, and responsibility. Dr. Booss chose early on to become a neurovirologist and began to make important contributions shortly after his appointment to the neurology faculty at Yale. Throughout his career he has been based primarily at the VA Medical Center in West Haven, CT. His scientific contributions arising from his laboratory efforts are considerable. First, he was very interested in experimental virus infections of the nervous system focusing primarily on animal models of cytomegalovirus. More recently he has written about many of the human challenges confronting us, viruses including West Nile encephalitis, smallpox and smallpox vaccination, and the enormous issue of retro viruses and AIDS.

There has always been a strong scientific thread between Dr. Booss's research and the issue of the cause of multiple sclerosis. Many of his 80-plus published articles deal with MS in some manner, ranging from the search for viruses in MS to the use of total lymphoid radiation as a treatment to the special promise of MS care provided to veterans by VA hospitals. Thoughtful contributions to



John Booss, MD, receiving a recognition award from Christopher Bever, MD, left, director of the MS Center of Excellence East. At right is Dennis Bourdette, MD, co-director of the MS Center of Excellence West.

the ethical issues of caring for patients with chronic neurologic diseases are also a highlight of Dr. Booss's productivity. His statements on the promise of neural stem cell graphing are of particular note.

Dr. Booss has made important contributions to the care and welfare of MS patients, especially veterans with MS through his ongoing administrative capacities. In 1993 he was named director of neurology for the Veterans Hospital Administration and was reappointed to this important national office in 1997 and again in 2001. Veterans' neurologic care in general has benefited from Dr. Booss's unflagging efforts. However, of special note is his interest in energizing MS care and research through the development of Veterans Administration MS Centers of Excellence. A well-thought-out review process initiated under his leadership resulted in the identification of two national MS VA Centers of Excellence—one based at

the VA medical center in Baltimore and a second that combines the VA centers in Portland and Seattle. These centers have successfully organized MS care and research at academic centers throughout the United States and are now having an impact on MS care in many of the nonacademic VA centers. It is hoped their efforts will improve the quality of care for all veterans regardless of where they live throughout the United States.

John Booss identified a very special and important area where he could contribute early in his career, and he faithfully and very successfully followed that career path, making very important contributions to our understanding of MS, to the care of veterans with MS, and to forthrightly considering the many ethical questions which this life-long neurologic disease stimulates.

*by Kenneth Johnson, MD, director,
Maryland Center for Multiple Sclerosis,
University of Maryland School of Medicine*

A Place to Start—Or How We Got from There to Here

In the early 1980s, PVA's Health Policy Department first documented the number of veterans with multiple sclerosis using Veterans Administration medical centers and proposed that action be taken to enrich VA's attention toward this seemingly underserved population. In 1993, Dr. Margaret Giannini, former VA director for the Research & Development Service, under contract to PVA, documented through a series of personal interviews the patchwork of VA services delivered to MS veterans. In 1994, PVA published "Economic Consequences of MS among PVA Members" as the first comprehensive estimate of direct and indirect costs associated with MS veteran prevalence and health-care utilization. In 2005, PVA and United Spinal Association collaborated for the ninth time to fund VA clinician attendance at the annual meeting of the Consortium for MS Centers (CMSC). These are but a few of the milestones over the past 20 years that have strengthened PVA's actions and commitment to MS program building.

Certainly, there are intervening milestones worth noting, such as the SCD veteran patient registry created by the Strategic Healthcare Group for Spinal Cord Injury and Diseases in 1996 and the establishment of VA's two MS centers of excellence in 2002.

In 1992, Dr. John Booss brought his experience and interest in multiple sclerosis to his new role as VA director of neurology. He quickly identified the relationship between program

building and program delivery. He often said that administrators and advocates can do very little to improve programs without the support of the clinicians. Dr. Booss suggested that an informal group that brought together MS clinicians across VA would be a good first step toward more program visibility. What he suggested to a small group of MS clinicians at the 1997 CMSC meeting in Calgary, Alberta, Canada, grew into the VA Special Interest Group of MS clinicians, headed first by Jodie Haselkorn, MD (VA Puget Sound Healthcare System); followed by Elizabeth Auld, PA (VA Connecticut-West Haven); Deborah Downey, NP (Cleveland); and now in the capable hands of Rachel Palmieri, NP (Albany). Today, the VA-SIG is the only recognized "section" of CMSC; 50-plus VA centers belong to the CMSC; and growing numbers of VA clinicians attend the annual CMSC meetings.

This newsletter is supported by PVA and produced in its Communications Department. *VASIGNature* has covered topics ranging from patient reimbursement coding, clinical practice guidelines, educational materials, clinical care hot spots, disease modifying therapies, and much more. Now everyone looks forward to each new issue to learn about the current issues in MS and about the accomplishments and programs devoted to MS in the VA. *VASIGNature* is becoming an important communication tool for the MS Centers of Excellence (COEs).

Certainly, the biggest step toward improving MS care for veterans became reality in 2002 when the two

MSCOEs were chosen and funded. These centers resulted from advocacy by PVA, United Spinal Association (USA), and other MS advocates, leading Congress to put funding into the Millennium Spending Bill.

Each of these accomplishments owes its success to fortunate opportunities and consistent players. Early in these events, John Carswell, PVA associate executive director for health policy; Vivian Beyda, United Spinal Association's associate executive director for research and education; Margaret Hammond, MD, VA's chief consultant for the Strategic Healthcare Group for Spinal Cord Injury and Diseases; and, of course, John Booss in his role as VA national director of neurology each played pivotal roles working together to realize their common goal of achieving stronger, more coordinated service delivery for MS veterans.

I am particularly pleased to have this opportunity to thank Dr. Booss for his early insights and long-standing partnership with PVA and USA, and for all he accomplished for VA MS clinicians and veterans with MS. He saw a need for working together; he suggested an untapped reserve of expertise to form the VA-SIG; and he watched over the VA-SIG and the growing list of accomplishments of the COEs up to the day he retired on September 1, 2005. We will miss his constant collaboration, but I think he left us with many reminders of what can be accomplished when good people with good ideas work together.

By Thomas E. Stripling, director,
PVA Research, Education &
Practice Guidelines

News from the Centers of Excellence

■ THE MS CENTER OF EXCELLENCE WEST (PORTLAND/ SEATTLE)

– John N. Whitaker-Dale E. McFarlin Multiple Sclerosis Colloquium

The VA MS Center of Excellence West, in conjunction with the Oregon Health and Science University MS Center, hosted the John N. Whitaker-Dale E. McFarlin Multiple Sclerosis Colloquium November 19 in Portland. The John N. Whitaker-Dale E. McFarlin MS Colloquium CME/CE initiative has been named in honor of Dr. John N. Whitaker and Dr. Dale E. McFarlin in recognition of their invaluable contributions to multiple sclerosis research and education.

This one-day meeting was part of a series of MS colloquia designed to provide resources and support to neurologists, nurses, therapists, and

other health-care professionals who diagnose and care for MS patients. The program examined all aspects of MS, including its natural history, immunology, symptoms, and treatment, as well as the practice of whole patient management in the context of a multidisciplinary approach to health care. MS specialists from the Pacific Northwest led the program. You may contact info@msscolloquium.org for a program brochure.

– MS Case Conferences

The Center of Excellence West has been offering case conferences throughout 2005. Direct participation is through the VANTS telephone network. Continuing medical education (CME) credit is available for those who call in to the conferences and can also be obtained by reading the transcripts of these case conferences.

The last case presentation of 2005, held December 1, was on the topic “TNF Antagonists & Monoclonal Antibodies in Multiple Sclerosis: A Case Presentation & Discussion.” The presentation was made by Ruth Whitham, MD.

PowerPoint slides are available by contacting the MS Center of Excellence–West, at (503)220-8262, ext. 53296. CMEs for this presentation can be obtained by logging on to the VA EES Web site at vawww.ees.aac.va.gov/librix/loginhtml.asp?v=librix. After logging in, click on search, and type multiple sclerosis as keyword.

The preceding four audio case conferences in 2004–05 were:

- Treatment Decisions in Secondary Progressive Multiple Sclerosis: A Case Conference (December 9, 2004)
- Cognitive, Emotional, and Psychosocial Issues in MS: A Case Presentation (February 3, 2005)
- Uveitis and Multiple Sclerosis: A Case Presentation (April 7, 2005)
- Complimentary and Alternative Medicine in Multiple Sclerosis (June 23, 2005)

– VA Regional MS Directors and Coordinators Meeting Planned

The VA MS Centers of Excellence East and West will be holding a joint regional MS directors and coordinators meeting at the Consortium of Multiple Sclerosis Centers’ annual meeting in Scottsdale, Arizona, May 31–June 3, 2006. The MS Centers of Excellence Regional Directors and Coordinators Meeting will be held Friday, June 2 from 4 p.m. to 6 p.m. This will include a one-hour meeting followed by a one-hour social event. Additional details to follow as the date approaches. If you would like additional information about this meeting, please contact Jennifer Jett at jennifer.jett@med.va.gov.

– Regional Council Meetings

The purpose of the MS Centers of Excellence is to bring together MS care providers and researchers from across the country to improve the clinical care of veterans with MS by establishing a hub-and-spoke system of care that serves the entire VHA. One strategy to assess, monitor, and encourage “best practices” of care for MS patients is to collaborate with other health-care professionals serving our veterans. The regional

CALENDAR

Annual Meeting: May 31–June 4, 2006: CMSC Scottsdale, Arizona

Monthly Teleconference: First Monday, 12:30 EST. Clinical topics in MS, led by Dr. Peggy Coffey (VA Tampa), Chair of the Clinical Care Committee. Lasting 30 minutes, they are designed to fit a busy clinical schedule while providing a forum in which to talk about the clinical care of veterans with MS. Dr. Coffey has 50 lines available for participants. For more information, contact Dr. Coffey at peggy.coffey@med.va.gov.

councils were established to provide advisory support to the Centers of Excellence to promote the goal of providing consistent “best clinical practices” nationwide. The councils are composed of at least one health-care provider from a hub or spoke within each VISN serving the respective East/West region. Council members actively participate in the annual conferences by providing feedback on the needs of veterans and the teams that provide care.

This year the MS Centers of Excellence West Regional Council meeting was held in Portland on September 17. Drs. Dennis Bourdette and Ruth Whitham sponsored this successful event, which focused on clinical networking, education programs, standards of care, and support for VA MS clinics and centers. The program opened with a salute to Dr. John Booss and his 32 years of federal service. Dr. Booss, the national director of neurology service, retired in September 2005, and his contributions to the field of neurology and more specifically to the understanding of MS are admirable. He was the leading force behind the establishment of the MS Centers of Excellence and the affiliated clinics. His service to the VA is recognized by all as exemplary. Also in attendance was Dr. Robert Ruff, chief of spinal cord injury at the Cleveland VA Medical Center, and chair of the National Neurology Advisory Group. He addressed optimizing the working relationships between the Centers of Excellence, neurology and spinal cord, and the Office of Research

and Development. Representatives from VISNs 5, 8, 12, 16, 17, 18, 19, 20, 22 and 23, along with Dr. Vivian Beyda from United Spinal Association and Mr. Artie Guerrero from the Paralyzed Veterans of America, participated in the program which used a discussion group format. The facilitated discussion groups yielded a variety of ideas to continue the partnership of providing consistent “best clinical practices” nationwide for veterans with MS.

In addition to the Regional Council meeting agenda, Oregon Health and Science University School of Medicine, Department of Neurology, and the Portland VA Medical Center sponsored a CME course on September 16, “Neurologists in the 21st Century: What’s New in 2006.” This coordinated event was designed to address general neurology topics, such as MS, movement disorders, and Alzheimer’s disease for practicing neurologists and other health-care providers. For more information on the participating speakers and their presentations, contact Jennifer Jett at jennifer.jett@med.va.gov.

Marsha L. Tarver, PhD, associate director of Education, MSCOE West

■ THE MS CENTER OF EXCELLENCE EAST (BALTIMORE)

– **Regional Council Meeting**

The MS Center of Excellence East hosted the annual meeting of the clinic directors and coordinators in their hub-and-spoke system on Thursday, October 13, in Baltimore. The following two days the focus

changed from the specific activities of the Center of Excellence to an educational program, Advances in Management of MS, which featured the annual Whitaker lecture as well as the annual Ray Kroc lecture.

– **Clinic Directors and Coordinator Meeting**

Thursday, October 13 was devoted to the many projects under way at the Centers of Excellence and supporting clinics, including the major research effort (a 15-year longitudinal study of veterans with MS) and the clinical and educational programs and research in progress. The longitudinal study has enrolled its

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-SIGNature editor at elizabeth.auld@med.va.gov (VA Connecticut Health Care System).

Thank you!



first patients, and progress is being made at the supporting clinics to allow participation. Coordinators were briefed on the various parts of the study: blood drawing, neuropsychologic online assessment, MS functional composite and the Web entry system of data collection. Directors met to discuss rating scales, MRI issues, and other administrative topics. Adam Darkins, MD, national director of care coordination, was the featured speaker in the afternoon session. His talk of care coordination opened a session focused on the

role of the regional centers in MS care coordination. Other talks explored the use of telemedicine and other electronic enhancements in home-based monitoring and regional MS patient consultations. These combined sessions were followed by two group sessions: the regional clinic directors discussed the problems with getting the CMSC MRI Guidelines adopted by VA neuroradiologists and the benefits and implementation details of adopting the MS standards of care for VA MS programs; the regional clinic coordinators met to discuss site problems, followed by a presentation and discussion led by Christine Martin, PhD, of the Caregiver Workshops and the CMSC MRI Guidelines.

*Elizabeth Auld, PA-C,
Editor, VASIGnature*

Health Science Center, Houston. Named in honor of John Whitaker, MD, one of the major supporters and designers of the VA MS Centers of Excellence, the Whitaker lecture alternates each year between the West Coast and the East Coast sites. Dr. Wolinsky spoke on “MRI in MS—A Coming of Age.”

The second lecturer, Joseph Berger, MD, professor and chairman, Department of Neurology, University of Kentucky, presented the Kroc Lecture. The Kroc lectureship is named for Ray Kroc, founder of McDonalds. Kroc’s sister had MS, and the foundation supported many MS projects. A leader in the field of HIV research and clinical care, as well as infectious and inflammatory diseases of the nervous system, Dr. Berger spoke on progressive multifocal leukoencephalopathy (PML), the CNS virus that caused the withdrawal of Tysabri from the market in the winter of 2005.

The clinical presentations covered a broad spectrum of clinical care issues, from diagnosis and treatment (MRI in Diagnosis, by Mitchell Wallin, MD; Clinically Isolated Syndrome by

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MS: Advances in Management

A recent multiple sclerosis symposium offered two parallel tracks—clinical and scientific—with two major lectures for the entire group. The first talk—the third annual Whitaker Lecture—was presented this year by Jerry Wolinsky, MD, Bartels Family Professor of Neurology, University of Texas



Jerry Wolinsky, MD, Bartels Family Professor of Neurology at the University of Texas Health Science Center in Houston, left, presented the third annual Whitaker Lecture this year, while Joseph Berger, MD, professor and chairman of the Department of Neurology at the University of Kentucky, presented the Kroc Lecture.

James Bowen, MD; Management of MS: The CMSC Consensus Recommendations, by Kathleen Costello, CRNP; and Long-Term Safety and Efficacy of Disease Modifying Therapies, by Robert Shin, MD) to symptom management.

Presentations covered the following symptoms: Fatigue (Cynthia Sullivan, PhD), Cognitive Impairment (Robert Kane, PhD), Spasticity (Joel Kent, MD), Pain (Marilyn Kassirer, MD), Depression (Cathy Lee Benbow, MSW), Rehabilitation (Michael Makley, MD and Kathy Zackowski, PhD, OT), Alternative Medicine and Acupuncture (Lixing Lao, PhD, L.Ac).

The scientific section included the following presentations: MS Biomarkers (Christopher Bever, MD), Metabolites in MS (William Regenold, MD), Cellular Immunological Markers of Therapeutic Response in MS (Suhayl Dhib-Jalbut, MD), Cytokines, Chemokines, and Retinoids in Lesion Pathogenesis (Walter Royal, MD), Role of Complement in Lesion Pathogenesis (Horea Rus, MD, PhD), Viruses in MS Pathogenesis (Micheline McCarthy, MD), Novel Neuroprotection Strategies in MS (Albert Lo, MD), Statins in MS (William Tyor, MD), Glatirimer Acetate and Interferons as Neuroprotectants (Suhayl Dhib-Jalbut, MD), Monoclonal Antibodies in MS (John Rose, MD), Targeting T Cell Receptors in MS (Dennis Bourdette, MD), and Cell Replacement Therapy (David Trisler, PhD).

Sponsored by an unrestricted grant

from Biogen-Idec, the meeting was refreshingly free of any hint of drug preference or industry pressure.

This meeting, as well as the meeting held in Portland earlier in the fall (see story page 5), offered a wealth of very timely and relevant information. The energy and talent evident in these lectures and these meetings, all focused on new and better understanding of all facets of MS management, should give hope to persons with the disease and to caregivers and clinicians.

DVDs of the two keynote speeches “MRI in MS—A Coming of Age,” by Dr. Wolinsky, and “Progressive Multifocal Leukoencephalopathy,” by Dr. Berger, can be requested by contacting Jane Stolte at the following address:

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Neurology/MS Service (127)
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(410) 605-7480 (MSCE)
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DVDs of two satellite broadcasts held earlier this year are also available and copies may be requested by contacting Jane Stolte. The two topics are “Fatigue and the Cognitive Effects of Multiple Sclerosis” (April 28, 2005) and “Treating Multiple Sclerosis: Making a Difference in Veterans’ Lives” (May 10, 2005).

Reminder...

You are *all* members of the VA-SIG (Special Interest Group of MS Providers). Here are some ways you can benefit from this membership:

Volunteer for a Committee: If you want the opportunity to take your passion for caring for our veterans with MS to a higher level, consider volunteering to work with one of the VA SIG committees or helping with the *VASIGnature*.

Run for Office: Or better yet, consider running for a spot on the steering committee. Contact any of the current steering committee members to volunteer for a committee or discuss running for office.

Submit stories for *VASIGnature*: Additionally, this newsletter needs the input and help of all of you—send back information on anything in your facility or area that would be of interest to others. Do you have a support group? Have you had some educational events? Are you encountering problems with getting the care you need for your veterans with MS: rehab, medications, equipment?

Contact Elizabeth Auld at elizabeth.auld@med.va.gov.