

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.

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A Letter from the VA-SIG Chair

Hello Everyone:

As this New Year beckons, I am hopeful there will be great strides made by VA nationwide in the fight against MS. **VA's Multiple Sclerosis Centers of Excellence** are a remarkable achievement. The idea of having the "best of the best" in MS treatment available at both **Seattle VAMC and Baltimore VAMC** will afford VA providers an invaluable resource for patient problem-solving. Once this resource becomes available, we will be able to network with the VA experts who know the specific challenges and unique problems of managing the veteran with MS. It will be much easier to problem solve with "experts" who understand their uniqueness.

I also feel that we all need to look at how our role as providers for MS patients in VA can impact our local community. I realize that we are all very busy in our workdays, but we also have a lot to offer the local community. *In many geographical areas, our VA's are the biggest healthcare provider.* We have a great opportunity to increase positive relations between the community and VA by becoming involved in our local MS chapters.

I have been invited to serve on the Clinical Advisory Committee for our Capital District MS chapter. I will also be doing a series of community presentations to the chapter's patient support groups. It was a real learning experience for the committee members to hear how many MS patients we treat and to hear about the services our VA offers veterans with MS. As members of the VA-SIG we need to communicate these services to the community. I have personally found that our local MS chapter is "hungry" for new ideas and new community resources. I would urge every member of our VA-SIG to get involved in your local MS chapter; it is a "win-win" opportunity.

If any of our VA-SIG members are involved in their local MS chapters, or have done VA or conference presentations, I would invite you to email us. We would like to use our newsletter to highlight the many accomplishments of our members.

In closing, I hope that 2003 brings everyone great strides toward better care for MS.

Sincerely,
Rachel Palmieri

PVA and the MS Centers of Excellence

On December 3, 2002, Dr. Robert Roswell announced that Portland/Seattle and Baltimore VA Medical Centers were to be designated VA's two Centers of Excellence in Multiple Sclerosis. This announcement was a long-awaited fulfillment of a PVA plan hatched nearly six years earlier. As almost everyone knows, PVA's traditional image is that of an advocate for veterans with traumatic spinal cord injuries. And, indeed, much of what PVA does is focused on the well-being and aspirations of SCI veterans. However, PVA, from congressional charter to mission statement, has been committed equally to the concerns and desires of veterans with spinal cord disease. Over my 20 plus years with PVA, various national and chapter initiatives have raised awareness of and treatment for veterans with MS, ALS, syringomyelia, and other spinal cord diseases. With Dr. Roswell's announcement, I must recognize perhaps the boldest of such initiatives in my tenure.

John Carswell, then PVA associate executive director for Health Policy, outlined the original plan in 1995 in response to a concern expressed by PVA's Field Advisory Committee (FAC). The FAC wished to rejuvenate PVA's direct participation in the goal to establish a distinct MS service within VHA. FAC members believed that the advent of disease-modifying therapies had radically changed the treatment "playing field" for MS veterans and

it was time for VA to move forward with a distinct service focus.

John Carswell and I gathered historical and current input from sources inside and outside VA to create a vision that could be endorsed by PVA's Board of Directors. PVA has never been a stranger to the MS field. In fact, the Eastern Paralyzed Veterans Association traditionally has been PVA's spearhead on MS issues. Their publication of the MS Quarterly was the milestone of much broader involvement in the field that included specific cooperation with the National Multiple Sclerosis Society. Their input and potential cooperation was much valued during Mr. Carswell's fact-finding activity.

Finally, Mr. Carswell proposed that "MS program building," as this initiative became known, consist of three primary foci. First, build a VA MS clinician identity among the diverse VA MS providers. Second, aggressively promote and support MS research. Third, maintain a visible and aggressive advocacy.

These goal statements were embodied in 12 objectives. Objective 2 stated, "Aggressively and persistently call for the establishment of at least two centers of excellence for research, education related to multiple sclerosis." Following endorsement by the PVA Board of Directors through a national resolution, we started a process of conceptualization and search for the opportunity that came to fruition in Dr. Roswell's December 3, 2002, announcement.

Our naiveté was that it should take only 2 or 3 years and that everyone understood what a "center of excellence" involved. We were

not convinced that a distinct service was a viable political or fiscal direction in the near term. And, as we wished to show real results in a short amount of time, in our view long-term political and fiscal strategies didn't hold much promise.

It took 5 years for our naiveté to become straight thinking. A fortunate opportunity arose to add specific language to VA's FY 2002 appropriations language. Discussions across and outside VA yielded a reasonable set of "functional specifications" to conceptualize the centers. An impressive competition involved five proposals and six distinguished reviewers. Finally, the December 3, 2002, announcement raised the curtain on the beginning phase of these two centers.

PVA and the Eastern Paralyzed Veterans Association are proud of what this announcement represents and we eagerly anticipate working as hard with our latest best friends in Portland/Seattle and Baltimore to bring best practices and relevant knowledge to the challenges of MS care across the VA system.

*Thomas E. Stripling, toms@pva.org,
PVA, Director of Research, Education
& Practice Guidelines*

Multiple Sclerosis Center of Excellence—East

The Multiple Sclerosis Center of Excellence for the eastern United States was awarded to the Baltimore VAMC. The Baltimore VA and its academic affiliate, the University of Maryland School of Medicine, have a long history of excellence in MS related research, education, and clinical care.

The director is Christopher T. Bever, Jr., MD, chief of the Neurology Service in Baltimore and professor in the Departments of Neurology and Pharmacology and Experimental Therapeutics in the University of Maryland School of Medicine. He has significant experience of funded basic research related to the mechanisms of tissue injury in MS as well as clinical research related to the use of potassium channel blockers in MS. He currently has Medical and Rehabilitation Merit Review grants.

Kathleen Costello, RN, NP, is the acting associate clinical director. She has been the clinical director of the Maryland Center for MS Treatment and Research at the University of Maryland and is the president-elect of the International Society of MS Nurses.

The research associate director is Suhayl Dhib-Jalbut, MD. He is the director of the VA MS Clinic and professor of Neurology at the University of Maryland School of Medicine. He has had sustained funding for studies of the role of viruses in MS and currently has VA Merit Review Funding as well as an NIH Mid-Career Development Award.

The acting associate director for epidemiology and biostatistics is Mary-Claire Roghmann, MD, MPH. She is hospital epidemiologist for the Baltimore VAMC and associate professor and head of the Health Outcomes Division in the Department of Epidemiology and Preventative Medicine at the University of Maryland School of Medicine. She is a VA funded investigator.

The communications associate director is Robert Kane, PhD. He is chief of Neuropsychology at the Baltimore VAMC and associate

professor of Psychology at the University of Maryland. He has a long history of funded research in remote neuropsychological testing and telemedicine.

Christine Martin, PhD, is the associate director for education and training. She is an assistant professor of Medicine in the University of Maryland School of Medicine and as president emeritus of the Human Anatomy and Physiology Society she has extensive experience in teaching, adult education, and faculty mentoring.

Other key personnel at the Baltimore VAMC are Douglas Bradham, Dr PH, health economist and health services researcher, Peter Gorman, MD, director of the Spinal Cord Injury Clinic, and Robert Lavin, MD, director of the Pain Management Program. An additional key person from the University of Maryland is Kenneth Johnson, MD, professor of Neurology and director of the Maryland Center for MS, who is the chair of the Steering Committee.

The proposal included several investigators at the Washington VA Medical Center, including Ross Fletcher, MD, chief of staff, who will support the bioinformatics aspects of the center; Mitchell Wallin, MD, MPH, who will support both the clinical and epidemiological aspects of the center; and Jeffery Wilkins, PhD, a neuropsychologist who will support the neuropsychological studies involved in the program.

The center will include a network of MS clinics that will be responsible for coordinating MS care regionally. The VA facilities with MS clinics that have been identified to date include the Tampa VAMC (Director: Jeffery Harrow, MD, PhD), Charleston VAMC (Director:

William Tyor: MD), Richmond VAMC (Director: Warren Felton, MD), Cleveland VAMC (Director: John Leigh, MD) and the Boston VAMC (Director: Marilyn Kassirer, MD). Additional clinics will be recruited to provide full coverage of VISN's 1 to 11.

The center will support a wide range of innovative projects and programs. The research program is focused on identifying prognostic indicators and predictors of response to therapy. This will be accomplished by establishing a longitudinal cohort study, which will follow clinical status, brain changes as measured by magnetic resonance image scans, cognitive function, affective state, and immunological responses.

The educational program will include not only traditional educational programs but also Internet based materials linked to the electronic medical record and academic detailing of local providers.

The clinical program will include the implementation of clinical practice guidelines in the computerized medical record, the use of disease managers to identify patients with special needs, and the application of telemedicine to promote the care of homebound veterans and to provide subspecialty consultations to patients and providers in centers without subspecialty providers.

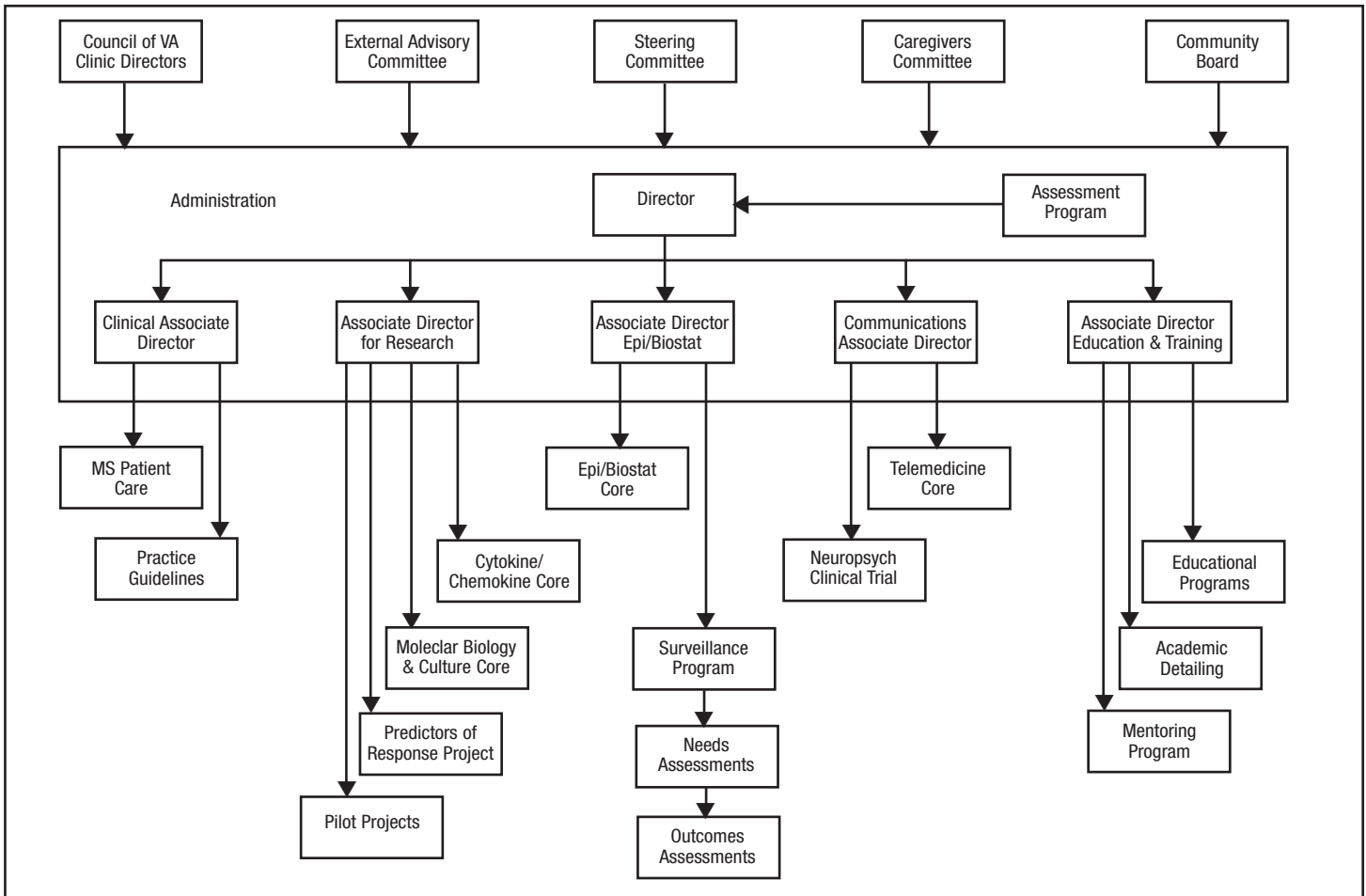
Contacts for the MS Center of Excellence-East, are:

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Research programs: Christopher T. Bever, Jr., M.D., 410-605-7061, christopher.bever@med.va.gov

The administrative structure of the Baltimore program is given below:



Multiple Sclerosis Center of Excellence—West

The VA Puget Sound Health Care System in Seattle and the Portland VA Medical Center collaborated to form the newly awarded MS Center of Excellence West (MS CoE West). The Northwest United States has one of the highest prevalences of MS in the world and these two VA centers and their academic institutions, the University of Washington and Oregon Health & Science University, have long been leaders in cutting edge management of MS; basic, clinical, and health services research in MS; the education of health professionals and others

impacted by MS; and biomedical and health informatics.

MS CoE West will establish four core programs to accomplish four major objectives:

1. Improve the clinical care of veterans with MS through a hub-and-spoke system of care.
2. Conduct, disseminate, and apply research relevant to the health needs of veterans with MS.
3. Provide a national program of MS education and training for VA health-care providers, veterans, and caregivers, as well as recruit new individuals to the field through the VA Special Fellowship Program.

4. Utilize state-of-the-art informatics and telehealth technology to enhance the clinical services, research, and educational components of the center, as well as supporting the epidemiological efforts that will acquire, synthesize, and analyze data to assess and inform VA strategies and practices of the MS health-care delivery.

MS CoE West is directed by Jodie K. Haselkorn, MD, MPH, and co-directed by Dennis Bourdette, MD. Dr. Haselkorn is an associate professor in Rehabilitation Medicine and an adjunct associate professor in Epidemiology at the University of Washington. She has managed vet-

erans with MS since 1989, served as the founding chair of the VA Special Interest Group of the Consortium of MS Centers, participated in the development panel for the Urinary Dysfunction Clinical Practice Guideline published by the Paralyzed Veterans of America for the MS Council, and chaired the development panel for the Spasticity Management Clinical Practice Guideline that is forthcoming. Dr. Haselkorn is nationally known as a methodologist and researcher and presently also directs the biostatistics and methodology core of RehabNetWest, a regional rehabilitation resource network funded by the National Institutes of Health. Dr. Haselkorn is active with numerous advocacy groups including the Paralyzed Veterans of America, Eastern Paralyzed Veterans Association, the National MS Society, and the Consortium of MS Centers.

Dr. Dennis Bourdette will co-direct the new center and will serve as the associate director of research & development. Dr. Bourdette is a neurologist and neuroimmunologist with two decades of experience directing an MS clinic and conducting nationally recognized MS research through VA Merit Review, VA RR&D, VA Cooperative Studies, NIH, and private funding. He has served as chief of Neurology at the Portland VA Medical Center and is presently the acting chair of Neurology at Oregon Health & Science University. Dr. Bourdette is also panel chair for "Immunizations and MS" Clinical Practice Guidelines.

The associate director of Clinical Care and the co-associate director of Clinical Care are Ruth Whitham,

MD, and James Bowen, MD, from PVAMC and VAPSHCS respectively. Both of these nationally regarded neurologists are recognized for their expertise in the clinical management of MS, as well as their numerous contributions to research, health professional education, and advocacy for individuals impacted by MS.

They, along with Lynne K. Walker, CRRN, RNC, and Julie Saunders, ARNP, look forward to establishing a hub-and-spoke system of care throughout the VISNs west of the Mississippi River. Lynne Walker is a nationally recognized rehabilitation nurse who has worked with veterans with MS for many years. She is a member of the Steering Committee of the VA Special Interest Group of the Consortium of MS Centers. Julie Saunders is a specialist in treating individuals with MS and has a long affiliation with the Consortium of MS Centers.

The Education Core is directed by Rhonda Williams, PhD, with assistance from Kelly Goudreau, DSN, Aaron Turner, PhD, Ruth Whitham, MD, and Lynne Walker, CRRN, RNC. This team has over 70 combined years of health professional and patient education expertise and experience. They look forward to implementing traditional and innovative education and training programs in conjunction with the VA Employee Education Service and other advocacy groups to enhance the care of individuals impacted by MS.

In addition, Dr. Whitham will direct the VA MS Fellowship for MS CoE West.

Michael Hatzakis, Jr., MD is the associate director for information

technology and communications. Dr. Hatzakis is a board certified specialist in Rehabilitation Medicine and is an engineer with vast industry experience in the applications of technology to people with disabilities. Dr. Hatzakis is responsible for internal communications, communications throughout the Western region, and development of the telehealth program in MS, and will direct the informatics program.

Drs. Bourdette and Bowen will serve as associate director and co-associate director of research and development for the new Center.

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They will encourage expansion of the VHA MS research portfolio and facilitate clinical trials that address the special health-care needs of veterans with MS. They plan to focus on pre-clinical development of novel immunomodulatory, neuroprotective, and neuroregenerative therapies for MS; clinical trials of promising disease modifying and symptomatic therapies for MS; and health services and epidemiological research.

The staff at the MS CoE West look forward to continuing to work with other professionals and advocacy groups at their own institutions *and with you* to improve the care of veterans and others impacted by MS.

To learn more and to get involved, check out the web site at www.va.gov/mswest or contact us at mscoewest@u.washington.edu. Please plan to attend the VA MS Centers of Excellence Platform Session at the Consortium of MS Centers, on Saturday morning, May 31, 2003, in San Diego.

Research Corner

MS Ritalin Study

An exciting new study is currently underway at the VA Puget Sound Health Care, Seattle Division, to evaluate the use of stimulants to improve cognitive functioning, fatigue, and mood for individuals with MS during inpatient rehabilitation. The study is funded through an NIH \$200,000 pilot grant through the RehabNetWest program.

Many people who have MS suffer from problems with concentration and memory. These cognitive deficits can result in significant barriers for the individual with MS.

Inpatient rehabilitation services represent an important treatment option for these individuals and have been shown to improve overall quality of life and disease management by providing intensive adaptive training and information about disease progression and therapeutic interventions. Cognitive deficits may interfere with patients' ability to benefit from these time-limited services. Pharmacological treatments that have shown to be effective at improving cognitive functioning in individuals with a traumatic brain injury or stroke could also serve to improve functional progress and ultimately minimize the impact of cognitive deficits for those individuals with MS. No study to date, however, has systematically examined the effect of stimulants upon cognition or rehabilitation function in individuals with MS.

The project is a 2-year randomized, double blind, placebo-controlled trial to evaluate the feasibility and efficacy of administering methylphenidate to individuals with MS in the course of inpatient rehabilitation. As this is a pilot study, the primary aim is to determine the feasibility and the additional data required to perform larger scale studies on the impact of stimulants on individuals with MS. The University of Washington Human Subjects Division has approved the project. The two principal investigators are on staff at the Seattle VA: Dr. Aaron Turner, psychologist and researcher with the Center of Excellence in Substance Abuse Treatment and Education, and Dr. Michael Hatzakis, physiatrist and assistant professor at the University of Washington.

New Organization for MS Rehab Therapists

The International Organization of MS Rehabilitation Therapists (IOMSRT) was formed to develop an international network of rehabilitation professionals interested in promoting and enhancing the role of MS rehabilitation professionals through sharing and disseminating information and research findings.

Membership consists of rehabilitation therapists including physical therapists, occupational therapists, and speech and language pathologists with an interest in MS. Other interested professionals may apply for associate membership. For more information, please contact Brian Hutchinson, PT, at bhutchinson@heuga.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*
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Thank You!