

## 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,

Spring is finally here! It has been a very long, very cold winter in the great Northeast. Between the snow and the cold, many of our patients had a tough time getting to their appointments. Fortunately, with the pleasant change in weather, our patients are coming in and we are able to take care of their medical needs.

I hope everyone is ready for the Consortium of Multiple Sclerosis Centers (CMSC) conference in Toronto. Our VA-SIG meeting, at which we will elect the new officers, is scheduled for Friday, June 4 from 6 p.m. to 7 p.m. Please plan to attend and participate in this very important meeting.

Our VA-SIG has been very busy over the winter. We have completely revised the VA-SIG Terms of Reference, which are our governing rules. These new changes will be reviewed at our meeting at the CMSC conference for membership approval.

The MS Centers of Excellence, in conjunction with our VA-SIG, will present a symposium at the CMSC conference on Saturday, June 5 from 9:30 a.m. to 12:30 p.m. The topic is secondary progressive MS: therapeutic challenges.

I look forward to seeing you in Toronto.

Stay safe!

Sincerely,  
Rachel Palmieri

## VA Developing ALS Registry

Amyotrophic lateral sclerosis (ALS) is an adult-onset, neuromuscular disease of unknown etiology. ALS is a disease of high priority to the Department of Veterans Affairs, particularly due to ongoing concerns about the health of veterans who served in the Gulf War. Efforts are needed to systematically identify and track veterans with ALS. Accordingly, VA is developing a national registry of veterans diagnosed with ALS.

This registry is funded by the VA Cooperative Studies Program (CSP#500A) and is directed by the Epidemiologic Research and Information Center (ERIC) at the Durham, North Carolina, VAMC, with cooperation from the VA Medical Center in Lexington, Kentucky. Eugene Z. Oddone, MD, MHSc, and Edward Kasarskis, MD, PhD, are coprincipal investigators of the registry. The ALS Association (ALSA), which is advising the registry study leaders, has played a lead role in advocating for the registry, boosting public awareness and ascertaining prospective enrollees.

### Objectives

The primary objectives for this registry are: (1) to provide VA with data on the current number and characteristics of veterans with ALS, as well as the ongoing identification of new cases; (2) to provide a mechanism for VA to inform veterans with ALS about clinical trials and other studies for which they may be eligible; and (3) to provide VA with an important and rich data resource for future studies examining the causes and impact of ALS.

### Methods

The registry will focus on comprehensive identification of veterans with ALS who may be eligible for other studies. Eligible participants will include all living veterans with a physician diagnosis of ALS. Veterans with possible ALS will be identified through VA medical records, the Veterans Benefits Administration (VBA), and self-referral.

Neurologists with expertise in ALS will review veterans' medical records to verify the diagnosis of ALS in accordance with the World Federation of Neurology (WFN) El Escorial ALS Diagnostic Criteria. Upon enrollment, veterans will be asked to complete a brief telephone interview. Registry participants will also be contacted by telephone bi-annually to assess health and functional status (ALS Functional Rating Scale).

Preliminary findings announced by VA in December 2001 noted a higher incidence of ALS among veterans who had been deployed to the Persian Gulf region during the Gulf War than among those not deployed. This study, funded by VA and the Department of Defense and involving other federal health agencies and the ALSA, has resulted in the first possible link between Gulf War service and a specific disease.

Enrollment in the registry began April 1, 2003. As of April 2004, 1,200 potential subjects had been screened, with 700 veterans screening eligible to participate in the registry, and 284 enrolled.

For more information about the ALS Registry, eligible veterans or their family members or friends can call 1-877-DIAL-ALS or e-mail [als@med.va.gov](mailto:als@med.va.gov).

## MS COES HOST SUCCESSFUL TELECONFERENCE

On April 19 the MS Centers of Excellence presented their first jointly sponsored educational program, titled "Cognitive and Neurobehavioral Issues in Multiple Sclerosis." The program was a collaborative V-TEL presentation, the first portion originating from Baltimore and the second broadcast from Seattle. Faculty for the program included speakers from both CoEs in addition to outside experts in the areas of neurocognitive changes in MS and in rehabilitation and intervention with the MS patient.

Thirty-two VA sites from across the country tuned in to the presentation, and more than 400 VA participants received CME credits. Speakers included CoE leadership from both coasts: Jeff Wilkin, PhD; Robert Kane, PhD; Mitch Wallin, MD; Aaron Turner, PhD; and Rhonda Williams, PhD, speaking on cognition and MRI; assessment approaches; mood, behavior and medications; social support; and psychosocial interventions, respectively.

Adding considerable expertise to the daylong program were Jill Fischer, PhD, speaking on MS-related cognitive impairment and treatment of MS-related cognitive dysfunction; and the team of David Clemmons, PhD, and Robert Fraser, PhD, discussing vocational and financial considerations.

*By Christine Martin, PhD, MS Center of Excellence-East*

## MS Center of Excellence Informatics Update

By MS Center of Excellence Workgroup

The MS Centers of Excellence Informatics group has been working on a number of projects. A summary of some of the products that have been produced or are nearing completion follows:

**Data Report.** A preliminary data report of the demographics, health utilization, and expenditures of care for approximately 26,000 veterans seen in the VHA from 1998–2002 was sent to the central office March 2004. VISN 5 and VISN 20 are in the process of validating that these veterans have MS by review of the electronic medical record.

**Data Repository.** The joint MS CoE–East and –West Informatics groups met in Seattle in November to establish the policies and procedures to create a data repository that will permit access for clinicians, managers, and researchers. The relational database structure is under way, and we target completion of Phase 1 by early fall 2004.

**CPRS Clinical Reminders.** To improve the quality of the data in the repository, a clinical reminder that solicits ethnicity and disability using EDMUS has been written and is being tested. A clinical reminder to encourage appropriate prescription of disease-modifying therapies and to obtain more accurate disease subtype and disability levels are under way. Both reminders should be available for viewing and distribution at the Consortium of MS Centers annual

meeting in June or by contacting us at the email address below. In addition, a proposal is being prepared to support the use of these clinical reminders to integrate the MS CoE Web site with CPRS.

**CPRS Note Template.** A number of note templates are under way. A neurology progress note has been developed and is in use in VISN 5. Another neurology template is undergoing revision after testing, and a rehabilitation evaluation progress note is under development.

**Web Site.** The infrastructure of a Web site for health professional and veteran education in MS-related issues has been developed and is continuing to grow. If you haven't visited the site yet, take a moment to check it out at [www.va.gov/ms](http://www.va.gov/ms) and give us feedback. We have established an active editorial board and welcome comments and suggestions. The site just developed secure user authentication so private administrative space can be moved to the public Web site and expanded to meet your needs. Please contact [mscoe-informatics@u.washington.edu](mailto:mscoe-informatics@u.washington.edu) for additional information.

**Telehealth.** The informatics group worked with the education groups to provide educational opportunities. The Cognitive and Neurobehavioral Issues In Multiple Sclerosis was the most recent and the largest attempt to date. On April 19 we simultaneously transmitted an educational program from Baltimore and Seattle to approximately 400 health providers within the Veterans Health Administration. If you did not attend the live broad-

cast, the slides are available on the Web site, and we are exploring dissemination of the videotape.

Clinical telehealth programs are under way at both MS CoE–East and –West. Home telehealth equipment is beginning to be field tested by MS CoE–West. We are working collaboratively to develop a MS telehealth toolkit.

The work described above has been largely led by the MS CoE directors of informatics, East and West, Douglas D. Bradham, PhD, and Michael Hatzakis, Jr., MD, with substantial support from Craig Allen, BA; Christopher Bever, MD; Drew Blazey; Dennis Bourdette, MD; William J. Culpepper, MA; Mary Ehrmantraut, RN, MS; Kathleen Flannery, PharmD; Jodie Haselkorn, MD, MPH; Mark Haselkorn, PhD; Jennifer C. Jett; Robert Kane, MD, PhD; Stephen Leipertz, PhD; Charles Lai, BS; Leah MacClellan, MS; Chuck Maynard, PhD; Amy Poel, MPH; Jane Stolte, Lynne Walker, CRRN; and Mitchell Wallin, MD, MPH.

Please let us know if you are interested in writing on a specific topic for the health professional or veteran education sections of the Web site, interested in serving as a test site for any of the software in development, willing to participate in validating veterans identified as having MS at your facility, or would like to participate in telehealth. We are interested in your feedback and participation. Drop us a line at [mscoe-informatics@u.washington.edu](mailto:mscoe-informatics@u.washington.edu). We look forward to speaking with you at the Consortium of MS Centers Exhibit Booth in Toronto.

## MS COE–East Clinic Coordinators Meeting

The MS Center of Excellence–East held its first eastern VISN MS Clinic Coordinators Meeting in Fort Lauderdale, Florida, April 24–27. The meeting included coordinators from VISN 1–West Haven, Boston; VISN 2–Albany, Buffalo; VISN 3–NY Harbor; VISN 4–Philadelphia; VISN 5–Baltimore, Washington, DC; VISN 7–Birmingham, Augusta, Charleston; VISN 8–Miami, Tampa; and VISN 10–Cleveland. The coordinators included various health-care team members: social workers, nurses, nurse practitioners, and an EEG technician. VA SIG leaders were also in attendance. Christine Martin, PhD, associate director for Education and Training, organized the meeting.

Objectives of the meeting included:

- understanding the evidence supporting the use of disease modifying therapies (DMT) in MS;
- describing the side effects of DMTs and their management;
- identifying the common symptoms of MS;
- understanding the concept of academic detailing and its application to the VHA;
- describing the current care delivery for veterans with MS; and
- discussing new strategies for health-care delivery within the VHA for veterans with MS.

The meeting was sponsored by an unrestricted educational grant from

TEVA pharmaceuticals, coordinated by the Multiple Sclerosis Foundation, and co-chaired by Kathleen Costello, RN, MS, CRNP, and Mary Ehrmantraut, RN, MS, CRNP.

Prior to the meeting, the coordinators filled out surveys to evaluate their models of care, characterize their veteran patients, and identify current and future patient and provider education needs. Mary Ehrmantraut summarized the survey results at the meeting. The survey identified the diversity of the clinics, including the differences in models of care within each center. Some models of care had a general neurology focus, whereas others were more rehabilitation medicine or primary care focused. In addition, most of the clinics varied in size and multidisciplinary support. All coordinators identified a need for more educational materials for their patients. The survey results will be presented as a poster at the 2004 CMSC meeting in Toronto.

The meeting also included presentations by Dr. Christopher Bever, director of the MS CoE–East, who discussed the use of DMTs and research initiatives in VA. The coordinators were updated on the longitudinal cohort study and telemedicine studies. Kathleen Costello presented on side effect management of DMTs and the role of health-care providers in MS care. As a method to validate knowledge, the coordinators were provided information on the MS nurse and MS specialist certification exams. In addition, the Multiple Sclerosis Foundation met with the coordinators to discuss patient and family advocacy strategies and provided patient education materials to the coordinators.

The concept of academic detailing was introduced to the coordinators by an outside consultant, Edwin Watson, from ePharmaceuticals. This concept of education has been used by the pharmaceutical industry for years. Academic detailing allows one to determine an educational need, identify the audience, and develop strategies to teach the topic to members of the health-care team. Academic detailing has been discussed as a way to initiate provider education at the various hub-and-spoke sites.

The meeting came to a close with discussions about future education topics and suggested care initiatives for veterans with MS. Many of the coordinators identified the need to standardize documentation with a CPRS template. At the close of the meeting, the coordinators were asked to identify sites within their VISN that have MS patients and provide them the questionnaire to complete as well. Identifying these clinics, using the hub-and-spoke model, will promote uniform MS care among veterans. In addition, the coordinators identified the need for more frequent discussion with the group through a coordinators' listserv or a monthly conference call. Clearly, collaboration between the VA SIG and the MS CoE will assist in the dissemination of information and initiatives to ensure the highest level of care for the veterans with MS. At present, a directors and coordinators meeting is planned for September 2004.

*By Mary Ehrmantraut, RN, MS, CRNP,  
MS Center of Excellence, VA Maryland  
Healthcare System*

## Home Care Options

Over the past several years the incidence of MS in the veteran population has increased. As veterans with MS age, increased home help needs will affect a greater percentage of male veterans over the age of 50. With MS statistically being a progressive disease better preparation and resources will be needed to assist veterans in the community and in their homes.

Nationally the United States is seeing a shift from care in nursing homes and residential care homes back to the patient's home. For the past two years the Durham VAMC has worked to coordinate the following 12 Home Care Programs, described below, into one group.

- Adult Day Health Care
- Bi-Pap
- C-Pap
- Durable Medical Equipment
- Home Dialysis
- Home IV
- Homemaker/Home Health Aid
- Home O2
- Home Ventilator
- Hospital Based Primary Care
- Respite
- Telemedicine

Descriptions of each home care option for eligible MS veterans follow:

■ **Adult Day Health Care** provides up to 8 hours a day, 5 days a week of care in a contracted facility for eligible veterans. The purpose is to provide caregivers with relief from the demands of providing 24-hour care. If nonservice-connected veterans participate in ADHC a copay may be required.

■ **Bi-pap & C-pap** programs provide devices to help veterans who have obstructive sleep apnea. The Neurodiagnostic Clinic evaluates patients with disorders of the muscles and/or nerves. Nurse practitioners and physicians in the clinic monitor patients for changes in prescriptions and functioning of equipment.

■ **Durable Medical Equipment** falls under the Prosthetics Department. The equipment, which is necessary for a patient to remain in his home, is provided after a physician or a therapist has made a request.

■ **Home Dialysis** is a home-care program that allows a patient to receive treatment at home. This eliminates travel several times a week for lengthy treatments at a dialysis center.

■ **Home Infusion**, a program managed by the Durham VAMC's Community Health Nurses, provides for contracted home health nurses who provide home IV therapy services. This expedites hospital discharges and allows veterans to return home much sooner while continuing on IV treatment. The patient must have a primary care provider in the home who can be taught to administer the treatment with backup from visiting nurses.

■ **Social Work Service** manages the **Homemaker/Homehealth Aide program**. It provides patients with homemaker services for 2 to 5 hours a day from 2 to 5 days a week. The homemaker/homehealth aide provides bathing, cleaning, laundry services, and light meal preparation. For heavy-care patients, like MS

patients, it may take a few hours each day to help bathe and dress a patient and change their bed linens.

■ **Respiratory Care Service** manages **Home O2 and Home Ventilator** services. Respiratory therapists evaluate, educate, and follow-up on patients who require constant oxygen or ventilators to remain in their homes. Since most ventilator-dependent patients are difficult for family members to care for in the home, the ventilator program is very small. The caregiver must be willing to devote 24 hours a day to the care of the patient, which, due to the ages of our veterans, is often too demanding for an elderly spouse.

■ **Hospital Based Primary Care** is a specialized program with a team approach. Patients must be within a

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](mailto:deborah.livingstone@med.va.gov)

Thank you!

certain distance from the Durham VAMC and fit other criteria to be eligible for services. A physician, social worker, nurse practitioner, physical therapist, and dietician are all members of the Interdisciplinary Team who follow this select group of patients and help them manage home living.

■ The **Respite** program is a new home-care program this year. It provides caregivers with relief from the pressures of caring for patients 24 hours a day, thus delaying or avoiding long-term nursing home care. A patient may be eligible for up to 6 hours per day, 30 days per year in their own home or 4 hours per day in a contracted facility up to 30 days a year of respite care.

## Ask the Experts

***My patients with MS frequently complain of difficulty thinking of the word or words they want to say. They note, “It’s on the tip of my tongue and I know what I want to say, but I can’t think of the word!” As a speech pathologist, what are your suggestions?***

Word-finding difficulty is a type of memory dysfunction and one of the most common cognitive changes seen in MS. Specifically, it is a “word retrieval” problem. An example of this problem would be difficulty recalling the name of someone or something you know well, even though you know what you want to say. Difficulty with word finding in conversation is particularly frustrating and annoying. One patient noted, “my vocabulary seems to be shrinking.” While there are no known medical treatments to improve word-finding, clinical trials are under way with various drugs, which may prove to have a positive effect on this type of memory.

Providing background information on this problem can be helpful. First of all, we all experience this “tip-of-the-tongue” phenomenon at times, some of us more than others. It is susceptible to getting worse when we are stressed, tired, or ill. While frustrating, this difficulty is often subtle and usually less noticeable to others than to ourselves. The time to do something about it is when it interferes with quality of life.

### What I Tell My Patients

Cognitive treatment includes learning to relax. Very often, getting tense or agitated makes the problem

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■ The last program in the Durham VAMC’s Home Care Coordination group is **Telemedicine**. This is an innovative method for providing care to veterans who are instructed in how to use the computer installed in the patient’s home. Information is transmitted back to a nurse practitioner at the VAMC or the emergency room via the computer screen and telephone. The patient receives regular calls from trained personnel at VA. During the pilot portion of this program, Telemedicine patients experienced reduced hospital visits. As a result, the program has been expanded.

Referrals to social workers are the place to begin. Experienced workers can assist with discharge planning for MS patients. Any veteran may be referred to any of the Home Care Programs at the Durham VAMC. Inclusion is based on eligibility and availability of resources. Some of the home-care programs do have waiting lists. Our MS patients benefit from case management by knowledgeable staff who know the patients’ needs and are familiar with the variety of options available at the Durham VAMC.

*By Linda Matich Lang, MSW, LISW, Spinal Cord Injury/Home Care coordinator, Durham VAMC*

worse. Many of my patients have noted, “When I lose a word or thought, I tense up; then the problem gets worse.” My advice is stop and take a slow, deep breath. Then try to describe or find a different word for what you are trying to label. Some people substitute words like “thingamajig” or “whatchacallit” to stall for more time when they are searching for a word. It sometimes helps to start describing attributes, like size, shape, color, place, associations, how long ago this happened, etc. This may relax or distract you, allowing the word you want to surface.

Managing word finding difficulty may involve some lifestyle adjustments. You may want to avoid situations that demand on-the-spot answers. Be willing to say to others, “well, let me think about that...” when you need more time to come up with a response. It is helpful to let people you love or work with know your MS has an impact on the way

your brain is processing information. A quiet environment may enable you to concentrate better. Have the TV and radio off, for example.

If your work or lifestyle demands a high degree of verbal agility, try to modify your schedule so speaking activities happen earlier in the day. Schedule phone calls in the morning, for example, rather than in the afternoon, when you’re more likely to experience increased word-finding difficulty due to fatigue. If particular names or titles regularly elude you, write them down and keep them prominently displayed or handy in a pocket. It’s not cheating to use this type of structure in your environment. It’s smart, proactive, and can relieve your anxiety.

Expect this problem to get worse when you are tired or ill. Let yourself off the hook when you’re sick or overly tired. I always like to remind people that they can also “talk with their hands” using simple gestures

when they’re too tired to talk, like a “thumbs up” for “OK,” “good,” or “yes.” In our highly verbal society, it’s good to remember that in many cultures people use gestures abundantly. Facial and hand gestures can be efficient and effective.

Try to have a sense of humor. If you mispronounce or misuse a word, try to see the humor. A patient said, “If you can’t spell a word more than one way, it’s not worth spelling,” and applied it to how he spoke. Fortunately, he was focused on communication, not perfection, which is what I tell my patients. The important thing is to keep communicating even though you may be doing it differently. Don’t retreat into silence! Approaching this concern with a sense of creativity and a willingness to learn new ways of doing things is crucial. And, always, have hope.

*By Deborah Livingstone, MS, speech - pathologist, Puget Sound Health Care System, Seattle Division*