

## 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.*

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## A Letter from the VA-SIG Chair

Hello Everyone,

I hope that this letter finds you all in good health. This year promises to be very exciting, as we will be accepting self-nominations for new VA-SIG officers. Please give serious consideration to this great opportunity to network with colleagues from various VA medical centers across the country.

By now everyone should have read the email sent out January 9 regarding the need to obtain VA passports if you intend to come to the June Consortium of Multiple Sclerosis Centers conference in Toronto. Please give this your immediate attention and start the passport process. As you all realize, this is one of the many changes since September 11, 2001. We lost more than our innocence on that day; we also lost our freedom from fear. Unfortunately, we know what it is like to live with the threat of terrorism on our soil.

Our VA-SIG is revising the "Terms of Reference" that govern our steering committee. The present terms are outdated and need to reflect the working relationship with the Centers of Excellence along with other needed updates. We will present these to the general membership at the CSMC VA-SIG meeting in June.

I wish you all a healthy 2004. Stay safe.

Sincerely,  
Rachel Palmieri

## Origin of DSS: To Present the Plan

It may be presumptuous, but it is accurate to state that the (Expanded) Disability Status Scale (DSS) was a direct result of World War II on both a macrohistorical and a microhistorical (personal) level.

On September 1, 1939, Germany invaded Poland as the final precipitant to the Second World War. Two days later England and France declared war on Germany. On September 8 President Roosevelt decreed a limited emergency, for which Congress authorized additional funds for rearmament and increased manning levels for the military. Earlier that year, for this nation with a population of 131 million, there were only about 335,000 personnel on active duty: 190,000 army, 125,000 navy, and 19,000 marine corps.

The “Sitzkrieg” in Europe ended the next spring. Germany invaded Norway and Denmark on April 9, 1940; the Low Countries on May 10; and France on May 22. By June 22 France had fallen. Earlier (June 10) Italy had entered the war on the Axis side. On August 27, 1940, the president authorized activation of the National Guard and the reserves for a period of 12 months of service, limited to U.S. territory. On September 16 Congress passed the Selective Training and Service Act, with the same limitations on location and length of service, following the president’s declaration of a state of national emergency (September 8). Between June 1940 and June 1941 the U.S. military more than tripled from 458,000 to 1.8 million men, of whom 1.5 million were in the army, 284,000 in the navy, and 54,000 in the

marines. By a single vote, Congress extended all periods of service to 18 months in August 1941. This was shortly after Germany had invaded Russia (June 22), resulting in the U.S.S.R. joining the Allies in Europe.

One day after the Japanese attack on Pearl Harbor on December 7, 1941, the United States and Britain declared war on Japan, with Germany and Italy following on December 11. The period of military service in the United States was extended to the duration of the war plus six months (December 13). On December 20, 1941, the Selective Service Act was amended to require all men ages 18 to 65 to register, and it authorized call-up of those ages 20 to 45. Both of the latter age limits were later reduced, to age 37 (September 1942) and 18 (December 1942). The army of the United States had been the recipient of all the draftees until an executive order of March 1943 required all personnel ages 18 to 38 to be procured only through the Selective Service System. This resulted in draftees serving for the first time in the previously all-volunteer navy, coast guard, and marine corps (17-year-olds could still volunteer for any branch of service).

Personnel of the U.S. military rose to 3.9 million in June 1942, 9.0 million in 1943, and 11.4 million in June 1944. Peak strength in June 1945 was 12.1 million, with 8.3 million in the army, 3.4 million in the navy (with the coast guard as part), and almost half a million in the marine corps. In all, the United States had 16.4 million men and women (the latter being 2 percent of the total) on active duty during the war.

Italy surrendered to the Allies on September 8, 1943; Germany on May 7, 1945; and V-J day was

August 15, 1945. Numbers in the U.S. military dropped precipitously to 3.0 million by June 1946 and to 1.6 million by June 1947.

Physicians were obviously part of this rise and fall. The army had 1,600 in June 1940—that number rising to 48,000 in July 1945 and then decreasing to some 22,000 in January and 13,000 in June 1946. During the war, the navy with its V12 program and the army with the Army Student Training Program (ASTP) sent more than 20,000 students through medical school as enlisted men.

The massive influx of veterans requiring medical care after the war caused political, academic, and medical leaders to seek ways to bring the Veterans Administration (VA) into the medical mainstream, as had been the case with the active military during the war. Active duty army physi-

### 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!

cians had already been assigned to some VA hospitals during the war from January 1944. By June 1945 physician manning of the VA comprised 600 civilians and 1,720 army officers, and some ASTP and V12 graduates continued serving in the VA until July 1948.

As to the Veterans Administration itself, Gen. Omar Bradley had been appointed administrator on August 15, 1945, and in September he brought in Maj. Gen. Paul Hawley for a position that would become chief medical director. They were responsible for the reorganization of the medical services of the VA in accord with Public Law 293, enacted January 3, 1946. Physicians, dentists, and nurses were removed from the standard civil service system into title 38, which stressed professional achievements for appointment.

In addition, wherever geographically feasible, close relationships with medical schools were to be established, and dean's committees set up to be responsible for much of the professional policies of their affiliated VA hospitals, including quality of patient care and supervision of intramural VA training and research programs. By January 1948 the medical staff of VA hospitals totaled 3,500 full-time and 2,000 part-time physicians, plus 700 academic consultants or attendings, and there were 2,000 doctors in VA residency programs.

The Servicemen's Readjustment Act of 1944, the GI Bill, provided three major benefits for all veterans: education grants for higher education or vocational training, mortgage loan guarantees for home buyers, and cash payments for those unemployed after discharge. The last had

provided \$4 billion for some 9 million veterans between 1944 and 1949. More than 3.5 million mortgages were partially guaranteed and were largely responsible for the rapid postwar growth of the suburbs. At its peak in 1947, more than 40 percent of all housing starts in the United States were funded by these guarantees. The GI Bill's education and training programs reached more than 8 million veterans between 1945 and 1956. College enrollments were 70 percent higher than prewar levels. In 1947 nearly half the nation's college students were veterans.

I had enlisted in the navy in 1944 and was released from active duty as pharmacist's mate second class in 1946. Thanks to the GI Bill, I was able to attend Cornell University Medical College from 1948 to 1952, after finishing college. The head of neurology at the New York Hospital–Cornell Medical Center had been, since its opening in 1932, Harold G. Wolff, professor of medicine (neurology). During the war he had been active as an American Neurological Association representative of the National Research Council and served on a number of committees for the army, navy, and the VA.

At Cornell in the second year, there was, under Wolff's direction, an obligatory course in neurologic diagnosis, distinct from physical diagnosis. A 54-page typed neurologic examination had to be carried out, which resulted in a 20-page handwritten report of all positive and negative findings, organized by body part and with measures of severity. Detailed mental testing was included as "highest integrative functions." Vision testing included not only corrected and uncorrected acuity, near

and far, but also mapped-out visual fields and color vision. All positive and pertinent negative findings were then summarized before offering the neuroanatomic formulation that preceded diagnosis.

Though then written in lesser detail, this was the format required in the clinical clerkships (and residencies) in neurology, with such exams at admission or first visit and at discharge. For students, each exam was checked and countersigned by the supervising neurologist or resident. I took my obligatory third year full-time neurology clerkship at the VA Hospital in the Bronx, New York, as well as a similar elective in the fourth year. Based on review of old records, it seems that Cornell had been using the Bronx VA for neurology clerkships since 1944, since this same unique examination format was found that far back for patients at admission and discharge. Further, the Bronx VA appears to have been a Dean's Committee hospital since 1946 or so, and it was there that I took my residency in neurology 1953–1956, with Wolff as director of training.

In 1953 at the VA, we were trying to evaluate a possible treatment for multiple sclerosis (MS)—isoniazid. It was clear that to do so we first needed a group with which to compare our patients, and, second, a way to measure change. For the former, we had the detailed records of veterans of WWII hospitalized between 1944 and 1953 with a diagnosis of MS, with, as noted above, both admission and discharge exams. They were all in the early years of their disease, with usually little or no fixed deficits before the bout that led to their admission.

It was possible to consolidate all their individual findings into separate and mutually exclusive neuroanatomic systems, which, with an “other” class, included all the neurologic abnormalities that could be found at examination, and to grade each of these from 0 (normal) to 5 (maximal impairment). The systems then were “pyramidal,” “cerebellar,” “brain stem,” “sensory,” “sphincter” (bowel and bladder), and “other.” (In later years, “other” was divided into “visual” (optic), “cerebral” (mental), and “other” (miscellaneous)). However, there was no valid way to add together scores for each of these systems or to assume that a score in one system was equivalent to the same score in another. These scores were not real numbers, but, rather, each one represented an individual ordinal ranking so that 2 was worse than 1 and better than 3 for the separate scales, but how much better or worse could not be determined, nor how changes in one scale compared with those in another—aside from the direction of the change. Therefore, the scales could not be directly combined.

These were the reasons behind the formulation of the Disability Status Scale, which ranged from 0 (normal) to 10 (death due to MS). Separate criteria for each step were given based on presence and severity in each functional system—not as a sum, but as a gestalt, the idea being the more the exam is abnormal in quality (systems) and quantity (scores), the more lesions there should be in the neuraxis. Some years later, additional steps to the scale were urged. Though the DSS itself was also an ordinal scale, at least in our hands with early MS patients in this and other series, its distribution was unimodal and rather

Gaussian. Thus it seemed that the only valid move was to divide each step from 1 through 9 into two parts, in order to offer the “son” of DSS, the Expanded Disability Status Scale.

*By John F. Kurtzke, MD, FACP*

*Dr. Kurtzke's career as a neurologist and epidemiologist spans nearly 45 years at the Washington DC VA Medical Center. Dr. Kurtzke was the recipient of the 2003 Consortium of Multiple Sclerosis Center's Lifetime Achievement Award. In addition to his clinical work as an attending neurologist, Dr. Kurtzke's research includes contributions on epilepsy, spinal cord injury, and MS.*

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## Potential VA Cooperative Study

**UPDATE**—There was a general agreement at the September 2003 meeting in Portland, Oregon, that a natural history study like the one being organized by Dr. Christopher Bever for the MS CoE–East would be excellent for a VA cooperative study, one that can utilize the resources of both CoEs. In addition to testing several key hypotheses (outlined in VASIGature Vol. 3.1), Dr. Bever's longitudinal cohort study also has the objectives of identifying predictors of long-term outcome in MS, examining correlation between MRI measures and clinical outcome, and identifying predictors of response to disease modifying agents. A telephone conference is planned with Drs. Bourdette, Herndon, Baumhefner, and a selection of other members of the VASIG Research Committee to finalize plans and, it is hoped, lay the groundwork for other potential VA cooperative studies. An updated VASIG Research Committee membership list is available from [robert.baumhefner@med.va.gov](mailto:robert.baumhefner@med.va.gov).

## A Team Approach to Annual Physicals for the MS Patient

Veterans with multiple sclerosis (MS) are eligible for care by the spinal cord injury (SCI) team at the Durham Veterans Affairs Medical Center (VAMC). These veterans must be neurologically stable and have health-care needs that are most appropriately addressed by the SCI team. Such health-care needs as functional impairment and some bowel and bladder or skin care problems, as well as social service needs, are reasons to consult the SCI team.

The annual physical includes an evaluation by the physician/nurse practitioner (NP), physical therapist, and SCI coordinator/social worker as well as any additional tests that may be needed.

Important reasons for annual physicals for MS and SCI patients include early detection, screening, prevention, education, and treatment. The protocol for the annual evaluation contains several parts. Patients who receive their physicals at the SCI clinic are scheduled for lab and blood work prior to their physicals. They receive blood tests for CBC; electrolytes; kidney function, including urine tests, KUB, renal ultrasound; and, if needed, EKG, chest Xrays, and mammograms or PAP smears.

Upon arriving at the clinic, patients are checked by nursing for vital signs. The exam room is equipped with a special scale that accommodates wheelchairs and with a low exam table with a trapeze to ease in transferring patients. Each room is larger than a typical exam room to allow ease of movement

with veterans who have wheelchairs or electric carts.

The SCI coordinator/social worker, physical therapist and nurse practitioner routinely meet with the patient and caregiver as a group. The team believes this expedites the visit and prevents repetition for the veteran and his family.

The SCI coordinator initiates the interview and completes a psychosocial assessment. The assessment includes information on date and level of injury, surgery, rehab, family, and marital history. The SCI coordinator also explores service history, insurance, income, and work history. Questions about smoking, drinking, and mental health history are also included. Because MS patients frequently have limited physical mobility, daytime activities and sleep patterns are explored. Screening for depression is completed as necessary.

Advance directives are always encouraged for patients with heavy care needs. The patient is asked whether he or she has designated a durable power of attorney for health care and whether this has been discussed with a family member. Also the issue of a DNR (do not resuscitate) order is addressed. If the patient has not completed an advance directive, he or she is educated about this and encouraged to complete one.

The physical therapist completes an assessment of activities of daily living, mobility, equipment, strength, and flexibility and explores any changes in abilities, such as new problems with falling or transferring. Any necessary equipment can be ordered or sent home with the patient. Veterans are evaluated for wheelchairs, cushions, and the need for shower chairs, bath rails, and ele-

vated toilet seats as necessary and may be referred to occupational therapy for an in-depth assessment if needed.

The nurse practitioner, along with input from the SCI physician, completes a history and physical examination, evaluates lab and blood tests, completes a health risk assessment, and may make other recommendations or consults depending on need. The provider will examine chronic conditions as well as family history, chronic pain, nutritional assessment, bowel and bladder management, and sexual dysfunction. For veterans who spend several hours a day in a wheelchair, skin integrity is an important focus for the nurse practitioner. If a veteran has serious skin care problems, a consult to the wound care nurse is sometimes required. Pain control and control for spasms are key areas of concern for MS patients. Because of the detail involved in the annual physical, the nurse practitioner uses a template to chart the annual physical results.

The MS patients may benefit from a variety of resources, and some veterans may also benefit from applying for "Aid and Attendance" or "Housebound" status through VA. These patients are encouraged to contact their local Paralyzed Veterans of America (PVA) national service officers or are referred to the PVA Office in Winston-Salem, North Carolina. Publications like *Wheels and Spokes* provide interesting articles for patients in wheelchairs. Some communities have basketball teams, pool leagues, and special fishing piers for wheelchair bound patients. Such information is shared with veterans interested in pursuing additional activities for any wheelchair-bound

patients. The current caregiver/support system is very important for the MS patient. Reduction of caregiver stress frequently is a topic addressed by the team. The Durham VAMC has an "Inpatient Respite Program" through the Extended Care Rehabilitation Center. Veterans may also apply for the "In Home Respite Program" or the "Adult Day Health Care" programs. This helps provide the caregiver with some relief from the stress of managing MS in the home.

The total case is reviewed at SCI rounds after all test results are available. The team, as a group, reevaluates whether the patient would benefit from any additional resources, with consults completed at that time. Such resources as home-based primary care, homemaker/home health aide, bowel and bladder programs, adult day health care, respite, or other community home care programs are often required. Patients may need further assistance from nutrition, home assessments for adaptive equipment, mental health, pain clinic consults, or wound care consults.

The goal of the team is to provide the best quality of life for our patients. The annual physicals on MS patients are a relatively small portion of the total veterans seen in the SCI clinic; however, the team's goal is to provide comprehensive exams with a multidisciplinary approach for all patients.

*By Linda Matich Lang, MSW, LISW, spinal cord injury/home care coordinator, Durham VAMC*

*The author would like to thank Dr. Helen Hoenig, chief, Physical Medicine & Rehabilitation Service at the Durham VAMC; Frankie Dunmore, NP; and Marianna Crane, NP for their editorial help with this article.*

## Update on the New RIGS

In August 2003, I attended the organizational meeting for Research Interest Groups (RIGS) to be associated with the Consortium of Multiple Sclerosis Centers (CMSC) Cooperative Studies Group (CSG). These RIGS will be responsible for proposing research projects to the Scientific Review Subcommittee of the Executive Committee for the CSG. Funding from the CMSC Foundation is not yet in place, but eventually the proposal process and approved projects will be supported by a statistical and data management center and an operations center. The executive committee has not yet been organized, but there is a CSG steering committee, including Dr. Christopher Bever and Dr. Jodie Haselkorn, both directors of the VA Centers of Excellence; Fred Foley, Ph.D.; Dr. Corey Ford; Dr. Kenneth Johnson; Dr. Rick Munschauer; Dr. James Simsarian; and Dr. Howard Weiner.

The following RIGS have been organized:

**Disease Modifying Agents and Pathogenesis**—Contacts: Dr. Steven Kamin at [kaminst@umdj.edu](mailto:kaminst@umdj.edu); or Dr. Kottil Rammohan at [rammohan.2@osu.edu](mailto:rammohan.2@osu.edu)

**Epidemiology**—Contact: Dr. Jeffrey Greenstein at [jigreenstein@aol.com](mailto:jigreenstein@aol.com)

**Psychosocial**—Contact: Fred Foley, Ph.D., at [ffoley1@aol.com](mailto:ffoley1@aol.com)

**Rehabilitation**—Contact: Susan Bennett, PT, Ed.D., at [sbennett@buffalo.edu](mailto:sbennett@buffalo.edu)

**Symptom Management**—Contact: Dr. Francois Bethoux at [bethouf@ccf.org](mailto:bethouf@ccf.org)

### **Disease Modifying Agents and Pathogenesis (DMAP) RIG**

**Report:** I was involved in the organization of the DMAP-RIG. Our mission statement was developed based on the following concepts:

1. foster investigation into the pathogenesis, diagnosis, and prognosis of MS;
2. develop new and optimize existing treatments to improve the natural history of MS;
3. develop and validate better outcome measures for disease detection, disease activity, and treatment effect (this was a broad area, and the CMSC might consider establishing an independent RIG to address this objective); and
4. standardize methods of patient assessment and data collection for long-term outcome measures.

It was unanimously agreed that a key element for future clinical study design in collaboration with industry was that the RIG should control the data generated. This would alleviate biased data reporting and allow inquiry into areas that otherwise might not be investigated. The group was divided as to the timing and content of our approach to industry collaboration. In general, such collaboration was viewed positively, but more productive when the RIG had successfully overseen meaningful clinical studies.

Until standing committees are established, ad hoc committees appointed by the co-chairs (and notified by email) will perform the business of the DMAP-RIG. Confidentiality of RIG issues is assumed. Individual members wishing to protect intellectual property

are encouraged to do so in publications. The CMSC will establish a secure web site for RIG members. The DMAP-RIG includes but is not limited to the individuals present at this meeting. Approximately 40 other members of the CMSC are currently interested in participating in this group. I represented the only VA represented in this membership, which consisted of directors from large university-based MS centers.

Potentially important areas for investigation discussed in the DMAP-RIG were as follows:

**1. Is MS a single entity with multiple phenotypes or a syndrome?** A significant number of members believed this was a high priority issue and wished to participate in an existing study proposed by Dr. Timothy Vollmer. In this proposal, patients with “MS variants” of low-lesion-burden primary progressive MS, Devic’s disease and MS presentation with a relatively isolated cognitive/gait disorder will be studied with genomic and proteomic techniques to learn whether they comprise unique subgroups based upon the proteins found in selected tissues or their genetic characterization. Members should contact Dr. Vollmer if they are interested in collaborating with the group at Barrow Neurological Institute.

**2. How is acute disseminated encephalomyelitis defined, and what is the natural history of patients with that diagnosis, particularly with respect to the development of MS?** A working group will decide whether a retrospective or prospective study is the most appropriate current technique to study this

issue. Members should express interest in this project to Dr. Rammohan, although a specific principal investigator has not been selected.

### 3. What clinical markers predict conversion of clinically isolated syndromes to MS?

### 4. What measures of the cerebrospinal fluid can be used to enhance diagnosis and prognosis of MS patients?

### 5. How can imaging be improved to trace cellular migration, to follow patients, and to apply quantitative techniques to clinical practice?

Developing new and optimizing existing treatments to improve the natural history of MS was discussed, including combination therapies, treatment failures, “induction therapy,” neutralizing antibodies, feasibility and timing of discontinuing immunomodulator therapy, primary progressive MS, and comparison of available therapies.

**Plasmapheresis:** It was decided to consider a study of the effect of plasmapheresis as compared to IV corticosteroid for the treatment of severe exacerbations. The suggestion was made to select centers in which physicians currently use plasmapheresis and to balance those with clinics that primarily or only used corticosteroid for the treatment of severe exacerbations. It was suggested that inclusion criteria be carefully defined to select comparable patients at all centers and that patients have relatively severe, and thus potentially disabling, exacerbations. Interest in this study should be communicated to the DMAP-RIG chairpersons.

**Outcome Measures:** Developing and validating better outcome measures for disease detection, disease activity, and treatment effect was also discussed. Because the National MS Society has no plans for the further development of the Multiple Sclerosis Functional Composite, it was believed that the RIG should attempt to refine the usefulness and significance of this instrument as an outcome measure for clinical trials. Valid patient-reported outcomes would reduce the cost and possibly improve the relevance of clinical research. Such outcomes are not universally accepted among MS practitioners. The DMAP-RIG could assess the validity of such outcomes. If their validity is established, they should be applied where possible to RIG clinical trials and MS investigators should be educated as to their use.

**Standardization:** Standardization of methods of patient assessment and data collection for long-term outcomes measures is needed. Implementation of a combined electronic database, record-keeping system, and research report system could reduce errors, improve completeness, and better document level of clinical services. The CMSC should consider a leadership role in partnering with a neurological office software company, such as Logician™, to develop software for MS CoEs. It is important that this system not add to the work and time required to collect data.

*By Robert Baumhefner, MD, VA-SIG Research Committee chair*

## Call for Nominations

The VA-SIG is looking for a few good women and men to serve as officers on its Steering Committee. Service entails a two-year commitment and offers an exciting chance to learn more about the VA-SIG and its impact on multiple sclerosis within VA. Elections will be held at the June Consortium of Multiple Sclerosis Centers (CMSC) VA-SIG meeting. If interested in the following positions, please email your name to Rachel.Palmieri@med.va.gov as soon as possible:

**Chair:** As chair, you not only represent the VA-SIG at various VA functions but also serve as a voting member on the CMSC. The chair works closely with PVA, the United Spinal Association (formerly EPVA), and Dr. John Booss, VA Central Office neurology chief. The chair also interacts with both Centers of Excellence (CoEs).

**Vice Chair:** Assists the chair with any duties deemed necessary. In the absence of the chair, the vice chair will conduct business.

**Research Chair:** Informs VA-SIG members of ongoing and planned VA cooperative research studies and facilitates participation from VA centers, acts as a liaison with the Research Interest Groups (RIGS) of the CMSC Cooperative Studies Group and the research sections of the CoEs, and solicits committee membership.

**Clinical Care Chair:** Develops guidelines with the CoEs on patient care issues and addresses other care needs.

**Education Chair:** Develops educational programs in conjunction with the CoEs.

**Newsletter Chair:** Affords the opportunity to develop editorial skills and work closely with PVA Communication staff.

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## Upcoming Symposium on Cognitive and Neurobehavioral Issues in MS—April 19

A four-hour symposium on cognitive and neurobehavioral issues in multiple sclerosis (MS) will be held April 19. It is the first jointly sponsored program to be held simultaneously at both MS Centers of Excellence (CoEs) and interactively broadcast by V-TEL to multiple VA hub sites throughout the country.

The symposium will offer the most current information concerning advances in the care of MS with regard to cognitive dysfunction, neurobehavioral correlates, functional implications of neurocognitive and psychiatric changes, and treatment with a focus on prophylaxis, compensatory strategies, and patient and family intervention. Attendees will enjoy expert presentations as well as tele-broadcast presenters from both coasts. Continuing Education Units will be offered for physical therapists, occupational therapists, doctors, social workers, nursing, psychology. There is no cost to VA employees.

The MS CoE–East program will be held in the John Dennis Auditorium, 2nd floor, at the Baltimore VAMC, from noon to 4:30 p.m. EST. The MS CoE–West (PSHCS, Seattle) program will be held in conference room 1/240, from 9 a.m. to 1 p.m. PST. For registration or broadcast information, contact Jennifer Jett at (503) 220-8262, ext. 53296.

## EDUCATIONAL OPPORTUNITIES

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### MS CoE–West

#### REHABILITATION PROFESSIONAL TRAINING WORKSHOP: COMPREHENSIVE CARE FOR PEOPLE WITH MS

Friday, March 5, 2004

8:30 a.m.–5 p.m.

Portland VA Auditorium, Portland, Oregon

**Please Note:** 9 a.m.–11 a.m. sessions are available via V-TEL throughout VISN 20.

*For more information call Jennifer Jett at (503) 220-8262, ext 53296.*

#### TOPICS:

This full day workshop—featuring the codirectors of the MS-CoE West and nationally recognized therapy experts on MS rehabilitation—will cover the following topics:

- Pathophysiology, Diagnosis, and Treatment of MS
- New NMSS group treatment video series: “Fatigue: Take Control”
- Keys to Efficient OT/PT Evaluations
- Diagnosis and Treatment of Spasticity in MS
- Gait and Mobility in MS
- Ordering Equipment in the VA System
- Cognitive Problems in MS
- Exercise Programs for MS

#### FACULTY:

Jodie Haselkorn, MD Codirector MS CoE–West

Dennis Bourdette, MD, Codirector MS CoE–West

Lois Copperman, PhD, OTR, OHSU, MS CoE–West

Cinda Hugos, MS, PT, OHSU, MS CoE–West

*Sponsored by the VA MS CoE–West, Oregon Health and Science University, and the PVA Education Foundation*

## Ask the Experts

### ***Multiple Sclerosis and Stress: Is there a Link?***

Early research studies on multiple sclerosis (MS) have speculated that stressful life events and psychological distress may stimulate MS exacerbations (Foley, F. W., 1987; Franklin, G. M., *et al*, 1988; Grant, I., *et al*, 1989; Kroencke, D. C., *et al*, 1999; Schwartz, C. E., *et al*, 1999; Warren, S., *et al*, 1991). Literature in the area of psychoneuroimmunology also speaks to the causal link between stress and health problems. We have long known that acute and chronic stressors can increase our susceptibility to the common cold, headaches, and gastrointestinal problems. Research in the area of psychoneuroimmunology has also found that the long-term effects of chronic stress results in an allostatic load, which reduces the body's resilience to stress. More recent studies on the impact of stress on MS have found a greater risk of exacerbation among those MS patients who report negative or uncontrollable life events. Kroencke and colleagues (1999) found that patients in the exacerbation phase report more daily hassles than those in the chronic phase. This finding suggests that major life stressors may not have as strong an influence on disease activity as chronic, daily stressors.

A study by Schwartz and colleagues (1999) investigating a bidirectional stress-illness hypothesis in people with MS (e.g., examining whether stress causes physical deterioration or whether physical deterioration causes stress) found an increased risk of disease progression

by level of stress. The researchers also found that older age served to reduce the impact of stress on disease progression. Additionally, the study showed an increased risk of reported stress by rate of disease progression. Again, older age was found to reduce the impact of disease progression on stress. Most important, these investigators concluded that "the risk of stress, given disease progression, was of greater clinical significance than the risk of disease progression given reported stressful events" (Schwartz, *et al*, 1999, pg. 4). In other words, patients who showed a faster rate of deterioration had a higher risk of reported stressful life events, and patients who reported more stressful events were at greater risk of functional deterioration. These findings indicate a relationship between self-reported measures of stress and disease progression and also suggest that patients with MS are increasingly vulnerable to the impact of negative events. In yet another study, Sibley (1997) found a positive correlation between patient-reported marital or job stress and subsequent exacerbation of MS.

Given what we already know about the impact of stress on MS, it seems necessary to provide MS patients with coping skills for reducing the impact of stress. Folkman and Lazarus (1986, 1988) have made a distinction between problem-focused coping and emotion-focused coping. Problem-focused strategies are used to handle stressful events that are under the individual's control (e.g., finances, work-related situations), whereas emotion-focused coping involves minimizing psychological distress for situations

perceived to be outside of the individual's control (e.g., by changing the meaning or interpretation of the situation). A study by Aikens, *et al.*, (1993) found that MS patients who scored higher on measures of depression reported more use of emotion-focused rather than problem-focused coping. Folkman and Lazarus (1986) found that problem-focused coping strategies are associated with a greater sense of self-control, perhaps because this approach to coping is likely to enhance self-efficacy.

A more recent study by Jean, *et al*, (1999), showed that MS patients utilize both problem-focused and emotion-focused strategies when dealing with a disease-related stressor. However, during periods of increased psychological distress, most patients utilized emotion-focused coping over problem-focused coping. These authors, like Folkman and Lazarus (1986), concluded that the purpose of coping responses is to alleviate psychological distress resulting from life stressors, and that successful coping requires the use of coping strategies that are appropriate to the individual's own resources and situation.

One way to assist patients in coping with stressful events is to **teach them problem-solving skills** (Meichenbaum, 1985). Here the patient is asked to define the stressor or stress reaction as a problem-to-be-solved and to set realistic goals as clearly as possible by stating the problem in behavioral terms (observable and measurable by you and others). The patient is then encouraged to generate a wide range of potential courses of action and to evaluate the pros and cons of such and rank each

possible solution from least to most desirable. This process is followed by patients rehearsing the strategies and behaviors they have planned through the use of imagery, role-playing, and practice. Finally, the patient is encouraged to try out the most practical and feasible solution and to reward himself or herself for having tried, despite the outcome.

**Teaching patients stress management skills** is yet another important tool to help patients reduce the impact of stress in their lives. The practice of stress management is an example of emotion-focused coping, as the goal is not to get rid of the stressor, but to learn more effective ways of tolerating the stress produced by the illness and/or other life factors. While the course of one's illness, or unprecedented life events are beyond the individual's control, stress management can be practiced anytime, anywhere, and by virtually anyone. Many patients with MS have to cope not only with everyday stressors, but also with disease-related stressors, which may also lead to a significant amount of uncertainty about the future course of the illness. Uncertainty about the future can open the door for chronic stress.

While chronic stress has an adverse impact on your body and mind, **there are ways to manage stress in order to minimize its harmful effects.** Dr. Herbert Benson, a cardiologist from Harvard University, has found that one way to combat the negative effects of stress is to elicit the "relaxation response." This response occurs when your body is profoundly relaxed, free of tension and anxiety. Although the stressors (e.g., illness) may still exist, the way to respond to them can change.

**There are numerous techniques to manage stress.** One of the most common techniques for stress reduction is **deep breathing**, also known as diaphragmatic breathing. Aside from being one of the most common forms of relaxation strategies, deep breathing is also one of the simplest to practice. The control of respiration is one of the most straightforward methods of stress management. Deep breathing can be practiced at any time and in almost any setting. For centuries, yogis have said, "life is in the breath." When we practice taking slow, deep breaths we are automatically optimizing the exchange of oxygen and carbon dioxide in our bodies, oxygenating our blood and involuntarily relaxing our muscles. Deep breathing also serves to slow us down, to become more aware of our breath, and hence, of our body. Diaphragmatic breathing involves learning to breath deeply and fully versus shallow and rapid.

The primary purpose of deep breathing is to get oxygen into the body and to get carbon dioxide, a waste product, out of the body. Following are some basic steps to keep in mind about proper breathing:

1. Rate of breathing and state of mind are inseparable. The slower you breathe, the calmer your state of mind.
2. With relaxed breathing, the shoulders do not move up and the chest does not expand. Instead, air flows smoothly in and out of the lungs rather than being blown out forcefully.
3. Initially, it is easier to practice relaxed breathing while lying on your back. Placing one hand over

the chest, and another over the abdomen, you can notice the abdomen expand with each inhalation and contract with each exhalation.

4. Inhaling through the nose and exhaling through the mouth can help slow breathing. However, the most important factor is to breathe in whatever way is most comfortable.
5. Be mindful of the breath. Keep track of the breath as it comes in and goes out of the body.

With regard to managing stress, deep breathing is helpful because of its quick and calming effect. Diaphragmatic breathing has been shown to help individuals with headaches, anxiety, hypertension, insomnia, and hyperventilation. It is also effective in reducing irritability, fatigue, and muscle tension.

Another method of relaxation is **meditation.** Meditation refers to a family of techniques that share a conscious attempt to focus attention in an uncritical manner and without dwelling on discursive or ruminating thought. Meditation involves the intention to focus attention on one thing at a time; it is unimportant what is focused on. In other words, attention can be focused on the breath, on a candle flame, on a picture or object on the wall, or on any other object. The idea is to quiet the mind by becoming single-focused during practice.

**Progressive muscle relaxation (PMR)** is yet another well-known systematic technique for achieving a deep state of relaxation. PMR involves tensing and releasing various muscle groups. This technique was developed by Dr. Edmund

Jacobson in 1905 in order to teach individuals the difference between a tense bodily state and a relaxed state. PMR is based on the idea that the body responds to anxiety-provoking thoughts and events with muscle tension. This bodily tension, in turn, increases the individual's subjective experience of anxiety. So by learning to identify your own physiological states of tension and relaxation, you can teach yourself specific instructions to elicit the relaxation response.

Another relaxation technique similar to PMR is **body scanning**. Body scanning does not require tensing of any of the muscle groups. In fact, body scanning only requires observing any areas of tension in the body and then telling yourself mentally to

release the tension. In involves identifying the tension and letting it go. During the body scan exercise, you use your mind's eye to scan the body, becoming aware of bodily tension. You also use your breath to focus on these areas of tension, and gently release the tension with the breath. Unlike PMR, body scanning is a less active approach to relaxation.

Finally, another common relaxation technique is **guided imagery**, which was developed by Arnold Lazarus in 1977. This method is often added to other relaxation techniques, such as PMR or diaphragmatic breathing, in order to deepen the state of relaxation. The use of images produces different perceptions, feelings, and behavioral responses that serve to

elicit the relaxation response. Imagine being in a favorite place to relax, perhaps on a beach, beside a soft flowing stream, under a shaded oak tree, or on a desolate island far away from your troubles.

**Visual imagery** is also used for goal rehearsal and coping imagery. In other words, think of a situation that produces a high state of anxiety for you, such as getting results from your latest medical exam. Now imagine that scenario play out in your mind. See yourself in the doctor's office receiving feedback, and rehearse possible responses he or she may give you, and your counter responses. When you note yourself becoming very anxious as you rehearse this scenario, take a few deep breaths and allow yourself to relax, and then start over again. Engaging in this type of goal rehearsal can eliminate anxiety by helping you feel prepared to effectively confront difficult situations.

As evidenced by the relaxation strategies mentioned, **there are many ways patients can learn to decrease and/or eliminate their response to daily stresses**. As practitioners, we need to identify those patients whose coping skills are ineffective and provide them with new and effective strategies to cope with daily hassles and with the stress of living with an almost pervasive sense of uncertainty about the future course of their illness.

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**(Editor's Note:** Reference citations are available on request. Email VA-SIGNature editor to request.)

## **"The Art and Science of Multiple Sclerosis"**

**2004 Annual Meeting  
of the  
Consortium of Multiple Sclerosis Center  
June 2-6  
Toronto, Canada**

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**See an overview of the 2004 meeting at [www.mscare.org](http://www.mscare.org).**

## EPVA Renamed, Refocused

Eastern Paralyzed Veterans Association is proud to announce that it will use its 57 years of experience and expand its mission from veterans with spinal cord injury or disease to include all paralyzed individuals. As of January 2004 Eastern Paralyzed Veterans Association became United Spinal Association.

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## Publications Target MS Care

Two publications now available assist in the care and everyday living needs for people with multiple sclerosis (MS).

A new personal financial planning guide for people with MS, *Adapting: Financial Planning for a Life with Multiple Sclerosis*, has been published by the Paralyzed Veterans of America (PVA), the National Endowment for Financial Education (NEFE), and the National Multiple Sclerosis Society (NMSS). The 72-page guide provides information on financial organization, planning, self-help, employment concerns, and benefits issues important for anyone with MS or the people who care for them.

This public service project was instigated by NEFE, an independent nonprofit foundation committed to educating Americans about personal finance and empowering them to make positive, sound decisions to reach their financial goals. NEFE seeks out partners such as NMSS and PVA to create specialized messages such as this book. In 2002 NEFE col-

laborated with the National Spinal Cord Injury Association (NSCIA) and PVA to publish *On the Move: A Financial Guide for People with Spinal Cord Injury*. Both publications are free and available, as single documents or in bulk quantities, for the cost of shipping and handling only. Contact the PVA distribution center at (888) 860-7244. Copies of *Adapting* can also be obtained from your local NMSS chapter by calling (800) FIGHT-MS (344-4867).

Also now available from the NMSS Professional Resource Center is *Nursing Home Care of Individuals with Multiple Sclerosis: Guidelines & Recommendations for Quality Care*, which discusses strategies to improve disease management and quality of life for people with MS who require substantial daily assistance. Traditional geriatric care often does not meet the demands of this unique population, which tends to be younger, more mentally alert, much higher users of facility services, and subject to far longer stays in extended care facilities. To fill the void, the new publication includes clinical practice information, practical tips, and best practices with regard to nursing and daily care, rehabilitation, psychosocial needs, and cognitive issues.

Copies of *Nursing Home Care of Individuals with Multiple Sclerosis: Guidelines & Recommendations for Quality Care* are available from the NMSS Professional Resource Center by calling (866) MS-TREAT (678-7328) or can be downloaded at no charge from the following web site: [www.nationalmssociety.org/pdf/forpros/MS\\_nursing\\_guide.pdf](http://www.nationalmssociety.org/pdf/forpros/MS_nursing_guide.pdf).

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