

Welcome to Our Latest Edition

Our goal is to provide a medium for VA MS professionals to share expertise and improve care for MS patients. We welcome your thoughts, comments, and participation.

Please pass this issue along. If you know someone who wishes to be included on the electronic distribution list, forward the email address to the editor.

A Letter from the VA-SIG Chair

Hello Everyone,

With the hot weather of August upon us, it is important to remember that this can be a tough time for people with multiple sclerosis (MS). With a consult, Prosthetics Services can provide room air conditioners. Depending on your facility, cooling vests may be available.

Our Centers of Excellence (COEs) continue to be a leader in research and clinical care of MS patients. I commend the East and West COEs on outstanding and well-attended presentations at the Consortium of Multiple Sclerosis Centers (CSMC) conference in Orlando. Nonindustry sponsored, the sessions were not slanted to a specific pharmaceutical company. Participants look to our VA COEs to present pure research, and we continue to lead in this aspect.

Election of officers in our VA-SIG will occur next year. I asked everyone at our VA-SIG meeting in Orlando to consider running for an office. I am now asking every VA-SIG member to consider running. We need to infuse new energy into the VA-SIG. Election carries a two-year commitment and really offers people a chance to work closely with the VA Central Office neurology leadership, Thomas Stripling from PVA, and Vivian Beyda from United Spinal Association. This is a great opportunity to develop management experience and work with a terrific group of people.

Offices that will be vacant in 2006 are chair, vice chair, and newsletter editor, as well as chairs of all committees (Clinical Care, Membership, Research, and Education.) If you have questions about these offices, I can be reached at (518) 626-6497 or via email at rachel.palmieri@med.va.gov. I look forward to seeing several people "step up to the plate" and run for these offices.

Wishing everyone a safe and enjoyable summer,

Rachel Palmieri
VA-SIG Chair

In this Issue:

MS Support Group	2
CMSC Conference	3
COE News	4
CRPS Template	5
Dates to Remember	6
Award Winners	7
VA-SIG News	9

MS Support Group Growing in Houston

The Michael E. DeBakey VA Medical Center (MEDVAMC) in Houston has many support groups, including ones for victims of stroke, Parkinsons disease, and cancer, as well as one for amputees. But what it didn't have until recently was a multiple sclerosis (MS) support group.

Soon after I assumed the position as neurology care line social worker at the MEDVAMC, I met a female veteran who told me of her struggles as a newly diagnosed MS patient. She talked about how very alone she felt dealing with MS issues as well as issues of being a disabled female veteran. She suggested that an MS support group be started at the MEDVAMC so patients could learn from each other. As I met other neurology patients with the diagnosis of MS, they, too, talked about their hopes for an MS support group at the MEDVAMC. I knew this call to action had to be answered. In partnership with my cofacilitator, Fe Funtanilla, RN, an MS support group at the MEDVAMC was formed.

What has happened since then has been very special and rewarding. For this MS group to be successful, we needed buy-in not only from the patients/veterans, but also from neurology, our facility, the Paralyzed Veterans of America, and the National MS Society, Lonestar Chapter. The idea of an MS support group open to the public and to include both veterans and nonveterans with MS met with unanimous approval.

Guidelines for the group included a focus on living successfully

with MS as well as a goal to be psychoeducational and supportive in nature. It would meet once a month: two consecutive months of psychoeducational groups and one month of support group. The format would be subject to change based on the consensus of the core members. Ideas for future topics would come from the core members, based on their need for information and support in order to live as fully as possible with MS.

Following written approval from management, we created a database using the ICD-9 code "340" (multiple sclerosis). After the initial database was created, each patient's chart was reviewed to make sure they truly carried the diagnosis of MS. Patients living too far from the facility and those who had died were deleted from the database. The Lonestar Chapter of the MS Society put the news about the new group in their newsletter, publicizing that it was open to nonveterans as well as veterans. People with MS who called for more information were asked if they also wanted to be added to the database in order to receive flyers regarding upcoming meetings.

The MS Society provided a \$300 stipend for refreshments for meetings. We put in place a performance improvement monitor to evaluate the support group and how each of the topics met members' needs and we developed end-of-group evaluations and new member questionnaires. We monitored the effect of each group topic or discussion on members' quality of life through a performance improvement plan. Performance scores for each monthly meeting are entered

into a performance improvement database for cumulative monitoring.

Having this MS support group at a university-affiliated VA facility offers special access to professionals who might be less available for a nonaffiliated MS support group. For example, a very well known urologist from Baylor College of Medicine brought his research team to talk about bladder problems and the latest research. Response from the group was astounding.

In time, the common ground of having MS and in many cases, also being a veteran, led to camaraderie among group members. Nonveterans with MS who attend the meetings are welcomed by the core group as warmly as veterans. The core group has become very strong—they attend other groups in the community together, go to movies and on outings together, talk on the phone regularly, and visit each other in the hospital. This core group has done a wonderful job of getting the word out about the MS support group at the MEDVAMC and helped our crossover success with persons with MS who are not veterans.

In an effort to make the MS support group more "group driven," members take turns hosting meetings, introducing the speakers, and corresponding with speakers. They are considering giving the group a name and creating T-shirts and stationery to strengthen the group's identity.

The members of the MS support group have given people who would have never had reason or opportunity to use a VA hospital the chance to do so. Some of those individuals are veterans who had never accessed our health-care sys-

tem and have now decided to enroll based on their experience at the MEDVAMC MS group. The MS Society has formed a strong alliance with the MEDVAMC and they come to the group also.

This group has meant something significant to members. A veteran diagnosed in 1997 said, "The group has been instrumental in the mental aspect of living with MS. I have had a chance to meet other vets with MS I didn't know before. Now we have that bond, I have become lifetime friends with many of the group members."

Another group member, a non-veteran who was diagnosed with MS in 2003, said, "A double 'thank goodness' for the MS support group

that has graciously accepted me as one its own. This group of individuals with MS has given me hope during my hopeless moments. I have become friends with many of these women and men during the last 16 months. These relationships now exist at the group but also away from the VA. We meet for lunch, go to the movies, visit each others' homes, and visit each other at the hospital whenever one of us is a patient."

By Lisa Whipple, LCSW
Neurology Social Worker
Michael E. DeBakey VAMC

Editor's Note: See Volume 4, Issue number 1 for a story on the MS support group in Pittsburgh. VA

Connecticut West Haven also has a very active support group for veterans with MS. We know there are many more. *VA SIGnature* is the ideal place for you to describe your program or group. In addition, as we collect news of support groups, Lisa Whipple and I are beginning discussions about how to share and benefit from our experiences. We might be able to link the groups in some way, allowing veterans with MS from all over the VA system to talk to each other. So if you have an MS support group to tell us about, contact me at elizabeth.auld@med.va.gov (VA Connecticut) and consider writing a short article.

Conference a Resounding Success

The annual meeting of the Consortium of Multiple Sclerosis Centers (CMSC) was held in Orlando, Florida, June 1–5, 2005. CMSC meetings are always a wonderful, important forum for learning about and sharing information on the multidisciplinary care of persons with MS. The VA representatives to CMSC, from the Centers of Excellence as well as the VA-SIG and others from around the VA system, play an increasingly important role in the meeting. In addition to being an educational forum, the CMSC meeting is the only time members of the VA-SIG—our special interest group that includes all interested providers of MS care to veterans—meet to conduct business and discuss problems, solutions, successes, and failures we all experience as we attempt to provide our patients with the best care. There is limited support available for VA-SIG members from PVA and the United Spinal Association. Now is the time to begin thinking about what you could do for next year's meeting: Ideas for presentations are being accepted now; formal requests for presentations or posters will be made in fall. Information on these processes and the program, as well as some of the presentations from this year's meeting, are available at www.ms.care.org. That site also links you to the *International Journal of MS Care*, the CMSC newsletter, and *VA-SIGnature*. Next year's meeting is planned for May 31 to June 4, at the Westin Kierkland Resort, in Phoenix.



VA success this year was particularly evident in the symposium "Neuroprotection and Neuroregeneration: New Avenues in the Treatment of MS," a panel chaired by Dennis Bourdette, MD, as well as the workshop chaired by Jodie Haselkorn, MD, MPH, titled "Caring for People with Advanced MS." In addition, two posters, one from the MSCOE East and one from the MSCOE West won almost all the poster prizes awarded by the CMSC. Information on the symposium and the workshop can be found on the Centers of Excellence Web site, www.va.gov/ms, and on the CMSC Web site.

News from the Centers of Excellence

The MS Centers of Excellence jointly presented a satellite program, "Treating Multiple Sclerosis: Making a Difference in Veterans' Lives," on May 10. This broadcast addressed the latest disease-modifying therapies for relapsing MS and secondary progressive MS. Program presenters were Jodie Haselkorn, MD, MPH, director MSCOE West; Dennis Bourdette, MD, codirector MSCOE West; Christopher Bever, MD, director MSCOE East; and James Bowen, MD, associate director of clinical care, MSCOE West. This two-hour broadcast has been selected by the Department of Defense and the Indian Health Service as an EES program that they will include in their training programs. For a DVD copy of the program, contact Marsha L. Tarver, PhD, associate director of education, MSCOE West, at marsha.tarver@med.va.gov. The broadcast is also available on tape in your local VA library.

The third annual John N. Whitaker Memorial lecture will be given this year in Baltimore October 14 and 15. The lecture will be presented by Jerry Wolinsky, MD, Bartels Family Professor of Neurology, University of Texas at Houston. Dr. Wolinsky, an authority on the use of magnetic resonance image scanning in MS patients will deliver the keynote address for a day-and-a-half long series of symposia on MS. One track will cover recent scientific advances in the use of biomarkers and in the study of MS lesion pathogenesis. A second clinical track will cover basic and advanced issues of disease manage-

ment, including use of disease modifying therapies, pharmacological symptom management and rehabilitation strategies. Details of the meeting will be announced soon. For information contact Christine Martin, PhD, associate director for education and training, MS Center of Excellence East, (410) 605-7060.

■ THE MS CENTER OF EXCELLENCE EAST

– Christine Martin, PhD, associate director of education for the MSCOE East, has been appointed to the National MS Society's Professional Education Committee.

– A valued member of the MS Center of Excellence East team, Mary Ehrmantraut, CRNP, recently accepted a clinical nurse practitioner position at National Institutes of Health, specifically to work with Dr. Henry McFarland on issues related to MS. She will continue to work with the MSCOE East as a consultant on several research projects.



Mary Ehrmantraut with Doug Bradham, a colleague at the Baltimore Center of Excellence.



– The MSCOE East welcomes Dr. Walter Royal, MD, as research associate director for the center. Until recently, Dr. Royal was the director of the MS program at the Morehouse School of Medicine in Atlanta. Royal, who grew up in Baltimore, received a bachelor's degree from Harvard University and MD from Dartmouth Medical School. He completed his residency training in neurology and fellowship training in neurovirology and neuroimmunology at the Johns Hopkins School of Medicine. He remained as a junior faculty member at Johns Hopkins and served as the director of the multiple sclerosis center there until he was appointed to the neurology faculty of Morehouse School of Medicine. He has research interests include MS and HIV infection.

■ UPCOMING EDUCATIONAL PROGRAMS

August 27 – Empowering MS Family Caregivers: joint program with the University of Maryland Center for MS. Instructors: C. Martin and K. Costello

September 8 – Patient Program at the Baltimore VA Medical Center: "Pain and Spasticity in MS"

September 22 – VA MS Specialty Provider program at the Baltimore VA Medical Center: "The Use of Intrathecal Medication"

November 12 – for National Family Caregivers Month, joint program

with the NMSS: “Communication and Problem-Solving Skills for MS Family Caregivers (for Caregivers)” and for veterans/patients with MS, “Health Insurance Issues”

■ NEWS FROM SEATTLE/PORTLAND

– Laura Schaben, MD, VA Special Fellow of the MSCOE West at Portland, Oregon, presented a poster in the “Works in Progress” poster session at the 2005 CMSC meeting in Orlando, Florida. Her poster, titled “Ginseng for Multiple Sclerosis Related Fatigue: Rationale and Study Design,” provided an overview of her ongoing research project. Dr. Schaben, with the support of her mentors Drs. Ruth Whitham and Dennis Bourdette, is conducting a clinical trial of high dose American ginseng extract HT-1001 versus placebo for the treatment of MS related fatigue. Dr. Schaben’s attendance at the CMSC was supported, in part, through a scholarship award from the CMSC.

– The Oregon Health Services University Department of Neurology, along with the MS Center of Excellence West, will present a CME course titled “Neurologists in the 21st Century: What’s New in 2006” on September 16 at the River Place Hotel in Portland, Oregon. This is a combined course designed to provide practicing neurologists with the most current information on general neurology topics, MS, movement disorders, and Alzheimer’s disease. Featured speakers will include Dr. Dennis Bourdette, Dr. Scott Zamvil, Dr. Roger Simon, Dr. Joseph Quinn, and Dr. Jay Nutt. For additional information about this program or

to register, contact Jennifer Jett at the MS Center of Excellence West at jennifer.jett@med.va.gov.

– Amy Poel, a PhD student in epidemiology at the University of Washington who is being mentored by MSCOE West director, Jodie Haselkorn, MD, MPH, presented a poster “Characteristics of Veterans with Multiple Sclerosis Who Die: A Preliminary Analysis.” These results were built upon the multiple sclerosis needs assessment study of veterans in VISN 20 designed and implemented by Drs. Rhonda Williams, Aaron Turner, Michael Hatzakis, and Jodie Haselkorn in 2002. The poster documented demographic and disease measures of veterans who died between 1995–2002 and compared these characteristics to those who were alive during the same time period. Increasing age, male gender, white race, and having never received a prescription for a MS disease-modifying therapy were independently associated with death in 1995–2002. Increasing age was the only significant predictor of mortality in a multivariate model. These data will form the basis of a further study of this population with additional data from the National Death Index to elucidate the underlying cause of death and perform a survival analysis to examine characteristics of patients and their disease that predict death.

Update on CPRS Template

The CPRS template for MS notes developed by the Centers of Excellence consists of a tool for new

patient and follow-up patient evaluations, as well as a clinical reminder to cue providers to enter certain data when prescribing disease modifying medications. The templates have proven to be very large and unwieldy, requiring too much time for and work for the IRM clinical application coordinators (CAC) trying to import it. The COE has thus distributed the simplest part of the big templates—the tool for generating the text for a follow-up clinic visit note on a patient with MS. You can obtain this simple template by contacting Gordon Campbell, FNP, at the Portland VA Medical

For this Newsletter:

What would you like to see here?

Please SUBMIT:

- Forum topics
- Clinical questions
- Research topics
- Ongoing MS projects
- QI issues
- Outcome measurements
- Team initiatives
- Announcements

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

Thank you!



Center. You can then either copy and paste it into your private CPRS template menu, if you have one, or you may send it to the CAC assigned to your clinical area to be added to the shared templates accessible to all users at your hospital. The template for new patient evaluations—a more complicated and powerful CPRS enhancement with access to Web-based features—is being refined and will be distributed later. The development team welcomes comments and suggestions as they try to improve these clinical aides.

VA-SIG STEERING COMMITTEE MEMBERS:

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

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

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

Edward Daly, MD
Edward.daly@med.va.gov
Chair, Membership Committee

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

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

Elizabeth Auld, PA-C
elizabeth.auld@med.va.gov
Editor, *VA-SIGnature*

DATES TO REMEMBER

Monthly, First Monday, 12:30 ET, ongoing—Telephone Conferences on Clinical Issues in MS Care

For more information contact Peggy Coffey, MD, at peggy.coffey@med.va.gov.

July 21—VHA Telerehabilitation and Multiple Sclerosis Teleconference

Channel 1, cosponsored by MSCOE East and West
Rebroadcasts:

- July 26, 3:00–4:30 p.m. ET
- August 3, 2005 10:00–11:30 a.m. ET
- August 22, 2005 1:00–2:30 p.m. ET

For more info contact MSCOE East, (410) 605-7480.

September 6–8—Annual Meetings of American Paraplegia Society

American Association of Spinal Cord Injury Nurses and Psychologists and Social Workers
Las Vegas

September 16—Neurologists in the 21st Century: What's New in 2006

CME course

RiverPlace Hotel
Portland, Oregon

For additional information about this program or to register, contact Jennifer Jett at the MS Center of Excellence West, jennifer.jett@med.va.gov.

September 17—MSCOE West Third Annual Regional Director's Meeting

RiverPlace Hotel
Portland, Oregon

Contact Jennifer Jett at jennifer.jett@med.va.gov.

October 13—MSCOE East Directors and Coordinators Meeting

Baltimore

Contact Jane Stolte, business manager, MSCOE East, (410) 605-7060.

October 14–15—Third Annual Whitaker Memorial Lecture

Baltimore

Contact: Christine Martin, PhD, associate director for education and training, MSCOE East, (410) 605-7060.

November 17—Joint East/West Satellite Symposium on Sexual Dysfunction and Intimacy in MS

May 31–June 4, 2006—CMSC Annual Meeting

Phoenix

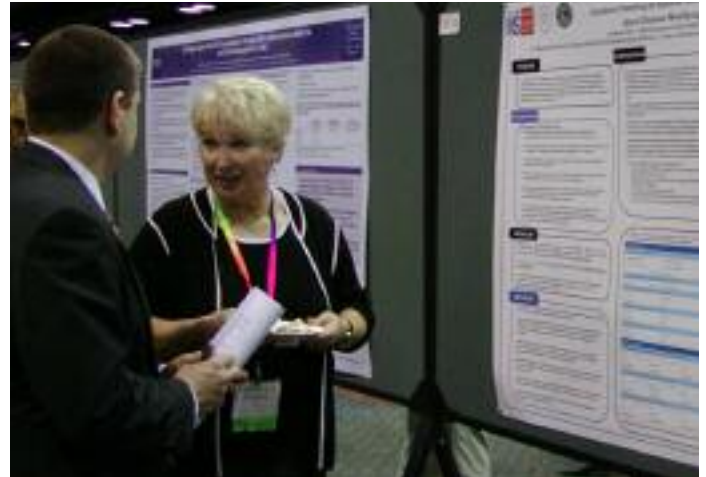
VA Researchers Win Awards

Nicole Deming, MA, from VA MSCOE West who is being mentored by Director Jodie Haselkorn, MD, MPH, won the prestigious Scheinberg Award for her presentation platform “Using the Lens of Relational Autonomy to Tackle Ethical Conflicts.” The Scheinberg Award is given to the presentation or poster that makes the biggest impact in advancing the care of people with MS. This award is named in honor of CMSC founding member Dr. Labe C. Scheinberg, a neurologist who specialized in the treatment of MS and former dean and neurology chair of the Albert Einstein College of Medicine.

Christine Martin, PhD, from VA MSCOE East received the Hope Award from the International Organization of MS Nurses (IOMSN) for her poster “Empowering Caregivers of Individuals with Multiple Sclerosis.” This award honors work that best reflects the mission of IOMSN “to improve the lives of all those persons affected by multiple sclerosis” and to inspire people with MS.

Dr. Martin’s project also won the prestigious Berlex award for advances in MS education. This award recognizes the outstanding poster or work investigating and assessing an educational intervention in MS populations. Her co-investigator colleagues at the MS Center of Excellence East were Kathleen Costello and Mary Ehrmantraut, both MS clinical nurse specialists. The CMSC/Berlex Awards are presented for the best

poster and best platform presentation depicting excellence in patient education. These awards are judged by a panel of CMSC members representing various disciplines caring for persons with MS. Criteria include patient education that provides factual information to people with MS, their families and significant others about the disease, treatments, and other MS related issues. Projects must increase knowledge and promote positive health outcomes and behaviors and include an adaptable intervention and robust evaluation.



Cris Martin discusses one of her posters with an interested colleague. Read an excerpt from her winning poster on page 8.

COE Posters and Platforms

- The Cost of MS: VHA and Private Sector Hospital Use and Expenditures 1999–2001 by Douglas Bradham, DrPH
- Case Validation of MS from VHA Extant Databases by William J. Culpepper, MA
- The Potential Use of Telehealth in Veterans with MS by Mary Ehrmantraut, RN, CRNP; Charlene Quinn, RN, PhD; Daniel Anderson, MS; Mitchell Wallin, MD; William Culpepper, MS; and Douglas Bradham, DrPH
- EDSS Ratings Derived Remotely and from Hands-on Examination: Teleneurology in Veterans with MS by Robert Kane, PhD; Mary Ehrmantraut, RN, CRNP; Mitchell Wallin, MD; Christopher Bever, MD; William Culpepper, MS
- Empowering Caregivers for Individuals with Multiple Sclerosis by Christine Martin, PhD
- Characteristics for Veterans with MS Who Die: A Preliminary Analysis by Amy Poel, MPH; Aaron Turner, PhD; Rhonda Williams, PhD; Michael Hatzakis, MD; James Bowen, MD; and Jodie Haselkorn, MD, MPH
- The Effect of Combination Therapy (Provigil + Avonex) on Quality of Life: 4 Month Follow-up, by Jeffrey Wilkin, PhD; Cynthia Sullivan, PhD; Mitchell Wallin, MD; Julie Chapman, PsyD; Robert Kane, PhD; Howard Rossman, DO; Sonda Lawson, MS, LLPC; James Simsarian, MD
- The Etiology and Incidence of Depression in Patients with MS by Jeffrey Wilken, PhD; Mitchell Wallin, MD; and Cynthia Sullivan, PhD
- Postural Support and Pulmonary Function in MS by Jacqueline Hall, MS, OTR/L, and Gary Herrero, MPT
- Effects of Static and Dynamic Standing in MS, by Christine Martin, PhD

- The Efficacy of an Academic Detailing Educational Intervention for Residents Who Treat MS Patients in the Veterans Health Administration by Christine Martin, PhD; Mary Ehrmantraut, RN, CRNP; William Joel Culpepper, MS; Kathleen Costello, RN, CRNP; Robert Shin, MD
- Ginseng for MS Related Fatigue: Rationale and Study Design by Laura Schaben, MD; Dennis Bourdette, MD; Ruth Whitham, MD; and Jesus Lovera, MD, MsPH
- Impact of Attention on Memory Functioning in MS: An Exploratory Study by Julie Chapman, PsyD; Jeffrey Wilken, PhD; Cynthia Sullivan, PhD; Mitchell Wallin, MD, MPH

Posters from Other VA Facilities:

- Soluble FAS Ligand (SFASL) Levels in Sera from Multiple Sclerosis Patients by Silvia Delgado, MD; Micheline McCarthy, MD, PhD; William Sheremata, MD; and Irving Vidaurre, Miami VAMC
- Botulinum Neurotoxin Type A (BONT-A) in the Management of Persistent Trigeminal Neuralgia (TN) in Multiple Sclerosis (MS) by Sally Zachariah, MD, FAAN, and Nick Ramandi, Bay Pines VAMC

Empowering Caregivers

The following is an excerpt from the award-winning poster by Christine Martin, PhD.

One of the foremost responsibilities of multiple sclerosis family caregivers is the necessity of becoming the conduit for communication between patient and provider. Many family caregivers express a myriad of feelings regarding their interaction with health-care professionals ranging from helplessness to intimidation. The National Family Caregivers Association (NFCA) recognized the need for increased communication skills and empowerment training for all family caregivers and developed an extensive training program in that regard called "Communicating Effectively with Healthcare Professionals." The project 1) emphasizes family caregiver self-empowerment, utilizing a diversified network of professionals and family caregivers to convey the philosophy and needed skills and 2) focuses specifically on improving understanding of medical terminology and communicating effectively with professionals in the health and social service system.

The Multiple Sclerosis Center of Excellence-East (MSCOE) adapted this workshop to meet the needs of our MS caregivers in two ways: We introduced vocabulary and common scenarios regarding symptoms and treatments specific to MS, and we developed a pre-post questionnaire to analyze the effectiveness of the training with regard to variables of self efficacy, comfort/confidence levels, and knowledge/skill improvement.

Significance was found in all 28 variables. Of notable interest was improvement in managing power in a caregiving relationship ($p < 0.000$) and confidence in using key principles of effective communication ($p < 0.000$). Self efficacy change in skills regarding empowerment and communication pre and post was significant ($p < 0.000$). Caregivers felt significant improvement in self-efficacy regarding their place in the health care team following completion of the training ($p = 0.001$). There was also significant improvement ($p = .021$) in self-efficacy beliefs regarding the ability to communicate well with health care professionals and organizational skills needed to provide information and records regarding their care recipients ($p = 0.012$).

Plans are under way to develop and evaluate additional curricula for the MS family caregiver population.

NEWS FROM THE VA-SIG

■ THE MEMBERSHIP COMMITTEE

The Membership Committee has a new chairman: Ed Daly, MD, Indianapolis VAMC. We welcome his interest in the work of the VA-SIG and look forward to working with him as VA-SIG membership grows.

■ THE CLINICAL CARE COMMITTEE

Dr. Peggy Coffey, chair of the Clinical Care Committee, has instituted an ongoing series of monthly telephone conferences on clinical topics relating to multiple sclerosis. Lasting but 30 minutes, they are designed to fit a busy clinical schedule while providing a forum in which to talk about the clinical care of veterans with MS. They are scheduled for the first Monday of every month, at 12:30 Eastern Time. For more information, contact Dr. Coffey at peggy.coffey@med.va.gov.

The first 30-minute phone conference on July 5 covered several topics. The educational topic was differentiating acute disseminated encephalomyelitis (ADEM) from MS. Discussion that followed focused on the new CPRS template generated by the Centers of Excellence (see story, page 5). The third area of interest was the new warning issued by Serono on the cardiotoxicity risks and monitoring recommendations for Novantrone® (Mitoxantrone).

Serono changed the labeling for Novantrone® in March, based on post-marketing reports of diminished cardiac function that occurred early in the treatment with Novantrone®. The new warning states that cardiac monitoring of MS patients should be performed at baseline and prior to

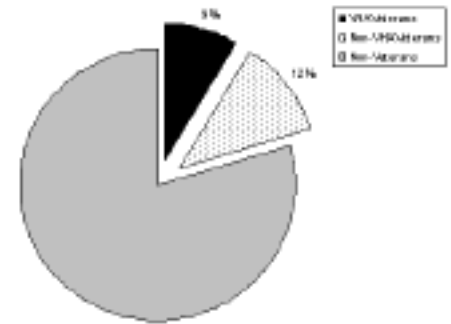
administration of every dose of Novantrone®. The medication should not be administered to anyone with an LVEF of less than 50 percent or to anyone experiencing a significant reduction in LVEF. Complete information is available in the prescribing information and at www.novantrone.com.

■ THE RESEARCH COMMITTEE

The North American Research Committee on Multiple Sclerosis (NARCOMS) Database is the largest and most comprehensive registry of MS patients in the world with more than 24,000 active participants. Large databases offer important insights into characteristics of specific diseases. The data in NARCOMS are being used to understand variations in the nature of MS and helping researchers in the search for ways to treat this debilitating disease. One of the unique features of NARCOMS is the inclusion of veterans as a separate category. One of the principal research interests of Dr. Albert Lo, MD, PhD, chair of the VA SIG Research Committee and director of the MS Clinic at VA Connecticut, is the ongoing analysis of the NARCOMS database, in particular the veteran component. His most recent published work can be found in *Multiple Sclerosis* 11: 33-40 (2005).

NARCOMS divides the veteran component into two parts: veterans who identify themselves as receiving their MS care through the VA and veterans who receive care only from the private sector. Many of us have the feeling that multiple sclerosis in veterans tends to follow a somewhat different course from nonveterans. If this is true, the better we understand the nature of MS in veterans, the better we will be able to treat them.

Proportion of Veterans in NARCOMS



In addition, the insights from veteran MS may provide valuable clues to explain some of the variability seen in MS.

However, a truly representative sample of veterans receiving their care from the VA is essential to getting good data and thus more reliable answers. The following figure illustrates very graphically the breakdown of nonveteran, non-VHA veteran, and VHA veteran. The VHA veterans represent only 9 percent of the total and comprise approximately 15 percent of the total number of VHA veterans with multiple sclerosis.

Greater veteran participation would allow the NARCOMS analysis to be more representative. This newsletter goes to many of the MS clinicians in VA. You can really help in this effort to increase veteran enrollment in NARCOMS. Additional information and the enrollment forms are available at the CMSC Web site (www.ms-care.org) or the VA MS Centers of Excellence Web site (www.va.gov/ms). Your patients can complete these enrollment forms electronically, or you can download them to be printed and mailed in.

For more information, contact Albert C. Lo, MD, PhD, at (203) 932-5711, ext. 5734, or albert.lo@yale.edu.