

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

I HAVE MS BUT MS DOES NOT HAVE ME

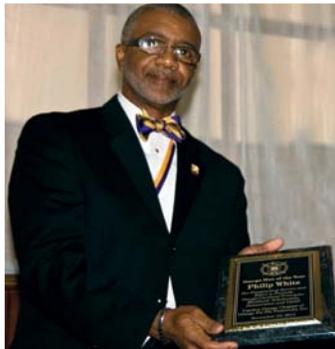
Every day I wake up, just like everyone else, and see the sun shining and the birds chirping and have the promise of the entire day set before me – 24 hours, 1,440 minutes – just like everyone else.

The only thing that makes my waking up a little different than your waking up is that “I have MS, but MS does not have ME.” I believe in the poem

“It Couldn’t Be Done” by Edgar Albert Guest: *“Somebody said that it couldn’t be done / But he with a chuckle replied / That “maybe it couldn’t,” but he would be one / Who wouldn’t say so till he’d tried.” (1-4)*

MS is just on the journey with me to do what is part of my DNA – teach, mentor, and lead. These three things have been part of my life career as a Retired Captain in the US Air Force and a community volunteer. You can do anything you set your mind to do and like any challenge, you get to decide every day how you will overcome the obstacle.

I have a “use it or lose it” philosophy about the cognitive and physical aspects of my disease. We all have a bank of mental and physical energy with which to get it done – and every day we get a new deposit to spend anew. Life with MS is a choice to be healthy and to choose how to spend my energy account. I have learned to listen to my body and know how to space out my activities to maximize my output for the results I seek to achieve. Whether it is celebrating the centennial of my fraternity, Omega Psi Phi Fraternity, Inc., serving as the Gateway MS Ambassador, or giving out over 15,000 school bags to students in the St. Louis Public Schools, I choose how to maximize my energy resources.



When I wake up and my body or my mind act like they want to hold me back, I remind them that I am directing this destiny and I do not say, “I can’t” because “*can’t*” only means “*constant act of not trying.*” I refuse to let that be a part of my life story. It may mean that I choose to do one or two things instead of the three or four that I might normally do,

but I continue on and so can you. MS means “MOST STUFF” to me, that on most days I can do most things.

You have a choice, remember that. You did not choose MS, but you do get to choose how you will handle MS. Living with a chronic illness is only limiting if you believe “I can’t” instead of “I can.” You must monitor your energy level, think of your longevity, and keep your mind sharp. Read a book, go to the museums, challenge yourself with a new task, eat a healthy diet, and exercise daily. I choose every day to put one foot in front of the other and use my 24 hours for the greatest good instead of allowing MS to stop me.

MS also challenges our cognitive abilities and I choose every day how to keep my mind sharp. I keep busy through volunteering with the Oasis Intergenerational Tutoring Reading Program, along

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with my work with VA, and serving as the Upsilon Omega Foundation Vice President and the Omega Center Manager (community service center). As an active member of my fraternity, I was challenged in 2011 to plan a huge centennial conference in St. Louis. Some thought it couldn't be done, but "I DID IT!"

What can life with MS look like? It looks like a man who was Area Captain for four states and who traveled to make history. It looks like a man, for the second time, who donned a tuxedo to attend the inaugural balls for the nation's re-elected first black

president. It looks like a man sitting proudly in the blue section of the inaugural ceremony. It looks like a man who mentors through the Boys and Girls Club, who reads at Lexington Elementary School, and who recruits through Team 100. It looks like 1,440 minutes of "I CAN."

Every new day is a new opportunity to be greater than your limitations. Remember, "You have MS, but MS does not have YOU."

*Philip White - St. Louis, MO as told to
Taye Foster Bradshaw*

MS EPIDEMIOLOGY: GULF WAR ERA VETERANS

The rates of MS in the US appear to be increasing over the last forty years. Recently, there have been relatively few studies that have looked at MS disease prevalence (total number of people with MS in a given area) and incidence (the number of new cases of MS in a given area). Researchers look at prevalence and incidence to understand the frequency of a disease over a large population of people in a given period of time and to understand the disease "burden." This information helps to describe trends and patterns of disease in order to understand possible factors that might contribute to the development of disease. These trends and patterns may also help with the development of preventive interventions and treatments. The study of disease patterns, trends, risk factors, and overall health within a population is called epidemiology. Epidemiologic studies also investigate how disease interventions influence health outcomes.

The US military population has provided a rich resource for epidemiological studies on MS. These studies date back to World War I when Dr. Fred M. Davenport, a distinguished epidemiologist and associate member of the US Armed Forces Epidemiological Board, presented the first nationwide



study of military draftees that were discharged for MS. These MS studies progressed to the next generation, those who served in World War II and the Korean Conflict, and then to a third cohort of those who served in the Vietnam War and later up to 1994. Most of these studies examined risk factors for MS at the onset of the disease and through the progression of the disease until death. Dr. John Kurtzke, an early pioneer and leader of MS epidemiology, authored virtually all of these studies using large military populations.

Along with Dr. Kurtzke, our Washington, DC-based group characterized a new nationwide incident cohort of MS from the US military population. A total of 2,691 Veterans who served in the military between 1990, the start of the Gulf War era, to 2007 and were service-connected for MS by the VA, were included in the epidemiological study. Our goal is to review this population and look for trends and MS risk factors within this cohort. While this project is still ongoing, I will share some of our early results that describe this Gulf War population.

This Gulf War era MS population had an average age of MS onset of 31 years. While the range of MS diagnosis was between 17 and 50 years, 31 years is the average age for men and women, which was similar across racial groups. We found that women of all races now have incidence rates for MS that are about three times higher than those in men. This finding correlates with the trend found for most countries throughout the world, where MS incidence and prevalence rates for women are increasing.

An interesting pattern was found in looking at rates

of MS by Service branch. We found that Air Force Veterans had the highest rate of MS, next was the Army, then Navy, Coast Guard, and the last group was the Marines. In fact, the rate of MS for Marines was about half that of the Air Force. Additionally, racial and ethnic minority populations (African American, Asian/Pacific Islanders, Native American/Alaska Natives, and Hispanics) in the US had rates for MS that were higher than previously reported.

So what do our preliminary observations of this population mean? MS is common and the rates are high for men, women, and all racial and ethnic groups. This newly defined Gulf War era MS cohort reflects the military and perhaps the US population. This is in contrast to earlier studies about racial groups and MS that found MS affecting Whites more often than any other racial group. We plan further studies of this cohort to assess risk factors for MS onset and progression.

One major line of study will be the impact of the military experience on the presence or severity of this disease. Rates were higher for the ‘boots on the ground’ Army and Air Force, and lower for the Naval services. This explanation does not seem at all likely to answer why Marines had much lower rates of MS. These findings were most unexpected and we will be exploring this in more detail.

We do know that in general, environmental risk factors as well as genetic risk factors contribute to

FAMILY AND CAREGIVER TELEPHONE CALL

Join the free monthly, telephone conference call to connect with caregivers and family members supporting individuals with MS. A variety of educational topics and resources will be discussed.

DATE: 4TH MONDAY OF EVERY MONTH

**TIME: 2 PM - 3 PM ET, 1 PM - 2 PM CT,
12 PM - 1 PM MT, 11 AM - 12 PM PT**

**TO PARTICIPATE: CALL (800) 767-1750
ACCESS CODE 43157#**

The VA has a National VA Caregiver Support Hotline for family members dealing with chronic illness. The Hotline toll-free number is (855) 260-3274 and it is open:

MONDAY - FRIDAY: 8 AM - 11 PM ET

SATURDAY: 10:30 AM - 6 PM ET

the onset of MS. What we will be exploring in more detail is this relationship to minority populations and branch of Service. Gulf War era Veterans with MS provide a unique resource for further study that can lead to better understanding and hopefully improved treatments. More about this study can be found in the article “The Gulf War era multiple sclerosis cohort: age and incidence rates by race, sex, and service” in the journal *Brain* 2012;135(6):1778-85.

Mitchell T. Wallin, MD, MPH - Washington, DC

DIET AND MS: IS THERE A RELATIONSHIP?

When people are diagnosed with MS, a common question asked is “What can I do to make myself not be affected much by MS?” We do not fully understand why MS occurs but increasingly, research points towards a connection between environmental factors such as diet, exposure to sunlight, low vitamin D levels, and initial exposure to viruses, bacteria, and other microbes during childhood. Recent studies also suggest a possible connection between dietary habits and our digestive system bacteria that in turn can affect our immune systems, and the development of autoimmune diseases such as MS.

A report published in 2008 that surveyed people with MS from around the world, (“Atlas of MS” by the World Health Organization and MS International Federation) indicated that diet change and nutrition were the most commonly used non conventional approaches for treating MS symptoms. Another survey done in 2008 by the Central Institute of Health at the University of Hedielsberg in Germany, looked at 1,573 people with MS and found that up to 40% of Americans with MS use some form of diet modification after diagnosis. Based on these results, people with MS appear interested in dietary approaches for MS management.

The neurologist Dr. Roy Swank, conducted one of the pioneering studies examining the role of diet in

MS in the late 1940's, an era when no medications for MS were available. He believed that diets rich in saturated animal fats could be bad for MS. He devised the "Swank Diet" as an MS treatment, which consists of no more than 10 to 15 grams of total saturated fat a day, fish and chicken as primary protein sources, and only dairy products containing 1% or less fat. He supplemented this diet with cod liver oil, which is enriched in omega-3 fatty acids. Dr. Swank studied the effects of this diet on survival and disability in 144 people with MS over a span of 50 years. The study included two groups of people with MS: 70 "good dieters" who followed a strict low-fat diet, consuming less than 20 grams of fat per day, while 74 "bad dieters" consumed more than 20 grams of fat per day.

Thirty-four years into the study, it was found that "bad dieters" had a death rate that was more than double that of the "good dieters." By 2000, 15 of the original participants in the study were alive, all of them belonging to the "good dieters" group with the majority of these participants (13 out of 15) still ambulatory. Although this study has been criticized for inadequate scientific proof, it remains a unique long-term study of an intervention showing possible benefits on survival and disability in people with MS.

Recent research involving approximately 9,000 people with MS suggests a relationship between MS related disability and vascular disease risk factors such as high blood pressure, high blood fats, and heart disease. This study found that the presence of one or more of these diseases increased the risk and onset of walking disability in MS and the risk increased with the number of each vascular condition.

In a recent two-year study, researchers studied blood fat (lipid) levels and compared them to MS-related disability and brain imaging (MRI) outcomes. It was found that higher low-density lipoprotein, or "bad" cholesterol, and total cholesterol levels were associated with higher MS disability and higher high-density lipoprotein, or "good" cholesterol, was associated with lower inflammatory disease activity on the brain MRI.

Researchers at the MS Center at Oregon Health and Science University in Portland, OR are studying a very low-fat vegan diet developed by Dr. John

PATIENT EDUCATION TELEPHONE CALL

Join the free monthly, telephone conference call and learn firsthand about MS from MS experts and other health care professionals.

DATE: 2ND MONDAY OF EVERY MONTH

**TIME: 8 PM - 9 PM ET, 7 PM - 8 PM CT,
6 PM - 7 PM MT, 5 PM - 6 PM PT**

TOPIC: DIFFERENT TOPIC EVERY MONTH

**TO PARTICIPATE: CALL (800) 767-1750
ACCESS CODE 43157#**

If you have questions about the call or topic of the month, please call (800) 463-6295, ext. 6623, send an email to MSCentersofExcellence@va.gov, or visit our website at www.va.gov/ms.

McDougall. Within this diet, meat, fish, poultry, and animal products are eliminated, total fat is less than 20% of daily intake, and refined flour is restricted. This study includes 61 people with relapsing-remitting MS and the goal of the study is to measure the effects of diet on brain MRI, MS relapse, disability, and blood-brain barrier disruption (neuroaxonal degeneration) in MS.

Upon review of the research, there appears to be a pattern supporting the idea that healthy dietary changes can be beneficial for MS and can decrease MS disability progression. *So, what is a person with MS to do?* First, there is no evidence that following a low fat diet is a "cure" for MS and it should not be used in place of appropriate use of disease modifying therapies. Second, it is reasonable to follow a healthy, low fat diet, such as that recommended by the American Heart Association. Third, for those who are motivated to adhere to a more stringent, well-balanced low fat diet, following the Swank Diet or a well-balanced vegan diet, such as the McDougall Diet, is safe and may be beneficial. More research needs to be done to determine whether a low fat diet is actually a partial treatment for MS. Until then using common sense is prudent. If you would like additional information on these low fat diets, visit www.swankmsdiet.org, www.drmcDougall.com, or www.americanheart.org.

Vijayshree Yadav, MD - Portland, OR

EASIER MEDICAL CARE FOR RURAL VETERANS

Your call: drive hours to your nearest VA medical facility vs. click on a monitor from a closer Community-Based Outpatient Clinic (CBOC). Some Veterans live many miles from a VA medical facility, making visits to their health care provider an all-day event. Others with chronic conditions require constant monitoring, but opt to stay at home rather than in the hospital. In both cases, VA's Telehealth provides greater access to health care through the use of telecommunications and videoconferencing. Veterans are finding Telehealth to be just what they need to receive personalized care from the VA.

The Veterans Health Administration (VHA) is the nation's leader in Telehealth technologies, which means health care providers and Veterans can meet for health services without physically being in the same place. Patricia Ryan, Associate Chief Consultant for VHA Telehealth Services notes that in 2011 over 380,000 Veterans used its clinic-based Telehealth services. She said another 100,000 patients nationwide were enrolled in VA's Home Telehealth program.

"With Telehealth, our Veterans can connect with VA specialists such as mental health, cardiology,

dermatology, gastroenterology, rheumatology, and urology," Ryan said. "This is important, because a large percentage of our rural Veterans are advancing in age. They have chronic health conditions that require constant monitoring. If it wasn't for Telehealth, we'd be hard pressed to deliver the kind of day-to-day observation they require."

Clinical Video Telehealth gives Veterans and health care providers the opportunity to conduct several aspects of medical examinations that do not require in-person visits. Veterans are able to visit a CBOC near their home, connect to VA medical facilities through videoconferencing, and transfer medical information by way of specially-designed telecommunications equipment.

Clinical Video Telehealth primary care is just one of the many ways in which Telehealth connects Veterans to health care services. VA provides services in telerehabilitation, teledermatology, telemental health, and teleretinal imaging, and the list is growing. Future plans are "to expand the size and scope of Telehealth programs to focus on expanding access to care for Veterans in rural locations," said Ryan. "This will reduce the need for travel to specialist services, thus increasing the quality and timeliness of care."

VA News Feature

TELEVIDEO MS TREATMENT AND MANAGEMENT

MS is a neurodegenerative disorder with a variety of symptoms that can interfere with the quality of life. The occurrence and severity of symptoms like fatigue, pain, and progressive impairment in walking may lead to reduced activities of daily living. We have found that many of the symptoms listed above can contribute to missed appointments, decreased social interaction, and inactivity linked to accelerated disability. To minimize these symptoms the VA provides MS specialists to address health care needs with medications and rehabilitative strategies. VA is looking at innovative



ways to help Veterans in rural areas receive MS specialty care with less burdensome travel.

Approximately 30 to 40% of Veterans with MS live in rural locations. Many Veterans travel more than 2.5 hours for a specialty care visit with their MS provider. The time and distance traveled places a large burden on both Veterans and their caregivers. Currently, collaborative centers are focusing on providing neurology visits to Veterans at the nearest CBOC with the goal of improving care and needless travel time.

HOW IS MS TELEHEALTH DONE?

At the CBOC, the MS specialist connects on a televideo link to observe, and speak with the Veteran about their current medical condition with the assistance of a Telehealth technician. The Telehealth technician remains in the room to assist with reflex testing, range of motion, walking, and transfer ability,

LEARN MORE ABOUT MS!

MSCoE produced free DVD's from our live education programs. Each DVD includes 1.5 hours of educational content provided by MS health care professionals. The DVD's are a great way to learn about MS in the comfort of your home.

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- ▶ **PAIN AND PALLIATIVE CARE IN MS**
- ▶ **SEXUAL INTIMACY AND MS**
- ▶ **STAYING MOBILE WITH MS PART I AND II: MOBILITY FOR PEOPLE WITH MS AND WHEELED MOBILITY AND MS**
- ▶ **UPDATES ON MS DISEASE MODIFYING THERAPIES**

If you are interested in receiving free DVD's, please call (800) 463-6295, ext. 6623 or send an e-mail to MSCentersofExcellence@va.gov.

while ensuring the Veteran's safety. The Telehealth technician is also responsible for maintaining the connection during the visit and adjusting audiovisual controls to enhance the experience for both the MS specialist and Veteran. Veterans and health care providers have been highly satisfied with their Telehealth visits with satisfaction rates of 90%. A majority of Veterans also reported that they would request future visits by Telehealth.

The Rural Veterans Tele-Rehabilitation Initiative from the North Florida/South Georgia Health Care

System serves as a model of care coordination for rural Veterans with mobility deficits and for implementation of distance technology. Clinic staff provide coordinated primary and neurologic care, neuro-rehabilitation, speech and language pathology, and social work for Veterans with MS.

This initiative is collaborating with the VA MS Centers of Excellence to help manage Veterans' rehabilitation care strategies while in their home using Telehealth. First, a face-to-face office visit is scheduled with an MS specialist to assess walking, strength, and range of motion. Following the visit, the Veteran receives a treatment plan based on current health assessment. Telehealth visits are then scheduled. These visits allow the MS specialist to view the Veteran, assess the individualized training program, and record progress. Any health changes are noted and revised treatments can be addressed. This approach eliminates travel issues like long, fatiguing car trips that are challenging for Veterans and their caregivers that can lead to missed appointments. Using this Telehealth appointment approach can save Veterans about 1,700 miles a year traveling to and from medical appointments.

Although Telehealth is not suitable for every Veteran, it is quickly becoming an option in many VA medical facilities and CBOC's. If you are interested in learning more about Telehealth, visit the VA website www.telehealth.va.gov. You can also check with your local health care provider to see what Telehealth opportunities are available in your area.

Sean C. McCoy, PhD - Lake City, FL

WHAT ARE MY VA BENEFITS FOR MS?

Veterans may be eligible for a broad range of programs and services provided by VA. These programs are based upon enrollment eligibility and discharge status from active military service. There are several categories of eligibility based upon a variety of factors. Some of these factors are related to time of service and priority groups. For example: If you are a Veteran that served in a theater of combat

operations after November 11, 1998 you are eligible for an extended period of eligibility for health care for five years post discharge. Enrollment Priority Groups range from 1 - 8, with 1 being the highest priority for enrollment. Priority Group 1 Veterans have service-connected disabilities rated 50% or more. Priority Group 8 Veterans have a gross household income above the VA national income threshold and the geographically-adjusted income threshold for their resident location, and who agrees to pay co-pays.

VA determines your eligibility for the comprehensive medical benefits package once you

enroll. You can enroll through the online application process at www.va.gov/healthbenefits, submission of VA's Application for Health Benefits (10-10EZ) at a local VA medical facility, or by calling VA at 1-877-222-VETS (8387). If you are already enrolled in VA health care, you can update your information online. More detailed information about VA eligibility status is found on the VA website listed above.

Women Veterans are eligible for the same VA benefits as male Veterans. Their eligibility is based upon the same Enrollment Priority Group process mentioned above. Once eligibility is determined, women Veterans can receive their medical care from specialized Women's Centers available at each VA medical facility.

SERVICE-CONNECTED BENEFITS: Service-connected (SC) status refers to Veterans who are disabled by an injury or disease that was incurred or aggravated during active military service. MS is a presumptive condition and benefits are based on the presumption that the disability is SC. Veterans with symptoms of MS while in the military or within seven years after honorable discharge may be eligible for SC disability.

NONSERVICE-CONNECTED BENEFITS: Nonservice-connected (nonSC) status refers to Veterans who have a disability or health issue that is not related to their military service. Veterans that are nonSC for their disability could be eligible for VA benefits under nonSC status.

PROSTHETIC AND SENSORY AIDS SERVICE: Veterans with MS are eligible for services from the Prosthetic and Sensory Aids Service (PSAS) program. The basic eligibility for prosthetic items is enrollment in the VA system and proper medical justification. Service connection does not have a role in eligibility except for certain programs.

PSAS is an integrated delivery system designed to provide eligible Veterans medically prescribed devices such as hearing aids, eyeglasses, speech and communication devices, home dialysis supplies,



orthopedic braces/supports/footwear, wheelchairs, home respiratory aids, hospital beds, and other daily-living aids.

HOME IMPROVEMENT GRANTS: There are several types of grants to make medically necessary home improvements like roll-in showers, wheelchair ramps, and widening of doorways. The Home Improvements and Structural Alterations (HISA) program will pay a lifetime benefit up to \$6,800 for home alterations for a SC disability and a lifetime benefit up to \$2,000 for other Veterans. The Specially Adaptive Housing (SAH) grant is generally used to make a home wheelchair accessible and has a maximum benefit of \$64,960. The Special Housing Adaptations (SHA) grant is limited to \$12,992 and is related to specific losses of hand mobility and blindness. The Temporary Residence Adaptation (TRA) grant is also available and can be used to adapt a temporary residence in order to make it more accessible.

MOBILITY BENEFITS: It is common for individuals who have MS to experience changes in their mobility, requiring different accommodations to help maintain mobility. If there is a change in mobility needs, a consult should be sent to Physical Medicine and Rehabilitation Services (PM&RS) or another appropriate interdisciplinary Mobility Clinic to evaluate the changes in mobility and prescribe the appropriate accommodations.

DRIVER REHABILITATION: Maintaining independence is important and the VA assists in getting Veterans with disabilities back on the road again. Services provided include driving assessments and training.

VEHICLE MODIFICATIONS: SC Veterans qualify for a one-time automobile adaptive equipment benefit up to \$19,505 toward the purchase of an automobile or other conveyance. SC and nonSC Veterans can apply for other vehicle modifications like van lifts.

RESPIRE CARE: VA recognizes the importance of supporting family caregivers and provides a temporary relief benefit for unpaid caregivers. This service is available to eligible Veterans who need assistance with daily living activities or require case management or skilled services. Respite care is available for up to 30 days in a calendar year and is



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VA Puget Sound Health Care System
1660 South Columbian Way (S-117-CoE)
Seattle, WA 98108

Portland VA Medical Center
3710 SW US Veterans Hospital Road (P3CoE)
Portland, OR 97239

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provided within a VA medical facility, community setting, or in the Veteran's home.

CLOTHING ALLOWANCE: SC Veterans may receive an annual monetary allowance up to \$753 for clothing damaged by prosthetic or orthopedic appliances.

PRESCRIPTION MEDICATIONS: The typical co-pay is \$8 per prescription for a 30-day supply. Depending upon eligibility status, co-pays can be waived.

AID AND ATTENDANCE: Veterans and survivors who are eligible for a VA pension and require the aid and attendance of another person, or are housebound, may be eligible for additional monetary payments.

MENTAL HEALTH SERVICES: VA works with Veterans to meet a variety of mental health needs. All mental health services provide support and focus on recovery. Eligible Veterans can receive services that include medications, counseling, and other mental health therapies. Visit the Mental Health website www.mentalhealth.va.gov.

mentalhealth.va.gov to take anonymous, self-guided screening tools for depression, PTSD, alcohol and drug abuse/dependence, and to find support services to address these issues.

The VA offers a variety of services and programs for Veterans and is committed to working with Veterans and their families toward a better quality of life. It is important to contact your local VA medical facility social work department to review your eligibility for the benefits discussed. The VA provides Patient Advocates to help with this process as well and you can always contact one of the Veterans Service Organizations like Paralyzed Veterans of America, United Spinal, and Disabled American Veterans for additional support. For additional information on VA benefits, visit <http://benefits.va.gov/benefits>.

Marsha L. Tarver, PhD - Seattle, WA
Robert Baum, Prosthetics Manager - Mesa, AZ

VISIT THE VA MS CENTERS OF EXCELLENCE WEBSITE AT [WWW.VA.GOV/MS](http://www.va.gov/ms).