

VA Multiple Sclerosis Centers of Excellence

MS VETERAN

Serving the Health Care Needs of Veterans with Multiple Sclerosis

All Who Wonder Are Not Lost

By Stephanie Hartzell - Portland, OR

I enlisted in the US Navy Nurse Corp in 1970. Upon graduating from my nursing program, I was commissioned an Ensign and off to the Pensacola, FL Naval Hospital I went. I was assigned to the emergency room and it was the start of my career in emergency nursing; one I had dreamed of but hadn't expected as such a new nurse. I enjoyed my time in the Navy; I learned much, got to travel and found I really liked warm weather!

I returned to Oregon for a good job in 1973. I worked in busy emergency departments over the next 25 years, becoming one of the first Nationally Certified Emergency Nurses in Oregon. I always had strange physical symptoms while in the military and upon returning to Oregon, I decided to get them investigated. I was diagnosed with MS in 1987 but I continued to work and function well until 1992.

I had a severe attack in 1992 that changed my life tremendously; suddenly I was so weak that I was in a wheelchair. I needed to sell a home I had lived in for 14 years, give up two dogs, temporarily quit school and find a new place to live, all from a rehab unit. I spent ten years in that wheelchair, but it didn't seem

to stop me too much from pursuing things I was interested in.

I purchased, through a VA grant, a lift-adapted van and explored the Pacific NW and Canada with my son. I participated in the Paralyzed Veterans of America Wheelchair Games, both winter and summer one year. Those games gave me confidence and self-esteem to continue with whatever I wanted to do in life, including completing a much-wanted bachelor's degree in nursing in 1995.

I began to feel like something was missing in my life after about 7 years of wheelchair life. I retired from nursing in 2000 due to fatigue and cognitive changes that made me feel unsafe nursing. I wanted desperately to walk all the time, even if it meant using crutches or two canes. I met with a special physical trainer and he thought he could help me. The gym I joined was small, with a little pool and indoor running/walking



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track with a grab bar the whole way! After 3 years of 3 times a week training and swimming I could walk with crutches and eventually walking sticks. I felt free and wonderful.

In February 2007 I had another severe attack that again really changed my life. My MRIs showed a huge increase in lesion load and I was prescribed daily shots of Copaxone. I never in my life dreamed of daily injections but I learned quickly and adapted my travelling to accommodate keeping my daily medication chilled. I began to feel good from the Copaxone and my MS was stabilizing. My next obstacle in life was overcoming my loneliness. I hadn't dated for over 10 years and I now felt my self-esteem was adequate to meet the challenges of the dating world.

I met Jerry, my husband, in spring 2007. I was thrilled to meet a man who could accept my illness. He read a lot, asked a lot of questions about my disease and began going to every doctor appointment with me to find out as much as he could. Jerry had travelled all over the globe for work and had a wanderlust for travel like I did. He also had a passion for gardening, rock hounding and dogs. We began travelling together in 2007 but after several years, we both realized it was getting harder to do. When Jerry suggested we find a permanent winter home somewhere warm, I was on board.

In 2012 we discovered a retirement development in southern Belize. We loved the amenities which included a pool, horses, beach, private island and

much more. We invested in a lot and began planning an accessible home. We completed our home in 2014 and began spending winters in Belize, returning to Oregon every 6 months for my health care needs.

In 2016 we sold our Oregon home as it was becoming too much work to handle two homes and gardens. We now spend 10 out of 12 months in Belize, returning to Oregon once a year for health care needs. I communicate with my VA health care team via secure messaging or phone. I have an emergency internist and neurologist should I need it here in Belize, and we subscribe to med-jet in case of emergency conditions. I feel confident in my own self-care and realize it is my responsibility to take good care of myself so I can continue living the quality of life I require to make me happy.

While in Belize I garden, swim, walk our dog, occasionally horseback ride, snorkel, kayak, boat, fish and much more. I have discovered I have a green thumb for growing orchids. We have travelled to many Mayan ruins including Tikal in Guatemala. We are able to afford weekly housekeeping staff and a gardener to help both of us out. We eat very healthy food and I have access to physical therapy, acupuncture and massage which I take advantage of. Despite now being secondary progressive and off all DMTs (~3 years), I feel that I am doing very well.

My life adventures and travel are not done. We are planning a trip to Paris, Barcelona and Italy in September 2019. I do believe that "all who wander are not lost."

MS Research Updates

By Jennifer S. Graves, MD, PhD, MAS - San Diego, CA VAMC

It has been an exciting last 25 years of MS research, advancing from no MS treatments to 17 approved therapies. Despite these great strides important questions remain about why some people with MS have milder forms of disease and why some have more aggressive forms. We also don't understand

what triggers the switch from relapsing MS into secondary progressive MS. New treatments are needed to slow both primary and secondary progressive MS. And we need better methods to capture people's MS symptoms and function so we can test new medications faster. Our research

program in San Diego, CA is tackling these important problems.

One key factor that has shown up repeatedly in MS research studies as driving disability from MS is age. For a very young 10-year-old person with MS, it may be 20-30 years before there are any signs of secondary progression (chronic problems with limb strength or walking), but for people presenting in their late 40's or 50's these problems can start much sooner after diagnosis (sometimes within 5 years). Our group has completed research demonstrating that biological markers of aging that can be measured in the blood are in fact associated with degree of disability in people with MS. For women with MS, we found that decreases in a marker of ovarian function, anti-Mullerian hormone, was associated with increases in disability and greater brain tissue damage. These results suggest menopause may be associated with a higher risk for a switch to secondary progressive MS.



In both men and women, we have measured another biological aging marker from the DNA of people with MS. Often referred to as the ultimate “biological clock,” the caps at the ends of human chromosomes are called telomeres. They protect our DNA during our lifetimes, but they shrink in length over time with age and this shrinking can be accelerated by toxins or stress. Exercise is one of the best methods to try to preserve telomere length. The shrinking of these telomeres triggers other biological events like changes in the immune system, including the development of a smoldering inflammatory state, “inflammaging.” We suspected that the shrinking of telomeres and triggering of the low-grade chronic inflammation might be important to the changes we see in people with MS as they age – less relapses but more slowly progressive increases in symptoms and disability. We measured telomere length in over 500 people with MS and found that telomere

shortening was associated with greater MS-related disability. We are now trying to understand what biological components of these aging pathways in the immune system can be identified as targets for new MS treatments. For people with MS today, we recommend avoiding toxins like cigarette smoke which can speed up the shortening of telomeres and aging and we recommend getting more exercise, the only proven “fountain of youth.”

In order to test new medications faster and get these drugs to people more quickly, the MS clinical research community recognizes we need better tools than the 140-year-old standard physical exam. We are committed to developing a 21st century neurological exam, leveraging technology from the computer control and video gaming industries to detect small changes in neurological function in people with MS. In our research group, we have repurposed sensor devices that can be worn as a bracelet, sold to move avatars in video games, to instead measure weakness and poor coordination in an objective, numerical way. Using these types of sensors we can try to detect problems, missed by even the best of neurologists, and we can quantify the subtle problems patients report to us – having “normal strength” but having trouble playing the piano or playing sports. We can also use technology to better capture subtle vision and cognition problems in

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Date: 2nd Tuesday of Every Month

Time: 8-9 pm ET, 7-8 pm CT,
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people with MS. We have an active program looking at the non-invasive tracking of eye movements to better capture these types of dysfunction.

The next decade of MS research holds great promise for developing new therapies to improve the lives of people with MS. In addition to the above projects, we run a clinical trials program to provide access to new treatments under study for MS. We also remain very interested in how one day we might be able to prevent MS altogether. In prior work, we have studied genetic and environmental factors that

increase risk for MS. Genes (your DNA) are hard to change, but understanding which ones are more important could allow better treatment development in the future. Environmental factors that can be changed are important to the concept of preventing MS. We have not found all of them yet, but for a few we can recommend lifestyle modifications to try to lower the risk. As a starting point, people with MS and their first-degree relatives should avoid tobacco smoke exposure, keep their vitamin D levels above normal, exercise regularly, avoid excessive weight gain and eat a healthy balanced diet.

New DMT for MS: Siponimod

By Kathy Tortorice, PharmD, BCPS - VA Pharmacy Benefits Management

Don't blink your eyes or you might miss something! Over the course of a month, the Food and Drug Administration (FDA) approved two new Disease Modifying Therapies (DMTs) for use in MS. What makes this even more of a record-breaking event is that these drugs are both used in active secondary progressive MS. In April 2019, cladribine (Mavenclad) was approved followed by the May 2019 approval of siponimod (Mayzent).

Siponimod is approved for the treatment of relapsing forms of MS, to include clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS) and active secondary progressive disease (SPMS) and cladribine is approved for the treatment of relapsing forms of MS, to include RRMS and active SPMS. Most previously available DMTs have not had approval for any forms of SPMS. Before April 2019, mitoxantrone was the only agent approved for the treatment of people with secondary progressive and "progressive relapsing MS," an older term synonymous with active SPMS. But, mitoxantrone has significant toxicities associated with its use.



Several clinical trials testing siponimod in people with RRMS and SPMS have been carried out and shown positive results. The BOLD study was completed in 2011. It aimed to assess the safety, tolerability, effectiveness and best dose of siponimod in people with RRMS over a 6-month period. The results showed that siponimod reduced the number of active brain lesions compared to a placebo, with higher doses having a greater effect. People who completed the BOLD trial could take part in an extension study to test the long-term safety of siponimod over 2 years. The treatment was well-tolerated overall, and the relapse rate remained low for the treatment groups.

The EXPAND trial, used siponimod 2 mg once daily or placebo in people with active SPMS and followed them for up to 3 years. At the start of the trial, the average time since people first noticed MS symptoms was 16.8 years and the average time since they developed SPMS was 3.8 years. The results showed that taking siponimod significantly reduced the risk of 3-month disability progression by 21%, compared to a placebo. Additionally, after 2 years of therapy, siponimod showed a significant decrease in the average relapse rate per year by 55% compared to placebo. The benefit of siponimod may become less pronounced with increasing age, disability, if

the person has had MS for longer and if they have diminishing signs of disease activity. Based on the results from the EXPAND study, for every 100 people treated with siponimod over an 18-month period, progression of disability would be prevented in five people.

The most common side effects reported by study participants taking siponimod were headaches, slowing of heart rate, dizziness and nose and throat infections. Most adverse events associated with siponimod therapy were not medically serious, and were treatable, or reversible upon discontinuation. Women of childbearing potential should use effective contraception during and for 10 days after stopping the drug because of potential risk for fetal harm.

People with MS who will be started on siponimod need to be tested for a specific enzyme used by

the liver to metabolize the drug. Additionally, people need to be tested to check their immunity to varicella zoster (Chicken Pox). Siponimod is started with 4-days of gradually increasing doses, to reach the maintenance dose. The maintenance dose of siponimod for most people is 2 mg taken once daily, and a reduced dose of 1 mg daily in people with specific liver enzyme genotypes (genetic makeup of a cell). If a person misses 4 days of therapy, they need to be restarted with the gradually increasing doses used when therapy was first started.

There are now over 15 DMTs approved for the treatment of MS. More are being approved each year, giving people with MS a variety of medications to help them manage their MS. If you think siponimod may be a good choice for you, talk to your MS provider.

Smoking & MS

By Aaron Turner, PhD, ABPP (RP) - Seattle, WA VAMC

All VA medical facilities are going smoke-free in October 2019. Most people are aware that smoking is the leading cause of preventable death in the US, and that it is associated with numerous health problems including cancer, stroke and heart disease. Smoking worsens many chronic illnesses, decreases sexual functioning and shortens the life span of the average smoker by 8 to 13 years.

Fewer people know that smoking may also be linked to MS. Several studies have shown that smokers have a higher risk of developing MS and that loved ones exposed to second hand smoke may also have an increased risk of MS. Some evidence suggests that smoking may be linked to a more aggressive disease course including increased brain lesions, greater brain atrophy, higher levels of disability and faster progression to secondary progressive presentation. Smoking may also complicate other challenges people face with MS, like decreasing lung functioning, making wounds or ulcers heal more

slowly and increasing fatigue.

The Good News

It is never too late to quit smoking and enjoy improved health and quality of life. Some benefits can be felt almost immediately. Many last for years to come.

Within 20 Minutes:

- ▶ Blood pressure, pulse rate and body temperature return to normal

Within 24 Hours:

- ▶ Oxygen level in blood increases to normal
- ▶ Smoker's breath disappears
- ▶ Your chance of a heart attack decreases

Within 72 Hours:

- ▶ Bronchial tubes relax making it easier to breathe

- ▶ Lung capacity increases making it easier to do physical activities

Within 2 Weeks to 3 Months:

- ▶ Circulation improves
- ▶ Walking becomes easier
- ▶ Lung function increases up to 30%

Within 1 to 9 Months:

- ▶ Coughing, sinus congestion, fatigue and shortness of breath decrease
- ▶ Your body's overall energy level increases
- ▶ Cilia re-grow in lungs, increasing the ability to handle mucus, clean lungs and reduce infection

Within 2 Years:

- ▶ Risk of coronary heart disease is half that of a smoker
- ▶ Heart attack risk drops to near normal

Within 5 Years:

- ▶ Lung cancer death rate decreases by almost half
- ▶ Stroke risk is reduced
- ▶ Risk of mouth, throat and esophageal cancer is cut in half

Within 10 Years:

- ▶ Lung cancer death rate is similar to that of a lifetime non-smoker
- ▶ Pre-cancerous cells are replaced

It's Never Too Late to Quit

Quitting isn't easy. Many people have smoked for years and just thinking about quitting is stressful and overwhelming, but it can be done. In fact, over the years millions of people have quit and so can you. People have many reasons for stopping their smoking, not all are related to health. Smoking is also expensive and time consuming. Think about why you want to quit. Write down the reasons you want to quit and keep the list where you can see

it. Another helpful strategy for people thinking of quitting is to keep track of when and why you smoke. It is easy to light up without giving it much thought. Knowing yourself, and what places, activities, people and moods are associated with your smoking, will help you combat your triggers for cigarette use and avoid high risk situations when possible.



Getting Started

If you're ready to quit smoking, your chances are better if you make a plan. Quitting works best when you are prepared. Here are some tips to START.

S = Set a quit date

T = Tell family and friends

A = Anticipate and plan for challenges you'll face

R = Remove cigarettes and other tobacco from your environment

T = Talk to your doctor about getting help to quit

Getting Help

All VA facilities offer some assistance with smoking cessation. Often people start by talking to their doctor or another provider. We've found that people with MS usually have a long list of things to discuss with their doctors. Remember, quitting smoking is probably the single best thing you can do for your long-term health. It deserves a place on your list! Many people quit smoking on their own, but your provider can put you in touch with a VA smoking cessation program that may include medications and counseling, both things that have been shown to be helpful to assist quitting. Help and support are also available from the VA's National Quitline 1-800-QUIT NOW. You can call this number any time, or in conjunction with the plan you establish with your healthcare team.

Coping Strategies for People with MS

By Mark Leekoff, MD, MPH - Baltimore, MD VAMC

MS is an unpredictable disease that is often accompanied by stress. Anxiety, depression and other psychiatric problems are often experienced by people with MS. The rates of these problems in people with MS are higher than in those who do not have MS. People with psychiatric problems in connection with MS tend to report lower satisfaction with life. Additionally, studies show that psychiatric problems can result in worsening of MS disability.

While psychological and social stress is common in those with MS, some people also experience post-traumatic stress disorder (PTSD). PTSD is a disorder involving prolonged reaction in those who have undergone a scary or dangerous event. PTSD can be due to trauma from the battlefield, sexual assault, childhood abuse or even due to a traumatizing medical diagnosis or procedure. A recent pilot study from the VA MS Center of Excellence East showed that a prior diagnosis of PTSD in those with MS may be linked with increases in the number of relapses (1.2 relapses in MS participants with PTSD in the two years of the study compared to 0.37 in MS participants without PTSD). Those with MS and PTSD were also more likely to have new MRI brain lesions (60% of MS participants with PTSD had new lesions in the two years of the study compared to 16.7% of MS participants without PTSD). It is thought that PTSD and the stress related to it may potentially lead to additional neurochemical changes, leading to further inflammation which leads to relapses and brain lesion. On the other hand, PTSD could lead to decreased adherence to MS medications but there was no correlation with this in the study. Given that psychiatric conditions associated with MS can lead to stress which can lead to worsened

outcomes, strategies should be implemented to reduce stress. Coping is a behavioral strategy that can help to mitigate stress.

One strategy for coping with MS-related stress is art therapy. While art as a form of therapy has been around for centuries, art therapy has become popular over the years to help people cope with chronic medical conditions. Artwork such as painting, writing or creating music can help people with MS bring their stress and worries into the open, which can help to decrease the stress. Studies have shown that art therapy in those with MS can also help increase confidence and improve emotional well-being. Art therapy can also help those who are more disabled work on improved arm control.

Another coping strategy shown to be useful is mindfulness. Mindfulness is defined as focusing on the present moment while understanding and accepting one's feelings, thoughts and sensations. Practicing mindfulness originated in Eastern philosophy as a method for relaxation. Mindfulness has been shown to also help with managing anxiety, depression and chronic pain. Classes in mindfulness can be

taken and typically last around 8 weeks. They tend to relate to different types of meditation such as being aware of the number and length of breaths being taken at a time, body awareness and yoga. The VA's



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Educational newsletter for Veterans!

War Related Illness and Injury Study Center is offering free, phone-based Mindfulness Meditation classes the first two Fridays of every month at 11 am EST. Simply call 1-800-767-1750, 54220# to join.

Exercise is another excellent way to cope. Exercises such as jogging, swimming and using a stationary bicycle have been shown to be helpful for those with and without MS. Your healthcare team, including the physical and occupational therapist, can help create a personalized program for you to address your specific abilities and needs. Another type of exercise worth seeking out is yoga. Yoga involves breathing and stretches that center on the spine. Depending on one's balance, changes can be made to ensure safety. Another similar exercise to yoga is Tai Chi which is more "gentle." Tai Chi also involves breathing, slow movement and relaxation.

Finally, studies have shown that having a pet helps some people cope with a health problem. Being around pets can help take your mind away from dealing with the stress with MS. It can also help with the stress of psychiatric conditions related to MS. A service pet is another option for those who need assistance with medical issues such as vision or walking. For those who do not want to own a pet, health care programs are increasingly adopting a pet program where specially trained pets work with people.

These are just a few of the coping strategies of many that exist. Combining multiple coping skills can be ideal. Discussion of these coping strategies with your treatment team, including physicians, mental health providers, physical therapists, occupational therapists and social workers, to optimize their effectiveness is essential.