

# VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

# MS VETERAN

## SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

### WE KEEP GOING... AND GOING...

Keep going... that's what I advise and what I practice to combat my MS. My wife, Michelle, and I bought a Roadtrek RV five years ago and well... we've put about 170,000 miles on it. Even while it was ordered we travelled to Canada to tour the factory. We have camped in our RV in 47 of the 50 states. (We somehow missed Michigan but are planning to take a fishing trip there in the spring.) Alaska will take a longer time so Michelle will need more time off from work. Now Hawaii... well you can see my difficulty driving there.

My favorite of our trips was when we drove to Washington state, spent several days driving and stopping along the coast of Oregon, camped among the redwoods of northern California, and I got the opportunity to cross the Golden Gate Bridge in San Francisco (well as far as they would let my wheelchair go). I would much rather still be in the Army I love. Unfortunately, shortly after I joined at the age of 18, I experienced some abnormal symptoms and had to leave. It was four years after I left the Army that I finally got a diagnosis for those symptoms... multiple sclerosis. I just wanted to shoot myself when I got my diagnosis, but Michelle (my fiancée



at the time) and I decided to face it all together. And we have had many adventures since.

Over the years, different activities have been available to me and I have taken on the challenges. When our son, Michael Jr., joined the Cub Scouts, and then the Boy Scouts, I was enlisted to craft out

many projects on my saws, help lead dens, and run the leadership training. I also headed the monthly leaders meeting to provide ideas and examples for Cub Scout dens. I hold an amateur radio license (KB3FQE) and deal with emergency communications. When a F4 tornado hit our county, nearly wiping La Plata, MD off the map, I worked with the communications section of the

Red Cross. On 9-11, I headed to the emergency operations center. For Hurricane Isabel, I was stationed at the hospital.

In 2011, we saw air guns as a competition choice at the National Veterans Wheelchair Games. I signed right up. I got my butt handed to me at the competition (I shot 89 out of 300), but I did reach my goal not to be in last place. For the 2012 Games, I did better; I shot 278... but still did not even place. I tried javelin though I had never thrown one before

### WE WOULD LIKE TO HEAR FROM YOU!

The VA MS Centers of Excellence would like to invite you to be involved. If you have poems, stories, or articles that you would like to share with other Veterans with MS, for posting on our website, please **e-mail them to:** [MSCentersofExcellence@va.gov](mailto:MSCentersofExcellence@va.gov). Or, **mail them to:** VA Puget Sound HCS/MSCoE - Attn: Marsha Tarver, PhD - 1660 South Columbian Way (S-117-MSCoE) - Seattle, WA 98108.

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and that was fun. In August this year, we drove across to San Diego, CA to attend the Cal-Diego PVA Air Rifle and Air Pistol Seminar on shooting, followed by a match. I took first place in air rifle (my category). I even beat some Marines... Go ARMY!

I know that all sports take practice. So, I keep practicing on the air rifle range I maintain in my yard. I go bowling at least weekly and I'm looking for a place to work on that javelin. I don't spend all my spare time practicing. We fish when the weather is good and I grow vegetables in a garden. Now this all sounds like there is nothing to battling MS and it's not nothing. I've missed out on doing things I wanted, spent holidays in hospitals, and missed important events. When my son did his Eagle Scout project, I was in the hospital and I hated missing it. However, I know this gave him the opportunity to shine on his own and he took a positive attitude about it.

We have visited hospitals on our trips. In fact, had it not been for my service dog, Gibson, I might not still be here. We were travelling to Texas for a baptism when I got a bowel obstruction. The vomiting dehydrated me and my other medications didn't clear... effectively overdosing me. I guess Gibson sensed something or heard the change in

my breathing while I slept and he woke Michelle up. She's a nurse and she recognized I was breathing too slowly and took immediate action. I had to be hospitalized on another occasion, while visiting an uncle in Connecticut. Nevertheless, we try to put a positive spin on things and consider these unexpected emergencies a part of visiting the area.

The RV makes it easier to travel as it gives us needed room to store all the necessary medicines, medical supplies, wheelchairs, air guns, fishing supplies, bowling balls, souvenirs, and the dog. It allows us to stop frequently to combat the fatigue of MS... travelling for a few hours and resting for a few hours. I had a local company put ladybugs all over the RV (for my wife's nickname doodlebug), a nativity (she collects them), a tiger (I love them), and the Army seal and US flag (to show our patriotism). The RV gets a lot of looks, smiles, and questions... but folks know who we are as we pass.

I hope that we'll get to meet you at the next Games in Tampa, FL. In the meantime, if you see the doodlebugs in Alaska... Florida... Texas (to see our grand twins), or who knows where - just wave - it's Michael Sack and I'm going to keep going!

Michael Sack - Waldorf, MD

## STEM CELL THERAPY

Oligodendrocytes (OLG) are cells of the brain and spinal cord that wrap a myelin sheath around neurons, or nerve cells. This myelin sheath is a cover that insulates the neurons in the brain and spinal cord and allows neurons to send signals correctly to other neurons, muscles, and organs of the body. In MS the myelin sheath becomes damaged and the OLG die. This leads to the death of the neurons and the loss of proper signals to muscles and other organs of the body.

The result of loss of correct signals to the muscles and other organs is loss of proper function. This can lead to visual issues, problems with walking, as well as other symptoms associated with MS. For human patients with MS, there is no USA Food and Drug Administration approved treatment to use stem cells to replace OLG. Stem cell therapy for replacement

of damaged or lost OLG is promising but largely untested. There are different types of stem cells that can be tested for replacement of OLG.

- 1 One type is *embryonic stem cells* that are grown from very young embryos. These embryonic stem cells are able to become all of the cells of the body.
- 2 Another type is *neural stem cells*. These are stem cells that develop from the embryonic stem cells and that become all of the cells of the brain and spinal cord. These neural stem cells can be grown from the fetal brain.
- 3 A third type is *oligodendrocyte progenitor cells* that normally becomes OLG in the brain and spinal cord. These oligodendrocyte progenitor cells can be grown from fetal brain and spinal cord.
- 4 A fourth type is *adult bone marrow stem cells* that can be grown from adult bone marrow.

These adult bone marrow stem cells can become blood and immune cells.

**5** And, a fifth type is *induced pluripotent stem cells* that are made by putting embryonic stem cell genes in a normal adult cell like a skin cell. These induced pluripotent stem cells can become all of the cell types in the body.

The different stem cell types have been tested in animal models of MS to learn whether they can become new OLG for replacing the damaged or lost OLG. One model is the Shiverer mouse, whose OLG do not make a proper myelin sheath. The Shiverer is a genetic mutant that does not make normal myelin basic protein (MBP), a critical protein in myelin sheath formation. Because there is no proper myelin sheath, the mice have poor neuronal insulation and conduction. As a result, they have continuous shivers, tremors, and seizures leading to early death at 15 to 18 weeks of age.

The Shiverer provides a clear model for determining the potential of stem cells to become OLG that make MBP and that make a proper myelin sheath.

OLG replacement therapy in Shiverer, using embryonic stem cells, was reported by the McKay laboratory in 1999. The transplanted embryonic stem cells became OLG that formed myelin sheath around neurons in the Shiverer brain and spinal cord. In the same year, the Snyder laboratory used neural stem cells to replace defective OLG in Shiverer brain, which dramatically reduced the mouse tremors. And in 2001, the Schwartz laboratory showed that neural stem cells transplanted into Shiverer brain formed OLG that made myelin basic protein. These results show, in animal models of demyelination like MS, that stem cells can be used to replace defective OLG.

There are ethical and technical challenges to be overcome in order to move these experiments in mice into clinical trials in people with MS. Some people believe that it is unethical to use human



Oligodendrocyte myelin sheath wrapping neuron in optic nerve

embryos to obtain OLG for transplantation into humans. Besides the ethical issues, these cells will be rejected as “foreign” when put into an adult, and immunosuppressant drugs, or anti-rejection drugs, would be needed to prevent this rejection. Techniques are being developed to isolate stem cells from adult bone marrow, fat cells, and other cell types, and these could be turned into OLG capable of making myelin.

By isolating these stem cells from the adult who will eventually receive the OLG, one avoids both the ethical concerns and the need to use immunosuppressants. Other technical issues include finding ways to deliver the OLG into the MS lesions. If there is one large MS lesion in the spinal cord causing most of a person’s symptoms, cells could be injected directly into the lesion. But if the person has multiple lesions in the brain and spinal cord, other ways will be needed to guide the OLG into the right locations.

Researchers are actively trying to develop ways to promote remyelination using stem cells. We should expect to see major advances in this area over the coming decade.

G. David Trisler, PhD - U MD School of Medicine  
Developmental Neuroscientist

### GET YOUR VACCINATIONS!

**INFLUENZA:** The VA provides a free influenza vaccine to enrolled Veterans. There are two forms of the vaccine: 1) a flu shot and 2) a flu nasal spray. Research has shown that the flu shot is safe when given to people with MS and does not worsen or trigger MS symptoms. The flu nasal spray has not been studied for its safety with MS and may carry more risks. It is recommended that people with MS receive a flu shot rather than the nasal spray.

**PERTUSSIS (WHOOPIING COUGH):** Booster doses of tetanus-diphtheria are needed at 10-year intervals. People age 19-64, and those 65 and older who are in contact with infants, should get a one-time dose of tetanus-diphtheria-pertussis to also protect against whooping cough.

# IMPROVING THE LINES OF COMMUNICATION

MS is a chronic and unpredictable disease. A diagnosis of MS can affect every aspect of a person's life, including the relationship between partners and spouses. The uncertainty of MS can influence the daily routine or rhythms of life between partners, spouses and other family members, and in turn, influence the lines of communication.

Couples who are living with MS may often find it challenging to their usual roles in the relationship and hard to make their relationship a priority. Learning and practicing some simple, yet effective, communication and listening skills can help foster a more supportive and intimate relationship between couples while managing MS.

In order to facilitate and practice effective communication skills with a partner/spouse, identifying what may impact a relationship while living with MS can be explored together. For example, one partner may need to re-shift his/her work schedule to accommodate the other partner's medical appointments, etc. Or, one partner may need to juggle more of the household responsibilities while the other partner may need to scale back social outings/engagements to accommodate changes with MS. As roles and responsibilities shift, communication between partners becomes even more of a priority in keeping a supportive relationship.

MS is expensive and takes time and energy to manage. The disease is often diagnosed in a person's most productive work years and can influence financial stressors between couples. Financial management of a chronic disease, as well as the time and effort it takes to re-think tasks and routines while managing MS, can affect communication between couples.

Though living with MS can have its challenges,



it can also be an opportunity for growth between couples. Relationships experiencing a life altering diagnosis can draw a couple closer, and foster more open, honest conversations between partners, thus can deepen mutual support and intimacy.

Fostering better communication and listening skills while juggling activities of daily life with MS can be challenging. Some basic tips outlined below can help facilitate a more open, positive, and supporting relationship between partners.

## COMMUNICATION TIPS FOR COUPLES

- 1** Make your relationship a priority by creating a culture of positivity. Schedule “date” nights or couple time each and every week. Routine scheduled time for each other will allow for a foundation of positive communication to begin and blossom throughout the relationship.
- 2** Become an active listener. Relationship experts believe that listening is 99% of the communication process. Give your partner all your attention and verbalize how important it is to listen to what is being said. This will help foster a positive foundation for effective communication.
- 3** When listening to your partner maintain good eye contact throughout the conversation, let your partner finish speaking without interruption, and clarify what is being discussed when needed. For example, “So, what I hear you saying is...,” helps ensure you and your partner are hearing and understanding each other.
- 4** Use “I” statements with your partner whenever possible. “I” statements are useful in conveying praise and stating concerns or requests. For example, “I feel \_\_\_\_\_, when you help me bring in the groceries. Thank you.” This statement clearly conveys an individual's feeling of appreciation.
- 5** Keep in mind that effective communication skills need daily practice. Make sure you pay attention to non-verbal forms of communication like body language and eye contact. And, remember to be patient and open to growing as a couple together while learning to improve communication.

Sometimes, couples may find they need more support and practice with their communication and

listening skills. There are a variety of resources which are available both within the VA Health Care System and community organizations such as the National MS Society.

The National MS Society has a program for couples and managing relationships called “Relationship Matters: Eight Hours to a Lifetime of Relationship Satisfaction.” This workshop is for couples living with MS and is offered as a live

presentation and a teleconference series. Please visit [thwww.nationalmssociety.org](http://thwww.nationalmssociety.org) to find your local chapter and to find out when the series is available.

Veterans with MS can contact their local VA Health Care Medical Facility and ask to speak with a social worker regarding options for family/couples counseling. If appropriate, a referral can be made by a primary care provider for couples counseling.

**Maggie Kazmierski, LCSW, MSCS - Baltimore VA**

## OPTIC NEURITIS

Vision is very important in almost everything we do, including watching television, reading a book, driving, and many other activities. When MS disturbs vision, it can have a significant impact on quality of life. People with MS can have many different kinds of vision problems, one of the most common being optic neuritis.

Optic neuritis is caused by inflammation or demyelination of the optic nerve, the nerve that connects the eye to the brain. People with optic neuritis generally complain of blurry vision or hazy vision affecting one eye. Often the center of vision is most affected, making it difficult to see people’s faces or creating a “line” in the center of their vision. Some people with optic neuritis describe the blur as a “film” over their eye. Color perception is usually affected as well, with colors seeming faded or less intense in the eye affected by optic neuritis. Optic neuritis is often associated with some eye pain or discomfort, especially with eye movements, which may be described as an ache or “sticking” sensation behind the eye.



In optic neuritis, the blurring of vision may gradually worsen over the course of a week or so. Afterward, there is usually a gradual recovery of vision, occurring over a 4 to 6 week period. Intravenous (IV) methylprednisolone (a type of steroid known as Solu-Medrol®) is often given to treat optic neuritis. IV steroids do not appear to improve the ultimate visual outcome, but they do

seem to speed up the recovery of vision. With or without steroid treatment, optic neuritis almost always gets better, though the vision in the affected eye may not return 100%. Vision in the optic neuritis eye might not be as clear as before, and colors may remain faded or “washed out.” Depth perception or 3-D vision is often not as good after an episode of optic neuritis, making it more difficult to judge distances, as when climbing stairs or reaching for objects.

More than half of all people with MS will experience optic neuritis at some point in their lives. In fact, for 15% to 20% of people with MS, optic neuritis will be the first sign of the disease. Not all people who get optic neuritis, however, will go on to develop MS. Many studies have examined this relationship between optic neuritis and MS over time. Depending on the study, the risk of developing MS after an episode of optic neuritis varies from 42% to 63% -- roughly 50/50 odds.

Brain magnetic resonance imaging (MRI) can be very useful in predicting which person with optic neuritis will go on to develop MS. People with optic neuritis who have a normal brain MRI scan have a relatively low risk of going on to develop MS, ranging from 8% to 25%, depending on the study. People with optic neuritis who have demyelination (also called “spots”, “plaques,” or “lesions”) on their brain MRI, have a much higher risk of developing MS, possibly as high as 80%.

Though this risk is significant, and much greater than the risk of MS in people who start out with a normal brain MRI, it should be noted that 20% to 40% of the “high-risk” people in these studies who

had an episode of optic neuritis did not go on to develop MS even after many years of follow up.

Though optic neuritis generally goes away on its own, with or without treatment, it is still important for people with optic neuritis to be seen by a

neurologist to find out if MS is likely or not. For people who already have a diagnosis of MS, it may still be important to see a neurologist after an episode of optic neuritis to review MS treatment options.

Robert Shin, MD - Baltimore VA

## THE VA MS CENTERS OF EXCELLENCE

The Veteran Affairs Multiple Sclerosis Centers of Excellence (MSCoE) were established by the Veterans Health Administration (VHA) in 2003. There are two national coordinating Centers within the VHA - *MSCoE East* located in Baltimore, MD and *MSCoE West* jointly located in Seattle, WA and Portland, OR. Through partnerships with Veterans, caregivers, health care providers, and MS advocacy groups the Centers hope to minimize disease impairment and increase the quality of life for Veterans with MS. The Centers are organized around four functional cores.

### CLINICAL CARE CORE

MSCoE is committed to implementing evidence-based health care services for Veterans with MS that improves the quality and consistency of services delivered across the country. To help in this process, a national integrated network of dedicated MS health care professionals has been established for care and referrals within the VHA.

This national integrated network facilitates the delivery of health care services close to home or at home using face-to-face visits, inpatient admissions, and telehealth. (Telehealth is the transmission of health related information, clinical or non-clinical, through the use of telecommunications technology.)

### EDUCATION AND TRAINING CORE

MSCoE is dedicated to increasing health care provider and Veteran knowledge, improving access to resources, and promoting self-efficacy and compliance. Our education programs are designed

to address the educational needs of Veterans, their caregivers and family members, and health care providers, and to empower Veterans to participate actively in their health care plans.

### RESEARCH AND DEVELOPMENT CORE

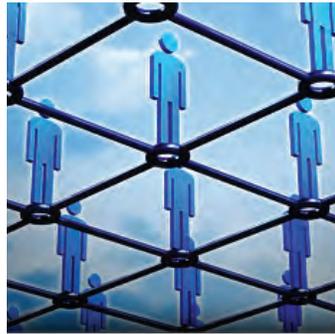
MSCoE is coordinating clinical and research programs to enhance participation of Veterans in health science research and clinical trials, incorporate findings of relevant research into the clinical care of Veterans, and establish a research agenda that addresses the unmet needs of Veterans with MS.

### INFORMATICS AND COMMUNICATIONS CORE

MSCoE is working to employ state-of-the-art informatics and telehealth technology to improve coordination and practices of MS health care delivery. The MSCoE website provides education for Veterans, caregivers, and health care providers as well as guidance on VA rules and regulations relating to MS. Our VA National MS Data Repository contains medical diagnoses of MS from 1998 to the present, allowing MSCoE to better understand the health care needs of Veterans with MS.

We are actively involved in the development of clinical tools to monitor medications and changes in an individual's ability to meet basic needs and maintain health and well-being. Through collaborations with VHA Rural Health and Telehealth Services, MSCoE is working to make telehealth available throughout the nation.

Through a specialized and collaborative integration of clinical care, education, research, and informatics, MSCoE is striving to increase and improve health care services for Veterans with MS, allowing Veterans with MS to maintain independence, productivity, and quality of life. For additional information about the Veteran Affairs Multiple Sclerosis Centers of Excellence and MS, please visit our website at [www.va.gov/ms](http://www.va.gov/ms).





## CAREGIVER EDUCATION CONFERENCE CALL

Join the free monthly conference call for caregivers and family members. These calls provide an opportunity for people supporting Veterans with MS to connect with others who are also supporting Veterans with MS. A variety of educational topics and resources will be presented along with a facilitated discussion.

**DATE:** 4<sup>TH</sup> 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#

## PATIENT EDUCATION CONFERENCE CALL

Join the free monthly conference call for Veterans with MS, and family members and caregivers of Veterans with MS. These calls allow attendees to learn firsthand about MS from MS experts. A different topic is presented every month and a question and answer time is available at the end of each call.

**DATE:** 2<sup>ND</sup> 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:** A DIFFERENT TOPIC IS PRESENTED EVERY MONTH

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

If you have questions about the calls or topic of the month, please contact Angela Young at (800) 463-6295, extension 7133 or send an e-mail to [MSCentersofExcellence@va.gov](mailto:MSCentersofExcellence@va.gov).

## PATIENT AND CAREGIVER EDUCATIONAL DVD'S

MSCoE produced free DVD's from our live, satellite education programs. Each DVD is studio produced and includes 1.5 hours of educational content provided by MS health care professionals, including real-life stories from Veterans with MS. The DVD's listed below are a great way to learn more about MS issues in the comfort of your home.

- ▶ MS COGNITION AND BRAIN IMAGING: UNDERSTANDING COGNITIVE DYSFUNCTION
- ▶ 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 a free set of DVD's or would like more information on the DVD's, please contact Jaimie Henry at (800) 949-1004, extension 53296 or send an e-mail to [MSCentersofExcellence@va.gov](mailto:MSCentersofExcellence@va.gov).





**VA**  
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Defining  
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in the 21st Century

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10 North Greene Street (NEU 127)  
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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

To be removed from or added to this mailing list, email [jaimie.henry@va.gov](mailto:jaimie.henry@va.gov) or call (800) 949-1004, extension 53296.

## JOIN MY HEALTHeVET

My HealtheVet is the VA's personal health record system. It was designed for Veterans, active duty Servicemembers, their dependents, and caregivers. My HealtheVet helps you partner with your health care team. It provides you opportunities and tools to make informed decisions.

All users who have a My HealtheVet account are able to view their self-entered information. If you are a Veteran enrolled at a VA facility and have an upgraded account, you may be able to view information you self-entered into My HealtheVet and parts of your official VA health record.

In the past year, more features have been added that allow you to view VA appointments and check lab results. The most popular feature is the online prescription refills. You can also view



your prescription history. If you have an upgraded account, you may also send a non-urgent Secure Message to participating members of your VA health care team. Secure Messaging is safe and secure, because the messages you send and receive are all kept within My HealtheVet.

Additionally, all your information comes together at the touch of a Blue Button



which is available on-line. Using the Blue Button is a simple way to collect all this data into a single file that you can save, store, and share as you like.

Use My HealtheVet and become an active partner in your health care. Remember, by working with your health care team and knowing your health conditions, you can learn to make healthy choices and better manage your health. Take time to register today and then get your upgraded account the next time you visit your VA facility.