

# VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE MS VETERAN

## SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

### WHERE THERE'S A WILL, THERE'S A WAY

There is a history of men joining the Navy in my family and following my graduation from high school, I decided that was something I wanted to do as well. I was a Naval aircrewman, with much of my time spent in the back of a P-3 Orion (long-range, anti-submarine warfare patrol aircraft), and I was an instructor for many years. I gladly dedicated almost 22 years of my life to the Navy. When I look back at my years in service, I can see how the Navy gave me an opportunity to pursue my interests as well as develop skills that I continue to use every day.

My first experience with MS occurred in the fall of 1987. I was stationed in Maine and my Squadron was deploying to Keflavik, Iceland. While in route, both of my legs went numb from the middle of my thighs to my toes. I was examined by a flight surgeon, but he couldn't find anything wrong with me. He said the numbness was likely a result of my body acclimating to the cold weather. This didn't make sense to me, but 3 weeks later the numbness went away and life went back to normal.

From about 1990 to 1995, I experienced an MS exacerbation about every 18 months, with each episode lasting a few weeks. The episodes started to feel like normal to me and I chalked it up to the aging process. From 1996 to 1999, I found that my legs were numb and tingling almost every day. I was sent to a neurologist at one point, but she couldn't find anything

wrong with me. Following an incident where I broke my ankle while running and my legs were shaking horribly in front of the flight surgeon examining me, I was sent to a neurologist who did a spinal tap and MRI. The very next day I was told that I had MS.

At the time, I had never heard of MS. I told my family about my diagnosis and my mother told me that my cousin had recently been diagnosed with MS as well. I wanted to learn all I could about the disease so I researched it on my own. I started an MS medication right away and the medication helped control my symptoms. I was devastated by my diagnosis of MS and unsure of my future. I had just been promoted to Senior Chief Petty Officer, transferred to a new Command, and I didn't want to leave the Navy. While I knew I couldn't fly anymore, I found there were a lot of other things I could still do in the Navy. I spent another couple of years at the training Command until I retired in 2003.

Following my retirement, I found that I qualified for Vocational Rehabilitation through the VA. I decided to attend college and earn a degree in teaching. I enjoyed being an instructor in the Navy and this seemed like a good second career for me. I earned a bachelor's degree in elementary education and I substituted and tutored for a couple of years.



#### VISIT OUR WEBSITE

For additional information on MS, visit the VA MSCoE website at [www.va.gov/ms](http://www.va.gov/ms).

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Although I enjoyed teaching young children, aviation was a part of me. In 2010, I was hired by an aviation systems engineering company (ASEC) to write curricula for a new Navy aircraft.

I thought my diagnosis of MS would cause me to have to change my whole life, but I'm still able to do most of the things I enjoy. While in the Navy, I was passionate about aviation and teaching. I fulfill that passion every day even though I'm not up in the air. I'm also passionate about staying active and keeping fit. Though I'm no longer able to run long distances, I've found ways to keep myself active and fit.

I participated in the National MS Society "Bike MS" for 3 consecutive years. I found riding a bike for exercise was just as enjoyable as running. The VA I receive my MS care from uses telehealth for some of their rehabilitation programs. The idea that I could participate in an exercise program from the comfort of my home was very appealing and I jumped at the opportunity to participate. The first tele-rehabilitation program I participated in required me to remotely sign into a video conferencing system and exercise using resistance bands. There were other Veterans exercising at the same time and we would chat and exercise together, which was enjoyable. After about a year, I was released from the program.

I then participated in the Brooks Adaptive Sports

and Recreation Program where I used handcycles for exercise. It was challenging for me to attend the sessions and after a short time, my arm strength weakened, making it difficult to participate. I left the Brooks Program and a few months later, I learned about a new tele-rehabilitation program at my VA. As a participant in the program, an exercise routine was developed for my specific needs. The program is similar to playing a video game, but my body is the game pad. It's a lot of fun to do and I look forward to exercising. The exercises are helping me increase my strength and I'm hoping I can soon participate again in the Brooks Program.

They say, "If you don't use it, you'll lose it!" and I'm doing my best to keep myself healthy and active. I have days where I find it difficult to stay active or I can't seem to find the time to fit everything in. On those days, I remember my motivators and this helps me reach my goals. I've been married for 30 years to Barbara, a wonderful woman who provides me with limitless support. I have three amazing sons who continue to bring me a tremendous amount of joy. I'm surrounded by family and friends who care about me. I've accomplished so many things in my life and have experienced some great adventures. I'm doing all I can to make sure I'm ready for the next adventure.

*Edward Robertson - Green Cove Springs, FL*

## COMMON SLEEP DISORDERS AND MS

Sleep plays an important role in your physical health and well-being. Sleep supports healthy brain functioning, is involved in the healing and repair of your heart and blood vessels, regulates mood, reduces stress, and even helps your immune system defend your body against foreign or harmful substances. The average adult needs 7-9 hours of sleep each day to function well. Yet, many people do not get adequate amounts of sleep.

People with MS often say they sleep poorly at night and are fatigued in the daytime. In the general population the three most common sleep problems reported are insomnia, sleep apnea, and restless

leg syndrome (RLS). Recent research suggests that people with MS have these problems even more often.

**Insomnia** is characterized by problems getting to sleep or staying asleep, or waking up too early. Insomnia can have multiple causes and is a significant

### GET YOUR INFLUENZA VACCINATION

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.

problem at some point for almost half of people with MS. Insomnia can be caused by nighttime MS symptoms that disrupt sleep, such as pain, muscle spasms, and urinary frequency. Medications, including some antidepressants (SSRIs), stimulants used to treat daytime fatigue, and corticosteroids used to treat MS exacerbations can also contribute to insomnia. Depression, which is common with MS, is also associated with insomnia. Although occasional self-medication of insomnia with over-the-counter sleep medications containing antihistamines can help, if you use them often they'll probably stop working and will also make you sleepy or foggy during the day. Many approaches can be effective for treating insomnia including adjusting your current medication regimen, addressing MS symptoms that are contributing to poor sleep, using non-medication cognitive behavioral therapy approaches, and, in resistant cases, using prescribed sleep enhancing medications.

**Sleep apnea** affects at least 1 in 5 Americans, and probably an even greater proportion of people with MS. Sleep apnea is characterized by repeatedly stopping breathing during sleep. The frequent pauses in breathing can cause fragmented sleep as well as low blood oxygen levels. Untreated, sleep apnea is associated with poor daytime functioning, mood and memory problems and, if severe, cardiovascular disorders such as heart disease and stroke. Sleep apnea may also worsen fatigue, poor energy, and daytime tiredness common in people with MS. Treatment of sleep apnea can reduce these symptoms which may have been attributed solely to MS.



**Restless leg syndrome (RLS)** is characterized by an uncomfortable urge to move your legs or, more rarely, other body areas. This urge is temporarily relieved by moving your legs. RLS symptoms are generally worst in the evening or at night. RLS is three times more common in people with MS than in the general population. RLS may affect up to 1/3 of individuals with MS and is more common in those who are older, have had MS for longer, have primary

### PATIENT EDUCATION TELEPHONE CALL

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

**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:** 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, call (800) 949-1004, ext. 53296, send an email to [MSCentersofExcellence@va.gov](mailto:MSCentersofExcellence@va.gov), or visit our website at [www.va.gov/ms](http://www.va.gov/ms).

progressive MS, and have greater disability. The exact cause of RLS is not known, but RLS appears to be linked with iron metabolism in the brain. Checking for low iron levels with a blood test, and replacing iron when low, can improve symptoms. Decreasing the intake of caffeine, nicotine, and alcohol, massaging your legs, and taking warm baths before bedtime may decrease RLS symptoms. When these interventions fail, medications to treat RLS symptoms are available.

In summary, sleep problems such as insomnia, sleep apnea, and RLS are common in individuals with MS. These sleep problems may be troublesome on their own and may contribute to daytime fatigue, poorer quality of life, and may be associated with greater disability. Fortunately, treatments are available for the most common sleep problems so if you have poor quality, unrefreshing sleep, it is important that you discuss your symptoms with your provider. Good sleep practices such as keeping a regular bedtime and wake time, protecting your sleep time from other activities, setting up your bedroom only for sleep, and limiting caffeinated beverages can also help. While symptoms may not completely resolve with treatment, substantial improvements in daytime functioning and an improved sense of well-being are possible.

**Eilis Boudreau, MD, PhD - Portland VA**  
**Michelle Cameron, MD, PT - Portland VA**

# PVA: A CHAMPION FOR VETERANS WITH MS

Paralyzed Veterans of America will soon celebrate 70 years of advocacy on behalf of Veterans with spinal cord injuries and diseases. Since World War II,



**Paralyzed Veterans  
of America**

Veterans who live with paralysis have seen incremental progress in terms of health, wellness, independence, and overall quality of life due to the organization's

role in raising awareness and providing meaningful services. A major part of its mission includes advocating for timely benefits, quality health care, civil rights, and equal opportunities for Veterans with MS.

## **BENEFITS**

Every year, PVA's national service officers encounter numerous Veterans with MS diagnoses who have no idea they are entitled to VA disability compensation. Whether a Veteran develops the condition 1 month or 20 years after leaving service, a Veteran may be eligible if service treatment records or post-service health records show a possible symptom of MS can be retrospectively identified within the 7-year period after active service, prior to the confirmed diagnosis. Documented blurry vision or weakness in the arms and legs thought to be anything but MS could be the key to receiving VA monetary benefits, as well as ancillary benefits. For example, a Veteran who loses the ability to walk may receive a grant to make a home and vehicle accessible. But it starts with having an expert in VA claims development review all military documents and health records in order to identify a symptom within the 7-year window and get an medical opinion from a physician on its likely association with MS.

## **HEALTH CARE**

For over 30 years, PVA has closely monitored health care in VA through annual site visits at every VA Spinal Cord Injury and Disorders (SCI/D) Center across the country and Puerto Rico. A site team consisting of registered nurses, clinicians, architects, and paralyzed Veterans assess quality of care against the standards outlined in VA directives. These SCI/D

Centers became the benchmarks for rehabilitation and acute care for Veterans who suffered trauma to the spinal cord as well as other spinal cord dysfunctions such as tumors and stenoses. Once it had become recognized that MS can often mirror the effects of spinal cord injury (loss of use of lower extremities, bowel and bladder dysfunction, chronic pain), PVA and VA partnered to implement policies that opened access to SCI/D care for Veterans with MS with affected spinal cords.

## **CIVIL RIGHTS**

While many Veteran service organizations derive their purpose from advocating for disabled Veterans, PVA is distinguished by being both an advocate for Veterans as well as the disabled community. MS respects no demographic boundaries so the extent to which the organization makes society more accessible for Veterans with mobility impairment also benefits non-Veterans with disabilities. The organization's professional team of architects promotes barrier-free design in public, private, and government construction, which promotes independence and encourages greater participation in society. Consistent

### **LEARN MORE ABOUT MS**

MSCoE produced free DVD's from our live education programs. They are a great way to learn more about MS in the comfort of your home.

- ▶ **BOWEL AND BLADDER MANAGEMENT IN MS**
- ▶ **MS AND EMOTIONAL DISORDERS: APPROACH TO MANAGEMENT**
- ▶ **MS, COGNITION, AND BRAIN IMAGING: UNDERSTANDING COGNITIVE DYSFUNCTION**
- ▶ **MS MODIFIABLE RISK FACTORS**
- ▶ **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**

If you are interested in receiving free DVD's, call (800) 949-1004, ext. 53296 or send an email to [MSCentersofExcellence@va.gov](mailto:MSCentersofExcellence@va.gov).

with that effort is our support for the UN Convention on the Rights of Persons with Disabilities. This treaty, which has hit barriers in Congress due to ideological differences, will benefit the 650 million people around the world living with disabilities, including 2.3 million with MS.

### **EQUAL OPPORTUNITY**

PVA launched its PAVE Program in order to help disabled and hard-to-place Veterans become job ready and achieve economic self-sufficiency. PAVE, which stands for Paving Access for Veterans Employment, does exactly that by rolling over barriers to employment such as low self-expectation, employer stigmas, health issues, and lack of access to VA benefits. The program's certified vocational counselors and employment analysts work with benefits experts and clinical advocates to holistically address a wide range of issues that prevent Veterans

with disabling conditions from competing in the job market, and they also educate employers.

### **MAKING A REAL DIFFERENCE**

MS impacts military Veterans at a high incidence rate according to recent research studies. For the 28,000 Veterans with MS who receive health care in the VA, the difference between living with the disease and living despite the disease begins with programs and services that empower and educate. PVA continues to lead on both fronts. For Veterans, family members, and caregivers who need assistance or want to learn more, go to [www.PVA.org](http://www.PVA.org) or call the PVA national office in Washington DC at (800) 424-8200. You can also connect with PVA on social media at [www.facebook.com/ParalyzedVeterans](http://www.facebook.com/ParalyzedVeterans) and <https://twitter.com/PVA1946>.

*Sherman Gillums, Jr. - Deputy Executive Director  
for Paralyzed Veterans of America*

## **SPOTLIGHT ON PROGRESSIVE MS**

By its very name, multiple sclerosis tells us that there are many (multiple) scars (sclerosis) in the brain, spinal cord, and optic nerves. When these scars or plaques are formed, they can be silent and only detected by magnetic resonance imaging (MRI) or they can cause symptoms. New plaque formation accompanied by new symptoms is called a relapse, attack, or exacerbation.

Progressive MS is the term given to forms of MS with a gradual neurological decline that is not due to clinical relapses or new MS plaques on MRI. The decline is slow, unlike the abrupt worsening of function that occurs during an MS relapse or after an MS relapse with incomplete recovery. MS providers suspect an individual has progressive MS when they report more difficulty performing tasks or when their neurological exams have deteriorated, and MRI's do not show new plaques that could account for these changes. People with secondary progressive MS (SPMS), who initially experienced relapses, and those with primary progressive MS (PPMS), who had progression from disease onset, fall under the category of progressive MS.

### **MS & ME: VETERAN YOUTUBE STORIES**

View the MSCoE produced videos to learn more about MS and Veterans living with MS. Go to [www.youtube.com/VeteransHealthAdmin](http://www.youtube.com/VeteransHealthAdmin) and type "MS & Me" into the VHA search channel.

By 10-20 years after diagnosis, approximately half of people with relapsing MS transition to SPMS. In addition, about 10-15% of newly diagnosed people have PPMS. So at any one time, roughly half of all people living with MS have a progressive form. For some, progression means a gradual loss of strength or balance, needing a cane to walk, or not being able to walk as far before needing a rest. For others, it is a decline in memory or bladder function, or hand coordination. Periods of decline may be followed by periods of neurological stability. There can even be the occasional relapse or new plaque on MRI. The course of progressive MS is unique to the individual.

Current disease modifying therapies (DMTs) for MS target the immune system in order to reduce inflammation in the brain, spinal cord, and optic nerves. Because they reduce clinical and radiographic relapses (MS plaques on MRI), these DMTs are FDA-approved only for relapsing forms of MS. To date, no

## CAREGIVER AND FAMILY TELEPHONE CALL

Join the MSCoE free, monthly conference call to connect with caregivers and family members supporting people with MS. A variety of educational topics and resources are discussed.

**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#

The VA has a National VA Caregiver Support Hotline for caregivers and 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

DMT studied in progressive forms of MS has slowed the rate of disability progression. Some people with progressive MS may take DMTs if there is evidence that inflammation is still a driving factor. The DMT, however, will help only the inflammation and not the progression. As always, potential benefits of DMTs have to be weighed against the possible side effects and medical risks.

If inflammation leading to new plaques isn't the driving force behind neurological decline in progressive MS, what is? There may be a number of forces at work. Studies that look directly at progressive MS brain tissue still show inflammatory cells, but in a different pattern than seen in relapsing disease. The immune cells in progressive disease cause a different kind of damage to the neurons, called oxidative stress. Oxidative stress is essentially an imbalance between the production of chemically unstable molecules containing oxygen and the ability of the body to counteract or detoxify their harmful effects. The already demyelinated neurons cannot tolerate this oxidative stress leading to early nerve death. In progressive MS, nerve cells also fail to produce enough energy to stay healthy and resist oxidative damage. Since the underlying causes of progressive MS are different than the causes of relapsing disease, treating progressive MS needs different strategies.

Fortunately, there are a growing number of treatments in clinical trials designed specifically for progressive MS. Investigators from France conducted a randomized controlled trial of biotin, a water-soluble vitamin thought to be needed for energy metabolism and myelin repair. In this study, 154 people with SPMS and PPMS were treated with either 300 mg/day of biotin or placebo (sugar pill) for 48 weeks. In the biotin-treated group, 13% had an improvement in their disability score at the end of the year compared with none in the placebo group. Unexpectedly, and unfortunately, 5% of people in the biotin group developed thyroid problems. Another trial is needed to both confirm these promising findings and better understand the short and long-term safety of this very high dose of biotin. Alpha lipoic acid is a fat and water-soluble antioxidant that may be able to combat the oxidative stress in progressive MS. Alpha lipoic acid is being studied in a clinical trial at the VA Portland Health Care System to see if it can slow the course of disease for people with SPMS. Supplements like biotin and alpha lipoic acid are appealing because they are easily found as over-the-counter supplements. However, I warn people with MS to avoid taking them until the evidence has shown that they are both effective and safe in the long-term.

The investigational medication ocrelizumab is showing promising results in the treatment of progressive forms of MS. A recent clinical trial involving 732 people with PPMS showed that people who received ocrelizumab (IV infusions every 6 months) experienced reduced progression of disability compared to people in the study who received placebo. The side effects from treatment with ocrelizumab were similar to those in the placebo group. The manufacturer of ocrelizumab plans to seek marketing approval from the US Food and Drug Administration in 2016.

Other health conditions not normally thought connected to MS may actually play a role in MS disability. In a large database study conducted by the Health Sciences Center in Winnipeg, Canada, people with MS who had even one cardiovascular risk factor (high blood pressure, high cholesterol, heart disease, peripheral vascular disease, or diabetes) needed a cane to walk an average of 6 years earlier than similar people with MS without any of those

conditions. The good news is that cardiovascular diseases are influenced by good diet and regular exercise, two “treatments” within everyone’s control. While no one particular diet has been determined to be “the best” for MS, most experts agree that good diets have similar features: high in fresh vegetables and fruits, whole grains, quality meats and fish, and low in processed (packaged) foods and simple sugars.

When it comes to exercise, even modest activity like treadmill walking or stationary cycling three times a week are generally safe and can improve mobility, thinking, and quality of life for people with MS. Given the known benefits of good diet and regular exercise for everyone, people with all forms of MS should start these positive lifestyle changes now!

*Rebecca Spain, MD, MSPH - Portland VA*

## TELE-REHABILITATION THERAPY AND EXERCISE

Telehealth is the provision of health care beyond the provider’s office using telecommunication. It changes the location where health care services are routinely provided, leading to improved access to care for Veterans in rural locations as well as improved Veteran access to specialty care services. Tele-rehabilitation is the provision of rehabilitation services using telehealth technology. It allows Veterans living in rural areas to take part in rehabilitation programs from the privacy of their home or at a VA clinic that is closer to their home. Currently, the North Florida South Georgia Veterans Health Service MS Comprehensive Care Center at the Lake City VA is piloting a tele-rehabilitation program with 15 Veterans with MS.

Veterans with MS who participate in the Lake City VA tele-rehabilitation program have a range of abilities, with some only having mildly impaired walking while others use a power wheelchair full-time. The Veteran is seen in person for an initial visit and then a home exercise (therapy) program is set-up for that Veteran. Once a Veteran has committed to the program, telehealth equipment is installed in the Veteran’s home for the completion of the exercise program as well as weekly follow-up telehealth visits with their provider.

### EQUIPMENT AND METHODOLOGY

Telehealth equipment, using a wireless card or local Wi-Fi network to connect to a secure network, can transmit a wide range of information. This may include audio and video images of the Veteran and the telehealth provider, with newer technologies

allowing for motion capture and monitoring of vital signs. Audio and video images can allow the Veteran and the telehealth provider to interact and discuss the Veteran’s health and care plan. Motion capture technologies can be used to evaluate how well, how fast, and how frequently the Veteran performs the home rehabilitation program and allows the provider to adapt and change the program to meet individual treatment goals. Monitoring of vital signs allows the provider to evaluate the body’s response to treatment and assess the Veteran’s overall condition while communicating with the Veteran in real-time.

### DELIVERY OF CARE

The home exercise programs are individualized for each Veteran but generally include stretching, strengthening, endurance, balance, coordination, and gait skills. For example, Veterans with MS who need



to work on muscle strength may be given rubberized bands with different levels of resistance to pull against for specific exercises. To work on balance Veterans may sit in a chair, stand behind a chair, be on their hands and knees, or kneeling on the floor while reaching or performing other balance challenges.

Each Veteran has a tele-rehabilitation appointment once each week that lasts 30 to 40 minutes. The therapist (physical, occupational, creative arts, speech, and/or recreational) meets with the Veteran at the weekly scheduled appointment time over the televideo equipment that was installed in their home, similar to having a scheduled in-person visit. Therapy activities are observed and individually progressed for each Veteran. For all Veterans participating in the



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VA Maryland Health Care System  
10 North Greene Street (NEU 127)  
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VA Puget Sound Health Care System  
1660 South Columbian Way (S-117-MCoE)  
Seattle, WA 98108

Portland VA Medical Center  
3710 SW US Veterans Hospital Road (P3MCoE)  
Portland, OR 97239

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tele-rehabilitation program safety is key. A caregiver or helper is asked to be there with the Veteran if the Veteran needs assistance to perform the exercises, otherwise it is just the therapist in the clinic and the Veteran in their home.

The live, weekly interaction allows the telehealth provider to address any treatment plan needs as well as answer questions and provide instructions to the Veteran or caregiver if needed. The tele-rehabilitation therapist also functions as a connection between the Veteran and their MS provider, helping to ensure any health concerns the Veteran may have are quickly addressed. Between scheduled appointments Veterans can use a computer exercise program that allows them to perform assigned exercises in standing or seated positions in their home. The computer exercise program allows the telehealth provider to monitor the activity of the arms and legs through the storage and forwarding of data. Feedback is provided to the Veteran by an animated figure on the screen and

verbal cues and performance numbers are available at the end of each session.

Over the last two decades the Veterans Health Administration has been at the forefront of telehealth innovation, investing in equipment, technology, and provider training. The Veterans Health Administration Office of Rural Health is expanding access for Veterans through telehealth to maintain physical functioning, and participate in rehabilitation and wellness programs from home. Telehealth can save Veterans fatiguing travel to and from appointments, can reduce waiting room times, and allows direct one-on-one interaction between Veterans and their provider. More than 95% of participants in the Lake City VA tele-rehabilitation program say they are satisfied with the connectivity and interactivity with the program. This program is showing promising telehealth potential for Veterans living in rural areas.

*Sean McCoy, PhD - Gainesville VA*  
*Toni Chiara, PT, PhD - Gainesville VA*