

# At the front



## Resources for veterans living with MS

by Aaron Dalton

Those who serve in the U.S. military do so in many ways and on many different fronts. And [thousands of these veterans also face a unique challenge: multiple sclerosis](#). Currently, there are no accurate estimates of the number of veterans living with MS, partly because only about 40% of veterans with MS, approximately 20,000, receive their care within the Veterans Health Administration (VHA).

Many receive care and treatment at the VHA-affiliated MS Centers of Excellence (MSCoE), a network with dozens of clinics across the country that offer comprehensive care to veterans with MS. This care is provided by a highly trained team of specialists that includes neurologists, psychiatrists, psychologists, physical therapists, occupational therapists, speech-language pathologists, nurses and social workers.

“Some veterans living with MS get treated in the private sector without realizing the fabulous benefits they may be able to access at the VHA,” says Jodie Haselkorn, MD, director of the MSCoE-West, located jointly in Seattle and in Portland, Oregon. “The VHA has access to all the FDA-approved disease-modifying therapies (DMTs) for MS. That’s not always the case in the private sector, and it enables us to make sure that veterans living with MS get on a safe, appropriate treatment that will have the most benefits.”

The centers coordinate and provide clinical care, rehabilitation services, education and information processing, and telehealth services. To gain a better understanding of MS, the centers conduct laboratory, clinical, epidemiological and health services research.

To help prevent burnout among caregivers, the Department of Veterans Affairs (VA) provides respite care services for eligible veterans whose caregivers need some relief. Home health aides, adult day health centers and community living centers are available. The services show that “the VHA recognizes how important caregivers are in helping veterans to manage living with MS,” Dr. Haselkorn says.

One ongoing research initiative at the VA—the [Million Veteran Program](#)—seeks to collect and perform whole genome screening on 1 million veterans as part of an effort to help untangle links between genes and MS. “MS is a complex disorder with a genetic component, but it’s unclear how much of an effect each gene has on the disease,” says Mitch Wallin, MD, director of the MSCoE-East in Baltimore, Maryland, and Washington, D.C. “We can only hope to sort out these connections if we can analyze a large number of genomes, so I would encourage any veteran with MS to sign up for the program.”

While MS is more prevalent among women in the general population, the military is still a male-dominated profession, so most veterans with MS are men. This demographic characteristic of the U.S. military allows the centers to better understand how MS affects men. “The disease is worse in men, especially among non-Caucasians,” Dr. Haselkorn says.

### **Service-connected status**

Veterans who have experienced a disability from an injury or disease that was incurred or aggravated during active military service can get what is known as service-connected (SC) status.

## **How can veterans living with MS apply for service-connected status?**

Online, through the mail or in-person at a VA regional office, independently or with the assistance of an attorney, claims agent or Veterans Services Organization (VSO) representative.

Veterans can strengthen their application for service-connected status by having accurate and detailed documentation of all relevant neurological symptoms and any MS-related medical visits.

To find out more about enrollment and eligibility for VA services, veterans can visit [vets.gov](https://www.vets.gov).

Service-connected status plays an important role in determining a veteran’s priority group rating with the VHA. Veterans with a higher priority group rating may have access to more health care benefits at lower or no cost in the VHA system. Other factors such as financial resources, wartime service and honors also play a role in determining a veteran’s priority group status and access to the VA’s health system.

Since MS can be difficult to diagnose promptly, the VHA generally presumes veterans are eligible for SC status if they can show evidence that their MS symptoms occurred during active duty or within seven years after they were honorably discharged, regardless of diagnosis date.

Dr. Wallin notes that veterans who are diagnosed with MS more than seven years after they have been discharged may still be able to obtain SC status if they can show evidence that their MS symptoms occurred during active duty or within seven years after they were honorably discharged.

Service-connected veterans also may be eligible to receive disability compensation from the VA.

There are many factors that can affect the amount of compensation the VA pays to disabled veterans.

To learn more, visit the [Veterans Benefits Administration](#).

To learn about the full range of services the VHA offers to SC and non-SC veterans living with MS, visit the VA's [Multiple Sclerosis Centers of Excellence](#).

While some veterans living with MS opt for private care, Dr. Haselkorn says there are other good reasons for them to seek treatment at a VHA facility. "At the VHA, we're accustomed to dealing with veterans living with MS. We appreciate and honor their service," she says. "I believe many of our patients benefit from the camaraderie they find at the VHA. When they roll or walk into one of our facilities, they find a group of people who really understand them, where they have been and what they are going through now."

## **Veterans' stories**

Each veteran takes his or her own path to diagnosis, treatment and living with MS. Here are six of their stories:

### **Garvis Leak**

Garvis Leak, 56, retired from the Air Force in 2011 as a decorated combat veteran, had served 26 years in the personnel career field at bases around the U.S. as well as in Germany, Japan and Turkey.

By 2012 he was having problems with low energy, fatigue and recurring migraine headaches. An MRI revealed Leak had MS. "I had actually experienced these same sorts of symptoms on several occasions while on active duty, but at the time I attributed them wrongly to stress and the tempo of operations associated with my job," he says.

As a result of his service-connected status, Leak can get treated for MS at his local VA medical center in Dayton, Ohio, without paying any out-of-pocket fees. He sees a neurologist there every three months.

“When I go the VA, I feel like they are family,” Leak says. “You meet other people there who have served in the military and are now living with MS. The shared experiences create a sense of comfort. It’s a great support system to talk and share our stories.”



**Deanna Deschenes (right), a former Navy mechanic, was diagnosed with MS nearly nine years after the end of her obligated service with the Navy. She lives with her family in Birmingham, Alabama.** Photo courtesy of Deanna Deschenes

While Leak previously received physical therapy at the VA, these days he exercises independently at a gym at least three days a week and participates in Bike MS rides and Disabled American Veterans walks. Drawing on his own experiences overcoming the challenges associated with his diagnosis, Leak operates his own business as a life coach and financial wellness adviser.

### **Deanna Deschenes**

The youngest of 10 children, Deanna Deschenes joined the Navy in 1989. “My decision may or may not have been influenced by [the movie] ‘Top Gun,’” she jokingly admits.

On active duty in Virginia and Florida for seven years, she worked as an aviation structural mechanic with safety equipment—ejection seats, air-conditioning systems, liquid oxygen and pressurization. She retired in August 1996, two days after giving birth to a daughter.

Although she experienced some visual problems and dizziness during her years of active service, it was only in December 2004 that she suddenly experienced optic neuritis, losing half her vision in both eyes. This led to her MS diagnosis in January 2005.



Now 48, Deschenes, who lives in Birmingham, Alabama, has received her MS treatment from private providers for more than a dozen years. But she has decided to apply for service-connected status in hopes of obtaining MS care through the VA system.

“I think the VA offers a high standard of care and great neurologists,” Deschenes says. “If I’m able to obtain service-connected status, I could get care at the VA without any out-of-pocket payments, which would be helpful.”

### **Robert Taylor**

Robert Taylor, 58, was born and raised in Detroit, then spent 20 years in the Army. He served as a courier carrying special classified messages, mail and news in Operation Desert Shield and Desert Storm in Saudi Arabia. He was a drill sergeant and non-commissioned officer.



**Robert Taylor experienced MS symptoms while he was in the military. Today he receives ongoing care through the VA.**

Photo courtesy of Robert Taylor

He left the military in 1997 and went to work in human resources for the South Carolina Department of Social Services. Around that time, Taylor started to experience tremors, temporary vision loss and problems with bladder control. He would get into an elevator for a meeting on another floor of his office building and find himself frozen on the spot. Unable to exit the elevator, he would sometimes ride up and down for 30 minutes before he could take a step forward to get out. In 2012, he was diagnosed with MS.

Taylor receives ongoing care through the VA that includes tests and appointments with occupational therapists and physical therapists.

Taylor realizes now that his symptoms began before he retired from the Army. “Looking back through my record, I can see that I started having symptoms during my active service immediately after I returned from a stint in Saudi Arabia. Suddenly, I was falling down on physical training runs. I had scuff marks on the toes of my shoes from foot drop. At the time, nobody ever told me that these could be signs of MS.”

Taylor is involved with the Society and serves as a District Activist Leader in South Carolina, where he lives today. He volunteers at health fairs to hand out information on MS and has twice attended public policy conferences in Washington, D.C., to speak with legislators about obtaining funding for MS research.

### **Tom Unrath**

Tom Unrath spent 20 years traveling the world with his family as an Air Force chaplain. He first experienced MS symptoms in 2001 while stationed at Grand Forks Air Force Base in North Dakota. A primary care manager at the base clinic began running tests to see whether Unrath might have MS.



**Tom Unrath first experienced MS symptoms while he was an Air Force chaplain. He says that MS has played a role in helping him become a better pastor.**

Unrath had not yet received a definitive diagnosis when he was transferred to Patrick Air Force Base in Florida. In 2003, he met with the chief of neurology at the University of Florida Health Shands Hospital in Gainesville, who diagnosed Unrath with MS.

“At that time, with a disease like MS, I was required to participate in a medical review board to see whether I was fit to remain on active duty,” Unrath says. “That was a bit nerve-racking, as I did not want to be suddenly kicked out of the military. I had pledged to serve for a full 20-year career. I had been trained, at great cost to the taxpayer, to fulfill this profession for which I was highly qualified, and which I felt called by God to do. Also, while a medical retirement would have allowed me to receive full benefits, it would have reduced my retirement pay.”

The review board allowed Unrath to stay on active duty, although he no longer qualified for international deployments.

Unrath retired from the military in 2007. After serving as an interim pastor for several congregations, he became part-time pastor at Messiah Lutheran Church in Cocoa, Florida, in 2010, and now serves there as quarter-time pastor.

Today, Unrath, 62, copes with fatigue, mobility problems and trigeminal neuralgia that can flare up to the point where he cannot eat, drink or even speak. Nonetheless, he says that his MS has played a role in helping him to become a better pastor.

“There have been several things in my life that have allowed me to become more empathetic to the difficulties that other people face,” Unrath says. “Eleven days before I received my final MS diagnosis, my daughter was killed in a car accident.

It was a double blow. But since then, I have helped lead support groups, both for people with MS and for parents whose children have died. These experiences have given me a greater understanding of the challenges that other people are going through.”

Unrath participates in MS activism with the Society in Florida and on Capitol Hill in Washington, D.C.

## **High-risk, high-reward research**

Congress passed legislation creating the MS Research Program (MSRP) in 2008.

Funded through the Department of Defense, the MSRP seeks to fund high-risk, high-reward research that has the potential to have a major impact on knowledge and treatment of MS.

MSRP is a peer-reviewed program in which the people making funding decisions include not just scientists, but also consumer reviewers—people living with MS or caring for those living with MS. Since the program is administered through the Department of Defense, many of

these consumer reviewers are veterans or spouses of veterans.

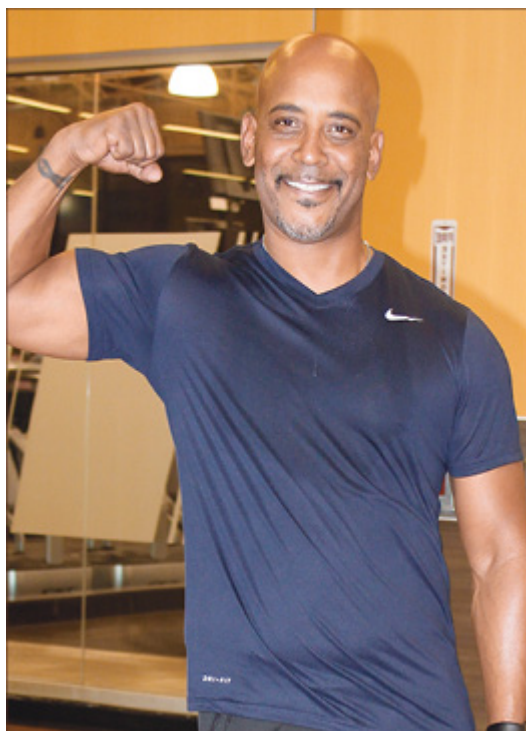
Over the past decade, the MSRP has distributed more than \$46 million in grant money. Much of this funding has been devoted to researching MS detection and diagnosis, clinical and experimental therapeutics, and the pathobiology of the disease.

He is also a peer reviewer for the Department of Defense's MS Research Program and part of the Society's Activism Advisory Committee. "Research toward a cure and ensuring that costs for MS medications are kept at a reasonable level where they are accessible to everyone who needs them—those are my top two priorities as an advocate," Unrath says.

### **Kenneth Johnson**

Kenneth Johnson grew up in Los Angeles and joined the Army. The military deployed him to Asia and the Middle East, where he fought in Operation Desert Shield and Desert Storm.

After his deployment, Johnson was participating in a field training exercise in Arizona when he suffered a spinal cord injury that ultimately led to his discharge after eight years of service.



**Kenneth Johnson makes exercising a priority to help manage his MS symptoms.** Photo courtesy of Kenneth Johnson

After working at a sheriff's department and a police department, he was a federal special agent and criminal investigator for more than seven years.



During his time as a special agent, Johnson began experiencing problems navigating stairs, walking long distances or standing for extended periods of time.

He was diagnosed with MS in 2014. “I didn’t know what to do at first,” Johnson says. “It took me about a year to figure out that if I didn’t do anything, this disease would eat me up. I started experiencing muscle degeneration and lots of pain that made it difficult for me to rest.”

Johnson realized he could only deal with his MS by strengthening his body. He eliminated processed foods from his diet and adopted a rigorous exercise routine that includes running, weight lifting and swimming. “Today, I make that one of my main priorities—to exercise every day for three hours per day,” he says.

Now 49 and living in Los Angeles, Johnson volunteers with the Society, helping wherever he is needed. Johnson serves as leader of a monthly MS support group that meets at the VA West Los Angeles Medical Center. He also attends classes on living with MS.

Johnson has service-connected status for his spinal cord injuries. But he also hopes to get service-connected status for his MS. Looking back, he believes he experienced MS symptoms during his military service. Pointing to the larger picture of military veterans living with MS, he says that connecting his MS to his time in the military is important for accurate documentation.

He makes regular visits to his local VA clinic to see his primary care physician and neurologist, while receiving physical therapy at a private facility in Pasadena, which is covered as a VA benefit. “The VA has taken really good care of me,” Johnson says.

### **Kevin Byrne**

Kevin Byrne grew up in the Bronx, attended the U.S. Military Academy at West Point, graduated from the aviation branch and ended up piloting Apache attack helicopters.

In September 2000, he was serving as a troop commander in Korea, in charge of approximately 120 soldiers in an air cavalry troop, when he began to experience numbness and tingling in his fingers and toes.

At first, he shrugged off the symptoms. “When you are a pilot, you generally don’t go to see a doctor for things like that, because you don’t want to get grounded,” he says. “But when the tingling spread into my neck and then started to affect my vision, I went to a general physician, who sent me to a neurologist. Within a couple of weeks, I had a diagnosis of MS.”

## **Possible links between military service and MS**

Recent research conducted by Mitch Wallin, MD, and others shows that the annual rate of new MS cases diagnosed in the U.S. military from 1990 to 2007 was 9.6 per 100,000

individuals. This is significantly higher than the annual MS incidence rate of 4.2 per 100,000 for the total U.S. population reported in the 1970s.

Dr. Wallin notes that some of the variation between MS incidence rates inside and outside the military may be due to differences in access to health insurance. Since all active duty U.S. military members and their immediate family members have access to health insurance through the military, they may be more likely to seek medical care for neurologic symptoms that can lead to an MS diagnosis. By contrast, uninsured or underinsured Americans outside the military might ignore or downplay such symptoms, meaning they might delay diagnosis or not get diagnosed even if they do have MS.

Dr. Wallin, Dr. Haselkorn and colleagues also published a study on veterans of the 1990–91 Gulf War that found the risk of developing MS was actually lower in U.S. military personnel who deployed to the Gulf War than among those who stayed behind on the home front.

“Whether deployment to other wars can increase the risk for MS is not clear and deserves further study,” Dr. Wallin says.

Although Byrne could no longer fly helicopters, he persuaded his commanding officers to let him stay in Korea to command an aircraft maintenance group. Nine months later, his symptoms had worsened and he was forced to return to the U.S. After additional testing at Walter Reed Medical Center, he received an honorable discharge from the military and a referral to the VHA.

“I’ve had a good experience with the VA,” Byrne says. “At the time, I was living in Pittsburgh, so I went to the VA hospital there. I had no idea what to expect, but I just walked up to the help desk and handed my records to the gentleman volunteering there. He looked them over, looked at me and said, ‘Welcome home, Captain Byrne.’ From that point on, they’ve really taken care of me.”

In the years after his diagnosis, Byrne built a career in the logistics and supply chain field. He got married, moved to Oregon and became a father to a girl named Eleanor. He subsequently wrote a children’s picture book called “My MS and E” about how he and his daughter grow, learn and celebrate life together despite Byrne’s MS.



**Kevin Byrne says his military training helped him cope with MS.** Photo by Keith Carlsen

“My background was math, science and engineering,” Byrne recalls. “I had no interest in any of the literary arts or things of that nature, so it’s kind of funny that writing has become one of the things that I enjoy so much.” All the profits Byrne earns from the book are donated to the MS Society.

By 2016, Byrne’s symptoms were worsening. He experienced increasing weakness along the left side of his body and numbness throughout his right side.

“I also have issues with vision, fatigue and incontinence, but the loss of [feeling in] my limbs is the big issue,” Byrne explains. “That’s what led me to my disability retirement.”

Now 46, Byrne publishes [neverstopneverquit.com](http://neverstopneverquit.com), a blog that focuses on living with MS, and he has participated in Bike MS events since 2003.

Today, Byrne is focusing on his rehabilitation and volunteering with the Society in Oregon, where he serves on the board of trustees.

Byrne is convinced that his military training has helped him cope with MS. “In the military, you learn to work and succeed with the resources that you have,” he says. “Instead of lamenting the fact that I have MS, I focus on the things I can do in spite of my limitations. At West Point, I learned that the only way to win against a fierce and determined enemy was to never stop and never quit. That has become my mindset. My MS will never quit until it is defeated, so therefore I will never quit until I manage to defeat MS.”

**Aaron Dalton is a freelance writer in Nashville, Tennessee.**

**Fall 2021**

For more information, visit the VA's [Multiple Sclerosis Centers of Excellence](#), [Disabled American Veterans](#) and [Paralyzed Veterans of America](#).

For additional resources from the Society, visit [Veterans with Multiple Sclerosis](#) or watch quarterly webinars for veterans through our [Ask an MS Expert program](#).