

# @Momentum



## **Strong networks of support**

I loved the article "[Power of Connection](#)" in the Fall 2018 Momentum magazine. When my daughter Stacey, now 16, was diagnosed two years ago, I quickly found the PMSA (Pediatric Multiple Sclerosis Alliance) group on Facebook. Connecting with other parents of children diagnosed with MS was a lifesaver for me. Having others in similar situations to ask questions to, and get support from, was invaluable. Over these past two years, I have met others living nearby from the PMSA group and made strong networks of support for myself and my daughter. We share doctor information, updates about our kids and each other, and meet for MS events. The power of connection really works!

**Julie M. Hirsch, Michigan**



**Garvis Leak received treatment for his MS at a VA medical center after he retired from the Air Force.** Photo courtesy of Garvis Leak

**Difference in VAs**

Thanks for the article "[At the front](#)" (Fall 2018). I am a veteran who got "lucky" with my MS diagnosis. You mention the MSCoE-West located in Seattle, which is great if you are near Seattle. I am currently stuck between two VA centers in California because of where I live and the care offered. This is so different and less coordinated than the experience I had at the Reno VA, which was modeled after the Seattle VA. I will explore more options with the leads from the article.

I joined the Army at age 39 in 2007. I was stationed at Walter Reed Army Medical Center in Washington, D.C., as an OR tech. In July 2008, I had the worst headache of my life. I threw up while on duty. I asked to go home. Instead, I was sent to the ER. I spent most of the evening there and had an MRI and a spinal tap, and I was diagnosed with MS. I started my first dose of steroids, and a long year in and out of the hospital because the medicine was not keeping the MS in check. I was discharged with 100 percent disability because I was in a pilot program where the VA gave you your rating before discharge. When I was in Reno, they switched my medicine to Tysabri, which has kept my MS in semi-check for almost 10 years. I just wanted to share how different VAs can be.

**Darcy Quimby, California**

## **Let's hear it! Share your thoughts and comments about this issue's stories.**

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- Email [editor@nmss.org](mailto:editor@nmss.org).
- Or send mail to **Momentum** Editor, National MS Society, 900 S. Broadway, Suite 200, Denver, Colorado, 80209. Letters to the editor must include your name and a way for our staff to contact you. Letters should be no more than 100 words and may be edited.

### **Inspiring variety of topics**

The Fall 2018 issue of Momentum was truly excellent. It gave a complete treatment of so many topics; it is inspiring. I have had MS since 1994, and I'm doing fine. I read for relaxation and exercise five to seven times a week, including chair yoga, free weights, and I play nine holes of golf twice a week. I'm happily married for 55 years to a loving and understanding wife. I've been retired for 18 years. Thanks so much for wonderful information and positive leadership.

**Richard Goldberg, Florida**

### **You can do it**

I just read Linda Bridges' article "[Just keep going](#)," (Fall 2018) and I had to sit right down and write. I was born in Boston in 1942. In 1990, I was diagnosed with MS after years of signs but

no MRI to confirm. Linda and I share the attitude of “keep going.” I took early retirement from being a paralegal, and my husband and I hit the road and the sea. And yes, I did climb Machu Picchu in 2003. People wondered what I was thinking, but I said, “Just watch.” After flying to Cusco from Lima and taking a train to Machu Picchu the next day, we climbed. Incas do not build stairs to code, but we managed. I keep a picture of us on my dresser, which I see each morning. It gives me some get up and go. So, you go, girl, and enjoy the history and views—and know in your heart that you can do it.

**Kathie Irvine, Florida**

### **Is it better to know?**

I was diagnosed with MS approximately 15 years ago. I have a relatively mild version of the disease, primarily affecting my right leg and foot, my stamina, and my energy levels. I also have had a poor outcome when using prescription drugs. I seem to get fewer or poor benefits from the prescriptions and many of the negative side effects. I don't like to read about prescription drug side effects because I am also afraid that it will have a psychological impact and I will think I have side effects as opposed to actually having them. So, when I was diagnosed with MS, I listened to what the doctor told me but deliberately did not read a lot about the symptoms or progression of the disease. There was one downside to the hide-my-head-in-the sand decision.

This past year, I started to have headaches that occurred only when I would cough. I was diagnosed and successfully treated for “cough headaches,” a symptom associated with MS. But while with my doctor, I saw something about an “MS hug” condition. I had not heard of it before, but I am now convinced that I had that problem. I am now rethinking my decision and wondering if I could avoid or slow down the progression of my disease if I were more aware or if I were proactively taking medications to deal with the symptoms. Am I doing myself a disservice by avoiding knowledge and not taking action that might postpone, delay, or eliminate some of the symptoms that might yet show up in my case? I have now decided I should start reading Momentum magazine. Is it better to know in advance or to react after the fact? That is the question I am wrestling with right now. I am just beginning to look for more answers.

**L.G., California**