YOU CAN ADVOCATE TO INCREASE CONGRESSIONAL FUNDING FOR THE MS RESEARCH PROGRAM AND VA MS CENTERS OF EXCELLENCE

Create your own WOW-HOW-NOW to help you do it.

WOW: MY IMPACT STATEMENT

Examples: “70,000 veterans live with MS in the United States and new research shows an increased association between deployment during military service and increased risk of developing MS. We owe it to our veterans to provide funding for their care and for research that may ultimately improve their treatment.”

“I’ve never served in the military, but research at the MS Research Program at the Department of Defense and clinical care and education efforts at the VA MS Centers of Excellence are filling large gaps in MS research and care for all people affected by MS. Congress should support federal investments that are working!”

HOW: IMPACT ON THE MS COMMUNITY AND POLICY MAKER’S ROLE IN THE SOLUTION
(You do not have to use all of the points below—just pick 1-2 that best support your impact statement.)

- Congress established the MSRP and the VA MS Centers of Excellence to address gaps in MS research, education, and care.
- The MSRP was established in 2009 and it remains the only federal research funding stream specifically for MS.
- The MSRP received $20 million, and the VA MS Centers of Excellence received $4.5 million in FY23. A $2 million increase would allow for the MSRP to fund additional studies including promoting repair, neuroprotection and remyelination and account for inflation.
- 70,000 veterans live with MS in the United States. 50,000 veterans are seen at the VA MS Centers of Excellence each year. Over half have “service-connected” MS.
- Funding for the VA MS Centers of Excellence has been largely stagnant at $2.5 million since they were established in 2003. While Congress provided an additional $2 million in FY23 to support the work of the Centers, additional consistent funding is needed for them to catch up.

NOW: THE ASK FOR POLICY MAKERS

- Can we count on you to support $22 million for the MS Research Program and $7.5 million for the VA MS Centers of Excellence in FY24?
- And will you submit a program request to the Appropriations Committee requesting $22 million for the MS Research Program and request report language requesting $7.5 for the VA MS Centers of Excellence in FY24?
My name is Nicole Hunt and I have had symptoms of multiple sclerosis (MS) since 2011. They started after an illness; however, I wasn’t officially diagnosed until almost a decade later. I had the flu bad at the end of 2011 and I didn’t feel normal after it subsided.

I felt dizzy, one pupil was larger than the other, I was walking crooked, and I couldn’t find my words. I was working full-time at a clinic in Washington at the time, and the doctor thought I might have had a blood clot or stroke. However, when I had an MRI, it showed multiple lesions (15+) on my brain. For years, I had various symptoms, saw numerous doctors, and suffered with the diagnosis of “demyelinating disease.” Then one July day in 2020, with stroke like symptoms, I drove myself 30 minutes to a hospital, had more testing, and was told by a remote neurologist from all the way across the country, that I had MS.

Prior to the start of my symptoms, I served in the United States Air Force. From 2002 until 2006, I was on active duty as a combat medic and spent time deployed in Iraq at a base medical facility. It was a great group of staff, and we worked in tent medical facilities, with limited resources, treating many trauma patients. We didn’t have the proper protection from radiation from the x-rays that were usually taken in the ER tent, but we managed. After my time in the Air Force, I worked as a civilian employee at Fort Bragg in North Carolina and at a VA hospital in Fayetteville, NC. Eventually I moved to Washington State and that was where my symptoms started.

It was a long road to a diagnosis for me and even when I finally received it, my MS was not deemed service connected. I went many years without receiving disease modifying therapies that could have slowed my disease progression. Still, I am thankful for the VA and the care I receive today. Although it’s not always ideal or fast care, it’s helped me in a lot of ways. I wouldn’t be able to afford the yearly MRI’s or my medication without it. I don’t have private insurance.

I support increased funding for the VA MS Centers of Excellence and increased funding for the MS Research Program at the Department of Defense. It’s my hope that they will receive additional funding and will be able to help others that have been in my shoes and continue to fight for an official diagnosis. The money could also help educate neurologists within the VA Health Care System about how to diagnose and manage this disease accurately, so that in the future, diagnose and treatment can come more quickly for others with MS.