

Hello and thank you for the opportunity to speak before you today. My name is Mandi Bailey, and I am the team lead of the ALS Hope Foundation's Veteran ALS Action Committee, a volunteer group of Veterans and caregivers impacted by ALS.

ALS is a 100% fatal disease with no known cure. And for reasons not yet fully understood, our Veterans are at a significantly higher risk of developing ALS. My family got a crash course in ALS and VA care when my stepdad, a proud Veteran, was diagnosed in 2017. Our local VA in Pensacola, Florida is understaffed and under resourced, but they did everything they could to ensure my stepdad was able to live his life with dignity until his passing on February 2, 2018.

Because of the lack of services and resources at our VA, we had to use community care in addition to the services we received at the VA. In our opinion, the care received inside the walls of our local VA Medical Center was far superior to the community care we received. I soon learned that we aren't alone in that opinion. In 2024, a survey was conducted by the Department of Veterans Affairs Veteran Experience Office that revealed the highest trust levels in years. Our Veterans know that by receiving care at the VA, they will be treated with the dignity and respect they deserve as U.S. Veterans.

It wasn't always this way. The VA has worked very hard to improve the care that they provide to Veterans, and in the ALS system of care much of the progress has come from allowing the stakeholders, like myself, to give feedback and being open to ideas and input from the community. Dr. Ileana Howard, Director of Neurology for ALS, has done a tremendous job of listening and has made considerable improvements to the ALS system of care by doing so. She has brought the voice of the Veteran to the table and it has made a huge difference.

While it is important to recognize how far the VA has come in its care for Veterans with Spinal Cord Injury and Disorder, we know that there is still room for growth. In 2021, the VA issued a directive informing the care of Veterans impacted by ALS, VHA Directive 1101.07 Amyotrophic Lateral Sclerosis System of Care, and recently a comprehensive ALS Handbook. The problem is that one VA is one VA. The services and resources at one facility are not the same as the services and resources at another. For example, my team co-lead, Jill Brattain's husband, Dave, received top notch care during his ALS journey at the Richard Roudebush VA in Indianapolis. Their team was proactive, knowledgeable, and responsive to their needs. The care Jill and Dave experienced is why the VA was called the Gold Standard in a recent report from the National Academies of Science, Engineering, and Medicine. In contrast, our care was held up by red tape, lack of knowledge, and scarce resources. Our team did what they could, and we are grateful, but there was so much we missed out on because of our zip code. **Consistency of care cannot happen without proper funding and support. Veterans and their families deserve uniformly high quality care through the VA.**

Additionally, that same National Academies report that praised the care provided by the VA should also serve as a wake up call. **We need to fund research that will give us answers to what is causing our military Veterans to be diagnosed at higher rates and what we can do to prevent and possibly even cure this disease.**

When you are diagnosed with ALS you quickly learn that the treatment options are few, and the options that are there might only buy you a few months. Many times the focus shifts to finding ways to remain engaged in life. Veterans are fortunate that the VA provides many of the tools they need to do this. Eye gaze computers, home modifications, wheelchairs, and accessible vans are just a few of the ways the VA helps our Veterans continue to have the best quality of life possible with ALS. VA providers go above and beyond to help Veterans living with ALS find ways to do things they love and are a critical part of caring for our Veterans. Not just for their physical health, but for their mental and emotional well being. Veterans already carry a higher risk of suicidal ideation, but a Veteran that was diagnosed with ALS's risk of suicidal ideation is almost 4 times higher. Staying engaged in the world has a big impact on the mental health of a Veteran facing a terminal diagnosis like ALS. I have seen the impact first hand. My dear friend and Veteran living with ALS, Dr. Mary Porter was feeling the weight of her diagnosis. Life was difficult and she was bracing for the inevitable until she was encouraged to try her hand at art, which lifted her spirits and she decided to see what else she could do. Fast forward to February of this year when she not only participated in the Invictus games, but she earned a gold medal. She is still active, finding new adaptive sports to try, and encouraging other Veterans to do the same. **Protecting the services provided to our Veterans can and will save lives.** We strongly suggest exemptions from hiring caps for positions funded by congressional mandated programs through special funds.

I'd like to leave you with the words of Brigadier General Thomas Mikolajcik from his congressional testimony on ALS in 2007. "If these soldiers were dying on the field rather than at home as a result of their service, we would leave no stone unturned. We would use the best existing resources and programs to make sure they had whatever they needed to survive, to ensure that no man or woman is left behind."

Thank you.

Resources:

1. Article: Veteran Trust Increased <https://news.va.gov/press-room/veteran-trust-va-increased-25-since-2016-high/>
2. VHA Directive 1101.07 <https://share.google/7Sgs7AeBt5XBJC3NM>
3. VA ALS Handbook https://www.va.gov/HEALTH/docs/Amyotrophic_Lateral_Sclerosis_Veteran_Handbook-Veterans_Health_Administration.pdf
4. National Academies of Sciences, Engineering, and Medicine <https://www.nationalacademies.org/our-work/amyotrophic-lateral-sclerosis-accelerating-treatments-and-improving-quality-of-life>
5. Article: Suicidal Ideation <https://pubmed.ncbi.nlm.nih.gov/33470429/>