

**STRENGTHENING SERVICES FOR VETERANS
WITH SPINAL CORD INJURY AND DISORDER**

HEARING
BEFORE THE
COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES SENATE
ONE HUNDRED NINETEENTH CONGRESS
FIRST SESSION

SEPTEMBER 17, 2025

Printed for the use of the Committee on Veterans' Affairs



Available via the World Wide Web: <http://www.govinfo.gov>

U.S. GOVERNMENT PUBLISHING OFFICE

61–681 PDF

WASHINGTON : 2026

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STRENGTHENING SERVICES FOR VETERANS WITH SPINAL CORD INJURY AND DISORDER

WEDNESDAY, SEPTEMBER 17, 2025

U.S. SENATE,
COMMITTEE ON VETERANS' AFFAIRS,
Washington, DC.

The Committee met, pursuant to notice, at 4 p.m., in Room SD-106, Dirksen Senate Office Building, Hon. Jerry Moran, Chairman of the Committee, presiding.

Present: Senators Moran, Cassidy, Tillis, Blumenthal, Hassan, King, and Duckworth.

OPENING STATEMENT OF HON. JERRY MORAN, CHAIRMAN, U.S. SENATOR FROM KANSAS

Chairman MORAN. Good afternoon. I need to end the silence in this room. We should be warm and welcoming, and we are glad you are here. I want to extend a particular welcome to all of our witnesses. Your presence and testimony are valuable as we work to fulfill our Nation's promise to care for those who served.

Veterans, particularly those with spinal cord injuries and disorders, are a testament to courage and resilience. The challenges they face are immense and often lifelong. For many, a new and different journey begins the moment they return home or receive their life-changing diagnosis, one marked by physical and emotional hurdles that require specialized care, innovative technology, and a dedicated support system. The VA's Spinal Cord Injury and Disorder System of Care is a critical lifeline for these veterans, making certain they receive quality care when needed.

During this hearing, we will examine the current state of the VA's SCI/D System of Care, identify where the VA is succeeding, and pinpoint areas where the VA should do better. We must make certain that the access to care and benefits is timely and efficient, that the VA is at the forefront of medical research and technology, and that veterans and their caregivers have the necessary resources and support they deserve.

I look forward to hearing from our witnesses this morning—I guess it is this afternoon—which include Shelly Hoover, a Navy veteran who has been living with ALS since 2013, and who will testify today using a speech generation device with eye-gaze technology.

Mandi Bailey, an ALS advocate who lost her Army veteran stepfather to ALS, and has since dedicated her efforts to supporting veterans with ALS and their caregivers.

Mary Ward, a spouse and caregiver to her Marine Corps veteran husband, who has been living with ALS for 15 years.

And Robert Thomas, an Army veteran and the National President of Paralyzed Veterans of America, which is the only veteran service organization dedicated to the veteran SCI/D community.

These witnesses will provide firsthand accounts of the needs and challenges of living with spinal cord injuries and disorders and how the VA and this Committee can best support these veterans and their families. I thank you all for being here, for your service to our country, and for their continued advocacy on behalf of others.

With that, I yield to the Ranking Member, Senator Blumenthal, for his opening remarks.

**OPENING STATEMENT OF HON. RICHARD BLUMENTHAL,
RANKING MEMBER, U.S. SENATOR FROM CONNECTICUT**

Senator BLUMENTHAL. I join Senator Moran in thanking you for being here. I know that as caregivers and veterans of very deep and immediate experience with spinal cord injuries and disorders, the challenge of being here is probably even more difficult than for many of our other witnesses. And so, your being here has special meaning.

I am glad we are focusing on a part of the veteran population that relies, probably more than any other group, on the VA. And that is a testament to the quality of the care that the VA provides. The employees who provide this kind of care are unmatched in the private sector, making these services extremely valuable but also vulnerable to the type of cuts and cancellations that we are seeing throughout the VA.

And, as VA continues to bleed employees due to this Secretary's harmful policies, the services provided to people who are directly involved in SCI/D are particularly at risk. So, I think today's hearing is very, very timely and important. Veterans who receive these services from VA cannot easily transfer their care to community providers, where facilities are often inaccessible and providers rarely receive specialized SCI/D training. And the training is not a luxury; it is essential. It is dealing with severe, life-threatening complications that can arise from seeing a provider who is not sufficiently trained. And I am very disturbed at how Secretary Collins has failed to provide any credible assurances that he will fight to preserve access to SCI/D care at the VA, which, even before these cuts, needed bolstering and expanding.

The Administration has left many veterans with SCI/D and their loved ones in limbo by failing to publish a rule to extend eligibility for participants in the Caregivers Program. And I think that is an immediate need that needs to be addressed. He has been slow-rolling implementation of the Elizabeth Dole Act, which would improve access to long-term care services for veterans with SCI/D. He is delaying implementation of critical funding increases for organizations that serve veterans experiencing homelessness. Congress intended these funds to help providers to keep their doors open and continue supporting veterans.

On both of these provisions, we have been given a lot of assurances that immediate implementation was not only possible, but also a priority for the VA. We are here, months later, with no con-

crete implementation timeline for either authority. I wish we could be using today's hearing to discuss expanding SCI/D care at the Department of Veterans Affairs rather than just fighting to keep the status quo and asking the VA to implement laws Congress has already passed. We approved those laws. We worked hard on them. And the VA is failing to implement them because of the leadership, not because the dedicated, hardworking VA workforce has any reluctance to do so. They want to serve.

So, I thank the Chairman for having this hearing and I look forward to hearing from you.

Chairman MORAN. Senator Blumenthal, thank you. Ms. Hoover, you are now recognized for your testimony. Thank you. Thank you for joining us, and thank you for communicating with us.

PANEL I

STATEMENT OF SHELLY HOOVER, EDD, NAVY VETERAN

Ms. HOOVER. Chairman Moran, Ranking Member Blumenthal, and distinguished Members of the Senate Committee, thank you for the opportunity to appear before you today. My name is Dr. Shelly Hoover, and I am a veteran of the United States Navy. For 12 years, I have been part of the Spinal Cord Injury and Disorder System of Care, and I stand here today as a testament to the life-saving care provided by the Veterans Health Administration. This testimony is the culmination of a decade spent advocating for the more than 4,000 veterans currently living with ALS.

My journey with ALS began in 2013. Initially, the VA's support felt focused on end-of-life care, a system designed to manage my death rather than empower my life. But I had a different plan. I proactively sought out an ALS multi-disciplinary clinic and worked to redefine my path. That experience drove me to seek a seat at the table with the VA ALS Executive Committee, ALSEC.

Working alongside a team of fellow advocates, we built a relationship of trust with the ALSEC. We urged them to make the ALS System of Care more user-friendly for veterans and their caregivers, and they listened. Under the visionary leadership of Drs. Ileana Howard and Sharyl Martini, the committee achieved significant improvements without any additional compensation for their work.

Their dedication led to the creation of a network of ALS Coordinators, including nearly all of the 170 VA medical centers; a comprehensive website to help veterans and caregivers navigate their care; and an internal training program for new coordinators and other departments.

This model, which integrates feedback from those with "boots on the ground" experience, demonstrates the power of collaboration and mutual trust. It is a gold standard for enhancing the veteran experience and improving morale for VA employees who care so deeply for those they serve.

Based on my lived experience, I offer two recommendations for continued improvement and future success:

Recommendation 1: Empower Stakeholders. All departments and workgroups within the Spinal Cord Injury and Disorder system must develop trusting relationships with both internal and external stakeholders. As the ALSEC has demonstrated, this approach enhances employee morale, empowers stakeholders, and, most importantly, improves the quality of care and the overall experience for veterans.

Recommendation 2: Ensure Full Funding. Congress must ensure the Veterans Health Administration is fully funded. In addition to budget cuts, congressionally allocated funds for special diagnoses, like ALS, cannot be spent due to VA-imposed hiring freezes and caps. Can that be corrected?

These funding shortfalls have had a direct and devastating impact on my health and safety. I recently experienced severe complications after a VA pharmacy, due to budget cuts, was unable to provide the liquid form of a prescribed chemotherapy drug. I suffered severe burns across my chest and pelvic region, an extreme and avoidable outcome. Delays are now a constant risk. For example, my replacement mic-key button, used for feeding and medications, is over a month late. How long before my current one breaks down and my stoma becomes infected?

Life-sustaining breathing and nutrition supplies that were once readily available now face delays of weeks or even months. For a person with my condition, this is not just an inconvenience, it is a grave threat. I will not die from ALS. I will likely die from infection, a risk dramatically increased by these supply delays.

Some may suggest that private Community Care is the solution, noting its budget was recently doubled. However, with one exception, my personal experience has been a disaster. I have endured 6-month delays and lost referrals, forcing my husband to spend countless hours on the phone. In one instance, a private medical office initially refused to treat me due to my tracheostomy, a clear violation of my rights.

By contrast, I have never experienced a delay or faced discrimination from the Durham VA Medical Center. It is clear to me that the VA is the best choice for veterans.

My family's legacy is deeply tied to military service, with eight of my immediate family members having served in the Army, Navy, and Marines. I am profoundly grateful for the exceptional care the VA provides, and my grandchildren are thankful that I am still here because of it.

To continue this gold standard of care, the Spinal Cord Injury and Disorder system must actively seek input from external stakeholders. And, above all, Congress must fully fund the VA to protect the health and lives of current and future veterans. Thank you.

[The prepared statement of Ms. Hoover appears on pages 37–38 of the Appendix.]

Chairman MORAN. Thank you. Thank you very much for your testimony and your service.

I now recognize Ms. Bailey.

**STATEMENT OF MANDI BAILEY,
VETERAN ALS ACTION COMMITTEE**

Ms. BAILEY. 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 that have been impacted by ALS.

ALS is a 100 percent 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 under-resourced and understaffed, 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 we received inside the walls of our local VA Medical Center was far superior to the community care we received.

I soon learned that we are not alone in that opinion. In 2024, a survey was conducted by the VA's Veteran Experience Office, and 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 the respect they deserve as U.S. veterans.

But it was not always this way. The VA has worked very hard to improve the care that they provide, and the ALS System of Care, much of the progress has come from allowing the stakeholders, like myself, to give feedback and being open to the input and ideas from the community. Dr. Ileana Howard, Director of Neurology for ALS, has done a tremendous job of listening, and has made considerable improvements by doing so. She has brought the voice of the veteran to the table, and it has made an immeasurable difference.

While it is important to recognize how far the VA has come in its care for veterans, we know that there is still room for growth. In 2021, the VA issued a 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 VA 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 at the Richard Roudebush VA in Indianapolis during his ALS journey. Their team was proactive, knowledgeable, and responsive to their needs. The care that 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 care throughout 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 as to what is causing our military veterans to be diagnosed at higher rates, and what we can do to prevent and possibly 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, and wheelchairs are just a few of the ways that the VA helps our veterans continue to have the best quality of life.

VA providers go above and beyond to help our 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, their risk goes up almost four times.

Staying engaged in the world has a big impact on the mental health of a veteran. I have seen the impact firsthand. 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. That 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. Now 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 these positions funded by congressionally mandated programs.

I would 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.

[The prepared statement of Ms. Bailey appears on pages 39–40 of the Appendix.]

Chairman MORAN. Thank you, Ms. Bailey.

And now, Ms. Ward, you are recognized for your testimony.

**STATEMENT OF MARY WARD, VETERAN SPOUSE/CAREGIVER
AND FELLOW, ELIZABETH DOLE FOUNDATION**

Ms. WARD. Thank you for inviting me to testify today. My name is Mary Ward, and I am the wife and full-time caregiver for my husband, Tom—

Chairman MORAN. Pull the microphone closer to you. Thank you.

Ms. WARD. I am the wife and full-time caregiver for my husband, Tom, a Marine Corps veteran diagnosed with service-connected

ALS over 15 years ago. I am also a 2016 Elizabeth Dole Foundation Fellow.

I would like you to pause and think of a simple pleasure you enjoy. For me, it has long been a Starbucks Vanilla Bean Frappuccino—three pumps of vanilla, fat-free milk, and whipped cream. For years, I thought the joy was in the ritual. But this past July, I realized I had redefined what it means to me. Now, it comes when I drink that Frappuccino, knowing there is a nurse at home with my veteran husband, ensuring he is safe and supported. In that moment, I am not a caregiver. I am me, doing something normal. That is the gift of respite. And it only took us eight years to get there.

To understand the importance of long-term care support, it helps to know our journey. In 2010, Tom was diagnosed with ALS, and in 2013, with Type 2 diabetes. He is rated 100 percent permanently and totally disabled. A typical day includes helping him from his bed to his wheelchair, checking his blood glucose frequently, responding to alarms, getting him showered and dressed, administering medications, assisting him with eating, and doing cough assist to help him clear mucus from his lungs.

Over the years we have experienced numerous struggles and small victories. For example, shortly after his diagnosis, the VA denied the Specially Adaptive Housing (SAH) grant and adaptive vehicle grant because Tom was not yet rated 100 percent. Despite having been diagnosed with a progressive terminal disease, it took two years before a policy change shifted that rating to 100 percent.

During that same period, the VA did give him a power wheelchair, but it stayed in the garage because we didn't have a handicap accessible home or vehicle that could accommodate it. Finally, after the wheelchair was delivered, the VA approved this vehicle grant.

Knowing the destructive nature of ALS, we got busy developing a plan for my future as a widow. In 2010, we moved from Durham to Wilmington to downsize and save money, and I accepted a virtual teaching position. And when I did that I left my State retirement behind. Finally, in 2013, the VA approved Tom for the SAH grant, but that didn't mean our wait was over. From start to finish, it took 27 months to make the house accessible. It is not a process I would want to repeat.

In 2016, we enrolled in the VA's Home-Based Primary Care Program (HBPC). However, because we no longer lived in the catchment area for Durham services, we would only have access through the Wilmington CBOC. If we chose Wilmington, we could no longer directly access the superior ALS care available at the Durham VA. We had to choose. After a series of mishaps due to the situation, including the inability to address a malfunction with Tom's non-invasive ventilator, we made the difficult choice to give up HBPC and move all care to Durham.

After learning about Veteran-Directed Care (VDC), I decided to apply for Tom. VDC is an innovative program that offers the veteran a budget for personal care services and allows more flexibility and control for his or her care. And even though I knew another veteran enrolled in the VDC through the Durham VA, I was re-

peatedly told by a social worker that it simply did not exist there, and I let it go. I didn't have the energy to take on another battle while caring for Tom and dealing with his increasing health complications.

I eventually tried again, but my attempts to access VDC were foiled until last year, when we were enrolled. Unfortunately, this still does not mean we received any services. When I asked for a timeline regarding funding, the response was, "30 days, 60 days, 90 days, I just don't know." With that lack of certainty and seemingly zero sense of urgency, we reluctantly withdrew from the program.

Recently, I realized I couldn't do it alone anymore. His ALS progression was more pronounced, his diabetes grew more complex, and I didn't realize how exhausted I was from the last few years of 24/7 caregiving. Together with the Elizabeth Dole Foundation, we pursued skilled nursing care as a possible alternative. At first I doubted Tom would qualify. He has multiple complex diagnoses, but he is not ventilator-dependent, which seems to be the criteria.

Finally, after the intervention of leadership, the VA approved skilled nursing care. A long time ago, someone asked Tom about me as his caregiver, and he said, "She is my wife first and caregiver second." That had insidiously changed over the last few years. The benefit of respite for me is clear. Because of it, the care I provide Tom is exponentially better. My sense of humor and joy has returned. At the end of the nurse's shift, I look forward to seeing him.

Just last week, one of our nurses discovered Tom's blood pressure was running high, despite medication. This finding likely prevented a crisis.

I share our story because while we have finally found the proper support, it should not have taken eight years, relentless advocacy, and national-level intervention to get here. Too many caregivers give up before they reach this point. They go unseen, unsupported, and burned out. Simply put, veterans suffer when their caregivers suffer.

I hope you will note the recommendations I outlined in my written testimony, especially the need to promote effective, proactive, and comprehensive care coordination.

For those with devastating injuries and illnesses, long-term care support, especially respite, is not a luxury. It is essential—for caregivers, for families, and for the veterans who depend on us.

I am grateful for the nurses who now come into our home, for the Elizabeth Dole Foundation's relentless advocacy, and for the VA staff who have stood by us. But the care we now receive should not be the exception reached only after years of struggle. It should be the standard. For every Frappuccino moment I now enjoy, there are thousands of caregivers still waiting for that moment to take a breath. Please make it possible for them to find joy again, and to see and feel that they matter, too. Their veterans' care, and sometimes their lives, depend on it. Thank you.

[The prepared statement of Ms. Ward appears on pages 41–47 of the Appendix.]

Chairman MORAN. Thank you, Ms. Ward.
And now, Mr. Thomas. Thank you.

STATEMENT OF ROBERT L. THOMAS JR., NATIONAL PRESIDENT AND CHAIRMAN OF THE BOARD, PARALYZED VETERANS OF AMERICA

Mr. THOMAS. Chairman Moran, Ranking Member Blumenthal, and Members of the Committee, I appreciate the opportunity to speak to you today on behalf of Paralyzed Veterans of America about the strengths and weaknesses of the VA care for veterans with Spinal Cord Injuries or Disorders, or SCI/D.

When I testified before the Committee in March, I expressed our frustration with the existing state of the SCI/D system and concerns about its future. We have relayed some of our biggest concerns to Secretary Collins, and he has signaled to us that the VA's specialized services and the care of catastrophically disabled veterans are a priority in this Administration. But they can't do it alone. Your leadership and support are needed to preserve and strengthen the SCI/D System of Care, and all VA care for catastrophically disabled veterans.

PVA firmly believes VA is the best health care provider for disabled veterans, particularly those with catastrophic disabilities. More importantly, our members consistently choose VA.

Recently, a PVA member expressed this sentiment when he relayed that while he has had surgery in the community, the VA doctors he sees at the Dwight D. Eisenhower VA Medical Center in Leavenworth, Kansas, understand the full nature of his trauma, and they provide the tailored support with post-surgery rehab and long-term support that increase his quality of life. Another PVA member in Colorado shared his contrasting experience between VA and community emergency room visits following a severe flare-up of MS. VA published his story, and I strongly encourage you to read it.

PVA has three primary concerns about the ability of VA's SCI/D System of Care to continue serving veterans both now and in the future. These concerns are ongoing staffing vacancies, delayed infrastructure improvements, and the continued shortage of specialty, long-term care beds.

Staffing levels for the SCI/D System of Care are detailed in VHA Directive 1176. The requirements outlined in this directive are based on the level of care needed to maintain the health and well-being of veterans with SCI/D. Unfortunately, VA leaders have long treated these as optional rather than directives based on best care standards. As a result, VA can only staff a nominal number of beds in some locations.

The impact of such practice is profound, causing severe delays in critically needed routine care, including annual exams and respite, as well as acute care needs. Such delays have real consequences for veterans who need care now. The VA must be able to staff to the level needed to serve veterans with SCI/D.

We also need new approaches to recruiting medical professionals in hard-to-recruit locations. Furthermore, the bureaucratic hiring process must be streamlined to allow professionals to be identified and onboarded as quickly as possible.

Secondly, we are concerned about delayed infrastructure improvements. VA's SCI/D System of Care is comprised of 25 acute care centers and 6 long-term care centers, with an average age of

nearly 40 years old. Many of the older centers have only had minor cosmetic renovations. More than a dozen SCI/D-related construction projects on the SCIP list continue to go unfunded year after year.

In reviewing VA infrastructure, decision-makers must remember that VA's SCI/D System of Care is unique, and not replicated outside the VA. We believe VA should return to the practice of placing greater emphasis on funding facilities that support the types of services like SCI/D care, which the Department uniquely provides. Investment in these areas would greatly strengthen VA's specialty care services and ensure their future availability.

Finally, our Nation's lack of adequate long-term care options is an enormous problem for people with catastrophic disabilities. There are very few long-term care facilities that are capable of appropriately serving veterans with SCI/D. With less than 180 beds, VA's six existing SCI/D long-term care facilities are not enough for the tens of thousands of veterans with SCI/D. Expanding projects, provide additional beds would be a good first step to ensuring quality care.

Many PVA members also depend on VA home and community-based services throughout their lives. We are very appreciative of Congress' passage last year of the Senator Elizabeth Dole Act. We need you to exercise your oversight authority to ensure the measure is implemented as Congress intended.

Thank you for the opportunity to present our views this afternoon. I will be happy to answer any questions.

[The prepared statement of Mr. Thomas appears on pages 48–57 of the Appendix.]

Chairman MORAN. Thank you, Mr. Thomas. Let me ask you, just that last sentence you indicated. Is the implementation far enough along, of the Elizabeth Dole Act, that you know of instances where we need to be exercising our oversight authority to get something on the right track that seems to be on the wrong track?

Mr. THOMAS. Thank you. That is a great question. So there are some limitations to the Veteran-Directed Care that come up through the Elizabeth Dole Act that we hear it is implemented all throughout the VA but individual members and all, that try and get on the program, are not able to get on the program because it is not at their VA facility.

Chairman MORAN. That is really important for us to know. The Elizabeth Dole Act, I think, is, again, one of the more and most significant pieces of legislation this Committee has enacted, but implementation is hugely important, and we will continue to work with you and PVA to make certain that that, and other instances, are brought to the VA's attention for correction. Make sense?

Mr. THOMAS. Yes, sir.

Chairman MORAN. Let me ask you, Ms. Ward, caregivers, especially for those with spinal cord injuries or disorders, as you indicated face major physical, emotional, and financial strain. You talked about respite care programs and they fall short. What reforms, changes would you suggest need to be pursued to make certain that caregivers receive adequate support without compromising their own health and well-being?

Ms. WARD. Well, I think that is where I think about the coordination of care. Personally, I am in the PCAFC program, and I access my caregiver support coordinator for respite care, to come here today, to get approval for that. And I only know that I have approval for that, that I could get approval for that, because the Elizabeth Dole Foundation worked with me to get the nursing care that my husband needed.

But I did not know who to ask to get that done, and that is a problem. And I should know. We are 15 years into this disease. I should know. And believe me, I know a lot about the VA and the bureaucracy and the challenges. But there is a point at which I am busy being a caregiver. I am busy trying to keep this guy alive, and I can't do all that.

So I need somebody at the VA who I can say, hey, I need this help. Do you understand what this program is? Can you get Veteran-Directed Care? Can you get long-term care for us? What can we do? How can you help me do the job that I need to do?

Chairman MORAN. You are actively engaged in the Elizabeth Dole Foundation. Tell me what services are offered that others ought to know about, someone in the same position you have been in. Where should they turn for help?

Ms. WARD. Well, if they are not in PCAFC, I do not have an answer for that. I do not know who they would go to. If you are in the Veteran ALS lane—let's call it that—in the VA, there is an ALS Coordinator at many of the VAs, and think Mandi Bailey probably can speak about that a little bit better than me. I do not access the ALS Coordinator because I actually knew more than our ALS Coordinator at first. So I could do her job or still be Tom's caregiver.

Chairman MORAN. Well, let me ask Ms. Bailey that question. I recognize—I think we recognize that the VA—let me just put it this way, many veterans do not know what services they are entitled to, do not know what is available. Obviously, communication is important, but particularly for caregivers. Tell me how you think we can help provide the information necessary to get people to the resources that they need?

Ms. BAILEY. In my opinion, a lot of it is going to come down to funding and support. In our area, we are a very underserved, under-resourced area. So everything that we did pretty much felt like it was sent out to the community care. The ALS Coordinator position is a fairly new thing that has been brought about. I believe that came in with the VHA Directive 1101.07. It was not around when my stepdad was going through ALS. For us it was calling our caseworker. And because of the understaffed nature of the VA where we live, sometimes it was hard to get a call back because she was busy herself, taking care of the many, many, many other families and veterans that she had to contend with.

So honestly, I think a lot of that is going to come down to funding and support. Our VA, last I heard, was 140 percent of capacity. They are wildly, wildly understaffed for what they are dealing with. They do not have the resources and time available while they are in those walls, doing their job, to be able to answer all those phone calls and get people connected with the resources that they need, and do the research to find out where they need to be sent.

So again, funding and support. Our VAs desperately need that funding and support to do their jobs the way that our veterans deserve.

Chairman MORAN. With that, let me call on the Ranking Member.

Senator BLUMENTHAL. Thank you. Again, thank you all for being here and for your excellent testimony. We have heard about community care providers outside the VA presenting accessibility challenges when SCI/D veterans or others who are non-ambulatory, disabled, or have complex health needs, try to get access to those private, non-VA facilities. I wonder if you could talk a little bit, from your experience, what you have seen or heard, Ms. Bailey, and others on the panel.

Ms. BAILEY. We were sent to the community to get our care, first to see a neurologist. At that point, there was not an on-staff neurologist at our local VA. Thank goodness there are now. We have a fantastic neurologist at our local VA. Unfortunately, they were not there for us.

It did take some time to get put into the schedule to see the neurologist, and we were his first people that he had dealt with ALS. When you are dealing with ALS, you want somebody who has knowledge, not somebody who says, "You know, this is the first time I've dealt with that." That was really, really difficult for us. It is scary. It is so scary.

We are grateful that he was willing to learn, but the care that was in the community was nothing like the care that we received at the VA. They at least knew what ALS was, and although it was held up by red tape and all of the limitations that they had, it was still far superior to the care that we received. We even had to go out of our VA when he needed his feeding tube done. We had to go to Biloxi, which is several hours away. That is a really difficult drive when you are taking care of somebody living with ALS who cannot move their arms and legs. You are the only person who is able to do that for them. And then you have to turn around and drive home the same day.

I cannot say that the community care in our area would have been much better. Again, lack of knowledge is a huge, huge problem. They do not understand the complex needs of ALS like the VA providers would.

Senator BLUMENTHAL. Others?

Mr. THOMAS. Yes. In addition to what Ms. Bailey just said, a lot of the community facilities do not have the adequate amount of wheelchair space when you go in there, or the proper equipment to move an individual in a wheelchair over to the exam tables or even give them a good X-ray. So we run into that issue all the time.

Senator BLUMENTHAL. I want to ask about mental health. I have a bill that is called the BRAVE Act, which includes a provision requiring the VA to establish a pilot program to ensure VA residential rehabilitation treatment programs. These are, in effect, inpatient, residential treatment, including for mental health. Maybe you can comment on the need for both inpatient and other kinds of mental health treatment programs.

Ms. BAILEY. As I mentioned in my testimony, when you are diagnosed with ALS, as a veteran, your suicidal ideation risk goes up

tremendously. Mental health, while it is addressed—typically there is a questionnaire or they are asking several questions to kind of assess how you are doing—I think there is a bigger need to address the mental health needs of veterans with spinal cord injury and disorder, especially in ALS. When you are given a terminal diagnosis it changes your entire outlook on the world.

My stepdad wanted to take his life because it became too much for him, and he did not, and I am thankful for that. But I wish that there had been more of a focus on mental health. I wish that he had had somebody like my friend, Dr. Mary Porter had, that would have encouraged him to try new things and to see that he could live with ALS, and you are not dying of ALS. I think that is a really important thing that needs to be addressed in the mental health area for ALS.

Senator BLUMENTHAL. Thank you. Any others? Thank you. Thank you, Mr. Chairman.

Chairman MORAN. Senator Tillis.

**HON. THOM TILLIS,
U.S. SENATOR FROM NORTH CAROLINA**

Senator TILLIS. Thank you, Mr. Chairman. Ms. Ward, welcome to the Committee. You may not know that I am actually sitting in the seat that was occupied by Senator Dole back in the day, and I am very proud of the work that she continues to do in this and so many other areas. So welcome to the Committee.

Before I ask a few questions, first, Dr. Hoover, we are going to be submitting for the record some questions that I would like to get from you, in terms of, sort of the fabric that has to come together to provide a network and supporting people suffering from this horrible disease.

And before I start there though, a couple of weeks ago I was walking down the hallway—I grew up in a family of six kids so I know how to like hear a lot of voices at once. I heard a Capitol Police officer say he was going to have to file an appeal or try to figure out a way to get care himself, not in this space. But I went up to him and asked him, I said, “Have you contacted your Congressman?” He is not from North Carolina. I said, “But look, I want to help you out. But make sure that you are using every available resource before you start spending money.” Which is why in the last Congress, I proposed the Patriot Bill of Rights, which is to make absolutely certain that any veteran knows that before you spend a dime on an attorney or even other support organizations, you put a call in to your U.S. Senator, put a call in to your Congressman.

What I wanted to do, and I have run into a little bit of pushback, mainly from people who benefit from patriots not knowing this, is to make sure before you sign an agreement with somebody who is going to act on your behalf and charge you for that fee, that you know what options are available that are not subject to a charge, like a U.S. Senator who is hell-bent on trying to clear cases, before you have to go anywhere else. That is what I do in North Carolina.

So we are going to reintroduce the Patriot Bill of Rights. It is pretty straightforward. If you are going after Camp Lejeune toxics, or you are trying to help somebody, I want a piece of paper down there that says these options were available to you. If you have not

used them, you may want to, before some of the benefits that you have worked hard for and deserve go to somebody else representing on your behalf.

We cannot close all cases. Some of them have to be adjudicated, and there is an appropriate place. But I do think that there are some organizations out there that hope they get a good outcome for the veteran they are representing, but frankly, they also want a good outcome for their pocketbook.

So in the remaining time I have here, Ms. Ward, spread the word in North Carolina. I have 473 days before I retire, and I am not counting those days because I am counting the days to get out of here, that is how much more time I have to help.

Ms. Bailey, and to everyone, I have a personal story on caregiving. I know how hard it can be. Even that coffee break, your testimony was very compelling. I believe everybody in the VA wants to do the right thing, but we are doing things inconsistently, and we are doing things on an uninformed basis. We do not need somebody providing care to a very specific disease that has very specific protocols for trying to provide the best care. We do not want somebody doing on-the-job training, to your point, Ms. Bailey.

There are good stories to be told, even in North Carolina. But the variation between just facilities within our State, and the variation across the country is unacceptable. I worked in management consulting for my entire career before I got into public service. There is such a thing as best practices. And what I would like you all to think about, from your respective organizations, let's shine some light on best practices that are going on in the VA, and then put pressure, that is oftentimes a resource issue.

But let's put pressure on everybody measuring up to what that best practice looks like, and let's make sure that the Secretary, who I have great confidence in, and everybody in the VA—I mean, people are working hard, but it is all about resource, connections, and setting high expectations and measuring the results.

So I am not going to ask you any questions here in the Committee, but we will be submitting some questions for the record to say how do we do it? How do we find one in every State, if there is a best practice, to say that every VISN should have a best practice model, and if they do not, we need to have one, in this case, and several others.

And count me in, in my remaining time to do everything I can to help. And in the meantime, count me in to make sure that every veteran knows, if they cannot even get a good response from a Congressman or a Senator from their State, we will work with those Senators first. We will do the casework in North Carolina for anybody. Thank you.

Chairman MORAN. Senator Tillis, thank you. You took me by surprise claiming the Dole seat because I thought, no, that is me.

[Laughter.]

Chairman MORAN. Wrong Dole. Senator Hassan.

**HON. MARGARET WOOD HASSAN,
U.S. SENATOR FROM NEW HAMPSHIRE**

Senator HASSAN. Thank you very much, Mr. Chair, and I appreciate you and the Ranking Member having this hearing today. To

our witnesses, thank you so much for testifying before us today and for your service to our country and to our veterans.

Ms. Bailey, I want to start with a question for you. First, my condolences for your family's loss. I did not know your stepfather but I am confident that he would be proud of your advocacy for veterans.

Your testimony touched upon an issue that I think is really important which is, access to high-quality care when you need it and where you need it. And in response to questions from Senator Blumenthal, you mentioned that after your stepfather's ALS diagnosis he had to use community care in addition to the care he received at the VA because of the lack of resources available. And you talked about the impact, you know, the lack of experience of that community care provider.

But this is beyond an individual profile of a particular condition or disease. My concern, because I am from New Hampshire, which does not have a full-service VA hospital, and also has a very high rural population of veterans who live far away from the nearest VA facility. Can you just expand on how veterans are affected when they cannot get all of the care that they need through a VA that is practically accessible to them?

Ms. BAILEY. There are a lot of things that can happen. First and foremost, I think there is kind of a mental aspect to it. At the VA, it is a culture. Our veterans like being at the VA. They prefer it, because those people understand them. Many of the VA providers and employees are veterans themselves, and there is a unique bond that veterans have and that trust that they have. So I think that is a big thing right there to look at.

You know, the lack of knowledge in these conditions like ALS, that is very, very important to address. And I think that having that in our family, and being sent to the community to get the care, it was frustrating. Our family questioned, should we even go back to this doctor? And that is dangerous when you are dealing with ALS. There are a lot of things that you need to consider—feeding tubes, breathing options, PT, OT, respiratory care. You need to make sure you are taking all of those things into account. And if you are sent to a community care physician or provider that does not really understand your condition, you are not as likely to go back and continue that care. And you have a problem with, well, is this going to go downhill a lot faster? What is this going to do?

So I think that making sure, even at those VAs that are not a full service, they are knowledgeable enough in the community to know—where should I send these people that know about ALS, that are going to treat my veterans the way they deserve to be treated; that are going to treat them like I would? So that is something to really kind of think about when we are using the community care.

It is an option, and I do think that it should stay an option. But I do not think it should be our go-to option for our veterans.

Senator HASSAN. I appreciate that very much. And a quick personal aside, my son has a feeding tube, and it was a neurologist who treats a whole lot of children with feeding tubes who figured out how we could get encapsulated medication into the feeding tube without clogging it. She also happened to be a mother, and I hap-

pened to think that that played something into it. But it really does make a huge difference.

Mrs. Ward, in your written testimony you discussed the need to fully implement provisions of the Dole Act, which President Biden signed into law at the start of this year. And I share your concern about the delayed implementation of the bill.

Senator Moran asked you about oversight, but as someone who has such personal knowledge about the challenges that veterans and caregivers face, can you please tell us a little more about how full implementation of the Dole Act would support caregivers and how its continued delay might affect you, your family, and our other veterans?

Ms. WARD. Yes. Thank you for the question. I think that the full implementation of the Dole Act would eliminate the sense that all these beautiful programs that we have at the VA, they are so siloed—

Senator HASSAN. Right.

Ms. WARD [continuing]. Is what it feels like. Like, how can I get home-based primary care, because I live in an area where I am too far from the main Durham VA. But why can't Fayetteville, which is where the Wilmington CBOC falls under, why can't they communicate well with Durham? Why can't I have that? Why is it so hard to get Veteran-Directed Care? I remember we did get it. We finally got it. But then we got skilled care, and we are not going to use services we do not actually need right now, just because we can get them. So nursing care really fits for our situation.

But then what about palliative care? How do we get that? Does my PCAFC Coordinator know about how to get palliative care? What about hospice, and how can we set it up so that this man, that I love so much, can stay at home for the rest of his life? And it should not take so much work.

And my sense of working with some of the people at the VA, they want to do the right thing. We have had pretty much a good experience with everybody that we have worked with the VA. But they do not know this program from that program. And my understanding of the Dole bill is that that is not there anymore. Those barriers are not there. There are so many barriers, that somebody like me, who is well educated and experienced with the VA, I sometimes cannot get access to these programs. And it is so tiring to fight them. I just want to go drink a Frappuccino somewhere.

Senator HASSAN. Yes, yes, yes. I hear you.

Ms. WARD. I am not even asking for a lot. I am not asking to go to Hawaii or Italy or something. I just want to have a little bit of peace, and I want to be able to take care of him at home. And whether my veteran has ALS or another spinal cord injury or traumatic brain injury, it does not matter. We all should be able to access this care so that we can keep doing what we do. It should not be siloed like it feels like.

Senator HASSAN. I appreciate that. I appreciate your indulgence, Mr. Chair, with the time. Mr. Thomas, I will submit a question for the record for you. Again, I appreciate all of you very much being here. We really value your care, your service, and your expertise. Thank you.

Chairman MORAN. Thank you. Senator King.

**HON. ANGUS S. KING, JR.,
U.S. SENATOR FROM MAINE**

Senator KING. Thank you, Mr. Chairman. Before I ask my questions I have to acknowledge that in the last five years I have lost two of my best friends to ALS. One was one of my oldest friends from high school football, and one was one of my very best friends in Maine, George Smith, who battled this disease, this awful disease, with such courage. And I can't not acknowledge these two guys that played such an important role in my life.

Ms. BAILEY, you said something, you just touched on it briefly, that I find very potentially important, and that is that veterans seem to contract ALS at something like twice the level of the population at large. And I will ask this of our second panel. Are there any theories on that? Because I have always viewed ALS as almost like being struck by lightning. But that suggests that there may be environmental causes that contribute to the contraction of this disease. Are there theories on this?

Ms. BAILEY. There are theories, anything from traumatic head injury, environmental exposures when they are overseas. There are a lot of different theories, but there is nothing concrete, which is why we need to support research that is going to dig into this a little bit deeper. There have been even studies that show some specific occupations inside the military are up to 10 times as likely to be diagnosed, and that is terrifying.

My husband served in the Army. My nephew just joined the Army. I want to make sure that, God forbid, if something happens to them that they are able to get the best care possible. And the research that can come from learning more about the veteran impact, it can go a long way in the civilian population, too.

Senator KING. I agree. Mr. Chairman, I think that is some research that we should really encourage. The VA is the likely place to conduct that research.

Ms. BAILEY. Absolutely.

Senator KING. Mr. Thomas, accessibility to long-term care. You touched on this in your testimony. My understanding is that this is one of the greatest problems facing our veteran community. Is that true?

Mr. THOMAS. Yes, it is.

Senator KING. And you mentioned a number. You said thousands. Do you have any idea how many SCI/D patients, veterans there are, in round numbers?

Mr. THOMAS. Well, Senator, I will have to get back to you with the exact number. But I would say it is more around 60,000.

Senator KING. But it is safe to say that it grossly exceeds the availability of resources, particularly for long-term care. Is that correct?

Mr. THOMAS. Yes.

Senator KING. We have talked a bit about the Elizabeth Dole Act, and I think I will join my colleagues and ask for you to give us your thoughts, perhaps in writing after this hearing, on how it is being implemented and not being implemented, and where the gaps are. Because one of our roles here—often in our business we pass the law and it is sort of, okay, we have done our thing. But

I do not believe that. I think part of our responsibility is to oversee the implementation and execution of these laws.

So it would be very helpful to us to sort of survey your colleagues, your contacts, your circle of friends in the community to tell us how this law is working and how we can improve it, and what we must do to improve it.

The other thing that bothers me, Mr. Thomas, you mentioned onboarding, and unfortunately at the VA now there is a hiring freeze. And there is hiring going on in certain areas, but the VA, as of the end of this month, I think, is going to be 30,000 people less than it was at the beginning of this year.

Do any of you see the staffing reductions as affecting the level of care and the responsiveness of the various VA facilities with which you engage? Mr. Thomas?

Mr. THOMAS. There has been a lot of lack of staffing on the SCI/D centers, you know, for a while, but we do see that the quality of care is still trying to be maintained. But we do need those nurses. We do need that team effect to make sure that our members get the quality care that they need.

Senator KING. And I think one of you mentioned burnout. I mean, we have got to maintain the good quality people that we have and not burn them out because of understaffing. Would you agree?

Mr. THOMAS. I would agree.

Senator KING. And finally, Dr. Hoover, I want to commend you for being here and providing your very compelling testimony. And we will look forward to your response to some of the questions after the hearing.

Thank you all. This has been very powerful testimony. And again, we cannot fix problems we do not know about. So the invitation is for you to tell us what needs fixing, whether it is administrative or whether it is a matter of the law. Take advantage of the fact that you have a group of U.S. Senators here who are totally committed to this issue and its amelioration and mitigation.

So thank you all for your testimony. Thank you, Mr. Chairman.

Chairman MORAN. Senator King, thanks for that summary. And I recognize now Senator Duckworth.

**HON. TAMMY DUCKWORTH,
U.S. SENATOR FROM ILLINOIS**

Senator DUCKWORTH. Thank you, Mr. Chairman, and thank you to all the witnesses who are here today. As you know, Mr. Chairman, this Committee has earned a longstanding reputation for prioritizing pragmatic bipartisanship. In my view, it is a commitment that all committees should strive to achieve.

Preserving the bipartisan nature of our work is especially critical amid this Administration's attacks on America's cities, and while Immigration and Customs Enforcement is actively stealing U.S. Department of Defense and U.S. Department of Veterans Affairs resources away from their core mission to support its invasion of Chicago.

Specifically, at Hines VA Hospital, my VA home where I get my care, it already suffers from limited parking that is inadequate for the level of patient demand. I think any veteran that goes to a VA

hospital shares the frustration across the country of the inadequate parking.

ICE has taken over 12 parking spots for operations at Hines VA, that have nothing to do with providing veterans with care, and this is causing anxiety and confusion among staff and patients. Diverting VA resources for ICE's reckless paramilitary immigration enforcement operations, not only does nothing to enhance veteran care, but it likely will harm care delivery.

Veterans should be able to safely access their health care services without fear of intimidation, harassment, or even detainment, and it is absurd to believe that allowing ICE to operate in any capacity on any VA campus will not adversely impact delivery of care for their patients. This is especially true at Hines.

The VA must establish a clear, strong policy against capitulation to ICE. Veterans and their family members that receive care at VA medical facilities across the country need to be protected. Otherwise, I am deeply concerned that patients will delay or cancel their appointments due to well-documented risks that they will be aggressively accosted by an out-of-control, secretive paramilitary force, and whisked away in unmarked vans, solely because of the color of their skin, what they look like, race, or the language that they speak.

If VA fails to stop ICE's theft of its resources, the Department will validate the veteran community's worst suspicions about the Trump administration, namely that President Trump is sabotaging VA's ability to carry out its mission and actively working to manufacture crisis that would justify privatization of the VA.

Earlier this year, VA cut 80,000 jobs, including doctors and nurses. A recent *ProPublica* article reported on the consequences of this massive disruption, noting, and I quote, "the VA this year is down more than 600 doctors and about 1,900 nurses. The number of doctors on staff has declined each month since President Donald Trump took office. The agency also lost twice as many nurses as it hired, between January and June."

The VA said it is working to address this, including by referring veterans to private providers and telehealth appointments. Meanwhile, waiting times for new patients seeking primary and specialized care are increasing, and I am gravely concerned that the Trump administration's dismantling of VA's capabilities and capacity is intended to create chaos that will achieve two of their main goals. First, they want to accelerate VA dependence on private sector providers, and second, they want to degrade VA's quality of care to justify privatizing our Nation's largest integrated health care system.

Dating back to President Trump's first term, we know he is surrounded by wealthy donors who would love nothing more than to dismantle VA and force all veterans, particularly veterans who need specialized care, into the often more expensive, yet less effective private sector health care system. After all, VA providers are trained so they can address the unique needs of veterans, and this is just not true for most non-VA providers. A non-VA provider may look at a veteran and see that they have prostate cancer, but not check them for ischemic heart disease or Leukemia B, two other conditions that are tied to Agent Orange exposure, for example.

Instead of siphoning resources away from the VA to a civilian health system that is already under duress, due to the Republicans' biggest Medicaid cut in history, we should be investing in VA civil servants while upgrading facilities and technologies to strengthen VA delivery of care.

To all of the panelists, what specific steps should the VA take to ensure there are enough providers and accessible facilities for treating veterans with SCI/D in a timely manner and with the dignity and respect that they deserve? Would any of you like to answer that? Do you have any steps that you think the VA should be taking to support spinal cord injury patients, also through providing providers as well as access to facilities?

Ms. BAILEY. Shelly and I mentioned in our testimonies stop any hiring freezes or hiring caps, support and fund additional positions. Those, I think, are going to be the biggest steps you can make. It is hard to serve our veterans with their hands tied behind their backs right now, and it feels like that is what a lot of them are doing.

Senator DUCKWORTH. Thank you. Thank you, Mr. Chairman.

Chairman MORAN. Senator Duckworth, thank you. I do not anticipate having a second round, but having said that I would like to ask a couple of questions myself, unless there is concern about being left out, anybody else? I just want to capitalize on just a couple of things.

First of all, community care. Is there ALS and these circumstances in which it makes sense, in your minds, to refer to a program, a hospital, a set of physicians that have expertise in this area, and it makes sense for the VA to allow for referral to that community care? Ms. Ward?

Ms. WARD. Yes, I would like to speak to that. We have an excellent ALS Center at the Duke, the Duke Center for ALS Care Clinic, a clinic experience for somebody with ALS. They fortunately do have clinic rooms that are large enough to support not just somebody who is in a wheelchair but family members that come along with them. And they stay in that room for hours. Every specialty comes to see them—respiratory care, pulmonary, social workers come through, the ALS Association will come through, your neurologist comes through. It is an exhausting experience. It is a great experience, though, because you get soup to nuts there.

But to try to get a community care referral, you have to get one for each specialty that is there, right. That is hard work, to get a community care specialty, for all to come together, so that you have a referral for every specialty care health care provider that comes to that room.

For us personally, we use Medicare, because it is easier. I mean, you know, is it the right thing to do? Probably not. We probably really should go through the VA to make that happen. But it is hard to do, though, too. I mean, I personally do not want to go through all that.

Chairman MORAN. I appreciate knowing that, and it seems to me that that is not a damning thing about referral to community care. It is a damning thing about the way we refer it to community care.

Ms. WARD. Yes.

Chairman MORAN. If we could get the referral fixed, that would be an improvement, and you would have, in this instance, the level of expertise, a combination of all the services in one location, that might make sense for a particular veteran or a veteran's family member. Because the standard in community care is what is in the best interest of the veteran, to be determined by the veteran and his or her provider. And in some instances there may be a program, as I say, a facility, a set of doctors, a continuum of care, that might make sense. And I want to make sure that is the case, in the best interest, that that is a possibility.

Mr. Thomas, let me conclude my questions with just a follow-up to something that has been said in response to my colleagues' questions. The issue of the ACCESS Act, one of the things that occurred, and the PVA supports the ACCESS Act, but one of the reasons that is true is because we addressed the concerns regarding the VA's referrals to community providers who are ill-equipped. We heard testimony today about maybe—not maybe—we heard testimony about this being a new thing, to a neurologist not treating an ALS patient. And the PVA advocated for provisions in the ACCESS Act to address this issue of referral to people who are ill-equipped to handle a referral. Is that true, and do you have anything to say about that?

Mr. THOMAS. So I would say that is true. And, you know, it is hard, when you get a referral and brought there into the community, as was stated, that individuals need to be able to choose who they want to choose, and we understand that and we are on board and agree with that.

But we need to be referred to doctors that truly understand the aspect of what SCI/D entails on the body. And a lot of times when we are referred out there to the community, they do not understand that. So that is why most of our members choose the VA.

Chairman MORAN. That makes sense to me, but I do want to highlight, at least it is my understanding the ACCESS Act includes language that veteran organizations, and I think including the PVA, encouraged be included in the ACCESS Act that deals with the concerns about referrals to someone who should not be referred to because it is a new experience for them, it is a new field for them—same field, I guess, a different kind of patient and a different kind of circumstance. And we want to make sure that the referral is actually to a provider that provides the expertise and experience that is actually helpful to the veteran. So we will continue to work on that, but I think that is part of our efforts in this ACCESS Act, to improve that circumstance.

Thank you all very much. Senator King summed it up very well. Thank you for being such advocates. Thank you, I recognize that in instances here it is very difficult for you to be away, difficult to be here, and we are grateful that you take the time. It demonstrates that you care about your loved ones, you care about people you do not even know because you want the system to work, you want the VA to work, and the process to care for those who served our country, and we are all grateful for that, and I thank you for your presence.

We are going to call up the second panel in just a moment. Thank you all for being here.

[Recess.]

Chairman MORAN. Let me call to the table the second panel. Testifying today, this afternoon, and almost this evening, on the second panel is Dr. Erica Scavella, and she is the Assistant Under Secretary for Health for Clinical Services at the U.S. Department of Veterans Affairs. I am going to use my prerogative and ask you to introduce who you are accompanied by.

Dr. SCAVELLA. Thank you—

Chairman MORAN. —If you would do that. Thank you, Doctor.

Dr. SCAVELLA. Yes, sir. Thank you so much.

PANEL II

STATEMENT OF ERICA SCAVELLA, MD, FACP, FACHE, ASSISTANT UNDER SECRETARY FOR HEALTH FOR CLINICAL SERVICE, U.S. DEPARTMENT OF VETERANS AFFAIRS ACCOMPANIED BY MANOSHA WICKREMASINGHE, MD, EXECUTIVE DIRECTOR, VA'S SPINAL CORD INJURIES AND DISORDERS (SCI/D) SYSTEM OF CARE

Dr. SCAVELLA. Good afternoon, Chairman Moran, Ranking Member Blumenthal, and Members of the Committee. Thank you for the opportunity to testify today. Joining me today is Dr. Manosha Wickremasinghe. She is the Executive Director of VA's Spinal Cord Injuries and Disorders System of Care. Together, our mission is to address, not just the immediate needs, but also the long-term challenges and opportunities facing the veteran community affected by spinal cord injuries and disorders, also known as SCI/D.

As we recognize the unique and evolving needs of veterans living with SCI/D, our response continues to center on specialized comprehensive care. These complex conditions require individualized approaches, and our commitment is to leverage the full depth of VA resources and compassionate expertise to optimize the quality of life for all veterans.

VA's SCI/D System of Care is the Nation's largest, most comprehensive integrated health care system dedicated to treating individuals with spinal cord injuries and disorders. Our Hub and Spoke System enhances health, well-being, functionality, and quality of life for over 24,000 veterans.

The veteran is central to all that we do and we strive to provide care that considers the whole person. We work as interdisciplinary teams to provide acute rehabilitation, specialized medical management, primary and preventive care, respite care, and long-term support. Annual comprehensive evaluations focus on health promotion, complication prevention, and early intervention, addressing the evolving needs related to SCI/D at any age.

To support veterans in their communities, our SCI/D System of Care includes the SCI/D Home Care Program. Members of interdisciplinary teams are available to support the transition and health care needs of veterans with SCI/D in the home or community. In addition to the SCI/D Home Care Program, the VA SCI/D System of Care leverages home- and community-based services such as Skilled Home Health Care, Homemaker/Home Health Aide,

and/or Veteran-Directed Care to ensure eligible veterans receive care comfortably within their home or the community.

Recent legislative progress has enabled VA to expand support for veterans facing complex medical conditions. For example, Section 120 of the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act, raises the maximum per-veteran expenditure cap for home- and community-based services from 65 percent to 100 percent of Community Living Center costs, while allowing exception for diagnoses such as SCI/D. These changes directly translate into expanded options for home-based care and greater financial flexibility.

As the Vietnam-era veteran cohort continues to age, the complexity of their needs increases. In response, VA is working to expand SCI/D long-term care capacity with two funded construction projects in North Texas, which is Dallas, and the VA San Diego Healthcare System. Both have had existing SCI/D acute and sustaining centers. Once completed, this will bring the total number of VA SCI/D long-term care centers to eight. Ensuring the availability of high-quality, long-term care for veterans with SCI/D is a prominent challenge and one that remains central to our resolution, our resource allocation, and planning.

Removing barriers for veterans with SCI/D requires ongoing investments in adaptive equipment and technology. In fiscal year 2024, VA processed more than 5,000 claims for vehicle conversions, hand controls, and entry/exit ramps, empowering safe and independent mobility for eligible veterans with service-connected disabilities.

Additionally, VA's SCI/D System of Care and Office of Advanced Manufacturing have partnered to ensure veterans have access to cutting-edge manufacturing technologies such as 3D printing, in health care. These technologies allow for the faster innovation and improved access to personalized health care solutions for veterans.

VA's SCI/D System of Care maintains a strong tradition of continuous quality improvement and performance measurement. Recent initiatives have modernized outcome measurement and reporting. For example, VA has developed standardized documentation for the Functional Mobility Assessment. This measure allows VA to evaluate veteran satisfaction with wheeled mobility access.

Chairman Moran, Ranking Member Blumenthal, this concludes my testimony. VA's SCI/D System of Care is committed to delivering high-quality care, ensuring veterans receive the care and support they deserve. My colleague and I are prepared to answer your questions.

[The prepared statement of Dr. Scavella appears on pages 58–61 of the Appendix.]

Chairman MORAN. Thank you very much. I am going to call on Senator King to begin the questioning.

Senator KING. Thank you, Mr. Chairman. I appreciate the courtesy. I want to thank both of you for being here. I hope you listened. There was a lot of praise for the VA in the last panel. There were some questions, but I think the consensus was that the veterans that have these SCI/D afflictions prefer the VA treatment system, and I hope you will take that back to your colleagues.

I do want to follow up on the comment that Ms. Bailey made about ALS affecting veterans in a greater proportion than in the general population. I hope that is something that will provoke some serious research. It strikes me that could be a very promising area of research and also, if something is dangerous for our veterans, we should know it. Dr. Scavella, is that something you are planning to pursue?

Dr. SCAVELLA. Yes, thank you for that question. We are aware of the increased propensity of veterans to develop ALS, and that is included in our ongoing research, to determine both presumed and causative agents. We have some suspicions and some thoughts on that, and there is ongoing research into that. But we do know that there is a correlation between having served and developing ALS. That is something that is in the literature, something that our Office of Research and Development is looking at.

Senator KING. I hope that is pursued on an urgent basis. That could have enormous benefits. If we can nail down a possible cause, that would be a huge breakthrough for thousands and thousands of people.

Second question, and I apologize having to leave. I have got an appointment in my office that has already been waiting for me. Last fall, the VA indicated an interest in fall prevention, which, of course, contributes to these kinds of spinal cords injuries as well as traumatic brain injuries. You were going to establish, I heard, a Fall Prevention Program. I have not heard much lately. Is that still in the works? I certainly hope it is.

Dr. SCAVELLA. Thank you for that question, Senator King. Fall Prevention, I have been a clinician with VA since 1999. Fall Prevention has been an ongoing effort. There may be some renewed attention to that. We want to make sure that veterans are not falling both in our facilities and in their homes, so that is something that is ongoing. I would be happy to take that back for the record to get you details on anything that is new.

Senator KING. I would appreciate that. One out of 4 people over 65 suffer a serious fall. It costs the economy \$80 billion a year, two-thirds of which comes from Medicare. So this strikes me as low-hanging fruit in terms of health care costs, let alone the trauma to families and individuals that are afflicted by, as I say, traumatic brain injuries, spinal injuries, and others. So I hope you will take that back, and let's up the emphasis. Thank you.

And Ms. Wickremasinghe—how did I do?

Dr. WICKREMASINGHE. Very well.

Senator KING. Very well.

Chairman MORAN. You are more courageous than I was.

Senator KING. I noticed, Mr. Chairman. I did not want to call attention to that. But you heard the testimony, and please describe the strategy for dealing with these serious injuries, SCI/D afflictions.

Dr. WICKREMASINGHE. Thank you for that question, Senator. As mentioned before, the VA SCI/D System of Care has 25 dedicated SCI/D centers and over 120 spoke sites. These are located within facilities which do not have our SCI/D centers. These spoke sites provide local primary care and SCI/D informed care.

Within our centers, we have large interdisciplinary teams that manage the complex care needs of our veterans, ranging from acute rehabilitation to ongoing care of secondary medical complications. We provide respite care. We have outpatient clinics. We have dedicated SCI/D home care programs, and we have dedicated SCI/D long-term care centers unique to VA.

Senator KING. Thank you very much. And I appreciate the outline and appreciate the work that you are doing, and I hope you were taking notes during the prior testimony. There are places where we can shore up the system.

Thank you very much, Mr. Chairman. I appreciate the courtesy.

Chairman MORAN. You are welcome, Senator King. Dr. Scavella, you heard, to follow up on Senator King's closing comment, you heard the testimony that occurred just moments ago. What is your takeaway? We heard correctly that there is lots of praise and appreciation for the VA and its capabilities of dealing with veterans and their caregivers. But what did you learn that you and the VA should be doing differently or better, and was there something that you want to highlight for this Committee that we ought to be doing to help you accomplish that?

Dr. SCAVELLA. Thank you for that question, Chairman Moran. I will say that we are very proud that we are partnering with each of the folks on your first panel. We worked extensively with Dr. Hoover to improve the care that is being provided for patients with ALS, based upon her direct input. She, in her testimony, did name one of the two physicians that we were able to assign to assist with ensuring that her voice and other voices are known. Mrs. Ward, Ms. Bailey, and Mr. Thomas also talked about the extensive partnership that we have had.

So I am very pleased to hear their testimony today, and we look forward to continuing to work with them to learn about what is not working, what we can improve upon, and anything new that comes up, as health care evolves and innovates and improves.

Chairman MORAN. Well, let me raise a couple of topics then. The Congress, Dr. Scavella, has allocated the full amount of funding that the VA has requested for medical services. Has there been any hindrance in making certain that SCI/D System of Care receives the necessary funding to provide the complex level care needed for these veterans? In other words, the VA asked Congress, in their budget, for this amount of money. We have appropriated this amount of money. The VA has that. Is it getting to the care and treatment programs, the care programs for these veterans that were described today?

Dr. SCAVELLA. Yes, thank you for that question. We are not aware of any challenges. I know that there was a focus in the previous panel about staffing. It has been made clear. We have communicated it that we have an exemption for the caregivers that are providing direct patient care in our system. That includes our clinicians, our nurses, our physicians. That includes our social workers, but it also includes those folks that make sure that the space is clean and safe for veterans to receive care. So in my understanding, we have adequate funding and are able to use those funds appropriately.

When looking at our staffing from September 2025 and comparing it to a year ago, it appears as if we have the same exact number of staff assigned to spinal cord injuries and disorders. Where there may be some differences perhaps with the differences in the categories, and we would be happy to take that back to make sure that we are still meeting the intent.

Chairman MORAN. It has been brought to our attention that, at least in commentary, I would say, is the way that I would describe this, that the VA's Spinal Cord Injury and Disorder system is understaffed, and it is the challenge of hiring and retaining highly skilled providers, particularly in rural areas. I think you just testified that the same amount of staff in this arena within the VA, it is the same as it was a year ago. Are there different challenges depending upon where those programs are located or where the veteran resides and needs care?

Dr. SCAVELLA. Yes, so I will highlight that a bit. We know that there can be some challenges, but with health care in general, not just within VA, for both attracting, recruiting, and retaining the talent that we need to provide this skilled care. We do have a number of modalities, I will let Dr. Wickremasinghe outline, related to how we can address those care needs in a rural setting.

Chairman MORAN. Thank you very much. Doctor?

Dr. WICKREMASINGHE. Thank you very much for the question, Mr. Chairman. You know, we recognize that providing care to our veterans located in rural areas is critical. We rely on transportation and telehealth, in addition to our spoke clinics, which really enhance our outreach. Our spoke clinics are located in areas closest to where our veterans live, many times, and that, in combination with telehealth and transportation, really, you know, are where, for us, the money is, you know, when trying to reach our rural veterans.

So for example, with telehealth, we have the VA Eastern Colorado Health Care System. That has expanded rural health care to VA Black Hills Health Care System. So we have SCI/D specialists who can participate in appointments with veterans who are served at Fort Meade in South Dakota. So this is occurring in many VAs.

In addition, we have telemental health. We have dedicated mental health providers within our interdisciplinary teams within our centers. So we have psychologists specialized in the care of veterans with SCI/D participating through telemental health, to reach our veterans.

A third example would be our tele-wound programs. Our veterans with spinal cord injuries many times have skin conditions resulting in pressure injuries. And instead of having our veterans drive in for follow-up appointments, we are able to use 3D imaging and cameras to see the wounds in real time and have our clinicians monitor progress. Sometimes, it also allows us to bring our veterans into our centers, sooner than later, when we see any changes in wounds.

Chairman MORAN. Thank you. I am going to ask another question and then turn to Senator Blumenthal, and I will continue with you, Doctor. We heard the circumstance described by our first panel about lack of knowledge of programs, where to go, and then the silos within the VA that make continuum of care a challenge,

or the length for the necessary components of care to be coordinated. What would you tell me about that, whether it is a problem, a challenge? How is it being addressed? What would you tell the first panel about that circumstance?

Dr. WICKREMASINGHE. Thank you for that question. I am not able to speak for the ALS System of Care. Within the SCI/D System of Care, however, we provide an interdisciplinary, comprehensive, lifelong continuum, that I mentioned earlier, with our Senator. And I can take that back for the record and get that information to you, through the subject matter experts.

Chairman MORAN. Thank you. What does the VA do to educate and help connect veterans with opportunities to participate in clinical research trials?

Dr. WICKREMASINGHE. VA is a nation's leader in health care research, Senator, and we currently have about 27 VA-funded trials and projects focused on veterans with spinal cord injuries and disorders. We have, for example, the Rehabilitation Research and Development Gordon Mansfield Spinal Cord Consortium, located in California, works with many VAs in the UCLA branches to focus on stem cell research.

We also, for example, in West Haven, Connecticut, we have a Rehabilitation Research and Development Center focused on addressing neuropathic or nerve pain, the chronic pain that affects many veterans with SCI/D, and so on and so forth. I could provide you much more detailed information for the record, as well.

Chairman MORAN. Thank you. Let me turn to Senator Blumenthal.

Senator BLUMENTHAL. Thank you. Thank you both for your service. Let me ask you, how have the cuts in numbers of workforce affected the work that you do? What number have you lost?

Dr. SCAVELLA. Thank you for that question, Ranking Member Blumenthal. I do not actually have the current data on our attrition rates. I can tell you and reassure you that within our direct patient care that there are exemptions in place to make sure that we are not affecting the ability to provide care in our facilities.

Senator BLUMENTHAL. So you have been affected, or not? I am not sure I understand your answer.

Dr. SCAVELLA. I am not aware of any effects related to staffing and the——

Senator BLUMENTHAL. Well, have you lost staff?

Dr. SCAVELLA. I am sure that we have lost staff and gained staff.

Senator BLUMENTHAL. You have lost staff, but you do not know how many?

Dr. SCAVELLA. I do not have that data in front of me to provide you with an accurate number, but we would be happy to take it back for the record.

Senator BLUMENTHAL. Well, do you have an estimate?

Dr. SCAVELLA. I do not have an estimate, sir.

Senator BLUMENTHAL. You have no idea.

Dr. SCAVELLA. I have heard numbers bandied about, but I would rather not give a number that is inaccurate in front of this Committee.

Senator BLUMENTHAL. Well, I have to say, you know, I am disappointed that you do not have at least an estimate, given that you

are responsible for this whole department. Do you have an estimate, Dr. Wickremasinghe?

Dr. WICKREMASINGHE. Thank you for the question. I would have to take that back for the record. I do not have the data on hand.

Senator BLUMENTHAL. How many nurse vacancies in SCI/D are there right now? How many nurse vacancies?

Dr. SCAVELLA. We do not have that data, sir.

Senator BLUMENTHAL. I am stunned. You do not have an answer, how many vacancies there are?

Dr. SCAVELLA. We would be happy to take that back for the record. I do not have that data in front of me. I do not want to give you an inaccurate number.

Senator BLUMENTHAL. How many recreational therapist vacancies are there?

Dr. SCAVELLA. I do not have that data in front of me, sir.

Senator BLUMENTHAL. How many doctor vacancies?

Dr. SCAVELLA. I do not have any data related to whether we are actually above or below the recommended staffing for any of the specialties.

Senator BLUMENTHAL. Are there more vacancies now for nurses—

Dr. SCAVELLA. I do not have—

Senator BLUMENTHAL [continuing]. Than there were in January of this year?

Dr. SCAVELLA. I do not have that data in front of me, sir.

Senator BLUMENTHAL. Let me posit, let me assume that staff are necessary to deliver services. Correct?

Dr. SCAVELLA. Correct.

Senator BLUMENTHAL. So the number of staff would seem to be related to the quality of your service. Correct?

Dr. SCAVELLA. So perhaps I can explain a bit. We have over 400,000 employees in Veterans Administration, the Department of Veterans Affairs. I do not have data on those fluctuations—

Senator BLUMENTHAL. I am talking about dealing with SCI/D. I am not talking about the whole Veterans Administration.

Dr. SCAVELLA. Okay.

Senator BLUMENTHAL. I am talking about dealing with those issues.

Dr. SCAVELLA. So as I testified a few minutes ago, it appears as if our staffing within SCI/D remains flat compared between September 2025 and September 2024. I do not have information about potential fluctuations in the types of staff that may have composed that number.

Senator BLUMENTHAL. You do not kind of monthly or quarterly assessment of what the recommended numbers are and how close you are to those numbers? You do not do a monthly report or any regular reporting?

Dr. SCAVELLA. We do monitor our staffing. I do not have that data in front of me today. I just had the flat number in that SCI/D—

Senator BLUMENTHAL. Well, what I am going to ask you to do is to provide me those numbers, vacancies for SCI/D nurses, recreational therapists, doctors, and other staff, month by month, to the present, over the past year.

Dr. SCAVELLA. Thank you for that. We will do that, sir. Thank you.

Senator BLUMENTHAL. When do you think you can have it?

Dr. SCAVELLA. I think we need to confer to make sure we have got the data available and how soon that will be. I am not sure what the normal turnaround will be, but we will commit to getting that information back to you.

Senator BLUMENTHAL. Did you discuss with anyone at the VA the possibility that you would be asked about these numbers?

Dr. SCAVELLA. Again, I had focused on the total numbers within the system. I did not focus on the breakdown.

Senator BLUMENTHAL. But did you talk to anybody at the VA in preparing to come here today about questions relating to staffing?

Dr. SCAVELLA. Correct, and that is why I had that number of being the same as September 2024 and September 2025.

Senator BLUMENTHAL. So you did talk to people. Did anyone say that you should not have the most current numbers on vacancies?

Dr. SCAVELLA. Nobody gave me that instruction, sir.

Senator BLUMENTHAL. Are people still leaving the VA, in your department?

Dr. SCAVELLA. So again, I speak for thousands of employees that do not just include SCI/D, so there is attrition and there is recruitment. So there is fluctuation every day in our staffing.

Senator BLUMENTHAL. Are you hiring?

Dr. SCAVELLA. We are hiring.

Senator BLUMENTHAL. Are you hiring more than you are losing?

Dr. SCAVELLA. Again, I do not have those gains and losses data in front of me, sir.

Senator BLUMENTHAL. Okay. How about cancellation of contracts? Do you have contracts with companies outside the VA?

Dr. SCAVELLA. I am going to defer to Dr. Wickremasinghe about any contracts related to SCI/D.

Dr. WICKREMASINGHE. Thank you for the question. At the national level we do not have contracts affecting our SCI/D System of Care, but I cannot speak for each of our facilities, so I would need to take that back for the record, please.

Senator BLUMENTHAL. How about the Hubs and Centers? They have contracts, right?

Dr. WICKREMASINGHE. I do not want to misspeak, so I would need to take that back for the record to find out more.

Senator BLUMENTHAL. You do not know whether the Hubs—do the Hubs and Centers report to you?

Dr. WICKREMASINGHE. At the national level I oversee policy, and the more detailed operational involvement, including contracts, many times is at the local level, at the facility level. And some of those contracts are national contracts, as well, but I do not have that information. I would need to take that back for the record, to make sure that we are providing the most accurate information.

Senator BLUMENTHAL. Well, my understanding is that you provide services through Hubs around the country. Correct? There are about 25 of them, or centers around the country, Hubs and Spokes?

Dr. WICKREMASINGHE. Yes. That is correct. We have 25 dedicated SCI/D centers, which are in our VA medical centers.

Senator BLUMENTHAL. And did they have contracts with private entities?

Dr. WICKREMASINGHE. I am not able to answer that question because that is not something that I am directly tracking or involved with. So I would need to take that back for the record.

Senator BLUMENTHAL. Well, I am perplexed. You are in charge of policy, which means meeting basic needs of individuals served by those 25 SCI/D centers, and you are saying you do not know whether they have contracts with service providers outside of their entities, and you do not know whether at the national level there are contracts?

Dr. WICKREMASINGHE. That is correct. Senator, because contracts do not fall directly under my office, we have—

Senator BLUMENTHAL. But you would know—you got a center. What is the nearest one to Connecticut? Boston?

Dr. WICKREMASINGHE. Yes.

Senator BLUMENTHAL. Okay. So you would know, in Boston, we have a certain kind of rehabilitation service that is provided by a contractor.

Dr. WICKREMASINGHE. For example, in Boston we have an SCI/D center, and that center operates under the national guidelines and standards set forward by VA. We have Directive 1176(2), which provides the standards for care of veterans with spinal cord injuries and disorders.

Senator BLUMENTHAL. Alright. Well, I hope maybe you can provide some more information.

I have been unhappy with the delays in implementing the Dole Act, as I expressed. Earlier, I have repeated those concerns. The VA touts its implementation of the Dole Act as a success. Do you regard it as a success?

Dr. SCAVELLA. Thank you for that question. We are happy to have the provisions set forth in the Dole Act, which will address several concerns that were raised here during this particular hearing. We are grateful for Section 120, which will help us with some very challenging situations that our patients have been facing. So we are happy for the provision.

Senator BLUMENTHAL. Don't you need more people to implement it properly and successfully, more staff?

Dr. SCAVELLA. I cannot comment on needing more staff if I do not know what the current staffing is capable of providing. So again, I would like to get back to you with accuracy of what has been implemented, how it has been implemented, as well as whether or not we do have any staffing challenges within the fact that we appear to have a flat staffing.

Senator BLUMENTHAL. Forgive me, but what I am hearing you say to me is you do not know whether you have enough staff to implement it successfully.

Dr. SCAVELLA. That is not what I meant to say, sir. What I am saying is—

Senator BLUMENTHAL. I am sorry. I apologize.

Dr. SCAVELLA [continuing]. I would like to make sure that as I am answering a question about a new provision and legislation that we are currently implementing—

Senator BLUMENTHAL. So you are not prepared to answer.

Dr. SCAVELLA. Correct. I want to make sure that I am providing accurate information pertaining to the new legislation.

Senator BLUMENTHAL. What is your opinion, Doctor?

Dr. WICKREMASINGHE. Thank you for the question, Senator. What I know is that VA is pursuing value-based care to address the Elizabeth Dole Act.

Senator BLUMENTHAL. I am going to finish my questions at this point. You know, it is not a failing to say, "We would like to have more staff." The reason I am asking these questions is, the VA has lost thousands of dedicated, hardworking members of its workforce. And my educated guess is that that has happened in your departments, and that it has affected performance. And it is not your fault. It is not your fault. It is the result of decisions made by Elon Musk, DOGE, tech bros, Secretary Collins, and the Trump administration, that has taken a chainsaw. It is the chainsaw that Elon Musk touted as he paraded on that stage, and it has affected your workers, but even more so, the brave veterans who are struggling with ALS and other spinal cord injuries. And that is a tragedy for our country.

So I hope maybe you can provide more information to me, because it will enable us to do better oversight. Thank you, Mr. Chairman.

Chairman MORAN. Thank you, Senator Blumenthal. There are no other questions, and therefore I want to again thank our witnesses, from the first panel and now from the second, for their testimony, and our Committee members and the audience for being here this afternoon.

The hearing record will remain open for five legislative days, should any Committee members want to submit additional statements for the record. And I ask our witnesses to respond to any questions that are provided for the record, once they are received that they are answered in a timely manner. I think we are done. We will adjourn the meeting, and thank you very much.

[Whereupon, at 5:45 p.m., the hearing was adjourned.]

A P P E N D I X

Prepared Statements

Testimony of Shelly Hoover, EdD
 Before the Senate Committee on Veterans' Affairs
 Oversight Hearing: Strengthening Services for Veterans with Spinal Cord Injury and Disorder

Chairman Moran, Ranking Member Blumenthal, and Distinguished Members of the Senate Committee:

Thank you for the opportunity to appear before you today. My name is Dr. Shelly Hoover, and I am a veteran of the United States Navy. For 12 years, I have been part of the Spinal Cord Injury and Disorder System of Care, and I stand here today as a testament to the life-saving care provided by the Veterans Health Administration. This testimony is the culmination of a decade spent advocating for the more than 4,000 veterans currently living with ALS.

My journey with ALS began in 2013. Initially, the VA's support felt focused on end-of-life care, a system designed to manage my death rather than empower my life. But I had a different plan. I proactively sought out an ALS multidisciplinary clinic and worked to redefine my path. That experience drove me to seek a seat at the table with the **VA ALS Executive Committee (ALSEC)**.

Working alongside a team of fellow advocates, we built a relationship of trust with the ALSEC. We urged them to make the ALS System of Care more user-friendly for veterans and their caregivers, and they listened. Under the visionary leadership of Drs. Illeana Howard and Sharyl Martini, the committee achieved significant improvements without any additional compensation for their work. Their dedication led to the creation of:

- A network of **ALS Coordinators**, including nearly all of the 170 VA medical centers.
- A comprehensive **website** to help veterans and caregivers navigate their care.
- An internal **training program** for new coordinators and other departments.

This model, which integrates feedback from those with "boots on the ground" experience, demonstrates the power of collaboration and mutual trust. It is a gold standard for enhancing the veteran experience and improving morale for VA employees who care so deeply for those they serve.

Based on my lived experience, I offer two recommendations for continued improvement and future success:

Recommendation 1: Empower Stakeholders

All departments and workgroups within the Spinal Cord Injury and Disorder system must develop trusting relationships with both internal and external stakeholders. As the ALSEC has demonstrated, this approach enhances employee morale, empowers stakeholders, and, most importantly, improves the quality of care and the overall experience for veterans.

Recommendation 2: Ensure Full Funding

Congress must ensure the Veterans Health Administration is **fully funded**. In addition to budget cuts, Congressionally allocated funds for special diagnoses, like ALS, cannot be spent due to VA-imposed hiring freezes and caps. Can that be corrected? These funding shortfalls have had a direct and devastating impact on my health and safety.

I recently experienced severe complications after a VA pharmacy, due to budget cuts, was unable to provide the liquid form of a prescribed chemotherapy drug. I suffered severe burns across my chest and pelvic region, an extreme and avoidable outcome. Delays are now a constant risk. For example, my replacement mic-key button, used for feeding and medications, is over a month late. How long before my current one breaks down and my stoma becomes infected? Life-sustaining breathing and nutrition supplies that were once readily available now face delays of weeks or even months. For a person with my condition, this is not just an inconvenience—it's a grave threat. I will not die from ALS; I will likely die from infection, a risk dramatically increased by these supply delays.

Some may suggest that private **Community Care** is the solution, noting its budget was recently doubled. However, with one exception, my personal experience has been a disaster. I've endured six-month delays and lost referrals, forcing my husband to spend countless hours on the phone. In one instance, a private medical office initially refused to treat me due to my tracheostomy, a clear violation of my rights.

By contrast, I have never experienced a delay or faced discrimination from the Durham VA Medical Center. It is clear to me that the VA is the best choice for Veterans.

My family's legacy is deeply tied to military service, with eight of my immediate family members having served in the Army, Navy, and Marines. I am profoundly grateful for the exceptional care the VA provides, and my grandchildren are thankful that I am still here because of it.

To continue this gold standard of care, the Spinal Cord Injury and Disorder system must actively seek input from external stakeholders. And, above all, Congress must fully fund the VA to protect the health and lives of current and future Veterans.

Thank you.

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/7Sqs7AeBt5XBJC3NM>
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/>

**Testimony of Mrs. Mary Ward
On Behalf of
The Elizabeth Dole Foundation
Senate Committee on Veterans Affairs
September 17, 2025**

Strengthening Services for Veterans with Spinal Cord Injuries, Diseases, and Disorders

Chairman Moran, Ranking Member Blumenthal, Members of the Committee, thank you for inviting me to testify today.

My name is Mary Ward, and I am the wife and full-time caregiver for my husband Tom, a Marine Corps veteran diagnosed with service-connected ALS over 15 years ago. Tom was 55 years old, and I was 50. We have two children and three grandchildren and live in Wilmington, NC. I am a retired teacher and a 2016 Elizabeth Dole Foundation Fellow.

I would like you to pause and think of a simple pleasure you enjoy by yourself. It could be that first quiet cup of coffee in the morning. Perhaps it's a solo drive with your favorite playlist. For me, it has long been a Starbucks Vanilla Bean Frappuccino — three pumps of vanilla, fat-free milk, and whipped cream.

For years, I thought the joy was in the ritual: stopping after grocery shopping, sitting in my car, sipping it while listening to music. But this past July, I realized I had redefined what joy means to me and the various ways in which it manifests itself in my life. Now, the joy that comes when I can drink that Frappuccino is knowing there is a nurse at home with my husband, ensuring he is safe and supported. In that moment, I am not a caregiver. I am me, doing something normal. That is the gift of respite. And it took eight years to get there.

My Caregiving Journey

To understand the vital importance of long-term care supports available through the Department of Veterans Affairs, it helps to know our journey.

I have been Tom's caregiver for decades. In 1993, he contracted encephalitis that left him with cognitive impairments, preventing him from ever working again and in 2010, he was diagnosed with Amyotrophic Lateral Sclerosis (ALS), for which he is service-connected. Veterans are more than twice as likely to get ALS as non-veterans.

In September 2013, he was also diagnosed with type 2 diabetes. Tom is rated 100% permanently and totally disabled, and ALS and diabetes are competing forces. ALS is considered a hypermetabolic disease, which complicates managing blood glucose, and as a result of the ALS, Tom is unable to give himself insulin injections.

The daily care for Tom ranges from assistance with activities of daily living (ADLs) to medication management to making his meals, doing his laundry, keeping the house clean, driving him to places he wants to go or needs to go, etc. Independent living is not possible for him. A typical day looks like this:

- Help him when he wakes to get from bed to wheelchair.
- Check his fasting blood glucose.
- Get him dressed.
- Give him his medications.
- Check his blood pressure.
- Give him coffee and a small bite to eat.
- Check his blood glucose. I do this throughout the day.
- Put his leg compression device on for an hour.
- Do a cough assist (assistance provided to ALS patients who no longer have the respiratory strength to clear phlegm from the lungs) before we shower.
- Shower, dry, groom, and dress him for the day.
- Do whatever needs to get done in the morning in terms of food shopping, laundry, etc. If I'm going out of the house, I will take him with me.
- I make all of his meals, cutting up food that needs it, pushing food onto his fork, and always determining blood glucose levels before we eat. Whatever his level is, then I figure out based on what we are eating how much insulin to give him. There is never a meal that we do not do this function. It has become a part of eating.
- Some nights, the alarms on his glucose monitor wake us. They go off once, twice, sometimes three times. The alarms indicate his glucose levels are dropping too low or rising too high. Either way, it requires attention.
- At 1 p.m., we have a private duty nurse to care for him until 5 p.m. Having a nurse is new for us. Approval for this level of care finally came in July 2025.
- During the day and evening, there are many small tasks I do and assistance I give to Tom. It isn't easy to enumerate them all. The bottom line is he cannot live independently. This understanding must be the takeaway from this "day in a life."

Tom's ALS diagnosis came in June 2010, a few days after our 30th wedding anniversary. I was teaching high school, and we were living in Durham, NC. The chief neurologist at the Duke ALS Clinic was the diagnosing physician. He was also a neurologist at the Durham Veterans Affairs Medical Center (VAMC). Through his social worker and the Paralyzed Veterans of America, he became service-connected with a rating of thirty percent. At that time, that was the initial rating for veterans with ALS, but thanks to the tireless advocacy of several veteran service organizations, the presumptive rating was changed from thirty percent to one hundred percent, permanent and total (P&T), in 2012.

Struggles and Small Victories

Unfortunately, the two years between Tom's diagnosis and this vitally important policy change were difficult, as obtaining the support we needed from the VA was anything but easy. The VA, for example, denied Tom the Specially Adaptive Housing (SAH) Grant and adaptive vehicle grant because, even though he had been diagnosed with a chronic, progressive disease, he was not yet rated 100% P&T. Although the VA did give him a power wheelchair, it stayed in the garage because we didn't have a handicap accessible home at that time. Finally, after the wheelchair was delivered, the VA approved the vehicle grant. Fortunately for Tom, he has a slowly progressive version of ALS, which meant we could withstand these delays.

Knowing the destructive nature of ALS, we got busy developing a plan for living with it that would work for both of us. In 2012, I gave notice at my brick-and-mortar school, and we moved to Wilmington, NC to downsize and save costs for what we know will be my future as a widow. I accepted a virtual teaching position for Advanced Placement Government and Politics with the state of North Carolina. When I did that, I left my state retirement behind; this job came with no retirement benefits.

Finally, in 2013, the VA approved Tom for the SAH grant, but that didn't mean our wait was over. From start to finish, having the house adapted and made accessible took 27 months. By the time the VA had approved all of the specifications for the project, it was January 2015, and the contractor didn't finish the work until July of that year. It is not a process I would want to repeat.

In 2016, due to our move, we moved Tom's VA primary care to the Wilmington Community-Based Outpatient Clinic (CBOC). The CBOC in Wilmington opened for care in 2013 and is part of the Fayetteville VAMC. We had heard good things about it, and we knew that it would save us from the long two-hour and forty-five-minute travel to the Durham VAMC. What we didn't understand, though, was that when we did that, we lost direct access to the specialty care that the Durham VAMC provides for veterans with spinal cord injuries and diseases. We would have to get referrals for each service from Fayetteville to go to Durham, and when the Durham VA ALS physician ordered equipment and/or services, it would have to go through the Wilmington CBOC Patient Aligned Care Team (PACT). Perhaps that sounds easy enough to do; however, all it did was add confusion and delays.

One reason we moved Tom's care to the Wilmington CBOC was to access the VA's Home-Based Primary Care program (HBPC). HBPC is a vital and supportive program that many veterans benefit from because it minimizes travel requirements for those with mobility challenges. However, because we do not live in the catchment area for Durham's HBPC services, we could only access HBPC through the Wilmington CBOC. Therefore, we had to choose. We could either access HBPC through Wilmington or have direct access to his ALS care, but we could not have both. After a series of mishaps due to this situation, including the inability to address a malfunction with Tom's non-invasive ventilator—without which he becomes hypoxic—we made the choice to give up HBPC and move all care to Durham. As much as we sorely needed it, it wasn't worth all the unforeseen and dangerous complications we experienced trying to navigate the bureaucracy.

Did Tom's care suffer during this time? No, I don't think so but only because I wouldn't let that happen. I leaned heavily on our non-VA primary care physician during that transition and continue to do so. Did the quality of my life suffer during that time? Absolutely. I carried the burden for him then and continue to do so today.

This lack of flexibility in the system forces us to choose between necessary services that could improve Tom's quality of life and even potentially extend his life expectancy. ALS and other diagnoses that fall under the spinal cord injury service are often very complex and don't fall into rigid categories—allowing some level of flexibility in care and services as well as comprehensive care coordination would maximize

the strengths of the VA and emphasize the concept of veteran-centric care. For example, an ALS clinic of excellence, such as the Duke ALS Center, provides soup-to-nuts care on a clinic day. The patient is assigned a clinic room when they arrive, and all of the specialties come to that room throughout the day: pulmonology, respiratory therapy, physical therapy, occupational therapy, speech therapy, social work, nutritional support, and neurology. It's a long, exhausting, but thorough and efficient day. We use Medicare benefits for this because the VA will not provide a community care consult for the clinic as a whole, as each specialty has to have its own referral.

These experiences have taught me something many veterans and their caregivers know all too well: the VA system has incredibly beneficial programs and services, but navigating that system is often confusing, fragmented, exhausting, and sometimes downright dangerous.

Over the years, I have had to escalate issues — from obtaining the non-invasive ventilator support mentioned above to hospital beds — up the VA chain of command, sometimes as far as the VISN director. Sometimes this advocacy has worked, but the one battle I kept losing was access to respite care. In 2017, the VA denied respite care while I was attending the Elizabeth Dole Foundation Convening in Washington, D.C. I pieced arrangements for Tom's care together to make it work, but it was far from ideal.

After learning about Veteran-Directed Care (VDC) from another Elizabeth Dole Foundation Fellow in North Carolina, I decided to apply for it for Tom. For those who are not aware, VDC is an innovative program within the VA that works in partnership with the Department of Health and Human Services. It offers the veteran a budget for personal care services and other expenditures to spend in a "consumer-directed" manner. In other words, the veteran has the flexibility to hire and fire support for Home and Community-Based Services, offering more flexibility and control of care to the veteran and caregiver. For those who can access the program, it is very popular and, importantly, often represents a cost savings for the VA.

However, even though I knew another veteran who was enrolled in VDC through the Durham VA, I was told by a Durham VA social worker that VDC simply didn't exist there. She was adamant about it. I let it go. I didn't have the energy to take on another battle while caring for Tom and dealing with his increasing health complications. I know many caregivers across the country who have faced similar challenges in accessing this program. They are given incorrect information, and they are unsure how and where to pursue it. It's frustrating beyond measure to know that these programs exist and not be able to access them.

Fortunately, in 2020, with the pandemic and Tom's diabetes becoming increasingly insulin-resistant, I began to see improvement in VA responsiveness. Our respiratory team became more helpful, prosthetics filled orders more quickly, and our Caregiver Coordinator from the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC) Caregiver Coordinator became an anchor of support. She has walked alongside us ever since, providing not just resources but also compassion and understanding.

Still, my attempts to access VDC were often foiled, until last year, when we finally got approved and were enrolled. Unfortunately, this still did not mean we received any services. When I asked for a timeline regarding funding and the actual provision of services, the response was: "30 days, 60 days, 90 days — I just don't know." With that lack of certainty and seemingly zero sense of urgency, we reluctantly withdrew from the program.

In the meantime, I leaned on my adult daughter and a friend, Lara, another Dole Caregiver Fellow and a survivor. Her veteran died from ALS over three years ago. Last year, it was Lara who traveled to care for Tom so I could be present for my daughter when she delivered her baby, my precious grandson Hayes. I didn't even consider asking the VA for help; I knew what the answer was likely to be.

The Turning Point

In the spring of this year, I realized I couldn't do it alone anymore. Tom agreed. His ALS progression was more pronounced, his diabetes care grew more complex, his glucose was dangerously erratic, and I didn't realize how exhausted I was from the last few years of 24/7 caregiving. In June, things came to a head when Tom became very sick from a diabetes medication he was on, which Tom's doctor then took him off. But since it was the only medication holding his insulin resistance at bay, his doctor cautioned that I would need to be even more vigilant. I seriously wondered, how? How could I be any more vigilant than I was? It wasn't humanly possible to continue as we were, to continue alone like I had been doing.

Through the resources of the Elizabeth Dole Foundation, together we pursued VDC and, at their encouragement, skilled nursing care as a possible alternative. At first, I doubted Tom would qualify for the skilled care of a nurse. He wasn't trach'ed and vent-dependent, which seemed to be the criteria. But through a deep and vulnerable conversation with EDF staff, I realized that skilled nursing care was the safest route for Tom and the way forward for me to have true respite. The hard-working staff at the Elizabeth Dole Foundation took our fight to the highest levels at the VA, and the VA actually approved private duty nursing care. It may not seem like a big thing to some people, but having someone else advocate for us was a huge relief. When we were approved, it was quite a moment for me. Maxim Healthcare, the agency we use for skilled nursing care purchased through VA, has made the process seamless and has allowed me, for a few hours a week, to be me again and not a caregiver. A long time ago someone asked Tom about me as his caregiver. He said she is my wife first and caregiver second. That has insidiously changed over the last few years. The benefit for me is clear, and the care I provide Tom because of respite is exponentially better. My sense of humor has returned. At the end of the nurse's shift, I look forward to seeing him.

Now, five days a week, from 1–5 p.m., a nurse comes into our home. The nurse monitors his health, catches issues I might miss, and allows me to step outside of my caregiving role for a few precious hours. Just last week, one of our nurses discovered Tom's blood pressure was running high, despite medication. This finding likely prevented a crisis.

For me, those hours are life-giving. I spend time with our youngest grandson, run errands, or simply sit in peace. I drink that Frappuccino, and for a moment, I remember who I am outside of caregiving.

What This Means for Policy

I share our story because while we have finally found the proper support, it should not have taken eight years, relentless advocacy, and national-level intervention to get here.

Too many caregivers give up before they reach this point. They go unseen, unsupported, burned out, and sometimes feel the only way out is to harm themselves. Simply put: veterans suffer when their caregivers suffer.

I therefore urge this committee to act on the following:

- **Expand and strengthen access to respite and home care** for veterans with complex conditions like ALS and spinal cord injuries, regardless of where they live. Those in rural areas need access to support, but even those living in places like ours with available resources are often not able to access needed support because of overly burdensome bureaucratic requirements, as well as staff shortages. *The Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* was signed into law on January 2, 2025. However, implementation of numerous sections that would help create a more straightforward path forward for respite, skilled home care, and expanded access to mental health care for caregivers has yet to occur nationally.

Relatedly, the Elizabeth Dole Foundation also supports the expansion of the innovative Technology Enabled Respite Homecare Model for which a successful preliminary pilot program concluded last year. The pilot offered access to high quality in-home care for veterans who need long term services while, at the same time, offering more control to the veteran and caregiver and increasing compensation for providers. The Elizabeth Dole Foundation encourages Congress to work with VA to further explore this model of care as an option for respite for veterans and caregivers.

- **Demand the immediate implementation of Section 120 of the Dole Act** so that there are no excuses preventing the provision of appropriate care in the home for the individual. This provision removed the 65% cap on non-institutional care expenditures, allowing the most vulnerable veterans to stay in their homes with appropriate care and support. While we have not run into this cap yet, too many other ALS, Multiple Sclerosis (MS), brain-injured, and spinal cord families are facing a horrible choice—stay in the home without appropriate support for the veteran or caregiver or move to a skilled nursing facility that will potentially shorten life expectancy and lower their quality of life standard.
- **Promote better proactive and holistic care coordination** so veteran families, especially those with the most complex needs, are not left to navigate the VA on their own. To help achieve this goal, the Elizabeth Dole Foundation supports the *Coordinating Care for Senior Veterans and Wounded Warriors Act*, which would establish a pilot program for certain veterans enrolled in both Medicare and VA to better manage and coordinate care. In addition, the Elizabeth Dole Foundation encourages Congress to work with the VA and stakeholder organizations to identify positive steps forward, such as the VA's establishment of the Lead Coordinator process intended to offer one point of contact for some complex cases, as well as address ongoing challenges, including those outlined here, that prevent veterans from accessing care and services promptly. The veteran community does not always need new programs. In many cases, we simply require access to the existing programs and services designed to help us.
- **Demand the expeditious discussion of and implementation of section 129 of the Dole Act.** "The Pathway to Advocacy," as it is called, requires the Secretary to establish a process to recognize outside organizations to assist veterans, caregivers, and survivors navigate the programs and services of the Veterans Health Administration (VHA). Similar in concept to the advocacy available from veteran service organizations in filing claims through the Veterans Benefits Administration (VBA), the establishment of this process would be a lifeline for families like mine struggling to navigate a very complex system and would complement the Department's existing social work and case management programs. We were fortunate to find people willing and able to help us, but, currently, not every veteran can easily get that level of support.
- **Ensure consistency in Veteran-Directed Care implementation and funding** so families do not face months of uncertainty while paying out of pocket. The Dole Act codified this program to push the VA in this direction—ensure its swift enactment with the

appropriate staffing across VDC and all of Geriatric and Extended Care (GEC) to make sure no other family endures our same struggles.

Closing

For those with devastating injuries and illnesses, long-term care support, especially respite, is not a luxury. It is not optional. It is essential—for caregivers, for families, and for the veterans who depend on us.

I am grateful for the nurses who now come into our home, for the Elizabeth Dole Foundation's relentless advocacy, and for the VA staff who have stood by us. But the care we now receive should not be the exception reached only after years of struggle. It should be the standard.

For every Frappuccino moment I now enjoy, there are thousands of caregivers still waiting for that moment to take a breath. Please make it possible for them to find joy again, and to see and feel that they matter, too. Their veterans' care, and sometimes their lives, depend on it.

Thank you.



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**STATEMENT OF
ROBERT THOMAS
NATIONAL PRESIDENT PARALYZED VETERANS OF AMERICA
BEFORE THE
SENATE COMMITTEE ON VETERANS' AFFAIRS
ON
"STRENGTHENING SERVICES FOR VETERANS WITH SPINAL CORD INJURY AND DISORDER"
SEPTEMBER 17, 2025**

Chairman Moran, Ranking Member Blumenthal, and members of the committee, I appreciate the opportunity to speak with you today on behalf of Paralyzed Veterans of America (PVA) about the strengths and weaknesses of Department of Veterans Affairs' (VA) care for veterans with spinal cord injuries and disorders (SCI/D). For nearly 80 years, PVA has been the leading voice on issues that affect catastrophically disabled veterans. Throughout the decades, we have championed critical changes within the VA SCI/D system by partnering with VA and working with members of Congress as they develop important processes and procedures that affect the lives of paralyzed veterans.

When I testified in March before a Joint Session of the House and Senate Veterans' Affairs Committees, I expressed our frustration with the existing state of the SCI/D system and a fair degree of trepidation about its future. We have relayed some of our biggest concerns to Secretary Collins and he has signaled to us on more than one occasion that VA's specialized services and the care of catastrophically disabled veterans will be a priority in this administration. But he can't do it alone. We need Congress's leadership and support to make the necessary changes to address long-standing systemic needs that will strengthen the system for veterans with SCI/D.

VA's SCI/D system of care uses a hub and spoke model. The 25 SCI/D centers are the hubs and each center has highly trained and experienced providers, including doctors, nurses, social workers, therapists, psychologists, and other professionals who can address the unique problems that affect veterans with SCI/D. VA's SCI/D system of care is the crown jewel of the VA's health care system. It is unequalled in the care it provides for the tens of thousands of veterans with SCI/D. This system is the difference between life and death for our members. It's because of this system of care that veterans can live in their own homes, travel, work, volunteer, and otherwise contribute to society.

PVA firmly believes VA is the best health care provider for disabled veterans, particularly those with catastrophic disabilities. More importantly, our members consistently choose VA's SCI/D system of care, because it provides a coordinated life-long continuum of services that has increased the lifespan of these veterans by decades. Beyond the loss of use of arms and legs, an SCI/D can affect other bodily systems, including skin, bowel, bladder, and breathing. Because of the profound and lasting effects of an SCI/D, which disrupts both physical and neurological functions, seeing a provider who understands the impact on each body system is a vital necessity.

Recently, a PVA member expressed this sentiment when he relayed that while he has had surgery in the community, the VA doctors he sees at the SCI/D spoke site at the Dwight D. Eisenhower VA Medical Center in Leavenworth, Kansas, understand the full nature of his trauma and they provided the tailored support with post-surgery rehab and long-term support that increase his quality of life. Other PVA members in Iowa and Nebraska relayed that while they regularly use the VA SCI/D clinic at the VA Nebraska-Western Iowa Health Care System, most, if not all, of them also travel to an SCI/D center (Minneapolis or Milwaukee) once a year for their annual exams. They choose VA over the community because of the comprehensive level of care they receive.

Most community care providers lack the knowledge, expertise, and time to properly understand the impact of SCI/D on body systems, which is the number one reason why most of our members choose VA direct care verses community care, even when it means traveling beyond the nearest medical facility. A PVA member in Colorado recently shared his contrasting experiences between VA and community emergency room visits following a severe flare-up of multiple sclerosis (MS). VA News published the story, and I strongly encourage you to read it.¹

We know that transportation to care can often be a significant barrier for catastrophically disabled veterans, especially for those living in rural areas. The absence of robust transportation infrastructure limits their options. The VA has implemented various programs to address these challenges, such as the Beneficiary Travel Program, Veterans Health Administration (VHA)-Uber Health Connect, and the Veterans Transportation Service, but each of these programs has problems or limitations that need to be addressed. That's why we support increasing access to beneficiary travel for these veterans and improving access to adapted vehicles.

Although VA's SCI/D system of care provides the best healthcare for paralyzed veterans, PVA has three primary concerns about the ability of the VA's SCI/D system of care to continue serving catastrophically disabled veterans both now and in the future. These concerns are ongoing staffing vacancies, delayed infrastructure improvements, and the continued shortage of specialty long-term care beds.

Staffing Vacancies—In March, I spoke about how the lack of proper staffing was undermining not just VA's SCI/D system of care, but VA's specialized services in general. Blinded veterans and those with traumatic brain injuries also benefit from VA's specialized systems focusing on specific conditions or diseases that require advanced knowledge, technology, and treatment approaches. This distinction is vital for ensuring veterans receive appropriate and effective care for their distinct health challenges.

¹ [An Army Veteran's contrasting ER experiences - VA News.](#)

Staffing levels for the SCI/D system of care are detailed in VHA Directive 1176. PVA strongly believes in each of the requirements outlined in this directive because they are based on the level of care needed to maintain the health and well-being of veterans with SCI/D. Unfortunately, some VA leaders have treated them as a guide rather than requirements based on best care standards. For example, at the end of July, using 1176 as our guide and focusing on nursing levels alone, we estimate that VHA's SCI/D system of care lacked 36 percent of its acute care nurses (896 of the 2475 recommended) and 7 percent of its long-term care nurses (short 23 out of 311 recommended).

In recent years, critically needed positions at SCI/D centers have gone unfilled. As a result, essential positions across VHA have been "lost" due to an inability to recruit for them. In some cases, they were even being "abolished." Specifically, many vacant positions in social work, nursing, and several therapy disciplines have been eliminated. We understand VHA inactivated nearly 500 SCI/D positions in fiscal year 2024 alone, and it is not surprising to us that some of the facilities that had the greatest number of reductions are the same ones that are unable to fully staff their full complement of recommended operational beds today. When medical staff leave, their vacated positions are often not backfilled, causing strain on the system and ultimately denying veterans access to health care services.

During PVA's annual visits to each SCI/D center, we identify critical vacancies at the facilities and provide that information to VA leaders. Totalling in the hundreds, VA typically agrees with roughly 80 percent of our recommendations, but only a small number of the positions are eventually filled. Too often at VA, we see "staffing on a wire," an unstable practice of maintaining just enough staff to handle a limited number of beds. Again, using 1176 as our guide, VA should have about 990 operational beds, but persistent staffing vacancies have shrunk that number to 639 (64 percent). The impact of such practice is profound, causing severe delays in critically needed routine care, including annual exams, colonoscopy preparation, and respite; and acute care, including admitting new injuries and addressing pressure wounds. Such delays have real consequences for veterans who need care now.

Additionally, these figures are based on nursing shortages alone. If we factored in provider shortages, the number of vacancies would be much worse. A good example of this is the Albuquerque SCI/D center. Of its 30 mandated beds, only 20 are operational due to nursing shortages, and of those 20 only 10 can be filled due to provider shortages. Shortages like these impair a facility's ability to adapt to changing life events like staff illnesses and injuries. Without proper staffing, veterans may be forced to accept care in the community, even when it is not the quality or type of care they would receive at a VA facility, and most importantly, when it is not their choice to do so.

Depending on the function level of an acute SCI/D patient, a nurse may spend an hour or more each time they enter a veteran's room doing physical transfers, repositioning, wound care, feeding assistance, bowel and bladder care, and other tasks. Nurses in other areas of work may be in and out of a patient's room in a matter of minutes. Despite the increased care that veterans with SCI/D require, not all SCI/D nursing staff, including Licensed Practical Nurses and Certified Nursing Assistants, receive specialty pay, which often elevates turnover rates. Due to nursing shortages in the SCI/D system of care, innovative and creative new approaches need to be reviewed, investigated, and implemented to attract, recruit, and retain nurses. This includes making specialty pay (5-10 percent above base)

mandatory, across the board throughout VHA), for all SCI/D nurses; along with the Education Debt Reduction Program, relocation assistance, bonuses, and all other current authorized incentives.

The PACT Act (P.L. 117-168) and the RAISE Act (P.L. 117-103) gave the VA new pay and bonus authorities to recruit in-demand health care workers, but we know that more needs to be done. Consistently relying on overtime to fill needs often leads to burnout. Giving VA additional tools, including additional financial resources so it can better compete for the highly qualified medical personnel it needs to care for catastrophically disabled veterans, is a must. New approaches are particularly needed in hard to recruit locations, such as Puerto Rico, Albuquerque, and Memphis. It is not only difficult to find and hire nursing staff in these areas, but also nearly impossible to find and hire medical providers, such as doctors, plastic surgeons, and specialists to fill the vacancies at these SCI/D centers.

PVA also supports efforts to streamline VA's hiring processes to allow clinicians to be identified and onboarded as quickly as possible. For too long, VA's processes have caused hiring delays and resulted in desperately needed clinicians taking positions in the community, which is able to bring nurses and other health care clinicians on board faster. While VA must ensure that medical professionals meet all necessary requirements, the process is overly bureaucratic and stands in the way of ensuring veterans have timely access to VA direct care.

Infrastructure—VA's SCI/D system of care is comprised of 25 acute care centers and six long-term care centers ranging in age from four to 70 years with an average age of nearly 40 years old. Many of the older SCI/D centers have only had minor cosmetic interior finish renovations. Consequently, we saw traumatic and disruptive incidents at several SCI/D centers last year. For example, a piping system failure at one facility flooded half of the SCI/D center. This caused the immediate evacuation of the acute and long-term care units and ultimate relocation of veterans with SCI/D into the unaffected patient care units and an adjacent community living center. Fortunately, the medical center was able to repair the plumbing system, restore the impacted areas, and move patients back into the SCI/D center in about a month. Meanwhile, a faulty HVAC design at another facility allowed condensation from the cooling system to form and drip onto patients while they were in bed. The problem, which PVA identified many years ago, was finally corrected when a construction project at the facility was completed late last year.

Many SCI/D centers (14 of 25) continue to use four-bed patient rooms, accounting for 61 percent of the mandated available in-patient beds. These rooms do not meet VA requirements and represent an antiquated and outdated patient-care philosophy in modern health care environments due to infection control concerns. When patients need to be isolated, the other beds in the room must be closed.

Current construction projects in the SCI/D system of care will add a new SCI/D acute and long-term care center at the Jennifer Moreno VA Medical Center in San Diego and a long-term care center at the Dallas Campus of VA's North Texas Health Care System. Due to the diligent and collaborative efforts of the VA medical center, VA's Office of Construction and Facilities Management, US Army Corps of Engineers, and the construction team, the state-of-the art project in San Diego, which began in April 2021, is expected to be open to veterans by early 2026. Unanticipated delays prolonged the initial construction of the new SCI/D long-term care center in Dallas, so it is now expected to be completed in the spring of 2027.

The SCI/D system of care is not immune to the design and construction delays inherent in the VA project funding and delivery system. There are currently two super-major, 10 major, and 16 minor SCI/D center projects either awaiting funding, in design, or pending approvals to proceed. VA has spent a significant amount of money and resources on these projects, most of which have languished within the department's Strategic Capital Investment Planning process. Also, replacement SCI/D center projects designed for the Bronx, New York, (acute and long-term care) and the Brockton, Massachusetts, (long-term care) VA medical centers intended to modernize and expand capacity were shovel-ready but abandoned by the VA.

In reviewing VA's infrastructure, decision-makers must remember that VA's SCI/D system of care is unique and not replicated outside of VA. PVA believes that VA should return to the past practice of placing greater emphasis on funding facilities that support the types of services, like SCI/D care, which the department uniquely provides. Greater investment in these areas would greatly strengthen VA's specialty care services and ensure their future availability.

Even with a comprehensive strategy and adequate infrastructure funding, VA's capacity to manage a growing portfolio of construction projects is constrained by the number and capability of its construction management staff. To manage a larger, more complex capital asset portfolio, VA must have sufficient personnel with appropriate expertise—both within VA's Central Office and onsite throughout the VA system. Thus, PVA strongly supports legislation that would improve staffing to manage construction of VA assets and ensure that there are concrete plans to improve the planning, management, and budgeting of VA construction and capital asset programs.

PVA also supports efforts to remove disability-related barriers throughout the health care system. Our members routinely face such barriers when accessing care at the VA and within the community. For example, we have heard of VA women's clinics that have examination rooms that are too small for veterans who use wheelchairs or lack overhead patient ceiling lifts. Although VA has worked to address access barriers for disabled veterans, establishing a Veterans Accessibility Advisory Committee would help ensure the VA is meeting the needs of veterans. We strongly support S. 1383, the Veterans Accessibility Advisory Committee Act of 2025, and urge swift passage of this legislation.

Long-Term Care Beds for Veterans with SCI/D—Our nation's lack of adequate long-term care options is an enormous problem for people with catastrophic disabilities. There are very few long-term care facilities that are capable of appropriately serving veterans with SCI/D. The VA is required to maintain 198 authorized (181 operating) SCI/D long-term care beds. Due to construction/renovation, only 167 are currently available. This is a critical deficit, as there are over 20,000 veterans with SCI/D receiving care and treatment within the VA system. This number fluctuates depending on several variables like staffing, women residents, and isolation precautions. When averaged across the country, that equates to about 3.4 beds available per state.

Currently, only one of VA's six specialized SCI/D long-term care facilities lies west of the Mississippi River. Even after the construction project in San Diego is completed, only 32 long-term care beds will be available for the thousands of veterans with SCI/D that reside in this area of the country. Many aging veterans with SCI/D need VA long-term care services, but because of the department's extremely

limited capacity, veterans sometimes remain in the acute setting for months or years at a significant cost because other placements are simply not available. Others must reside in nursing care facilities outside of VA that are not designed, equipped, or staffed to properly serve veterans with SCI/D. As a result, veterans staying in community nursing facilities often develop severe medical issues requiring chronic re-admittance back into an acute VA SCI/D center.

The North Texas project I previously mentioned includes shell space for an additional 30 long-term care beds (60 total) and would provide shared resident dining, kitchen, and living areas to support them, as well as common resident gathering areas and space to support staff on that level. There is currently no funding to support building out the shell space. The need for long-term care beds is particularly severe in the south-central region as there is not a VA SCI/D long-term care center within 1,000 miles of Dallas despite a significant regional population of veterans with SCI/D. Not funding this project postpones the opportunity to further address the shortage of VA long-term care beds for the aging population of veterans with SCI/D. We strongly recommend that Congress provide the additional funds to construct this part of the project.

Veterans with SCI/D also depend on a wide range of services and support available to veterans throughout VA. Many PVA members depend on VA home and community-based services (HCBS) throughout their lives. We are very appreciative of Congress's passage last year of the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act (P.L. 118-210). This bill made critically needed improvements to help veterans access VA HCBS. One of the most important provisions in the new law raised the cap on how much the VA can pay for the cost of home care from 65 percent of the cost of nursing home care to 100 percent, and even more if it's in the veteran's best interest. Intended to bring veterans with ALS and other catastrophic disabilities immediate relief, we are greatly disappointed that this provision has not been implemented. We urge the committee to intervene and correct this as quickly as possible.

Another section of the new law requires the VA to administer its Veteran Directed Care (VDC), Homemaker and Home Health Aide, Home-Based Primary Care, and Purchased Skilled Home Care programs at all medical centers within two years of the date of enactment of this legislation. Our members are very interested in VDC because it allows them to prioritize their own care needs and select their own care providers from their local communities. VDC is particularly effective in rural areas that have limited or no access to home health agency care.

According to the VA, VDC programs were established at all major VA facilities last year, but the feedback we have received from the field suggests some of them exist in name only. Some locations lack dedicated staff to manage the program, and insufficient funding often constrains the number of veterans who can participate in it at many others. We understand VA wants to expand VDC and enroll more veterans, but the department is having a difficult time finding agencies willing to participate in it. Unfortunately, this is a pretty common problem as many VA facilities do not have the appropriate Aging and Disability Network Agencies within their catchment areas to support veterans as they plan for and direct their long-term services and supports. VA is currently examining ways to execute Veteran Care Agreements (VCA) with alternative VDC providers. We encourage Congress to support these efforts and make sure VA has proper funding for the expansion of this important program.

Veterans with SCI/D also depend on VA's Bowel and Bladder program. SCI/D can significantly impact a person's quality of life, and neurogenic bladder and bowel dysfunction are crucial aspects of their care. These conditions affect many veterans with SCI/D and can lead to complications, re-hospitalizations, and mortality. Managing neurogenic bladder and bowel requires specialized attention, can be costly, often demands significant caregiver support, and is essential to veterans' health and well-being.

VA's Bowel and Bladder program is administered by VHA's SCI/D National Program office. Veterans with SCI/D who qualify for bowel and bladder care may receive that care through a home health agency, a family member, or an individually employed caregiver. The clinic of jurisdiction, or VA medical facility, authorizes bowel and bladder care under the Office for Integrated Veteran Care (IVC), to enrolled veterans with SCI/D who are dependent upon others for bowel and bladder care while residing in the community. Once designated caregivers successfully complete training from the VA, all necessary forms are forwarded to IVC for approval. Additionally, the caregiver must obtain a National Provider Identifier, complete a VCA, track the amount of time needed to perform the veteran's bowel and bladder care daily, and submit it along with a VA Form 10-314, Request for Payment of Bowel and Bladder Services, to be reimbursed.

The current program is fraught with challenges for caregivers and is unevenly applied across the VA. Timely reimbursement and the tax treatment of payments are the chief complaints of PVA members. Unlike virtually all other VA payments, including those provided through the Program of Comprehensive Assistance for Family Caregivers, Bowel and Bladder program reimbursements are taxable. Even family caregivers are considered federal contractors and must pay self-employment tax.

Another reason to make the Bowel and Bladder program a statutory requirement is that it fails to offer veterans due process. There is no formal notification to the veteran, caregiver, or the provider that a VCA agreement must be renewed. Hence, due to the lack of notification, veterans and caregivers continue to file monthly claims, but payments stop, and they don't know why. Getting the program reinstated is difficult and may result in the veteran losing their caregiver due to lack of payment. The whole process starts all over again, with the veteran having to find, train, and formally designate a caregiver which can take weeks or months to complete, putting the veteran with SCI/D at risk of not receiving timely care. Also, neither the veteran nor the caregiver is notified if they file a monthly claim that has errors or missing information. They simply don't get paid and it is up to them to find out why.

The Bowel and Bladder program is a life-sustaining program providing support to veterans with SCI/D. Codifying the program would allow Congress to finally resolve the tax burden and delayed payments for family members who perform bowel and bladder care. And because our members are the principal users of the program, we will seek ample opportunities to "shape" the program's language.

Most veterans with SCI/D also depend heavily on access to high quality wheelchairs and other assistive devices for their health and independence. Aside from lingering supply chain issues, most prosthetics-related concerns, with a few exceptions, have returned to normal following the pandemic. We now see minor delays in processing and receiving parts, equipment, and/or durable medical equipment.

The most significant delays we have seen recently involve VHA's national contract with Scootaround for the repair of VA-issued wheelchairs, powerchairs, and scooters. Because it has been challenging for the company to find enough dedicated vendors in certain parts of the country, veterans were waiting for sometimes a week or two to receive needed assistance. Veterans often end up returning to their VA medical center's Prosthetics Department to bypass the contractor and obtain the necessary parts and repairs directly.

Scootaround appears to be gradually resolving operational issues and improving service delivery. That said, in certain regions where Scootaround has consistently underperformed due to vendor shortages, many affected VA medical centers bypass the contractor and place orders themselves, resulting in more timely and effective service for veterans. We urge the committee to provide rigorous oversight of this rollout to ensure veterans' access to prosthetics, including needed repairs, is not delayed.

When considering the unique needs of veterans with SCI/D, it is important to note that not all such veterans receive their care through the SCI/D system. Specifically, some SCI/D centers do not provide treatment for veterans with amyotrophic lateral sclerosis (ALS) or MS. Veterans at these locations and elsewhere are likely to receive care through their medical center's neurology department.

Every VA medical center has an ALS Coordinator and about a dozen of VHA's clinics have been designated as Certified Treatment Centers of Excellence and Recognized Treatment Centers. To be certified as a center of excellence, an ALS clinic must meet rigorous clinical care and treatment standards, participate in ALS-related research and successfully complete a comprehensive site review. Providers at these locations possess a high degree of expertise in treating the disease because it is their sole focus. While VA is a leader in the delivery of care for ALS, a 2024 study by the National Academies discussed the importance of establishing an integrated, nationwide system of care and research for individuals living with ALS, as well as at-risk genetic carriers.² The study also recommended that, "Congress should allocate specific funding to create a VA network for ALS clinical care, research, education, and innovation to align with the new system of care outlined in this report."³ We urge consideration of this recommendation.

Likewise, VA's MS Centers of Excellence (MSCoE), East and West, are gold standards of interdisciplinary MS care, research, education, and informatics. MScOE East is at the Baltimore and Washington, D.C. VA medical centers. MScOE West is jointly based at VA Puget Sound Health Care System in Seattle and the VA Portland Health Care System. Together, they coordinate the delivery of MS care via a national hub and spoke network. Each VISN has at least one MS Regional Specialty Program (RSP) that serves as a hub for MS specialty consultation, clinical care, and education within that region. RSPs provide MS specialized care, coordinate services across facilities, and support surrounding VA sites through consultations and telehealth. This network ensures nationwide access to care for veterans with MS. VA providers at each of these locations have specialized knowledge of service-related health concerns such as exposure to military hazards, PTSD, and other challenges that are unique to veterans. VA health care professionals are attuned to the cultural and psychological factors affecting veterans, providing a more

² National Academies of Sciences, Engineering, and Medicine. 2024. Living with ALS. Washington, DC: The National Academies Press. <https://doi.org/10.17226/27739>.

³ *Id.* at 129.

supportive and understanding environment. MS healthcare in the VA is superior to the private sector due to its specialized focus, coordinated care, cost efficiency, and veteran satisfaction and veterans with MS should be made aware of its availability.

Finally, PVA is concerned about our members' access to inpatient mental health and substance use disorder (SUD) treatment, specifically, residential rehabilitation treatment programs (RRTP). While research is limited on the impacts of SUD for veterans with SCI/D, data suggests that individuals with SCI/D are disproportionately at-risk of SUD. Because of the risk factors associated with SCI/D veterans, it is critical that VA ensure they can engage in residential SUD programs tailored to at-risk veterans.

Significant medical comorbidities are also expected because of injury or trauma, which is especially true when discussing the lifecycle years beyond acute injury. These complexities make the holistic treatment of veterans with SCI/D critical for their independence and well-being. However, if a veteran needs help from a caregiver with an activity of daily living, they are unable to access RRTP, even within the VA.

Recently, VA provided a list of seven locations that would accept PVA members. However, after speaking with a social worker for one of the programs, it was brought to our attention that per VHA Directive 1162.02, the Mental Health Residential Rehabilitation Program,⁴ no veteran with an additional nursing need is authorized for admission into an RRTP. In Section 3(d), the admission criteria for the program, clearly states that, a veteran must be "capable of self-preservation (ability to protect oneself from harm) and basic self-care (able to independently complete activities of daily living such as bathing, dressing without assistance, take medications, etc.)."⁵

Many of the most vulnerable and at-risk veterans are barred from accessing this critical program. One PVA member shared his experience of trying to access such treatment. During an intake call, a few days before his check-in date, he mentioned using a wheelchair. The nurse informed him that because he needed to use a wheelchair he wouldn't be able to participate in the program. This veteran struggled with an addiction to pain medication after sustaining an injury and he was ready to receive treatment. To be told that he was unable to receive the care he needed was devastating. Thanks to the love and tireless support of his wife this veteran finally freed himself from the addiction he struggled with but not without a cost. It strained his relationship with his wife, who was also his caregiver, and he lacked the mental health support to help him with his darkest thoughts, but he remains with us today and he hopes his story can help prevent another veteran from experiencing the same awful situation. We appreciate this committee's recent support of a pilot program to provide this type of care to veterans with SCI/D through VA's direct care system and urge its swift passage.

Chairman Moran, Ranking Member Blumenthal, and members of the committee, I would like to thank you once again for the opportunity to present our views on some of the most critical needs of PVA members. We look forward to continuing our work with you to ensure that veterans get timely access to high quality healthcare and all the benefits that they have earned and deserve. I would be happy to answer any questions.

⁴ [VHA Directive 1162.02, Mental Health Residential Rehabilitation Treatment Program.](#)

⁵ *Id.*

ROBERT L. THOMAS JR.
PVA NATIONAL PRESIDENT & CHAIRMAN OF THE BOARD



"PVA has changed my life by introducing me to things that I believed to be over when I became injured, such as the National Veterans Wheelchair Games, and showing me that you can still live a fulfilling life although you have sustained a catastrophic injury."

Robert Thomas grew up in Cleveland, Ohio and played football and basketball. He enlisted in the U.S. Army shortly after graduating high school in 1987. Thomas served as a power generation equipment specialist at Fort Sill, Oklahoma; Camp Humphreys, South Korea; and Fort Bragg, NC. While on active duty, in 1991, Thomas had a diving accident that severed his fifth and sixth vertebrae. He was introduced to PVA through the Cleveland VA. PVA helped him navigate his new life by working to obtain his earned benefits through the VA and reintegrating him back into society through

social outings with the recreational therapist.

Thomas joined PVA in 1993 as a member of the Buckeye Chapter of PVA in Ohio, and a little while later, began volunteering with the chapter. He took some time off to earn his associate degree in information technology and returned to the Buckeye Chapter of PVA board in 2010. He served as the chapter's vice president from 2012-2015, and as the chapter's representative on the national Field Advisory Committee and the Resolution Committee.

Thomas was reelected in May 2024 during the organization's 78th Annual Convention and began serving his second one-year term as President and Chairman of the Board on July 1, 2024. He initially joined PVA leadership at the national level in 2015 as the parliamentarian and was elected to serve on the Executive Committee in 2017.

Thomas continues to serve PVA because he wants to help lead the organization well into the future. "My inspiration to serve stems from PVA's past and present leadership," Thomas says. "Being a member for 30 years and seeing how unselfishly each leader, member, employee, and volunteer gives of themselves makes me want to continue to serve an organization that does so much for veterans and the disabled community."

In addition to serving as the President and Chairman of the Board for PVA, Thomas currently serves as the chair of PVA's Education Foundation. He was also appointed to the VA's Family Caregiver and Survivors Advisory Committee. Thomas and his wife, LaShon, live in Macedonia, Ohio. Thomas enjoys reading, watching sports, and playing adaptive sports like power soccer, bowling, air guns, and scuba diving.

**STATEMENT OF
ERICA M. SCAVELLA, M.D., FACP, FACHE
ASSISTANT UNDER SECRETARY FOR HEALTH FOR CLINICAL SERVICES
VETERANS HEALTH ADMINISTRATION (VHA)
DEPARTMENT OF VETERANS AFFAIRS (VA)
BEFORE THE COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES SENATE
ON
"STRENGTHENING SERVICES FOR VETERANS WITH
SPINAL CORD INJURY AND DISORDER"**

SEPTEMBER 17, 2025

Good afternoon, Chairman Moran, Ranking Member Blumenthal, and members of the Committee. Thank you for the opportunity to testify before you today. Joining me is Dr. Manosha Wickremasinghe, Executive Director of VA's Spinal Cord Injuries and Disorders (SCI/D) System of Care. Together, our mission is to address not just the immediate needs, but also the long-term challenges and opportunities facing the Veteran community affected by SCI/D.

Overview of Comprehensive Care

As we recognize the unique and evolving needs of Veterans living with SCI/D, our response continues to center on specialized, comprehensive care. These complex conditions require individualized approaches, and our commitment is to leverage the full depth of VA resources and compassionate expertise to optimize the quality of life for all Veterans.

VA's SCI/D System of Care is the Nation's largest, most comprehensive integrated health care system dedicated to treating individuals with SCI/D. VA has 25 SCI/D Centers (also known as Hubs), which offer primary and specialty care provided by specialized interdisciplinary teams. These SCI/D Centers work closely with other designated VA medical facilities that do not have SCI/D Centers (called Spoke

facilities). Our Hub and Spoke system enhance the health, well-being, functionality, and quality of life for over 24,000 Veterans. Spoke facilities, aligned with specific Hubs, expand access to SCI/D-informed care Nationwide.

The Veteran is central to all that we do, and we strive to provide care that considers the whole person. We work as interdisciplinary teams to provide acute rehabilitation, specialized medical management, primary and preventive care, respite care, and long-term support. Annual comprehensive evaluations focus on health promotion, complication prevention, and early intervention--addressing the evolving needs related to SCI/D at any age.

Supporting Community Independence

To support Veterans in their communities, our SCI/D System of Care includes the SCI/D Home Care Program. Members of interdisciplinary teams are available to support the transition and health care needs of Veterans with SCI/D in the home or community setting. In addition to the SCI/D Home Care Program, the VA SCI/D System of Care leverages home- and community-based services such as Skilled Home Health Care, Homemaker/Home Health Aide, and/or Veteran-Directed Care to ensure eligible Veterans receive care comfortably within their home and/or community.

Recent legislative progress, including the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act (P.L. 118-210), has enabled VA to expand support for Veterans facing complex medical conditions. For example, section 120 of P.L. 118-210 raises the maximum per-Veteran expenditure for home- and community-based services from 65% to 100% of Community Living Center costs, which can now be applied to diagnoses such as SCI/D. These changes directly translate into expanded options for home-based care and greater financial flexibility.

Addressing Challenges for Aging Veterans

As the Vietnam-era Veteran cohort continues to age, the complexity of their care needs increase. In response, VA is working to expand SCI/D long-term care capacity with two funded construction projects at VA North Texas Health Care System (HCS) and VA San Diego Healthcare System, both of which have existing SCI/D acute and

sustaining centers. Once completed, this will bring the total number of VA SCI/D long-term care centers to eight. Notably, these dedicated SCI/D long-term care facilities are unique to VA. Ensuring the availability of high-quality, long-term care for Veterans with SCI/D is a prominent challenge—one which remains central in our resource allocation and planning.

With treatment advances extending life expectancy, many Veterans live decades with SCI/D, encountering age-related challenges layered on to their original disabilities. VA leads the Nation in adopting the Age-Friendly Health Systems model, which promotes evidence-based practices aligned with what matters most to Veterans and their caregivers.

Advancing Accessibility and Technology

Removing barriers for Veterans with SCI/D requires ongoing investments in adaptive equipment and technology. In fiscal year 2024, VA processed more than 5,000 claims for vehicle conversions, hand controls, and entry/exit ramps, empowering safe and independent mobility for eligible Veterans with service-connected disabilities.

Additionally, VA's SCI/D System of Care and Office of Advanced Manufacturing have partnered to ensure Veterans have access to cutting-edge manufacturing technologies, such as 3D printing, in health care. These technologies allow for faster innovation and improved access to personalized health care solutions for Veterans.

Continuous Quality Improvement

VA's SCI/D System of Care maintains a strong tradition of continuous quality improvement and performance measurement. Recent initiatives have modernized outcome measurement and reporting by adopting Section GG from the Inpatient Rehabilitation Facilities Patient Assessment Instrument, a nationally recognized tool that tracks changes in mobility and self-care independence.

Additionally, VA has developed standardized documentation for the Functional Mobility Assessment (FMA), in collaboration with the original creators of FMA from the University of Pittsburgh. This measure allows VA to evaluate Veteran satisfaction with wheeled mobility devices.

Standardized clinical documentation and data reporting tools provide actionable insights to clinicians and leaders, supporting transparent communication and ongoing care improvements. These efforts also facilitate the transition to VA's new Oracle Health electronic health record system.

Conclusion

Chairman Moran, Ranking Member Blumenthal, this concludes my testimony. VA's SCI/D System of Care is committed to continuing to deliver high-quality, evidence-based care, ensuring Veterans receive the care and support they deserve. My colleagues and I are prepared to answer any questions you may have.

Questions for the Record

Department of Veterans Affairs (VA)
Questions for the Record Submitted to
Erica Scavella, MD, FACP, FACHE
Assistant Under Secretary for Health for Clinical Services
From the Committee on Veterans' Affairs United States Senate
"Strengthening Services for Veterans with Spinal Cord Injury and Disorder"

September 17, 2025

Questions for the Record from Ranking Member Richard Blumenthal

Question 1: How many spinal cord injury and disorder (SCI/D) staff has the VA lost in the last eight months?

VA Response: As of November 2025, there were 141 losses of SCI/D staff since January 2025. However, VA experienced significant growth in staffing during fiscal year (FY) 2022 and FY 2023. In addition, SCI/D staff has a vacancy rate of approximately 10%, down from 19% in FY 2022.

Question 2: How many SCI/D nurse vacancies are there currently at VA? How many were there in January 2025?

VA Response: As of November 2025, there were 172 SCI nurse vacancies. In January 2025, there were 186 SCI nurse vacancies.

Question 3: How many SCI/D physician vacancies are there currently at VA? How many were there in January 2025?

VA Response: As of November 2025, there were 27 SCI physician vacancies, up from 20 vacancies in January 2025. Despite this increase, the overall staffing remains strong due to the significant additions made in previous years, particularly in FY 2022-23.

Question 4: How many recreational therapist vacancies are there currently at VA? How many were there in January 2025?

VA Response: As of November 2025, there were 168 recreational therapist vacancies, compared to 84 vacancies in January 2025.

Question 5: How many vacancies are there overall in VA's SCI/D workforce? How many were there in January 2025?

VA Response: There were 397 vacancies overall in the VA SCI/D workforce, compared to 387 vacancies in January 2025. VA experienced significant growth in staffing during FY 2022 and FY 2023. In addition, SCI/D staff has a vacancy rate of approximately 10%, down from 19% in FY 2022.

Question 6: Have any of VA's SCI/D Hubs been impacted by contract cancellations? If yes, please provide a list of relevant contracts.

VA Response: No, SCI/D Hubs have not been impacted by contract cancellations.

Question 7: What staffing shortages does VA currently face in positions required for implementation of the *Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act*?

VA Response: VA is dedicated to the implementation of the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act. As VA continues to work through implementation, VA will strategically hire staff in hard to recruit and retain occupations such as Dental Assistants, Medical Support Assistants, and Social Workers, as needed.

Questions for the Record from Senator Angus King

Question 1: As we discussed in the hearing, my office was briefed last fall by the VA about their intention to implement a new falls prevention strategy at the Department, which included the establishment of a falls prevention program. This was great news—and in line with my SAFE STEPS for Veterans Act. However, since then, we haven't heard anything further about these plans.

Can you provide me with an update? In January 2025 emails to my staff, VA Office of Congressional and Legislative Affairs shared that the Department was looking at establishing either an Office of Falls Prevention or a Falls Prevention Program, justified via 38 USC 7301(b).

VA Response: The new Veterans Health Administration (VHA) Fall Prevention and Management (FPM) program implementation and rollout began during the first two quarters of FY 2025. The FPM program is managed by the VHA National Center for Patient Safety (NCPS), aligned within the Office of Quality and Patient Safety (QPS). Several strategic activities were addressed in FY 2025, including drafting VHA policy and creating awareness of the new program.

In FY 2025, VA established and implemented a national FPM Steering Committee (FPMSC) to provide oversight for the program. The FPMSC members and consultants represent VHA multidisciplinary stakeholders from national, regional, and facility entities engaged in FPM priorities. The Veterans Experience Office is included as a voting member to capture the voice of the Veteran to inform FPM program initiatives. FPMSC workgroups have been established to address: 1) Fall Risk Screening Standardization; 2) Health Record Documentation Standardization; 3) Reporting and Data Analysis Guidance; and 4) Interdisciplinary Collaboration and Education for VHA personnel and Veterans.

Question 2: As noted over email to my staff from the Office of Congressional and Legislative Affairs in January 2025, VA staff shared that the Department was developing a national policy for the VHA Fall Management and Prevention Program. Can you provide me with an update?

VA Response: The draft directive outlining proposed VHA national policy for FPM is under review. It includes input from key FPM stakeholders, including VHA program offices, Veteran Integrated Service Networks (VISNs), facilities, and the VHA policy office. VHA anticipates publication during the fourth quarter of FY 2026.

Question 3: As noted over email to my staff from the Office of Congressional and Legislative Affairs in January 2025, VA staff shared that the Department was developing awareness campaign materials about the Fall Prevention and Management National Program. Can you provide me with an update?

VA Response: VHA launched a national campaign to emphasize the establishment and implementation of the new VHA FPM program during the second quarter of FY 2025 and is ongoing. Consistent messaging has been provided through multiple and varied platforms, including but not limited to:

- FPM program overview presentations delivered to multidisciplinary professional stakeholders in FPM (for example, doctors, nurses, therapists, other clinical specialists, patient safety and quality management professionals, and executive leaders);
- Community of practice forums with FPM stakeholders across diverse settings and learning events, including several sessions highlighting FPM in VHA, delivered during the NCPS Patient Safety Symposium; and
- Discussions with stakeholder organizations external to VHA about opportunities to collaborate on FPM initiatives.

VHA hosted a virtual event on September 23, 2025, during Fall Prevention Awareness Week, to highlight FPM Strong Practices underway across the continuum of Veteran care. The interactive educational event was coordinated in collaboration with several VHA stakeholder offices and hosted over 1,200 attendees with a keynote address from the National Council on Aging emphasizing fall prevention priorities for aging Americans.

Finally, VHA has a robust internal Knowledge Management Center for FPM. The site hosts an opportunity for professional networking, provides direct links to extensive resources, and includes a frequently asked questions section for open-source access to relevant guidance.

Questions for the Record from Senator Marsha Blackburn

Question 1: Complex Rehab Technology manufacturers, who provide individually configured manual and power wheelchair systems for veterans with ALS, spinal cord injuries, and other neurological diagnoses, shared concerns about unexpected procurement delays earlier this year. During that time there was a

lack of clarity and transparency about what policy changes were being implemented and what new processes entailed. These delays led to decreased access to critical medical device technology for veterans. What, if any, action has been taken to provide national procurement process direction for VISNs and manufacturers to enhance efficiency in serving our nation's veterans?

VA Response: Prosthetic and Sensory Aids Service is in the process of developing a solicitation for a national contract for powered wheeled mobility devices. An industry day has been held, and another is in development. No review is required for individually prescribed equipment and devices up to \$100,000.

Question 2: Different VA facilities rarely follow the same procurement processes, which can create additional burdens and delays in providing medically necessary mobility equipment to veterans with diagnoses such as ALS and spinal cord injury. Are there any plans by the administration to standardize the procurement process across VA clinics nationwide to ensure there is a reliable and predictable process available to veterans in need of complex rehab technology?

VA Response: The development of a powered wheeled mobility national contract supports standardization efforts across the enterprise. Once in place, it will improve efficiency of procurement in support of Veterans.

Question 3: I continue to be concerned with veterans accessing SCI-D care within VA and community care, especially as it relates to examination spaces and clinical infrastructure. How could VA improve the community care referral process for veterans with SCI-D?

VA Response: VA continues to look for opportunities to improve the community care referral process for Veterans. VA is embedding language in community care consult templates to prompt ordering providers to identify the presence of mobility issues that will require additional assistance at imaging centers. This change will help ensure Veterans are scheduled at facilities that can most appropriately address their needs. Additionally, care coordination processes include identification of any comorbidities or need for assistance with activities of daily living that might impact scheduling or receiving services in the community to ensure the Veteran's needs are proactively identified and supported.

**Department of Veterans Affairs
January 2026**

Senator Richard Blumenthal, Ranking Member
Questions for the Record
Senate Veterans' Affairs Committee
“Strengthening Services for Veterans with Spinal Cord Injury and Disorder” Hearing
September 17, 2025

Questions for Shelly Hoover

1. What challenges have you experienced when having to access health care outside of VA facilities?
2. Why is it important for veterans with spinal cord injuries and disorders to be able to access inpatient mental health rehabilitation programs?

Responses were unavailable at the time of publication. Contact U.S. Senate Committee on Veterans' Affairs for additional information.
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**Senator Maggie Hassan
Questions for the Record
Senate Veterans' Affairs Committee
Strengthening Services for Veterans with Spinal Cord Injury and Disorder
September 17, 2025**

Question for Robert L. Thomas, Jr., *National President and Chairman of the Board, Paralyzed Veterans of America*

1. In the testimony you submitted to the Committee, you discussed the need to update VA facilities for veterans with spinal cord injuries and disorders. Can you please discuss this further and provide some additional details about the infrastructure issues that are affecting spinal cord injury and disorder veterans, and how important it is for VA facilities to be upgraded to support them?

Response: As buildings and their systems age, maintaining operational efficiency, safety, and compliance becomes increasingly complex. Currently, VA's 25 acute care centers and six long-term care centers range in age from four to 70 years with an average age of nearly 40 years old. Many of the older ones have not been fully renovated, which is why we have seen an increase in the number of disruptive infrastructure failures at several of them. For example, one of our "middle aged" facilities is currently 37 years old. Due to age and deterioration, it has experienced a couple of significant issues within the past year alone. In September 2024 a plumbing piping system failed flooding half of the SCI/D Center. The flood forced the immediate evacuation of the acute and long-term care units and ultimate relocation of veterans with SCI/Ds into unaffected patient care units and an adjacent community living center. Fortunately, the medical center was able to repair the plumbing system and move residents back into the SCI/D Center in late October 2024. Additionally, the electrical system at this Center is undersized to accommodate the current level of electrical demand for equipment and devices and needs to be upgraded. This is a common problem with many of VA's older SCI/D facilities, and it limits opportunities to treat patients, let alone effectively renovate areas of the center while waiting for a replacement center to be funded, designed and constructed.

Over half (56 percent) of the department's 25 acute care SCI/D centers are still using four-bed patient rooms and shared bathrooms which are not allowed by VA requirements. SCI/Ds are particularly vulnerable for both community-acquired and healthcare-associated infections due to factors such as diminished immunity, frequent contact with the healthcare system and use of invasive medical devices like catheters. Due to infection control issues in the shared bedrooms and bathrooms, lone veterans with an SCI/D are frequently isolated in a four-bed patient limiting bed availability and veterans' access to care by as much as 75 percent.

We want to point out that the VA has already invested significant initial design costs for major design projects at several SCI/D centers, only to put them on hold due to poor budget management or other factors. Expediting the completion of these readily achievable projects

would greatly improve the SCI/D system of care and in many cases eliminate the problems described above. For your convenience, we've attached detailed listings of all of VA's pending SCI/D-related construction projects, so you have a better understanding of how many of them have gone unaddressed year after year. Also, we would be more than happy to discuss the contents of these lists with you or your staff.

As stated previously, PVA strongly believes that VA should return to the past practice of placing greater emphasis on funding facilities that support the types of services, like SCI/D care, which the department uniquely provides. Greater investment in these areas would greatly strengthen VA's specialty care services and ensure their future availability.



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SCI/D LONG-TERM CARE CENTERS PRIORITIES Updated October 2025

- Eliminate all shared Resident Bedrooms and Bathrooms while maintaining the VA-Mandated SCI/D LTC bed totals at each hub
- Increase quantity of SCI/D Long-Term Care beds

HUB	VISN	PRIORITY PROJECT
Augusta, GA ¹	7	New SCI/D Long-Term Care Center at Uptown Campus <u>Project Origination:</u> TBD <u>Design Status:</u> Not submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Brockton, MA	1	Option 1: New 96-Bed Long-Term Care Center <u>Project Origination:</u> 2009 <u>Design Status:</u> 65% Construction Documents (2012) <u>Construction Status:</u> TBD Option 2: SCI/D Long-Term Care Center Expansion and Renovation <u>Project Origination:</u> 2019 <u>Design Status:</u> Submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Dallas, TX	17	New SCI/D Long-Term Care Center <u>Project Origination:</u> 2008 <u>Design Status:</u> 100% Construction Documents Complete (2020) <u>Construction Status:</u> Construction Completion schedule January 2027 Additional 30-Bed SCI/D Long-Term Care Center <u>Project Origination:</u> 2021 <u>Design Status:</u> Submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Hampton, VA	6	SCI/D Long-Term Care Center Expansion and Renovation <u>Project Origination:</u> 2011 <u>Design Status:</u> 95% Construction Documents Complete (2023) <u>Construction Status:</u> Anticipated Completion FY29

HUB	VISN	PRIORITY PROJECT
Hines, IL	12	SCI/D Long-Term Care Center Expansion and Renovation <u>Project Origination:</u> TBD <u>Design Status:</u> Not submitted to SCIP - No Current Funding <u>Construction Status:</u> TBD
Long Beach, CA	22	New SCI/D Long-Term Care Center <u>Project Origination:</u> 2021 <u>Design Status:</u> Submitted to SCIP – No current funding <u>Construction Status:</u> TBD
Milwaukee, WI ¹	12	New SCI/D Long-Term Care Center <u>Project Origination:</u> TBD <u>Design Status:</u> Not submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Minneapolis, MN ¹	23	New SCI/D Long-Term Care Center <u>Project Origination:</u> 2017 <u>Design Status:</u> Submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Palo Alto, CA ¹	21	New SCI/D Long-Term Care Center <u>Project Origination:</u> 2019 <u>Design Status:</u> Submitted to SCIP - No current funding <u>Construction Status:</u> TBD
San Diego, CA	22	New SCI/D Long-Term Care Center <u>Project Origination:</u> 2010 <u>Design Status:</u> Design completed 2019 <u>Construction Status:</u> Scheduled for completion January 2026
St. Louis, MO (JB) ¹	15	New SCI/D Long-Term Care Center <u>Project Origination:</u> TBD <u>Design Status:</u> Not submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Seattle, WA ¹	20	New SCI/D Long-Term Care Center <u>Project Origination:</u> TBD <u>Design Status:</u> Targeting FY28 SCIP Submittal <u>Construction Status:</u> TBD

HUB	VISN	PRIORITY PROJECT
Tampa, FL	8	SCI/D Long-Term Care Center Expansion and Renovation <u>Project Origination:</u> 2020 <u>Design Status:</u> Project Book Completed in 2023 <u>Construction Status:</u> TBD

1. These SCI/D Centers currently do not have a Long-Term Care Center and PVA Architecture is actively advocating for these VA Medical Centers to start planning due to the lack of community resources that meet the unique and complicated needs of our members.



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SCI/D PROJECT DELAYS

Updated October 2025

- The following SCI/D Centers have projects that were advocated for improved accessibility, eliminate all four (4) patient bedrooms and shared bathrooms and increase therapy gym capacity.
- Majority of projects listed below have focused multiple years of VA staff time, effort and funding with little-to-no progress

HUB	VISN	PRIORITY PROJECT
Albuquerque, NM	22	SCI/D Acute Care Center Expansion and Renovation <u>Project Origination:</u> 2014 <u>Design Status:</u> 100% Construction Documents Complete (2024) <u>Construction Status:</u> Project Cancelled – No Funding
Augusta, GA	7	SCI/D Acute Care Center Expansion and Renovation <u>Project Origination:</u> TBD <u>Design Status:</u> Submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Brockton, MA	1	SCI/D Long-Term Care Center Expansion and Renovation <u>Project Origination:</u> TBD <u>Design Status:</u> Submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Bronx, NY	2	New 92-bed SCI/D Center <u>Project Origination:</u> 2012 <u>Design Status:</u> 65% Design Development Complete (2014) <u>Construction Status:</u> Project Cancelled – No Funding
Cleveland, OH	10	SCI/D Acute Care Center Outpatient Clinic Expansion <u>Project Origination:</u> 2018 <u>Design Status:</u> 100% Construction Documents Complete (2019) <u>Construction Status:</u> Project Cancelled – Future FY28 SCIP Re-Submission
Dallas, TX	17	SCI/D Acute Care Center Renovation <u>Project Origination:</u> TBD <u>Design Status:</u> Not submitted to SCIP - No current funding <u>Construction Status:</u> TBD

HUB	VISN	PRIORITY PROJECT
Denver, CO	19	SCI/D Home Environment Apartment Renovation <u>Project Origination:</u> July 2024 <u>Design Status:</u> Design completed September 2025 <u>Construction Status:</u> TBD
Hampton, VA	6	SCI/D Long-Term Care Center Expansion and Renovation <u>Project Origination:</u> 2011 <u>Design Status:</u> 95% Construction Documents Complete (2022) <u>Construction Status:</u> FY26 Funded- Anticipated Completion FY29
Hines, IL	12	New SCI/D Long-Term Care Center <u>Project Origination:</u> TBD <u>Design Status:</u> Not submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Memphis, TN	9	SCI/D Outpatient Clinic Addition <u>Project Origination:</u> January 2019 <u>Design Status:</u> Design completed December 2019 <u>Construction Status:</u> 90% completed, currently on hold awaiting restart SCI/D Acute Care Patient Unit 1 East Renovation <u>Project Origination:</u> April 2022 <u>Design Status:</u> 100% Construction Documents Complete (2023) <u>Construction Status:</u> Awaiting construction funding SCI/D Acute Care Center Multi-Phased Expansion and Renovation and New 20-Bed SCI/D Long-Term Care Center <u>Project Origination:</u> TBD <u>Design Status:</u> Submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Miami, FL	8	SCI/D Acute Care Center Expansion and Renovation <u>Project Origination:</u> TBD <u>Design Status:</u> Submitted to SCIP - No current funding <u>Construction Status:</u> TBD
Richmond, VA	6	SCI/D Expansion (Phase 2) <u>Project Origination:</u> 2023 <u>Design Status:</u> 35% Design Development (2024) <u>Construction Status:</u> Delayed- Funding not Approved FY26

HUB	VISN	PRIORITY PROJECT
Richmond, VA	6	SCI/D Acute Care Wing '1V' Renovation (Phase 3) <u>Project Origination:</u> 2018 <u>Design Status:</u> 100% Construction Documents Complete (2019) <u>Construction Status:</u> Project Cancelled- Not Funded
San Antonio, TX	17	SCI/D Acute Care Center Patient Care Unit (PCU) Renovation <u>Project Origination:</u> August 2022 <u>Design Status:</u> 100% Construction Documents Complete (2024) <u>Construction Status:</u> Awaiting completion of SCI/D PCU temporary relocation
Seattle, WA	20	SCI/D PT/OT Gym Expansion (Phase 1) <u>Project Origination:</u> 2018 <u>Design Status:</u> 100% Construction Documents Complete (2020) <u>Construction Status:</u> Delayed- Not Approved FY26 SCI/D Interior Renovation (Phase 2) <u>Project Origination:</u> 2018 <u>Design Status:</u> 100% Construction Documents Complete (2020) <u>Construction Status:</u> Project Cancelled New SCI/D Long-Term Care Center <u>Project Origination:</u> TBD <u>Design Status:</u> Targeting FY28 SCIP Submittal <u>Construction Status:</u> TBD
San Juan, PR	8	Relocated Dedicated SCI/D PT/ OT Gym <u>Project Origination:</u> 2018 <u>Design Status:</u> 25% Schematic Design Completed (2024) <u>Construction Status:</u> Design Funding Approved FY26
St. Louis, MO (JC)	15	New Bed Tower w/ 30-bed SCI/D Acute Care Center <u>Project Origination:</u> 2018 <u>Design Status:</u> 25% Schematic Design in progress (2024) <u>Construction Status:</u> Delayed- Pending FY28 approval
West Roxbury, MA ¹	1	SCI/D Acute Care Center Expansion and Renovation <u>Project Origination:</u> TBD <u>Design Status:</u> Major Project submitted to SCIP – no current funding <u>Construction Status:</u> TBD

1. This SCI/D Center is currently located on three separate floors two of which are above grade causing significant safety issues during emergency egress events.

Statement for the Record



Statement for the Record

Veterans MS Alliance (VMSA)

Before the U.S. Senate Committee on Veterans' Affairs

Hearing on "Strengthening Services for Veterans with Spinal Cord Injury and Disorder"

September 17, 2025

Chairman Moran, Ranking Member Blumenthal, and members of the Committee, on behalf of the Veterans MS Alliance (VMSA), thank you for the opportunity to submit this statement for the record. We are deeply grateful for the Committee's ongoing commitment to addressing the needs of veterans living with complex neurological conditions.

The Need

Multiple sclerosis (MS) is a chronic and unpredictable disease of the central nervous system, consisting of the brain and spinal cord, that can cause a wide range of symptoms from mobility impairment and fatigue to cognitive decline. Veterans and service members are at a significantly higher risk of developing MS compared to the general population. In fact, the [prevalence of MS among veterans](#) is 2–3 times higher than in civilian populations for certain groups.¹

This reality not only has impacts on the health and quality of life of veterans, but also military readiness and the long-term costs to the Department of Veterans Affairs (VA) and the broader healthcare system.

¹ Deussing EC, Jankosky CJ, Clark LL, Otto JL. Estimated incidence of multiple sclerosis among United States Armed Forces personnel using the Defense Medical Surveillance System. *Mil Med.* 2012 May;177(5):594-600. doi: 10.7205/milmed-d-11-00326. PMID: 22645888.

Our Mission & Work

The Veterans MS Alliance was founded to fill a critical gap in care and support for veterans with MS. VMSA aims to provide a veteran-centered support model that serves as a gateway for veterans and families to connect with a comprehensive set of services, resources, and community. We work in partnership with organizations such as the National MS Society and Paralyzed Veterans of America to amplify impact, build programs, and ensure no veteran faces MS alone. Our mission is to remove the administrative barriers that too often stand between veterans with MS and the benefits and services they have earned.

Veteran Experience

The challenges of navigating MS within the VA system are not theoretical; they are lived experiences for countless veterans. Even those with extensive knowledge of the VA process and connections to veteran-focused organizations often struggle for years to access consistent care. For example, we know of veterans who, despite years of living with MS, were only able to begin receiving care through the VA after years long delays. This reality underscores how complex and burdensome the process can be, even for those who are well-informed and persistent.

Veterans with MS, who are already managing fatigue, pain, cognitive impairment, and mobility challenges, should not also have to endure repeated administrative obstacles to access the benefits and care they deserve.

VA Rating for MS

Under the current rating system, MS as a diagnosis is listed at 30%. Once this 30% rating is awarded, it falls entirely on the veteran to continue documenting and reopening their case to get the full range of symptoms associated with the disease recognized and rated. The current 30% rating does not reflect the profound and debilitating nature of the disease. This initial rating fails to account for its broad and progressive impact, leaving veterans to repeatedly reopen their cases and document additional symptoms just to receive proper recognition. By setting the bar so low with the current 30% rating, the system places an unfair burden on veterans. The baseline rating must be reconsidered to accurately reflect the severity of MS and its impact on those who serve.

The founder of VMSA has lived this experience firsthand. Despite working with highly trained and experienced Veterans Service Officers, and despite years of persistence, her full range of MS-related symptoms and medical issues has yet to be reflected in her disability rating. This lived reality underscores the broader systemic problem: if even a determined veteran, supported by knowledgeable professionals, struggles to secure an

accurate rating, countless others without such resources are left at an even greater disadvantage.

While we are grateful that MS is considered a presumptive service-connected condition, the current structure is an undue burden. Many veterans, already managing fatigue, cognitive impairment, and mobility issues, do not pursue a more accurate rating, leaving them without the support they critically need. We believe this process can and must be streamlined.

Requests to the Committee

We respectfully request that the Committee work with VA to address the following actions:

1. Increase awareness and outreach to veterans regarding MS.

Many veterans and VA healthcare staff are unaware of higher prevalence of MS in the veteran community, of MS symptoms, or of the fact that MS is a presumptive service-connected condition. Increased outreach would ensure earlier diagnosis and treatment, which improves outcomes and reduces long-term costs.

2. Streamline the VA disability rating process for MS.

The current system places too heavy a burden on veterans to prove and re-prove their symptoms. We urge the Committee to work with VA to develop a rating process that accounts for the full spectrum of MS symptoms from the beginning, rather than relying solely on the 30% baseline. There is a wealth of scientific literature documenting the common and progressive symptoms of MS, which can provide the evidence base needed to reform and simplify the process for veterans.

3. Expand access to VA specialty care and Telehealth for veterans with MS.

MS requires care from neurologists and other specialists, yet many veterans face long waits or live far from specialty clinics. Telehealth can help bridge these gaps, particularly for veterans with mobility challenges who may struggle to travel long distances. Expanded access would reduce barriers to care and ensure veterans can receive timely treatment and disease management.

Conclusion

MS is a lifelong disease that affects not only the health of veterans but also their families, communities, and the VA system itself. Veterans have already given so much in service to our nation; they should not have to fight for recognition, care, or community after diagnosis.

VMSA stands ready to partner with the Committee, VA, and allied organizations to ensure veterans with MS receive the care, support, and dignity they deserve.

Thank you for your commitment to strengthening services for veterans living with spinal cord injury, disorders, and MS.