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501(C)(3) Veterans Non-Profit

STATEMENT OF

ROBERT THOMAS

NATIONAL PRESIDENT AND CHAIRMAN OF THE BOARD

PARALYZED VETERANS OF AMERICA

BEFORE THE

HOUSE VETERANS' AFFAIRS COMMITTEE

CONCERNING

"A CALL TO ACTION: MEETING THE NEEDS OF THE SPINAL CORD INJURY AND DISORDERS (SCI/D) VETERAN COMMUNITY"

JUNE 13, 2024

Chairman Bost, Ranking Member Takano, and members of the committee, I appreciate the opportunity to testify on behalf of Paralyzed Veterans of America (PVA) and the tens of thousands of veterans with spinal cord injuries and disorders (SCI/D) who rely heavily on the benefits and healthcare available through the Department of Veterans Affairs (VA). The VA is the care provider of choice for veterans with catastrophic disabilities. In truth, it is the only choice for veterans with SCI/D.

Since a service-connected spinal cord injury (SCI) left me paralyzed, I have spent nearly 35 years navigating the VA's health care and benefits systems. The care and benefits available through the VA not only saved my life, but have given me the ability to have a family, work, and serve my fellow veterans, most recently as PVA's National President and Chairman of the Board. I use the Louis Stokes VA Medical Center in Cleveland, Ohio. I'm fortunate that I have a VA SCI/D center less than 30 miles from my home. It gives me tremendous comfort knowing that there are medical professionals who understand my injury and can help me navigate the healthcare challenges that result from having an SCI.

I receive my medical care through VA's direct care system, except when emergencies dictate receiving care at the nearest hospital. About 10 years ago, I was in a motor vehicle accident. Following the accident, I was taken to a community hospital for immediate care. My wheelchair was in my now damaged vehicle and I was stuck on a bed, unable to get up or move. During the accident, I hit the spinner nob on my steering wheel that helps me drive my adapted vehicle. I recall the emergency room doctor asking me if I was in pain from the accident. I told



the doctor that I was paralyzed and unable to feel such pain. Rather than give me x-rays to see if I had broken ribs, I was given pain medication and released.

I knew that I needed to get to the VA as they know how to care for veterans with SCI/D. Once at the VA, I was able to get a thorough exam. Thankfully, my ribs were only bruised and not broken. I was fortunate. I know first hand why people with SCI who didn't serve tell me that they wish they could access the care and supports available through the VA.

The lives of veterans with SCI/D depend on having access to VA-provided care through VA's SCI/D system. Without this care, I don't know where I would be and many of the men and women seated behind me would say exactly the same if they were speaking with you today. That's why we become very concerned when SCI/D centers have to close beds because they don't have enough nurses to properly staff them. It's why we become concerned when our members don't have access to quality in patient mental health and substance use disorder treatment. It's why we become concerned when our medical centers aren't kept up to date with needed equipment and infrastructure enhancements. We need the care that's available through the VA for our ongoing health and independence.

Veterans Health Administration (VHA) Directive 1176 provides the staffing guidelines needed in order for SCI/D centers to properly care for veterans with SCI/D. 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. That's why it's important for SCI/D centers to have higher staffing levels than other wards. Those higher numbers are actually the minimum of what is needed to provide an excellent standard of care for veterans with catastrophic disabilities.

When we hear from medical center leaders that the staffing requirements don't have to be adhered to, we know that means SCI/D veterans will not receive the proper level of care. It also means overworked clinical providers who must fill in the staffing gaps to help ensure that veterans do not fall through the cracks and veterans with SCI/D waiting longer for assistance from nurses who are stretched to the breaking point. Despite the increased care that veterans with SCI/D require, not all SCI/D nursing staff, such as licensed practical nurses and certified nursing assistants, receive specialty pay, which often elevates turnover rates.

We need every level of VHA, including VA Central Office, the Veterans Integrated Services Networks, and the individual medical facilities, to take seriously the requirements of VHA Directive 1176. It's based on the needs of catastrophically disabled veterans and what's best for our care. We need the VA to properly deploy its resources and request the funding it actually needs to provide the level of care for paralyzed veterans outlined in this directive. If the VA system of care isn't properly funded to ensure that staffing levels meet the needs of veterans with SCI/D, then our government is defaulting on its obligation to them. It is defaulting on the promise made to care for us should we become catastrophically injured or ill in our service to this great nation. This is a disservice to those who have served and dissuades those who would serve.

It's not just acute care post-injury or diagnosis that we depend on, it's also the lifelong care that allows us to remain in our homes, to work and volunteer, and live in our communities with our families. My wife, LaShon, is not only my spouse, she is also my caregiver. Her daily support is necessary to help me get out of bed each day, to take care of my grooming needs, dress, and satisfy a number of other activities of daily living (ADL). In fact, it is only due to her support that I am able to be with you today. I can't overstress the importance of caregiver support. It's comforting knowing that there is someone available in the middle of the night if I have a health issue or need assistance. I can't imagine being at home alone without her support, comfort, and security.

I'm grateful that Congress and the VA have begun to recognize the sacrifice of family caregivers. I was approved to join VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC). I appreciate the recognition it provides to my wife for the years of support she has given to me. However, even though I am a quadriplegic, I was assigned to the lowest tier. Out of curiosity, I asked a nurse in the program what it would take for a veteran to be placed in the higher tier. Essentially, she told me they would have to be bedbound and incoherent in order for that to happen. VA's current PCAFC requirement fails to recognize that veterans who are able to have a measure of independence still may need significant caregiver assistance in completing their ADLs. Paralyzed veterans need the VA to revise its rule and fix this problem.

Although my wife provides most of my home care needs, assisting a person with an SCI/D is a 24/7, 365-day duty. I often depend on other family members who can assist me so that my wife can take care of her own healthcare and other personal needs. Some of my fellow veterans must solely depend on paid caregivers from the direct care workforce. That's why PVA is fighting so hard for passage of the Elizabeth Dole Home Care Act. This legislation would expand access to home and community-based services throughout the VA, including the Veteran Directed Care (VDC) program. VA recently expanded the program to my VA and I'm now in the process of hiring caregivers, including my sister, to assist me. This program is critical for SCI/D veterans.

Unfortunately, Andrew, a veteran with ALS, had to switch from the VDC program to the PCAFC earlier this year because expenses related to his care were expected to exceed the cap on how much the VA can spend on each veteran's home care. The VA is prohibited from spending more than 65 percent of what it would cost if a veteran was provided nursing home care. I mentioned Andrew's situation when I testified in March. Since then, we have learned that switching programs won't keep him under the cap, leaving his family to scramble as they try to figure out how to accommodate his care at home.

The Elizabeth Dole Home Care Act would fix this problem. We need Congress to pass the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act (H.R. 8371), which includes this important legislation. I and my fellow paralyzed veterans have waited patiently for Congress to pass the provisions in this bill. We are tired of waiting for improved home care supports and believe that the backing of every major veterans organization should be enough to get H.R. 8371 through Congress, without further delay. Andrew can't wait anymore. His wife Lisa can't wait anymore. We can't wait anymore for Congress to do the right thing and pass this bill.

For veterans with SCI/D who need access to facility-based long-term care, the options are quite limited. I'm fortunate that my SCI/D center has a specialized long-term care facility. Most veterans are not so lucky. In fact, there are less than 200 authorized long-term care beds in the entire VA SCI/D system of care. The number of beds currently available is actually closer to 150. There are two projects currently under construction that will add long-term care beds in Dallas and San Diego. We are grateful that these major construction projects received funding, however, they will only superficially serve the need.

Community nursing homes are not always a back stop for veterans with SCI/D. Veterans who have the highest chronic care needs may have difficulty finding a facility that will accept them, especially close to home. We need VA to prioritize projects and initiatives that will result in more long-term care beds for those veterans who need the supports that facility-based care provides. These veterans can't depend on the community to provide the quality care they need.

I'm grateful for the support I receive through the VA, but my fellow veterans and I are concerned about the future of the VA's SCI/D system of care. We worry about whether or not we will have the supports and services needed to help us remain healthy throughout our lives. We cannot be served in the community the way we can

be served through the VA. That's why we need robust staffing, updated infrastructure, and access to services and supports as we age. Otherwise, we are in danger of living diminished, shortened lives. This is not what we fought for and it's not what we will settle for.

Thank you for the opportunity to provide you with my perspective on VA's SCI/D system of care. I would be happy to answer any questions.

Information Required by Rule XI 2(g) of the House of Representatives

Pursuant to Rule XI 2(g) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2023

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$479,000.

Fiscal Year 2022

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$ 437,745.

Disclosure of Foreign Payments

Paralyzed Veterans of America is largely supported by donations from the general public. However, in some very rare cases we receive direct donations from foreign nationals. In addition, we receive funding from corporations and foundations which in some cases are U.S. subsidiaries of non-U.S. companies.

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 Medical Center. 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 elected as President of PVA May 2023 during the organization's 77th Annual Convention, to begin a new, one-year term on July 1, 2023. 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 President of 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.