

ANNUAL LEGISLATIVE PRESENTATION

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NATIONAL PRESIDENT

PARALYZED VETERANS OF AMERICA

BEFORE A JOINT HEARING OF THE

HOUSE AND SENATE COMMITTEES ON VETERANS' AFFAIRS

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Chairman Tester, Chairman Takano, Ranking Member Moran, Ranking Member Bost, and members of the Committees, I appreciate the opportunity to present Paralyzed Veterans of America's (PVA) 2022 policy priorities. For more than 75 years, PVA has served as the lead voice on a number of issues that affect severely disabled veterans. Our work over the past year includes championing critical changes within the Department of Veterans Affairs (VA) and educating legislators as they have developed important policies that impact the lives of paralyzed veterans.

Today, I come before you with our views on the current state of veterans' programs and services, particularly those that impact our members—veterans with spinal cord injuries and disorders (SCI/D). Our concerns and policy recommendations are particularly important in light of the continuing discussions around the delivery of VA health care, including the review of the department's assets and infrastructure. Proper consideration must be given to how any such reforms will impact veterans, like PVA members, who must rely almost exclusively on VA for their health care, and specifically depend upon VA's specialized systems of care.

BACKGROUND—Our organization was founded in 1946 by a small group of returning World War II veterans, all of whom were treated at various military hospitals throughout the country as a result of their injuries. Realizing that neither the medical profession nor the government had ever confronted the needs of such a population, these veterans decided to become their own advocates and to do so through a national organization.

From the outset, PVA's founders recognized that other elements of society were neither willing nor prepared to address the full range of challenges facing paralyzed individuals, whether medical, social, or economic. They were determined to create an organization that would be governed by the members themselves and address their unique needs. Being told that their life expectancies could be measured in weeks or months, these individuals set as their primary goal to bring about change that would maximize the quality of life and opportunity for all people with SCI/D.

Over the years, PVA has established ongoing programs to secure benefits for veterans; review the medical care provided by the VA's SCI/D system of care to ensure our members receive timely, quality care; invest in research; promote education; organize sports and recreation opportunities; and advocate for the rights of veterans and all people with disabilities through legal advocacy and accessible architecture. We have also developed long-standing partnerships with other veterans service organizations (VSOs).

PVA, along with the co-authors of The Independent Budget (IB)—DAV (Disabled American Veterans) and the Veterans of Foreign Wars of the United States (VFW), continue to present comprehensive budget and policy recommendations to influence debate on issues critical to the veterans we represent. We recently released our budget recommendations to inform the debate on VA funding for fiscal years (FY) 2023 and 2024 advance appropriations.

COVID-19's CONTINUED IMPACT ON VA's SCI/D SYSTEM OF CARE

Health care providers and systems around the world have been hit hard by the pandemic with many systems, including VA, having to redirect resources to care for patients with COVID-19. Overall, VA has done a commendable job minimizing the pandemic's impact for veterans who are inpatients in one of the VA's 25 SCI/D facilities and those who reside in one of the six VA SCI/D long-term care centers. They have kept infections of inpatients and staff to a minimum and maintained stringent measures to protect this extremely vulnerable population.

The isolation of SCI/D patients, however, comes at a high cost. The lack of recreational activities, day trips, and in-person therapy sessions weigh heavily on the psyche of patients and adversely affect their physical and mental wellbeing. Limited caregiver and visitor access has also been very difficult for many paralyzed veterans, particularly those who live in long-term care centers. Regrettably, their VA medical providers have had to serve as their outlet for pent up frustrations.

Insufficient staffing within the SCI/D system is an enduring concern and its current shortfalls cannot be entirely attributed to the ongoing pandemic. For the past few years, staffing levels have hovered around 70 percent, meaning the system lacks nearly a third of the nurses it needs to properly care for the veterans it serves. VA needs the authority to provide additional pay, compensation, and retention incentives to make VA service more attractive to health care and related support professionals. Congress and VA should also place greater emphasis on providing specialty pay for Registered Nurses (RNs), Licensed Vocational Nurses (LVNs) and Certified Nursing Assistants (CNAs) who work within the SCI/D system of care.

The liberal use of telehealth has been a lifeline for thousands of SCI/D veterans who receive outpatient care through VA. However, SCI/D veterans are "high touch" patients. VA telehealth must not be viewed as a long-term solution to providing needed care. These veterans must be able to resume face-to-face meetings with their providers as quickly and as safely possible.

COVID-19 also caused the deferral of thousands of elective procedures, resulting in a huge backlog of care. However, in truth, the term "elective procedure" does not apply to our members because every touchpoint increases the department's ability to detect well-known secondary complications of an SCI/D such as bowel or urological complications, infections, autonomic dysreflexia, degeneration of the spine, pressure sores, overuse of the shoulders, and

compression syndromes. The early identification and treatment of complications related to lifestyle, aging, and living with an SCI/D are critical. VA has resumed yearly comprehensive preventative health evaluations for these veterans in many locations. It is imperative that these annual evaluations be conducted as quickly as possible to maximize veterans' health, prevent complications, and help them get the most out of life.

PVA PRIORITY: STRENGTHEN AND IMPROVE VA'S HEALTH CARE SYSTEM AND SERVICES

Protect Specialized Services—PVA firmly believes VA is the best health care provider for disabled veterans. The VA's SCI/D system of care provides a coordinated life-long continuum of services for veterans with an SCI/D that has increased the lifespan of these veterans by decades. VA's specialized systems of care follow higher clinical standards than those required in the private sector. Preserving and strengthening VA's specialized systems of care—such as SCI/D care, blind rehabilitation, amputee care, and polytrauma care—remains the highest priority for PVA. However, if VA continues to woefully underfund the system and understaff facilities, their capacity to treat veterans will be diminished, and could lead to the closure of facilities and reductions in services offered to them.

Staffing Vacancies—While the roots of the current staffing crisis precede the pandemic, there's no denying that COVID-19 has made matters much worse. Despite hiring thousands of staff through relaxed hiring and management practices to respond to the pandemic, VA's staffing levels remain relatively unchanged. Comparing VA's FY 2021 third and fourth quarter VA Maintaining Internal Systems and Strengthening Integrated Outside Networks (MISSION) Act (P.L. 115-182) Section 505 reports, VA closed out the third quarter with 33,139 vacancies and the fourth quarter with 47,310 vacancies. The increase of 14,171 vacancies means Veterans Health Administration (VHA) staffing levels now mirror its November 2019 levels when the department had 49,000 openings. The prolonged lack of adequate staffing reduces patient safety and requires existing nursing and other clinical staff to work long hours which contributes to work-related injuries and staff burn out.

VA's ability to meet the highest standards of care for our veterans relies on more than just having the right number of physicians and nurses. They also need qualified and well-trained housekeepers. At the end of FY 2021, VA reported that only 55 percent of its 3,566 environmental positions were filled which heightens the health risks to veteran patients, particularly those who have compromised immune systems.

Lengthy, cumbersome hiring processes make it difficult to hire and retain staff, which prohibits SCI/D centers from meeting adequate staffing levels necessary to care for this specialized population. PVA estimates there is a shortage of several hundred nurses in the SCI/D system of care. Considering veterans with SCI/D are a vulnerable patient population, the reluctance to meet legally mandated staffing levels is tantamount to willful dereliction of duty. SCI/D centers with nursing shortages limit bed availability for admission to an SCI/D center, reducing access for specialized care delivery. Veterans are often admitted to a VA non-SCI/D ward and treated by untrained SCI/D clinicians for days or weeks until an SCI/D bed becomes available. As SCI/D long-term care facilities are exceptionally limited, veterans with SCI/D who have chronic medical issues are being treated in community institutions, by providers not trained in SCI/D. This results in compromised quality of care and poor outcomes.

Recently, VA unveiled a 10-step human infrastructure plan that includes working with Congress to increase pay and compensation for health care providers; expedite the hiring process by leveraging hiring authorities and redesigning the national onboarding process; invest in education by funding scholarship programs for employees and working with the President on loan forgiveness; and better protect employees from COVID-19 by pursuing the latest workplace safety measures.

The VA Nurse and Physician Assistant Retention and Income Security Enhancement (VA Nurse and Physician Assistant RAISE) Act (H.R. 5575) would support the first step of the department's plan by allowing VA to make critical adjustments to current pay limitations and significant compressed pay schedules between compensation levels. We urge Congress to pass this bill without delay and provide VA with the resources it needs to fulfill its mission to take care of veterans.

Infrastructure—Inclusion of the Asset and Infrastructure Review (AIR) process in the VA MISSION Act was an important step toward creating a more flexible and dynamic VA system needed to provide quality care for future veterans. VA recently delayed releasing its recommendations for realigning health care facilities due to COVID but we are more concerned that the members of the Commission itself have not been named. Deciding whether certain aging VA facilities should be closed entirely or replaced with new structures should not be rushed. The fact that panel members have not yet been seated threatens to undermine the effectiveness of, as well as confidence in, the AIR process.

In reviewing VA's infrastructure, decisionmakers must remember that VA's SCI/D system of care is unique and not replicated outside of VA. The VA SCI/D system of care provides a coordinated life-long continuum of services for SCI/D veterans and is highly regarded as one of VA's Centers of Excellence. Congress and VA must make a concerted effort to ensure the system is preserved.

Oversight of VA MISSION Act Implementation—Congress should continue its rigorous oversight of the VA MISSION Act to ensure VA meets its obligations to our veterans under the law, including a stringent evaluation of the Veterans Community Care Program (VCCP). The VA MISSION Act directed needed changes to VA's delivery of health care in the community and at VA health care facilities around the country. PVA supported the VA MISSION Act. We believe that integrated community care will strengthen VA's ability to serve veterans with catastrophic disabilities.

Regarding the accessibility of care in the community, we have heard of several instances where care was delayed because consults were lost or slow to be processed. In some cases, the veteran was approved for care in the community, but the provider never received the necessary paperwork, which hampered their ability to deliver care. Some veterans took matters into their own hands to coordinate care that VA staff should have handled. There are still instances where veterans were erroneously charged for care they received through the VCCP or Urgent Care. Other times, veterans were told they would be contacted regarding care they would receive in the local community, but the call never came.

Additionally, veterans and their caregivers have experienced problems in receiving prompt payment through VA's Bowel and Bladder program, which falls under the VCCP. Bowel and

bladder care for veterans with SCI/D is a supportive and necessary medical service for those unable to manage bowel and bladder functions independently. The clinic of jurisdiction, or VA medical facility, authorizes such care under the VCCP to enrolled veterans with SCI/D who are dependent upon others for bowel and bladder care while residing in the community. 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.

For caregivers to receive payment for the care they provide, they must follow a process of submitting timesheets. Over the past year, PVA has received a steady stream of complaints from members and their caregivers about the bowel and bladder program. They range from VA failing to pay caregivers after they submitted their claim to home health agencies not receiving timely payment. In one case, VA failed to compensate the agency nearly \$180,000 for services provided to veterans in their care.

The department recently changed its policy and all claims for reimbursement through the bowel and bladder program are being processed through a single, nationwide location. From our experience, it's been a rocky start and many original problems like slow, or no payments still exist. Providing this specialty care is critical to the health and well-being of veterans with SCI/D. Any lapses in the delivery of this care, even one day, can have a detrimental impact on the health of SCI/D veterans. Given the serious nature of the payment issues described above and the adverse impact they have on veterans and providers alike, we urge the Committees to closely monitor the implementation of the department's new payment process.

Mental Health—Wounds and injuries that result in paralysis for military personnel during deployments are highly complex and difficult to evaluate and treat. These challenges are complicated by the reality that gender differences call for an advanced understanding of differing health care needs to be effective, particularly in cases involving catastrophic injuries or illnesses and mental health. Thus, it is essential more research is conducted on how mental illness presents in veterans with SCI/D, especially women veterans.

There is also inconsistency in VA's ability to meet the inpatient mental health needs of veterans with catastrophic disabilities. VHA is obligated to provide inpatient mental health care to those in need, which includes veterans with SCI/D. According to VA, there is no readily available list of VA facilities that can provide on-site inpatient mental health care to veterans with SCI/D. Services provided vary based on Veterans Integrated Service Networks (VISNs) and local arrangements to provide care.

Congress should conduct oversight of VA's ability to meet the mental health needs of veterans with SCI/D, including the department's ability to handle the detoxification and withdrawal needs of individuals within this population living with substance use disorder. Currently, there are limited or no opportunities for inpatient residential substance abuse treatment for SCI/D patients.

Increased Access to Assisted Reproductive Technologies (ART)—Hundreds of veterans have been able to start or grow their families since VA began providing services to veterans with service-connected infertility. We are thankful for this provision and would like to see it made a permanent part of the health benefits package of veterans enrolled in VA health care.

We would also like to see the services expanded. VA's current temporary authority prohibits the use of gametes that are not a veteran's and his or her spouse's. Because they require donated gametes, they are ineligible for in vitro fertilization (IVF) through VA, which is confusing as donated gametes are authorized for use in VA-provided artificial insemination.

Also, due to the complex care needs of women veterans with SCI/D, many of these veterans are unable to carry a pregnancy to term. These women veterans need the services of a surrogate to have a child. We call on Congress to mandate that VA establish permanent authorization of ART to include IVF services, gamete donation, and surrogacy for veterans with service-connected infertility, and include the treatment of veterans' spouses in applicable cases.

To improve access to fertility services, Congress should pass the Veteran Families Health Services Act (H.R. 2734/S. 1280) or the Veterans Infertility Treatment Act of 2021 (H.R. 1957) to expand and improve access to ART for servicemembers and veterans and permanently authorize funding to provide IVF and ART.

Care of Women Veterans With SCI/D—Women are the fastest-growing demographic of veterans in the country. While this is truly something to celebrate, we rarely consider what it will mean to care for the growing number of women veterans seeking treatment at VA facilities. PVA's powerful cohort of women veterans can offer a unique perspective to accessing care when they engage with VA services. All women veterans deserve the highest standards when seeking gender-specific care, but access to these services is limited for many PVA members.

VA has a robust SCI/D system of care supporting the needs of paralyzed veterans; however, outside of that system, our members see limited access to care. One such limitation is that mammography services are often physically inaccessible to our women members. Mammography services are critical in ensuring the health of our women veterans who see an increased prevalence of breast cancer compared to their civilian counterparts.

One of our women members recently went to VA for a mammogram, and her experience was harrowing. This member has used a wheelchair since a military vehicle accident in 1999 left her with high-level paralysis that limits her arm function. Multiple staff attempted to lift and manipulate her body to attempt to perform a proper mammogram from her wheelchair. Understandably, this member doubts the accuracy of the scan since the machine was not fully accessible to a wheelchair user. This example is just one of many stories of women veterans not receiving equitable access to gender-specific health care. Passage of the Making Advances in Mammography and Medical Options for Veterans Act, or the MAMMO Act (H.R. 4794/S. 2533), would help ensure that women veterans with SCI/D will be able to receive improved access to mammography within VA and the community.

Equal access goes beyond mammography services. VA must ensure that all aspects of care are accessible to veterans with mobility limitations. OB/GYN clinics, routine medical exams, and other specialty appointments may also be inaccessible for non-ambulatory veterans. As VA and Congress work together to oversee the implementation of accessible medical equipment throughout the department, PVA asks for transparency and cooperation from both. On a related matter, H.R. 5212, the Improving Oversight of Women Veterans' Care Act of 2021, would require VA to produce an annual report on veteran access to any gender-specific care

that is outsourced to community care contracts. We know that veterans prefer to receive care at VA when available, and PVA believes this data would show a growing demand for accessible gender-specific care.

Emergency Care—On September 9, 2019, the U.S. Court of Appeals for Veterans Claims (CAVC) ruled in *Wolfe v. Wilkie* that VA's 2018 reimbursement regulation violates the Emergency Care Fairness Act of 2010 that requires VA to reimburse veterans for the emergency medical expenses they incur at non-VA facilities that are not covered by the veteran's private insurance. The CAVC certified the case as a class action and ordered the department to remedy its unlawful regulation by reimbursing veterans for all their past and future out-of-pocket emergency medical expenses not covered by the veteran's private insurance other than copayments. It has been over two years since the CAVA issued its ruling and VA still has not fully complied with it. VA must begin fully implementing the *Wolfe v. Wilkie* court ruling, which will require significant additional funding to meet the costs for previously provided emergency care.

PVA PRIORITY: IMPROVE ACCESS TO VA'S LONG-TERM SERVICES AND SUPPORTS

Insufficient Long-Term Care Beds and Services for Veterans with SCI/D—PVA continues to be concerned about the lack of VA long-term care beds and services for veterans with SCI/D. Many aging veterans with an SCI/D are currently in need of VA long-term care services. Unfortunately, VA is not requesting, and Congress is not providing, sufficient resources to meet the current demand. In turn, because of insufficient resources, VA is moving toward purchasing private care instead of maintaining long-term care in-house for these veterans. However, it is especially difficult to find community placements for veterans who are ventilator dependent or have bowel and bladder care needs.

Our nation's lack of adequate long-term care options presents an enormous problem for people with catastrophic disabilities who, because of medical advancements, are now living longer. There are very few long-term care facilities that are capable of appropriately serving veterans with SCI/D. VA operates six such facilities; only one of which lies west of the Mississippi River. All totaled, the department is required to maintain 198 authorized long-term care beds at SCI/D centers to include 181 operating beds. When averaged across the country, that equates to about 3.6 beds available per state.

Many aging veterans with SCI/D need VA long-term care services but because of the department's extremely limited capacity, they are often forced to 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.

VA has identified the need to provide additional SCI/D long-term care facilities and has included these additional centers in ongoing facility renovations, but most of these plans have been languishing for years. Last year, work began on a replacement acute SCI/D care facility in San Diego that will add 20 new long-term care beds into the system. Next year, construction is expected to begin on a new long-term care SCI/D center at the VA North Texas Health Care System, designed to include 30 SCI/D long-term care beds. If everything stays on track, the project could be completed sometime in 2025.

The North Texas project also includes shell space for an additional 30 long-term care beds 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 fully 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.

PVA strongly recommends that Congress provide supplementary funding to construct the full complement of 60 SCI/D resident beds at the VA North Texas Health Care System to complete the project in one construction phase.

Improve Availability of VA’s Home and Community-Based Services (HCBS)—In February 2020, the U.S. Government Accountability Office (GAO) released a report entitled, “Veterans’ Use of Long-Term Care Is Increasing, and VA Faces Challenges in Meeting the Demand.”¹ The report describes the use of and spending for VA long-term care and discusses the challenges VA faces in meeting veterans’ demand for long-term care and examines VA’s plans to address those challenges. From FY 2014 through FY 2018, VA data shows that the number of veterans receiving long-term care in these programs increased 14 percent (from 464,071 to 530,327 veterans), and obligations for the programs increased 33 percent (from \$6.8 to \$9.1 billion). VA projects demand for long-term care will continue to increase, driven in part by growing numbers of aging veterans and veterans with service-connected disabilities. Expenditures for long-term care will increase as well and are projected to double by 2037. According to VA officials, the department plans to expand veterans’ access to noninstitutional programs, when appropriate, to prevent or delay nursing home care and to reduce costs.

Long-term care services are expensive, with institutional care costs exceeding costs for HCBS. Studies have shown that expanding HCBS entails a short-term increase in spending followed by a slower rate of institutional spending and overall long-term care cost containment. Reductions in cost can be achieved by transitioning and diverting veterans from nursing home care to HCBS if they prefer it and the care provided meets their needs. VA spending for institutional nursing homes grew from \$3.5 billion to \$5.3 billion between 2007 and 2015; however, the number of veterans being cared for in this setting has remained relatively stable—partially attributed to expanding HCBS—indicating the cost of institutional care is rising. Despite doubling HCBS spending between 2007 and 2015, VA currently spends just over 30 percent of its long-term care budget on HCBS, which remains far less than Medicaid’s HCBS national spending average for these services among the states. VA must continue its efforts to ensure veterans integrate into and are able to participate in their community with reasonable accommodations.

Veteran Directed Care (VDC) Program

PVA strongly believes that VA and Congress must make HCBS more accessible to veterans. One of the programs that should be expanded to all VA medical centers is the VDC Program.

¹ [GAO-20-284, Veterans’ Use of Long-Term Care Is Increasing, and VA Faces Challenges in Meeting the Demand](#)

The VDC program allows veterans to receive HCBS in a consumer-directed way and is designed for veterans who need personal care services and help with their activities of daily living. Examples of the types of assistance they can receive include help with bathing, dressing, or fixing meals. It is also for veterans who are isolated, or whose caregiver is experiencing burden. Veterans are given a budget for services that is managed by the veteran or the veteran's representative.

Unfortunately, the VDC program is only available at 69 of VA's medical centers, with an enrolled population of about 4,900 veterans. Our members and other veterans are consistently asking for help in getting this program implemented at their VA health care facility. I am one of these veterans as this program is not available at the West Palm Beach VA, which is my VA medical center. Another PVA member has been waiting over two years for the Cleveland VA to implement the program. VA recently announced plans to add new VDC programs at 70 medical centers over five years but we believe Congress should accelerate that schedule and provide the dedicated funding necessary so every VA medical center can offer a robust VDC program as soon as possible.

Homemaker and Home Health Care Aides

Another concern our members have voiced is VA not authorizing adequate hours to care for their home care needs. In accordance with Title 38, 1720C subsection (d), the cost of VA home health care services shall not exceed 65 percent of the amount it would cost if the veteran was placed in a nearby nursing home. Even if we use costs at the higher end of the spectrum for nursing homes and home health aides, this formula should result in 50 hours or more of VA home care per month.

A VA physician determines and prescribes the number of home care hours a veteran needs in accordance with VHA Handbook 1140.6 entitled, "Purchased Home Health Care Service Procedures." A physician might put in a consult for 28 hours, but the request may only be authorized for 21 hours or less. Veterans often contact PVA as the hours of care they receive are not adequate, and we must initiate an appeal to secure more assistance.

In April 2018, VHA issued a Home Health Care Changes Educational Memo describing a new methodology for determining the number of home care hours veterans are to receive. The memo noted that the changes could significantly impact the amount of services available to individual veterans, "specifically [those] engaged with the Home Health Aid and Home Maker Services." While we recognize VA's challenge with limited resources and that our veterans are not the only ones using VA long-term care, is it reasonable for doctors who know their patients the best to prescribe 28 hours, but the veteran only be authorized for 14? Is it reasonable for a veteran with a terminal disease to only receive 4 or 6 hours a week? We believe that such little home care for catastrophically disabled veterans is in fact not reasonable.

Veterans also have had difficulty receiving authorized care as agencies are having trouble finding sufficient numbers of workers to provide needed care. So often, people assume that because VA provides caregivers or nurses, we must be well cared for. Unfortunately, that is not always the case. For example, on a Saturday morning late last fall no nurse arrived to help me get out of bed. The previous day the VA-contracted home health agency informed me that they had not been able to find a nurse to assist me on Saturday morning.

I called the scheduler and asked what I should do. She informed me that they would continue to try to find someone to assist me. When no one showed up the next morning, I called the agency and was notified that nobody would be coming by, even though they told me they would continue to make calls. Then, to my astonishment, they informed me that it was my responsibility to find a backup nurse for situations like this.

Trapped in my bed, I realized nobody was coming for me for hours. This meant I would not be able to care for my bladder needs. Also, I was not going to be able to take my medications or even drink anything. I was alone and felt abandoned.

Luckily, I was able to reach the nurse who was to assist me that evening. She was shocked at the situation and agreed to come help me. Without her assistance, I do not know what would have happened. Following this incident, I contacted my VA social worker and she informed me that it was my responsibility to have back up care if the agency cannot serve me. This was extremely disappointing to me. When care providers fail to see the seriousness of our situations, it is dehumanizing, and it cannot be allowed to continue.

Congress must recognize that the veterans' population is aging and that veterans like PVA members are catastrophically disabled and at the same time losing regained function due to age. Veterans who must rely on caregivers, including those who have limited or no family support, have earned the right to live in their homes in a dignified and safe manner.

Workforce Shortages

Even when veterans have access to VDC, it can be challenging to find home care workers. Veterans have the option of using an agency to help them find a caregiver, but that greatly reduces the funds the veteran has available for the hours of service they need. Agencies typically will charge 20 to 25 percent above what they pay their worker. So, while the veteran may be paying out the VA authorized limit of \$20 per hour, the actual worker will be making \$12 or \$13 per hour.

The shortage of caregivers or home care workers is not unique to VA. Acute shortages of home health aides and nursing assistants are cropping up across the country, threatening care for older Americans and those with serious disabilities. A vigorous national effort is needed now to help curb the effects of these shortages and bolster the direct care workforce. Legislation like H.R. 2999, the Direct CARE Opportunity Act, and S. 2344, the Supporting Our Direct Care Workforce and Family Caregivers Act, would expand workers' earning potential and provide the financial assistance for transportation, childcare, and housing that direct care workers need to stay in their jobs.

Increasing pay for essential caregivers is a necessary component of attracting and retaining a diverse set of people to provide HCBS but raising pay alone is not sufficient to solve the crisis we face. Utilizing multiple strategies such as raising public awareness about the need and value of caregiving jobs, providing prospective workers quality training, and developing caregiving as a sound career choice are a few of the other changes that could help turn this problem around.

Finally, for veterans with catastrophic disabilities, the need for a caregiver does not go away when hospitalized. Neither community hospitals nor VA medical centers are adequately staffed or trained to perform the tasks SCI/D veterans need. Currently, veterans with high-level quadriplegia and other disabilities must pay out of pocket for their caregivers or caregivers donate their time, as veterans cannot receive caregiving assistance through VA programs while in an inpatient status. This limitation must be addressed as these veterans not only need their caregivers while hospitalized but also to ensure that they can be timely discharged home.

In light of the need to improve access to HCBS, PVA is proud to support the Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act (H.R. 6823). This critically important legislation would make urgently needed improvements to VA HCBS, including several that target our concerns about current program shortfalls. We call on Congress to quickly pass this desperately needed legislation.

Assistance for Family Caregivers—VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC) also needs enhanced congressional oversight as VA sets to expand the program to veterans of all eras by October 1, 2022. This comes as VA has significantly tightened eligibility for the program making it both difficult to remain in and be deemed eligible for it. Between October 1, 2020, and January 6 of this year, the PCAFC received 127,500 caregiver applications. Of this number, 116,500 applications were processed and 16,600 were approved, and 101,500 were found not eligible and/or denied (87.9 percent).

VA has reported that the three main reasons veterans were found not eligible or denied are 1) applying during the wrong phase, 2) not having a service-connected condition rated 70 percent or greater, and 3) not meeting the requirement of needing full-time assistance with an activity of daily living (ADL). Two out of the three reasons given for denial were based on VA's stringent regulatory requirements which are inconsistent with Congress's legislative intent. These requirements make it impossible for many catastrophically disabled veterans to qualify for the PCAFC.

A PVA member with a spinal cord injury at the T-5 level is one of these individuals. He is service connected at 100 percent for loss of use of both feet; 100 percent for loss of anal sphincter control; and 60 percent for neurogenic bladder. His combined service-connected rating of Special Monthly Compensation, R-1, is the second highest level available. This veteran had been part of the PCAFC for several years but was recently informed that he is being discharged from the program because he no longer meets its requirements. The explanation that was given to the veteran was that it did not appear as if he needs assistance each time that he performs an ADL.

PVA is currently exploring the most appropriate appeal option for this individual, but he is a good example of the catastrophically disabled veterans that VA is eliminating from the program. The requirement for a veteran to need assistance with an ADL every time they perform that task was imposed by the department through the regulatory process. VA Secretary McDonough acknowledged problems with the new program eligibility rollout, including the high rate of denials during a Senate Veterans' Affairs Committee hearing on December 1, 2021, and more recently during a press conference in February. Congress and VA must examine the impact of veterans being removed from the program, including those with SCI/D, while ensuring that the final expansion of the program to all eras of eligible veterans is not delayed.

PVA PRIORITY: BENEFITS IMPROVEMENTS AND APPEALS REFORM IMPLEMENTATION

Oversight of the Veterans Appeals Improvement and Modernization Act (P.L. 115-55)—The Veterans Appeals Improvement and Modernization Act of 2017 ("AMA") was a historic change to the claims and appeals process. While VA continues to implement this historic legislation, we continue to have concerns, and look forward to working with VA and Congress on continued oversight and improvements.

Although AMA launched on February 19, 2019, PVA representatives still do not have full access to VA's claims and appeals tracking software program "Caseflow," newly designed for AMA. Additionally, our representatives do not receive timely notice of action in our members' claims – as representatives, we should receive notice when the claimant does.

While VA's Duty to Assist Veterans obligations under AMA have not decreased, several major claims development issues specifically affecting PVA members have become problematic: PVA representatives have not yet been informed of the new Outside Medical Opinion process, which is critical for medically complex claims, and the adequacy rates of VA medical opinions and VA examinations are being challenged at an alarming rate.

Adequate and accurate exams continue to be an issue for all veterans, as they were before AMA. Investigations from the VA Office of Inspector General (VA OIG) have quantified the problem. VA OIG estimated that more than half of the 62,500 claims of the spine were incorrectly processed by the Veterans Benefits Administration (VBA) in the first six months of claims decided in 2018.² The VA OIG report described VBA "processing errors" as those that included improper evaluations, missed secondary conditions, and evaluations based on inadequate exams. Our experience is this continues to be the case. When VA obtains a medical opinion, adequacy is non-negotiable.

We look forward to working with VA and Congress to ensure veterans are receiving fair and timely adjudications of their appeals, and that the department provides the information necessary for all stakeholders to make sure that it is meeting its goals.

Automobile Allowance Grants and Adaptive Equipment—For an individual with disabilities, freedom and independence improves mental health. Relying on others for everything, especially transportation can be frustrating, leaving a veteran feeling helpless. Having access to an adapted vehicle allows a veteran to feel stronger and fosters pride in their ability to maintain their health, meet work and family obligations, and attend community engagements.

VA's Automobile Allowance was initially created by Congress to assist severely disabled World War II veterans with the purchase of an automobile or other conveyance. Little has been done to ensure the program still meets the needs of catastrophically disabled veterans. Vehicles that meet the dimensions for adaptation are larger in size; thus, they tend to be more expensive, running anywhere from \$30,000 to \$60,000 and higher. The current allowance is a one-time

² [Accuracy of Claims Decisions Involving Conditions of the Spine, Department of Veterans Affairs Office of Inspector General, September 5, 2019.](#)

payment of \$22,355.42, which does not cover the whole cost of the vehicle. The lifespan of the average adapted vehicle is 10 years.

Uncontrollable factors are increasing the cost of suitable vehicles for these veterans. They include a reduced inventory of suitable vehicles due to COVID-19 and the world-wide computer chip shortage and increased demand for vehicles like Mercedes-Benz Sprinter and Ford Transit vans by home delivery companies. To put this impact in perspective, a vehicle which cost a veteran about \$37,000 in 2016 exceeds \$57,000 today. That figure does not account for the cost of accessories or modifications not reimbursed by VA—all of which is borne by the veteran.

The current benefit does not match the lifespan of SCI/D veterans. Due to the high cost of adapted or adaptable vehicles, veterans are driving vehicles well past their lifespan. For example, one of our members received his automobile allowance 43 years ago and his vehicle now has over a half a million miles. Repairs are costly, but he cannot afford to purchase a new vehicle.

To ensure veterans with service-connected disabilities have access to safe, reliable transportation, Congress must pass the Advancing Uniform Transportation Opportunities for Veterans Act or the AUTO for Veterans Act (H.R. 1361/S.444), which would allow eligible veterans to receive a second Automobile Allowance after 10 years. Another bill, the Care Access Resources for Veterans Act or the CARS for Vets Act (H.R. 3304) would also allow a second grant after 10 years but includes additional language designating certain vehicle modifications (e.g., van lifts) under the definition of medical services for VA health care purposes.

VA's Automobile Adaptive Equipment (AAE) program helps physically disabled veterans enter, exit, and/or operate a motor vehicle or other conveyance. VA provides necessary equipment for veterans with qualifying service-connected disabilities such as platform wheelchair lifts, under vehicle lifts, power door openers, lowered floors/raised roofs, raised doors, hand controls, left foot gas pedals, reduced effort and zero effort steering and braking, and digital driving systems.

The program also provides reimbursements (to service-connected veterans) for standard equipment including, but not limited to, power steering, power brakes, power windows, power seats, and other special equipment necessary for the safe operation of an approved vehicle. Support for veterans with non-service-connected disabilities is limited to assistance with ingress/egress only. Veterans need the independence AAE provides, allowing them to transport themselves to and from work, medical appointments, and other obligations. Congress must pass legislation that allows veterans who have non-service-connected catastrophic disabilities to receive the same type of adaptive automobile equipment as veterans who have service-connected disabilities.

VA Home Improvement Programs—Improvements are long overdue for VA's Home Improvements and Structural Alterations (HISA) program. As the name suggests, HISA grants help fund improvements and changes to an eligible veteran's home. Examples of qualifying improvements include improving the entrance or exit from their homes, restoring access to the kitchen or bathroom by lowering counters and sinks, and making necessary repairs or upgrades

to plumbing or electrical systems due to installation of home medical equipment. The lifetime HISA benefit is worth up to \$6,800 for veterans with service-connected conditions and \$2,000 for veterans who have a non-service-connected condition. These rates have not changed since 2009 even though the cost of home modifications and labor has risen at least 40 percent during the same timeframe. As a result, that latter figure has become so insufficient it barely covers the cost of installing safety bars inside a veteran's bathroom. We urge Congress to pass the Autonomy for Disabled Veterans Act (H.R. 5819), which would raise HISA grant rates to \$10,000 for service-connected disabled veterans and \$5,000 for non-service-connected disabled veterans, and tie HISA grants to the Consumer Price Index (CPI) to help ensure rates remain current.

Clothing Allowance—VA's clothing allowance is an annual sum of money paid to veterans with service-connected disabilities who have clothing that is damaged by their prosthetic or orthopedic devices (such as a wheelchair) or by medicine they are using for a skin condition. Veterans must apply for clothing allowance with their local VA medical center by August 1 each year. The requirement to reapply annually is burdensome for VA and veterans alike. PVA believes veterans with static conditions should not be required to reapply each year. Instead, their annual payments should automatically renew once their eligibility and the permanent status of their condition has been established. Congress must pass the Brian Neuman VA Clothing Allowance Improvement Act (S. 2513) or the Mark O'Brien VA Clothing Allowance Improvement Act (H.R. 4772), which would make clothing allowance payments automatic until VA determines the veteran is no longer eligible to receive the benefit or wants to receive it.

Special Monthly Compensation (SMC) Rates—There is a well-established shortfall in the rates of SMC paid to the most severely disabled veterans. SMC represents payments for "quality of life" issues, such as the loss of an eye or limb, the inability to naturally control bowel and bladder function, the inability to achieve sexual satisfaction, or the need to rely on others for ADLs like bathing or eating. To be clear, given the extreme nature of the disabilities incurred by most veterans in receipt of SMC, PVA does not believe that a veteran can be totally compensated for the impact on quality of life, however, SMC does at least offset some of the loss of quality of life. Many severely disabled veterans do not have the means to function independently and need intensive care on a daily basis. They also spend more on daily home-based care than they are receiving in SMC benefits.

One of the most important SMC benefits is Aid and Attendance (A&A). PVA recommends that A&A benefits be appropriately increased. Attendant care is very expensive and often the A&A benefits provided to eligible veterans do not cover this cost. Many PVA members who pay for full-time attendant care incur costs that far exceed the amount they receive as SMC beneficiaries at the R-2 compensation level (the highest rate available). Ultimately, they are forced to progressively sacrifice their standard of living in order to meet the rising cost of the specialized services of a trained caregiver; expensive maintenance and certain repairs on adapted vehicles, such as accelerated wear and tear on brakes and batteries that are not covered by prosthetics; special dietary items and supplements; additional costs associated with needed "premium seating" during air travel; and higher-than-normal home heating/air conditioning costs in order to accommodate a typical paralyzed veteran's inability to self-regulate body temperature. As these veterans are forced to dedicate more and more of their monthly compensation to supplement the shortfalls in the A&A benefit, it slowly erodes their overall quality of life.

Benefits for Surviving Spouses—Many of our oldest veterans are passing away and, in most situations, their widows were their primary caregivers for 40 years or more. Therefore, many of them did not have careers, could not work, or even go to school. In addition to this loss of income, because many of them could not work, they earned no Social Security work credits. So, when a service-connected SCI/D veteran passes away monthly compensation that may have been upwards of \$8,000 a month stops, and their widow receives only about \$1,400 per month in Dependency and Indemnity Compensation (DIC). Occasionally, adjusting to this precipitous drop of revenue into the household can be too difficult for some surviving spouses and they are forced to sell their homes and move in with friends or family members.

Losing a spouse is never easy and having a security net to provide financial assistance after the passing of a loved one eases this burden. DIC is intended to protect against spousal impoverishment after the death of a service-disabled veteran. For 2022, this compensation starts at \$1,437.66 per month and increases if the surviving spouse has other eligible dependents. DIC benefits last the entire life of the surviving spouse except in the case of remarriage. For surviving children, DIC benefits last until the age of 18. If the child is still in school, these benefits might go until age 23.

The rate of compensation paid to survivors of servicemembers who die in the line of duty or veterans who die from service-related injuries or diseases was created in 1993 and has been minimally adjusted since then. In contrast, monthly benefits for survivors of federal civil service retirees are calculated as a percentage of the civil service retiree's Federal Employees Retirement System or Civil Service Retirement System benefits, up to 55 percent. This difference presents an inequity for survivors of our nation's heroes compared to survivors of federal employees. DIC payments were intended to provide surviving spouses with the means to maintain some semblance of economic stability after the loss of their loved ones. Survivors who rely solely on DIC benefits face significant financial hardships at the time of their spouse's death. PVA strongly believes the rate of compensation for DIC should be indexed to 55 percent of a 100 percent disabled veteran's compensation.

Additionally, if a veteran was rated totally disabled for a continuous period of at least eight years immediately preceding death, their eligible survivors can receive an additional amount (currently \$305.28) per month in DIC. This monetary installment is commonly referred to as the DIC "kicker."

Unfortunately, survivors of veterans who die from Amyotrophic Lateral Sclerosis (ALS) rarely receive this additional payment. ALS is an aggressive disease that quickly leaves veterans incapacitated and reliant on family members and caregivers. Many spouses stop working to provide care for their loved one who, once diagnosed, only has an average lifespan of between three to five years; thus, making it very difficult for survivors to qualify for the kicker.

VA already recognizes ALS as a presumptive service-connected disease, and due to its progressive nature, automatically rates any diagnosed veteran at 100 percent once service connected. The current policy fails to recognize the significant sacrifices these veterans and their families have made for this country. PVA strongly endorses the Justice for ALS Veterans Act (H.R. 5607/S. 3483), which would allow these survivors to receive this additional amount of compensation. We urge Congress to pass this legislation as quickly as possible.

Finally, to date more than 20,000 veterans have died from COVID-19. There are many service-connected conditions that are known to aggravate COVID symptoms and the relationship between the two should be taken into consideration when determining eligibility for survivor benefits. Congress should pass H.R. 746/S.89, the Ensuring Survivors Benefits During COVID-19 Act, which directs VA to obtain a medical opinion that determines whether a service-connected disability was the principal or contributory cause of death for a veteran who died from COVID-19.

PVA PRIORITY: INCREASE EMPLOYMENT PROSPECTS FOR VETERANS WITH DISABILITIES

Many federal government programs support employment opportunities for the larger veteran community, but most of these programs focus on transitioning servicemembers. However, we see older veterans and veterans with significant disabilities often left out of the target demographics for several of these programs. These older veterans, particularly our catastrophically disabled veterans, see a higher unemployment rate than the younger veterans, and PVA is committed to finding creative ways to solve this problem.

At PVA, our Veterans Career Program (VCP) assists veterans with employment and education opportunities. Many veterans engaging with VCP are disabled veterans seeking more appropriate employment for themselves and their lifestyles. Our counselors report a high volume of veterans seeking help with appeals after initially being denied access to VA's Veteran Readiness and Employment (VR&E) program services. VR&E is fundamentally an employment assistance program for disabled veterans, but at PVA, we see catastrophically disabled veterans denied access to these critical benefits because the VR&E counselors deem them too disabled to work. The unemployment rate is often over 6.5 percent for these veterans, which is currently three percent higher than veterans who do not report a disability. Furthermore, many are discouraged and are no longer even seeking employment. This disparity must be considered when examining VR&E's process for determining access to services for catastrophically disabled veterans.

Recently, PVA convened a workgroup that will focus on VR&E oversight and engagement. The goal of this workgroup is to collaborate with the VR&E program to increase outreach engagement and improve outcomes. With several veterans service organizations and community partners engaged, this workgroup would like to see increased transparency from VA. We need data showing enrollment in the various tracts, an accurate count of counselors, and the employment outcomes at the end of each tract. Also, we would like to see increased collaboration with existing agencies such as the Department of Labor's Veterans' Employment and Training Service (DOL VETS) and the American Job Centers so there is better engagement with on-the-job training opportunities. PVA also believes there are creative ways to ensure that our most vulnerable veterans are not denied access to the VR&E program.

Discussions continue to take place about the ratio of VR&E counselors to the veterans enrolled. PVA understands the intent of the goal ratio, but lacking a clear understanding of outcomes and performance, such a goal seems arbitrary. Without increased transparency of the VR&E program, there is no way to ensure the program's success. Reducing the administrative burden for VR&E counselors is essential; however, PVA is more concerned that the program is accessible and equitable for the enrollment of significantly disabled veterans. There are

creative solutions to the issues facing VR&E, but until we understand the complexities of the problem, our attempts will be unsuccessful.

Finally, as a result of the COVID-19 pandemic, we are grappling with the traditional notion of what it means to work. Although there are now increased work-from-home opportunities, in addition to in-person full-time employment opportunities, VR&E, DOL VETS, and other federal employment programs need to find ways to engage a growing number of veterans who can only commit to part-time work due to their disabilities. Veterans should not be denied access to employment programs because of their disabilities, and PVA believes it is long past time to begin to meet the needs of these veterans.

Chairman Tester, Chairman Takano, Ranking Member Moran, Ranking Member Bost, and members of the Committees, I would like to thank you once again for the opportunity to present the issues that directly impact PVA's membership. We look forward to continuing our work with you to ensure that veterans get timely access to high quality health care and all the benefits that they have earned and deserve. 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 2022

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

Fiscal Year 2021

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$455,700.

Fiscal Year 2020

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$253,337.

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.



CHARLES BROWN

*National President
Paralyzed Veterans of America (PVA)*

“PVA came to my bedside and started helping me build a life print for the rest of my life.”

– Charles Brown

Charles Brown was elected PVA national president in May 2021, during the organization’s 75th Annual Convention, to begin a one-year term on July 1, 2021. He previously served as senior vice president for three years.

From a very young age, Brown knew he wanted to serve his nation and had a calling to work with military aircraft. He joined the U.S. Marine Corps in 1985 and was trained in aviation ordnance. In 1986, Brown sustained a spinal cord injury as a result of a diving accident while serving in Cherry Point, NC.

During his initial rehabilitation at the Department of Veterans Affairs’ Spinal Cord Injury center in Augusta, GA, he was introduced to PVA and became a member of the Southeastern Chapter.

“PVA helped me through the process of filing for benefits,” Brown says. “They gave me ideas for accessible bathrooms and entrances to my house. They have offered me sporting opportunities I never would have thought about.”

In 1987, he moved back to his native Missouri. Wanting to give back to the organization who had given so much to him, Brown served on the Gateway Chapter board in a multitude of capacities, including Americans with Disabilities Act coordinator, advocacy director, treasurer, and vice president.

While in St. Louis, Brown helped establish the Rolling Rams quad rugby team. “I really enjoyed helping to build the team,” Brown remembers. He recalls recruiting players by making phone calls to rehab facilities, and even talking to people in wheelchairs at the mall.

The team really took off when a couple of recreational therapists got involved and brought athletes with them. "It's a blessing to know that you can get things done when you have the right people in the right positions," he says.

Seeking a more wheelchair-friendly climate, Brown relocated and joined the Florida Chapter of PVA in 1999. In Florida, he served in a number of positions, including hospital committee chair, secretary, hospital liaison, national director, and president. Brown has also served on numerous national committees, including strategic planning, planned giving, and resolution.

Brown believes in helping his fellow Veterans improve their quality of life and is passionate about continuing to help PVA improve the accessibility of our nation.

He says, "PVA is in great hands, not because of me but because of the team that PVA is and has been for 75 years. Together, we are all the face of PVA and we will continue to let everyone know that we count, that our voice matters, and that we deserve the same rights as everyone else."

Currently on the USA Boccia team, Brown was selected team captain for the Parapan American Games in Guadalajara, Mexico. Ranked 63rd in the world after one international tournament, he fully believes that an active life has kept him healthy.

Brown resides in Loxahatchee, FL and enjoys classic cars, fishing for fun, and spending quality time with family.