ANNUAL LEGISLATIVE PRESENTATION

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NATIONAL PRESIDENT

PARALYZED VETERANS OF AMERICA

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HOUSE AND SENATE COMMITTEES ON VETERANS' AFFAIRS

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Chairman Tester, Chairman Bost, Ranking Member Moran, Ranking Member Takano, and members of the Committees, I appreciate the opportunity to present Paralyzed Veterans of America's (PVA) 2023 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). Access to VA's specialized systems of care is the center of their universe because they rely on it perhaps more than any other group of veterans served by VA.

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 programs to secure benefits for veterans; reviewed the medical care provided by the VA's SCI/D system of care to ensure our members receive timely, quality care; invested in research; promoted education; organized sports and recreation opportunities; and advocated for the rights of paralyzed veterans and all people with disabilities. 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 The IB Veterans Agenda for the 118th Congress and our budget recommendations for VA for fiscal years (FY) 2024 and 2025 advance appropriations.

VA's SCI/D SYSTEM OF CARE

VA's SCI/D system of care is a hub and spoke model. The 25 SCI/D centers are the hubs. 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.

The SCI/D system was severely impacted by COVID. Although operations began to normalize in 2022, they are still not where we hoped they would be three years into the pandemic. Many facilities continue to impose strict isolation requirements for residents, resulting in a mental health crisis due to lack of interaction and isolation. Essential programs, like peer mentoring, in-person support groups, and therapy offerings (i.e. gym hours and off-site recreation activities) remain very limited or unavailable. Visitor restrictions, which don't appear to be evidence based, also remain in many locations and change frequently, adding to residents' frustrations.

The response to COVID isn't solely to blame for the slow return to normal. The lack of sufficient staffing has impaired virtually every facet of care across the system. We hope to work with you and VA to improve the quality of care and the quality-of-life for these veterans as soon as possible.

My statement addresses several specific priorities we hope you will pursue this year but it is not inclusive of every area of concern for our members. Some interests not covered here include the implementation of the PACT Act, access to VA dental care, improved employment opportunities for veterans with catastrophic disabilities, as well as VA's electronic health record modernization. We continue to work on these and other areas of interest for paralyzed veterans and the broader veterans community.

I also want to thank you for your efforts to ensure passage of the Veterans Auto and Education Improvement Act (P.L. 117-333), which allows VA to provide an additional automobile allowance; and the Consolidated Appropriations Act, 2023 (P.L. 117-328), which contained language eliminating the burdensome requirement for veterans to apply for their clothing allowance each year. We appreciate that the Committees have always worked together in a nonpartisan way to address the needs of America's veterans, and PVA looks forward to working with you on matters of mutual concern.

PVA PRIORITY: PROTECT ACCESS TO VA'S SPECIALIZED HEALTH CARE 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 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, the department's capacity to treat veterans will be diminished, and could lead to the closure of facilities and service reductions.

Staffing Vacancies—Caring for veterans with SCI/D requires sharp assessment, time- and labor-intensive physical skills, and genuine empathy. Nurses who work in SCI/D must possess unique attributes and specialized education. All Registered Nurses, Licensed Practical Nurses, Certified Nursing Assistants, and Nurse Practitioners working with the SCI/D population are required to have increased education and knowledge focused on health promotion and prevention of complications related to SCI/D. This includes the prevention and treatment of pressure injuries, aspiration pneumonia, urinary tract infections, bowel impactions, sepsis, and limb contractures.

Staffing shortfalls have a direct, adverse impact on the SCI/D system. Due to an insufficient number of nurses, care at one of VA's SCI/D units was suspended in 2022, and veterans with acute SCI/D needs were admitted to non-SCI/D units. Other facilities capped admissions due to insufficient numbers of SCI/D nurses and are still working to fill vacancies. Another VA SCI/D center has not had access to a plastic surgeon for over a year, and until recently, there was also not one available in the community. As a result, some veterans were transferred to VA medical centers two states away for critical surgery, while non-SCI/D providers and a lone nurse trained in wound care were left to manage countless other urgent cases.

When I appeared before the Committees last year, the SCI/D system was short 600 nurses; today, that number is relatively unchanged. 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 nursing assistants) receive specialty pay, which often elevates turnover rates.

Workforce provisions in the RAISE Act (P.L. 117-103) and PACT Act (P.L. 117-168) have given VA more flexibility to provide competitive salaries and fill critical slots needed to provide care. The full impact of these new authorities on the SCI/D system of care remains to be seen. However, we know that more needs to be done. Passage of S. 10, the VA CAREERS Act, would give VA the additional tools needed to allow the department to better compete for the highly qualified medical personnel it needs to care for catastrophically disabled veterans.

Offering competitive pay isn't the only problem. If VA is not able to quickly hire high quality employees, it will lack the staff needed to accomplish its mission. Right now, VA's hiring process often moves too slowly prompting many qualified individuals to accept employment in the private sector. The lengthy time needed for credential checks, introductory paperwork, and other pre-work requirements needs to be scrutinized and streamlined where possible.

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 three to 70 years with an average age of 38. Many of the older centers have only had cosmetic or basic renovations. Fourteen of the 25 acute care SCI/D centers continue to use four-bed patient rooms, accounting for 61 percent of the available in-patient beds. These four-bed patient rooms do not meet VA requirements and are no longer safe due to infection control issues. This high percentage of four-bed patient rooms limits available bed capacity whenever patients need to be isolated.

Furthermore, the number of long-term care beds for veterans with SCI/D is woefully inadequate for an aging veteran population with care needs not readily met in the community. Only one of VA's six specialized long-term care facilities lies west of the Mississippi River. Until construction projects at the Dallas and San Diego VA Medical Centers are completed, only 12 long-term care beds are available for the thousands of SCI/D veterans that reside in this area of the country.

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 seven major and 15 minor SCI/D center projects either awaiting funding, in design, or pending approvals to proceed beyond their current status. 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 (SCIP) process. Also, replacement SCI/D center projects designed for the Bronx VA (acute) and the Brockton VA (long-term) intended to modernize and expand capacity were shovel-ready but abandoned by the VA.

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 that is often unmatched anywhere in the community. 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 areas like SCI/D care would greatly strengthen VA's specialty care services and ensure their future availability.

Even with a comprehensive strategy and adequate infrastructure funding, VA's internal 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. PVA strongly supports S. 42, the Build, Utilize, Invest, Learn and Deliver (BUILD) for Veterans Act of 2023, which seeks to 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 PRIORITY: EXPAND ACCESS TO VA'S LONG-TERM SERVICES AND SUPPORTS

Insufficient Long-Term Care Beds and Services for Veterans with SCI/D—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.

As of last month, only 168 beds were actually available. This number fluctuates depending on several variables like staffing, women residents, isolation precautions, and deaths. When averaged across the country, that equates to about 3.4 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 some of these requirements have been incorporated in a pair of construction projects but most of their plans have been languishing for years. In 2021, 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. Construction of a new long-term care SCI/D center at the VA North Texas Health Care System was scheduled to begin last spring, but has been delayed until October of this year. If everything stays on track, this facility, which is designed to include 30 SCI/D long-term care beds, will be completed in the spring of 2026. However, based on the ongoing delays, this schedule may be subject to further change.

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 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 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. Also, Congress should direct VA to reassess its current SCI/D long-term care capacity and future SCI/D long-term care needs so adequate resources can be authorized and appropriated.

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 the 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.

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

VA has identified the need to provide additional SCI/D long-term care facilities and some of these requirements have been incorporated in a pair of ongoing construction projects but most of their plans have been languishing for years. 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.[2] 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 doubled between 2016 and 2021; 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 2016 and 2021, 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.

Caps on Care

VA is currently prohibited from spending on home care more than 65 percent of what it would cost if the veteran was provided nursing home care. When VA reaches this cap, the department can either place the veteran into a VA or community care facility or rely on the veteran's caregivers, often family, to bear the extra burden. Depending on the services available in their area, some veterans must turn to their state's Medicaid program to receive the care they need, even for service-connected disabilities.

Amyotrophic lateral sclerosis (ALS) is presumptively related to military service and is rated by VA at the 100 percent level. And yet, we are aware of many ALS veterans who are not receiving proper home care. One veteran with ALS who uses a gastrostomy tube, has a tracheostomy and is ventilator dependent was only able to get a nurse to come to his home for two-hour visits, two times per week to check his vitals. Unfortunately, these hours were not enough to care for his medical complexities and the VA was unable to provide additional services due to cost. Instead, VA told him he could receive 24/7 skilled nursing at a facility. Another ALS veteran needs 120 hours of skilled care per week in order for him to be at home with his wife and family. Medicaid authorized 70 hours per week but the VA was unable to approve the additional coverage due to the cost and instead the veteran is in a much costlier facility. And another ALS veteran lives with his wife in their home but his wife is responsible for around 130 hours of care a week on her own. She can no longer afford to pay out of pocket for additional care. The VA's only option was to place the veteran in a facility due to cost.

It isn't just ALS veterans who are impacted by this cap. A 39-year-old SCI veteran who is tracheostomy dependent has been in a facility since 2019 due to the cost of his care. He has a 10-year-old daughter that he has not been able to see since before COVID. Another veteran with a form of multiple sclerosis who has a gastrostomy tube, a tracheostomy and is ventilator dependent is on the verge of ending up in a facility. His family needs 8 hours of care per day on the weekdays but VA is only able to approve 16 hours per week due to costs. Congress needs to allow VA to cover the full cost of home-based care services for these veterans and others like them without exhausting their caregivers and leaving them struggling to cobble together the services and supports they need to stay home with their families.

[2] Do noninstitutional long-term care services reduce Medicaid spending?

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. 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 (ADL). Examples of the types of assistance they can receive include help with bathing, dressing, or fixing meals. VDC also offers support 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 not available at many VA medical centers and it currently has an enrollment of only about 6,000 veterans. Our members and other veterans are constantly asking for help in getting this program implemented at their VA health care facility. Milton, a PVA member, is one of many veterans waiting more than four years for the Cleveland VA to implement the program. Even if the program is available at a particular facility, veterans may not be aware of it or given the opportunity to enroll. Although VDC is apparently available at my VA Medical Center, I was not made aware of it until last year. After several attempts to learn about accessing the program, I was told I had not been considered for the program. Veterans should be given the choice to access this program where it is available.

Last year, VA announced plans to expand the VDC program to 75 additional sites over a five-year period. We are pleased that VA's Under Secretary for Health recently directed the Veterans Health Administration (VHA) to accelerate the timeline and we urge Congress to provide the necessary funding so every VA medical center can offer a robust VDC program as quickly as possible.

Homemaker and Home Health Care Aides

Another major concern of our members is VA not authorizing adequate hours to care for their home care needs. As previously noted, the cost of VA purchased home health care services may not exceed 65 percent of the amount it would cost if the veteran was placed in a 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 needed by a veteran 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, they must receive the hours their doctor believes are needed for their care. Veterans also have had difficulty receiving authorized care as agencies are having trouble finding sufficient numbers of workers to provide it. People often assume that veterans home care needs are fully cared for because of the care provided through VA. Unfortunately, that is not always the case. Last year, I shared my personal story about a day when no nurse arrived to help me get out of bed. The VA-contracted home health agency providing my care was unable to find a nurse to assist me that Saturday morning. I called the agency that morning and was notified that nobody would be coming by and 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. 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. Fortunately, I was able to reach the nurse that was coming to assist me that evening and she came to 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. VA's community home care providers must be held accountable for providing the care that we have earned with our service.

Direct Care Workforce Shortages

Even when veterans have access to programs like VDC or Homemaker Home Health, it can be challenging to find home care workers. That is the experience of Ron, a PVA member who sustained a traumatic spinal cord injury in a vehicle accident in the spring of 2020. After spending four months in rehabilitation, he was released to an assisted living facility that did not meet his needs; so, he briefly lived with his mother while he and his family built an accessible home. In the fall of 2020, VA authorized 24-hour care for him in his home and Ron was thrilled to have this option. His wife is very supportive but often feels sad and helpless because she is physically unable to care for him. He depends entirely on the home health staff for his daily care, health, and welfare. Unfortunately, because VA did not have home care staff, he had to go through a community agency. Despite having many hours authorized, he has never found enough qualified people to fill them. He is fortunate when he has someone to get him out of bed and help him through the day. Oftentimes, he goes to bed at 7 p.m. because help isn't available at his usual bedtime of 9 or 10 p.m. He regularly spends weekends in bed because no staff is available to assist him and he is depressed and frustrated because he can't find the direct care workers he needs to assist him with daily activities.

Another PVA member, Vicky, had similar problems. Since 2002, a spinal cord injury and other medical conditions has left her unable to stand or transfer unassisted. VA offers her 25-30 hours of home care per week but direct care staffing where she lives now is virtually nonexistent. Shortly after the pandemic and lockdowns hit, her staffed shifts fell from seven to none. That left much of her care in her husband's hands and with no end in sight for resolving their home care crisis, they decided he should retire from his job at a local hospital in the fall of 2020. The decision for him to retire was easy because they understood the gravity of the situation, but it was not without consequences. Leaving the workforce adversely affected his retirement and their household income.

The shortage of caregivers or home care workers is not unique to VA. Across the country, there is an increasing shortage of direct care workers, and a national effort is needed to expand and strengthen this workforce. I share these stories to emphasize how precarious the HCBS/long-term care system is and how the lack of home care providers is adversely impacting the care and quality-of-life of veterans with SCI/D. Veterans with disabilities have the right to quality care in their homes. 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 veterans with SCI/D 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 tremendous need to improve access to HCBS, PVA strongly supports H.R. 544/S. 141, the Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act. This critically important legislation would make urgently needed improvements to VA HCBS, including several that target our concerns about current program shortfalls. We appreciate the Senate Veterans' Affairs Committee's recent markup of an amended version of this legislation. However, we call on Congress to quickly pass this desperately needed legislation as written, including removing the 65 percent cap on services. If properly caring for these veterans is too costly for our nation, then we seriously question the commitment to care for catastrophically disabled veterans such as those with ALS.

Assistance for Family Caregivers—Executing the Program of Comprehensive Assistance for Family Caregivers (PCAFC) continues to be challenging for the VA. As of February 3, VA reported having nearly 11,000 applications in process but their approval rate remains relatively low. VA has also had difficulty implementing program regulations consistently across the system as well as communicating eligibility and requirements to veterans and their caregivers. We were pleased that the department extended the transition period for legacy applicants and legacy participants until September 30, 2025, but are disappointed that action has yet to be taken to revise the restrictive rules that are preventing seriously injured catastrophically disabled veterans from qualifying for the program.

To their credit, VA worked closely with caregivers; veterans; and VSOs, including PVA, to identify changes that could be made under existing authorities and those that would require congressional action. Unfortunately, no changes have been made yet and each day of delay prevents hundreds of veterans from accessing the benefits this important program provides.

I would also like to raise a concern about how VA decides which tier veterans are assigned to in the PCAFC. VA currently has two categories for determining stipend payments, tier one and tier two. Tier one is for veterans whom VA has determined can self-sustain in the community and Tier two is for veterans who are determined to be unable to self-sustain in the community. VA defines "unable to self-sustain in the community" to mean an eligible veteran that requires personal care services each time he or she completes three or more of the seven ADLs, and is fully dependent on a caregiver to complete such ADLs or has a need for supervision, protection, or instruction on a continuous basis. VA defines inability to perform an ADL to mean the veteran or servicemember requires personal care services each time he or she completes one or more of the ADLs.

VA has determined that many PVA members are eligible for Special Monthly Compensation (SMC). SMC is a higher rate of compensation paid due to special circumstances such as the need for aid and attendance by another person or a specific disability, such as loss of use of one hand or leg. SMC ratings range from K through S, with R-2 being the highest level. We are at a loss to explain how our members with the highest SMC rating receive the lower level of compensation through PCAFC if they can even get in the program at all. PVA National's Senior Vice President is one of these individuals. Robert is a quadriplegic who suffered an injury while serving in the Army back in 1991. He also has an SMC rating of R-2—*the highest level.* However, he applied for VA's PCAFC and was subsequently approved but assigned into tier one—*the lowest PCAFC payment tier*. We are concerned that VA has two separate programs to determine the need for assistance with ADLs that are resulting in different determinations. We hope the Committees will expand their oversight of PCAFC and work with VA to eliminate these types of decisions.

PVA PRIORITY: IMPROVE VA BENEFITS AND HEALTH CARE SERVICES FOR PARALYZED VETERANS AND THEIR SURVIVORS

Special Monthly Compensation (SMC) Aid and Attendance 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 that loss. 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). 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. One PVA member reported he was parsing out his care because the money he currently receives falls well short of his needs. Instead of having someone help him with daily bathing, he started having them do it every other day and now sometimes it's every third day. 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 and can lead to health issues.

Both SMC and A&A are subject to annual cost-of-living (COLA) increases but the formula used to establish the increase often understates the actual rate of increase in goods and services required by these individuals. Also, the baseline rates have not been examined by Congress in years. We urge the Committees to review and subsequently increase the rates of SMC and A&A soon to ensure these benefits meet the needs of veterans, their spouses, surviving spouses, and parents.

Military Sexual Trauma – The last Congress passed several provisions intended to improve VA services and access to benefits related to military sexual trauma (MST). PVA is hopeful the changes will improve the experience of MST survivors while engaging with VA. By having VHA and the Veterans Benefits Administration coordinate with one another to provide information and resources to survivors, there should be fewer gaps in care experienced and the claim application process should improve.

Although we are hopeful that these new provisions will make improvements, there is still work to be done. Per the Department of Defense's (DOD) Annual Report on Sexual Assault for FY 2021,[3] 8.4 percent of active duty women and 1.5 percent of active duty men experienced unwanted sexual contact the year before the survey was conducted. In FY 21 alone, the military services saw a 13 percent increase in sexual assault reports over the previous year. According to DOD's calculations, that's an estimated 35,000 people who might seek benefits and services from VA as a survivor of MST.

Congress and VA must continue to identify gaps in support and ensure that all MST survivors are treated with dignity and respect. Because of the lasting psychological and physiological impacts of this trauma, it is critical that VA fully train its MST coordinators and ratings officials to the sensitive nature of these claims as well as the range of issues and symptoms experienced with MST, particularly for veterans with complex injuries and illnesses.

Concurrent Receipt—The issue of concurrent receipt falls under the purview of the Armed Services Committees but it is closely linked with this Committee's efforts. A pair of changes approved by Congress in the mid 2000's allowed military retirees with over 20 years of service and VA disability ratings of 50 percent or greater to receive their military retired pay and VA disability compensation payments without offset. A lone exception to the 20-year requirement was granted for servicemembers retired under the Temporary Early Retirement Act. Despite these reforms, thousands of military retirees continue to have their military retirement offset by VA disability

[3] Department of Defense Fiscal Year 2021 Annual Report on Sexual Assault in the Military

payments today. Congress should pass legislation allowing all military retirees to retain their full military retired pay and VA disability compensation without any offsets.

Benefits for Surviving Spouses—Our oldest veterans are passing away and, in the case of many of our members, their surviving spouses were their primary caregivers for 40 years or more. Many of them were not able to work outside of the home. When a service-connected SCI/D veteran passes away, monthly compensation that may have been upwards of $10,000 a month stops, and their surviving spouse receives roughly a fifth of that per month in Dependency and Indemnity Compensation (DIC), it creates a tremendous hardship on those left behind. Adjusting to this precipitous drop of revenue into the household can be too difficult for some surviving spouses who may be forced to sell their homes and move in with friends or family members.

Losing a spouse is never easy but knowing that financial help will be available following the death of a loved one can ease this burden. DIC is intended to protect against survivor impoverishment after the death of a service-disabled veteran. In 2023, this compensation starts at $1,562.74 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 before a certain age. 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 one.

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 surviving spouse can receive an additional amount (currently $331.84) per month in DIC. This monetary installment is commonly referred to as the DIC "kicker."

Unfortunately, surviving spouses of veterans who die from 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, has an average lifespan of between three to five years; thus, making it very difficult for survivors to qualify for the kicker.

As previously stated, 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 and I urge Congress to approve legislation allowing the surviving spouses of veterans who died of service-connected ALS to the DIC kicker.

VA and some in Congress concurred with our position during an October 20, 2021, House Veterans Affairs Subcommittee on Disability and Memorial Affairs legislative hearing, but other Members felt there might be additional conditions that should be considered. We agree with that observation. In the meantime, however, it is wrong to withhold higher compensation rates to the surviving spouses of veterans who die from ALS while we determine what these other conditions might be.

Transportation Programs and Supports—On behalf of our members, I want to again express our deepest appreciation for passage of the Veterans Auto and Education Improvement Act of 2022 (P.L. 117-333). The rising cost of adaptable vehicles hinders many veterans from purchasing needed replacement vehicles. By authorizing VA to give these veterans an additional auto allowance if 30 or more years have passed since their initial grant, you have given them the means to not only purchase a new vehicle but also preserve their independence. We urge VA to implement this change as soon as possible. Also, we hope you would consider providing a similar auto allowance to veterans with non-service-connected catastrophic disabilities. Like those with service-connected disabilities, these veterans served honorably. They are eligible for VA healthcare and having access to an adapted vehicle helps them get to and from their appointments at the VA, particularly if they live in a rural area.

The Veterans AUTO and Education Improvement Act also changed the definition of "medical services" to include certain vehicle modifications (e.g., van lifts) offered through VA's Automobile Adaptive Equipment (AAE) program. While we greatly appreciate this change, we still have concerns about the AAE program. The AAE program helps disabled veterans enter, exit, and/or operate a vehicle. VA provides the adaptive equipment needed like wheelchair lifts, power door openers, lowered floors, raised doors, and hand controls to allow a service-connected veteran to drive a vehicle. However, non-service-connected veterans only receive assistance with ingress/egress. Again, the need for independence of movement to get to VA appointments, to their jobs, and allow them to live a productive life is the same regardless of the status of their condition. It's past time for VA to include non-service-connected veterans fully in the AAE program.

A robust network of public transportation such as buses, subways, and paratransit services for people with disabilities is often not available outside of urban areas. VA's Veterans Transportation Service provides transportation to help veterans who live within a VA medical center's catchment area to get to and from medical appointments. Unfortunately, it is not available at all VA facilities and may not help veterans who live beyond a certain distance of the medical center. Congress and VA must work together to improve travel options for catastrophically disabled veterans, including those who live in rural areas.

Finally, VA's Beneficiary Travel Self-Service System (BTSSS) needs immediate attention. Launched in late 2020, the new cloud-based system was intended to improve the process for veterans to submit and track transportation reimbursements using VA's secure web based BTSSS portal. However, PVA members and other veterans routinely voice concerns over how difficult the system is to navigate. One member shared that the kiosks were removed from his clinic and replaced with QR codes. However, this veteran did not have a smart phone, so he was unable to access the portal when he needed it. Another member recently moved, and he was blocked from accessing the portal because his address didn't match VA records. When he tried to correct his information with the assistance of VA staff, they were still unable to gain access to the platform.

As VA modernizes and upgrades platforms and engagement methods, it is critical to remember that many veterans do not have equitable access to computers, broadband, and even smart phones. The traditional ways of accessing VA benefits are still necessary for our rural, low-income, disabled, and aging veterans. To ignore them and their needs, is not an option.

Life Insurance Benefits—Congress passed a provision included in the Johnny Isakson and David P. Roe, M.D. Veterans Health Care and Benefits Improvement Act of 2020 (P.L 116-315) reforming the Service-Disabled Veterans Life Insurance (S-DVI) program. The newly implemented Veterans Affairs Life Insurance (VALife) program provides guaranteed acceptance whole life coverage of up to $40,000 to veterans with service-connected disabilities. Lesser amounts are available in increments of $10,000. Under this plan, the elected coverage takes effect two years after enrollment as long as premiums are paid. If the veteran passes away during the two-year period, then premiums are refunded but no benefit is paid. Requiring a two-year waiting period for full insurance coverage has a detrimental effect on veterans with ALS, because many do not live that long. The same issue applies to veterans with other terminal diseases like service-connected cancers. Additionally, under SDV-I, veterans rated 100 percent service connected did not have to pay premiums. In 2023, under VALife, if a 100 percent service-connected veteran is 79 years old, the premium for a $20,000 policy would be $242.80, and for a $40,000 policy, it would be $485.60. If a veteran has a 50 percent disability and applies for a $40,000 policy, **half** of their monthly compensation would be taken to pay for insurance premiums. Congress must reinstate the premium waiver for veterans with 100 percent service-connected disabilities and waive the two-year contestability period for veterans with ALS and other service-related disabilities. Additionally, there is no form to complete for VALife, the only way to apply is online. This can be a significant challenge for catastrophically disabled veterans and VA should consider increasing the number of ways interested veterans can apply for the program.

Home Modification Grants—Improvements are long overdue for VA's Home Improvements and Structural Alterations (HISA) program. 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. A lifetime HISA benefit is worth up to $6,800 for veterans who need a housing modification due to a service-connected condition. Veterans who rate 50 percent service connected may receive the same amount even if a modification is needed due to a non-service-connected disability. Veterans who are not service connected but are enrolled in the VA healthcare system can receive up to $2,000.

These rates have not changed since 2010 even though the cost of home modifications and labor has risen more than 50 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.

During a March 16, 2022, House Veterans' Affairs Health Subcommittee hearing, the VA recommended that a $9,000 HISA grant be made available to all disabled veterans, regardless of service connection. We strongly agree with their single grant proposal but believe its new value should be at least $10,000. The higher amount is more appropriate because in 2023 the national average for a bathroom remodel project in the U.S. is $11,000.[4]

[4] 2023 Bathroom Remodel Cost Calculator | Modernize

We also agree with VA that future rates should be tied to an index focused on construction costs like the Turner Building Cost Index. This is the formula VA currently uses to determine annual rates for its other home modification programs, such as the Specially Adapted Housing program. Indexing the benefit would help keep future HISA grant rates current.

Health Care and Benefits for Women Veterans—Among the veteran population, women are the fastest-growing cohort. Women veterans, including those with SCI/D, need access to comprehensive, gender-specific care, services, and support that meet them where they are. VA should be providing the highest standards of care when it comes to quality, privacy, safety, and dignity. VA has a robust SCI/D system of care to serve the needs of veterans with SCI/D, but there needs to be greater collaboration with SCI/D centers and gender-specific care for our women veterans.

PVA is pleased that Congress provided over $840 million for gender-specific care and programs in VA's current budget. Through your oversight role, we ask that you ensure VA provides the detailed spending plan directed by the Consolidated Appropriations Act, 2023 (P.L. 117-328) to explain how the department plans to use this funding. This would help ensure the funds are being used for gender-specific care, and guarantee that women veterans with SCI/D are not ignored when it comes to resource allocation.

I also want to again express our appreciation for last year's passage of the Making Advances in Mammography and Medical Options for Veterans (MAMMO) Act (P. L. 117-135), which will help reduce barriers to women veterans with SCI/D seeking mammograms. PVA urges VA to consider working with external stakeholders, such as VSOs, in developing the strategic plan for VA breast health services. The perspective of women veterans with mobility limitations should always be included in conversations around access to care.

While progress has been made with the passage of the MAMMO Act and the Dr. Kate Hendricks Thomas Supporting Expanded Review for Veterans in Combat Environments Act or the (SERVICE) Act (P. L. 117-133), other accessibility issues across the VA system of care still need to be addressed. VA needs to do an assessment of accessible medical diagnostic equipment to ensure that all veterans have the same access to health care and services. Exam room tables and chairs and imaging equipment may be inaccessible for non-ambulatory veterans. As VA and Congress work together to oversee the implementation of accessible medical equipment across the system, PVA asks for transparency and cooperation from both.

Assisted Reproductive Technologies—Recognizing the need for assisted reproductive technology (ART) options, Congress granted temporary authorization in 2016 for the VA to provide in vitro fertilization (IVF) to veterans with a service-connected condition that prevents the conception of a pregnancy. This temporary authorization has been reapproved multiple times, but Congress has always stopped short of permanently authorizing it and expanding the types of ART provided to veterans. While PVA is grateful for these provisions, it is time to permanently fund these treatments and include infertility as part of the regular medical service package offered by VA.

Under current VA regulations, only veterans with a service-connected infertility diagnosis, or their spouse, are eligible to receive fertility treatments within VA. Additionally, a veteran is required to produce their own gametes, meaning they must produce their own eggs or sperm in order to receive IVF. If a veteran's service-connected disability prevents them from producing their own genetic material, VA's regulations prevent them from accessing this important benefit.

The prohibition on donated gametes is arbitrary since donations may be used for other ART services such as artificial insemination. Women PVA members may face additional hurtles if their disability prevents them from carrying a baby to term. For these woman, gestational surrogacy might be the only option, which is another form of ART that VA does not allow.

Infertility should be classified as a medical diagnosis which would allow all veterans to access treatment, regardless of service connection. Including infertility into the medical benefits package will also remove antiquated barriers to ART for unmarried and LGTBQ+ couples. Lastly, VA should allow for the use of donated genetic materials and conduct research into the viability of a surrogacy program.

To improve access to fertility services and ensure that all veterans can receive treatment if they receive an infertility diagnosis, Congress should pass H.R. 544, the Veterans Families Health Services Act as quickly as possible.

Chairman Tester, Chairman Bost, Ranking Member Moran, Ranking Member Takano, 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 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.

Fiscal Year 2021

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

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 re-elected PVA national president for his second term in May 2022, during the organization's 76th Annual Convention, to begin a one-year term on July 1, 2022. 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.