

**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**

**MARCH 3, 2020**

Chairman Moran, Chairman Takano, and members of the Committees, I appreciate the opportunity to present Paralyzed Veterans of America's (PVA) 2020 policy priorities. For nearly 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 those who served.

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 discussion about reforming the delivery of VA's health care system. As the Committees and the Administration advance system reforms, proper consideration must be given to how those reforms will impact veterans who rely primarily on VA for their health care, and particularly those veterans who almost exclusively use 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 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 individuals with an SCI/D, 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 veterans and individuals 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—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 funding for the VA for Fiscal Years (FY) 2021 and 2022.

## **STRENGTHEN AND IMPROVE THE VA HEALTH CARE SYSTEM AND SERVICES**

***Oversight of VA MISSION Act Implementation (P.L. 115-182)***—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.

The initial launch of the new Veterans Community Care Program (VCCP) had minimal impact on our members. The first challenge we encountered was a new policy for individual family member caregivers to be reimbursed for bowel and bladder care. VA announced eligible family member caregivers would need to obtain a National Provider Identifier (NPI). VA explained that the NPI number was needed to ensure individual family member caregivers could be loaded into VA's updated payment and authorizations systems, and for a Veterans Care Agreement (VCA) to be issued.

To receive payment beginning October 1, 2019, the family member caregiver was required to submit the NPI along with a signed VCA to their local VA Community Care staff. In some cases, VA did not communicate this requirement sooner than a few weeks prior to the end of the fiscal year. Seven months later, there is still some confusion how payments may impact an individual's tax liability since caregivers are required to have an NPI. We believe the payments should not be taxable because bowel and bladder care is a component of VA medical services.

With regard to accessing care in the community, we have learned 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. A number of veterans took matters into their own hands to complete coordination VA staff should have managed. Finally, there have been several instances where veterans were erroneously charged for care they received through the VCCP. In sum, it appears a closer examination of the administrative and payment components of the VCCP is warranted. The Committees should also review the scheduling process. According to our field staff, the process is improving, but lag time between the initial eligibility determination and the scheduling process means the veteran is not always seen within wait times established by VA.

***Title 38 Protections for Community Care***—PVA remains deeply concerned about the exclusion of protections for injuries that occur as a result of community care. Title 38 U.S.C. § 1151 protects veterans in the event that medical malpractice occurs in a VA facility and some additional disability is incurred or health care problems arise by providing clinical appeal rights, no-cost accredited representation, and congressional oversight and public accountability. However, if medical malpractice occurs during community care, the veteran must pursue standard legal remedies, and is not privy to VA’s non-adversarial process. If these veterans prevail on a claim, they are limited to monetary damages instead of enjoying the other ancillary benefits available under Title 38 intended to make them whole again. Congress must ensure that veterans who receive care in the community retain current protections unique to VA health care under 38 U.S.C. § 1151.

***Protect Specialized Services***—PVA firmly believes VA is the best health care provider for veterans. The VA’s SCI/D System of Care, comprised of 25 SCI Centers and six long-term care (LTC) facilities, 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 the VA’s specialized systems of care—such as SCI/D care, blinded rehabilitation, amputee care, polytrauma care, and mental health care—remains the highest priority for PVA. However, if VA continues to woefully 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.

Nearly 49,000 VA staffing positions went unfilled last year. In September 2019, VA’s Office of the Inspector General<sup>1</sup> reported that 131 of the 140 VA medical facilities had severe shortages for medical officers and 102 of the 140 facilities had severe nurse shortages. Additional shortages in Human Resources Management positions compounded this problem department-wide. In 2015, SCI/D nurses worked more than 105,000 combined hours of overtime due to understaffing. A system that relies upon floating nurses, not properly trained to handle SCI patients, overworks existing SCI/D nursing staff. This leads to burn out, injury, and loss of work time or staff departure and is unacceptable. In some circumstances, it even jeopardizes the health care of veterans.

VA’s ability to meet the highest standard of care to our veterans relies on more than just having the right number of physicians and nurses. They also need qualified and well-trained housekeepers. Last year, at some VA medical facilities, staffing levels for environmental

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<sup>1</sup> VAOIG September 30, 2019 Report - <https://www.va.gov/oig/pubs/VAOIG-19-00346-241.pdf>

(custodial) employees dipped below 50 percent, which heightens the health risks to veteran patients, particularly those with compromised immune systems, such as those with serious illnesses or catastrophic injuries. Low pay, a cumbersome hiring process, and a lack of qualified applicants are often cited as major contributing factors to the VA staffing problem.

Staffing problems have a direct, adverse impact on the SCI system. 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 600 nurses in the SCI/D System of Care. Considering SCI/D veterans 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 LTC 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. Given the direness of this situation, PVA strongly advocates for Congress to provide enough funding for VA to reform its hiring practices and hire additional medical professionals, particularly physicians, nurses, psychologists, social workers, and rehabilitation therapists, to meet demand for services in the SCI/D System of Care and ensure the positions, pay, and other incentives they offer are competitive with the private sector.

***Expand Eligibility for VA's Comprehensive Family Caregiver Program***—Section 161 of the VA MISSION Act requires the VA Secretary to expand VA's Comprehensive Family Caregiver program to include veterans who incurred a serious injury on or before May 7, 1975; and two years later, to those who incurred or aggravated a serious injury in the line of duty after May 7, 1975, through September 10, 2001. The law further required (Section 162) the Secretary to implement an information technology system that fully supports the program and allows for data assessment and comprehensive monitoring of the program on or before October 1, 2018.

Last year, VA informed VSOs that VA officials were in the process of hiring more than 680 employees to work with the caregiver program and amending a host of operating procedures to simplify and reform the existing program. To date, however, VA has failed to meet any of the deadlines to expand the caregiver benefits spelled out in the VA MISSION Act. This means thousands of eligible veterans and their caregivers will have to wait longer than Congress intended. Currently, there are over 20,000 veterans enrolled in the caregiver program, and VA officials estimate the expansion could provide monthly stipends to more than 41,000 new veteran families in coming years. PVA calls on Congress to perform effective oversight to press VA to implement the expansion of caregiver benefits to eligible veterans and caregivers by June. Also, since Congress intended the final phase of the expansion to service-connected injured veterans be initiated on October 1, 2021, we call on Congress to hold the department to that date so these veterans will not experience unnecessary delays.

There is, however, another deserving group of veterans who were not included under the original program or the expansion: veterans with service-connected illnesses such as amyotrophic lateral sclerosis (ALS) or the hundreds of other illnesses included in the VA's Presumptive Disease List. This too is unjust. For this program to be genuinely inclusive of all our nation's veterans and their caregivers, it must not exclude those with service-connected illnesses. Therefore, PVA urges the Committees to approve H.R. 4451, the "Support Our Services to Veterans Caregivers Act" by Representatives Ruiz and Higgins which would expand the program to veterans with service-connected catastrophic illnesses, not just injuries, from all eras of service.

Likewise, we urge the members of these Committees to support S. 2216, the "TEAM Veteran Caregivers Act" by Senators Peters and Blackburn which seeks to ensure that future intake, downgrade, or discharge actions pertaining to the comprehensive caregiver program are executed in a timely and impartial manner. As VA prepares to roll-out the expansion of the program to veterans of all eras, this bill will help ensure that adequate controls are in place to govern what VA must consider before downgrading or terminating a veteran's participation in the program.

***Improve Access to VA's Long-Term Services and Supports***—PVA continues to be concerned about the lack of VA LTC beds and services for veterans with SCI/D. Many aging veterans with an SCI/D are currently in need of VA LTC services. Unfortunately, VA is not requesting and Congress is not providing sufficient resources to meet the current demand. In turn, as a result of insufficient resources, VA is moving toward purchasing private care instead of maintaining LTC in-house for these veterans. Even though it is especially difficult to find placement for veterans who are ventilator dependent.

VA designated six specialized LTC facilities because of the unique, comprehensive medical needs of veterans with SCI/D, which are usually not appropriately met in community nursing homes and non-SCI/D-designated facilities. SCI/D Centers provide a full range of services and address the unique aspects of delivering rehab, primary, and specialty care. These veterans require more nursing care than the average ambulatory hospitalized patient. Additionally, in SCI/D LTC units, the distribution of severely ill veterans is even more pronounced as a sizable portion requires chronic pressure ulcer, ventilator, and bowel and bladder care due to secondary complications of SCI/D issues.

The Long Beach VA Medical Center is the department's newest facility and it is also the only SCI/D LTC Center located west of the Mississippi to serve 11 acute SCI/D Centers. It has a capacity of 12 inpatient beds and because it is always full, it has a long wait list to receive admissions. Unfortunately, the woefully inadequate number of beds available barely addresses the high demand. In these instances, the only option is to place the veteran into the local community where they receive suboptimal care by untrained SCI/D-health professionals.

Four of the six SCI/D LTC Centers have sufficient staffing. Of the other two facilities, one has some staffing needs and the other is in dire need of personnel. Thus, some facilities are operating at or near capacity, while others only achieve a fraction of theirs.

Although VA has identified the need to provide additional SCI/D LTC facilities and has included these additional centers in ongoing facility renovations, such plans have been languishing for years. In accordance with the recommendations of “*The Independent Budget Policy Agenda* for the 116th Congress,” PVA recommends that VA SCI/D leadership design an SCI/D LTC strategic plan that addresses the need for increased LTC beds in VA SCI/D Centers.

VA also offers a number of specialized long-term services and supports to include Spinal Cord Injury-Home Care, Medical Foster Homes, Veterans Directed Care, and Respite Care. All of these programs are covered by VA, with the exception of the Medical Foster Home program. In accordance with VA Policy, Veterans Health Administration Directive 1141.02(1), Medical Foster Home Procedures, VA may refer veterans to a VA approved medical foster home, but VA does not have the authority to cover the cost of services provided.

***Permanent Access to In-vitro Fertilization (IVF)***—In September 2018, Congress approved legislation extending IVF services for qualified wounded veterans for another two years. That legislation also included a modification lifting what was a three-year limit on the coverage of cryopreservation of embryos. Continued provision of procreative services through VA will ensure that these veterans are able to have a full quality of life that would otherwise be denied to them as a result of their service. PVA calls on Congress to go a step further and make such services a permanent part of the medical benefits package at VA. Congress has a moral obligation to restore to veterans what was lost in service, to the fullest extent possible.

VA’s current temporary authority prohibits the use of gametes that are not a veteran’s and his or her spouse’s. For some veterans, their injuries destroyed their ability to provide their own sperm or eggs for IVF. Because they require donated gametes, they are ineligible for IVF through VA. This is an unexplainable requirement that only harms those who need this service the most. A cruel irony of the prohibition of donated gametes for IVF is that there is no such prohibition when veterans pursue artificial insemination. Only in the provision of IVF can VA not authorize care if the use of donated gametes is necessary. Congress must correct this restriction. Finally, Congress should allow further services to address the needs of women veterans whose injuries prevent a full-term pregnancy.

While we are pleased that procreative services remain temporarily available for catastrophically disabled veterans, more must be done. We encourage the members of the Committees to support S. 319/H.R. 955, the “Women Veterans and Families Health Services Act of 2019” by Senator Murray and Representative Larsen, which would make this service a permanent part of the medical benefits package at VA.

***Prosthetics***—The VA’s mission is to care for the disabled veteran in a uniform and standardized manner. Within VA, the Prosthetics and Sensory Aids Service (PSAS) is charged with providing prosthetics, orthotics, and adaptive equipment to replace missing parts of the body and support bodily functions to enable veterans to regain independence and mobility. However, due to a lack of training and knowledge and poor communications, prosthetics care is inconsistent from facility

to facility. Lack of flexibility within national prosthetic policy robs VA providers of the capability of providing individualized care that meets the true needs of the veteran. Providers fight rigid, antiquated policies instead of determining what is best for the patient and how best to deliver that care. Furthermore, VA Handbooks and Directives are so outdated, they fail to incorporate advances made in prosthetics during the Post-9/11 era.

Except for the Home Improvement and Structural Alterations Program and the policy on clothing allowance, the VA Handbooks and Directives are all over a decade old. For the last three years, VSOs have been told that there are rewrites in progress, and yet much needed policy changes are on hold. And frustratingly, those most knowledgeable about prosthetics are rarely asked to participate in the critical development phase of these directives.

Furthermore, providing prosthetics through community health care systems creates additional burdens on the PSAS system. The administrative responsibility for VA prosthetics staff to properly manage, maintain the quality of prosthetics, and control overall program costs cause additional delays, could generate inappropriate and non-standard care, and/or increase complaints about the VA's delivery of these critical services. We want to ensure veterans receive the best quality of care, especially when it comes to prosthetic devices, and believe the best place for them to go for this care is VA.

The advances in prosthetics technology and complexities of function have greatly enhanced disabled veterans' ability to assimilate back into their communities. However, the cost of technology, materials development, scientific research, engineering skills, and the knowledge required to produce and manufacture prosthetics are only going to continue to increase. In order to meet the demand, VA must ensure adequate funding, a continuous training program for prosthetics and clinical staff, and updates to their VA handbooks and policies. This will ensure that VA continues to lead the world in prosthetics and rehabilitation through their integrated delivery system.

**Care of Women Veterans With SCI/D**—More than half a million women veterans are currently using VA health care and, as increasing numbers of women join the individual services, the number of women veterans using VA health care will continue to rise. In order to best serve the needs of this rising number of women veterans, VA facility leaders must be accountable for providing access to comprehensive gender specific mental and physical health care with high standards of care regarding the quality, privacy, safety, and dignity of that care. Women veterans deserve an environment that is sensitive to their needs and free from harassment.

The VA must ensure that all women's health clinics are easily accessible for disabled women veterans. Unfortunately, the first hurdle that women veterans with catastrophic disabilities may encounter, might be something as simple as the entrance to the VA women's health clinic. The next hurdle is that some of VA's exam rooms are too small to accommodate a woman veteran in a wheelchair or fit a portable lift; other rooms may not be big enough for a larger wheelchair to enter at all. If the patient cannot enter the exam room or be placed upon the exam table, the physician may be forced to examine the patient in her wheelchair leaving her at risk of further

injury and diminishing the quality of the exam and any care provided; not to mention the lack of privacy. PVA stands ready to lend support to VA in the future development and remodeling of VA facilities to ensure access to these women who served.

There is also room for improvement in meeting the gender-specific healthcare needs of catastrophically disabled women. We urge VA to ensure that women veterans have timely access to mammograms regardless of their disabilities, within VA facilities or in VA funded community care. PVA recommends VA establish clinical guidelines for treating physicians to follow when prescribing contraceptives for women with limited mobility issues to ensure the method selected by the provider does not pose a risk to the health of this population such as deep vein thrombosis, a side effect among many common oral contraceptives but highly dangerous to our women veterans. VA must also ensure that prosthetists and administrators at every level understand women's prosthetic needs. To advance the understanding and application of prostheses for women, VA must include academic affiliates, other federal agencies, and for-profit industry in their research. The needs of catastrophically disabled women veterans must no longer be an afterthought. Instead, their needs must be a part of all decision-making processes.

## **BENEFITS IMPROVEMENTS AND APPEALS REFORM IMPLEMENTATION**

***Oversight of the Veterans Appeals Improvement and Modernization Act (P.L. 115-55)***—PVA helped design and pass the Veterans Appeals Improvement and Modernization Act (AMA) of 2017 reforming the appeals process. The new system offers three review options: a “higher-level review” by a more senior claims adjudicator; a “supplemental claim” option for new and relevant evidence; and an “appeal” option for review by the Board of Veterans’ Appeals (BVA). Under the new framework, claimants may choose the option that meets their needs and, if properly implemented, this should reduce the time it takes to process appeals yet ensure that veterans receive fair decisions.

Even though the new program launched on February 19, 2019, PVA representatives still do not have full access to the Casflow program used to track and process benefit claim appeals; they have not yet been informed of the new Outside Medical Opinion process; and are concerned with administrative process errors stemming from BVA's takeover of certifying appeals. We also have strong concerns regarding the 30-minute time limit that has been placed on in-person hearings. These hearings are intended to provide veterans with an easy process in a non-adversarial environment to finally vocalize their story—many of whom have waited years to do so. Time limits make this process less than hospitable, and it appears VA is once again shifting responsibility to the veteran to assist with the reduction of the backlog of hearings.

PVA is anticipating your continued oversight to ensure lingering issues like the ones described are resolved. Also, we believe that an ongoing, strong, and close collaboration with VA and Congress is vital to ensuring the implementation and utilization of the new appeals system is conducted with maximum transparency and effectiveness. VA must also provide clear metrics to measure the progress and success of the AMA and strengthen Congress's ability to hold VA accountable for meeting targets and goals.



## ***Benefits Improvements for Catastrophically Disabled Veterans***

PVA believes it is time to improve benefits for the most severely disabled veterans, particularly in regard to the way automobile and housing grants are dispensed and the rates of Special Monthly Compensation.

***Automobile Allowance Grants and Adaptive Equipment***—VA's Automobile Assistance Grant program was originally established in August 1946 to assist severely disabled World War II veterans with the purchase of an automobile or other conveyance. Changes made in subsequent years increased eligibility and allowed modest increases to the grant itself. However, little has been done to ensure the program, as it currently exists, is meeting the needs of disabled veterans. Access to an adapted vehicle is essential to the mobility and health of catastrophically disabled veterans who need a reliable means of transportation to get them to and from work, meet family obligations, and attend medical appointments. Because of the high cost to procure replacement vehicles, veterans may retain vehicles beyond their reliability point which places them, and those around them, at risk when the vehicle they are operating is unsafe or unreliable.

PVA asks the members of the Committees to support H.R. 5761, the "Advancing Uniform Transportation Opportunities for Veterans Act," which was recently introduced by Representatives Meuser and Brindisi. This legislation would allow eligible veterans to receive an Automobile Allowance Grant every ten years for the purchase of an adapted vehicle. We recommend 10-year increments because government agencies and industry standards place much of an average vehicle's useful life within that timeframe. Additionally, vehicles that have been modified structurally, including modifications to accommodate the weight of veterans and their wheelchairs, can have a decreased lifespan. However, on average, the cost to replace modified vehicles is more than double the value of the current auto grant and several thousand more when the vehicle is used. Since vehicles do not last a person's lifetime, veterans should have the ability to purchase a vehicle once every ten years without having to bear the full replacement cost once the adapted vehicle has exceeded its useful life.

Younger veterans who are injured may retain or be able to recover a fair degree of their strength and mobility during the acute restoration period after the injury that made them eligible for the grant program. A sedan may be suitable for these veterans during these periods. However, it eventually becomes useless when veterans are forced to purchase a minivan or similar transportation that can accommodate a motorized wheelchair as their condition deteriorates or the repetitive stress injuries resulting from pulling themselves into, and out, of vehicles (along with their wheelchairs) forces them to change automobiles. If given the chance for a second or subsequent grants, veterans might also be inclined to take advantage of some of the new assistive technologies that have recently become available like lane assist or adaptive cruise control. These assistive technologies would help some veterans maintain their driving independence and make all eligible veterans, and those with and around them, much safer.

In addition, VA must continue to reimburse for adaptive equipment requirements as stated in the statute. Veterans should not have to submit an itemized list of this equipment to qualify for the grant. The handbook governing Automobile Adaptive Equipment (AAE) was written nearly two decades ago. VA has written new guidance that is expected to be released soon, but PVA and the other VSOs were given little opportunity to provide advice during this process or suggest methods to incorporate new technology into AAE.

Access to an adapted vehicle is essential to the safe mobility and health of disabled veterans. As soon as VA releases its guidance, we encourage the Committees to conduct an oversight hearing on this program to ensure it effectively addresses the needs of eligible veterans.

Additionally, we hope the Committees will help us hold VA accountable once the new AAE directive is enacted by establishing a task force of VA and VSO experts to write and review recommendations for reimbursement of AAE. This should include a process to conduct a yearly review and update of the AAE Directive. Congress should consider setting in place some sort of mechanism to review the effectiveness of the AAE program and advise members annually of the results from the new policy guidelines. Finally, PVA supports legislation to allow veterans who have non-service-connected SCI/D to receive the same type of adaptive automobile equipment as veterans whose injuries are service connected.

***Specialty Adaptive Housing Grant Program for Veterans***—For the past several years, PVA has advocated for an increase in the value and uses of VA’s Specialty Adapted Housing (SAH) grant program, to prioritize the status of veterans with ALS, and establish a supplementary housing grant. We are pleased that the House already passed Representatives Bilirakis and Levin’s legislation addressing each of these issues in H.R. 3504, the “Ryan Kules Specialty Adaptive Housing Improvement Act of 2019.” We also appreciate that a companion bill introduced by Chairman Moran and Senator Sinema, S. 2022, the “Paul Benne Specialty Adaptive Housing Improvement Act of 2019” is working its way through the Senate. We sincerely hope Congress can give final approval to S. 2022 or H.R. 3504 as quickly as possible.

There are also a couple of other areas of concern with the SAH program that the Committees need to address. First, finding and selecting an eligible builder often creates the biggest delay in getting adaptations made to a veteran’s home. The bid process gives the veteran the freedom of selecting a builder based on proposed adaptations and associated costs. However, locating a builder is often a lengthy process. Once the veteran has selected the builder with whom he or she would like to work, the builder must then register with the federal government.

The SAH program is one of VA’s most critical programs and more resources must be used to promote it to the homebuilder and remodeling industries. Congress should create a pilot program using some of the program’s current personnel whose sole focus will be to promote the merits of the program to potential builders. This could increase the number of certified builders/remodelers available nationwide, reducing the time it takes to build the home or make the required adaptations. The pilot should have a dedicated funding stream of at least \$150,000 annually to ensure the team marketing this program can do its work.

PVA is also concerned about inconsistencies in the administration of the SAH program. Some of our service officers have raised concerns about the quality and speed of the work which seemed to depend entirely on the geographic location of the veteran. This is troubling since compared to other programs, SAH is a very small program and it should not be as difficult for VA to maintain a standard across the board. Veterans should not be punished for where they choose to reside. Instead, they should be able to receive quality service regardless of the location of their residence.

***Special Monthly Compensation (SMC)***—There is a well-established shortfall in the rates of SMC paid to the most severely disabled veterans that VA serves. 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 the activities of daily life 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 injured 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-A&A beneficiaries at the R2 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 of ALS Veterans***—Dependency and Indemnity Compensation (DIC) is a tax-free monthly benefit paid to eligible survivors of military service members who died in the line of duty or eligible survivors of veterans whose death resulted from a service-related injury or disease. Eligible survivors can receive an additional amount of \$284.57 per month in DIC if the veteran was rated totally disabled for a continuous period of at least eight years immediately preceding death. This extra payment is commonly referred to as the “DIC kicker.”

VA regulations recognize ALS as a presumptive service-connected disease and, due to its aggressive nature, it is automatically rated at 100 percent once service connected. However, because the average life expectancy for a person with ALS is two to five years, spouses of

deceased veterans with ALS rarely qualify for the additional DIC benefit given the eight-year requirement.

This policy fails to recognize the significant sacrifices these veterans and their families have made for this country. PVA urges Congress to quickly pass, H.R. 4748/S. 3091, the “Justice for ALS Veterans Act of 2019” by Representatives Cisneros and Fitzpatrick and Senators Coons and Murkowski, which would entitle future surviving spouses of veterans who died of service-connected ALS to the DIC kicker.

Chairman Moran, Chairman 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. As VA continues to evolve in a manner that can improve access to veterans seeking care, it will be imperative to remember that any changes to the VA health care system will directly affect our members, and other veterans with specialized health care needs, who use the VA almost exclusively for services. We cannot stress enough the need to preserve and strengthen the VA health care system while more resources, including the community, are leveraged to expand access to care.

We look forward to continuing our work with you to ensure that veterans get timely access to high quality health care and all of the benefits that they have earned and deserve. I would be happy to answer any questions that you may have.

### **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 2020***

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

#### ***Fiscal Year 2019***

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events  
— Grant to support rehabilitation sports activities — \$193,247.

#### ***Fiscal Year 2018***

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events  
— Grant to support rehabilitation sports activities — \$181,000.

### **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.

**DAVID ZURFLUH**  
**National President, Paralyzed Veterans of America (PVA)**



David Zurfluh felt a duty to serve his country and follow in the footsteps of his grandfather (Navy), dad (Army), brother Tom (Air Force), and extended family who served in all military branches. When Zurfluh was in high school, he narrowed down the branches he wanted to serve in between the Marine Corps and the Air Force. His friend flipped a coin to determine his path — heads for Air Force and tails for the Marine Corps. The coin landed on heads, and Zurfluh's path was set in motion.

A member of the U.S. Air Force from 1987 to 1995, Zurfluh served as a jet engine mechanic and a crew chief in Operation Desert Shield and Operation Desert Storm. While on active duty, in April 1995, he was injured in a motor vehicle accident in Hachinohe, Japan, suffering a shattered left arm, broken left wrist and a broken neck. Zurfluh was diagnosed with incomplete quadriplegia. After three weeks navigating through three hospitals, he wound up at the Seattle VA Medical Center.

Zurfluh was at his lowest point when two PVA National Service Officers came to his bedside and told him they would take care of him and do everything they can to make him as whole as possible. Zurfluh became a member of PVA when this life-changing moment occurred, in 1995.

Zurfluh spent one year as an inpatient, and two years as an outpatient in the Seattle VA Spinal Cord Injury Unit. After finishing rehab, Zurfluh wanted to do all he could for the organization that gave him dignity and purpose again. He determined to make it his life's mission to help veterans with spinal cord injury, disorders, and related diseases like MS and ALS.

A native of the state of Washington, Zurfluh started volunteering at the PVA Northwest Chapter, helping local members. He held chapter-level positions as legislative director, vice president, president, and member of the sports committee. Zurfluh realized that he could help even more PVA members by serving at the national level. In 2010, he was elected to the Executive Committee as national vice president, serving three consecutive terms. In May 2014, he was elected as national senior vice president and re-elected for two consecutive terms.

In May 2017 he was elected as national president and re-elected for a second term in May 2018. In May 2019, during the PVA's 73<sup>rd</sup> Annual Convention, Zurfluh was re-elected as national president for a third consecutive one-year term which began July 1, 2019.

Zurfluh has served on the Veterans Legislative Coalition in Olympia, WA, and as co-chair of the West Slope Neighborhood Coalition in Tacoma, WA. In addition to his work on behalf of PVA in Washington, DC, Zurfluh currently serves on the National Board of Advisors of the Museum of Aviation Foundation, is a lecturer at Holy Rosary Church in Tacoma, WA, and volunteers at local food banks. His hobbies include hand cycling, shooting sports (trap, handgun, and archery) golf and snow sports.

Zurfluh travels extensively throughout the country advocating for and serving Paralyzed Veterans of America and wants people to know that "We specialize in SCI/D veterans, but we serve all veterans; if a veteran needs help and comes through our doors or calls, we help them, their caregivers and their loved ones, period."