# **Annual Legislative Presentation**

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## **National President**

# **Paralyzed Veterans of America**

# Before a Joint Hearing of the

#### House and Senate Committees on Veterans' Affairs

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Chairman Isakson, Chairman Roe, and members of the Committees, I appreciate the opportunity to present Paralyzed Veterans of America's (PVA) 2018 policy priorities. For more than 70 years, PVA has served as the lead voice on a number of issues that affect severely disabled and catastrophically injured veterans in this country. Our work over the past year includes championing much-needed 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 injury or disease (SCI/D). Our concerns and policy recommendations are particularly important in light of the continuing discussion about reforming the delivery of veterans' health care. As the Committees and the Administration advance reforms to the VA health care system, proper consideration must be given to how those reforms will impact veterans who rely primarily on the VA for their health care, and particularly those veterans who access the VA exclusively through specialized systems of care.

Additionally, we thought it would be appropriate to reflect on some of the important achievements in 2017. However, even in the case of some of those legislative accomplishments, significant work remains to ensure proper implementation of those new requirements.

**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 a spinal cord injury, 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 spinal cord injury—it remains so today.

Over the years, PVA has established ongoing programs in service representation to secure our members' and other veterans benefits; Medical Services to ensure our members receive timely, quality care; research; education; sports and recreation;; advocacy for the rights of veterans and all people with disabilities; accessible architecture; and communications to educate the public about individuals with spinal cord injury. We have also developed long-standing partnerships with other veterans' service organizations. PVA, along with the co-authors of *The Independent Budget*—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 are proud that *The Independent Budget* policy agenda has been presented for more than 30 years. We also recently released our budget recommendations to inform the debate on funding for the VA for FY 2019 and FY 2020.

Today, PVA is the only congressionally chartered veterans service organization dedicated solely to the benefit and representation of veterans with spinal cord injury or disease.

PROTECT SPECIALIZED SERVICES—Preserving and strengthening the VA's specialized systems of care—such as spinal cord injury and disease care, blinded care, amputee care, polytrauma care, and mental health care—remains the highest priority for PVA. As we have stated many times, the VA is the best health care provider for veterans. The VA's specialized services, particularly spinal cord injury care, follows higher clinical standards such as the Commission on Accreditation for Rehabilitation Facilities, which is not required in the private sector. We appreciate the fact that Secretary Shulkin, has strongly affirmed that privatizing health care for veterans is not something that will happen on his watch. We also appreciate that the leaders of these two Committees on both sides of the aisle have reiterated their rejection of privatizing VA health care. And yet, that pressure still exists, even from people advising President Trump on these matters.

Many advocates of greater access to care in the community also minimize, or ignore altogether, the devastating impact that pushing more veterans into the community would have on the larger VA health care system, and by extension the specialized health services that rely upon the larger system. Broad expansion of community care could lead to a significant decline in the critical mass of patients needed to keep all services viable. We recognize that VA is faced with a daunting challenge given the ever-growing demand for health care services. We understand that leveraging community care is a necessary part of timely access to services, but community care must be the exception, not the rule. We cannot turn our backs on the number of veterans who reap the benefits of being treated as a "whole" person in the connective care culture at the VA, such as a woman veteran who needs specialized care for her spinal cord injury in

coordination with psychological care for the Post Traumatic Stress Disorder she incurred on her third deployment to Afghanistan. She will also likely need gynecological care, anatomically specialized prosthetics, and possibly obstetrics at some point. For her, care in the community would be a matter of piecing together a giant puzzle with each piece being only one aspect of her care. That care may come together eventually but, like a puzzle, the cracks will still be obvious even when the full picture is complete. She, and other PVA members with unique, specialized needs, are the reason PVA must carefully monitor the expansion of community care as we champion the preservation of those multidisciplinary, coordinated VA services that are critically important to paralyzed veterans.

With this in mind, we strongly advocate for Congress to provide sufficient funding for VA to hire additional clinicians, particularly physicians, nurses, psychologists, social workers, and rehabilitation therapists to meet demand for services in the SCI/D system of care. In 2015, SCI/D nurses worked more than 105,000 combined hours of overtime due to understaffing. This is an unnecessary and dangerous trend that has led to staff burnout, low morale and in some circumstances jeopardized the health care of patients. For years, facility directors have disregarded the established capacity requirements and staffed spinal cord injury centers like non-specialty/general rehabilitation or geriatric units. This trend does not account for the unique skills required of nursing staff in an SCI/D unit. The result is a system that relies upon floating nurses, not properly trained to handle SCI patients, and overworking the existing SCI/D nursing staff, which in turn leads to burn out, injury, and loss of work time or staff departure. Far too many veterans are without the responsive bedside care they need. PVA estimates there is a shortage of 1,000 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.

**EXPAND ELIGIBILITY FOR VA CAREGIVER SUPPORT SERVICES**—The current Program of Comprehensive Assistance for Family Caregivers is only available to veterans seriously injured due to their military service on or after September 11, 2001. The majority of PVA members are excluded from the Family Caregiver Program because of the arbitrary date of injury requirement and the exclusion of veterans with service-connected diseases, such as Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS), both of which have a catastrophic impact on activities of daily living, and eventually leave veterans dependent on caregivers.

Caregivers are the most important component of rehabilitation and eventual recovery for veterans with catastrophic injuries. Their wellbeing directly impacts the quality of care veterans receive. The caregiver program is a clinical program intended to improve or retain a veteran's independence and wellbeing. The assistance provided to the caregivers is to enable them to provide high quality care for their disabled veteran. This is the only clinical program for service-connected disabled veterans that arbitrarily denies access by era served. For eight years, Congress has justified their decision to treat veterans unequally because of cost concerns.

For decades, pre 9/11 caregivers have sacrificed in the shadows. Most have had to compromise their careers, financial security, and wellbeing. For aging veterans and their caregivers, the program supports (respite, monthly stipend, paid travel to veterans appointments) are urgently needed. Without these services the quality of care provided by the caregiver is compromised and the veteran is more likely to be placed in a long-term care facility that would be much more costly to the government. Both the exclusion of "serious illnesses and diseases," and the use of the "date of injury" as eligibility requirements for such an important clinical service are unjust and as a result, the veterans and their families suffer.

Congress continues to find excuses to deny access. It has never been more urgent for those excuses to stop. As the largest cohort of veterans (Vietnam-era) ages, the demand for long-term care resources will continue to grow significantly. Catastrophically injured veterans will require the most intensive and expensive institutional care. By providing their caregivers the means to care for the veterans at home with family, they will have the opportunity to live more normal lives, while also delaying the costs of institutional care. It is time for Congress to do the right thing for all veteran caregivers.

We are pleased that the Senate Veterans' Affairs Committee has approved S. 2193, the "Caring for Our Veterans Act of 2017," legislation that would finally correct this inequity. We thank Chairman Isakson and Ranking Member Tester for your tireless effort to begin providing assistance to these veterans and their families. We call on the Senate to approve this legislation as soon as possible. We also call on the House VA Committee to immediately consider similar legislation. The time for debating this need has passed. The time for real action is now.

FUNDING FOR THE DEPARTMENT OF VETERANS AFFAIRS FOR FY 2019 and FY 2020— The IBVSOs have serious concerns about the FY 2019 advance appropriations requested by the Administration and subsequently approved by Congress. Recent events with an endless parade of Continuing Resolutions have proven why the advance appropriations was so critical to VA. But it is only valuable if it is properly funded. We are concerned that the Administration has not yet indicated its desire to correct this problem before it has catastrophic consequences for the VA.

We also believe it is necessary to consider the projected expenditures under the Choice program authority that the Administration planned in FY 2018 and how that impacts the baseline that will dictate the funding needs for FY 2019. The Administration revised the FY 2018 budget for Choice to \$2.1 billion. This means that the VA projected to spend more than \$60.4 billion in Medical Services and more than \$73.3 billion in overall Medical Care funding in FY 2018. These considerations inform the decisions of The Independent Budget to establish our baseline for our funding recommendations for both FY 2019 and the advance appropriations for FY 2020.

For FY 2019, the *IB* recommends approximately \$82.6 billion in total medical care funding. Congress previously approved only \$76.6 billion for this account for FY 2018 (which included approximately \$3.2 billion in medical care collections and \$2.1 billion for the Choice program).

Additionally, *The Independent Budget* recommends approximately \$84.5 billion for total Medical Care for FY 2020. This recommendation reflects the necessary adjustment to the baseline for all Medical Care program funding in the preceding fiscal years.

IMPLEMENTATION OF THE ANNUAL CAPACITY REPORTING MANDATE FOR SPECIALIZED SYSTEMS OF CARE—As we have emphasized, repeatedly, the VA has not maintained its capacity to provide for the unique health care needs of severely disabled veterans—veterans with spinal cord injury and disease, blindness, amputations, and mental illness—as mandated by P.L. 104-262, the "Veterans' Health Care Eligibility Reform Act of 1996." As a result of P.L. 104-262, the VA- developed policy that required the baseline of capacity for VA's Spinal Cord Injury/Disease System of Care to be measured by the number of available beds and the number of full-time equivalent employees assigned to provide care. Under this law, the VA was also required to provide Congress with an annual "capacity" report to be reviewed by the Office of the Inspector General. While this requirement lapsed in 2008, Congress reinstated it in September, 2016. The report has to be completed.

In addition to the inaction to hire the necessary nursing staff to meet the need in the SCI/D system of care there have been reports of reductions of both inpatient beds and staff in the acute and extended-care settings. VA has eliminated staffing positions that are necessary for an SCI/D center or clinic to maintain its mandated capacity to provide care, or has operated with vacant health care positions for prolonged periods of time. When this occurs, veterans' access to VA care decreases, remaining staff become overwhelmed with increased responsibilities, and the overall quality of health care is compromised. For years, the needs of SCI/D veterans have been further unmet or delayed due to limited admissions through hospital census capping; artificially suppressing demand. A recently updated nurse staffing methodology will likely open access to the appropriate inpatient care.

Again, we call on the Committees to conduct real oversight to ensure that the VA is meeting capacity requirements within the recognized specialized systems of care, in accordance with P.L. 104-262 and P.L. 114-223. Despite our repeated warnings about these capacity problems, the House and Senate VA Committees have conducted very little meaningful oversight on VA's ability to deliver specialized health care services.

In October of 2017, the VSO community became aware of VA's plan to move nearly \$1 billion dedicated to programs such as Women's Health, Mental Health, Research, and Suicide Prevention, to a general purpose fund for an unclear purpose. While the VA has claimed that it will be used to reinvest in "foundational services"—which includes spinal cord injury/disease care, there has been no guarantee that will actually occur at this point. It seems the real impact of this dramatic shift of funds from special purpose to general purpose is to provide more resources and flexibility to Veterans Integrated Service Networks (VISNs) and Medical Center Directors. PVA has long argued for the need for medical centers to be fully equipped to meet the needs of their patients. And while we understand the ultimate intent of this shift of resources we are deeply concerned by such a dramatic realignment of resources and the potential impact on veterans.

VA has not provided VSOs or Congress any detailed explanation for how the proposed cuts to critical programs will better serve veterans. Given the magnitude of the proposed repurposing and the potential to devastate critical programs, PVA and others in the VSO community have been diligently engaging with VA to pause the move until the extent of the impact is understood. We will continue to monitor this action as the consequences for some key programs in VA could be severe. While VA has promised that "foundational services" will benefit from this shift, we do not believe that it should be at the expense of other critical services within VA.

TITLE 38 PROTECTIONS FOR COMMUNITY CARE—PVA is deeply concerned about the exclusion of Title 38 protections in the conversations regarding expansion of community care. When veterans receive treatment at a VA medical center, they are protected in the event that some additional disability is incurred or health care problem arises. Under Title 38 U.S.C. § 1151, veterans can file claims for disability as a result of medical malpractice that occurs in a VA facility. However, when PVA asked VA if this protection extends to veterans served in the community, we were told that those veterans do not have 1151 protections. If medical malpractice occurs during outsourced care, the veteran must pursue standard legal remedies unlike similarly situated veterans who are privy to VA's non-adversarial process. Adding insult to literal injury, these veterans, if they prevail on a claim, are limited to monetary damages instead of enjoying the other ancillary benefits available under Title 38 intended to make them whole again.

This is simply unacceptable. Congress must ensure that these protections follow the veteran into the community. Congress must ensure veterans who receive care in the community retain current protections unique to VA health care under title 38 U.S.C., particularly including medical malpractice remedies governed by 38 U.S.C § 1151, clinical appeal rights, no-cost accredited representation, and Congressional oversight and public accountability.

GREATER FOCUS NEEDED TO IMPROVE PROSTHETICS SERVICES— The VA's 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. The advances in prosthetics technology and complexities of function have greatly enhanced disabled veterans' ability to assimilate back into the community. However, the cost of technology, materials development, scientific research, engineering skills, and knowledge required to produce and manufacture prosthetics has significantly increased. The sophistication to then fit the prosthetic to the disabled veterans' bodies requires individuals specifically trained to do so. No group of veterans appreciates the importance of prosthetics more than veterans with spinal cord injuries or diseases that have resulted in lost mobility.

The VA's mission is to care for the disabled veteran in a uniform and standardized manner but PSAS has unfortunately demonstrated that this is not occurring as envisioned. Prosthetics services vary widely from VA medical center to medical center. The primary reasons are the national prosthetic policy is changed at local VA medical centers to hold down costs; a lack of training; lack of knowledge; and poor communications. In addition, the VA Handbooks and Directives are woefully inadequate to the task of meeting the challenges of the advances made in prosthetics for the last 15 years. The majority of the Handbooks and Directives are over a decade old. The VSOs have been told there are rewrites in progress, but we have not been asked to participate in the critical development phase of these directives. The result will ultimately be flawed because those VSOs most knowledgeable about prosthetics are not included in development of the final product. Lack of direct stakeholder engagement has long been a problem for VA, resulting in the need for major revisions and clarifications after the fact, once those policies are applied out of the abstract and actually impact the lives of veterans.

The Automobile Adaptive Equipment (AAE) program is a prime example of all that is wrong with VA prosthetics implementation. The Handbook governing AAE was written 18 years ago. The VA is currently trying to rewrite it with a new directive, but there have been multiple delays. There was only one forum where input was sought from VSOs, and there has been no follow up from VA. PVA and other VSOs have met with VA many times in the last two years to provide recommendations as to how to improve the provision of AAE. We have offered to provide guidance and help to rewrite the Directives and suggest methods to incorporate new technology into AAE. At this point, VA has refused to accept help and has refused to include VSOs in the development of rewriting the AAE Directive.

Automobile Adaptive Equipment is essential to the mobility and health of disabled veterans. Unfortunately, the actions of VA have moved AAE to the top of our priorities that must be addressed by VA. We encourage the Committees to conduct oversight of this program specifically to shed light on the problems inherent in much of the policy redesign that is going on behind closed doors at VA. Additionally, we hope the Committees will help us hold the VA accountable for quickly updating and rewriting the AAE Directive by establishing a taskforce of VA and VSO experts to rewrite the AAE policy and to review recommendations for reimbursement of AAE. This should include a process to conduct a yearly review and update of the AAE Directive.

Meanwhile, the Clothing Allowance reimbursement program—a common benefit for veterans with catastrophic disabilities, particularly those who use mobility equipment—was rewritten with some input from VSOs. Unfortunately, it was finalized and distributed to the field without a review by VSOs. The document contains flaws that cause significant problems with implementation every year. The VA mistakenly believes they can work in the dark to produce policies that affect disabled veterans nationwide.

Prosthetics equipment will continue to increase in complexity and costs. The VA must meet the demand by ensuring an adequate budget, a continuous training program for prosthetics and clinical staff, and increased staff. The VA will make a serious mistake if it attempts to mitigate costs by reducing the personnel who administer the program. The VA must include its partners in more than name alone.

VA is also recently proposed a new prosthetic rule that would modify regulations governing prosthetic and rehabilitative items and services. PVA has commented on the proposed rule and we are concerned that the regulations as written will lead to the denial of critical prosthetics and services to our members and other disabled veterans, and we strongly urge VA to make changes before finalizing these regulations. These items and services are critical to our members' overall health and well-being, their quality of life, their independence and reintegration into regular activities, and their participation in the community through sports and other activities. We specifically request: 1) the agency's specific reassurance that this proposed rule will not result in any reduction of devices, items, equipment, or services currently available to qualifying veterans, and 2) that the agency amend the regulation before finalizing it.

PVA requests language changes in two specific ways. While we understand that VA is moving to update and reorganize its regulations by creating a new subchapter to cover prosthetics and rehabilitation, we believe the "promote, preserve, or restore" language in current § 17.38(b) should be maintained in new § 17.3230. Removing the language appears to be a substantive change that could result in reducing services to veterans. Congress has not enacted any law requiring such a change, and if the agency intends to continue current practices under the new regulations, there is no reason to delete this language.

Given how long the current regulations have been in effect, the proposed changes will be difficult to implement. We urge VA to include PVA and other stakeholders in drafting any handbooks, directives, or other guidance that will be used to implement any new regulations that are promulgated. We welcome the opportunity to work with the agency in drafting or reviewing any materials.

Another potentially major problem the VA will have is the attempt to provide prosthetics through the community health care systems. The administrative burden for VA prosthetics staff to properly manage, maintain the quality of prosthetics, and control the costs will lead to more delays, inappropriate and non-standard care, and will increase the complaints about the VA's delivery of these critical services. It is incumbent upon Congress to conduct more thorough oversight of the VA's prosthetics program to ensure that the VA is doing all it can to restore lost mobility and independence for veterans who rely upon prosthetics equipment and services.

**THE VETERANS MOBILITY SAFETY ACT**—Directly related to our concerns about prosthetics is the ongoing work surrounding implementation of P.L. 114-256, the "Veterans Mobility Safety Act." PVA led the charge during the last Congress in passing P.L. 114-256. The adaptive automobile equipment program is an important issue for our members, as they are the highest

users of this particular benefit. Veterans with catastrophic disabilities have a critical need for mobility to help maintain a high quality of life and allow them to continue to be active members of their communities despite their disabilities.

Prior to this law's enactment, VA had no requirement to ensure that adaptive equipment was being installed on vehicles in a safe and adequate manner. Although VA was required to ensure the equipment itself met safety standards, anyone willing to do the installation labor was eligible for reimbursement. The law now obligates VA to update the automotive adaptive equipment program handbook to reflect new safety standards governing equipment installation.

Attempting to satisfy the law's requirement to consult with VSO's and a host of industry and safety organizations, VA began the process of developing the new set of safety standards by issuing a Notice of Request for Information in the Federal Register. The shortfall of using the rulemaking process as a means of consultation in this instance is that it leaves all parties speaking at the same time. VA simply collects the comments all at once, and it is left on its own to judge the merits and second and third order effects that would result if those recommendations were implemented. This is hardly the productive dialogue that was expected in this legislation. VSOs were included in the consultation mandate to provide the perspective of the ultimate beneficiaries and vet the motives behind recommendations and proposals related to this policy. Our input helps ensure recommendations do not inadvertently benefit business interests at the expense of the disabled veterans this program is meant to serve. This Committee should require VA to comply with the spirit of the law and carry out the required consultation through a working group.

**IMPROVE BENEFITS FOR CATASTROPHICALLY DISABLED VETERANS**—PVA believes it is time to improve benefits for the most severely disabled veterans, particularly with regards to the rates of Special Monthly Compensation.

There is a well-established shortfall in the rates of Special Monthly Compensation (SMC) paid to the most severely disabled veterans that the 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. Many veterans 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 Aid and Attendance benefits be appropriately increased. Attendant care is very expensive and often the Aid and Attendance 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-Aid and Attendant 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 "premium seating" during air travel, and higher-than-normal home heating/AC 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 Aid and Attendance benefit, it slowly erodes their overall quality of life.

REFORMING THE BENEFITS CLAIMS AND APPEALS PROCESS—In March 2016, PVA joined the Board of Veterans Appeals, VBA, and other major veterans service organizations to form a working group with the goal of reforming the appeals process. Working with Congress these actions led to the Veterans Appeals Improvement and Modernization Act of 2017. We applaud the efforts of your Committees and all of Congress to pass this important legislation. With the number of pending appeals recently passing 470,000, VA previously projected that the inventory would climb to over two million over the course of the next decade if the system was not changed. Under the existing appeals system, ten years from now, veterans could expect to wait six years for a decision. To assist in speeding up these appeals, VA implemented its Rapid Appeals Modernization Program or RAMP. While PVA believes reform is necessary, procedural reform and greater efficiency must not dilute substantive rights and benefits that veterans have earned and deserve.

Layer upon layer of substantive and procedural rights have been added over time to this unique system of administrative law governing veterans' disability claims. But these developments also produced unintended inefficiencies and an inability to identify faults in the process. A long-term fix requires a comprehensive overhaul of the entire claims process, not just appeals. The legislation consolidates and streamlines redundant processes, provides veterans with more information to help make strategic decisions, and increases protection of the claim's effective date. Ultimately, the increased efficiency and information will produce faster decisions with a greater degree of accuracy, reducing mistakes that lead to avoidable delays. PVA has concerns this is not happening with implementation of the RAMP process. While designated a pilot program, we feel VA is rapidly adding more and more veterans to the program before fully analyzing the outcomes and metrics. We are concerned that this program is meant more to reduce the appeals backlog for the political benefit of VA rather than to significantly help veterans.

It is incumbent upon the Administration to request, and for Congress to supply, the resources to implement the new framework and simultaneously tackle the ballooning inventory of appeals. It is critical, however, that veterans do not find themselves worse off in the end then had they simply stayed with the old programs. We appreciate the fact that the House VA Committee recently conducted an oversight hearing on this issue. We encourage both Committees to continue to regularly evaluate the progress of this reform to ensure that it is achieving the goals originally outlined for appeals modernization.

ACCOUNTABILITY AND DEALING WITH THE ADMINISTRATIVE BUREAUCRACY OF VA—
It is no secret that VA's administrative bureaucracy has ballooned in recent years. Arguably, resources devoted to expanding administrative staff have significantly jeopardized the clinical operations of VA. We believe serious consideration needs to be given to rightsizing the administrative functions of VA to free critical resources and dedicate them to building clinical capacity.

Additionally, VA has struggled with the notion of accountability. Too often, VA staff who should be terminated are "removed," but not in the way the ordinary citizen in the workforce would envision that action. VA has allowed too many VA employees who have compromised the public's trust to collect a full paycheck while under reassignment in one of those positions that are neatly tucked away from public view, or to simply retire with full benefits. The public has grown tired of this happening. So have America's veterans. While Congress has provided the

VA secretary the authority he needs to prevent this from continuing, it is imperative that Congress provide the oversight to be sure the secretary uses this authority when appropriate.

## PROVIDE PROCREATIVE SERVICES FOR CATASTROPHICALLY DISABLED

**VETERANS**— In September 2016, Congress passed and President Obama signed into law, a temporary authorization for the Department of Veterans Affairs (VA) to provide in-vitro fertilization (IVF) to veterans with severe service-connected conditions that prevent the conception of a child. On January 19, 2017, IVF services became available through VA. However, these services are set to expire on September 30, 2018, and at that time the ban on IVF goes back into effect. Severely wounded and disabled veterans will once again have to shoulder the total cost for any attempts to have children.

No group of veterans is more affected by the ban on IVF than PVA's members—veterans with spinal cord injury or disease. PVA has long sought an end to the VA ban on providing IVF. The continued provision of procreative services through VA would 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. Congress must pass legislation to repeal the ban on IVF and make such services a permanent part of the medical benefits package at VA. It is Congress that has a moral obligation to restore to veterans what has been lost in service, to the fullest extent possible. It is Congress that sends young men and women into harm's way and it is Congress that must provide the health care that meets the needs that result from that service.

From 2001 to 2013, over 2,000 service members suffered a genitourinary injury, resulting in the loss of, or compromised ability, to have a child. While the Department of Defense does provide procreative services to service members and retired service members, VA has been prohibited from doing so. Since age is a factor in successful fertilization and completion of a pregnancy, delaying the provision of IVF services can have a deleterious effect on veterans' family building success. Additionally, VA's current temporary authority prohibits the use of gametes that are not of the veterans and their spouse. For many 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.

While we were very excited to see procreative services made available for catastrophically disabled veterans, and are thrilled to learn of several families that are now expecting, our work is not done. We strongly support, and encourage Congress to pass, S. 700, the "Women Veterans and Families Health Services Act of 2017" to repeal the ban on IVF and make this service a permanent part of the medical benefits package at VA.

**INCREASE LONG-TERM CARE RESOURCES**—PVA continues to be concerned about the lack of VA long-term-care (LTC) beds and services for veterans with spinal cord injuries or disease. Approximately 50 percent of our members are now over 65 years of age. These aging SCI/D veterans are currently in need of VA LTC services at the 24 VA SCI/D centers (or "hubs"). Unfortunately, we believe the VA is not requesting and Congress is not providing sufficient resources to meet the current demand. As a result of insufficient resources, the VA is moving toward purchasing private care instead of maintaining acute care and long-term care inhouse at SCI/D centers.

The VA has designated SCI/D long-term-care facilities because of the unique comprehensive medical needs of SCI/D veterans, which are usually not 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. SCI/D veterans require more nursing care than the average 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 tracheotomy care due to secondary complication of SCI/D issues.

The demand for additional LTC facilities in SCI/D is ever-present. From 2009 to 2013, the VA increased required available beds in LTC units at SCI/D centers by an annual average of 16 percent. However in 2014, the number of SCI/D LTC beds was not increased. Since 2009, the number of SCI/D veterans in those LTC units has increased by an average of more than 14 percent per year. Often, the existing LTC units do not have space available for new SCI/D veterans and thereby have long waiting lists for admission. An increase in SCI/D LTC required beds would reduce or eliminate waiting lists and ease the SCI/D LTC demand in the acute SCI/D centers.

Currently, the VA operates only seven (7) SCI/D LTC facilities, with the newest facility being located at the Long Beach VA Medical Center. In 2014, PVA conducted a survey of its members in certain geographic regions regarding their LTC plans. The percentage of members that stated they planned to live at an SCI/D LTC Center ranged from seven (7) percent to 20 percent. The San Diego/Long Beach region responded the highest for likelihood to use an SCI/D LTC center. However, currently there is only one SCI/D LTC unit with a capacity of 12 inpatient beds. Unfortunately, this woefully inadequate number of beds available barely addresses the high demand in that region. In fact, residing in an SCI/D center was the third most common response behind residing with family and not being sure of one's LTC plans.

In anticipation of the need for additional LTC services among the SCI/D veteran population, PVA conducted a survey in 2013 and 2014 to examine the non-VA LTC landscape. More than 400 VA-contracted skilled nursing homes and State Veterans Homes within a 50-mile radius of the 24 SCI/D centers were contacted. Three hundred and forty-three (343) skilled nursing homes, including 19 State Veterans Homes completed the survey. The results were astounding. Only 49 (approximately 14 percent) VA-contracted nursing homes accepted ventilator patients. Only nine of the 49 facilities were on the East Coast; 25 were in the central US; and 16 were located on the West Coast. Additionally, State Veterans Homes cannot ease the ventilator caseload as none of the State Veterans Homes surveyed could accept ventilator patients. Private skilled nursing facilities are generally not trained and staffed to care for SCI/D veterans. They also lack the equipment needed to treat the most severe cases. Thus, a plan to increase purchasing of LTC at VA-contracted nursing homes would be detrimental to SCI/D veterans.

While 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 pending for years. To ensure that SCI/D veterans in need of LTC services have timely access to VA centers that can provide quality care, both the VA and Congress must work together to ensure that the Spinal Cord Injury System of Care has adequate resources to staff existing SCI/D LTC facilities. PVA, in accordance with the recommendations of *The Independent Budget* Policy Agenda for the 115<sup>th</sup> Congress, 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.

## ENSURE EFFECTIVE OUTREACH BY VA TO VETERANS WITH SPINAL CORD

**INJURY/DISEASE**—PVA members, as well as all veterans with spinal cord injury served by the VA (approximately 43,000), are encouraged to complete comprehensive annual examinations and preventative screenings at VA spinal cord injury and disease centers. These services help prolong veterans' lives and maintain good health, while also allowing the VA to study longitudinal information on the course of spinal cord injury and disease over individuals' lifetimes.

Unfortunately, we still encounter too many cases where veterans do not know they are entitled to an annual examination or have not been encouraged by a VA clinician to complete one. As a result, those veterans eventually end up at one of the 24 VA SCI Centers; however, instead of preventative care, it is to treat a severe bedsore, a renal, circulatory, or respiratory condition that has progressed to a point requiring critical intervention, or some other acute health condition typically associated with spinal cord injury or disease.

PVA believes an adequately staffed system of care with statutorily mandated staffed beds, coupled with a proactive outreach and education program, will improve what is already regarded as the best spinal cord injury and disease system of care in the world while also guaranteeing the best health care option for catastrophically disabled veterans. Ultimately, while the VA Choice program may serve other segments of the veteran population well (an assertion that is clearly debatable), our members have overwhelmingly made their choice. That choice is the VA spinal cord injury system of care. Congress and the Administration owe it to those veterans to ensure that choice is indeed a viable one.

Chairmen Isakson and Roe, and members of the Committees, I would like to thank you once again for the opportunity to present the issues that impact PVA's membership directly. As the 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 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 2018

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

## Fiscal Year 2017

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$275,000.

#### Fiscal Year 2016

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$200,000.

## **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

David Zurfluh was elected Paralyzed Veterans of America's (Paralyzed Veterans) National President at its 71st Annual Convention in May 2017, and took office July 1, 2017.

Immediately prior to becoming president, Zurfluh had served as National Senior Vice President since May 2015. A member of the 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. He was injured in 1995 in a motor vehicle accident while on active duty in Hachinohe, Japan, suffering a shattered left arm, broken left wrist and a broken neck. He was diagnosed with incomplete quadriplegia spending one year as an inpatient, and two years as an outpatient in Seattle VA spinal cord injury unit.

Zurfluh joined Paralyzed Veterans in 1995. He has been active since 2003, with the Northwest Chapter.

He has held chapter-level positions as legislative director, vice president, president, and member of the sports committee. A native of Washington, presently serves on the Veterans Legislative Coalition in Olympia, WA, and is co-chair of the West Slope Neighborhood Coalition.

In addition to his work on behalf of Paralyzed Veterans, Zurfluh is a lector at Holy Rosary Church and volunteers at local food banks. His hobbies include handcycling, shooting sports (trap, handgun, and archery), golf and snow sports.

President Zurfluh divides his time between Seattle, Washington and Washington, DC.