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Chartered by the Congress of the United States

January 12, 2016

Honorable Mitch McConnell
Majority Leader
U.S. Senate
Washington, DC 20510

Dear Majority Leader McConnell:

On behalf of Paralyzed Veterans of America (PVA), I would like to offer you an outline of the priority issues that PVA will devote its advocacy efforts to during the second session of the 114th Congress. These issues reflect areas of concerns for our members as both veterans with spinal cord injury or disease and people with disabilities. Additionally, we remain a steadfast advocate for all veterans and people with disabilities.

With this in mind, I would like to outline our top priorities that we believe the Senate should consider during the second session of the 114th Congress. PVA's National Legislative and Advocacy programs will be focused on these issues throughout the year. Our priorities include:

Legislative Program Priorities (Veterans Issues):

1. Veterans Health Care Reform.
2. Expand Eligibility for the VA Comprehensive Caregiver Program.
3. Procreative Services for Catastrophically Disabled Veterans.
4. Protection of Specialized Services, to Include Reinstatement of Annual Capacity Report.
5. Problems with Denial of Clothing Allowance for Catastrophically Disabled.

Advocacy Program Priorities (Disability Community Issues):

1. Air Carrier Access Problems for People with Disabilities.
2. Complex Rehabilitation Technology.
3. The "Seniors and Veterans Emergency (SAVE) Benefits Act."

Following is a brief overview of each of the issues outlined above. We encourage the House leadership to address each of these areas directly as they will have a significant impact on PVA members, veterans with a spinal cord injury or disease, such as ALS or MS.

Veterans Health Care Reform

Implemented in the wake of well-publicized Department of Veterans Affairs (VA) failures to provide access to medical services, the "Veterans Access, Choice, and Accountability Act of 2014" (the "Choice Act") made progress toward alleviating pervasive problems. However, the law also exacerbated the complexity of the VA health care system. It left a confusing landscape to navigate for not only veterans and community providers, but VA employees who support them as well. Congress again acted and passed the "VA Budget and Choice Improvement Act of 2015," calling on VA to design and implement a plan to consolidate all non-Department provider programs. Operating on a tight deadline, VA presented its plan to Congress at the end of 2015. PVA and its partners in *The Independent Budget* (IB)—Disabled American Veterans and Veterans of Foreign Wars—met frequently with VA officials throughout the planning process, offering unique insight and expertise regarding proposed aspects of the plan. We are pleased that many of our key recommendations were incorporated into the new choice plan, such as ensuring through care coordination that VA remains accountable for the care veterans receive, regardless of where that care is delivered.

The IB veterans' service organizations (IBVSOs) strongly believe that veterans have earned and deserve high-quality, comprehensive, accessible and veteran-centric care. To support this belief, we leveraged historical expertise, extensive conversations with veterans around the country, and survey data to develop a veterans' health care framework centered on veteran perspectives. This collective input shows that veterans prefer to receive their care from VA, they like the quality of care received at VA, and they believe that VA is best suited to provide veteran-specific health care. Our framework presents comprehensive policy ideas designed to immediately impact the delivery of care, while laying out a long-term vision for a sustainable, high-quality, and veteran-centered health care system.

The long-term vision is to provide high-quality health care closer to home by seamlessly combining the capabilities of the VA health care system with public and private health care providers in the community. To achieve this outcome, reform must address four fundamental ideas: (1) restructuring the veterans health care delivery system, (2) redesigning the systems and procedures that facilitate access to health care, (3) realigning the provision and allocation of VA's resources to reflect the mission, and (4) reforming VA's culture with workforce innovations and real accountability. Restructuring the system in a way that establishes integrated health care networks designed to leverage the capabilities and strengths of existing local resources will provide more efficient, higher quality and better coordinated care. If this new structure is coupled with a shift in the access eligibility paradigm to one of clinical need and patient/doctor decision-making instead of a national arbitrary time and distance analysis, it will further enhance the quality and convenience of care.

We also propose that VA employ a Quadrennial Veterans Review, similar to the Quadrennial Defense Review. The ability to take the long view of prospective personnel and infrastructure resources will offer continuity of planning across administrations and

better prospects for meeting future demand with sufficient resources. Finally, a strong, trustworthy VA workforce is the cornerstone of providing the care veterans deserve. Changing the workforce culture and restoring faith in the institution requires a holistic approach that strengthens VA's ability to recruit, train and retain quality professionals dedicated to placing veterans' interests first.

Our framework should be used to inform and drive legislative and regulatory proposals. It is essential that as VA passes through this watershed moment, we ensure that reforms focus on veterans' experience, service delivery, management, accountability and planning process changes needed to meet the unique and complex health care demands of the men and women who have served and sacrificed.

Expand Eligibility for the VA Comprehensive Caregiver Program

The current VA Comprehensive Family Caregiver Program is only available to a veteran seriously injured due to their military service on or after September 11, 2001. Congress should eliminate the unjust date of injury requirement and include "service connected illness" as a criterion for the program. Doing so will give the majority of veterans' caregivers access to critically needed support services. Caregivers are the most critical component of rehabilitation and eventual recovery for veterans with catastrophic injuries. Their well-being directly impacts the quality of care provided to veterans. No reasonable justification, other than cost considerations, can be provided as to why pre-9/11 veterans with a service-connected injury or illness should be excluded from the caregiver program.

The caregiver program includes respite care, a monthly stipend, paid travel expenses to attend veteran's medical appointments, and healthcare through CHAMPVA. Without these support services the quality of care provided by the caregiver is threatened and the veteran is more likely to be placed in a costly institutional setting. Both the exclusion of "serious illnesses and diseases," and the use of the "date of injury" as an eligibility requirement for such an important benefit are unjust. As a result, the veteran and their family suffer.

As the largest cohort of veterans (Vietnam era) age, 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 them at home with family, they will have the opportunity to live a more normal life while also delaying the costs of institutional care. PVA urges the Senate to pass S. 1085, the "Military and Veteran Caregiver Services Improvement Act", legislation that would expand access to veterans injured on or before September 10, 2001.

Procreative Services for Catastrophically Disabled Veterans

The VA is prohibited from providing assisted reproductive technology, in particular in-vitro fertilization (IVF), to veterans with a service-connected condition that prevents the

conception of a child. From 2001 to 2013, over 1,200 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 reproductive services to service members and retired service members, VA does not.

When a veteran has a loss of reproductive ability due to a service-connected injury, they must bear the total cost for any medical services should they attempt to have children. It is often the case that veterans cannot afford these services and are not able to receive the medical treatment necessary for them to conceive. For many veterans procreative services have been secured in the private sector at great financial and personal cost to the veteran and family.

PVA has long sought an end to the VA ban on providing reproductive services, particularly IVF. Reproductive assistance provided as a health care benefit through VA would ensure that these veterans are able to have the highest quality of life that would otherwise be denied to them as a result of their injury during service. PVA urges the Senate to pass S. 469, the "Women Veterans and Families Health Services Act." It is Congress that sends young men and women into harm's way. It is Congress that has a moral obligation to restore to veterans what has been lost in service, to the fullest extent possible. And it is Congress that must provide health care services and benefits that address the needs of veterans that result from their service.

Protection of Specialized Services, to Include Reinstatement of Annual Capacity Report

The VA is the best health care provider for veterans. The VA's specialized services, to include spinal cord injury care, most often cannot be duplicated in the private sector. However, these services are expensive and threatened by cost-cutting measures. Even with VA's advances as a health care provider, some political leaders continue to advocate providing health care to veterans by contracting for services in the community. This would move veterans out of the "veteran-specific" care within VA, lead to a diminution of existing services, and increase health care costs in the federal budget.

Further, the critical mass of patients needed to keep all services viable could significantly decline. All primary care support services are critical to the broader specialized care programs provided to veterans. If primary care services decline, then specialized care is also diminished. Specialized services, such as spinal cord injury care, are part of the core mission and responsibility of the VA. These services were initially developed to care for the unique health care needs of veterans.

The provision of specialized services is vital to maintaining a viable VA health care system. However, the VA has not maintained its capacity to provide for the unique health care needs of severely disabled veterans. Reductions in both inpatient beds and staff in VA's acute and extended care settings have been continuously reported throughout the system of care, particularly since the capacity reporting requirement

expired in 2004. Congress must ensure VA is able to maintain its capacity to provide for the special treatment and rehabilitative needs of veterans. With this in mind, we encourage Congress to consider legislation that will reinstate the capacity reporting requirement originally established by P.L. 104-262, the "Veterans' Health Care Eligibility Reform Act of 1996."

Problems with Denial of Clothing Allowance for Catastrophically Disabled

PVA continues to receive feedback and complaints from our National Service Officers about prosthetics services, particularly in the area of clothing allowance for veterans with catastrophic disabilities. VHA Handbook 1173.15 (dated May 14, 2015) has flaws that have caused problems in three main areas with regards to the Clothing Allowance. First, veterans with wheelchairs that have clothing guides are denied the Clothing Allowance. Second, standard power wheelchairs without modifications are denied the Clothing Allowance. And third, the Static (benefit automatically paid) versus Reapply provision for obtaining the benefit coupled with the letter sent to veterans by VA in 2014 has caused confusion, increased paperwork and in many cases has caused veterans to lose their Clothing Allowance benefit all together.

Specifically, Paragraph 8a in the Handbook provides guidance for items that tend to wear and tear clothing including manual wheelchairs "*without clothing guards…wheelchairs (power, electric) without special modifications are not approved*." The implication is that wheelchairs *with clothing guards* and power chairs without special modifications do not create wear and tear. As a result, veterans have been denied Clothing Allowance. The VA Clothing Allowance Frequently Asked Questions dated September 30, 2014, confirms the denial.

Veterans (in fact any person with a disability) who uses a wheelchair can attest that there is more to wear and tear than clothing guards and special modifications. Veterans, who go through the daily ordeal of transferring from chair to car and back, from bed to chair and back, and from chair to commode or shower and back, as well as other activities, can verify those activities wear and tear their clothes.

The third problem area began with the letter sent by the Veterans Benefits Administration (VBA) in 2014 to inform veterans that they may be eligible for more than one Clothing Allowance. The letter caused confusion among many veterans who filled out a form to apply for more than one Clothing Allowance. The result was veterans who had been on a Static (recurring benefit) status were transferred to a Reapply status. Many of those veterans who had been on a Static status for decades did not realize they had been transferred and had to reapply each year for their Clothing Allowance. Consequently, they did not apply and did not receive their Clothing Allowance benefit for 2014. Those veterans want to be returned to Static status so they do not have to reapply every year and they want to receive the Clothing Allowance benefit they missed as a result of this confusion. Unfortunately, VA is allowing this problem to persist unnecessarily.

Air Carrier Access Problems for People with Disabilities

Nearly 30 years ago, President Ronald Reagan signed the Air Carrier Access Act (ACAA) into law. The ACAA prohibits discrimination against people with disabilities in air travel. Despite progress, too many travelers with disabilities still encounter significant barriers, such as damaged assistive devices, inaccessible lavatories, delayed assistance, and lack of seating accommodations. Access for people with disabilities in air travel must move into the 21st century. Otherwise, people with disabilities will be left behind unable to compete in today's job market or enjoy the opportunities available to other Americans.

To address disability-related complaints under the ACAA, passengers with disabilities may file a complaint with the specific airline or the Department of Transportation (DOT). In July 2015, DOT released the latest figures on complaints filed directly with airlines. In 2014, passengers filed 27,556 disability-related complaints as reported by 173 domestic and foreign air carriers, which represents a nine percent increase over 2013. Top complaints with U.S. carriers for passengers with paraplegia or quadriplegia include failure to provide assistance, seating accommodation, and storage and delay of assistive device. In 2014, passengers also filed 777 disability-related complaints directly with DOT.

Looking to the future, passengers with disabilities need improved structural access to aircraft, including accessible lavatories and better stowage options for assistive devices. Improved training for air carrier personnel and their contractors that includes a focus on industry best practices will also be crucial in closing remaining service gaps. The ACAA also must be strengthened by amending it to include a private right of action for passengers with disabilities.

Complex Rehabilitation Technology

PVA also believes a separate Medicare Complex Rehabilitation Technology (CRT) benefit is needed. CRT refers to products and services, including medically necessary individually configured manual and power wheelchair systems, adaptive seating systems, alternative positioning systems and other mobility devices that require evaluation, fitting, design, adjustment and programming. Such technology is designed to meet the specific and unique medical and functional needs of someone diagnosed with a catastrophic illness or disability.

In 2008, Congress recognized that complex rehab power wheelchairs are unique and more specialized than standard durable medical equipment (DME) and should be treated differently. As a result these items were exempted from inclusion of Medicare's new DME competitive acquisition program. However, a separate CRT benefit structure was not established at that time. CMS has recognized the unique measure of other customized assistive devices and has created a separate and distinct classification for orthotics and prosthetics (O&P) i.e. custom braces and artificial limbs. PVA urges Congress to pass the "Ensuring Access to Quality Complex Rehabilitation Technology

Act," a bipartisan bill that will create a separate benefit category for complex rehab technology.

The "Seniors and Veterans Emergency (SAVE) Benefits Act"

Veterans with service-connected disabilities and low-income veterans will see no increase in their compensation and pension benefits in 2016 because the Social Security Administration (SSA) announced last October that there would be no cost-of-living adjustment (COLA) in retirement, survivors and disability benefits this year. For many years, veterans' service-connected disability compensation and low-income veterans' pension benefits have been tied to the Social Security COLA. As a result, when SSA offers no inflation adjustment to beneficiaries, this has an adverse impact on over 4 million veterans with service-connected disabilities and another 300,000 low-income veterans on pension.

PVA supports S. 2251, the "Seniors and Veterans Emergency (SAVE) Benefits Act," a bill that would provide a one-time payment of $550 to Social Security beneficiaries as well as veteran recipients of compensation and pension to address the lack of inflation adjustment in benefits this year. More than 1 out of 5 adult Social Security beneficiaries have served in the military, and veterans and their families comprise 35 percent of the Social Security beneficiary population. At a time when health care costs, utilities, and many other necessary expenses continue to rise, this very modest provision will help millions of veterans with disabilities and their families. We urge Members of Congress to cosponsor this legislation and act quickly on its passage.

PVA stands ready to work with the Senate to ensure that the needs of veterans, particularly those with catastrophic disabilities, as well as their families and all people with disabilities are properly met. If you have any questions, please do not hesitate to contact me. Thank you.

Respectfully,

Carl Blake

Carl Blake
Associate Executive Director
for Government Relations
Paralyzed Veterans of America

Cc: Honorable Harry Reid, Minority Leader
Honorable Johnny Isakson, Chairman, Committee on Veterans' Affairs
Honorable Richard Blumenthal, Ranking Member, Committee on Veterans' Affairs
Honorable Orrin Hatch, Chairman, Committee on Finance
Honorable Ron Wyden, Ranking Member, Committee on Finance

Honorable John Thune, Chairman, Committee on Commerce, Science, and Transportation
Honorable Bill Nelson, Ranking Member, Committee on Commerce, Science, and Transportation
Honorable Lamar Alexander, Chairman, Committee on Health, Education, Labor and Pensions
Honorable Patty Murray, Ranking Member, Committee on Health, Education, Labor and Pensions