

STATEMENT FOR THE RECORD
PARALYZED VETERANS OF AMERICA
FOR THE
HOUSE COMMITTEE ON VETERANS' AFFAIRS
SUBCOMMITTEE ON HEALTH
ON
"VETERANS' ACCESS TO REPRODUCTIVE HEALTHCARE"
JULY 1, 2020

Chairwoman Brownley, Ranking Member Dunn, and members of the Subcommittee, Paralyzed Veterans of America (PVA) would like to thank you for this opportunity to provide input as you examine the Department of Veterans Affairs' (VA) reproductive services and continuity of care during major disruptions such as natural disasters and pandemics.

PVA member Chris Hull felt a strong call to serve following 9/11. After joining the Army, his vision of a successful military career was quickly dashed when a tragic vehicle accident landed him in the hospital. He suffered a traumatic brain injury, broken back, and a broken neck which left him with quadriplegia. He endured multiple surgeries, illnesses, and infections during his seven months of inpatient therapy and rehab. With the help of VA, Chris worked to regain his abilities. He is now an avid wheelchair rugby player and mentor for newly injured veterans with spinal cord injuries.

Despite his injuries, he never let go of his dream to have a family. He and his wife Ash could not afford to pay for the reproductive assistance doctors said he needed; so, they were thrilled when Congress authorized VA to provide in vitro fertilization (IVF). On April 25th of this year, they welcomed their new baby girl into the world. This good news story and others like it is what this benefit is all about—*restoring to veterans what has been lost in service, to the fullest extent possible.*

IVF

Less than four years ago, veterans who suffered service-connected genitourinary injuries bore the full cost of reproductive assistance like IVF if they desired to have a family. In September 2016, Congress temporarily authorized VA to provide IVF services to veterans with severe service-connected conditions that prevent the conception of a child. IVF services became available at VA in January 2017, and approximately 500 veterans and their spouses have used this service to begin or grow their families since

that time. Congress reauthorized the program for another two years in September 2018 and unless they do so again, and soon, veterans who lose reproductive ability due to a service-connected injury will once again bear the total cost for any medical services should they attempt to have children.

Although VA covers certain therapies for those with service-connected disabilities that result in infertility, there are gaps in this care. VA's current temporary authority prohibits the use of gametes that are not a veteran's and his or her spouse's. 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 should repeal this restriction and allow other services to address the needs of women veterans whose injuries prevent a full-term pregnancy.

Additionally, some women veterans with a catastrophic injury may be able to conceive through IVF but are unable to carry a pregnancy to term due to their disability. In such an instance, use of a surrogate may be their only option. Thus, the current authorization is not inclusive of all women veterans with a catastrophic reproductive injury.

Reauthorization of IVF services will be required until Congress makes its provision a permanent part of VA's medical benefits package. The uncertainty of reapproval every two years is very disruptive to the family and their financial planning. For example, Chris Hull and his wife Ash now face the choice of rushing to grow their family because they are worried this service might not be reauthorized. While we are very excited that procreative services remain temporarily available for catastrophically disabled veterans and thrilled to learn of veterans and their spouses who are expecting, our work is not done. We strongly encourage the members of this Subcommittee to support legislation like H.R. 955, the Women Veterans and Families Health Services Act of 2019, which would make this service a permanent part of the medical benefits package at VA.

Eventually the IVF program may become part of the Community Care Network (CCN) when the Patient-Centered Community Care (PC3) system is shut down. The transfer could occur as early as this fall and shifting this skillfully managed program as it is now to VA's medical centers may greatly diminish its effectiveness and create problems for its intended beneficiaries. Applications for IVF services should receive the same level of attention and care as the physician that will eventually provide them. Congress and VA should examine future plans for the program to include ways the department could

manage all requests for reproductive services through a single entity as it is now, rather than the CCN where individual VA medical centers might only encounter one or two requests per year.

Conversations About Reproductive Health and Family Planning

PVA wants to ensure VA is empowered to provide individualized and well-coordinated sexual health interventions specific to the cultural, religious, physical, emotional, cognitive, sexual orientation, and gender identity needs of the patients served. There is more that can be done to improve the care for both men and women with spinal cord injuries and disorders (SCI/D).

Multiple studies have demonstrated the association of sexual function after an SCI with quality of life.¹ A 2010 study found that, “many professionals are uncomfortable providing information about sexuality within the context of rehabilitation after spinal cord injury.”² The impairment or loss of bowel and bladder control, which can increase the risk of experiencing incontinence during or following sexual activity, might impair a veteran’s desire to participate in sexual activity.³ Sexual activity also increases a veteran’s risk of experiencing Autonomic Dysreflexia.⁴

Individuals with SCI/D report having intimate relations for a multitude of reasons including to fill a need for intimacy, a sexual need, self-esteem, to keep a partner, and reproduction.⁵ Providers need to initiate conversations about sexual health, desire to have a family, and incontinence with men and women with an SCI/D. These conversations need to happen when veterans first enter VA’s SCI system of care, and at various touch points during their lives. VA already has training programs to educate providers on the reproductive cycle for veterans. PVA suggests they could go further to develop training scripts that ask whether veterans would like to have a family, whether they are having sex, and whether they are enjoying it. This would reduce discomfort of providers in asking these types of questions and increase the likelihood they will be asked. Providers should have these conversations about sexual health or family

¹ Anderson, K., Borisoff, J., Johnson, R. et al. The impact of spinal cord injury on sexual function: concerns of the general population. *Spinal Cord* 45, 328–337 (2007). <https://doi.org/10.1038/sj.sc.3101977>

² Consortium for Spinal Cord Medicine (2010). Sexuality and reproductive health in adults with spinal cord injury: a clinical practice guideline for health-care professionals. *The journal of spinal cord medicine*, 33(3), 281–336. <https://doi.org/10.1080/10790268.2010.11689709>

³ *Ibid.*, 332

⁴ Autonomic dysreflexia is a syndrome in which there is a sudden onset of excessively high blood pressure. It is more common in people with spinal cord injuries that involve the thoracic nerves of the spine or above (T6 or above).

⁵ *Ibid.*, 332

planning throughout the veteran's life. We suggest VA's Office of the Inspector General review the program to ensure these conversations are being had, how often, and what training is done around veteran reproductive health.

To achieve and maintain sexual health, sexual rights should be respected, protected, and exercised to the fullest. Providers should not assume because a veteran does not have sensation in the genital area that he or she is not sexually active. While SCI/D veterans may not be able to feel the sensations, they desire the intimacy with their partners that sex provides. In fact, improving sexuality is a main priority for paraplegic patients.⁶ VA should provide training on assistive devices and how to incorporate these devices when engaging in sexual activity. VA needs to ensure providers are also aware of and well-trained in the intersection of military sexual trauma (MST) or other traumas and injuries, and the effect it has on sex, intimacy, and family life as an essential part of whole health and screening.

While efforts have been made to make reporting of sexual harassment and assault during military service easier, the problem of MST continues. Male survivors of MST account for 50 percent of all military sexual trauma.⁷ They face strong stigmas around reporting. We are pleased to see VA screening for MST with all veterans and hope this practice continues to ensure veterans are not delaying or obstructing their recovery by not reporting.

When it comes to women veteran specific healthcare, VA women's health is providing some of the most comprehensive care using their whole health model throughout the reproductive continuum. This care includes services such as physical therapy that promote pelvic health, the use of complementary alternative modalities to help with the symptoms of menopause, and women specific prosthetics to manage reproductive health. They are working to get bladder scanners in primary care clinics to see if veterans have residual post urine issues from stress and urge incontinence. Behavioral health coaches are brought in to assist with matters of incontinence. VA is also working to embed physical therapists in gynecological clinics.

Improving Care

⁶ Otero-Villaverde, S., Ferreiro-Velasco, M., Montoto-Marqués, A. et al. Sexual satisfaction in women with spinal cord injuries. *Spinal Cord* 53, 557–560 (2015). <https://doi.org/10.1038/sc.2015.53>

⁷ O'Brien, C., Keith, J., & Shoemaker, L. (2015). Don't tell: Military culture and male rape. *Psychological Services*, 12(4), 357–365. <https://doi.org/10.1037/ser0000049>

There is always room for improvement in meeting the gender-specific health care needs of catastrophically disabled women. PVA encourages VA to ensure SCI and other specialty care providers are working side by side with the mainstream VA health system so veterans with SCI/D will receive collaborative, comprehensive health care. This will help ensure all VA health care providers are aware of the specific health concerns of veterans with SCI/D when it comes to contraception and family planning. For women veterans with SCI/D, there are certain oral contraceptives that increase their risk for deep vein thrombosis. Menstruation, pregnancy and labor, sexual intercourse, and symptoms of menopause increase the likelihood of a veteran having autonomic dysreflexia. Women veterans should be asked early and often about their plans to have a family, sexual health, and screening for caregiver or inter domestic partner violence (IPV). VA providers are just now getting regular training on IPV screening. Many are uncertain with how to respond if a veteran says yes. Providers should also be screening for rape as it has been found to be the trauma most associated with Posttraumatic Stress Disorder (PTSD) among women.

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. Providers both in VA and those who serve these women in the community need to be fully educated on their specific needs and risks.

Attention must also be given to infrastructure barriers. Unfortunately, something as simple as inaccessible entrances to a VA women's health clinic or exam rooms that are too small to accommodate a woman veteran in a wheelchair or fit a portable lift presents barriers to women veterans with SCI/D from obtaining care. If a room cannot accommodate a large wheelchair, or the patient cannot 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 development and remodeling of VA facilities to ensure access for all women veterans.

Reproductive Health Cancer Screenings

Breast health is an area of concern for both women and men with SCI/D. Because the veteran focuses on their health needs related to the SCI/D, and difficulties accessing needed care, other preventative care such as breast exams, prostate exams, and pap smears may be neglected.

Veterans, both men and women, face an elevated risk of developing breast cancer. Men and women veterans with SCI/D have unique risk factors in breast cancer screening and treatment due to decreased mobility and complications of oncologic treatment. Early detection of cancer is key to positive treatment outcomes. While breast cancer rates are relatively low among men, about one percent, Dr. Anita Aggarwal at the Washington, DC, VA Medical Center conducted a study comparing breast cancer in male and female veterans and found cancer rates among men to have risen by 26 percent since 1975. Dr. Aggarwal's study on the incidence of breast cancer among male veterans states, "With men, there's a delay in detection. There is less awareness, no screening. And men don't palpate their breasts every month."⁸

Men with SCI/D are also more likely to be diagnosed with breast cancer at a later stage. Providers should remind veterans of both genders, and their caregivers, to do monthly breast examinations. While self-breast exams do not lead to an increase in survival of breast cancer, a monthly self-examination can help a veteran to bring to the attention of their physician any changes that might warrant additional screening. Veterans with SCI/D may be unable to self-palpitate their breasts, and therefore, may miss the opportunity to initiate this discussion with their health care provider. The opportunity for the provider to help a veteran become aware of their personal risk factors is also missed.

VA has demonstrated a concerted effort to improve breast health care. According to VA, it has increased sites performing mammograms by 62 percent since 2010 and is screening patients aged 50-74 at a higher rate than the private sector.⁹ VA health care providers should be working with their patients to determine the best age to begin screening based on their personal risk factors. We also urge VA to ensure they are capturing the information on breast health in their internal records system when a veteran goes to community care for breast imaging.

We have heard reports from some of our women members that they are sent to community clinics that did not have accessible imaging machinery or examination tables. PVA would like to know, when VA sends a veteran with SCI/D to a community care provider for breast imaging, what are their procedures for ensuring the health care

⁸ Aggarwal A, Liu ML, Krasnow SH. Breast cancer in male veteran population: an analysis from VA cancer registry. *J Community Support Oncol*. 2014;12(8):293-297. doi:10.12788/jcso.0066

⁹ US Department of Veterans Affairs, V. (2017, September 18). VA.gov: Veterans Affairs. Retrieved June 24, 2020, from <https://www.womenshealth.va.gov/WOMENSHEALTH/OutreachMaterials/ReproductiveHealth/UnderstandingYourMammogram.asp>

provider has accessible equipment, appropriate staffing, and knowledge in the care of veterans with SCI/D?

In addition to concerns about breast cancer, according to the American Cancer Society, about 1 in 9 men will be diagnosed with prostate cancer in their lifetime. A 2011 study found a decreased risk of prostate cancer among veterans with SCIs, however, when veterans with SCIs are diagnosed with prostate cancer, it is often found at a more advanced stage than those who do not have SCIs.¹⁰ The increased risk of advanced disease supports the need for careful screening of male veterans with SCI/D for prostate cancer.

Mental Health

Individuals with SCIs are at an increased risk of developing mental health disorders and secondary chronic diseases.¹¹ Almost 40 percent of individuals experience depression in the year following their injury. This can lengthen time for recovery and rehabilitation as well as increase symptoms of anxiety, catastrophic thinking, and perceived lack of control.¹² An often-unspoken component of reproductive health is reproductive mental health. Most available research focuses on the intricate relationship between reproductive and mental health focuses on married women of reproductive age primarily due to the larger burden of reproductive health conditions falling on women. There is little research on men's reproductive mental health, less data available on the reproductive mental health for men and women with SCI/D, and even less when those men and women are veterans.

Research

The lack of evidence on reproductive health and veterans is glaring. We need more research on the reproductive continuum of men and women veterans with SCI/D. In the past, attitudes that individuals with SCI should be “happy to be alive” and need to “learn to live without sexual pleasure” have clouded research and, if and when research was

¹⁰ Patel, N., Ngo, K., Hastings, J., Ketchum, N., & Sepahpanah, F. (2011). Prevalence of prostate cancer in patients with chronic spinal cord injury. *PM & R : the journal of injury, function, and rehabilitation*, 3(7), 633–636. <https://doi.org/10.1016/j.pmrj.2011.04.024>; Westgren N, Hultling C, Levi R, Seiger A, Westgren M. Sexuality in women with traumatic spinal cord injury. *Acta Obstet Gynecol Scand*. 1997;76(10):977-983. doi:10.3109/00016349709034913

¹¹ Michigan Medicine - University of Michigan. (2020, April 22). Spinal cord injury increases risk for mental health disorders. *ScienceDaily*. Retrieved June 25, 2020 from www.sciencedaily.com/releases/2020/04/200422101536.htm

¹² Mehta S, Orenczuk S, Blackport D, Teasell RW (2020). Mental Health after a Spinal Cord Injury. In Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, Noonan VK, Loh E, McIntyre A, Queree M, editors. *Spinal Cord Injury Rehabilitation Evidence*. Version 7.0: p 1-54

done, focused solely on matters of fertility and reproduction.¹³ Until we have this research, we cannot understand all the various factors that come into play in reproductive health such as race, ethnicity, gender, and disparities in care.

Likewise, there has been little research and attention given to female infertility and the impact of service on reproductive health from other military-related sources like toxic exposures from chemicals and burn pits. All VA facility leaders must be accountable for meeting women veterans' standard of care for quality, privacy, safety, and dignity. To advance the understanding how SCI/D affects the reproductive life cycle of women veterans, VA must include academic affiliates, other federal agencies, and for-profit industry in their research as a majority of research on SCI and sexuality has focused on men, who are more likely to have SCIs.¹⁴

VA's Women Health Programs

PVA commends VA for its commitment to improving women veterans' health and related programs. Thanks to their recent organizational restructuring, the Chief Officer for Women's Health now reports directly to the Executive in Charge, Veterans Health Administration. We appreciate the heightened visibility of the program, and we encourage Congress and VA to provide ongoing support as other changes are made to improve care for women veterans.

Natural Disasters

During a June 3rd hearing held by this Subcommittee to evaluate VA mission readiness and the department's ability to respond to natural disasters, Mr. Daniel Sitterly, VA's Assistant Secretary for Human Resources and Administrations/ Office of Security and Preparedness, spoke of a VA emergency response plan that has not yet been shared with the veterans' community. Therefore, it is still difficult to comment on VA's natural disaster preparedness, let alone how VA plans to respond to protect and serve the reproductive needs of veterans during natural disasters. One of our main concerns is the accessibility of benefits and services during major disruptions such as natural disasters and pandemics. Veterans may be delaying or unable to obtain reproductive care during natural disasters. Putting off breast examinations, pap smear, and prostate exams gives unidentified cancers—of which veterans have higher incidence rates—the chance to fester and delays time-sensitive treatments. In some places, contraceptive access may be limited so unintended pregnancies may occur and men and women

¹³ Anderson, K., Borisoff, J., Johnson, R. et al. The impact of spinal cord injury on sexual function: concerns of the general population. *Spinal Cord* 45, 328–337 (2007). <https://doi.org/10.1038/sj.sc.3101977>

trapped in homes may be subjected to intimate partner or caregiver violence. To help combat these situations, Congress should ensure VA is properly funded and develops the appropriate flexibility to minimize the adverse effects that natural disasters have on their day-to-day operations and veterans' access to needed benefits and services.

PVA would once again like to thank the Subcommittee for the opportunity to present our views on VA reproductive and related services and would be happy to answer any questions 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.