WRITTEN TESTIMONY

Brittany Elliott

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Legislative Hearing
H.R. 6373, The VA Spinal Trauma Access to New Devices (STAND) Act

Introduction

Madam Chairwoman Miller-Meeks, Ranking Member Brownley and distinguished members of the subcommittee.

My name is Brittany Elliott and I am a medically-retired United States Marine Corps Veteran. I am honored to join you today to discuss the critical importance of H.R. 6373, the VA Spinal Trauma Access to New Devices Act, or the STAND Act. I am joined here today by my father, full-time caregiver and exoskeleton companion, Morgan Elliott.

Background

By way of background, I am a medically-eligible Veteran in terms of VA healthcare and I am fully paralyzed from my chest down as a result of a head-on collision with a drunk driver on July 3rd, 2015.

As you can imagine, our journey to date has been a long one: One filled with great personal successes, but also great frustration and disappointment as it relates to the bureaucratic obstacles we have witnessed over the course of our VA journey.

I want to be clear: I am thankful that I, like many of my military brothers and sisters, have access to VA healthcare as it is indispensable to me and my family as a resource. Having said that, I am very concerned that many Spinal Cord Injury (SCI) Veterans like me continue to be effectively ignored when it comes to legitimately assessing their overall healthcare needs and the types of technologies that can assist them in regaining a sense of normalcy.

My story, is exactly mine, but many others with whom I routinely interact, share similar concerns and encounter many of the same obstacles while seeking care at the VA.

For the subcommittee's background, I was injured in 2015. After a month of intensive hospitalization, I was mistakenly sent home for a short period of time by my private sector providers. Due to ongoing and lasting issues, associated with the trauma, I was forced to return to the hospital, this time the Lt. Col. Luke Weathers, Jr. VA Medical Center in Memphis Tennessee, where I stayed for an additional five weeks of intensive treatment and rehabilitation. That time was followed by nearly three very tough years re-entering life in a wheelchair at my home outside of Nashville, Tennessee.

In late 2017 I was introduced, through social media and other means—NOT THE VA, to a device that I thought may have some utility for me if I were to ever regain the ability to stand and walk—The ReWalk personal powered exoskeleton. I approached my care providers at the Memphis VA and started pushing to gain access to the technology. After significant hesitation by my local providers, I was finally able to get them to agree to enroll me in VA's landmark study on the device, but that came at a significant cost to me and my family, especially my Dad as my full-time care-giver.

The VA Co-Op study was being undertaken at several VA facilities across the country, but not in Memphis. So, I was forced to travel, using my own limited resources, to the St. Louis, Missouri VA Medical Center at Jefferson Barracks. While there, I spent three weeks undergoing intensive training on the device (I might add this is normally an 8-week process, but I am a Marine, after all, and was able to power through the training at a faster pace) and successfully completed the trial. At which point, I was able to take the device home and start using it. I took it everywhere: Disney World, Sea World, Bush Gardens and multiple county fairs. It very quickly became an integral part of my new life and provided me opportunities otherwise unavailable to those in wheelchairs.

Unfortunately, the story doesn't end there. When I returned to my new home VA, the St. Louis VA in 2018, my provider (the VERY SAME PROVIDER who entered me into the trial) informed me that she would not support my continued use of the device AND TO THIS DAY has failed to provide any substantive rationale for that decision. As a result, the device was promptly returned to the VA and I was left in a chair and told "you should get used to it because that's all you can expect." Well, as a trained U.S. warfighter, THAT'S SIMPLY NOT GOOD ENOUGH, especially in light of all the training I had already successfully completed with the device and given how it had effectively changed my life over the course of its use.

For the next four (4) years, yes, that's right, four (4) years, I was engaged in a local and regional battle to regain access to the device that had already begun to change my life. Unfortunately, the VA bureaucracy is extremely strong and literally no one would stand up clinically and advocate on my behalf, even in light of my having successfully completed VA's own study on the device!

Finally, and thanks to a forward-thinking and supportive clinician at the Sonny Montgomery VA Medical Center in Jackson, MS, I was seen, re-evaluated over the course of weeks, AGAIN ON MY OWN DIME, and ultimately provided a new device which I still have today and use every day of my life. I am eternally grateful to this provider as his disposition was not one that lent itself to the institutional bureaucracy, but one that carefully considered the entirety of the evidence and the utility of this device for me--a young, vibrant, and motivated Marine.

I am confident this fight never needed to happen, but the system in many cases, it seems to me, is built to protect itself instead of the Veterans it serves.

While many of you saw me walk in here today, and while standing and walking are clearly critical elements of this device, it's what you don't see that may be the most life-changing for me. For instance:

- My bone density has returned to almost normal levels as a function of me standing and bearing weight that I would not be able to accomplish in a chair;
- My core strength has been improved and sustained allowing me to sit upright, which is not a given, considering my level of injury;
- While in a chair, I was having several urinary tract infections (UTIs) every month that were becoming increasingly difficult to combat with antibiotics and serious infections were

causing serious challenges. Using this device, my UTIs have now decreased to around 2 per year—A DRAMATIC AND POTENTIALLY LIFE-SAVING REDUCTION;

- I have lost weight, which in a chair is nearly an impossibility due to the lack of mobility or activity overall; and
- My mental health has dramatically improved. When I stand, I get to look people in the eye, shake their hand properly and be addressed as a person, not simply patted on the back and often overlooked altogether---this is HUGE for a Marine like me!

Even in light of the well-recognized health-related advantages to standing and being ambulatory, VA often relies on the fact that sufficient capacity in the various SCI centers and related "hubs", nationally, does not exist to do the extensive training associated with the device. At the same time, however, they seem equally unwilling to send Veterans into the community, through the existing and expanding Community Care Networks (CCN), for training by those who have already been professionally trained on the devices. It seems to me, you can't have it both ways….. You either treat those who are clinically-eligible, or follow the law and send them into the community. Unfortunately, this is rarely the case.

<u>STAND Act</u>
I am aware that we are here to discuss the STAND Act, but I wanted to ensure that my interest in this legislation was explicitly clear and I am confident my experience lends itself to this critical effort.

With regard to the bill, I am so grateful to General Bergman and his staff for his authoring, and I also want to personally thank Chairman Bost, Ranking Member of the subcommittee Brownley and Congresswoman Dingell for their willingness to co-lead this effort. My thanks as well to those who have agreed, and continue to agree, to co-sponsor the STAND Act.

Equally important, I am supremely thankful for the public support that has been provided by the Paralyzed Veterans of America (PVA), the Disabled American Veterans (DAV) and the Reserve Organization of America (ROA) and the Independence Through Enhancement of Medicare and Medicaid, or ITEM Coalition, a coalition of industry and non-profit organizations supporting assistive technologies, generally.

In my view, the bill is critical for a few reasons, and I will relate them to my personal experience and to those with whom I routinely interact across the VA SCI spectrum:

- As you all know, the bill seeks to codify what VA is already supposed to be doing in the way of performing annual examinations—I can tell you with certainty, they are not. I have had 5 exams over the last eight (8) years and I had to push for several of those myself. So, the requirement for VA to proactively solicit participation in annual examinations from enrolled SCI Veterans is not only important as it relates to assistive technologies like mine, but to the overall health and well-being of this important population. It's VERY hard for me to hear VA claim to be the best at SCI care in the world, and at the same time know that many Veterans who need routine care simply are not getting it;

- Additionally, like me, I think it's imperative that VA assess the viability of assistive technologies for ALL Veterans with SCI as simply allowing them to stay in chairs, if they are clinically-eligible for other devices, is just simply not good enough. The STAND Act mandates this type of assessment;
- One thing I've learned over my years of fighting the VA is that clinical behavior is very difficult to change. One way to accomplish change however, is to demand accountability for those responsible for making clinical decisions. This bill seeks to accomplish this by two means:
  - Make the VA reportable to Congress on their success against the metrics I mentioned; and
  - Hold VISN leadership accountable, through their annual performance evaluations for these same metrics;
  - Institutional change doesn't come easy, but it seems to comes easier if those in charge are held accountable and understand that some level of oversight is effectively in place.
- Finally, and I think this is important, VA failing to consult Veterans about the opportunities that exist for them is one thing, but their continued unwillingness to engage the manufacturers of these technologies when considering how the technologies can work for Veterans is disturbing. I know, based on my own experience, they will fall on their "objectivity sword" all day long, but the manufacturers and scientist who build these technologies possess the technical information that can truly assist in informing these types of important decisions for SCI Veterans.

Conclusion

Madam Chairwoman, Ranking Member Brownley and members of this subcommittee I am very thankful to you and all those who have supported this bill as it can be truly life-changing for those like me, who have faithfully served their nation. But lack of system capacity, an unwillingness for VA leadership to allow Veterans to enter the community for training and just flat-out bureaucratic red-tape continue to hamper other Veterans' ability to gain access to these important technologies that are truly life-changing.

As I have already stated, ensuring others have access to technologies like mine is indeed my new mission in life and with your continued support I am confident more Veterans will be able to reclaim their lives and fulfill their ongoing obligations to family, community and country. I proudly stand, AND I MEAN STAND, in strong support of this bill as its importance can be truly immeasurable for those who are simply trying to rebuild their lives and who are seeking the VA's support to get them there. With your collective help this will be an easier path for others who are currently waiting and those who will inevitably follow.

I truly appreciate the opportunity to appear before you today and I am happy to respond to any question you may have.