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STATEMENT OF ARIANA DEL NEGRO FOR PRESENTATION BEFORE THE SENATE COMMITTEE ON VETERANS' AFFAIRS

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Mr. Chairman, members of the Committee, and panel members, thank you for the opportunity to participate in this vital forum on veterans' care and benefits in Hawaii. By sharing our story today, I hope to increase awareness regarding the gaps in medical care for veterans receiving treatment in Hawaii, as it is my opinion that the military healthcare system here on Oahu, as it now stands, is insufficiently prepared to address the needs of our wounded veterans and their families suffering from traumatic brain injury (TBI). There is much work to be done that requires diligent initiatives for research, education, and family support. My hope is that our story demonstrates the importance of prompt referral to centers specifically tailored to the individual needs of each wounded warrior and highlights the need to streamline the transition from active duty to veteran status.

My name is Ariana Del Negro and sadly, I represent one of the many military wives/caregivers coping with the hardships of having a soldier return wounded from Iraq or Afghanistan. But I'm one of the lucky ones. My husband and I are well educated, I work in the healthcare industry, and we are financially independent. What we have had to endure over the course of the last 10+ months struggling to navigate through a convoluted, outdated, unprepared bureaucratic military healthcare system has been absolutely untenable. If it has been this difficult for us, I cannot imagine what it must be like for the other families -- those with warriors who return far worse off than my husband; families with children; with mothers who have to work to supplement the family income; and those who don't know that the care they are receiving is far inferior to what they need and, importantly, deserve. The wounds suffered from these injuries extend beyond the soldier; the frustrations, gaps in care, and lack of support also wound the families fighting for their loved ones. There are soldiers and families out there that need help and the onus to get them that help falls on the nation for whom these warriors fought to protect democracy and freedom.

On September 28, 2006, my husband suffered a TBI when a 7,000 pound VBIED (vehicular-borne improvised explosive device) detonated 45 yards from where he was standing. He was exposed to 3 concussive forces: first the explosion; then the engine block from the vehicle which struck him on the back of the head as he was thrown into the air; and finally when he hit his head again after falling to the ground on his back, where he remained unconscious for at least 10 minutes. He spent 3 days in the intensive care ward at Balad Military Hospital and was subsequently released and returned to his base in Iraq with the anticipation that the fog of his mild/moderate (closed-head) TBI would subside sufficiently enough that he could return to full duty.

An Army Ranger, my husband is a well-respected member of his battalion and held one of the most esteemed and coveted positions for a lieutenant -- that of a Scout Platoon Leader responsible for collecting intelligence in an area rich with diverse religious and political sects.

He commanded deep respect from his men and performed his job to the highest degree of excellence and professionalism. He deserved the same from the system that he served.

Instead, this brain-injured soldier and Purple Heart recipient was returned 3 weeks later to his home base in Hawaii and told to follow-up with the system for evaluation and treatment. My husband could barely keep his balance, let alone figure out where he was supposed to go and who he was supposed to see. Unfortunately, the system he reported to didn't know either. From his first doctor's appointment in Hawaii, it became abundantly clear that the system was "reactive", not "proactive". There was no initiative taken to get him care; we had to do it all alone, facing obstacle after obstacle along the way. In short, referrals were not made, diagnostic tests were not ordered, complaints of mental duress (anxiety) went ignored, and there was absolutely no communication or consensus between the providers we were ultimately able to see (and only able to see after demanding that those appointments be made). In my opinion, regardless of the medical setting -- military or otherwise -- this care or the lack thereof amounts to negligence and malpractice.

My husband describes the struggles we have had with Tripler Army Medical Center as being as painful as sustaining the injury itself. Perhaps some of our difficulties were related to the fact that a closed-head TBI is literally a hidden injury; an injury with the potential for subtle (yet devastating) sequelae that go unnoticed by those who are unfamiliar with the individual's function before his or her injury. Healthcare professionals are used to having physical evidence of an injury, but typically, the diffuse axonal injury pattern that results from the blast wave of pressure from an exploding IED cannot be neuroimaged and proper identification and referral to treatment are made on the basis of neurologic examination, self- and family-reported symptoms, and the results of neuropsychological testing. Oftentimes, this can lead providers to think that soldiers are malingering, shirking out of having to return to duty in Iraq or Afghanistan. Such accusations were wrongly thrust upon my husband, adding salt to an open wound. This was a system that was supposed to heal wounds, not create new ones. It failed and it has not failed us only; it has failed many of the returning wounded warriors.

However, my husband was fortunate enough to have remarkable support from his Command. His Commander took interest in my husband's case, provided support, and dedicated many hours of his time seeking resolution to our long list of outstanding issues. Without his support (and the support of the 25th Infantry Division), it's likely that I would be sharing a different story with you.

Early Disappointments

My husband returned to Hawaii approximately 3 weeks after he was wounded. At that time, he complained of debilitating headaches, chronic vertigo, memory lapses, anxiety, and hearing loss. He always leaned to the left, had hand and facial tics, and could not maintain eye contact when speaking. Two weeks thereafter, some symptoms worsened and new ones emerged. He developed a significant stutter, had difficulty with word recall, and had a propensity to drop things. It was also at this time that he began to withdraw socially, avoiding public and busy areas. His time was mostly spent sitting, staring blankly. My husband is an exceptionally accomplished and strong individual and it was very hard for me to see him struggle with simple tasks.

After much insistence, he was referred for speech pathology and received speech cognition therapy once a week. The next mountain to be climbed was to get his vision checked and then to obtain referral for vestibular and audiology testing. During this time his symptoms persisted, and although some subsided, they never fully resolved. After 14 long and frustrating weeks of not being a priority in the system, after no coordinated plan of care meeting was organized, and after being denied access to additional care (ie, occupational therapy), our request to be referred to the Defense and Veterans Brain Injury Center (DVBIC) in San Diego for thorough evaluation and intensive treatment was finally granted. We waited another 6 weeks for all paperwork to be finalized and then reported to the DVBIC at Balboa Naval Medical Center who coordinated with the Community Re-entry Program at Sharp Rehabilitation Center (civilian) for follow-up care. All told, it took us more than 5 months to get access to excellent care. This was 5 months of valuable time lost, during what should have been the important acute rehabilitation stage of TBI.

Fine Example of Excellent Care and Invaluable Education

The care in San Diego represented the complete antithesis of what we received in Hawaii. The providers at Sharp addressed all of my husband's needs (physical, occupational, and speech therapy), integrated our requests into their rehab program, and provided amazing support to both of us. My husband underwent intensive rehabilitation 6 hours a day, 4 days a week -- care he should have received all along. We had biweekly coordination meetings with providers at both Sharp and Balboa who met with us to discuss his progress, make suggestions, and ask for feedback. And, importantly, they educated us. We learned that our situation was not unique and that many closed-head TBI patients face similar obstacles and frustrations that compound their symptoms. They explained that the adverse effects of the injury would have resolved faster had some of the frustration with his medical care been avoided. They also explained that my husband would have probably made greater progress during rehabilitation had he been referred earlier in the treatment process; likely he would have reached the same degree of benefit, but at a much faster rate. Importantly, they also explained to us that there may be some symptoms that will never resolve and that the success of his rehabilitative therapy requires us to recognize reasonable goals while maintaining practical expectations.

Shortly after coming home from Iraq, my husband commented that because he wasn't missing a limb and/or didn't have scars on his head or body, he didn't consider himself as seriously wounded as those with visible injuries, a sentiment reinforced by Tripler Army Medical Center's lack of initiative for his care. The absence of a visible sign of his injury took away from its severity, as well as his perceived need to treat it. The education we received from Sharp Rehabilitation as well as from the DVBIC helped alleviate some of those concerns and provided affirmation to my husband that he was seriously injured and did deserve the best possible care. It is our hope that with greater awareness of the consequences of TBI, providers will appreciate the importance of educating and supporting the patient and his/her family.

My husband left San Diego a changed man. He regained his ability to accomplish complex tasks, his speech was fluid, he was able to run, and he passed a driving evaluation. He has since returned to duty in an administrative capacity, working with his unit's Rear-Detachment here in Hawaii. Although he still suffers from intermittent headaches, vertigo, fine motor skill deficits, and some memory problems, they are far less intense than when he first came home and he has applied the lessons we learned in San Diego and is accepting and compensating for these limitations accordingly.

Our success with Sharp's Community Re-entry Program was the result of receiving excellent individualized care and education from a multidisciplinary group of providers who worked well together and integrated the family unit into the decision-making process. This medical model supports the plans outlined in Section 3 of the Veterans Traumatic Brain Injury Rehabilitation Act of 2007 (cited as S. 1233) describing rehabilitation programs that provide individualized care and family support to veterans with TBI. Section 3 of S. 1233 also identifies the importance of periodic evaluation and adjusting care as needed, which we experienced at the Sharp Rehabilitation Center.

Comprehensive Care: When a Referral Is Really Necessary

My husband was very high-functioning after his injury and was not an individual who one would typically consider eligible for intensive rehabilitation. However, with the increasing awareness of the deleterious and long-term consequences of TBI -- namely through the adoption of the DVBICs across the country -- my husband was properly identified as someone who could benefit from such care. We utilized all of the tools at our disposal to the fullest. We knew that he was one of the lucky ones to get treatment and it is our hope that the success he (and Sharp Rehabilitation, in collaboration with the DVBIC and Balboa Naval Medical Center) achieved sets a fine example for what the standard of care should be for all soldiers returning with TBI. Our experience at the Sharp Rehabilitation Center also represents the importance of extending civilian healthcare services to returning soldiers. Programs, such as the one at Sharp, have experience with the injury, have an effective and efficient program in place, and clearly yield excellent results. More initiatives need to be taken to institute similar programs partnering military and civilian healthcare services. In addition, consideration must be given to properly pairing the offerings of a rehabilitation center with the specific needs of a veteran with TBI. In our case, and because my husband was high-functioning, referral to the Sharp Community Re-entry Program was more appropriate than referral to the Veterans' Affairs (VA) Palo Alto Health Care System because the latter primarily manages patients with more severe TBIs. Veterans with TBI will be greatly served by having access to non-Department facilities for rehabilitation, as outlined in Section 4 of S. 1233.

Our referral to the DVBIC in San Diego was absolutely appropriate, but the decision should have been made much earlier. In fact, my husband never should have been returned to Hawaii for evaluation and treatment of TBI. Typically, soldiers that are wounded and returned home are routed to Landstuhl for referral to Walter Reed or another center adequately equipped to treat the specific injury. Tripler was not an experienced center for TBI and should have recognized the importance of referring my husband to a center that could provide the necessary comprehensive care. This also speaks to the importance of Section 4 of S. 1233 for referral to a non-Department facility when "the Secretary is unable to provide such intervention, treatment, or services at the frequency or for the duration prescribed in such plan". Tripler's unpreparedness to adequately treat TBI was reflected in the fact that appointments were few and far between and no coordination efforts were put forth to institute a plan of care for my husband's treatment -- a necessary course of action mandated in Section 3 of S. 1233.

Since our return from San Diego, awareness of TBI has increased and programs are now being instituted to assist wounded warriors at all Army facilities, including Tripler. I am pleased to know that Tripler recognizes the need to make the care of wounded soldiers its top priority and has begun to implement programs that have the potential to improve tracking and coordination of care, as well as support for families.

Although these initial steps are very promising, I remain concerned that much more work needs to be done before Tripler Army Medical Center has the necessary tools in place to effectively coordinate and manage the care of soldiers or veterans with TBI. Noted in Section 3 of S. 1233, and also listed in a Veteran's Health Initiative,[ ] optimal care for TBI requires a multidisciplinary approach consisting of a team of providers from at least 9 specialties. I do not believe that Tripler will be able to establish a team that could coordinate or collaborate effectively enough to yield the necessary outcomes owed to a TBI wounded warrior, at least not at the present time.

Access to Resources

We hope to work with Tripler and its faculty to help ensure that no other wounded warriors and their families endure the same hardships that we faced. Furthermore, it is our hope that we will be given the opportunity to meet with some of the soldiers and their families to provide support, whether that be as simple as lending an ear or a shoulder or helping them gain access to important resources.

It is critically important that soldiers and their families are proactively made aware of the resources that are available to them; they shouldn't have to seek them out. I wouldn't have known about the DVBIC unless I had actively sought out information and made contact with both Walter Reed and San Diego. I wouldn't have known that my husband wasn't getting the standard of care if I didn't work in the healthcare industry and if I hadn't done extensive research to educate myself on TBI and the multiple disciplines that must work together to treat the condition.

Our endeavors paid off, it would seem. But what about those individuals who, in addition to the needs of their wounded loved one, have to tend to the needs of their children, or who don't have the flexibility with their work, or who don't have the benefit of higher education, or who don't know that they can ask questions? Those are the families in need. These families need immediate access to resources, they need advocates, and they need support. It's one thing to develop resources -- it's another to actually utilize them. If the families don't know these resources exist, then they are certainly not likely to ever reap the benefits from said programs.

Transitioning From Active Duty to Veteran Status

The above traces the trials and tribulations that my husband and I faced during the early phases of his injury. Our frustrations, I fear, will continue for months and years to come. My husband is still on active duty and we are no closer to definitively determining his potential for return to full duty status than we were when he first returned from Iraq in October 2006. Unfortunately, the obstacles we faced during active duty will likely be inevitably revisited once he is discharged from the service and once he enters and seeks care in a backlogged and overwhelmed VA system (described as such after reading media accounts); whether that happens in the next year or in 12 years when he retires, remains to be determined.

Although my husband is still on active duty, our experience represents what most young veterans suffering TBI have had to face before being discharged from the service. We must be able to learn from these initial experiences to avoid similar obstacles within the VA system. The continuum of care begins on the battlefield, moves to the military healthcare system, and then to the VA system. The Dignity for Wounded Warriors Act of 2007 (H. R. 1268) aims to overcome many of the limitations associated with wounded servicemembers' access to care. However, the success of both S. 1233 and H. R. 1268 are contingent on establishing an effective transition system. As noted in Section 2 of S. 1233, a collaborative effort between the Department of Defense and the VA is absolutely necessary to facilitate care and streamline the transition of soldiers from active duty to veteran status. More research and greater awareness of blast-related TBIs will likely facilitate this transition process.

More Research Is Needed!

Recovery from and treatment for TBI requires patience. The complexity of the injury and its pathophysiology require a long-term multi-tiered management approach. In the acute setting, management is focused on stabilizing the patient and ruling out life-threatening complications, such as shrapnel wounds or spinal injuries. The second step is assessing and treating the intermediate effects of the injury, namely, neurocognitive difficulties, reflected in self-reports of symptoms such as forgetfulness, anxiety, headaches, balance difficulties, and other sequelae commonly associated with post-concussive syndrome. Less defined at this time, however, is what will be needed in the long run. How long should care be administered? When is a patient considered fully recovered and what are the long-term consequences of closed-head TBI (ie, epilepsy, Alzheimer's, Parkinson's)? Answers to these questions remain ambiguous, at best.

Data suggest that a person with a mild TBI who does not receive early adequate treatment and education is more likely to endure a long recovery process with lingering symptoms. However, these data are largely based on older studies evaluating outcomes of patients who sustained a TBI in an automobile accident, a fall, or a sports injury. It does not take into consideration that a blast-related TBI may injure cells at a more severe microscopic, sub-cellular level.[,] Injury to this fine of a degree may influence outcomes and possibly require longer periods for maximum recovery than TBIs suffered in a non-combat setting.

There is little doubt that more research on blast-related TBI is needed, particularly as it relates to the effects of exposure to multiple primary blasts and long-term outcomes. TBI in a combat environment is a complex injury. A thorough understanding of the nuances of the injury, whether physically evident or otherwise, is absolutely essential to identify effective therapies and maximize outcomes. Currently, much of the evidence on blast-related TBIs is derived from animal studies, which have helped researchers understand the pathophysiologic effects of the injury; however, the implications of these findings in the clinical setting have not been well studied. As the number of TBI wounds increase, so too does the need for allocated funding to support clinical research and facilitate the drafting of practice guidelines, as well as the need to develop educational tools and implement training requirements for all providers.

The importance of more research in this area is recognized in Section 5 of S. 1233, which states that the "Secretary shall establish a program on research, education, and clinical care to provide intensive neuro-rehabilitation to veterans with a severe traumatic brain injury". However, this language excludes the majority (80%) of TBI injuries -- those classified as mild or moderate. It is my opinion that without documentation from large clinical studies with long-term follow-up, it may be premature to assume that veterans with mild or moderate TBI do not need the same services offered by this initiative. Furthermore, persistent post-concussive syndrome (defined as symptoms that continue beyond 6 months post-injury) is more common after mild TBI than moderate or severe TBI and individuals with persistent post-concussive syndrome are likely to continue to suffer symptoms for a number of years.

It took months for me to convince my husband that he deserved the same priority of care as those soldiers with visible injuries. Hopefully, with more research and greater awareness, soldiers in similar situations will be counseled appropriately by the system responsible for helping these individuals maximize their potential. These soldiers (and their families) need validation and they need dedicated support.

I am aware that this continues to be an ongoing learning process, but I also believe that measures need to be put in place to assess the efficacy of these programs, that specific benchmarks need to be set to reduce the length of time between presentation and treatment initiation, and that processing of disability claims must be streamlined. The proposed programs set forth by S. 1233 and H. R. 1268 are promising in theory, but without adequate resources and without intense coordination and organization, the therapy and these efforts will likely fail for most.

I urge you and your colleagues to remain steadfast in your endeavors to ensure: (1) that soldiers with TBI and their families get the care that they need and deserve; (2) that appropriate funding be allocated for research; and (3) that immediate actions are put into place to increase the awareness of the devastating effects of TBI. It's time that the excellence that these soldiers dedicated and displayed in the war zone be matched by the system for which they sacrificed.

I thank you for your time.