ARIANA DEL NEGRO, WIFE OF 1LT CHARLES GATLIN

STATEMENT OF ARIANA DEL NEGRO, WIFE OF 1LT CHARLES GATLIN, FOR PRESENTATION BEFORE THE SENATE COMMITTEE ON VETERANS' AFFAIRS

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Mr. Chairman, Committee Members, thank you for allowing me the opportunity to participate in this vital forum on the issue of providing coordinated care to servicemembers, veterans, and their families. My name is Ariana Del Negro and I represent one of the many families with a loved one injured in Iraq or Afghanistan who are now entering the awkward and unfamiliar transition phase between active duty and veteran status. I am here today not only to tell you about the numerous obstacles my husband and I faced when he first returned home from Iraq, but also to describe the excellent care he ultimately received for his traumatic brain injury (TBI). My husband and I believe that there is much work to be done and hope that sharing our experiences will help create a model of care for servicemembers and veterans with TBI and their families that establishes: (1) strong support networks and access to information; (2) timely, comprehensive, and coordinated care; and (3) appropriate funding for the continued research and training required to provide a high standard of long-term care to the ever-increasing numbers of warriors suffering from TBI.

The wounds suffered from these injuries extend beyond the soldier; the frustrations with gaps in care and lack of support also wound the families fighting for their loved ones. These servicemembers, veterans, and families need our help, and the responsibility to provide them with that help falls on the nation for whom these warriors bravely fought.

Our Story

My husband, 1LT Charles Gatlin was the Scout/Sniper Platoon Leader of his Infantry Battalion. He was honored to hold this highly coveted position, one which was reserved for the "best" lieutenant in the Battalion. He took pride in having the degree of skill and professionalism required for the position, particularly because his work gathering intelligence helped both to ensure the safety of his fellow soldiers and to meet the larger objective of unifying a politically and religiously diverse area. My husband commands deep respect from his soldiers and continues to perform his job (albeit in a different capacity) with the highest degree of excellence and professionalism.

On September 28, 2006 in Kirkuk, Iraq, my husband suffered a closed-head TBI after a very large vehicular-borne improvised explosive device (VBIED) detonated less than 20 yards from where he was standing. He was exposed to three 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 ten minutes.

The screening and care my husband received in the battlefield and in the theater was excellent, proficient, and per protocol. Within one hour of his injury, my husband was medevaced to Balad Medical Hospital where he was admitted in serious condition. After three days in the intensive care ward, he was eventually discharged from the hospital and returned to his base in Kirkuk in hopes that his initial TBI symptoms would subside enough that he could return to the field of combat within a few weeks. I believe that my husband was returned to his base in Kirkuk instead of being medevaced to Landstuhl Regional Medical Center in Germany because of his insistence that he be back with his men in the field. During the four weeks my husband spent back in Kirkuk, he had to depend on his medic and roommate, CPL Joshua Harmon. CPL Harmon tended to him, helped him dress, assisted him when moving from room to room, and checked his pupils each night. (Sadly, on August 22, 2007, CPL Harmon and nine of his fellow Scout platoon members died in a helicopter crash outside of Kirkuk, Iraq. To CPL Harmon and his family, and to the families of his fallen comrades, thank you.)

After spending approximately four weeks in Kirkuk without resolution of his symptoms, my husband was returned back to his home base in Hawaii. He could barely keep his balance, let alone figure out where he was supposed to go and whom he was supposed to see for his medical care. Unfortunately, the system he reported to, Tripler Army Medical Center, did not know either.

My husband had sustained what is now known as the "signature wound" of the Global War on Terror. However, he was injured before this phrase was coined and before the full implications of the injury were recognized. The general lack of awareness of TBI at the time of his injury, coupled with its "silent" symptoms, were significant barriers when my husband first sought medical treatment upon his return from Iraq.

A closed-head TBI is literally a hidden injury; an injury with the potential for subtle yet devastating symptoms that go unnoticed by those who are unfamiliar with the individual's functioning prior to his or her injury. Healthcare professionals are used to having physical evidence of an injury, but mild, closed-head TBIs typically do not show up on brain scans and referrals for treatment must be made on the basis of neurological exams, self- and family-reported symptoms, and the results of neuropsychological testing.

When he first returned home from Iraq, my husband complained of debilitating headaches, chronic vertigo, memory lapses, anxiety, and hearing loss. He leaned to the left, developed hand and facial tics, and could not maintain eye contact when speaking. Two weeks later, as some symptoms worsened, new symptoms emerged. He developed a significant stutter, had difficulty recalling words, and frequently dropped objects. Unable to drive, this fiercely independent man lost his autonomy and was forced to depend upon others for his basic needs. 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. Watching my husband, an exceptionally accomplished and strong man, struggle with such simple tasks was very difficult.

Early Disappointments

The phrase "twice wounded," often used to describe the struggles wounded warriors face when seeking care in the military healthcare system may seem clichéd, but it is exactly what my husband experienced after he returned from Iraq. He describes the struggles we encountered at Tripler as being as painful as sustaining the injury itself.

Treating TBI requires a multidisciplinary approach from as many as nine specialists. However, the single most important component of treatment is effective communication and coordination among these providers. Although Tripler had the resources required to effectively treat TBI, they lacked that crucial coordination. Coupled with Tripler's lack of experience managing TBI and post-concussive syndrome (a diagnosis made when a patient continues to exhibit symptoms from TBI beyond one month), this lack of coordination compromised and slowed my husband's recovery. Despite his worsening symptoms, we had to fight for every referral he needed -- audiology, vestibular testing, ophthalmology, speech therapy, etc. And, even after we were referred to and met with these specialists, no two specialists agreed about what my husband needed; we spent our days shuttling from one appointment to the next, only to discover that the recommendations made by one provider were deemed unnecessary by another.

Many of the providers we saw had little or no experience with blast-related TBI. When my husband told the doctors treating him at Tripler that his injury was caused by a VBIED, they asked him what a VBIED was. Likewise, when my husband - the brave infantryman who had insisted on remaining in Kirkuk after his injury - actually summoned up the courage to acknowledge to his neurologist that he was experiencing anxiety, his neurologist simply responded: "See me in two weeks." Had this neurologist instead taken the time to find out what my husband's responsibilities were in Iraq and what he witnessed, he would perhaps have realized that exposure to these stressors meant my husband was at increased risk for depression, anxiety, and other psychological issues. In my husband's case, these risks were exponentially compounded by the fact that several symptoms associated with post-concussive syndrome secondary to TBI are psychological in nature. Whether due to a lack of combat experience, poor training, or overwhelming caseloads, these doctors simply did not have the knowledge or skills to treat my husband's injuries.

Similarly, because doctors cannot see physical evidence of TBI, they sometimes wrongly conclude that servicemembers suffering from TBI are malingering and trying to shirk their duties and avoid returning to Iraq or Afghanistan. One of the physicians treating my husband in Hawaii made exactly this kind of accusation against my husband, which added salt to an already open wound.

My husband was unable to drive, which placed responsibility for taking him to each and every one of his appointments and to and from work on me, his lone caregiver. Because of the adverse cognitive and communication effects of his injury, I also had to act as his representative, speaking and processing information on his behalf. But the system at Tripler was far from encouraging and supportive of my efforts. Many of the people we encountered seemed to be less than pleased with a wife who was outspoken, informed, and persistent. One physician even went so far as to suggest that my husband was receiving poor care because of my outspokenness.

Finally, after 14 long and frustrating weeks of struggling with the system to get my husband the care he needed, our request for referral to the Defense and Veterans Brain Injury Center (DVBIC) at Balboa Naval Medical Center in San Diego, California for thorough evaluation and comprehensive treatment was granted. After waiting another six weeks for the paperwork to be finalized, we finally arrived in San Diego. All told, it took us more than five months to get access to this excellent level of specialized healthcare. These were five valuable months lost in the crucial 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 DVBIC at Balboa coordinates its care with the Community Re-Entry Program at Sharp Rehabilitation Center, a center with more than 20 years of experience in rehabilitative care. The providers at Sharp and at Balboa 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 finally received the care he should have received all along. He underwent intensive rehabilitation 7 hours a day, 4 days a week. We had biweekly coordination meetings with all of my husband's providers who met with us to discuss his progress, make suggestions, and ask for feedback.

The care my husband received in San Diego represented what we should have been receiving all along. I use the term "we" because the caregiver and family unit are integral to a successful rehabilitative process. In stark contrast to the care in Hawaii, where my involvement was discouraged, the program in San Diego integrated the caregiver into the rehabilitative process.

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. Shortly after coming home from Iraq, for example, my husband commented that because he was not missing a limb and/or did not have scars on his head or body, he questioned whether he was as seriously wounded as those with visible injuries; a question reinforced by his experiences with some of the doctors he encountered at Tripler. The education we received at the DVBIC and Sharp provided affirmation to my husband that he was seriously injured and deserved the best care possible. They explained that the adverse effects of his injury would have resolved faster had some of the frustration with his medical care been avoided. They also explained that my husband probably would have made greater progress during rehabilitation had he been referred earlier in the treatment process. Although he likely would have recovered to the same degree, he would have done so at a much faster rate. Importantly, they also explained that there may be some symptoms that will never resolve and that the success of his rehabilitative therapy depends on our ability to set reasonable goals and maintain realistic expectations.

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 was able to regain his autonomy, enabling me to (semi-) retire from my roles of caregiver and chauffeur. Now I can be a wife and he can be a husband. He has since returned to duty in an administrative capacity as his Battalion's Rear-Detachment Executive Officer in Hawaii. Although he still suffers from intermittent headaches, vertigo, fine motor skill deficits, and some memory problems, they are less intense than when he first came home. He has applied the lessons we learned in San Diego and is learning to accept and compensate for his limitations.

Throughout this process, my husband and I have done our best to keep a sense of perspective, returning time and time again to our sense that we are one of the lucky families. My husband and I are both well-educated and make a good living. Working in the healthcare industry, I have been able to rely upon my medical background to find appropriate resources. My husband was also fortunate to receive remarkable support from his Command. His Commander, MAJ William J. O'Brien, in the spirit of a true Infantryman, dedicated a significant amount of time and effort to ensure that my husband received the care he rightly deserved. Without MAJ O'Brien's support, and the support of the 25th Infantry Division, it's likely that I would be sharing a different story with you today.

However, if it has been this difficult for my husband and me, we 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; families with mothers who have to work outside the home to help support their families; and those who do not know that the care they are receiving is far inferior to what they need and, importantly, deserve.

Support for Families at All Stages in the Recovery Process

The success we had at Sharp Rehabilitation demonstrated that in addition to providing adequate funding and training, it is important that systems be created to provide support for servicemembers, veterans, and their families. Our frustrations with my husband's initial care alienated us; we had nothing to compare our own experience with, and had no communication with other families in similar situations. Less than one week after our request for referral to the DVBIC was honored, The Washington Post published the first in its series of articles on Walter Reed, chronicling the frustrations wounded servicemembers, and their families faced trying to navigate through a complicated and bureaucratic system. The Washington Post articles were bittersweet: the sweet of knowing we were not alone coupled with the bitter of knowing we were not an exception. These articles also validated my belief that it is not just the individual servicemember who bears the brunt of injury. The unrealistic expectations that the system places on the caregiver add further burden to an already stressful and taxing situation.

It is critically important that servicemembers and their families are proactively made aware of the resources that are available to them; they should not have to seek them out. I would not have known about the DVBIC unless I had actively sought out information and made contact with both Walter Reed and San Diego. I would not have known that my husband was not getting the appropriate standard of care if I did not have a medical background and if I hadn't done extensive research to educate myself on TBI. I made sure that I was armed with knowledge for each doctor's appointment and I did the best I could to educate my husband. What is clear from our own experience is that there are many families in need. These families need immediate access to resources, they need advocates, and they need support. It is one thing to develop resources but it is another to actually utilize them. If the families do not know that these resources exist, they are unlikely to ever be able to reap benefits from those programs.

I am pleased that the reports from The President's Commission on Care for America's Returning Wounded Warriors (commonly referred to as the Dole-Shalala Commission), as well as the Veterans Disability Benefits Commission, recognize the pivotal role of family in the treatment process and I strongly advocate for an amendment to the Family Medical Leave Act, extending unpaid leave from 12 weeks to 6 months for caregivers tending to the needs of a servicemember. I believe, however, that the legislation should go one step further to include those tending to the needs of wounded veterans, particularly since many of the diagnoses for TBI and PTSD are made after servicemembers are separated from active duty.

The Importance of Timely and Coordinated Care

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; in essence, they practiced "relationship-based healthcare". This medical model is outlined in pending legislation, such as the Veterans Traumatic Brain Injury Rehabilitation Act of 2007 (S. 1233).

My husband was very high-functioning after his injury and was not an injured servicemember for whom the military typically considered intensive rehabilitation necessary. However, 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 finally properly identified as someone who could benefit from such care.

Our experience at the Sharp Rehabilitation Center also demonstrates the importance of extending civilian healthcare services to servicemembers and veterans. Programs such as the one at Sharp have experience with these types of injuries, have an effective program in place, and clearly yield excellent results. More initiatives need to be taken to institute similar programs partnering military, veteran, 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 servicemember/veteran with TBI. Employing the valuable resources of these non-Department facilities could help reduce the heavy burden on the Department of Veterans' Affairs (VA) -- a burden likely to grow in parallel with the number of wounded.

Staffing Shortages and Lack of Training Compromise Care

As noted in Dole-Shalala Commission Report, the chances of recovery from TBI are greatest when prompt and correct care is administered. Communicating this message to healthcare providers is pivotal to ensure that all servicemembers and veterans have immediate access to care. Meeting this objective, however, is contingent on providing appropriate, timely, and comprehensive training to health care professionals, with an emphasis on the signs and symptoms of TBI and PTSD. It is also dependent upon adequate long-term funding.

This also speaks to the staffing shortages of healthcare providers in the military and VA systems. Tripler Army Medical Center is the largest military medical treatment facility in the entire Pacific Basin, covering an eligible population of 400,000 servicemembers, veterans, and their families. Yet, when my husband first arrived at Tripler for care, there were only three neurologists in the entire hospital. Furthermore, there was only one full-time neuropsychologist, a provider described in a Veterans Health Initiative as "the key player in diagnosing cognitive impairments" in patients with post-concussive syndrome. Neuropsychological testing is a labor-intensive process and the results of the testing require careful and detailed analysis to ensure a fair assessment. Given the recent findings of the Neurocognition Deployment Health Study that deployment to Iraq increases the risk of neurological compromise, the caseload for these neuropsychologists will undoubtedly increase.

More Research Is Needed!

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 closed-head TBI wounds increase, so too does the need for allocated funding to support clinical research and new practice guidelines.

For example, much of the data on TBI are largely based on older studies, evaluating outcomes of patients who sustained a TBI in an automobile accident, a fall, or a sports injury. These studies do 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.

Although much has been learned about the recovery and treatment process for TBI, much remains unknown, particularly about the long-term effects of these injuries. For example, how long should care be administered? When is a patient considered fully recovered? What will the long-term consequences of closed-head TBI be - epilepsy? Parkinson's? Alzheimer's? Answers to these questions remain ambiguous at best. Applying the tragic lessons learned from exposure to Agent Orange, we should prepare for the likelihood of long-term adverse effects from this conflict as well.

Transitioning From Active Duty to Veteran Status - Action is Needed

Although my husband is still on active duty, our experience represents what many young veterans suffering TBI have had to face before being discharged from the service. We fear that without major reform, the obstacles and frustrations we faced within the Army's medical system will not be significantly different from those we may encounter when we enter the VA healthcare system. Although the VA and Department of Defense (DoD) systems are separate entities, the two departments share similar bureaucratic problems. We need to learn from the experiences of servicemembers and families such as ours in order to avoid similar obstacles within the VA system. The continuum of care must begin on the battlefield, move to the military healthcare system, and continue through the VA.

We are encouraged by recent initiatives proposed by Congress, the DoD and the VA to improve the care and support for servicemembers, veterans, and their families, particularly as it relates to developing a strong collaboration between the two departments to streamline the transition process. There is little doubt that the systems to accomplish these goals are in place; however, they are still in the early stages of implementation and, as with any natural process, it will take time for them to mature to the degree desired. While the development of these initiatives are imperative for the future, we must not lose focus and overlook the fact that today's servicemembers and veterans continue to face a number of obstacles and hardships. Unless immediate action is taken, these individuals will continue to fall through the large cracks borne of years of neglect and empty promises.

Conclusion

Although The Washington Post articles in February 2007 have turned much-needed public attention to the hardships that both servicemembers and veterans face, they were hardly the first warnings about these problems. For years, the Government Accountablity Office has issued reports documenting the significant backlog in the VA disability system, the outdated nature of the VA Schedule for Rating Disabilities, and the incompatibility of electronic health records between the VA and DoD systems. Concerns regarding blast-related TBIs were also addressed prior to The Washington Post articles. On August 11, 2006, the Armed Forces Epidemiology Board presented its findings on the acute and long-term health implications of TBI in military servicemembers to the Assistant Secretary of Defense for Health Affairs. The Board's recommendations closely mirror those made in the Dole-Shalala Commission Report.

I ask of you: why did it take a series of articles in The Washington Post for these concerns to suddenly be regarded as serious? And, if only little progress has been made in response to reports over the course of the past few years, why should we believe that recommendations in the new reports will suddenly transform the status quo? Reform has been needed for years and some of the recommendations made in these reports will take still more years to implement. Where does that leave today's and tomorrow's generation of veterans?

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 ensure that these changes are made, to assess the efficacy of these programs, and to set specific benchmarks. Thus far, we have a wealth of data and an abundance of recommendations. However, until these recommendations are actually integrated into the existing system and successfully applied, they will remain nothing more than notes on a page.

In the end, my husband and I hope that you and your colleagues will work to make other returning servicemembers and veterans just as fortunate by implementing systems that (1) provide family members with support and assistance navigating the system; (2) that facilitate coordinated care; and (3) that fund further long-term research of the devastating injuries of TBI and PTSD. It is time that the excellence that these servicemembers and veterans dedicated and displayed in the field of combat be matched by the system for which they sacrificed.