

STATEMENT OF
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Mr. Chairman and members of the Senate Appropriations Defense Subcommittee, thank you for allowing me the opportunity to testify before you today. My name is Kathy Rentfrow, and I am a volunteer with the Dystonia Medical Research Foundation or "DMRF". The DMRF is a patient-centered non-profit organization dedicated to serving dystonia patients and their families. The DMRF works to advance dystonia research, increase dystonia awareness, and provide support for those living with the disorder. Most importantly, I am a proud military spouse and the mother of a child suffering from dystonia.

Dystonia is a neurological movement disorder that causes muscles to contract and spasm involuntarily. Dystonia is not usually fatal, but it is a chronic disorder whose symptoms vary in degrees of frequency, intensity, disability, and pain. Dystonia can be generalized, affecting all major muscle groups, and resulting in twisting repetitive movements and abnormal postures or focal, affecting a specific part of the body such as the legs, arms, hands, neck, face, mouth, eyelids, or vocal chords. At this time, no known cure exists and treatment is highly individualized. Patients frequently rely on invasive therapies like botulinum toxin injections or deep brain stimulation (DBS) to help manage their symptoms.

At age 6, while our family was stationed in Washington State, my daughter Melissa was diagnosed with generalized dystonia at Madigan Army Medical Center. What began as muscle spasms in her left shoulder and progressed throughout the entire arm, her right hand, legs, and vocal chords. Now at age 15, Melissa is luckier than many dystonia patients, and this is in large part to the superior care she receives as a military dependent. Due to my husband's position as a permanent military professor at the U.S. Naval academy, our daughter is able to receive care at Walter Reed Army Medical Center. Melissa responds well to treatment with medications, but still needs to take upwards of 20 pills per day. Unlike many dystonia sufferers, Tricare covers the extensive costs of her medications. Although she does not have use of her left arm, she is able to walk and talk without more invasive treatments like botulinum toxin injections or DBS. Dystonia affects not only Melissa's quality of life, but also that of our entire family.

Dystonia is not a discriminatory condition, as it affects people of all backgrounds and this increasingly includes military personnel. Conservative estimates suggest that dystonia affects no less than 300,000 Americans. However, the incidence of dystonia has seen a noticeable increase since our military forces were deployed to Iraq and Afghanistan. This recent increase is widely considered to be the result of a well documented link between head injuries, other traumatic injuries, and the onset of dystonia. Until a cure for dystonia is discovered, it remains vital we learn more about the exact causes of the condition and develop more effective and efficient treatments for patients.

Although federal dystonia research is conducted through a number of medical and scientific agencies, the DOD's Peer-Reviewed Medical Research Program remains the most essential program studying dystonia in military and veteran populations. The DMRF has been receiving increasing reports of dystonia from service personnel and family members, as well as increased antidotal evidence from medical professionals linking dystonia to traumatic brain injury or "TBI". As the committee is aware, TBI has emerged as a trademark injury of the current war efforts in Iraq and Afghanistan, often sustained as the result of improvised explosive devices. More and more, TBI and other traumatic injuries are serving as the catalyst for the onset of dystonia. As military personnel remain deployed for longer periods, we can expect dystonia prevalence in military and veterans populations to increase, particularly in combat personnel.

Dystonia severity and symptoms can vary dramatically from person to person, often drastically effecting quality of life. A June 2006 article in *Military Medicine*, titled *Post-Traumatic Shoulder Dystonia in an Active Duty Soldier* reported that, "Dystonia after minor trauma can be as crippling as a penetrating wound, with disability that renders the soldier unable to perform his duties." The article goes on to say that although battlefield treatment may not be practical, "awareness of this disorder [dystonia] is essential to avoid mislabeling, and possibly mistreating, a true neurological disease."

The DMRF would like to thank the Subcommittee for adding dystonia to the list of conditions eligible for study under the DOD Peer-Reviewed Medical Research Program in the fiscal year 2010 DOD Appropriations bill. Unlike other federally funded medical research programs, conditions eligible for study through the Peer-Reviewed Medical Research Program must affect members of the armed services and their families. As traumatic injuries and dystonia among service personnel increases, it is critical that we develop a better understand of the mechanisms connecting TBI and dystonia. We urge Congress to maintain dystonia as a condition deemed eligible for study through the Peer-Reviewed Medical Research Program, as the number of current military members and veterans with dystonia swells.

Thank you again for allowing me the opportunity to address the Subcommittee today. As the mother of a child suffering from dystonia, and as a military spouse concerned with the well-being of our troops and veterans, I hope you will continue to include dystonia as condition eligible for study under the DOD Peer-Reviewed Medical Research Program.