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Introduction

Thank you Chairman Inouye, Ranking Member Stevens and distinguished Members of the Committee, for allowing me to provide testimony at this hearing.

My name is Shawn O'Neil and I work with the National Multiple Sclerosis Society. I am here today on behalf of the more than 400,000 Americans and nearly 26,000 U.S. veterans who live with the devastating effects of multiple sclerosis or MS. Together, we ask for your help to fund MS research under the Congressionally Directed Medical Research Programs (CDMRP).

No Cure for Multiple Sclerosis

Multiple sclerosis is a chronic, unpredictable, often-disabling disease of the central nervous system. It interrupts the flow of information from the brain to the body and stops people from moving. Every hour someone new is diagnosed. MS is the most common neurological disease leading to disability in young adults. But despite several decades of research, the cause remains unclear, and there is no cure.

The symptoms of MS range from numbness and tingling to blindness and paralysis. MS causes loss of coordination and memory, extreme fatigue, emotional changes, and other physical symptoms. These problems can be permanent, or they can come and go.

The National MS Society recommends treatment with one of the FDA-approved "disease-modifying" drugs to lessen the frequency and severity of attacks, and to help slow the progression of disability. But unfortunately, the cost is often financially prohibitive. The FDA-approved drugs for MS range from \$16,000 to \$25,000 a year, and the treatment will continue for life.

Multiple Sclerosis and U.S. Veterans

Testimony from individual veterans, along with evidence from recent studies, suggests that Gulf War veterans could have an increased risk of developing multiple sclerosis.

Dr. Mitch Wallin is a neurologist who currently treats veterans with MS at the Department of Veterans Affairs' MS Center of Excellence in Baltimore and is a professor at Georgetown University. Dr. Wallin recently published a formal professional hypothesis stating that deployed Gulf War veterans are at an increased risk for developing MS because of exposure to neurotoxins.

Dr. Wallin plans to explore this hypothesis through research at the VA. Based on existing research and his work with veterans living with MS, Dr. Wallin authored a letter to the Chairman and Ranking Member of this subcommittee urging you to support funding for MS research in the CDMRP. Some of the research includes:

- The *Annals of Neurology* recently identified 5,345 cases of MS among U.S. veterans that were deemed "service-connected."
- The Congressionally-mandated Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) found evidence that supports a probable link between exposures to neurotoxins and the development of neurological disorders. Further, RAC recommended more federal funding to study the negative effect of neurotoxins on the immune system.

AND

- A recent epidemiological study found an unexpected, two-fold increase in MS among Kuwaiti residents between 1993 and 2000. This rapid increase in an area of the world with previously low incidence rates for MS further suggests an environmental trigger for MS. Possible triggers include exposure to air particulates from oil well fires, vaccines, sarin, or infectious agents.

As news circulates of a potential link between MS and military service, more and more veterans have been coming forward with their stories and symptoms. They uncover a unique health concern among our veterans, and they represent the possibility that something in the environment could trigger this disease ... which could unlock the mystery of MS.

Sergeant Paul Perrone's Story

Paul Perrone is a 42-year-old father from New Hampshire. A retired U.S. Air Force Sergeant and veteran of the Persian Gulf War, Paul was diagnosed with MS in August 1998.

Initially, Paul was diagnosed by the military with chronic fatigue syndrome, asthma, and rhinitis. Many people with MS often are mis-diagnosed at first. However, his symptoms worsened. He had extreme fatigue and vertigo. Although Paul loved his work with the Air Force, he no longer felt healthy enough to remain on active duty. Paul asked for an Air Force medical evaluation board and eventually was medically retired from the Air Force in 1994.

Then, after developing optic neuritis in one eye, a civilian doctor recommended an MRI, which led to his current MS diagnosis. Paul is a passionate and extremely well-informed veteran on nearly every aspect of the military, gulf-war

syndrome, veterans' benefits ... and MS. It has been his absolute conviction that an environmental agent triggered his MS either through inoculations or exposure to neurotoxins during his combat service.

Paul is just one of many veterans who are fighting this personal battle. Many more stories are untold, or many individuals might not want to come forward. But the cases of MS among U.S. veterans are certainly evident. And now emerging research supports this potential link.

For the nearly 26,000 veterans, and for many more individuals with MS nationwide, more research is critical. Dr. Wallin and others might be on the heels of identifying an environmental trigger. Now we just need to pinpoint what and how.

The Need for More MS Research

Given all the evidence, we strongly believe that the Department of Defense (DoD) has a responsibility to identify and research all diseases that could be related to military service, including MS. On April 5, Senators Obama and Coleman sent the subcommittee a letter with 21 of your colleagues' signatures urging you to support this \$15 million appropriation for MS research under the Congressionally Directed Medical Research Programs (CDMRP).

The cause, progress, or severity of symptoms in any one person living with MS cannot yet be predicted or cured. But advances in research and treatment can help. We appreciate your consideration. With your commitment to more research, we can move closer to a world free of MS. Thank you.