



National  
Multiple Sclerosis  
Society

# Please Support MS Research Funding in the Congressionally Directed Medical Research Programs

## What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- MS interrupts the flow of information within the brain, and between the brain and body.
- Symptoms range from numbness and tingling to blindness and paralysis.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.

## MS and Military Service

- More than 23,000 veterans with MS receive care through the Veterans Health Administration.
- According to a 2003 study in the *Annals of Neurology*, 5,345 veterans that served in Vietnam and the first Gulf War were diagnosed with MS that was deemed "service-connected."  
The relative risk for developing MS also was significantly higher for this group of veterans than those who served in World War II and the Korean War.
- An advisory committee commissioned by the VA recently recommended further study into the potential link between combat service and the increased risk of developing MS. By studying this population, scientists might be able to understand the cause and triggers of MS and develop effective treatments.

## Request

We ask Congress to appropriate \$10 million in FY 2014 for the Multiple Sclerosis Congressionally Directed Medical Research Program (CDMRP), which provides funding for novel MS research.

## Background on MS CDMRP

- The CDMRP is a peer-reviewed program that funds high-risk, high-reward research.
- This CDMRP takes prudent measures to ensure that its work is not unnecessarily duplicative from the work done by other research organizations, such as the National Institutes of Health.
- The CDMRP is funded through the Department of Defense (DoD) via the Defense Appropriations Act. Dollars for the CDMRP are added every year during the budget process by members of Congress, in response to requests by advocates and disease survivors.
- In FY 2008, MS was first listed as a topic area eligible to compete for funding through DoD's Peer Reviewed Medical Research Program. The DoD received 108 grant applications for MS funding of which the DoD was able to fund three.
- After 2008, Congress established a specific MS program within the CDMRP. In total since 2008, MS research has received nearly \$25 million in funding.
- The MS Program in the CDMRP specifically encourages applications that address critical needs of the MS community and concentrate on: the biological basis of disease progression, risk factors leading to the prevention of MS, drug discovery, and biomarkers for preclinical detection of MS. Additional information can be found at:  
<http://cdmrp.army.mil/pubs/pips/msrppip.pdf>.

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In her early thirties, EJ Levy was an active hiker and skier with a fast-paced internet job. But her life took a dramatic turn in 2001 when she started tripping, falling down and dragging her right leg. Within six months she received a diagnosis of multiple sclerosis (MS), the most common neurological disease leading to disability in young adults.

EJ's symptoms progressed quickly; within two years she had left her job and moved to the same apartment building as her parents so they could assist her with daily living activities. She could walk a block or two with the

help of a cane and used a wheelchair for longer distances. Like many people newly-diagnosed with MS, she feared that she would need to rely on a wheelchair full time in the future. "I was scared of being dependent on a wheelchair. I was scared of getting worse and worse. I had traveled the world before I got sick – I was super independent," she says.

After trying several first-line disease-modifying therapies with no slowing of the disease's progression, EJ became frustrated. Her neurologist then encouraged her to try 4-aminopyradine, a treatment known to improve nerve conduction, which was only available through a compounding pharmacy. EJ remembers that just three days after taking the drug, she walked unassisted. "Being able to easily walk again after four years of barely being able to move my leg was incredible," she said. A few years later, EJ was asked to speak to an FDA advisory council about the impact of this drug.

In January 2010, the FDA approved use of Ampyra (Fampridine-SR) with the same active ingredient, 4-aminopyradine, to improve walking ability in people with all types of MS. Ampyra does not modify the course of the MS disease, nor is it a cure for MS, but is meant for symptomatic treatment – specifically to aid in walking.

Today, EJ is able to walk without a cane and has completed many hikes up to five miles. "It's about quality of life," she says. "Having my mobility and my life back is priceless. When I lost my mobility and became dependent on other people, it felt as though I lost a part of who I was."

While it took a private pharmaceutical company to fully develop Ampyra, many of the ideas for therapies begin with information derived from public funding. In fact, over 20 percent of all therapies approved by the Food and Drug Administration (FDA) contained ideas that were funded by the National Institutes Health (NIH) and/or the Congressionally Directed Medical Research Program (CDMRP). Without these sources of public funding for research, numerous therapies would likely go undeveloped. As our nation seeks consensus on priorities, we must value this public research to replenish ideas and knowledge for new therapies. Without this investment, the country may rob EJ and millions like her the hope of new treatments and ultimately, a cure.