



National
Multiple Sclerosis
Society

Please Support MS Research Funding at the National Institutes of Health (NIH)

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.

Background on NIH Funding

- NIH is the country's premier institution for medical research and the single largest source of biomedical funding in the world.
- NIH received \$30.7 billion in appropriations in FY 2012, which is the same as FY 2011. However, this is less than NIH received previously. In FY 2010 NIH received \$31 billion in appropriations and an additional \$10.4 billion through enactment of the American Recovery and Reinvestment Act.
- Even prior to the decrease in funding in FY 2011, the annually appropriated NIH budget was increased by less than the rate of medical inflation over the last several years.
- Less than six cents of every dollar spent on health is spent on research while 31 cents per dollar is spent on hospital care. Investing in health research has the potential to help achieve the goals of increasing health care quality while decreasing costs.

Request

We urge Congress to continue its partnership with the National MS Society by allocating at least \$32 billion in FY 2014 for medical research at the National Institutes of Health (NIH) that can help prevent, treat, and cure diseases, such as MS.

NIH: A Vital Partner in MS Research

- The Society regards the NIH as an invaluable partner to finding a treatment for progressive MS, additional therapies for relapsing MS and a potential cure for the disease.
- Approximately \$115 million of FY 2012 NIH appropriated funding was directed to MS-related research.
- The Society often acts as a co-financer of NIH projects and dedicates a sizable amount of money to MS research annually. In 2012, the Society invested \$43.2 million in MS research projects and has made a commitment to increase our research budget.
- The NIH has helped make significant progress in understanding MS-lesions, analyzing how the immune system responds to different stimuli and providing the basic research to develop the MS therapies.
- NIH scientists were among the first to report the value of MRI in detecting early signs of MS before symptoms even develop. Advancements in MRI technology allow doctors to monitor the progression of the disease and the impact of treatment.



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.