



Increase Funding for Spinal Cord Injury Care, Data, Research and Program Supports

BACKGROUND

For 55 years, the Spinal Cord Injury (SCI) Model Systems program, sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), has been the backbone of a comprehensive, multidisciplinary system of care, research, and resources for people with SCI. The services they provide encompass the entirety of the rehabilitation process from emergency services at injury through a person's return to full participation in the community. In addition to comprehensive care for individuals with SCI, these Model Systems conduct a wide range of research and provide information to patients, professionals, and the public both nationally and internationally.

Over time, however, federal funding for SCI Model Systems has not kept pace with the SCI community's needs. While the SCI community achieved a victory in 2022 by restoring the capacity of the SCI Model Systems program to include 18 Model Systems receiving funding up from 14, the average amount of funding each individual Model System receives has barely changed. Prior to 2022, this funding had remained stagnant at \$6.5 million total annual funding since 2006. In restoring the capacity of the SCI Model Systems program to 18 funded centers, overall base funding now stands at \$8.5 million, but the amount each SCI Model System receives still stands at approximately \$470,000 (including accounting for inflation: \$974,896). The purchasing power of these federal funds has not kept up with inflation or the approximate 50% growth of the SCI community since 2000. While Congress has increased funding for medical research at the National Institutes of Health (NIH) between 2015 and now by an additional \$21.1 billion annually, an increase of 70% to \$51.1 billion, the SCI Model Systems program has not benefited from that funding because NIDILRR is housed within the Administration for Community Living (ACL) and not NIH.

The lack of a meaningful per-Model System funding increase since 2006 has resulted in stretched budgets and increased burdens for SCI Model Systems. As the spinal cord injury community has grown, the funding provided for the premier care, rehabilitation, and services provided by the SCI Model Systems has not kept pace. Overall, the amount of inpatient rehabilitation provided per patient has been dropping significantly nationwide over the past two decades, leaving many newly-injured individuals with an SCI less prepared to re-enter their communities than they otherwise should be.

In the current FY22-FY26 funding cycle, there are SCI Model Systems located in Alabama, California (2), Colorado, District of Columbia, Florida, Georgia, Illinois, Massachusetts, Michigan, Minnesota, New Jersey, New York, Ohio, Pennsylvania, Texas (2) and Virginia. SCI Model Systems were formerly located in Arizona, Kentucky, Louisiana, Missouri, Ohio, Pennsylvania, Virginia, Washington, and Wisconsin.

REQUEST TO MEMBERS OF CONGRESS AND APPROPRIATORS - TOTAL FUNDING REQUEST: \$21.6 million

- Increase funding for [SCI Model Systems](#). This program is long overdue for a significant funding increase that considers inflation and the approximate 50% growth in the SCI population since 2000 (from approximately 200,000 to more than 300,000) - **\$17.5 million**.
- Increase funding for the [National Spinal Cord Injury Statistical Center \(NSCISC\)](#), which serves as the premier source of spinal cord injury-related statistical data in the United States - **\$1.9 million**.
- Increase funding for the [Model Systems Knowledge Translation Center \(MSKTC\)](#), which works with the NSCISC and the SCI Model Systems on research and translating the data into useful fact sheets on various topics related to spinal cord injury that are used not only in the United States but globally - **\$2.2 million**.