



CHRISTOPHER & DANA
REEVE FOUNDATION
TODAY'S CARE. TOMORROW'S CURE.®

National Association of State Head Injury Administrators
6/15/2022

EXPLORING THE RESOURCES AND SUPPORTS OF THE NATIONAL PARALYSIS RESOURCE CENTER

The National Paralysis Resource Center website is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$8,700,000 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government

Our Mission

We are dedicated to curing spinal cord injury by advancing innovative research and improving the quality of life for individuals and families impacted by paralysis.

Today's Care. Tomorrow's Cure.®

Today's Care

“ We created the National Paralysis Resource Center to help people navigate the chaos of paralysis with reliable information, referral services, and a message of hope.”

-- Dana Reeve

Today's Care. Tomorrow's Cure.®

Information Specialists
114,000+ families have received one-on-one assistance in 170 languages



Global Leader in Spinal Cord Research
\$140 million has been awarded to researchers around the globe to speed the development of treatments and therapies for spinal cord injury

Quality of Life Grants
\$33 million+ awarded to over 3,300 non-profit programs in all 50 states



Peer & Family Support Program
17,000+ people have received support from 500+ certified peer mentors who are also living with paralysis

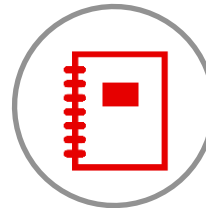
1st call made when loved one is diagnosed with paralysis

Virtual Community
3M+ users visit ChristopherReeve.org and social media channels annually



Team Reeve®
\$7 million has been raised from running marathons to hosting local events

**Reeve Summit:
Where Care, Cure and Community Connect**
Annual summit with a spectrum of care and cure topics designed for the community and professionals



Paralysis Resource Guide
223,000+ copies distributed to the Reeve Foundation's community

“

Once you
choose hope,
anything's
possible.

— CHRISTOPHER REEVE

National Paralysis Resource Center

With partnership from the Administration for Community Living, the National Paralysis Resource Center (NPRC) provides much-needed free educational information, programs, emotional support and individualized assistance to Americans living with paralysis, along with their caregivers, families and medical professionals.

Inquiry Process



You can ask a question by online form, phone call or email. An Information Specialist will listen to your concerns and will gather pertinent information.



The Information Specialist will research based on your concerns, location, available resources, language preference, etc.



You will receive a customized answer and resources.

Conditions Served by the National Paralysis Resource Center

- Information Specialists can assist with paralysis caused by any condition.

Acute Flaccid Myelitis

Amyotrophic Lateral Sclerosis

Arteriovenous Malformation

Brachial Plexus Injury

Acquired Brain Injury

Cerebral Palsy

Friedreich's Ataxia

Guillain-Barre Syndrome

Lyme Disease

Multiple Sclerosis

Post Polio

Spina Bifida

Spinal Cord Injury

Spinal Muscular Atrophy

Spinal Tumors

Stroke

Transverse Myelitis

**On this journey...you
will have many
questions.**

“What should I be looking for in a rehabilitation program?”

I am a Veteran, am I eligible for VA services?

“How can I learn more about home modification, now that I will be returning home?”

“My family caregiver is burnt out, we both need help...”

“My wheelchair is falling apart, and my insurance will not cover a new one. Are there any programs around me to help get it back in working order?”

Information and Referral Services

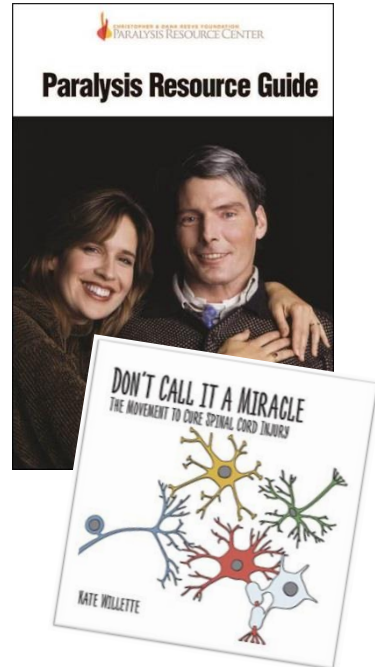
Information Specialists provide individualized support to people living with paralysis, as well as their family and caregivers.

Online: ChristopherReeve.org/ask

Call: 1-800-539-7309

Email: InfoSpecialist@ChristopherReeve.org

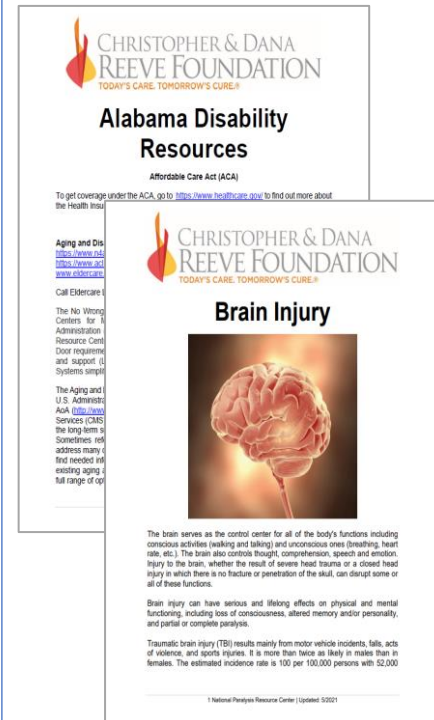
Free Materials & Resources



Books

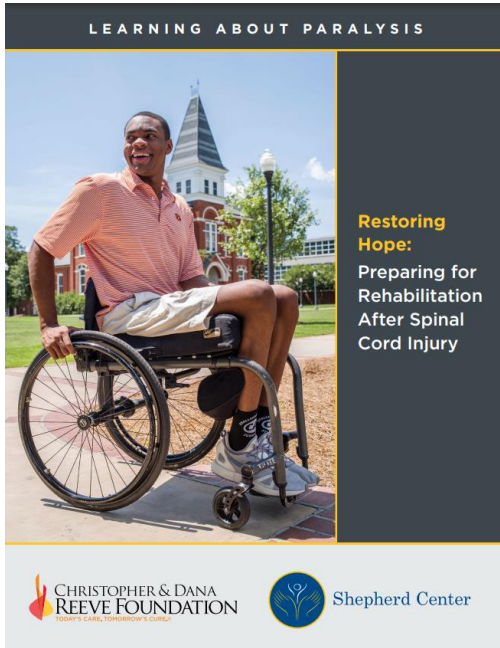


Wallet Cards



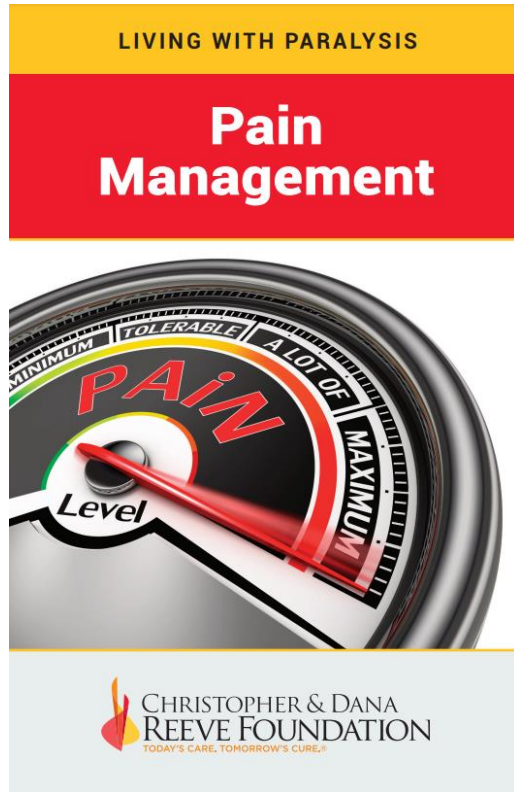
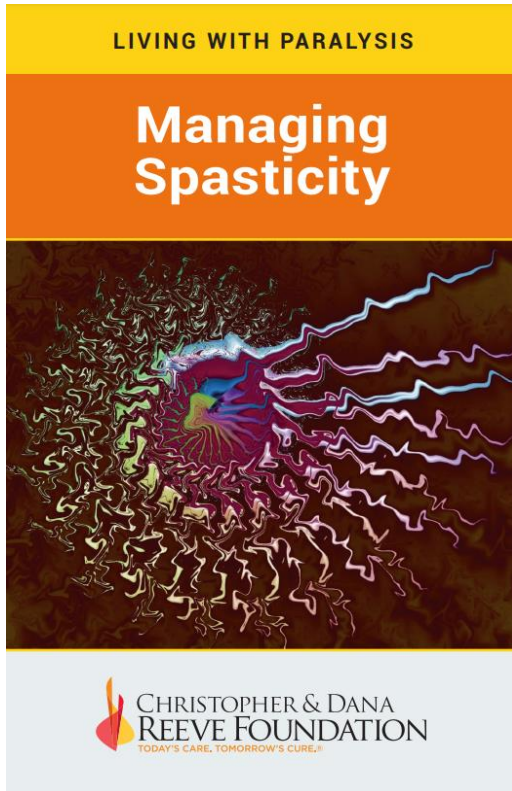
Fact Sheets

Publications



Our publications are pertinent to a wide variety of disabilities.

Publications



Our publications are pertinent to a wide variety of disabilities.

Military & Veterans Program Mission Statement

The **Military & Veterans Program (MVP)** extends expertise in spinal cord injury and paralysis to include resources and community connections for service men and women, as well as veterans living with paralysis, whether through combat-related, service-related, or non-service-related events.

Information for Newly Injured

- Newly Injured Packet
- Rehabilitation Info & Referral
- Next Steps
- Funding/ Insurance

Resources for Caregivers

Reeve Foundation website

- Special section for caregivers
 - Information on the caregiver role
 - Specific caregiver resources
 - Caregiving tip sheet compiled by the IS team
 - Webcast from Nurse Linda
- Blogs by caregivers, including current mentors (in Blog section of the website)
- Can find more caregiver content on the Reeve Foundation's YouTube channel


For caregivers

To be a caregiver, you need to have support, resources, and information to help navigate life with paralysis and care for your loved one. We're here to help, starting with the tips, insights, and free services below.

Quick Links


- Your role as a caregiver >
- Resources for caregivers >

Useful resources




Your role as a caregiver >

A letter from Dana Reeve to fellow caregivers on the valuable support they provide to their loved ones.



Resources for caregivers >

Here are a few caregiving tips and resources compiled by our team of information specialists.



Ask Nurse Linda

[Register for this live webinar](#) >

Peer & Family Support Program

The Peer & Family Support Program is a national peer to peer mentoring program that provides support and information on local and national resources to people living with paralysis as well as their family members and caregivers.



Other Reeve Foundation Programs

Research

The Reeve Foundation has awarded over \$140 million to support a pipeline of innovative research that will rapidly transform quality of life for families impacted by paralysis.

Quality Of Life Grants Program

Awards financial support to nonprofit organizations that mirror the Reeve Foundation's mission.

Advocacy and Education

Advocacy for changes that make a real difference in the lives of people with paralysis, as well as their families and caregivers

“ So many of our dreams
at first seem impossible,
then they seem
improbable and then,
when we summon the
will, they soon become
inevitable.”

– Christopher Reeve



Questions

For Additional Information:

Bernadette Mauro

Director, Information and Resource Services

(410) 530-0148

BMauro@ChristopherReeve.org

Paralysis Resource Guide (book): www.ChristopherReeve.org/Guide

Fact Sheets: www.ChristopherReeve.org/factsheets

Wallet Cards: www.ChristopherReeve.org/cards

Patient Education Booklets:

<https://www.christopherreeve.org/living-with-paralysis/free-resources-and-downloads/education-booklets>

Spinal Cord Injury Model Systems: Overview

Yuying Chen, MD, PhD
NASHIA Webinar, June 15, 2022



What is SCIMS?



A network of rehabilitation facilities throughout the United States that provide continuous, comprehensive, multidisciplinary care for persons with SCI,

designated by



TBIMS

Traumatic Brain Injury Model System

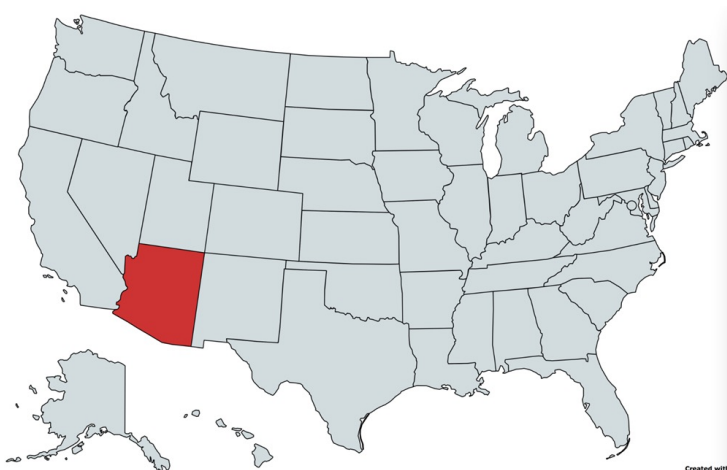
Since 1987

- Traumatic Brain Injury Model System
- Burn Model System (since 1994)
- One Data and Statistical Center for each of the 3 Model Systems
- One Model Systems Knowledge Translation Center for all 3 systems

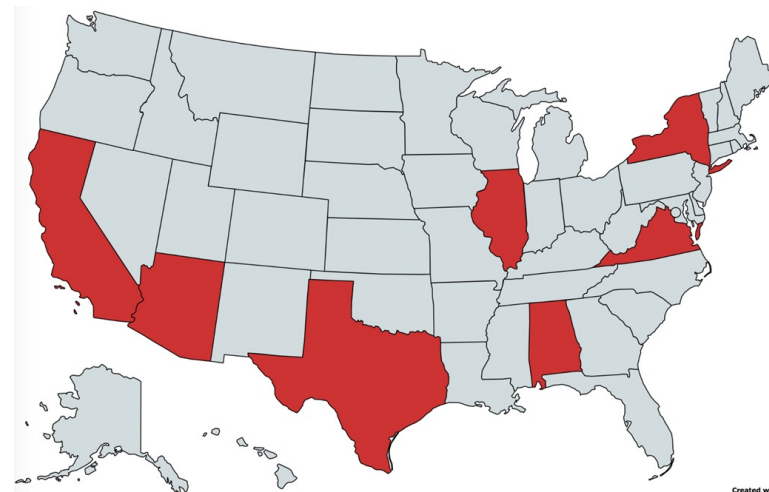


SCIMS Centers

1970: First SCIMS Center in Phoenix, AZ



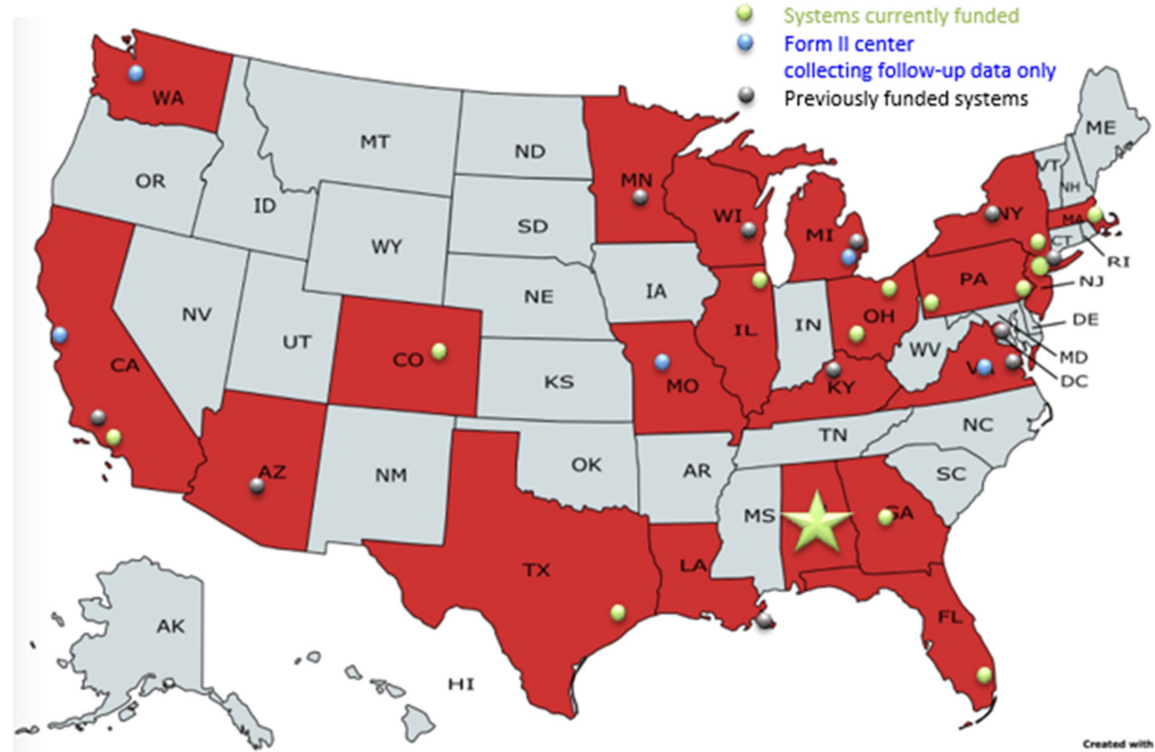
1972: Seven SCIMS Centers



SCIMS Database 1972-2021

- 29 SCIMS centers
- 21 States + DC
- 50,026 people with SCI enrolled
- 127,991 follow-up records (up to 45 years)

★ National SCI Statistical Center at UAB



SCIMS Centers 2021–~~2026~~ 2022 (n=14)

SCI Centers 2021-2022	TBI 2017-2022	Burn 2017-2022
California, Santa Clara Valley MC	F2	
California, Rancho Los Amigos NRC		
Colorado, Craig Hospital	v	
District of Columbia, MedStar NRH		
Florida, University of Miami		
Georgia, Shepherd Center		
Illinois, Shirley Ryan AbilityLab		

Note. F2 = Form II follow-up data collection only

SCIMS Centers 2021–~~2026~~ 2022 (n=14)

SCI Centers 2021-2022	TBI 2017-2022	Burn 2017-2022
Minnesota, University of Minnesota	(Mayo)	
New Jersey, Kessler Foundation	v (& JRI)	
New York, Icahn SOM at Mount Sinai	v (& NYU)	
Ohio, Case Western Reserve University	(OSU)	
Pennsylvania, University of Pittsburgh	F2	
Texas, Baylor Scott & White Institute	v	(UT Southwestern)
Virginia, Virginia Commonwealth University	v	

Note. F2 = Form II follow-up data collection only

Form II Centers 2021–~~2026~~ 2022 (n=5)

SCI F2 Centers 2021-2022	TBI 2017-2022	Burn 2017-2022
Alabama, UAB	v	
Missouri, University of Missouri		
Pennsylvania, Thomas Jefferson University	(Moss)	
Virginia, UVA and Woodrow Wilson Rehab		
Washington, University of Washington	v	v

Note. F2 = Form II follow-up data collection only

Purpose of SCIMS Database

Demonstration

Originally, store information on patients with SCI treated at SCIMS centers across the country to demonstrate the efficacy of a comprehensive multidisciplinary care system



Research and Knowledge Translation

Trends over time since 1970s

- Who (get SCI), How, What
- Uses: Prevention, health care needs projection, etc.

Longitudinal course living with SCI

- Physical & psychosocial well-being, life expectancy, costs of care
- Uses: Knowledge building to improve care & services, set rehabilitation standards, inform policy and best practices, etc.

Infrastructure for collaborative research

SCIMS Database Structure

Acute Care

Rehabilitation

Community Living

Form I or Registry

- **Initial** hospital care data
- Registry (vs Form I): People residing outside catchment area are enrolled in the Registry, less detailed data collection than Form I, and no longitudinal follow-up data are collected for Registry cases

Form II

Follow-up data obtained currently in post-injury years 1, 5, and every 5 years thereafter

Fact Sheets, Data Sheets, Reports



Traumatic Spinal Cord Injury Facts and Figures at a Glance



2022 SCI Data Sheet

The Spinal Cord Injury Model Systems was created in 1970 as a prospective longitudinal multicenter study on demographics and the use of services by people with traumatic spinal cord injury in the United States.

This data sheet is a quick reference on demographic and condition statuses for 35,675 persons with SCI. Data were collected through 2021 by federally funded SCI Model Systems and five Form II



Recent Trends in Causes of Spinal Cord Injury



2021 SCI Data Sheet

Vehicular accidents accounted for 2,956 (38.09%) of spinal cord injuries and ranks 1st in causes of spinal cord injury.

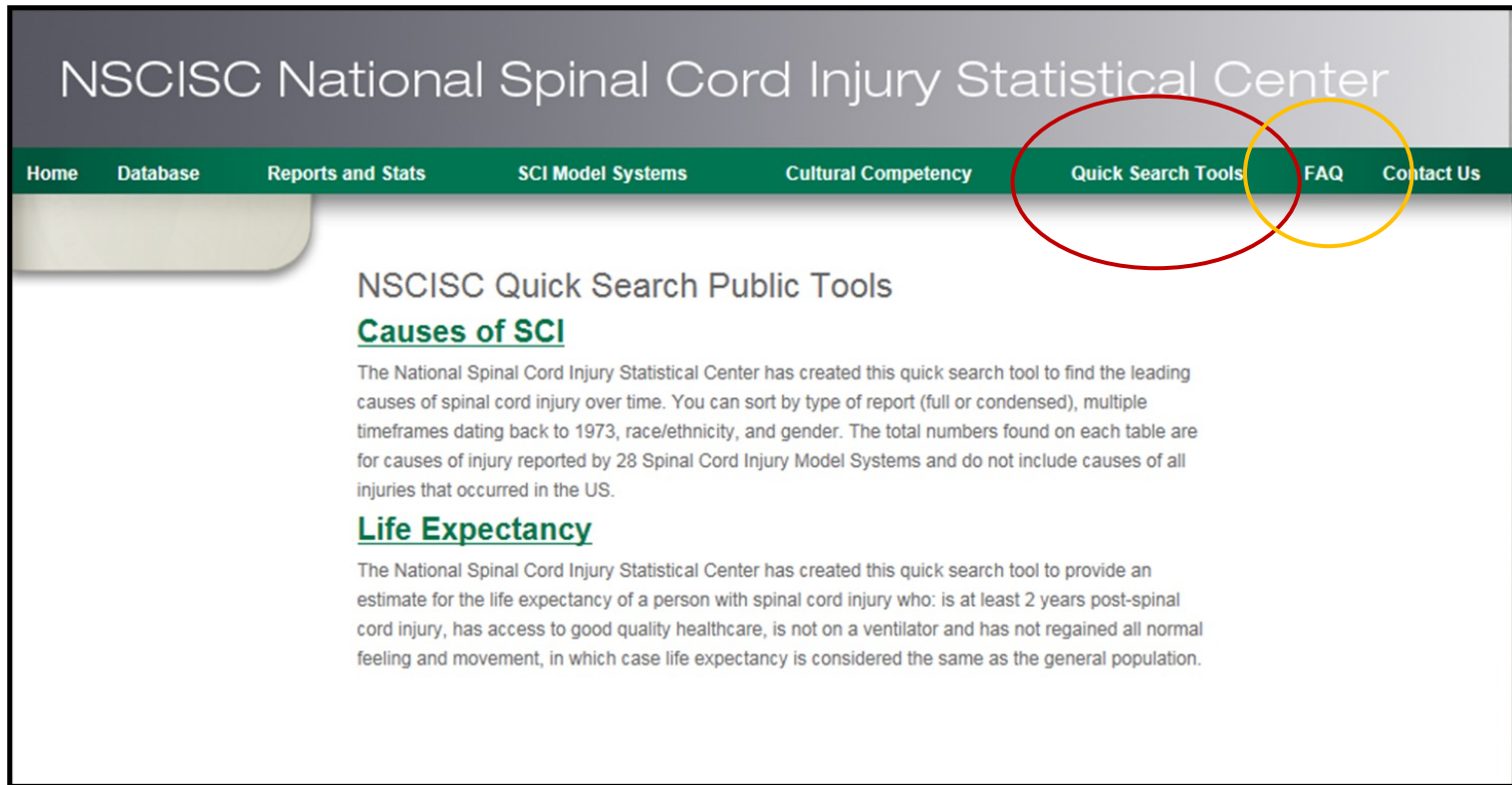
NSCISC National Spinal Cord Injury Statistical Center

Spinal Cord Injury Model Systems

2020 Annual Report – Complete Public Version



Public Tools



The screenshot shows the website header for the NSCISC National Spinal Cord Injury Statistical Center. The navigation menu includes: Home, Database, Reports and Stats, SCI Model Systems, Cultural Competency, Quick Search Tools, FAQ, and Contact Us. The 'Quick Search Tools' and 'FAQ' items are circled in red and yellow respectively. Below the navigation bar, the page title is 'NSCISC Quick Search Public Tools'. There are two sections: 'Causes of SCI' and 'Life Expectancy', each with a descriptive paragraph.

NSCISC National Spinal Cord Injury Statistical Center

Home Database Reports and Stats SCI Model Systems Cultural Competency **Quick Search Tools** FAQ Contact Us

NSCISC Quick Search Public Tools

Causes of SCI

The National Spinal Cord Injury Statistical Center has created this quick search tool to find the leading causes of spinal cord injury over time. You can sort by type of report (full or condensed), multiple timeframes dating back to 1973, race/ethnicity, and gender. The total numbers found on each table are for causes of injury reported by 28 Spinal Cord Injury Model Systems and do not include causes of all injuries that occurred in the US.

Life Expectancy

The National Spinal Cord Injury Statistical Center has created this quick search tool to provide an estimate for the life expectancy of a person with spinal cord injury who: is at least 2 years post-spinal cord injury, has access to good quality healthcare, is not on a ventilator and has not regained all normal feeling and movement, in which case life expectancy is considered the same as the general population.

Leading Causes of Spinal Cord Injury

The National Spinal Cord Injury Statistical Center has created this quick search tool to find the leading causes of spinal cord injury over time. You can sort by type of report (full or condensed), multiple timeframes dating back to 1973, race/ethnicity, and gender. The total numbers found on each table are for causes of injury reported by 28 Spinal Cord Injury Model Systems and do not include causes of all injuries that occurred in the US.

Please Select the Report Parameters:

Type of Report: Etiology Groups Only ▾

Injury Date Range: 1973 - March 2014 ▾

Race/Origin: Any Race / Total ▾

Sex: ALL ▾

Submit Request

Group Etiology Categories Include:

'Vehicular Accidents': auto accidents in jeeps, trucks, dune buggies, and buses; Motorcycle accidents in 2-wheeled, motorized vehicles including mopeds and motorized dirt bikes; Boats; Fixed-wing aircraft;

Life Expectancy Calculator

Life expectancy estimates are based on the actual long-term survival experiences of persons treated at any current or previously funded model spinal cord injury care system or any of the three Shriners Hospital spinal cord injury units (Philadelphia, Chicago and Sacramento) with follow-up through January 2022. A person-year data set was created in which each year of follow-up for each person was treated as a separate observation. Logistic regression was then used to determine the impact of each risk factor on the likelihood of dying each year. A life table is then constructed using standard statistical procedures based on the annual age-specific probabilities of dying and the selected combination of risk factors, and the life expectancy is derived from that life table. A more complete description of the statistical methods used for this life expectancy calculator can be found in the following reference: Strauss D, Shavelle R, DeVivo MJ, Day S. An analytic method for longitudinal mortality studies. *J Insur Med* 2000;32:217-225.

These estimates should be interpreted cautiously. Life expectancy reflects the average experience of a group of similar individuals. Some individuals will not survive as long while others will survive longer. These estimates are based solely on the chosen factors below. Many other factors can also influence life expectancy and may need to be considered on a case by case basis.

[US Provisional General Population Life Table – 2020](#)



Person's current age

Injury Date

Male or Female
 Male Female

Ethnicity
 White Black Native American Hispanic* Asian* Other*

Current Level of Education
 Less than HS HS Grad/GED College Grad Post Grad

Type of Insurance
 Worker Comp/Private Medicare/Medicaid/Other

Ventilator Used
 No Ventilator Ventilator

Cause of the spinal cord injury
 Sport MVA Fall Violence Other

Current level of the spinal cord injury
 C1-4 C5 C6-C7 C8-S3

Current completeness of the SCI (AIS)
 A B C D

Life Expectancy: 21.82

Census number for general population: ** 35.6

[Calculate](#)

* Due to data limitations, life expectancy estimates for persons of Hispanic ethnicity and Asian race are based on spinal cord injury data for Whites and will therefore be slight underestimates of life expectancy for these individuals.

** US general population estimates for Whites, African Americans and Hispanics in the absence of spinal cord injury are based on 2020 provisional age-sex-race-specific life tables published by the National Center for Health Statistics. Comparable estimates for Native Americans and Asians are based on life tables derived as a fixed percentage of White age-sex-specific life expectancy (Native American male 94.0%, Native American female 95.9%, Asian male 109.7%, Asian female 106.4%).

Please answer the next questions based on the cause of injury, current neurologic level of injury and degree of completeness of the injury [American Spinal Injury Association Impairment Scale (AIS)]. Determination of the level and AIS grade should be based on the Motor Exam Guide and

▼ References:
 1. DeVivo MJ, Stover SL. Long-term survival and causes of death. In: Stover SL, DeLisa JA, Whiteneck GG, editors. Spinal cord injury: clinical outcomes from the Model Systems. Gaithersburg (MD): Aspen, 1995, pp 289-316.

NSCISC Data Request Form



De-Identified Data
from the SCIMS
National Database,
collected before
October 1 2016,
are freely available for
download

Email*

First Name*

Last Name*

Institution*

Institution Type* Non-Profit Organization
 Commercial Organization
 Acedemic

Number of years in scientific research less than 5
 5 - 10
 10+

Study name*

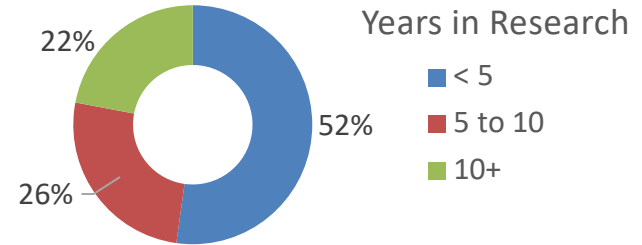
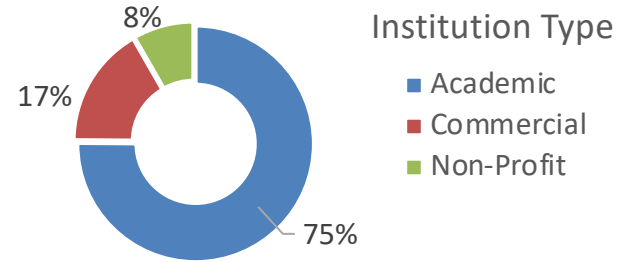
Describe this request

Register

Cancel

Public Data Download

- 220 requests, Dec 2018 – Jan 2022 (TBI = 94 and Burn = 47)
- Research: Neuro/Motor recovery, Technology use, Quality of life, Cluster analysis, Exploratory, Prediction models, Value based care solutions
- Education: Teaching SCI, Student capstone project, Statistics lecture
- Others: Comparable data, Commercial viability of a new drug



86.2% US

13.8% Other –Brazil, Canada, China, Czech, Finland, Germany, India, Iran, Israel, Japan, Malaysia, Mexico, Romania, UK

NSCISC Website (www.uab.edu/nscisc)

⚠ This website is still under development. If you have any questions please contact nscisc@uab.edu [Updates are coming soon!](#)

WELCOME

NSCISC

The National Spinal Cord Injury Statistical Center (NSCISC), located at the University of Alabama at Birmingham (UAB) Department of Physical Medicine and Rehabilitation, supports and directs the collection, management and analysis of the National SCIMS Database.



SCIMS Research Activity Areas

Contributions to the National SCI Database

- Enrollment of new inpatients (Form I)
- Follow-up of discharged patients (Form II)

Site-specific research projects

- Research carried out within each center

Module projects

- Collaborative research involving several SCIMS centers

Highly Productive

Numerous presentations,
articles, and book chapters

Journal special issues in 1999,
2004, 2011, 2016, and 2022

Life expectancy estimates for
about 25 court cases each year

VOLUME 97, NO 10
OCTOBER 2016

Archives of Physical Medicine and Rehabilitation

IN THIS ISSUE:

Spinal Cord Injury Model System (SCIMS) Focus Issue:

Changing Demographics of Acute SCI—Older Age and More Falls	Chen et al
Longer Time Before Starting Rehabilitation Predicts Worse Functional Outcomes Post-SCI	Herzer et al
Cause-Specific Mortality Post-SCI Varies by Injury Severity, Socioeconomic, and Health Factors	Krause et al
New Methods to Predict the Variable Life Satisfaction After SCI	Pretz et al
Wheelchair Breakdowns—Prevalence, Repairs, and Related Consequences	Toro et al
Current SCI Databases—Assets and Limitations	Charifue et al

THE OFFICIAL JOURNAL OF
ACRM
AMERICAN CONGRESS OF
REHABILITATION MEDICINE

Improving lives through
interdisciplinary rehabilitation research



ELSEVIER

SCIMS Contributions to SCI Community Education

Collaboration with MSKTC to develop materials (msktc.org/sci)

MSKTC
SCI • TBI • BURN

Model Systems
Knowledge Translation
Center

Search

Follow Us: [f](#) [t](#) [y](#)

Home Spinal Cord Injury Traumatic Brain Injury Burn Injury Knowledge Translation Model Systems About

Access Spinal Cord Injury Resources

Find Resources for Staying Healthy in a Pandemic

Spinal Cord Injury (SCI)
Access Spinal Cord Injury Resources

Traumatic Brain Injury (TBI)
Access Traumatic Brain Injury Resources

Burn Injury
Access Burn Injury Resources

What is the MSKTC?

Welcome to the Model Systems Knowledge Translation Center (MSKTC). The MSKTC is a national center that helps facilitate the knowledge translation process to make research meaningful to those with Spinal Cord Injury, Traumatic Brain Injury and Burn Injury. [Learn More >](#)

Living with Spinal Cord Injury (SCI)

<https://msktc.org/sci>

ALL TOPICS



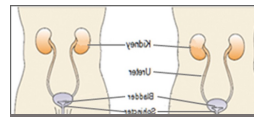
Adjusting to Life



Aging and SCI



Autonomic Dysreflexia



Bladder Management



Bone Loss after SCI



Depression and SCI



Driving after SCI



Employment after SCI



Exercise and Fitness after SCI



Gait Training and SCI



Managing Bowel Function



Managing Pain after SCI

Living with Spinal Cord Injury (SCI)

<https://msktc.org/sci>

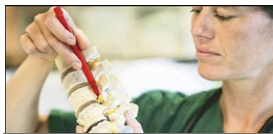
ALL TOPICS



Personal Care Attendants



Pregnancy and SCI



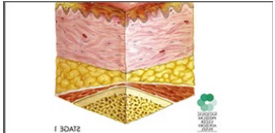
Respiratory Health and SCI



Safe Transfer Techniques



Sexuality after SCI



Skin Care and Pressure Sores



Spasticity and SCI



Surgical and Reconstructive Treatment of Pressure Injuries



Understanding SCI



Urinary Tract Infection and SCI



Wheelchair Information

Spinal Cord Injury Resources

<https://msktc.org/sci/sci-resources>

Factsheets



Slideshows



Hot Topics



Quick Reviews



Videos



Acknowledgements



Questions?

Contact Yuying Chen

nscisc@uab.edu

yychen@uab.edu