KEEP ON ROLLING

UNITE 2 FIGHT PARALYSIS

On February 17, 2026, over 100 advocates from the spinal cord injury (SCI) and scientific communities came together in Washington, D.C. for U2FP's Capitol Roll. These individuals included SCI scientists and researchers, industry and foundation representatives, advocacy organizers, and especially those living with SCI and their family members.

All told these advocates attended over 60 meetings with legislators and their staff, asking for increased funding and practical policy changes to improve spinal cord injury research outcomes.

It was a great start, but it was only the beginning. We need YOU to continue making the case to your congressional representatives.

This information packet includes a compelling set of facts and graphs that make clear the need for changes to policy and budget for spinal cord research. Review them carefully and then use and share them in conversation with your federal legislators.

Find Your Congressional Members

EXPAND SCIRP

Thank you for recently restoring the Spinal Cord Injury Research Program (SCIRP) to $33M. Congress should restore and expand SCIRP to beyond FY24 levels ($40M).

Why Federal SCI Research is essential

- Spinal Cord Injury (SCI) is a chronic condition affecting 350,000 Americans. It can happen to anyone at any time and has a significant health and quality of life impact.
- The SCI population is too small to be profitable for competitive market research, but too large (350K) to be given "orphan condition" designation by the FDA.
- Federal costs of health care for the SCI population is approximately $10B/year.
- Each research development that prevents a secondary condition (eg pressure sore, UTI, lung infection, blood pressure drop, et al) decreases the cost of care and increases independence.
- Opportunity loss (eg loss of employment) is approximately $33B/year.
- 70% of people with SCI are unemployed after injury and rely on social services.

Why CDMRP SCIRP is essential

- Only Federal Research Program that focused solely on SCI.
- SCI research is already underfunded compared to other diseases/conditions and SCIRP comprised 1/3 of Federal funding at $40M
- Emphasis on Innovation and Impact, Translation to clinic, Deliverables and Shovel-Ready therapies. SCIRP Coordinated with the NIH, VA and private funders to reduce funding redundancy.
- Prioritized the warfighter's care and recovery. SCI is 8-10 times more likely during combat and there are 42K veterans living with SCI in the US.
- Run from within military culture: goal oriented, nimble, responsive, accountable. Cannot be replicated in other agencies.
- Was not in competition for Defense spending, but funded as a Congressional Special Interest project and added to Department of Defense budget to manage.
- People with SCI inform award decisions by participating in peer reviewed research.

[1] National Spinal Cord Injury Statistics Center (NSCISC) Traumatic Spinal Cord Injury Facts and Figures at a Glance 2024

[2] Schoenfeld et al., Nature Spinal Cord, Spinal cord injury within the United States military (Mar. 8, 2011)

[3] U.S. Dept. of Veterans Affairs, VA Research on Spinal Cord Injury (June 10, 2021);

United for SCIRP

Shepherd Center

PVA Paralyzed Veterans of America

Craig H Neilsen Foundation

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North American Spinal Cord Injury Consortium

Christopher & Dana Reeve Foundation

United Spinal Association

National Institutes of Health: A Stakeholder's Perspective

More Funding, Smarter Funding, Informed Funding

NIH is the largest investor of Spinal Cord Injury (SCI) research in the US. Small changes can leverage this investment toward real-world outcomes for the SCI population and the taxpayer. NIH is excellent when it comes to the first half of their mission to "seek knowledge" but it should improve the second half: "application of that knowledge to enhance health."

SCI FACTS

- Open Enrollment: SCI can happen to anyone, at any age, anytime
- Chronic: Because SCI affects the central nervous system, it doesn't just go away
- It's about so much more than walking! "Secondary Conditions" make the situation VERY complicated
- SCIs are COSTLY!
  - $10B annual cost of care to the Fed. (See *Fact sheet about Spinal Cord Injury Research Funding*)
  - $32B annual opportunity cost: ie, loss of employment for the injured AND their families. (See *2025 MSKTC Annual Fact Sheet*)
  - But the current investment in research is a mere $135! (See *Fact Sheet about Spinal Cord Injury Research Funding*)

SOLUTIONS

More Funding

- Investment in SCI should increase! (See *Graph 3: Funding vs. Condition Burden*)
- In NIH, there is no committed investment to the amelioration of SCI. For example, in NINDS it must compete with 600 other conditions.
- "Cross Talk" is the contribution of research findings in one condition having relevance to research in other conditions. SCI research has a pedigree for answering research questions in more mechanistically specific conditions. For example: Axonis with the development of KCC2. Starts in SCI, leads to efficacy in epilepsy. SpineX to Cerebral Palsy and NervGen to Multiple Sclerosis.

Smarter Funding

- NIH should emphasize TRANSLATIONAL potential with regard to what is funded. Clinical outcomes regarding secondary conditions and comprehensive recovery should be the goal of research within the National Institutes of HEALTH!

Informed Funding

- NIH needs lived-experience input on the Study Section. This will align priorities with community needs, improve study design and clinical trial recruitment and retainment. SCIRP as a gold standard!

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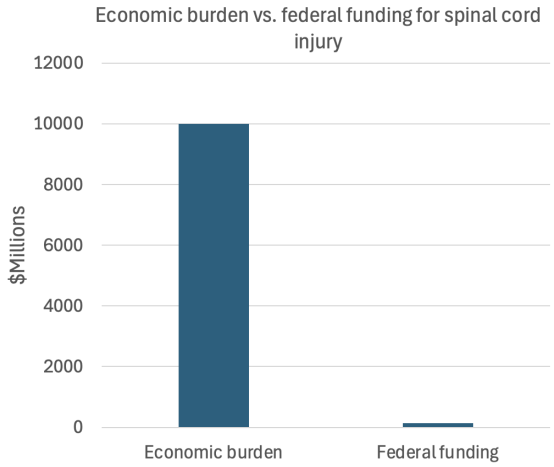
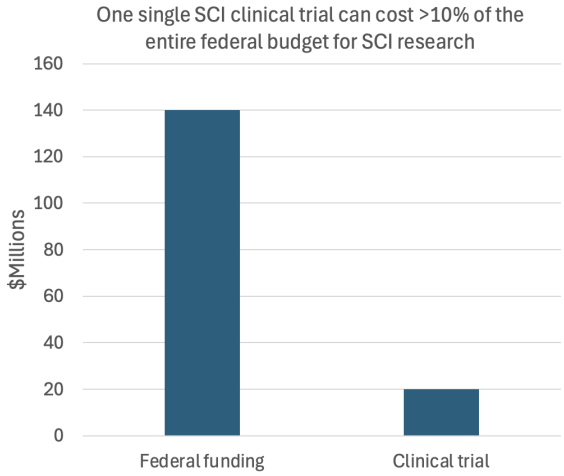
Fact sheet about Spinal Cord Injury Research Funding

(Prepared by J. Dulin using data from: Gillespie et al. (2025). Funding Distributions, Trends, Gaps, and Policy Implications for Spinal Cord Injury Research: A Systematic Analysis of U.S. Federal Funds. J. Neurotrauma https://doi.org/10.1177/08977151251392895.)

- **The average lifetime cost of SCI to an individual is approximately $3-5 million** *(Source: https://sites.uab.edu/nscisc/files/2025/02/2025-Facts-and-Figures.pdf)*
- **The economic burden of SCI to the U.S. healthcare system is approximately $10 Billion** (*Source: DeVivo MJ. Causes and costs of spinal cord injury in the United States. Spinal Cord, 1997; 35(12):809–813)*
- **The annual level of federal funding for SCI research is about $130-$150 million, or only 1.4% of the total cost of healthcare** *(Source: Gillespie et al., 2025, J. Neurotrauma)*



- **A typical SCI clinical trial costs between $8-20 million, or about 10% of the entire federal SCI research budget** *(Source: Gillespie et al., 2025, J. Neurotrauma)*



- **The CDMRP SCIRP program is the major funder of SCI clinical trials (more than 95% of federally-funded trials are funded by SCIRP), with 56+ total clinical trials since 2012** *(Sources: Gillespie et al., 2025, J. Neurotrauma; https://cdmrp.health.mil/funding)*

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AI Says SCIRP is Mission-Critical to CDMRP

Congressionally Directed Medical Research Programs	Relevance Score*	Budget ($ mm) FY 2024	FY 2025	Funding (%)
Military Burn Research Program	10	10	10	0%
Toxic Exposures Research Program	10	30	15	-50%
Peer Reviewed Medical Research Program (PRMRP)	10	370	150	-59%
Spinal Cord Injury Research Program	**10**	**40**		**-100%**
Combat Readiness Medical Research Program	10	5		-100%
Hearing Restoration Research Program	10	5		-100%
Joint Warfighter Medical Research Program	10	20		-100%
Peer Reviewed Orthopaedic Research Program	10	30		-100%
Reconstructive Transplant Research Program	10	12		-100%
Traumatic Brain Injury and Psychological Health Research Program	10	175		-100%
Vision Research Program	10	20		-100%
Alcohol and Substance Use Disorders Research Program	9	4		-100%
Tick Borne Disease Research Program	9	7		-100%
Peer Reviewed Cancer Research Program	8	130	130	0%
Prostate Cancer Research Program	8	110	75	-32%
Epilepsy Research Program	8	12		-100%
Lung Cancer Research Program	8	25		-100%
Amyotrophic Lateral Sclerosis Research Program	7	40	40	0%
Rare Cancers Research Program	7	18	18	0%
Breast Cancer Research Program	7	150	130	-13%
Arthritis Research Program	7	10		-100%
Glioblastoma Research Program	7	10		-100%
Multiple Sclerosis Research Program	7	20		-100%
Parkinson's Research Program	7	16		-100%
Alzheimer's Research Program	6	15	15	0%
Melanoma Research Program	6	40	40	0%
Ovarian Cancer Research Program	6	45	15	-67%
Kidney Cancer Research Program	6	50		-100%
Bone Marrow Failure Disease Research Program	5	8		-100%
Lupus Research Program	5	10		-100%
Neurofibromatosis Research Program	5	25		-100%
Pancreatic Cancer Research Program	5	15		-100%
Duchenne Muscular Dystrophy Research Program	4	10	13	25%
Autism Research Program	4	15		-100%
Tuberous Sclerosis Complex Research Program	4	8		-100%
		1,509	650	

* Grok 4.1: Assign a score from 0 to10 to each research program based on how relevant they are to the mission of the DoD Congressionally Directed Medical Research Program

AI DoD/CDMRP Program Relevance Scoring

CDMRP Mission Statement

"The CDMRP fills research gaps by funding high impact, high risk and high gain projects that other agencies may not venture to fund.

While individual programs are unique in their focus, all of the programs managed by the CDMRP share the common goal of advancing paradigm shifting research, solutions that will lead to cures or improvements in patient care, or breakthrough technologies and resources for clinical benefit.

The CDMRP strives to transform health care for Service Members and the American public through innovative and impactful research."

SCIRP Mission Statement

"To fund research and encourage multidisciplinary collaborations for the development and translation of more effective strategies to improve the health and well-being of Service members, Veterans, and other individuals with spinal cord injury"

Grok 4.1 Prompt:

"Assign a score from 0 to 10 to each research program based on its relevance to the mission of the DoD Congressionally Directed Medical Research Program (CDMRP)."

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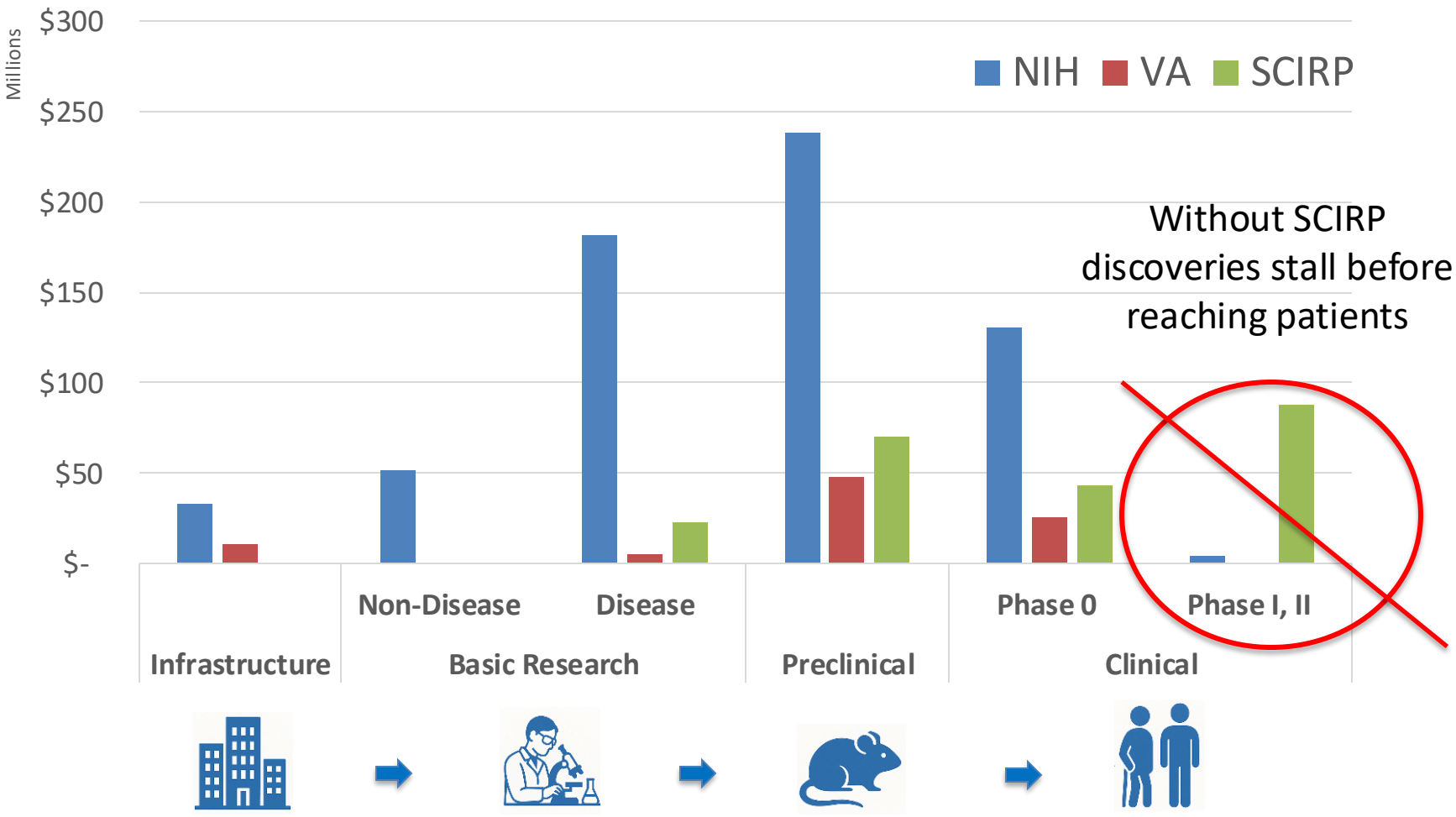
Translational Pipeline at Risk

SCIRP Is the only program doing advanced clinical trials



Source: 2017-2023 federal grant data

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Explanation of “Translational Pipeline”

This graph visualizes the relative importance of the TYPE of research carried out by the 3 largest Federal funders of SCI research: The NIH, VA and DoW. The X axis represents the translational stages of research from basic or exploratory research to clinical or human trials.

The assumption is that all health-related research should be directed toward a health outcome for human beings and eventually implemented into the population. This occurs along a “translational pipeline” from early, discovery stages to early “pre-clinical” or animal research, to late stage pre-clinical to clinical trials.

The financial and temporal investments that come before clinical trials are immense and Federal grant programs the DoW run SCIRP take research to the stage where it is usable for humans, namely clinical research. SCIRP is responsible for 95% of the SCI clinical trials funded by the Federal Government. Cuts or reductions to the SCIRP budget mean that prior translational research investment will be wasted.

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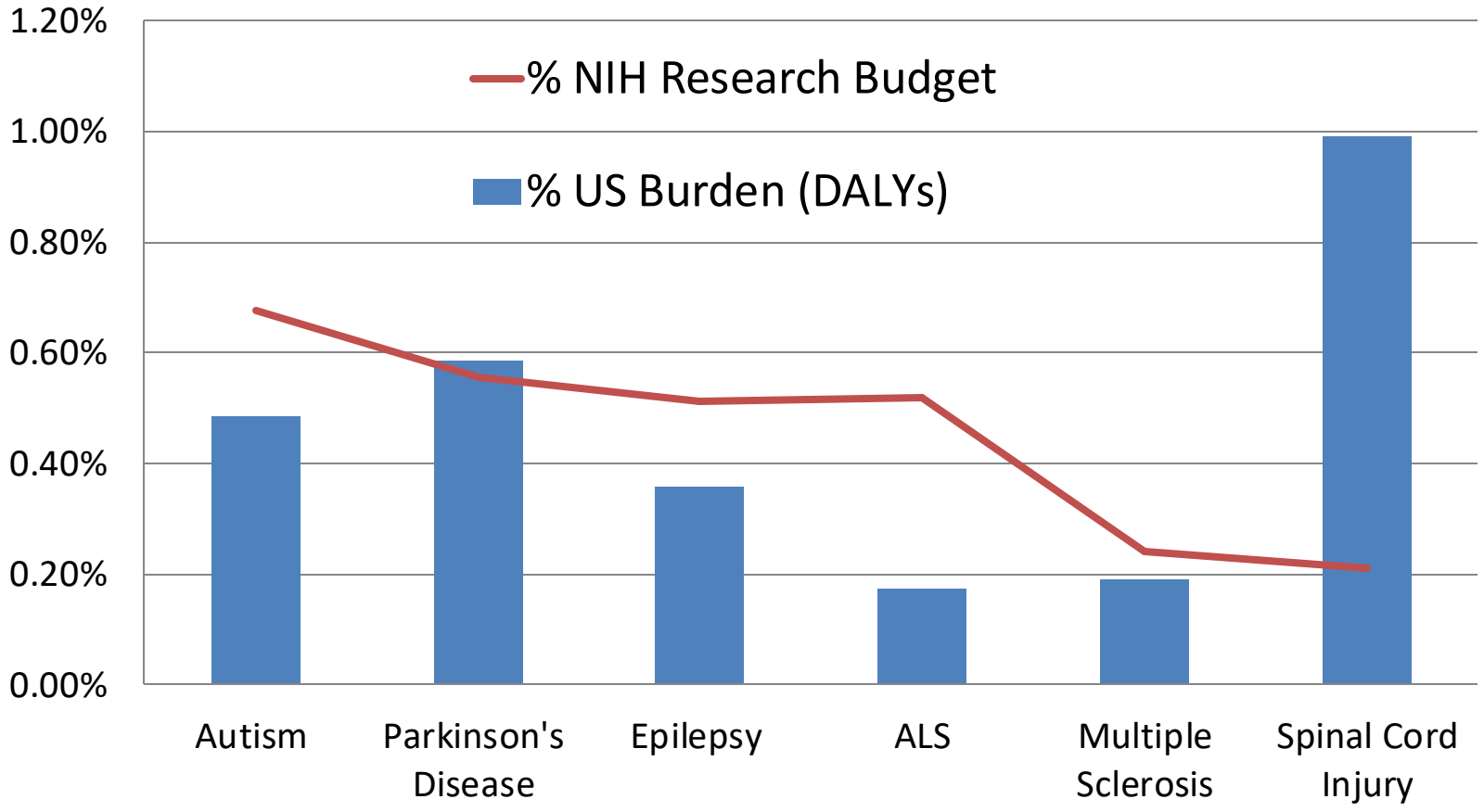
Funding vs Burden

for Low-Prevalence Neurological Conditions



Source: NIH 2024; IHME GBD 2023

DALY (Disability Adjusted Life Year) = YLDs (Years Lived with Disability) + YLLs (Years of Life Lost)

ALS DALY assumes all Motor Neuron Disease; SCI DALYs are calculated as IHME GBD 2023 YLD (reported) plus estimated YLL (IHME does not directly estimate YLL for SCI) using the GBD 2023 "Injuries by Nature" category average YLL/YLD ratio and should be interpreted as an approximation.

Low-Prevalence < 3mm

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Explanation of “Funding Vs. Burden”

This graph visualizes the research investment within the NIH, relative to the “condition/disease burden” of rare neurological conditions.

The assumption is that the taxpayer should be investing in conditions or disease research relative to the “burden” of living with that condition based on the Disability Adjusted Life Years (DALYs). The current NIH investment in research for spinal cord injury is disproportionately low compared to its “burden” on the individual in terms of quality of life and the taxpayer in terms of healthcare and opportunity costs.

NSCISC
National Spinal Cord Injury Statistical Center
Spinal Cord Injury Model System

Traumatic Spinal Cord Injury Facts and Figures at a Glance

2025 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 (tSCI) in the United States.

This data sheet is a quick reference on demographic and condition status for 37,866 people with tSCI collected through 2024 by 31 federally funded SCI Model Systems and 4 Form II (follow-up) centers and entered into the National SCI Database. This data sheet does not include the 16,175 people who were added to the SCI Database registry due to not fully qualifying for follow-up.

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Website: uab.edu/NSCISC

Incidence

The 2024 population size in the United States was estimated to be about 341 million people. The most recent estimate of the annual incidence of traumatic spinal cord injury (tSCI) is approximately 54 cases per one million people in the United States, which equals about 18,421 new tSCI cases each year. New tSCI cases do not include those who die at the location of the incident that caused the tSCI.

- **Data Source:** Jain NB, Ayers GD, Peterson EN, et al. Traumatic spinal cord injury in the United States, 1993-2012. JAMA. 2015;313(22):2236-2243.

Prevalence

The estimated number of people with tSCI living in the United States is approximately 308,620 persons, with a range from 259,374 to 393,913 persons.

- **Data Source:** Lasfargues JE, Custis D, Morrone F, Carswell J, Nguyen T. A model for estimating spinal cord injury prevalence in the United States. Paraplegia. 1995;33(2):62-68.

Age at Injury

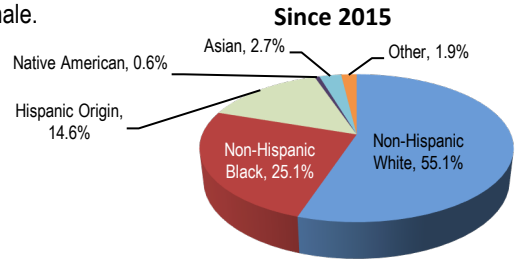
The average age at injury has increased from 29 years during the 1970s to 44 years since 2015.

Sex

About 78% of new tSCI cases since 2015 are male.

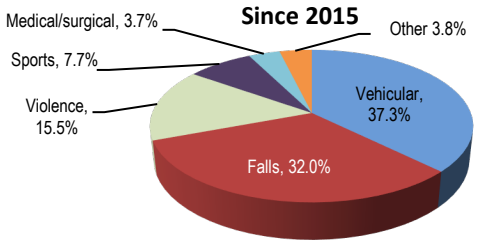
Race/Ethnicity

About 25% of recent injuries have occurred among the Black – Not Hispanic or Latino population. Yet, about 12% of the U.S. population is Black – Not Hispanic or Latino.



Cause

Vehicle crashes and falls account for almost 70% of recent injuries. Acts of violence (mostly gunshot wounds) and sports/recreation injuries account for about 23%.



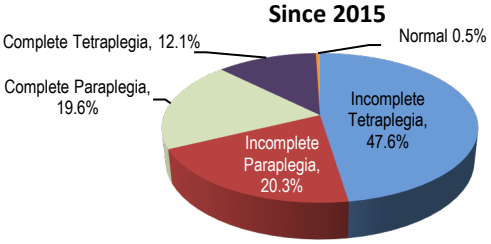
Lengths of Stay

The average lengths of stay in the hospital acute care unit have declined from about 30 days in the 1970s to about 19 days since 2015. The average rehabilitation lengths of stay have also declined from about 110 days in the 1970s to about 37 days since 2015.

- **Note:** Lengths of stay have been shown on this data sheet in averages since 2024. Lengths of stay in previous years were shown in median.

Neurological Level and Extent of Lesion

Recently, incomplete tetraplegia is the most frequent neurological category. The frequency of incomplete and complete paraplegia is almost the same. Less than 1% of persons experienced complete neurological recovery by the time of hospital discharge.



SCIMS
Spinal Cord Injury Model System
Since 1970

MSKTC.org
SCI · TBI · BURN
Model Systems Knowledge Translation Center

Education

Since 2015, 24% of persons with tSCI have a college degree at the time of their injury, compared with 44% of people who survived 40 years of injury.

Education (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
High School Only	52.3	52.8	49.1	45.8	41.7	35.6
College or Higher	23.6	25.8	29.0	28.8	34.3	44.2

Employment Status

Since 2015, 18% of persons with tSCI are employed at year 1 post-injury. The employment rate increases over time before peaking at 30 years post injury.

Status (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
Employed	65.0	17.8	25.6	29.0	30.3	27.0
Student	6.7	5.4	2.4	0.7	0.3	0.1

Marital Status

Since 2015, the percentage of people who are married is relatively consistent up to year 30 post-injury, with single/never married status slowly decreasing and divorce status slowly increasing.

Status (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
Single	44.7	43.5	38.2	36.1	34.3	24.8
Married	36.9	36.3	34.1	35.1	35.1	44.1
Divorced	8.8	10.3	18.4	19.8	22.4	21.7

Re-Hospitalization

Since 2015, about 29% of persons with tSCI are re-hospitalized at least once during any given year following injury. About 18 days is the average length of stay when re-hospitalized. Diseases of the genitourinary system are the leading cause of re-hospitalization, followed by disease of the skin. Respiratory, digestive, circulatory, and musculoskeletal diseases are also common causes.

Historical Lifetime Costs

The average yearly expenses (health care costs and living expenses) and the estimated lifetime costs that are directly attributable to tSCI vary greatly based on education, neurological impairment, and pre-injury employment history. The below estimates do not include any indirect costs such as losses in wages, fringe benefits, and productivity (indirect costs averaged $95,309 per year in 2024 dollars).

Severity of Injury	Average Yearly Expenses (in 2024 dollars)		Estimated Lifetime Costs by Age at Injury (discounted at 2%)	
	First Year	Each Subsequent Year	25 years old	50 years old
High Tetraplegia (C1–C4) AIS ABC	$1,410,163	$244,879	$6,256,937	$3,438,706
Low Tetraplegia (C5–C8) AIS ABC	$1,018,966	$150,222	$4,571,708	$2,812,009
Paraplegia AIS ABC	$687,262	$91,042	$3,059,615	$2,007,933
Motor Functional at Any Level AIS D	$460,224	$55,900	$2,090,344	$1,475,423

Data Source: Economic Impact of SCI published in the journal Topics in Spinal Cord Injury Rehabilitation, Volume 16, Number 4, in 2011.
American Spinal Injury Association Impairment Scale (AIS) is used to grade the severity of a person's neurological impairment following tSCI.

Historical Life Expectancy

Since the 1970s, life expectancies have increased steadily for people with tSCI during their first year of injury. However, life expectancies after their first year have not changed since the early 1980s and remain substantially below the life expectancies of the general population. An individualized Life Expectancy Calculator is available at uab.edu/nscisc/life-expectancy-calculator.

Age at Injury	No tSCI	Life Expectancy (years) for Post-Injury by Severity of Injury and Age at Injury									
		For Persons Surviving the First 24 Hours					For Persons Surviving at Least 1 Year Post-Injury				
		High Tetraplegia (C1–C4) AIS ABC	Low Tetraplegia (C5–C8) AIS ABC	Paraplegia AIS ABC	Motor Functional AIS D (Any Level)	Ventilator Dependent (Any Level)	High Tetraplegia (C1–C4) AIS ABC	Low Tetraplegia (C5–C8) AIS ABC	Paraplegia AIS ABC	Motor Functional AIS D (Any Level)	Ventilator Dependent (Any Level)
20	57.1	28.0	34.9	40.3	48.4	8.2	28.7	35.5	40.7	48.7	14.2
40	38.8	17.5	21.6	26.4	32.1	6.7	18.2	22.1	26.7	32.3	10.5
60	22.1	10.0	11.6	14.5	17.8	3.3	10.9	12.0	14.8	18.0	7.0

Historical Causes of Death

During the first year of injury, the three leading causes of death among people with tSCI were respiratory diseases (mostly pneumonia and influenza), other heart diseases (often unexplained heart attacks that usually do not represent a true underlying cause of death), and infective and parasitic diseases (mostly septicemia secondary to urinary or pressure injury infections). Among people surviving the first year after injury, respiratory diseases were the leading cause of death (19.6%), followed by infective and parasitic diseases (13.1%), cancer (12.1%), hypertensive and ischemic heart diseases (11.0%), and other heart diseases (7.2%).

- **Data Source:** National Spinal Cord Injury Statistical Center. 2024 Annual Statistical Report for the Spinal Cord Injury Model Systems. University of Alabama at Birmingham: Birmingham, Alabama.

 This is a publication of the National Spinal Cord Injury Statistical Center in collaboration with the Model Systems Knowledge Translation Center. Publication content was developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90SIMS0016 and 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). Content does not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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