

## Other SCI Resources

- **Model Systems Knowledge Translation Center (MSKTC)** works closely with SCI Model Systems researchers to develop consumer fact sheets on a number of topics, including pressure ulcers, wheelchairs, etc. ([www.msktc.org](http://www.msktc.org)).
- **Spinal Cord Injury Rehabilitation Evidence (SCIRE)** summarizes and critically reviews existing scientific literature on a broad range of rehabilitation topics ([www.scireproject.com](http://www.scireproject.com)).
- **National Spinal Cord Injury Association** provides information, peer support and advocacy to people with SCI ([www.spinalcord.org](http://www.spinalcord.org)). NSCIA is the membership division of United Spinal Association ([www.unitedspinal.org](http://www.unitedspinal.org)). United Spinal Association's mission is to improve the quality of life of all people living with SCI. They also offer wheelchair repairs through Wheelchair Medic ([www.wheelchairmedic.com](http://www.wheelchairmedic.com)).
- **Paralyzed Veterans of America** ([www.pva.org](http://www.pva.org)) supports SCI research and education and has published both consumer guides and clinical practice guidelines on a diverse number of areas in SCI, including bowel and bladder management, pressure ulcers, upper limb pain, sexuality, etc.
- **The Reeve Foundation Paralysis Resource Center** provides comprehensive information and referral resources for people living with SCI ([www.christopherreeve.org](http://www.christopherreeve.org)).

## Contact Numbers

*Driver Rehabilitation:* ..... 800.248.3221, ext. 2322  
*NeuroRecovery Network:* ..... 973.243.6873  
*Outpatient Medical Services/Clinic:* ..... 973.243.6999  
*Physical/ Occupational Therapy:*.....800.248.3221, ext. 2241  
*Psychological Services:* ..... 973.324.3634  
*SCI Research:* ..... 800.248.3221, ext. 3567/6985  
*Urology:* ..... 800.248.3221, ext. 2274  
*Vocational Rehab:* ..... 800.248.3221, ext. 2361  
*Wheelchair Clinic:* ..... 973.677.4251

## Interested in participating in research?



Visit  
[KesslerFoundation.org/  
ResearchandYou](http://KesslerFoundation.org/ResearchandYou)  
or call Kessler  
Foundation  
973-324-3567



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## Northern New Jersey Spinal Cord Injury System

## Research and You



**Spinal Cord Injury Model System**  
**SCIMS | NIDRR**  
A NIDRR Funded Program



**The Northern New Jersey Spinal Cord Injury System** (NNJSCIS) is one of only 14 Spinal Cord Injury Model System (SCIMS) centers of care in the country funded by the National Institute on Disability and Rehabilitation Research (NIDRR).

The NNJSCIS, a SCIMS Center of Care since 1990, is a cooperative effort of Kessler Foundation, Kessler Institute for Rehabilitation, Rutgers New Jersey Medical School and University Hospital.

The NNJSCIS provides a comprehensive continuum of state-of-the-art care for persons with spinal cord injury (SCI) from the time of injury through rehabilitation, return to the community, and long-term follow-up.

Each year, our system of care treats more than 100 newly injured persons with traumatic SCI and provides outpatient follow-up to more than 1,500 persons with chronic SCI. The NNJSCIS conducts cutting-edge SCI research, ranging from clinical trials to epidemiological studies and development of outcome measures.

In addition to providing a multidisciplinary system of rehabilitation care specifically designed to meet the needs of individuals with SCI, each SCIMS center is mandated to engage in three types of research activities:

1. Contribute data to the National Spinal Cord Injury Model System database;
2. Conduct a site-specific research study;
3. Participate in a multi-center collaborative module study.

## Our database

Newly injured patients with SCI are invited to participate in a longitudinal national database of persons with SCI. This information is used to further our understanding of SCI and the long-term consequences of this injury so that we may develop improved treatments and systems of care.

All data reported and published from the model systems database are de-identified in order to protect the privacy of participants. Since 1973, more than 28,711 people have provided information for the National SCI Statistical Center database. It is used by researchers throughout the country to improve care for persons with SCI.

## SCI: Facts & Figures at a Glance

There are approximately 12,000 new spinal cord injuries each year. An estimated 270,000 people are living with SCI in the US today.

**Age:** Spinal cord injury primarily affects young adults. The average age at time of injury used to be 28.7 years, with most injuries occurring between the ages of 16 and 30. However, as the age of the general population of the US has increased, so has that of the SCI population. Now the average age at injury is 41.0 years.

**Gender:** Overall, 80.6% of all spinal cord injuries occur in men.

### Causes of SCI:



## What is a clinical trial?

A clinical trial is a research study designed to answer specific questions about a new treatment or new way of using current treatments. It may be difficult to tell the difference between a clinical trial and a treatment program claiming to be a clinical trial. One should be cautious of unproven treatments offered for a fee. The International Collaboration on Repair Discoveries (ICORD) has produced an easy-to-read booklet addressing many of the questions people have regarding clinical trials in SCI. *Experimental treatments for spinal cord injury: What you should know* is available for download free at the ICORD website (ICORD.org).

## How does one find out about current SCI clinical trials?

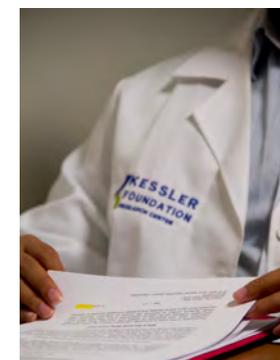
### The Spinal Cord Outcomes Partnership Endeavor (SCOPE)

provides an updated table of current SCI clinical trials for interventions to improve neurological function.

See their website:

[www.scopesci.org](http://www.scopesci.org).

Another resource is ClinicalTrials.gov, a web-based registry of clinical trials on a wide range of conditions, including spinal cord injury. ClinicalTrials.gov lists not only SCI clinical trials for interventions to improve neurological function, but also those relating to other complications associated with SCI.



# Northern New Jersey Spinal Cord Injury System

*at*



## *Some of our ongoing research...*

### **Combination Therapy to Restore Lost Function after SCI**

The purpose of this study is to determine the efficacy and safety of combination therapy with dalfampridine and locomotor training therapy to improve walking and other functions in people with motor incomplete SCI. Dalfampridine is a medication approved to improve walking in persons with multiple sclerosis.

### **Neurological Recovery after SCI**

The goal of this study is to collect neurological data on persons with SCI so we can better understand recovery after injury.

### **Measuring Functional Activities in SCI**

The purpose of this study is to better understand functional activities in individuals with SCI, how these abilities change over time, and how abilities respond to different treatment approaches.

### **Equity & Quality in SCI Assistive**

**Technology** The purpose of this research study is to look at the assistive (wheelchair) technology used by individuals with SCI. The project will examine the characteristics that impact the quality of assistive technology received and the outcomes experienced by individuals with SCI.

## Quality of Life in SCI

The purpose of this study is to develop a better understanding of quality of life of persons with SCI and how it changes over time.

## Long-term Followup in Persons with Ventilatory-Dependent Tetraplegia Managed with Diaphragmatic Pacing Systems

The goal of this study is to determine the utilization, effectiveness, satisfaction, durability and safety of the Diaphragm Pacing System.

## Impact of Blood Pressure on Health & Quality of Life

The purpose of this research study is to develop a set of questions that will help us understand the effects of blood pressure problems on overall quality of life in the SCI population.

## Collaboration on Mobility Training (COMIT)

The goal of this multi-center clinical trial is to improve manual wheelchair skills and minimize manual and power wheelchair breakdowns in people with SCI through structured training programs.

To learn more about our SCI research projects, contact us at 973.324.3567 or go to [KesslerFoundation.org](http://KesslerFoundation.org).



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