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# The Spinal Cord Injury Model System (SCIMS)



Funded by the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education, Washington, D.C.

*Version date: January 2010*

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# Definition of Traumatic Spinal Cord Injury (SCI)

- Any injury to the spinal cord via blunt or penetrating trauma
- Manifests as variable loss of neurological function below the injury site:
  - Motor and sensory impairment
  - Autonomic, bowel, bladder and sexual dysfunction
- Degree of loss depends on level and completeness of injury

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# The Genesis of the SCIMS

- Despite advances in understanding SCI, approaches to treatment remained largely fragmented, and comprehensive rehabilitation failed to become widely adopted in the Western Hemisphere ... until **John Young (1919–1990)** resolved to correct this.
- With the assistance of J. Paul Thomas, then director of the Medical Sciences Program at the Rehabilitation Services Administration, John Young obtained a federal grant in 1971 to demonstrate the superiority of comprehensive versus fragmented SCI care in Phoenix, Arizona...
  - ...and called this demonstration a “Model System”



Donovan, 2006

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# The Genesis of the SCIMS

- “A Model System must be able to meet the needs of a person with SCI by competently treating the direct injury as well as all organ systems affected (of which there are many); the functional deficits that result, by providing training and equipment; the psychological adjustments that must be made; the vocational/avocational pursuits that must be changed; and the providing of long-term specialized care.”

~ John Young



Donovan, 2006

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# The Genesis of the SCIMS

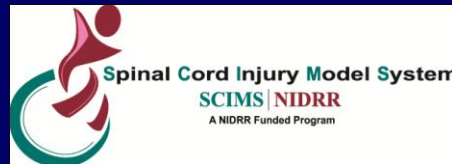
- Dr. Young's accomplishments were quickly realized and NIDRR soon designated more SCIMS
- Though centers have changed over the years, the SCIMS program has remained in existence since 1971
  - In 2006, 14 centers funded by NIDRR (funded through 2011)



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# Project Design

- The SCIMS program was established by the Rehabilitation Services Administration in the early 1970s
- The SCIMS are specialized programs of care in spinal cord injury which gather information and conduct research with the goal of improving long-term functional, vocational, cognitive, and quality-of-life outcomes for individuals with SCI

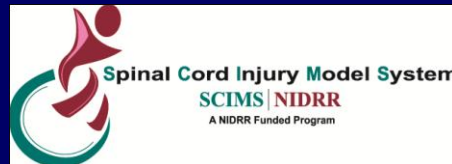


Lammertse, Jackson and Sipski, 2004; NIDRR

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# Project Design

- SCIMS grantees contribute patient records to a national database maintained by a national statistical center which tracks the long-term consequences of SCI and conduct research in the areas of medical rehabilitation, health and wellness, technology, service delivery, short- and long-term interventions, and systems research.
- Each SCIMS is charged with disseminating information and research findings to patients, family members, health-care providers, educators, policymakers and the general public.



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# Project Design

- The first SCIMS grant was awarded to Good Samaritan Hospital in Phoenix, AZ in 1971
  - The success of this demonstration project of comprehensive service delivery led to the establishment of six additional centers in 1972 creating a program with a national scope
  - By 1975, variables to be included in a national collaborative database were established
  - Since 1971, a total of 27 centers have been funded as a SCIMS center

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# Project Priorities, Priority One 2006 - 2011

- ❑ Contribute to continued assessment of long term outcomes of SCI by enrolling at least 30 subjects per year in the national database
- ❑ Contribute to improved outcomes for persons with SCI by proposing and participating in at least one collaborative research module project
- ❑ Contribute to improved long-term outcomes of persons with SCI by conducting one site-specific research project to test innovative approaches to treating and evaluating SCI outcomes in accordance with NIDRR's long range plan



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# Project Priorities, Priority One 2006 - 2011

- Provide a multidisciplinary system of rehabilitation care specifically designed to meet the needs of individuals with SCI, encompassing a continuum of care
- Address the needs of people with disabilities including those from traditionally underserved populations
- Coordinate with the Model Systems Knowledge Translation Center to provide scientific results and information for dissemination to clinical and consumer audiences
- Ensure participation of individuals with disabilities in all aspects of SCIMS research



# Current SCI Model Systems



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# Centers & Key Personnel

## □ Federal Program Management

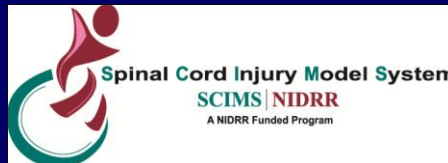
- National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington D.C.

- Project Officer: Theresa San Agustin, M.D.

## □ National SCI Statistical Center

- University of Alabama at Birmingham, Birmingham, AL

- Principal Investigator: Yuying Chen, M.D., Ph.D.



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# Centers & Key Personnel

(listed in state alphabetical order)

- UAB Model Spinal Cord Injury Care System, Birmingham, AL
  - Principal Investigator: Amie B. Jackson, M.D.
    - <http://www.spinalcord.uab.edu/show.asp?durki=19769>
- The Rocky Mountain Regional Spinal Injury System, Englewood, CO
  - Principal Investigators: Daniel P. Lammertse, M.D. and Susan Charlifue, Ph.D.
    - <http://www.craighospital.org/Research/Abstracts/SCIMS.asp>
- National Capital Spinal Cord Injury Model System, Washington, D.C.
  - Principal Investigator: Suzanne L. Groah, M.D.
    - <http://nrhrehab.org/Research/Scientific+Centers/NCSCIMS/default.aspx>

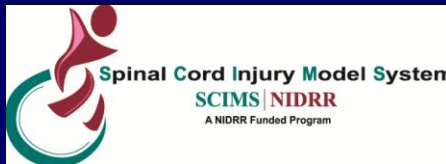


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# Centers & Key Personnel

(listed in state alphabetical order)

- Georgia Regional Spinal Cord Injury System, Atlanta, GA
  - Principal Investigator: David Apple, Jr., M.D.
    - <http://www.shepherd.org/research/model.asp>
- Midwest Regional Spinal Cord Injury Care System, Chicago, IL
  - Principal Investigator: David Chen, M.D.
    - <http://www.ric.org/research/centers/MidwestRegionalSpinalCordInjuryCareSystem/MRSCICS.aspx>
- The NERSCIC, Boston, MA and Wallingford, CT (Gaylord Hospital)
  - Principal Investigators: Steve Williams, M.D. (Boston) and Dave Rosenblum, MD (Wallingford)
    - <http://www.bmc.org/rehab/nerscicnetwork.htm>



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# Centers & Key Personnel

(listed in state alphabetical order)

- University of Michigan Model Spinal Cord Injury Care System, Ann Arbor, MI
  - Principal Investigators: Denise G. Tate, Ph.D. and Anthony Chiodo, M.D.
    - <http://www.med.umich.edu/pmr/modelsci/>
- Northern New Jersey Spinal Cord Injury System, West Orange, NJ
  - Principal Investigator: David S. Tulsky, Ph.D.
    - <http://www.kmrrec.org/nnjscis/>
- Mount Sinai Spinal Cord Injury Model System, New York, NY
  - Principal Investigator: Kristjan T. Ragnarsson, M.D.
    - <http://www.mssm.edu/rehab/spinal/>



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# Centers & Key Personnel

(listed in state alphabetical order)

- Northeast Ohio Regional Spinal Cord Injury System, Cleveland, OH
  - Principal Investigator: Gregory A. Nemunaitis, M.D.
    - <http://www.metrohealth.org/body.cfm?id=2283&oTopID=2283>
- Regional Spinal Cord Injury Center of the Delaware Valley, Philadelphia, PA
  - Principal Investigator: Ralph Marino, M.D.
    - <http://www.spinalcordcenter.org/>
- University of Pittsburgh Model Center on Spinal Cord Injury, Pittsburgh, PA
  - Principal Investigator: Michael L. Boninger, M.D.
    - <http://www.upmc-sci.org/>



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# Centers & Key Personnel

(listed in state alphabetical order)

## □ Texas Model Spinal Cord Injury System, Houston, TX

- Principal Investigators: Daniel Graves, Ph.D. and William Donovan, M.D.

- <http://www.memorialhermann.org/locations/tirr/content.aspx?id=1232>

## □ Northwest Regional Spinal Cord Injury System, Seattle, WA

- Principal Investigator: Charles H. Bombardier, Ph.D.

- <http://sci.washington.edu/>



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# Contracted Centers for Follow Up Data Collection

- Three centers are currently under contract to provide follow up data (i.e., Form II) only
  - St. Joseph's Hospital and Medical Center, Phoenix, AZ
    - Principal Investigator: Candyce Williams, M.D.
  - Santa Clara Valley Medical Center, San Jose, CA
    - Principal Investigator: Kazuko Shem, M.D.
  - Virginia Commonwealth University, Richmond, VA
    - Principal Investigator: William McKinley, M.D.
  - University of Missouri, Columbia, MO
    - Principal Investigator: Yuying Chen, Ph.D. (UAB)

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# Formerly Funded Centers that Contributed to the National SCI Database

- Arizona, Phoenix – 1973-1985 (currently contracted)
- California, Downey – 1980-1981; 1983-2006
- California, San Jose – 1973-1985; 1990-2006 (currently contracted)
- Florida, Miami – 1979-1981; 1984-1985; 2000-2006
- Louisiana, New Orleans – 1983-1985
- Michigan, Detroit – 1982-2000
- Missouri, Columbia – 1979-1981; 1995-2006 (currently contracted)
- New York, NYU – 1973-1990
- New York, Rochester – 1982-1990
- Virginia, Fishersville – 1973-1983; 1985-1990
- Virginia, Richmond – 1995-2006 (currently contracted)
- Wisconsin, Milwaukee – 1995-1999



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# The Model Systems Knowledge Translation Center (MSKTC)

- University of Washington, Seattle, WA
  - Principal Investigator: Kurt Johnson, Ph.D.
    - <http://msktc.washington.edu/>
- Goal 1: To enhance understanding of the quality and relevance of the SCI, TBI, and Burn Injury Model Systems Programs' research findings via a systematic review of evidence
  - MSKTC collaborates with Model System programs to conduct systematic reviews on high priority health topics to inform clinical practice.
- Goal 2: To enhance the use of knowledge of advances in SCI, TBI, and Burn injury research among consumers, clinicians, and other end-users of such information.
  - MSKTC conducts research to identify information needs, develops evidence-based consumer information, and provides training and technical assistance to improve information quality and dissemination among model systems.



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# The Model Systems Knowledge Translation Center (MSKTC)

- Goal 3: To create a centralized web-based resource for effective and uniform information dissemination and facilitation of knowledge translation among Model Systems
  - The MSKTC website provides:
    - Searchable database of Model System research publications
    - MSKTC systematic review summaries and link to articles
    - List and links to all Model Systems, and their research projects
    - Model system evidence-based consumer factsheets
    - Webcasts to improve knowledge translation activities of Model Systems



# Accomplishments through 2009: SCI Systematic Reviews & Consumer Factsheets

	Completed	In Process
<b>Systematic Reviews</b>	<ul style="list-style-type: none"> <li>• SCI and Measures of Major Depression</li> </ul>	<ul style="list-style-type: none"> <li>•SCI &amp; UTI Surveillance</li> <li>•SCI &amp; Measures for Predicting Outcomes of Employment</li> <li>•Prevention and Treatment of Bone Loss in SCI</li> <li>•SCI &amp; Adverse Exercise Effects</li> <li>•Women with SCI</li> <li>•Sleep/Obstructive Sleep Apnea &amp; SCI</li> </ul>
<b>Consumer Factsheets</b>	<p><u>Skin Care &amp; Pressure Sores</u></p> <ul style="list-style-type: none"> <li>•Part 1: Causes and Risks</li> <li>•Part 2: Preventing Pressure Sores</li> <li>•Supplements:               <ul style="list-style-type: none"> <li>How to do Pressure Reliefs (Weight Shifts)</li> <li>Building Skin Tolerance for Pressure</li> <li>Areas of the Body at High Risk for Pressure Sores</li> </ul> </li> <li>•Part 3: Recognizing and Treating Pressure Sores</li> <li>•Supplement: Stages of Pressure Sores: Illustrations</li> </ul> <p><u>Pain after Spinal Cord Injury</u></p> <p>Supplement: Activity Modification for Musculoskeletal Pain</p>	<ul style="list-style-type: none"> <li>•SCI &amp; Wheelchair prescription</li> <li>•SCI &amp; Transfers</li> <li>•SCI &amp; Exercise</li> <li>•SCI &amp; Bone Health</li> <li>•SCI &amp; Spasticity</li> <li>•SCI &amp; Depression</li> </ul>



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# SCIMS Research Activity Areas

- Site-specific research projects
  - Research carried out within each center
- Module projects
  - Collaborative research involving several SCIMS
- Contributions to the National SCI Database
  - Enrollment of new inpatients
  - Follow-up of discharged patients

# Site-Specific Projects

(listed in state alphabetical order)

Center	Project Title
<b>Birmingham, AL</b>	Effect of Nicotine on SCI Pain / Use of Neurologic Examination to Predict Urinary Tract Function Post-SCI
<b>Englewood, CO</b>	Comparison of High vs. Low Tidal Volume in Ventilator Weaning in Sub-Acute Cervical SCI
<b>Washington, D.C.</b>	Practice-based Evidence Study of Pressure Ulcer Prevention / SCI Navigator Pilot Project
<b>Atlanta, GA</b>	Psychological Status during Inpatient Rehabilitation and One Year after Onset / Validation of Clinical Measure of Wheelchair Seat Cushion Degradation

# Site-Specific Projects

(listed in state alphabetical order)

Center	Project Title
Chicago, IL	Low-cost Devices to Delivery of Intensive Treadmill Training / Outcomes of Rehabilitation Care for Medicare and Medicaid Beneficiaries
Ann Arbor, MI	Efficacy of Venlafaxine XR as Preventive Therapy for Depression and Pain Following New SCI
West Orange, NJ	Long Term Respiratory Complications of SCI

Note: Boston MA Site specific project merged with module “Quality of Life in SCI: The Next Generation of Instruments”



# Site-Specific Projects

(listed in state alphabetical order)

Center	Project Title
New York, NY	Modified-release Formulation of Morphine Sulfate for Neuropathic Pain after SCI
Cleveland, OH	Trunk Muscle Electrical Stimulation to Stabilize Seated Posture
Pittsburgh, PA	Implementation of Guidelines for Prevention of Upper Limb Pain in Spinal Cord Injury: A Randomized Trial
Philadelphia, PA	Capabilities of Arm and Hand in Tetraplegia

# Site-Specific Projects

(listed in state alphabetical order)

Center	Project Title
<b>Houston, TX</b>	Botulinum Toxin A Treatment of Detrusor External Sphincter Dyssynergia During Early SCI
<b>Seattle, WA</b>	Scheduled Telephone Intervention for SCI and Families

# Module Projects

(listed in state alphabetical order of lead center)

Module Project Title	Lead Center (City)	Collaborating Centers (City)
<b>UAB Motor Recovery Index</b>	Birmingham, AL	Ann Arbor, MI, Philadelphia, PA and Houston, TX
<b>Identifying the Best Measure of Participation</b>	Englewood, CO	New York, NY; Ann Arbor, MI; Atlanta, GA; Cleveland, OH; Boston, MA; West Orange, NJ and Chicago, IL
<b>Impact of SCI on Labor Market Participation</b>	Atlanta, GA	Seattle, WA; Englewood, CO; and New York, NY
<b>Measuring QOL in SCI: The Next Generation of Instruments</b>	West Orange, NJ and Boston, MA	Seattle, WA; Ann Arbor, MI; Chicago, IL; New York, NY; and Englewood, CO



# Module Projects

(listed in state alphabetical order of lead center)

Module Project Title	Lead Center (City)	Collaborating Centers (City)
<b>Development and Validation of the Thoracic-Lumbar Control Scale to Measure Strength and Coordination of Trunk Muscles</b>	Houston, TX	Birmingham, AL, Ann Arbor, MI and Seattle, WA
<b>Assistive Technology for Mobility</b>	Pittsburgh, PA	West Orange, NJ; Chicago, IL; Cleveland, OH; Washington DC and Philadelphia, PA
<b>Natural History of Depression within One Year after SCI</b>	Seattle, WA	Ann Arbor, MI and Houston, TX

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# Collaborative Projects, Priority Two (2006-2011)

- Multi-site research projects to conduct research that contributes to evidence-based rehabilitation interventions and clinical practice guidelines that improve the lives of individuals with SCI
  - Three or more SCIMS centers (may include non-SCIMS sites)
  - Conduct research to improve long term outcomes to answer questions of significance to SCI rehabilitation



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# Collaborative Projects

- ❑ **Controlled Trial of Venlafaxine XR for Depression After SCI: A Multi-site Study**
  - Goal: To examine the efficacy and tolerability of venlafaxine XR as a treatment of major depressive disorder
  - Lead Center, PI: Northwest Regional Spinal Cord Injury System, Charles Bombardier, Ph.D.
  - Collaborating Centers
    - ❑ UAB Model Spinal Cord Injury Care System
    - ❑ University of Michigan Model Spinal Cord Injury Care System
    - ❑ Midwest Regional Spinal Cord Injury Care System
    - ❑ Baylor College of Medicine



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# Collaborative Projects

## □ Improving Spinal Cord Injury Rehabilitation Outcomes

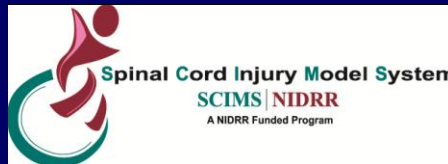
- Goal: To isolate specific components of rehabilitation interventions, and to determine how, and to what degree, each component is associated with outcomes
- Lead Center, PI: The Rocky Mountain Regional Spinal Injury System, Gale Whiteneck, PhD, FACRM
- Collaborating Centers
  - Mount Sinai Spinal Cord Injury Model System
  - Midwest Regional Spinal Cord Injury Care System
  - Georgia Regional Spinal Cord Injury System
  - National Capital Spinal Cord Injury Model System
  - Carolinas Rehabilitation, Charlotte, NC



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# National SCIMS Database

- Captures approximately 13% of all new SCI occurring in the U.S.
- Established at the University of Alabama at Birmingham in 1983
- Coordinates data collected by all SCIMS Centers
  - Registry – 11,053 participants (1986 – 2009)
  - Form I – 26,852 participants (1986 – 2009)
  - Form II – 120,568 participants (1985 – 2009), up to 35 years post injury



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# National SCIMS Database Goals

- Examine longitudinal course of SCI
- Evaluate trends over time
  - Etiology, demographics, injury characteristics, health services delivery, treatment outcomes
- Establish rehabilitation outcomes standards
- Facilitate other research
  - Generate research hypotheses
  - Identify study subjects



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# National SCIMS Database Data Sharing Policy

- SCIMS centers are requested to share manuscript proposals and grant applications using the National SCI Database and other centers
- Prohibited from comparing SCIMS centers
- Confidentiality agreement signed with National SCI Statistical Center
- All publications must acknowledge the National SCI Statistical Center, SCIMS centers and NIDRR
  - Must include disclaimer that opinions expressed are those of the authors and not necessarily those of the other entities

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# National SCIMS Database Data Sharing Policy

## □ External Requests

- Requestor provides a proposal outlining the purpose of study, commercial use/relationships, confidentiality protections, responsible party, data required and proof of IRB approval
- Proposal reviewed by NSCISC and Executive Committee; final proposal forwarded to NIDRR Project Officer
- Decision to release data made by a majority vote of Project Directors
- Date up to 5 years prior to request date will be available
- Copy of manuscript must be sent to NSCISC for review prior to submission for publication
- All publications must acknowledge the NSCISC, SCIMS and NIDRR with disclaimer



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# Eligibility for SCIMS

- Presence of an external traumatic event that results in a SCI including surgical procedures, radiation, and medical complications
- Temporary or permanent loss of sensory and/or motor function as a result of the traumatic event
- Admission to the system within one year of injury

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# National SCIMS Database Structure

- Form I or Registry (Inpatient data collection at enrollment)
  - Initial hospital care data
  - Patients residing outside the 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 collection)
  - Follow-up data on Form I participants
  - Currently in years 1, 5, 10, and every 5 years thereafter

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# Data Collection Sources

- Medical record review
  - May be supplemented by site-specific data collection forms completed by clinicians or by inpatient interview
- Neurological examination
  - Typically conducted as part of routine SCI care
- Patient interview
  - Telephone, mailed questionnaire, in-person interview
- Death records

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# Follow-up Guidelines

- Make at least six contact attempts by phone using most current number
  - Different times of day
  - Evenings and weekends
- Attempts should be made to schedule a clinical follow-up visit
- Mail survey to participant if unable to reach by phone or in person

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# National SCIMS Database Variables

- Demographics
- SCI characteristics (severity, etiology)
- Associated injuries and medical complications
- Hospitalizations
- Medical, functional, and psychosocial outcomes measures

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# Demographics (at time of injury)

- Age
- Sex
- Race/Ethnicity
- Primary language (English or other)
- Marital status
- Level of education
- Veteran status
- Place of residence at admission and discharge
- Occupational status and job census code

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# SCI Characteristics

- Date of Injury
- Etiology/external cause of injury
- Nature of injury
  - Level
  - Completeness
  - Syndromes, if present (i.e., central cord, anterior cord, Brown-Sequard)
- Work-relatedness of injury

# Neurological Exam

- Collected at:
  - Initial system admission for patients admitted to system on same day as injury
  - Admission to rehabilitation
  - Discharge from rehabilitation
  - First anniversary of injury
- Data collected include:
  - Date of exam
  - Motor scores (C5-S1) and motor levels (left and right)
  - Presence of anal sensation and/or sphincter contraction
  - Sensory level (left and right)
  - Level of preserved neurologic function (left and right)
  - Category of neurologic impairment
  - ASIA Impairment Scale, A – E

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# Associated Injuries

- Presence of vertebral injury
- Presence of other associated injuries:
  - Traumatic brain injury
  - Non-vertebral fractures requiring surgery
  - Facial injuries affecting sensory organs
  - Major chest injury
  - Amputation
  - Hemorrhaging
  - Organ damage requiring surgery

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# Initial Hospitalization

- Length of stay in system (acute care and/or rehab)
- Spinal surgery
- Use of immobilization devices (at rehab discharge)
  - Halo
  - Thoracolumbosacral orthosis (TLSO)
- Height and weight (at rehabilitation admission and discharge)
- Method of bladder management (at discharge)
- Utilization of mechanical ventilation (at rehabilitation admission and discharge)

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# Initial Hospitalization

- Functional status measured using motor subscale of FIM (Functional Independence Measure)
  - Self care such as eating, grooming, bathing, dressing, and toileting
  - Bowel and bladder management
  - Transfers such as bed to chair, toilet, and tub/shower
  - Locomotion such as walking, wheelchair, stairs
- FIM Assessed at rehab admission and discharge

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# Follow-up Data Collection

- Current socio-demographic information
  - Marital status
  - Level of education
  - Place of residence
  - Occupational status and job census code
- Re-hospitalizations over the last 12 months
  - Length of stay
  - Reason
- Use of VA Health System services

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# Follow-up Data Collection

- Impairment and neurological status
  - Neurological exam (required for Year 1 only)
  - Method of bladder management
  - Use of mechanical ventilation at Year 1
  - Pain
- Functional status – motor FIM
- Height and Weight
- Alcohol Use

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# Follow-up Data Collection

- Self-perceived health status (two items from SF-36)
  - Rating of health on five point scale ranging from “Excellent” to “Poor”
  - Health now compared to one year ago
- Satisfaction with Life Scale
  - Five item self-report scale

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# Follow-up Data Collection

- Patient Health Questionnaire (PHQ-9)
  - 9 item screening tool for depressive syndrome
- Craig Handicap Assessment and Reporting Technique, short form (CHART-SF)
  - Measure of societal participation
  - Dimensions assessed include physical independence, mobility, occupation, social integration

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# Follow-up Data Collection

- Assistive technology use
  - Mobility aids for ambulation
  - Wheelchair or scooter use
  - Modified vehicle availability and use
- Information/communication technology use
  - Computer
  - Internet/Email
  - Cell phone
  - Key information sources

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# Death Information

- Date of death
- Primary and secondary cause(s) of death
- Whether or not an autopsy was performed

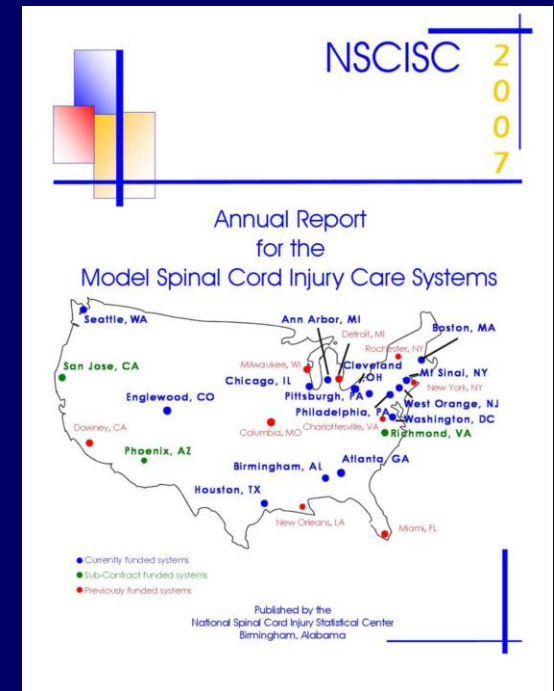
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# Data Quality

- Data Collection Syllabus
  - >350 page instruction manual
- Data collectors' training conferences
- Software Quality Control procedures
  - Range and legal value checks
  - Cross-variable and cross-record consistency
- Data quality monitoring reports
  - Follow-up tracking report
  - Subject recruitment & enrollment report
  - Missing data report
- Supportive site visits to review system-specific procedures

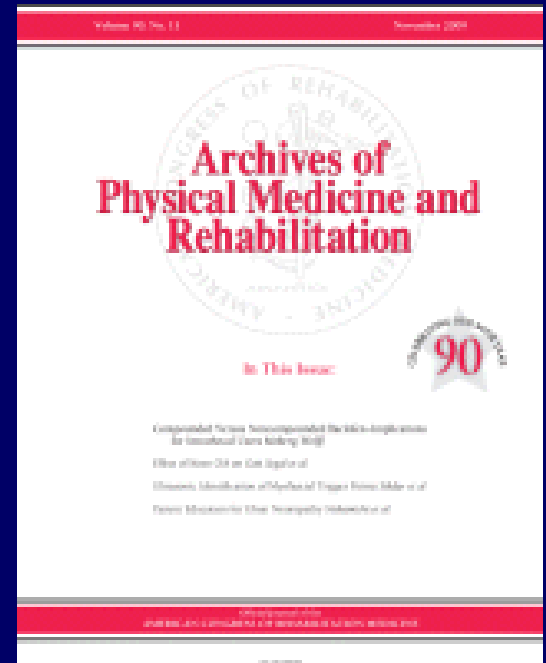
# Internal Dissemination

- Annual Data Report
  - Produced by the National SCI Statistical Center
- Benchmark Reports



# External Dissemination

- Peer-reviewed publications
- National professional meetings
- Compilation of database research contributed by SCIMS investigators
  - Books (1986, 1990, 1995) and special issues of Archives of Physical Medicine and Rehabilitation (1999, 2004)
  - Special Issues in Archives of PMR in 2010



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# External Dissemination

- Systematic Reviews in collaboration with MSKTC
  - Measurement of Depression in SCI (completed)
  - Under Development
    - SCI and UTI Surveillance
    - SCI and Measures for Predicting Outcomes of Employment
    - Prevention and Treatment of Bone Loss in SCI
    - SCI and Adverse Exercise Effects
    - Women with SCI
- Consumer Information (collaboration with all centers)
  - Skin Care and Pressure Sores

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# External Dissemination

- Online Syllabus and Data Collection Forms
  - (<http://www.spinalcord.uab.edu/show.asp?durki=24480>)
- Facts & Figures at a Glance
  - Published annually by the National SCI Statistical Center
    - <http://www.spinalcord.uab.edu/show.asp?durki=116979>
- Annual Statistical Reports, Public Version
  - Published annually by the National SCI Statistical Center
    - <http://www.spinalcord.uab.edu/show.asp?durki=116891>
- Slide show to educate others about the SCIMS



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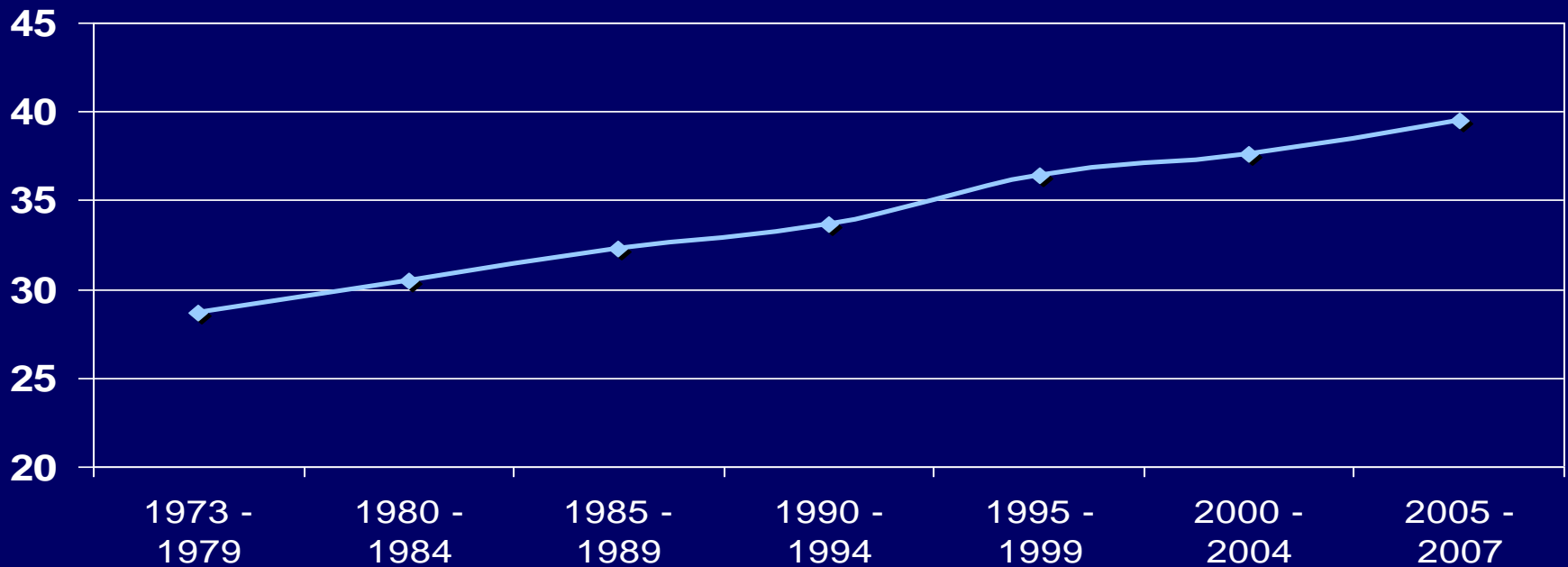
# National SCI Model Systems Descriptive Data Summary From 1973 to 2007

Source:

Annual Report (2007) for the Model Spinal Cord Injury Care Systems  
National SCI Statistical Center, Birmingham, AL

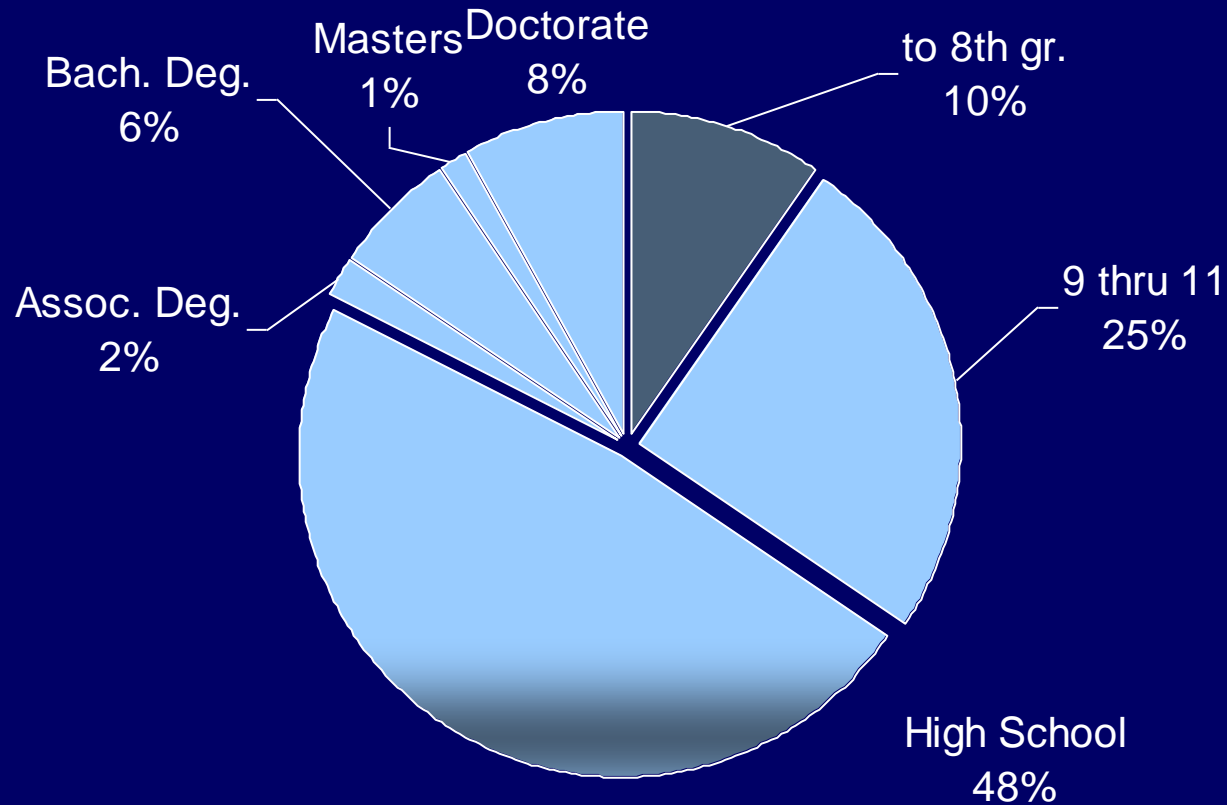


# Age at Injury & Gender

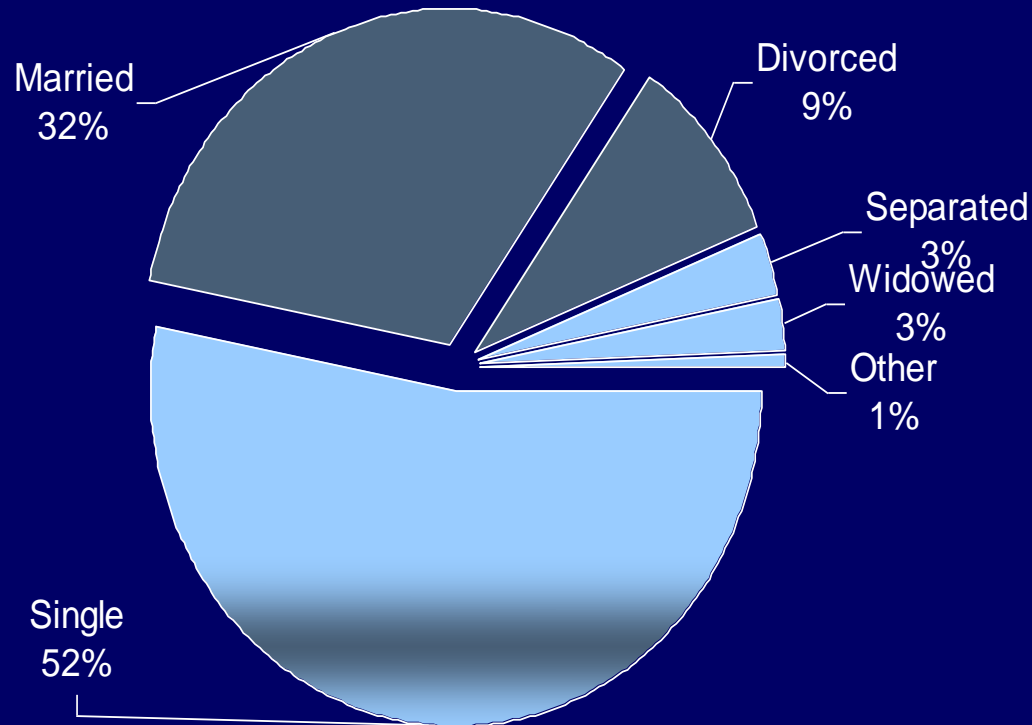


Males – 20,572 (80.9%) and Females – 4,840 (19.0%)

# Education (time of injury)

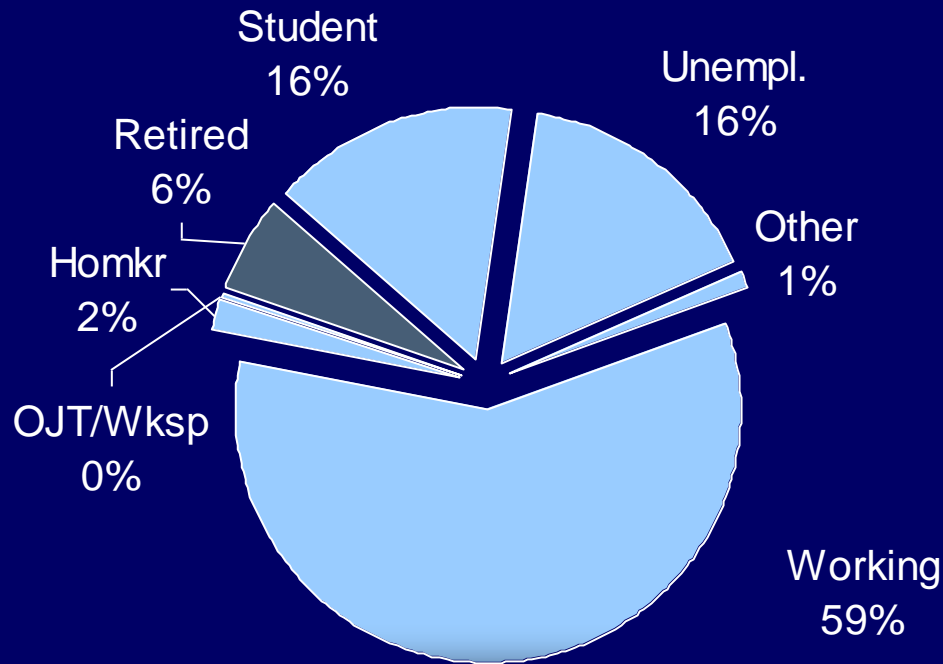


# Marital Status (time of injury)

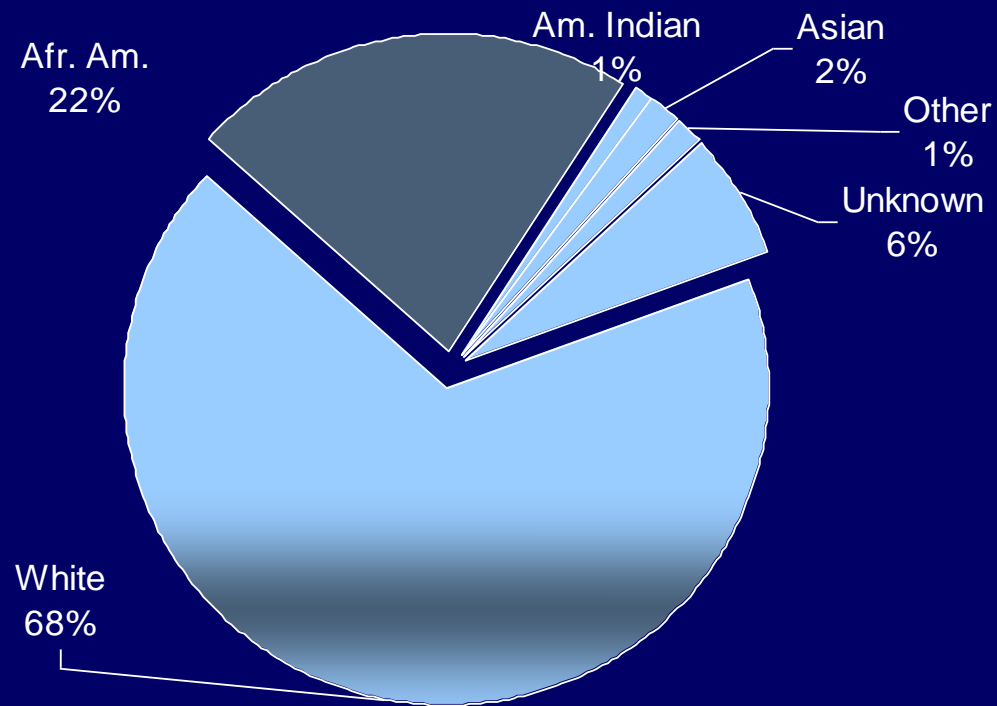


# Occupational Status

(time of injury)



# Race



# Long-Term Survival

(Life expectancy in years)

Age at Injury	Survive first 24 hours					Survive >1 year post-injury				
	Motor Fx Any Level	Para	Low Tetra (C5 – C8)	High Tetra (C1 – C4)	Vent. Dep., Any Level	Motor Fx Any Level	Para	Low Tetra (C5 – C8)	High Tetra (C1 – C4)	Vent. Dep., Any Level
20	52.6	44.8	39.8	35.3	18.1	53.0	45.5	40.8	36.9	25.1
40	34.1	27.3	23.1	19.6	8.0	34.5	27.9	23.9	20.8	12.2
60	17.7	12.7	9.8	7.6	1.8	18.1	13.1	10.3	8.4	3.6



Fact and Figures, 2009

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# Major Accomplishments of the SCIMS

- Provides critical information about course of recovery, trends in cause and severity, health service delivery and costs, treatment and rehabilitation outcomes
  - Benchmark for the judicial system to determine awards for care based on future needs
- Setting standards for assessment, treatment and management of persons with SCI nationally and around the world
  - In collaboration with the American Spinal Injury Association and Paralyzed Veterans of American, development of Clinical Practice Guidelines



Ditunno et al., 2003

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# Major Accomplishments of the SCIMS

- Research agenda has broadened from emphasis on acute care to include social and environmental factors, physical functioning and technology
- Clinical excellence of the SCIMS provided the foundation from which clinical research focusing on key issues of health of persons with SCI grew dramatically in the last three decades
  - Development of new measurement tools to capture neurological, psychosocial and emotional functioning



Ditunno et al., 2003

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# Major Accomplishments of the SCIMS

- National SCI Database – the largest in the world
  - SCI statistics have been widely used and referenced
    - NSCISC web site – average 81 visits per day
    - Google search for “SCI statistics” – NSCISC site ranked first among 1,010,000 sites
    - Google Scholar search for “SCI statistics” – 4 (including numbers 1 and 2) of the top 10 listed worldwide publications were based on the SCIMS database
  - Produce specific life expectancy estimates for an average of 32 court cases per year



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# Research Contributions of the SCIMS

- 1970s
  - Emergency and acute care outcomes
  - Trends in patient demographics and injury characteristics
  - Medical rehabilitation treatment outcomes
- 1980s
  - Development of classification systems (ASIA impairment scale, pain)
  - Pre-existing conditions and secondary complications
  - Psychosocial and vocational outcomes
- 1990s
  - Health care cost issues
  - Functional independence outcomes
  - Pain and sexuality
  - Community integration and consumer involvement



Tate and Forchheimer, 2002

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