





Keynote Presentation

Saturday, March 11, 2023



Philip S. Requejo, PhD Co-Director – Southern California Spinal Cord Injury Model System (SoCal-SCIMS) CEO – Rancho Research Institute









Sara J. Mulroy, PhD, PT

- Director of the Pathokinesiology Lab (1996-2022)
- Co-Director and Research Director of the Southern California SCIMS (2011-2021)
- Director of the Southern California SCIMS (SoCal-SCIMS) (2021-2022)



Objectives

- To honor her professional legacy of excellence and dedication to Spinal Cord Injury rehabilitation research and the SoCal-SCIMS.
- Provide increased awareness for the role of Spinal Cord Injury Model Systems in recovery (and rehabilitation) for individuals with spinal cord injury.

Southern California Spinal Cord Injury Model System "SoCal-SCIMS"









Sara's Contributions to Rancho's SCIMS

- She had over 30 years of clinical and research experience in SCI rehabilitation and have served as Co-Director of Rancho's Model System and principal investigator of its site-specific studies for the past two cycles (2011-2021).
- Principal investigator (PI) or co-investigator or on multiple NIH and NIDILRR-funded research grants documenting the shoulder demands of wheelchair propulsion, ambulation with assistive devices, activities of daily living, and car transfers for individuals with SCI.
- Her research initially focused on the biomechanics of the weight-bearing shoulder and development of interventions to prevent and treat shoulder pain after SCI and more recently has shifted to the identification of contributors to and management of chronic pain after SCI.
- PI on a highly successful RCT of an exercise program to treat shoulder pain in persons with SCI called STOMPS.
- PI on a 3-year longitudinal NIH study of shoulder pain and physical function after SCI. We identified significant risk factors for shoulder pain onset including weakness in critical shoulder muscles.







Sara's Contributions to Rancho's SCIMS (cont...)

- We then evaluated two different programs designed to *prevent* shoulder pain onset in a clinical trial as part of our SCI Model System (2011-2016). We identified that the prevention programs significantly reduced the rate of shoulder onset regardless of intervention delivery format.
- Using an RCT, we evaluated the outcomes and sustainability of two programs for promotion of physical activity (PA) after SCI: a novel, whole of day activity accumulation (WODAA) approach to increase overall PA and decrease sedentary time versus a more traditional planned aerobic exercise program (2016-2021).
- Utilized remote activity monitoring and an electronic smartphone app to query individuals throughout the day on their current activities and moods (ecological momentary assessment) to understand the contexts of physical activity and pain management strategies in the lives of persons with SCI.
- Developed and pilot-tested a community-based pain management program for individuals with paraplegia from SCI who have neuropathic pain utilizing a participatory research design.
- Current research focuses on identifying contributors to chronic pain after SCI and development of effective pain management interventions.







What is SCIMS?

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

 designated by National Institute on Disability, Independent Living and Rehabilitation Research





John Young, MD (1919-1990)







SCIMS Center	Years Funded*	Baylor, Texas, 2021-2026 *New Center - Baylor					
Alabama, Birmingham	1972-2016 2016-2026 ;	,,,	33 Institutions have been designated as an SCI				
Arizona, Phoenix	1970—1985; 2006—2011 [†]		Model System at some point since 1972				
California, Downey	1980—2006; 2006—2011 [†] ; 2011—2016	2016-2026 (Out 1 cycle since 1980) - Rancho	model bystem at some point since 2572				
California, Northridge‡	1982		Currently 18 institutions have this designation				
California, San Jose	1972—1985; 1990—2006; 2006—2016 [†]	2021-2026 *New Center — Santa Clara	currentity, to institutions have this designation				
Colorado, Denver	1974-2016	2016-2026 ***Continuously Funded since 1974-	Craig Hospital				
District of Columbia,	2006-2011	2021-2026 *New Center - DC					
Washington							
Florida, Miami	1979-1985; 2000-2006; 2011-2016	2016-2026 (Out multiple cycles since 1979) - Mi	ami				
Georgia, Atlanta	1982—2016	2016-2026 **Continuously Funded since 1982 -	- Shepherd Center				
Illinois, Chicago	1972—2000; 2006—2016	2016.2026 **Continuously Funded since 1974 – Shirley Ryan					
Kentucky, Louisville	2011-2016	2010-2020 Continuously Funded Since 1974	Shinley Nyan				
Louisiana, New Orleans	1982—1985		Active Centers 2016 - 2026				
Massachusetts, Boston,	1975—1990; 1995—2016						
Boston University			WASHINGTON MONTANA DAKOTA				
Massachusetts, Boston,	2011–2016 2016-2026		SOUTH WISCONSIN MAINE				
Spaulding-Harvard			OREGON IDAHO WYOLING DAKOTA				
Michigan, Ann Arbor	1985—2016		NEBRASKA IOWA Chingo				
Michigan, Detroit	1983—2000		NEVADA				
Minnesota, Minneapolis ⁺	1982	2021-2026 *New Center - Minnesota	San Finisco, UTAH COLORADO KANSAS MISSOURI VIRGINIA DE NU				
Missouri, Columbia	1979–1981; 1995–2006; 2006–2016		CALIFORM OLas Vegas				
New Jersey, West	1990—2016		Los A geles ARIZONA NEW MEXICO ARKANSAS CAROLINA SOUTH				
Urange		2016-2026 **Continuously Funded since 1990 -	Kessler San Diegoo				
New York, New York,	1990-2011; 2011-2016	2016-2026 (Out 1 cycle since 1990) - Mt. Sinai	I DUISIANA				
Mt Sinai	1070 1000 0000 0011 [†]		Houston				
New York, New York,	1972-1990; 2006-2011		Gulfor				
New York University	1000 1000		Mexico A				
New York, Rochester	1982-1990						
Dino, Cleveland	1995-2000; 2000-2011	2016-2026 (Out multiple cycles since 1995) - Oh	io				
Perinsylvania,	1979-2016 2010-2021	NF — Philly, Magee Rehab					
Prinauerprina	2000-2016		and a second				
Dittchurah	2000-2010	2016-2026 **Continuously Funded since 2000	- Pittsburgh				
Texas Houston	1072-2011 2011-2016 2016 202	6					
Virginia, Fishersville	1972-1990: 2006-2016 [†]						
Virginia, Richmond	1995-2006: 2006-2011 [†]	2021-2026 *New Center, VCU					
Washington, Seattle	1974—1985: 1990—2016						
Wisconsin, Milwaukee	1995—2000						
	1- 2010 2021	NE OSU					
Unio State, Columb	lia 2016-2021	NF - USU					







SCI Model System Activities

- Deliver high-quality system of care for patients with SCI Emergency Care through Post-Rehab
- * Enter 30-40 newly-injured individuals with traumatic SCI into the National SCI Database In-person follow-up at 1-year post-injury Phone follow-up questionnaires at 5 years post-injury and every 5 years thereafter Currently following approx. 1700 individuals
- * Conduct a site-specific research study designed to improve health/function of individuals with SCI
- * Conduct/Lead a multi-site research module (usually questionnaire-based) in collaboration with other centers
- > Participate in multi-site research modules lead by other centers.
- Participate in Model System knowledge translation activities (committees, papers, presentations, fact sheets, research using data base, etc.)







Rancho's SCI Model System Site-Specific Research Study



Principal Investigator: Sara Mulroy (smulroy@dhs.lacounty.gov)





Pathokinesiology Laboratory

"A Randomized Clinical Trial to Evaluate a Community-based, Nonpharmacologic Program to Enhance Active Pain-Management Strategies for Individuals with SCI"

> Principal Investigator: Sara Mulroy, PT, PhD Co-Investigator: Lisa Lighthall Haubert, MPT, DPT Co-Investigator: Rebecca Lewthwaite, PhD





Pathokinesiology Laboratory

Primary Specific Aims

Phase I – Development

1. To further develop, refine, and expand our recently piloted community-based, non-pharmacologic intervention program designed for individuals with paraplegia who have neuropathic (NeuP) *to also serve individuals with nociceptive musculoskeletal pain (NocP-M) and those with tetraplegia*.

2. To evaluate the feasibility, acceptability, and impact of the community-based, non-pharmacologic intervention program developed in Aim 1 for individuals with NocP-M and those with tetraplegia.

PAIN MANAGEMENT PROGRAM

Week 1:

Introduction/Understanding pain

Options for managing pain – Benefits of Relaxation

Week 2, 3, 4 :

Relaxation Classes, 2x/week

Meditation/Education vs Meditation/Heart-Rate Variability Biofeedback

Weeks, 5:

Active Pain Coping - Task Persistence, Pacing

Exercise Benefits and Management Strategies

Week 6:

Prevention of Shoulder (STOMPS ex) and Back Pain (Seating/Posture Evaluation)

Weeks 7, 8, 9:

Exercise Classes, 2x/week at Wellness Center

Week 10:

Review & Set Goals for Future





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Pathokinesiology Laboratory

Phase I – Development Methods

1. Convene a **Development Team** for adapting the program to also address nociceptive (Musculoskeletal) pain. This team will include clinicians with expertise in treatment/prevention of shoulder and low back pain in persons with SCI and individuals with paraplegia who have chronic musculoskeletal pain. They will draft the additions to the program.

2. A **Beta-Test Team** of four individuals with paraplegia and chronic musculoskeletal pain will participate in the adapted program and provided feedback to the Development Team.

3. We will repeat the process to modify the program to be appropriate for individuals with tetraplegia who have upper extremity weakness to ensure that the modules (primarily exercise) are appropriate or can be adapted for lower levels of upper extremity strength.





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Phase II – Randomized Clinical Trial (RCT)

1. To compare changes in pain interference (*our primary outcome measure*) at program end between individuals who enrolled immediately in the pain management program and those who were delayed in enrollment.

2. To compare changes in pain interference between individuals who participate in Meditation+HRVBT compared to those who receive Meditation+Sham Education for the relaxation module.





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Pathokinesiology Laboratory



Background

Heart rate variability (HRV) (i.e., variability of R-R intervals of the EKG):

- HR increases during inspiration, slows during expiration (via reflexes linked to respiration)
- Reflects autonomic ns balance: decreased HRV reflects indicates sympathetic drive and/or decreased parasympathetic function
- Associated with stress and various illnesses including chronic pain

HRV biofeedback training (HRVBT): HR recorded with sensor (ear or fingertip), providing real-time HRV feedback with instruction in paced, deep breathing at resonance frequency and positive thoughts to maximize HRV peaks

- Improves vagal HR regulation, reduces anxiety and psychological stress, and used successfully to reduce chronic pain in multiple populations.
- Not yet been evaluated as a treatment for chronic pain in the SCI population.









Outcome Measures

The International Spinal Cord Injury Pain Basic Data Set (ISCI-Pain BDS) questionnaire and recording of HRV at rest and during paced deep breathing conducted at baseline and at program end.

Variables of interest included:

Pain Intensity and Pain Interference scores from the ISCI-Pain BDS

Heart Rate

age

SDNN – Standard Deviation of the time between R-R peaks, a measure of HRV

Coherence – the synchronization of breathing with heartrate, normalized by

Other measures of the frequency content of HRV

Progress – Phase I

Modification/Expansion of 9-Week Pilot Program to 10-Weeks:

• New Week 6 - Prevention of Shoulder (STOMPS ex) and Back Pain (Seating/Posture Evaluation)

• Participant Recruitment:

- 4 / 4 Design Team 1 (Paraplegia, NocP-M)
- 3 / 4 Pilot Test Team 1 (Paraplegia, NocP-M)
- 3 / 4 Design Team 2 (Tetraplegia, NocP-M and/or NeuP)
- 2 / 4 Pilot Test Team 2 (Tetraplegia, NocP-M and/or NeuP)
- Design Team 1, Meeting #1: Completed February 24th
 - Program Revision, Based on Feedback: Ongoing March 28
- Pilot Test Team 1:
 - Baseline Evaluations: March 21st 25th
 - 10-Week Program: March 28th June 3rd (Feedback with Design Team following Weeks 5 & 10)



SCIMS Database

- 1970: First SCIMS center designated in Phoenix, AZ
- Started in 1975 with 10 centers
 - Retrospective data collection back to 1973

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- 32 centers have ever contributed data to database
- National SCI Statistical Center at UAB since 1983

Visit the SCI Model Systems Database: <u>https://www.nscisc.uab.edu/.</u>

1970 – 2026: 32 SCIMS Centers



across 21 States and District of Columbia







Scope of Database

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 & 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 collaboration



SCIMS Database Structure

Acute Care

Rehabilitation

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Community Living

Form I or Registry

- Initial hospital care data
- Registry (vs Form I) started in 1986: 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



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Definition of SCI

- Occurrence of an <u>acute traumatic lesion</u> of neural elements in the spinal canal (spinal cord and cauda equina), resulting in temporary or permanent sensory and/or motor deficit
- Exclusions:
 - Intervertebral disc disease
 - Vertebral injuries in the absence of spinal cord injury
 - Nerve root avulsions and injuries to nerve roots and peripheral nerves outside the spinal canal
 - Cancer, spinal cord vascular disease, and other nontraumatic spinal cord diseases

National Spinal Cord Injury Model Sys Database

The National SCIMS Database has been in existence since 1973 and cap new SCI cases in the U.S. Since its inception, 31 federally funded SCI Mc the National SCIMS Database. As of June 3, 2022, the database contain who sustained traumatic spinal cord injuries. To assure comparability of various centers, rigid scientific criteria have been established for the col information entered into the database. National Spinal Cord Injury Stati quality control procedures that further enhance the reliability and valid

What Is The National SCIMS Database - 2022



Definition and Eligibility

Public De-Identified Data

Access to De-Identified Data



Eligibility Criteria

• Presence of an external traumatic event (including iatrogenic injury)

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- Sensory or motor impairment
- Admission to SCIMS within 1 year of injury
- Not completed an organized rehabilitation program before admission to SCIMS
- Residing in SCIMS' catchment area
- Completed rehabilitation or deceased at discharge



þ			RANCH Research Inst	IO itute			ICHO LOS AM	
	National Database Status as of November 11, 2022				Status	N	%	
	Form	Ν	Timeframe		Deceased	12,562	34.6	
	Form I	36,275	1972-2022		Neuro	2,444	6.7	
	Form ll (not lost)*	130,681	1975-2022		recovery Withdrawn	1,328	3.7	
-	Registry	15,515	1986-2022		ID Unknown	845	2.3	
*	Total 30 245 r	narticinants:			Eligible-FU	12,461	34.4	
	Longest follow	w-up, 45 yea	rs (n=210)		Eligible-Lost	6,635	18.3	

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Sources of Data





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Data Quality Assurance

- Data collection guidelines
- Training and technical assistance
- On-site QA every 6 months
 - Form I re-abstraction
 - Data entry accuracy
 - Form II interview coding consistency
 - Form II interviews verification
- Data quality monitoring
- Web-based data management system
 - Software QC error checks
 - Data management tools

Reinforcement

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- Data collector's certification
- Site support visit to each center
- Benchmark management plan

Refinement

- Data Committee meeting quarterly
- Project Directors' meeting biannually









Web Resources

What Is The National SCIMS Database - 2022

Using National SCIMS Database - 2022

Definition and Eligibility

Public De-Identified Data

Access to De-Identified Data

Database Research

Database Publications Updated July 2022

Approved Data Access Requests Updated July 2022

Data Collection Forms

SCIMS Data Collection Forms 2021-2026 SCIMS Data Collection Forms 2016-2021 SCIMS Data Collection Forms 2011-2016 SCIMS Data Collection Forms 2006-2011 SCIMS Data Collection Forms 2000-2006

Data Dictionary

Data Dictionary 2016 - 2021

Data Dictionary 2011 - 2016

Data Dictionary 2000 - 2006

Q DeVivo Award 2024

✓ Annual Statistical Report







Fact Sheets, Data Sheets, Reports

NSCISC列

Spinal Cord Injury Model System

Vehicular accidents

accounted for 2,956

(38.09%) of spinal

cord injuries and ranks

1st in causes of spinal

cord injury.

National Spinal Cord Injury Statistical Center

Traumatic Spinal Cord Injury Facts and Figures at a Glance



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

NSCISCダ National Spinal Cord Injury Statistical Center

Spinal Cord Injury Model System

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

Spinal Cord Injury

Recent Trends in Causes of

NSCISC National Spinal Cord Injury Statistical Center

Spinal Cord Injury Model Systems

2021 SCI Data Sheet

2021 Annual Report – **Complete Public Version**





Download our De-Identified Data! Freely use our data for your own research or projects.

De-Identified Data collected before September 1, 2021 are freely available for download. De-Identified Data are stripped of all HIPAA-defined identifiers, including names, geographic subdivisions smaller than a state, elements of dates (except year) related to an individual, telephone numbers, fax numbers, email addresses, social security numbers, and medical record numbers.

Download

Just fill out the short form and you'll have access to download.

Version 2021 AR

De-identified data collected before September 1, 2021 are available for request, including during initial hospital care (Form I); data obtained at post-injury years 1, 5, 10, 15, 20, 25, 50 (Form II); and mortality data (Record Status).

Dataset	No. Observations	No. Observations coded as Lost	No. Persons	No. Variables	Data Collection Period	
Form I	35,675	NA	35,675	658	1972-2021	
 Form II	131,217	58,377	32,541*	325	1973-2021	
Record Status	35,675	NA	35,675	12	NA	I Med

Version 2016 AR

De-identified data collected before October 1, 2016 are available for request, including da initial hospital care (Form I); data obtained at post-injury years 1, 5, 10, 15, 20, 25, 30, 35 and mortality data (Record Status).

	Dataset	No. Observations	No. Observations coded as Lost	No. Persons	No. Variables	Data Collection Period	
	Form I	32,159	NA	32,159	417	1972-2016	
	Form II	113,360	52,645	29,202*	276	1973-2016	_
lici	Record Status	32,159	NA	32,159	12	NA	



Public Data Download

- 258 requests, Dec 2018 Dec 2022
- 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



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Public Tools

N	SCISC	Natio	nal Spinal C	ord Injury S	Statistical Co	ente	۶r	
Home	Database	Reports and Stat	ts SCI Model Systems	Cultural Competency	Quick Search Tools	FAQ	Contact Us	
		NSC	CISC Quick Search I	Public Tools				
		Cau	ses of SCI					
		The Na causes timefrar for caus injuries	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 Na estimat cord inj feeling	ational Spinal Cord Injury Statistical C te for the life expectancy of a person jury, has access to good quality heal and movement, in which case life ex	Center has created this quick sear with spinal cord injury who: is at thcare, is not on a ventilator and spectancy is considered the same	rch tool to provide an least 2 years post-spinal has not regained all normal e as the general population.			



SCIMS Database

Strengths

- Long history, longitudinal follow-up, large sample size, and geographic and participant diversity
- Excellent case identification procedures
- Standardization of data collection methods and measures
- Multi-level and comprehensive data quality control procedures

Limitations

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- Limited representation: database does not include persons who are never treated at SCIMS centers
- Hospital-based (not population-based) study sample: data not appropriate for incidence and prevalence estimates
- Loss to follow-up issues







Model Systems Knowledge Translation Center Spinal Cord Injury Resource Inventory

Model Systems Knowledge Translation Center

http://www.msktc.org/

A project funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082)









Model Systems Knowledge Translation Center



Three overarching goals guide the work of the MSKTC:

- Goal 1: Enhance the understanding of the quality and relevance of knowledge among researchers and multiple users on the topics of SCI, traumatic brain injury (TBI), and burn injury (Burn).
- Goal 2: Enhance the knowledge of advances in SCI, TBI, and Burn research among diverse audience members who need this information.
- **Goal 3:** Create a centralized repository of empirical information and resources on research in SCI, TBI, and Burn areas and actively conduct outreach and dissemination activities to communicate this knowledge.











Living with Spinal Cord Injury (SCI)

ALL TOPICS





https://msktc.org/sci







https://msktc.org/sci

Living with Spinal Cord Injury (SCI)

ALL TOPICS









Major Accomplishments of the SCIMS

- Provides trends in SCI demographics, causes, and severity
 - Crucial for the design of preventive measures
 - Useful for projecting health care needs and allocating resources
- Provides information about the course of recovery, health service delivery and costs, treatment, and rehabilitation outcomes
 - Benchmark for the judicial system to determine awards for life care needs
- Sets standards for the assessment, treatment, and management of persons with SCI nationally and internationally
 - Development of the Clinical Practice Guidelines in collaboration with American Spinal Injury Association and the Paralyzed Veterans of America

Ditunno et al., 2003 Chen et al., 2016





Major Accomplishments of the SCIMS

- Research agenda has broadened from emphasis on acute care to include social determinants of health, physical and psychological functioning, and technology
 - Rapid expansion propelled by consumer involvement and advances in research methodology
- Clinical excellence of the SCIMS provided the foundation from which clinical research focusing on key issues about the health of persons with SCI grew dramatically in the last five decades
 - Development of new measurement tools to capture neurological, psychosocial, and emotional functioning

Ditunno et al., 2003 Chen et al., 2016





Major Accomplishments of the SCIMS

- National SCI Database—the largest and longest in the world
 - The SCI statistics have been widely used and referenced
 - Google search for "SCI statistics"—NSCISC website ranked first
- Produced specific life-expectancy estimates for court cases in the United States and also countries outside the United States, such as Canada, Australia, England, Scotland, Northern Ireland, Ireland, and Hong Kong









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