

Developing a Point of Access for SCI Research

In November 2011, the SC SCIRF fund awarded Roper Rehabilitation Hospital a three-year \$150,000 grant to develop a Point of Access to Spinal Cord Injury (SCI) Clinical Research.

Project Goals and Aims: The stated goals of the SCIRF11-005 funded project are 1.) to develop a research infrastructure within the Roper Rehabilitation Hospital Center for Spinal Cord Injury clinical setting and 2.) to utilize the infrastructure to enroll participants into a clinical research database that will interface with existing surveillance and database programs within the SCIRF and state SCI research community.

Aim1: Establish a long term, prospective, patient database to collect and store comprehensive clinical, laboratory, and psychosocial data from patients with SCI who come to the Center for Spinal Cord Injury.

Aim 2: Develop a well-characterized pool of persons with SCI who are interested in participating in future research on SCI, and who have consented to be contacted regarding research participation.

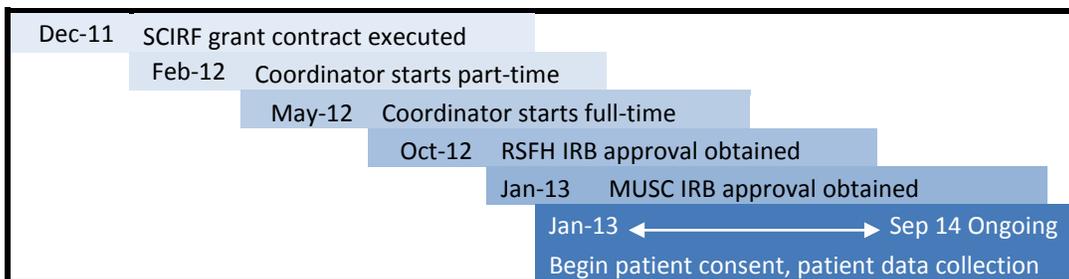
Primary Activities include hiring a project coordinator, creating an infrastructure, and establishing a patient-consented database of clinical, laboratory, and psychosocial data.

Report Overview: This project report provides an overview of outcomes data, project related milestones, completion status of stated objectives and activities and a narrative summary of project accomplishments to date.

Summary Patient Outcome Report as of 04/15/2014

Unduplicated Patients	Patient Consents	Consents Insured	Consents for Peers	Consents for Counselor	Deaths
76	56	32	74	37	1

Project Milestones



He who has health, has hope. And he who has hope, has everything.

--Ancient Proverb

Funding Health. Giving Hope.

Our Mission

As a community-based not-for-profit hospital system, Roper St. Francis is founded on the mission of *healing all people with compassion, faith and excellence.*

Our Vision

Roper St. Francis grant programs share a commitment to the system vision to *provide the best outcome for every patient, every time.*



Objectives Checklist and Timeframe for Completion:

Objective 1: Develop research capacity and infrastructure during initial 6 months of funding period	
Activity	Status
Hire and train Project Coordinator	Complete
Gain regulatory approval from Roper and MUSC IRBs for research database protocols	Complete
Collaborate with SCI researchers to identify priority information to be included in database	Complete
Create a CSCI research participant and patient outcome tracking database infrastructure	Complete
Develop a protocol for systematic data collection	Complete
Create capacity for implementing research protocols from collaborators	Ongoing

Objective 2: Implement the Center for Spinal Cord Injury database	
Activity	Status
Collect clinical, laboratory, and psychosocial data from CSCI patients	Ongoing
Monitor “benchmarks” of research “point of access” success (i.e. number of patients enrolled into database and recruited into other SCI studies, investigator satisfaction, etc.),	Ongoing
Systematically review data relevant to patient needs in order to tailor clinical services to meet priority needs effectively.	Ongoing

Patient Recruitment and Consent: Once IRB approval was obtained, nearly 100% of patients approached regarding database participation have consented to participate. A data collection form was developed, based on the nursing assessment form, to allow for easier collection and retrieval of SCI-specific clinical information from the medical record for inclusion in the database. Although clinic staff was involved in the development of the form, in practice, the form proved to be more complicated than anticipated and not feasible for patient and nurse to complete during the clinic visit. The form is currently under revision. In the interim targeted clinical data is located throughout the medical record and is being extracted and entered into the research database REDCap. Until the database contains sufficient numbers of persons to review patient needs and tailor clinical services to meet priority needs effectively, a patient satisfaction survey tool was implemented to collect data on perceived needs of the persons served. Currently, 56 patients have consented to database participation.

Patient Satisfaction Survey Methodology and Report: Patient satisfaction tools and needs assessment forms have changed five times since July 2011. The first tool was a team conference at the end of the clinic with each patient where patients shared what would be of help to them the most. A tool was sent to the home with narrative responses 2011 and 2012 with an 11% return rate in 2011 and 14% in 2012. In 2013 the survey was mailed with a stamped return envelope with a 30% return rate in 2013 and in the first two months of 2014. An online option for survey completion via Survey Monkey was added in January 2014 for those on e-mail.

Findings: Once a Likert scale was added to the survey 64% rated the Center as excellent; 33% rated it very good and one patient rated it good. Once peer mentoring and counselor services started, Likert scales were added for rating of the these services with 84% of patients rating the peer mentoring program as excellent and 75% of patients rating the counselor services as excellent.

Lessons Learned for Program Improvement Based on Surveys:

- Offering counselor services
- Offering speech therapy services
- Offering peer mentoring services
- Offering the therapy gym for workouts
- Offering the center services more frequently than monthly
- Offering needed equipment like shower chairs, ramps, wheelchair cushions for those that did not have insurance or resources to secure
- Providing neurosurgeons with brochures
- Offering a physiatrist with specialized training in SCI
- Offering a driving assessment program that includes on-the-road evaluation and training
- Offering vocational training
- Improving organization and wait times
- Improving long wait times to get into seating clinic at MUSC

Completed Patient-generated Action Items:

- Obtained 5 grants for patient equipment, supplies and ramps totaling \$162,500 excluding SCIRF funds
- Partnered with MUSC to offer a basic seating clinic to address basic needs while waiting on appointment at MUSC clinic or avert need for another clinic visit entirely
- Partnered with Carolinas Employee Assistance Program to secure counseling services during the center's operation
- Obtained peer mentoring training grant establishing a structured peer mentoring program
- Added the following services to the program- physiatrist certified in SCI, counselor, formal peer mentoring program, speech therapist as needed, driving assessment program
- Delivered brochures to local neurosurgeon offices and invited physicians to the center to observe
- Rearranged center operations several times to improve efficiencies and decrease wait times
- Built 29 ramps in 20 cities at no expense to patients allowing some patients freedom to leave their home after years of confinement

Items in Development:

- Establishing appointment with vocational rehab
- Requesting additional grant funds to open center one more day per month
- Continuing fund-raising to provide full endowment to cover the center operations for second day per month
- Establishing protocol for research in use of exoskeleton
- Offering a family/ caregiver support meeting during clinic

Project Milestones	
Jul-11	Begin endowment program to sustain program
Jul-11	First Clinic Day
Jul-11	Receive Yaschik grant for \$5000 for patient supplies
Nov-11	Receive Wells Fargo \$50,000 grant to operate center
Nov-11	Receive Neilsen \$45,000 grant to build ramps, purchase pressure mapping system
Dec-11	Receive SCIRF \$150,000 grant to hire coordinator, build infrastructure, begin database collection
Dec-11	Receive SC Association of Neurological Surgeons \$10,000 grant for operations, patient supplies
Feb-12	Coordinator starts part-time
May-12	Coordinator starts full-time
Jun-12	Receive Yaschik grant for \$5000 for patient supplies
Oct-12	RSFH IRB approval obtained
Nov-12	Begin caregiver mentor services
Jan-13	MUSC IRB approval obtained
Jan-13	Receive Neilsen grant for \$32,500 for peer mentoring program development
Jan-13	Begin obtaining consents and entering patient information into RedCap
Mar-13	Peer mentoring program development begins
Mar-13	Recreational therapist added to the program
May-13	Counselor services offered at the clinic
Jul-13	Receive SCIRF grant for \$300,000 to recruit SCI physiatrist and purchase exoskeleton
Jul-13	Formal peer mentoring training offered by Inger Ljungberg, MPH from National Rehabilitation
Jul-13	Dr. Jeffrey Tubbs begins as fellowship-trained SCI physiatrist
Aug-13	Four peer mentors begin seeing 100 patients over the next 6 months
Sep-13	Receive \$10,000 grant from Bon Secours for driving program and ramps
Aug-13	Peer mentoring database initiated
Jan-14	Purchase exoskeleton and begin training of clinicians
Mar-14	Driving program begins