

Grant 12-004

PI: Diane Epperly

**Title: South Carolina Spinal Cord Injury Association
(SCSCIA) Cooperative Agreement**

Year Three: Progress from November 1, 2014 through April 29, 2015

Goals and Objectives

Goal 1: Create a greater awareness of spinal cord injury research to individuals with spinal cord injuries in South Carolina and the professionals who work with them.

Year Three, Objective 1.1: Keep abreast of SCIRF-funded studies recruiting participants and communicate to individual and professional members of SCSCIA through a range of communication tools and existing training venues.

January 2015: The following study was posted on the SCSCIA website: *Community-based Virtual Reality Group Exercise Training in Persons With SCI* being conducted by Jennifer Trilk, Ph.D. (SCIRF 2014 1-01) (University of South Carolina School of Medicine Greenville in partnership with Roger C. Peace Rehabilitation Hospital, Greenville).

February 2015: The following study was posted on the SCSCIA website and on the association's Facebook page: *Measuring Outcomes after Spinal Cord Injury throughout South Carolina: A System of Tracking, Research, and Referral*, (SCIRF #09-001) being conducted by Lee Saunders.

Year Three, Objective 1.2: Provide updates at least twice annually to individuals who have registered their interest in research participation with SCSCIA.

February 2015: A mass mailing was sent out to 1,093 members of the South Carolina Spinal Cord Injury Association with spinal cord injuries about participating in a survey for the study *Measuring Outcomes after Spinal Cord Injury throughout South Carolina: A System of Tracking, Research, and Referral*, (SCIRF #09-001) being conducted by Lee Saunders.

Contact information on 62 people was turned over to Lee Saunders as a result of the mailing. These 62 people also registered their interest in research participation and were added to SCSCIA's research database. SCSCIA's database now contains names of 92 people with spinal cord injuries.

Note: Updates are also sent about relevant non-SCIRF funded studies in order to maintain ongoing communication and interest about research opportunities. Updates are targeted to individuals based on geography and requirements of studies that require on-site participation.

April 2015: A mailing was sent about the study *Community-based Virtual Reality Group Exercise Training in Persons With SCI* being conducted by Jennifer Trilk, Ph.D. (SCIRF 2014 1-01) (University of South Carolina School of Medicine Greenville in partnership with Roger C. Peace Rehabilitation Hospital, Greenville) to nine people with spinal cord injuries registered with SCSCIA from the Greenville/Spartanburg area.

April 2015: A mailing was sent out on a study about the benefits of nutrition education in people with spinal cord injuries. The study is being conducted at Carolinas Rehabilitation Hospital in Charlotte, North Carolina. The mailing was sent to six people with spinal cord injuries in York County registered with SCSCIA.

Year Three, Objective 1.3: Actively seek out and promote other spinal cord injury research studies in South Carolina and other states that present viable participation options for South Carolinians with spinal cord injuries.

The following studies have been promoted through the SCSCIA website, Facebook, Twitter and email distribution lists:

January 2015: The Assistive Robotics and Technology Lab at the University of South Carolina: A research study on attitudes and acceptance of tele-wellness technology by persons with limited mobility and how tele-technology (such as Skype) can be beneficial.

February 2015: The Miami Project: A research study entitled *Clinically Meaningful Changes in Wheelchair Propulsion Stress*. Since the study only requires two onsite visits in Miami, it was presented as an opportunity should people be traveling to Miami.

March 2015: The National Dialogue on Family Support: A research survey for people with disabilities and their caregivers on issues and concerns associated with care giving.

April 2015: University of Massachusetts Medical School, Worcester, MA: Online survey research project on health experiences of mothers with physical or mobility disabilities before, during and after pregnancy.

April 2015: Miami Project: A web-based study on day-to-day experiences of individuals living with spinal cord injury and chronic pain.

May 2015: Carolinas Rehabilitation Hospital, Charlotte, North Carolina: A study on the benefits of nutrition education in people with spinal cord injuries.

May 2015: Master of Occupational Therapy student at Worcester State University, Worcester, Massachusetts: A survey study on how occupational performance is impacted by sleep quality in individuals with a spinal cord injury, with and without varying levels of pain.

May 2015: University of South Carolina School of Medicine Greenville in partnership with Roger C. Peace Rehabilitation Hospital, Greenville: A study on the effects of hand cycling exercise on overall fitness, heart health and quality of life.

May 2015: Department of Kinesiology, Sport Studies, and Physical Education, College at Brockport, State University of New York: An online survey study to determine the accessibility of accommodation facilities with the life experiences of people with disabilities.

Year Three, Objective 1.4: Collaborate with Catherine Graham to identify other means to increase the visibility of the South Carolina Spinal Cord Injury Research Fund and knowledge about spinal cord injury research in South Carolina.

November 2014: Information on the webcast *Healthcare Access and Utilization After Spinal Cord Injury* with Dr. Lee Saunders was disseminated by posting in SCSCIA website, emailing to mass distribution lists, and posting on Facebook and Twitter.

December 2014: Catherine Graham provided information on *Community-based Virtual Reality Group Exercise Training in Persons With SCI* (Jennifer Trilk, Ph.D., SCIRF # 2014 I-01). See work on objectives 1.1 and 1.2 which was distributed to the email list.

January 2015: A progress report on the Interdisciplinary Spinal Cord Injury Center (SCIRF #1105) was posted on the SCSCIA website, disseminated to members with spinal cord injuries and professional members through email distribution lists, posted on association's Facebook page and tweeted on Twitter.

February 2015: Catherine Graham provided information on *Measuring Outcomes after Spinal Cord Injury throughout South Carolina: A System of Tracking, Research, and Referral*, (SCIRF #09-001) being conducted by Lee Saunders (See work on objective 1.2).

Goal 2: Extend the reach of the South Carolina Spinal Cord Injury Association through expansion of the established Breeze group network (Midlands, Orangeburg, Spartanburg, Charleston, and Rock Hill) into unserved cities.

Year Three, Objective 2.1: Work one-on-one with leadership in Greenwood and Greenville to provide the ongoing support, resources and feedback necessary to build a foundation for brand new groups.

Attendance is low at Greenwood meetings (highest attendance has been eight). Continue to encourage the leader, who is committed to giving the group a year to build membership. Greenville group is thriving under the leadership of two Roger C. Peace therapists. January attendance was as high as 40 people, with only a minority of group members being hospital inpatients. Greenwood and

Greenville leaders attended all-day Breeze leader team-building event on May 1 at Riverbanks Zoo. The goal of the event was to build working relationships between group leaders, particularly for new leaders, to give each other support and share ideas.

Greenwood Group Meetings:

November 24, 2014

Meeting at Expo 300 Bowling Alley

Seven attended

Activity: The group had a bowling night.

December

No meeting was held because of Christmas holiday.

January 26, 2015

No members attended.

February 23, 2015

Three attended.

Topic: HASCI Waiver

March 23, 2015

Activity: card game night

Eight attended.

April 27, 2015

Eight attended.

Topic: Community work incentives

Greenville Group Meetings:

November 20, 2014

31 attended.

Topic: Nutrition

Speaker: Crystal Robinson, Clinical Nutrition Specialist, Greenville Hospital System

December 18, 2014

34 attended

Activity: group Christmas party

January 15, 2015

40 people attended.

Topic: Community-based Virtual Reality Group Exercise Training in Persons With SCI (SCIRF Grant #2014 I-01)

Speaker: Jennifer Trilk

February

Did not meet due to inclement weather.

March 19, 2015

26 people attended.

Topic: Community work incentives

April 16, 2015

Topic: Coloplast catheters and ROAR (Rediscovering Outdoor Activities and Recreation)

Sixteen attended.

Year Three, Objective 2.2: Provide the leadership in Colleton County and Hampton/Allendale/Fairfax Counties with the tools needed to start two groups to serve these communities.

The individual who volunteered to establish a Hampton/Allendale/Fairfax Counties group decided that he had too many other commitments to take this on. Because of the rural nature of this area and the inherent challenges that come with that, the association will not pursue a new group in this area at this time.

The Colleton County group has held its first four meetings. The highest attendance was eight; the lowest was zero. The leader was not able to attend the May 1 team-building event.

Colleton Meetings**January 22, 2015**

Eight attended.

Meet-and-greet

Speaker: Angela Jacildone

Topic: Services of SC Spinal Cord Injury Association

February 26, 2015

Five attended.

Activity: Group discussion on family relationships after spinal cord injury.

March 26, 2015

No members attended.

April 23, 2015

No members attended.

A new group has formed in Horry County. The leader received one-on-one training by phone in January. After three meetings with no turnout, an on-site visit was made to the leader and her mother, who is helping with the group. Ideas for compelling topics were brainstormed and a more extensive list of topic ideas was sent as a follow-up. The leader is looking at putting out a schedule of meeting topics for the next few months. She and both her parents made good connections with other leaders at the May 1 event.

Horry Meetings

April 1, 2015

Two attended.

Activity: Group discussion on how to generate interest in the group.

Goal 3: Strengthen the impact of the association's one-on-one peer visitor program.

Year Three, Objective 3.1: Incorporate personalized peer visitor stories highlighting the availability of trained peer visitors in each of the following venues: Outspoken newsletter, website, Facebook, twitter, new Vocational Rehabilitation training program that will be developed, and in-service presentations.

The following peer visitor promotion was done:

February 2015

Posted about availability of peer visitors on Spinal Cord Injury USA Facebook page.

March 2015

Posted peer visitor story featuring the perspectives of Sherwood Toatley and Dot Colson on SCSCIA website, Facebook and Twitter.

April 2015

Alex Jackson, a member of the Trident group, shared his experience as a peer visitor in his Tuesday Talk With Alex blog:

(<https://tuesdaytalkwithalex.wordpress.com>)

Also directed users to his blog through Facebook and Twitter posts.

April 2015

Article about Jessica Heinz receiving peer visit was posted on SCSCIA website, Facebook page, and Twitter, and sent out via email distribution lists.

Year Three, Objective 3.2: Better equip peer visitors to serve as research "ambassadors" during their visits and monitoring how many individuals register their research interest with SCSCIA after peer visits.

A research component will be included in the annual peer visitor training to be held in the fall.

Of the seven peer visits made between November 1, 2014 and April 30, 2015, none of these individuals has registered their research interest with SCSCIA.

Year Three, Objective 3.3: Increase the number of annual peer visits from 23 in FY 2014 by 30 percent to 30 visits.

The number of peer visits for the first half of the grant period is well below the anticipated amount by this point. This is despite the concerted effort the association has been making to disseminate articles about the peer visitor program, promoting the program at all in-services and offering visits, as appropriate, when people call the offer for other assistance.

| | |
|-------------------|--|
| November 20, 2014 | Visit in West Columbia resident |
| January 15, 2015 | Visit to Greer resident |
| January 16, 2015 | Visit to West Columbia resident |
| January 24, 2015 | Visit to individual in North Charleston nursing home |
| March 17, 2015 | Visit to Florence resident |
| April 20, 2015 | Visit to Union resident |
| April 28, 2015 | Visit to Lexington resident |

Goal 4: Continue to offer spinal cord injury prevention education in the Midlands through the national ThinkFirst injury prevention program.

Year Three, Objective 4.1: Incorporate speakers and health educators with spinal cord injuries to conduct presentations in public and private schools.

SCSCIA currently utilizes seven individuals with spinal cord injuries as VIP speakers (Voices for Injury Prevention) and four individuals with spinal cord injuries as health educators.

Year Three, Objective 4.2: Schedule a total of 40 presentations in middle and elementary schools for an estimated 880 students.

A total of 18 presentations were completed between November 1, 2014 and April 30, 2015 that reached 447 students. The presentations were done in schools in Richland and Lexington County.