

Abstract

The South Carolina Spinal Cord Injury Association (SCSCIA) is a 501C (3) non-profit organization affiliated with the National Spinal Cord Injury Association. We are the only statewide organization specifically for people with spinal cord injury (SCI). With a state headquarters in Columbia, SCSCIA is developing a statewide SCI peer support network. It is assisting five local SCI support groups and helping others to develop networks. SCSCIA provides consumers/families with information and assistance through its resource library, web site, toll-free telephone access, and periodic newsletters. SCSCIA conducts special outreach efforts to the assist newly injured persons. The organization is also involved in systems advocacy activities to improve the quality of life for all with SCI. We held the Statewide Conference for People with Spinal Cord Injury during May 2003 which was attended by 160 people. Thirty exhibits of durable medical equipment, supplies, professional organizations and researchers presented existing and future treatment for the SCI. Presently we are providing secondary prevention workshops in Columbia, Charleston, Florence and Greenville, SC for spinal cord injured individuals and their families. We are sponsoring state legislation (H-4652) to change present handicapped parking laws to obtain better enforcement and definition of eligibility.

Kermit L. Short the Principal Investigator is a spinal cord injured quadriplegic and is the Executive Director of the Spinal Cord Injury Association. He obtained his BS Degree in Business Administration from Wright State University and his Masters of Hospital and Health Administration from the University of Alabama in Birmingham. He will be the primary person responsible for managing the 2005 Statewide Conference.

We propose a one-year project with two distinct initiatives. The **first initiative** will be to collaborate with the South Carolina Spinal Cord Injury Research Fund (SCSCIRF) and Southeastern Paralyzed Veterans Association in sponsoring and conducting a statewide conference for people with spinal cord injury and their families on May 12, 2005. The conference will feature presentations by both state and national experts who practice and teach state-of-the-art treatment and research which enable people with SCI an opportunity to improve their quality of life. The conference will provide education related to the following areas **1)** Status reports of both national and SCSCIRF-funded research related to cure and improved functional ability after SCI. **2)** best practices for wheelchair selection and seating support surfaces, **3)** Family and individual advocacy for resources, and **4)** current practices in rehabilitation medicine that benefit the person with SCI.

The conference exhibits will include a variety of commercial vendors, professional organizations and public agency representatives. The purpose of the exhibits is to provide attendees with practical, updated information about products and services that may improve their quality of life.

SCSCIA will coordinate with the USC School of Medicine's Center for Disability Resources to evaluate the effectiveness of the conference; Participant satisfaction as well as effectiveness of the presentation will be measured.

The **second initiative** is aimed at bridging the gap created by the lack of organized rehabilitation for persons with SCI in South Carolina. It proposes to provide education and advocacy directly (via consumer education) and indirectly (by educating health care providers) to help prevent common secondary medical conditions frequently experienced after spinal cord injury. These conditions include pressure ulcers, urinary tract infections, pneumonia, thromboembolism and sepsis. This initiative would commence August 1, 2004. Beth H. Bradley, RN MN, CWOCN is a nurse employed by the South Carolina Spinal Cord Injury Association as a SCI Nurse Educator. She will be the Primary Educator for this initiative. She has collaborated with the patient education department at the Shepherd Spinal Center in Atlanta, Georgia to develop the course curriculum. She is a Masters prepared nurse with additional certification in wound, ostomy, and continence. Not only does she have clinical expertise in the hospital and homecare areas, but she also provides continuing education workshops in her specialty in cities throughout the US. She is a member of the national Wound Ostomy, and Continence Nursing Certification Board.

This second initiative will consist of two major activities:

- 1) Develop and distribute education packets appropriate for SCI patients in acute care trauma centers. We will distribute these packets along with inservice education to case managers and discharge planners in trauma centers that provide care to patients after their injury. Not only will the packets provide important health information to newly injured patients, but it will also provide information about advocacy and peer support that we offer. We hope to be able to put patients and families in contact with local peers soon after injury through this effort. We also have the potential for improving the database of people with SCI.
- 2) Develop an in-service education program for nurses and physical therapists in home care agencies. Reproducible patient education materials and education videos would be made available to this group of caregivers who most often see the SCI patient after discharge from an acute care facility. By increasing the home care clinicians' level of knowledge we may prevent many secondary medical conditions that occur in the first year after injury. We will also provide information regarding available community and internet educational resources to improve quality of care for people with SCI. Educational information will be placed on our web site www.scscia.org.