

1005B

Final Report

This report details the outcomes of all major objectives established in the Contract Proposal submitted by the South Carolina Spinal Cord Injury Association (SCSCIA) to the South Carolina Spinal Cord Injury Research Fund. Upon notification of the contract award, staff of the Spinal Cord Injury Association began working to establish working plans and procedures to accomplish stated tasks and activities required to achieve those objectives set forth in the contract proposal.

In order to clearly show the progress and accomplishments made toward achieving these objectives this report will be organized in the following manner.

- 1) Each major objective, along with required tasks and activities to accomplish this objective, will be outlined.
- 2) A separate "Outcomes" section will follow that specifies progress toward, and achievement of, all objectives.

OBJECTIVE ONE

To re-activate, update and upgrade the SCSCIA website to allow for direct links to all relevant research and direct service programs, with a particular emphasis on the activities of the S.C. Spinal Cord Injury Research Fund, and to serve as a central communication point for persons with spinal cord injury and their families or caregivers.

Required tasks and Activities

1. To implement the technical aspects required to re-activate and upgrade the existing site and add new features including direct links to relevant organizations; an interactive message board to allow persons with spinal cord injuries to communicate directly their needs for services or information, or to ask or respond to questions from other injured persons or professionals; staff e-mail links for expedited communication; a statewide events calendar to publicize events of interest to persons with spinal cord injuries; and the ability to register persons on a database of injured persons.
2. To professionally assess the functioning and update the website on a quarterly basis.
3. To train staff at SCSCIA to be able to add to the website on an interim basis.

To collaborate with staff of the Spinal Cord Injury Fund to establish a prominent link with their website and to include links to other jointly identified research programs whose findings and activities are relevant to persons with spinal cord injury

OBJECTIVE ONE OUTCOMES

Initial planning for updating and re-launching the SCSCIA website were conducted with CCS Development Group which specialized in internet development and marketing. Issues examined included: (1) technical capacities required to re-activate and upgrade the accessibility and appearance of the current website; (2) the ability to establish an interactive message board feature that would allow persons to post and respond to messages, announcements, and questions related to their specific service, care or equipment needs; (3) the method for including the full text of the quarterly newsletter onto the website; (4) determine the requirements to allow for increased linkages to other related Internet sites or resources relevant to those affected by spinal cord injury; and (5) use of the website to increase the visibility of the organization and its services. In addition, it was decided to include an interactive "Discussion Forum" that would allow persons to post questions or information on the website that could be answered or distributed in a timely fashion.

After initial planning SCSCIA was notified that, due to organizational re-structuring, CCS Development Group would have to withdraw from the project. SCSCIA subsequently took these plans and contracted with Mr. Bradley J. Matney to provide website, multimedia and training services to the organization. Activities undertaken in support of this objective have resulted in the following outcomes.

1. The SCSCIA website has been fully updated, with a new format and is now fully functioning.
2. The website prominently features a direct link to the Spinal Cord Injury Research Fund website as well as information to allow injured persons to participate directly in current research activities.
3. The SCSCIA website now features an interactive "Discussion Forum" that allows users to post questions for staff, or other persons with injuries, that can be answered in a timely manner. This forum is regularly monitored by SCSCIA staff to insure that all inquiries receive prompt attention and any required referrals for services or information are made.
4. The SCSCIA website is capable of tracking the number of persons who utilize featured information or links.
5. Individuals can use the website to register as a member of SCSCIA or to place their names on the organizational mailing list.
6. A statewide events calendar, linked to the SCSCIA newsletter is now available to highlight opportunities for educational resources or service access.

7. E-mail addresses for all SCSCIA staff are clearly listed to allow direct access for information, referral, or available services.
8. The SCSCIA website is being regularly updated to include new information or links to related organizations.
9. SCSCIA staff are being trained to do in-house modifications of the website to insure that information is added on a timely basis.

OBJECTIVE TWO

To upgrade the format of the SCSCIA newsletter, develop internal capacity to produce content and layout, and re-establish a quarterly statewide mailing.

Required Tasks and Activities

1. To identify and contract with a professional experienced in newsletter design and layout to review the existing newsletter format, coordinate the masthead and image with the website format, produce specific layout templates for SCSCIA, newsletter preparation in 2006
2. To provide training to identified SCSCIA staff that will allow for in-house design and layout of the newsletter each quarter beginning in 2007
3. To link the newsletter electronically to the website allowing greater access than through mailings only
4. To actively work with the Spinal Cord Injury Research Fund to insure that all information and findings from research activities are included in the newsletter and distributed on a timely basis to those with injuries, their families or caregivers
5. To update and expand the SCSCIA mailing list by contacting those persons and organizations currently listed to ensure that all information is correct

OBJECTIVE TWO OUTCOMES

1. Staff at SCSCIA have worked to re-design the agency newsletter through evaluating various computer publishing programs, and consulting with persons with experience and expertise in multimedia applications. This effort has now resulted in a finalized design for the statewide newsletter which will begin distribution in the first quarter of 2007. Newsletters will be published and distributed on a quarterly basis. In support of this effort, UROMED - a national

provider of disposable medical products providing service to individuals with chronic conditions such as Multiple Sclerosis, Spinal Cord Injury, Transverse Myelitis, and Spina Bifida -has agreed to sponsor the newsletter by providing all printing services.

2. Staff of SCSCIA now have the capacity to develop layout, copy and graphics for the newsletter and link this directly to the agency website. As the first newsletter is finalized, staff at SCSCIA will contact staff at the Spinal Cord Injury Research Fund to gather any information for inclusion in each quarterly issue.
3. As part of the planning process for newsletter distribution SCSCIA has been updating the organization's mailing list by verifying names and addresses of individuals using in-house staff as well as community volunteers and peer group leaders. Also, as part of the website update, persons can register to receive the newsletter online.

OBJECTIVE THREE

To develop a working database of individuals with spinal cord injuries, their families and caregivers that allows for the identification of persons who would be willing to participate in research activities conducted by the South Carolina Spinal Cord Injury Research Fund. Outreach activities to build this database of individuals will include contact with persons currently on the SCSCIA mailing list, distribution of informational brochures, the ability to register for inclusion in the database on the upgraded website, through contact information regularly published in the newsletter, and through personal communication in community presentations including current and future members of local peer support groups now operated by SCSCIA. Controls will be established to maintain the confidentiality of person registering on the database.

Required Tasks and Activities

1. To identify the needed categories of information required to establish a working, confidential information database. These categories would include, but not be limited to, identifying information, place of residence, contact information, type of injury, service needs, willingness to participate in any research activities and other relevant data. Inclusion in the database will be strictly voluntary.
2. To work with staff of the Spinal Cord Injury Research Fund to distribute public information materials generated by the Research Fund to persons who might be willing to participate in research activities
3. To reprint the existing SCSCIA information brochure to include information on the relationship between SCSCIA and the Spinal Cord Injury Research Fund and

opportunities for persons to participate in research projects or activities

4. To utilize the SCSCIA mailing list, internet website and quarterly newsletter as vehicles to identify persons willing to participate in research projects
5. To distribute information on a personal basis utilizing current and future participants in local peer support groups now established and managed by the SCSCIA
6. To expand the number of local peer support groups, and regularly invite staff or researchers of the Spinal Cord Injury Fund to meet with current and future groups to give personal updates of research findings and their relevance to those affected by spinal cord injury

OBJECTIVE THREE OUTCOMES

1. In preparation for the establishment of a database of persons willing to participate in research activities SCSCIA has developed a secure online sub-web to insure confidentiality of all individuals.
2. Calls for volunteers to participate in research activities will be included in each issue of the quarterly newsletter as well as in the SCSCIA membership form.
3. The SCSCIA website currently has a direct link to SCIRF as well as the "Oral Health Survey for People With Spinal Cord Injury" which is sponsored by MUSC.
4. Points of contact have been requested by SCSCIA to identify SCIRF staff or researchers willing to meet with local peer support groups.
5. SCSCIA has expanded their peer support groups throughout the state. In addition to existing groups in Charleston, Sumter, Florence, Chester and Spartanburg, new support groups have been formed in Greenville, Anderson/Pickens, Orangeburg, Horry County, and York/Rock Hill. A new group in Columbia is scheduled for start-up in Columbia in February. Staff from SCIRF will be regularly invited to make presentations to these groups to present current research activities and identify persons willing to participate in research projects or activities.

OBJECTIVE FOUR

To acquire the services of an independent evaluator to assist in the design and management of instruments and data required to track project results and outcomes, and assist in the submission of quarterly reports to the Spinal Cord Injury Research Fund that include recommendations for future activities based on documented results.

Required Tasks and Activities

1. Contract with project evaluator for required services
2. The Project Evaluator will assist in the development of needed instruments for data collection to document project outcomes, including the database identifying persons with spinal cord injuries, their families and caregivers who would be willing to participate in research activities of the Spinal Cord injury Research Fund.
3. The Project Evaluator will assist the Executive Director of SCSCIA in the preparation of quarterly reports.
4. The Project Evaluator will meet regularly with program staff of SCSCIA and the Spinal Cord Injury Research Fund to insure that project goals and activities are being accomplished and that future planning is well coordinated and mutually beneficial.

OBJECTIVE FOUR OUTCOMES

1. SCSCIA contracted with Mr. Jules W. Riley to serve as the evaluation consultant for this project. Mr. Riley has an extensive history of project management and evaluation and has previously worked on several SCSCIA projects which gives him a unique insight into agency operations.
2. Mr. Riley participated in all initial planning activities for project start-up and worked with the former SCSCIA Executive Director to develop ongoing management plans to assure that project goals and objectives were met.
3. Following the hiring of Mr. Lee Carter as the new executive director of SCSCIA Mr. Riley has been meeting regularly with him and agency staff to review all project objectives and insure that all stated tasks have been addressed and/or completed.
4. Mr. Riley is currently meeting regularly with SCSCIA staff to fully incorporate project activities and initiatives into future agency strategic planning. Specific plans are now being formulated for the preparation of a second contract proposal to be presented to SCIRF. A meeting with key SCIRF staff is being planned for early February to discuss future planning to insure that activities are mutually supportive and continue to positively build on the working relationship between SCIRF and SCSCIA.