

GENERAL ASSEMBLY REQUEST

INTRODUCTION

STATEWIDE SICKLE CELL CHAPTERS OF VIRGINIA, INC. (SSCCV)

History

Representatives of five sickle cell chapters from Danville, Fredericksburg, Hampton, Norfolk and Richmond met in the spring of 1977 to discuss plans for a joint statewide conference.

During this meeting the initial plans were made for the first conference on September 22-23, 1978 in Norfolk. Since that time other conferences were held **by the original statewide chapters** in Fredericksburg, Danville, Hampton, Norfolk and Richmond.

It was determined after the continued success of annual conferences that the chapters should incorporate into a statewide organization for a greater impact as a collective body on political, economic and service delivery systems.

Since the incorporation of the original five chapters, chapters in Lynchburg, South Boston and Rocky Mount have been added **and conferences have been held by Lynchburg and Rocky Mount.**

Mission Statement

To educate the public, implement service programs, encourage support for research and empower persons who live with Sickle Cell Disease and advocate on their behalf.

Purpose

The purpose of this organization is to provide leadership with health professionals and the general public to develop a health policy and plan of action regarding the impact of sickle cell disease.

"Striving to improve the quality of life."

Goals

- * Organize, sponsor and participate in statewide educational conferences to be hosted by rotating among member chapters.
- * Develop and promote the implementation of service programs' standards that will be in the best interest of the affected population.
- * Develop positions and promote favorable resolution of issues and activities that could have an adverse effect on sickle cell programs or the affected population.
- * Develop and distribute educational materials, written and visual, about the sickle cell problem for all segments of our society.
- * Assist in the organization and development of other chapters in the state.
- * Provide on-going technical assistance to active member chapters and other interested groups and organizations.
- * Encourage adequate support for research activities leading to improving treatment and eventual cure.
- * **To encourage patients to share experiences about what works for each individual in terms of diet, medication, pain management, pain partners, stress management and the psycho-social aspects of having SC Diseases to gain feelings of empowerment and to dispel the Sickle Cell Myths.**

Statewide Sickle Cell Chapters of Virginia, Incorporated is a non-profit tax-exempt community-based organization, hereafter **known as Statewide or SSCCV.**

THE PROBLEM

Sickle cell anemia is a chronic anemia and **incurable** disease of the blood that is inherited. This disease is produced when the sickle cell gene is transmitted by both parents to a child. The red blood cells of a person born with sickle cell disease have a tendency to change from their normal round shape to a "quarter-moon" or sickle-like shape. Sickled cells cannot squeeze through tiny blood vessels so they often jam up, blocking the flow of blood and oxygen to body parts and causing extreme pain. A pain crisis can last for hours, days or even weeks and may occur several times a year.

Today, approximately 1 in 375 African American children is born with a serious sickle cell disorder, making it the most common long term illness identified in this population. Between 70,000 and 80,000 people in the USA suffer with Sickle Cell Disease of which over 3,000 are in Virginia. Over 2,000,000 people in the USA have Sickle Cell Trait and approximately 115,000 are in Virginia. Unfortunately, these figures do not include the expanding Hispanic and Middle Eastern populations because their data is not readily available. The areas that two of our chapters operate within have increasing numbers in both of these populations.

DALLAS, Sept. 27 /PRNewswire/ -- "Sickle Cell Disease is one of the most prevalent and costly genetic disorders in the U.S. Today, **one in every 4,000 Americans is born with a form of SCD and many experience chronic anemia, stroke, spleen and kidney dysfunction, pain crises, and susceptibility to bacterial infections. Moreover, the National Institutes of Health (NIH) estimates that almost one-third of adults with SCD develop pulmonary hypertension, a life-threatening condition resulting in a 10-fold greater risk of death.**"

"Due to this high disease burden, the Sickle Cell Disease Association of America (SCDAA) reports that Sickle Cell Disease in which abnormal hemoglobin causes red blood cells to become stiff, sickle- shaped and unable to flow easily through blood vessels -- **results in an estimated 750,000 hospitalizations a year. The cost of these hospitalizations is estimated at \$475 million annually.**"

THE RESOLUTIONS

FAMILY ASSISTANCE - Family Expenses

Because of the high volume of hospitalizations for persons with sickle cell disease, they and their families incur expenses that often go beyond the hospital stay. Families incur medication expense, numerous insurance deductibles and lost of wages because a parent needs to stay out of work to care for the child at home or be with them in the hospital. When a family loses wages, they wind up behind on regular household payments such as rent, utilities, telephone and food.

All eight (8) chapters of the statewide organization help families with expenses where possible, but our resources are limited. Of the eight (8) chapters, six (6) are volunteer organizations and dependant on donations. With greater funding, we would be able to assist families in a larger and more meaningful way.

PATIENT CONSULTANT SERVICES

SSCCV has already identified several vendors that are able to deliver services to our clients/patients that would improve their ability to cope with their disease and improve their quality of life. The services include stress management, self-esteem and breathing techniques and strategies in the management of chronic pain.

FAMILY ASSISTANCE – Tutorial Assistance

Many SCD clients miss so much time from school that they fall behind in their classes. We would like to employ persons to serve as teachers or tutors to help the clients to keep up with their studies. Community and church already have tutorial programs but these programs require a child to come to them. SCD clients often are too sick or weak to go to them and need someone to come to them in the hospital or home. Although there already is a requirement for homebound instruction, we feel that having persons who are more knowledgeable and understanding of the SDC client creates a better learning environment.

PRINTING OF EDUCATIONAL LITERATURE

SSCCV would like to continue to print literature about Sickle Cell Disease in an effort to better educate the public. We have only been able to distribute a limited amount of literature at health fairs and educational meetings. SSCCV has a small supply of two forms of literature. Usually, one or the other form is distributed, depending on the audience. There is so much more information we could pass on to the public if we had the resources.

OFFICE SUPPLIES – Stationary, Envelops and Stamps

SSCCV would like to take distribution of our educational materials to another level. With the office supplies (stationary, envelops and stamps), we would like to do mass mailings of our literature.

STATE OFFICE – Computers (2) & Software Web Page Design, Rent & Utilities and Staff Person

The Board of Directors of SSCCV determined that too much needed to be done to continue with only quarterly regular meetings, long distance phone calls and e-mails in between and no staff. The board further determined that with more and more couples of mixed races, that the need for greater effectiveness and regularity was a must. After reviewing our history, accomplishments, unfinished efforts and the declining role of some operations in the sickle cell field, the board concluded it must establish an office that would be open on a daily basis and have two full time staff persons to meet the needs of SCD clients in the State of Virginia. Richmond had already been our central meeting point for our quarterly meetings so the board decided to establish an office in Richmond which would also be closest to the State Health Department and VCU/MCV. The Board of Directors of SSCCV has taken the step of naming a volunteer to serve as Administrator for the organization until permanent staff can be hired. The main staff person would be an Executive Director who would have the responsibility of working with and for all eight chapters and serve as the principle SCD educator in the state. The second staff person is necessary to keep the office open and fully running while the Executive Director is meeting essential parties in and out of the offices. This staff needs a place to operate from, with the ability to meet the obligations of rent and utilities, computer equipment to work with and a web site clients and interested person could use to locate us.

CONCLUSION

Statewide Sickle Cell Chapters Of Virginia, Inc. (SSCCV) feels strongly that we must establish a physical presence on a daily basis with a central full time effort to help SCD clients. However, our resources are limited to the dues that eight (8) chapters pay (\$150.00 each per year) and small fund raising dollars. SSCCV needs the assistance of the Virginia General Assembly to help fund these needs. Once all aspects are in place, we will be in the position to devote time to grant writing to obtain more funding from other sources to meet the continued needs of the sickle cell community. The grant writing efforts will not materialize over night. As such, we are asking for funds over a four (4) year period, in declining amounts each year, to insure the organizational stability. The following presents our dollar and category requests. SSCCV hopes that you will support our request.

REQUEST FOR COMMUNITY BASED FUNDING FOR SICKLE CELL DISEASE

		<u>1st Year</u>	<u>2nd Year</u>
a.	Patient Assistance		
	1. Family Expenses	\$100,000.00	\$100,000.00
	2. Patient Consultant Services	\$190,000.00	\$190,000.00
	3. Tutorial Assistance	\$ 5,000.00	\$ 5,000.00
b.	Printing of Educational Literature	\$ 4,000.00	\$ 4,000.00
c.	Office Supplies		
	1. Stationary	\$ 3,000.00	\$ 2,000.00
	2. Envelops	\$ 3,000.00	\$ 2,000.00
	3. Stamps	\$ 3,000.00	\$ 2,000.00
d.	State Office		
	1. Computers (4) & Software	\$ 7,000.00	\$ 0.00
	2. Rent & Utilities	\$ 25,000.00	\$ 20,000.00
	3. Staff Person (4 Statewide)	<u>\$110,000.00</u>	<u>\$100,000.00</u>
		\$450,000.00	\$425,000.00