

STATEWIDE SICKLE CELL CHAPTERS OF VIRGINIA, INC.

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REPORT

Report to the House Appropriations and Senate Finance Committees of the Virginia General Assembly on Community-Based Sickle Cell Programs

September 30, 2013

What is Sickle Cell Disease?

Sickle Cell Disease is a chronic anemia and inherited blood disorder where normal round shaped red blood cells change from their normal round shape to a "quarter-moon" or sickle-like shape. This disease is produced when the sickle cell gene is transmitted by both parents to a child. Sickled shaped cells cannot squeeze through small 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 days or even weeks and may occur several times a year. Lack of oxygen flow can also damage muscles, bones and internal organs and lead to strokes and other serious medical problems.

Nationally, approximately 1 in 500 African American children is born with a serious sickle cell disorder, making it the most common long term illness identified in this population. However, in Virginia, approximately 1 in 325 African Americans suffer with Sickle Cell Disease and 1 in every 1100 to 1400 Hispanics, far higher than the national average. Up to 100,000 people in the USA suffer with Sickle Cell Disease of which around 4,000 are in Virginia. Over 2,000,000 people in the USA have Sickle Cell Trait and approximately 155,000 are in Virginia.

DALLAS, Sept. 27, 2006 /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.**"

Background

The Commissioner of Health has the responsibility for sickle cell screening and treatment under the Code of Virginia. Screening of all newborns for sickle cell disease began in Virginia during July of 1989. At the beginning of the program, centers for comprehensive follow-up care were not available. In 1994, Virginia began providing statewide comprehensive sickle cell services to decrease the morbidity and mortality among children.

The June 30, 2011 report to the House Appropriations and Senate Finance Committees of the Virginia General Assembly on Community-Based Sickle Cell Programs submitted by the Virginia Department of Health made the following statements. **“The provision of comprehensive care is a time-intensive endeavor that includes ongoing patient and family education, periodic comprehensive evaluations and other disease-specific health maintenance services, psychosocial care, genetic counseling, and transition services. However, research demonstrates that the medical management model alone cannot address the multiple social, psychological, and educational needs of individuals living with chronic illnesses such as sickle cell disease.”**

Community-based programs provide resources to support the development of coping strategies and support for families impacted by sickle cell disease by addressing unmet educational, social, and psychosocial needs. Statewide Sickle Cell Chapters of Virginia, Inc. (SSCCV), also known as Sickle Cell Chapters of Virginia or Statewide, a non-profit 501(c)(3) tax-exempt community-based organization, has a network of nine (9) community-based sickle cell disease organizations (chapters) that provide a variety of services across the Commonwealth. The chapters are located in Danville, Fredericksburg, Hampton, Lynchburg, Norfolk, Richmond, Rocky Mount, South Boston and Northern Virginia. Most of the chapters in this network have operated since 1972.

There are four comprehensive sickle cell centers under contract for services in the state. The centers are Children’s Hospital of the King’s Daughters in Norfolk, Virginia Commonwealth University Health System in Richmond, University of Virginia in Charlottesville and D. C. Children’s Medical Center in **Washington, D.C.** which replaced INOVA Hospital in Fairfax, Virginia. It should be noted that only Virginia Commonwealth University Health System provides clinical care for adult clients.

It is estimated that the State of Virginia has about 4,000 sickle cell clients/patients. The centers care for around 1,100 to 1,200 of them. The centers provide care and services to patients of the centers, but generally, do not provide services to non-patients of their hospitals. That means that the centers are only serving around 30% of this population. **This demonstrates the very need for a network of community-based programs to serve the 70% of clients who still need services.**

Those of us involved in community programs define community-based sickle cell programs as ones that work to assist any client needing services who is in the care of a private physician or any client receiving services from sickle cell centers who needs or wants additional service.

General Assembly Background

According to figures from the Virginia Department of Health, between 1995 and 2007 the number of sickle cell patients needing services increased by 136%. The 2007 General Assembly provided increased funding to \$450,000 a year for medical (hospital) management services for individuals living with sickle cell disease and a yearly allocation of \$100,000 from general funds was approved for grants to community-based programs that provide education and family-centered support for individuals suffering from sickle cell disease. The purpose of the community-based allocation was to assist individuals and families living with sickle cell disease to develop the necessary skills and resources to improve their health status, family functioning, and self-sufficiency.

Starting in FY09, annual appropriations were as follows:

- FY09 - \$95,000
- FY10 - \$81,000
- FY11 - \$90,000
- FY12 - \$90,000
- FY13 - \$88,200

Item 288Q of the 2010 Appropriation Act required the Virginia Department of Health (VDH) to develop criteria for distributing these funds, including specific goals and outcome measures and to submit an annual report detailing program outcomes to the House Appropriations and Senate Finance Committees of the Virginia General Assembly.

Item 288Q of the 2011 Appropriation Act required the Virginia Department of Health (VDH) to allocate its \$90,000 appropriation for community-based sickle cell programs by contract to Statewide Sickle Cell Chapters of Virginia (SSCCV). This funding is to be used for grants to community-based programs that provide patient assistance, education, and family-centered support for individuals suffering from sickle cell disease. Statewide (SSCCV) developed criteria for distributing these funds including specific goals and outcome measures.

During FY12 Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded five contracts to member chapters.

During FY13 Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded six contracts to the following member chapters.

Blue Ridge Area Sickle Cell Association (BRASCA)	Rocky Mount	\$ 4,511.00
Fredericksburg Area Sickle Cell Association (FASCA)	Fredericksburg	\$ 4,675.00
Sickle Cell Association of Central Virginia	Lynchburg	\$ 3,523.00
Sickle Cell Association of the Peninsula (SCAP)	Hampton	\$12,143.00
Sickle Cell Association of Richmond – OSCAR	Richmond	\$25,048.00
Sickle Cell Association (SCA)	Norfolk	\$30,100.00
Statewide Sickle Cell Chapters of Virginia (Advertisement, Materials, etc.)		<u>\$ 8,200.00</u>
Total		\$88,200.00

All six chapters receiving grant awards were required to conduct a “Survey of Needs” with as many of their registered clients as possible. This activity enables the chapters to determine who needs what services and how best the services can be delivered.

All chapters provide sickle cell education in the community through participation in health fairs or forums, church activities and various civic or health related events. Many of the community-based program activities provide a focus on mental and social well-being. Stress-reducing activities have a positive effect on physical well-being. During the course of the grant year, chapters try to provide whatever services they have available. These services vary from chapter to chapter based in part on funds and man-power available. Some of the services include support group meetings, calls to check on clients, visitations, information or referral assistance, job training, assistance with obtaining disability benefits, employment and vocational rehabilitation.

Community-Based Sickle Cell Program Activities as of June 30, 2013

The six aforementioned organizations were awarded funding to begin community-based services on July 1, 2012. The following information provides a summary of the community-based activities performed as of June 30, 2013. Monthly activity and financial reports are submitted by each chapter to the “Statewide Administrator” for review and approval and submitted to the Virginia Department of Health by the 15th of each month.

Blue Ridge Area Sickle Cell Association

The Rocky Mount chapter serves the cities of Martinsville, Roanoke, and Salem and the counties of Franklin, Henry and Roanoke.

Type of Assistance offered:

“Survey of Needs” Conducted

Number of Participants: 22

Home Visits To Clients

Number of Participants: 4

Hospital Visits To Clients

Number of Participants: 3

Financial Assistance to Clients

Number of Recipients: 2

Type of Educational Program offered:

Health Fairs/Festivals (2)

Number of Attendees: 600

Distributed Sickle Cell Literature (4)

Number of Pieces: 330

Type of Support Group offered:

Client Support Group (All Clients)

Average Number of Participants: 4

Telephone Conversations/ E-mails

Number: 190

Other Activities:

Birthday Cards to Clients

Number Sent: 14

"Thinking of You" cards to clients so they will know that we care.

Number Sent: 21

Newsletters Distributed

Number Sent: 64

Forwarded e-mail of newsletter from "Sickle Cell Info" in Atlanta, GA. to expand knowledge

Number Sent per Month: 40

Monthly Meeting (open to clients)

Average Number of Participants: 10

Partnered with the Virginia Blood Services to collect blood

Number of Participants: 17

Hosted 30 minute radio program to increase awareness about Sickle Cell and Sickle Cell Month (September) covering Franklin, Henry and Roanoke Counties

Number of Participants: 2

Narrative/Other Information:

The chapter contacted a number of churches to increase awareness about Sickle Cell and educate more people.

Fredericksburg Area Sickle Cell Association

The Fredericksburg chapter serves the city of Fredericksburg and the counties of Caroline, King George, Spotsylvania, and Stafford.

Type of Assistance offered:

“Survey of Needs” Conducted

Number of Participants: 23

Assistance to Family of Deceased Client

Number of Participants: 1

Transportation

Number of Participants: 4

Housing Assistance

Number of Participants: 2

Type of Educational Program offered:

Health Fairs (4)

Number of Attendees: 1282

Presentations (12)

Number of Attendees: 219

Type of Support Group offered:

Heart To Heart Client Support Group (9)

Total Number of Participants: 33

Other Activities:

Birthday Cards to Clients

Number Sent: 7

"Thinking of You" cards to clients so they will know that we care.

Number Sent: 9

Forwarded e-mail of newsletter from "Sickle Cell Info" in Atlanta, GA. to expand knowledge

Number Sent Per Month: 52

Cards to Persons in Hospitals

Number: 6

Post Cards to Community

Number: 204

40 Year Anniversary of Organization

Number of Participants: 160

Family and Friends Event

Number of Participants: 86

Zumbathon

Number of Participants: 63

Walk-A-Thon

Number of Participants: 284

Planning Meetings (6)

Number of Participants: 46

Narrative/Other Information:

For the month of November, FASCA participated in a local community health fair. The chapter held the annual Family and Friends fellowship honoring FASCA members, community organizations, Sickle Cell clients and other individuals who have contributed their time to our organization throughout the year. The speaker for this occasion was the author, Judy Johnson, who wrote an autobiographical novel called Living with Sickle Cell Disease-The Struggle to Survive. She gave excerpts and information based on her struggles with the disease.

Sickle Cell Association of the Peninsula

The Hampton chapter serves the cities of Hampton, Newport News, Poquoson, Williamsburg and Yorktown.

Type of Assistance offered:

“Survey of Needs” Conducted

Number of Participants: 106

Counseling Services

Number of Participants: 67

Home Visits

Number of Participants: 69

Assisted with Antioch Baptist Church AIM Center Feeding, Clothing and Grocery Programs

Total Number of Participants: 2385 **Average Number of Participants:** 398 per month

Type of Educational Program offered:

Health Fairs (11)

Number of Attendees: 1174

Presentations of Sickle Cell and Agency Information (8)

Number of Attendees: 463

Public Awareness

Number of Participants: 1368

Education

Number of Participants: 1511

Type of Support Group offered:

Regular Client Support Group Meetings (9)

Total Number of Participants: 164 **Average Number of Participants:** 18

Scholarship Follow-up

Number of Participants: 20

Other Activities:

Birthday Cards to Clients

Number Sent: 74

"Thinking of You" cards to clients so they will know that we care.

Number Sent: 11

Forwarded e-mail of newsletter from "Sickle Cell Info" in Atlanta, GA. to expand knowledge

Number Sent Per Month: 52

Amazing Run for Sickle Cell

Number of Participants: 212

Skate for Sickle Cell

Number of Participants: 175

Distribution of Thanksgiving and Christmas Baskets

Number of Participants: 10

Christmas Party for Clients and Family
Number of Participants: 175
Thanksgiving Planning
Number: 30

Narrative/Other Information:

In partnership with Antioch Baptist Church AIM Center, a hot meal, groceries and clothing are offered every Wednesday. The chapter also participated in their tutorial program to help children that need extra help in school. The chapter helped serve 2,385 people on six occasions. This is also used as an opportunity to give out sickle cell literature and locate new clients.

Sickle Cell Association of Richmond-OSCAR

The Richmond chapter serves the cities of Colonial Heights, Hopewell, Petersburg and Richmond and the counties of Amelia, Charles City, Chesterfield, Hanover and Henrico.

Type of Assistance offered:

“Survey of Needs” Conducted is conducted in the beginning months of the program to see what the client rates as their most needed services.

Number of Participants: 41

Information or Referral Assistance to Clients and Families

Average Number of Participants: 210

Financial Assistance to Clients for rent, utilities, medical bills, etc. (Funded by the Annual Unity Ride for Sickle - Non Grant Funds)

Number: 14 for total of \$5,670.12

Scholarships to Clients (Funded by the Annual Unity Ride for Sickle - Non Grant Funds)

Number: 4 for total of \$800.00

Donation to the MVC Foundation for the Florence Neal Cooper-Smith Sickle Cell Initiative (Chair at VCU) (Funded by the Annual Unity Ride for Sickle)

Number 1 for total of \$1,000.00

Alma Morgan provides contract consulting services with Transition Clients regarding education and vocational needs.

Number of Participants: 28

Pierre Ames/Opportunity Matters providing in-home contract services for clients in areas of Advocacy education and representation

Assist in obtaining Disability Benefits

Advise clients of available services through the Department of Vocational Rehabilitation

Support services to individuals who require assistance to prevent homelessness, poor health, poor nutrition or financial hardships and to maintain their independence.

Assist individuals with disabilities in finding alternatives to work from their homes when they are unable to secure

Number of Participants: 29

Type of Educational Program offered:

Health Fairs (2)

Number of Attendees: 350

Presentations of Sickle Cell and Agency Information (8)

Number of Attendees: 389

Distribution of Sickle Cell Literature

Number of Pieces: 1125

Special Client Information Mailing - Each adult and transition client was mailed a copy of a 14 page booklet "About Sickle Cell Disease and Sickle Cell Trait" to better educate them about their disease.

Number Sent: 345

Type of Support Group offered:

Adult Support Group Meetings (9) but Transition Group (transition from pediatric to adult care) clients are invited. Topics of support group meetings and e-mails to educate clients on overcoming health and psychological issues including Pain Management, Stress Management, Nutrition, Resources within the organization and Open Topic Discussions by Clients

Total Number of Participants: 389 **Average Number of Participants:** 43

Other Activities:

Mailed birthday cards to clients having birthdays during this month
This is done so clients know that the organization is thinking about them.

Also mailed birthday cards to board members

Number Sent: 262 Clients 6 Board Members

"Thinking of You" cards to clients so they will know that we care.

Number Sent: 281

Each month the organization forwards to clients that we have e-mail addresses for, the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA. E-mail list has increased from 35 to 99.

Number Sent: 1224 **Average Number of Participants:** 102

Calls to clients to obtain information or update contact information

Number of Participants: 130 + 169 special calls **Average Number:** 11

Contact was made with churches to educate and obtain support for Sickle Cell

Number of Participants: 14

Tape a 30 minute radio program about the effects of Sickle Cell Disease and the up-coming 5th Annual Motor Cycle Unity Ride for Sickle Cell that previous had around 300 riders and 100 supporters.

Number of Participants: 4 including 1 medical doctor and 1 client

Narrative/Other Information:

The chapter held the 5th Annual Motorcycle Unity Ride for Sickle Cell from Petersburg to Richmond with over 300 participants, raising money to help with client bills, scholarships and other program needs not covered by the state grant.

Scholarships (\$200.00 each) to Transition Graduates who apply

Financial Assistance to Clients and Families (maximum of \$500.00 per family during a one year period)

Sickle Cell Association

The Norfolk chapter serves the cities of Chesapeake, Franklin, Norfolk, Portsmouth, Suffolk, Virginia Beach and the counties of Accomack, Isle of Wight, Northampton and Southampton.

Type of Assistance offered:

“Survey of Needs” Conducted

Number of Participants: 161

Dental Care Referrals

Number of Participants: 19

Housing/Utility Assistance

Number of Participants: 37

Employment Referrals

Number of Participants: 37

Social Security Benefits Assistance

Number of Participants: 62

Medication Referrals

Number of Participants: 1

Medical Referrals

Number of Participants: 1

Type of Educational Program offered:

Health Fairs (28)

Number of Attendees: 3296

Presentations of Sickle Cell and Agency Information (21)

Number of Attendees: 2161

Type of Support Group offered:

Client Enrichment C.A.R.E. group (11)

Total Number of Participants: 176 **Average Number of Participants:** 16

Counseling Sessions (10)

Total Number of Participants: 704 **Average Number of Participants:** 70

New Client Intake

Total Number of Participants: 12

Other Activities:

Birthday Cards to Clients

Number Sent: 37

"Thinking of You" cards to clients so they will know that we care.

Number Sent: 306

Contacts with clients by telephone, e-mail, home and hospital visits

Number Made: 1861

Trait Carries “Know Your History”

Number of Participants: 1592

Family Fun Day

Number of Participants: 87

Sickle Cell Trait Information Mailings to Churches

Number of Participants: 48

Food Basket Distribution

Number of Persons Reached: 10

Radio and T.V. Interviews (3)

Number of Persons Reached: 37,000

Narrative/Other Information:

Sickle Cell Clients are referred to the Referrals by Psychosocial Intervention Program to help with developing their coping skills and the transition from pediatric care to adult care.

The chapter established a program partnership for Sickle Cell children and their families with Children's Hospital of the King's Daughters (CHKD) and continues to get referrals from CHKD on transitioning patients into adult care at Eastern Virginia Medical School (EVMS).

The chapter participated in Advocacy Day on Capital Hill in Washington with the national organization "Sickle Cell Disease Association of America.

Sickle Cell Association of Central Virginia

The Lynchburg chapter serves the cities of Bedford and Lynchburg and the counties of Amherst, Appomattox, Bedford and Campbell.

Type of Assistance offered:

“Survey of Needs” Conducted

Number of Participants: 8

Information or Referral Assistance to Clients and Families

Number of Participants: 35

Financial Assistance to Clients (Funded by Non Grant Funds)

Number: 21

Hospital/Home Visits To Clients

Number of Participants: 55

Type of Educational Program offered:

Health Fairs (1)

Number of Attendees: 39

Presentations (3)

Number of Pieces: 94

Type of Support Group offered:

Client Support Group

Average Number of Participants: 4

Other Activities:

Birthday Cards to Clients

Number Sent: 10

"Thinking of You" cards to clients so they will know that we care.

Number Sent: 33

Forwarded e-mail of newsletter from "Sickle Cell Info" in Atlanta, GA. to expand knowledge

Number Sent Per Month: 12

Calls to clients

Number of Participants: 249 **Average Number Per Month:** 21

Monthly Meeting

Average Number of Participants: 5

Narrative/Other Information:

An annual motorcycle ride was held that raised \$9,995.00 for the chapter.

Statewide Sickle Cell Chapters of Virginia

Statewide Sickle Cell Chapters of Virginia, Inc. T/A Sickle Cell Chapters of Virginia, also know as “Statewide”, is an umbrella organization that co-ordinates and oversees activities of nine (9) area chapters around the State of Virginia. The Board of Statewide is composed of two (2) persons from each chapter. It authorizes actions of its Administrator, George Harris Carter.

Type of Assistance offered:

“Survey of Needs” Conducted

Number of Participants: N/A Conducted by Chapters

Type of Educational Program offered:

Health Fairs and Presentations

Number of Attendees: N/A Conducted by Chapters

Distributed Sickle Cell Literature

Number of Pieces: 1,200 to Grant Chapters

Type of Support Group offered:

Client Support Group

Average Number of Participants: N/A Conducted by Chapters

Other Activities:

Meetings Held in Richmond and Conference Calls

Average Number of Participants: 10

Birthday Cards to Clients

Number Sent: N/A Conducted by Chapters

"Thinking of You" cards to clients so they will know that we care.

Number Sent: N/A Conducted by Chapters

Forwarded e-mail of newsletter from "Sickle Cell Info" in Atlanta, GA. to expand knowledge

Number Sent Per Month: 58 Persons in all our chapters so they can send to clients.

Narrative/Other Information:

We feel that clients are in the community that are unaware of our chapters and the services they provide. We started a campaign to try and reach out within our community areas through newspaper ads placed in various papers around the state to attract new Sickle Cell Clients. Funded was limited but eleven responses were received.

Ad
**DO YOU HAVE SICKLE CELL DISEASE?
FOR ASSISTANCE, EDUCATION
AND SUPPORT, PLEASE CALL
SICKLE CELL CHAPTERS OF VIRGINIA
804-321-3350**

Statewide Sickle Cell Chapters of Virginia is working with Dr. Wally Smith to assist with the VCU grant from the National Institute of Health (NIH).