

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

June 29, 2012

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 eight (8) 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 and South Boston. Most of the chapters in this network have operated since 1972. Statewide is working to develop chapters in the Charlottesville and Northern Virginia areas.

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 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.

A **50%** state budget cut reduced the appropriation for this program to \$50,000 in FY09.

The Governor’s Budget Plan reinstated \$90,000 funding for community-based sickle cell programs in FY 2010.

Nothing was said to the community programs when the funds were restored. The restored funds were re-allocated by the Virginia Department of Health to the Comprehensive Sickle Cell Centers.

Starting in FY09, annual appropriations were as follows:

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

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.

Community-Based Organizations Funding Status FY11

The Virginia Department of Health issued a Request for Proposals (RFP) for community-based Sickle Cell Support Services on July 16, 2010. The RFP solicited non-clinical activities that provide assistance, education, and family-centered support for individuals with sickle cell disease. VDH issued three contracts to begin community-based services on October 1, 2010 in response to the RFP to the following organizations:

Fredericksburg Area Sickle Cell Association, Inc	Fredericksburg	\$25,000.00
Sickle Cell Association of Richmond – OSCAR	Richmond	\$30,000.00
Children’s Hospital of the King’s Daughters	Norfolk	<u>\$35,000.00</u>
Total		<u>\$90,000.00</u>

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 to the 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) will develop criteria for distributing these funds including specific goals and outcome measures. Because of this change, the contracts with the three FY2011 vendors were terminated.

Community-Based Organizations Funding Status FY12

Statewide Sickle Cell Chapters of Virginia issued a Proposal for community-based Sickle Cell Support Services in June, 2011. The proposal solicited non-clinical activities that provide assistance, education, and family-centered support for individuals with sickle cell disease. Statewide issued five contracts to begin community-based services on July 1, 2010 in response to the proposal to the following organizations:

Blue Ridge Area Sickle Cell Association (BRASCA)	Rocky Mount	\$ 5,000.00
Fredericksburg Area Sickle Cell Association (FASCA)	Fredericksburg	\$18,366.62
Sickle Cell Association of the Peninsula (SCAP)	Hampton	\$19,142.71
Sickle Cell Association of Richmond – OSCAR	Richmond	\$23,356.76
Sickle Cell Association (SCA)	Norfolk	<u>\$24,133.91</u>
Total		\$90,000.00

All five chapters receiving grant awards are 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 March 31, 2012

The five aforementioned organizations were awarded funding to begin community-based services on July 1, 2011. The following information provides a summary of the community-based education and outreach activities performed as of March 31, 2012. Monthly activity and financial reports are submitted by each chapter to the Virginia Department of Health by the 15th of each month. Contracted chapters will continue to conduct activities until the end of the fiscal year (June 30, 2012). A majority of the activities provided focus on mental and social well-being. These stress-reducing activities have a positive effect on physical well-being of those who suffer with Sickle Cell Disease and their families.

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: 6

Home Visits To Clients

Number of Participants: 10

Hospital Visits To Clients

Number of Participants: 11

Scholarship Applications

Number of Participants: 4

Type of Educational Program offered:

Health Fairs (2)

Number of Attendees: 237

Distributed Sickle Cell Literature

Number of Pieces: 470

Type of Support Group offered:

Client Support Group (All Clients)

Average Number of Participants: 4

Family Counseling

Average Number of Participants: 4

Other Activities:

Monthly Meeting (open to clients)

Average Number of Participants: 10

Membership Drive Conducted

Number of Attendees: 80

Held social activity for clients and families

Number of Participants: 50

Partnered with the Virginia Blood Services to collect 45 pints of blood

Number of Participants: 30

TV Appearance to promote Sickle Cell and the Virginia Blood Services blood drive to collect 45 pints of blood

Number of Participants: 2

Narrative/Other Information:

The chapter used some of their funds to obtain a computer to help maintain records and audio visual equipment for community education.

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

Employment Assistance

Number of Participants: 2

Employment Contact

Number of Participants: 1

Referral for job listing

Number of Participants: 3

Housing Assistance

Number of Participants: 9

Type of Educational Program offered:

Health Fairs (7)

Number of Attendees: 2205

Presentations of Sickle Cell and Agency Information (6)

Number of Pieces: 398

Type of Support Group offered:

Heart To Heart Client Support Group (6)

Total Number of Participants: 47 **Average Number of Participants:** 8

Other Activities:

Client meeting with doctor from the National Institute of Health (NIH)

Number of Participants: 16

Family and Friends Event

Number of Participants: 45

Worked on newsletter

Revised pamphlet for education

Narrative/Other Information:

The chapter provided programs for clients and families to explain services offered by Service Delivery Agencies such as social services, social security and disability resources, medical assistance, legal aid, etc. The chapter offered some computer training to clients/families.

The support group set objectives and goals and have been very active by reaching out to other clients and families trying to build a closer relationship by calling, sending cards, helping the family during hospital stays, etc.

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: 20

Counseling Services

Number of Participants: 17

Testing

Number of Participants: 3

Home Visits

Number of Participants: 31

Telephone calls to clients to check on them

Number of Participants: 90

Assisted with Antioch Baptist Church AIM Center Feeding Program of 7 months

Total Number of Participants: 1405 **Average Number of Participants:** 200 per month

Assisted with Antioch Baptist Church AIM Center Clothing Program of 7 months

Total Number of Participants: 315 **Average Number of Participants:** 45 per month

Assisted with Antioch Baptist Church AIM Center Grocery Program of 7 months

Total Number of Participants: 1037 **Average Number of Participants:** 148 per month

Type of Educational Program offered:

Health Fairs (1)

Number of Attendees: 125

Presentations of Sickle Cell and Agency Information (12)

Number of Attendees: 456

Distribution of Sickle Cell Literature

Number of Pieces: 60

Type of Support Group offered:

Regular Client Support Group Meetings (7)

Total Number of Participants: 109 **Average Number of Participants:** 15

Other Activities:

T.V. Program Appearance on Sickle Cell

Number of Participants: 3

Amazing Run for Sickle Cell

Number of Participants: 130

Skate for Sickle Cell

Number of Participants: 80

Distribution of Thanksgiving and Christmas Baskets

Number of Participants: 12

Christmas Party for Clients and Family

Number of Participants: 102

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. This is also used as an opportunity to give out sickle cell literature and locate new clients.

The chapter used some of their funds to obtain a computer to help maintain records.

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: 52

Information or Referral Assistance to Clients and Families

Average Number of Participants: 67

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

Number: 10 for total of \$3,982.95

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

Number: 5 for total of \$1,000.00

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: 17

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: 38

Type of Educational Program offered:

Health Fairs (2)

Number of Attendees: 525

Presentations of Sickle Cell and Agency Information (2)

Number of Attendees: 120

Distribution of Sickle Cell Literature

Number of Pieces: 1250

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: 306 **Average Number of Participants:** 34

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: 215 Clients 4 Board Members

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: 764 **Average Number of Participants:** 85

Calls to clients to obtain information or update contact information

Number of Participants: 41 **Average Number:** 5

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 4th Annual Motor Cycle Unity Ride for Sickle Cell that previous had around 400 riders and 100 supporters.

Number of Participants: 5 including 1 medical doctor and 2 clients

Narrative/Other Information:

Scholarships (\$200.00 each) to Transition Graduates

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: 82

Clothing Assistance

Number of Participants: 2

Food Assistance

Number of Participants: 32

Housing Assistance

Number of Participants: 25

Scholarship Assistance

Number of Participants: 1

Transportation Assistance

Number of Participants: 6

Utility Assistance

Number of Participants: 3

Employment Referrals

Number of Participants: 18

Medical Referrals

Number of Participants: 17

Social Security Benefits Assistance

Number of Participants: 2

Type of Educational Program offered:

Health Fairs (3)

Number of Attendees: 914

Presentations of Sickle Cell and Agency Information (33)

Number of Attendees: 1806

Type of Support Group offered:

Client Enrichment C.A.R.E. group (9)

Total Number of Participants: 96 **Average Number of Participants:** 11

Family Counseling Sessions (6)

Total Number of Participants: 18 **Average Number of Participants:** 3

Individuals Counseling Sessions (6)

Total Number of Participants: 140 **Average Number of Participants:** 23

Liaison Community Outreach (3)

Total Number of Participants: 26 **Average Number of Participants:** 91

Support Services referrals for medical, housing, food and clothing

Total Number of Participants: 25

Other Activities:

Children’s Hospital of the King’s Daughters (CHKD) Referrals (5)

Total Number of Participants: 76 **Average Number of Participants:** 15

Eastern Virginia Medical School Clinic Visits (EVMS) (6)

Total Number of Participants: 516 **Average Number of Participants:** 86

Client Follow-up Mail Contacts (3)

Total Number of Participants: 406 **Average Number of Participants:** 135

Sickle Cell Intervention Counseling Program (6)

Total Number of Participants: 121 **Average Number of Participants:** 20

Referrals by Psychosocial Intervention Program

Total Number of Participants: 25

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).

Assistance to clients (food, housing, utilities) is provided through community donations.

The Psychosocial Intervention Project was funded by Sentara Healthcare Foundation.