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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, 2014

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 the Sickle Cell 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 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 funds was approved for grants to community-based programs. The purpose of the community-based allocation was to provide education and assist individuals and families living with sickle cell disease to develop 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
- FY14 - $105,000

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.

Item 288Q of the 2011 Appropriation Act required the Virginia Department of Health (VDH) to allocate the appropriation for community-based sickle cell programs by contract to Statewide Sickle Cell Chapters of Virginia. This funding is to be used for grants to community-based programs that provide services for individuals suffering from sickle cell disease. "Statewide" 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.

During FY14 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	$ 4,553.00
Heart of Gold Sickle Cell Foundation of Northern Virginia	Northern Virginia	$14,255.00
Sickle Cell Association	Norfolk	$30,380.00
Sickle Cell Association of Central Virginia	Lynchburg	$ 3,556.00
Sickle Cell Association of the Peninsula	Hampton	$12,256.00
Sickle Cell Association of Richmond – OSCAR	Richmond	$25,282.00
Statewide Sickle Cell Chapters of Virginia (Advertisement, Materials, etc.)		$14,718.00
Total		$105,000.00

All chapters receiving grant awards have been required to conduct a “Survey of Needs” with as many of their registered clients as possible. Several years of surveys have been conducted. The surveys have enabled chapters to determine what services are needed, by whom and how best the services can be delivered to clients.

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, sending "Birthday" and "Thinking of You" cards, 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, 2014

The six aforementioned organizations were awarded funding to begin community-based services on July 1, 2013. The following information provides a summary of the community-based activities performed as of June 30, 2014. 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: 18
Home Visits To Clients
Number of Participants: 4
Hospital Visits To Clients
Number of Participants: 3
Financial Assistance to Clients
Number of Recipients: 3

Type of Educational Program offered:

Health Fairs/Festivals/Presentations (4)
Number of Attendees: 2056
Distributed Sickle Cell Literature (3)
Number of Pieces: 1820

Type of Support Group offered:

Client Support Group (All Clients)
Average Number of Participants: 8
Telephone Conversations/ E-mails
Number: 190

Other Activities:

Birthday Cards to Clients
Number Sent: 74
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 97
Newsletters Distributed
Number Sent: 220
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: 12
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.

Held a Walk-a-thon (79 participates)

Held Fun Day for clients and families with lunch and gospel music (125 participates)

A vehicle with Sickle banner and marchers paraded through the streets of the Christmas parade of 2500 people.

Prepared for school awareness program for teacher, administrators, nurses and athletic department (2 schools).

Appeared on local television to promote Sickle Cell and the blood drive.

Participated in Blood Drive, Warren Street Festival (2 Days), Sep Festival and the Juneteen Celebration in Roanoke

The Heart of Gold Sickle Cell Foundation of Northern Virginia

Northern Virginia serves the cities of Alexandria, Fairfax and Falls Church and the counties of Arlington, Fairfax, Fauquier and Loudoun.

Type of Assistance offered:

“Survey of Needs” Conducted
Number of Participants: 43
Information or Referral Assistance
Number of Participants: 119
Financial /Scholarship Assistance
Number of Participants: 0

Type of Educational Program offered:

Health Fairs (1)
Number of Attendees: 20
Presentations (2)
Number of Attendees: 155

Type of Support Group offered:

Support Group
Total Number of Participants: 2
Affordable Care Information Session
Total Number of Participants: 13
E-mail info on SC Congressional Caucus
Number Sent: 100
Partnership with ASBC Singles Ministry
Total Number of Participants: 25

Other Activities:

Birthday Cards to Clients
Number Sent: 5
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 12
Forwarded e-mail of newsletter from "Sickle Cell Info" in Atlanta, GA. to expand knowledge
Number Sent Per Month: 50
Cards to Persons in Hospitals
Number: 6
Meetings (6)
Number of Participants: 36
Contacts With Clients
Number: 13
Assistance With Hospital Admission
Number: 1

Narrative/Other Information:
The Heart of Gold Sickle Cell Foundation of Northern Virginia is both a new organization and new to the grant program. While the area has a sizable population of Sickle Cell Clients, HIPPA laws prevent the area hospitals from supplying their information. The chapter must rely on referrals. Both Service Coordinators have worked with Richmond Administrator on functional activities for the chapter. While their activities numbers are low, their involvement in health activities has been high as demonstrated in the narrative below.

Sponsor for "Stomp out Sickle Cell" walk. Had a sponsors table, distributed Sickle Cell Disease informational cards, Heart of Gold informational materials, and gathered email and phone information from approximately 20 persons interested in the Heart of Gold Foundation. Service Coordinator (Kargbo) attended Annual INOVA Hospital Pain Awareness Day on September 24th and made presentation on behalf of Heart of Gold Foundation on the trials and tribulations of SCD patients. Service Coordinator (Pearson) and Board Member (Pearson) met with Children's National Medical Center staff to discuss partnership. Heart of Gold has been asked to lead support group for transitioning adolescents. Service Coordinator (Kargbo) also attends Sickle Cell Association of Richmond-OSCAR support group meeting at VCU in Richmond Virginia. Service Coordinator (Pearson) met with Dr. Martin Brown of Inova Hospitals about starting a "trial" sickle cell protocol for emergency room patients. Service Coordinator (Pearson) had a conference call with Virginia Hospital Center nursing staff about advocating for sickle cell patients. Service Coordinator (Pearson) sent letters to the City of Alexandria City Council and Mayor informing them of National Sickle Cell Month in September and about establishing a proclamation. Board Member (Bey) contacted Inova Blood Services about recruiting more African American Blood Donors for future blood drives.
-sent emails reminding people to register for SOS walk & posted info on FB
-wrote letters to local news stations/radio stations about SC awareness month

Service Coordinator met with Alexandria City Public Schools (ACPS) nurse to organize information session with Children's National Medical Center in December. Did follow up with Children's National Medical Center staff to coordinate with ACPS. Service Coordinator did follow up with pain nurses at Alexandria Hospital for assistance in pain awareness seminar. Board member made contact with Alfred Street Baptist Church Health and Wellness Ministry for Board support in Affordable Care Seminar in November. Board Member ordered books for distribution to teenaged patients of Children's National Medical Center Northern Virginia entitled "Hope and Destiny".

Established contact with physicians at Virginia Hospital Center in Arlington VA re: weekly adult sickle cell clinic. Still trying to develop outreach plan and get clients to self-identify. Held joint bowling fundraiser with Alfred Street Baptist Church Singles Ministry, and disseminated information about Heart of Gold to the group. Emailed information to local elected officials, church group and sororities to support the Congressional Black Caucus Sickle Cell Advocacy Day in April.

Multiple meetings with Dr. Amoah for Inova Hospital to set up a clinic for sickle cell patients. Completed flyer announcing Northern Virginia Adult Sickle Cell Clinic with Dr. Amoah.

The Heart of Gold Foundation participated in the Community Partnership event sponsored by the Ivy Foundation of Northern Virginia in Alexandria, VA. The Heart of Gold Foundation sponsored a World Sickle Cell event at James Polk School in honor and memory of those suffering with SCD. The Heart of Gold informational ad was published in the Washington Post Express and will be published for 3 weeks. The Washington Post Express has a distribution of over 300,000 persons in the metropolitan Washington DC area. The Heart of Gold foundation continued to support the first adult Sickle Cell clinic in northern Virginia through distribution of information. Made contact for ads in the Alexandria Times and Health Net publications. Contacted President of Pain Connection Support Group for future meeting.

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: 284
Information or Referral Assistance
Housing-Employment-Medical-Food
Number of Participants: 135
Follow-Up Needs Assessments
Number of Participants: 54

Type of Educational Program offered:

Health Fairs (28)
Number of Attendees: 3553
Presentations of Sickle Cell and Agency Information (21)
Number of Attendees: 1542

Type of Support Group offered:

Client Enrichment C.A.R.E. group (11)
Total Number of Participants: 161 **Average Number of Participants:** 15
Counseling Sessions
Total Number of Participants: 1028 **Average Number of Participants:** 86
Follow-up Home-Hospital-Telephone
Number Made: 1796
New Client Intake
Total Number of Participants: 11

Other Activities:

Birthday Cards to Clients
Number Sent: 61
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 132
Forwarded e-mail of newsletter from "Sickle Cell Info" in Atlanta, GA. to expand knowledge
Number Sent Per Month: 36
Family Fun Day
Number of Participants: 66
Radio and T.V. Interviews (3)
Number of Persons Reached: 37,000

Narrative/Other Information:

Held the second Annual Family Fun Day Camp with 66 families in attendance. Participant activities included indoor swimming, nature trail walks, fishing clinic, massage therapist for the adult clients, crafts and games, photos to take home, talent show and a cookout.

Held blood drive with Red Cross. Health Fair participants were able to get free flu shots from Walgreens, talk to EVMS Patient Navigators for the Hydroxyurea Study, meet with the Novartis Rep on Iron Overload, schedule appointments with Legal Aid Society to discuss legal questions and many other vendors and community resources.

Participated in a number of Parades
Provided 10 Thanksgiving baskets to Sickle Cell Families
Provided 10 Christmas baskets to Sickle Cell Families
Nursing Intern Students developed a survey for clients to assess their pain
Worked with University Disability Services to coordinate services for clients.
Participated in Transition Retreat and providing a session on Stress Management

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: 6
Information or Referral Assistance to Clients and Families
Number of Participants: 3
Financial Assistance to Clients (Funded by Non Grant Funds)
Number: 49 for $6,430.19

Type of Educational Program offered:

Health Fairs (1)
Number of Attendees: 100
Presentations (5)
Number of Pieces: 396

Type of Support Group offered:

Client Support Group
Average Number of Participants: 5

Other Activities:

Birthday Cards to Clients
Number Sent: 13
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 48
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: 127 **Average Number Per Month**: 13
Monthly Meeting
Average Number of Participants: 5
Hospital/Home Visits To Clients
Number of Participants: 38

Narrative/Other Information:

An annual motorcycle ride was held.
Literature place in Church Bulletins at 10 Churches
Appeared on local TV to inform the public about Sickle Cell 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: 44
Counseling Services
Number of Participants: 31
Assisted with Antioch Baptist Church AIM Center Feeding, Clothing and Grocery Programs
Total Number of Participants: 4277 **Average Number of Participants:** 356 per month

Type of Educational Program offered:

Health Fairs (10)
Number of Attendees: 1861
Presentations of Sickle Cell and Agency Information (10)
Number of Attendees: 588
Afrikan American Festival (3Days)
Number of Participants: 18000

Type of Support Group offered:

Regular Client Support Group Meetings (12)
Total Number of Participants: 154 **Average Number of Participants:** 12

Other Activities:

Birthday Cards to Clients
Number Sent: 97
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 106
Forwarded e-mail of newsletter from "Sickle Cell Info" in Atlanta, GA. to expand knowledge
Number Sent Per Month: 17

Narrative/Other Information:

Presentations to groups, churches, schools, a community college and Walmart
Resumed the partnership with the Antioch Baptist Church AIM Center by providing free lunch, clothing and groceries to members of the Hampton community. (AIM partnership providing free lunch, clothing and groceries). This is also used as an opportunity to give out sickle cell literature and locate new clients.
Promoted education and awareness by doing presentations during all three days of the Afrikan American Festival

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: 57

Information or Referral Assistance to Clients and Families
Average Number of Participants: 231

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 $5,659.14

Scholarships to Clients (Funded by the Annual Unity Ride for Sickle - Non Grant Funds)
Number: 2 for total of $400.00

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: 46

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: 32

Type of Educational Program offered:

Health Fairs (4)
Number of Attendees: 565
Presentations of Sickle Cell and Agency Information (6)
Number of Attendees: 1574
Distribution of Sickle Cell Literature
Number of Pieces: 2139

Special Client Information Mailing - Each adult and transition client was mailed a copy of a 14 page booklet "Overcoming Pain: Living With Sickle Cell Disease" to better educate them about their disease.
Number Sent: 325

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: 349 **Average Number of Participants:** 35

Other Activities:

Mailed birthday cards to clients having birthdays during each month
This is done so clients know that the organization is thinking about them.
Also mailed birthday cards to board members
Number Sent: 264 Clients 6 Board Members

"Thinking of You" cards to clients so they will know that we care.
Number Sent: 282

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.
Average Number of Participants: 105

Calls to clients to obtain information or update contact information
Number of Participants: 216

Contact was made with churches to educate and obtain support for Sickle Cell
Number of Participants: 14

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

Narrative/Other Information:

Administrator attended the 3 day Sickle Cell Disease Association of America Conference in Baltimore, MD.
In July each client was mailed a one page copy of a news article from GlycoMimetics (a biotechnology company) entitled "Sickle Cell Trial Shows Promising Early Results:. GMI-1070 is intended to treat vaso-occlusive crisis of sickle cell disease (VOC) by inhibiting the cell activation and enhanced cell adhesion that causes the ischemia and pain. VCU/MCV was one of the trial sites. We feel that giving clients such information gives them a better understanding of the disease and what is going on to treat it.
Stress can cause a Sickle Cell Crisis. In August each client was mailed a copy of a "Stress Management" pocket pal to help them understand the causes of stress and what can be done to

reduce it. Clients were also sent a calendar of the month of September with each day having information on Sickle Cell. We feel that giving clients such information gives them a better understanding of the disease.

Administrator attended a weekend camp for the "Transition Group" at Camp Hanover to give a presentation on "Empowerment".

The Administrator, and volunteer Sandy Smith met in October with Kelly Woodard, News Director of Television WRIC Channel 8 about the station taking the lead to bring awareness about Sickle Cell Disease to the public. In November, George Harris Carter, Administrator, taped a segment with Amie McLain of Channel 8 to air January 14th. A segment was taped the same day with Dr. Wally Smith that is scheduled to air December 13th. Other segments will air on the 14th of February, March and April and another late in April.

The organization received 3 Christmas Cards from clients and 1 thank you card for financial assistance.

The Administrator and several clients participated in the FDA Meeting on Sickle Cell Disease in Silver Springs, Maryland on February 7th.

E-mailed clients an in-depth interview on receiving blood transfusions at VCU.

We have started airing radio ads to attract clients and inform the public about SCD.

On Tuesday, April 22nd, Sylvia Alexander-Wall and George Harris Carter appeared on Channel 8 News at 9 to talk about Sickle Cell Disease and the May 3rd Unity Ride for Sickle Cell.

On Tuesday, April 29th, Sylvia Alexander-Wall and George Harris Carter appeared on Channel 6 Virginia This Morning during the 9 o'clock hour to talk about Sickle Cell Disease and the May 3rd Unity Ride for Sickle Cell.

On Tuesday, April 29th, Channel 8 presented another segment on Sickle Cell Disease with Florence Neal Cooper Smith (referred to as the "Mother of Sickle Cell in the State of Virginia) and Pastor Hodge and the involvement of 2nd Baptist Church of South Richmond in the Unity Ride for Sickle Cell.

Held the 6th Annual Sickle Cell Unity Ride. The Unity Ride was held to raise sickle cell awareness and funds to help with client bills, scholarships and other program needs not covered by the state grant. The motorcycle ride was about 22 miles from Petersburg to Richmond with around 450 riders, clients and friends.

Financial Assistance to Clients and Families (maximum of $500.00 per family during a one year period and Scholarships ($200.00 each) to Transition Graduates who apply.

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

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
Information or Referral Assistance to Clients and Families
Number: **20**

Type of Educational Program offered:

Health Fairs and Presentations
Number of Attendees: N/A Conducted by Chapters
Distributed Sickle Cell Literature
Number of Pieces: N/A Conducted by Chapters

Type of Support Group offered:

Client Support Group
Average Number of Participants: N/A Conducted by Chapters

Other Activities:

Meetings 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: 65 Persons in all our chapters so they can send to clients.
Radio Ad Referrals
Number: 16
Served on FDA Sickle Cell Panel
Number Reached: 300 in person and 300 on line

Narrative/Other Information:

The Statewide Administrator attended the Sickle Cell Disease Association of America's national conference in Maryland that included three days of numerous informative sessions.

We feel that clients are in the community that are unaware of our chapters and the services they provide. We started a radio fifteen and thirty second ad campaign to try and reach out within each grant funded chapter community to attract new Sickle Cell Clients. Funding was limited but sixteen responses were received.

15 Second Ad

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

30 Second Ad

OVER 4,000 PEOPLE IN VIRGINIA SUFFER
WITH SICKLE CELL DISEASE AND
APPROXIMATELY 155,000 VIRGINIANS
HAVE SICKLE CELL TRAIT.
DO YOU OR SOMEONE YOU KNOW
HAVE SICKLE CELL DISEASE?
FOR ASSISTANCE AND SUPPORT
OR JUST SICKLE CELL EDUCATION,
PLEASE CALL
SICKLE CELL CHAPTERS OF VIRGINIA
804-321-3350
CALL US TODAY
804-321-3350

Statewide FDA Meeting Report

On February 7, 2014, the Food and Drug Administration (FDA) held a public meeting on Sickle Cell Disease in Silver Spring, Maryland from 10:00 a.m. to 4:00 p.m. The purpose of the meeting was to hear patient perspectives on the health effects of sickle cell disease and on treating sickle cell disease. The meeting allowed FDA to hear patients' views on the impact of sickle cell disease on their daily lives and the types of treatment benefit that matter most to patients. FDA was interested in getting a better understanding of patient views on the disease, including the symptoms that matter most, limitations to current treatment and patients' thoughts on new treatment approaches for sickle cell disease. FDA used the following two topics for the meeting:

> TOPIC 1: THE EFFECTS OF SICKLE CELL DISEASE THAT MATTER MOST TO YOU
> TOPIC 2: PERSPECTIVES ON TREATMENTS FOR SICKLE CELL DISEASE

Statewide Sickle Cell Chapters of Virginia, Inc. offered financial reimbursement to clients who wanted to attend. A total of **ten clients** took advantage of this opportunity at a total cost of **$1,861.95**.

One client with SS represented the new Northern Virginia Chapter
    This client spoke during an open comment period.
Four clients represented the Richmond Chapter (two with SS and two with Sickle Beta Thalassemia)
    One client with SS and one with SBT spoke during an open comment period.
    Due to time constraints one client with SS was not able to speak but submitted comments on-line after the meeting.
    George Harris Carter with SBT served on the panel on TOPIC 1 and spoke during the open comment period at the end.
Four clients represented the Hampton Chapter (one with SC and three from one family, each with Sickle Beta Thalassemia)
    One client with SC spoke during the open comment period at the end.
One client with SS represented the Norfolk Chapter

The persons who served on the panels were to speak about their own situations for about three minutes but often went over. During my time on the panel, I stated in part the following: Hearing loss is a problem related to sickle cell but is not listed in most publications. I have lost 80% of hearing in my left ear and 30% in my right ear. Some years ago during a sickle cell presentation by Dr. Wally Smith, he mentioned that hearing loss was a problem. I stated that I had hearing loss in my left ear. Two other males indicated they had hearing loss in their left ear also. Only four studies have been presented, two by Dr. Smith who is here today.

I also stated that our Nurse Practitioner in Richmond recently wrote “Sickle Cell Disease has a great impact on oral hygiene. We have patients as young as in their 30’s that have dentures – have lost all their teeth because of the damage from lack of oxygenated blood and sickling in the microvasculature.”

After the panel presented, persons from the audience were able to make statements. Several telephone calls were taken from persons on-line. During the meeting FDA distributed clickers to clients and care givers so they could respond to various questions presented by FDA. Persons who participated on line were also able to respond and their responses were very similar to the persons present.

A full recording of the meeting has been posted on the FDA website:
http://www.fda/ForIndustry/UserFees/PrescriptionDrugUserFee/ucm370867.htm
Comments can still be submitted by April 8, 2014.

The following are some of the comments from the clients about the FDA meeting:
"It was the best sickle cell meeting I have ever attended"

"I felt good that the government was taking this much of an interest in sickle cell."

One client wrote the following:
I would first like to thank you and Statewide Sickle Cell Chapters of Virginia, Inc. for making it possible to attend the Food and Drug Administration's Public Meeting on Sickle Cell Disease on February 7, 2014. Your funding assistance made it possible to attend the public meeting and share my perspective on the health effects of and treating Sickle Cell Disease. This was definitely a once in a lifetime opportunity for our community.

Attending the public meeting really put into perspective challenges our Sickle Cell communities face on an individual and systemic level. I was proud to hear about initiatives and programs individuals and organizations develop to advocate for and promote the well being of our community. I was especially touched to see people living with Sickle Cell Disease achieving higher levels of education and having successful careers as medical doctors, researchers, attorneys, advocates, artists, entrepreneurs, and much more. This proves while Sickle Cell Disease can be debilitating, it is not an excuse from achieving higher education, having a successful career, and being self-reliant. Seeing all of this has given me the motivation to work even harder toward my dreams and goals. This was money and time well spent.