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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, 2015

What is Sickle Cell Disease?

Sickle Cell Disease is an 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, 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 1,200 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.

Funding Level

Starting in FY08, annual budget appropriations were as follows:

- FY08 - \$100,00 for three of our eight chapters
- FY09 - \$95,000 for three of our eight chapters
- FY10 - \$81,000 for three of our eight chapters
- FY11 - \$90,000 for five of our eight chapters
- FY12 - \$90,000 for five of our eight chapters
- FY13 - \$88,200 for five of our eight chapters
- FY14 - \$105,000 for six of our nine chapters
- FY15 - \$105,000 for six of our nine chapters
- FY16 - \$105,000 for six of our nine chapters

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 and FY13, Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded five contracts to member chapters.

During F14 and FY15, Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded six contracts to member chapters.

Six chapters received the following funding during FY15:

Blue Ridge Area Sickle Cell Association (BRASCA)	Rocky Mount	\$ 5,218.00
Heart of Gold Sickle Cell Foundation of Northern Virginia	Northern Virginia	\$16,336.00
Sickle Cell Association	Norfolk	\$34,814.00
Sickle Cell Association of Central Virginia	Lynchburg	\$ 4,075.00
Sickle Cell Association of the Peninsula	Hampton	\$14,045.00
Sickle Cell Association of Richmond – OSCAR	Richmond	<u>\$30,512.00</u>
Includes \$1,540.00 to pay some bills for Statewide Sickle Cell Chapters of Virginia (Materials, supplies, accountant and administrators fees, etc.)		
Total		\$105,000.00

All chapters receiving grant awards have previously 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, assistance with obtaining disability benefits, employment and vocational rehabilitation.

Community-Based Sickle Cell Program Activities as of June 30, 2015

The six aforementioned organizations were awarded funding to begin community-based services on July 1, 2014. The following information provides a summary of the community-based activities performed as of June 30, 2015. 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:

Calls from Clients/Family for information/assistance.

Number: 13

Information or Referral Assistance to Clients and Families

Number: 7

Financial Assistance to Clients for rent, utilities, medical bills, and college scholarships, etc.
(Funded by - Non Grant Funds)

Number: 6 for total of \$461.00

Home Visitation

Number: 14

Hospital Visitation

Number: 32

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 2615

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 8

Number of Attendees: 5165

Blood Drive Donors or Volunteers; Every donation of blood save three (3) lives.

Number of Attendees: 50

Type of Support Group offered:

Meetings

Number of Participants: 123

Other Activities:

Birthday cards sent to clients having birthdays during each month.

This is done so clients know that the organization is thinking about them.

Number Sent: 16

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

Number Sent: 61

Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.

Number Sent: 99

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 134

Calls to clients to obtain information or update contact information

Number: 94

Narrative/Other Information:

August - Had an internet ad in a local online paper.

October - Fund raising project and walk-a-thon were a success. Placed ad for sickle cell in newspaper and on radio.

November - A successful fund raising project was held November 16th and was advertised on radio, TV and in the newspaper.

December - A Christmas parade float with Sickle Cell participants was seen by 1500 spectators.

January - Donated and presented 14 books into the Franklin County Elementary School libraries in memory of former teacher and BRASCA board member, Fannie Gentry.

February - The annual blood drive was a success. Three churches volunteered and prepared lunch for donors, staff and all who were present. Carilion Franklin Memorial Director is being invited to our next business meeting to voice some of the concerns when clients are visiting the emergency room.

March - Three Franklin Memorial Hospital staff members attended the monthly meeting to resolve some of the issues when clients visit the emergency room. Each case was discussed.

Continuing to work on the ads for the tri county area. A committee is working on the web page.

April - The three Franklin Memorial Hospital staff members who attended the monthly meeting were told that positive results were realized when clients now visit the emergency room.

Completed the ad campaign in the tri area that will reach between 5,000 and 8,000 persons. This coverage was printed matter and telecasting.

May - The Chapter supported a beauty queen contestant who used Sickle Cell as her platform. An ad was placed in the program and 250 attended the event.

June - The beauty queen contestant who used Sickle Cell as her platform presented to the Board her presentation and allowed information be placed on our web site. The web site is completed.

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:

Calls from Clients/Family for information/assistance.

Number: 4

Information or Referral Assistance to Clients and Families

Number: 7

Financial Assistance to Clients for rent, utilities, medical bills, and college scholarships, etc.
(Funded by - Non Grant Funds)

Number: 10 **Hospital Care Kits**

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 3705

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 4

Number of Attendees: 290

Blood Drive Donors or Volunteers; Every donation of blood save three (3) lives.

Number: 5

Number of Attendees: ?

Posted Sickle Cell information on Facebook page and sent to clients.

Number: 20,300

Sickle Cell Walk

Number of Participants: 50

Type of Support Group offered:

Meetings

Number of Participants: 10

Other Activities:

Birthday cards sent to clients having birthdays during each month

This is done so clients know that the organization is thinking about them.

Number Sent: 1

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

Number Sent: 28

Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.

Number Sent: 514

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 32

Calls to clients to obtain information or update contact information

Number: 11

Narrative/Other Information:

The Heart of Gold Sickle Cell Foundation of Northern Virginia has a sizable area and population of Sickle Cell Clients, HIPPA laws prevent the area hospitals from supplying their information. The chapter must rely on referrals. While their activities numbers are low, their involvement in health activities has been high as demonstrated in the narrative below.

August - Ad published in the Washington Post Express for three weeks (free newspaper with distribution of 300,000). Advertisement also in local Health News Publication. Advertisements in the local Health News publication. Advertisements included information for Heart of Gold as well as advertisement of first Adult Sickle Cell Clinic in Northern Virginia. Letters sent to churches and local fraternities and sororities about Heart of Gold, upcoming SOS Walk, Adult Sickle Cell Clinic and upcoming Blood Drive.

September - Advertisements in the local Health News publication. Advertisements included information (phone/email) for Heart of Gold as well as advertisement of first Adult Sickle Cell Clinic in Northern Virginia. Participated as a sponsor in the Stomp out Sickle Cell walk on the Washington DC National Mall on September 13th. Team Heart of Gold had 10 team members. Distributed information to 50 persons. Participated in the Alfred Street Baptist Church Blood Drive and Health Fair on September 27th. Over 20 persons stopped by the Heart of Gold Table and pick up informational materials. A segment on Sickle Cell Month ran on Fairfax County's access channel 16. Show was produced by Board Member Valerie Bey and featured local Sickle Cell parent and physician from Children's National Medical Center Northern Virginia. Also received a Proclamation from the City of Alexandria and Councilman John Chapman recognizing Sickle Cell Month. Fairfax County Proclamation for Sickle Cell Month from Supervisor Catherine Hudgins.

October and November - Letters written to Virginia Hospital Center in Arlington, VA and Inova Alexandria Hospital with recommendations for improvements in the care of patients with SCD.

December - Heart of Gold had a table at the Children's National Medical Center Northern Virginia Holiday Party on December 14th in Arlington, Va. Distributed books, Heart of Gold contact information, Adult Sickle Cell clinic information, and pamphlets to families with children suffering from SCD. Eight clients filled out survey of needs forms. Posted New Year's Message on Facebook with information about Heart of Gold and advocacy.

January - Posted information on Facebook page regarding Sickle Cell Advocacy. Had meeting with Pain Management Nurse at INOVA Alexandria hospital. Continued to update client list and try to identify new clients in service area.

February - Posted Sickle Cell information on Facebook page and sent to clients. Board Member donated blood at Virginia Blood Services Bloodmobile on February 28th at Howard University Hospital. Wrote letter to INOVA hospital about care for sickle cell patients. Distributed information via Facebook and webpage from Howard University Adult Transition Program on study of Sickle Cell patients.

March - Posted Sickle Cell information on Facebook and webpage and sent to clients. Increased of 35 followers on webpage. Wrote letter to INOVA hospital about care for sickle cell patients. Posted information about "bullying" in hospital on webpage and Facebook. Distributed information via Facebook and webpage about Sickle Cell Advocacy Day in Silver Spring Maryland in April. Volunteered in Dr. Amoah's Office to assist with Adult Sickle Cell Clinic.

April - Posted Sickle Cell information on Facebook and webpage and sent to clients. Participated and distributed information at Omega Psi Phi Fraternity Chapter in Stafford, VA

Fish Fry on April 25 2015 and distributed new informational brochures and also to help them with a blood drive. Advocated and visited patient at INOVA hospital. Posted information about sickle cell disease on webpage and Facebook. Distributed information via Facebook and webpage about Sickle Cell Advocacy Day in Silver Spring Maryland in April. Volunteered in Dr. Amoah's Office to assist with Adult Sickle Cell Clinic.

May -Advocated and visited patients at INOVA hospital. Distributed information via Facebook and webpage about Sickle Cell. Volunteered in Dr. Amoah's Office to assist with Adult Sickle Cell Clinic and provided brochures for distribution. Met with staff at INOVA Alexandria Hospital (Pain Management), left brochures for distribution.

June - Posted Sickle Cell information on Facebook and webpage and emailed to clients. Advocated and visited patients at INOVA hospital. Provided Heart of Gold Brochures for Blood Drive at First Mount Zion Church, Dumfries, Virginia. Supported event on June 6 sponsored by Howard University for persons suffering from SCD. Distributed information on World Sickle Cell event and blood drive (Virginia Blood Services) on June 19 at Howard University. Volunteered in Dr. Amoah's Office to assist with Adult Sickle Cell Clinic and provided brochures for distribution. Interview scheduled with CBS radio on June 9th. Additional 20 likes on Facebook page.

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:

Calls from Clients/Family for information/assistance.

Number: 370

Information or Referral Assistance to Clients and Families

Number: 92

Financial Assistance to Clients for rent, utilities, medical bills, and college scholarships, etc. (Funded by - Non Grant Funds)

Number: 8 for total of \$2,000

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 3423

Health Fairs/ Presentations of Sickle Cell and Agency Information (XX)

Number: 52

Number of Attendees: 4368

Blood Drive Donors or Volunteers; Every donation of blood save three (3) lives.

Number: 3

Number of Attendees: ?

Type of Support Group offered:

Clients Meetings

Number of Participants: 129

Volunteer Meetings

Number of Participants: 96

Other Activities:

Birthday cards sent to clients having birthdays during each month

This is done so clients know that the organization is thinking about them.

Number Sent: 68

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

Number Sent: 96

Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.

Number Sent: 469

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 1087

Calls to clients to obtain information or update contact information

Number: 331

Narrative/Other Information:

August - Held the third Back to School Family Fun Day Camp in Chesapeake, VA. This was a partnership effort with Children Hospital, Shrine Desert of Virginia, and Optima Health Care. Sickle Cell families enjoyed a day of crafts, swimming in an indoor pool, fishing clinic and a cookout. Volunteers distributed school supplies to school age children.

September - Held 21st Annual Walk for Sickle Cell and Health and Awareness Fair to kick off events for Sickle Cell Awareness Month. Held two blood drives with area churches. Display posters and brochures were given to area churches on Sickle Cell Sabbath observances. Intern students from the School of Social Work at Norfolk State University and TCC assist with client contacts and follow up. Intake calls from new families were taken after the Annual Walk was publicized on the local radio and television stations.

October - Held first Zumba for Sickle Cell Challenge in Suffolk to at youth recreation center involved in Sickle Cell education and awareness.

November - Provided education on sickle cell disease and awareness about Agency services in the Pharmacy class at Hampton University. There were 210 students in attendance at the event. Volunteers were recruited for other community awareness booth displays. Gave out 13 food baskets and 20 turkeys to sickle cell families for Thanksgiving.

December - Provided 12 Christmas food baskets to families and held the first toys giveaway and Christmas Dinner for Sickle Cell families on the Virginia Eastern Shore.

January - Informed clients of a interview study being conducted by SCDA to assess hospitalizations and any barriers to care that they may have experienced. Twenty -two participants were contacted to participate.

February - Guest speaker on Sickle Cell Disease for Old Dominion University and Bryant & Stratton College Black History Month events.

March - Planning Young Adults Transition Meet and Greet to introduce new and existing clients to available services and resources. The Meet and Greet will be held in June end of school year. Community resources, job fair and a social event is planned. Two groups were given presentations to inform them about the sickle cell traits and Agency services.

April - Participated in Advocacy Day in Washington, DC with the National Sickle Cell Office. Provided training to volunteers and clients on the Advocacy information for the Re-authorization of the Sickle Cell Treatment Act. Recruited Eastern Virginia Medical School Public Health students as interns in the community to identify sickle cell families and determine the types of disease in the family as well as provide ongoing education about the disease.

May - Participated in area-wide health and awareness fairs at churches to reach persons with sickle cell disease and the trait. Co-hosted a blood drive with the Kappa Alpha Psi on the Saturday before Mother's Day and sat up a health information booth.

June - Held Juneteenth Festival on Virginia Eastern Shore to celebrate World Sickle Cell Day on June 20, 2015. Sickle cell families and community participated in the Annual Walk for Good Health and visited the information booth. Partnered with CHKD to hold Young Adults meet and Greet as an ongoing support group session. The young adults participated in discussion groups, played games, danced and had pool passes.

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:

Calls from Clients/Family for information/assistance.

Number: 60

Information or Referral Assistance to Clients and Families

Number: 14

Financial Assistance to Clients for rent, utilities, medical bills, and college scholarships, etc.
(Funded by - Non Grant Funds)

Number: 33 for total of \$3,623

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 648

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 10

Number of Attendees: 224

Type of Support Group offered:

Meetings

Number of Participants: 56

Hospital Visitation

Number: 13

Home Visitation

Number: 6

Other Activities:

Birthday cards sent to clients having birthdays during each month

This is done so clients know that the organization is thinking about them.

Number Sent: 10

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

Number Sent: 27

Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.

Number Sent: 99

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 16

Calls to clients to obtain information or update contact information

Number: 46

Narrative/Other Information:

An annual motorcycle ride was held.

Literature placed 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:

Calls from Clients/Family for information/assistance.

Number: 188

Information or Referral Assistance to Clients and Families

Number: 81

Financial Assistance to Clients for rent, utilities, medical bills, and college scholarships, etc.
(Funded by - Non Grant Funds)

Number: 22 for total of \$1,650

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 5794

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 18

Number of Attendees: 9561

Type of Support Group offered:

Meetings

Number of Participants: 204

Other Activities:

Birthday cards sent to clients having birthdays during each month

This is done so clients know that the organization is thinking about them.

Number Sent: 78

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

Number Sent: 87

Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.

Number Sent: 448

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 137

Calls to clients to obtain information or update contact information

Number: 175

Narrative/Other Information:

Helped in partnership with Antioch Baptist Church to serve people with hot lunch, groceries and clothing.

October Served 217 people

November Served 311 people

December Served 521 people

Gave away Christmas Food Baskets to 4 families

January Served 332 people

Made a presentation to 3rd graders at Newsome Park Elementary School in Newport News.

February Served 482 people

Promoted education and awareness in our community by attending a Community Health Fair at the Hampton Roads Convention Center in Hampton VA this fair promoted the registration of health insurance on the healthcare.gov website.

March Served 376 people

Promoted education and awareness by presenting at the St. Johns Catholic Church.

April Served 411 people

SCAP promoted education and awareness in our community by attending a health fair at Calvary Baptist Church in Newport News.

May Served 338 people

SCAP promoted education and awareness in our community by attending a health fair at Morningside Baptist Church in Hampton.

June Served 487 people

Promoted education and awareness in our community by hosting our 25th annual Afrikan American Festival in Hampton.

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:

Calls from Clients/Family for information/assistance.

Number: 197

Information or Referral Assistance to Clients and Families

Number: 16

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

Number: 10 for total of \$4,495.00

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

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:

Distribution of Sickle Cell Literature

Number: 3452

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 18

Number of Attendees: 1864

Blood Drives-Every donation saves 3 lives. Many Sickle Cell Clients need transfusions monthly

Number: 6

Number of Attendees: $514 \times 3 = 1542$ number of lives saved

Special Client Information Mailing - Each client was mailed information to better educate them about their disease and provide them with inspiration. We feel that giving clients such information gives them a better understanding of the disease and what is going on to treat it.

Number Sent: 1946

Type of Support Group offered:

Adult Support Group Meetings 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

Number of Participants: 53

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: 257

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

Number Sent: 278

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.

Number Sent: 1260

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 29

Calls to clients to obtain information or update contact information

Number: 196

Taped a 30 minute radio program about the effects of Sickle Cell Disease and the up-coming 7th

Annual Motor Cycle Unity Ride for Sickle Cell.

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

Calls received as a result of Radio ads

Number: 5

Narrative/Other Information:

July- Purchased to mail to clients later, Holiday Greeting Cards and 2015 Monthly Planner. Also purchased 3 in 1 key chain as a promotion for the organization.

August - Our goal is to get valuable information to each client. Having information presentations at support group meetings is a benefit to those who attend while those who do not miss out. E-mailing the information would only reach 1/3 of our clients. Therefore we are putting more focus on mailing information to each client. September - Made 2 presentations , had 2 TV interviews, participated in 4 blood drives and a training session with Virginia Blood Services. We are now working with Tiffany and Ronald Dews who have two children with Sickle Cell, Melanie Mitchell of Virginia Blood Services and Thomas "Tommy P" Page from Roanoke who lost one of his three children with sickle cell to improve things for clients, educate the public and increase blood donations for sickle cell clients.

October - Administrator attended the 3 day Sickle Cell Disease Association of America Conference in Baltimore, MD. This month we sent two pieces of information on Hydroxyurea. The first one was Hydroxyurea: Is it Your Hope For Better Days? by the University of Florida. The second one was Start Healing in Patients with Hydroxyurea! A Research Study to Help People with Sickle Cell Disease by VCU.

November - This month we sent each client a copy of an article "FDA Helps Tackle Sickle Cell Disease. This article is a follow-up to the February FDA meeting. We also sent each client a 12 Month Appointment/Calendar Book to help them keep track of their appointments.

December - This month we sent each client a Holiday Greeting Card.

January - Support Meeting - A healthy New Year - by Anthem Caremore

February - "Thinking of You cards sent to each client. Participated in a blood drive at "White Oak" with Virginia Blood Services to get donations to help Sickle Cell patients. Response was good but would have been better if it had not snowed starting at 1:00 and made us stop at 4:00 instead of 7:00 P.M. The radio station gave all day coverage to the blood drive and allowed the Administrator to speak about Sickle Cell and the monthly need for blood.

March - On Monday, March 16th Channel 8 TV presented a segment on Sickle Cell Disease with a 13 year old client Jasmine China. Other segments will follow.

April - This month we provided two "Words of Wisdom" we hope will give clients direction, inspiration and support. On Thursday, April 16th Channel 8 TV presented a segment with a mother of two children with Sickle Cell who also works for Virginia Blood Services. On Monday, April 27th Channel 8 TV Noon News interviewed George Carter and Sylvia Alexander-Wall about Sickle Cell and the 7th Annual Motorcycle Unity Ride for Sickle Cell.

May - On Saturday, May 2nd, held the 7th Annual Sickle Cell Unity Ride to raise sickle cell awareness and funds to help clients pay medical, utility bills, etc that they are unable to pay. The motorcycle ride was about 22 miles from Petersburg to Richmond with 346 riders and around 100 supporters, friend and clients at 2nd Baptist Church of South Richmond. That day, Channel 8 presented a segment about Sickle Cell and show many of the bikes in the 7th Annual Motorcycle Unity Ride for Sickle Cell. During the month, Radio One stations air a 30 second commercial ad about Sickle Cell by one of our clients.

June - Mailed information about Capital Area Health Network which can provide other medical & dental services. During the month, Radio One stations air a 30 second commercial ad about Sickle Cell by one of our clients. On June 5th participated in Health Fair in Charles City. On June 13th participated in Health Fair with DTLR in Richmond. On Saturday, June 27th, participated in a blood drive in honor of one of our sickle cell clients.