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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 26, 2016

**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 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 social, psychosocial and educational 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 - \$100,000 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, FY15 and FY16, 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 FY16:

Blue Ridge Area Sickle Cell Association (BRASCA)	Rocky Mount	\$ 4,944.00
Heart of Gold Sickle Cell Foundation of Northern Virginia	Northern Virginia	\$15,482.00
Sickle Cell Association	Norfolk	\$32,994.00
Sickle Cell Association of Central Virginia	Lynchburg	\$ 3,862.00
Sickle Cell Association of the Peninsula	Hampton	\$13,311.00
Sickle Cell Association of Richmond – OSCAR	Richmond	\$34,407.00
Includes \$6,951.00 to pay some bills for Statewide Sickle Cell Chapters of Virginia (Materials, supplies, accountant, Administrator and Grant Administrator.		
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, 2016**

The six aforementioned organizations were awarded funding to begin community-based services on July 1, 2015. The following information provides a summary of the community-based activities performed as of June 30, 2016. Monthly activity and financial reports are submitted by each chapter to the “Statewide Grant Administrator” for review and approval and submitted to the Virginia Department of Health by the 15<sup>th</sup> 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:** 7

Information or Referral Assistance to Clients and Families

**Number:** 5

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

**Number:** 5 for total of \$600.00

Home Visitation

**Number:** 65

Hospital Visitation

**Number:** 43

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 1078

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 11

**Number of Attendees:** 5725

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

**Number of Attendees:** 35

**Type of Support Group offered:**

Meetings

**Number of Participants:** 110

**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:** 23

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

**Number Sent:** 63

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

**Number Sent:** 108

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 61

Calls to clients to obtain information or update contact information

**Number:** 66

## **Narrative/Other Information:**

### **Rocky Mount**

July - Paid ad for local festival for two-days, volunteers scheduled for festival for membership drive in August. Planning two fund raising events and walk-a-thon. Continuing website maintenance.

August - Set up and distributed material at two festivals, one a two-day event and the other in the Roanoke area. The membership drive began in August, will continue. Planning a fund raising events and walk-a-thon, committee working. The website is up and running, visit us at [www.brasca.org](http://www.brasca.org). The scholarship will be given out in January, 2016, when the student transfers to Radford University. The annual blood drive is scheduled for 13 February 2016.

September - The fund raising event and the awareness day was a success. Working on upcoming blood drive. The membership drive began in August and will continue. There were 35 new members.

October - Planning an annual fund raising event and walk-a-thon next year. Planning upcoming blood drive, churches notified, volunteers getting donors. Membership drive continues. There were 45 new members. Preparing for Christmas parade and lighting of Christmas tree with client's names who are deceased. Sickle Cell literature distributed at Resource center in Roanoke.

November - Planning and working on upcoming blood drive, committee report they are working on having a bone marrow testing at the blood drive in February 2016. This is through Virginia Blood Services. A Sickle Cell Client will represent the chapter in the Franklin County Christmas parade. A banner was purchased to decorate the vehicle she will be riding. Sickle Cell literature was distributed at Department of Social Services Resource center, Franklin County.

December - Donated to Carillion Franklin Memorial Hospital love light tree to honor those Sickle Cell clients who have past. Planning and working on upcoming blood drive in February 2016. The Franklin County Christmas parade was a success. There was an estimate of 2500 spectators.

January - Distributed material to Franklin Memorial Hospital for display. There was very little contact with clients due to inclement weather this month. There seem to be more hospitalizations this month than usual. One client was in UVA hospital for 10 days. Planning and working on upcoming blood drive on 13 February 2016.

February - The annual blood drive was a huge success. Five clients were hospitalized this month. Three remain in the hospital. The committee decided to host a second blood drive in September at the annual Sickle Cell awareness event. A committee worked on the hearing survey. Thank you cards went out to the supporters and churches who helped make the blood drive a success.

March - The committee completed the audiology survey. The planning continues for the September awareness event. The annual beauty pageant is in the planning stage. A page ad was purchased. One client had hip surgery and is recovering. An awareness event is planned for Henry County.

April - The annual beauty pageant was a success. Provided transportation to Danville for Client with Legal Aid Society. There were 4 clients hospitalized this month.

May - The event planning committee for walk-a-thon and awareness event scheduled later this year continue to meet and plan. An awareness event was planned for Henry County. The transported client to Danville with Legal Aid Society reported a positive outcome. There were 6

clients hospitalized this month. A delayed scholarship was awarded to a Client for the next school year.

June - The event planning committee for walk-a-thon and awareness event scheduled for later this year continue to meet and plan. There were 5 clients hospitalized this month.

**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:** 12

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:** 1 for \$300.00 0 **Hospital Care Kits**

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 2,687

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 4

**Number of Attendees:** 786

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

**Number:** 0

**Number of Attendees:** 0

Posted Sickle Cell information on Facebook page for viewing.

**Number:** 20,000 views

Sickle Cell Walk

**Number of Participants:** 0

**Type of Support Group offered:**

Meetings

**Number of Participants:** 0

**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:** 0

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

**Number Sent:** 134

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

**Number Sent:** 3,040 and others

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 40

Calls to clients to obtain information or update contact information

**Number:** 5

## **Narrative/Other Information:**

### **Northern VA**

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

July - Donation (non-grant funds) made to Children's National Medical Center's "Brainy Camp" to support camper suffering from SCD. Information distributed at Health Fair sponsored by First Mount Zion Baptist Church, Dumfries, Virginia. Information distributed on Facebook and Chapter webpage. Information distributed at Inova Alexandria Hospital re: Adult Sickle Cell Clinic in Northern Virginia.

August - Information distributed on Facebook and Chapter webpage. Letters sent to 20 churches in Northern Virginia including brochure and business card discussing Sickle Cell Awareness Month, upcoming Stomp Out Sickle Cell Walk and the importance of blood donations. Facebook page increased number of "likes" by 8 persons. Web page logged 240 viewers

September - Information distributed on Facebook and Chapter webpage. Heart of Gold Foundation was a sponsor for the 9th Annual "Stomp Out Sickle Cell" Walk on the National Mall in Washington, D.C. on September 12. Health Fair at Alfred Street Baptist Church, Alexandria, VA. Distributed information at the Ivy Foundation of Northern Virginia Community Awards Ceremony on September 30.

October - Information distributed on Facebook and Chapter webpage. Posted information on Facebook page about hearing loss in SCD patients. Service Coordinator contacted Dr. Elizabeth Yang, Centers for Blood Disorders to support Holiday Party. Heart of Gold will have an information table at this event on December 12, 2015 in Fairfax, Virginia. Received acknowledgement from Children's National Medical Center for continued financial support of the Brainy Camps program.

November - Information distributed on Facebook and Chapter webpage. Posted information on Facebook page about hearing loss in SCD patients. Service Coordinator had conference call with Pain Management Nurse at Alexandria Hospital for assistance in developing materials regarding SCD and pain management.

December - Participated in INOVA Center for Blood Disorders Holiday Party on December 12. Distributed "Hope and Destiny" books, workbooks and hospital care kits (contained toothbrush, toothpaste, toys). Discussed future cooperative events with Dr. Elizabeth Yang and Social Work Staff for Sickle Cell adolescents.

January - Produced Public Service Announcement on the importance of Blood Donations for SCD patients. Posted on Facebook Page-over 290 persons viewed in 10 days. Distributed video to other member organizations of the Statewide Sickle Cell Chapters of Virginia. Also sent to the National Institutes of Health, the Ad Council and the INOVA Hospital Minority Blood Donation Program. Working on draft checklist for patients to have with them with admitted to the hospital.

February - Produced Public Service Announcement on the importance of Blood Donations for SCD patients posted on Facebook. During February an additional 20 likes and 80 shared posts. Finalizing draft checklist for patients to have with them with admitted to the hospital. Service

Coordinator visited General Assembly with Statewide Administrator to enhance awareness about SCD.

March - Facebook followers increased to 231 from 220. Pain management card drafted and will be sent to print in April. PSAs on USB drives have been sent to local media and the March of Dimes. Copies will be sent to other Statewide Sickle Cell Chapters.

April - Pain Management Card developed by Service Coordinator Pearson was printed and will be distributed in May. Fairfax County Board of Supervisors was contacted by Service Coordinator Bey for Proclamation in September for "Sickle Cell Awareness Month". Fairfax County Cable Channel 16 agreed to air PSA. Will reach more than 250,000 households in Fairfax County. Service Coordinator Pearson enrolled chapter in "Do More 24" a United Way fundraising and awareness campaign which will take place in June. Heart of Gold was asked to join the SiNERGE Project Community Based Collaborative. This group is part of the NIH HRSA funded North East Regional Sickle Cell Collaborative Project.

May - Pain Management Card developed by Service Coordinator Pearson was printed and will be distributed to local doctor's offices and Inova Hospital System. PSA thumb drive with 30 second video and 30 second audio was distributed to Sickle Cell Virginia chapters. Service Coordinator Pearson enrolled chapter in "Do More 24" a United Way fundraising and awareness campaign which will take place in June through the United Way. This program has the potential to reach more than 10,000 persons. Heart of Gold begun collaboration with the SiNERGE Project Community Based Collaborative. This group is part of the NIH HRSA funded North East Regional Sickle Cell Collaborative Project. Heart of Gold will register a team in June for the "Stomp Out Sickle Cell" walk scheduled for September, a collaboration with Howard University Hospital and Faces of our Children. Service Coordinator Pearson contacted through Twitter celebrity Junior (Keir Spates) of the nationally syndicated Steve Harvey Morning show about HR 1807, the Sickle Cell Bill in Congress. Mr. Spates suffers from SCD. He responded and the message was seen by his 21,000 followers.

June – Participated in the "Do More 24" a United Way fundraising and awareness campaign on June 2, 2016 and raised \$490. This program reached more than 10,000 persons. Heart of Gold continued the collaboration with the SiNERGE Project Community Based Collaborative. This group is part of the NIH HRSA funded North East Regional Sickle Cell Collaborative Project. Heart of Gold will participate in the "Stomp Out Sickle Cell" Walk scheduled for September, a collaboration with Howard University Hospital and Faces of our Children.

**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:** 173

Information or Referral Assistance to Clients and Families

**Number:** 72

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

**Number:** 41 for total of \$4,450

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 2,617

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

**Number:** 51

**Number of Attendees:** 3,814

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

**Number:** 3

**Number of Attendees:** 77

**Type of Support Group offered:**

Advocacy & Community Resources Meetings

**Number of Participants:** 225

Transition Young Adults Meetings

**Number of Participants:** 55

**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:** 92

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

**Number Sent:** 628

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

**Number Sent:** 754

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 1,175

Calls to clients to obtain information or update contact information

**Number:** 481

## **Narrative/Other Information:**

### **Norfolk**

July - Held the Young Adults Meet and Greet Pool Party. Identified a new client and followed up to complete intake information.

August - Held the Annual Sickle Cell Family Fun Day Camp and Back to School event on August 17 at EW Young Campsite. The activities included volunteer coordinated fishing clinic, arts and crafts, nature scavenger hunt, outdoor recreation games of basketball, bowling and indoor swimming. Twenty-five students received school supplies in a backpack and other students from Middle through College received school supplies. A \$1,200 scholarship was awarded to a volunteer participant who is attending college.

September - Clients held the first benefit to help families with emergency financial needs with a Las Vegas style Casino Night. Sickle Cell families kicked off the Annual Walk for Sickle Cell on September 19, 2015 alongside the Walk Grand Marshall. Clients received information about the SCDA Conference and will be informed of advocacy events on issues that affect Sickle Cell Disease.

October - Held a webinar on Nutrition for Sickle Cell patients in the office and invited clients and their families. Twelve families participated and other families will be mailed and emailed a copy of the cookbook when the copies are received. Hosted an "Unveiling Sickle Cell Services" forum for 75 community leaders, churches, clients and volunteers to present the services offered by the Association.

November - Invited Sickle cell families and volunteers to 43rd Birthday celebration of the Agency on November 13, 2015. Distributed 13 Thanksgiving food baskets to sickle cell families (7 were given on the Virginia Eastern Shore). Sent 93 brochures on Agency services along with "Thinking of You" Thanksgiving cards.

December - Held Sickle Cell families "Lunch with Santa" event on December 12, 2015 where 25 families participated and all children received toys. Sickle Cell adult clients and volunteers participated in "Holiday Ugly Sweater Party" on December 20, 2015. Participants were given a copy of the cookbook Eating Well with Sickle Cell - High Energy Nutrition Recipes, published by Nemours a national project of Synergie. Christmas food baskets were given to 10 sickle cell families by the Hiram Grand Masonic Lodge and 32 children were given Toys for Tots gifts from Salvation Army, Samaritan House and YWCA, Volunteers collected and wrapped gifts for children at CHKD clinic.

January - Presented at the Annual Martin Luther King Service held at First Baptist Bute Street, Norfolk that has 200 churches who are members of the Metro Baptist Ministers Conference. Blood drive was postponed because of the snow storm.

February - Invited clients to participate in a webinar on Managing Pain in Sickle Cell Patients provided by Karen Proudford Foundation in Baltimore Maryland. Notes from the webinar on pain management was emailed to 68 clients on the email list and copies to be mailed to the clients on mail list.

March - Clients were invited to attend Advocacy training. They were educated on Get Connected Sickle Cell Disease a national patient registry that is patient driven and connects them with current research, treatments and events across the country.

April - Clients were informed of the Advocacy initiative passed in Maryland on Services for Adults with Sickle Cell Disease- Infusion Center - Study. The efficacy of Infusion Centers to treat pain is being researched in the Hampton Roads area. It is proposed that Infusion Centers

would be a cost effective treatment for pain, offer genetic counseling and provide outreach regarding support services needed by the patients.

May - Clients were contacted regarding the National Sickle Cell Advocacy Day scheduled for June 9, 2016 in Washington, DC. Clients updated intake forms are being conducted to help clients get connected with a health care home and resources.

June - Released information about Opioids and is scheduling a roundtable discussion with the Pharmacist to openly talk about the safe use of opioids in sickle cell patients. Enrolled 30 sickle cell clients in the Get Connected patient powered data base. Held an advocacy training session for 12 participants who were scheduled to attend the national sickle cell advocacy day in Washington, DC. Explained how to talk to their legislators and what healthcare issues were currently a priority.

**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:** 25

Information or Referral Assistance to Clients and Families

**Number:** 15

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

**Number:** 24 for total of \$3,097

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 546

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 11

**Number of Attendees:** 375

**Type of Support Group offered:**

Meetings

**Number of Participants:** 64

Hospital Visitation

**Number:** 1

Home Visitation

**Number:** 28

**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:** 9

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

**Number Sent:** 36

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

**Number Sent:** 32

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 10

Calls to clients to obtain information or update contact information

**Number:** 50

**Narrative/Other Information:**

**Lynchburg**

July - Death claimed our oldest client (age 54) on Sunday, July 26, 2013. We donated \$500.00 toward funeral expenses.

September - Day in Park and Community Education Session at Diamond Hill Baptist Church

November - Former Board member passed away Nov. 8, 2015. Client now on dialysis.

Participated in Health & Wellness Fair sponsored by AKA Sorority on Nov. 21, 2015.

February - Client with SS disease passed away at age 35.

April - Memorial donations to a deceased client \$721.00 to date.

**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:** 162

Information or Referral Assistance to Clients and Families

**Number:** 103

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

**Number:** 8 for total of \$665.00

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 1,389

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 5

**Number of Attendees:** 483

**Type of Support Group offered:**

Meetings

**Number of Participants:** 135

**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:** 66

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

**Number Sent:** 116

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

**Number Sent:** 605

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 31

Calls to clients to obtain information or update contact information

**Number:** 270

## **Narrative/Other Information:**

### **Hampton**

July - SCAP promoted education and awareness in our community by presenting a sickle cell information video at Shilo Baptist Church in Hampton. SCAP also gave \$100 each to 2 graduating seniors with sickle cell on their way to college in the fall.

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

September Served 217 people.

October Served 250 people.

November Served 310 people.

December Served 410 people.

Held Christmas party for 60 clients. Distributed 15 food baskets and 5 turkeys to clients in need.

January Served 362 people.

Cleaned the client list and sent cards to clients.

February Served 512 people.

Added new clients by reaching out though the community. Making calls to check on clients.

Also providing clients with where they can receive proper care and listen to those who just need someone to talk with.

March Served 812 people.

Added new clients by reaching out though the community. Making calls to check on clients.

Also providing clients with where they can receive proper care and listen to those who just need someone to talk with. Made a visit to CHKD to introduce our chapter to the Sickle Cell Ward and met family members providing them with contact info if they ever need us for anything.

April Served 812 people.

Added new clients by reaching out though the community. Making calls to check on clients.

Also providing clients with where they can receive proper care and listen to those who just need someone to talk with. Reached out by phone to different community organizations that may have sickle cell members to let them know we are here to service them if needed.

May Served 876 people.

Added new clients by reaching out though the community. Making calls to check on clients.

Also providing clients with where they can receive proper care and listen to those who just need someone to talk with.

June Served 891 people.

Added new clients by reaching out though the community. Making calls to check on clients.

Also providing clients with where they can receive proper care and listen to those who just need someone to talk with.

## **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:** 199

Information or Referral Assistance to Clients and Families

**Number:** 10

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:** 9 for total of \$3,200.00

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

Contract Services for Client Advocacy Education and Representation

**Number of Participants:** 2

### **Type of Educational Program offered:**

Distribution of Sickle Cell Literature

**Number:** 6,385

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 18

**Number of Attendees:** 2,565

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

**Number of Attendees:** 162

**Number:** 162 X 3 = 406 number of lives saved

### **Type of Support Group offered:**

Adult Support Group Meetings where Transition Group (transition from pediatric to adult care) clients are invited. We are putting more focus on getting valuable information to each client by mail, not just persons who would attend support group meetings. Topics of mailings, meetings, e-mails are to educate clients on overcoming health and psychological issues including Pain Management, Stress Management, Nutrition and Resources within the organization.

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:** 3,336

### **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:** 253

"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:** 1,372

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 41

Calls to clients to obtain information or update contact information

**Number:** 266

Taped a 30-minute radio program about the effects of Sickle Cell Disease and the up-coming 7<sup>th</sup> Annual Motor Cycle Unity Ride for Sickle Cell.

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

Special mailings and e-mails to clients on Loss of Hearing Study in persons with Sickle Cell Disease and to Churches about Sickle Cell Month.

**Number:** 666

## **Narrative/Other Information:**

### **Richmond**

We are putting more focus on getting valuable information to each client by mail, not just persons who would attend support group meetings.

July - Provided two "Words of Wisdom" we hope will give clients direction, inspiration and support.

Make the most of yourself, for that is all there is.

Not only must we be good, but we must also be good for something.

August - Provided two "Words of Wisdom" to give clients direction, inspiration and support.

Each new day offers a chance to shine.

Success is a ladder you cannot climb with your hands in your pockets.

September - This month we provided each client with a calendar of the month of September with a sickle cell fact for each day of the month.

October - This month we provided two "Words of Wisdom" we hope will give clients direction, inspiration and support. What we see depends on what we look for.

How we view an obstacle affects our ability to overcome it. We also mailed each client bookmark cards with 50 Tips For Healthier Eating. We hope this will encourage clients to eat a healthier diet for their own good.

November - This month we mailed each client a 2016 Month Planner (calendar) book so each person can keep track of appointments.

December - This month we mailed each client a Holiday Card. A special mailing was sent to two churches to encourage members to donate blood during the month of January (Blood Donation Month) to assist sickle cell clients who require monthly blood transfusions. Forwarded to clients (107) an e-mail about a Sickle Cell Educational Briefing February 9, 2016 in Annapolis, MD.

January - This month we provided two "Words of Wisdom" we hope will give clients direction, inspiration and support. No one can make you feel inferior without your consent. Kindness in words creates confidence. Kindness in giving creates love. A special announcement was made at one church to encourage blood donations during January (Blood Donation Month) to assist clients who require blood transfusions. Mailed each client a research survey being conducted by Dr. M. Dawn Nelson, Ph.D., an Associate Professor of Audiology at Central Michigan University studying the association between dizziness/balance and hearing problems and Sickle Cell Disease.

February - This month we provided two "Words of Wisdom" we hope will give clients direction, inspiration and support. For success, attitude is equally as important as ability. Goodwill... is an immeasurable and tremendous energy, the atomic energy of the spirit.

Worked with Virginia Blood Services on two blood drives during February to get donations for sickle cell clients who require regular blood transfusions. One of our clients was killed in the tornado in Waverly, VA.

March - This month we provided two "Words of Wisdom" we hope will give clients direction, inspiration and support. For success, attitude is equally as important as ability. Goodwill... is an immeasurable and tremendous energy, the atomic energy of the spirit.

Had meeting with lead persons for our 8th Annual Unity Ride for Sickle Cell from Petersburg to Richmond to take place on May 7th.

April - We provided two "Words of Wisdom" we hope will give clients direction, inspiration and support. Seeing a goal through to the end can lead to something amazing. We need love and creative imagination to do constructive work.

Had meeting with lead persons for our 8th Annual Unity Ride for Sickle Cell from Petersburg to Richmond to take place on May 7th. One of our Service Coordinators spoke on a radio program (broadcasted on three radio stations) about Sickle Cell and the Unity Ride.

May - This month we provided two "Words of Wisdom" we hope will give clients direction, inspiration and support. A cloudy day is no match for a sunny disposition. In about the same degree that you are helpful, you will be happy.

One of our clients appeared on WXEX TV Channel 8 Noon News program (broadcasted in Metro Richmond and beyond) to talk about Sickle Cell and the Unity Ride. We held our 8th Annual Unity Ride for Sickle Cell from Petersburg to Richmond on May 7th. Over 250 motorcycle riders participated. The Unity Ride is the organization's largest fund raiser. The funds are used to provide financial assistance to clients in need and support other things not funded by our state grant.

June - We are putting more focus on getting valuable information to each client by mail. This month we provided two "Words of Wisdom" we hope will give clients direction, inspiration and support. Tough times never last, but tough people do. The smallest good deed is better than the grandest of good intentions.