

# STATEWIDE SICKLE CELL CHAPTERS OF VIRGINIA, INC.

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## REPORT

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

September 26, 2017

#### **What is Sickle Cell Disease and what is its impact?**

Sickle Cell Disease is an inherited blood disorder where normal soft round shaped red blood cells change to a hard sticky sickle or quarter-moon 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. There is no universal cure.

Nationally, approximately 1 in 500 African American children is born with Sickle Cell Disease, 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**

Screening of all newborns for Sickle Cell Disease began in Virginia during July of 1989. Since 1989, an average of 75 newborns have been identified yearly with Sickle Cell Disease. 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.”**

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 needed 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.

**Our Chapters/Community-based programs provide resources to address unmet social, psychosocial and educational needs.** They also provide coping strategies and support for families impacted by Sickle Cell Disease. Many of the community-based programs provide a focus on mental and social well-being as well as stress-reducing activities that have a positive effect on physical well-being. Some of the services include support group meetings, calls to check on clients, visitations, sending sickle cell information, "Birthday" and "Thinking of You" cards, providing referral assistance, assistance with obtaining disability benefits, employment and vocational rehabilitation. All chapters provide sickle cell education in the community through participation in health fairs, forums, church activities and civic or health related events. These services vary from chapter to chapter based in part on funds and man-power available.

All chapters receiving grant awards have previously conducted several years of “Surveys of Needs” with as many of their registered clients as possible. The surveys have enabled chapters to determine what services are needed, by whom and how best they can be delivered to clients.

There are four comprehensive sickle cell centers under contract 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, but generally, do not provide services to non-patients of their hospitals. That means that the centers are only fully 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.** Community-based sickle cell programs work to assist any client/patient needing services.

### **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 yearly for medical/hospital management services for individuals living with Sickle Cell Disease and a yearly allocation of \$100,000 was approved for grants to community-based programs. 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
- FY17 - \$105,000 for four 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.

During FY17, Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded four contracts to member chapters.

Two chapters that previously participated in the grant program did not do so in FY17. Lynchburg decided that due to the age and size of its membership, that they wanted to concentrate their efforts on raising funds to help their clients with medical bills and other financial assistance that the grant does not provide. Hampton had new officers and struggled to meet the grant requirements in FY16, mostly to spend organization funds first and wait for reimbursement with grant funds and did not apply for funding in FY17.

Four chapters received the following funding during FY17:

Blue Ridge Area Sickle Cell Association (BRASCA)	Rocky Mount	\$ 5,994.00
Heart of Gold Sickle Cell Foundation of Northern Virginia	Northern Virginia	\$18,769.00
Sickle Cell Association	Norfolk	\$39,999.00
Sickle Cell Association of Richmond – OSCAR	Richmond	\$33,287.00
PLUS		
Statewide Sickle Cell Chapters of Virginia		\$ 6,951.00
(Operational expenses for Statewide including materials, supplies, accountant fee, Administrator and Grant Administrator)		
Total		\$105,000.00

#### **Community-Based Sickle Cell Program Activities as of June 30, 2017**

The four aforementioned organizations were awarded funding to begin community-based services on July 1, 2016. The following information provides a summary of the community-based activities performed as of June 30, 2017. 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:** 16

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:** 14 for total of \$977.55

Home Visitation

**Number:** 63

Hospital Visitation

**Number:** 63

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 897

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 12

**Number of Attendees:** 1300

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

**Number of Attendees:** 26

**Type of Support Group offered:**

Meetings

**Number of Participants:** 125

**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:** 25

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

**Number Sent:** 68

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:** 220

Calls to clients to obtain information or update contact information

**Number:** 522

## **Blue Ridge Area Sickle Cell Association - Continued**

### **July**

Planning walk-a-thon in September. Planning festival in August. Memberships for year begin in August. A donation was given to client to repair air conditioner in their home. (\$80.00)

### **August**

The walk-a-thon is September 17. The Warren Street Society Festival in August was a great success. Over 200 people passed through the booth in 2 days. Scholarship recipient went off to college. The annual blood drive is scheduled for early 2017.

### **September**

The walk-a-thon was a success. Donations were received, membership increased. There were 81 people who participated in the walk and others attending to hear the speakers. The annual blood drive is being planned, volunteers being contacted. Virginia Blood donated 50 tee shirts. The organization bought 50 tee shirts and all were distributed. The tote bags were donated; personal journals and SC information was distributed to all clients who attended. A family who had a bone marrow transplant shared their story.

### **October**

Donations were received from a local elementary school that cooperated in raising funds for BRASCA in school walking club. The school raised \$1,009.83 in two weeks and will continue throughout the year. BRASCA will have its first Christmas party of clients and friends in December. We purchased medication for one client. We sent one board member to Richmond to a state meeting. Distributed information at Oktoberfest in Henry County, as well as the local hospital. There were no October birthdays.

### **November**

Donations continue to come in for walk we had in September. BRASCA will have its first Christmas party of clients and friends in December. We purchased medication for one client and gave traveling expenses to another family who travelled to Duke University. We paid traveling expenses for member who went to the state meeting (non-grant funds). There were three hospitalizations this month. One client is waiting for a hip replacement. We recognized 5 members who passed in the Carilion Love Light Tree program.

### **December**

Planning recognition for those who helped with the School walk. The Christmas party for clients and friends was a success. There were five hospitalizations this month. One client is still waiting for a hip replacement. 2 volunteers were recognized at the Christmas party for their support during each walk-a-thon. Plans continue for the blood drive in February. A total of 45 participated in the Holiday social, 50 at the Martinsville, VA festival and 50 at the Love Light Tree Carilion ceremony.

### **January**

The recognition for those who helped with the School walk is scheduled for March. The committee is working with Carilion Hospital in developing a relationship during hospital stays both in Franklin County and Roanoke. A meeting is scheduled for the Henry County clients who live in that area. Purchased pre-printed literature for distribution. The client who is waiting for a hip replacement is scheduled for February. BRASCA will meet with the elementary faculty where two students attend. Our goal for the blood drive on February 11th is 50 pints.

## **Blue Ridge Area Sickle Cell Association - Continued**

### **February**

The committee is working with Carilion Hospital in developing a task force to help during hospital stays both in Franklin County and Roanoke. The next meeting is in March. A date has not been set for the Henry County clients who live in that area. The client who had a hip replacement is recovering. The blood drive was a success. Two clients who had needs were met. The committee is still working on the 501c3 status.

### **March**

We presented a plaque to the faculty for the outstanding fund raising project. We also presented a plaque to the teacher who initiated the project. A Carilion Pharmacist, (Dr.) gave a presentation on opioid usage, dosage and new regulations. Henry County did not have a meeting date set. The walk-a-thon committee is planning their event. Newspaper articles and web posting were done as a result of the successful blood drive.

### **April**

Solicitation letters are being mailed for the up coming walk in September. We purchased an ad in the program for one client who participated in a pageant. There were three hospitalizations this month. Committees continue to meet for up coming events. We helped (1) client financially. We distributed (25) pamphlets to Carilion Franklin Memorial for display.

### **May**

Plans continue for the walk-a-thon scheduled for September in Franklin County. We distributed information received from the statewide chapter regarding research efforts in a health care issue. There were four hospitalizations this month. Committees are working toward upcoming events. We helped (3) clients financially. We distributed (60) pamphlets to a senior citizen group who invited us to attend. Continue to work with Carilion task force.

### **June**

Plans continue for the walk a thon scheduled for September in Franklin County. We distributed literature to 2 sorority clubs who will participate in the walk. Committees working toward up coming events and membership drive. We helped (2) clients, financially. We recognized the classrooms and teachers at the school that had the fund raising project in the spring. The Carillion task force seem to be working well. The Statewide grant project was completed for 2016-17 and 2017-18 was submitted.

## **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:** 21

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 - Non Grant Funds)

**Number:** 4 for \$1,500.00      **Hospital Care Kits**

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

Pieces of Literature Distributed

**Number:** 3,106

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 6

**Number of Attendees:** 801

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

**Number of Attendees:** 2

Posted Sickle Cell information on Facebook page for viewing.

**Number:** 20,000 views

Sickle Cell Walk

**Number of Participants:** 500

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

Meetings

**Number of Participants:** 105

### **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:** 295

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

**Number Sent:** 480 and others

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 69

Calls to clients to obtain information or update contact information

**Number:** 14

### **The Heart of Gold Sickle Cell Foundation of Northern Virginia - Continued**

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 activities has been high as demonstrated in the narrative below.

#### **July**

Hearts of Gold Brochures were distributed at the Blood Drive/Health Fair at the First Mt. Zion Baptist Church, Dumfries, VA. Call received from client interested in information as she is preparing for college. Service Coordinator discussed sponsorship opportunity for the Stomp Out Sickle Cell Walk 2016, scheduled for September 10 on the National Mall, Washington, D.C.

#### **August**

Service Coordinator Pearson finalized the sponsorship agreement for the Stomp Out Sickle Cell Walk 2016, scheduled for September 10 on the National Mall, Washington, D.C. Fairfax County Board of Supervisors will issue a proclamation for National Sickle Cell Awareness Month. Letters were mailed to 40 churches informing them of National Sickle Cell Month and encouraging their members to donate blood and to participate as a member of "Team Heart of Gold" at the SOS Walk in Sept. CDC opiates guideline brochure was developed. Produced a video that will be shown on Fairfax County Channel 16 on the importance of knowing your sickle cell status. This video is also available on You Tube and the Heart of Gold Facebook page.

#### **September**

Participated as a sponsor for the 10th Annual Stomp Out Sickle Cell Walk, Washington, D.C. Received a proclamation from the Fairfax County Board of Supervisors for Sickle Cell Awareness Month. Participated in Health Fair and Blood Drive at the Alfred Street Baptist Church, Alexandria, VA. Program produced by Service Coordinator Bey showed for the month of September on Fairfax County Cable Channel 16 promoting awareness of Sickle Cell Anemia. Participated in Sickle Cell Walk in Rocky Mount, Virginia. Met with Fairfax County Health Department Staff about learning Sickle Cell Trait Status. Distributed Pain Management Cards to clients and hospitals. Shared information on NIH clinical study with clients and on web. Began development of Mothers Against Sickle Cell Blog and Support Group. Sent contribution to Brainy Camps from fundraising dollars.

#### **October**

We received donation from Ivy Foundation of Northern Virginia for \$250.00. Conducted "Booster" fundraiser campaign and received \$129.00. Wrote letters to national elected officials to support Sickle Cell Disease Initiatives. Brainy Camps of the National Children's Medical Center requested a partnership. Distributed Public Service Announcement thumb drive to State of Virginia Sickle Cell Chapters. Service Coordinators attended Statewide Sickle Cell meeting in Richmond. Distributed information about studies at NIH.

#### **November**

We received donation from individual supporter for \$25.00. Conducted "Giving Tuesday" campaign on November 29. Met with Dr. Elizabeth Yang, INOVA Children's Hospital about partnership efforts (Service Coordinator Pearson and Bey). Brainy Camps of the "National Children's Medical Center" requested a future partnership and plan to meet in December. Began Facebook page "Mothers About Preventing Sickle Cell" as a support group/outreach activity. Conducted a "Toys for Sickle Cell" fundraiser.

## **The Heart of Gold Sickle Cell Foundation of Northern Virginia - Continued**

### **December**

Participated in INOVA Children's Hospital Holiday Party on December 9th. Distributed informational books, brochures and toys. Continued online support group on Facebook "Mothers About Preventing Sickle Cell" as a support group/outreach activity. Encouraged public to donate to Heart of Gold through the Amazon Smile campaign. Responded to college student client and encouraged her on ways to maintain her health.

### **January**

Continued online support group Mothers About Preventing Sickle Cell. Provided information to the Carpenters Shelter in Alexandria Virginia for a homeless resident with a Sickle Cell Child. Developed and printed a brochure on transition, which will be distributed in February.

### **February**

Responded to client in need of assistance with places to get financial assistance and health insurance. The client had just turned 26 and was no longer eligible for parent's insurance. Referred to social security and Medicare/Medicaid. We received inquiry from Sickle Cell Consortium about becoming a credentialed member. Treasurer is reviewing the requirements. Continued on-line support group Mothers About Sickle Cell prevention.

### **March**

Service Coordinator Pearson attended National Sickle Cell Consortium representing Heart of Gold Foundation in Atlanta, Georgia. Pamphlets on transition from pediatric to adult care were distributed.

### **April**

Distribution continued of pamphlets on transition from pediatric to adult care. Service Coordinator Pearson developed bracelets with Heart of Gold information for clients. Plan to distribute before World Sickle Cell Day. Service Coordinator Pearson contacted Brainy Camps about sponsorship of camper with SCD. Service Coordinator Pearson developed postcard for distribution to physician offices informing them of the services of Heart of Gold Foundation. Service Coordinator Pearson contacted the United Way to enroll Heart of Gold in "Do More 24 Campaign", a fundraising effort scheduled for June.

### **May**

Distribution continued of pamphlets on transition from pediatric to adult care. Service Coordinator Pearson developed bracelets with Heart of Gold information for clients. Plan to distribute before World Sickle Cell Day. Service Coordinator Pearson contacted Brainy Camps about sponsorship of camper with SCD. Service Coordinator Pearson developed postcard for distribution to physician offices informing them of the services of Heart of Gold Foundation. Service Coordinator Pearson contacted the United Way to enroll Heart of Gold in "Do More 24 Campaign", a fundraising effort scheduled for June.

### **June**

Distribution continued of pamphlets on transition from pediatric to adult care. Heart of Gold successfully participated in the United Way "Do More 24" and raised \$1,400.00. These funds were donated to Brainy Camps for scholarships for 3 youth suffering from SCD. Service Coordinator Bey contacted the Fairfax County Board of Supervisors. They will recognize September as Sickle Cell Awareness Month. New initiative for the fall is "know your status" and we have contacted local physicians to participate in program.

**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:** 358

Information or Referral Assistance to Clients and Families

**Number:** 75

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

**Number:** 36 for total of \$2,833.00

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 1,863

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 38

**Number of Attendees:** 2,459

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

**Number of Attendees:** 53

**Type of Support Group offered:**

Advocacy & Community Resources Meetings

**Number of Participants:** 210

Transition Young Adults Meetings

**Number of Participants:** 12

**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:** 119

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

**Number Sent:** 404

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

**Number Sent:** 1,457

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 758

Calls to clients to obtain information or update contact information

**Number:** 398

## **Sickle Cell Association - Continued**

### **July**

Held the End of School year pool party for sickle cell youth and their families. The event had 47 participants at the community center. Gave a presentation on Agency services and the national initiative "Get Connected". Afterwards the families signed up for the national conference in Baltimore, Family Fun Day Camp in August and enrolled in the "Get Connected" patient driven registry.

### **August**

Held a Sickle Cell Family Fun Day and Back-To-School supplies and giveaway on August 27, 2016. There were 102 participants that responded to the flyer about the free event. Attendees needed to register for the food count, however 53 actually attended. There were a number of other back to school supplies giveaways on the same day in the area. Sickle cell families were able to meet the Agency Board of Director volunteers and Masonic Lodge and Eastern Star partners who helped with donating the shoes, food and school supplies. Referrals are still being sent to the Agency by Children's Hospital to pick up school supplies and get services.

### **September**

Held a Strengthening of Family Forum and Health Awareness Fair for Sickle Cell families on September 17, 2016. Local pharmacist from Walgreens was guest speaker at the forum on Pain Management and Opioids. His discussion centered on the 14-point guidelines for opioid prescriptions given to sickle cell patients. The 30 participants had the opportunity to discuss how they were managing their pain. A follow-up forum will be held at a later date to invite other sickle cell families who could not attend. Hampton University invited the Association to set up an information booth at their quarterly blood drive where 46 students were recruited to donate blood.

### **October**

Calls to clients to update case files and refer for medical services. Mailed brochures to 30 clients on the Get Connected program and discussed the importance of having a medical home with a doctor to follow them.

### **November**

Held blood drive at Hampton University where 58 students had pre-registered to give blood. This will be a quarterly scheduled event on campus with the Health Services Clinic. Thanksgiving food baskets were given to 16 sickle cell families and completed updated case files on new clients. Made home visits to 3 families who were unable to come to the office.

### **December**

Held first Bowling with Santa event to promote public awareness about Organization, resources, and program. Thirty-eight participants came out for the free bowling and refreshments. Photos were taken with Santa and gifts were distributed. The event is being planned for next year. The second event provided fifteen families with Christmas food baskets along with toys donated by Salvation Army. Client's intakes and updated information at each event were put in the client database.

### **January**

Participated in two blood drives and gave information on the importance of blood donations for sickle cell patients. Showed video on Sickle Cell Disease and Blood Donations. Completed six new client intakes and provide financial assistance to three persons.

### **Sickle Cell Association - Continued**

#### **February**

Held two health fairs at client's school as a part of the Black History Month Celebration. Recognized Charles Drew in the Assembly for research in the medical field of blood transfusions and gave the importance of donating blood and the use by sickle cell patients.

#### **March**

Sickle Cell client presented on a panel at a churchwomen conference. There were 30 participants at the conference session on health care issues. The client spoke on living with the disease, overcoming obstacles and being productive in her community as a volunteer.

#### **April**

Participated in two blood drives: One at a church and the other at Hampton University that included a booth display explaining the importance of minority donors and the need by sickle cell patients. Clients stopped by the booth to take flyers to their classes on campus for distribution.

#### **May**

We contacted clients who were enrolled in "Get Connected" and referred by SCDA. Follow up calls to determine if the clients had a medical home and found one client who needed a doctor referral (his doctor was leaving the practice). All the clients have a medical home and will be on the email list for newsletters and client related events.

#### **June**

Partnered with the Shriners who sponsored their annual rodeo and 30 tickets were given to sickle cell children and their parents. Sent educational flyers on Hydroxyurea information to two new client intakes.

**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:** 308

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 the Annual Unity Ride for Sickle - Non Grant Funds)

**Number:** 17 for total of \$7,613.81

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 \$1,500.00

Contract Services for Client Advocacy Education and Representation

**Number of Participants:** 0

**Type of Educational Program offered:**

Distribution of Sickle Cell Literature

**Number:** 3,828

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 9

**Number of Attendees:** 1,222

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

**Number of Attendees:** 35

**Number:** 35 X 3 = 105 number of lives saved

**Type of Support Group offered:**

We are putting more focus on getting valuable information to each client by mail, not just to 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:** 1,946

**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:** 248

### **Sickle Cell Association of Richmond-OSCAR - Continued**

"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:** 1,283

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:** 243

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

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

Annual Motor Cycle Unity Ride for Sickle Cell

**Number of Participants:** 217

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:** 834

Ran ads to raise more awareness about Sickle Cell Trait/Disease to educate more members of the public. The ad was run in the Free Press Newspaper (100,000 readers) and on a radio station listened to by persons of childbearing age (130,000 households). It was also sent by G-O Fencing to 100,000 IP address going to smartphones. Part of Unity Ride radio program in April was broadcasted to 130,000 households.

**Number of Households Reached:** 460,000

## **Sickle Cell Association of Richmond-OSCAR - Continued**

### **July**

We are putting more focus on getting valuable information to each client by mail. This month, we mailed a guide that provides tips on getting financially and physically fit. From the financial perspective, the guide covers topics such as credit, credit card debt, budgeting, retirement planning, saving, insurance and identify theft. In terms of being physically fit, the guide covers topics such as developing and maintaining a well-balanced exercise program, walking, strength training, stretching exercises and nutrition.

### **August**

We are putting more focus on getting valuable information to each client by mail. This month, clients received two mailings: (1) a 16 page "**Resource Guide**" that lists other services that can be obtained and where to get them (addresses and phone numbers). (2) Sickle Cell Awareness Month Calendar (September is National Sickle Cell Month) and a healthy habits pocket pal. The calendar highlights Sickle Cell Disease facts for all 30 days of September. The pocket pal describes 12 health habits that individuals can develop to become happier and healthier; for example, choosing nutritious foods, getting regular exercise, avoiding tobacco, having necessary health tests and vaccinations, practicing stress management, getting plenty of rest, staying positive and creating an active social life.

### **September**

We are putting more focus on getting valuable information to each client by mail. In August we sent clients and other interested persons the Sickle Cell Month Calendar that highlights Sickle Cell Disease facts for all 30 days of September, which was Sickle Cell Awareness Month. We mailed it in August so persons would have it in front of them the entire month of September. The organization helped plan and participated in the "Sickle Cell Walk For Life" held on September 24th on the campus of Virginia Union University. About 75 people participated in the walk.

### **October**

On October 15th, Statewide Sickle Cell Chapters of Virginia sponsored an Educational Session that was hosted and paid for (grant funds) by Sickle Cell Association of Richmond-OSCAR. The session was designed to update all of the nine chapters on the national sickle cell conference, results of a recent hearing loss study, the importance of blood donation, a new communications network for patients called "Get Connected" and most importantly, a presentation about the new opioid guidelines affecting our clients.

### **November**

We are putting more focus on getting valuable information to each client by mail. In November we sent each client a 2017 yearly pocket planner.

### **December**

We are putting more focus on getting valuable information to each client by mail. In December we sent each client a Holiday Card with a tear off twelve (12) month calendar that can be stuck on an appliance. We received a Holiday Card from a client and mother saying, "You have been a blessing in our lives". We also received e-mail from a client saying, "The December news letter was absolutely full of knowledge and promising!!! I must have said THANK YOU GOD at least 3 times while reading the mail. It offered hope for the future especially to the kids. I just wanted to thank you for the amazing job you're doing and providing us with updated news".

## **Sickle Cell Association of Richmond-OSCAR - Continued**

### **January**

We are putting more focus on getting valuable information to each client by mail. In January we sent each client two "Words of Wisdom". A bright attitude can help us reach our full potential and A good sense of humor is essential to deal with the world's reality. We also requested that clients let us now when they have a change in address or phone number.

### **February**

Presenting information at support group meetings benefits those who attend while those who do not miss out. E-mailing information only reaches 1/3 of our clients. Therefore, we are putting more focus on getting valuable information to each client by mail. This month we sent a "Thinking of You" card to clients so they will know that we are thinking about them.

### **March**

Presenting information at support group meetings benefits those who attend while those who do not miss out. E-mailing information only reaches 1/3 of our clients. Therefore, we are putting more focus on getting valuable information to each client by mail. This month we sent two "Words of Wisdom". Focus and commitment put us on the path to excellence and Character is not made in a crisis – it is made over a lifetime.

### **April**

Presenting information at support group meetings benefits those who attend while those who do not miss out. E-mailing information only reaches 1/3 of our clients. Therefore, we are putting more focus on getting valuable information to each client by mail. This month we sent our clients a notice about the "Unity Ride for Sickle Cell" on May 6th, to raise awareness about Sickle Cell and to raise funds so the organization can provide financial assistance to our clients. We want the clients to come out to support the ride and thank the riders. Taped a 30-minute radio program about the effects of Sickle Cell Disease and the up-coming 9<sup>th</sup> Annual Motor Cycle Unity Ride for Sickle Cell.

### **May**

Presenting information at support group meetings benefits those who attend while those who do not miss out. E-mailing information only reaches 1/3 of our clients. Therefore, we are putting more focus on getting valuable information to each client by mail. The "Unity Ride for Sickle Cell" was held on May 6th, to raise awareness about Sickle Cell and to raise funds so the organization can provide financial assistance to our clients. The ride was a success and money is still coming in for client assistance. In May we sent each client two "Words of Wisdom". A champion is a dreamer that refused to give up and You get more joy out of the giving to others, and should put a good deal of thought into the happiness you are able to give.

### **June**

Presenting information at support group meetings benefits those who attend while those who do not miss out. E-mailing information only reaches 1/3 of our clients. Therefore, we are putting more focus on getting valuable information to each client by mail. In June we sent each client two "Words of Wisdom". Anything un-attempted remains impossible and lasting success is built on a foundation of strong values. During June we ran an ad to raise more awareness about Sickle Cell Trait/Disease to educate more members of the public. The ad was run in the Free Press Newspaper (100,000 readers) and on a radio station listened to by persons of childbearing age (130,000 households). It was also sent by G-O Fencing to 100,000 IP address going to smartphones. Part of Unity Ride radio program in April was broadcasted to 130,000 households.