

# 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 28, 2023

#### **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.

**The 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. All chapters provide sickle cell education in the community through participation in health fairs, forums, church activities and civic or health related events. Some of the services include sending clients sickle cell information, "Birthday" and "Thinking of You" cards, support group meetings, calls to check on clients, visitations, providing referral assistance, assistance with obtaining employment, disability benefits, and vocational rehabilitation. These services vary from chapter to chapter based 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 Pediatric Specialist of Virginia at INOVA Hospital in Fairfax, Virginia. It should be noted that only Virginia Commonwealth University Health System provided clinical care for adult clients (near 700) until recently. **Now a new adult center has been established at the INOVA Adult Sickle Cell Center in Fairfax, Virginia.**

It is estimated that the State of Virginia has about 4,000 sickle cell clients/patients. The centers care for around 1,500 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
- FY18 - \$105,000 for four of our nine chapters
- FY19 - \$105,000 for four of our nine chapters
- FY20 - \$105,000 for four of our nine chapters
- FY21 - \$105,000 for four of our nine chapters
- FY22 - \$105,000 for four of our nine chapters
- FY23 - \$105,000 for three 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 FY14, 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, FY18, FY19, FY20, FY21 and FY22, Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded four contracts to member chapters.

**MEMO ON COVID – 19 PANDEMIC**

Much of the grant years FY21, FY22 and FY23 occurred during the COVID - 19 Pandemic. The grant funded chapters were unable to have their full and normal contact with their clients and the public during the pandemic. As such, much of the chapter activity numbers being reported are lower.

Four chapters received the following funding during **FY23**:

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
<b>PLUS</b>		
Statewide Sickle Cell Chapters of Virginia		<u>\$ 6,951.00</u>
(Operational expenses for Statewide including materials, supplies, accountant fee, Administrator and Grant Administrator)		
<b>Total</b>		<b>\$105,000.00</b>

**Community-Based Sickle Cell Program Activities as of June 30, 2023**

The four aforementioned chapters were awarded funding to begin community-based services on **July 1, 2022**. The following information provides a summary of the community-based activities performed as of **June 30, 2023**. 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.

**Rocky Mount Grant Withdrawal And Funds Transfer**

Due to a number of adverse circumstances (resignation of an officer, recent death of immediate family member, two vital persons with sickle cell or children with sickle cell, overwhelmed individuals and inability to maintain desired fund level) the Rocky Mount Chapter was no longer able to continue in the grant program. The Virginia Department of Health was informed.

The Rocky Mount Chapter had been awarded (\$2,160.00 for Staff and Contractual Services, \$3,200.00 for Operating Expenses and \$634.00 for Telephone/Cell Phone/Equipment) a total of \$5,994.00.

The unspent funds (all funds) assigned to Rocky Mount were transferred to the “Operating Expenses” of Statewide.

\$5,994.00 awarded in the beginning to Rocky Mount was transferred to Statewide in **September**.

\$1,277.49 of those funds was spent in **October** on educational material for three non-grant funded chapters listed below:

\$390.32 (**50**) + \$161.95 (100 of 3) = \$552.27 for Blue Ridge Association for Sickle Cell Anemia  
\$200.66 (**25**) + \$161.95 (100 of 3) = \$362.61 for Sickle Cell Association of Central Virginia  
\$200.66 (**25**) + \$161.95 (100 of 3) = \$362.61 for Fredericksburg Area Sickle Cell Association-  
FASCA

**RESOURCES-PUBLICATIONS PURCHASED**

<u>TITLE</u>	<u>FROM</u>	<u>PRODUCT #</u>
About Sickle Cell Disease and Sickle Cell Trait	Channing Bete	CBC0267
Sickle Cell Disease Facts for You	Channing Bete	CBC0401
About Pain Management (16 Pages)	Channing Bete	CBC0124
About Living with Chronic Pain (16 Pages)	Channing Bete	CBC0588
About Relaxation Techniques (16 Pages)	Channing Bete	CBC0171
Stress Management (Pocket Pal)	Positive Promotions	BC-39
Medication Recorder (Pocket Pal)	Positive Promotions	BC-51
Medical ID (Pocket Pal)	Positive Promotions	BC-23

\$4,716.51 of those funds (determined by formula) was transferred in **November** to “Operating Expenses” of three grant funded chapters as follows:

\$ 950.00 to Heart of Gold Sickle Cell Foundation of Northern Virginia  
\$2,050.00 to Sickle Cell Association  
\$1,716.51 to Sickle Cell Association of Richmond - OSCAR

**These funds were ONLY spent to purchase literature from Channing Bete and/or Positive Promotions and/or on advertising (newspaper, radio and/or bill boards) and would not be used to pay for any Staff/Contractual Services or Phone Services/Equipment.**

**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, Loudoun and Prince William.

**Type of Assistance offered:**

Calls from Clients/Family for information/assistance

**Number:** 7

Information or Referral Assistance to Clients and Families

**Number:** 9

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

**Number:** 4 for \$1,850.00

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 7,361

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 5

**Number of Attendees:** 1272

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

**Number of Attendees:** 207

Posted Sickle Cell information on Facebook page for viewing.

**Number:** 0

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:** 413

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

**Number Sent:** 8056 and others

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 174

Calls to clients to obtain information or update contact information

**Number:** 5

Distribution of Chapter Newsletter

**Number:** 116

## **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 activity numbers are low, however, their involvement in health activities has been high as demonstrated in the narrative below.

### July

Sent letters to local churches informing them that September is Sickle Cell Awareness Month and included dates and locations of upcoming Blood Drives. Also included a copy of Annual Newsletter. Contact INOVA Fairfax Hospital Adult Sickle Cell program staff to discuss September webinar and informational materials that can be provided for clients. Contacted Howard University to be listed as a sponsor for the: upcoming Cure Sickle Cell Walk September 17th.

### August

Sponsored Blood Drive with American Red Cross on August 31, 2022 in Springfield, VA. Sent letters to local churches in Arlington County, Fairfax County, Loudoun County, Stafford County, City of Manassas, City of Alexandria requesting announcements that September is Sickle Cell Awareness Month and included dates and locations of upcoming Blood Drives. Also sent information about Sickle Cell Awareness Month to local Fraternities and Sororities and encouraged members to donate blood. Confirmed presentation with INOVA Fairfax Hospital Adult Sickle Cell program staff to discuss September 21st webinar and informational materials that can be provided for clients. Confirmed with Howard University to be listed as a sponsor for the: upcoming Cure Sickle Cell Walk September 17th. Confirmed with Prince William County NAACP to be a speaker at a webinar for Sickle Cell Awareness on September 19th. Confirmed with Fairfax County Board of Supervisors a Proclamation to be awarded in September for Sickle Cell Awareness Month. Facebook followers increased by 26 persons in the month of August.

### September

Sponsored Blood Drive with American Red Cross on September 8, 2022, in McLean, VA (still waiting donor numbers). Sent letters to local churches in Northern Virginia requesting announcements that September is Sickle Cell Awareness Month and included dates and locations of upcoming Blood Drives. Also sent information about Sickle Cell Awareness Month to local Fraternities and Sororities and encouraged members to donate blood. Did a presentation during the INOVA Fairfax Hospital Adult Sickle Cell webinar on September 21st with 72 participants. Attended and distributed informational materials the Cure Sickle Cell Walk September 17th at Howard University with over 700 participants. Did public service announcement and feature on Fairfax County Channel 16, which has the capability to reach all of Fairfax County (population 1.1 million) for September 8 Blood Drive and Sickle Cell Awareness Month. Launched podcast "Defining Sickle Cell" on the Heart of Gold webpage ([heartogold.org](http://heartogold.org)) with interview with Sickle Cell Warrior. Presented a Proclamation by the Fairfax County Board of Supervisors for Sickle Cell Awareness Month. Facebook followers increased by 51 persons in the month of September.

### October

Sponsored Blood Drive with American Red Cross on September 8, 2022, in McLean, VA (29 units). Sponsored Blood Drive August 31 in Springfield, VA and 46 units collected. Facebook followers increased by 6 persons in the month of October. Blood Drive sponsored on October 26 in Springfield VA--awaiting information on number of donors. Sent information to Top Ladies of Distinction to sponsor Blood Drive.

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

### November

Sent Spanish Language brochures on Sickle Cell Disease to non-profit clinic in Woodbridge Virginia. Facebook followers increased by 21 in the past month. Sent information to local groups via email about upcoming blood drives in December (McLean Community Center) and January (Hilton Springfield). Sent holiday greeting cards to clients and donors.

### December

Facebook followers increased by 12 in the past month. Sent donation (non-grant funds) to Children's Hospital and Heart of Gold Scholarship fund. Sent letters to 25 Fraternities and Sororities in Northern Virginia to encourage their membership to donate blood at upcoming blood drives. Organized meeting (January 11) with INOVA Adult Sickle Cell Social Worker to discuss initiatives that could help our clients.

### January

Blood Drive at Sherwood Hall Library 46 units collected. Upcoming Health Fair at Springfield Town Center, Springfield VA February 25, 2023 in partnership with Alpha Kappa Alpha Sorority, Inc. Meeting and tour scheduled of Inova Hospital Adult Sickle Cell Center February 22, 2023. Two upcoming blood drives in February. VCU sickle cell needs survey distributed to clients and community groups.

### February

Participated in Health Fair at Springfield Town Center, Springfield VA February 25, 2023 in partnership with Zeta Chi Omega Chapter of Alpha Kappa Alpha Sorority, Inc. Over 500 participants. Distributed information in both English and Spanish on Sickle Cell Disease and Sickle Cell Trait. Met with Inova Hospital Adult Sickle Cell Center on February 22, 2023 received a tour of the facility, information on services and support and tentatively began planning for a joint Juneteenth event. Received request to support blood drive at St. John's Baptist Church, Arlington in April, 2023. Accepted invitation to participate in Manassas African American Festival in August, 2023.

### March

Sent information to 30 churches and 30 organizations informing them of the Inova Adult Sickle Cell Clinic. Began planning for joint Juneteenth/World Sickle Cell Day event with Inova Adult Sickle Cell Team on June 18 2023, at Cameron Run Park Alexandria. Meeting was held with Alpha Kappa Alpha Sorority Inc. about event to support Sickle Cell Disease Patients in October 2023. Shared information via social media about upcoming blood drive at St. John's Baptist Church, Arlington, VA on April 29, 2023. Shared information via social media about upcoming American Red Cross Blood Drives at the Hilton Springfield, Springfield, VA in May, July and August.

### April

Supported Blood Drive at St. John Baptist Church, Arlington, VA on April 29th. 30 persons registered. Made scholarship donation to Sickle Cell Summer Camp sponsored by Children's National Medical Center. The funds will support one camper. Updated webpage. Begin preliminary planning for a Sickle Cell Month event in September. Will provide informational materials for Inova for World Sickle Cell Day on June 19th to distribute to patients.

### May

Printed and began distribution of yearly newsletter. Co-Sponsored Blood Drive with American Red Cross in Springfield. Awaiting participant numbers. Recorded podcast with INOVA Dr. Sheinei Alan in honor of World Sickle Cell Day and Juneteenth. Drafted letters to Fairfax County Board of Supervisors to support a proclamation for Sickle Cell Awareness Month in September.



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

June

Posted podcast entitled "Blood Sweat and Cells" on June 19th, World Sickle Cell Day. The podcast was an interview with Dr. Shenei Alan, Director of Clinical Research INOVA Adult Sickle Cell Center. Have been contacted by INOVA to participate in a webinar during Sickle Cell Awareness Month on September 28. Have confirmed participation in the Manassas African-American Festival on August 5, 2023 in Manassas, Virginia. Have been contacted and scheduled a meeting in August with Novo Nordisk, a pharmaceutical company about partnering. Received a response from the Chairperson of the Fairfax County Board of Supervisors that he will sponsor a proclamation during Sickle Cell Awareness Month in September.

### **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:** 188

Information or Referral Assistance to Clients and Families

**Number:** 86

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

**Number:** 15 for total of \$3,077.80

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

Pieces of Literature Distributed

**Number:** 3820

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 37

**Number of Attendees:** 5430

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

**Number of Attendees:** 207

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

Advocacy & Community Resources Meetings

**Number of Participants:** 139

Transition Young Adults 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:** 267

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

**Number Sent:** 839

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

**Number Sent:** 1,584

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 901

Calls to clients to obtain information or update contact information

**Number:** 157

## **Sickle Cell Association - Continued**

### July

Held two blood drives one at Mt Nebo Baptist Surry and another at Bethany Baptist Church Chesapeake. The blood drives collected 47 pints of usable blood. Presentations were given to the churches to recruit blood donors. Sickle Cell Disease Association and MARAC sent the 2022 CDC Prevention publication on U.S. Monkeypox Outbreak "What You Need to Know" and forwarded to sickle cell clients. Developing a clients-based Paint Art Therapy that is planned for September for Sickle Cell pain management.

### August

Distributed information on Sickle Cell Disease to the staff and professors at Norfolk State University "Welcome Back on Campus" event and Norview Community Day Back-to-School event held at Norview Middle School on August 27 reaching over 320 persons and signing up two new sickle cell families.

### September

September is National Sickle Cell Awareness Month that was commemorated with the in-person Annual Walk for Sickle Cell at Norfolk State University with over 600 participants with teams from community social and civic organizations, fraternal organizations, schools, churches and businesses. Gethsemane Community Church held its 30th Annual community fair on September 17, 2022 and information and school supplies were given to 150 participants. Set up information tables at the three-day City-wide Revival from areas churches reaching over 900 persons. The online radio station MSE Network featured Judy Anderson on the Rich-Live Tuesday Talk Radio Show on September 27, 2022 reaching a national and international audience. NSU held an information fair on September 29, 2022 for the staff and students with over 200 participants coming by the booth. Set up a booth display at 1st Lynnhaven Baptist Church the entire month.

### October

Held one blood drive at Mt Nebo Baptist Church and collected 22 usable pints of blood. Recruited and trained volunteers for community events and fairs. The volunteers will assist with community presentations, health fairs and special events to expand the reach of services. Followed up with new clients identified during September at the Walk for Sickle Cell. Attended the Patient Centered Outcomes Research Institute conference on advances in Sickle Cell research for community-based model partnerships.

### November

Met with the Shriners on volunteer efforts needed for 2023. They agreed to continue support of sickle cell families with food baskets and any emergency transportation if needed. The organization donated 15 complete Thanksgiving baskets. One presentation was given to the Eastern Stars of Newport News on sickle cell families to serve during the New Year 2023. They plan on matching the Shriners in their community initiatives for Sickle cell families.

### December

Provided Christmas food baskets for 10 sickle cell families, emergency financial assistance for four families of 9 persons and one educational scholarship. Held the 50th Annual Commemorative Gala and recognized 5 Sickle Cell Warriors for their volunteer work at the Association.

### January

Held one blood drive at Mt. Nebo Baptist Church collecting 24 usable pints of blood. Setup information booth at Martin Luther King Service at Kings Fork High School, Suffolk.

## **Sickle Cell Association - Continued**

### February

Met with Bryant & Stratton Medical Advisory Board to discuss current information and research on Sickle Cell Disease. Met with Red Cross Diversity Team to discuss Sickle Cell Warrior blood drives in the 757 region and plan monthly drives. Met with CDC Workgroup on developing the Data Snapshot fact sheet for the state of Virginia.

### March

Gave presentations to classes at Bryant & Stratton College Med Tech students, Health & Awareness Annual Kidney Disease Prevention symposium, and Baptist General Convention. Information booth displays were set up at Suffolk Community Centers Health Fair & Blood Drive (2), Bryant & Stratton College, Baptist General Convention and Lynnhaven Baptist Church, Virginia Beach. Virtual presentation to Phi Beta Sigma Fraternity, Roanoke Virginia on how to set up a blood drive to help sickle cell patients a follow-up training on Red Cross Sickle Cell Warrior blood drives will be given to the Fraternity full membership at April meeting. Held one focus group meeting with sickle cell clients on how to involve them in the advocacy program. Spoke to national congressional representatives during Sickle Cell Advocacy Day on Capitol Hill. Participated in the 4th Annual SCCAPE conference held by VCU March 27-31, 2023.

### April

Held blood drive at Mt Nebo Baptist and had 24 blood donors. Focus group virtual meeting with 5 sickle cell clients on advocacy and upcoming events. Presentation for ECHO meeting during John Hopkins - William E Proudford monthly meeting. Passed out literature at the Community Leaders Brunch held during "Something in the Water" event on April 28, 2023.

### May

Gave presentation to area LINKS organizations to address the need to partner on community blood drives. A blood drive was then scheduled at Shiloh Baptist Church parking lot reaching 20 donors. Gave a presentation to the Northeast Region SiNERGe collaborative on the Sickle Cell advocacy efforts in the Hampton Roads area.

### June

Met with the Metro Baptist Ministers Conference to inform the churches about the "Shine the Light on Sickle Cell" campaign for World Sickle Day (June 19) and requested a resolution of support from the Conference. The Resolution passed and the Association has renewed the commitment for support from this organization since the COVID-19 pandemic. Gave a presentation to National Epicureans at their convention and distributed Statewide Sickle Cell brochures for members to connect with the local Chapters across the state. Held one blood drive with Freedom VA organization and spoke at their annual Parents in the Park cookout for legislators and voting constituents on the critical need for health care for Sickle Cell Patients. Attended Juneteenth Festivals held in Hampton VA and on the Virginia Eastern Shore where information was distributed on "Shine the Light on Sickle Cell" and World Sickle Cell Day.

### **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:** 209

Information or Referral Assistance to Clients and Families

**Number:** 0

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:** 4 for total of \$2,000.00

Contract Services for Client Advocacy Education and Representation

**Number of Participants:** 0

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

Distribution of Sickle Cell Literature

**Number:** 2,700

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 6

**Number of Attendees:** 700

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

**Number of Attendees:**

**Number:** 32 X 3 = 96 number of lives saved

Sent Information to Church Members

**Number:** 658

#### **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 and 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:** 1,275

Special Mailings

**Number Sent:** 1946

Letters to Churches

**Number:** 323

#### **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:** 270

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

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

**Number Sent:** 320

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:** 1,284

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 222

Calls to clients to obtain information or update contact information

**Number:** 111

Ran Newspaper Ads in the Richmond Free Press about Sickle Cell Trait/Disease and other ads that sort to get more African Americans to donate their blood which is more compatible to most clients, that reached (100,000 readers per week). Sickle Cell Trait/Disease advertisement on Radio One was broadcasted to 130,000 households for each of over 50 ad spots broadcasted. (Ads ran July, August, September, October and June)

**Number of Households Reached:** 24,174,000

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

We are putting our focus on getting valuable information to each client by mail.

### July

We mailed each client a pocket pal "Smart Choices, Healthy Foods". Also purchased 55 radio time ads about Sickle Cell Trait/Disease run on a radio station listened to by persons of child-bearing age (130,000 total households reached during each ad). (7,150,000). Four different Newspaper Ads in the Richmond Free Press for four weeks (100,000 readers per week for four weeks total 400,000).

One 4" x 2 column ad about Sickle Cell Trait/Disease.

One 4" x 2 column ad to request African American donors to give blood.

One 5" x 2 column ad about Sickle Cell Trait/Disease.

One 5" x 2 column ad to ask African Americans to give blood

### August

In August, we mailed each client a letter with a list of Counseling Referrals for Mental Health and later we sent a September Sickle Cell Month Calendar. We also mailed the September Sickle Cell Month Calendar along with a letter talking about the organization and what September means nationally and locally to Church members and other Churches. Gave the September Sickle Cell Month Calendars to two Churches (100 each).

### September

Made a church presentation that was also videotaped for future use. Participated in Health Fairs at a Church Homecoming and at Virginia Union University. Also purchased 55 radio ads about Sickle Cell Trait/Disease run on a station listened to by persons of child-bearing age (130,000 households reached by each ad total of 7,150,000). Four different Newspaper Ads in the Richmond Free Press for four weeks (100,000 readers per week for four weeks total 400,000).

One 4" x 2 column ad about Sickle Cell Trait/Disease.

One 4" x 2 column ad to request African Americans donate blood.

One 5" x 2 column ad about Sickle Cell Trait/Disease.

One 5" x 2 column ad to request African Americans donate blood.

### October

In October, we mailed each client a pocket pal "Medical I D Pocket Pal".

Participated in a Community Information Fair at a southside Church held by the Richmond In

October, we mailed each client a pocket pal "Medical I D Pocket Pal".

Participated in a Community Information Fair at a southside Church held by the Richmond Alumnae Chapter of Delta Sigma Theta Sorority. We have a partnership with the sorority.

### November

In October, we mailed each client a "Monthly Planner" so they can keep track of their appointments.

### December

In December, we mailed each client a "Season's Greeting Card with a stick-up Yearly Calendar attached". Blood Donation Letters were sent out to members of the home Church plus to other Churches asking people to call the Red Cross and set-up an appointment to donate blood during January because that is National Blood Donation Month. The focus is on sickle cell patients needing transfusions as well as all persons in need.

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

### January

We mailed each client two "Words of Wisdom" (1) The measure of a man is in the lives he's touched and (2) The greatest good you can do for another is not just to share your riches, but to reveal to him his own.

Blood Donation Letters were e-mailed to two organizations asking people to call the Red Cross and set-up an appointment to donate blood during January because that is National Blood Donation Month. The focus is on sickle cell patients needing transfusions as well as all persons in need.

### February

In February, we mailed each client a "Healthy Habits For Life" magnet to remind them of the things they need to do every day to stay healthy. Sent the magnet to other Churches and gave one large donor Church 100 magnets to give to members. Sent each client a "Thinking of You" card so they would know we care.

### March

In March, we mailed each client two "Words of Wisdom". (1) **You must be the change you wish to see in the world** and (2) **When you have people together who believe in something very strongly...things happen.**

See TV report below.

OSCAR - Television Interviews

March 30, 2023 Report

One of our adult sickle cell clients has a pod cast and asked to interview George Carter. The interview was held on Friday, March 10<sup>th</sup> and lasted for about 25 minutes and was broadcasted on two public access channels on Saturday and Sunday, March 25<sup>th</sup> and 26<sup>th</sup>.

<https://youtu.be/Bik1u7xLFQ0>

The interview covered a wide range of sickle cell topics including:

Contact Information for Sickle Cell Association of Richmond - OSCAR

Talking about the pain

My first crisis

Hearing loss with Sickle Cell patients

Need for Blood donations

Things a client needs to do like:

Drink plenty of water

Get 8 hours or more of sleep

Eat the right foods

Avoid stress

Do things in moderation

CBS TV-6 aired several segments on sickle cell on Thursday, March 30<sup>th</sup>, one in each half hour starting a 4:00 P.M. through 6:30 P.M.

**4pm** (Approx 7 min) – 2 Men thriving with sickle cell (George Carter & James Frazier) with expert Dr. Wally Smith

<https://www.wtvr.com/news/local-news/sickle-cell-disease-george-carter-march-30-2023>



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

**5pm** (Approx 5:20 min) Need for more adult sickle cell centers especially in Tidewater with expert Dr. Wally Smith

A patient from the Tidewater area named Taylor Mickel, who came to Richmond to attend VCU. Based on the care she has received; she does not want to return to Tidewater.

<https://www.wtvr.com/news/local-news/sickle-cell-treatment-access-rural-virginia-march-30-2023>

**5:30pm** (Approx 5 min) – Interview with Trei Banks of the American Red Cross; details on VSU and VU Sickle Cell Blood Drive

He announced that starting on April 1<sup>st</sup>, the Red Cross will start provide the testing for sickle cell disease and trait. Also, that the Red Cross will hold a blood drive on April 4<sup>th</sup> from 12-5 at Virginia Union University and Virginia State University

<https://www.wtvr.com/news/local-news/red-cross-sickle-cell-disease-march-30-2023>

**6pm** (Approx 6:30 min) – Feature story on The Hunters who lost their son to sickle cell at the age of 28 with expert Dr. Smith

<https://www.wtvr.com/news/local-news/sickle-cell-disease-samuel-boykin-hunter-march-30-2023>

**6pm** (Approx 2:27 min) - CS6 Gives “surprise” to George Carter

George Carter was the March CBS Recipient for a \$500.00 Visa gift card for his contribution to the community.

<https://www.wtvr.com/cbs-6-gives/george-carter-sick-cell-disease-march-30-202>

Total time more than 26 minutes (26min 20 sec) of total coverage over the 4 newscasts and around 50,000 households.

### April

In April, we mailed each client a letter stating that April was Stress Awareness Month and reminding clients that stress can cause a sickle cell crisis. We also sent a Pocket Pal “Keeping It Simple, Stress Less, Relax More” to each client.

### May

In May, we mailed each client two "Words of Wisdom" (1) Love is a fruit in season at all times. And (2) The sun does not shine for a few trees and flowers, but for the wide world's joy.

Also purchased 55 radio time ads about Sickle Cell Trait/Disease run on a radio station listened to by persons of child-bearing age (130,000 total households reached during each ad).

(7,150,000

Four different Newspaper Ads in the Richmond Free Press for four weeks (100,000 readers per week for three weeks total 400,000).

One 4" x 2 column ad about Sickle Cell Trait/Disease.

One 4" x 2 column ad to request African American donors to give blood.

One 5" x 2 column ad about Sickle Cell Trait/Disease.

One 5" x 2 column ad to request African America donors to give blood.

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

June

In June, we mailed each client two "Words of Wisdom" (1) If we were supposed to talk more than we listen, we would have two mouths and one ear. And (2) When we do the best we can, we never know what miracle is wrought in our life, or in the life of another.

Also purchased 55 radio time ads about Sickle Cell Trait/Disease run on a radio station listened to by persons of child-bearing age (130,000 total households reached during each ad).

(7,150,000

Four different Newspaper Ads in the Richmond Free Press for five weeks (100,000 readers per week for four weeks total 500,000).

One 4" x 2 column ad about Sickle Cell Trait/Disease.

One 4" x 2 column ad to request African American donors to give blood.

One 5" x 2 column ad about Sickle Cell Trait/Disease.

One 5" x 2 column ad to request African America donors to give blood.

One 5" x 2 column ad about Sickle Cell Trait/Disease.

Purchased 16 Television Ads of 15 seconds each on WTVR Channel 6 during the 6 and 11 news cast. 89,000 viewers x 16 = 1,424,000

$7,150,000 + 500,000 + 1,424,000 = 9,074,000$

## **Statewide Sickle Cell Chapters of Virginia**

### **July 2022 through June 2023**

Statewide is an umbrella organization (not a chapter) that has nine-member chapters. We do not have clients, but when contacted by clients, we refer them to the chapter in their area. We sent Chapters and chapter members e-mails of sickle cell information from (NHLBI) National Heart, Lung and Blood Institute or other national sources so they could send the information to clients to expand their knowledge.

October

Using unspent funds transferred from the Rocky Mount Chapter to Statewide. Statewide purchased eight different pieces of educational information directly or indirectly related to Sickle Cell Disease from two different companies. The purchased material was delivered to three chapters in Rocky Mount, Lynchburg and Fredericksburg to educate their client and general population.

November

Using unspent funds transferred from the Rocky Mount Chapter to Statewide, \$4,716.51 of those funds was transferred to "Operating Expenses" of three grant funded chapters as follows:

\$ 950.00 to Heart of Gold Sickle Cell Foundation of Northern Virginia

\$2,050.00 to Sickle Cell Association

\$1,716.51 to Sickle Cell Association of Richmond - OSCAR.

These funds will ONLY be spent to purchase literature and/or on advertising

**The following represents a report of the actions of Statewide Sickle Cell Chapters of Virginia and its Administrator, George Harris Carter on behalf of SCD patients. Some of the following activities have been reported on the statewide monthly reports to the Virginia Department of Health in the past along with some newer unreported activities.**

George Carter is a 77-year-old male who suffers with Sickle Beta Zero Thalassemia. He has been working with various sickle cell organizations for over 40 years. Currently, he primarily serves as the Administrator (unpaid Executive Director) of Statewide Sickle Cell Chapters of Virginia and Sickle Cell Association of Richmond - OSCAR. He also serves as a Sickle Cell Disease Patient Consultant for the Food & Drug Administration (FDA) and formerly served on the Interagency Pain Research Coordinating Committee (IPRCC) of the National Institute of Health (NIH).

During the last several years, Statewide and George Carter have taken on a more national pain profile against the negative impact of the opioid crisis on Sickle Cell Patients and advocate for those who suffer from sickle cell.

### **Hearing Loss in Sickle Cell Patients**

In February of 2014, George Carter represented sickle cell patients as a patient consultant on a panel at a Food & Drug Administration (FDA) Conference in the Washington area. He highlighted hearing loss that is caused by sickle cell and the balance problems that resulted.

M. Dawn Nelson, PhD. CCC-A was contacted by the FDA and asked if she would do a study on hearing loss. Only four (4) studies had been done previously and none dealt with loss of balance.

On October 12, 2018, at the annual convention in Baltimore, Maryland, the national organization had a formal session on hearing loss in Sickle Cell Disease. M. Dawn Nelson, PhD. CCC-A spoke on the topic **“We’ve Fallen But We Must Get Up; Dizziness, Falling and Hearing Loss in Individuals Living with Sickle Cell Disease”**.

Statewide and Sickle Cell Association of Richmond – OSCAR have been working with M. Dawn Nelson, PhD in Audiology at Central Michigan University on a Hearing Loss Brochure to be used by Statewide Chapters entitled "Hearing Loss, Dizziness, and Fall Risk in Persons with Sickle Cell Disease". This brochure is the only chapter brochure in the country about both Hearing Loss and Sickle Cell Disease. It also talks about Dizziness, Risk of Falling and Lack of Balance. All grant funded chapters have printed them to distribute to clients and the public.

### **Statewide 2020**

In June of 2020 sent a letter to the Center for Disease Control and Prevention (CDC) about the Adverse Effects of the CDC Opioid Guidelines on Sickle Cell Patients supporting continued support for the proper use of opioids.

### **November of 2020**

George Carter participated as a member in the National Institute of Health’s (NIH) Interagency Pain Research Coordinating Committee (IPRCC) meeting. He stated that the committee report needed to reflect that until a real replacement for Opioids is found and approved by the FDA, “proper use of Opioids must be continued for proper pain management.

### **Early 2022**

M. Dawn Nelson, PhD. CCC-A has now published her work on the topic **“We’ve Fallen But We Must Get Up; Dizziness, Falling and Hearing Loss in Individuals Living with Sickle Cell Disease”**.