

# 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 27, 2022

#### **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 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 (between 300 and 400).

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
- 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

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.

Four chapters received the following funding during FY20:

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 (Operational expenses for Statewide including materials, supplies, accountant fee, Administrator and Grant Administrator)		\$ 6,951.00
Total		\$105,000.00

### **Community-Based Sickle Cell Program Activities as of June 30, 2022**

The four aforementioned chapters were awarded funding to begin community-based services on **July 1, 2021**. The following information provides a summary of the community-based activities performed as of **June 30, 2022**. 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.

### **MEMO**

#### **COVID – 19 PANDEMIC**

Much of the grant year plus the previous grant year occurred during the COVID - 19 Pandemic. All four grant funded chapters were unable to have their normal contact with their clients and the public during the pandemic. As such, much of the chapter activity numbers being reported are lower this year.

**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:** 5

Information or Referral Assistance to Clients and Families

**Number:** 1

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

**Number:** 2 for total of \$150.00

Home Visitation

**Number:** 11

Hospital Visitation

**Number:** 10

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 365

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 3

**Number of Attendees:** 275

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

**Number of Attendees:** 24

**Type of Support Group offered:**

Meetings

**Number of Participants:** 35

**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:** 15

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

**Number Sent:** 26

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

**Number Sent:** 101

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 0

Calls to clients to obtain information or update contact information

**Number:** 0

Local TV promotion of Sickle Cell Walk in Franklin County, VA.

**Number of Households Reached:** 54,200

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

July

None

August

Distributed flyers at a community fun day that was sponsored by local churches. We attended a memorial service for a former CEO/founder. We began our new membership drive. We are working on getting fundraisers together for national sickle cell awareness month. We are working on having a blood drive. Weekly messages are posted on our facebook page by a service coordinator.

September 25, 2021

One of our clients was on a discussion panel with residents and doctors at the Virginia Tech School of Medicine. We had a doughnut fundraiser. Membership drive is ongoing.

October

A family requested brochures on sickle cell anemia to be given out at their family reunion. The membership drive is ongoing. We are currently working on a blood drive for February 2022. The Brasca facebook page is being managed and monitored weekly.

November

The membership drive is still ongoing. A blood drive is planned and being worked on for February 2022. Sickle cell brochures were given out at a family event, as requested. The Brasca facebook page is being monitored weekly.

December

Brasca is currently working on a blood drive for February 2022. The Brasca facebook page is being monitored weekly. Membership drive is still ongoing.

January

Membership drive is still ongoing. Brasca's facebook page is being monitored weekly. Working on getting donors to donate blood at our upcoming blood drive with the Red Cross.

February

We had a successful blood drive. We collected 24 pints of blood. We also passed out brochures about sickle cell at the blood drive. We are still continuing with our membership drive as well.

March

A committee is working on the end of year fiscal spending. Three clients were on a sickle cell awareness discussion panel with 2 doctors for students at Virginia Tech School of Medicine. A committee is working on creating a new sickle cell anemia video for the local cable company.

April

Preparing a video about Brasca to be ran on Cable 12. Also preparing a Brasca ad to be ran on WYTI radio station. 2 of our clients were on a sickle cell discussion panel at this year's Academy of Emergency Medicine conference that was in Baltimore, Maryland.

May

Finishing up the end of year report for the statewide grant. Distributed 55 pieces of sickle cell information. Working on a world sickle cell day project.

June

We are planning a new membership drive. The fundraising committee is planning fundraisers to raise money for our chapter. One client received an invitation from the Virginia Tech School of Medicine to be on a sickle cell discussion panel.

**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:** 8

Information or Referral Assistance to Clients and Families

**Number:** 4

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

**Number:** 4 for \$ 200.00                      **Hospital Care Kits**

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 6,298

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 0

**Number of Attendees:** 0

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

**Number of Attendees:** 280

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:** 313

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

**Number Sent:** 396 and others

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 67

Calls to clients to obtain information or update contact information

**Number:** 1

Distribution of Chapter Newsletter

**Number:** 102

## **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

Jointly sponsored Blood Drive with American Red Cross at Haymarket-Gainesville Library (Prince William County). Video made by Red Cross with Service Coordinator Valerie Bey speaking on behalf of the Foundation. Upcoming Blood Drives will be in Fairfax, Loudoun and Prince William County.

August

Jointly sponsored Blood Drive with American Red Cross at McLean Community Center on August 19. Established partnership with the Third District of Omega Psi Phi Fraternity, Inc. and the American Red Cross for future blood drives. Received request from Prince William NAACP to participate in Sickle Cell Webinar in September for National Sickle Cell Awareness Month. Sent emails to churches for National Sickle Cell Month.

September

Sponsored two blood drives with the American Red Cross (ARC). September 9, Claude Moore Center-Sterling, VA (Loudoun County) and September 23, Hilton Hotel, Springfield, VA (Fairfax County). At these two drives, there were 65 total donors and 57 units collected. Also volunteered at the ARC blood drive sponsored by State of Virginia Delegate Candi King on September 24 at Northern Virginia Community College, Woodbridge, VA (Prince William County). On September 22, the Fairfax County Board of Supervisors proclaimed September as Sickle Cell Awareness Month and a Proclamation was awarded to Service Coordinator Valerie Bey. Contacted by new client scheduled for upcoming bone marrow transplant. Sent \$100 donation to help with expenses and have referred to places for financial assistance. Donated toys to Children's National Medical Center for Sickle Cell patients. Toys were donated by Top Ladies of Distinction of Alexandria, a community partner.

October

Sponsored two blood drives with the American Red Cross (ARC) in late October. Donor information not yet available. Donated \$50 grocery gift card to client (non-grant funds). Contacted staff at Children's National Medical Center on behalf of client.

November

Sponsored two blood drives with the American Red Cross(ARC) in late October and one blood drive in early November. Donor information not yet available. Contacted staff at Pediatric Specialist of Virginia for outreach to children with Sickle Cell Disease in Northern Virginia.

December

Sponsored one blood drive with American Red Cross in December at McLean Community Center. Posted information about COVID testing. Gave Holiday Gift package (non grant funds) to Client and family. Client recently had bone marrow transplant and is recovering in Ronald McDonald House. Next blood drive in mid-January.



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

### January

Sponsored Blood Drive with American Red Cross at the Hilton Springfield on January 19th. There were 36 total donors and 27 units of blood collected. Sent email to Northern Virginia Baptist Association encouraging member churches to support blood drives and let us know if any members had SCD and needed support. Sent Spanish language SCD brochures and SCD hearing loss brochures to Pediatric Specialist of Northern Virginia (Dr. Elizabeth Yang) and Children's National Medical Center Sickle Cell Unit (Dr. Barbara Spellers-Brown, DNP) for distribution to clients.

### February

Meeting with American Red Cross to develop schedule of blood drives for 2022. Information sent to Community Partners Top Ladies of Distinction and Ivy Foundation of Northern Virginia to ask for support for blood drives and information distribution.

### March

Informational material and books about children with SCD (My Friend Jen and Breaking the Sickle-the Story of Dr Faye McBarnette) sent to Psi Psi Omega Chapter of Alpha Kappa Alpha Sorority, Inc. (North Stafford County) for their African American book drives. These books will be distributed in the schools in Stafford County. Facebook followers increased from 503 to 521. Discussed with Fairfax County Health Department forming a partnership through the "Real Talk" initiative to inform the African American Community about SCD, knowing SCD status and the importance of blood donations.

### April

From June 2021 through April 2022, the Heart of Gold co-sponsored 8 blood drives with the American Red Cross and supported 1 blood drive sponsored by Delegate Candi King. The statistics from the blood drives are as follows: June 2021-24 units, July 2021-27 units, August 2021-33 units, September 2021- 21 units, October 2021 35 units, November 2021-34 units, December 2021-28 units, April 2022 24 units. The next two blood drives are May and June 2022. The Heart of Gold was contacted by Inova Fairfax about partnering on an Adult Sickle Cell Program.

### May

Blood Drive sponsored in partnership with American Red Cross on May 11. Awaiting donor statistics. Contacted and set up meeting in June with Inova Fairfax Hospital re: Adult Sickle Cell Program. Posted message on Facebook asking for input from Adults and transitional young adults for ideas to improve care for SCD patients.

### June

Facebook followers increased by 52 persons in the past month. Information about World Sickle Cell Day posted on Facebook and Instagram. Data from April Blood Drive--24 units collected. May/June Blood Drive data not yet available. Interim President and Board Member/Service Coordinator Williams had an introductory call with INOVA re: Adult Sickle Cell Program partnership. Informational materials on Heart of Gold will be provide for INOVA and letters about Adult Sickle Cell Clinic will be sent to clients and local organizations. An informational webinar will be held in September 2022 and Heart of Gold will be a presenter. Annual newsletter was published and distributed to donors, clients, community partners, churches and civic groups. Children's books on Sickle Cell (My Friend Jen) were donated to the Zeta Chi Omega Chapter of Alpha Kappa Alpha (AKA) Sorority Inc. (Arlington/Alexandria) for the annual African American Book Drive. Heart of Gold has been asked to participate in a COVID awareness webinar on June 30 sponsored by Zeta Chi Omega Chapter of AKA.

### **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:** 120

Information or Referral Assistance to Clients and Families

**Number:** 69

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

**Number:** 14 for total of \$2,852.92

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

Pieces of Literature Distributed

**Number:** 768

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 11

**Number of Attendees:** 633

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

**Number of Attendees:** 242

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

Advocacy & Community Resources Meetings

**Number of Participants:** 49

Transition Young Adults Meetings

**Number of Participants:** 37

#### **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:** 242

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

**Number Sent:** 147

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

**Number Sent:** 1,560

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 505

Calls to clients to obtain information or update contact information

**Number:** 134

## **Sickle Cell Association - Continued**

### July

Gave virtual presentation to National Epicureans convention on the current updates for sickle cell disease treatment, research and local efforts. Held two blood drive at Surry Community Center and at First Church Ministries, Newport News reaching 26 donors.

### August

Met with volunteers from Hiram Grand Lodge and Venus Court Order of Eastern Stars to collect back-to-school supplies for sickle cell families. Distributed 20 backpacks with school supplies to sickle cell children. Contacted CHKD to assist with the distribution of school supplies in Hematology Clinic other families called office for pick up.

### September

Participated in three TV interviews to promote National Sickle Cell Awareness Month and give information on Sickle Cell Disease. Six sickle cell patients gave their stories of living with sickle cell disease. Held one virtual support group meeting with guest speaker from Eastern Virginia Medical School on update on COVID-19.

### October

Held one blood drive at Mt. Nebo Baptist Church and had 27 participants to donate blood. Sponsored two sickle cell families to participate on the virtual National Conference. The participants have agreed to become volunteers in the areas where they live, Williamsburg and Suffolk. Participated in one health fair sponsored by the breast cancer support group fair in Hampton Virginia.

### November

Provided 15 food baskets for sickle cell families who participated in the Thinking of You group meeting. One participant needed financial assistance and gave them a gift card to purchase food and supplies. Presented at the Chi Eta Phi Nursing Sorority Virtual Conference on Equity in Care for Sickle Cell Patients, spoke on the need for better adult treatment and resources including what does a medical home require.

### December

Provided 12 food baskets for sickle cell families who participated in the Thinking of You group meeting. One participant needed financial assistance and received a gift card. Presented at the CDC Workgroup meeting December 14, 2021 on the program services and activities of the Sickle Cell Association for sickle cell clients and their families.

### January

Held two blood drives, one in Williamsburg by Massage Therapy collecting 37 donations and a second one was held at Mt. Nebo Baptist Church, Surry collecting 30 pints of blood. Contact with sickle cell patients who need blood transfusions to see if they were having any problems. One patient need more frequent transfusions and expressed a critical delay in her getting matched for blood. Will host a blood drive next month to promote more awareness about sickle cell patients needing blood.

### February

Held one blood drive in Portsmouth that was co-sponsored by American Legion Post 190, Kadosh Lodge #7, Judith Chapter #45, and Your Wellness, Inc. collecting 26 donations in observance of Black History Month. Provided medical transport for client clinic visit to VCU. Family of 5 persons having an infant with sickle cell disease were homeless and helped with temporary housing assistance while we searched to permanently housing.

## **Sickle Cell Association - Continued**

### **March**

Planned Youth Retreat health resources fair for Baptist General Conference. Put together 100 resource bags of information and giveaways. Sent information to community, legislators, and sickle cell clients about the SCCAPE Conference that was held by VCU/MCV Sickle Cell Clinic on March 29-April 1, 2022.

### **April**

Held three blood drives one at the Attucks Theater, Williamsburg Marriott and Mt Nebo Baptist Church collecting 51 pints of blood. Sending letters to clients, churches and businesses informing them that the Organization is back open for in person meeting. COVID protocol is still being practiced to insure the safety of visitors to the office and that we are open to attend community fairs. Invited sickle cell clients to attend SCDAAs Advocacy training on April 5th. Presented to the John Hopkins SiNERGe Project on the Shine the LIght events planned for June 19th. Met with representatives from Global Blood Therapeutics on the needs of Adult Sickle Cell patients in the Hampton Roads area and asked for their help to discuss the matter with their medical contacts.

### **May**

Held a Partners and Benefactors Reception to present Association services. Two sickle cell clients gave their stories "Living with Sickle Cell." Contacting Sickle Cell clients for the second annual cookout in the Park to Shine the Light on Sickle Cell planned in June. Met with representative from Eastern Virginia Medical School on the Health Disparities studies program planned for EVMS, Norfolk State University and Old Dominion University. The collaboration was first discussed during legislative visit to Richmond in February on adult Sickle Cell patients health care needs.

### **June**

World Sickle Cell Day was observed on June 19, 2022 to raise awareness about Sickle Cell Disease on the local, state, national and international levels. It was designated by the United Nations through a resolution from the Republic of Congo in 2008. Several events were held to commemorate the observance including proclamations from area cities office of the mayors, and Shine the light on Sickle Cell/Juneteenth Heritage Festival in Northampton County on Virginia Eastern Shore. Billboards were posted on the interstate in Hampton, VA and in Chesapeake, VA. A focus group session on "Speak Up, Speak Out - How to Advocate for Yourself" was held on Saturday, June 18, 2022 with Sickle Cell families to learn how to reach legislators and tell their stories about living with Sickle Cell.

### **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:** 179

Information or Referral Assistance to Clients and Families

**Number:** 1

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:** 3 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:** 1,996

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 4

**Number of Attendees:** 675

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

**Number of Attendees:**

**Number:** 29 X 3 = 87 number of lives saved

Sent Information to Church Members

**Number:** 250

#### **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:** 2,641

Special Mailings

**Number Sent:** 1319

Letters to Churches

**Number:** 233

#### **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:** 279

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

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

**Number Sent:** 330

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:** 1,306

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 287

Calls to clients to obtain information or update contact information

**Number:** 93

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:** 8,050,000

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

### July

We are putting our focus on getting valuable information to each client by mail. In July, we sent each clients a brochure entitled "Hearing Loss, Dizziness, and Fall Risk in Persons with Sickle Cell Disease" to inform them about hearing loss. Hearing loss is a problem that rather gets the attention it should, and many clients do not realize the problem it is. This brochure is the only brochure in the country about both Hearing Loss and Sickle Cell Disease. Placed Newspaper Ad in the Richmond Free Press for one week (100,000 readers per week). One 5" x 2 column ad to request African America donors to give blood.

### August

We are putting our focus on getting valuable information to each client by mail. In August, we sent each client two Words of Wisdom. (1) Attention to detail sharpens the quality of our work and (2) Taking pride in all we do inspires us to go above and beyond.

Placed Newspaper Ad in the Richmond Free Press for two weeks (100,000 readers per week). ).

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

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

### September

In September, we took part in an outdoor health fair and a blood drive with the Red Cross.

Taped with others, a TV-6 commercial for the health fair. We asked people to contact the Red Cross and donate blood to help sickle cell patients and others. Purchased newspaper ad in the Richmond Free Press about Sickle Cell Trait/Disease that was run (100,000 readers per week for four weeks total 400,000). 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).

Placed Newspaper Ad in the Richmond Free Press for FOUR weeks (100,000 readers per week).

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

Two 5" x 2 column ad Abut Sickle Cell Trait/Disease.

### October

In October, we took part in an outdoor health fair. Sent out revised brochure about Sickle Cell Disease and the organization.

Placed Newspaper Ad in the Richmond Free Press for two weeks (100,000 readers per week).

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

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

### November

In November, we mailed each client a 2022 yearly pocket planner so they could keep track of their appointments.

### December

In December, we mailed each client (329) and Church members (78) and other Churches (35) a season's greeting card. Each greeting card has a twelve month tear off calendar that can stick to an appliance. We sent letters to Church members (78) and to other Churches (36) to encourage blood donations during the month of January (National Blood Donation Month) to help sickle cell patients in need of transfusions.

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

### January

In January, we mailed each client two Words of Wisdom. (1) Individually we are special; together we are spectacular and (2) Showing others the way helps us all grow to our full potential. During National Blood Donation Month we sent out e-mails to encourage people to donate to help sickle cell patients in need of transfusions and notices about the blood shortage. We established an alliance with the local chapter of 100 Black Women. We supplied and they distributed letters to inform people about the blood shortage and that they could donate six (6) times a year.

### February

In February, we mailed each client two Words of Wisdom. (1) Balancing our obligations makes for a fuller life and (2) The options are unlimited when we allow ideas to flow freely. We also mailed out "Thinking of You" cards to every client. During February, we got a local radio station and two sister stations to broadcast a monthlong FREE ad asking people to donate blood for sickle cell patients who need regular transfusions. It asked African Americans to contact the Red Cross and donate because African American donations were down by over 70%.

### March

In March, we mailed each client two Words of Wisdom. (1) The path of integrity always takes us in the right direction and (2) Changing times give us the opportunity to see things in a new way. George Carter was asked by the National Coalition of 100 Black Women Inc., Richmond Metropolitan Area Chapter to be a part of their 4th Annual Health Summit panel discussion on Sickle Cell Disease and answer questions put to the panel. The panel session was held on March 26th from 10 to 12. A variety of person served on the panel including in-state and out-of-state medical persons.

### April

#### April is Stress Awareness Month

In April, we mailed each client a letter about stress and an E-Z Stick-Up with information about stress and how to manage it entitled "You've Got This! Keeping Stress At Healthy Levels"

### May

In May, we mailed each client with two "Words of Wisdom" (1) Impressive results arise when everyone's creative input is welcomed and (2) If you find it in your heart to care for somebody else, you will have succeeded.

### June

In June, we mailed each client with two "Words of Wisdom" (1) It is only in the giving of oneself to others that we truly live. And (2) All the beautiful sentiments in the world weigh less than a single lovely action. 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 total)

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 request African America donors to give blood.



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

**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 76-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 over the last several months 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 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**".