

# 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 25, 2020

#### **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 (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

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 and FY20, 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		\$ 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, 2020**

The four aforementioned chapters were awarded funding to begin community-based services on July 1, 2019. The following information provides a summary of the community-based activities performed as of June 30, 2020. 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:** 5

Information or Referral Assistance to Clients and Families

**Number:** 2

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

**Number:** 28 for total of \$1,460.00

Home Visitation

**Number:** 7

Hospital Visitation

**Number:** 24

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 215

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 11

**Number of Attendees:** 5020

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

**Number of Attendees:** 32

**Type of Support Group offered:**

Meetings

**Number of Participants:** 83

**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:** 28

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

**Number Sent:** 56

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

**Number Sent:** 84

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 38

Calls to clients to obtain information or update contact information

**Number:** 9

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

**Number of Households Reached:** 79,511

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

### July

Preparing for the annual walk in September at the local High School in Franklin County. The 19th Warren Street festival is the kick off for the membership drive. Provided transportation expenses for (2) clients, \$100.00 each. One client was hospitalized twice in the month of July. The web sites are being maintained. We received one new client this month. Blood drive scheduled confirmed with Red Cross 2-08-20.

### August

Preparing for the annual walk in September at the local High School in Franklin County. The 19th annual Warren Street festival was a success as well as the membership drive. Contacted 21 churches asking for support for the walk and membership drive. The web sites are being maintained. Blood drive scheduled confirmed with Red Cross 2-08-20 in Franklin County. The local TV station is seen in 5,000 homes which has promoted Sickle Cell in our area.

### September

The annual walk in September at the local High School in Franklin County was a success. There were vendors, walkers, supporters, activity for the children, refreshments, door prizes, memorial service and information shared. The membership drive continued. Several churches donated the use of chairs and tables. The website shared information and pictures. The American Red Cross blood drive is scheduled for 2-08-20 in Franklin County. The local TV station is seen in 5,000 homes. They continue to solicit and announce the upcoming blood drive.

### October

The membership drive continued. The web site is being managed by the service coordinator. The American Red Cross blood drive is scheduled for 2-08-20 in Franklin County. The local TV station is seen in 5,000 homes. They continue to solicit and announce the upcoming blood drive and awareness. End of the year activities are being planned by a committee. Volunteers are being notified of the events and scheduled.

### November

The membership drive continues. The web site is being managed by the service coordinator. The American Red Cross blood drive is scheduled for 2-08-20 in Franklin County. The local TV station is seen in 5,000 homes and continues to solicit and announce the upcoming blood drive and awareness. Ten Festival of trees were decorated by non-profits as a fund-raising event for Franklin County children. The decorated tree would be given to a Sickle Cell client at the end of the event. The most unwrapped toys left under the tree would be the winner.

### December

The membership drive continues. The web site is being managed by the service coordinator. Past donors are being notified of the upcoming blood drive. The date is 2-08-20 in Franklin County. The local TV station is seen in 5,000 homes and continues to solicit and announce the upcoming blood drive and awareness. Ten Festival of trees event was a success. Non-profits decorated trees as a fund-raising event for Franklin County children. BRASCA participated in the Christmas parade and was view by 20,000 residents on 12-8-19. Donation made to Carilion Love light tree in memory of deceased members.

### January

The membership drive continues. The web site is being managed by the coordinator. The upcoming blood drive is 2-08-20 in Franklin County. The local TV station is seen in 5,000 homes and continues to solicit and announce the upcoming blood drive. The 17 churches were notified of the blood drive. Planning for the new year by the Board.

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

### February

The membership drive continues. The web site is being managed by the coordinator. The blood drive was a success on 2-08-20 in Franklin County. The local TV station is seen in 5,000 homes and continues to solicit and announce Sickle Cell events. The BRASCA Board met and resulted in election and event planning for the year. A Sickle Cell family is scheduled to appear on a medical board panel for discussion about their struggle. On 2/29, we came in contact with a family in Martinsville, VA that has Sickle Cell Disease and carry the trait. We gave out information and brochures and contact information.

### March

The membership drive continues. The web site is being managed by the coordinator. The local TV station is seen in 5,000 homes in the tri counties. The Board did not meet due to the state epidemic. A Sickle Cell family was scheduled to appear on a medical board panel for discussion about their struggle. We gave out information and brochures to the new family we found in the Henry County area. The Board will continue to work from home.

### April

The membership drive continues. The web site is being managed by the coordinator. The local TV station is seen in 5,000 homes in the tri counties. The Board will continue to work from home due to the state epidemic crisis. A local newspaper will run an ad looking for those who may have Sickle Cell disease. The Board will continue to plan for Fall events.

### May

The membership drive continues. The web site is being managed by the coordinator. The local TV station is seen in 5,000 homes in the tri counties. The Board will continue to work from home due to the state epidemic crisis. A local newspaper will run an ad looking for trait carriers. The Board will continue to plan for Fall events.

### June

The web site is being managed by the coordinator. The local TV station is seen in 5,000 homes in the tri counties. The Board will continue to work from home. The Board will continue to plan for Fall events. A blood drive is being planned. One application for scholarship has been received.

**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:** 7

Information or Referral Assistance to Clients and Families

**Number:** 2

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

**Number:** 0 for \$ 0.00                      **Hospital Care Kits**

**Type of Educational Program offered:**

Pieces of Literature Distributed

**Number:** 4,214

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 2

**Number of Attendees:** 600

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

**Number of Attendees:** 0

Posted Sickle Cell information on Facebook page for viewing.

**Number:** followers

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:** 379

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

**Number Sent:** 262 and others

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 40

Calls to clients to obtain information or update contact information

**Number:** 2

Distribution of Chapter Newsletter

**Number:** 3



### **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

Fairfax County Board of Supervisors will issue a Proclamation for National Sickle Cell Month at the September Board meeting. This event will be televised on County Channel 16, which reaches the entire Fairfax County population via cable or live stream. Service Coordinator Pearson established a partnership with Kroger linking Heart of Gold with the supermarket's loyalty card.

August

Fairfax County Board of Supervisors will issue a Proclamation for National Sickle Cell Month at the September Board meeting. This event will be televised on County Channel 16, which reaches the entire Fairfax County population via cable or live stream potential of nearly 1,000,000 persons. Service Coordinator Pearson established a partnership with Kroger linking Heart of Gold with the supermarket's loyalty card. Heart of Gold will participate in the Stomp Out Sickle Cell event on September 21, 2019 at Howard University.

September

Fairfax County Board of Supervisors, sponsored by Supervisor Catherine Hudgins, issued a Proclamation for National Sickle Cell Month at the September Board meeting. This event was televised on County Channel 16, which reaches the entire Fairfax County population via cable or live stream potential of nearly 1,000,000 persons. Service Coordinator Pearson posted Sickle Cell Month information on Facebook Page reaching more than 300 followers. Heart of Gold participated in the Stomp Out Sickle Cell event on September 21, 2019 at Howard University. Over 400 persons were in attendance. Informational brochures, bags, pens, books were distributed. Two new clients identified. For Sickle Cell Month, Service Coordinator Bey took photos of a family with at Sickle Cell member to highlight "Faces of Sickle Cell" gallery. Established partnership with the "Top Ladies of Distinction, Alexandria City Chapter". They will be donating items (toys, toiletries) for distribution during the holiday season.

October

Information posted on Facebook page by Service Coordinator Pearson. Facebook followers increased from 327 to 348.

November

Heart of Gold accepted an invitation to participate in the "Community of Hope" Holiday Party for children with blood disorders on December 7, 2019. This event is jointly sponsored by INOVA Health Foundation and Children's National Medical Center. Heart of Gold will have a display table with informational materials. Heart of Gold published a new brochure for students with SCD. Heart of Gold wrote a letter supporting a research initiative application by the Pediatric Specialist of Virginia. Additionally, Heart of Gold has been asked to serve on the Citizen Advisory Board.

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

December

Heart of Gold participated in the "Community of Hope" Holiday Party for children with blood disorders on December 7, 2019. This event is jointly sponsored by INOVA Health Foundation, Pediatric Specialist of Northern Virginia and Children's National Medical Center. Heart of Gold had a display table with informational materials. Heart of Gold received a large donation of toys from the Top Distinction of Ladies Alexandria City Chapter for the event and is in development of a partnering agreement with the organization.

January

Heart of Gold Service Coordinator Pearson advertised upcoming activities for World Sickle Cell Day in June. Service Coordinator Pearson also initiated a campaign with Top Ladies of Distinction Alexandria City Chapter for donations for care kits for hospitalized patients. The care kits, which contain toiletries and books, will be distributed to local clinics and hospitals.

February

Facebook followers increased to 350. Information on upcoming clinical trials has been posted.

March

Facebook followers increased to 351. Posted and shared information about COVID-19 precautions.

April

Facebook followers increased to 353 an increase of 2. Posted and shared information about up to date COVID-19 precautions. Distributed newsletter and "Know your Status " Booklet to 45 persons.

May

Facebook followers increased to 363 an increase of 10. Posted and shared current information about COVID-19 precautions. Distributed newsletter and "Know your Status " Booklet to 25 persons.

June

Purchased cloth face masks (non-grant dollars) and distributed to 25 clients. Sent letters to clients for World Sickle Cell Day. Posted information about COVID precautions and recommended good practices.

### **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:** 304

Information or Referral Assistance to Clients and Families

**Number:** 156

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

**Number:** 16 for total of \$2,458.00

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

Pieces of Literature Distributed

**Number:** 4,485

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 47

**Number of Attendees:** 3,719

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

**Number of Attendees:** 164

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

Advocacy & Community Resources Meetings

**Number of Participants:** 43

Transition Young Adults Meetings

**Number of Participants:** 164

#### **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:** 273

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

**Number Sent:** 650

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

**Number Sent:** 1,593

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 1,350

Calls to clients to obtain information or update contact information

**Number:** 347

## **Sickle Cell Association - Continued**

### July

Sponsored a community blood drive at Mt. Nebo Church and distributed Red Cross and Sickle Cell flyers on "Why is your race important as a blood donor?" ...be a special match for a patient in need! A sickle cell patient talked about their need for blood donations that they receive every month.

### August

Contacted sickle cell patients to pick up school supplies donated by Eastern Stars. They donated 25 backpacks with school supplies to be distributed to students. Another Eastern Stars chapter collected school supplies to be given out during the school year as needed. Recruited sickle cell patients to attend the ASH conference in Washington, DC on September 14, 2019.

### September

Sickle cell clients organized teams for the Annual Walk for Sickle Cell and spoke on the field with family and friends supporting the effort to raise awareness about the disease. Some spoke on camera of the local TV station. 12 Sickle cell patients and their family's rode in two vehicles and marched in the Annual Fish Bowl parade hosted by the Arabia Temple Shriners promoting Sickle Cell Awareness Month. One sickle cell family member attended the ASH Conference in Washington, DC and at the VCU Sickle Cell Care Coordination for Achieving Patient Empowerment held in September.

### October

The Sickle Cell Association participated in 10 area churches health fairs and gave four presentations. The presentations were given by sickle cell patients that told their stories about living with sickle cell disease. The community-wide Malloween as held at local mall where Sickle cell patients where more than 600 children stopped by the information booth. Five sickle cell families were identified at the event. Follow up will be provided to identify service needs and complete intakes.

### November

Twelve Sickle cell clients were asked to present their story at the Unmasking Sickle Cell Soiree. The clients told their stories of living with sickle cell disease, challenges and accomplishments. Each was presented a "Making A Difference" plaque as sickle cell warriors to help educate the community about the disease. One performer was given a scholarship to attend the liberal arts program in January 2020. Fifteen families were given Thanksgiving food baskets. Hand-sewed pillows were made for Ayana Hope Cell Pillow Program and given to sickle cell children in the hospital during Thanksgiving Day. Unfortunately, she experienced pain and was hospitalized after Thanksgiving Day.

### December

Provided 11 sickle cell families with food baskets donated by local Masonic lodges and Eastern Stars. Sickle Cell Family Peer Advocates held their annual Christmas Party for families in the Hampton Roads area where food and gifts were exchanged. Worked with the Kidney Prevention and Awareness organization to distribute bottled water and information on the disease at 2 health fairs. Radio spot announcements on five Praise Radio stations aired during December to inform persons about know your trait status to a potential listening audience of 142,000 and an undetermined number on their internet station.

## **Sickle Cell Association - Continued**

### January

Presented at the Martin Luther King Service held at First Baptist Bute Street on the current state of Sickle Cell Disease and what the Association is doing in the community. Met with foster parents at Portsmouth Social Services on information about the disease and Agency services and provided intake on new client. Presented 2020 calendar of events and services at HR Gazette newspaper Community Network meeting.

### February

Black History Month presentations and health awareness fairs to educate and advocate for better health resources for sickle cell patients. Expressed the need for more blood drives in the minority community and especially churches. Set up information booth at Norfolk State University Nursing Department Black History Health Care Fair to update nursing students on the state of Sickle Cell Disease.

### March

Participated in one event before the Governor's mandate to "Stay Home" and the rest of the scheduled events for the month of March were cancelled. Sent out cards and emails to clients with Facts Sheets from SCDAA on the CoVID-19 Protocol and CDC information for cleaning home during Pandemic.

### April

Sent out Health Alert Fact Sheet on Recommendations for CoVID-19 preparedness for sickle cell patients. Following the Commonwealth of Virginia Governors Executive Order all community events were cancelled. Mid Atlantic Red Cross held one blood drive at Mt. Nebo Baptist Church and had 36 donors for blood. Left brochures for donors on the need for blood by sickle cell patients.

### May

Continue to send out Health Alert Fact Sheet on Recommendations for CoVID-19 Preparedness for sickle cell patients. Following the Commonwealth of Virginia Governors Executive Order all community events were cancelled. Mid Atlantic Red Cross held one blood drive at Hiram Grand Lodge, Portsmouth and had 28 donors to give blood. Left brochures for donors on the need for blood by sickle cell patients.

### June

Continue to send out Health Alert Fact Sheet on Recommendations for CoVID-19 Preparedness for sickle cell patients. Following the Commonwealth of Virginia Governors Executive Order all community events were cancelled. Mid Atlantic Red Cross held one blood drive at Military Circle Mall and had 30 donors to give blood. Left brochures for donors on the need for blood by sickle cell patients. Gave COVID Relief Care Kits that include bleach, disinfectant spray, paper

**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:** 237

Information or Referral Assistance to Clients and Families

**Number:** 2

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:** 12 for total of \$5,526.77

Contract Services for Client Advocacy Education and Representation

**Number of Participants:** 0

**Type of Educational Program offered:**

Distribution of Sickle Cell Literature

**Number:** 2,479

Health Fairs/ Presentations of Sickle Cell and Agency Information

**Number:** 16

**Number of Attendees:** 1,037

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

**Number of Attendees:**

**Number:** 0 X 0 = 0 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:** 3,730

Special Mailings

**Number Sent:** 778

**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:** 294

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

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

**Number Sent:** 340

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:** 1,405

Letters to churches to educate and obtain support for Sickle Cell

**Number Sent:** 107

Calls to clients to obtain information or update contact information

**Number:** 266

Ran Newspaper Ads in the Richmond Free Press about Sickle Cell Trait/Disease that reached (100,000 readers per week for two weeks total 200,000). Sickle Cell Trait/Disease advertisement on Radio One was broadcasted to 130,000 households during each of 43 ad spots broadcasted.

(Ads ran July, August, September, October and June)

**Number of Households Reached:** 2,063,000

## Sickle Cell Association of Richmond-OSCAR - Continued

### July

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 July, we sent each client two "Words of Wisdom":

- (1) Shared insight creates an environment where everyone thrives.
- (2) Creative ideas flow freely where there is acceptance and trust.

Newspaper Ad in the Richmond Free Press about Sickle Cell Trait/Disease was run (100,000 readers per week for two weeks total 200,000).

### August

We are putting our focus on getting valuable information to each client by mail. In August, (3 mailings). We sent each client a 16-page booklet entitled "Emergency Preparedness Guide" talking about all types of emergencies and how to plan and adjust to them. Sent each client a September Month Calendar with 30 pieces of information about sickle cell. Sent a letter to each client urging them to take a free bus trip to Washington, D.C. to take part in a meeting with the American Society of Hematology. This meeting would discuss the barriers to taking part in drug trials and how to overcome it. The clients will help to create a SCD Patient-Oriented Research Priority Report. Newspaper Ad in the Richmond Free Press about Sickle Cell Trait/Disease was run (100,000 readers per week for two weeks total 200,000).

### September

We are putting our focus on getting valuable information to each client by mail. In September, we distributed copies of the September Month Calendar with 30 pieces of information about sickle cell to Statewide chapters and other persons. Took 28 people to Washington, D.C. to meet with the American Society of Hematology to discuss the barriers to taking part in drug trials and how to overcome it. The clients helped to create a SCD Patient-Oriented Research Priority Report. Newspaper Ad in the Richmond Free Press about Sickle Cell Trait/Disease was run (100,000 readers per week for four weeks total 400,000). 55 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). See additional information below.

9-07-19	Health Fair – Mosby Memorial	Participants	200	Literature Taken	800
9-11-19	Face Book hospital event	Viewers on Line	159	Literature Taken	25
9-12-19	Children’s Hospital table set up	Participants	30	Literature Taken	120
9-14-19	Trip to D.C for ASH meeting	Participants	28	Literature Taken	56
	Total attendance at the meeting from D.C., Virginia and Maryland was 108				
9-17-19	Training Event (hospital)	Participants	75	Literature Taken	150
9-21-19	Participated in city sickle cell walk	Participants	60	Literature Taken	150
9-21-19	Table Event Health Fair	Participants	100	Literature Taken	200
9-26-19	Adult Clinic Visit	Participants	10	Literature Taken	150
9-28-19	Sickle Cell Breakfast	Participants	22	Literature Taken	35
9-28-19	Presentation – 1 <sup>st</sup> Church	Participants	50	Literature Taken	50
9-30-19	Participated in VSU sickle cell walk	Participants	75	Literature Taken	350
		Total	809	Total	2,086



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

October

We sent each client two "Words of Wisdom" 1. How wonderful it is that nobody need wait a single moment before starting to improve the world and 2. Vitality shows not only in the ability to persist, but in the ability to start once. Ran a Newspaper Ad in the Richmond Free Press about Sickle Cell Trait/Disease (100,000 readers per week for two weeks total 200,000).

November

We are putting our focus on getting valuable information to each client by mail. In November, we sent each client a 2020 yearly pocket planner so they could keep track of their appointments.

December

We sent each client a season greeting card. We sent letters to church members to encourage blood donations during the month of January (National Blood Donation Month).

January

We sent each client two "Words of Wisdoms". 1. Progress always involves risk; you can't steal second base and keep your foot on first. and 2. The highest reward for a person's toil is not what he gets for it, but what he becomes by it.

February

We sent each client two "Words of Wisdoms". 1. People with many interests live, not only longest but happiest. and 2. When you do the common things in life in an uncommon way, you will command the attention of the world. We received the following message from a client. THANK YOU FOR ALL OF YOUR SUPPORT THROUGH SENDING ME LETTERS, CARDS, AND FLYERS. EVERYTHING OSCAR STANDS FOR AND FOR ALL OF YOUR SUPPORT REALLY MEANS A GREAT DEAL TO ME. AGAIN, THANK YOU FOR ALL THAT OSCAR DOES FOR THE SICKLE CELL COMMUNITY. MAY GOD CONTINUE TO BLESS EACH AND EVERY PERSON WHO IS ASSOCIATED WITH THIS WONDERFUL ORGANIZATION.

March

We sent each client two "Words of Wisdoms". 1. What happens is not as important as how you react to what happens. and 2. What lies behind us and what lies before us are tiny matters compared to what lies within us.

Newspaper Ad in the Richmond Free Press about Sickle Cell Trait/Disease was run (100,000 readers per week for three weeks total 300,000).

April

We sent each client a letter about April being National Stress Awareness Month and including two pocket pals with information about stress "Dealing With Day-To-Day Stress & Anxiety" and "Mental & Emotional Fitness" and a Stress-O-Meter. Sent letters about Sickle Cell Disease and Stress Month to Churches.

Newspaper Ad in the Richmond Free Press about Sickle Cell Trait/Disease was run (100,000 readers per week for three weeks total 300,000).

May

We sent each client two Words of Wisdom (1) The virtue lies in the struggle, not in the prize and (2) Vitality shows not only in the ability to persist, but in the ability to start over.

Newspaper Ad in the Richmond Free Press about Sickle Cell Trait/Disease was run (100,000 readers per week for three weeks total 300,000).

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

June

In June, we sent each client Two Face Masks (paid for with Non-State Grant Funds). Sickle Cell is an underlining health condition for clients. Many clients are unable to pay for masks. Most stores clients go to do not have masks for sale. Places having masks only sell them in bulk. COVID-19 has caused us to continue to limit our activities.

Newspaper Ad in the Richmond Free Press about Sickle Cell Trait/Disease was run (100,000 readers per week for two weeks total 200,000). Sickle Cell Trait/Disease advertisement on Radio One during the month was broadcasted to 130,000 households during each of 43 ad spots broadcasted.

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

**The following pages 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 74-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. He serves as a Sickle Cell Disease Patient Consultant for the Food & Drug Administration (FDA) and on the Interagency Pain Research Coordinating Committee (IPRCC) of the National Institute of Health (NIH).

During the last three 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-Report-October 2018**

### **National (SCDAA) – Opioid Backlash**

George Carter attended the Sickle Cell Disease Association’s national conference and spoke to member organizations and national staff about the opioid crisis backlash on sickle cell patients and stressed a need for the national organization to appeal to the CDC to amend the opioid guidelines to grant an exception for sickle cell just as has been done in Virginia and California. He supplied material information and offered his assistance in working to gain CDC approval. He participated in a conference call with members of Board of the Directors and provided information Virginia’s organization used to get an exception, suggested what data was needed to be submitted and later provided a draft letter for them to use.

## **Statewide-Report-November 2018**

### **NIH MEETING**

George Carter attended the meeting (as a member) of the National Institute of Health’s (NIH) Interagency Pain Research Coordinating Committee (IPRCC) in Maryland. A number of reports were given discussing various types of pain, the use of opioids and other pain management methods. George Carter spoke to members about the opioid crisis backlash on sickle cell patients and stressed that it has created an overall pain management crisis.

### Statewide Report-March, 2019

The Sickle Cell Community Consortium invited George Carter to its fourth annual meeting in Atlanta, GA., to speak on **SICKLE CELL EXEMPTION TO OPIOID POLICIES AND OVERCOMING THE RESTRICTIONS**. The presentation was intended to explain to sickle cell organizations in other states what Statewide Sickle Cell Chapters of Virginia, Inc. had done to get a medical board exemption for sickle cell in the State of Virginia.

### Statewide Report-May, 2019

George Carter was invited by Howard University in Washington, D.C. to be a part of a panel. The purpose was to interact with sickle cell audience and address their questions and concerns. The focus was on: Advocacy for patient care.

### May 28,2019

George Carter participated as a member in the National Institute of Health's (NIH) Interagency Pain Research Coordinating Committee (IPRCC) conference call meeting. He noted that the CDC has released a commentary in the New England Journal of Medicine (4-24-19) Advising Against Misapplication of the Guidelines for Prescribing Opioids for Chronic Pain. The article says in part, the following:

CDC is raising awareness about the following issues that could put patients at risk:

- **Misapplication of recommendations to populations outside of the Guideline's scope.** The Guideline is intended for primary care clinicians treating chronic pain for patients 18 and older. Examples of misapplication include applying the Guideline to patients in active cancer treatment, patients experiencing acute sickle cell crises, or patients experiencing post-surgical pain.
- **Misapplication of the Guideline's dosage recommendation that results in hard limits or "cutting off" opioids.** The Guideline states, "*When opioids are started, clinicians should prescribe the lowest effective dosage. Clinicians should... avoid increasing dosage to  $\geq 90$  MME/day or carefully justify a decision to titrate dosage to  $\geq 90$  MME/day.*" The recommendation statement does not suggest discontinuation of opioids already prescribed at higher dosages.

### November of 2019

George Carter participated as a member in the National Institute of Health's (NIH) Interagency Pain Research Coordinating Committee (IPRCC) in-person 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.

### December of 2019

George Carter was contacted by a sickle cell chapter in Florida asking for assistance in getting a medical board exemption for sickle cell in their state. He provided documents to help them.

### May of 2020

George Carter participated as a member in the National Institute of Health's (NIH) Interagency Pain Research Coordinating Committee (IPRCC) conference call meeting. He again 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.