

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, 2021

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. 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

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 and FY21, 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, 2021

The four aforementioned chapters were awarded funding to begin community-based services on July 1, 2020. The following information provides a summary of the community-based activities performed as of June 30, 2021. 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 15th of each month.

MEMO

COVID – 19 PANDEMIC

The entire 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: 4

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: 1 for total of \$300.00

Home Visitation

Number: 0

Hospital Visitation

Number: 0

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 400

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: 0

Type of Support Group offered:

Meetings

Number of Participants: 41

Other Activities:

Birthday cards sent to clients having birthdays during each month.

This is done so clients know that the organization is thinking about them.

Number Sent: 23

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

Number Sent: 70

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

Number Sent: 77

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: 10

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

Number of Households Reached: 200

Blue Ridge Area Sickle Cell Association - Continued

July

The committee is gathering information for the sickle cell TV presentation due in September. Three applications are being reviewed for scholarships. The Board continue to work from home. The Red Cross blood drive have not been rescheduled. All the patients seem to be safe and healthy. The social media is managed by the Service Coordinator. A new account for the Web site is to be renegotiated.

August

The committee is gathering information for the sickle cell tv presentation due in September. Three applications are to receive scholarships. The Board continue to work from home. The Red Cross blood drive have not been rescheduled. The membership drive began in August. A project is being planned to increase membership. The social media is managed by the Service Coordinator. A new account for the Web site is to be renegotiated.

September

The facebook page manager sent out useful information for September. The web site is managed by one of the coordinators. The membership drive began in August. The Board continues to work from home. A project is being planned to increase membership and funding raising. A new account for the web site is to be renegotiated.

October

The web site is managed by one of the coordinators. The membership drive continues. The Board continues to work from home. The project to increase membership and funding raising was a success. A new account for the web site is to be renegotiated. A blood drive is being planned for November.

November

The facebook page is managed by the Service Coordinator. The Board continue to work from home. The Red Cross blood drive was cancelled. The membership drive began in August. and continues. The project planned to increase membership was a success.

December

The facebook page is managed by the Service Coordinator. The Board continue to work from home. The Red Cross blood drive was cancelled. The membership drive began in August. and continues. All members are well. There has been limited hospital stays. We are still not able to meet at Franklin Memorial Hospital at our regular time.

January

The facebook page is managed by the Service Coordinator. An inspirational message is posted weekly The Board continue to work from home. The Red Cross blood drive was cancelled. The membership drive continues. There were no hospital stays. Those who had covid 19 had a mild case and have recovered. The board is still not able to meet at Franklin Memorial Hospital.

February

The facebook page is managed by the Service Coordinator. An inspirational message is posted. The Board continue to work from home. The membership drive continues. There were no hospital stays. The board is still not able to meet at Franklin Memorial Hospital.

March

The facebook page is managed by the Service Coordinator. An inspirational message is posted. The Board continue to work from home. The membership drive continues. There were no hospital stays. The board is still not able to meet at Franklin Memorial Hospital. A board meeting is planned for April.

Blue Ridge Area Sickle Cell Association - Continued

April

The facebook page is managed by the Service Coordinator. An inspirational message is posted. The Board continue to work from home. The membership drive continues. There were no hospital stays. The board is still not able to meet at Franklin Memorial Hospital.

May

The facebook page is managed by the Service Coordinator. An inspirational message is posted. The Board continue to work from home. The membership drive continues. There were three hospital stays. The board is still not able to meet at Franklin Memorial Hospital.

June

The facebook page is managed by the Service Coordinator. An inspirational message is posted weekly. The Board continue to work from home. The membership drive continues. The board is still not able to meet at Franklin Memorial Hospital. A monthly meeting is planned.

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: 3

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

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 5,492

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: 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: 329

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

Number Sent: 380 and others

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

Distribution of Chapter Newsletter

Number: 780

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

Heart of Gold sent thumb drives with informational videos to other Statewide Chapters that had requested the videos for their local television markets. Children's books on Sickle Cell were donated to a Prince William County teacher who requested African-American educational materials for her school.

August

Letters were sent to the Board of Supervisors in Fairfax County, Prince William County, and Loudoun County, as well as the City Council in the City of Alexandria, requesting Proclamation to recognize September as Sickle Cell Awareness Month. To date, Fairfax County has three Supervisors sponsoring a proclamation, and a Supervisor in Prince William County has agreed to sponsor a proclamation. Information on "Cure Sickle Cell Event" at Howard University posted on Facebook-accessible to 365 Followers.

September

Three Board of Supervisor Members in Fairfax County, Virginia sponsored at proclamation recognizing September as "National Sickle Cell Awareness Month". A Board of Supervisors member in Prince William County Virginia sponsored a proclamation for "National Sickle Cell Awareness Month". Board Member Mrs. Pearson Hurley met with the Honorable Andrea Bailey, Supervisor, Potomac District Prince Williams County to discuss future partnerships. Supervisor Bailey is interested in co-sponsoring a blood drive in conjunction with Sentara Hospital in Woodbridge, Virginia. Heart of Gold was contacted by a Nurse at United Healthcare for a recommendation for an internal medicine doctor for a SCD patient. Information was provided. Service Coordinator Pearson posted a video about Sickle Cell Awareness Month. She also posted daily information about SCD. Facebook followers have increased significantly to 485 (from 365).

October

Heart of Gold contacted by Prince William County Board of Supervisor member about sponsoring Blood Drive/Sickle Cell event. Information posted on Facebook by Service Coordinator Pearson about wellness, new studies for sickle cell patients, pain triggers.

November

Heart of Gold contacted American Red Cross about sponsoring Blood Drive. Informational Materials posted on Facebook. Fundraiser started to provide grocery gift cards to clients impacted by COVID.

December

Informational Materials posted on Facebook. Fundraiser started to provide grocery gift cards to clients impacted by COVID. Donation received from Community Partner Ivy Foundation of Northern Virginia.

January

Partnership to sponsor blood drive in Prince William County established with the Office of the Honorable Andrea Bailey, Board of Supervisors, Prince William County. Conference call was held with American Red Cross Representative Meosha Hudson to learn about requirements to sponsor blood drive.

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

February

Board Member Melanie Pearson Hurley participated in a virtual Black History Month (BHM) celebration sponsored by Prince William County Supervisor Franklin. During the program, participants were informed of the importance of blood donations from the African American Community and the importance of African American Blood for Sickle Cell patients. She encourages persons to participate and consider sponsoring blood drives. Over 110 persons participated in the virtual BHM celebration.

March

CEO and Service Coordinator Clarissa Pearson passed away on March 10, 2021 due to complications of Sickle Cell Disease. Board member and Treasurer Melanie Hurley will assume her duties temporarily. Tribute page on Facebook reached 4,391 persons. Discussions have continued with American Red Cross representative and the staff of the Honorable Andrea Bailey, Vice-Chair, Prince William County Board of Supervisors to sponsor a Blood Drive.

April

Established partnering agreement with American Red Cross to co-brand/sponsor 8 blood drives in 2021 in Loudoun, Fairfax and Prince William County.

May

Began advertisement for 2021 blood drives. There will be a total of eight blood drives in Northern Virginia--four at the McLean Community Center (Fairfax County), one at the Douglas Community Center (Loudoun County), one at the Haymarket-Gainesville Library (Prince William County) and one at the Claude Moore Community Center (Fairfax County).

Information about blood drive will be on Fairfax County Cable Channel 16.

June

Continued advertisement for 2021 blood drives with emails to churches, civic organizations, civil rights organizations, HBCU alumni associations and fraternities and sororities. The next Blood Drive is July 30 at Haymarket-Gainesville Library, Prince William County. Information about blood drive and the importance of African-Americans donating to help persons with sickle cell has aired as a Public Service Announcement on Fairfax County Cable Channel 16. Brochure on hearing loss in persons with Sickle Cell was printed.

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: 138

Information or Referral Assistance to Clients and Families

Number: 96

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

Number: 24 for total of \$7,330.00

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 571

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 3

Number of Attendees: 157

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

Number of Attendees: 692

Type of Support Group offered:

Advocacy & Community Resources Meetings

Number of Participants: 39

Transition Young Adults Meetings

Number of Participants: 78

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: 253

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

Number Sent: 196

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

Number Sent: 1,566

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 281

Calls to clients to obtain information or update contact information

Number: 153

Sickle Cell Association - Continued

July

No community events have been held due to COVID-19 restrictions. Held two blood drives one at Gethsemane Community Fellowship Church and at Mt Nebo Baptist Church. Distributed information on the importance of blood donations for sickle cell patients. Met with Masons and Eastern Stars to receive a donation and gave information about the upcoming blood drives. Sent letters to churches to put sickle cell clients on their Food Pantry distribution list. Gave sickle cell families COVID Relief care bags that included thermometer, reusable face masks, bleach, disinfectant spray, and information from CDC/SCDAA on COVID-19 protection steps for sickle cell patients and caregivers.

August

No community events have been held due to COVID-19 restrictions. Held three blood drives in a series of drives in partnership with the Mid-Atlantic Region Red Cross. This is an ongoing effort to get much needed blood for sickle cell patients who require frequent blood transfusions in emergency treatment during the COVID pandemic.

September

In observance of the month of September which is Sickle Cell Awareness Month held the 27th Annual Walk for Sickle Cell Final Mile at Military Circle Mall on September 30, 2020 for a limited number of Walkers and Walgreens provided flu shots in compliance to COVID-19 restrictions. Radio interview September 8th on 95.7 R&B with sickle cell client, Association Executive Director and Red Cross Medical Director to inform public of the upcoming blood drives and the Walk reaching over 150,000 listeners. Held one blood drive in a series of drives in partnership with the Mid-Atlantic Region Red Cross, sponsored by the City of Norfolk at the Attucks Theater and reached 26 donors. This is an ongoing effort to get much needed blood for sickle cell patients who require frequent blood transfusions in emergency treatment during the COVID pandemic.

October

Held a Zoom Support Group Meeting on October 19, 2020 with 15 sickle cell participants on the topic "Stop the Pain-Empowering the Sickle Cell Patient" guest speaker was Matt Baker, PharmD with Global Therapeutics. The hour session talked about current treatment therapies and research to have new interventions to stop the recurring pain episodes in sickle cell patients. Radio interview October 29th on 95.7 R&B with sickle cell disease as the topic of discussion for Black Health Issues podcast heard by an estimated 300,000 listeners. Held four blood drives in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross. The drives were through a city-wide initiative in the City of Norfolk at the Attucks Theater and Scope Exhibition Hall that reached 66 donors. This is an ongoing effort to get much needed blood for sickle cell patients who require frequent blood transfusions during emergency treatment in the COVID pandemic.

November

Held seven blood drives in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross. The drives were through a city-wide initiative in the City of Norfolk at the Scope Exhibition Hall, Gethsemane Baptist Church, Hampton, Grove Baptist Church, Portsmouth and Hampton Coliseum that reached 248 donors. This is an ongoing effort to get much needed blood for sickle cell patients who require frequent blood transfusions during emergency treatment in the COVID pandemic. Partnered with Hiram Grand Lodge, Portsmouth Medina Temple #3 of Newport News and Venus Court #1 OES of Newport News to give 16

Sickle Cell Association - Continued

families Thanksgiving food baskets. Provided transportation assistance to 5 sickle cell clients through the COVID Patient Transportation Support grant.

December

Held one blood drive in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross reaching 27 donors. The drives will continue next year through city-wide initiatives in the City of Norfolk and Virginia Beach. Gave 18 Christmas food baskets to sickle cell families through food donations from Medina Temple #3 of Newport News and Venus Court #1 OES of Newport News. Held one zoom support group meeting and gave 25 license frames in collaboration with the National Northeast Sickle Cell collaborative effort.

January

Held two blood drives in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross reaching 34 donors.

February

Held two blood drives in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross at the Attucks Theater and Boil Bay Seafood City restaurant in Norfolk reaching 44 donors.

March

Held a blood drive in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross at the Attucks Theater in Norfolk reaching 10 donors. Gave a virtual presentation on World Kidney Day, March 11, 2021 on the topic Sickle Cell and Kidney Disease to 31 participants.

April

Held 4 blood drives in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross at the Attucks Theater in Norfolk, Gethseman Community Church, Newport News, Surry Community Center, and Delta Sigma Theta Sorority at Marketplace Tech Center, Newport News reaching 62 donors. Gave Channel 10 TV media presentation to Red Cross Coastal Virginia at Community Awards Event where the Association was recognized on April 28th.

May

Held 2 blood drives in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross at the Attucks Theater in Norfolk, and New Jerusalem Baptist Church in Virginia Beach, VA reaching 24 donors. Gave a webinar presentation in the Red Cross educational series on Sickle Cell Disease and Demand for Minority Blood Donors for 62 registered participants.

June

Held 2 blood drives in a series of drives through a partnership with Mid-Atlantic Region of American Red Cross at Gethsemane Baptist Church, Newport News, and Boil Bay Seafood Restaurant in Norfolk, VA reaching 18 donors. Sponsored an Advocacy Day Luncheon on June 19, 2021 as a part of the World Sickle Cell Day with Delegate Cliff Hayes who champion **House Bill 907 for sickle cell treatment. An in-depth discussion on the need for transition care and adult sickle cell treatment center in the Hampton Roads area was presented.** He has invited sickle cell patients to visit him in Richmond during the next 2022 General Assembly Session.

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: 267

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: 6 for total of \$3,000.00

Contract Services for Client Advocacy Education and Representation

Number of Participants: 0

Type of Educational Program offered:

Distribution of Sickle Cell Literature

Number: 2,378

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 2

Number of Attendees: 537

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

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: 2,770

Special Mailings

Number Sent: 1810

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: 344

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: 1,386

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 106

Calls to clients to obtain information or update contact information

Number: 149

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: 8,650,000

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 client a sixteen-page booklet entitled "About Food and Drug Interaction" to help them prevent any negative reactions.

August

In August, we mailed each client two Words of Wisdom (1) There are no shortcuts to any place worth going and (2) If you don't paddle your own canoe, you don't move. Mailed each client a September Month Calendar with information about sickle cell for each of the 30 days. Sent a letter to a number of Churches informing them that September is National Sickle Cell Month and asking them to contact us for literature, a speaker or be a part of a Church activity for their members. We also asked their members to contact the Red Cross and donate blood. Sent letters to persons on our list asking them to 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 two weeks total 200,000).

September

In September, we took part in an outdoor combined health fair and blood drive with the Red Cross. 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). Arranged for Radio One in Richmond to do a (free) PUBLIC SERVICE ANNOUNCEMENT (wording attached) to help get more African American blood donations.

October

In October, we mailed each client a sixteen-page booklet entitled "Managing Your Medications" which provided guidelines and tips for taking medications. Purchased newspaper ad in the Richmond Free Press about Sickle Cell Trait/Disease that was run (100,000 readers per week for two weeks total 200,000).

November

In November, we mailed each client a 2021 yearly pocket planner so they could keep track of their appointments.

December

In December, we mailed each client (350) and Church members (76) 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 (76) and to other Churches (35) to encourage blood donations during the month of January (National Blood Donation Month) to help sickle cell patients in need of transfusions.

January

In January, we sent each client two Words of Wisdom. (1) Our attitude toward life determines life's attitude towards us and (2) The right attitude helps us start each day with a bright outlook Arranged for Radio One in Richmond to do a (free) PUBLIC SERVICE ANNOUNCEMENT during January (National Blood Donation Month) to help get more African American blood donations for sickle cell patients.

Sickle Cell Association of Richmond-OSCAR - Continued

February

In February, we sent each client stick-up card entitle " KEEP MOVING" explains ten (10) Healthy Ways to Stay Energized ALL DAY.

March

In March, we sent each client two Words of Wisdom. (1) We have to dare to be ourselves, however frightening or strange that self may prove to be. And (2) Social change is better achieved by being for something than against something. George Carter was requested to make a presentation on sickle cell to the Old Dominion Emergency Medical Service (EMS) Society. The presentation was made at their headquarters to some present and other EMS Personnel on line virtually from around parts of the State. This was an opportunity to influence the care and understanding emergency medical workers give sickle cell patients they transport to hospitals.

April

Stress Awareness Month

In April, we sent each client a pocket pal with information about stress and how to manage it and a meter to measure their stress level.

May

In May, we sent each client two Words of Wisdom (1) Hope is the dream of the walking man. (2) Every failure brings with it the seed of an equivalent success. Three different Newspaper Ads in the Richmond Free Press for three weeks (100,000 readers per week for three weeks total 300,000).

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

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.

June

In June, we sent each client two Words of Wisdom. (1) **Our level of success is a reflection of how high we set our sights and (2) Peak achievement requires the determination to step up to every challenge.** Three different Newspaper Ads in the Richmond Free Press for **four** weeks (100,000 readers per week for three weeks total **400,000**).

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

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.

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. 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 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 75-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 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.