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

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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

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 and FY19, 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 FY19:

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 PLUS	Richmond	$33,287.00
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, 2019

The four aforementioned organizations were awarded funding to begin community-based services on July 1, 2018. The following information provides a summary of the community-based activities performed as of June 30, 2019. 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.

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: 8

Information or Referral Assistance to Clients and Families

Number: 7

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

Number: 3 for total of $980.75

Home Visitation

Number: 23

Hospital Visitation

Number: 26

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 730

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 18

Number of Attendees: 3117

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: 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: 28

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

Number Sent: 65

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

Number Sent: 108

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 326

Calls to clients to obtain information or update contact information

Number: 209

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

Number of Households Reached: 5,102

Blue Ridge Area Sickle Cell Association - Continued

July

Distributed information to a family reunion (brochures). Distributed newspaper article to clients regarding opioid regulations and the fight to have higher dosages as treatment. Continuing to work on walk-a-thon project. Working on putting a display in a local library for August-September awareness. Paid the yearly website fee. We helped a client with medicine, as he does not have medication until 31 August, when he will become 21. Hosted a get-to-gether for clients and staff. Preparing for a two-day festival August 17-18. Our membership drive will begin in August

Continuing to work on walk a thon project scheduled for September 15th at the local High School. The display was placed in a local library for August-September awareness. A face book page has been set up and maintained. We had a picnic where planning for next years events were discussed. The two-day festival August 17-18 was a success and our membership drive began.

September

Due to the inclement weather, the walk was canceled. There was no expense since there was a long-range forecast. The display remained in the local library throughout September. The Facebook page has been getting much attention. The local TV station allowed time for BRASCA to come and give information about organization. Two families went also to tell of their lifetime illness and how the disease has affected their life. The membership drive continues.

October

A service coordinator manages the Facebook page for the month of October. The local TV station continues to air the sickle cell educational clip provided by the Northern Virginia Chapter. A family requested funds and support for a 32-year old who died but did not receive funds or finances anywhere else. The membership drive continues and we are reaching out to the community churches to support fund raising efforts. The blood drive is in the planning stages.

November

The service coordinator manages our Facebook page. Our group participated in the annual Christmas parade in Rocky Mount and a car decorated with sickle cell information by a client displayed our information. A board member presented information to her sorority. The membership drive continues. The blood drive is in the planning stage. A Christmas party is being planned.

December

The face book page is managed by the service coordinator. Fans are being designed to distribute at the Martin Luther King, Jr. breakfast scheduled for January 21, 2019. The membership drive continues. The blood drive is in the planning stage. A Christmas party was canceled, scheduled for another date. Red Cross is scheduling the next blood drive.

January

The membership drive continues. The blood drive was cancelled by Red Cross. They could not fit us into their schedule at this time. The newly appointed Business Administrator at Carilion Franklin Memorial Hospital was invited to our regular business meeting. He wants to continue the working relationship that we have had. Plans are to have a fundraising event in the coming month. The walk-a-thon committee will be meeting soon.

Blue Ridge Area Sickle Cell Association - Continued

February

The membership drive continues with the media, churches and clients. All were also notified that the blood drive was cancelled by Red Cross. Planning the first stages for walk scheduled for September 2019. A fund-raising event is scheduled for April 2019. An event is also being scheduled for the Roanoke area.

March

Committees continue to plan fund raising event and walk. Sent notices to clients and Board members to inform of CBS's feature with NIH effort on 60 minutes to cure Sickle Cell Disease. It aired March 10, 19 at 7:00p EDT.

April

The fundraising event was a success. Another event is in the planning stage for the month of May. The walk committee has confirmed the date of September 21st at the local High School. The event in Roanoke was rained out, but pamphlets were sent to be distributed at a later date. A Health Care Center allowed us to put pamphlets in their lobby in Roanoke.

May

The fundraising event was a success. The walk is scheduled for September 21st at the local High School. Pamphlets were distributed at a resource center in Rocky Mount. The date has been confirmed for the blood drive. Committees continue to meet. Year-end spending for the grant continues. A local tv station will air our Sickle Cell public announcement.

June

The fundraising events continue to be a success. The walk is scheduled for September 21st at the local High School. Plans are going well. Committees continue to meet. Year ending spending for the grant completed. A local tv station allowed a panel to come on and discuss the everyday living with sickle cell and the importance of blood donations. Two clients also went before a Board of Doctors to answer personal questions about their struggle with the disease. The Roanoke Health fair is scheduled for August 10. The scholarship committee reported that there are (3) applicants. We helped one client with travel expenses, another with medical transport.

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: 13
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 – Non-Grant Funds)
Number: 1 for $75.00 **Hospital Care Kits**

Type of Educational Program offered:

Pieces of Literature Distributed
Number: 3,559
Health Fairs/ Presentations of Sickle Cell and Agency Information
Number: 3
Number of Attendees: 4,500
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: 342 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: 184
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 277
Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.
Number Sent: 277 and others
Letters to churches to educate and obtain support for Sickle Cell
Number Sent: 50
Calls to clients to obtain information or update contact information
Number: 8
Distribution of Chapter Newsletter
Number: 283

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

Scholarship recipients attended Brainy Camps of the Children's National Medical Center in July. Letters sent to local churches asking them to recognize National Sickle Cell Month in September.

August

Information booth at African-American Cultural Fair, Manassas, VA on August 4, 2018. Over 4,000 persons in attendance. Received call from new client about new opioid rules and Service Coordinator provided information. Sent letters (22) to Fraternities and Sororities in Northern Virginia inviting them to participate in Sickle Cell Month events and to support blood drives. Sent letters to clients and donors informing them of Sickle Cell Month activities. Posted information on Facebook page and on newly revised webpage (heartogold.org).

September

Information booth at Stomp Out Sickle Cell Event at Howard University Hospital. Four new potential clients. Over 250 persons in the attendance. Sent reminder letters to clients and donors informing them of Sickle Cell Month activities. Service Coordinator Pearson posted daily information on Facebook page on Sickle Cell Awareness Month and ongoing studies and activities.

October

Updated Heart of Gold Webpage. Number of likes/following on Facebook page increased to 283. Service Coordinator Pearson posted 31 items on Facebook page with information on clinical trials, legislation, advocacy information and health information. Draft brochures on Opioid use and Knowing your Sickle Cell Status were forwarded to Statewide for approval.

November

Updated Heart of Gold Webpage. Number of likes/following on Facebook page increased to 285. Service Coordinator Pearson posted 37 items on Facebook page with information on clinical trials, legislation, advocacy information and health information. Draft brochures on Opioid use, OB/GYN Health and Knowing your Sickle Cell Status were forwarded to Statewide for approval. Board Member Hurley was featured in her organization's newsletter with a story about the Heart of Gold Foundation and Sickle Cell advocacy. This newsletter is distributed electronically to approx. 200 persons at the Department of Energy Headquarters. Heart of Gold was invited by the INOVA Children's Hospital to participate in a Holiday Party for children with blood disorders on December 8.

December

Participated in Thrill of Hope/INOVA Children's Hospital Holiday Party for children with blood disorders. There were over 250 participants. Distributed informational pamphlet, books, bags and stuffed toys. Four new SCD clients signed up for additional information from Heart of Gold. Holiday greetings were sent to clients and to previous donors (50 persons) Sent contribution (grocery gift card) to client who is out of work and undergoing procedure for stem cell transplant. Recently, another client has had successful bone marrow transplant and she will be

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

interviewed in a video this spring. Service Coordinator Pearson posted 28 items of interest on Facebook page, including legislative information, information on studies, general health and nutritional information for the SCD community. Facebook following increased by 1 to 286.

January

Service Coordinator Pearson posted items of interest on Facebook page, including general health and nutritional information for the SCD community. Facebook following increased by 1 to 287. Draft Brochure on opioids was sent to Statewide for review/comment. Completed yearly newsletter and distributed to clients and donors.

February

Service Coordinator Pearson posted items of interest on Facebook page, including general health and nutritional information for the SCD community. Letters written to INOVA Blood Services and American Red Cross about partnerships during Blood Drives.

March

Chapter newsletter sent to clients, donors and community groups. Service Coordinator Pearson posted items of interest on Facebook page, including general health and nutritional information for the SCD community. Facebook following increased to 302 --an increase of 24 persons and likes increased to 315 persons.

April

Letter sent to INOVA Blood Services to discuss partnership with them on Blood Drives. Draft completed on information for parents of school aged children. Service Coordinator Pearson posted items of interest on Facebook page, including general health and educational information for the SCD community. Facebook following increased to 316 since March --an increase of 14 persons.

May

Draft checklist completed on information for parents of school aged children and ready for publication. Brochures on Opioid and SCD, OB/GYN issues and SCD, and Know your Status are awaiting approval from the Statewide Administrator. Service Coordinator Pearson posted items of interest on Facebook page, including general health and educational information for the SCD community. Facebook following increased to 339 since April --an increase of 23 persons. In honor of mothers suffering from SCD, we conducted a special promotion on our Facebook page for a donated gift. We received over 293 "likes" and the information was shared 33 times. We are planning to attend World Sickle Cell event at Howard University on June 19th and are beginning to plan events for National Sickle Cell month in September.

June

Brochures on Opioids and SCD, OB/GYN issues and SCD, and Know your Status were approved by the Statewide Administrator and were sent for publication. Service Coordinator Pearson posted items of interest on Facebook page, including general health and educational information for the SCD community. Facebook following increased to 339 since April --an increase of 23 persons. Registered for a vendor table at the Manassas African American Heritage Festival in August. Planning to participate in Sickle Cell Awareness Month events in September.

Sickle Cell Association

The Norfolk chapter serves the cities of Chesapeake, Franklin, Norfolk, Portsmouth, Suffolk, Virginia Beach and the counties of Accomack, Isle of Wight, Northampton and Southampton.

Type of Assistance offered:

Calls from Clients/Family for information/assistance
Number: 246
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: 10 for total of $2,579.93

Type of Educational Program offered:

Pieces of Literature Distributed
Number: 5,644
Health Fairs/ Presentations of Sickle Cell and Agency Information
Number: 49
Number of Attendees: 6,543
Blood Drive Donors or Volunteers; Every donation of blood save three (3) lives.
Number of Attendees: 7

Type of Support Group offered:

Advocacy & Community Resources Meetings
Number of Participants: 641
Transition Young Adults Meetings
Number of Participants: 4

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: 234
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 310
Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.
Number Sent: 1,591
Letters to churches to educate and obtain support for Sickle Cell
Number Sent: 574
Calls to clients to obtain information or update contact information
Number: 255

Sickle Cell Association - Continued

July

Clients planned July Fourth Birthdays Blood Drive to encourage more donors for the "Make A Match" program in partnership with American Red Cross. Information on Make A Match-Blood Donors and Sickle Cell Disease was distributed. There were 28 donors who contributed to the campaign. The next scheduled event will be in September at the Annual Walk for Sickle Cell.

August

Held "Unity in Community" event with partner Bethany Baptist Church, Chesapeake to give students health care screenings and back to school supplies. Sickle cell clients participated in the community parade with a car and steppers carrying the organization banner. A second "Gathering of the Community" was held in Norfolk the next week representing the founder of the Association and Sickle Cell families came out to get school supplies. The three-day Africana Fest was held in Virginia Beach where the Sickle Cell Association was the designated charity. Hosted an information booth for the upcoming blood drive in September.

September

September is National Sickle Cell Awareness Month and the clients attended health fairs, churches, and businesses to give out the national ribbons. Appeared on TV with the clients for the Hampton Roads show to talk about upcoming events and Agency services. Client did a documentary spot on WVEC TV 13 Health Scope Living with Sickle Cell Disease. Held one blood drive at Hampton University and presented information on "You might be a special Match". The presentation gave the critical need for blood donations for sickle cell patients.

October

Participated in the Annual Mall-O-ween event at the Military Circle Mall to give out goodies and information on sickle cell disease. Patient support group was given information about available studies on sickle cell disease and got scholarships for seven sickle cell clients to attend the National Convention in Baltimore, MD. Sickle cell parent went on Channel 13 Noon News to talk about their children with sickle cell and support from the Association. Sickle cell children participated in Norfolk State University Homecoming Parade with a public awareness banner at the step-show.

November

Service Coordinator was speaker at the 7th Annual Health & Awareness Care Givers Dinner held at Fort Story Army Base in Virginia Beach, Virginia. Over 300 guests were informed about her experience living with Sickle Cell Disease. An information table provided literature on the disease and how to reach the Agency for services. One blood drive was held at Hampton University student center. An information table gave participants literature on the critical need for blood by sickle cell patients.

December

Sickle Cell families received food baskets from Hiram Grand Lodge and American Legion Lodge #14. Client Support Group held a Christmas get together at Eastern Virginia Medical School.

January

Clients were special guests at Martin Luther King services held at area churches in Norfolk and Chesapeake. Churches will be contacted to set up health fairs and blood drives. One blood drive was held at an area church and 18 pints of useable blood was collected. Donors picked up literature on the critical need for blood donations for sickle cell patients.

Sickle Cell Association - Continued

February

Participated in a seminar on Opioid and Substance Abuse Prevention series sponsored by the Hampton Roads Community Action Agency. Sickle Cell client gave her experiences in living with sickle cell disease at the seminar for an audience of 35 persons. Black History program held at a church in Chesapeake, VA with over 122 persons attending where sickle cell clients gave their history of sickle cell in their families and how they have lived with the disease into adulthood. Brochures and giveaways were given to participants.

March

Conducted a session on kidney disease in sickle cell patients at the annual Health Awareness Kidney Prevention workshop for 150 participants. Information was disseminated on how sickle cell patients' kidneys are affected and what treatment measures are available. Recently there was an appeal on local news to help a sickle cell patient get a living donor for a kidney transplant. A patient who had a transplant told her story and participants were then asked to visit the information table to get more information on sickle cell disease and the organization services.

April

Set up a display booth at two blood drives. One was held at Hampton University by the Health Center and the Mt. Nebo Baptist Church along with a health fair and seminar. Had the clients to write letters to their legislators for Advocacy Day and delivered letters on April 9, 2019 for visits made to ask for support of the Sickle Cell Disease Association of America's request for research support at NIH and support for Robust Funding for NIH and FDA in FY 2020.

May

Participated in the May Day on the Eastern Shore where participants were invited to visit the table for information and display of “Know your family history”. Some persons were able to trace their family genealogy back three generations to who they thought had sickle cell trait and family members with sickle cell disease. Smaller groups will be meeting at the Juneteenth event to try to get more information on who had sickle cell trait in their families.

June

Held World Sickle Cell Day event on June 19 with clients manning the health booth at Military Circle Mall. The clients sent social media invites to clients to attend the "Shine the Light on Sickle Cell" that night. Fifty-three participants attended where they set up a Sickle Cell Peers and Family information table. One client performed a modern dance and gave her story about living with sickle cell disease and her achievements in local and state pageants. She was given a scholarship by the Sickle Cell Association to perform in the National competition in California this summer.

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: 301

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 the Annual Unity Ride for Sickle – Non-Grant Funds)

Number: 15 for total of $7,247.62

Contract Services for Client Advocacy Education and Representation

Number of Participants: 0

Type of Educational Program offered:

Distribution of Sickle Cell Literature

Number: 6,420

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 21

Number of Attendees: 3,284

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

Number of Attendees: 77

Number: 77 X 3 = 231 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: 3,620

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: 269

Sickle Cell Association of Richmond-OSCAR - Continued

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

Number Sent: 314

Each month the organization forwards to clients that we have e-mail addresses for, the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.

Number Sent: 1,284

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 31

Calls to clients to obtain information or update contact information

Number: 202

Special Mailing:
Hearing Study

Number Sent: 20

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: 1,560,000

<u>Sickle Cell Association of Richmond-OSCAR - Continued</u>

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": “There is no shortcut to any place worth going” and “Our attitude toward life determines life's attitude toward us”. Newspaper Ad in the Richmond Free Press reaching over 100,000 homes. Free Press Newspaper ad (100,000 readers per week for two weeks total 200,000) Richmond Free Press edition July 5-7 article entitled “Sickle cell advocate wins fight for high-dose opioids”. The article featured a picture and interview with George H. Carter.

August

In August we sent each client two Words of Wisdom: (1) "Accept challenges, so that you may feel the exhilaration of victory." (2) "Excellence is not a skill. It is an attitude." Towards the end of August, we also sent clients and other interested persons the Sickle Cell Month Calendar that highlights Sickle Cell Disease facts for all 30 days of September, which is Sickle Cell Awareness Month. (The mailing is done towards the end of August so that the information is received by September 1st.) Additionally, several board members staffed vendor tables and presented information on Sickle Cell Disease at two events - the African American Awareness Festival sponsored by Louisa County and the Car, Bike and Truck Show sponsored by Richmond Harley Davidson. Free Press Newspaper ad (100,000 readers per week for two weeks total 200,000). Richmond Free Press edition August 23-25 article entitled “New regulations to help people with sickle cell anemia”. The article featured a picture of George H. Carter and let it be known that the new regulations were not only in effect but had been published for doctors to see.

September

31 letters were sent to Churches. Free Press Newspaper ad (100,000 readers per week for four weeks, a total of 400,000). An ad about Sickle Cell Trait/Disease was run on a radio station listened to by persons of child-bearing age (130,000 total households reached). Taped a 30-minute radio program about the effects of Sickle Cell Disease and Sickle Cell Month. The program was broadcasted to 130,000 households on September 15th on Radio One hosted by “Miss Community” Clovia Lawrence. George Carter as Chairman of the organization, took the opportunity to introduce to Richmond the new President, Tiffany Dews and new Administrator Dionne Bobo. Also, speaking was Dr. India Sisler, a member of our Advisory Board and the Director of the Virginia Commonwealth Pediatric Sickle Cell Program.

Provided support and 500 pieces of literature for a blood drive held in the name of “Chases Sickle Cell Awareness” on 9-22-18 on Short Street in Orange Virginia.

25 people donated blood. 14 plus people were in line to give but no more blood bags were available. The President served as afternoon speaker on sickle cell in one local church.

400,000 Previous Advertising Numbers / 530,000 September Advertising Numbers

Sickle Cell Association of Richmond-OSCAR - Continued

October

Free Press Newspaper ad about Sickle Cell Trait/Disease was run (100,000 readers per week for two weeks total 200,000). Participated in AARP Health Fair of about 250 people giving out about 500 pieces of literature. We sent each client two "Words of Wisdom": **Laughter is the closest distance between two people. (And) The true sign of intelligence is not knowledge but imagination.** Received a thank you card from the Church that Tiffany Dews (President) spoke at along with two checks for a total of $317.00. The President, Tiffany Dews and Administrator, Dionne Bobo attended part of the Sickle Cell Disease Association's national conference in Baltimore, MD and gained valuable information.

November

This month we mailed each client a 2019 Month Planner (calendar) book so each person can keep track of their appointments.

December

George Carter participated in a telephone conference call with members of the Legislative Committee of the Board of Directors of Sickle Cell Disease Association of America. He spoke about the opioid crisis backlash on sickle cell patients and stressed that it has created an overall pain management crisis. He once again encouraged the organization to try to get an exemption for sickle cell from the CDC Opioid Guidelines.

January

In January, we mailed each client two "Words of Wisdom": (1) Change is difficult but often essential to survival. (2) Life is ten percent what happens to you and ninety percent how you respond to it.

February

This month we mailed each client two "Words of Wisdom": (1) Freedom is not worth having if it does not include the freedom to make mistakes. (2) If you want to stand out, don't be different; be outstanding. A "Thinking of You" card was sent to each client to let them know that we are keeping them in mind.

March

This month we mailed each client two "Words of Wisdom":
(1) Your vision will become clear only when you can look into your own heart.
(2) Boldness has genius, power and magic in it.

The Sickle Cell Community Consortium invited George Carter to its fourth annual meeting in Atlanta, GA. The presentation was intended to explain to sickle cell organizations in other states what had done to get a medical board exemption for sickle cell in the State of Virginia.

April

We mailed each client two "Words of Wisdom":
(1) The right kind of nurturing and support makes beautiful things happen.
(2) Our combined efforts empower us to soar higher and farther.

Sickle Cell Association of Richmond-OSCAR - Continued

May

We sent mailed client two "Words of Wisdom":

(1) Sow good services, sweet remembrances will grow from them.

(2) Praise to a human being represents what sunlight, water and soil are to a plant - the climate in which one grows best. The eleventh annual "Unity Ride for Sickle Cell" was held on Saturday, May 4th. The Ride is held annually to raise awareness about Sickle Cell and to raise funds so the organization can provide financial assistance to our clients.

June

On June 19th we hosted a community event in which we had 8 volunteers to assist with face painting, registration, games, trivia, and basketball. We had 9 sickle cell families attend the event and a total of 47 participants, this includes the community partners, Station 6 Fire Department, Athletes for Awareness and the youth from First African Baptist Church. The turnout was a success and the feedback from the sickle cell families was that they enjoyed being in a family setting that allowed them to relax and not think about pain. They would like to see more community events in which they are away from the hospital. Overall this event was a huge success!!!

We sent each client a copy of the 3-4-4 Nutritional Method of Eating by Cayenne Wellness Center. This is a two-sided form where 3-4-4 stands for three items to eat for breakfast, four items for lunch and another 4 items to eat for dinner. We are hoping to get our clients to eat healthy so they can stay healthy.

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, during FY19 on behalf of the patients in Virginia and the nation. The following activities have been reported on the statewide monthly reports to the Virginia Department of Health.

George Carter is a 73-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 two years' time, Statewide and George Carter have taken on a more public and national pain profile against the negative impact of the opioid crisis on Sickle Cell Patients.

Statewide and George Carter's main focus is to advocate for those who suffer from Sickle Cell Disease and distribute as much information about sickle cell and uplifting messages to patients.

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 to inform and encourage more participation from industry in combating Sickle Cell Disease and its effects. One of the things George Carter highlighted in his presentation was the personal hearing loss that had been 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.

Dr. Dawn Nelson conducted a survey two plus years ago with sickle cell patients across the country about any hearing loss and balance issues they were having. Statewide and George Carter worked with her to get patients to complete the survey. She received over 138 responses to the survey. We are proud to say that 74, over half (over 50%) of the responses to the survey were from Statewide patients in several State of Virginia grant funded chapters under the State of Virginia grant program.

We have been pushing for more public education about hearing loss and balance issues in patients with Sickle Cell Disease. In October of 2017, we managed to get The Sickle Cell Disease Association of America (the national sickle cell organization through its Medical Director) to allow a concurrent (side) session presentation about hearing loss in patients. After that successful presentation, the national organization decided to do more on this subject. On October 12, 2018, at the annual convention in Baltimore, Maryland, the national organization had a formal session during the Charles F. Whitten Memorial Lecture (to the full convention audience) 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**".

Dr. Nelson acknowledged to the conference audience how much George Carter and Statewide did for her and said that she would not be there if it was not for George Carter. Her last presentation slide showed a picture of George Carter and Statewide's name.

Statewide and its Administrator, George Carter are proud to have promoted a more public and national profile on hearing loss and balance issues.

<u>We plan to continue to take a lead role in issues that do or may affect all clients in the sickle cell community. One of these may include taking the platform on matters relating to Cannabis Oils and what positive measure it could have for sickle cell patients in a pain crisis or in chronic pain.</u>

Statewide-Report-October 2018

National Conference – Opioid Backlash

George Carter attended all of the Sickle Cell Disease Association's national conference in Baltimore, MD. and gained valuable information. George Carter spoke to member organizations and national staff at their business meeting and CEO luncheon 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. Getting exceptions state by state would be too difficult. He supplied material information and offered his assistance in working to gain CDC approval.

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. He gained valuable information and met other members of the committee from a variety of federal agencies and organizations. 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-December, 2018

George Carter participated in a conference call with members of Board of the Directors the of Sickle Cell Association of America to advise how he felt the organization could and should seek an exception to the CDC Opioid Guidelines for Sickle Cell Disease. He 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-March, 2019

The Sickle Cell Community Consortium invited George Carter to its fourth annual meeting in Atlanta, GA., March 13th through March 17th all expenses paid, to speak on March 15th. He was recommended to the consortium by a doctor working with sickle cell in Michigan. Mr. Carter gave a forty-minute presentation to persons attending the conference. The presentation was entitled **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. The presentation was intended to inform states what things may or may not work in attempts to get various boards of medicine to grant an exemption for sickle cell in other states. The presentation also provided some ways to overcome the negatives facing patients as a result of the opioid crisis. Mr. Carter provided the attendees with a sample letter to use to request medical board approval of an exemption for sickle cell.

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. How can community organizations promote patient care and ensuring that evidence-based guidelines for care are being implemented and accessible and to all.

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 understand what need to be done and a sample letter to use to request medical board approval of an exemption for sickle cell.

George Carter participated as a member in the National Institute of Health's (NIH) Interagency Pain Research Coordinating Committee (IPRCC) conference call meeting on May 28th from 2:30 p.m. to 5:00 p.m. A number of reports were given to update the committee on the status of various pain management methods. I (George Carter) brought out 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 ≥90 MME/day or carefully justify a decision to titrate dosage to ≥90 MME/day." The recommendation statement does not suggest discontinuation of opioids already prescribed at higher dosages.