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REPORT
Report to the House Appropriations and Senate Finance Committees of the Virginia General Assembly on Community-Based Sickle Cell Programs

September 25, 2024

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**."

TODAY
The cost and the effects of sickle cell have multiplied many, many times since 2006.

Background

Screening of all newborns for Sickle Cell Disease began in Virginia during July of 1989. Since 1989, an average of 75 newborns have been identified yearly with Sickle Cell Disease. At the beginning of the program, centers for comprehensive follow-up care were not available. In 1994, Virginia began providing statewide comprehensive sickle cell services to decrease the morbidity and mortality among children.

The June 30, 2011, report to the House Appropriations and Senate Finance Committees of the Virginia General Assembly on Community-Based Sickle Cell Programs submitted by the Virginia Department of Health made the following statements. **"The provision of comprehensive care is a time-intensive endeavor that includes ongoing patient and family education, periodic comprehensive evaluations and other disease-specific health maintenance services, psychosocial care, genetic counseling, and transition services. However, research demonstrates that the medical management model alone cannot address the multiple social, psychological, and educational needs of individuals living with chronic illnesses such as sickle cell disease."**

Statewide Sickle Cell Chapters of Virginia, Inc. (SSCCV), also known as Sickle Cell Chapters of Virginia or Statewide, a non-profit 501(c)(3) tax-exempt community-based organization, has a network of nine (9) community-based Sickle Cell Disease organizations (chapters) that provide a variety of needed services across the Commonwealth. The chapters are located in Danville, Fredericksburg, Hampton, Lynchburg, Norfolk, Richmond, Rocky Mount, South Boston and Northern Virginia. Most of the chapters in this network have operated since 1972.

The Chapters/Community-based programs provide resources to address unmet social, psychosocial and educational needs. They also provide coping strategies and support for families impacted by Sickle Cell Disease. Many of the community-based programs provide a focus on mental and social well-being as well as stress-reducing activities that have a positive effect on physical well-being. All chapters provide sickle cell education in the community through participation in health fairs, forums, church activities and civic or health related events. Some of the services include sending clients sickle cell information, "Birthday" and "Thinking of You" cards, support group meetings, calls to check on clients, visitations, providing referral assistance, assistance with obtaining employment, disability benefits, and vocational rehabilitation. These services vary from chapter to chapter based on funds and man-power available.

All chapters receiving grant awards have previously conducted several years of "Surveys of Needs" with as many of their registered clients as possible. The surveys have enabled chapters to determine what services are needed, by whom and how best they can be delivered to clients.

There are four comprehensive sickle cell centers under contract in the state. The centers are Children's Hospital of the King's Daughters in Norfolk, Virginia Commonwealth University Health System in Richmond, University of Virginia in Charlottesville and now an adult center has been established at the INOVA Adult Sickle Cell Center in Fairfax, Virginia. **The tidewater area has the highest number of clients/patients in the entire state. <u>It should be noted that Children's Hospital of the King's Daughters in Norfolk provides clinical care to the younger clients but does NOT provide clinical care for nearly 500 ADULT clients.</u>**

It is estimated that the State of Virginia has about 4,000 sickle cell clients/patients. The centers care for near 1,800 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 45% of the sickle cell population. **This demonstrates the very need for a network of community-based programs to serve the 55% of clients who still need services. Also, some of the center clients will still need some services we offer that centers do not provide.** Community-based 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. Both of the funding levels were reduced over several following years before reductions were stopped.

Funding Level

Starting in FY08, annual budget appropriations were as follows:

- FY08 - $100,000 for three of our eight chapters
- FY09 - $95,000 for three of our eight chapters
- FY10 - $81,000 for three of our eight chapters
- FY11 - $90,000 for five of our eight chapters
- FY12 - $90,000 for five of our eight chapters
- FY13 - $88,200 for five of our eight chapters
- FY14 - $105,000 for six of our nine chapters
- FY15 - $105,000 for six of our nine chapters
- FY16 - $105,000 for six of our nine chapters
- FY17 - $105,000 for four of our nine chapters
- FY18 - $105,000 for four of our nine chapters
- FY19 - $105,000 for four of our nine chapters
- FY20 - $105,000 for four of our nine chapters
- FY21 - $105,000 for four of our nine chapters
- FY22 - $105,000 for four of our nine chapters
- FY23 - $105,000 for three of our nine chapters
- FY24 - $105,000 for three of our nine chapters

Item 288Q of the 2010 Appropriation Act required the Virginia Department of Health (VDH) to develop criteria for distributing these funds, including specific goals and outcome measures and to submit an annual report detailing program outcomes to the House Appropriations and Senate Finance Committees of the Virginia General Assembly.

Item 288Q of the 2011 Appropriation Act required the Virginia Department of Health (VDH) to allocate the appropriation for community-based sickle cell programs by contract to Statewide Sickle Cell Chapters of Virginia. This funding is to be used for grants to community-based programs that provide services for individuals suffering from Sickle Cell Disease. "Statewide" developed criteria for distributing these funds including specific goals and outcome measures.

During FY12 and FY13, Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded five contracts to member chapters.

During FY14, FY15 and FY16, Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded six contracts to member chapters.

During FY17, FY18, FY19, FY20, FY21, FY22 and FY23, Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded four contracts to member chapters.

MEMO ON COVID – 19 PANDEMIC

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

Three chapters received the following funding during **FY24**:

Heart of Gold Sickle Cell Foundation of Northern Virginia	Northern Virginia	$20,130.00
Sickle Cell Association	Norfolk	$42,520.00
Sickle Cell Association of Richmond – OSCAR PLUS	Richmond	$35,550.00
Statewide Sickle Cell Chapters of Virginia (Operational expenses for Statewide including materials, supplies, accountant fee, Administrator and Grant Administrator)		$ 6,800.00
Total		$105,000.00

Community-Based Sickle Cell Program Activities completed as of June 30, 2024

The three aforementioned chapters were awarded funding to begin community-based services on **July 1, 2023**. The following information provides a summary of the community-based activities performed as of **June 30, 2024**. 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.

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: 12
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: 468 for $10,025.00

Type of Educational Program offered:

Pieces of Literature Distributed
Number: 8,917
Health Fairs/ Presentations of Sickle Cell and Agency Information
Number: 12
Number of Attendees: 4,850
Blood Drive Donors or Volunteers; Every donation of blood save three (3) lives.
Number of Attendees: 160
Posted Sickle Cell information on Facebook page for viewing.
Number: 0
Sickle Cell Walk
Number of Participants: 0

Type of Support Group offered:

Meetings
Number of Participants: 0

Other Activities:

Birthday cards sent to clients having birthdays during each month
This is done so clients know that the organization is thinking about them.
Number Sent: 0
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 474
Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.
Number Sent: 8,930 and others
Letters to churches to educate and obtain support for Sickle Cell
Number Sent: 180
Calls to clients to obtain information or update contact information
Number: 6
Distribution of Chapter Newsletter
Number: 206

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 and an online presence. Some of their activity numbers are low, however, their involvement in health activities has been high as demonstrated in the narrative below.

July

Board members are helping INOVA Sickle Cell Clinic Plan and execute Sickle Cell Town Meeting scheduled for September 27, 2023. Wrote letter to Fairfax County Board of Supervisors Chair Jeff McKay to speak and as Sickle Cell Town Meeting and he accepted and will present a Proclamation on behalf of the County recognizing Sickle Cell Awareness Month. Coordinating with Dr. Elizabeth Yang to plan a Sickle Cell Awareness Month event for pediatric patients. Will have a display and distribute information at Manassas African American Festival, August 5, 2023. Have confirmed as a participant for the Howard University "Cure Sickle Cell 2023" event on September 23, 2023. Sent letters to churches, fraternities, sororities and communities groups informing them about upcoming blood drives and Sickle Cell Awareness Month. On July 21, 2023, had a collaboration call with Pfizer Pharmaceutical about partnering and collaboration to inform the community of new treatment options for SCD patients. Updated Social Media pages. Donations of $1750 received for Heart of Gold Scholarship through the Alfred Street Baptish Church Foundation. This scholarship is available to persons in the DMV area.

August

Participated in the Manassas African American Heritage Festival on August 5, 2023 with over 2,000 persons in attendance. Sent information to churches and local community groups about the upcoming INOVA Sickle Cell Town Hall Meeting on September 27 at the INOVA Adult Sickle Cell Clinic. Heart of Gold will have a display table and will receive a proclamation acknowledging National Sickle Cell Month from the Chairman of the Fairfax County Board of Supervisors. Established collaboration with Fairfax County Health Department Representatives and Community Services Board. On September 23, Heart of Gold will participate in the Howard University Cure Sickle Cell event. Met with a representative of Novo Novartis pharmaceutical company on August 25 to discuss future collaboration. Increased followers on Facebook by 15 persons. Released new podcast "Parenting a Sickle Cell Child" featuring Board Member Clarence Pearson, MD, over 40 persons have viewed to date.

September

Released podcast, "Sickle Cell Trait" with Dr. Shenei Alan, INOVA Adult Sickle Cell Clinic. Participated as a co-sponsor with INOVA Adult Sickle Cell Center of the 2nd Annual Sickle Cell Town Hall on September 27th with donation of $750 to provide nutritious dinner for SCD patients and families. Over 150 persons in attendance. Guest Speakers included, Dr. Wally Smith, VCU, Dr. Campbell, Children's National Medical Center, INOVA Blood Services, a panel of SCD warriors, dance by SCD warriors, spoken word in support of SCD. A Sickle Cell Awareness Month Proclamation was presented by Fairfax County Board Chair Jeff McKay. A $1750 donation was made to the Heart of Gold Scholarship fund managed by the Alfred Street Baptist Church Foundation. This scholarship is in memory of Clarissa Pearson and is available to students in the Metropolitan DC Area. Supported the "Cure Sickle Cell" event at Howard University on September 30 as a sponsoring organization with over 500 attendees. Sent informational material to BRASCA chapter for upcoming event in October.

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

Met with representatives from the American Red Cross to get information on changes to eligibility requirements and to obtain informational materials on the importance of blood donations for SCD patients for November event.

October

Received call from Northern Virginia Baptist Association about a partnership to sponsor blood drives. Completed podcast on "Sickle Cell and Women's Health". Met with Virginia Pediatrics about collaboration for Holiday Party in December. Prepared materials for Alpha Kappa Alpha Sorority Inc. Northern Western Cluster meeting November 18, 2023 in Reston, VA. The Heart of Gold is the featured charity and over 700 persons will be in attendance.

November

The Heart of Gold Sickle Cell Foundation of Northern Virginia was the featured charity at the Mid-Atlantic Region Northern Western Cluster Meeting in Reston VA on November 18, 2023. Over 750 members of Alpha Kappa Alpha Sorority, Inc. were present. During the meeting, an informational video about the importance of blood donations and the importance of knowing sickle cell status was viewed. Over $13,000 in donations were presented to the Heart of Gold. Informational materials were distributed. The Heart of Gold staff participated in a conference call with Dr. Elizabeth Yang, INOVA Pediatrics to discuss a workshop for transitional SCD patients.

December

The Heart of Gold Foundation received Holiday Blanket donations (over 75 blankets) from the Top Ladies of Distinction Alexandria City Chapter and the Top Ladies of Distinction Haymarket/Gainesville Chapter. Blankets were delivered to Children's National Medical Center for the Sickle Cell Unit.

January

Interim President Hurley was featured on the Rotary Times telecast in December 2023 to talk about Sickle Cell Disease and the Heart of Gold Foundation. This program is aired to Rotary Club members throughout Northern Virginia. In January, 2024, Mrs. Hurley was a featured speaker at the Alexandria City NAACP Book Nook Event. The Heart of Gold donated 20 children’s books about Sickle Cell Disease and Scientist who have worked to cure Sickle Cell Disease to the Charles Houston Center in Alexandria, VA. The Heart of Gold is partnering with INOVA Blood Services for a Black History Month Blood Drive on February 1. Additionally, Heart of Gold is sponsored two Red Cross Blood Drives in January (still awaiting units donated) and will sponsor another Red Cross blood drive in February.

February

A Heart of Gold Board member supported (and donated a unit of blood) the INOVA Fairfax Blood Drive on Feb 1. Informational materials were distributed. There were 39 successful donors (14 first time donors). Heart of Gold Board member participated in a conference call on Feb 8 with Resource Staff at the Alexandria City Jail and was requested to participate in a Resource Fair at the Jail (scheduled for Apr 24) to inform the population about Sickle Cell Disease, Sickle Cell Trait and the importance of blood donations. On Feb 12, Heart of Gold Board Members participated in a conference call with the Pfizer Senior Sickle Cell Patient Affairs Liaison on sponsorship opportunities. On Feb 21, Heart of Gold Board Members participated in a conference call sponsored by the Sickle Cell Association (Norfolk) entitled "Cell and Gene Therapy-Casgevy" presented by the Vertex Pharmaceutical Patient Educator. On Feb 24, Heart of Gold volunteers participated in the "Feel the Heritage Fair" sponsored by the Arlington County NAACP and the Arlington County Government. Over 800 persons were in attendance-

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

children's book about SCD and informational materials were distributed. On Feb 28, Heart of Gold Board Members met with Melwood/Camp Accomplish, a camp for SCD children 8-18. A donation of $2500 (non-grant) was made to support scholarships for SCD campers.

March

Heart of Gold Board President visited Camp Accomplish during their open house (March 4) and met with staff to discuss upcoming "Super Campers Always" SCD camp in June. Heart of Gold President gave a presentation at the McLean Rotary Club monthly luncheon (March 12) on SCD and the importance of blood donation. The District Governor of the Rotary Club requested a future meeting on a partnership with Heart of Gold in Northern Virginia. Heart of Gold President participated in a panel sponsored by the Howard University American Red Cross Chapter on Sickle Cell Disease and community-based organizations (March 12). Heart of Gold President attended an open house (March 27) at the Work Innovation Skill Hub Center. This Fairfax County Center provides skilled training for persons to gain better employment. It also has special programs for persons with disabilities to improve resume and interview skills and gain self-advocacy. Heart of Gold had two planning conference calls with INOVA, Childrens National and Howard University for planned Sickle Cell Transition from Pediatric to Adult Care Workshop scheduled for June.

April

The Heart of Gold participated in the Annual Re-Entry Resource Fair at the Alexandria City Jail on April 16 at the invitation of the Alexandria City Sheriff Sean Casey. Informational material re: "Do you know your Sickle Cell Status" was distributed to participants. On April 25, Heart of Gold Board members met with INOVA Adult Sickle Cell Center to discuss plans for the upcoming World Sickle Cell Day event (June 22) and Blood Drive, which Heart of Gold will co-sponsor. The Heart of Gold will have an informational table at this event. INOVA requested Heart of Gold assistance to inform the community of current clinical trials for both SCD persons and persons with the Sickle Cell Trait.

May

The Heart of Gold Board Members met with Pfizer on May 6 to learn about participation in the "Community Connect Program". This program is designed to assist Community Based Organizations provide educational programs to Sickle Cell Warriors and Families and Community Organizations. Program topics include: Sickle Cell 101 and Self-Advocacy. The Heart of Gold received a donation of ten $50 gift cards from Giant Food. These gift cards will be distributed to needy Sickle Cell Warriors and Families. The Heart of Gold donated $2500 to the INOVA Adult Sickle Cell Center to assist in the purchase of a vein finder. This medical device will help the 200 plus SCD warriors that are getting treatment at the Center and reduce the number of painful needle sticks. The Heart of Gold received a donation of $3600 from the Northern Virginia Chapter of Jack and Jill, Inc. in Memory of Clarissa Pearson, our Founder and former member of that Chapter.

June

The Heart of Gold supported a blood drive at St. John Baptist Church, Arlington, Va on June 15th and 21 units of blood were donated. The Heart of Gold was a co-sponsor of the INOVA World Sickle Cell Day/Juneteenth Celebration/Blood Drive and 23 units of blood were donated. Over 175 persons attended the health fair and received informational materials from Heart of Gold. Approximately 75 SCD warriors and families attended the World Sickle Cell Day luncheon and program. Heart of Gold donated snacks, sandwiches, juice and water and signage for the event.

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: 157
Information or Referral Assistance to Clients and Families
Number: 71
Financial Assistance to Clients for rent, utilities, medical bills, and college scholarships, etc. (Funded by – Non-Grant Funds)
Number: 11 for total of $4,278.87

Type of Educational Program offered:

Pieces of Literature Distributed
Number: 2,870
Health Fairs/ Presentations of Sickle Cell and Agency Information
Number: 47
Number of Attendees: 4,177
Blood Drive Donors or Volunteers; Every donation of blood save three (3) lives.
Number of Attendees: 281

Type of Support Group offered:

Advocacy & Community Resources Meetings
Number of Participants: 266
Transition Young Adults Meetings
Number of Participants: 0

Other Activities:

Birthday cards sent to clients having birthdays during each month
This is done so clients know that the organization is thinking about them.
Number Sent: 235
"Thinking of You" cards to clients so they will know that we care.
Number Sent: 401
Forward each month to clients the e-mail of the newsletter from Sickle Cell Info in Atlanta, GA.
Number Sent: 1,596
Letters to churches to educate and obtain support for Sickle Cell
Number Sent: 732
Calls to clients to obtain information or update contact information
Number: 120

Sickle Cell Association - Continued

July

Held two blood drives one at Mt Nebo Baptist Church, Bethany Baptist Church Chesapeake and Bryant and Stratton College collecting 74 pints of usable blood. Presentations were given to two community groups - Order of Eastern Stars and National Epicureans and health information displays at Bryant & Stratton College, Optima Health Community Partners meeting; SiNERGe meeting and web meeting with Vertex Pharmaceuticals. One client requested medical transport to a hospital in Richmond for a blood transfusion.

August

Held a blood drive at Bethel Worship Center Church International, Portsmouth collecting 20 donations. Presented to faculty and staff at Norfolk State University at the Open House campus event. Four health fairs reached 226 persons and provide a Back-to-School Backpack event on August 19 along with literature distribution on Sickle Cell Disease.

September

Held a blood drive at Bayport Credit Union collecting 47 donations. Presented to participants at community health awareness fair held at Bethany Baptist Church, Chesapeake and employees at Canon and Bayport Credit Union. Six health fairs reached 532 persons. Hosted the first Sickle Cell Education Series webinar on September 26, 2023 with a presentation by Melissa Mattice McDonnell, Pharmacist and Senior Medical Science Liaison Global Medical Affairs North America with Vertex Pharmaceutical on CRISPR as a treatment for Sickle Cell Disease. Presented the current research on CRISPR as a technology that can be used to edit genes. The information given emphasized the current research trial studies of CRISPR, by finding a specific bit of DNA inside a cell and is not approved by FDA.

October

Presented at the Sickle Cell Disease Association of America 51st Convention on the Sickle Cell Association services as a Community-Based Organization. Association was recognized for the community work at the "Impacting Lives 2023" ceremony hosted by the New Journal & Guide newspaper. Participated in Shiloh Church Community Day blood drive and on the Virginia Eastern Shore at Nandua High School Health Awareness Day. Display and blood drive was sponsored by the African American Cultural Museum and held at Virginia Wesleyan University.

November

Met with Masonic Organization and Eastern Stars to express appreciation at the Annual Shriners Ball for their continued support and the need for families living with Sickle Cell Disease. They donated 15 food baskets which were distributed to families in Hampton, Newport News, Suffolk, Norfolk, Chesapeake and Virginia Beach. Blankets donated by SCDAA were also distributed to 20 families.

December

Held annual Sickle Cell Families Christmas party for an evening of games, refreshments and distribution of blankets, "Pain is Real" t-shirts and food baskets. Gave a brief presentation on the Agency services available to sickle cell families and contact information. Family on the Eastern Shore was referred by CHKD with critical need for housing since the existing structure has severe mold which has contaminated all the children clothes including the 4 year old with sickle cell disease and asthma. Clothes were donated and continue to work on getting housing in the area nearer to Children Hospital to limit the two hours plus travel for monthly blood transfusions. Held 51st Annual Gala on December 2 with over 200 guests to recognize and thanks community donors.

Sickle Cell Association - Continued

January

Information table at Annual Martin Luther King services on January 15 at Nansemond River High School, Suffolk. There were over 300 participants attending the service and health awareness fair. Participated in the Community Day Resource Fair at Norfolk State University on Saturday, January 27 reaching over 126 participants. Mount Nebo Baptist held its quarterly blood drive and health fair reaching 24 donors. Red Cross Sickle Cell Warriors blood drive was held at First Baptist Bute Street with 19 donors.

February

Held one blood drive at Tidewater Community College and collected 38 useable pints of blood. A presentation was given to the health and nursing classes during Black History Month Expo. An education series webinar was presented on Casgevy: Cell and Gene Therapy Treatment for Sickle Cell Patients and their families. Met with Eastern Virginia Medical School physicians on planning the opening of an adult Sickle Cell Clinic in the Hampton Roads area. Attended the Rare Disease Advocacy Week in Washington, DC and presented the national FY 2025 Sickle Cell Federal Requests to legislators in Congress.

March

Presentation to the Links of Hampton on their Cruise for a Cause about the latest approved treatments for sickle cell patients reaching 250 guests. Setup a display table at the Links of Suffolk Annual Community Health Fair and gave the AFLAC sickle cell ducks education series on pain to participants visiting the booth. Held a webinar education series hosted by VERTEX Pharmaceutical on the latest treatment CASGEVY that was approved December 8, 2023 by FDA.

April

Participated in the Norfolk State University Foundation 5K Race with an information display table. Held a webinar for patients and families to discuss Cell and Gene Therapy as an option for treatment for Sickle Cell pain. Held one blood drive with 21 blood donors at Mt. Nebo Baptist Church. Spoke at the NAACP meeting held on the Virginia Eastern Shore and then had a table display at the "Return to our Roots- Earth Day Festival" on Saturday April 20, 2024 in Exmore, VA.

May

Met with Johns Hopkins committee on World Sickle Cell Day plans for June 19th and discussed media contacts to promote public relations and social media campaigns. Sent Mother’s Day wishes to clients and fact sheet on Agency services. SCDAA held Advocacy Day in Washington, DC to support funding for the Sickle Cell Disease and Other Inheritable Disorders Research, Surveillance, Prevention, and Treatment Act of 2023 as well as requested appropriations for the Sickle Cell Disease Treatment Act and Sickle Cell Data Collection Program through CDC. Sickle Cell families were made aware of these requests and asked to contact their legislators. Hel meetings with pharmaceutical representatives on latest treatments given out at two presentations.

June

Participated in 5 World Sickle Cell Day events held for Juneteenth Celebrations. The events were three on Virginia Eastern Shore, one in Hampton and one in Portsmouth. The Eastern Shore held a two-day celebration with one for "Shine the Light on Sickle Cell" benefit dance at Do Drop Inn that ended with guests receive a flashlight to participate in lights on for sickle cell. A presentation on the latest treatments for sickle cell disease was given on Sunday, June 16, 2024 at Sunday services at New Mt. Zion Church and at the Shin ehte Light dance event.

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: 144
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: 11 for total of $9,500.00
Contract Services for Client Advocacy Education and Representation
Number of Participants: 0

Type of Educational Program offered:

Distribution of Sickle Cell Literature
Number: 3,770
Health Fairs/ Presentations of Sickle Cell and Agency Information
Number: 9
Number of Attendees: 975
Blood Drives-Every donation saves 3 lives. Many Sickle Cell Clients need transfusions monthly
Number of Attendees:
Number: 0 X 3 = 00 number of lives saved
Sent Information to Church Members
Number: 572

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: 2,459
Special Mailings
Number Sent: 1,883
Letters to Churches
Number: 95

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: 272

Sickle Cell Association of Richmond-OSCAR - Continued

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

Number Sent: 308

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: 1,712

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 185

Calls to clients to obtain information or update contact information

Number: 100

Sickle Cell Association of Richmond-OSCAR - Continued

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

July

In July, we mailed each client a copy of our Sickle Cell Brochure with information in it on the disease and the organization.

Also purchased 55 radio time ads about Sickle Cell Trait/Disease run on a radio station listened to by persons of child-bearing age (130,000 total households reached during each ad). (7,150,000

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

One 4" x 2 column ad about Sickle Cell Trait/Disease.
One 4" x 2 column ad to request African American donors to give blood.
One 5" x 2 column ad about Sickle Cell Trait/Disease.
One 5" x 2 column ad to request African America donors to give blood.

August

In August, we mailed each client two "Words of Wisdom" (1) For me, I am driven by two main philosophies, know more today about the world than I knew yesterday. And along the way, lessen the suffering of others and (2) Believe you can and you're halfway there. We mailed each client a copy of the September Month Calendar with 30 pieces of information about sickle cell. We also mailed church members a copy of the September Month Calendar with 30 pieces of information about sickle cell and asking them to contact the Red Cross and donate blood. Participated in health fair during a Church Homecoming (800 pieces distributed). Upon request, we sent fifty each of three (3) pieces of literature (150 total) to various organization as follows: Charles City, Chase City, Emporia, Petersburg and four (4) in Richmond. (1,200 total)

September

In September, George Carter and Dr. Wally Smith appeared on TV channel 8 (Show Case) after the news to talk about sickle cell and hearing loss (**150,000** households) (It was also aired in August but not covered on the August Report (**150,000** households). We purchased 55 radio ads about Sickle Cell Trait/Disease run on a station listened to by persons of child-bearing age (130,000 households reached by each ad total of **7,150,000**). Four different Newspaper Ads in the Richmond Free Press for four weeks (100,000 readers per week for four weeks total **400,000**).

One 4" x 2 column ad about Sickle Cell Trait/Disease.
One 4" x 2 column ad to request African Americans donate blood.
One 5" x 2 column ad about Sickle Cell Trait/Disease.
One 5" x 2 column ad to request African Americans donate blood.

October

In October, we mailed each client a Brochure on Hearing Loss. We also purchased four different Newspaper Ads in the Richmond Free Press for four weeks (100,000 readers per week for four weeks total **400,000**).

One 4" x 2 column ad about Sickle Cell Trait/Disease.
One 4" x 2 column ad to request African Americans donate blood.
One 5" x 2 column ad about Sickle Cell Trait/Disease.
One 5" x 2 column ad to request African Americans donate blood.

Sickle Cell Association of Richmond-OSCAR - Continued

November

In November, we mailed each client a Monthly Planner so they can keep their scheduled appointments.

December

In December, we mailed each client a Holiday Greeting Card so they know we are thinking of them. Mailed to Churches and Church members letters to urge people to donate blood to the Red Cross during January for Sickle Cell Patients during Blood Donation Month.

January

In January, we mailed each client two **"Words of Wisdom", (1) Freedom is a state of mind. (2) You will find that it is necessary to let things go; simply for the reason that they are heavy.**

In January, (the first week) Preston Page (a sickle cell client) and Jonathan McNamara of the Red Cross appeared on TV channel 8 (Show Case) after the news to talk about sickle cell and the need for blood donations to help sickle cell patients (**150,000** households) (It was also aired in the last week of January which was National Blood Donation Month) (Paid for with Grant Funds)

February

In February, we mailed each client two **"Words of Wisdom", (1) Difficult roads often lead to beautiful destinations (2) Two things define you. Your patience when you have nothing and your attitude when you have everything.** We also mailed each client a “Thinking of You Card” so they would know we are thinking of them.

We supplied materials for two presentations at Virginia Union University, one was connected to Delegate Deloris McQuinn. She was supporting sickle cell legislation.

During the month, we e-mailed members of the Virginia General Assembly information about Sickle Cell Disease and requesting support for several bills and budget amendments regarding sickle cell.

March

In March, we mailed each client two **"Words of Wisdom", (1) Life is about using the whole box of crayons. (2) Don’t ask for an easier life; ask to be a stronger person.**

During the month, we e-mailed members of the Virginia General Assembly information about Sickle Cell Disease and requesting support for several bills and budget amendments regarding sickle cell. Sickle Cell got more attention and legislation during this General Assembly Session than any other.

April

In April, we mailed each client a letter stating that April was Stress Awareness Month and reminding clients that stress can cause a sickle cell crisis. We also sent a E Z 2 Stick-Up Magnet “You’ve Got This! Keeping Stress At Healthy Levels.” to each client.

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

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

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

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

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

Sickle Cell Association of Richmond-OSCAR - Continued

May

In May, we mailed each client two - "Words of Wisdom" (1) Mistakes are proof that you are trying and (2) It's not who you are that holds you back, it's who you think you're not. We gave each client who graduated from high school and finished the sickle cell program for young adults a $1,000.00 scholarship to go to college or take some advanced study program. Eight clients received scholarships. Total $8,000.00

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

One 4" x 2 column ad about two Sickle Cell traits/Diseases.
One 4" x 2 column ad to request African American donors to give blood.
One 5" x 2 column ad about Sickle Cell Trait/Disease.
One 5" x 2 column ad to request African American donors to give blood.

June

In June, we mailed each client two **- "Words of Wisdom"** (1) Don't stumble over something behind you and (2) No one ever injured their eyesight by looking on the bright side.

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

One 4" x 2 column ad about two Sickle Cell Trait/Disease.
One 4" x 2 column ad to request African American donors to give blood.
One 5" x 2 column ad about Sickle Cell Trait/Disease.
One 5" x 2 column ad to request African America donors to give blood.

NEWS COVERAGE DURING March, 2023- Sickle Cell Association of Richmond-OSCAR

One of our adult sickle cell clients has a pod cast and asked to interview George Carter. The interview was held on Friday, March 10th and lasted for about 25 minutes and was broadcasted on two public access channels on Saturday and Sunday, March 25th and 26th.
https://youtu.be/Bik1u7xLFQ0

The interview covered a wide range of sickle cell topics including:
Contact Information for Sickle Cell Association of Richmond - OSCAR
Talking about the pain
My first crisis
Hearing loss with Sickle Cell patients
Need for Blood donations
Things a client needs to do like:
    Drink plenty of water
    Get 8 hours or more of sleep
    Eat the right foods
    Avoid stress

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

4pm (Approx 7 min) – 2 Men thriving with sickle cell (George Carter & James Frazier) with expert Dr. Wally Smith
https://www.wtvr.com/news/local-news/sickle-cell-disease-george-carter-march-30-2023

5pm (Approx 5:20 min) Need for more adult sickle cell centers especially in Tidewater with expert Dr. Wally Smith
A patient from the Tidewater area named Taylor Mickel, who came to Richmond to attend VCU. Based on the care she has received; she does not want to return to Tidewater.
https://www.wtvr.com/news/local-news/sickle-cell-treatment-access-rural-virginia-march-30-2023

5:30pm (Approx 5 min) – Interview with Trei Banks of the American Red Cross; details on VSU and VUU Sickle Cell Blood Drive
He announced that starting on April 1st, the Red Cross will start provide the testing for sickle cell disease and trait. Also, that the Red Cross will hold a blood drive on April 4th from 12-5 at Virginia Union University and Virginia State University
https://www.wtvr.com/news/local-news/red-cross-sickle-cell-disease-march-30-2023

6pm (Approx 6:30 min) – Feature story on The Hunters who lost their son to sickle cell at the age of 28 with expert Dr. Smith
https://www.wtvr.com/news/local-news/sickle-cell-disease-samuel-boykin-hunter-march-30-2023

6pm (Approx 2:27 min) - CS6 Gives "surprise" to George Carter
George Carter was the March CBS Recipient for a $500.00 Visa gift card for his contribution to the community.
https://www.wtvr.com/cbs-6-gives/george-carter-sick-cell-disease-march-30-2023

A total of 26 minutes and 20 seconds of coverage over 4 newscasts reaching 50,000 households.

NEWS STORY – July 1, 2024

How four new Virginia laws impact those living with sickle cell disease: 'This will raise awareness'

By: GeNienne Samuels
Posted at 10:16 PM, Jul 01, 2024
RICHMOND, Va. -- On July 1, four new laws go into effect that directly impact those living with sickle cell disease and those who are unaware that they may have the disease and/or be a carrier of the trait.

Spreading awareness about sickle cell disease and its impacts is something that CBS 6 Anchor GeNienne Samuels has been passionate about for over a year. So, she began giving a voice to those in the CBS 6 community living with sickle cell disease. Every patient that GeNienne spoke to explained that the disease often leaves them suffering in silence because their medication isn't strong enough or some doctors just don't understand how to treat them.
Take 29-year-old Walter Davis of Colonial Heights for example, who described his pain as 'debilitating.'

“I would say it's grueling. It is mentally, physically, emotionally exhausting because it doesn't stop," Davis said. "It felt like I was getting beat with a sledgehammer or a metal bat.”

WTVR
Walter Davis and GeNienne
Because of this crippling pain, Davis elected earlier this year to participate in a gene therapy trial, acting as one of 33 participants in the United States. However, most patients do not have access to this level of treatment.

As of July 1, there is relief. Four of the six bills submitted are now laws.
First, a law that will allow doctors to prescribe and pharmacists to distribute opioids without fear of legal retribution. Something that Dr. Wally Smith, a Lawrence Neil Cooper Smith Professor of Sickle Cell disease at VCU says will improve pain management for sickle cell patients.
“This is a disease that cripples and disables patients from childhood on. And they're on these opioid pain medicines because there's nothing else today that really takes the pain away acutely," Dr. Smith said. "Naming the disease, putting it in sort of the same category is cancer is very important in making a safe prescribing environment for the doctors, and then to make it possible for the patients to get access to sometimes lifesaving pain medication.”

GeNienne shared George Carter's story last year, as well. Carter runs OSCAR, the Sickle Cell Association of Richmond. He helped jump start this law by going through the Attorney General to get an Executive Order put through providing safe harbor to doctors. Now it's extended to all professionals, including pharmacists.

The second law creates a statewide registry of sickle cell disease case information, providing centralized data to determine how many people in the commonwealth have sickle cell disease, which in turn will help prove the need for funding and accountability.
Dr. Smith explained the importance of the law.

“We still don't know how many people in the United States have sickle cell disease. The reason we don't know is the way the original legislation was passed in the National Sickle Cell Disease Control act. It only provided for newborn screening. If mom didn't tell you, you don't know what your status is. What this does is make it so that the entire age range data will be known. 35, 36, 50, 70-year-old people will discover they have sickle cell disease as a result of this.”

WTVR
Dr. Wally Smith
“We [will] now know how long people live," Dr. Smith said. "So if you know how long people live and you can measure how long they're living over time, you have built in accountability for improving the quality and the quantity of lives of patients that live with this disease.”
The third law makes sickle cell disease or trait screening tests available to all adults in the Commonwealth. According to Dr. Smith this increased awareness will help reduce the disease being passed on to offspring.

“The number of children born with sickle cell disease is not going down. It's going up. And so is the need to have everybody know their sickle cell trait status. And to know that one in four children born to two parents, each of whom have sickle cell trait, every time there's a one in four chance that that child will have sickle cell disease. That's a very important and under recognized fact, so unrecognized that people don't even ask about it when thinking about having a child. So, this will raise awareness and the need to ask.”

Finally, Dr Smith says the fourth law calls for an annual Department of Medical Assistance Services review of medication and treatment for sickle cell disease, which will add accountability for the state government to be aware of what’s available and then have payment sources in place for patients.

Dr. Smith says he feels encouraged about the progress so far but believes there is still room for improvement in the areas of getting more funding for treatment and community programs.

THANK YOU

Sickle Cell Association of Richmond – OSCAR is deeply grateful to **GeNienne Samuels** and CBS WTVR 6 for all the great coverage that was provided for sickle cell disease, the clients and the organization for over 30 minutes of free news coverage.

NOTE:

George Carter and Dr. Wally Smith appeared on TV channel 8 (Show Case) after the news to talk about sickle cell and hearing loss for about 5 minutes of coverage that we had to use grant funds to pay for. We also used grant funds to pay for a 5-minute interview with one of our clients, Preston Page and Jonathan McNamara from the Red Cross to encourage blood donations by African Americans for persons with sickle cell.

Statewide Sickle Cell Chapters of Virginia
July 2023 through June 2024

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

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 78-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 serves as the Administrator (unpaid Executive Director) of Statewide Sickle Cell Chapters of Virginia and Sickle Cell Association of Richmond - OSCAR. He also serves as a Sickle Cell Disease Patient Consultant for the Food & Drug Administration (FDA) and formerly served on the Interagency Pain Research Coordinating Committee (IPRCC) of the National Institute of Health (NIH).

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

In the future, we plan to be involved in identifying and correcting the unfair pricing of drugs that sickle cell clients need.

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**". In early 2022 this work was published.

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.

FOUR SICKLE CELL BILLS THAT PASSED THE VIRGINIA GENERAL ASSEMBLY

Statewide lobbied members of the General Assembly by phone and e-mail to support legislation to assist the sickle cell community. The following House Bills were passed along with two budget increases.

HB257 - Sickle Cell Anemia Prescription of Opioids for Pain Management

HB252 – Sickle Cell Disease: Statewide Registry Created, Collection of Disease Case Information Report

HB255 - Adult Wellness Screening Sickle Cell Disease or Sickle Cell Trait

HB820 – Sickle Cell Disease: Annual Review of Medication and Treatment Report

George Carter requested increases for two existing sickle cell programs that are administered by the Virginia Department of Health as follows:

Bill	Previous $	Increase Request	Increase Approved	Present $
SB30 #4 - Pediatric	$305,000	$295,000	$145,000	$450,000
SB30 #5 - Adult	$805,000	$145,000	$ 75,000	$880,000