

STATEWIDE SICKLE CELL CHAPTERS OF VIRGINIA, INC.

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REPORT

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

September 26 2025

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 of sickle cell medical care has multiplied many, many times since 2006. Many patients are living longer causing them to experience more negative physical problems. Those problems include lose of hearing, causing loss of balance and falls. BASU says the cost per patient is \$37,000.00 to \$40,000.00 per patient totaling \$3.8 Billion per year.

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.

The comprehensive sickle cell centers under contract in the state are as follows:

Virginia Commonwealth University Health System in Richmond	(Pediatric and Adult)
University of Virginia in Charlottesville	(Pediatric and Adult)
Carilion in Roanoke	(Pediatric and Adult)
Pediatric Specialist of Virginia in Northern Virginia	(Pediatric)
INOVA Adult Sickle Cell Center in Fairfax, Virginia	(Adult)
Children’s Hospital of the King’s Daughters in Norfolk	(Pediatric)
Sentara EVMS Comprehensive Sickle Cell Program in Tidewater	(Adult)

It is estimated that the State of Virginia has about 4,000 sickle cell clients/patients. The centers care for about 1,950 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 49% of the sickle cell population. **This demonstrates the very need for a network of community-based programs to serve the 51% 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
- FY25 - \$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.

During FY24 and FY25, Statewide Sickle Cell Chapters of Virginia issued Proposals for community-based Sickle Cell Support Services and awarded three contracts to member chapters as follows:

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

The three aforementioned chapters were awarded funding to begin community-based sickle cell services on **July 1, 2024** and continue through **June 30, 2025**. 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 information provided on the following pages is a summary of the **Community-Based Sickle Cell Program Activities completed as of June 30, 2025**

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, Loudoun and Prince William County.

Type of Assistance offered:

Calls from Clients/Family for information/assistance

Number: 6

Information or Referral Assistance to Clients and Families

Number: 3

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

Number: 823 for \$5,480.00

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 9,650

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 8

Number of Attendees: 1,053

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

Number of Attendees: 110

Posted Sickle Cell information on Facebook page for viewing.

Number: 0

Sickle Cell Walk

Number of Participants: 0

Facebook Distribution Information: 9600

Type of Support Group offered:

Meetings

Number of Participants: 162

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: 664

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

Number Sent: 8,864 and others

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 67

Calls to clients to obtain information or update contact information

Number: 4

Distribution of Chapter Newsletter

Number: 162

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

Financial assistance provided to client suffering from homelessness in the form of grocery store gift cards (non-grant funded). The Heart of Gold met with INOVA Adult Sickle Cell Center Staff to plan the 4th Annual Town Hall Meeting Scheduled for September 11, 2024 in Fairfax Virginia. Approximately 200 persons are expected to be in attendance and the Heart of Gold will have a display table and educational materials. The Heart of Gold received a commitment from the Fairfax County Board of Supervisors designating September as Sickle Cell Awareness Month in Fairfax County. The Heart of Gold will sponsor a webinar in early October "Transition from Pediatric to Adult Care"

August

The Heart of Gold met with INOVA Adult Sickle Cell Center Staff to plan the 4th Annual Town Hall Meeting Scheduled for September 11, 2024 in Fairfax Virginia. Approximately 200 persons are expected to be in attendance and the Heart of Gold will have a display table and educational materials. Letters were mailed to local community groups and churches about Sickle Cell Awareness Month and encouraging blood donations. The Heart of Gold had preliminary discussions with Dominion Energy to sponsor blood drives at up to 3 Northern Virginia locations.

September

The Heart of Gold co-sponsored t with INOVA Adult Sickle Cell Center Staff the 4th Annual Town Hall Meeting Scheduled on September 11, 2024 in Fairfax Virginia. Approximately 150 persons were in attendance. Heart of Gold donated \$1500 (non-grant) to support a nutritious dinner for participants. Presentations were made by NIH, Children's National Medical Center and INOVA on cutting edge treatments for SCD patients. A panel of SCD warriors shared their experiences, including pregnancy challenges, participating in clinical trials and self-advocacy. A dance group led by a SCD warrior performed and a local poet dedicated a poem to SCD warriors and caregivers. The Heart of Gold distributed educational and informational materials along with vendors from the Maryland Sickle Cell Association, DC Sickle Cell Association, Fairfax County Health Department and Community Services Board, Melwood Camp Accomplish and Work Innovation Skills Hub. Heart of Gold also served as a sponsor for the Cure Sickle Cell Walk on September 14, 2024 at Howard University. Over 700 persons registered for the walk and educational and informational materials were distributed. On September 24, the Fairfax County Board of Supervisors will issue a proclamation designating September as "Sickle Cell Awareness Month" on Fairfax County. This presentation will be televised on County Cable Channel 16 and on streaming services.

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

October

The Heart of Gold supported a Blood Drive with the Top Ladies of Distinction Haymarket/Gainesville Chapter. Informational materials on Sickle Cell Disease were distributed. 25 persons participated and there were 20 units of blood collected by the American Red Cross. Healthy snacks were donated to the INOVA Adult Sickle Cell Center. These snacks, including water and juices are provided to clients who come to the center for infusion treatments, or who may not have access to food. Sickle Cell educational materials and children's books were delivered to the Pediatric Specialist of Virginia Clinic. These materials included information in both English and Spanish.

November

The Heart of Gold provided support to the Adult Sickle Cell Clinic Support Group (meal with non-grant funds). Information was shared with the group on an upcoming Self-Advocacy Webinar.

December

The Heart of Gold sponsored a webinar on December 3 entitled "Tools For Self Advocacy for Sickle Cell Patients and Caregivers". This webinar, was presented by Ms. Natasha Chambers, Senior Sickle Cell Patient Affairs Liaison for Pfizer and was attended by 21 persons. The Heart of Gold, in conjunction with community donors, Top Ladies of Distinction Alexandria City and Haymarket Gainesville Chapters donated snacks, beverages and blankets to the Inova Adult Sickle Cell Clinic on December 19th. The Heart of Gold also donated children's books about Sickle Cell and toys to Pediatric Specialist of Northern Virginia Sickle Cell Clinic on December 19th. The Heart of Gold donated the food and beverages for the monthly support group at the Inova Adult Sickle Cell Clinic. Letters were sent to Neabsco Baptist Church, Dale City, VA and Shiloh Baptist Church, Alexandria, Virginia regarding upcoming blood drives and requesting a table to distribute information about the importance of blood donations to Sickle Cell patients, new blood donation guidelines and information about Sickle Cell Disease and Sickle Cell Trait.

January

Letters were sent to churches and community organizations noting that January is "Blood Donation Month". A copy of the Heart of Gold pamphlet on Blood donation eligibility was included with each letter.

February

The Heart of Gold donated \$2500 to Melwood for Super Campers Always, a weeklong summer camp for children with Sickle Cell Disease and their families. This donation will fully pay for 5 camp scholarships. The Heart of Gold completed two podcasts in February--The Power of Peer Support, with Inova Adult Sickle Cell Center staff and a Sickle Cell Warrior. The second podcast was with Melwood about the Super Campers Always summer camp.

March

The Heart of Gold attended and made a brief presentation at an open house sponsored by Melwood on March 26. This open house featured Melwood sub-organizations that support persons with disabilities, including job training and support. The Heart of Gold contacted Dominion Energy and Top Ladies of Distinction Alexandria City Chapter about future blood drives. The Heart of Gold met with Blue Bird Bio on March 12 and received information about their gene therapy for SCD. A future podcast is planned. The 2025 newsletter was distributed via email to 56 SCD warriors.

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

April

The Heart of Gold participated in the Top Ladies of Distinction Haymarket/Gainesville Chapter Community Fair on April 6. We gave brief presentation about the organization and the importance of blood donations. There were over 175 persons in attendance. On April 17, the Heart of Gold sponsored a webinar for the Inova Adult Sickle Cell Support Group on Emotional Wellness. This presentation was conducted by the Pfizer Senior Sickle Cell Patient Affairs Liaison, Natasha Chambers. A donation of \$50 from Safeway was used to provide the meal and beverages for the participants. Over 20 persons participated in the webinar. Heart of Gold sponsored a blood drive with the American Red Cross in Springfield VA--there were 17 participants. Letters were emailed to local organizations about the upcoming Heart of Gold sponsored May 14 blood drive in Springfield VA. The Heart of Gold received and donated \$500 (non-grant funds) to the Heart of Gold Foundation Scholarship at the Alfred Street Baptist Church Foundation.

May

The Heart of Gold sponsored a Sickle Cell Blood Drive on May 14th with the American Red Cross. There were 41 registrants for this blood drive. In early May, the Heart of Gold made a food and beverage donation to the Inova Adult Sickle Cell Clinic. On May 21, the Top Ladies of Distinction Haymarket/Gainesville Chapter made a food and beverage donation to the Inova Adult Sickle Cell Center. On May 28, the Heart of Gold had a display table with information on Sickle Cell Disease and the importance of blood donations at the Prince William Alumnae Chapter of Delta Sigma Theta Sorority, Inc. Blood Drive in Dale City Virginia. information was sent to local community groups and churches on upcoming blood drives in June, July and August. A confirmation was received from the City of Alexandria re: the presentation of a Proclamation designating September as Sickle Cell Awareness Month in Alexandria. A confirmation was received from Fairfax County re: the presentation of a Proclamation designating September as Sickle Cell Awareness Month.

June

The Heart of Gold sponsored a blood drive with the American Red Cross on June 11 in Springfield Virginia. There were 32 participants. The Heart of Gold had a display table and distributed information to blood drive participants. The next American Red Cross blood drives are July 2 and August 27 in Springfield, Va. Emails were sent to local community groups asking for support at the blood drives. On June 19th, Inova held a World Sickle Cell event and Heart of Gold donated information materials. On June 26, a meal (non grant funds) and beverages were donated to the Inova Adult Sickle Cell Center Support Group. The Heart of Gold and University of Virginia Medical Center Manassas have formed a partnership to improve the wellness of Sickle Cell patients to reduce in-patient care. This initiative will start in August 2025.

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: 198

Information or Referral Assistance to Clients and Families

Number: 89

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

Number: 19 for total of \$6,387.32

Type of Educational Program offered:

Pieces of Literature Distributed

Number: 13,907

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 38

Number of Attendees: 4,603

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

Number of Attendees: 455

Type of Support Group offered:

Advocacy & Community Resources Meetings

Number of Participants: 874

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: 225

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

Number Sent: 271

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

Number Sent: 1,536

Letters to churches to educate and obtain support for Sickle Cell

Number Sent: 580

Calls to clients to obtain information or update contact information

Number: 193

Sickle Cell Association - Continued

July

Held two blood drive at Bethany Baptist Church, Chesapeake, VA and Mt Nebo Baptist Church, Surry collected 47 pints of blood. Set up health information booths at the blood drives and two community events held on Virginia Eastern Shore at Onley Baptist Church and at Virginia Beach Community Youth Center. Sent out literature to the churches to invite persons needing information on the cell and gene therapies to call to schedule an educational seminar.

August

Held one blood drive and collected 22 pints of blood. Set up health information booths at the blood drive and three community events held on Virginia Eastern Shore in Nassawadox and at Norfolk State University, Portsmouth Health Center and Bryant and Stratton College. Sent out literature to the churches to invite persons to the 31st Annual Walk for Sickle Cell encouraging participants in the health fair information and screening clinic.

September

Participated at five blood drives at Tidewater Community College, Arabia Temple, Mount Nebo Baptist Church, Bethany Baptist Church and Canon Company where 147 pints of blood were collected. Health information booths were setup at the blood drives. Sent out literature to the clients to speak with their doctors on the latest therapies and change changes in the removal of Oxbryta from patient medication lists. Held 31st Annual Walk for Sickle Cell with over 650 participants each receiving Sickle Cell fact sheet on the disease and trait.

October

Participated at two blood drives at Shepherdsville Baptist Church in Gloucester, Virginia and Norfolk State University Student Center where 83 pints of blood were collected. Health information booths were setup at the blood drives and at Jerusalem Baptist Church, Virginia Beach. The Association was recognized at the 120th Anniversary Celebration - Impacting Lives of the Journal and Guide Newspaper. Attended the 52nd Annual National Sickle Cell Convention to learn the latest treatments for Sickle Cell Disease.

November

Met with Shriners of Virginia at the Annual Charity Ball to receive their contribution and gave remarks on the Association services. Delivered 15 Thanksgiving food baskets and toiletries to sickle cell families. Distributed information to adult sickle cell clients on the Sentara-EVMS Comprehensive Sickle Cell Program services. Attended Rare Disease Advocacy Training for State of Virginia and presented issues relative to sickle cell patients living in Virginia. Provided sickle cell patients updated resources received at the SCDA Convention about the Medic Alert ID bracelet.

December

Attended the three-day virtual conference sponsored by American Society of Hematology for the 66th Annual Meeting and Exposition in San Diego, CA. The sessions featured the latest education and scientific information on Sickle Cell Disease. Topics included Charging Toward New Therapies in Hematologic Malignancies, Health Equity Spotlight: Pioneering Inclusivity in Hematology, Journey in Stem Cell Biology and Resilience in Science and Marrow Matters: A New Era in Red Cell Discovery and Anemia Management. Participated in one health fair that was held in Portsmouth to Celebrate Healthcare and community blood drive collecting 32 pints of blood. Gave 15 families Christmas Food Baskets and one special Joy Gift Box for a Sickle Cell Child.

Sickle Cell Association - Continued

January

Health fair displays and presentations were held at the Martin Luther King Service held in Suffolk, VA at Oak Street Baptist Church; two-day Celebrate Healthcare at Hampton Roads Conference Center; an information table at the Women Care Fair in Chesapeake and Rare Disease Virginia briefing before meeting with legislators to thank them for supporting 2024 Sickle Cell bills in Virginia General Assembly. One blood drive was held at Mt Nebo Baptist Church Surry that collected 29 pints of blood.

February

One blood drive held at Tidewater Community College, Portsmouth, VA collecting 33 pints of blood. Presented at Bryant and Stratton College, Virginia Beach Campus Annual Medical Technology meeting on recent advances in treatment for sickle cell disease. Spoke to legislators with Rare Diseases Virginia on the current impact of proposed changes in Medicaid Expanded Care. Sent information to churches during Black History Month relating sickle cell disease in the region and State. Appeared on the Hampton Roads Show with a sickle cell client to current services available for persons living with Sickle Cell Disease.

March

One blood drive held at Chesapeake Square Mall, Portsmouth, VA collecting 26 pints of blood. The blood drive was in partnership with Top Ladies of Distinction Hampton Roads Chapter and Top Teens of America. Attended the SCCAPE Conference in Richmond entitled "Sickle Cell Care Coordination for Achieving Patient Empowerment. The conference was an opportunity to learn the latest treatments and care coordination efforts across the state of Virginia.

April

One blood drive held at YMCA, VA collecting 32 pints of blood. The blood drive was in partnership with Delta Sigma Theta Sorority Norfolk Alumni Chapter. Participated in Health Awareness fairs were held at Norfolk State University, Portsmouth Community Athletic Center, First Lynnhaven Baptist Church and Exmore Community Day on Virginia Eastern Shore. Support services provide transportation to medical appointments, completed paperwork for client applying for Medicaid since moving to Virginia and provided health supplies for patient in need of home health care.

May

Held educational lunch forum on "Gene Therapy -Journey in life of Sickle Cell Patients" with 26 families attending. Recognized that there are a lot of questions that Sickle Cell families need before making the critical decision for Cell and Gene Therapies. Had a display table on sickle cell disease on the Virginia Eastern Shore that many churches represented wanted to schedule presentations on current research and treatment for sickle cell. Will be planning an educational session on Medicaid changes that may affect sickle cell patients and their families as a representative of Rare Disease Legislative issues.

June

Participated in an educational tour display for "World Sickle Cell Day-Shine the Light on Sickle Cell" on June 19th at Fort Monroe, Hampton. Juneteenth Celebration events were held on June 15, 2025 at Millpoint Park Hampton as an educational information vendor for over 400 participants. Display health awareness information tables were setup on Saturday, June 21 at the Eastern Shore Juneteenth Festival with 150 participants and on Sunday, June 22nd at a "Shine the Light on Sickle Cell" Jazz Brunch on the Virginia Eastern Shore in Nassawadox County for 25 guests.

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: 190

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: 7 for total of \$5,770.13

Contract Services for Client Advocacy Education and Representation

Number of Participants: 0

Type of Educational Program offered:

Distribution of Sickle Cell Literature

Number: 1160

Health Fairs/ Presentations of Sickle Cell and Agency Information

Number: 7

Number of Attendees: 1060

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: 465

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: 1,800

Special Mailings

Number Sent: 2,100

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: 266

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

July

In July, we mailed each client a booklet- "About Food and Drug Interaction"

August

In August, we mailed each client two "Words of Wisdom" (1) Be a voice not an echo. and (2) Never say anything which doesn't improve the silence.

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 aired twice = **300,000** households)

Purchased 55 radio time ads on Radio One about Sickle Cell Trait/Disease listened to by persons of child-bearing age (130,000 total households reached during each ad). (**7,150,000** households)

Ran two Newspaper Ads in the Richmond Free Press about Sickle Cell Trait/Disease and two other ads that sort to get more African Americans to donate their blood which is more compatible to most clients, that reached (100,000 readers per week x 4 weeks = **400,000** households).

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.

October

Ran two Newspaper Ads in the Richmond Free Press about Sickle Cell Trait/Disease and two other ads that sought to get more African Americans to donate their blood, which is more compatible with most clients, that reached (100,000 readers per week x 4 weeks = **400,000** households)

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.

November

Sent each client a 2025 Pocket Planner, to keep track of their appointments.

December

Sent each client a Holiday Greeting Card.

Sent each Church Member a Holiday Greeting Card.

Sent each Church Member a letter stating that January is National Blood Donation month and requesting they donate.

Sent individual Churches a letter stating that January is National Blood Donation month and requesting they donate.

January

In January, we mailed each client two **"Words of Wisdom", (1) Set a goal that makes you want to jump out of the bed in the morning. (2) To thrive in life you need three bones: a wishbone, a backbone and a funny bone.**

In January, 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 x 2** households) (It was also aired in January which was National Blood Donation Month) (Paid for with Grant Funds).

Sickle Cell Association of Richmond-OSCAR - Continued

Ran two Newspaper Ads in the Richmond Free Press about Sickle Cell Trait/Disease and two other ads that sort to get more African Americans to donate their blood which is more compatible to most clients, that reached (100,000 readers per week x 4 weeks = **400,000** households).

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.

February

In February, we mailed each client two "Words of Wisdom", (1) Mastering others is strength. Mastering oneself makes you fearless (2) To handle yourself, use your head; to handle others, use your heart. We sent each client a "Thinking of You" card

March

In March, we mailed each client two "Words of Wisdom", (1) If passion drive you, let reason hold the reins (2) You make a living by what you earn; you make a life by what you give.

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 "Stress Management" Pocket Pal to each client. We also sent the information to 93 Church members.

May

We sent each client two Words of Wisdom, (1) **If you cannot do great things, do smart things in a great way. And (2) A child can ask questions that a wise man cannot answer.**

We gave 50 (Tape measures/ Flash lights) to Church members.

Ran two Newspaper Ads in the Richmond Free Press about Sickle Cell Trait/Disease and ran two other ads that sort to get more African Americans to donate their blood which is more compatible to most clients, that reached (100,000 readers per week x 4 weeks = **400,000** households).

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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.

June

We sent each client two Words of Wisdom, (1) There is great power in letting go, and there is great freedom in moving on. And (2) Try not to become aa person of success, but rather try to become a person of value.

Purchased 55 radio time ads on Radio One about Sickle Cell Trait/Disease listened to by persons of child-bearing age (130,000 total households reached during each ad). (**7,150,000** households) Presentations took advantage of World Sickle Cell Day.

Issued check for \$3,000.00 for 3 Sickle Cell graduates this year for scholarships, \$1,000.00 each.

ASK Childhood Cancer Foundation

5211 West Broad Street, Suite 100

Richmond, VA 23230

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 that Statewide lobbied members of the General Assembly for.

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

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 Florence 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 all of the 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

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.

George Carter is a 79-year-old male who suffers with Sickle Beta Zero Thalassemia. He has been working with various sickle cell organizations and for sickle causes for over 40 years. Currently, he serves with Statewide Sickle Cell Chapters of Virginia and Sickle Cell Association of Richmond - OSCAR. He has also served 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).

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 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 them to distribute to clients and the public.

We continue to work with Dawn Nelson on this topic.

The following letter was sent by George Carter to show the concern for sickle and the clients.

Date: November 10, 2024

To: By E-mail
Pfizer, Inc
U.S. Food and Drug Administration (FDA)

CC: By E-mail (Soon)
Members of Congress
Virginia General Assembly
Virginia Department of Health
Press Core
Dr. Wally Smith

From: George H. Carter
804-321-3350
804-337-8361

Subject: OXBRYTA
Rush to Judgement by Pfizer
Request for "Compassionate Use" of OXBRYTA While Data Review Continues

I am George Carter, a 78-year-old male who suffers with Sickle Beta Zero Thalassemia. I have been working with various sickle cell organizations for over 40 years. Currently, I am serving as the Administrator (unpaid Executive Director) of Statewide Sickle Cell Chapters of Virginia and Sickle Cell Association of Richmond - OSCAR. I have also served 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).

I am a sickle cell patient who was prescribed the standard prescription of Oxbryta (three, five hundred milligram tablets) after dinner each day. After having a lot of side effects, my doctor and I decided to stop taking Oxbryta completely. Seven days later, I went into sickle cell crisis. My Hemoglobin (HGB) blood count had dropped from 8.2 to 5.5. Because my HBG was below 7.0, I was able to qualify for two pints of blood. My doctor and I realized that I should have come off slowly, not all at one time.

Later, I went back on Oxbryta, with a reduced dosage. First, one per day and later prescribed, two a day. Like many other sickle cell patients, I have other medical issues including high blood pressure, asthma and bronchitis. Oxbryta helped me keep myself stable. I was doing well and Pfizer took the drug off the market suddenly. **I am sure Oxbryta has helped keep other patients stable as well.** I alerted some doctors **NOT** to take patients off too quickly.

I believe taking Oxbryta off the market with the limited data I read and not providing for a supply to get patients off at a proper pace created an unnecessary Public Health Crisis.

From Pfizer of September 25, 2024 with parts underlined and bolded by George Carter.

Pfizer Inc. (NYSE: PFE) announced today that it is voluntarily withdrawing all lots of OXBRYTA[®] (voxelotor) for the treatment of sickle cell disease (SCD) at this time, in all markets where it is approved. Pfizer is also discontinuing all active voxelotor clinical trials and expanded access programs worldwide.”

“Pfizer has notified regulatory authorities about these findings and its decision to voluntarily withdraw OXBRYTA from the market and discontinue distribution and clinical studies **while further reviewing the available data and investigating the findings.**”

“We advise patients to contact their physicians to discuss alternative treatment **while we continue to investigate the findings from our review of the data.**”

“The company will keep patients, regulatory authorities, investigators and clinicians **informed about actions and appropriate next steps for OXBRYTA.**”

Based on Pfizer’s statements above, I read that the company did not properly investigate the data before **Rushing to a Decision** to withdraw Oxbryta from use for whatthey say are safety concerns. **“A RUSH TO JUDGEMENT”**

From The Sickle Cell Disease Association of America’s Medical and Research Advisory Committee (MARAC) Statement: Pfizer’s Voxelotor (Oxbryta®) Withdrawal

“The FDA has received questions about whether to allow some individuals living with sickle cell disease to continue voxelotor on a “compassionate use” basis. However, for now we cannot assume that “compassionate use” will be allowed”.

EMA and FDA control release of information.

1. Of the 8 deaths in the GBT440-032 randomized study of children with abnormal stroke risk: “Most of the fatal cases in the voxelotor group describe incidence of infection, including 3/8 who developed fatal malaria and 2/8 patients with sepsis.” “The study recruited 236 children (2y-15y) from Egypt, Ghana, Kenya, Nigeria, Oman, Saudi Arabia, USA and the United Kingdom.”
2. Of the 8 deaths in the open-label GBT440-042 of voxelotor for leg ulcers: “In 4 cases, malaria was identified either the cause or contributing factor.” “Eighty-eight patients at least 12 years of age were enrolled in Brazil, Kenya and Nigeria.”

From – View of Data By George Carter

According to the data I saw, 2 groups had 8 persons to die in each group, for a total of 16 deaths. From what I have learned, 7 of the 16 deaths involved someone with malaria, 2 from sepsis and 7 unknown. All of the deaths seem to have occurred on the African Continent, where good health care is harder to come by.

BY THE NUMBERS – PATIENTS ON OXBRYTA

236 children were in the first study outside of the U.S. with 8 deaths

88 patients were in the second study outside of the U.S. with 8 deaths

324 patients were in the two studies outside of the U.S. with a total of 16 deaths

250 (approximate) patients at Virginia Commonwealth University (VCU) with NO DEATHS

500 (approximate) patients around the State of Virginia including (VCU) with NO DEATHS

1,000's plus 1,000's of patients in the United States with NO DEATHS

NO DEATHS TOOK PLACE IN THE UNITED STATES.

More patients used Oxbryta in the State of Virginia with no deaths then overseas with 16 deaths

1,000's plus 1,000's of patients in the United States used Oxbryta with no safety issues.

Many of those patients are now living with a problem trying to keep their Hemoglobin (HGB) blood count up and stay out of a sickle cell crisis.

**ON BEHALF OF THE 1,000'S PLUS 1,000'S OF PATIENTS IN THE UNITED STATES
NEEDING TO USE OXBRYTA, I ASK YOU TO APPROVE A RETURN USE AND
DISTRIBUTION OXBRYTA ON A FULL REGULAR BASIS OR AT LEAST FOR
COMPASSIONATE USE**

INTERESTING FINANCIAL FOOTNOTE

When I was first offered Oxbryta the cost was just over \$2,500.00 per month. Pfizer took over the company. Later, I was told the price was over \$7,400.00. At the time the drug was taken off the market the price was over \$11,700.00. Stockholders are not going to be happy with that much income loss per month.

Please allow us to use Oxbryta again.

Thank you.