

# The Heart Of Gold Sickle Cell Foundation of NOVA

Serving as an advocate for adults and children with sickle cell disease 2024-2025 edition



## Thriving, Not Just Suviving

Living with a chronic illness like sickle cell disease presents unique challenges, but it doesn't preclude a fulfilling and healthy life. It requires a proactive approach, where you become your own best advocate, prioritizing your physical, mental, and emotional well-being. This article focuses on empowering you to take charge of your health journey and live your best life, despite the hurdles.



## VA. Legislation Supporting SCD

Change doesn't happen overnight. But in Virginia, legislative sessions proved that dedicated advocacy can lead to meaningful progress for those living with sickle cell disease. Several important bills have been signed into law, representing a significant step forward in improving access to care, resources, and support. This article provides a comprehensive overview of the newly passed legislation and its potential impact on the sickle cell community across the Commonwealth.



## Heart of Gold Scholarship Recipent

We are pleased to announce the recipient of the Heart of Gold Scholarship Award went to Alexis Montgomery who graduated from Mount Vernon High School with a 3.84 GPA. She attends Hampton University.

P.O. Box 23681 Alexandria, Va. 22304

703-370-3234 | info@heartogold.org

www.heartogold.org

# PRESIDENT'S MESSAGE



We are excited and energized to continue and expand our community advocacy, education, and support for Sickle Cell Warriors in 2025.Our primary focus areas this year include:

·Educate the community to know and document their Sickle Cell Trait status to support informed decision-making about childbearing and health;

·Educate the community of new protocols for blood donors to increase the number of donors;

·Educate the African-American and Afro-Latino communities on the importance of blood donations for patients with Sickle Cell Disease (SCD) and increase the donor pool among these groups;

·Educate SCD patients about cutting-edge treatments that can improve quality of life;

·Advocate, through dissemination of information, legislative changes that support SCD patients; and,

·Educate medical professionals and social workers throughout the region about care options for SCD patients.

Through our community partnerships and generous donors, we are able to support the Inova Adult Sickle Cell Center, Pediatric Specialist of Virginia, Melwood Camp Accomplish, and American Red Cross and Inova Blood Services blood drives.

One critical area for patients with SCD is the transitional period from pediatric care to adult care. We hope to continue to sponsor webinars on "self-advocacy" and develop programming, in conjunction with medical and social work professionals, to aid in this transitional phase.

As we enter our 14th year, we strive to continue the vision of our Founder Clarissa Pearson (1979-2021) to make a significant contribution to support and advocate for Sickle Cell Warriors. We will take on one battle at a time until we are victorious over SCD!

*Melanie Pearson Hurley*

# Our Mission

Improving the quality of life for individuals and communities affected by sickle cell disease (SCD) and sickle cell trait (SCT) through education, advocacy, community empowerment, and equitable access to knowledgeable and compassionate care. To effectively achieve our mission, The Heart of Gold Sickle Cell Foundation of Northern Virginia, Inc. actively advocates for improved quality of care, direct access to services for sickle cell patients and community education and awareness through outreach programs and targeted events.

The Heart of Gold Sickle Cell Foundation of NOVA

# Vein Finder Improves Care




Photo: Melanie Pearson Hurley, Heart of Gold, Dr. Sheinei Alan, Inova Adult Sickle Cell Center, and Valerie Bey Heart of Gold,

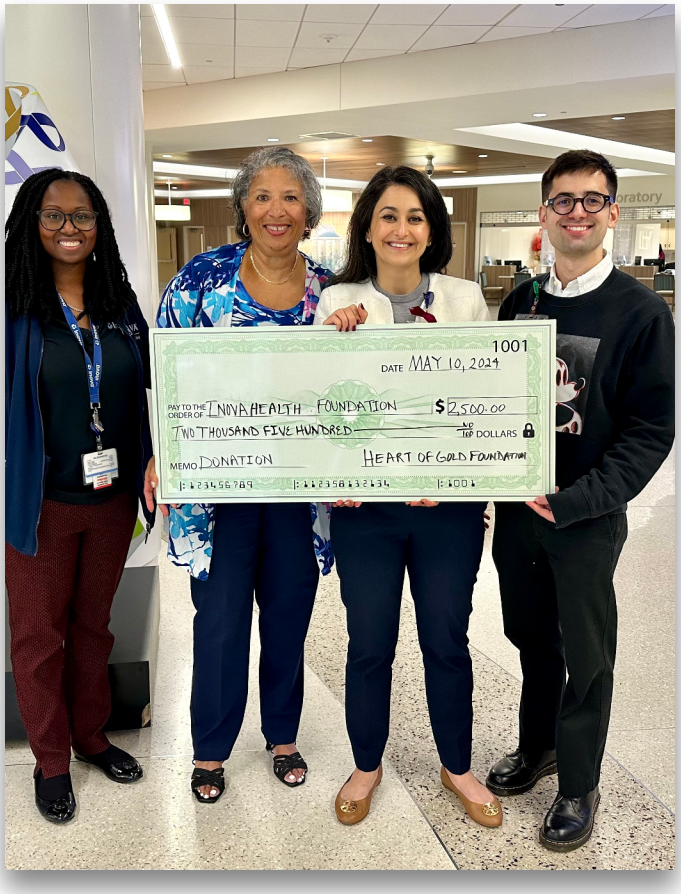



Photo: Donisha Holley, Inova Adult Sickle Cell Center , Melanie Pearson Hurley, Heart of Gold,, Dr. Alan and Dr. Mendez-Marti Inova

**New Vein Finder to Improve Care for Sickle Cell Patients at Inova**

The Heart of Gold Sickle Cell Foundation of Northern Virginia partnered with the Inova Adult Sickle Cell Clinic to donate $2,500 towards a new vein finder device. This generous contribution will significantly enhance the care of patients at the Inova Adult Sickle Cell Center.

This cutting-edge technology will revolutionize how physicians care for individuals with sickle cell disease (SCD). By making procedures like infusions, blood draws, and transfusions more efficient and comfortable, the vein finder will improve the overall patient experience.

For people with SCD, monthly blood draws are essential for monitoring responses to therapies. However, frequent blood draws can be challenging due to the potential for scarring and vein damage over time. This can lead to anxiety and discomfort, especially for those who have experienced difficulties with vein access in the past. The new vein finder will help alleviate these challenges by making it easier for healthcare professionals to locate and access veins quickly and efficiently.

"We are so happy to support better care for those battling sickle cell disease," said Heart of Gold President CEO Melanie Pearson Hurley. "Together, we are making a real difference in the lives of those in need!"

# World Sickle Cell & Juneteenth



## The Heart of Gold Celebrated World Sickle Cell Day and Juneteenth with Community Outreach Event.

What an incredible day of community and connection at the World Sickle Cell Day and Juneteenth Event at the Inova Center for Personalized Health!

The Heart of Gold Sickle Cell Foundation, alongside amazing community partners, proudly supported the Inova Adult Sickle Cell Center in hosting this unforgettable event.

We were moved by educational presentations, delicious food, dance, poetry, and a panel of inspiring sickle cell warriors of all ages who shared their powerful stories of overcoming challenges and celebrating victories in managing their disease.

This event was truly inspiring, and we are so grateful to have been part of it as sponsors.

Together, we are stronger and more empowered to make a difference! Let's continue to support and uplift each other in this journey.

Thanks to everyone who stopped by to meet us!



# SICKLE CELL TOWN MEETING

September marked Sickle Cell Awareness Month, and this past year, the Inova Adult Sickle Cell Center hosted a pivotal town meeting to unite advocates, county agencies, and the public to raise awareness about sickle cell disease (SCD). This event, organized in collaboration with The Heart of Gold Sickle Cell Foundation of Northern Virginia, was a resounding success that inspired and informed attendees.

The gathering featured a panel of courageous sickle cell warriors who shared their stories of struggle, triumph, and resilience. Their moving testimonies illuminated the challenges faced by individuals living with this life-threatening inherited blood disorder, which affects approximately 100,000 Americans-disproportionately impacting those of African or Latino descent.

Approximately 200 attendees engaged in presentations that highlighted the importance of understanding SCD and the sickle cell trait.

Notable speakers included Dr. Drew Campbell, Director of the Comprehensive Sickle Cell Program at Children's National Hospital, and Dr. Elizabeth Kreiger from VCU, provided insights into cutting-edge therapies and breakthrough research. Additionally, Marcus Allen, Program Director for Children and Youth with Special Health Care Needs at VDH, shared valuable information on public health initiatives.

The event took place at the Inova Conference Center on the campus of The Inova Schar Cancer Center in Fairfax, VA. Attendees enjoyed dinner, entertainment, and door prizes while learning about gene editing therapy and the critical need for blood donations from people of color to support those affected by SCD.





Photo: Dr. Drew Campbell, Children's Hospital

Sickle cell disease causes red blood cells to take on a "sickle" shape, leading to blockages in blood flow and oxygen delivery throughout the body. This can result in extreme pain, respiratory issues, organ failure, and even fatal strokes. Although advancements in newborn screening, immunizations, and treatments like hydroxyurea have improved survival rates, individuals with SCD continue to face acute pain crises and serious health complications.

When asked about the importance of a specialized Adult Sickle Cell Center, Dr. Sheinei Alan, Director of Clinical Research at the Adult Sickle Cell Center stated:

"By creating a medical home that caters specifically to the needs of adult sickle cell patients, we ensure continuous, coordinated care and support that improves health outcomes and reduces the frequency of hospitalizations. We are proud of this advancement and its impact on enhancing the quality of life for those living with sickle cell disease in our community."

Despite progress in care, a national shortage of trained physicians remains a challenge for effective treatment. Events like this town meeting are crucial for fostering community support and ensuring individuals living with sickle cell disease receive comprehensive care.

The Inova Sickle Cell Center is the only specialized clinic in Northern Virginia dedicated to treating patients with this chronic condition. The Inova  Adult Sickle Cell Center is located at 8081 Innovation Park Dr., 4th Fl., Skyline Clinic, Fairfax, VA 22031. If you have a sickle cell crisis, call 571-472-1390 to request a same-day urgent appointment.

# Sickle Cell Awareness Month 2024

## Sickle Cell Howard University Move-On

We were happy to participate in Howard University's 18th Annual Cure Sickle Cell Now Movement event, held on September 14, 2024. The annual event was held in front of Howard University Hospital at 2401 Georgia Ave., N.W. Washington,DC.

The Heart of Gold met with other sickle cell advocates, government agencies, and sickle cell warriors to hand out resource information, children's books, and gift bags. There was a 5K Fun Run/Walk , Yoga, plenty of music , raffle prizes and fun.






## Rocky Mount VA Sickle Cell Awareness Month Walk-a Thon

The Heart of Gold was happy to join the Blue Ridge Association for Sickle Cell Anemia in celebrating Sickle Cell Awareness Month. The chapter had an illuminating display paying tribute to the memory of fallen sickle cell warriors. They introduced community partners, and many from the community showed up to get educated about sickle cell disease and participate in a 5K walk.




BRASCA volunteers




Photo: Valerie Bey and Dr. Clarence Pearson

# Sickle Cell Proclmation 2024

## Proclamation Sickle Cell Awareness Month

Board member, Valerie Bey had the honor of speaking at the Fairfax County Board of Supervisors Proclamation, Ceremony designating September as Sickle Cell Awareness Month.

A heartfelt thank you to the Board for sponsoring this important proclamation and for their commitment to raising awareness about sickle cell disease.

Joining Valerie Bey were Heart of Gold Community Partners:

-Inova Adult Sickle Cell Center

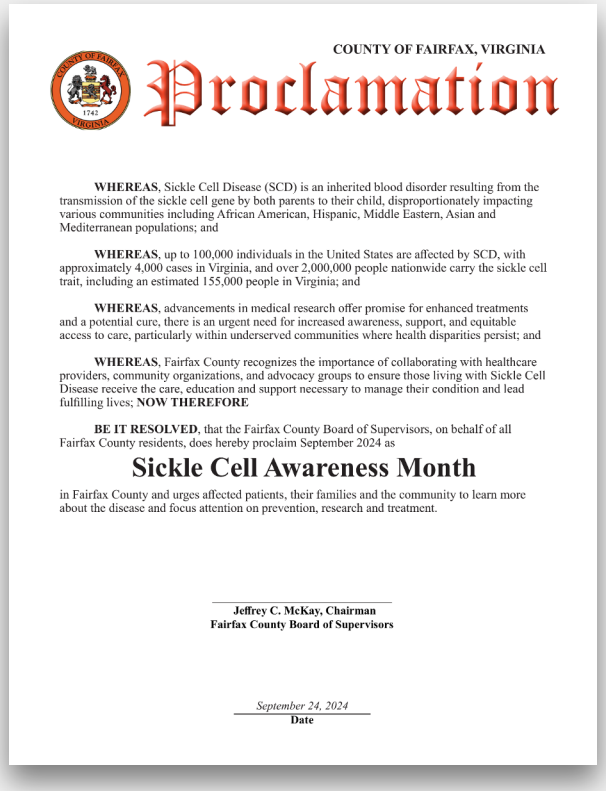
-Alpha Kappa Alpha Sorority Inc, Northern/Western VA Cluster

-Jack and Jill of America, NOVA Chapter

-Top Ladies of Distinction

-Melwood

Together, we are dedicated to supporting those affected by sickle cell disease and making a positive impact in our community.



COUNTY OF FAIRFAX, VIRGINIA

Proclamation

**WHEREAS**, Sickle Cell Disease (SCD) is an inherited blood disorder resulting from the transmission of the sickle cell gene by both parents to their child, disproportionately impacting various communities including African American, Hispanic, Middle Eastern, Asian and Mediterranean populations; and

**WHEREAS**, up to 100,000 individuals in the United States are affected by SCD, with approximately 4,000 cases in Virginia, and over 2,000,000 people nationwide carry the sickle cell trait, including an estimated 155,000 people in Virginia; and

**WHEREAS**, advancements in medical research offer promise for enhanced treatments and a potential cure, there is an urgent need for increased awareness, support, and equitable access to care, particularly within underserved communities where health disparities persist; and

**WHEREAS**, Fairfax County recognizes the importance of collaborating with healthcare providers, community organizations, and advocacy groups to ensure those living with Sickle Cell Disease receive the care, education and support necessary to manage their condition and lead fulfilling lives; **NOW THEREFORE**

**BE IT RESOLVED**, that the Fairfax County Board of Supervisors, on behalf of all Fairfax County residents, does hereby proclaim September 2024 as

**Sickle Cell Awareness Month**

in Fairfax County and urges affected patients, their families and the community to learn more about the disease and focus attention on prevention, research and treatment.

**Jeffrey C. McKay, Chairman**
**Fairfax County Board of Supervisors**

*September 24, 2024*
**Date**

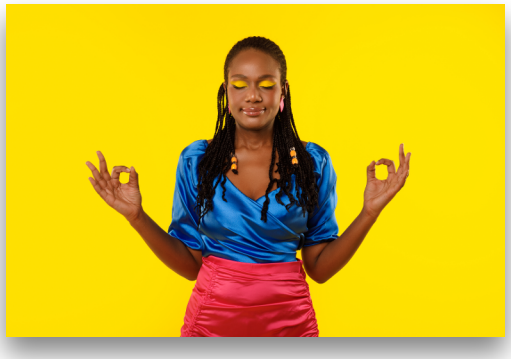




Heart of Gold Sickle Cell Foundation of NOVA, Community partners and the Fairfax County Board of Supervisors

# Thriving, Not Just Surviving

## Prioritizing Your Well-being with Chronic Illness



Living with a chronic illness like sickle cell disease presents unique challenges, but it doesn't preclude a fulfilling and healthy life. It requires a proactive approach, where you become your own best advocate, prioritizing your physical, mental, and emotional well-being. This article focuses on empowering you to take charge of your health journey and live your best life, despite the hurdles.

**Becoming Your Own Advocate: A Key to Well-being**



Navigating the healthcare system with a chronic illness can be complex. Being your own advocate means actively participating in your care, understanding your condition, and communicating effectively with your healthcare team. This involves:

- **Educating Yourself:**Learn as much as you can about your specific condition, including symptoms, treatments, potential complications, and current research. Reliable sources like the Sickle Cell Disease Association of America (SCDAA) and the National Institutes of Health (NIH) can be invaluable.
- **Asking Questions:**Don't hesitate to ask your doctor questions, even if they seem basic. Understanding your treatment plan and the rationale behind it is crucial for adherence and positive outcomes. Prepare a list of questions before your appointments to ensure you cover everything.
- **Keeping Records:**Maintain a detailed record of your symptoms, medications, test results, and doctor's notes. This information can be incredibly helpful for tracking your progress and identifying patterns.
- **Seeking Second Opinions:**If you're unsure about a diagnosis or treatment plan, don't hesitate to seek a second opinion from another specialist. It's your right to explore all available options.



**Prioritizing Your Health: Body, Mind, and Spirit**

A holistic approach to well-being is essential when living with a chronic illness. This means nurturing your body, mind, and spirit:

**Body:**

- **Regular Check-ups:**Adhere to your recommended schedule for annual check-ups and specialist visits. These appointments are crucial for monitoring your condition, managing symptoms, and preventing complications. Don't wait for a crisis to seek medical attention.
- **Medication Adherence:**Take your medications as prescribed by your doctor. If you experience side effects, discuss them with your physician; don't simply stop taking your medication without professional guidance.
- **Healthy Diet:**A balanced diet rich in fruits, vegetables, whole grains, and lean protein is essential for maintaining your overall health and managing sickle cell symptoms. Stay hydrated by drinking plenty of water. Consult with a registered dietitian for personalized dietary recommendations.
- **Regular Exercise:**Engage in moderate physical activity that you enjoy and that's appropriate for your condition. Consult with your doctor or a physical therapist to develop a safe and effective exercise plan. Even gentle activities like walking or stretching can be beneficial.
- **Pain Management:**Effective pain management is crucial for improving your quality of life. Work closely with your doctor to develop a comprehensive pain management plan that may include medication, physical therapy, and complementary therapies.

**Mind:**

- **Stress Management:**Chronic illness can be stressful. Find healthy ways to manage stress, such as meditation, deep breathing exercises, yoga, or spending time in nature.
- **Mental Health Support:**Don't hesitate to seek professional help if you're struggling with anxiety, depression, or other mental health concerns. Talking to a therapist or counselor can provide valuable support and coping strategies.
- **Mindfulness and Relaxation:**Practice mindfulness techniques to stay present and reduce stress. Engage in activities that bring you joy and relaxation, such as reading, listening to music, or pursuing hobbies.

**Spirit:**

- **Connecting with Others:**Maintain strong social connections with family and friends. Join a support group for people with sickle cell disease to connect with others who understand your experiences.
- **Finding Meaning and Purpose:**Explore activities that give your life meaning and purpose, such as volunteering, creative pursuits, or spiritual practices.
- **Self-Care:**Prioritize self-care activities that nurture your mind, body, and spirit. This could include taking a warm bath, getting a massage, or simply spending time alone to recharge.

Living with a chronic illness requires resilience and self-advocacy. By prioritizing your physical, mental, and spiritual well-being, you can thrive, not just survive, and live a full and meaningful life. Remember, you are not alone, and there are resources and support available to help you on your journey.

# Super Campers Always



A fun, supportive, and empowering environment for children and teens with Sickle Cell Anemia and their friends, siblings, and allies

Super Campers Always is a collaboration between Melwood and Children's National Hospital that creates a fun, inclusive environment. Campers with and without disabilities and chronic health conditions, as well as their siblings, friends, and allies, are welcome.

Super Campers Always is designed to reduce the social isolation often associated with sickle cell anemia and increase every camper's knowledge and understanding of it.

It provides opportunities for campers to become better self-advocates and self-managers of their condition.



The Heart of Gold Sickle Cell Foundation supports Super Camper Always by donating to support the cost of sickle cell campers needing financial assistance to attend camp.

Camp Accomplish is pleased to offer need-based scholarships. Anyone seeking a scholarship must indicate their interest on the initial camper application.

To ensure our financial aid resources go as far as possible, we also encourage families to seek other avenues for support. Below is a sample listing of support groups that may be contacted for financial assistance.

* Respite Care Services/Developmental Disability Administration

* County Departments of Social Services

* Developmental Disabilities Administration Low-Intensity Support Services (LISS) Program

* Health Services for Children with Special Needs (DC residents)



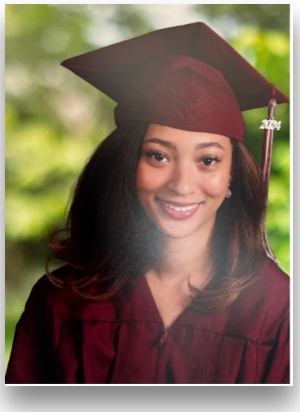
Financial Support for HSCSN Participants

This summer, Camp Accomplish is partnering with Health Services for Children with Special Needs, Inc. (HSCSN) to offer a unique benefit for attending summer camp. If you are an HSCSN Enrollee between ages 5-18, you can apply to attend the camp week of your choice and HSCSN will cover the costs!

visit **https://campaccomplish.org** for more information

# OUTREACH NEWS

## Scholarship Recipient



We are pleased to announce the recipient of the Heart of Gold Scholarship Award went to Alexis Montgomery who graduated from Mount Vernon High School with a 3.84 GPA.

She attends Hampton University, where she majors in Education. In high school, she served as a manager of the Volleyball and Basketball Teams and Class President in her Junior and Senior years. Alexis' community service includes mentoring underclass students at Mount Vernon High, New Student tour guide, and delivering mulch to her community.

Alexis' honors include the National Honor Society and the Presidential Award. Alexis has strong educational goals. Her caring and mature demeanor will serve the Child Development Program well. She looks forward to continuing her education at Hampton University. Alexis is a member of Alfred Street Baptist Church.

Dear Heart of Gold Foundation Donor,

Alexis said, "It is an honor to be selected for the Heart of Gold Foundation Legacy Scholarship for the 2024-2025 school year. With your assistance, I can work towards my educational and career goals without financial concern. I greatly appreciate your generous financial contribution to my higher education."

For information on The Heart of Gold scholarship visit the Alfred Street Baptist Church Foundation at alfredstreet.org



## Educational Webinar




The Heart of Gold Sickle Cell Foundation recently partnered with Pfizer to host an impactful webinar titled "Educational Support Webinar: Community Connection Tools for Self-Advocacy." The virtual event was led by Natasha Chambers, a Senior Sickle Cell Patient Affairs Liaison with Pfizer. drew a large online audience of sickle cell patients, caregivers, and advocates eager to learn more about self-advocacy and community resources.

Chambers provided valuable insights into the importance of self-advocacy for individuals with sickle cell disease. She emphasized the need for patients to actively participate in their healthcare, effectively communicate their needs to medical professionals, and access available resources.

The webinar also highlighted the critical role of community connections in fostering support, sharing knowledge, and promoting empowerment among those affected by sickle cell disease. Chambers shared practical examples and strategies for building strong support networks and leveraging community resources to improve overall well-being.

The webinar served as a powerful reminder of the importance of self-advocacy and community support in navigating the challenges of sickle cell disease.

The Heart of Gold Sickle Cell Foundation and Pfizer are committed to continuing their efforts to educate and empower individuals with sickle cell disease and their families. Through collaborative initiatives like this webinar, they aim to improve the quality of life for those affected by this condition and foster a stronger, more connected sickle cell community.

# OUTREACH NEWS

## SCD Education Inside Alexandria City Jail

**Heart of Gold Sickle Cell Foundation Takes Education Inside Alexandria City Jail**

To reach an often-overlooked population, the Heart of Gold Sickle Cell Foundation brought critical information about sickle cell trait and disease management directly to the inmates and staff of the Alexandria City Jail.

President and CEO, Melanie Pearson Hurley, led the presentation, emphasizing the importance of understanding the sickle cell trait, particularly for those who may have family members or are planning to have families. Sickle cell disease is an inherited blood disorder that can cause severe pain, organ damage, and other health complications.

"Many people are unaware that they carry the sickle cell trait," explained Melanie Pearson Hurley, “This is especially crucial for the incarcerated population, who may have limited access to healthcare and genetic testing. By educating them, we empower them to make informed decisions about their health and the health of their loved ones."

The presentation covered a range of topics, including:

***“Of all the forms of inequality, injustice in health care is the most shocking and inhumane.” - Martin Luther King Jr.***




Melanie Pearson Hurley, Heart of Gold and Alexandria City Sheriff Sean Casey,

- **What is sickle cell trait and sickle cell disease?**
- **How is sickle cell trait inherited?**
- **What are the potential health risks for those with sickle cell trait?**
- **How can individuals with sickle cell trait manage their health?**
- **Where to find resources and support for sickle cell trait and disease.**

Jail staff were also included in the presentation, providing them with a better understanding of the unique needs of inmates with sickle cell disease. This knowledge can help ensure that affected individuals receive appropriate medical care and support while incarcerated."We are grateful to the Sheriff Sean Casey for his partnership in this important initiative," said Ms. Hurley, "By working together, we can improve the lives of those affected by sickle cell disease and reduce health disparities in our community."

# BLOOD DRIVES : Why Diverse Donations Matter

Blood donation is a critical act of service that can save lives in moments of need. Each pint of blood can help save up to three lives, making it one of the most profound gifts you can offer to your community.

**The Importance of Blood Donations for Sickle Cell Patients**

Patients with sickle cell disease often require frequent blood transfusions throughout their lives. For these individuals, transfusions from donors of a similar ethnic background are vital because they are more likely to be a close genetic match. This reduces the risk of complications and improves treatment efficacy.

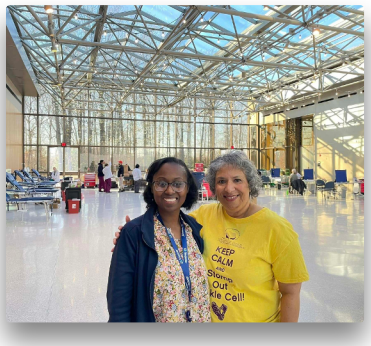


Photo: Donisha Holly from Inova Adult Sickle Cell Center and Melanie Pearson Hurley, CEO/President of Heart of Gold,

This past year The Heart of Gold Sickle Cell Foundation supported several blood drives for the American Red Cross and Inova Blood Services. We posted on social media and sent letters to our supporters which include Fraternity and Sorority organizations, churches, and community groups. Everyone rallied to support the cause. We will continue to support blood drives this year and work to raise awareness on the importance of donating blood and helping sickle cell patients manage their illness.

If you would be interested in hosting a blood drive or joining us in our efforts support this badly needed resource, please reach out via email or phone call so we can work together. at info@heartogold.org




Ernestina Attafuah, St. Johns Church and Melanie Pearson Hurley, f Heart of Gold,

## New FDA Blood Donation Requirements

The U.S. Food and Drug Administration (FDA) has updated its guidelines to ensure the safety and availability of blood donations while making the process more inclusive.

Even if you were deferred in the past, you may be able to donate now.

Visit https://www.redcrossblood.org/faq.html#eligibility for key updates on blood donations.

Together, we can make a difference. Your donation is not just blood; it's hope for a healthier tomorrow. Thank you for considering this life-affirming act of kindness.

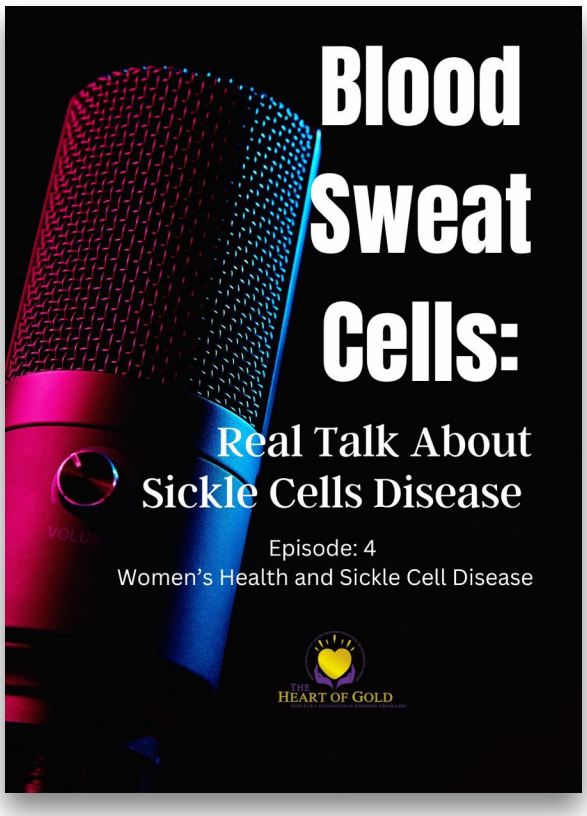
For more information on how you can become a blood donor or host a blood drive, visit Red Cross Blood Services at www.redcrossblood.org or Inova Blood Services at www.inovablood.org

# Blood, Sweat, Cells Podcast

**Tune In to "Blood, Sweat, and Cells: Real Talk About Sickle Cell Disease"**

Join us for "Blood, Sweat, and Cells," a podcast dedicated to providing in-depth, educational information about sickle cell disease. Each episode features interviews with patients, doctors, advocates, and researchers, who share their personal experiences and professional insights on living with and treating this chronic condition. Our goal is to educate and advocate for the sickle cell disease community, empowering individuals to live their best possible lives.

Subscribe to "Blood, Sweat, and Cells" on all major podcast platforms, including Spotify and Apple Podcasts, so you don't miss an episode.






We're constantly unraveling compelling stories and delivering comprehensive information about sickle cell disease.

Have a topic you'd like us to explore? We'd love to hear from you! Email us at BSCpodcast@icloud.com with your suggestions. Your input is invalable as we work to empower and educate our community. Join us on this important journey of knowledge, empathy, and growth for those affected by sickle cell disease.

*"You may not control the challenges you face, but you control how you face them. Embrace your strength, celebrate your resilience, and live your best life, one moment at a time."*

**Anonymous**

# VA. Legislation Supporting SCD

## Key legislation that was passed in 2024 benefiting sickle cell patients living in Virginia.

**HB 255 - Adult Wellness Screening for Sickle Cell Disease**

**Summary:** This bill mandates that every adult in the Commonwealth may be offered screening tests for sickle cell disease or the sickle cell trait as part of their annual health examination. It also requires healthcare professionals to provide education and appropriate counseling regarding the results of any such test.

**Impact:** Increases early detection and awareness of sickle cell traits, which can lead to early management and prevention of complications.

**HB 257 - Sickle Cell Anemia; Prescription of Opioids for Pain Management**

**Summary:** This legislation exempts prescribers from certain requirements of the Prescription Monitoring Program when prescribing opioids for pain management related to sickle cell anemia.

**Impact:** Facilitates easier access to necessary pain management medications for individuals suffering from sickle cell disease, improving their quality of life.



**HB 820 - Sickle Cell Disease; Annual Review of Medication and Treatment**

**Summary:** Directs the Department of Medical Assistance Services to conduct an annual review of all medications and forms of treatment for sickle cell disease covered under the state plan for medical assistance services. Requires an annual report of findings and recommendations to be submitted to key legislative health committees.

**Impact:** Ensures ongoing evaluation and improvement of the treatments available to sickle cell patients, promoting better health outcomes.

For more details, visit **Virginia's Legislative Information System (LIS)** This is a website that provides access to bills, resolutions, amendments, and other legislative documents.You can search by keyword, bill number, or subject.

# Community Corner




**Delivering warmth and care to those in need!**

Melanie Pearson Hurley (President of The Heart of Gold Sickle Cell Foundation) and Sheila Howell (Top Ladies of Distinction Alexandria City Chapter) generously donated blankets and snacks to the Inova Sickle Cell Center. Pictured  L-R Donisha Holley, Dr. Alan, Emilia Williams, Beth Cesaro, Inova Adult Sickle Cell Center,  Sheila Howell , Top Ladies and Melanie Pearson Hurley, Heart of Gold

# Heritage Festival

Heart of Gold had an amazing time at the 'Feel the Heritage Festival' at the Drew Community Center! This incredible, free event by Arlington County Parks & Recreation honored Black History Month with flair. We were thrilled to share tote bags, educational materials, and books to spread awareness about SCD.

The turnout was fantastic, with live music, dance, local vendors, fun children's activities, tasty treats, and an unbeatable community vibe.




Senator Tim Kaine and Melanie Pearson Hurley, Heart of Gold



Page Gordon Sr, and Page Gordon Jr.

# Warrior Spotlight

Incredible news!

Join us in celebrating the amazing accomplishment of our very own Sickle Cell Warrior, Page Gordon!

Page's incredible resilience and determination have led him to George Mason University and the Honors College this fall!

As a University Scholar, Page has been awarded a full-tuition scholarship for four years!This is a huge achievement, and we couldn't be more proud of him!

Let's all shower Page with congratulations and encouragement as he embarks on this exciting new chapter!

# Beacon of Hope: Cards Bring Joy to Warriors



Edna Williams,
Board Member, Heart of Gold Sickle Cell Foundation

In the realm of chronic illness, a simple act of kindness can illuminate the darkest of days. At The Heart of Gold Sickle Cell Foundation, we've witnessed this firsthand through the heartwarming work of our dedicated board member, Edna Williams.




Month after month, Edna sends "Thinking of You" cards to individuals and families affected by sickle cell disease, offering a tangible reminder that they are not alone in their journey

Sickle cell disease presents daily challenges, and the weight of living with a chronic illness can often feel isolating. Edna's thoughtful gesture provides a powerful counter-narrative, fostering connection and lifting spirits. "*The cards create a sense of community and let our warriors know we are thinking of them,*" shares Edna Williams. *"It's remarkable to see the impact of such a simple act of compassion."*

*"Whenever we connect with the community at health fairs and events, individuals eagerly share stories of how much these cards mean to them. It brightens their day to know someone cares,"* Edna adds. *"For many, receiving the cards is a source of joy and encouragement."*

Edna's dedication exemplifies the spirit of  The Heart of Gold's mission to advocate for and support those impacted by sickle cell disease. Her commitment to spreading hope, one card at a time, serves as an inspiration to us all. Thank you, Edna, for being a beacon of light for our sickle-cell warriors.

# Power of Support Groups for Chronic Illness



Living with a chronic illness can be incredibly challenging.Beyond the physical symptoms, there's the emotional toll of navigating a complex healthcare system, managing unpredictable flare-ups, and dealing with the isolation that can come from feeling misunderstood.But there is hope and strength to be found in shared experience.Support groups offer a safe space for individuals with chronic illnesses to connect, share their stories, and find solace in knowing they're not alone.

The Benefits of Support Groups:

Support groups provide a unique form of support that goes beyond what family and friends can offer.Here are some of the key benefits:

Reduced Isolation:Chronic illnesses can be incredibly isolating.Support groups bring together people who understand what you're going through, fostering a sense of community and belonging.

Emotional Validation:Sharing your experiences with others who understand can be incredibly validating. It can help you process your emotions and feel less alone in your struggles.

Practical Advice and Tips:Support groups are a treasure trove of practical advice and tips for managing your illness.You can learn from others' experiences and find new ways to cope with your symptoms.

Increased Empowerment:Connecting with others who are living well with their chronic illness can be incredibly empowering. It can give you hope and inspire you to take control of your health.

## The Heart of Gold Sickle Cell Foundation: Supporting the Sickle Cell Community

At The Heart of Gold Sickle Cell Foundation, we understand the importance of support groups for individuals living with sickle cell disease. That's why we're committed to supporting a local sickle cell support group by providing meals for their monthly meetings. We believe that breaking bread together is a powerful way to build community and foster connection.

The Inova Adult Sickle Cell Center has a monthly support group that meets the third Tuesday of the month from 6 pm - 7 pm  located at  8081 Innovative Park Drive on the 6th floor.

We're proud to support this group and the incredible work they do in empowering individuals with sickle cell disease. We believe that everyone deserves access to the support and resources they need to live their best lives, regardless of their health challenges. To learn more, contact Donisha Holley at 571-472-1957 or

email at Donisha.Holley@inova.org

# PARTNERS AND RESOURCES

## INOVA ADULT SICKLE CELL CLINIC

571.472.1390 -8081 - Innovation Park Drive 4th floor Skyline Clinic Fairfax, Va. 22031
https://www.inova.org/our-services/inova-schar-cancer-institute/specialty-programs/hematology/sickle-cell-program

## CENTER FOR DISEASE CONTROL AND PREVENTION

https://www.cdc.gov/ncbddd/sicklecell/materials/infographic-5-facts.html

## AMERICAN ACADEMY OF FAMILY PHYSICIANS

Tips for preventing a sickle cell crisis - http://www.aafp.org/home.html

## AMERICAN SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC.

.http://www.sicklecelldisease.org

## VIRGINIA DEPARTMENT OF HEALTH

https://www.vdh.virginia.gov/sickle-cell-programs/services/

## CLINICAL TRIALS

http://clinicaltrials.gov/

## SICKLE CELL CHAPTERS OF VIRGINIA, INC.

sicklecell.virginia@yahoo.com

## INOVA BLOOD SERVICES

https://www.inovablood.org/donate-blood/multicultural-blood-donors-and-sickle-cell/

## NMDP

(Formally known as the National Marrow Donor Program and Be the Match)
https://bethematch.org

## NATIONAL HEART, LUNG, and BLOOD INSTITUTE

https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease

## AMERICAN RED CROSS

https://www.redcross.org

# PARTNERS AND RESOURCES

THE TOP LADIES OF DISTINCTION ALEXANDRIA CITY CHAPTER

THE TOP LADIES OF DISTINCTION HAYMARKET GAINESVILLE CHAPTER

ALPHA KAPPA ALPHA SORORITY, INC. ZETA CHI OMEGA CHAPTER

MELWOOD CAMP ACCOMPLISH
https://campaccomplish.org

PEDIATRICS SPECIALIST OF VIRGINIA
https://psvcare.org

IVY FOUNDATION OF NORTHERN VA.

CHILDRENS NATIONAL MEDICAL CENTER
https://www.childrensnational.org


## Acknowlegments:

Special Thanks to Printing Productions, Inc. Sterling, VA.



The Heart of Gold Sickle Cell Foundation of Northern Virginia, Inc.
P.O. Box 23681 Alexandria, Va. 22304
703-370-3234 | info@heartogold.org

www.heartogold.org



Funded by a grant from the State of Virginia