



The Heart of Gold Sickle Cell Foundation of Northern Virginia, Inc.

Serving as an advocate for adults and children with sickle cell disease 2022-2023

2022-2023

ABOUT US

The Heart of Gold Sickle Cell Foundation of Northern Virginia, INC. was incorporated as a 501(c) (3) organization in 2011. This non-profit organization was the brainchild of our former founder, President and CEO, Clarissa Pearson. Clarissa was a sickle cell survivor who understood the limited resources and challenges for people living with sickle cell disease and their families that cared for them.



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PRESIDENT'S MESSAGE

As we have progressed beyond the COVID pandemic, It has been an exciting year for the Heart of Gold Sickle Cell Foundation of Northern Virginia as we continue our goals to educate, advocate and support the community of Sickle Cell Warriors.

We've continued our partnership with the American Red Cross and through our blood drives have collected nearly 300 units of blood. Our outreach program continues to encourage African American churches and organizations to donate blood so that Sickle Cell patients receive blood that is most compatible. The initiative by the American Red Cross to "blue tag" blood from African American and Afro-Latino donors and prioritize these blood products for Sickle Cell patients has been very successful.

Recently, we have partnered with the inova Adult Sickle Cell Center. This comprehensive Center is the first supporting the Adult Sickle Cell population in Northern Virginia. The Center will not only support the medical needs of the Adult Sickle Cell patients but provides social services and transportation support.

Finally, due to the continued financial support of our donors, the first Heart of Gold Clarissa Pearson Scholarship was awarded in 2022 through the Alfred Street Baptist Church Foundation.

In 2023, we will continue to sponsor blood drives, participate in local health fairs and community events, and advocate and support Sickle Cell Warriors.

Interim President

Melanie Pearson Hurley

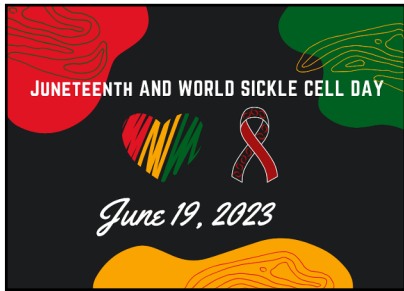


Our Mission

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 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.

World Sickle Cell Day

Juneteenth and World Sickle Cell Day: Celebrating and Addressing Well Known Disparities on one Day



On June 19th, 1865, the last enslaved people learned they were free almost 2 ½ years after the

Emancipation Proclamation formally ended slavery in the U.S. Now, recognize as a day of celebration, Juneteenth is also a day to reflect on the long road and struggles toward social justice both past and present.

That's why June 19th is even more relevant to be internationally recognized as World Sickle Cell Day. Sickle cell disease disproportionately affects people of color. When we educate our community about SCD, we help those living with the disease, who like enslaved people of the past, suffered great pain in silence due to racism and ignorance. Education about SCD status, signs, symptoms, treatment, helps confront health inequity in our community, while celebrating the triumphs of sickle cell warriors living with the disease.

This June 19th 2023, The Heart of Sickle Cell Foundation will partner with INOVA's Adult Sickle Cell Center to celebrate Juneteenth World Sickle Cell Day with a special podcast. This day we will honor the past and present in the long road to social justice health equity. Tune in and listen to 'Defining Sickle Cell' as we introduce the new Adult Sickle Cell Center Clinic at INOVA Hospital. The podcast will post on our website and be also be available on Apple, Spotify and Google.

2023 Scholarships

The Heart of Gold Foundation of Northern Virginia and the Pearson Family are continuing two scholarship opportunities for students in the Metropolitan Washington D.C. Area. Working in conjunction with the Alfred Street Baptist Church Foundation, the Heart of Gold Foundation established a legacy scholarship in memory of our Founder and Chief Executive Officer Clarissa E. Pearson.

This scholarship is available for students pursuing a degree in Mass Communications or Education. Also, the Pearson Family established the Edith C. Pearson R.N. legacy scholarship for students pursuing a degree in Nursing.

The scholarship criteria is as follows:

1. Graduate from a high school in the Washington, DC metropolitan area (Washington, D.C.; Alexandria, VA; Arlington County, VA; Fairfax County, VA; Falls Church, VA; Prince William County, VA and Prince Georges County, MD; Montgomery County, MD; or Charles County, MD) by June 30, of each year, or be a member of Alfred Street Baptist Church.
2. US citizenship.
3. Membership at the Alfred Street Baptist Church is not required.
4. Admitted to and committed to attend a four-year institution.
5. Demonstrated commitment to community service.
6. Maintain a solid academic record with a 2.75 or higher grade point average and SAT/ACT scores (if available).
7. Exhibit financial need.

Further information to apply for the scholarships or to make a donation to support these scholarships is available at alfredstreet.org and click on the ASBC Foundation tab.

INOVA[®] ADULT SICKLE CELL CENTER

The Heart of Gold Sickle Cell Foundation of Northern Virginia is proud to partner with INOVA Adult Sickle Cell Center. The center provides services for patients 18 years and older with sickle cell disease. In addition to comprehensive outpatient care for sickle cell anemia services include:

- * Same-day appointments for urgent needs such as a patient experiencing a sickle cell crisis
- * Ongoing pain management
- * Medications to reduce the harmful effects of red blood cell sickling
- * Social services support
- *SCI Infusion Clinic
- *IV fluid and pain medication for patients experiencing a sickle cell pain crisis

To receive services, you first need have to schedule an appointment with an INOVA Sickle Cell Center Physician. Call 571-472-1390 for routine and urgent appointments.

Infusion clinic appointments are tightly managed. If you are more than 30 minutes late to your infusion appointment, you will need to be rescheduled.

The INVOA Sickle Cell Center has a dedicated team working together to provide the care you need..

Sheinei Alan, MD, PhD

Najeebah Bade, MD

William Ershler, MD

Chad Zik, MD

Laura Faeder, NP

Margaret Holbrook, PA

Rania Fusisi, RN

Hallie Stollof, LMSW

If You Have a Sickle Cell Crisis

Call 571.472.1390 and request a same-day urgent appointment. If you are sick or have a fever, let them know, so triage can be arranged.

Please give 24 hours' notice if you wish to cancel or reschedule an appointment.

If your appointment is on a Monday, please call on the Friday before.

To cancel or reschedule your appointment, call 571.472.1390, select option 2, then select option 1.

If you are more than 30 minutes late to your appointment, you might need to be rescheduled.

LOCATION: 8081 Innovation Park Drive

4th floor Skyline Clinic

Fairfax, Va. 22031



SICKLE CELL VIRTUAL TOWN MEETING



In September, 2022, INOVA Adult Sickle Cell Clinic hosted a virtual town meeting. This meeting brought together a number of key stakeholders in the fight against sickle cell disease, including The Heart of Gold Sickle Cell Foundation of Northern Virginia and other advocacy groups, as well as specialists, physicians, and hematologists who are passionate about helping patients with sickle cell and their families.

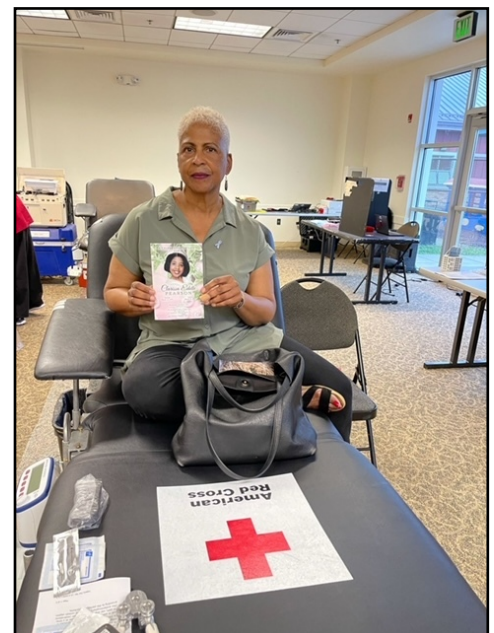
The purpose of this town meeting was to provide a platform for open and honest dialogue about the challenges faced by those living with sickle cell, as well as the latest research and developments in the field. We are proud to say that the discussion was both informative and productive, with participants sharing their ideas, experiences, and insights into the disease and its impact on individuals and communities.

One of the key themes that emerged from the meeting was the importance of collaboration and partnership in the fight against sickle cell. It was clear that there is a need for greater awareness and understanding of the disease, as well as increased access to care and support for those living with it. By working together, we can make a real difference in the lives of those affected by sickle cell.

POWER OF BLOOD DRIVES

The Heart of Gold Sickle Cell Foundation partnered with The American Red Cross to host several community blood drives in 2022 as part of an initiative to grow the number of Black blood donors to help more patients with sickle cell disease. In 2023 we will continue our partnership with the Red Cross and work with INOVA Blood Services to help sickle cell patients, the majority of whom are Black and/or of African descent, whom rely on Black blood donors to provide lifesaving transfusions as part of their treatment. Patients who require regular blood transfusions, like those with sickle cell disease, may develop an immune response against blood from donors that is not closely matched to their own.

In 2022, during the Martin Luther King Celebration in Reston, The NAACP also partnered with the Red Cross to help increase awareness among blood donors of color. A public service announcement was produced by Heart of Gold Board member Valerie Bey for Cable Channel 16. Visit the following link on YouTube to see the PSA - https://youtu.be/LV8Z_1aJOX8.



SICKLE CELL AWARENESS MONTH

September 2022, Howard University sponsored 'Cure Sickle Cell Now' Event' for Sickle Cell Awareness Month. It was the 50th anniversary of HU Center for Sickle Cell Disease. It was a great turnout of advocates, patients and supporters in front of Howard University Hospital. The Heart of Gold Sickle Cell Foundation was thrilled to participate. We circulated brochures, booklets, and bags with our logo to help educate the community about SCD and our presence in Northern Virginia. Medical Consultant Dr, Clarence Pearson participated in the 5k in memory of our founder and his daughter Clarissa Pearson. We saw many old friends and met a few new ones.

Miss Virginia Outstanding Teen , Top Ladies of Distinction , Cure Sickle Cell NHLBI, Be The Match and many other advocates here today supporting sickle cell warriors and their families



LR -Fairfax County Executive, Bryan Hill, Interim President Heart of Gold, Melanie Hurley, Braddock District Supervisor, James Walkinshaw, Heart of Gold board member, Valerie Bey, Fairfax County BOS Chair, Jeffery McKay, Franconia District Supervisor, Rodney Lusk, and Providence District Supervisor, Dalia Palchik

Much appreciation to the Fairfax County Board of Supervisors and Fairfax County County Executive, Bryan Hill for their continued support of Sickle Cell Awareness Month. A Proclamation in 2022 was made for recognition of the Heart of Gold Sickle Cell Foundation for our community work.



Heart of Gold Medical Consultant, Dr. Clarence Pearson



BeTheMatch Team Washington D.C.



Ms. Ayana Johnson, the Sickle Cell Disease Association National Teen Ambassador and currently Miss Virginia's Outstanding Teen 2022 and Traci Mondoro, Ph.D leads NHLBI lead collaborative to accelerate genetic therapies to cure sickle cell disease.



SICKLE CELL WARRIORS

Miss Virginia Teen

Ayana Johnson was crowned Miss Virginia's Outstanding Teen in 2022. Ayana, who is from Suffolk, Va., made it her mission during her reign

to have a social impact initiative entitled, Ayana's R.E.A.D. - Readiness to Empower, Advocate and Diminish Hopelessness in Chronic Illness.



Diagnosed with sickle cell disease at birth, Ayana learned to manage her illness and become a voice to those who feel like they cannot advocate for themselves. Ayana is available for public speaking engagements, so look for her in upcoming podcast and public appearances.

Zoe Davis

Yorktown High School graduate Zoe Davis shines not only as an honors student, but also as an inspiring advocate for others with sickle cell anemia. Despite missing school for weeks at a time due to the disease, Zoe served as a cheerleader, a debate team member, and a leader for the Black Student Union club. As a sophomore, Zoe and two friends successfully petitioned their school to add an African American history class. In addition, Zoe represented Virginia Girls State and became Senior Teen President of the Northern Virginia Chapter of Jack and Jill of America -- an organization that supports African American children.

STATEWIDE SICKLE CELL CHAPTERS

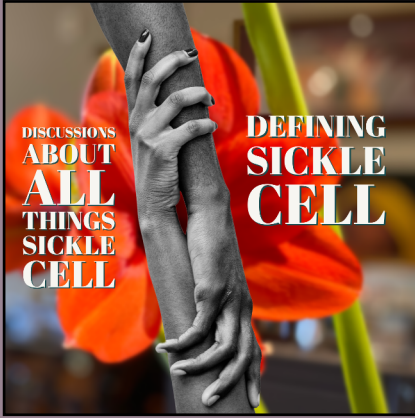
Sickle Cell Chapters of Virginia is a non-profit 501 (c) (3) statewide service organization representing nine (9) local chapters and their clients throughout the State of Virginia. Chapters are located in Danville, Fredericksburg, Hampton, Lynchburg, Norfolk, Northern Virginia, Richmond, Rocky Mount and South Boston.

The mission statement is to educate the public, implement service programs, encourage support for research and empower persons who live with Sickle Cell Disease and advocate on their behalf.

Heart of Gold Board member, Edna Williams is the President of all the Statewide Chapters in Virginia. If you have relatives, friends or family members living with sickle cell disease in another area of Virginia, have them reach out to another Chapter for information and or assistance. To connect with another chapter visit <https://sicklecell-virginia.org/>



PODCASTS



The Heart of Gold Sickle Cell Foundation of Northern Virginia has started a new Podcast series titled:

Defining Sickle Cell

Plans are to interview different guest on topic of interest to sickle cell patients and their families.

Our very first podcast was with sickle cell warrior Nicole Long.

Nicole is a married woman who discussed how she took ownership of her lifestyle to manage her sickle cell.

If you have an idea for a show, give us a call or send us an email. We would love to hear from you.

All podcast can be found on our webiste as well as all main podcast hosting sites.



Super Camp Always



We are proud to sponsor sickle cell warriors from Virginia for the Super Campers Always camp this Summer 2023. The Heart of Gold Sickle Cell Foundation donated \$500 to help with campers fees.

The camp was developed by Brainy Camps in conjunction with the Hematology and Oncology Departments of Children's National.

Brainy Camps Association is a consortium of residential camps for children, teenagers, and young adults with chronic health conditions.

In addition to fun, the goal of Super Campers Always is to reduce the social isolation that is often associated with this condition and increase every camper's knowledge and understanding of sickle cell anemia.

The camp provides opportunities for the children and teens to work with professional staff and become better self-advocates and self-managers of their condition. Parents can feel comfortable that their children are under the care of trained and experienced doctors, nurses and healthcare professionals who are experts in the field.

Dr. Andrew Campbell, hematologist and head of the sickle cell anemia program at Children's National, leads the camp's medical team. Additional medical staff, including doctors, nurses, social workers, physical therapists, and psychologists, are on-site 24 hours a day and counselors are trained to deal with issues related to sickle cell disease.

Campers participate in a myriad of activities. Support groups and educational programs promote knowledge, skill development and social connections and campers gain a better understanding of their condition, strengths and self-worth.

Please contact Brainy Camps at brainycamps@childrensnational.org for more information.



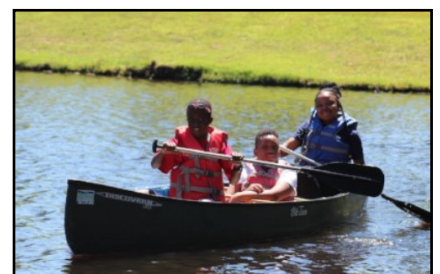
Send A Sickle Cell Warrior to Camp

If you know of deserving children living in Northern Virginia with sickle cell disease who are interested in attending Brainy Camp next summer, and are in need of help with tuition, give us a call or send us an email.

phone:

703-370-3234

email: edna.williams@heartogold.org



Project Linus Blankets For Sickle Cell Patients



Melanie Pearson Hurley, Heart of Gold Acting President holding donated blankets

Project Linus was established in 1995 to provide comfort to children who are seriously ill, traumatized, or in need with new, handmade blankets.

The organizations mission is to provide love, a sense of security, warmth and comfort to children who are seriously ill, traumatized, or otherwise in need through the gifts of new handmade blankets and Afghans lovingly created by volunteer “blanketeers”. Additionally, Project Linus strives to provide a rewarding and fun service opportunity for interested individuals and groups in the local communities for the benefit of children.

Ms. Annabelle Hammer of the Fairfax County Chapter reached out to the Heart of Gold Foundation with a generous offer to provide blankets for pediatric patients suffering from Sickle Cell Disease.

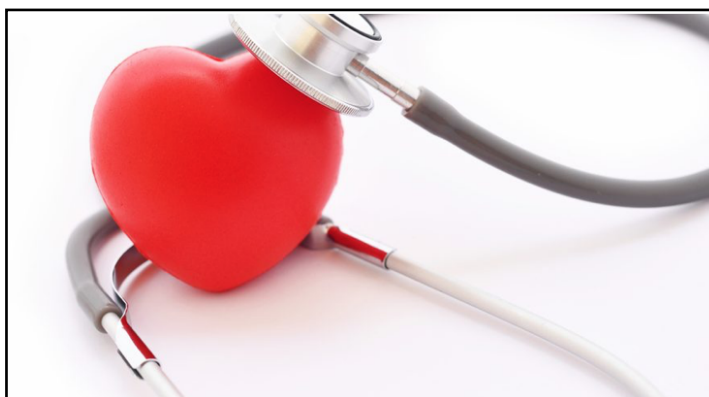
Because there are not any Project Linus chapters in the District of Columbia, the Heart of Gold was pleased to deliver 20 blankets to our community partners at Howard University Center for Sickle Cell Disease.

NEW THERAPIES

We are excited to share with you a treatment that soon should be available for sickle cell patients. Researchers have been studying a new therapy called LentiGlobin - a gene-based treatment where patients' own stem cells are harvested and corrected with a gene that makes non-sickle hemoglobin. Treatment options currently available such as hydroxyurea, crizanlizumab, and voxelotor aim to reduce painful crises but do not alleviate the disease.

Excitingly, this new treatment has shown promise towards a cure for sickle cell anemia. This research gives hope to millions of people around the world who suffer from this painful and debilitating disease. For more information please talk to your physician and copy the link below in your web browser:

<https://sicklecellanemianews.com/news/bluebird-responds-fda-sickle-cell-gene-therapy-production/visit>



Disclaimer

This site is strictly a news and information website about the disease. It does not provide medical advice, diagnosis or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of

Sickle Cell app for Android Users

If you own an Android, there is a new app said to help sickle cell patients manage their care.

Managing sickle cell disease better with physical and mental symptom diary, medicine alerts, disease education, patient community, and much more.

Salveo Therapeutics and the news magazine African Sickle Cell News and World Report— known as Sickle Cell News are collaborating to promote a new free application (app) that seeks to empower sickle cell disease (SCD) patients to take more control of their health and well being.

This is particularly needed, Sickle Cell News said in a press release, in regions such as sub-Saharan Africa where the blood disorder is endemic.

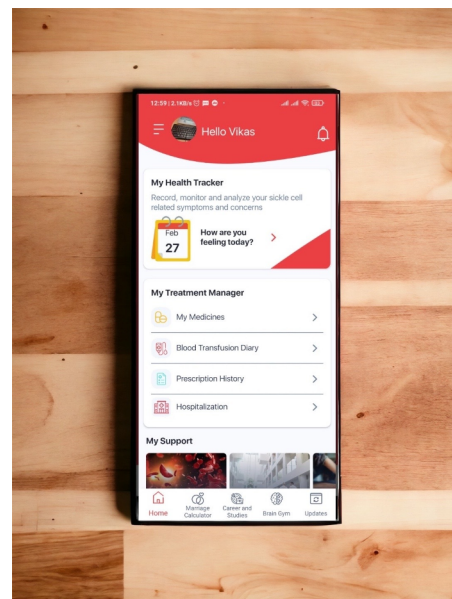
Called the My Sickle Care App, the Android-based tool enables patients to track and manage their disease to help improve their life quality. For example, patients can log in episodes blood transfusions, sleep patterns, and daily water intake.

The app also covers broader issues, such as career options, mental health, and nutrition.

According to the partners, patients and their family members may use the app to keep track of medications and receive alerts when it's time to take them. In addition, they can use the application to remind them of upcoming medical appointments.

My Sickle Care App features a community section to help SCD patients globally connect and share views and experiences with each other. It also has frequently asked questions and resources sections, as well as educational videos aimed at heightening disease awareness while guiding patients and their parents and caregivers.

With the app, those with the blood disorder can instantly share personal data with clinicians to help their care team make informed treatment decisions.



RESOURCES

INOVA ADULT SICKLE CELL CLINIC

571.472.1390 - 8081 - Innovation Park Drive 4th floor Skyline Clinic Fairfax, Va. 22031

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. (SCDAA)

<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 HOSPITAL

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

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

[RedCrossBlood.org/ourblood](https://www.redcrossblood.org/ourblood)

COVID 19 VACCINES AND BOOSTERS

<https://www.vaccines.gov>



The Heart of Gold Sickle Cell Foundation of Northern Virginia

P.O.Box 23681
Alexandria, VA
22304
703-370-3234

www.heartogold.org

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