

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

Serving as an advocate for adults and children with SCD



Who Are We?

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 Clarissa Pearson, a sickle cell survivor who understood the limited resources for people with Sickle Cell Disease.

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Thrill of Hope



President's Message

While others were worried about 'Building a Wall,' the Sickle Cell Community was finally able to break one down with the discovery of the new wonder drug, Endari (K-Gultimene), the increased success with Stem Cell treatments and the passing of S.2465, "Sickle Cell Disease and other Heritable Blood Disorders Research, Surveillance, Prevention and Treatment Act of 2018."

Not only that, the Sickle Cell Community honored Florence Neil Cooper, who was a timeless leader in an effort to raise the awareness of Sickle Cell Disease. Because of her efforts, Virginia now screens all newborns for Sickle Cell Anemia.

Nevertheless, we still had to fight some battles, such as a pain medication shortage due to Hurricane Maria that devastated Puerto Rico, and the drastic changes that were made by pharmacies and Doctors with the ongoing debate of the Opioid Crisis. At times, our patience and our pain tolerance were tested but we soldiered on and stayed strong becoming the Sickle Cell Warriors that we are today.

As we roll into 2019, it is our continued goal to help individuals with Sickle Disease and their families live their best life. We believe that when we all work together, nothing can stop us from breaking the Sickle Cell Cycle.

2019 is the year of the Warrior and the sharing of their stories. It is our wish, to share with our Sickle Cell Warriors how they can say goodbye to the pain and finally regain who they are, a "Warrior" that is finally able to win the war on Sickle Cell Disease.

Clarissa Pearson

President and CEO

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



SICKLE CELL DISEASE
OCCURS IN ONE OUT OF
EVERY 500 AFRICAN AMERICAN
BIRTHS AND 1 OUT OF
EVERY 30,000 HISPANIC AMERICAN
BIRTHS.
SICKLE CELL TRAIT OCCURS
IN APPROXIMATELY
1 IN 12 AFRICAN AMERICANS.



In the Community

Heart of Gold Sickle Cell Foundation in the Community

During 2018, Heart of Gold was very active in the Metropolitan Area community .

In June, we were invited to participate in the Annual Health and Wellness Fair at the U.S. Department of Housing and Urban Development Headquarters in Washington,

In partnership with the Red Cross in 2021, The Heart of Gold Sickle Cell Foundation of Northern Virginia, Inc. held 12 blood drives collecting an average of 27 units of blood per drive. Our goal in 2022 is to do even better !

Continuing our partnership with the Red Cross we will position ourselves in neighborhoods with more Black/African American populations and where we have more contacts in the community for a wider outreach of people to donate blood.

African American blood donors have a unique ability to help patients with sickle cell disease and support the health of their community. The Red Cross critically needs Black and African American blood donors, as well as those who haven't given before, to give blood. www.redblood.org please use HEARTOFGOLD as the spender code. Thank you.



In Loving Memory



In Loving Memory of Edith Chinn Pearson, R.N.

Since the creation of the Heart of Gold Foundation, one of our staunch supporters was Edith Chinn Pearson, R.N., grandmother of CEO Clarissa Pearson. Mrs. Pearson spent many years advocating for those suffering from Sickle Cell Disease (SCD). As a nursing student in the 1940s at the segregated St. Philip School of Nursing in Richmond, Virginia, she became aware of the suffering and lack of concern for those with SCD.

Grandma Edith was often a caregiver during Clarissa's childhood--giving medications, starting IV fluids at home for hydration, and maintaining a loving presence during hospitalizations. She often said

"I wished there was a cure for this damn disease." On March 25, 2018, Edith transitioned at the age of 93. The Heart of Gold Foundation will continue to strive educate, advocate and to find a cure for SCD.

Sickle Cell Warrior Page Jr.



Heart of Gold is proud to continue support of Brainy Camps Association (BCA) of Children's National Medical Center. In honor and memory of Mrs. Edith Chinn Pearson R.N., over \$1,400 in contributions were received by Heart of Gold. These funds provided two scholarships for children with SCD to attend camp in 2018.

Brainy Camps provides an opportunity for children with SCD and other diseases to attend summer camp. Their mission is to help youth with chronic health conditions live well and reach their potential. They advance these goals through our weeklong condition-specific residential summer camps, as well as through year-round support and leadership programs. The programs provide children with chronic illnesses the opportunities to meet peers, mentors and counselors with the same conditions and discover that they are not alone in the world.

The primary goal of BCA camps and programs is to help youth with chronic health conditions live well and reach their potential. The camp programs provide chronically ill children with an opportunity to meet peers, mentors and counselors with the same conditions and discover they are not alone in the world. Having experienced the loss of peers at much too young an age, they live with a keen awareness of their own vulnerability. The hurdles they face are many, including continuing medical care, over-protection by worried parents, stigmatization by peers and society, social isolation, and fear due to the unpredictability of their conditions. In the safe environment of camp, where the condition is shared and respect is the norm, individual boundaries are challenged and children begin to develop a sense of personal strength and self-worth. For many families, attendance at our residential camps is the first time their children have the opportunity to be away from home for more than the length of a school day. Medical staff with expertise in the conditions served manage each camp, making parents feel safe to leave their children in our charge. Staff training and experience in caring for chronically ill children and our 2:1 camper-staff ratio further helps to allay parental concerns.

Opioids and Sickle Cell Patients

George Harris Carter, Administrator for the nonprofit Statewide Sickle Cell Chapters of Virginia, pushed to ensure people who suffer from sickle cell disease can get sufficient dosage of opioids needed to control excruciating pain.

On June 15, 2018, Gov. Ralph S. Northam approved a regulation that allows physicians to provide those with SCD, higher levels of opioids for treatment of pain without being forced to the rigid scrutiny that is normally required when prescribing opioids.

The governor's action endorses the state Board of Medicine's 12-6 vote in February, 2018, to add sickle cell disease to the short list of exemptions from tough regulations governing the prescribing of opioids.

Medical Advisors

Heart of Gold is fortunate to have two medical advisors committed to supporting our mission and goals. Dr. Clarence E. Pearson is Board Certified Internal Medicine and Cardiology physician. A graduate of the Medical College of Virginia (now Virginia Commonwealth University Medical School), he served 20 years in the U.S. Army and most recently works for the Veterans Administration. Dr. Pearson, who has the Sickle Cell Trait, has extensive expertise in pain management. We are honored that he also serves on our Board of Directors.

Michael Q. Smith, MD, F.A.C.O.G is Board Certified Obstetrics/Gynecology Physician. Dr. Smith is a graduate of the University of North Carolina–Chapel Hill Medical School. Dr. Smith has participated in numerous local programs promoting teen sexual education and well- being. Dr. Smith, has the Sickle Cell Trait. A resident of Northern Virginia, Dr. Smith currently practices at the Rappahannock Women’s Health Center in Fredericksburg, Virginia. His empathy for those with SCD and his willingness to support the Heart of Gold are truly appreciated.

Blood Donations People of Color

Those with Sickle Cell Disease need frequent blood donations, sometimes as often as every few weeks to survive. The most compatible blood transfusion for a critically ill patient with SCD is most likely to come from someone with the same ethnic, racial and genetic background as the patient.

While high rates of Sickle Cell Anemia is prevalent in black communities, statistics show *people of color currently donate less than one percent of the country’s blood supply.*

Be a hero in your community, make a pledge to donate blood and save the life of someone with Sickle Cell Disease.

If you or someone you know has Sickle Cell Disease and live in the Northern Virginia area please reach out to the Heart of Gold Foundation so we can keep you informed about programs and services near where you live.



Virginia Medicaid Expansion

Effective January 1, 2019, Medicaid eligibility has expanded in the State of Virginia! This coverage is now available to Virginia residents ages 19-64 not already in or eligible for Medicare. Income requirements must be met which vary by household size.

Childless adults are now eligible with an income at or below \$1,397 monthly or \$16,754 per year. Parents (family of 3) are eligible with an income at or below \$2,391 monthly or \$28,677 per year. Persons with disabilities are eligible with an income at or below \$1,397 monthly or \$16,754 per year.

To determine eligibility, go to www.coverva.org. This website also has a screening tool and Frequently Asked Questions.

WHAT SERVICES ARE COVERED?

The new coverage will include preventive care, doctor visit, prescriptions, hospital stays, mental health care and more. New coverage will also include care coordination for individuals with complex medical and behavioral conditions.

HOW TO APPLY?

There are several ways for individuals to apply for new adult coverage:

- Call the Cover Virginia Call Center at 1-855-242-8282 (TDD 1-888-221-1590)
- Complete an online application at Common Help: www.commonhelp.virginia.gov
- Complete an online application at The Health Insurance Marketplace: www.healthcare.gov
- Mail or drop off a paper application to your local Department of Social Services
- Call the Virginia Department of Social Services Enterprise Call Center at 1-855-635-4370 (if you also want to apply for other benefits)

The rules have changed.

Find out if you may be eligible for
new quality, low cost health
coverage for adults.



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