

HEART OF GOLD SICKLE CELL FOUNDATION OF NORTHERN VIRGINIA, INC.

Serving as an advocate for adults and children with SCD

PRESIDENT'S MESSAGE

In this new year, I feel we can now live with a new sense of hope which is ironic since our theme for this year was "making sense of your new normal". I decided on this theme, when I wrote on our page how I was slowly learning how to manage as the girl with two disease; sickle cell & pulmonary hypertension. With the success of stem cell transplants, what a wonderful feeling it must be to have "your new normal" consists of now being able to live a life with a whole new outlook, being able to continue through life doing things you never imagined doing. It's exciting to sit back and watch all of the new strides being made to finally help end the suffering of sickle cell. It's almost as if someone turned on the lights, woke up, and said enough is enough. Now, the FDA has approved at least 4 new life saving medications and of course the overwhelming success of stem cell transplants have continued to cure sickle cell. The CDC also acknowledged that patients with SCD were not a consideration when they were creating the Opioid Guidelines. This year has proven to me that time really does bring a change and because fundraising can be difficult at times. We have implemented a new type of fundraising called "Shop for a Cause" which allows our supporters to donate all year round without even thinking about it, just by signing up. For instance, our shop for a cause stores include:

When you shop & smile, amazon.com donates 1% to Smile.amazon.com/theheartofgoldsicklecellfoundation.org. Link your Amazon Account - [Go to smile.amazon.com](https://www.amazon.com/Smile) - Search for The Heart of Gold Sickle Cell Foundation of Northern Virginia, Inc.

Kroger - Link your Kroger Card [Visit www.kroger.com](http://www.kroger.com)

Look for (DU777) The Heart of Gold Sickle Cell Foundation of Northern Virginia, Inc. - You shop & Kroger donates a 0.5% percentage. You keep all fuel points and donations from our supporters allow us to send a child with sickle cell to camp and provide our clients with gas or food cards. Regardless of the amount, we always appreciate the sacrifice. What better sacrifice than to donate blood. I receive blood transfusions every 4 weeks and with the pulmonary hypertension it can be a lot to bear. Please donate blood, you never know whose life you may save.

Clarissa Pearson, President

The Heart of Gold Foundation of Northern Virginia, INC.

SICKLE CELL WARRIOR GALLERY

The Heart of Gold Foundation had the pleasure of sponsoring a photo session for one of its sickle cell families. Our hope is to provide more families the opportunity to share their personal stories with the public on how they cope as a family when one member has SCD. This is the Folks

family. Tre, has lived most of her life with sickle cell disease. Thanks to bone marrow transplant, she is now sickle cell free. Her brother D.J. donated his stem cells. Tre told us "He was a baby when we got tested, but when he got older and can sorta understand what was going on his first words were "yes yaya i want to help you feel better."

**1 in 365
African
Americans
are born with
sickle cell**

In 2020, we hope to sponsor more photo sessions for our sickle cell clients.



Brainy Camps Associations

Heart of Gold is proud to continue support of Brainy Camps Association (BCA) of Children's National Medical Center. In 2019 we provided two scholarships for children with sickle cell disease to attend camp. The primary goal of BCA camps 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, their condition is shared and respect. Individual boundaries are challenged and children begin to develop a sense of personal strength and self-worth. For many families, attendance at BAC 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. Staff training and experience in caring for chronically ill children and the 2:1 camper-staff ratio further helps to allay parental concerns.

COMMUNITY ACTIVITIES

During 2019, The Heart of Gold Sickle Cell Foundation of Northern VA., was very active in the Metropolitan Area. During Sickle Cell Awareness Month, we participated in the Annual "Stomp Out Sickle Cell" Walk at Howard University Hospital. This annual event includes free testing to determine sickle cell status, children's activities, and a 5k walk. We distributed educational material on opioids, care for pregnant women with SCD and resource material for parents and students on navigating the school system when living with SCD.

On September 12th, 2019, Fairfax County Government proclaimed September as Sickle Cell Awareness Month in Fairfax County, Supervisor Cathy Hudgins from the Hunter Mill District, presented the motion and with Chairman of the Board of Supervisor,, Sharon Bulova, presented a proclamation to the Heart of Gold Sickle Cell Foundation of Northern Virginia, Inc. for our outstanding work in the community.

In attendance were Board Members - Melanie Pearson Hurley, Valerie Bey also Dr. Elizabeth Yang from Pediatric Specialist of Virginia attended. Board Member, Valerie Bey gave a speech encouraging people to know their sickle cell status before having children and to register to become a bone marrow donor.

In December we attended the Annual "Thrill of Hope" Holiday Party sponsored by the Hope Association and INOVA Pediatric Specialist. For the past seven years, Heart of Gold has been a participant and supporter of this event for children with blood disorders.

Children attending the party received toys this year through a partnership with the Alexandria City Chapter of Top Ladies of Distinction. This group of remarkable women made sure little ones with SCD were provided with gifts during the party.

The Heart of Gold Sickle Cell Foundation hopes to continue its partnership with the Ladies of Distinction in helping patients and their families. In 2020, they also provided hospital care kits for young children, teens and adults who have frequent hospital stays due to SCD.

Leapcure is a patient advocacy group that informs patients about ongoing clinical trials to advance research on sickle cell disease. We were fortunate to partner with this group and post information on social media and on our website. We partnered with Pediatric Specialist of Virginia and BeTheMatch to produce a video on sickle cell

awareness and the benefits of bone marrow transplants. Our Media Specialist and Board Member, Valerie Bey produced a video about a young girl who gave her bone marrow to her little sister so she could have a bone marrow transplant. Dr. Elizabeth Yang, Director of the Sickle Cell Program for Pediatrics Specialist of Virginia and Beth Carrier, from BeTheMatch were also participates and contributed to the video. The video also explains the benefits of hydroxyurea and the process and life saving benefits of being a bone marrow donor.

The video can be seen on YouTube at the following address:

<https://www.youtube.com/watch?v=QtOt5hq8A8E>

The Heart of Gold Sickle Cell Foundation of Northern Virginia is a 501(c)(3) non-profit. All donations, both financial and in-kind are tax deductible. Donations can be mailed in care of :
Heart of Gold Sickle Cell Foundation of Northern Virginia

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Website:<http://heartogold.org/>

Like us on Facebook:<https://m.facebook.com/hearogold11/>



Heart of Gold Board Member, Melanie Pearson Hurley receiving hospital kits from Top Ladies of Distinction Alexandria City Chapter



L to R - Supervisor Kathy Hudgins, Hunter Mil District Supervisor, Valerie Bey, Heart of Gold Board Member, Board of Supervisor's Chairman, Sharon Bulova, Dr. Elixabeth Yang, Pediatric Specialist of Virginia and Melanie Pearson Hurley, Heart of Gold Board Member



Thrill of Hope Holiday Party

PULMONARY HYPERTENSION

Patients with sickle cell disease sometimes develop other illness. One such disease is pulmonary hypertension. Our CEO and President was diagnosed with this rare condition last year. To help educate the public and patients at risk, one of our medical advisors, Dr. Clarence Pearson, did an interview to explain the diagnoses and current treatment.

Dr. Clarence E. Pearson is Board Certified in Internal Medicine and Cardiology. A graduate of the Medical College of Virginia (now Virginia Commonwealth Medical School), he served 20 years in the U.S. Army and most recently works for the Veterans Administration. He also serves on the Heart of Gold Sickle Cell Foundation Board of Directors.

What is pulmonary hypertension?

Pulmonary hypertension is when you have high blood pressure, but it is limited to your lungs. (This is just like the high blood pressure you have when they take your BP at the doctors' office, only it is only high in your lungs) in adult sickle cell patients, this is not a rare condition, and occurs in about 1/10 adults with sickle cell disease.

Is this something that commonly happens to patients with Sickle Cell?

In adults, there are many causes of pulmonary hypertension such as; repeated blood clots to your lungs, chronic obstructive lung disease, and heart valve or muscle problems on the left side of the heart! Right heart failure refers to one of the complications of pulmonary hypertension. When the pressure in the lungs is too high, the heart muscle from the right sided heart chamber is not strong enough to pump blood effectively and efficiently. (the same thing happens with the left heart chamber when the blood pressure in your arms measures too high) When the heart or any other organ in your body cannot keep up with the work requirements the organ is supposed to do. Then it "fails." (Hence the terms heart failure, kidney failure, lung failure , etc)

What are the symptoms of Pulmonary hypertension?

The symptoms of pulmonary hypertension are most evident when there is right heart failure. The symptoms include; fatigue, shortness of breath, chest pain, swelling of the legs and fullness around the stomach to name a few.

Is Pulmonary Hypertension hard to diagnose?

It is not hard to diagnose. The diagnosis can be made with an Ultrasound of your heart (echocardiogram) sometimes, you may also need a cardiac/heart catheterization.

Can Pulmonary Hypertension/right heart failure be reversed?

I wouldn't say it can be reversed in most cases. With treatment, it can improve and/or stabilize, but I wouldn't think in terms of being reversed. The treatment revolves around doing your best to adhere to your regular sickle cell routine; regular check ups, packed RBC

transfusions if needed, hydroxyurea, and other sickle cell measures and medication. There ARE specific medication for sickle cell patients with pulmonary hypertension. The most important thing to know is YOU NEED TO SEE A PULMONARY HYPERTENSIONS SPECIALIST that works with sickle cell patients.

VA 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.

HOW TO APPLY?

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

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

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)



SUPPORT

We want to thank our community partners; Ivy Foundation of Northern Virginia, Top Ladies of Distinction Alexandria City Chapter, Pediatric Specialist of Virginia, for their continued support. 2020 will present new challenges, however with your help, we will be there to support families and patients living with sickle cell disease in the Northern Virginia area. In the coming months here are a few of our goals.

Support more blood drives and develop educational material to increased participation from communities of color.

Provide churches and places of worship with ideas on educating those of child bearing age on the importance of knowing their sickle cell status.

Spread the word for all people, especially people of color, to register as stem cell donors.

Develop educational material on the simple process involved if selected as a stem cell match for someone with sickle cell disease.

Provide financial support to at least two children who want to attend Brainy Camps during the Summer.

Continue to post the Statewide Newsletter on our website and social media page on new information and treatments for sickle cell disease.

Inform clients of clinical trials on sickle cell disease.



Brainy Camp



Heart of Gold Board Members with Howard University President, Dr. Frederick at Sickle Cell 5k at Howard University hospital



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