



The Heart Of Gold Sickle Cell Foundation of NOVA

Serving as an advocate for adults and children with sickle cell disease 2023-2024 edition



Are you a valued employee battling sickle cell disease or any other chronic illness? Learn some techniques to prioritize and advocate for your health while at work.

If you have sickle cell disease, there are specific accommodations you can request to create a more supportive work environment.



Introducing the Heart of Gold Sickle Cell Foundation's groundbreaking initiative of 2023: the captivating podcast, "Blood, Sweat and Cells: Real Talk About SCD." This one-of-a-kind series delves into the intricacies of sickle cell disease, offering profound educational insights



Find out about The Sickle Cell Town Meeting, presented by the INOVA Schar Cancer Institute Adult Sickle Cell Center, in collaboration with The Heart of Gold was a resounding success that left attendees inspired and informed. The event brought together a panel of courageous sickle cell warriors who shared their personal stories of struggle, triumph, and resilience. Their moving testimonies shed light on the challenges faced by those living with sickle cell disease.

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www.heartogold.org

PRESIDENT'S MESSAGE



The Heart of Gold Sickle Cell Foundation of Northern Virginia has had an exciting 2023! We have continued our blood drive partnerships with the American Red Cross and have supported INOVA Blood Services drives to help meet the need of our Sickle Cell Warriors.

We are so excited with our new series of podcasts “Blood, Sweat and Cells” which provides medical information, first person accounts of living with Sickle Cell Disease (SCD) and insights from the families of our SCD warriors. This program is produced by our own Board Member Valerie Bey and is available on our webpage.

In September 2023, we co-sponsored the first in-person Sickle Cell Town Hall Meeting with the INOVA Adult Sickle Cell Program. Medical experts and a panel of Sickle Cell Warriors contributed to a very successful event. Also, in September, we participated in the annual Walk for Sickle Cell at Howard University—a worthwhile event that educates and advocates for Sickle Cell Warriors and Families.

Our Community Partnerships are key to our success in educating and advocating. We are grateful to the continued support from the Ivy Foundation of Northern Virginia, Alpha Kappa Alpha Sorority, Inc. Zeta Chi Omega Chapter, Top Ladies of Distinction Alexandria City Chapter, and the Top Ladies of Distinction Haymarket Gainesville Chapter.

In 2024, we hope to encourage more African American and Afro-Latino persons to donate blood to aid our Warriors. We will work with the medical professionals to provide information on the cutting-edge medications and treatments that one day may cure SCD. Lastly, we will continue to encourage persons to “Know Their Sickle Cell Status”

When our Founder Clarissa Pearson established the Heart of Gold in 2011, she could not have imaged the worldwide impact the Heart of Gold would have to improve the lives of SCD warriors. The Board of Directors proudly carries forth to make her vision a reality!

President

Melanie Pearson Hurley

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.

The Heart of Gold Sickle Cell Foundation of NOVA

AKA CLUSTER SERVICE PROJECT



The Alpha Kappa Alpha Sorority, Inc. (AKA), Mid-Atlantic Region Northern Western Cluster Meeting was held on November 18, 2023, in Reston, Virginia and the Heart of Gold Sickle Cell Foundation was selected as the recipient of the Cluster Service Project.

The purpose of the Service Project was to collect monetary donations from participating chapters to support sickle cell treatment, advocacy, and services in Northern Virginia through the Heart of Gold.

During the meeting, a Heart of Gold informational video was shown featuring the mother of a child with SCD discussing the struggles and pain of her child.

Informational materials about the Foundation and Founder Clarissa Pearson, who was a member of AKA, and the importance of knowing your Sickle Cell status were distributed to over 700 participants.

With the generous donations received, the Foundation will be able to increase our scholarships to Camp Accomplish (a week-long camp for children with SCD), support the INOVA Hospital Adult Sickle Cell Clinic, provide information to the community on the importance of knowing their sickle cell status, and sponsor a workshop and provide computers for SCD youth transitioning to college.

Empowering Lives, Transforming Futures Understanding Sickle Cell and Supporting Hope

The Heart of Gold Sickle Cell Foundation of Northern Virginia, Inc. was founded in 2011 by Soror Clarissa E. Pearson (Alpha Pi '01). Though Clarissa suffered from Sickle Cell Disease, it did not diminish her ambition. She established the foundation to improve the quality of life for individuals and communities affected by Sickle Cell Disease and Sickle Cell Trait through education, advocacy, community empowerment, and equitable access to knowledgeable and compassionate care. Since its inception, the Heart of Gold Foundation established a partnership with the American Red Cross to encourage African-Americans to donate blood. Through this partnership, over 300 units of blood were collected in 2022. Other community partners include the Ivy Foundation of Northern Virginia, Zeta Chi Omega Chapter, Top Ladies of Distinction Alexandria City Chapter, and the INOVA Hospital Adult Sickle Cell Center.

Clarissa became an Ivy Beyond the Wall in March 2021 after a valiant battle against Sickle Cell Disease. She was a proud Alpha Kappa Alpha Sorority Inc. Legacy—survived by her mother, Soror Gaynelle Pearson and aunt Soror Melanie Pearson Hurley. She was predeceased by her aunt Soror Joyce Hancock. She is also survived by her father, Dr. Clarence E. Pearson, daughter, Chelsea Pearson-Maldonado, aunts, uncles, and cousins.

AMERICAN RED CROSS SICKLE CELL BLOOD DONOR PROGRAM

It is estimated that over 90,000 Americans have Sickle Cell Disease. Ninety percent of all Sickle Cell Disease in the United States occurs in people of African descent. Sickle Cell Disease is an inherited blood disorder that affect the red blood cells that carry vital oxygen throughout the body. Most patients manage their disease effectively through blood transfusions and medications.

If you are African American or Afro-Latino, you are in a special position to help. Because of the need for repeated blood transfusions throughout a patient's lifetime, it is important that donated blood is as closely matched as possible to the recipient. In most cases, a close donor recipient is found among persons of the same ethnicity.

The American Red Cross designates blood donations from African Americans and Afro-Latino persons with a "blue tag" so that the donation is prioritized for persons with Sickle Cell Disease.



SICKLE CELL TOWN MEETING

The Sickle Cell Town Meeting, presented by the INOVA Schar Cancer Institute Adult Sickle Cell Center, in collaboration with The Heart of Gold was a resounding success that left attendees inspired and informed. The event brought together a panel of courageous sickle cell warriors who shared their personal stories of struggle, triumph, and resilience. Their moving testimonies shed light on the challenges faced by those living with sickle cell disease.

Alongside these remarkable individuals, community advocates offered valuable resources to support and empower the sickle cell community. Medical professionals provided updates on cutting-edge therapies and breakthrough research, offering hope for a brighter future in the treatment of this condition. Dr. Wally Smith and Dr. Andrew Campbell, renowned experts in the field, shared their expertise and insights, leaving attendees enlightened.

The event took on an even greater significance as Fairfax County Chairman McKay took to the stage to present a proclamation declaring it Sickle Cell Awareness Month in Fairfax County. This official recognition underscored the importance of raising awareness about sickle cell disease and fostering a more supportive and understanding community.



Chairman Jeffery McKay



Dr. Wally Smith



Melanie Pearson Hurley, President/CEO
The Heart of Gold Sickle Cell Foundation of NOVA

Adding to the already touching atmosphere, Bennie Herron captivated the audience with an inspirational poem, amplifying the message of hope, unity, and determination.

The Heart of Gold Sickle Cell Foundation of NOVA was proud to help plan and participate in this incredible event. Dr. Sheinei Alan's dedication and enthusiasm were evident throughout, as she worked tirelessly to ensure its success.

Looking ahead, we encourage everyone to mark their calendars and join us next year for this exceptional gathering. Let's continue to keep the information flowing and take proactive steps towards understanding our sickle cell trait status. Together, we can make a difference in the lives of those affected by sickle cell disease and create a more inclusive and supportive community for all.

DR. BEAR'S CLOSET



Top Ladies of Distinction, Inc. Alexandria City Chapter Member Sheila Howell-Flowers donating holiday blankets to Heart of Gold CEO/President, Member Melanie Hurley

The Top Ladies of Distinction Alexandria City Chapter and Haymarket Gainesville Chapter with community partner The Heart of Gold, donated holiday blankets for Sickle Cell Patients at Children's National Medical Center in December 2023. Over 70 blankets were donated for the Sickle Cell Unit through the "Dr. Bear" donation program.



Dr. Bear donation team at Children's National Medical Center

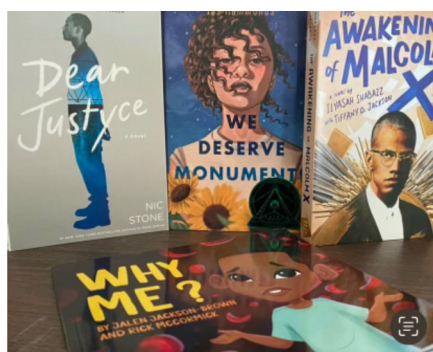


Heart of Gold CEO/President, Melanie Hurley receiving holiday blanket donation from Top Ladies of Distinction, Inc. Haymarket Gainesville Member, Tika Trotter-Mason

Dr. Bear's Closet Wish List

Children's National Hospital accepts donations of brand-new toys, books, games, clothing, gift cards, and more for Dr. Bear's Closet throughout the year. For information email: volunteerservices@childrensnational.org or call (202) 476-2062.

MLK DAY OF SERVICE



On Martin Luther King Jr. Day January 13, 2024, The Heart of Gold participated in an unforgettable celebration packed with pure fun and knowledge. The event was hosted by the Alexandria NAACP, in collaboration with Alexandria West Rotary Club, and Alpha Kappa Alpha Sorority, Inc. Zeta Chi Omega. Nestled within the vibrant walls of the Charles Houston Recreation Center in Alexandria, this event was a true testament to the power of community and collaboration. Together, we brought together various organizations and talented African American authors to create a day that would leave a lasting impact on all who attended. One of our key contributions was the generous giveaway of children's books focused on sickle cell disease. These weren't just ordinary books; they were carefully crafted to empower children and their families facing this condition. In addition, they aimed to raise awareness and educate those who may not be familiar with sickle cell disease. The atmosphere was electric with excitement as children flocked to the book nook, eagerly exploring the vibrant range of titles on offer. With each turn of the page, imaginations soared and knowledge took flight. Our goal was simple yet profound: to enlighten young minds while fostering compassion and understanding.

The collaboration between community organizations and the exceptional African American authors created an environment that radiated warmth, diversity, and inclusivity. It was a beautiful manifestation of Dr. Martin Luther King Jr.'s spirit, as his legacy of love, equality, and service permeated every corner of the event. This extraordinary celebration not only honored the memory of Dr. King but also embodied his principles of unity and progress. It served as a gentle reminder that each of us has the power to make a difference by dedicating our time, energy, and resources to uplift others and champion important causes.



Alexandria NAACP
in partnership with
Alexandria West Rotary Club,
Alpha Kappa Alpha Sorority, Incorporated®
Zeta Chi Omega Chapter
celebrate

Martin Luther King, Jr. Day Book Nook Dedication and Book Giveaway



1

Read books by
African American
authors to children

2

Donate children's
books by African
American authors

3

Meet African
American authors



Youth of all
ages are
welcome!

Saturday, January 13, 2024

1:00 p.m. - 3:00 p.m.

Charles Houston Recreation Center

901 Wythe St.

Alexandria, VA 22314

For more information: kulbreth@gmail.com

"Books are the keys to wisdom and knowledge. They open minds, hearts, and souls, and illuminate the path towards a better future."

- Martin Luther King Jr.

SICKLE CELL WARRIOR SPOTLIGHT

Kadijah Montgomery

In this newsletter, we are thrilled to shine a spotlight on a remarkable individual who embodies dedication, passion, and a commitment to excellence.

Meet Kadijah Mansaray, a 17-year-old high school senior, whose remarkable achievements and volunteer work have left a lasting impact on both her school community and beyond.

As an academic scholar, Kadijah consistently excels in her studies, earning a spot on the honor roll each year. She takes great pride in her International Baccalaureate (IB) courses, particularly her IB language and literature HL course, where her writing skills have flourished and ignited her passion for reading.

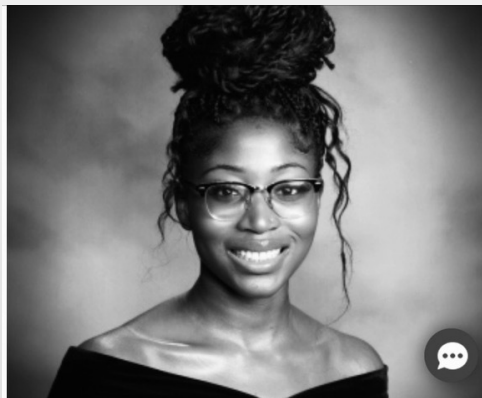
Kadijah's leadership abilities are evident as she serves as the Vice President of her high school's DECA Business club, where she actively contributes to shaping the future of the club. Additionally, she is a valued member of her school's chapter of the National Honors Society, showcasing her commitment to academic excellence and community engagement.

Beyond academics, Kadijah embraces a well-rounded lifestyle by actively participating in sports and employment. For nearly two years, she has dedicated her time to working with Wegmans, gaining valuable professional experience. In a testament to her determination, Kadijah has recently ventured into Winter Track, demonstrating exceptional progress and setting her sights on Spring Track.

Driven by a desire for personal growth, Kadijah embarked on a fitness journey six months ago. The results have been astounding – witnessing noticeable changes in her body, core strength, and overall muscle development. This commitment to self-improvement reflects her tenacity and resilience in all areas of life.

Despite her busy schedule, Kadijah finds joy in spending quality time with her younger brothers. Family holds an immeasurable value in her life, and her close bond with her siblings has shaped her into a compassionate and supportive individual. Kadijah's little brother has been her constant companion growing up, teaching her the importance of unwavering support during challenging times. Moreover, the recent addition of a baby brother has gifted her valuable lessons in patience, compassion, and love.

Kadijah draws immense inspiration from her hardworking mother, who single handedly raised her and her brother while ensuring they had financial stability, food, and shelter. She takes great pride in her mother's progress and looks forward to witnessing continued success in her occupation. Her impact will continue to reverberate and inspire others along the way.



What inspired you to become involved with The Heart of Gold?

My first interest in volunteering happened when I visited Sierra Leone, West Africa. While in America, I rarely encounter fellow sickle cell patients, leading me to overlook the severity of the condition. However, my perspective shifted when I witnessed numerous sickle cell children in Sierra Leone suffering due to a lack of medication, health education, and overall healthcare. Upon returning, I extensively researched various organizations and ultimately chose the Heart Of Gold Sickle Cell Foundation. What stood out to me was that the organization was founded by Clarissa Pearson, who, like myself, was born with sickle cell disease. She sadly passed away in 2021 and I wanted to also help with the organization's goal of continuing her vision of providing support to individuals and families dealing with sickle cell. Additionally, The foundation's location in Northern Virginia was also appealing, as it allows me to actively participate in events and programs to support their cause.

How has your personal experience motivated you to volunteer?

My brother, Mohadam (Momo), and I were born with sickle cell anemia. Throughout our childhood, we were blessed to have a mother who never gave up on us, supporting us through every pain crisis. On some late nights, she would dedicate over 12 hours to her nursing shift and still manage to take one of us to the hospital when a sudden sickle cell crisis occurred. Despite the challenges, she never gave up. I'm also grateful for my Hematologist, Dr. Elizabeth Yang, who has been by my side for multiple years.

SICKLE CELL WARRIOR SPOTLIGHT

How has your personal experience motivated you to volunteer? (cont)

"Dr. Yang has consistently encouraged us to take our medicine, maintain a healthy diet, and engage in regular exercise. Both my mother and Dr. Yang worked tirelessly to ensure that my brother and I could experience as much of a normal childhood as possible.

My goal is to extend this possibility to all sickle cell patients. I aim to eliminate the struggles that my mom faced when caring for us. Through volunteering, I strive to reduce the suffering associated with sickle cell and provide resources and programs to ensure that all families and individuals affected can lead fulfilling lives.

Additionally, my perseverance, cultivated through diverse responsibilities as the eldest sister, excelling academically and maintaining a strong work ethic, empowers me to inspire other sickle cell patients and families. I hope to show them that their adversities are not impediments to their potential, but rather crucial elements to their personal development."

How does your work with the foundation align with your personal goals?

"Currently, I am engaged in social media management, where I contribute to crafting digital posts aimed at raising awareness about sickle cell. This role has not only expanded my knowledge but also enhanced my skills in digital creation, aligning seamlessly with my interest in UI/UX design and career aspirations in technology consulting. Through my current work, I can improve my tech skills while concurrently playing a part in spreading awareness about the gravity of sickle cell anemia."



Kadijah Mansaray serves as an inspiration to us all through her academic achievements, leadership roles, commitment to fitness, and unwavering dedication to family. Her story is a shining example of how one individual can truly make a difference in their community. As she prepares to embark on new adventures beyond high school, we are confident that Kadijah's impact will continue to reverberate and inspire others along the way. Welcome to The Heart of Gold Sickle Cell Foundation Kadijah

OUTREACH NEWS

ROTARY CLUB

The Rotary Club is an international membership organization made up of diverse groups of people who share a passion for and commitment to enhancing communities and improving lives across the world. Interim Heart of Gold President, Melanie Pearson Hurley, was honored to be interviewed for the Rotary District 7610 "Rotary Times" television program in December 2023. The show features local community leaders and is produced and hosted by Rotarian Dr. Deborah Jackson, a member of the Rotary Club of McLean.

Melanie shared information about the establishment of the Heart of Gold and the dreams of Founder Clarissa Pearson. Additionally information was provided on advancements in the treatment of SCD, the importance of blood donations and the challenges faced by SCD warriors and their families.

HOWARD UNIVERSITY

Sickle Cell Awareness Month

We were happy to participate in Howard University's 17th Annual Cure Sickle Cell Now Move-On event, held on September 30, 2023.

The annual event was held in front of Howard University Hospital at 2401 Georgia Ave, NW, 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 through Howard University campus, Yoga, and plenty of music, vendors, raffle prizes and fun.



SUPER CAMPERS ALWAYS

The Heart of Gold is proud to continue our support of presenting scholarships to youth with SCD to attend Summer Camp.



Formerly known as "Brainy Camps," The summer camp sponsored by Children's National Medical Center is now called "Camp Accomplish" and they have joined forces with Melwood to enhance all campers experience.

This summer, the Sickle Cell Anemia 'Super Campers Always' Camp will run June 23 - 28, 2024. This is a fun, supportive, and empowering environment for children and teens with Sickle Cell Anemia with the support of medical leader: Children's National Hospital Sickle Cell Program.

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.

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. visit <https://campaccomplish.org> for more information.

BLOOD DRIVES : A Lifesaving Contribution

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.

This past year The Heart of Gold Sickle Cell Foundation supported several blood drives for the 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.

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

Introducing the Heart of Gold Sickle Cell Foundation's groundbreaking initiative of 2023: the captivating podcast, "Blood, Sweat and Cells: Real Talk About SCD." This one-of-a-kind series delves into the intricacies of sickle cell disease, offering profound educational insights.

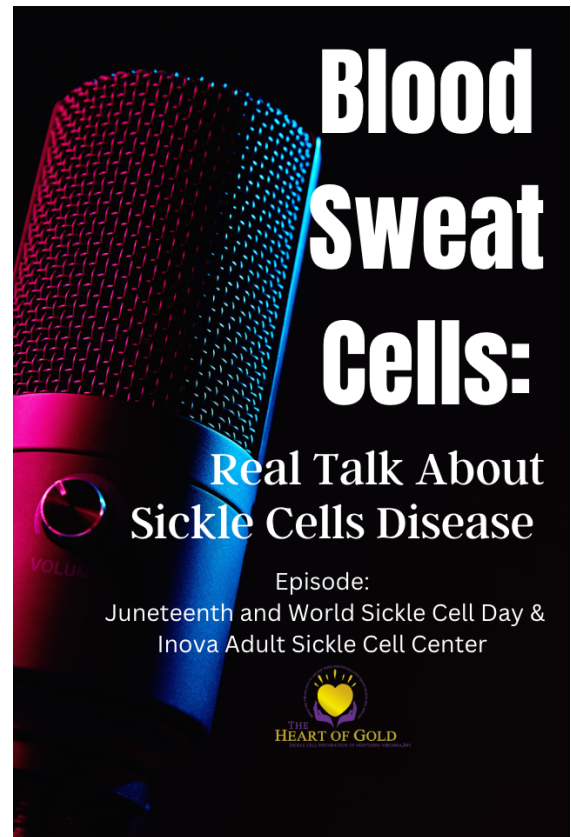
Across five captivating episodes, we had the privilege of engaging with an array of remarkable individuals. From patients and doctors to researchers, their unique perspectives shed light on their personal experiences living with and treating this chronic condition. Our primary goal in producing this podcast is to serve as advocates for patients with sickle cell disease, empowering them to lead lives brimming with quality and fulfillment.

Board member Valerie Bey took the reins as our media expert, utilizing her skills to script and edit each episode. Under her skillful guidance, "Blood, Sweat and Cells" can now be accessed on esteemed podcast platforms such as Spotify and Apple Podcasts.

Our inaugural episode was a celebration of Juneteenth and World Sickle Cell Day, titled "Working Toward Health Equity for All." Unveiling compelling connections between African American history and these two pivotal occasions, we drew attention to the Adult Sickle Cell Center in Northern Virginia and its invaluable services. Accompanying us on this journey was the esteemed Dr. Sheinei Alan, Director of Clinical Research at the INOVA Adult Sickle Cell Center. Her knowledge and expertise served as a guiding light, illuminating pathways towards enhanced outcomes and an improved quality of life for those grappling with sickle cell.

Furthermore, our subsequent episodes dived into essential topics such as women's health, parenting in the face of SCD, coping with the loss of a child impacted by sickle cell, and comprehensive understanding of being a carrier of the sickle cell trait.

Be sure to subscribe to our awe-inspiring podcast as we continue unraveling more riveting stories and delivering comprehensive educational information about sickle cell disease. You can find "Blood, Sweat and Cells" on all major podcast platforms.



We enthusiastically invite you to drop us a line at BSCpodcast@icloud.com, sharing the topics you'd like us to explore in future episodes. Your input is invaluable in shaping this remarkable podcast that aims to empower and educate our community.

Together, let's embark on an indelible journey, fostering knowledge, empathy, and growth for those impacted by sickle cell disease.

Sickle Cell Disease in the Workplace

Are you a valued employee battling sickle cell disease or any other chronic illness? It's essential to prioritize your health while at work.

In the United States, the Americans with Disabilities Act (ADA) ensures that employers with 15 or more employees provide reasonable accommodations for individuals with chronic illnesses.

If you have sickle cell disease, there are specific accommodations you can request to create a more supportive work environment.

Here are some suggestions tailored to help sickle cell warriors thrive in the workplace:

- 1. Hydration:** Always keep a water bottle nearby to maintain proper hydration levels and combat the dehydration often associated with sickle cell disease.
- 2. Temperature Control:** Avoid extremes in temperature, as both hot and cold conditions can trigger sickle cell crises. Speak to your employer about adjusting the indoor climate to ensure optimal comfort.
- 3. Dress Code Modifications:** Requesting modifications to the dress code can help you manage your symptoms better. Dressing in layers allows you to adapt to changing temperatures and minimize discomfort.
- 4. Workstation Comfort:** Ensure your workstation is suitable for your needs. Consider requesting an ergonomic chair or cushion to support your back and reduce pain or fatigue.
- 5. Breaks and Rest Opportunities:** Regular breaks can help prevent overexertion and minimize the risk of triggering pain or fatigue. Communicate with your supervisor about taking necessary breaks throughout the day.
- 6. Remote Work Options:** If your condition fluctuates, discuss remote work options with your employer. This flexibility could allow you to work from home during periods when pain or complications make commuting difficult.



Remember, everyone's accommodation needs may vary.

Gathering documentation from your healthcare provider about your condition can strengthen your request for workplace accommodations.

Initiate a conversation with your employer or Human Resources department to discuss these accommodations openly and constructively.

Advocating for your needs in the workplace is crucial. By working together, you and your employer can create a supportive environment that helps you manage your symptoms and excel in your professional endeavors.

Stay strong, stay proactive, and prioritize your health as you navigate the workplace as a sickle cell warrior. You've got this!

Edna Williams

Edna Williams is a highly versatile and active professional. She holds a prominent position as a board member for the Heart of Gold Sickle Cell Foundation of Northern Virginia. In addition to her role there, she is the President of Statewide Sickle Cell Chapters in Virginia. Beyond her commitments to these organizations, Mrs. Williams is the Operations Manager at GovCIO, where she manages a wide range of responsibilities that demand her constant attention.

In February, during black history month GovCIO featured Mrs. Williams in their company newsletter to highlight her achievements.



Celebrating Edna Williams: A Champion for Sickle Cell Patients

In the heart of our community at GovCIO there thrives a spirit of compassion and dedication that extends beyond the office walls. One shining example of this spirit is Operations Manager Edna Williams, a valued member of our team who in her spare time, serves on the board of 'The Heart of Gold Sickle Cell Foundation of Northern Virginia.' This non-profit organization is committed to educating the public about Sickle Cell Disease (SCD) and advocating for patients and their families as they navigate the complexities of this chronic illness.

As we honor the rich tapestry of history and achievement during Black History Month, it is with immense pride that we spotlight Edna's tireless work advocating for those affected by sickle cell disease. Sickle cell disease is a group of inherited red blood cell disorders that affect hemoglobin, the protein that carries oxygen through the body. Normally, red blood cells are disc-shaped and flexible enough to move easily through the blood vessels. In sickle cell disease, red blood cells become crescent- or "sickle"-shaped due to a genetic mutation. These sickled red blood cells do not bend or move easily and can block blood flow to the rest of the body. The blocked blood flow through the body can lead to serious problems, including stroke, eye problems, infections, and episodes of pain called pain crises. To manage this chronic illness, many patients require frequent blood transfusions to alleviate severe pain and prevent serious organ complications.

Edna's role with The Heart of Gold Sickle Cell Foundation has been pivotal in elevating public understanding about the critical need for blood donations, particularly from African American communities and people of color. Her advocacy shines a light on the fact that blood from donors with genetic similarities can significantly improve transfusion outcomes for those battling SCD. Edna's passionate efforts have not only raised awareness but also motivated many within our own ranks to donate blood—a simple yet profound act of solidarity.

Let us collectively celebrate Edna Williams for her relentless dedication to improving the lives of individuals with sickle cell disease. Her work is a testament to the power of community involvement and serves as an inspiring reminder that our collective actions can have a lasting impact that resonates well beyond the observance of Black History Month. Register today at <https://www.redcrossblood.org>

Your contribution can save lives and honor the legacy of resilience and strength.

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](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>



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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>

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