

NBCI and its 150,000 Churches Join the Sickle Cell Fight to Support Sickle Cell Warriors Worldwide



Tabatha McGee
Executive Director of Sickle Cell Foundation of Georgia, Inc.



Rev. Dr. William Flippin Sr.
Senior Pastor,
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Reverend Anthony Evans
President of the National Black Church Initiative,
2022 Stellar Award Winner



Dr. Lakiea Bailey Ph.D.
Executive Director at Sickle Cell Consortium



Regina Hartfield
President and CEO of the Sickle Cell Disease Association of America

The National Black Church Initiative (NBCI) and its 150,000 African American and Latino churches are leveraging their collective power and community influence to highlight the prevailing needs of those who directly and indirectly suffer from Sickle Cell Disease (SCD) and its subsequent crippling and debilitating effects.

NBCI continues to contribute financial resources to address rising costs associated with SCD. Such costs adversely impact the lives and livelihoods of those affected by SCD. NBCI continues to secure multitudes of volunteers to ensure that everyone who is living with sickle cell and their families are protected. In fact, NBCI is vowing to commit some 25,000 volunteers here in the state of Georgia and tens of thousands throughout the country.

To that end, this is why NBCI will endorse and work vigorously for the passage of potential legislation sponsored by Congresswoman Barbara Lee and Senator Chris Van Hollen. The Sickle Cell Disease Treatment Centers Act of 2022, as supported by the Georgia Black Congressional State Legislative Caucus, will establish and fund a nationwide system for sickle cell disease treatment centers as well as provider and patient training and education resources.

Tabatha McGee is the Executive Director of Sickle Cell Foundation of Georgia, Inc. She is a results-oriented leader with a strong record of performance in turnaround and high-paced organizations. She develops partnerships with company stakeholders, shareholders, industry regulators and other relevant parties. Tabatha collaborates with the Board of Directors to identify, create and implement strategic plans to actualize business objectives. She also develops the organizational culture and promotes transparency and collaboration throughout the organization.

When introduced, this bill authorizes \$535 million for fiscal year 2023 and each fiscal year thereafter to achieve the goals of the particular legislation.

Over the past year, Reverend Anthony Evans, President of the National Black Church Initiative, has launched an aggressive statewide sickle cell program. The aim of the sickle cell program is to foster overall understanding of SCD and to demonstrate recommitment by the Black church to address critical issues impacting SCD.

In January 2022, NBCI hosted a reception for all major SCD organizations and warriors at the Whitney Hotel in Atlanta, Georgia. Highlights from the reception can be found at the following website: youtu.be/zKDW6XGvr3k Our keynote speaker was the honorable Dr. Lakiea Bailey, Executive Director of the Sickle Cell Consortium. Dr. Bailey gave what was considered not only a comprehensive explanation of what Sickle Cell is, but all the medical ramifications of coping with this disease.

She was able to give an inspiring presentation to a general audience of her peers and those who knew less about the disease. She also covered two major issues of the disease that deal with stigma and mental health.

We were all amazed at the breadth, length, and depth of her scientific intellectual knowledge of the disease. Due to her astounding knowledge of SCD, she was able to give us an idea of what scenarios may come next.

The session was videotaped and has been watched extensively since the airing of the lecture. Therefore, we were excited to provide you with the link so that you may watch and be informed on SCD: youtu.be/zK-DW6XGvr3k.

Subsequently, in March 2022, NBCI engaged in a collaborative partnership with Global Blood Therapeutics (GBT) by hosting a State of the State of Sickle Cell Disease. The keynote speaker, Dr. Ted W. Love, M.D. offered insightful perspectives for the attendees. Highlights from this event can be found at the following website: youtu.be/YiQr0ZyrA6s.

The success of these two groundbreaking events have generated a need for NBCI to host more topic-focused dialogue. One of the upcoming events include a practically-focused dialogue about critical issues and implications concerning emergency room visits of SCD patients and the crises they encounter.

Rev. Dr. William E. Flippin, Sr., is the visionary pastor of The Greater Piney Grove Baptist Church in Atlanta, Georgia. The Nashville, Tennessee native received the Master of Divinity (M.Div.) degree, cum laude, from Candler School of Theology at Emory University, where he was a Benjamin E. Mays Fellow and a scholar for the Fund for Theological Education. He also earned the Doctor of Ministry (D.Min.) degree from McCormick Theological Seminary in Chicago, Illinois. Understanding that ministry is holistic in nature, Dr. Flippin received certification as a Life Transformational Coach and a Leadership Coach Trainer.

A second event involves a more scientifically-focused dialogue focusing on issues unique to the Sickle Cell Trait and the effects on patients.

Additionally, having the expertise of Regina Hartfield, asd President and CEO of the Sickle Cell Disease Association of America (SCDAA), be part of this collaborative effort is important toward its success. The mission of SCDAA is to advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure.

The SCDAA has one of the most effective websites and a mobile app for Sickle Cell Warriors and their family members who are thinking of participating in clinical trials.

This is an award-winning clinical trial finder and mobile app, and we encourage our Sickle Cell warriors throughout the country and the world to utilize this app when you are contemplating joining a clinical trial protocol. sicklecelldisease.org/clinical-trial-finder/

What You Should Know About Sickle Cell Disease



What Is Sickle Cell Disease?

Sickle cell disease (SCD) is a group of inherited red blood cell disorders.

- Healthy red blood cells are round, and they move through small blood vessels carrying oxygen to all parts of the body.
- In SCD, the red blood cells become hard and sticky and look like a crescent-shaped farm tool called a "sickle":
- Sickled cells die early, which causes a constant shortage of red blood cells.
- Sickled cells can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body. These blockages cause repeated episodes of severe pain, organ damage, serious infections, or even stroke.

What Causes Sickle Cell Disease?

SCD is inherited in the same way that people get the color of their eyes, skin, and hair.

- A person with SCD is born with it.
- People cannot catch SCD from being around a person who has it.

Who Is Affected by Sickle Cell Disease?

According to the CDC, SCD affects approximately 100,000 Americans, mainly Blacks or African Americans. CDC says:

- SCD occurs among about 1 out of every 365 Black or African-American births.
- SCD occurs among about 1 out of every 16,300 Hispanic-American births.

SCD affects millions of people throughout the world and is particularly common among those whose ancestors come from sub-Saharan Africa; regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy.

This information and more about sickle cell can be found at [cdc.gov/ncbddd/sicklecell/data.html](https://www.cdc.gov/ncbddd/sicklecell/data.html)

What Health Problems Does Sickle Cell Disease Cause?

The following are some of the most common complications of SCD:

"Pain Episode" or "Crisis": Sick cells don't move easily through small blood vessels and can get stuck and clog blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time.

Infection: People with SCD, especially infants and children, are more likely to experience harmful infections such as flu, meningitis, and hepatitis because the disease impacts a person's immune system making them susceptible to these and other infections.

Hand-Foot Syndrome: Swelling in the hands and feet, often along with a fever, is caused by the sickled cells getting stuck in the blood vessels and blocking the blood from flowing freely through the hands and feet.

Eye Disease: SCD can affect the blood vessels in the eye and lead to long term vision damage.

Acute Chest Syndrome (ACS): Blockage of blood flow to the lungs can cause acute chest syndrome. ACS is similar to pneumonia; symptoms include chest pain, coughing, difficulty breathing, and fever. It can be life-threatening and should be treated in a hospital.

Stroke: Sick cells can clog blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.

Donating to NBCI

New clinical research studies are happening all the time to find better treatments and, hopefully, a cure for sickle cell disease.

People who participate in these studies might have access to new medicines and treatment options.

Donating to NBCI will help our organization access these studies and provide resources to our constituents.

Donate safely to NBCI at <https://square.link/u/vEr3LxAO>

Sickle Cell & Mental Health

NBCI will focus on black men's mental health while living with sickle cell disease. Our aim is to launch a \$20MM program in September with special emphasis on men in the church starting in Atlanta, Georgia.

Volunteering for NBCI

NBCI needs 25,000 volunteers in Georgia, would you be one? If interested, please email dcbc2002@gmail.com



NBCI Vows to Raise 25,000 Volunteers for Sickle Cell Foundation of Georgia, Inc.

Please sign up to be a volunteer at <https://sicklecellga.org>



A patient and caregiver panel was moderated this year by Reginald French, President, Sickle Cell Foundation of Tennessee. This global panel will discuss the caregiver experience throughout the continuum of care.



"I'm honored to be a part of the 2022 SCD Therapeutics Conference as the moderator of a timely and relevant panel discussion focused on the caregiver experience in SCD. Each year the SCD Therapeutics Conference provides excellent information on a range of topics and this year will be no different. I strongly encourage the SCD community to attend this important conference and continue to learn from each other's experiences."

- Reginald French
President, Sickle Cell Foundation of Tennessee

Global Blood Therapeutics (GBT) and the Sickle Cell Disease Association of America (SCDAA) were excited to hold the 11th Annual 2022 Sickle Cell Disease Therapeutics Conference (SCDTC) Wednesday, September 14, 2022. The event was conducted remotely via digital platform and this unique conference brought together key sickle cell disease stakeholders focused on discussing issues impacting the SCD community.



Barbara Lee
Congresswoman
13th District of California



Rep Chris Van Hollen
United States Senator
of Maryland

Congresswoman Barbara Lee and Senator Chris Van Hollen introduced The Sickle Cell Disease Treatment Centers Act of 2022 in September, comprehensive legislation that will create comprehensive treatment centers throughout the country and provide much needed support to the SCD community. This important development is welcome news to tens of thousands of Sickle Cell warriors, researchers, physicians, and African American activists like Dr. Lakiea Bailey, Dr. Regina Hartfield, Tabatha McGee, and many others around the country.

The National Black Church Initiative whose 150,000 churches constitute 27.7 million African American church goers will work hand in hand with the congress and the White House to see that this legislation is passed. This is a part of the black church's Sickle Cell push to make sure that all our members and all African Americans are treated with respect and dignity and not stigmatized for their chronic, hereditary condition.

Homelessness Surrounding Sickle Cell

Of the 100,000 Americans who have sickle cell disease, 90 percent of them are Black.

The risk of homelessness increases with the disease due to its physical and mental challenges on patients, financial instabilities, and limiting job opportunities.

This is why NBCI is prioritizing educating all employers on how to deal with this disease, heighten their awareness, and mitigate any discrimination that occurs within jobs.



Rep. Gloria Frazier
GA House of Representatives

You can find a template letter encouraging your elected official to co-sponsor the Sickle Cell Disease Treatment Centers Act of 2022 [here](#). This site linked will easily identify your elected officials and help auto populate the letter and send it directly to your Member of Congress

Rep. Gloria Frazier and members of the Georgia Congressional Black Caucus should be cited for their early support of the legislation. The members of the Caucus who support this legislation are: State Senator Tonya P. Anderson, Chief Deputy Whip Debra Bazemore, Representative Kim Schofield, Representative Billy Mitchell, Senator Ed Harbinson, Stacy Abrams, Representative Mandisha A. Thomas, Senator Donzella James, Senator Kim Jackson, Representative Rhonda Burnough, Representative Doreen Carter, Representative Karen Bennett, and Administrative Assistant Prayer Idowu.

Finding Good Medical Care

People with sickle cell disease can live full lives and enjoy most of the activities that other people do.

The following tips will help you, or someone you know with sickle cell disease, stay as healthy as possible.

Prevent Infections

Common illnesses, like the flu, can quickly become dangerous for a child with sickle cell disease. The best defense is to take simple steps to help prevent infections.

Mortality

Sickle cell-related death among Black or African American children younger than 4 years of age fell by 42% from 1999 through 2002.

This drop coincided with the introduction in 2000 of a vaccine that protects against invasive pneumococcal disease.

Best Practices for Living with SCD

Get Regular Check Ups

Regular health checkups with a primary care doctor can help prevent some serious problems.

- Babies from birth to 1 year of age should see a doctor every 2 to 3 months.
- Children from 1 to 2 years of age should see a doctor at least every 3 months.
- Children and adults from 2 years of age or older should see a doctor at least once every year.

SCD Treatment

After many years of lagging innovation, finally, there are more treatment options for people living with SCD.

Learn more about SCD, its complications and treatments at: [cdc.gov/ncbddd/sicklecell/facts.html](https://www.cdc.gov/ncbddd/sicklecell/facts.html)

Join a Community

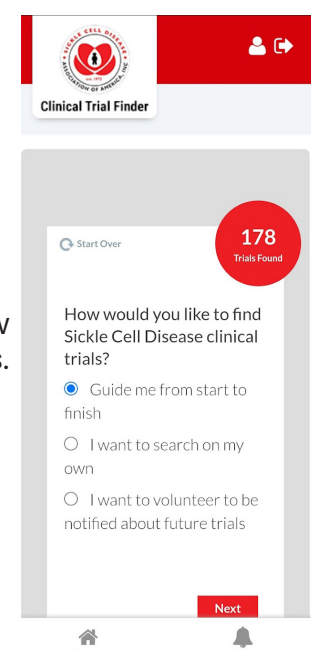
CURE SICKLE CELL NOW Move-On Event 2022 - took place on September 17, 2022. If you have participated in the Stomp Out Sickle Cell Walk/Move-On events, and for these past two years, we've been virtual, we were happy to announce that we feel we can safely return to an outside event this year. Sickle Cell warriors gathered in front of Howard University Hospital at 2401 Georgia Ave, NW, Washington, DC to start the event. The 5K Fun Run/Walk through the historic Howard University campus provided Zumba, plenty of music, vendors, raffle prizes and fun.

Look for Clinical Studies

New clinical research studies are happening all the time to find better treatments and, hopefully, a cure for Sickle Cell Disease.

People who participate in these studies might have access to new medicines and treatment options.

Visit the Sickle Cell Disease Association of America (SDAA) clinical trial finder: <https://www.sicklecelldisease.org/clinical-trial-finder/>.



Welcome from the NBCI President



The National Black Church Initiative (NBCI) is a coalition of 150,000 African American and Latino churches with 27.7 million members working to

eradicate racial disparities in healthcare, technology, education, housing, and the environment. The NBCI's mission is to provide critical wellness information to all its members, congregants, churches and the public.

NBCI recognizes that due to Sickle Cell Disease (SCD)'s chronic and lifelong challenges, many young adults with the disease are at risk for health-related stigmatization. SCD can affect all aspects of their life including their physiological, psychological, and social well-being.

Different levels of stigma can lead to disadvantages such as discrimination in jobs, in schools, and within families, and may impact the the quality of health care received by individuals with the disease.

Therefore, NBCI is developing patient-related resources and interventions to ensure patients with SCD can minimize stigma while dealing with their disease.

NBCI will prioritize educating the Black community and how to support them.

Trainer of Trainers Program

NBCI will launch a "Trainer of Trainers" program throughout its churches so that each congregation will have a dedicated Health Corps Volunteer to provide education, resources and support to those who have SCD.

Educating Employers

NBCI will develop short videos on stigma and employer laws to send out to all employers, specific to sickle cell, what to expect and how to handle employees with the disease.

Donate to NBCI

Donating to NBCI will help our organization access these studies and provide resources to our constituents.

Donate safely to NBCI at <https://square.link/u/vEr3LxAO>



Please Sign Up to Be a Volunteer Sickle Cell Educator Trainer

You may sign up to be a volunteer at the following:

- sicklecellga.org
- sicklecelltn.org/contact/
- info@sicklecelldisease.org
- sicklecellconsortium.org/warrioruniversity/



Photos by William H. Joseph



BECOME A WARRIOR IN THE FIGHT AGAINST SICKLE CELL

TRAINERS

OF

TRAINERS

The Trainer of Trainers seminar is designed to identify individuals in our congregation who want to become volunteer educators on sickle cell disease. Trainers will work in conjunction with all of the Sickle Cell organizations in Georgia and provide technical support, education and offer assistance in outreach. This corps of members will be our primary source in the Black Church to assist the Sickle Cell Foundation of Georgia in carrying out its tasks within the state.

FOR MORE INFORMATION

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