SICKLE CELL

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NEWS & WORLD REPORT

SPECIAL EDITION MARKING WSCD 2024

Per Adua Adastra

Judy Johnson
81, MEd

Laurel Brumant-Palmer
60, 1st Class

S.K Tusuubira
33, PhD

Toyin Oshinowo
44, PhD

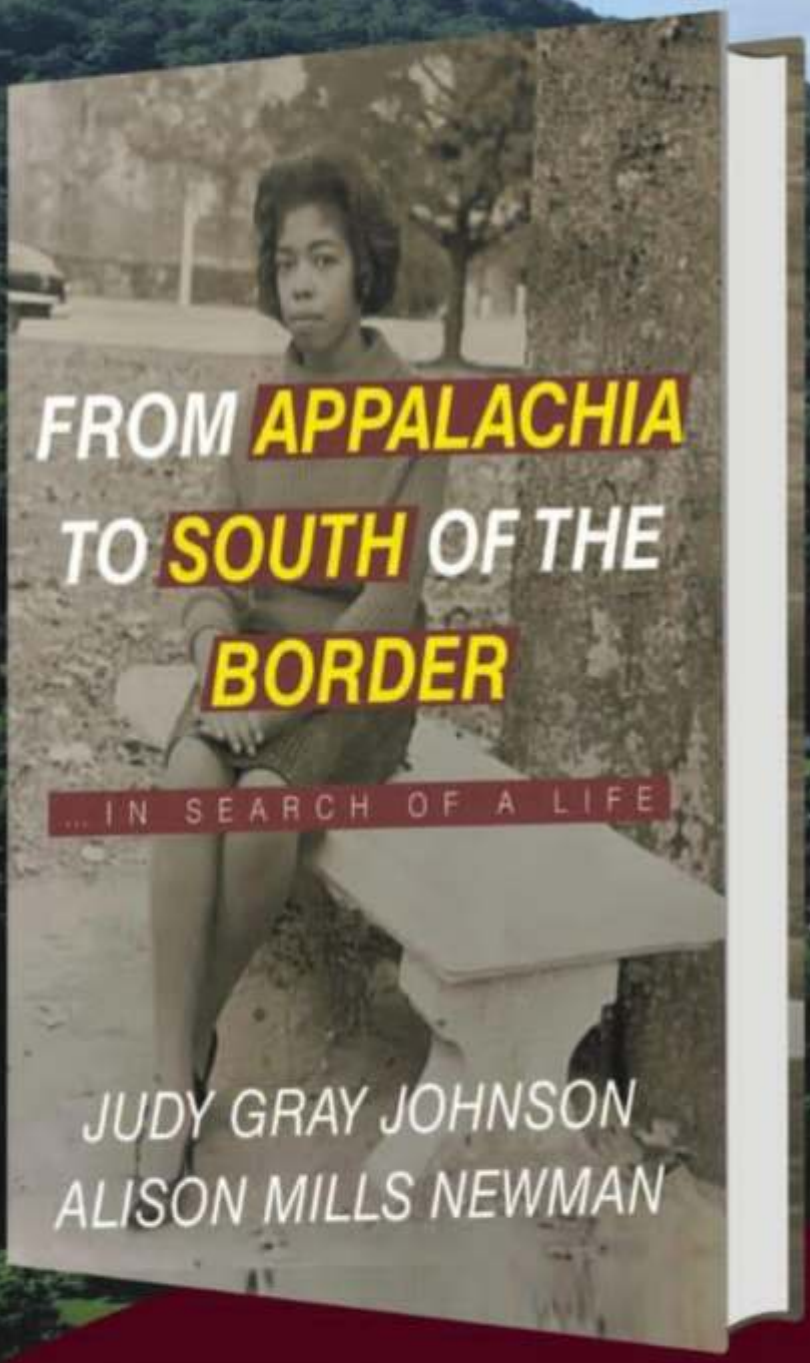
AGLOW, TAHF Mark WSCD in Ogun State

OGUNDOYIN Family Donates N5m to SCHAF

Global Action Network for Sickle Cell and Other Inherited Blood Disorders

#GANSID
#SickleCellAwareness
#SickleCellDisease

JUNE 19
WORLD SICKLE CELL DAY



The 1940s was not a good period to be born with sickle cell anaemia. Judy Carol's SCD bared its fangs suddenly and dramatically at the age of 4. Until well past adolescence, all she had to rely on for comfort was liniment recommended by a doctor for her mysterious pain eruptions and a mystified but loving family. A hospital was never recommended.

Despite facing poverty and health issues, Judy Carol exhibited a tremendous amount of strength, determination, vision, and responsibility. This book is a testament to the human spirit and the power of resilience. It serves as a reminder that no matter the obstacles, there is always a way forward.

ABOUT THE AUTHOR

Judy Gray Johnson graduated from South Carolina State with a bachelor's degree in elementary education in 1964. She earned a special education on MEd from Virginia State University in 1971, and completed the coursework for a doctorate in educational administration and supervision from Virginia State Polytechnic Institute and State University in Blacksburg, Virginia

World Marks Sickle Cell Day 2024

WORLD SICKLE CELL DAY
JUNE 19

SUPPORTING OUR FIGHTERS, STRENGTHENING OUR SURVIVORS, HONORING THE TAKEN & STANDING BY OUR WARRIORS.

Mission:
To inform, teach and help reduce the burden of sickle cell on family and society

Vision:
To be the world's best-known resource magazine for the world's most commonly-inherited blood disorder

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Sharif K. Tusuubira, 37, (*left*), PhD, Quantitative Genetics: 'Mom named me *Tusuubira*, because she had hope that I will not die...' ...**PG 12**

Born in the 1940s, **Judy Carol Johnson**, (*right*) lived through sickle cell anaemia to her 20s with just liniment for treatment. Now 81, she is educating the world about SCD through prolific book publications ...**PG 16**

Despite the difficulties of life under the spell of SCD, **Laurel Brumant-Palmer, 60,** *(left)* had 1st Class in Graphic Design Visual Comm & Illustration. 'I did not want to bring a child into this world to go through what I did.' ...**PG 33**

Toyin Oshinowo, **44**, (*right*) PhD Engineering, is all for making genotype a big issue in marriage - of not deliberately bringing children into the world to grapple with avoidable health hurdles. ...**PG 9**

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All about

Sickle Cell Disease

For New Parents
For The Un-initiated
For Veterans

Sickle cell disease (SCD) is a ***group*** of inherited red blood cell disorders. Red blood cells contain hemoglobin, a protein that carries oxygen. Healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body. In someone who has SCD, the hemoglobin is abnormal, which causes the red blood cells to become hard and sticky and look like a C-shaped farm tool called a 'sickle.' The sickle cells die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, they get stuck and clog the blood flow. This can cause pain and other serious health problems such as infection, acute chest syndrome and stroke.

Types of SCD
There are several types of SCD. The specific type of SCD a person has depends on the genes they inherited from their parents. People with SCD inherit genes that contain instructions, or code, for abnormal hemoglobin.

Most common types of SCD:

HbSS
People who have this form of SCD inherit two genes, one from each parent, that code for hemoglobin 'S.' Hemoglobin S is an abnormal form of hemoglobin that causes the red cells to become rigid, and sickle shaped. This is commonly called sickle cell anemia and is usually the most severe form of the disease.

HbSC
People who have this form of SCD inherit a hemoglobin 'S' gene from one parent and a gene for a different type of abnormal hemoglobin called 'C' from the other parent. This is usually a milder form of SCD.

HbS beta thalassemia
People who have this form of SCD inherit a hemoglobin 'S' gene from one parent and a gene for beta thalassemia, another type of hemoglobin abnormality, from the other parent. There are two types of beta thalassemia: 'zero' (HbS beta0) and 'plus' (HbS beta+). Those with HbS beta0-thalassemia usually have a severe form of SCD. People with HbS beta+-thalassemia tend to have a milder form of SCD.

Rare types of SCD:
Rare SCD types include HbSD, HbSE, and HbSO and many others.
People who have these forms of SCD inherit one hemoglobin 'S' gene and one gene that codes for another abnormal type of hemoglobin ('D', 'E', or 'O'). The severity of these rarer types of SCD varies.

Sickle Cell Trait (SCT)
HbAS
People who have sickle cell trait (SCT) inherit a hemoglobin 'S' gene from one parent and a normal gene (one that codes for hemoglobin 'A') from the other parent. People with SCT usually do not have any of the signs of the disease. However, in rare cases, a person with SCT may develop health problems; this occurs most often when there are other stresses on the body, such as when a person becomes dehydrated or exercises strenuously. Additionally, people who have SCT can pass the abnormal hemoglobin 'S' gene on to their children.

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Maiden Speech of the United Nations on 1st World Sickle Cell Day 2009

The UN World Sickle Cell Day was first celebrated on June 19, 2009, during the tenure of Mr. Ban Ki-Moon, the 8th Secretary General of the United Nations Organization. We reprint below the text of his speech ahead on that seminal day for people with SCD around the world...

Last December (2008), the United Nations General Assembly took the welcome step of adopting a resolution recognizing sickle-cell anaemia as a public health problem.

Sickle-cell anaemia is an inherited condition that affects hundreds of thousands of babies born each year, mostly in low- and middle-income countries. I am pleased to lend my voice to the effort to raise global awareness about it. The more people understand the disease, the better we can respond. Understanding is also critical to eliminating the harmful prejudices associated with the condition.

Although sickle-cell anaemia cannot be cured, it can be managed through simple measures such as increasing fluid intake, pursuing a healthy diet, taking folic acid supplements and taking medication as needed. We must ensure that these affordable, common-sense interventions are available to all people suffering from the disease so that they can enjoy healthy and productive lives.

The United Nations, in working to strengthen health systems worldwide, also encourages research on sickle-cell anaemia and helps build capacity to conduct screenings for the disease. I urge Governments, civil society and all other partners to do their part to improve the quality of life of people with sickle-cell anaemia and enable them to live full, productive lives.

- Ban Ki-Moon, UN Secretary General 2007-2016

'The more people understand the disease, the better we can respond ...'

AU Commission Chairperson, H.E Moussa Faki Mahamat

What is The African Union (AU) Doing About Sickle Cell?

Sickle Cell Disease is a major public health issue in Africa, with an estimated 2 million children born with the disease each year on the continent.

What exactly has Africa been doing to stamp out ignorance and assist people living with SCD on the continent?

In 2008, the African Union declared May 8 as African Sickle Cell Day. However, the 'Day' has been subsumed by World Sickle Cell Day (June 19) and indeed has never been marked. Except for diplomats who were in service at the time, few Africans are aware of this declaration.

In 2016, the African Union declared sickle cell disease a public health priority and adopted the Sickle Cell Disease Resolution. This committed AU member states to implement national programs to prevent and control the disease.

The AU's key objectives are to increase awareness, strengthen surveillance systems, improve access to early diagnosis and comprehensive care, and promote research and development.

The AU has collaborated with the World Health Organization, the Sickle Cell Disease Foundation of Africa, and other partners to develop a continental framework to combat sickle cell disease.

Initiatives include establishing national registries, training healthcare workers, improving newborn screening, and ensuring availability of essential medicines and technologies.

Many African countries have implemented national sickle cell control programs, though coverage and access to care remains limited in some areas.

The AU has called for increased domestic health financing and international support to scale up sickle cell programs across the continent.

Overall, the African Union's efforts aim to reduce the significant health and socioeconomic burden of sickle cell disease in Africa through a coordinated, multi-stakeholder approach

On the whole, African countries are not doing much, compared to other nations where SCD is less of a burden, to support citizens with SCD.

WHEN IT'S ABOUT LIFE...

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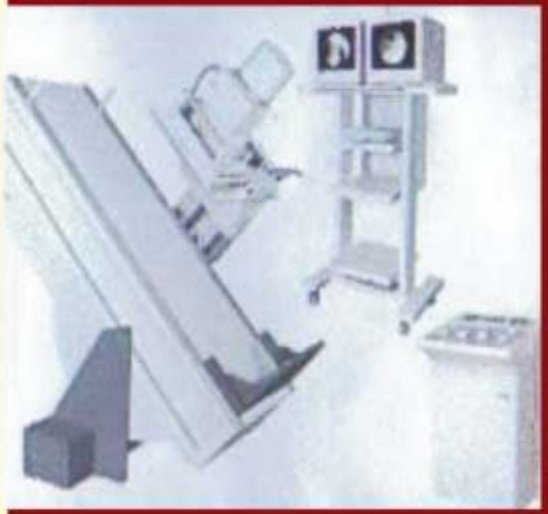

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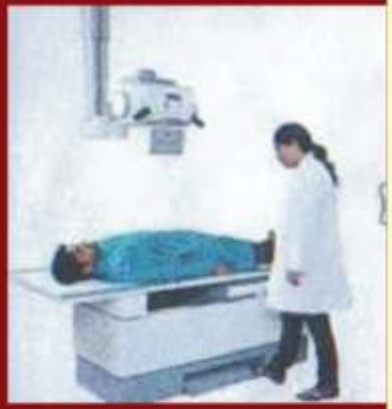

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TOYIN OSHINOWO: RARE GENOTYPE FOR AN AFRICAN

By Tosin Fawemida

There are literally hundreds of unusual genotypes that science laboratory technology has yet to develop machines to identify. Some years ago, *SICKLE CELL NEWS* carried the story of an adult SS Warrior whose parents were reportedly AA.

The resulting distrust and hot arguments and genuine doubts all but tore the family apart. For many years, there was no answer to the gargantuan puzzle.

Born 44 years ago in Nigeria, it was fortunate for the Oshinowos that the family repatriated to the UK when the man of the house went to pursue postgraduate medical studies. Toyin was only one year old then.

As a medical student, Dr. Oshinowo wanted the best for his offspring. Knowing his genotype was AS, he went for an AA partner, a nurse.

'In Nigeria, my dad's Hb results confirmed AS,' Toyin Oshinowo, an Engineering PhD recalls, 'while mom's was stated to be AA.'

Had the family remained in Nigeria, Toyin's sickle cell symptoms would have been pencilled down as a severely symptomatic AS. After all, SCT carriers are not created equal.

'No single public or private laboratory in 1980 Nigeria, including Teaching Hospitals, had the capability to ascertain my true genotype,' says Toyin.

The father's Hb, as given in Nigeria was indeed accurate - AS; but the mom's AA was far off the mark.

With the child manifesting full-

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Protocol for Prospective Participants in Clinical Studies: Jobelyn in the Treatment of Type-2 Diabetes

FOR LAGOS & OGUN STATE, NIGERIA RESIDENTS ONLY

Eligibility Criteria and Study Procedures

Age and Gender: Adult males and females aged 20 years and above.

Residency: Must be residents of Lagos State, Nigeria.

Health Condition: Latest diagnostic report showing an HbA1c reading greater than 5.5.

Self-Monitoring Capability: Ability to measure fasting blood sugar (FBS) levels twice daily and forward these results on a weekly basis.

Consent: A signed consent form is required for participation, detailing the study's purpose, procedures, potential risks, and benefits.

Monthly Reporting: Provision of an HbA1c report on a monthly basis.

Completion Commitment: Willingness to sign a compiled report at the study's conclusion.

Combination with Current Drug Regimen: Participants will initially continue their current drug regimen in combination with the *Jobelyn* supplement. The study team will closely monitor participants' health indicators and will determine when it may be safe and beneficial to reduce or skip their current medications in favor of relying solely on *Jobelyn* for diabetes management.

Monitoring and Adjustment: Regular monitoring will be essential during this transition phase. The study team will provide guidelines on when and how adjustments to medication can be made, based on individual health progress and in consultation with participants' healthcare providers.

Safety Measures: Participants will be closely monitored for any adverse reactions or significant changes in their health status. Adjustments to the study protocol may be made to ensure participant safety.

Our Obligations

Supplement Provision: The Sorghum bicolor supplement, *Jobelyn*, will be provided free of charge for the entire duration of the study.

Medical Support: Participants will have access to informed medical support to address any questions or concerns related to the supplement and its integration with their current treatment regimen.

This guideline ensures that the study accommodates participants' existing treatment plans while exploring the potential of *Jobelyn* as a standalone treatment for Type-2 diabetes. It emphasizes safety and individualized care, acknowledging that adjustments to diabetes management should be made cautiously and under medical supervision.

Jobelyn® is a product of Health Forever Product Ltd,
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Sharifu Tusuubira

From The Slums of Uganda to 'God's Own Country'

By Sharifu K Tusuubira, PhD

Hope is priceless, and I hold it dearly in the special chambers of my heart, body, and soul. I think that is why my beloved mother named me Tusuubira, which can flatly be translated as 'We hope'. It is this name that tells the story of my life. I was born in Wandegeya a city suburb of Kampala, alongside the biggest slum at the time 'Katanga.'

I was born in the '90s when sickle cell was for many a death sentence. Sickle cell then, as it is the case in some places now, was unknown and associated with many myths and misperceptions. Before coming into this world, my parents had a wonderful love life, but everything changed with my arrival.

A couple of months after my birth, my parents separated. I suspect their separation had something to do with my illness. My mum named me Tusuubira, because she had hope that I will not die. In spite of all that everyone was telling her, she always hoped that I will be different, and she always held onto that hope.

As a child growing up, the Mulago Sickle Cell Clinic was only 1.6 km from home. Often my mother would carry me on her back, along Hajj Kasule road or via Katanga to the clinic when I was sick. My mother is a police officer, so we lived in Wandegeya police barracks, where like other youngsters, I really loved to play. I would wake up every day and just run around or play soccer or *duulu* (it's a game we played by

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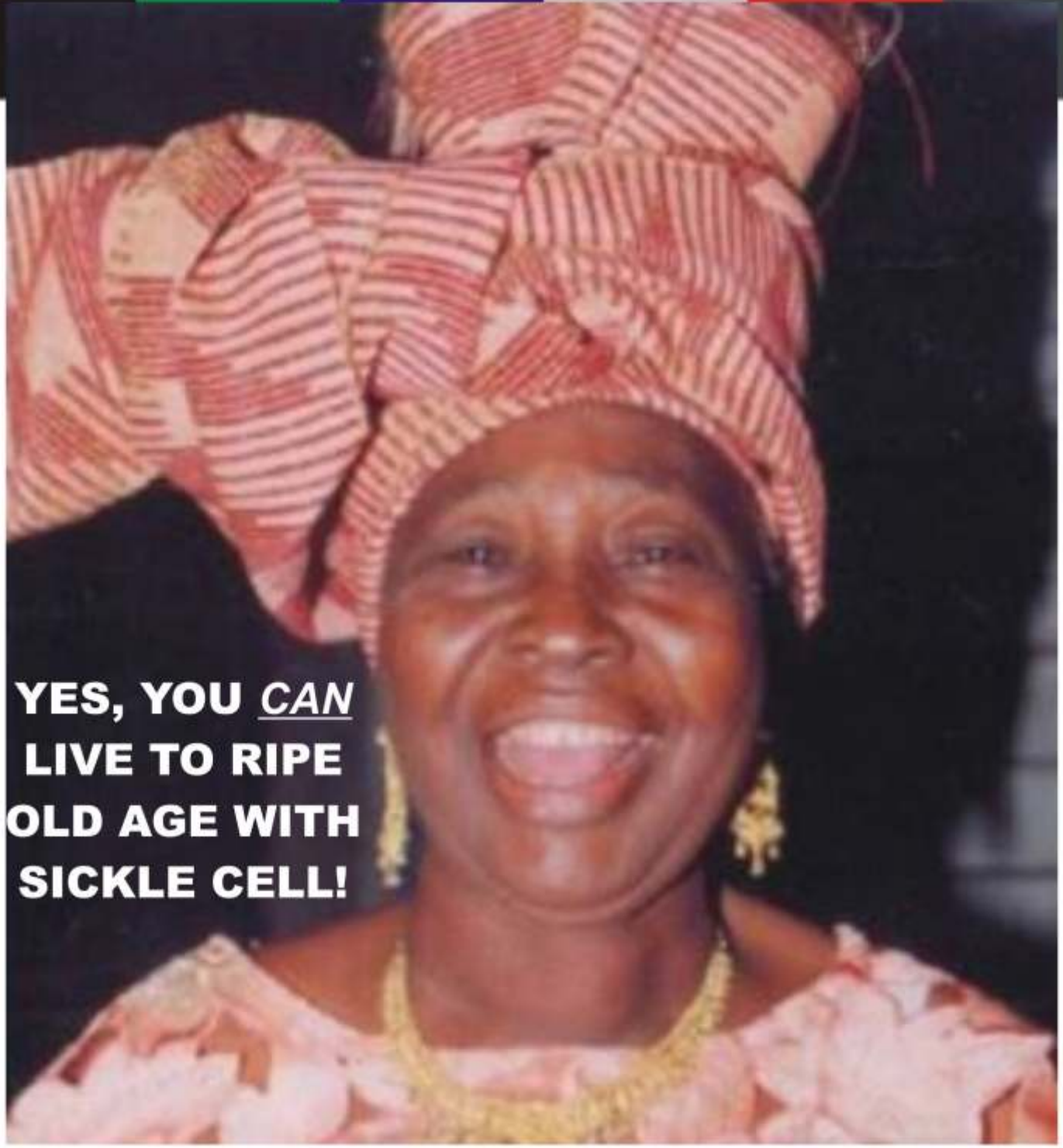

Alhaja Onikoyi-Laguda ***(1925 - 2020)*** *gained global renown as one of the oldest with SCD. Her genotype was* ***SC****, although, in her early years, she exhibited all the classical symptoms of* ***SS****. She gave birth to six children, all by normal delivery. Onikoyi was 83 years old when the above picture was taken*

Here are some tips for living to old age with SCD:

Manage proactively:

- Regularly see a hematologist or sickle cell specialist for comprehensive care.

- Closely monitor symptoms and get early treatment for sickle cell crises.

- Stay hydrated and avoid triggers like extreme temperatures, high altitudes, and strenuous exercise.

- Take hydroxyurea or other medications as prescribed to reduce complications.

Maintain a healthy lifestyle:

- Eat a nutritious diet rich in folic acid, iron, and fluids to support red blood cell production.

- Exercise regularly at a moderate pace to improve circulation and oxygen flow.

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Living Long With SCD

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- Get enough sleep and manage stress, as fatigue and anxiety can worsen symptoms.

- Avoid tobacco, excess alcohol, and recreational drugs, which can exacerbate sickle cell issues.

Prevent infections and complications:

- Get recommended vaccinations like the flu and pneumonia shots.

- Promptly treat any infections, as sickle cell patients are more prone to complications.

- Use prophylactic antibiotics if recommended to prevent serious infections.

- Manage chronic conditions like high blood pressure, diabetes, or kidney disease.

Undergo regular screening and monitoring:

- Get routine eye exams to detect vision problems related to sickle cell.
- Monitor organ function through blood tests, imaging scans, and other screening.
- Attend appointments with specialists like cardiologists, nephrologists, and neurologists.

Advocate for your care and participate in research:

- Be an active partner with your healthcare team in managing your condition.
- Consider enrolling in clinical trials or research studies to advance sickle cell treatments.
- Connect with sickle cell support groups and organizations for resources and community.

With proactive disease management, a healthy lifestyle, and a team-based approach to care, many individuals with sickle cell disease can achieve a normal lifespan.

📣 Unveiling the World Sickle Cell Day Emblem 📣

Screenshot the emblem 📸

Here's why your voice matters:

- Sharing the **#WorldSickleCellDay** emblem on your social feed helps raise awareness about sickle cell disease
- It amplifies the voices of those affected, and fosters a supportive community.
- By tagging **@iblooddisorders**, you contribute to a global movement advocating for better care and research.

Judy Johnson:
No Proper Diagnosis, No Proper Treatment

By Fatai Sulayman MBBS

Born in January 1943, it took 16 years for anyone, doctors included, to figure out what the matter was with Judy Gray Johnson. Even after she was diagnosed with sickle cell anaemia, no one told her about it. American medical practice in the 1950s - and relatives of children affected by serious illnesses - sought to insulate innocents from bad news.

For the next forty years, Johnson acquired only a superficial knowledge of SCD, afraid to find out too much about an illness she overheard was potentially fatal.

As a growing child, Johnson never ceased to complain of pain in her legs, arms and chest. For all this, she was treated with liniment. Due to constant tiredness, she became a recluse, and described as a 'lazy child lying on bed all day'.

When Johnson had an episode of pain that lasted 24 hours every day for two weeks, the small community in West Virginia in which she grew up was convinced that the child was living under a curse. Yet the treatment remained liniment. The pain would subside on its own as most sickle cell pain did, seemingly having a mind all their own, treatment or no. As she got better, the passage of time would prime her for yet another attack...

Despite the challenge of intermittent illness, Johnson participated in the American civil rights confrontations of the 1960s. On one occasion, she spent days in solitary confinement until the National Association For The Advancement of Coloured People (NAACP) got her free. It was a shock for the sheltered young sickly activist to share prison space with criminals and serial burglars.

Johnson's duel with SCD has hardly abated. In August 2015, she underwent surgery for avascular necrosis (AVN). She has also had her left shoulder replaced and undergone partial replacement of the right.

'In old age,' says Johnson, 'I have suffered more than when I was growing up - my crises episodes have become more

Her foray into politics had her in solitary confinement and sharing space with hardened criminals and burglars.

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Complementary Treatments For Sickle Cell

Here are some alternative and complementary medical treatments that may be beneficial for people with sickle cell disease:

Herbal Remedies:

- Some herbs like turmeric, ginger, and garlic have anti-inflammatory properties that may help manage sickle cell pain and complications.
- Devil's claw, boswellia, and cat's claw are other herbs that may provide pain relief.

Acupuncture and Traditional Chinese Medicine:

- Acupuncture may help reduce sickle cell-related pain, inflammation, and other symptoms.
- Traditional Chinese herbs and practices like cupping may also have benefits.

Nutritional Supplements:

- Supplements like omega-3 fatty acids, antioxidants, and L-glutamine may help improve red blood cell function and reduce complications.
- Folic acid, vitamin D, and zinc are also important supplements for sickle cell patients.

Hyperbaric Oxygen Therapy:

- Breathing pure oxygen in a pressurized chamber may help increase oxygen levels and reduce sickle cell crisis pain.

Massage Therapy:

- Massage can help improve circulation, relieve muscle pain, and promote relaxation for sickle cell patients.

Spiritual and Mind-Body Practices:

- Practices like meditation, yoga, and guided imagery may help manage stress and sickle cell pain.

It is important to discuss any alternative treatments with your healthcare provider, as they can interact with prescription medications or have other risks. Integrating complementary therapies with standard medical care may provide the best overall approach for managing SCD.

Do bear in mind that these treatments should not replace your regular medical care. Indeed you should seek medical advice before embarking on any complementary therapy.

frequent handwashing with soap helps prevent infections

Sickle Cell Disease

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Cause of SCD

SCD is a genetic condition that is present at birth. It is inherited when a child receives two genes—one from each parent—that code for abnormal hemoglobin.

Diagnosis

SCD is diagnosed with a simple blood test. SCD can be diagnosed while the baby is in the womb. Diagnostic tests before the baby is born, such as chorionic villus sampling and amniocentesis, can check for chromosomal or genetic abnormalities in the baby. Chorionic villus sampling tests a tiny piece of the placenta, called chorionic villus. Amniocentesis tests a small sample of amniotic fluid surrounding the baby.

Because children with SCD are at an increased risk of infection and other health problems, early diagnosis and treatment are important.

Talk to your doctor to find out how to get tested and to explain the results after testing.

Complications

People with SCD may start to have signs of the disease during the first year of life, usually around 5 months of age. Symptoms and complications of SCD are different for each person and can range from mild to severe.

Prevention and Treatment of SCD Complications

General Prevention Strategies

Management of SCD is focused on preventing and treating pain episodes and other complications. Prevention strategies include lifestyle behaviors as well as medical screening and interventions to prevent SCD complications.

Lifestyle Behaviors

There are simple steps that people with SCD can take to help prevent and reduce the occurrence of pain crises, including the following:

- Drink plenty of water.
- Try not to get too hot or too cold.
- Try to avoid places or situations that cause exposure to high altitudes (for example, flying, mountain climbing, or cities with a high altitude).
- Try to avoid places or situations with exposure to low oxygen levels (for example, mountain climbing or exercising extremely hard, such as in military boot camp or when training for an athletic competition).
- Simple steps to prevent harmful infections include the following:

- Wash your hands often. Washing hands with soap and clean water many times each day is one of the best ways people with SCD, their family members, and other caregivers can help prevent an infection.

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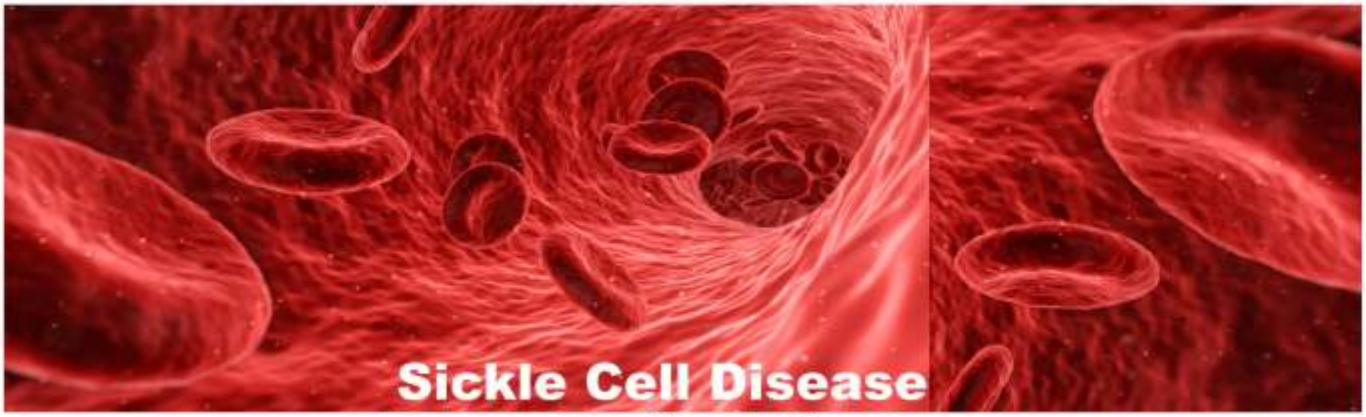

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Prepare food safely. Bacteria can be especially harmful to children with SCD.

Medical Screenings and Interventions to Prevent Complications

Prevention of Infections

Vaccines can protect against harmful infections. It is important that children with SCD get all regular childhood vaccines. Similarly, it is important for children and adults to get the flu vaccine every year, as well as the pneumococcal vaccine and any others recommended by a doctor.

Penicillin greatly reduces the risk of infections in people with HbSS and has been shown to be even more effective when it is started earlier. To decrease the risk of infection, it's important that young children with HbSS take penicillin (or other antibiotic prescribed by a doctor) every day until at least 5 years of age. Penicillin on a daily basis is usually not prescribed for children with other types of SCD unless the severity of the disease is similar to that of HbSS, such as HbS beta0-thalassemia.

Prevention of Vision Loss

Yearly visits to an eye doctor to look for damage to the retina (the part of your eye that senses light and sends images to your brain) are important for people with SCD to avoid vision loss. If possible, it's best to see an eye doctor who specializes in diseases of the retina.

If the retina is damaged by excessive blood vessel growth, laser treatment often can prevent further vision loss.

Prevention of Stroke

Children who are at risk for stroke can be identified using a special type of exam called *Transcranial Doppler ultrasound* (TCD). If the child is found to have an abnormal TCD, a doctor might recommend frequent blood transfusions (a procedure in which new blood is put into a person's body through a small plastic tube inserted into a person's blood vessels) to help prevent a stroke.

People who have frequent blood transfusions are usually watched closely because there can be serious side effects. For example, because blood contains iron, transfusions can lead to a condition called iron overload, in which too much iron builds up in the body. Iron overload can cause life-threatening damage to the liver, heart, and other organs.

Therefore, it is important for people with SCD receiving regular blood transfusions to also receive treatment to reduce excess iron in the body. This type of treatment is known as *iron chelation therapy*.

Management of Pain Crises

When pain crises do occur, clinical management may include the following:

√Intravenous fluids (giving fluids directly into a person's vein)
√Pain-reducing medicine
√Hospitalization for severe pain crises
√Specific Treatments to Prevent SCD Complications

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Dominick Bibbs and Dr. Michael Eckrich, Atrium Levine Children's Hospital

Is Charlotte Becoming A Center For Sickle Cell Treatment?

By Greg Lacour

Dr. Michael Eckrich and his team at Atrium Health Levine Children's Hospital lead a cutting-edge effort to cure a dreaded disease

- CHARLOTTE MAGAZINE

By the time Dominick Bibbs entered high school, the episodes of excruciating pain—'crises,' as sickle cell disease patients call them—had increased in frequency from twice a month to twice a week. The pain would target his knees and elbows, sometimes his lower back. At times, it was sharp, stabbing; others, it was a dull, diffused ache.

When the crises came, Bibbs knew he'd be down for days, unable to function. No school, no play, no socializing—just pain medicine and waiting for the agony to ease. He'd already had his enlarged spleen, another consequence of his condition, removed at age 4. It was in his late teens, when the agony seldom relented, that Bibbs started to understand the broader implications of the disease. Tens of thousands of others suffer through similar pain, and most, like him, are Black. Bibbs got clear on two important things: He had an opportunity to help others; and he couldn't—and almost certainly wouldn't survive to—take much more of this.

'That's when I wanted to get into the trial to help people other than me,' Bibbs explains. We're speaking via Zoom, and his mother, Nicole Searles-Bibbs, has joined us. Bibbs is 22, completing his nursing school prerequisites at Prairie View A&M University in Texas. He mentions that he has one more spring-semester final exam to take after this call.

'That's how I got introduced to Dr. (Michael) Eckrich, and Dr. Eckrich talked to me and explained that I could change or be a factor in changing, like, the—what's the word?'

'Change the world of sickle cell,' his mother interjects. She's at home in San Antonio, where Bibbs grew up and later underwent the treatment that allows him to live.

'Yeah. 'Change the world of sickle cell," Bibbs echoes. 'I didn't want people to have to go through what I went through.'

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'Yeah. 'Change the world of sickle cell," Bibbs echoes. 'I didn't want people to have to go through what I went through.'

The Story of Dominique Bibbs

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Both Searles-Bibbs and Bibbs' father, Derell, knew they carried the sickle cell trait. But, she says, not having kids 'wasn't an option for us.' They learned their son had the disease three months after his birth.

A doctor in Chicago discovered sickle cell disease in 1910. Until a generation ago, a diagnosis typically meant a painful life and early death, usually before adulthood. The disease mainly affects Black people. A study published last year examined nearly 75,000 U.S. patient records from 2016 through 2018 and found that 93.4% of SCD patients were Black, compared to 4.8% Hispanic and 1.8% white. About 100,000 Americans have the disease, and it affects one in every 365 Black births, according to the Centers for Disease Control. (By comparison, it occurs in one of every 16,300 Hispanic births.)

Medical researchers have concluded that the sickle cell trait is a genetic modification that evolved to combat the malaria parasite. That's why people of African ancestry are so susceptible to the disease. Both Searles-Bibbs and Bibbs' father, Derell, knew they carried the sickle cell trait. But, she says, not having kids 'wasn't an option for us.' They learned their son had the disease three months after his birth.

Eckrich, who oversaw Bibbs' life-altering treatment in 2021, still keeps in touch. That's partly out of necessity. Eckrich is in Charlotte now, and Bibbs has to fly in every few months for checkups. But the two have developed a personal bond, too. 'He was a doctor,' Bibbs says, 'who always told me the truth.'

Eckrich, 47, is a pediatric hematologist and oncologist who began his faculty career in 2012 at Levine Children's Hospital, now owned by Atrium Health. He left for Methodist Children's Hospital in San Antonio in 2016 and, over the next five years, led a team that conducted clinical trials to develop a new treatment for sickle cell disease. Levine Children's recruited him back in 2021, along with members of his team, and Eckrich now leads the Lifespan CuRED Hemoglobinopathy program in Charlotte. Bibbs took part in the clinical trials in San Antonio, which joined others around the country and led to the Food and Drug Administration's (FDA) approval of the new treatment in December.

'I just saw him a couple of weeks ago. It's been a privilege to care for him,' Eckrich says. 'He was one of the first few patients brave enough to go through this when there were a lot of unknowns. We explained that to him at the time, and he was committed to make this journey not only for himself but for other folks with sickle cell disease.'

The treatment, which goes by the brand name Casgevy, uses a technology called CRISPR/Cas9 to edit patients' stem cell DNA in a laboratory before reinjecting it so it can produce healthy blood cells. If the treatment succeeds over the long haul—and early results show promise—it could offer SCD patients a chance at long, productive, agony-free lives.

'Sickle cell disease was the first genetically described disease to be linked to a specific gene, and that gene has a single nucleotide change,' Eckrich says, referring to the basic structural component of DNA.

'So, in the whole genome, one nucleotide changes, and you have the difference between a

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Of CHRONIC PAIN and PERSISTENT FEVER

I am a 50-year-old African-American woman, my hb is SS. Is chronic pain and soreness normal for my age and genotype? Is my lack of ability to concentrate normal? What about chronic headaches? I also have immensely painful back and hip pain.
I no longer work outside of my home. My husband is understanding (or seems to be) regarding my many hospitalizations. As one gets older, what does one do to improve quality of life?

You may be experiencing chronic pain from sickle cell disease. This does occur from damage due to prolonged sickling in the bones. I would also think that you and your doctors should consider other causes for the pain. The fact that it is bad in the morning suggests that it may be related to other types of disease like rheumatoid arthritis. I have a number of older patients that have both and respond very well to the treatment of the arthritis. You should have x-rays of hips and shoulders if they hurt to make sure you do not have avascular necrosis from sickle cell.

If none of these are present, you may benefit from treatment with hydroxyurea to decrease the rate of pain associated with sickle cell disease. You also may benefit from a good chronic pain management plan.

- *Lewis Hsu* (MD)
(Sickle Cell Information Center, Georgia, USA)

Our 7 year old daughter is always having a high body temperature. Her body is always warm! Her brothers and sisters keep away from having body contact with her.
She feels isolated from the rest of the family. The doctors say to give her paracetamol, but the effects don't last long. How long shall we continue to give paracetamol when it doesn't solve the problem for more than a few hours?
Other doctors say there's nothing to get worried about. But we are worried. Please advise.

Fever or pyrexia to use the appropriate medical term, is when the body temperature is consistently above 37 degrees centigrade over 18 hours, taken at 6 hours interval.

Prolonged fever is when that raised temperature lasts more than 72 hours in spite of the person having been treated for malaria plus analgesic.
A persistent fever for more than 72 hours is classified as 'Pyrexia of Unknown Origin (PUO). Your daughter who had a persistent hot body for a long time falls into this category.
Most fevers in children are due to self limiting viral infection, characterized by flu-like illness. Prolonged fever which has resisted diagnosis requires thorough investigation.

The child should be taken to a tertiary hospital with facilities for blood culture, and where appropriate, comprehensive clinical examinations would be conducted.

If at the end of it all the child remains feverish, she should be regularly tepid-sponged. Paracetamol should be discontinued. This actually becomes a case of Pyrexia of Unknown Origin (PUO), which, in my more than 40 years of medical practice, I prefer to call Pyrexia of Un-identified Origin.

The parents should then take solace in the fact that every possible cause of the fever has been eliminated.

- Dr. Ojum Ogwo, Nigeria

Bibbs Odyssey:

Casgevy offers SCD patients a chance at long, productive, agony-free lives

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patient who has a debilitating disease for their whole life, or they don't have anything. We've known about that for a long time. So this new technology has always been a little bit of a holy grail.'

The disease has been a terror for parents and children for more than a century. SCD encompasses a range of inherited blood disorders that cause a defect in hemoglobin, a protein that carries oxygen in red blood cells. The defect produces hard, sticky, sickle-shaped red blood cells instead of soft, round, healthy ones. The defective cells die early, which leads to a shortage of red blood cells; and their shape and rigidity make them clog blood vessels, which inhibits blood flow and can cause intense pain, anemia, organ damage, and stroke.

Patients' odds of surviving beyond childhood began to improve after the Civil Rights Movement highlighted racial disparities in health care. In 1972, Congress approved federal programs for sickle cell education, research, treatment, and detection. Screening for newborns, which allows treatment to begin a short time after birth, was in place in all 50 states by the mid-2000s. In 1998, the FDA approved hydroxyurea, a drug developed for cancer treatment that can halve the rate of severe pain episodes in SCD patients.

But as effective as it is, hydroxyurea only manages symptoms. It doesn't cure SCD. All the while, the pain is apparent only to the sufferer.

'If somebody's having sickle cell pain, there's no swelling, no redness,' says Dr. Lewis Hsu, a pediatric hematologist, director of the Pediatric Sickle Cell Program at the University of Illinois Chicago, and chief medical officer for the Maryland-based Sickle Cell Disease Association of America. 'In many cases, there's no change in lab tests. All you have is a patient report. So, there's a lot of misunderstanding and stigma where people just don't believe the person is having this bad pain.'

Since the early 1980s, the only cure for SCD has been a bone marrow transplant from a donor, often a patient's relative. But less than 20% of eligible patients can find matching donors, Hsu says, and even those run the risk of immune rejection or graft-versus-host disease, in which donor immune cells attack the recipient's tissues.

That's what makes the CRISPR/Cas9 treatments so important—potentially revolutionary, Eckrich says. The use of the patients' own cells dramatically reduces the possibility of immune rejection and eliminates the risk of graft-versus-host disease. The FDA's approval of Casgevy means Levine Children's can begin to treat patients as an authorized treatment center, he says.

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Tsuubura, Priceless Hope
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shooting seeds into a hole, but with our fingers). However, I would always feel pain after playing. On some occasions, I would be playing soccer, and then all of a sudden, get pains in my chest or legs. I would be carried home. Situations like these would get people around us to voice many things about my health.

In one instance, I had gone out to play and other kids were like *'Temuzanyanayemulwadde'* which literally means 'do not play with him, he's sick' or 'he cannot play such and such games: he is sick.' This always made me feel very bad. I would overhear people or say *'oy'omwanamulwadde'* meaning 'that child is sick' as I walked by. Because kids didn't want to play with me, I would spend most of the time in Katanga slum, where the kids didn't know about my health issues and thus wouldn't mind playing with me.

As a child, I would get into terrible SCD episodes, where I would cry all night, often asking mum to cut off the limbs that were causing me pain. I always asked, *why am I like this*? Why is it only me who gets this pain? I don't remember ever getting an answer!

This situation was very hard on my mother because her supervisors never understood why she was often absent from work. At one time, they even subjected her to disciplinary action. My mum would cry - mostly because of my health but also because her supervisors did not understand the situation, in addition to what was said in the neighbourhood.

I attended Nakasero Primary school, where in P.7 we had a class of morning math starting at 7am. I would walk from Wandegeya to school very early in the morning; most times I would feel pain in my cheekbones due to the morning coldness even though I was wearing warm clothes. Sometimes my feet would hurt, especially in the rainy season. I would not attend school but my mum would take the initiative to explain to the teachers why I had been away.

When I joined high school, I always had yellow eyes, distended belly and I was the smallest in class. A couple of times, I would have some friends questioning why I looked the way I did. I didn't really have an answer, even though I knew it was sickle cell. I just didn't know how to make them understand. I later went to boarding school, something that was very hard to cope with, because I was sick for most of the time during first term. Fortunately, the school administration was very lenient; they would let my mum visit every two weeks although we had a one visitation rule per month. The school nurse was also very helpful. She was

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Dominick Bibbs Opts In For A Cure

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the effects of chemo to cure SCD can be as debilitating as SCD

'For the last 20 years, our approach has always had to be, for patients with severe disease who would consider having a transplant, to discuss all the risks of having a transplant from somebody else,' he says. 'Now, we're able to consult and see patients and discuss the risks of what we call an autologous transplant—basically getting your own stem cells, after they've been edited, back to you.

'Many of the key parts of the operation are still as difficult and high-risk, but we have expertise in doing them. We've been doing autologous transplants for patients for a long, long time, and we really understand how to do those safely. Some of the complications that patients face afterwards are, frankly, much easier to deal with, so we can do these procedures with much less risk to the patient.'

One of those risks comes from chemotherapy. SCD is not a cancer, but treatment for it often resembles treatment of leukemia; both are diseases in which patients produce insufficient or defective blood cells. When SCD patients prepare to receive stem cell transplants, doctors administer chemo drugs to kill defective stem cells and make room for healthy, modified ones.

But the effects of chemo can be as debilitating as SCD. (For example, Bibbs received doses of the common chemo drug busulfan and spent much of the next year recovering more from the drug than from SCD.) Eckrich and other researchers and clinicians want to refine Casgevy treatment so it requires less chemo.

'If we can treat a patient with sickle cell disease, improve their quality of life, and have the net impact that we've had for many of these patients, and hopefully will continue to have, the future for many of these (blood) diseases is going to be bright,' Eckrich says. 'When you get rid of those barriers—and CRISPR will allow us to genetically get rid of some of those barriers—transplantation becomes much, much easier.'

Charlotte's is one of five St. Jude clinics that have tracked about 1,300 patients in the Sickle Cell Clinical Research and Intervention Program (SCCRIP), which gathers data on the long-term effects of current SCD treatments.

Dominick Bibbs met Dr. Eckrich as he approached his high school graduation. Even with his crises, during which he couldn't make it to class and teachers had to visit his home in San Antonio, he was still on track to graduate on time in 2020. Another doctor treating Bibbs learned about Eckrich's clinical trials at Methodist Children's Hospital and recommended it. Bibbs had to wait until his 18th birthday to enroll. He applied and was accepted. Then COVID delayed many medical procedures, and Bibbs was left with his pain.

At first, Bibbs was hesitant to enter the trials. 'I had to think about it for a little minute,' Bibbs says. 'But then, once it started getting worse, it was at the point where I didn't even think I was going to make it past 18 or 19. … I said, 'There's nothing worse that can happen, so I might as well try it.''

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Bibb's CRISPR Treatment

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The crises stopped that day. Bibbs says he hasn't had one since. But it took him nearly a year to get over the effects of the chemo. He enrolled at Prairie View in the fall, not recovered yet. He got winded just walking to class. 'I was still bald,' he says. 'I got tired very quick.'

Bibbs decided to take the 2020-21 school year off for treatment rather than enroll in college. When his treatment finally began in early 2021, he spent 39 days in the hospital and made visits to an apheresis clinic that withdrew his stem cells. Doctors installed a catheter in his chest for removing and reinjecting blood and cells and for his chemo.

Between visits, he endured more rounds of chemo. In his already weakened state from years of SCD, Bibbs endured the chemo with difficulty. He had no energy, and he developed mouth sores, a common side effect, that made eating difficult. 'Not very fun,' Bibbs says. Meanwhile, doctors in a lab made precise modifications to the DNA in his stem cells so they would produce fetal hemoglobin to prevent 'sickling' and improve blood flow—at least theoretically, curing the disease.

When we speak in early May, Bibbs has just passed his third 'birthday,' April 19, 2021, the day doctors returned the edited cells to him. 'We actually have a video of it,' Searles-Bibbs says. 'They're in this Hydro Flask-type thing, and when you open it, smoke comes out, and then it's just three little vials that his stem cells are in, and they just inject him through his IV to go back through his port into his body.'

The crises stopped that day. Bibbs says he hasn't had one since. But it took him nearly a year to get over the effects of the chemo. He enrolled at Prairie View in the fall, not recovered yet. He got winded just walking to class. 'I was still bald,' he says. 'I got tired very quick.'

By spring 2022, though, he felt his energy coming back. He started to hang out with friends. He joined the historically Black fraternity Kappa Alpha Psi and threw himself into its community projects. In his rare free time, he takes occasional trips to Houston, about an hour away, to eat out. 'I'm a big steak connoisseur,' he says with an impish grin. Before his treatment, he took 10 medications every day. Today, he takes an occasional Motrin for mild chronic pain.

Now comes a mystery that only time will solve: Whether the treatment has cured his SCD or is only a temporary fix. Researchers have no specific reason to suspect it won't last.

'There is an enormous amount of ongoing clinical research still needed in this field for us to understand that these treatments are durable, and potentially curative, without the trade-off. Right now, it appears that's the case,' Eckrich says. 'To understand those questions, we really do need the longitudinal approach, where we have a lot of data over a lot of time to help inform us about which way to go and how to strategize. So, I'm grateful for centers that make that commitment.'

Bibbs is still a young man, and given what he's endured and how little he socialized growing up, he's a bit shy. He's quick to downplay the significance of his treatment, not just for him but others. 'Dominick is a very humble person, and I don't think he realizes the impact he has on the sickle cell world. We're always telling him, 'You need to tell your story.' But he's so nonchalant about it,' Searles-Bibbs says as her son listens. 'He's just, 'OK, I just did what I needed to do,' and it's like he doesn't realize how serious and how much of an impact this has in the sickle cell community and for African Americans.'

The Fortress Called Hope

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Sharifu Tusuubira and advisor John Kelly

caring and compassionate. I am very happy that my former school nurse. Hajjat, now works in the sickle cell children ward at Mulago Hospital where, she has continued to care for many more warriors.

I learned that it is important to be a self-advocate; I started being open about having sickle cell to friends.

The most challenging times were national exam times, because of the extra exam stress. I would break down and get into episodes. In A-Level especially Form 6, I developed chronic back pain from all the reading and sleepless nights. However, at this time I had built a tribe of friends who were very supportive and understood my condition. A month to the national exams, I was admitted in Mulago for almost 3 weeks; I thank Allah that I was able to pass the exams and join Makerere University on a government scholarship.

At Makerere University, I had my turning point into considering engagement into active advocacy. This followed a personal heartbreak moment where a lady I was in love with, told me she couldn't be mine because of sickle cell. This was draining emotionally, I felt like I had no place in the world. This time was very challenging because I didn't have many people who could help me figure out how to get over the situation. I did not know any other sickle cell person who I could relate with. After a brief period of feeling low, I decided that it was time for me to get involved and change the status quo of how sickle cell was perceived.

I was now at University, emotionally things were not going well. Professionally I had a similar challenge. I had so many ideas about what I could do but still did not have any mentors to look up to. This was a challenge I had throughout as a lad growing up with sickle cell. I did not have people with sickle cell to serve as my mentors. I did not have people to give me that feeling that with my sickle cell, I could still make it in life.

I decided to seek out people I could relate with, and this was through professional connections: something that I hoped could help me get where I wanted to be. I hoped that I could be that mentor for other young people growing with sickle cell in Uganda.

Only 20 at the time, I was in the process of finishing my Bachelor's degree at Makerere University. I wanted to proceed to graduate school but my mum had no money. I talked to one of my Professors, Dr. Jesica Nakavuma from a project I was working on. With her support, I was able to secure funding for my master's study from the project. It was a big blessing because I enrolled even before my undergraduate graduation. When I graduated at 21 years of age, I was already sitting exams for my 1st semester of master's class.

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TAHF Goes On Back-To-Back, SCT/SCD Awareness Campaigns All Over Nigeria

When your country bears such a cataclysmic burden of a health condition, as does Nigeria with SCD, you don't leave it to government alone to shoulder the responsibility of sensitization and support.

In an uncommon gesture of solidarity with families affected by SCD, the Temitayo Awosika Help Foundation (TAHF), in collaboration with Access Corporation, traversed the length and breadth of the country, delivering aid to school-aged children and, in the process, directly and indirectly sensitizing Nigerians, old and young about SCT/SCD.

TAHF was established by the Dr. Olubayode Awosika Family in memory of Temitayo Awosika (1980-1999) who lived with sickle cell anaemia.

More about TAHF's nationwide SCT/SCD campaign on the July-Sept 2024 edition of SICKLE CELL NEWS.

Can't Sleep Naturally? Try These Tips

Without good natural sleep, good health is in jeopardy

Here are sgeneral tips for good sleep hygiene that can help promote better, more restful sleep naturally:

Maintain a consistent sleep schedule - Go to bed and wake up at the same time every day, even on weekends. This helps regulate your body's internal clock.

and quiet - Use blackout curtains, turn off electronics, and keep the temperature between 65-70°F. Minimizing distractions and light can improve sleep quality.

Avoid caffeine, nicotine and alcohol close to bedtime - Caffeine and nicotine are stimulants that can keep you

to bedtime as it can be stimulating.
Manage stress and anxiety - Try relaxation techniques like deep breathing, meditation or gentle yoga to calm the mind before bed.

Use your bed only for sleep and sex - Avoid work, TV or other activities in the bedroom to maintain a strong

Create a relaxing bedtime routine - Do calming activities like reading, light stretching, or taking a warm bath 30-60 minutes before bedtime. This cues your body it's time to wind down.
Keep the bedroom cool, dark

awake. Alcohol may help you fall asleep initially but can disrupt sleep later in the night.
Exercise regularly, but not right before bed - Physical activity during the day can promote better sleep, but avoid intense exercise close

association between your bed and sleepiness.
Focusing on these healthy sleep habits can go a long way in helping you achieve more restful, natural sleep without the need for medications.

Laurel Brumant-Palmer:
My Story of Determination & Survival

*Against all odds, **Laurel Brumant Palmer** turned 60 on Boxing Day, 2023, which she attributes to nothing but the grace of God. Laurel studied Graphic Design, Visual Communication and Illustration at the University of West London, where she bagged First Class.*
A committed SCD advocate, Laurel pays scant attention to stigmatization but focuses her attention on what she wants for herself and for the SCD community. In this interview with SICKLE CELL NEWS, she recalls life growing up and what it takes to be an old hand at surviving a perilous health condition ...

By Abro Onyekwe

Diagnosis

I was diagnosed with HbSS at 3 years of age. I had two siblings with SS who are deceased. I grew up in the UK.

I was diagnosed after my first ever painful crisis, which needed admission to hospital. My parents knew very little about Sickle before they got married. The only thing they were really told was that they should not have any more children after my diagnosis of HbSS.

Family

My parents had 3 children prior to me: my eldest sister (SC) and my eldest brother (AS) both born in the Caribbean with my parents having no knowledge of genotype or SCD.

My brother who was 1 year older than me was diagnosed with SC but did not have any real symptoms. It was only when I was born and started suffering from painful crisis that my parents realised that this condition was serious. This meant constant admission to hospital for me and disruption for the entire household. My brother was never admitted to hospital for SC but was regularly admitted to hospital as he suffered from severe Asthma.

My mother gave birth to my two sisters who were AA and AS within the next four years.

Memorable Crises

I wouldn't class any individual sickle crisis as 'memorable'. The excruciating pain and experience are not memories that you ever want to recollect. So those crisis are not given a place in my head as a memory to think of.

Complications

My body has undergone severe battering from SCD. I have had Pneumonia, Gallbladder and Spleen removed; swollen legs that just would not go down so I had to be put in traction for months in hospital.

I had AVN. The hip replacement failed. The implement fractured my femur and I had to have a second operation 12 days later to fix this.

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'I was born with a genetic blood disorder, and I had no choice but live with the cards that I was dealt'

- Laurel B. Palmer

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Hospital Admissions

To give a rough guess, my admissions would be in the hundreds. I can recollect as a child spending at least a couple of weeks every month in hospital with a crisis. This was less frequent as a teenager because of the effective treatment I began receiving.

At around the age of 16 I began to have regular top up blood transfusions to control the severity and frequency of my crisis. This then led to me having Exchange transfusions until the age of 48 then my veins packed up and my groin could no longer be accessed to administer treatment.

Discrimination

I personally have experienced very little discrimination or stigmatization for having Sickle Cell. I know many people who have, and I do not condone any form of discrimination or stigmatization.

World view

I grab life with both hands and give thanks every day for even the smallest blessings. The rain and storms will come, we cannot prevent them but if you try to stand strong and overcome the torrential rain and wind you will grow with experience.

A positive mindset will help to fertilize your growth. I was born with a genetic blood disorder, and I had no choice but live with the cards that I was dealt. It hurt so bad when the cards fell. I experienced several loses during the game. But I picked those cards up and many people helped me to navigate the way I played.

Marriage

We did check my partner's genotype and had a lot of discussions. I did not want to bring a child into this world with Sickle Cell Disease, to pass through what I did.

'I did not want to bring a child into this world with Sickle Cell Disease, to pass through what I did'

Carrier Unions

I have no right to be judgmental about the choices that anybody makes. However, I believe that anyone that has experienced sickle cell crisis would never ever want to inflict that form of excruciating pain that takes you to hell and back on any human being. Not for all the love or money in the world.

It is not only knowing about the risks to their offspring it is also about having to watch your offspring suffer horrendously for the sake of love and knowing that you were aware and made that choice on their life.

That would be crazy! Let them spend some time on a Sickle Cell ward and I can assure you they will change their minds.

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'I really did not see any future for me, but I also never gave up'

- Laurent B. Palmer, Sickle Cell Warrior, 60

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50/50 Chances

I was given a 50/50 chance on many occasions in hospital by my consultants, especially when I was a child. My crisis and level of pain was out of this world and many times I would be diagnosed as critically ill and was not expected to pull through.

Luck Not Involved

Firstly, I do not believe that my life or living this long has anything to do with 'luck'. If that was the case, I can guarantee you that my 'luck' should have run out a long time ago.

With God there is no 'luck'. He alone determines when our story begins and when our story ends.

The environment and my mindset also contributed to my strength to fight and press on no matter how difficult things became.

My amazing family, the love support and care of incredible parents and siblings who were there for me when I was not well; the medical team who cared for me and made me feel as if I was part of an extended family; my husband, children, friends all those who helped me through my journey in a positive way.

A word to new parents

Once upon a time my parents were also a little anxious but that was because nobody was surviving beyond a certain age with Sickle Cell.

I have been through so many complications and my story of survival has been incredible.

In my younger years, I was unable to visualize a life or future living with Sickle Cell Disease. Pain was my life and it felt as if there was no space for anything else. I really did not see any future for me, but I also never gave up.

Do not let anxiety take over your special relationship or quality of time with your child. Try not to wrap them up too much in cotton wool but at the same time really ensure that they are 100% educated about Sickle Cell and know that they are special and loved.

Never ever give up and always believe and have hope that things can only get better when they seem at their worst. Try to be as positive as possible and help your child to also be as positive as they can. They will respond to whatever you are surrounding them with.

Ibadan, Nigeria, WSCD 2024 SCHAF, Ogundoyin Family Hold Celebrations

Members of the top echelons of the Oyo State government from the Deputy Governor to Commissioners, Permanent Secretaries and members of the State House of Assembly witnessed the marking of World Sickle Cell Day 2024. It was, incidentally, the 33rd anniversary of the passing of business mogul, industrialist and arch philanthropist, Chief Adeseun Ogundoyin (1940 - 1991). Ogundoyin bravely lived the sickle cell challenge, an achiever whose business acumen is still spoken of to this day. His son, Debo Ogundoyin, 37, is the Speaker of Oyo State House of Assembly (OYSHA) and Chairman, Conference of Speakers of all State Legislatures of Nigeria.

Ogunlesi Hall, venue of the auspicious event, was jam-packed with researchers, lecturers, retired academicians, royalty, secondary school students and teachers, the crème de la crème of civil servants, security personnel, chaplains of religious institutions, and, of course, Sickle Cell Warriors on the most important day on the global SCD calendar. At least two Vice Chancellors of Nigerian universities added an ivory tower coloration to the occasion.

In his opening speech, Deputy Governor Abdulraheem Adebayo Adeleke Lawal recalled that the late Adeseun Ogundoyin had the Midas touch in business. Dabbling into politics, he sponsored candidates to electoral office, including sponsoring a presidential candidate. Deputy Governor Lawal also recalled that Ogundoyin once bought 10 brand new Mercedez Benz cars for his friends as a surprise - almost like a prank.

Rt. Hon Debo Ogundoyin recalled that he was only 4 years old when his father passed on.

'I hardly knew my dad,' he said.

However, individuals like Prince Dotun Oyelade, Oyo State Information Commissioner, filled in the gaps, painting the picture of a man who relentlessly pursued his goals, a successful man who gave generously and endlessly to people and causes close to heart.

OYSHA donated N1 million to further SCHAF's SCD awareness and advocacy

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Dr. Tusuubira with Nurse Practitioner Donna McCurry

Sharif Tusuubira: the colour of hope

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it is important for anyone living with sickle cell especially in Africa to dream big and challenge the narrative ...

ThroughD my work, I have received numerous honours and awards: in 2017 I was selected for the prestigious Mandela Washington Fellowship a program run by the United States Department of State, where top leaders are selected from across Africa for professional development experience in the USA.

I also received the 2018 Clarke International University award for most outstanding community outreach. In 2020, I received the International Sickle Cell Advocate of the Year award at the 7th Sickle Cell Advocates of the Year awards courtesy Sickle Cell 101. I have also been named among the *100 Leaders of Impact in 2021* by the Global Thinkers Forum.

During the Mandela Fellowship, I met Ruby Goka an award-winning author from Ghana who has worked with me on two books, a children's picture book and young adult book for sickle cell awareness in Uganda. The children's book is meant to be given out to children at sickle cell centers to help them understand the condition while the young adult book is meant to be given out in schools to help students understand this condition.

I also met with Donna McCurry a sickle cell nurse practitioner, and she has since grown to become a close friend and colleague. My interactions with her have been key in helping me understand the value of home management in sickle cell care. I spent most of the past two years developing programming around this theme. Donna has been key in helping me learn and continue active advocacy with Sickle Cell Midwest (Uriel E. Owens Sickle Cell Disease Association of the Midwest).

In 2024, graduated with a Ph.D. in Genetics from the University of Kansas.

These five years have a roller coaster of health issues from chronic priapism, advanced retinopathy, stroke that impaired my vision and ability to use my right hand. *Alhamdulillah,* despite all those odds, I was able to finish the program in time. My wife Sophia and kids have been my biggest supporters through this journey.

I will be moving on to work in pharmaceutical manufacturing, where I hope to impact the lives of other patients like me through enabling access to life changing therapies.

Looking back, I have come to understand that it is important for anyone living with sickle cell especially in Africa to dream big and challenge the narrative. It is important for young people to become proactive and take charge championing innovate solutions to sickle cell challenges. Above all, it is our responsibility to become role models for all young warriors across the globe.

SCAHF, OGUNDOYIN FAMILY MARK WSCD

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activities while the Ogundoyins donated N5 million for the 'empowerment of sickle cell patients'.

Donations by the Oyo State Government and from the Ministry of Social Welfare and Poverty Alleviation were not made public.

500 Sickle Cell Warriors received cash gifts and routine medication for 3 months. Nearly a dozen scions of the Adeseun Ogundoyin Family graced the event. The family pledged to be fully involved, henceforth, in annual WSCD activities.

SICKLE CELL

continued from page 19

SCD is a disease that worsens over time. Treatments are available that can prevent complications and lengthen the lives of those who have this condition. These treatment options and their effects can be different for each person, depending on the symptoms and severity of their disease. It is important to understand the benefits and risks of each treatment option.

Currently, the USFDA has approved four treatments for SCD:

Hydroxyurea may help people with SCD ages 2 years and older.

L-glutamine or ENDARI® may help people with SCD ages 5 years and older.

Voxelotor, or OXBRYTA® may help people with SCD ages 4 years and older.

Crizanlizumab, or ADAKVEO® may help people with SCD ages 16 years and older.

Several other treatments and therapies for SCD have recently been developed that are still undergoing clinical trials and thus have not yet been approved by the FDA.

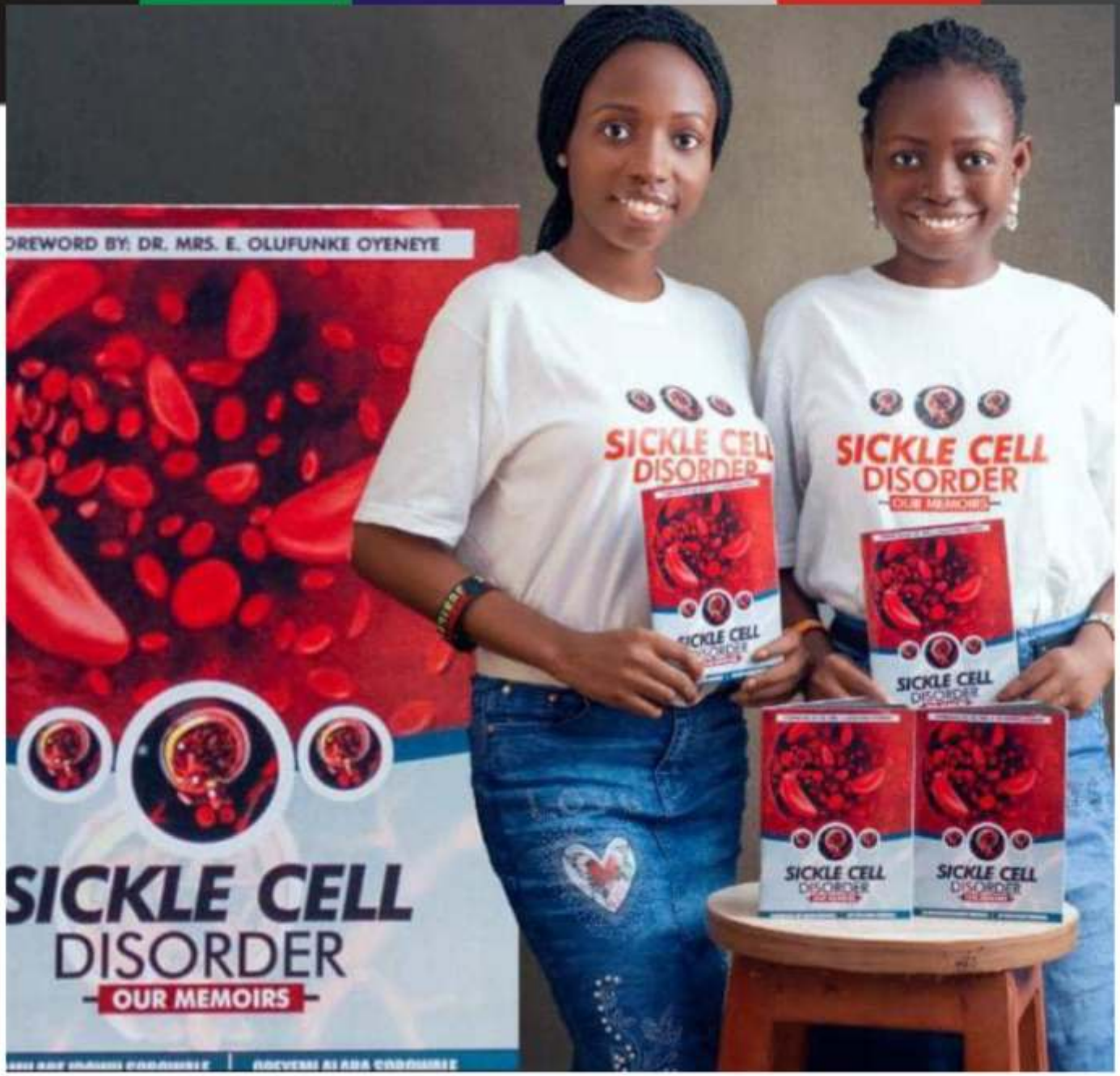
Sickle Cell Cure

The only therapy approved by the FDA that may be able to cure SCD is a bone marrow or stem cell transplant.

Bone marrow is a soft, fatty tissue inside the center of the bones, where blood cells are made. A bone marrow or stem cell transplant is a procedure that takes healthy cells that form blood from one person—the donor—and puts them into someone whose bone marrow is not working properly.

Bone marrow or stem cell transplants are very risky and can have serious side effects, including death. For the transplant to work, the bone marrow must be a close match. Usually, the best donor is a brother or sister. Bone marrow or stem cell transplants are most common in cases of severe SCD for children who have minimal organ damage from the disease.

https://www.cdc.gov/ncbddd/sicklecell/facts.html



Sickle Cell Disorder:

Our Memoirs

By

Oluwadamilare Idowu & Opeyemi Alaba ***Sobowale***

Two Sisters, A brilliant Chartered Accountant and a consummate Fashions Designer/Animal Health Technology graduate Merge Pens to Write a Compelling Memoir

Our parents gave birth to 5 Sickle Cell Warriors. My sister, a chartered accountant, and I are the sole survivors.

Stigmatization is a major challenge we have living with this condition.

While in school, I wrote some of my exams on hospital bed. When people look at my CV, they are surprised that someone with SCD can do so well.

I have been in a relationship that ended when the guy asked, 'If we get married who will pay your hospital bills?'

I didn't initially take the question serious but when he asked repeatedly, I knew it was time to call it quits. I would rather stay single and not be verbally and emotionally harangued at every turn.

When I was born, I was declared AA from one of the popular laboratories in Lagos. At the age of 3, I showed my true colours, prompting a rerun of my genotype. SS.

My family's sickle cell journey is incomplete without the doggedness and ruggedness of a lioness God blessed us with. Our

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OLUWATOYIN OSHINOWO

rare breed, rare genotype

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'Life With SCD Not a Walk in the Park'

Toyin Oshinowo is all in support of making genotype a big issue in marriage - of not deliberately bringing a child into the world to contend with preventable health challenges.

'I can tell you that living with sickle cell is no picnic - I have many memories to share, memories of raw agony, of limitations, of struggling to keep up in a society not meant for folks with a health deficit ...'

Toyin is unhappy with the situation in which SCD is not counted as a disability in Nigeria, which would have granted Warriors many custom privileges.

Saddled with, nay, *blessed* with a special child with an extremely uncommon Hb for an African, Toyin's dad dived deep into research and traced the origins of her Thalassemia gene to Ijebu-land.

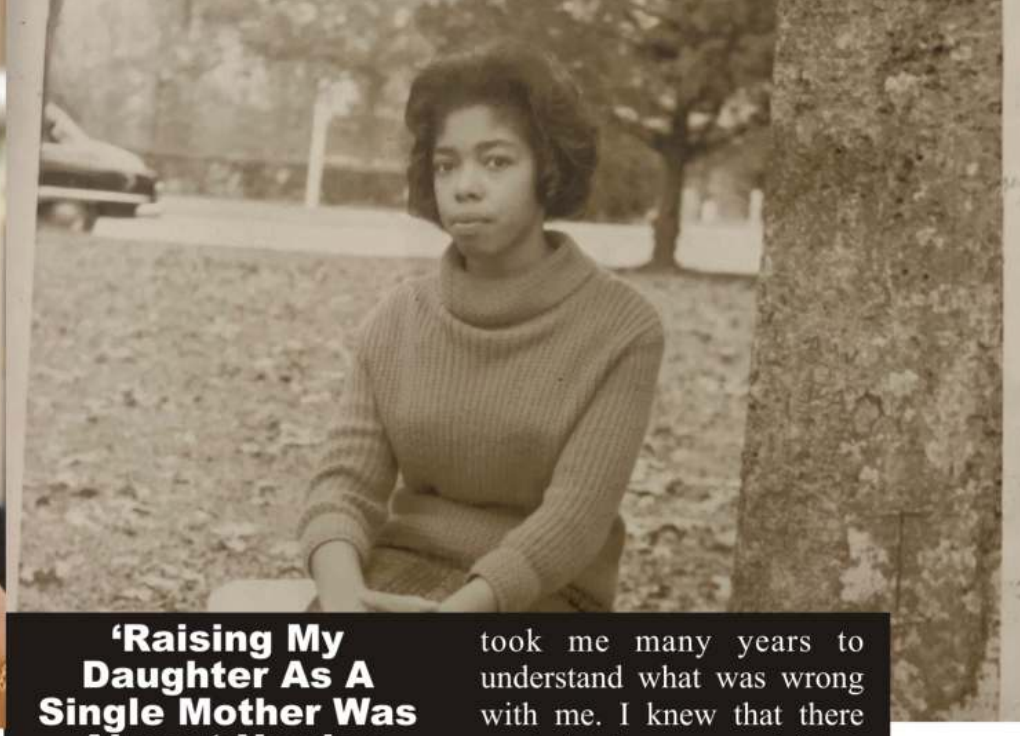
Despite all the ups and downs that come with sickling, Toyin worked super hard and obtained a doctorate in Engineering. An *agbalumo* junkie, Toyin leads a busy life, what with tentacles in financial services, product management and blogging.

blown SS symptoms in England, the parents' Hb was retested. Father, AS, Mom, AThalassemia (AThal) - the child was SThalassemia (SThal)!!

44 years on, few genotype machines in her country of birth, including in Teaching Hospitals, can detect Toyin's variety of SCD. Ordinarily, it isn't the kind of Hb you'd find in an African - her Hb was more to be found in the Middle East and Asia.

With her proper diagnosis, doctors assured the parents that the child's symptoms will be 'very mild', the family had nothing, nothing to worry about. How wrong the experts proved to be!

Toyin has struggled with practically similar issues of pain crisis, severe shortage of blood, repeated infections as any typical SS Warrior. She once had a crises episode which left her comatose for three days. In all, she spent one week at the US hospital. Her bill: a whopping $36000!



Judy Gray Johnson

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frequent and more severe.'

Through all the ebb and tide, the octogenarian has remained steadfast in fighting for fair treatment and dignity for people with SCD in America and throughout the world. Her memoirs, *Living With Sickle Cell Disease - the struggle to survive* is a classic of fortitude in the face of adversity. Her other book, *Resilience: How To Cope With SCD* is a manual on helping the child with sickle cell (and other disabilities for that matter) be the best they can be.

A health advocate and public speaker for over 50 years, Johnson has a Bachelor's degree in Elementary Education, a Master's degree in Special Education and finished coursework for a doctorate in Educational Administration and Supervision.

Johnson traces her roots to Cameroun, West Africa. Her only child, Loree, 53, is a medical doctor.

'Raising My Daughter As A Single Mother Was Almost Harder Than My Struggle With SCD'

*In this interview with **Tosin Fawemida,** Ms Judy Gray Johnson dwells more on her SCD worldview.*

How do you feel when you hear of babies being born with SCD these days?

I wonder how prepared the parents are to take care of this child. I shudder to think about what these babies will go through in life: a life of pain, doctors, and hospitals... It is critical that we continue advocacy for awareness so that prospective parents will know what to expect down the road if they choose to walk that road.

81 years with SCD - what does it take to survive this disorder?

There has to be a strong determination to survive. I knew that I could not fight all battles. Therefore, I concentrated on that which I could do something about. It took me many years to understand what was wrong with me. I knew that there needed to be a cure, which at that time did not exist. I wanted to blame someone for my illness but could not. It was no one's fault. My time was spent learning how to survive rather than blaming others for my problems.

What would you say is the most serious challenge you faced living with Sickle Cell?

The most serious challenge has been trying to raise a child as a single parent and holding down a job so that I could take care of my daughter. Unfortunately, there is a lot of discrimination in the work place and I rarely talked about my illness. I did not want anyone to think I could not handle a job because of SCD.

If you had your life to live all over, would you like to face the SCD puzzle again?

No, I would not like to engage with SCD again. But, what choice would I have? I would do whatever was necessary to survive.

'Sickle Cell means much more than can be expressed in words. Living with Sickle Cell is not a walk in the park'

Two Warrior Sisters Put Pen to Paper

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Mum. She kept reassuring us that we won't die but live to thrive. She quit her job to focus on taking care of us. People advised her to cast us aside to hasten our return to where we came from!

'These ones are here to stay,' she used to tell them, quietly but determinedly.

Many times my sister and I will fall ill at the same time. I remember how mum slept on the hospital floor just to look after us. I remember when I was to receive transfusion on one of my major crisis. The medical personnel remarked the blood was still cold and can't be used until it was warm. Mum took the blood and wrapped it in her abdomen for minutes. Soon the blood was warm enough to use.

Sickle Cell means much more than can be expressed in words. Living with Sickle Cell is not a walk in the park. This was why we wrote *Sickle Cell Disorder: Our Memoirs* - to shine a light upon SCD from a family angle, to add our quota to efforts to enlighten an ignorant/unconcerned world about the world's most-commonly inherited blood condition. Mum duelled with SCD in her offspring for more than 3 decades. She passed away in 2023, after completing her assignment over her surviving Warriors.

On WSCD (June 19, 2024), we invited an elderly woman living with Sickle Cell Disorder to share her journey with us. In audience were Warriors from far and near.

Sickle Cell is not the end of the world, lets' endeavour to make every day count.

I am delighted to share that my sister and I have not been hospitalized for the past two years - to God be the glory!

Opeyemi Alaba Sobowale is a graduate of Animal Health Technology and runs a Fashion House in Lagos. She makes beautiful dresses, headwear and bags. She can be reached on +2349098737506

On WSCD 2024, we invited an elderly woman living with Sickle Cell Disorder to share her journey with us. In audience were Warriors from far and near

Her Excellency, Mrs. Bamidele Abiodun

Abeokuta, June 19 2024

Ogun State Glows On WSCD 2024

.....AGLOW, TAHF, OTHERS COLLABORATE TO MARK A REMARKABLE DAY

Sickle Cell Warriors and Champions from across Ògùn State Nigeria trooped to the state capital Abeokuta, for a landmark WSCD celebration. They came from far and near, many from LGAs bordering Lagos and Oyo State to June 12 Cultural Centre, Kuto.

Crops of journalists from government and private print and electronic media were on hand to cover an event graced by First Lady, Her Excellency Mrs. Bamidele Abiodun.

All the way from Lagos, officers of Temitayo Awosika Help Foundation (TAHF), led by Executive Secretary, Dr. Sola Adebekun, were there as well, with a mission to gift school bags and accessories to school aged Warriors, part of TAHF's phenomenal nationwide outreach.

The keynote address was delivered by Dr. Mrs. Funkẹ Oyeneye, AGLOW Sickle Cell Club's Founder/CEO (*see keynote address on page 47*) while goodwill messages came from TAHF, UNFPA and the Sickle Cell Club of Ijebu-land.

Her Excellency, Mrs. Abiodun encouraged Warriors to be the best version of themselves and pledged her support for their well-being. She also called for collaboration across the board to to tackle the worrying prevalence of SCD in Nigeria. as well as ensure a better life for individuals and families affected by the genetic blood disorder.

The Governor's wife noted that it was important to speak with one voice to advance sickle cell care, eliminate stigma and encourage all living the sickle cell challenge in Nigeria and Africa as a whole.

'Let's Harness The Spirit of Scientific Inquiry to Create A Better Life for People With SCD'

Text of Keynote Address at the 2024 World Sickle Cell Day Celebrations, held at the June 12 Cultural Centre Kuto, Abeokuta, Nigeria on WSCD, June 19, 2024.

By
Dr. Mrs. Elizabeth Olufunke Oyeneye, Aglow Sickle Cell Club, Abeokuta, Nigeria.

Introduction

I would like to extend my gratitude to Her Excellency, the wife of the governor of Ogun State, Mrs. Bamidele Abiodun the convener of this laudable event, Ajose Foundation, MOT Foundation, UNFPA, Temitayo Awosika Help Foundation, Aglow Sickle Cell Club, Sickle Cell Club of Ijebuland, Federal Medical Centre Sickle Cell Club and other Sickle Cell Clubs in Ogun State, the tireless researchers, the compassionate healthcare providers, and, most importantly, the courageous individuals and families affected by sickle cell disorder.

Sickle cell disease, a debilitating inherited blood disorder, has cast an indelible mark on the African populace, a consequence of the evolutionary genetic advantages conferred by the sickle cell trait in mitigating the detrimental effects of malaria (Pauling et al., 1949). This double-edged inheritance has exacted a hefty toll, with SCD representing a leading cause of mortality and morbidity across much of the continent. Yet, the path from initial descriptions to modern disease management has been a sprawling, multifaceted venture spanning centuries of incremental progress.

Beacons of Hope

On this World Sickle Cell Day 2024, as we gather here in Ogun State, Nigeria, a nation that has borne a disproportionate share of the SCD burden, we must harness this momentum and embrace a future where people living with SCD across Africa can transcend their affliction and realize their full potentials. No longer must they be consigned to a life of brevity and suffering.

The journey has been long, fraught with formidable obstacles that have tested our collective resolve. Yet, the resilience of SCD warriors and their loved ones, coupled with the indomitable spirit of scientific inquiry, has propelled us to this pivotal juncture. We stand at the cusp of unprecedented breakthroughs, armed with cutting-edge technologies and a growing global commitment to alleviate the scourge of this condition.

Let this World Sickle Cell Day 2024 serve as a rallying cry, a beacon of hope that illuminates the path forward. Through sustained investments in research, clinical infrastructure, and awareness campaigns, we can usher in a new era where SCD is no longer a death sentence, but a manageable condition that need not preclude a fulfilling and productive life.

First, we must prioritize research and innovation. We need more effective treatments, better

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'Nigeria ... must harness this momentum and embrace a future where people living with SCD across Africa can realize their full potentials'

WE REIGN SICKLE CELL CORPORATION

THROUGH CRISIS & PAIN, TOGETHER WE REIGN

WORLD SICKLE CELL DAY:

We Reign Sickle Cell Corporation Educates 1000+ about SCD

By Tosin Fawemida

Crestview, Florida, USA
19 June 2024

To mark World Sickle Cell Day 2024, the **We Reign Sickle Cell Corporation** held an event to galvanize public interest in sickle cell disease.

The purpose of We Reign is to increase SCD awareness, provide a network for sickle cell clients and develop a system of services that will assist adolescents living with the disease through their transition from pediatric to adult clinical services.

'Our mission is to be a central hub with a global reach to connect community based organizations (CBOs) to individuals out of reach, to increase advocacy, and develop channels for the advancement of research of improved treatments,' says Founder/Chairman, Allison Morris.

A community advocate with over 30 years of volunteering efforts in the local community and an avid supporter of the arts, Allison Morris earned Magna Cum Laude to obtain an Associates in Applied Science in Industrial Management Technology.

We Reign Board members include Founder/Vice-Chairman, De'Carlo Garcia, an Electronic Avionics graduate, Wanjiku Jackson, caregiver to a Sickle Cell Warrior and a Master of Science in Management, Tarah Paine and Katrina Kirby.

We Reign Sickle Cell Corporation marked World Sickle Cell Day 2024 alongside the local community to also celebrate **Juneteenth** which falls on the same day. It has proven to be a significant day to address issues that affect people from around the world and are continuing to deal with and thrive with.

'Let's continue raising awareness and supporting those affected by both sickle cell trait and sickle cell disease,' Allison Morris says.

Bowen University, Iwo, Nigeria
19 June 2024

Bowen Champion Group Marks World Sickle Cell Day

Organized by Bowen Champion Group, events marking WSCD 2024 took place at Bowen University Worship Centre and Bowen Radio 101.9 FM.

The commemorations began early with Public Enlightenment and free Genotype Testing in Iwo, Osun State, Nigeria. It was all in the spirit of raising awareness about sickle cell disease and, crucially, of promoting premarital screening for the condition.

Features of the Public Enlightenment included:

- Video clips from prominent healthcare professionals and board members of the Bowen Champion Group.
- The burden of sickle cell disease.
- Clinical manifestations of the condition.
- Pattern of inheritance of sickle cell disease.
- Prevention of Sickle Cell Disease
- Premarital screening and Counseling
- Recent advances in the management of sickle cell disease.
- Lived experience and testimonials

Affiliated with the Nigerian Baptist Convention, Bowen University was established in 2001. Its 4500-strong student population takes courses in various fields including Engineering, Medicine, Law and the Arts.

STAND TALL, CHEER UP, AND SPEAK UP!!! PUBLIC SCHOOL WARRIORS!! STAND TALL!! CHEER UP!!! SPEAK UP!!!

2024 Public Schools Sickle Cell Annual Congress: Welcome Address

By Rev. Mrs. Adebimpe Abraham-Alowonle

Permit me to appreciate God, the giver and preserver of lives for this opportunity. I would also want to appreciate all the principals seated here for all your support and care. I want to appreciate all school counselors, facilitators, friends of sickle cell association, parents/caregivers and all warriors seated here today. Allow me to welcome you to the 2024 Public Schools' Sickle Cell Congress titled: **Rising Above the 'Red Curve Challenges'.**

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Ikorodu Public Schools Mark WSCD

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This year's theme was birthed by the ugly reports we kept receiving on the poor psychological management of sickle cell disorder by some Warriors. I would like to mention a few of these issues like suicidal tendencies, academic withdrawal, educational termination, mental disorder etc. We have experienced facilitators here who will be handling these sessions and talking to us about them. No Warrior is expected to stop schooling nor should any take their life.

The counselors here will be given the opportunity to give reports on the sickle cell events happening in their schools. We initially experienced some issues on getting permission to function from the Lagos State Government, however to the glory of God, this has been granted to us.

We will be inaugurating and co-opting our school counselors into our Awareness team in order to have them visit other public schools as well. We applaud the **Temitayo Awosika Help Foundation (TAHF)** for the gifts of school bags, note books, mathematical sets, pens etc that were given out to our warriors. We still seek absolute support from our parents and care givers.

On 19 June 2024, in celebration of world Sickle Cell Day, students of Majidun Senior Grammar School presented tuition fee to Warrior Tobi Akintunde, to pay his school fees and enable him pursue studies in Banking and Finance at Yaba College of Technology. This demonstrates solidarity with a brilliant but financially-challenged fellow student.

No Warrior is permitted to withdraw from schooling as a result of their Red Curved challenge. None is permitted to be bullied or intimidated.

Henceforth, our slogan to rise above the Red Curved Challenge shall be:

STAND TALL, CHEER UP, AND SPEAK UP!!!
PUBLIC SCHOOL WARRIORS!!
STAND TALL!!
CHEER UP!!!
SPEAK UP!!!

Rev. Mrs. Abraham-Alowonle is Founder/Convener, Ikorodu Public Schools Sickle Cell Club

Time to Tackle the SCD Conundrum

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management strategies, and a cure. We must explore new technologies, like gene editing and gene therapy, and invest in clinical trials especially in Nigeria.

Second, we must improve access to quality healthcare. The Governor of Ogun State, Prince Dapo Abiodun, CON, through the Ogun State Health Insurance Agency (OGSHIA) has improved access to care greatly for people living with SCD, pregnant women and all citizen of Ogun State. This was not the case hitherto as health insurance providers gave no hope to sufferers as they feared frequent hospital visits from them. Strengthen healthcare systems, training of healthcare professionals, and ensuring equal access to treatment and care as presently being practised in Ogun State.

Third, we must amplify the voices of patients and families affected by Sickle Cell Disease. We must support patient advocacy groups, raise awareness, and reduce stigma. The office of the wife of the Governor, Ogun State and Ajose Foundation is supporting advocacy for people living with SCD. Well-meaning citizens and philanthropists are equally supporting the course of SCD in Ogun State. Numerous Sickle Cell Clubs in the State are contributing their quotas through public enlightenment, research, care, support group and experience sharing, training, among other support to the SCD community.

Fourth, we must drive policy changes that prioritize Sickle Cell research and treatment. We must work with governments, international organizations, and non-governmental organizations (NGOs) to ensure that Sickle Cell Disease is a global health priority towards ameliorating its effects.

In this audacious quest, we must remain resolute, undeterred by the obstacles that may arise. For the sake of the millions afflicted, for the sake of generations yet unborn, we must persevere. Together, through an unwavering spirit of collaboration and compassion, we can rewrite the narrative of sickle cell disease in Africa, transforming anguish into hope, suffering into resilience.

'In this audacious quest, we must remain resolute, undeterred by the obstacles that may arise. For the sake of the millions afflicted, for the sake of generations yet unborn, we must persevere'

The road ahead is hard, but the destination is a world where no child is denied the opportunity to dream, to thrive, and to leave an indelible mark on humanity. On this World Sickle Cell Day 2024, let us renew our vow to make that world a reality.

Thank you.

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