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SICKLE CELL NEWS & WORLD REPORT

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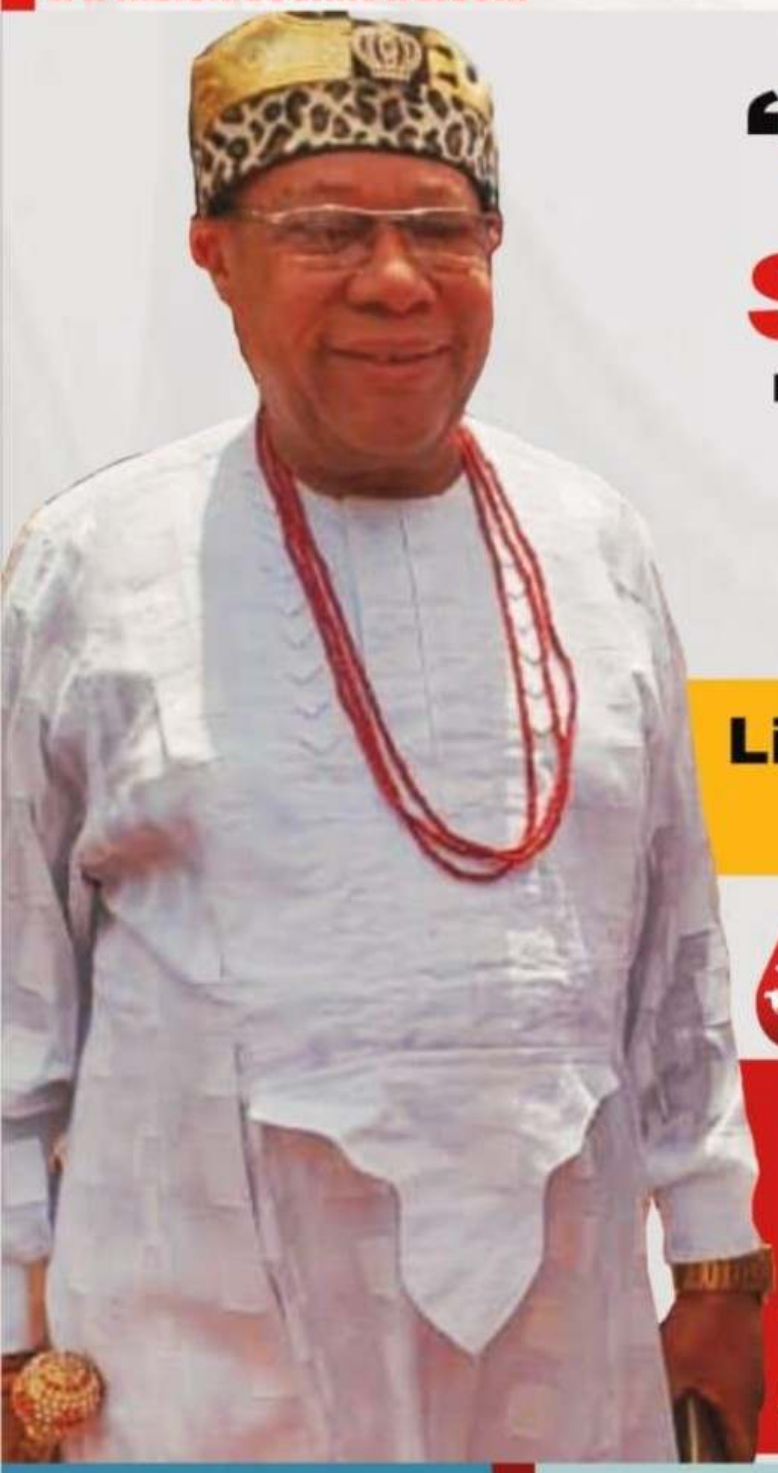

'SCT Awareness Is Crucial For SCD Prevention

Desperation Makes People Believe in Miracles That Don't Exist ...'

- HRH Eze Obinna Eziakonwa
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Living Healthy In Spite Of Kidney Issues

THALASSAEMIA INTERNATIONAL FEDERATION

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SCD and The Social Model Of Disability

- Toluwalope Onuwe,
University of Bristol, UK

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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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'I Discovered Sickle Cell Demands Lots Of Deliberate Self-Care ...'

- Beatrice Olumhense

I first heard about sickle cell disease as a child but felt its impact more than I could actually understand it. Nevertheless, as I grew older, I comprehended that it was a lifetime condition that demanded a lot of deliberate self-care to live the best version of oneself. I have adopted the term '*Sickle Cell Warrior*' because we are veritable troopers trying to make it through life with this disorder.

Beyond the major impact of SCD on Warriors, very little is discussed about the tremendous economic and emotional toll on families with sickle cell offspring. It has consequences on the parents' dreams for their family, their careers, and other children in the family. I have witnessed deep mental health scars on patients and parents abandoning their marriages due to a lack of knowledge and maturity required to cope with the issues raised by SCD.

Beyond accurate pre-marital and child diagnosis, there should be more emphasis on supporting caregivers. I hope we get to a place where government offers free healthcare packages till graduation from tertiary institutions, and affordable HMO plans that are accessible across the country. The cost of this lack of care is felt in the missing productivity of the millions living with SCD in Nigeria and the in the ruined families who find it hard to uplift themselves from the lifelong cost implications.

Sickle Cell Warrior Beatrice Olumhense is a marketing leader and founder of a luxury home fragrance brand known as PatrickRow Maison. She writes from Lagos, Nigeria

SICKLE CELL NEWS Not Meant Primarily For People With Sickle Cell!

Ayoola Olajide

A lot of our readers out there believe that this publication is exclusively for Sickle Cell Warriors. Wrong, dead wrong!

Granted that SCWs may benefit from the contents, *Sickle Cell News* is actually meant for those without sickle cell: the AAs and ASs of the world, particularly the latter, whether or not they are aware of their blood genotype.

With the ever-rising cost of production, especially in an importation-addicted, dollar-dependent economy, what better way to reach out to our target audience in their homes and offices or in transit than online!

The Sickle Cell Education Centre (**https://education.sicklecellnews.com/free-download**) emerged as a result of the burning desire to fellowship with those who are ignorant of SCD, though have it lurking within them.

Anyone, anywhere, as far as they have access to the internet, can read, download or share this unique addition to global sickle cell education and awareness.

Appreciation to **Baats Clinical Engineering Ltd,** Ibadan, plus the Lagos-based **Fidson Pharmaceuticals Plc**, **Health Forever Product Ltd,** and **SIFAX Group**, for making this possible. You deserve your slots on the Sickle Cell Awareness Hall of Fame!

To partner with us on the formidable journey of extinguishing ignorance of this 100% preventable health condition, do email us at ***sicklecellnews@gmail.com***

LETTERS BEARING NAME AND ADDRESS OF THE WRITER SHOULD BE EMAILED TO:

scdjournal@yahoo.com

Botched BMT

Your cover story, *Botched Bone Marrow Transplant - Negligence, Lies or Overconfidence?* makes interesting reading. As a parent considering BMT for my daughters, I want to assume that BMT of 13 years ago, when the subject underwent BMT, is very different from the same procedure today.

I concede, though, that while success rates are ever on the rise, we are yet to get to a 100% confidence level, so to say. Will we ever get there, anyway?

Chinedum Ohafia
Kumasi, Ghana

Admitting Mistakes

As they say, no human being - and definitely no human institution - is above error. It would have been a good idea if the Cancer Centre that undertook Princess Chinwendu Eke's BMT had apologized to the family. Perhaps they are apprehensive of the legal implications of tendering an apology? Perhaps they want to avoid setting a precedent at all cost?

Government allowing the Centre to shield behind a quickly-formulated law barring prosecution has not helped matters.

Anyway, the family should simply take heart and move on.

Ayao Acheampong
Abengourou, Cote D'Ivoire

When BMT Fails

BMT failure is a nightmare for a committed medical team; perhaps more so for the family. The prayer of millions is for the cost to go down and for the success rate to rise to 100%. Hopefully, one day, we will get there.

Foluso Usanga
Makurdi, Nigeria

India Eradicates SCD By 2047

India's much-publicized policy to end SCD within two decades is both laudable and laughable at the same time. India's health authorities are probably not unaware that sickle cell is neither a lifestyle nor acquired health condition to wipe out in a couple of years, so why make a publicity stunt of this dream?

Nevertheless, if the world's third biggest SCD subcontinent manages to reduce SCD incidence to the barest minimum by 2047, that would be an achievement of no mean significance.

Good luck, India, the world is watching!

Sharafdeen Lalonpe
Erin-Ile, Nigeria

Nigeria Goes For BMT

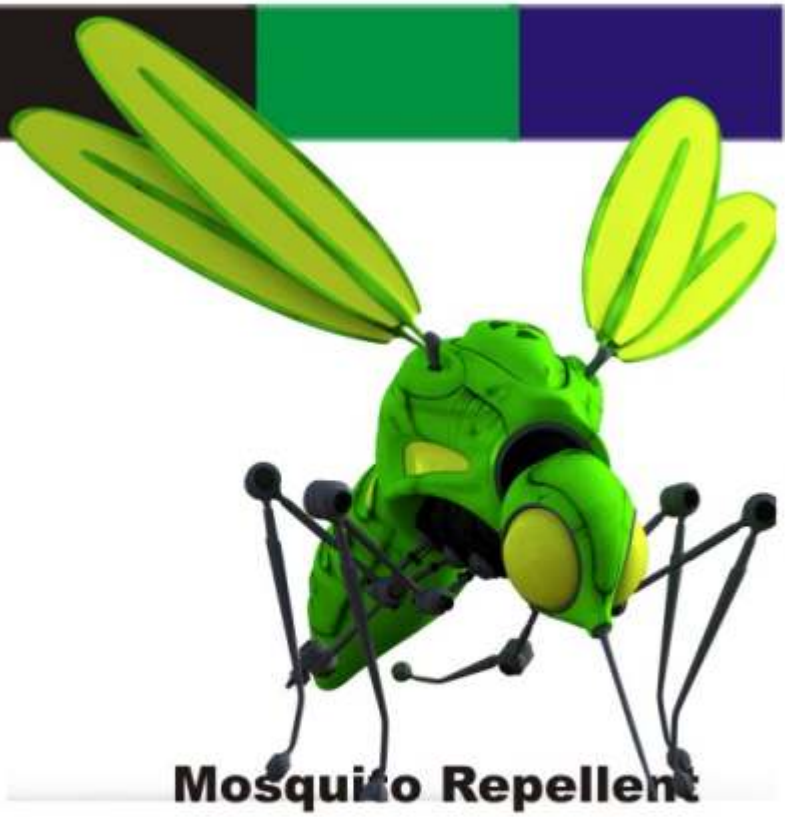
It is a good idea for Nigeria to go into the lucrative BMT trade, if only for the sake of its own citizens. The drainage of millions of dollars' worth of foreign exchange to other countries will finally be plugged.

Other countries in the West African subregion will benefit hugely from a next-door neighbor offering such vital services.

In the long and short run, this move is a plus for every West African family with SCD in their closets.

Hopefully, the services will be as reliable as those received in other countries.

Boubba Ahmed
Birnin Konni, Niger



Mosquito Repellent Industry Earnings To Exceed $6b by 2027

- EINPRESSWIRE

According to a new report published by Allied Market Research, titled, '*Mosquito Repellent Market by Type and Distribution Channel: Global Opportunity Analysis and Industry Forecast, 2020–2027*', the global mosquito repellent market is projected to reach $6.0 billion by 2027, registering a CAGR of 5.6% from 2020 to 2027. In recent years, the demand for mosquito repellents has increased due to rise in incidences of mosquito borne diseases, such as zika virus, malaria, dengue, west Nile fever, and others in countries such as Europe, Asia, and North America. The impact of mosquito borne diseases is expected to increase in the coming years, owing to increase in the population of mosquitoes and transmission of virus from pregnant ladies to their children. Various key market players coupled with NGOs and local governments have participated to improve the level of awareness among people residing in urban and rural areas against different mosquito-borne diseases. This is expected to drive the mosquito repellent market growth globally.

There is a considerable increase in awareness of mosquito-borne disease, which boosts the demand

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Avoid or Minimize Meat Consumption if Your Blood Sickles

- Dietitian

Dietitian Margaret Hanson has identified a carnivorous lifestyle as less than ideal for individuals with sickle cell disorder. Mrs. Hanson stated that meat-eating introduced toxins into the body system that trigger crises and indeed other health issues. The dietitian was speaking at Tema, Accra, Ghana during events marking World Sickle Cell Day themed *Sickle Cell Disease and Prevention Through Pre-Conception Screening.*

The event was organized by Sickle Cell Condition Advocates (SICCA) in collaboration with the Ghanaian Academy of Science and Arts. Founded by Charlotte Owusu, SICCA plans to reach out to final year students of Senior Secondary Schools, starting in Accra, to become ambassadors and advocates for premarital and preconception genotype screening.

Mrs. Hanson stated she was not prescribing vegetarianism but only wanted to encourage Ghanaians to imbibe fruits not as desert but as

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EVERY 'WARRIOR' IS DIFFERENT

Amazing Amazon/Sickle Cell Conqueror Mariam V. Lawal, PhD posits that though two may have the same health condition, the manifestations may be starkly dissimilar ...

One thing every sickle cell warrior detests is to be judged. Sometimes, parents and caregivers are unwittingly guilty of this. They accuse their warriors of faking illness, being lazy or unserious because, in their estimation, another sickle cell warrior with the same HbSS genotype looks healthier and is able to perform certain tasks more easily than their own warrior. We need to draw the line here.

Every SCD warrior is different. Just like no two individuals are alike, there is a wide spectrum of variability in the severity of SCD. A lot of factors come into play in this variability. That is why you will come across a SCD warrior who hardly displays symptoms despite being very physically active, and another who is habitually in and out of hospital after every little stress.

Medical Science has for long proven the differences among SCD warriors with respect to health status and clinical presentation. That is why physicians are there to treat the individual, not just the disorder. Some causes of these variabilities are explainable, while others still fall beyond the scope of scientific reasoning. Some of the notable factors affecting variability in the clinical presentation of SCD include the retention of foetal haemoglobin (HbF) through to adulthood, genetic factors such as the co-inheritance of alpha-thalassemia, glucose 6-phosphate dehydrogenase (G6PD) deficiency, haemoglobin (Hb) levels and the presence of other medical conditions (co-morbidities).

Another factor is the individual will of a warrior, their psychological outlook to the disorder

Science has also shown that an interplay of these factors may pose either favourable or unfavourable outcomes for individual Warriors, especially with respect to the development of sickle cell complications such as stroke, acute chest syndrome, avascular necrosis and leg ulcers. These factors are at best not modifiable as the warrior is born with them.

There are also other factors that can influence the health of Warriors, which are however, modifiable. These are mostly environmental and social factors. These include climate/weather, socio-economic status, access to quality healthcare and patient-modifying factors. It is on record that many Warriors do well with ready access to quality healthcare services, and this is mostly influenced by the socio-economic status of the warrior.

Warriors born into poverty, usually struggle with access to quality care and needed medications, which has a negative outcome on their health and their survival. Most Warriors in the world live in low-income countries, where healthcare services are generally poor. This has a multiplier effect on their quality of life.

Another factor is the individual will of a warrior, their psychological outlook to the disorder and self-care routines. These factors can make a huge difference.

The variability in SCD presentation may explain why some warriors don't make it beyond childhood, while others weather on into old age, even though, with various

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Celebrated Artivist Nikkolas Smith illustrates the realities of people with Sickle Cell

Red Cross harnesses the power of artistic activism — known as artivism — to show how blood donors help in the fight against sickle cell

On World Sickle Cell Day 2023, Celebrated artist Nikkolas Smith revealed exclusive artwork illustrating the important role blood donations play for people living with sickle cell disease, the most common — yet often invisible to the public eye — genetic blood disorder in the U.S., which predominantly affects those in the Black community.

The digital portrait commissioned by the American Red Cross, entitled '*Transfusion*,' is a call to raise broader awareness about SCD and the important role donors who are Black play in providing a compatible blood match. One in three African Americans are a match for people with sickle cell disease.

'People will sometimes say to me, 'you don't look sick," said Bell. 'And I respond, 'well, what does sick look like?'

Smith sat down with four sickle cell warriors of various ages — Tiereny Bell, Dr. Rubin Beaufort, Dreylan Holmes and Erica Hunter — to capture and represent their lived experiences in '*Transfusion*.' From 12-year-old Dreylan Holmes' misunderstood experience at school leaving him isolated from friends to Tiereny Bell's excruciating pain limiting her work schedule as an epidemiologist, warriors' experiences are vast and common, yet widely still under-represented in everyday conversation.

'People will sometimes say to me, 'you don't look sick,'' said Bell. 'And I respond, well, what does sick look like?'

WHY SICKLE CELL DISEASE?

An estimated 100,000 people across the U.S. — the majority of whom are of African descent — have sickle cell disease and may require regular blood transfusions to help manage their disease. Blood transfusions are essential in managing the very real pain and long-term health of those with sickle cell disease, which distorts soft and round red blood cells and turns them hard and crescent-shaped, both of which are depicted in Smith's artwork. As a result, blood has difficulty flowing smoothly and carrying oxygen to the rest of the body, which may lead to severe pain, tissue and organ damage, anaemia, and strokes.

'What stood out to me the most when speaking with these incredibly brave sickle cell warriors is how much constant pain they endure due to the malfunctioning cells in their body, but also the level of determination they have to maintain in order to push through until their next blood transfusion,' Smith said.

HOW BLOOD DONORS HELP

Unfortunately, frequent transfusions can make finding

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Dr. Adeleke Olorunnimbe Mamora

Nigeria Develops Plant Medicine For SCD, Other Disease Conditions

Black Africa's most populous nation and world's SCD capital, Nigeria, has developed a herbal treatment for SCD that will minimize sickling and enhance health, according to Dr. Adeleke Olorunnimbe Mamora, outgoing Minister of Science, Technology and Innovation.

The Minister made this disclosure May 2023 during a press briefing at the Presidential Villa, Abuja highlighting the achievements of each Ministry in the administration of President Mohammadu Buhari.

.

'Nigeria has a very large population of sickle cell disease patients and carriers; to that effect, we have developed products from plants that combat sickling and therefore reduce the number of attacks that usually result from sickle cell anaemia,' Mamora says.

The population of Nigeria is expected to hit 350 million by 2050 with a quarter of the population 'carrying' the sickle cell gene.

A medical doctor turned politician, Mamora, 70, was formerly Minister of State for Health.

Dr. Mamora also made known that the Ministry of Science, Technology and innovation has come up with 'globally-recognized' herbal treatment for hypertension, hepatitis and typhoid.

High blood pressure is a widespread health concern in Nigeria.

'The anti-hypertensive drinks,' Mamora reveals, 'are sourced from local herbs, offering a natural approach to managing blood pressure.'

Scientists and experts at the Ministry collaborated with stakeholders in the herbal and traditional medicine industry to develop the products.

$6b Mosquito Repellent Industry

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for mosquito repellents. In addition, rise in global temperature provides favourable conditions for the breeding of mosquito, leading to increase in penetration of mosquito repellents in the global market.

Furthermore, the development of natural herb-based mosquito repellents has reduced various side effects of the repellents on human health such as skin rashes, breathing problems, and other health hazards. Nowadays, consumers in the developed regions have started using neem-based sprays, creams, oils, citronella oil, birch tree bark, and other plant-based ingredients. The change in the consumer preferences toward herb-based mosquito repellents is expected to garner the growth of the mosquito repellent market during the forecast period.

Polyphenol-rich Sorghum bicolor leaves extract: Natural treatment for chronic inflammation

Millions of people battle constant tiredness, brain fog, pain, and inflammation every day. Having chronic inflammation compromises our immunity. It also increases our risk of developing one or more chronic diseases. Even low-grade inflammation over a while can lead to issues like high blood pressure, diabetes, arthritis, psoriasis, depression, digestive problems, and other conditions.

And there is no cure. Medications can help manage symptoms of chronic inflammation. But, over time, taking many pills brings different challenges. Each pill has its own side effects, and many drugs interacting together can also affect the body.

It's no surprise that many are turning to natural remedies for relief - the medical community is also getting on board. Nowadays, there is more research into plant-based therapies to treat chronic conditions.

Science has proven that chronic, low-grade inflammation can turn into a silent killer that contributes to cardiovascular disease, cancer, type 2 diabetes and other conditions.

The fact that three out of five people around the world die from a disease linked to inflammation seriously raises red flags.

Discover highly effective ways to ways to tame inflammation and help:

- Treat asthma and allergies
- Treat autoimmune diseases—IBD, rheumatoid arthritis, lupus, multiple sclerosis, and psoriasis
- Protect your heart
- Protect yourself from dementia, depression and stroke
- Combat inflammation in metabolic diseases
- Fight against cancer
- Manage Sickle Cell

A natural treatment for chronic inflammation

One such treatment for chronic inflammation is the *Sorghum bicolor leaf* — a powerful herb rich in polyphenols. Polyphenols are packed with antioxidants, and a diet rich in polyphenols boosts the immune system. They can help protect against chronic diseases and autoimmune conditions like:

- Cardiovascular disease and stroke
- Diabetes
- Arthritis
- Cancer
- Chronic viral infections
- Sickle-cell anaemia
- Other anaemia, and much more

In recent years, dietary polyphenols have attracted significant interest among researchers due to their potential chemopreventive/protective functions in the maintenance of human health and diseases. It is believed that dietary polyphenols/flavonoids exert powerful antioxidant action for protection against reactive oxygen species (ROS)/cellular oxidative stress (OS) towards the prevention of OS-related

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'SCT Awareness Is Crucial For SCD Prevention'

Desperation makes people gullible

- HRH Eze Obinna Eziakonwa

By Ayoola Olajide, reporting from Okpala

The reality of sickle cell in Nigeria, of all countries in the world, is that even though your genotype is AA and you consequently have no immediate family member with sickle cell anaemia, the probability is high, very high, that you are impacted one way or another.

Take the monarch of Okpala Autonomous Community, HRH Eze Obinna Eziakonwa. His Hb is AA, and there was specifically no need to be picky - as far as genotype is concerned - who he marries. An avid interest in books outside regular school curriculum led the young prince - then in secondary school - to enamor himself of the rudiments of genetics, which would not make meaning until much later in life.

Once he discovered his Hb to be AA, he knew he could take chances and marry practically anyone.

'When it was time to marry,' the Eze recalls in an interview with *Sickle Cell News* at the magnificent palace in Okpala, 'genotype was not on my mind.'

It turned out his wife was AA.

SCD Close to Skin

Although he and his family are free of sickle

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American Red Cross Commissions Art To Raise SCD Awareness

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compatible blood types more difficult when patients develop an immune response against blood from donors that is not closely matched to the blood of the recipient.

'Sickle cell disease can be inherited by anyone of any race and ethnicity, but in the U.S., the great majority of individuals who have the disease are of African descent,' said Dr. Yvette Miller, executive medical director of the Red Cross. 'Nikkolas' art reinforces that donating blood helps sickle cell warriors stay in the fight, while inspiring each of us to roll up a sleeve so they don't have to fight alone.'

Dr. Rubin Beaufort, a retired mechanical engineer, has received more than 240 blood transfusions to date and still endures high levels of pain regularly. 'We're facing this every single day, not just once in a while,' he shared, emphasizing the ongoing need for blood.

Dr. Rubin Beaufort, a retired mechanical engineer, has received more than 240 blood transfusions to date and still endures high levels of pain regularly. 'We're facing this every single day, not just once in a while,' he shared, emphasizing the ongoing need for blood.

Forty-one-year-old microbiologist Erica Hunter, who was forced to retire from her job early due to complications of the disease, has received more than 50 blood transfusions to date.

'I was so moved to learn how [sickle cell warriors'] health greatly improves after every generous blood donation and transfusion,' Smith reflected. 'My hope is that we can exponentially increase the number of lifesaving blood donations and transfusions this year.'

Smith's art is part of the Red Cross Sickle Cell Initiative, which seeks to address health disparities associated with sickle cell disease by increasing much-needed blood donations from individuals who are Black through community partnerships and helping to ensure closely matched blood products are available for patients.

SOURCE: *American Red Cross*

FACT

According to the American Centers for Disease Control (CDC), 1 in 13 African-American babies is born with the Sickle Cell Gene/Trait (SCT); between 1 and 3 million Americans have SCT, the majority African-Americans. The CDC estimates that ***more than 100 million people worldwide have SCT.***

Medical student Emily Sowah was one of only 15 medical students from across the USA selected for the 2023 ElevateMeD Scholarship Program.

Sowah 'can't believe' she was selected as ElevateMeD Scholar

Emily Sowah has spent a lot of time in hospitals and doctor's offices — and that was before she was a student at OSU College of Osteopathic Medicine.

'My mom has sickle cell anaemia, and so do I,' said Sowah, who will soon begin rotations as a third-year medical student. 'I spent a decent amount of time in hospitals. They used to be scary, but the more I went and came out better, the more I got used to it and thought it was a magical place where sick people went and came out healthy.'

'I spent a decent amount of time in hospital ... My mum has sickle cell anaemia, so do I.'

Sowah, who is from Edmond, studied biology and psychology at the University of Oklahoma, but it wasn't until she attended a Minority Association of Pre-Medical Students, or MAPS, Conference at OSU Center for Health Sciences that she was introduced to OSU's medical school.

'I fell in love with the place. The Tandy building was brand new, and the students seemed happy to be there, and that's what I wanted in a medical school,' she said. 'If I was going to spend four years going through tough curriculum, this was the place I wanted to do it. They made me feel like I was already a part of the family and I hadn't even applied yet.'

At OSU-CHS, Sowah has been active across campus serving as a student ambassador, Student Government Association president, and she's participated in three global health trips, something she is passionate about.

That dedication to leadership and helping her community are just a few of the reasons Sowah was one of only 15 medical students from across the country selected for the 2023 ElevateMeD Scholarship Program, which aims to develop talented medical students from under-represented backgrounds into the next generation of

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A Social Theory Of Disability

By Toluwalope Onuwe
University of Bristol
United Kingdom

The social model of disability posits that a person is made disabled more by attitudes and societal structures than by their medical conditions (Foundation for People with Learning Disabilities, 2016). The social theory of disability makes a distinction between 'impairment' and 'disability'.

An impairment is brought about when a part of one's body is not functioning per medical definition while disability is brought about, not from impaired bodies, but from an un-welcoming reception in a world of the able-bodied, who create the physical structures, institutional norms, and social attitudes in a way that excludes and/or maligns people with impaired bodies (Goering, 2015; The Foundation for People with Learning Disability, n.d.). In essence, the social model of disability surmises that disability is a social construct.

The social model of disability was applied to chronic diseases by Sara Goering in her article '*Rethinking disability: The social model of disability and chronic disease*', (2015). In her article, Goering argues that the non-impaired have built a society that works for them thus, excluding the impaired. For instance, they build stairs and escalators leaving out wheelchair ramps.

What does this mean for Sickle Cell Disease?

Let us take for example a school environment. The classes are either too hot or too cold (triggers for crises); the SCD pupil is not allowed water or toilet breaks as often as they need (SCD patients need adequate hydration to keep their blood flowing and they do not concentrate urine well and require frequent toilet breaks); classes often happen on the fourth or fifth floor (especially in government public schools) mandating a student with SCD to climb several flights of stairs several times a day in and out of classes; students with SCD may not be exempted from engaging in physical activities; and finally, SCD students are often absent from school due to sicknesses that they miss out on classes and sometimes on important exams and there are no policies or guidelines to help them recover lost grounds (Dyson, 2021).

Research has shown that compared to healthy individuals, SCD students' academic performance is negatively affected in a class environment; however, when all educational activities were moved online during the COVID-19 pandemic, 60% of SCD students performed better than 40% of students

'... the built and social environment of the traditional classroom has a debilitating effect on students with Sickle Cell Disorder. It is small wonder that some children with SCD do not finish school which further impacts negatively on their future quality of life, the economic burden on parents, society, and the nation at large'

An impairment is brought about when a part of one's body is not functioning per medical definition while disability is brought about, not from impaired bodies, but from an un-welcoming reception in a world of the able-bodied ...

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Same Genotype, Different Experiences, Dissimilar Signatures!

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complications. It also explains the differences in worldview, quality of life and response to various treatments. At this point, it is imperative to advice Warriors to study themselves, and know what triggers their pain crisis episodes, their capacity to withstand various physical activities and routines.

Even though we already know the common triggers, there is always some variability among warriors on how they react to various stimuli.

Permit me to digress with some of my personal experiences. I have this Warrior friend. I never knew she had SS genotype until the first time I met her at our haematology clinic.

I asked whether her genotype was SC (known to have milder clinical presentation), but she told me she was SS. This warrior looks more fragile in build than I am, but she hardly ever falls ill, and she is usually very physically active. Some things I never dream of doing, because I know it will cause me to fall into a crisis, she does without any problems.

When she got married and started trying for children, she had some of the complications associated with sickle cell, but nothing as serious as those I experienced in the same situation. She had smooth normal deliveries, no difficulties whatsoever. She was never indicated for emergency or caesarian deliveries, compared to my pregnancies which were severely complicated, and I had to have all caesarian section deliveries.

I remember how a mutual friend made a subtle, but offensive comment about the stark differences between me and the Warrior friend. I just looked away, because I understood what I had been through and that every warrior's challenges are different.

It will interest you to know that there are some other warriors who are far more sickly than I am. There are some complications of SCD I have had to deal with, which some other Warriors have never experienced, and may never experience. Some Warriors I knew lost the battle for life before my very eyes while I soldiered on. I do not see this as a feat of my own strength, but only by the Hand of the All-Knowing Life-Giver.

Parents, friends and caregivers should stop judging SCD Warriors. It is enough struggle to have to deal with this complex disorder. These kinds of judgements, stereotyping and stigmatization give rise to psychological trauma in warriors. Some Warriors start looking at themselves as being inadequate, or they start avoiding those who judge them unkindly. Some are driven to the extreme, and start abusing drugs. We don't need others to aggravate our pain out of their poor understanding.

Don't tell a Warrior that he/she is pretending. Don't call them lazy, don't make them feel worthless. Parents, please stop telling your Warriors that they are draining your funds. Stop comparing their health status to that of your friend who also has a Warrior. It remains your duty to raise them, show them love and care.

Above all, parents, spouses, friends, caregivers, colleagues, classmates, roommates, please be mindful always that every Warrior is - and will always be - different!

Nupur Mittal:

The Philosophy & Practice of Pediatrics

Nupur Mittal is a pediatric hematologist-oncologist with Lurie Children's & Rush: Advancing Children's Health, a clinical affiliation dedicated to providing high-quality pediatric specialty care to children.

Since June 2020, she has been serving as Co-Director of the Adolescent and Young Adult (AYA) Sarcoma Program at Rush University Medical Center. She also offers her services at RUSH Pediatric Specialty Care - RUSH University Children's Hospital, Pediatric Infusion Center - Rush University Medical Center, and at the Center for Cancer and Blood Disorders at Ann & Robert H. Lurie Children's Hospital of Chicago.

'Our philosophy here is to really maintain a very, very close loop of communication with all of the members of the family — not just the close family. We always encourage extended family. We encourage whoever is close to the child — their friends — to be a part of these discussions. We're not just treating the patient. When you're in pediatrics, the family is an extended part of that, and a big part of that, because you have to explain everything really well to the family,' says Dr. Mittal.

In her line of work, she takes care of children with a variety of blood disorders, as well as children and young adults who present with different kinds of cancers — whether they are cancers of the blood — like leukemias — lymphomas or organ cancers. Her clinical interests include anemia, childhood leukemias, and sickle cell anemia.

Her career in medicine began after she earned her medical degree from Maulana Azad Medical College in India in 2004. She then went on to perform her residency in pediatrics at the said establishment in 2007.

Upon relocating to the United States, Dr. Mittal completed her residency in pediatrics at the University of Illinois Hospital in 2011, an additional residency in pediatrics at Children's Wisconsin in 2012, and her fellowship in pediatric hematology/oncology at the University of Illinois Hospital in 2015.

Dedicated to clinical excellence, she is board-certified in pediatrics and pediatric hematology-oncology by the American Board of Pediatrics (ABP). The mission of the ABP is to advance child health by certifying pediatricians who meet standards of excellence and are committed to continuous learning and improvement.

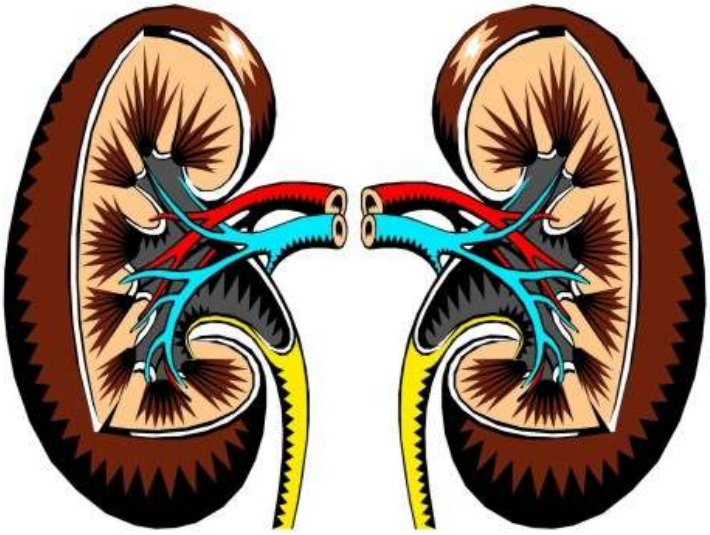
Teaching medical students, Dr. Mittal serves as an Assistant Professor within the Department of Pediatrics at RUSH Medical College.

Pediatric oncology is a medical specialty focused on the care of children with cancer. A pediatric hematologist-oncologist is a physician who has special training and experience to diagnose and treat blood disorders and cancers in children, teens, and young adults.

- ISSUEWIRE

Kidney Health, Inc Releases Video On Healthy Living With Kidney Issues

Maintaining a healthy diet is crucial for individuals living with chronic kidney disease (CKD) to manage their condition effectively. Recognizing the importance of diet in kidney health, *Healthy Kidney Inc.* has released a video offering a wide range of diet recommendations specifically tailored for kidney disease patients.



According to medical experts, diet plays a vital role in managing kidney disease. By adopting a targeted approach to nutrition, individuals with CKD can optimize their kidney function, enhance their overall health, and potentially slow the progression of the disease. *Healthy Kidney Inc.*'s video serves as a comprehensive resource for individuals seeking expert guidance on dietary considerations for kidney disease.

Through this video, *Healthy Kidney Inc.* seeks to address the pressing need for reliable and personalized diet recommendations for those living with kidney disease. The video incorporates evidence-based insights and practical tips from leading nephrologists and dietitians, ensuring that viewers receive accurate information.

Dietary choices directly affect kidney function and overall health. Foods and beverages can impact blood pressure, fluid balance, and the levels of certain minerals in the body, such as phosphorus and potassium. For individuals with CKD, it becomes even more important to pay attention to their diet to maintain optimal kidney function and manage associated complications.

The video produced by *Healthy Kidney Inc.* emphasizes the importance of personalized dietary recommendations for individuals with CKD, as each person's nutritional needs may vary based on their specific condition, stage of kidney disease, and other health factors. By offering expert insights and evidence-based information, the video equips viewers with the knowledge to make informed dietary choices.

Managing sodium intake is a critical aspect of a kidney-friendly diet. Excess sodium can lead to fluid retention and increased blood pressure, which can strain the kidneys. The video highlights the importance of reducing sodium consumption and provides practical tips on selecting low-sodium food options, reading labels, and cooking with less salt. In addition, the video addresses the significance of protein intake in managing kidney disease. While protein is essential for overall health, excessive protein consumption can burden the kidneys. *Healthy Kidney Inc.*'s experts outline the recommended amount of protein

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Prof Adeyinka Falusi and the SCHAF team at Oja Oba, Ibadan

SCHAF

takes SCD awareness to religious institutions, schools, and markets in Ibadan

On WSCD June 19th 2023, the Sickle Cell Hope Alive Foundation (SCHAF) organized an Awareness Rally at Oja-Oba Market, Ibadan to mark World Sickle Cell Day. The event was aimed at raising awareness about Sickle Cell Disease and its impact on individuals and families.

The ultimate objective is to sensitize and gear youths towards the informed decision of PREVENTION & AVOIDANCE. The rally was well-attended, with market youths from the community coming together in support of the program.

The event was led by Professor (Mrs.) Adeyinka Falusi, the Founder and Trustee of Sickle Cell Hope Alive Foundation, and an internationally renowned SCD/Cancer researcher and advocate. She gave an edifying talk on the disease, highlighting the challenges of SCD, the importance of early detection, treatment, and management. The Oyo State National Youth Service Corps (NYSC) supported with a Music band. Electronic and print media were also on hand to cover the event.

On Sunday 18th June SCHAF drove its SCD awareness machine to the Redeemed Christian Church of God, where Professor Falusi gave a sensitization talk on Genotype, Sickle Cell Trait and Sickle Cell Disorder.

On June 23, SCHAF planted ***KNOW YOUR GENOTYPE*** (KYG) clubs at selected secondary schools and at the University of Ibadan. KYG is one of SCHAF's flagship programmes. Wherever KYG takes root, an entire school community, teaching and non-teaching staff included, is inducted into sensitivity about the imperative of genotype awareness in curbing SCD.

TIF Launches Novel Approach To Thalassemia, SCD Education

... it's accessible on any device and free of cost

The Thalassaemia International Federation (TIF) has introduced a novel approach to health education and created a unique platform for healthcare specialists and individuals with thalassaemia and sickle cell disease. The platform is known as TIFLIX (Thalassaemia International Federation LIbrary eXtended).

The brand-new video library powered by TIF gathers a wealth of audiovisual content on everything you need to know about thalassaemia and sickle cell disease, presented by top-notch haematologists and other experts.

Whether you are looking to learn more about the diagnosis, management and complications of these diseases or new advances and therapies, clinical trials, blood safety and adequacy, challenges in care and much more, TIFLIX will become your one-stop destination for all the latest information, expert advice, and educational resources.

TIFLIX is accessible from any device, whether that is your phone, tablet or computer. By joining TIFLIX, you have access to exclusive content and resources, available only to members. Membership is free for everyone without any hidden costs.

TIFLIX can be accessed at **https://tiflix.tv** .

With headquarters in Nicosia, Cyprus, TIF was founded in 1986 by a group of patients and parents representing thalassemia associations in Cyprus, Greece, Italy, UK and USA. The organization has evolved into an umbrella foundation with 232 member organizations in 62 countries.

The aim of TIF is to find effective treatment for those with the condition, prevention through education and ultimately, a cure.

THALASSAEMIA INTERNATIONAL FEDERATION

Because Mimi is not an African-American, many medical services providers meeting her for the first time often do not believe she can be with sickle cell, leading to delays in treatment:

'Are you sure you have sickle cell?'

the story of a 37-year-old lawyer and mother of four

from https://www.cdc.gov/ncbddd/sicklecell/stories/mimi.html

'When I'm in that moment of pain in the emergency room, I can't even think for myself. The pain is debilitating and they're asking me questions like, 'Are you sure you have sickle cell? We need to look into this," says Mimi, a 37-year-old lawyer and mom of four.

Mimi's medical history is similar to that of many individuals with sickle cell disease (SCD): she has experienced severe pain since a young age, frequently sought care in the emergency department (ED), and has received numerous blood transfusions (when healthy blood is given to a patient through one of their blood vessels). But Mimi's genetic (inherited) blood disorder comes as a surprise to many healthcare providers when they first meet her because of one detail: she's not African American.

A commonly held myth about SCD is that it only affects individuals of African descent. Although SCD is most common among African Americans in the United States, it can also affect Hispanics, and people whose ancestors come from countries in South Asia (such as India), southern Europe (such as Greece and Italy), and the Middle East (such as Saudi Arabia and Lebanon).

SCD is a disease one is born with and is now a part of the newborn screening program for all (US) states. But because Mimi was born before this program started in her state, she was not diagnosed until she was 5. Because of Mimi's Arab-American background, a sickle cell diagnosis did not occur to many of her healthcare providers.

'I was about 3 years old when I started presenting with pain in my wrists and ankles. My parents would take me to the emergency room and the doctors would take an X-ray. They wouldn't be able to find anything; they would just send me back home. My parents had psychologists telling them I was faking the pain,' recalls

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Menopause and Sickle Cell Disorder

By Dr. Tonye Wokoma, MFSRH, FRCOG
Consultant, Sexual and Reproductive Health

Menopause is a biological process that occurs in women. It is a natural part of ageing and usually happens between the age of 45 and 55 years, marking the end of a woman's reproductive years.

During the menopause transition, release of eggs from the ovaries gradually falls resulting in a decrease in hormone production, particularly e*strogen*. Other hormones produced in the ovaries include *progesterone* and a small amount of *testosterone*. The period, often many years leading up to this final menstrual period is known as the *perimenopause*. It's called *Premature Ovarian Insufficiency* (POI) if a woman goes through menopause under the age of 40.

This hormonal transition can lead to various symptoms including hot flushes, night sweats, changes in menstrual pattern, mood swings, sleep issues, joint pain, vaginal dryness, lack of libido and many others. These symptoms are experienced by 75% of women and in 25% of women, can be severe and debilitating, impacting the woman's personal, work and family life. Menopause is a biopsychosocial phenomenon and therefore each woman's experience differs based on her unique biological, psychological, and social makeup and life experience.

Not all women with SCD will go through an early menopause, as individual experience varies

Sickle Cell Disease (SCD) is an inherited blood disorder that primarily affects red blood cells causing the normally spherical and flexible red blood cells to become rigid and crescent-shaped, resembling a sickle. These abnormal red blood cells can obstruct blood flow leading to pain, organ damage and a variety of complications. SCD primarily affects women of African, Mediterranean, Middle Eastern and South Asian descent. It is a lifelong condition requiring ongoing medical management and monitoring.

There is currently limited research specifically examining the relationship between SCD and menopause. Some studies suggest however, that women with SCD may experience an earlier menopause compared with the general population. This of course has implications for fertility and childbearing.

The reasons for this potential association are not fully understood and may be influenced by various factors including the chronic inflammation, oxidative stress, transfusion-related complications and ovarian sickling - all these have an impact on the reproductive system.

Menopause itself does not directly affect SCD, as SCD is a genetic disorder. However, the symptoms and challenges associated with the menopause such as hormonal changes and potential bone density loss may add a layer of complexity for women with SCD.

The symptoms of SCD itself including chronic pain, fatigue

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As a woman approaches middle age, her menstrual cycle thins and eventually stops

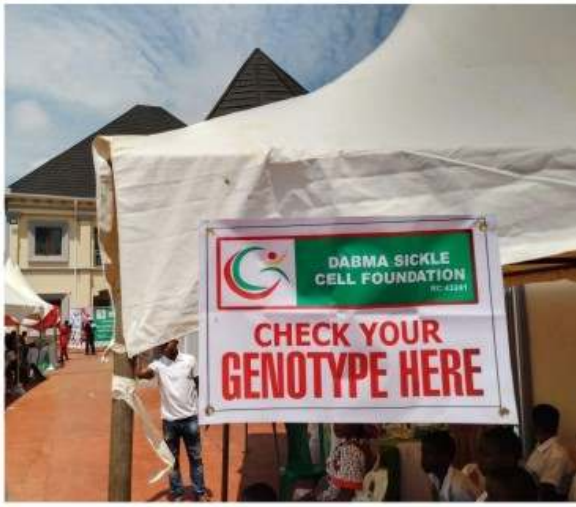
DABMA, SCAPPN TAKE SCD ENLIGHTENMENT TO RURALITES

By Ayoola Olajide, reporting from Ama-Asaa, Okpala

Africa's rural areas are best known for being the bastions of myths, misconceptions *and* superstitions about all things under the sun. For rural dwellers, SCD has many unpalatable soubriquets, including, in Nigeria, the stamp *Àbíkú* (among the Yorùbá) and *Ọgbanje* (among the Igbo). What better way to mark WSCD than shed the light amongst the rustics right where they dwell?

This was precisely what DABMA Sickle Cell Foundation, in collaboration with Society For Healthy Living (SHL), Sickle Cell and Young Stroke Survivors (SCYSS), Mesotho Group Ltd and Sickle Cell in Africa Patients Network (SCAPPN) did at Umuohie-Ukwu, Ama-Asaa, Okpala Autonomous Community, Ngor-Okpala Local Government Area, Imo State, Nigeria on June 16, 2023.

For a rural SCD outreach, the attendance was impressive, not to mention the urbanites, who came all the way from Port Harcourt, Abuja and Lagos. Guests and participants were hosted in the ancestral compound of Pa Ibekwe Dickson Anyanwu.



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Mimi's Pain Dismissed in Emergency Department Many Times

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Mimi. It wasn't until one particular doctor requested a blood test that her family discovered she has SCD.

Throughout her life, healthcare providers have doubted Mimi when she told them she had SCD. This has caused delays in Mimi getting the treatment she needs.

'I'd have to wait for the blood work to come back for them to help me with anything - sometimes for several hours in the emergency room for any sort of pain relief,' says Mimi.

Like many individuals with SCD, Mimi's pain has been dismissed in the Emergency Department several times.

'This has happened as recently as the last few years, where they're extremely dismissive. And I have to explain to them step by step what's going on, what I need. I just need some pain relief. They may give me a little bit, but they send me home,' she says.

What is going through Mimi's mind during these frustrating experiences?

'It's just the pain. Like please make it stop. There is nothing else you can think about except, please make it stop, please hurry. I've been in tears; I would be crying and waiting. I remember a nurse many, many years ago who told me, 'Relax, it's not that much of a big deal.' That is extremely frustrating,' says Mimi.

Although Mimi has had negative experiences seeking health care for her SCD, she's also had some great experiences.

'I've had some amazing providers, some absolutely wonderful doctors and nurses who know my history. My hematologist here in Atlanta told me, 'You just come in and we will see you immediately."

My parents had psychologists telling them I was faking the pain

During her time living in Sydney, Australia, Mimi had a hematologist who was always on standby along with his team ready to take her in during an SCD-related health issue.

While Mimi has been through many challenges as someone with SCD, she says her condition has only encouraged her to be 'grateful for every minute.'

Growing up, she loved to be active in extracurricular activities at school including ballet, jazz, and swimming, but would often have to miss practices and performances when she ended up in the hospital for pain or other SCD-related health issues.

'I hated being in the hospital as a child. I'd be so grateful when I came out.'

Mimi credits her motivation in life and her career to having missed out on so much as a child because of her condition. Originally from Atlanta, Georgia, Mimi moved to Sydney, Australia for school. She ended up starting a family there, which includes her four children, and living in Sydney for 18 years.

Pastor Ibekwe (in red cap) with guests at the occasion

DABMA, SCAPPN

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The normal fare of free health screening, including, of course, genotype, was made available to hundreds of participants including preschoolers, primary and secondary school students as well as all willing adult attendees.

Schools present at the occasion included Macwo Group of Schools, Okpala, Victory Comprehensive High School, Amankwu, Smart Children Academy, Mgbala Ohekelem, Okpala, and Mother Care Bible Secondary School, Okpala. Others were Beaches Foundation Academy, Umuohie-Ukwu, Ngor-Okpala and County School, Umuohie/Umukabia.

In his opening speech, Pastor Emmanuel Dickson Ibekwe, Chairman, DABMA Sickle Cell Foundation Board of Trustees stated that the august event would be the first of many more to hold in rural Imo. He alluded to the imperative of early diagnosis, a point buttressed by Dr. Mrs. Udo Ikejiaku, Head, Sickle Cell Unit, Federal University of Technology, Owerri Teaching Hospital. Dr. Ikejiaku stressed that when diagnosed at birth or shortly thereafter, children with SCD stood a better chance of survival.

Charles Okoroafor, Project Director, SCYSS valiantly debunked the myths surrounding SCD with particular reference to physique and lifespan. Whereas Ugochukwu Ahiarakwe, SHL's Founder/CEO delved on various issues pertinent to SCD - nutrition, lifestyle and the use of supplements.

Mrs. Uwa Isioma Emokaro representing Mesotho Group Ltd, reiterated the commitment of the company to adding value to human life, in particular to the vulnerable population and the health-challenged. Mrs. Uwa stated that MGL involved itself in SCD awareness as part of its corporate and public services objectives.

'Supporting Sickle Cell awareness is part of Mesotho Group's corporate and public services objectives'
- Mrs. Uwa Isioma Emukaro

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SCDAA Teams with MedicAlert Foundation to Improve Emergency Outcomes During Sickle Cell Crises

Regina Hartfield
SCDAA President/CEO

The Sickle Cell Disease Association of America (SCDAA) announced a pilot program with MedicAlert Foundation to enhance the safety and well-being of people living with sickle cell disease.

Acute pain episodes known as *sickle cell crises* are one of the most common and debilitating symptoms of sickle cell disease. These crises can be unpredictable and extremely painful, lasting from a few hours to a few weeks. They're the No. 1 reason people with SCD seek emergency treatment.

However, patients seeking treatment for a sickle cell crisis face hurdles to getting the care they need in the emergency department. Many emergency physicians are not well versed in SCD treatment protocols. And with the rise of the opioid crisis, emergency department providers are cautious about providing the powerful pain medication needed to quell a sickle cell crisis. Sometimes sickle cell patients are unfairly labeled as 'drug seekers' by emergency department personnel who don't understand the disease.

The SCDAA and MedicAlert pilot program aim to improve access to timely, effective emergency care for people experiencing a sickle cell crisis. MedicAlert Foundation is a leading nonprofit providing lifesaving medical identification and emergency response services for millions of people living with chronic health conditions.

'Delayed treatment in a sickle cell crisis can lead to long-term organ damage and other health complications — not to mention the unnecessary pain the person with sickle cell disease must endure,' said Regina Hartfield, president and CEO of the Sickle Cell Disease Association of America. 'MedicAlert has decades of experience storing critical health information and making it available to emergency personnel. We want to leverage that to improve the experience for people seeking treatment for a sickle cell crisis.'

The pilot program will provide participants with a MedicAlert digital health profile to securely store their health information, treatment and pain plans, medications, physician information, emergency contacts and more. Each participant will also receive a customized Smart Medical ID Card, which provides easy access to their health information and physician-prescribed pain management plan via a QR code.

The goal is to decrease time to diagnosis and treatment, improving health outcomes from a sickle cell crisis. When seeking emergency treatment, participants can use the Smart ID Card to share their health history with emergency department personnel — confirming their sickle cell disease status and providing the critical details needed for personnel to provide care.

'Through this collaboration, we hope to equip and empower sickle cell patients with tools to help them quickly get the care they need during a pain crisis,' stated Karen Cassel, MedicAlert Foundation's president and CEO.

Children and babies had their genotype verified

DABMA, SCAPPN

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Describing herself as a 'passionate sickle cell advocate and praying physician', Dr. Mrs. Udo Ikejiaku, Head of Sickle Cell Unit, Federal University of Technology Owerri Teaching Hospital, emphasized the benefits of early diagnosis to minimize risks and complications. Recalling the case of a 10-year-old pentazocine-addicted SCW who was hospitalized for acute chest syndrome, osteoarthritis and avascular necrosis, she charged warriors to take to heart the discipline of self-care and compliance with medical prescriptions. The patient was slowly weaned off the addiction, treated for other issues and left the hospital in good health.

Dr. Udo Ikejiaku

Dr. Ikejiaku encouraged warriors to always stay hydrated, noting that ordinary water was the #1 'drug' for SCD.

Sharing his experience, Sickle Cell Warrior Christopher Chimeremezie recapped to the audience the hard journey of self discovery, moving from 'painful' self-isolation, self-hatred and death wishes to self acceptance.

'In primary and secondary school, despite prolonged absence from studies, I usually came top of the class,' he recalled.

In his remark, Special Guest of Honour, His Royal Highness Eze Obinna commended Pastor Ibekwe for flagging off SCAPPN's rural SCD outreach in Ama-Assa, Okpala. The monarch expressed hope that WSCD activities in 2024 will similarly take place in his domain.

Guests at the occasion included Engr Blessing Ibekwe, Dr. Umeweni Oseloka, Chief Kenneth Nwaokwa, Rev Obinna Chimezie, priest, St. John's Anglican Church, Umuohie/Kabi and his wife, Mrs. Ifeoma Chimezie. The others were Mrs. May Nwankwo, Pastors Sam Okwu and Gad Njoku and Mr. George Nwankwo, Chairman/CEO, Gaymay Nig. Ltd.

Health screening services were provided by Link Medical Diagnostic & Research Laboratories.

Dr. Ikejiaku noted that ordinary water was the #1 'drug' for SCD

The Habit of Meat-Eating

Dietitian speaks at Ghana's WSCD Event

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the main course.

According to Owusu, 85% of all SCD births in the world occurred in Africa, where 20-30% of the population carries the Sickle Cell Trait (SCT). About 16000 children are born annually with sickle cell anaemia in the West African country, roughly 2% of the population.

Speaking at the event, Madam Tina Gifty Naa Ayeley Mensah, Deputy Health Minister, referred to the physical, emotional and financial strain of SCD, stating that the disorder constituted a threat to the economic and social development of a country.

Madam Ayeley commended SICCA for successfully conducting a pilot project in three Northern Regions of the country.

In his address, WHO Country Representative, Dr. Owen Kaluga enjoined health policy administrators in Africa to put in place policies that addressed the multi-disciplinary health needs of people living with sickle cell disorder.

The event was attended by top public office holders, community and religious leaders, civil society groups and students.

Apart from its outlook toward the future, the SICCA will in the here and now assist indigent families and individuals with SCD to procure proper health care and help in the payment of hospital bills. It will also organize workshops for health professionals as well as the general public to disseminate information beneficial to the care and suppression of stigmatization of sickle cell warriors.

Kidney Health

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or individuals with CKD and offer guidance on selecting high-quality protein sources while maintaining a balanced diet.

Furthermore, the video emphasizes the importance of monitoring phosphorus and potassium levels in the diet. Individuals with CKD often need to limit their intake of foods high in these minerals to prevent complications and maintain optimal kidney function. *Healthy Kidney Inc.*'s experts provide valuable tips and practical advice on managing these dietary considerations. *Healthy Kidney Inc.*'s video emphasizes the importance of an integrated approach to diet recommendations.

It highlights the significance of combining nutrition with other aspects of kidney disease management, such regular exercise and ongoing medical supervision. By considering the holistic needs of individuals with kidney disease, the video guides viewers towards a comprehensive approach to improving their health outcomes. As viewers engage with *Healthy Kidney Inc.*'s video, they will discover the empowerment that comes from having a comprehensive resource that caters specifically to their dietary needs.

Richard Coker: A Passion For Women's Rights

The release, in April 2023, of more girls from the 2014 Chibok School Girls Abduction Saga was something of a posthumous 51st birthday gift for Sickle Cell Warrior Richard Coker

It was a coincidence, really, but the release of more captives from the Boko Haram/Chibok Girls saga of 2014 on the eve of Richard Coker's 51st posthumous birthday triggered memories among folks who knew him intimately.

'Richard was filled with a desire to see women's rights and empowerment not only enshrined on paper, but implemented in practice,' recalls his mom, Chief (Ms) Julie Coker, one of the first women in TV/Broadcasting in Africa.

Richard passed on full 10 years before the Chibok Kidnap saga. Had he been alive, he would have stood on the forefront of global efforts to have the girls released unharmed and unconditionally. As it was, a lurid combination of SCD complications and leukemia took him out early on at the age of 32, on the cusp of becoming a force to reckon with in the Uk's competitive film and video industry.

A regular face at the Cannes Film Festival in Paris, and a talented videographer, Richard brushed his illness aside, even

Richard Coker (1972 - 2002)

on deathbed, learning Japanese to enhance his language skills for a pet project.

The Chibok Girls' Saga

In 2014, close to 300 girls aged 16 to 18 attending Girls' Secondary School, Chibok, Borno State, Nigeria were abducted by Boko Haram Islamic insurgents. 57 girls managed to escape while the remainder were herded by bus and on foot into the impenetrable Sambisa forest hideout of the terrorists. Some were subsequently used as bargaining chips for millions of dollars in ransom, many were used as sex slaves and forced into marriage with Boko Haram commanders and friends. The Christians among them were forcefully converted into Islam, with the exception of Leah Sharibu, who reportedly stood her ground.

In what some of his friends dubbed a ' telling posthumous birthday gift', a few more of the Chibok girls were released in April 2023.

'Richard would have rejoiced at this 'gift',' a family member says, 'but would have remained distressed at the thought that other girls still languished in captivity.'

Richard Coker deplored the exploitation of women and girls in any manner - the denial of their freedom in particular.

It is estimated that about 100 girls remained with their abductors, nine years after the horrendous saga began. Of those freed, many have received scholarships to study at American universities while many have settled back in their homelands in northern Nigeria, content to have their freedom back. No matter where they dwell, life would never be the same again for the Chibok Girls, freed or in captivity.

REDCURVE SICKLE CELL FOUNDATION MARKS WORLD SICKLE CELL DAY

The idea to establish an organization to bring together and assist Sickle Cell Warriors and their caregivers was conceived in 2015. Carried to Facebook in 2016, it surfaced on WhatsApp as a group christened, *I Love Someone With Sickle Cell*.

On every festive occasion such as Easter, Christmas and New Year, the founders of *I Love Someone* send routine meds and food items to Warrior families around Nigeria. This is in addition to footing hospital bills and catering to special needs all year round.

In 2023, the group changed its name to *Red Curve SC Foundation*, having been formally registered as a Non-Governmental Organization by Nigeria's Corporate Affairs Commission.

The NGO's maiden WSCD activities took place with a road walk and lots of fanfare in Lagos.

RCSCF team includes Pastor Ololade Abisogun-Dyson, a Sickle Cell 'Hero-mom' (President), with Mrs. Oritsetserundede Ajagbonna as Secretary. Trustees include Messrs Femi Feyide, Olaoludeji Abisogun, and Kayode Soremekun as well as Dr. Jennifer Alieze, a haematologist at the University College Hospital (UCH), Ibadan.

Pastor Emmanuel Dickson Ibekwe welcomes HRH Eze Eziakonwa

HRH Eziakonwa: No Personal Truck With SCD But ...

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cell, he has close friends and extended family members whose children grapple with the sickling challenge.

One of his cousins went through a 'harrowing experience' looking after children with sickle cell anaemia.

'It was traumatic for us all when one of them passed away.'

One of the Eze's close friends discovered he and his wife are carriers of the sickle cell gene after their second child was diagnosed with sickle cell anaemia. The illness seriously affected the child, not to talk of severely straining the family's finance resources

After a lot of soul searching whether to have more children, with the inherent risk of producing a child/children with sickle cell, the couple decided to hang their childbearing boots.

Faith Healing

An Agric Engineering graduate of the then University of Ife (now Obafemi Awolowo University), Ile Ife, Eze Eziakonwa does not allow his Christian faith to becloud his judgment.

'The churches are deceiving worshipers with ludicrous claims of healing.'

Worshipers, he asserts, fall into the snares of the church because they are desperate for a transformation in their circumstances.

'Desperation for a change make people gullible and more than willing to believe anything!'

Personal Experience

Although the Eze was speaking to SCD, he has also experienced the treachery of religion in his own family. This was long before he became king.

High blood pressure seemed to run in his first wife's family. In her early twenties, she developed high blood pressure and received proper medical attention to manage the problem.

At some point she joined a popular church in Lagos. After a few prayer sessions, she declared herself cured. The pastor said so, and she knew it

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MAISCEF, AYUC MARK WSCD IN ABUJA

The Awareness Walk to mark the World Sickle Cell Day 2023 which took place on the Saturday 17th June 2023 was the 10th Edition of the annual event organized by Maidunama Sickle Cell Foundation (MAISCEF). The 2023 Edition took place in collaboration with the African Union Youth Commission (AYUC); a 5km walk which took off from Jabi Recreational Park, Abuja.

It was a fun-filled, educational walk. Flyers relating to genotype were shared with motorists and pedestrians. After the walk there was blood donation, distribution of free routine drugs, free genetic counseling sessions, genotype testing and malaria test.

Supporters of the august event included the Federal Capital Territory (FCT) Internal Revenue Service (IRS), Aso Savings, Wellahealth, Mojeaga Herbal Remedy, Epiconsult and Diagnosis, Nigeria Red Cross and Rotary International district 9125.

With Headquarters in Abuja, Nigeria, MAISCEF was established in 2009 by Sickle Cell Warrior Rabi Maidunama with the sole objective of filling the gap in sickle cell awareness in Africa's most populous nation and the world's SCD capital.

AYUC was founded in 2017 by youth leaders from the 55 African Union (AU) member countries.

Combating Stigma:

Methodist Le Bonheur Healthcare offers tips for those living with SCD

Methodist Le Bonheur Healthcare recommends individualized patient treatment plans to alleviate or control pain, minimize organ damage, prevent infections and live healthy with the disease.

Millions of people throughout the world, including nearly 100,000 Americans, have sickle cell disease, an inherited blood disorder that affects red blood cells. The disease occurs in approximately one of every 365 Black or African-American births and in one of every 16,300 Hispanic-American births.

'Alarmingly, the prevalence of sickle cell disease in Shelby County, Tenn., USA, where Memphis is located, is significantly higher than the reported national average,' said Rana Cooper, nurse practitioner with the Methodist Comprehensive Sickle Cell Center.

'Fortunately, Memphis is a hub for innovative sickle cell research. Methodist Le Bonheur Healthcare provides world-class and evidence-based patient care to help individuals with SCD live longer and healthier.'

People living with SCD may experience anaemia, jaundice, fatigue, vision problems, frequent infections, stroke and frequent pain episodes commonly referred to as a sickle cell pain crisis. Symptoms can be mild or severe enough to require emergency care or frequent hospitalizations.

Sickle cell disease symptoms can be managed with long-term and continuous care from a comprehensive sickle cell center or a healthcare provider well trained in sickle cell disease.

Methodist Le Bonheur Healthcare

The Methodist Comprehensive Sickle Cell Center customizes patient treatment plans that address:

Blood transfusions
Counseling
Exercise
Medication management
Nutrition

Sickle cell disease (SCD) or the sickle cell trait (SCT) can be confirmed with genetic testing or a blood test. If you are unaware of your sickle cell status, contact your healthcare provider.

About Methodist Le Bonheur Healthcare

Methodist Le Bonheur Healthcare has been caring for patients and families regardless of their ability to pay for more than 100 years.

Guided by roots in the United Methodist Church and founded in 1918 to help meet the growing need for quality healthcare in the greater Memphis area, MLH has grown from one hospital into a comprehensive healthcare system with 13,000 Associates supporting six hospitals, including nationally ranked Le Bonheur Children's Hospital, ambulatory surgery centers, outpatient facilities, a hospice residence and physician and specialty practices serving communities across the Mid-South.

From transplants and advanced heart procedures to expert neurology services and compassionate cancer care, Methodist Le Bonheur Healthcare offers clinical expertise with a focus on improving every life we touch.

Disability As A Social Construct

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without SCD (Alhazmi et al., 2021). The authors surmised that the finding that SCD students did better in online than traditional education underlines the hypothesis that the built and social environment of the traditional classroom has a debilitating effect on students with SCD. It is small wonder that some children with SCD do not finish school which further impacts negatively on their future quality of life, the economic burden on parents, society, and the nation at large.

'What is to be done?

Nigeria, as the touted sickle cell capital of the world, needs to develop guidelines at the minimum, and policies at best, to support the vast number of children with SCD in schools across the nation. The study done by Ola et al. (2019) in Lagos State trialing the guidelines developed for students with SCD in the UK (Dyson, 2016) on students with SCD and their teachers, has a lot of promise as it was concluded that young people in both the intervention and control groups showed a significant decrease in absenteeism and self-reported lack of support and an increase in self-reported support from their teachers. However, this study and its promising results can only be scaled effectively if there is an educational policy governing support for, not only children with SCD in schools but also for all students with one form of chronic disease or another. If something is not done expeditiously, the country runs the risk of continuing to disable her children born with SCD.

As it stands today in Nigeria, the disparity in SCD long-term outcomes is sharply polarized by socio-economic status. It will take policy to change this trend.

Toluwalope Onuwe is a doctoral student at Walden University, USA. She currently works at Bristol University, UK as a clinical research practitioner.

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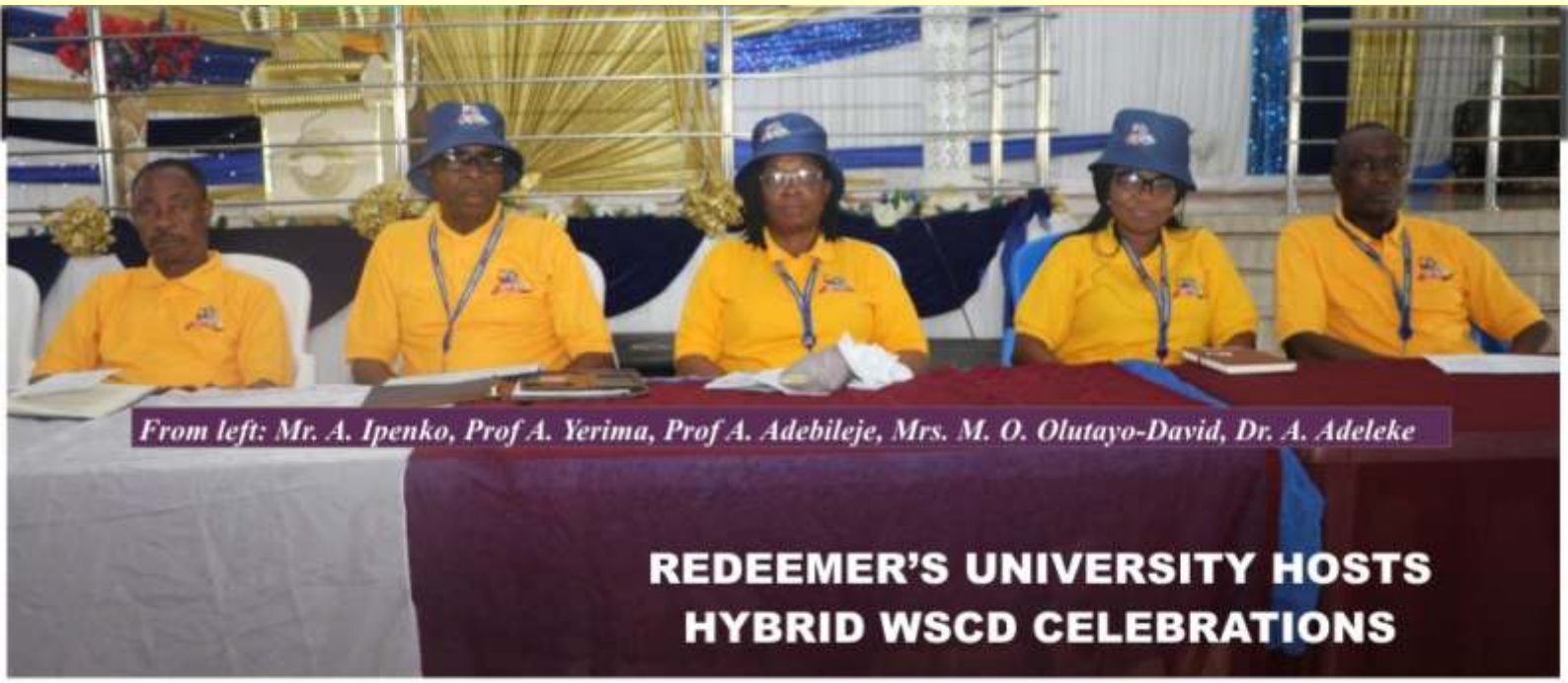

From left: Mr. A. Ipenko, Prof A. Yerima, Prof A. Adebileje, Mrs. M. O. Olutayo-David, Dr. A. Adeleke

REDEEMER'S UNIVERSITY HOSTS HYBRID WSCD CELEBRATIONS

World Sickle Cell Day dawned early at Redeemer's University (RUN), Ede, Osun State, Nigeria. Accompanied by riveting fanfare, Principal officers of the university, along with students and invited guests did a Walk around the campus, displaying banners highlighting the occasion - a special day for special people picked by the United Nations to raise awareness about 'one of the world's foremost genetic blood diseases'.

Held in collaboration with the university's Centre For Gender, Humanitarian and Development Studies (CGHDS), RUN's Sickle Cell + Club hosted participants to a hybrid meeting online and in-person at the University Auditorium.

Dr. O. O Ayemonisan, MD, RUN'S Health Centre, presented the lead paper based on the theme, *Building and Strengthening the Global Sickle Cell Community,* while Mr. Molade James, a laboratory scientist, delivered a lecture entitled, *The Importance of Blood Donation to SCD Management.*

Under the session, *The Challenge of Stigmatization and the Gift of Pain to Children*, two SCD advocates stepped forward to share their experiences:

Ayoola Olajide, Editor, *Sickle Cell News*, recounted his journey living with sickle cell anaemia, the harrowing experiences of pain, hospitalization, blood transfusions and fatigue; while Pastor Abel Olukayode Adewale narrated his experience as a parent to six children with sickle cell anaemia. Less than two weeks earlier (June 9), the family lost the fourth one, a 30-year-old.

Pastor Adewale enjoined the audience, in particular the students, to ensure they check their genotype before marriage and not allow emotion to cloud their judgement.

'Know your genotype and its implications for your unborn children,' he said, 'avoid the error of ignorance.'

'In my humble opinion, S should keep away from S in any and every form.'

A signal part of the June 19 celebrations at RUN was the investiture of distinguished lecturers and others as Life Patrons/Matrons of the Sickle Cell + Club. This was anchored by Dr. Olatundun Oluwatoyin Ilesanmi, Acting Director of the Centre For Gender, Humanitarian and Development Studies (CGHDS). Among the Life Patrons were Prof Oyewale Tomori, a former Vice chancellor of the university, Prof Jide Osuntokun, Prof Anthony Akinlo, Prof Ahmed Yerimah, Prof O. G. Adeyemi, Prof Christian Happi, Prof Bayo Oloyede and Mr. Olukayode Akindele.

Honoured as Life Matrons were Prof Adebola Adebileje, Prof Bola Adeleke and Mrs. Mofoluso Oyenike Olutayo-David.

In an interview with Nigerian Television Authority (NTA), Ogun State during the course of the event, Dr. Ilesanmi stated that the essence of the whole exercise was to sensitize the community about the realities of SCD and to address the misconceptions and stigma surrounding the blood disorder.

Scholarship for Sickle Cell Warrior Emily Sowah:

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physician leaders.

Sowah was encouraged to apply, and was nominated by Assistant Dean of Diversity Brenda Davidson.

'Emily deserves this award because of her love of medicine. She is hardworking, kind and committed to serving others,' Davidson said. 'She possesses empathy and values people, and is also humble, trustworthy and compassionate.'

ElevateMeD is providing Sowah with a $16,500 scholarship each year for the remainder of her time in medical school, as well as other resources such as leadership training, mentoring and debt management education.

'I still can't believe it. I'm very thankful. I have loans from my undergraduate education and medical school isn't cheap,' she said. 'This scholarship will help me pursue my interest in global health and it puts my mind at ease.'

Even without such a heavy financial burden, Sowah still has plenty to do and think about as she prepares to take her board exams before starting rotations in July.

'You're continually studying. It doesn't feel like there's enough time in the day. You try and balance being a student, being a leader, being a friend, being a sister and daughter,' she said. 'Finishing the first two years of medical school, I look back and can't believe I did that — you see that you can do things that you never thought possible.'

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HRH Eze Obinna Eziakonwa Supports Anambra Sickle Cell Law

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for herself, she said.

'When my wife told me she had been cured,' recalls Eze Eziakonwa, 'I admonished her to keep taking her medications, and to do so religiously.'

But, in her religious fervor, she cast aside his advice, including the warnings of her doctors. She developed fatal complications just a few months after her unyielding adherence to what the pastors told her.

Faith and Folly

The religious fervor gripping Africa's most populous nation - and SCD's most-endemic country - does not spare medical doctors and others in the orthodox healthcare space. Many doctors accept hook and line tales of Hb change spewed by testimony-givers in their denominations. In most cases, the heads of church medical departments are trained medical doctors who themselves unquestioningly swallow the preposterous doctrine of 'nothing impossible'!

'Everything is wrong in a system where religion grinds science to dust,' Eze Eziakonwa says.

Anambra State SCD Law

A statute exists, at least on paper, banning and criminalizing the marriage of sickle cell carriers in Nigeria's Anambra State. The Bill was ratified by the State House of Assembly and signed into law by the Governor in 2019. A similar law exists in Abia State, which however did not proffer punishment to the enterprise of SCT unions. The Abia State Sickle Cell Law imposes sanctions on institutions, religious bodies, marriage registries and families that wed couples without confirming their blood groups and genotypes. Both seemingly grandiose attempts at curbing the incidence of SCD are emblematic of the frustration of government over an intractable issue, which burdens family and the health system no end.

'I am in support of such attempts to discourage SCT unions,' the Eze declares.

Every Nigerian, he says, must be cautioned through advocacy such as his cousin Pastor Emmanuel Dickson Ibekwe, Chairman, Board of Trustees, Dabma Sickle Cell Foundation champions, to warn them of the implications of sickle cell trait.

'Ignorance is the singular route by which sickle cell spreads,' he says, 'No human being will want to bequeath SCD's train of trouble on their offspring.'

MENOPAUSE

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and other complications may interact with menopause symptoms, potentially exacerbating them.

Not all women with SCD will go through an early menopause, as individual experience varies. Each woman's medical history and distinctive circumstances will influence her menopause transition.

Women who have been diagnosed with early menopause (under the age of 45 or POI) are advised to have estrogen replacement because of the adverse impact of an early menopause on bone and heart health.

To be continued

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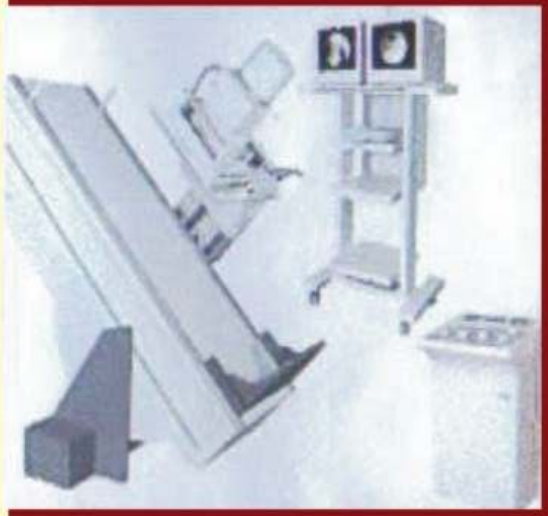

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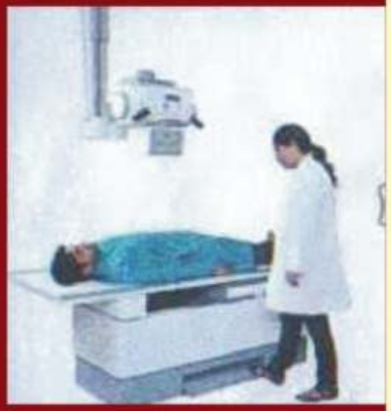

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