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SICKLE CELL

NEWS & WORLD REPORT

www.sicklecellnews.com

WARRIOR
(noun) /'wɑrɪər, /'wɔrjər/
someone living with a particular health condition;
(first used in relation to SCD)

TIWA SICKLE CELL DISEASE FOUNDATION:

A Mission to Empower Warriors

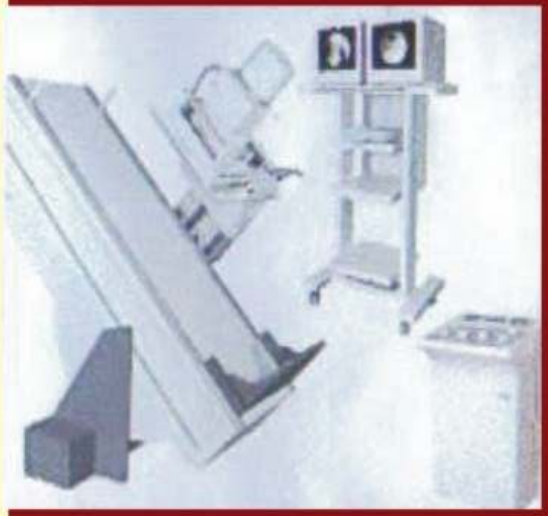
"If you are affected by sickle cell in any manner, you've probably used the term. 'WARRIOR': I touched your life!"

Tosin Ola-Weissmann
RN/BSN, Founder, President/CEO,
Sickle Cell Warriors Inc.

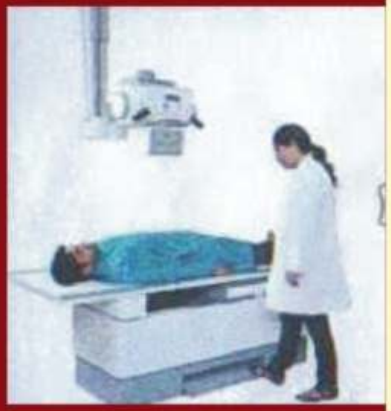
Why I Choose To Celebrate Having Sickle Cell

WHEN IT'S ABOUT LIFE...

• SALES • REPAIRS • MAINTENANCE



X-Ray Machines, Radiotheraphy machine
Ultrasound,
Dental Chairs e.t.c



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baats2000@yahoo.com, www.baats.org

WARRIOR (noun)

/ˈwɔɹlɜ-/, /ˈwɔɹjɜ-/ - someone living with a particular health condition;

(first used by Tosin Ola in relation to SCD on May 5, 2005)

THE POWER OF PRAYING PARENTS

Prayer is the way to walk with God. As a child, **Janet** and **Joseph Ola** prayed fervently over their first child, affirming life - long, productive and fulfilled. Till today, their prayers have never failed to calm the most turbulent sickle cell storms!

Almost 20 years ago, **Tosin Ola** kicked against being called **'SICKLER'** and sparked a new word that caught the imagination of millions around the world ... She finally broke the jinx, the stigma of a word long used to describe, demean and depersonalize people affected by the world's most-commonly inherited blood disorder.

WARRIOR VICTORIES

- Doctors said she would not live beyond childhood. She turned 43 on October 2!
- Another said she could never have children. She has biological children and more!
- Some told her to her face she would never find anyone to marry her! Her parents were once advised to keep mum about SCD to improve the chances of her sisters getting married!

FROM PAGE 12 ...

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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Contents

CREDITS

Publisher
Scell Media

Editor
Ayoola Olajide

Writers/Correspondents
Tai Aladei
Toun Fawemida
Fatima Garba Mohammed
Abra Onyekwe

Contributing Editors
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I MARRIED A SICKLE CELL WARRIOR IN FAITH AND LOVE

Paul Odumu

I first encountered the term 'Sickle Cell' during my medical school days. It was just another clinical condition in the textbooks—a disease like any other, and forgotten soon after exams. Little did I know that this word would come to define a significant part of my life, reshaping my perception of both medicine and human resilience.

My perspective on (SCD) took a profound turn during my internship when I met the woman who would later become my wife. She, too, was a medical professional, and we shared a belief in God's healing power. Despite her SS genotype, our love and faith in a better future prevailed, and we chose to unite in marriage.

Over the course of our 25-year marriage, my wife and I have weathered the storms of SCD together. We've witnessed her battles with the disease, and through it all, our faith has remained unshaken. We have been blessed with three children, all born naturally, defying the odds that SCD can impose.

Living with my wife, I have gained profound insights into the struggles of Sickle Cell Warriors. It has made me a more compassionate doctor, one who truly understands the physical and emotional toll of SCD.

Our collective responsibility includes fostering understanding, support, and hope for a brighter future for SCD warriors worldwide.

Dr. Paul Odumu, BmBch, FWACP FM, FIMSUK is HOD, Family Medicine Residency Program, 44 Nigerian Army Reference Hospital, Kaduna

ANYONE FACING ANY CHALLENGE IS A WARRIOR!

Ayoola Olajide

In his Welcome Address at the recently-concluded Sickle Cell Summit 3.0 organized by TonyMay Foundation, BoT Chairman, Chief Andrew Otokhina stated that people with sickle cell are referred to as 'Warriors' because each time they have crisis, 'it is like they have gone to war!'

In formulating the 'Warrior' phenomenon, Sickle Cell Warrior Tosin Ola-Weissman's name goes down in history, marking one of those remarkable moments when a personal inspiration becomes a household product.

I did a double take the other day while browsing: I came across a family sharing its journey raising a child with thalassemia. The parents referred to themselves as Thalassemia Warrior Parents and to the child as a Thalassemia Warrior!

That was when it dawned on me that Tosin Ola-Weissmann's momentary inspiration and the subsequent new application to an ancient word had spread its usability - and its wings - to other areas of compromised health. I have come across usages like Hemophilia Warrior, Albinism Warrior, Down's Syndrome Warrior, Autism Warrior, TB Warrior, HIV Warrior, Arthritis Warrior, Cancer Warrior, and so on.

Soon, this word will percolate beyond the worlds of inheritable, communicable and non-communicable health conditions even to the non-health sectors.

Ayoola Olajide
Editor

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

scdjournal@yahoo.com

Desperation and Gullibility

I can't agree enough with HRH Eze Obinna Eziakonwa, Asa I of Ama-Asa, Okpala Autonomous Community, Ngor-Okpala, Imo State about the direct and cyclical relationship between desperation and gullibility. Wherever there is adequate healthcare infrastructure, hardly would you find the kind or level of desperation for a reprieve that you find in milieus where same facilities are lacking.

In an environment of deprivation, the sick are easily scammed - and on occasion have to pay the ultimate price for the deceptions of the cure industry, personified by imams and pastors and herbal medicine charlatans.

Solomon Inuwa
Kafanchan, Nigeria

Government Intervention Required

To curb the excesses of the clergy government in developing countries and indeed in some so-called developed countries, the health authorities should try to rein in the religious assemblies where unverifiable cures are preached. This is in the interest of the legion of followers who accept hook-and-line anything a 'man of God' proclaims.

The irony of it is that even well-educated people - including doctors and pharmacists - in developing nations cast science aside in favour of religion.

Francis Opoku
Suhum, Ghana

Sickle-Cell Affects *All* Races

Thank you for the article curated from the NCBI about the American lawyer and mother of four who lives with sickle cell anaemia. That she experiences delays while medical personnel verify and re-verify her genotype illustrates the fact that many still consider sickle cell a Black-only health condition.

Okeke Chika
Rhode Island, USA

Turning Impairment Into Disability

The theory is sound, which points the primary source of disability to social and health infrastructure policymakers' negligence! This negligence (or unconcern?) helps to exacerbate an individual's physical health impairment, transforming it into a disability.

Sickle Cell Disorder and its orthopedic complications are a prime example of an illness society makes more painful by inattention to the infrastructure needs of warriors. SCD can temporarily or chronically render an apparently fit child or adult physically impaired, at which time they require social support to keep functioning.

Aboubakar Muhammad
Niamey, Niger

Well Done, Thalassemia International Federation (TIF)

Kudos to the Thalassemia International Foundation (TIF) for the educational series on Thalassemia and sickle cell, two genetic blood diseases similar in many respects.

I have visited the TIFLIX website and I am amazed at the educational content available there.

The contents therein has improved my knowledge and informed me more about my sixteen-year-old's sickle-cell beta zero thalassemia condition.

Sylvia Johanna
Venice, Italy

CARING FOR UNDERPRIVILEGED CHILDREN WITH SCD

Insights From Sickle Cell Orphanage And Underprivileged Home, Agulu, Anaocha LGA, Anambra State, Nigeria

By Aisha Edwards-Maduagwu,National Coordinator/CEO, Association of People Living With SCD (APLSCD)

People with Sickle Cell can live full, productive lives and excel in all activities that others do. They can get married and bear children, but should not exceed their capacity in child bearing.

After my marriage, with support from my family, I found the first dedicated sickle cell home in Nigeria, taking care of vulnerable and orphaned sickle cell children from 1 year to teenage. Living with SCD myself, I have a clear grasp of the situation and the requisites for an effective management.

Firstly, we found an appropriate location for the home, which ensures quiet and serenity - well away from the hustle and bustle of the city. The accommodations are engineered for conduciveness to good health. Sickle Cell patients don't need environments where they would feel suffocated or a smoke- or noise-polluted atmosphere, which can be detrimental to their health.

We began with about six poor and abandoned sickle cell children. We discovered the circumstances surrounding the births of some among them to be that of what I dub 'pre-marital misadventures'. Their mothers gave birth to them premaritally. They could not follow the mother to her new home because of their health challenges; and no man would agree to accept them under his roof, knowing the financial consequences of doing so. In most cases, the birth mother would leave them in the care of aged parents, who are often poor and ill-equipped to manage a child with a special health challenge such as SCD.

We start off by giving the inmates a sense of belonging, in an attempt to reverse the psychological trauma engendered by feelings of abandonment. We are now 22 in number, all on different rungs of the educational ladder from primary to secondary school.

Sickle cell advocacy for the underprivileged can be energy-sapping. The journey can be emotionally-draining and overwhelming. However, cultivating a positive outlook is essential to getting positive results.

In my humble opinion, government ministries responsible for women's and children's affairs should not place children with Sickle Cell in conventional orphanages. These children usually have special needs, which these conventional homes are often incapable of providing. Special needs children require special homes.

Flashback to GAAF 2021 SCD Awareness Week: Left to Right Dr. John Ademilua , GAAF Founder, CEO Noble Dotun Alabi and Mom Bernice Alabi at Christ School Boys, Ado Ekiti

GAAF Declares 12 Days of Climate/SCD Awareness In Southwest Nigeria

The Gabriel Adewunmi Alabi Foundation (GAAF) has declared 12 days of SCD awareness campaign in Southwest Nigeria, starting November 20th and ending 1st December.

For the past three years, GAAF has conducted SCD Awareness outreaches at secondary schools in Ekiti State with a vision to sensitizing the very young to genotype issues long before they are introduced to the world of romance, marriage and childbearing..

Schools to be visited include Obalatan Grammar School, Ilupeju, Itapa High School, Ayede Grammar School, Oye-Igbo High School, and St Augustine College, all in Oye LGA, Ekiti State. Secondary schools in Oyo and Osun States will also be visited.

In line with its custom, GAAF will pay a courtesy visit to the Oloye of Oye, HRH Oba Oluwole Ademola. In 2022, the GAAF team, led by Founder/CEO Noble Dotun Alabi and Chairman Noble Sola Ojo called on the Olojudo of Ido Kingdom, HRH Oba Ayorinde Faboro, Ajiboyede III.

From April 2023, GAAF decided to add climate and environmental issues to its SCD awareness drive at secondary schools. The aim is to alert the policy makers of tomorrow to the imperative of tree planting to help combat desertification, improve air quality and promote organic, climate-friendly agricultural practices. Henceforth, trees will be planted at every school the organization visits.

Named after Engineer Gabriel Adewunmi Alabi (1935 - 1973), GAAF was founded in 2019 and has branches in the UK and Ghana. In the short term, the organization plans to widen its activities to all States in Nigeria.

Plans to widen GAAF advocacy to Nigeria's west African neighbours is close to fruition.

#Global Handwashing Day:

Hand-washing Is **Good** Frequent; Hand-washing Is **Better**; But Frequent Hand-washing With Soap Is **Best**

Handwashing with soap is key to protecting public health, and leads to benefits in nutrition, education, economic growth, and more.

Handwashing with soap is easy:
Everyone can protect themselves, their families, and their communities through handwashing with soap. Though it requires few resources—soap and a small amount of water—the benefits are significant.

Handwashing with soap is effective:
When handwashing with soap is practiced regularly at key times, such as after using the toilet or before contact with food, it can dramatically reduce the risk of diarrhea and pneumonia, which can cause serious illness and death. Handwashing with soap also helps prevent the spread of other infections, including influenza and Ebola.

Handwashing with soap is affordable:
A review conducted in 2017 analyzed proxy measures of handwashing behavior in Multiple Indicator Cluster Surveys and Demographic & Health Surveys from 51 countries between 2010 and 2013, and found that the differences in soap availability were small or nonexistent in the countries, signifying that availability of soap is almost universal. Despite the fact that the world's poorest households are less likely to have access to soap, cost is not the principal barrier to handwashing with soap.

Most individuals around the world can afford multipurpose soap bars, or detergent to make soapy water. Many households that do have access to soap often use it for laundry, dishwashing or bathing, rather than handwashing.

Investments in handwashing promotion are highly cost effective, and can maximize the health benefits of other interventions—from access to clean water and sanitation infrastructure to nutrition promotion.

Diarrhea and pneumonia are leading causes of death for children under the age of five. Handwashing with soap is among the most effective and inexpensive ways to prevent these diseases. This simple behavior can save lives, cutting diarrhea by almost one-half and acute respiratory infections by nearly one-quarter. Handwashing with soap impacts not just health and nutrition, but also education, economics, and equity.

Global Handwashing Day is celebrated every October 15.

Affordable and Effective Management of SCD: Harnessing the Power of Antioxidants and Sorghum Bicolor (Jobelyn)

Sickle Cell Disease (SCD) is a challenging health condition to manage, especially due to the high cost of treatment and medications. Despite the lack of a universal and affordable cure, there are alternative options that can help individuals with SCD effectively manage their condition without breaking the bank.

One significant factor in SCD complications is Oxidative Stress, which is an imbalance between the production and accumulation of Oxygen Reactive Species (ORS) in cells and tissues. Research studies from Teaching Hospitals in Nigeria, Cameroon, Ghana, and other countries have highlighted the role of Oxidative Stress in the development and maintenance of SCD issues and complications.

Research studies from Teaching Hospitals in Nigeria, Cameroon, Ghana, and other countries have highlighted the role of Oxidative Stress in the development and maintenance of SCD complications

To combat Oxidative Stress and its detrimental effects, the intake of antioxidants is recommended. While the human body produces antioxidants naturally, the levels are often insufficient, leading to the gradual onset of dysfunction. Including antioxidant-rich foods like fruits and vegetables in the diet is beneficial.

Sorghum Bicolor *(Jobelyn)* has been scientifically tested and proven to have one of the highest levels of antioxidants in the world. Daily intake of *Jobelyn* has shown promising results in managing SCD. The benefits include:

- ✓**reducing the need for blood transfusions,**
- ✓**minimizing the frequency and severity of crises,**
- ✓**alleviating bone and joint issues,**
- ✓**positively impacting manifest or underlying health conditions.**

Jobelyn is an affordable and accessible option for individuals with SCD, making it a viable alternative to expensive medications.

By incorporating antioxidants like *Jobelyn* into their diet, Sickle Cell Warriors (SCWs) can proactively address the underlying oxidative stress, effectively manage their condition and prevent costly complications.

To learn more about the anti-inflammatory capabilities of Jobelyn please visit:

https://www.healthforeverng.com/post/natural-treatment-for-chronic-inflammation-polyphenol-rich-sorghum-bicolor-leaves-extract

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- Reduces oxidative stress

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I CHOOSE TO CELEBRATE HAVING SICKLE CELL

By Tosin Ola-Wolowon

I choose to celebrate the fact that I'm alive. My parents were told when I was 4 that I would not live past childhood – I am 43 now. I celebrate because I beat those odds over and over again. In fact, I have outlived the doctor who proclaimed it. I eat cake for the birthdays that I had no cake to eat because I was admitted in the hospital, dealing with excruciating pain. There was a party happening alright, but it was inside my body, a thousand trolls smashing my bones and joints with hammers and pickaxes over and over again. Every beat of my heart caused pain. Sickle cell crisis can strike at any time with no warning, can last a few hours, days, weeks, even months.

My boarding school principal told my parents to take me home and stop wasting money on my education. He said I could never thrive academically due to my frequent absences related to SCD pain episodes; I celebrate because I graduated high school and won 8 - 1st place top - awards, completed my RN program with Honors, and my Bachelors degree in Nursing as a Magna cum Laude. I have two post-graduate degrees – Master's in Nursing and another Master's in Business Administration (emphasis in Healthcare Management).

Sickle cell crisis can strike at any time with no warning, can last a few hours, days, weeks, even months

Independence

I choose to celebrate my independence, autonomy, and industry. I make my own money, pay my own bills, and have been doing so since I became an adult. I am a registered nurse, and have held my license unblemished for 24 years, working in so many areas – the ICU, ED, telemetry, PCU StepDown, surgical, oncology, PACU, travel nurse, school nurse. I have forged my career pathway, and in spite of my frequent hospitalizations, I

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SCDAA Holds 51st Annual National Convention

The 51st Annual National Congress of the Sickle Cell Disease Association of America (SCDAA) Inc., holds from October 11 to 14 in Arlington, Virginia. Founded in 1972, the SCDAA conducts annual events to foster the exchange of scientific and clinical information by distinguished scientists from around the world. It also holds educational workshops, interactive panel discussions, advocacy lectures alongside other special events.

The SCDAA convention offers excellent opportunities to connect with healthcare professionals, pharmaceutical companies as well as SCD advocates and other stakeholders.

For three years (2020 to 2022), the Convention was unable to hold in-person due to the COVID 19 pandemic, which kept the world under lock and key.

Convention speakers include: Vence L. Bonham, acting deputy director and associate investigator at the National Human Genome Research Institute with the National Institutes of Health; Dr. Oladipo Cole, an adult hematology and oncology fellow at Washington University School of Medicine in St. Louis, Missouri; Dr. Foluso 'Joy' Ogunsile, medical director of Memorial Healthcare System's Sickle Cell Day Center in Florida; Dr. Kim Smith-Whitley, global chief medical affairs officer for patient advocacy and external collaborations at Pfizer; and Dr. Aisha T. Terry, president-elect of the American College of Emergency Physicians.

'We're highlighting the importance of working together this year as we move into a new era of sickle cell history with new efforts in research and treatment ongoing,' said Regina Hartfield, president and CEO of the Sickle Cell Disease Association of America.

Nigeria to Host 5th Global SCD Congress in 2025

The Global Sickle Cell Disease Network (GSCDN) has announced that the 5th Global Congress on Sickle Cell will take place in Abuja, Nigeria from June 3 to 6, 2025.

In its announcement, the GSCDN stated that it was 'immensely pleased' to host the Congress in partnership with the Sickle Cell Support Society of Nigeria (SCSSN). SCD stakeholders as well as industry partners are expected to participate actively in the event.

Aside from the Congress held in 2019 under the auspices of the Olusegun Obasanjo Foundation (OOF) and other partners, the last time Nigeria hosted a Congress of global proportion on SCD was in 1985 (at Durbar Hotel, Festac Town, Lagos).

Established in 2010, on the sidelines of the Global Congress in Accra, Ghana, the SCSSN brings together Nigerian scientists, haematologists and other specialists from around the world to add their own quota to the country's crises of SCD research and care.

Headed by Dr. Isaac Odame, the GSCDN is a community of clinicians and scientists dedicated to the study of SCD globally, particularly in low and medium income countries.

'I Was Determined To Not Allow SCD Hinder My Ambition'

- Aishat Damilola Taofeeq, 1st Class Psychology graduate

While some with sickle cell use the health condition as a prop on which to explain away their, well, failures or inadequacies, Aishat Damilola Taofeek sees in SCD a stepping stone rather than a stumbling block! Despite being well-educated, her parents were starkly ignorant of their genotype and its implications for their offspring.

Aishat was diagnosed with sickle cell anaemia at the age of 5, after bouts of bothersome indispositions attributed to other causes.

The diagnoses seemingly opened the floodgates of SCD, culminating in severe splenic enlargement when she was 12.

'Despite being unable to sit or stand or breath well,' Aishat recalls, 'it took several hours to be attended to at the hospital.'

In her reckoning, excluding those years before conscious tally kicked in, she has been hospitalized roughly 25 times due to SCD crises.

Aishat attended the Lagos State University, passing out in 2018 with 1st Class Honours in Psychology. A masters in Psychology with specialization in Developmental Psychology is in view.

The SCW experienced several serious crisis during her days at LASU. There was days she would be discharged from hospital and still appear for tests same day. There were also days when she made class presentations and sat for exams in acute pain.

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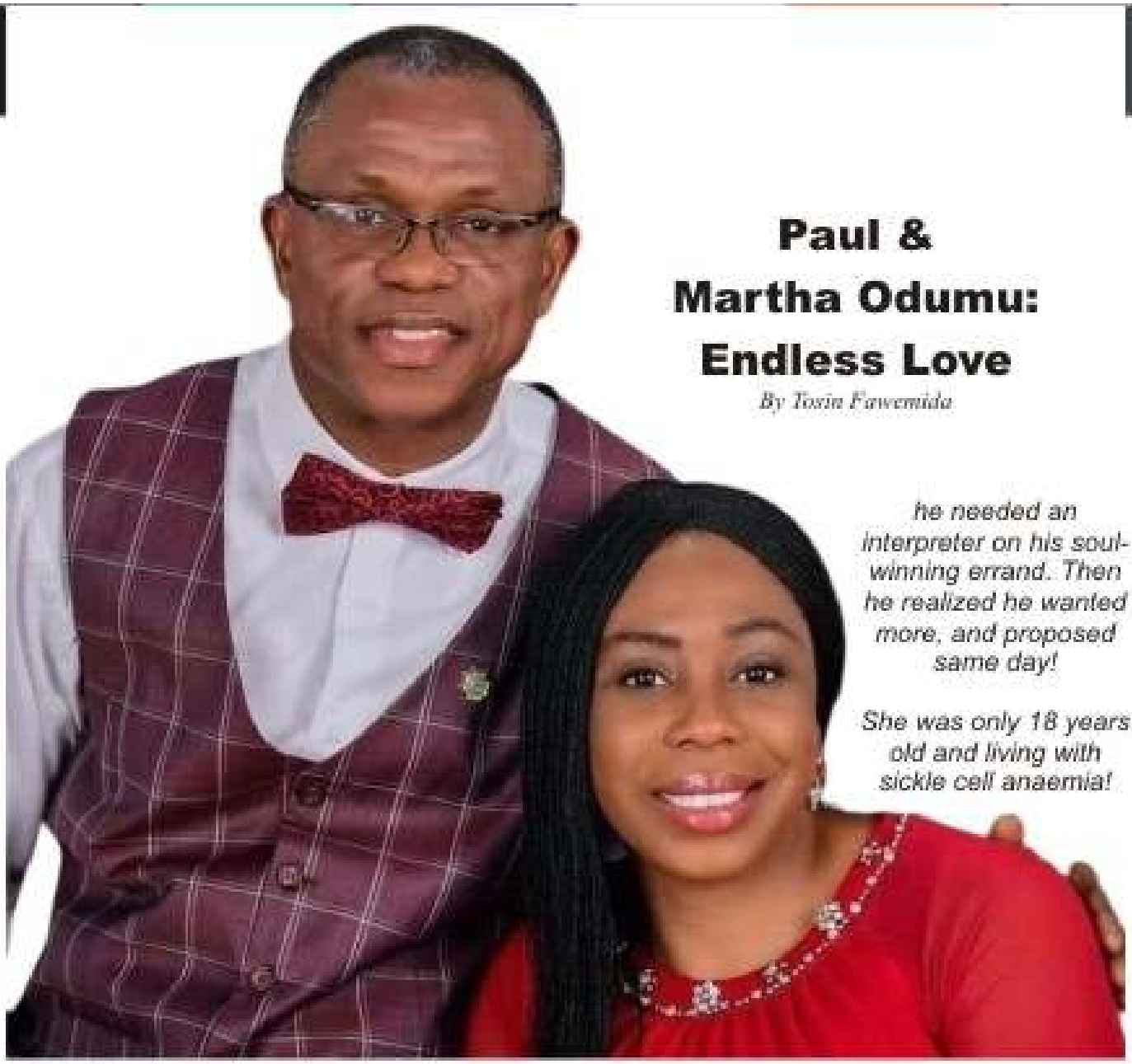
DO YOU WISH TO SUPPORT OUR WORK?

Ignorance of genotype is a major contributor to the diagnosis of SCD in an offspring. Your support will help sustain the provision of this educational magazine at no cost to readers from around the world. Do send donations to **SCELL MEDIA RESOURCES** account at **GTB** ac no 0015151637/**First Bank** account no 2011666024, and **Paypal:** paypal.me/scdjournal (SCELL MEDIA RESOURCES)

Paul & Martha Odumu: Endless Love

By Tosin Fawemida



he needed an interpreter on his soul-winning errand. Then he realized he wanted more, and proposed same day!

She was only 18 years old and living with sickle cell anaemia!

Her parents were nurses; but in the 1960s and 70s, premarital genotype verification was a non-issue. The couple already had three healthy children; so when the fourth presented with frequent illness, sickle cell was the last thing on their minds.

Once reality sunk in, the pious parents did all they could to help the special child to thrive, physically and spiritually.

Martha Ngufan gave her life to Christ, as she said, at the age of 10, in secondary school. After completing secondary school, she went on to study Nursing. Then a young medical intern was posted to her locality, and given accommodation right opposite her parent's house. The young man was a Christian, zealous for his faith and eager to preach the Good News of the Gospel and wins souls for the Kingdom.

Not being of Tiv ethnicity, Dr. Paul Odumu, an Idoma, couldn't speak the native dialect, and required an interpreter as he preached. As fate would have it on a particular day, he went to minister at the Tuberculosis Unit of the Mission Hospital. None of his regular interpreters was at hand, so he approached the bashful teenage nursing student he often sighted around to help. Though not total strangers, it was practically the first time they would have a conversation. She agreed.

'We had a tremendous harvest of souls on that day,' Martha recalls on her blog.

On their way back to their houses, Paul invited her in for tea. Right while they were having tea, he dropped a bomb: *'will you marry me?'*

She was flabbergasted, and could only stare at him. Noticing her discomfort, he asked her to put 'it'

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1st WARRIOR Celebrates Having Sickle Cell

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excelled at my job, trained student nurses and held many leadership positions.

I have 3 of my own business, with the best boss ever (myself!), and can pace myself as my body feels. I would not have had the courage to start my own empire without sickle cell giving me that resilience, inner strength and willpower. Once you've beaten death, you can beat anything.

Failed Relationships, Blessed Marriage

Because of sickle cell, I felt I was destined to be alone and single forever. A crisis is so horrible to witness that all suitors flee shortly afterwards. The longest relationship I had was 6 months. An ex said no man will ever marry me; another chose my birthday to marry someone else. Although betrothed, he was persuaded to marry another because his family felt I could not give him children.

I celebrate because, thanks to SCD, I didn't waste time, heart, or shed too many tears on these fools – they fell out early before they could steal my years and my heart. I celebrate the fact that due to SCD, I found my perfect match, bone of my bone, flesh of my flesh. I choose to celebrate the amazing 18-year relationship, blessed 13-year marriage to my darling husband, love of my life, best friend, soul mate who loves me so much, and embraces my culture, country, and family as if it was his own. Our love story is better than a fairytale, because it happens every single day. Orion gets me, he was custom built for me and I for him. Even our quirks and foibles align to become strengths like rice to soup. We make each other better individuals. I'm grateful he's my life partner. He adores me, I'm a lucky spoiled wife, treated like a princess, honoured with a cleaning crew weekly so as not to overexert myself.

I am planning celebrations for my 80th birthday party and God willing...

Miscarriages

I was told after two heartbreaking miscarriages that I should just give up, that I could not carry to term. I had an OBGYN remove me as her patient, saying I was too high risk to have children. I choose to celebrate because I had a smooth and easy delivery, labor felt like mild cramps compared to the pain of sickle cell. I was at home in 'labor' for 12 hours just chilling, thinking I was waiting for the real labor to begin!

I celebrate that I have my amazing miracle twin boys – perfection personified, angelic, loving souls, my gifts from God, who are 8, who make me laugh every day and bring tremendous joy to my life.

I celebrate because each day that I open my eyes, I am beating the odds. According to the CDC, a typical American dies by natural

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'Poor Access to Expert SCD Care Compromising Life Expectancy in Asia'

- Dr. Akshat Jain,
Director, SCD Program for Children and Young Adults,
Loma Linda University Children's Hospital, California, USA

On a recent trip to India, Dr. Akshat Jain, the renowned Inherited Blood Disorders specialist had series of meetings with the Health Ministers and top bureaucrats for discussions on improving sickle cell care on the subcontinent. With an official roadmap to 'eliminate' SCD by 2047, the meeting was even more crucial.

An experienced researcher, Dr Jain has extensive experience in clinical trials design and implementation and has served as global and national principal investigator on many groundbreaking clinical trials since 2011.

In this interview with *SICKLE CELL NEWS*, Dr. Jain compares SCD management in the USA to that of India and states that eliminating SCD may take longer than planned.

How do you compare SCD clinical services in the USA and India?

India is where the USA was 40 years ago in terms of SCD diagnostics, care, expertise and resources.

Life expectancy for most people with SCD in India is under 10 years. Medical expertise is lacking and is the biggest unmet need. SCD cannot be treated as Thalassemia or Malaria, for which there is plenty of ingenious expertise in the country, that is why SCD patients are having life expectancy 50 years shorter than the USA.

Lack of trained experts, absence of standardized national guidelines for management, poor access to HPLC testing, absence of newer therapies, absence of universal safe blood banking, absence of policies for infection prevention are some of the challenges that need to be tackled as though on a war footing.

India has announced an ambitious plan to eradicate SCD by 2047. Is it possible to wipe out SCD?

The current policies and initiatives in India would not be able to wipe out SCD. Firstly, just 1 out of the 4 approved medications has been studied in Indian patients, and the medication is out of reach for >75% of patients. Secondly, the infrastructure for effective therapies in India at this time is limited to only big cities, bringing the number to less than

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Life expectancy for most people with SCD in India is under 10 years... SCD cannot be treated as Thalassemia or Malaria, for which there is plenty of ingenious expertise in the country, that is why SCD patients are having life expectancy 50 years shorter than the USA

Marriage Proposal At First Interaction

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in prayer. *It must be love at first sight*, she thought to herself.

Weeks later, while she was yet to respond to his totally unexpected proposal, sickle cell struck, landing her in groaning pain on hospital bed. Beautiful and fair, she had none of the stigmata of SCD. She had not divulged her status, not knowing his own, and unsure if the revelation would leave him disconcerted.

When he went to visit her, and learnt of her sickle cell, he stood his ground, reminding her of Divine favour and Divine power to heal and restore. And that was it!

Paul and Martha tied the knot on November 15, 1997. A Postgraduate Midwife, she was just 21 and he, 29.

Shared Dreams

Nothing could sunder the couple's shared passion to shepherd lost souls unto salvation. There was also the medical side of their conjoined professional companionship.

To England and the USA, Martha went to further her nursing education. The couple established the Odumchaje Christian Medical Mission (OCMM) in 1998, an NGO focused on providing affordable holistic medical services to underserved communities in Nigeria. In 2021, OCMM was formally registered as Helping Team International in the USA, with the aspiration to globalize their philanthropic medical services.

Mrs. Odumu's SCD advocacy grows in leaps and bounds while her soulmate, 'My Paul', as she fondly calls him, is the head of training in Family Medicine at Nigeria's Ministry of Defence.

The lovebirds are blessed with two God-fearing, God-loving children, now young adults.

Beautiful and fair, she had none of the stigmata of SCD. She had not divulged her status, not knowing his own, and unsure if the revelation would leave him disconcerted

* Mrs. Megan Adediran, President, HFN, during the Workshop in Ilorin

HAEMOPHILIA FOUNDATION OF NIGERIA HOLDS WORKSHOP

The Haemophilia Foundation of Nigeria (HFN) September 2023 organized workshops around Nigeria tagged, *Beyond Borders, Connecting Healthcare Professionals for Bleeding Disorder Care*.

The first of the one-day workshops took place at the Pharmacy Complex hall, University of Ilorin Teaching Hospital (UITH), Ilorin, Kwara State.

Other centres for the Workshop included Abuja and Port Harcourt.

Established in 2005 by Mrs. Megan Adediran, parent to two children with the disorder, HFN is dedicated to improving and sustaining care for people with inherited bleeding disorders in Nigeria. It is thought that far more Nigerians are living with various forms of hemophilia than statistics suggest.

The Workshop was supported by the World Hemophilia Foundation, part of the PACT-2023 programme of activities.

GENOTYPE FOUNDATION HOSTS BMT 'SEMINAR'

On Sept 15, Mrs. Doris Obemiloye, Founder/CEO, Genotype Foundation turned 61. Customary with GF, a special gathering of SCD stakeholders to mark the day was held at the Lagos Airport Hotel. Mr. Emmanuel Adetos of Avo Eri Health Foundation took the audience on a virtual Bone Marrow Transplant tour - eligibility, HLA, funding, free transplant opportunities and so on.

A Nigerian family that successfully undertook BMT in Armenia shared its experience by video link. An excited and happy parent, Mrs. Omotola Yunus, mother of the recipient, Ameera Yunus, encouraged

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Tosin Ola-Weissmann:

The Making of a Warrior

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causes at 77-85 but my life-span with SCD is 42-45 years. I have met older folks with SCD but they are the exception, not the rule. I am planning major celebrations for my 80th birthday parties and God willing, I will be there. I celebrate each hospital admission that I came home from because not every warrior comes home.

At 43, I am old in sickle cell years. In childhood, I had two ischemic strokes, several heart anomalies, and a section of my lungs suffered necrosis due to acute chest syndrome. My grandma's teeth are better than mine! I have a walker, I use a cane indoors. I have Stage 3 Avascular Necrosis (AVN) in both hips and will require two hip replacements once they break. Through it all, I have so much to be thankful for.

I have faced death numerous times and lived to tell the tale. I celebrate that I know God. I have felt His presence in my life over and over again. I am closer to Him because in my deepest, most terrifying moments, my body wracked with unimaginable pain, my sickle red blood cells clotting and clumping, my circulation sluggish, my tissues ischemic and dying, feeling like 1,000 men stabbing me with knives, I cried out and He delivered me. Every single time I should have died, I miraculously recovered.

There are days where I am in agonizing pain and I can't get up. Some months, I am in severe pain 25 days out of 30. I choose to celebrate that in the midst of my pain, I found strength I never knew I had.

Family Rejections

For many families, dealing with a chronic illness like SCD is hard. On top of the financial impact, I've heard horror stories of those who abandon or neglect their sick kids. Some warriors are merely tolerated, treated like a burden, constantly disrespected, abused and insulted, even at home. A sickle cell warrior mentee of mine in New York has to take the metro bus to the ED every time she is in crisis after 3:30pm because her dad does not want to lose his parking spot! She can't take the train since climbing up and down stairs is too painful when she is in crisis, so she takes the bus for over an hour to get to the hospital. In severe pain. Alone.

You may not have heard of me, but if you're affected by sickle cell, you've probably heard the term, and used it. I touched your life

Loving Family, Friends

I choose to celebrate my amazing family who have carried and cared for my broken body since day 1. I celebrate my parents, whose love brought me here. They prayed for five years to have a child, and they got me. Back then, there was 100% ignorance of the implications of sickle cell trait in West Africa. My parents turned their guilt into goodness, they instilled in me all my core values.

I celebrate my parents, Pastor (Dr.) Joseph & (Dr.) Mrs Janet Ola, whose knees are as hard as rock for the times they have prayed for me, for the tears they have cried for and with me, for

'My parents' knees are calloused for endless hours of praying for me'

Tosin Ola-Weissmann
President/CEO
Sickle Cell Warrior, Inc

holding me and our family together all these years through all the trials. When I'm in a crisis, my dad is in the fire with me. He can't eat, sleep, or relax until he knows I'm doing better. He holds a spiritual vigil, fasting and praying for weeks at a time. My mom intuitively knows when I'm in crisis even if she is thousands of miles away. She is my compass, my lodestone, and my angel.

Family 'Skeleton'

My parents were told by many of their closest friends that we should keep my sickle cell a secret in order to protect my younger sisters' marriage potential. Beyond close family, I never talked about my SCD growing up. It was a family skeleton we ignored as much as we could until the next crisis hit. For me, it was a heavy burden to bear because I was the only one with it in my family.

'Don't Call Me A Sickler'!

I realized quite early that words have power, words matter, and I stopped referring to myself as a Sickler. To some, it's just a word, but to me, it was a label I did not want attached to me.

I had heard the nurse outside my room say to the aide, 'Tell the *Sickler* I will bring her pain meds in 15 minutes.'

It was the way he said it… Instantly, it triggered me, first to tears, then to anger. I called my sister. I could barely explain why I was so upset by the S-word. She suggested I do something about it. I asked the RN for paper and a Sharpie right before his break.

When he got back 30 minutes later, I had made two signs; one for my door, and one right above my bed: *'Don't Call Me A Sickler - Call Me A Sickle Cell Warrior.'*

I started signing off my blog as the Sickle Cell Warrior. Unbeknownst to me, I had ignited a global movement. Google it. Tosin Ola was the first person to use the term *'sickle cell warrior'* in reference to SCD patients in any print or electronic media.

You may not have heard of me, but if you're affected by sickle cell, you've probably heard the term, and used it. I touched your life, humanized our condition, and changed the world.

Doctors, nurses, people affected with SCD, their family members, sponsors, scientists, legislators, researchers, even the Rear Admiral of the US NIH used it in my presence! Now everyone across the world uses that term. Besides owning the trademark and copyright, every time I hear that phrase, 'Sickle Cell Warrior', I know that I accomplished part of my destiny.

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'Every time I hear that phrase, 'Sickle Cell Warrior', I know that I fulfilled part of my destiny'

BONE OF HER BONE, FLESH OF HIS FLESH

Tosin Ola Puts Up An Ad For a Friend And Got a Life Partner, An American Of Jewish Ancestry Who Loves African Culture

How did you meet Orion Weissmann?

We met online in 2005. I had just relocated to California and I had been there for a few months and been dating different guys. But these were horrible, nonsense guys. So I complained to my girlfriend and she advised I write down my precise needs in a man and place an ad online with 50 questions and 3 of my pictures. The *Craiglist* ad was only up for three days and I got 104 men showing interest. My future husband said it felt like applying for a job!

I began the process of reading, weeding out the prospects. Of the three candidates I eventually picked, Orion was the only man who answered all my 50 questions in his email reply. We were 93% matched and clicked even more during our phone calls. Our first in-person date was October 30 2005.

He told me later that when he saw me for the first time, his thought was, *Yeah, I'm gonna marry this girl.*

As for me, what made me think I'm gonna marry this man was when I had my first sickle cell crisis and noticed his reaction. Normally when I have a crisis, that's what sends all the men running fast in the opposite direction, as fast as they can run. But he was there, he came, he was there, he was there for me.

At what stage did you tell him about sickle cell anaemia? Did he know much about SCD prior to your revelation?

I told him that I had sickle cell about three months into our relationship. I explained what it was towards the end of our date. I assumed he was just going to not speak to me again, like all the other guys I had dated. When I told him about sickle cell, he said, wow, I can't believe you deal with all that. Our date was over, so he had to go: 'I'll see you tomorrow.' He gave me a kiss and left.

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SEX and SCD

.... when utmost pleasure turns to hospital-level pain event

managing sex as a trigger of sickle cell crises

By Sickle Cell Warrior Tosin Adesoye, MBBS

Dr. Adesoye

Does sex trigger sickle cell crises?
Should sex trigger sickle cell crises?
Why should sex trigger sickle cell crises?

Nothing is generalized in sickle cell disease because of the difference in severity which are due to factors that may not always be controllable.

Not all sickle cell crises triggers are avoidable, some can only be managed and sex is one of those triggers that fall under this category.

As much as there are sickle cell warriors for whom sex does not trigger crises, sex triggering crises for *some* is a relatively common complaint, which makes it worthy of discussion.

From my personal observation, women complain more than men about sex-triggerred pain. I am not sure if that is as a result of men being shy to discuss their sex life in relation to crises or the fact many men attain orgasm more quickly than women and release more happy hormones, which probably plays a role.

Sex can be like a double-edged sword for some warriors. Some say sex helps with their SCD and makes them feel better; some tell of sex occasionally dumping them in the doldrums of pain crises. Others have complained of crises after sex and sometimes priapism after the exercise.

Sex has a combination of triggers jumbled into one:
✓Sexual intercourse is like a physical activity and physical exertion triggers crises;
✓You tend to perspire a lot during sex, which leads to dehydration. Dehydration is a known trigger of sickle cell crises.

The happy hormones released during sex, which includes the natural pain killer 'endorphins' may not always be able to handle the pain caused by these factors, hence the crises.

AVOIDING SEX-TRIGGERED SICKLE CELL CRISIS

✓Prioritizing your health must be your first concern, love yourself that much.

✓Get a partner that will prioritize your health needs over theirs if need be. Anything short of an understanding partner may not be good for you.

✓Get to know and understand your body; a sickle cell warrior that understands his/her body should know when he/she is stressed and should rest or else he/she risks crisis.

✓It is a wrong move to try to have sex when you are feeling emotionally or physically stressed. If your partner wants it, let him/her know you are not good for sex just yet. Aggravating an already present trigger can easily initiate a crisis during or after sex.

✓If you are unwell e.g you have an infection or you are just recovering from an illness or you just had a surgery, those are already triggers, don't add another trigger to it . Wait until you are fit!

✓Hydrate sufficiently before, during and after sex if necessary. This helps manage the dehydration that occurs among

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It is a wrong move to try to have sex when you are feeling emotionally or physically stressed

Ekawat Surantoj *Mary Akua Ampomah* *Laurie Joseph*

GANSID Holds Inaugural Global Gathering October 20-21, 2023

The Global Action Network For Sickle Cell and Other Inherited Blood Diseases (GANSID) holds its inaugural congress virtually from October 20-21, 2023. With the theme, *There's Power In the Collective*, the gathering brings together stakeholders in the Inherited Blood Disorders (IBDs) Community to identify opportunities for collective actions to improve outcomes for people impacted by inherited blood disorders and enable cross-disease information exchange and best-practices sharing.

GANSID encourages the formation and development of national and regional Inherited blood disorder organizations throughout the world, and intends to assist and motivate such organizations through disease-specific and cross-disease exchange of skills and knowledge.

Speakers at the inaugural GANSID meeting are drawn from around the world, and include Dr. Mary Akua Ampomah, a clinical psychologist and former President/CEO of the Global Alliance of Sickle Cell Disease Organizations (GASCDO); Dr. Laure Joseph, a haematologist at AP-HP Necker Hospital, Paris, France with interest in bone marrow transplantation and gene therapy clinical trials; and Ekawat Suwantaroj, President, Thai Hemophilia Patient Club, Committee member of the National Hemophilia Foundation of Thailand and lay member, World Federation of Hemophilia (WFH).

Others from the roll call of distinguished speakers include Dr. Alayo Sopekan, FMH, Nigeria, Professor Adlette Inati, Professor of Clinical Medicine at the Lebanese-American University School of Medicine, Cesar Garrido, President, World Hemophilia Foundation, and Vinita Srivastava, a Health and Social care expert from India.

The co-chairs for the 2023 Congress are GANSID CEO, Mrs. Laure Tunji-Ajayi, MSM, and Professor Adekunle Adekile MD, PhD, member of GANSID's Scientific Working Committee.

Stakeholders from low and medium income regions of the globe with IBDs stand to benefit from membership as well as participation in the GANSID Congress: they get to interact with similar organizations and experts from advanced milieus. Through data-driven advocacy, collaboration, and capacity building, GANSID empowers member organizations and advances cross-disease initiatives to improve outcomes for people living with sickle cell & other inherited blood disorders.

The historic Congress is sponsored by Agios, Roche, Novo Nordisk, Vertex and Taskop Global Consulting.

Mrs. Edith Otokhina addressing the audience at Summit 3.0

TonyMay Foundation Hosts Summit 3.0

Healthcare professionals, legal and business consultants, SCD stakeholders and the public converged at Lagos Airport Hotel September 14 2023 for discussions on changing the perception of sickle cell in Nigeria.

The Summit was organized by TonyMay Foundation, the third in a series of formal discussions on SCD, which debuted in 2015, aimed at placing, maintaining and imprinting SCD issues on public consciousness in Nigeria.

In his opening speech, Chief (Barrister) Andrew Otokhina, Chairman, Board of Trustees, TonyMay Foundation, stated that continuous discussions on SCD will help to stamp out ignorance and open up ideas for better ways of managing the disorder.

'The number of Nigerians with Sickle Cell Trait and the number down with the disease is mind-blowing,' Chief Otokhina stated, reiterating TonyMay Foundation's commitment to confronting the 'monster draining the black man of personnel and resources'.

The Keynote Speaker at the Summit was Mrs. Chinyere Okorocha, Partner and Head/ Health and Pharmaceutical Sector, Jackson, Etti and Edu, Lagos, ably represented by Mrs. Uwa Ohiku.

The Moderators were Clara Nnorom, sales/marketing guru and human resources specialist, Adebukunola Telefusi, Executive Director, Xcene Research and Mrs. Nike Opalemo, CEO, Nike Opalemo Sickle Cell Foundation.

Panelists included Ms Toyin Adesola (SAMI), Stephen Aribatise (Codix Pharma), Prof Nkiruka Nnoyelum Odunukwe (NIOMR), Dr. Olanrewaju Ajayi (FMC, Ebute Meta), Peter Oshikoya (SAMI), Dr. Kwaku Marfo (Novartis), Ayoola Olajide (*Sickle Cell News*), Kevin Wake (USA) and Sharon Browne-Peter (USA). The MC of the day was all-round media expert and visionary storyteller, Tosan Atsemude.

TonyMay Foundation was founded in memory of Sickle Cell Warriors Tony and May Otokhina, with a mission to find a lasting solution to the SCD conundrum in Nigeria.

Menopause & Sickle Cell

(Part II)

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

The available treatments for Sickle Cell Disorder may also have long term impacts on the reproductive health of a woman. Women on certain management options for SCD such as hydroxyurea, are advised not to conceive and use contraception. With Haematopoietic stem cell transplantation (HSCT), the only curative treatment for SCD, the conditioning treatments containing alkylating agents and total body irradiation may contribute to loss of ovarian function and infertility.

Management of Menopause Symptoms

The management of symptoms of menopause includes:

- Lifestyle changes; diet exercise, smoking cessation. Mind body interventions: mindfulness, yoga, CBT
- Hormone Replacement Therapy (HRT)
- Alternative non hormone therapies; SSRI's, SNRI's, Gabapentin, Clonidine, Oxybutinin.
- Ongoing psychological support.

Hormone Replacement Therapy (HRT) is the most effective treatment for menopausal symptoms. It involves the use of medication containing hormones typically Estrogen with or without progestogens. It is not commonly used in women from countries where SCD is prevalent for various reasons, including fear of the potential risks. SCD is associated with an increased risk of blood clots and oral HRT also has a small increased risk.

Transdermal HRT (HRT absorbed through the skin), however has a neutral effect on the clotting system and is safe to use. The decision to use HRT in women with SCD should be made on an individual basis. It is crucial to have a discussion with your healthcare provider to find the best approach for managing your menopause symptoms.

HRT carries a small increased risk for breast cancer, but this again will need to be put into context over and above the background risk. There is a greater risk for breast cancer with obesity, increased alcohol intake, lack of exercise and smoking. Again, an informed decision with a knowledgeable healthcare provider is vital. The significant benefits of HRT including symptom treatment, prevention of the deterioration of bone and heart health are often forgotten.

Menopause and SCD both carry considerable social stigma, making it difficult for women to seek help. It was not so long ago that the myth that people with SCD did not live long was being perpetuated.

Tackling stigma requires collective effort from individuals, communities, and society. Strategies include raising awareness, challenging stereotypes, and providing advocacy and support. Modern treatments for menopause are relatively safe and without side effects. In women who already bear a cumulative burden of chronic stress and life events, continued suffering with menopause symptoms should not be an option.

From India With Love

... Parents of Children Cured of SCD & Leukemia Share Tips on Coping With The BMT Process

By Titi Aladei

It was a reunion of sorts when BMT Specialist Dr. Kharya Gaurav, of Apollo Hospital, India came to Nigeria and rallied round his patients for a seminar/get-together in Abuja and Lagos. The first meeting took place in Abuja's Fraser Suites while the second took place at Radisson Hotel, GRA, Ikeja; the attendees were parents of children who underwent BMT for SCD and leukemia. Others looking to transact BMT for their wards were there as well, emboldened and encouraged by the success stories they were going to hear.

The stories were stories of success, but the process was unenviable, to say the least. If you have the means and are thinking of BMT for your ward, don't overlook these tips from those who have been there.

Take Extra Funds With You:
You may have received your bill for X amount in dollars. But be prepared to spend up to twice more! Take extra funds with you - unplanned medical needs are sure to arise. If you don't have twice the amount you're billed, take minimum 50% extra with you. You won't know you're in for a money-gulping odyssey until you're on your journey and there's no turning back!

Brace up For an Emotional Roller-Coaster:
'I have occasionally felt like hitting and yelling at or wringing the doctor's neck!' says a parent, recalling the days of frustration elicited by her child's initial poor response to treatment. Some parents actually harass the BMT team who, fortunately remain calm, knowing from experience, that it's a phase most care-givers go through. 'Dr. Guarav's calmness infuriates me to high heavens!' says another parent.

Take Local Foods Along:
Indian cuisine is not so bad, but neither you nor your child is accustomed to it. As much as you can, take foods the child is used to with you to India. Some children get turned off by foreign diet at a time they need all the nourishment they can get pre-BMT. Will you be able to hold down nourishment when the child you took to India to get a cure turns away from food he/she is not used to?

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'Despite The Huge Challenge of SCD, I Made First Class!'

- Aishat Damilola Taofeeq

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'I was really determined to not let SCD be the reason I wasn't going to make a First Class. I wanted to be an example to other Warriors, that regardless of what we go through, we can achieve our goals.'

Like most other Warriors, Aishat has been face to face with stigmatization. An instance etched in memory was when she applied for redeployment to a less physically-demanding section of the hospital where she observed National Youth Service.

The redeployment took a long time coming and she fell ill practically every weekend, missing work and being queried. The redeployment did happen at last, but not without her boss making the stinging comment:

'I thought you wanted us to hide your shame!'

Still single, Aishat, 26 pledges to make genotype a cardinal part of the characteristics of her knight. After all, experience is the best teacher. (Aishat admits that she sometimes blames her parents - usually at the peak of a severe pain crises - for the health challenge resulting from *their* ignorance).

Blaming one's parents for the gift of SCD is tantamount to saying: 'why did you two choose to bring this ordeal upon sinless, innocent me!'

'I thought you wanted us to hide your shame!'

'God has been my rock, I never expected to make it this far,' she says. 'Having a strong family support system, determination and perseverance helped me to cope with the challenges of living with sickle cell.'

Dr. Tee: SEX AND SCD

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some warriors as a result of sexual activity.

✓Stay away from sex styles and positions that are energy-sapping; staying in some sex positions is actually like a rigorous exercise. If you are a sickle cell warrior you are better off taking it lying supine;

✓Know your limitations, many rounds of sex within a short period of time may trigger crises;

✓Learn to engage in foreplays when you are not fit enough to go all the way;

✓Avoid rough and aggressive sex, it can easily trigger crises for some warriors;

✓If you are a warrior that usually experiences crises during sex, taking oral analgesics before the act won't be a bad idea at all. Talk to your doctor about it.

TAHF Launches Project FHP 100 For Warriors

By Ayoola Olajide

Saturday August 12 would have been his 43rd birthday. Temitayo Awosika would probably have done what his family did on his behalf: the Awosikas rallied round Sickle Cell Warriors to help cushion the negative effects of harsh economic and financial realities in Africa's most populous nation and the world's highest SCD-endemic country. Cognizant that increasing healthcare costs would negatively impact Warriors, the Foundation memorializing Temitayo Awosika rolled out Project FHP 100 on August 13, exactly 24 years after his demise.

Temitayo Awosika Help Foundation (TAHF) was established in 1999, few months after the family suffered the devastating loss of a beloved child. Ever since, TAHF has relentlessly pursued its vision of giving hope and succour to SCWs and the poor in society. Where many families would buckle and probably back out in weird revenge against a condition that took away their loved one, the Awosikas turned their full attention to SCD, bearing its financial burden and providing a spiritual, emotional and psychological shoulder for Warriors to lean on.

'We will do everything within our means to develop and procure effective medications and supplements to manage sickle cell,' pledged Dr. Mrs. Dere Awosika, MFR, mni, Temitayo's mum, at the occasion.

A fellow of the West African Postgraduate College of Pharmacy, Dr. Mrs. Awosika gained decades of experience in public administration, banking and finance, which comes handy in a country beset with health policy administration issues.

On his part, Temitayo's dad and TAHF's Founder, Dr. Olubayode Awosika, encouraged Warriors to vigorously pursue their ambition, noting that they were not in any way disadvantaged by SCD.

'Take your medications as prescribed, stay well-hydrated, take a break as necessary, but never lose sight of your dreams.'

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Westminster Cathedral, NHS (UK), Richard Coker Foundation Mark Nigeria's 63rd Independence Day With Blood Donation Drive

By Fatima Garba Mohammed

Independence Day is a special day in every country; and nationals living abroad often make it a point to rivet public attention on their country's cultural strides and political achievements.

Nigeria is renowned for its SCD/SCT statistics: the sheer number of babies born annually with SCA, the sheer numbers with SCA (estimated to be between 4 and 6 million citizens) and SCT (between 60 and 70 million, the majority unaware) are enough to stagger an elephant.

One of the hallmarks of SCD is anaemia - constant shortage of blood, which often pulls Warriors willy-nilly down a tunnel of mental, physical and social health consequences.

blood donated by someone of the same racial background is more beneficial to the recipient

Cognizant of the value of blood in the management and prevention of SCD complications, the Westminster Cathedral, in collaboration with the National Health Service (NHS) UK and Richard Coker Foundation (RCF) hosts a blood drive on October 18, to mark Nigeria's 63rd Independence Day. The majority of people with SCD/SCT on earth are people of African origin, yet less Africans donate blood than other racial groups.

According to the NHS, Africans use up to 14% of donated blood but contribute fewer than 5%.

Although anyone can receive blood donated by any human being, blood donated by someone of the same racial background is more beneficial to the recipient, according to blood scientists.

Ordinarily, the Westminster Cathedral holds a monthly meeting with the NHS officers. The RCF is participating in the meeting to project its SCD sensitization and advocacy mission and showcase Nigeria's culture on Independence Day, says parishioner and Co-Chair, RCF, Chief Ms Julie Coker.

Just as the trio of Westminster Cathedral, NHS and RCF is doing in the UK, the American Red Cross, is in October, teaming up with partners in the Black community to host blood drives and encourage blood donors who are Black to support the blood transfusion needs of people with sickle cell.

SIDE EFFECTS OF BONE MARROW TRANSPLANT

Donor and recipient face a number of backlashes from the BMT process

Bone Marrow Transplant can be health-enhancing and life-saving; yet it is not without effects on DONOR and RECIPIENT.

DONOR:

Donating bone marrow (stem cells) is fairly safe and straightforward. Side effects are usually momentary and include:

- Chest Pain
- Stiffness of hands (tetany)
- Low Blood Pressure
- Fever
- Chills
- Flushing
- Foul taste in the mouth
- Headache
- Hives
- Nausea
- Pain

These events may result in complications such as:

infections, anaemia, bleeding, indigestion, diarrhoea, nausea and vomiting, inflammation and soreness in the mouth, clotting of small veins in the liver, damage to the kidneys, liver, lungs and heart.

RECIPIENT:

While BMT is mostly safe, factors that may induce complications include:

- The disease itself
- Age and health of recipient
- Whether chemotherapy or radiation was used before the procedure
- Quality of the match between donor and recipient
- Type of Transplant received (autologous, allogenic or umbilical cord blood).

Some effects that may appear after the transplant include:

- Cataracts
- Delayed growth in children
- Infertility
- Early menopause
- Graft failure
- Graft-Versus-Host-Disease
- Infection (including the VK virus)
- Pain
- Inflammation and soreness in mouth, throat, oesophagus and stomach (mucositis)

Because of its risks and side effects, BMT is not normally recommended for everyone with sickle cell or other blood diseases. The procedure is usually recommended for those with frequent and severe illness and hospitalization, serious complications and progressive organ damage. Those with mild illness are encouraged to maintain their health by adhering to routine health behaviours - regular intake of medications, regular health checks, good nutrition and hydration, and so on.

All in all, the benefits of BMT far outweigh the side effects.

A BMT donor just after the harvesting of stem cells from her body

Veterans of BMT Issue Advice

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Steel Yourself For Scary Moments:
Mrs. VG's daughter developed the BK Virus in the process of BMT. The BK Virus is one of those opportunistic viruses lying in wait for transplant recipients to undermine the whole process. Infections are common and have to be battled. Graft Versus Host Disease (GVHD) is the scariest of them all.

Memories of those moments will haunt you for a long time.

Prepare To Be Physically, Mentally and Financially Drained:
Watching your child go through the very process that would rid them of SCD or leukemia or other inherited blood disorder is one of the most body-draining exercise of all time, according to parents who have been there. Moments of doubts and regret, moments of angst and self-blame, cliff-hanging moments when you're unsure the nickel would drop into place, metaphorically speaking, will be many. At the same time, you are also being financially-suctioned to the point of begging from friends and relations and fellow transplant families!

'I sold property to get us to India,' recalls another parent, 'yet it was not nearly enough.'

Take The Risk, It's Worth The Freedom:
Although success rates are improving every day, there's still the risk of failure based on several factors. Despite that, families that have undergone BMT for their kids agree that the procedure is well worth it.

'If you have the means, please go for it,' advise the parents, 'it's the best gift you can give your child - freedom from pain and uncertainties.'

Genotype Foundation

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parents to throw their hat into the BMT ring even if they were not completely financially ready.

'God provides in mysterious ways,' she says. Her daughter began the journey with the family having much less than the amount required for the costly procedure. However, with the support of friends, relations and well-wishers, everything turned out right.

Gbemiloye took the opportunity to appreciate staff members and supporters, including the management of the hotel, which had given her organization free use of its facilities for the past 18 years.

Speaking at the occasion, Sickle Cell Anaemia Warrior Elder John Owhighogho Arure, 68, urged everyone all sickle cell warriors to 'manage (SCD) well, so you can live well.'

MY GENOTYPE IS SC, MY WIFE'S AA. HOW ON EARTH CAN WE PRODUCE A CHILD WITH SS!

Having grown up with three older siblings with SS, I have been acutely conscious of my genotype and its implications as a child. Being SC, I married a woman whose genotype is AA. My wife gave birth to three children. #1 is AS, so is #3. We recently discovered #2 to be SS after grueling pain crises episode, which lasted for days when she was 11 years old.

How can AA and SC produce SS? Something is fishy! Our marriage, built on trust, is set to hit the rocks!

Ike Onuoha, Enugu, Nigeria

THIS MIGHT BE A CASE OF MISDIAGNOSIS OF HB PHENOTYPE - A PERVASIVE CHALLENGE IN NIGERIA

●The wife has probably been given a *wrong* result either for herself or for the child. (We know, however, of girls who falsify their genotypes to get married to a particular partner at all costs)!

●This family needs to take a **POINT OF CARE TEST** (PoCT) to avoid human errors of batched samples, which sometimes occur in the cellulose acetate electrophoresis tests. This is the crazy situation experienced by families all over Nigeria with unregistered, and poorly run labs dishing out erroneous results and breaking families. Having carried out the test in a reputable hospital, the chances of that are slim.

●I urge the entire family to go for a proper screening using (PoCT) to screen and HPLC for confirmation. That is where the HPLC will be beneficial for confirmation distinguishing SS from SBthal. The child's SBthal could probably have been mislabeled SS.

Government has a critical role to play in the registration of qualified laboratories. Having a *national plan* on SCD in place and inculcating SCD Education in the curriculum from primary school to university in Nigeria will go a long way.

Adeyinka Gladys Falusi
FAS, FAMNS
Professor of Haematology

Temitayo Awosika: 24 Years in Mind

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Dr. Awosika praised men who stood by their wives in looking after their health-challenged children (of the more than 300 attendees, only 3 were fathers!).

Nevertheless, Dr. Awosika singled out a recurrent male face that presents itself at practically every TAHF event: Alhaji Waheed Ade Tijani. Alhaji Tijani, 81, lost his 19-year-old son, Sodiq Tijani, to SCD complications, yet he remained steadfast to SCD advocacy. He travels 60 kilometres to and from his Sango Otta, Ogun State residence to Ogudu, Lagos State, towing along as many Warriors as would go with him, to attend TAHF gatherings.

Hundreds of SCWs smiled home with health insurance e-cards for their use whenever crises looms or barges in without warning.

Dr. Sola Adebekun, TAHF's Executive Secretary, cherished Temitayo Awosika as a caring and compassionate human being, whose ideals the organization will unwaveringly pursue.

The Project FHP 100 For SCWs comes with free comprehensive outpatient treatment. For those on admission, it includes free accommodation, infusions and professional services.

'With timely medical intervention devoid of worry about finances, this TAHF initiative will help save and prolong the lives of Warriors.' says Dr. Adebekun.

The FHP 100 health insurance scheme is the result of TAHF's collaboration with Med-In Specialist Hospital and Access Bank PLC.

Dr. Akshat Jain

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a dozen for a country with close to one million patients.

You are doing SCD-related research in Nigeria. Exactly what is it about?

Through a grant project, what we are doing is bring expertise from the USA for an exchange program to train technicians, nurses, clinical providers in diagnosis and treatment. We also intend to create treatment guidelines for sickle cell Pain, Stroke, Avascular necrosis, Renal dysfunction and Leg Ulcers that can be used in pediatric and adult care in Southern Nigeria. Other aspects of our work in Nigeria have to do with epidemiologic research to understand the barriers to care in African patients for SCD and crucially, to establish digital health infrastructure so patients in rural and remote areas can seek care on a digital device.

TSCDF Sets SCD Awareness On Fire

No sooner had Tiwa Sickle Cell Disease Foundation (TSCDF) received its Registration Certificate from Nigeria's Corporate Affairs Commission in March 2023 than it went into action. As of September 2023, TSCDF supports no less than 100 Sickle Warriors in Kwara, Oyo, Ondo, Lagos, Osun, Ogun and Rivers State, in addition to the Federal Capital Territory.

TSCDF champions a two-prong approach to SCD advocacy: first, to assist the living with the disorder in every possible manner and second, to do everything humanly possible to minimize SCD births in Nigeria and Africa as a whole.

TSCDF is currently on a drive footing hospital bills, paying for or subsidizing school fees, handing out food palliatives and providing free routine and complications-specific medications to indigent Warriors and their families across Nigeria. The organization forever looks for ways to put a smile on the countenance to mask the pain and stress of living with or caring for someone with SCD.

The brain behind TSCDF is no other than Hikmat Temitope Abiona (Odesanmi), 28 a master's degree holder in Global Health from De Montford University, Leicester, UK. Hikmat's brother lives with sickle cell and recently got married. Having grown up to witness the many sides of a hydra-headed health condition, establishing TSCDF is, for Hikmat, an act of *aleibadat walshukr*.

'I might have married someone with sickle cell anaemia,' Hikmat says, half in earnest, but none ever came along to propose!'

Such is her identification with a health condition that concentrated an entire family's emotional resources on a single individual.

TSCDF, Hikmat vows, will relentlessly pursue sensitization activities that will lead to behaviour change to help bring down the incidence of SCD in Africa's most populous - and the world's heaviest-burdened SCD - country.

Having grown up to witness the many sides of a hydra-headed health condition, establishing TSCDF is, for Hikmat, an act of *aleibadat walshukr*.

The Power Of Praying Parents

It was the couple's first child after 5 years of marriage. Now the gift of the womb is beset with unrelenting illness!

In this interview with Sickle Cell News, Tosin Ola-Weissmann recaps how her parents' faith imbued her SCD journey with confidence

Your parents are Nigerian - tell us more about them?

My parents are Pastor (Dr.) Joseph Adebisi-Ola, and Dr. Mrs. Janet Olufunmilayo-Ola. They were schoolmates at the Adventist College of West Africa (ACWA), in Ilishan Remo, Ogun State, Nigeria. They got married in 1975, waiting five frustrating years before they had their first child (me).

My parents are as much in love today as they were in 1975.

What do you think it was like for them when they discovered you had a serious health challenge?

Mom found me crying and holding on to my leg at the age of four. Prior to that I used to be ill frequently. Mom thought maybe I'd hurt my leg. At first the hospitals I was taken to found nothing wrong. I was later diagnosed with sickle cell anaemia. And that was what prompted my parents to bring me to America for better care. We arrived in America on January 2, 1984.

I knew I was not going to die because my parents already told me so - and I believed them!

This health condition they knew nothing about thoroughly challenged my parents! It was scary for them.

One time I was in a crisis and crying non-stop. Mom just laid me on the bed and got down on her knees and said *God, if you're going to take this child, take her take her right now, or deliver her from this illness!*

Every time I'm sick, my parents say 'you will live, you will not die because we have the covenant with God that we will not see our children die!'

They prayed over me countless times - so many times I really began to believe that I have no portion with premature death. My mom will say you will see the full measure of your days and you're going to live to be an old lady.

Even in the midst of the worst crisis, like when I was deathly ill and in a coma for days, I knew I was not going to die because my parents already told me so - and I believed them! Sometimes the pain is really bad and I wish I was dead; but I always knew God has me here for a purpose - a great purpose.

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When Parents Pray ...

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At what age did you have a stroke? How exactly did it affect you? Did it make you fearful for the future?

I had a silent stroke between the ages of four and six. It was during a crisis, and my parents took me to the hospital. The only residual effect is that my right eye and left eye are not equal. My right eye is a bit smaller. Again, the strength in my right leg and left leg is not equal. I tend to drag my right leg a little. It's a bit droopy when I walk, just a little bit. I think there may be some mental effects as well, like memory loss from tissue damage.

Did the stroke make me fearful of the future? No, because, for me, it wasn't as bad as it is in some other people. It was a minor stroke; it's referred to as a silent infarct. So it didn't make me fearful of the future as much.

The main thing I noticed is that it affected my memory. My long-term memory is not as good as my sisters'. They recall dates, events, people, things that happened in our childhood. And for me, it's like a blur.

For instance, when my sisters recall that we went to Badagry Beach for Christmas in 2003, and say we did this and that, I remember nothing of it.

Since leaving for the USA at the age of four, have you visited Nigeria regularly?

We came back to Nigeria when I was 10 and stayed until I was 18. We had to go back because I kept having crises. I also had typhoid, pneumonia and stuff. I can't spend more than two weeks in Nigeria on any visit. I don't know how Nigerians with sickle cell cope!

I loved and still love *ẹba*, *asaro* (yam porridge), *ẹfo*, okro and *aadun*.

SCHAF DISTRIBUTES PALLIATIVES TO SICKLE WARRIORS IN IBADAN

In celebration of September SCD Awareness Month 2023, the Sickle Cell Hope Alive Foundation (SCHAF), Ibadan, Nigeria held a palliative cum free drugs and supplements distribution drive at the Apex Event Centre, opposite Muslim Praying Ground, Yidi, Ibadan.

A testament to SCHAF's unwavering commitment to brightening the lives of Warriors, the exercise brought together other stakeholders including healthcare professionals and the media.

A Union Made in Heaven

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'God must have had me in mind when He was molding my husband!'

I cried that night because I thought I would never see him again.

I remember calling my aunt and I was like, oh my gosh, every single guy, when I tell them I have sickle cell, we end up breaking up. I really like this guy. And she said, 'If it's meant to be, it will be. Just relax; stop crying. You're gonna cry yourself into a pain crisis.'

He was working, so I didn't hear from him all day. I thought he wasn't even gonna come. I didn't even get dressed. And then he miraculously arrived the next day for our date.

No sooner he settled down than he started firing questions at me: When were you diagnosed? Have you heard of *Niwosan* - it's from Nigeria? Look at this study. Have you considered bone marrow transplant? Blah, blah, blah.

I was flabbergasted that he showed up at all; and he showed up armed with books, thoughtful questions and research materials on SCD. *This man is amazing*, I thought to myself, *I'm not gonna let him go*.

He didn't know anything about sickle cell before I told him, that's why he went to the library to do a research. He later dug into his own family and discovered that they have the recessive thalassemia gene.

It wasn't long after my revelation that I had the first major crisis which required hospitalization. He has been by my side ever since, no shaking.

Orion has turned out to be quite a lover of African culture - how does he demonstrate this?

He loves Afrobeat music, discovered it before it was even in pop culture. He loves African cuisine: he eats *eweda* and *amala* with his hands, loves pounded yam, jollof/moinmoin. Give him any Naija, Moroccan or Ethiopian food and he is happy.

Even though he is by skin color a non-African, in his heart he is an African. He has more friends than I do that are Nigerian.

Born in America, my husband is a citizen of the world. Orion has traveled to every continent. He speaks English, German and Hebrew fluently. He understands a little Yoruba, Tagalog and Amharic. His mom is of Iraqi-Israeli ancestry while his dad is a mix of Argentinean and Swiss.

Right now he is working on a project that will make available one million affordable housing units in Ethiopia. A similar project is planned for Nigeria. My husband loves Africa and its people no end.

At the airport, when he first set foot on Nigerian soil, he exclaimed: *'I have arrived home!'*

The moment he settled in, he started exploring, going to places like Onigbongbo Market (Ikeja), and other places on his own!

When he visits with royalty, he curtsies and prostrates like any trained and cultured Yoruba man would do.

Every relationship must have its low periods. How do you deal with the challenges of those low periods?

Orion is very close to my parents, as I am to his. His mom travels long distances to visit me or take care of me in the hospital. When tough times come, my mom tells me, *'You got a good man - don't lose him over nonsense.'*

God must have had me in mind when He was molding my husband!

United States of America

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SICKLE CELL WARRIORS

Reg. No. 7,147,689

Registered Aug. 29, 2023

Int. Cl.: 36, 44

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Panelists for SCDAA's Masterclass Series Seminar Two - All Things Considered

The Masterclass on Sickle Cell Disease: On the Cusp of a Cure seminar series was created by a partnership between ***Sickle Cell Disease Association of America (SCDAA Inc.), Pfizer,*** *and* ***Entertainment 2 Affect Change***

Tesha Samuels

Tesha's life was transformed by an autologous gene therapy transplant in 2018 that put her in remission from sickle cell disease. A lifelong advocate, Tesha shares her experience as a gene therapy transplant recipient with the hope of inspiring sickle cell warriors and policy makers.

Tesha established *Journey to ExSCellence*, a nonprofit dedicated to provide advocacy and support to adult sickle cell warriors and their caregivers.

In recognition of her advocacy, she was awarded the Sigma Gamma Rho Sorority Inc. Ollie V. Greene Humanitarian Award in 2020 and 2021. Tesha also champions other rare diseases.

Shanetta Richardson

Shanetta is president of the Sickle Cell Association of the National Capital Area Inc. and founder and president of *'I Am Sickle Cell Inc.'* From Washington, D.C., she's a sickle cell warrior and ambassador.

Despite not finishing high school as a result of SCD complications, Shanetta persevered to obtain her GED and moved on to higher education. Shanetta holds a degree in business administration and a master's in health service administration.

Shanetta's work has earned her many awards, and she has been featured in *Ebony Magazine*, and NBC News 4, among others.

Clifton R. Kirkman II

Clifton is a 34-year-old sickle cell warrior, advocate and freelance journalist.

As a Detroit native with a bachelor's degree in electronic media and film studies, Clifton not only seeks out compelling stories in and around his city but also serves as the social media specialist for the Sickle Cell Association of America - Michigan Chapter.

Freelance journalist and loving father to a 9-year-old daughter, Clifton holds a Bachelor of Science degree in Electronic Media and Film Studies from Eastern Michigan University. One of Clifton's life missions is to educate others about SCD.

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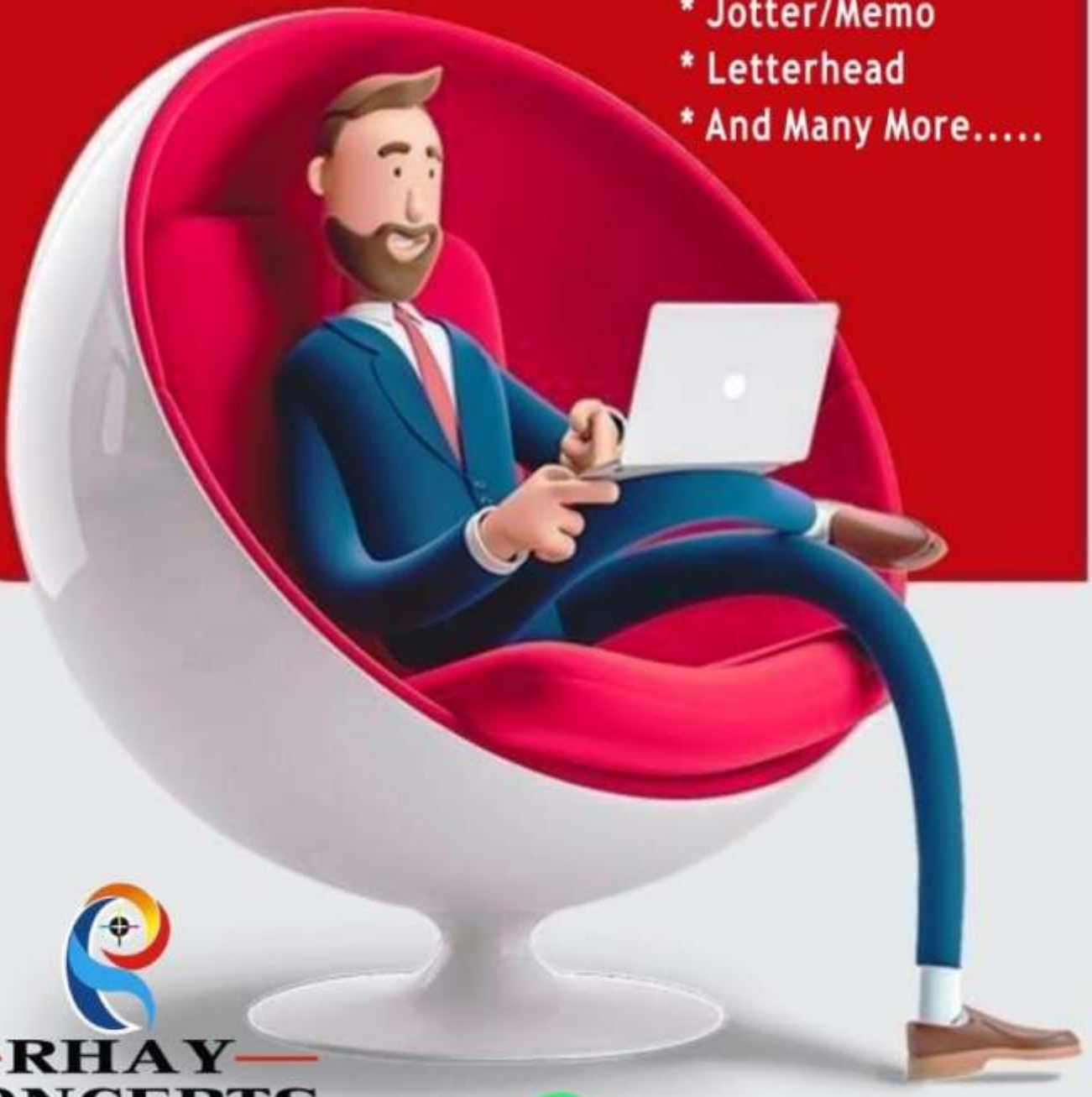

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SYMPTOMATIC - LIFE OF A SICKLE CELL TRAIT CARRIER

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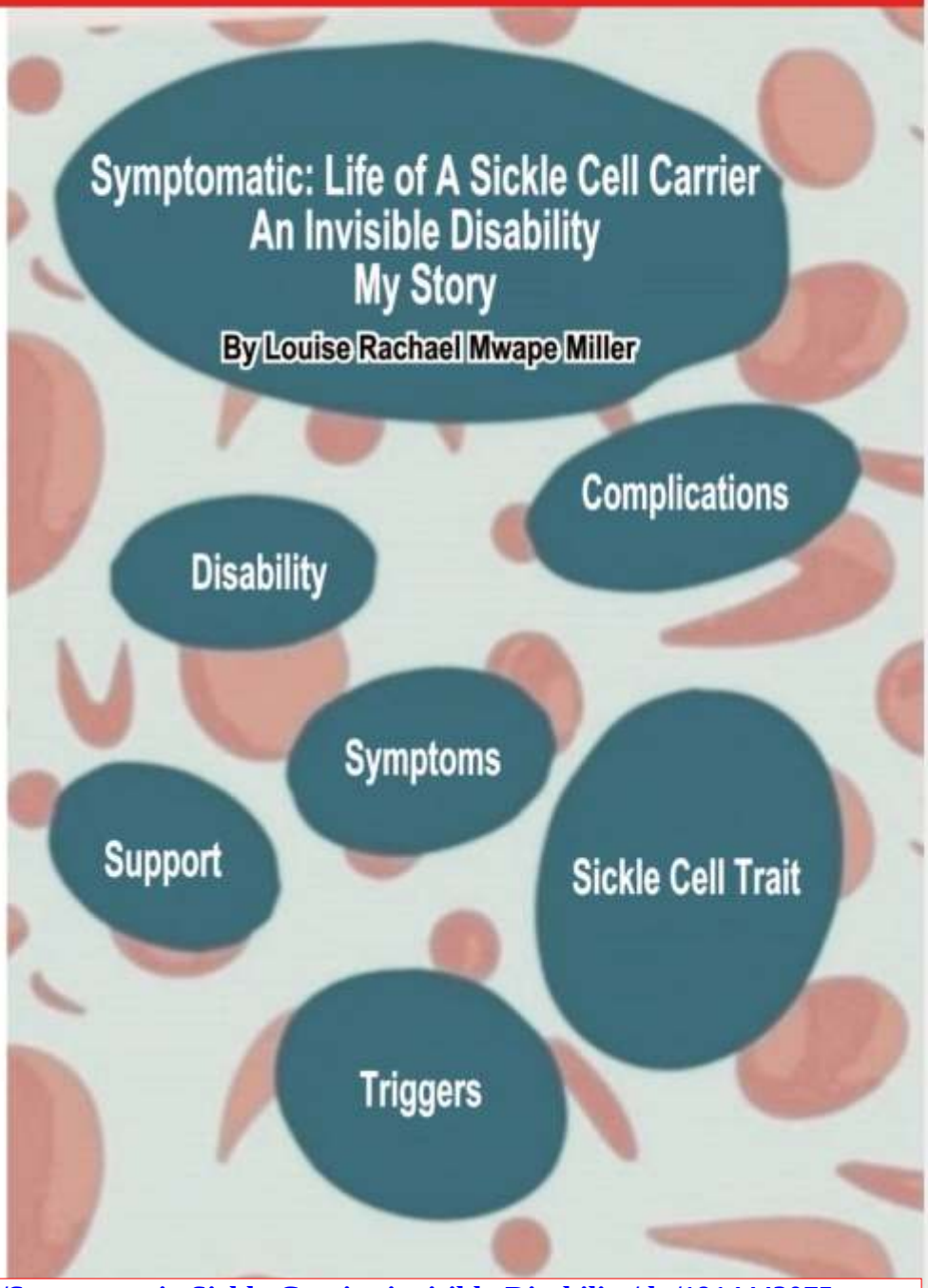
This is a first-hand account of the author's personal experiences with a so-called rare blood condition, not widely researched, yet stereotyped as benign.

This book provides an intimate, never before disclosed experience with the author, who has been symptomatic all her life.

Growing up in a community where the full blown disease was commonly recognized and dominant, her experiences as a carrier were never validated in early childhood, because of a gross lack of awareness in the medical world and in clinical publications and textbooks.

This is her story from a faith-filled perspective! This book aims to spread awareness of the dangers and highlight the risks risks of such gross ignorance.

Lulu's book is a ***MUST-READ*** **IF YOU HAVE SCD/SCT!!!**



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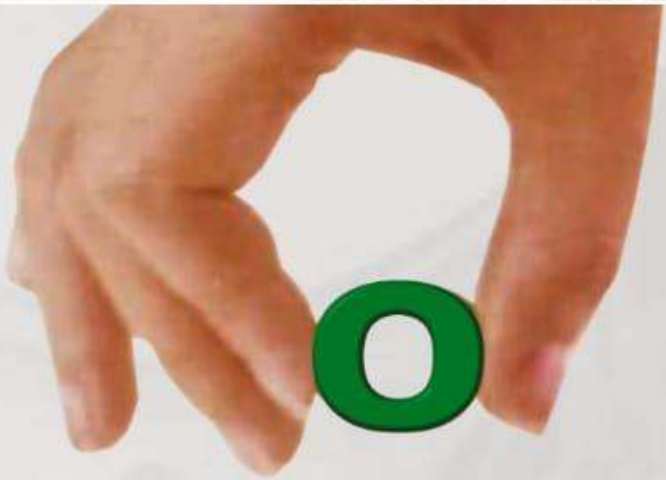

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