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SICKLE CELL NEWS & WORLD REPORT

www.sicklecellnews.com

THREE AMAZONS WHO DEFIED THE ODDS

Diamond: 1927 - 2022

Falconer: 1933 - 2022

Onikoyi-Laguda: 1925 - 2020

I got diagnosed with SCA aged 22: all my 5 siblings probably with SCA too!
- Elder John Arure, 66

Duchess Doris Gbemiloye @ 60:
The story of God's own Genotype Foundation

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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

The *African Sickle Cell News & World Report* is an educational magazine for the global sickle cell community. Views and opinions expressed are not necessarily those of the publisher.

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I Am Hopeful This Disease Will Soon Be Vanquished!

-

Mofolorunso Adekunle Enigbokan, PhD

From 1977 to 1978, while pursuing a Master's degree in Microbiology at Texas Southern University in Houston, Texas, I investigated the antibacterial effect of *Fagara xanthoxyloid* (an African chewing stick). The research was conducted in Dr. Sunday Fadulu's laboratory. The study of the medicinal properties of *Fagara* continued after I graduated. It was later discovered that extracts of that particular root and its congener, when ingested orally, had a beneficial effect on sickle cell disease patients. The extract significantly reduced the number of sickle cell crisis experienced by the patients in clinical studies performed in Nigeria and Gabon.

After I obtained a Ph.D degree in Pharmacology and Toxicology from Howard University College of Medicine in Washington, D.C., I did postdoctoral training at M.D. Anderson Tumor Institute in Houston, Texas before joining the Faculty at Texas Southern University in 1987. While conducting my research in Cancer Chemotherapy, I was able to rejoin the ongoing sickle cell disease investigation in Dr. Fadulu's laboratory. We obtained a U.S. patent on one of the extracts.

Before we could conduct a clinical study at Riverside Hospital in Houston, Texas, a friend of mine succumbed to the disease and there was a financial mishap at that hospital that put the project on hold.

I am hopeful that this dreadful disease will be vanquished soon.

Prof Enigbokan is Professor of Pharmacology and Toxicology, Texas Southern University, College of Pharmacy and Health Sciences, Houston, TX, USA

I Got To Know Of SCD As A Teenager

-

Tonye Wokoma, SRH

I had heard of SCD in casual conversations, but it first became real to me as a teenager when I entered secondary school - Federal Government Girls College, Abuloma - and began making new friends. One of these new friends was with sickle cell anaemia. The disorder came along with regular excruciating bone pain crisis for her, where she had to be taken to the Sick Bay. Sometimes nothing given her there appeared to help.

My friend was the life and soul of a party, except when she was ill. Despite the challenges she faced, she pursued her education, went on to become a medical doctor, got married and had children.

Later in medical school, my interest was sparked seeing women go through illnesses and conditions that could have been controlled or prevented. Amongst these were women affected by Sickle Cell.

Ever since, I have come to meet or know of motivating SCD warriors. I have also listened to some heart-breaking stories.

I believe everyone should have their genotype checked prior to marriage and having children. Issues of this sort are never black and white but having the knowledge and the right support is always beneficial.

Hull, UK-based Dr. Wokoma is a Consultant in Sexual & Reproductive Health & Community Gynaecology

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

scdjournal@yahoo.com

Living With SCD, Living With Cancer

Your interview with Reetesh Naik who lives with SCA but also battling cancer makes for sober reading and reflection. This is about the second time you will be featuring Sickle Cell Warriors who are also facing other serious health challenges (the first was Elvie Ingoli of the German SCD Association).
I pray Reetesh similarly overcomes the cancer as did Elvie. SCD is a handful on its own.

Otwabe Henry
Mombasa, Kenya

World SCD Day - Thank You, UNO

The United Nations did the world a favour by declaring a Day for SCD (June 19). Although SCD and its many variants affect people of all races, it is predominantly an African and Indian phenomenon.

For at least one day in 365, Warriors and non-Warriors alike on those continents will learn something of SCD if not on radio and TV, if not on social media, but from colorful street parades the day has become synonymous with worldwide. However, organizers of WSCD events need to include rural dwellers in their campaigns.

Odiambo Gianna
Rwanda

Diagnosed @ 62!

In most cases comparatively milder than SCD-SS as it is, it is amazing that Cynthia Curinton James' SCD-SC did not show up until she was 62, and only after a plane trip. My own niece was born with Hb-SC but was diagnosed at the age of 9, when she suddenly presented with bone pain crises. Wonders, indeed, shall never end.

Anie Appiah
Dansoma, Ghana

Sorghum Bicolor *Jobelyn* Phytoceutical Testimonial

Ordinarily I have no trust for drug user testimonials, believing that users have received inducement to 'air' the product. But when a specialist medical doctor issues a herbal medicine/supplement testimonial based on personal experience, I am more than willing to listen!
Kudos to Dr. Oluranti Ekpo who already has an SCW child before adopting an HIV positive baby. That *sorgum bicolor* (*Jobelyn*) is effective for both the children's conditions is a testimonial to the efficacy of plant medicine.

Kingsley Osadolor
Ughelli, Nigeria

Dr. Rafiu Isamotu's Submission

The statement by Osun State, Nigeria, Health Commissioner Dr. Rafiu Isamotu to the effect that 'every African family has SCD in its loins' is true. The puzzle is that despite the harsh lessons SCD has taught families, hundreds of thousands of babies are still being born with it every year. People should realize that this disorder is 100% preventable!

Conquest Fitzgerald
Calabar, Nigeria

From The Editor

Who Will Survive, Will Survive

- Ayoola Olajide

Over the years, we have featured Sickle Cell Warriors who have broken the glass ceiling of lifespan. Among those, Wale Fanu (1950 - 2022), and Alhaja Asiata Aduke Onikoyi-Laguda (1925-2020). Despite the harsh realities of living in a medical third world continent, SCD did not hinder their survival to old age.

In 2015 when Onikoyi-Laguda turned 90, we did a special edition on her journey with sickle cell and featured the stories of other Warriors of advanced years, including Ernestine Diamond who recently passed away aged 94. The lives of these old folks confirm the maxim of 'never say never in medicine'.

Being diagnosed early may be an advantage but how about Warriors like Cynthia James Currinton who was not diagnosed until she was 62 (July-Sept 2022 edition)? How about Elder John Arure, 67, who did not know he was a sickle cell anaemia until he was 22? Yet they survived without medication, without treatment!

This calls to mind an African adage which states that, whatever the (untoward) situation, whatever the uncertainties, whoever will live will live! And vice versa.

Africa Moves To Curb SCD Prevalence

- WHO Africa

African health ministers have launched a campaign to ramp up awareness, bolster prevention and care to curb the toll of sickle cell disease, one of the most common illnesses in the region but which receives inadequate attention.

More than 66% of the 120 million people affected worldwide by sickle cell disease live in Africa. Approximately 1000 children are born with the disease every day in Africa, making it the most prevalent genetically-acquired disease in the region. More than half of these children will die before they reach the age of five, usually from infection or severe anaemia.

In the African region, 38 403 deaths from sickle cell disease were recorded in 2019, a 26% increase from 2000. The burden of sickle cell stems from low investment in the efforts to combat the disease. Many public health facilities across the region lack the services for prevention, early detection and care for sickle cell disease. Inadequate personnel and lack of services at lower-level health facilities also hamper effective response to the disease.

The campaign, launched at a side event on enhancing advocacy on sickle cell disease during the Seventy-second World Health Organization (WHO) Regional Committee for Africa—the region's flagship health meeting, aims to shore up political will and engagement as well as financial resources for sickle cell disease prevention and control across the region. It also seeks to raise public awareness of the disease in schools, communities, health institutions and the media and advocate stronger health systems to ensure quality and uninterrupted services and equitable access to medicines and innovative tools.

'Most African countries do not have the necessary resources to provide comprehensive care for people with sickle cell disease despite the availability of proven cost-

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A TALE OF TWO GIRLS WITH SICKLE CELL DISORDER

Sickle Cell Warriors Asiata Aduke Onikoyi-Laguda and Ernestine Diamond lived to their 90s, breaking the glass ceiling of age in SCD. Their survival to ripe old age was something of an affront to medical science ...

By Tosin Fawemida

In 2003, the Sickle Cell Disease Association of America (SCDAA) honoured Mrs. Ernestine Diamond as the oldest person in America living with sickle cell. Ernestine, a mother of four children was 76 years old then. If she wasn't actually the oldest, she was definitely among the oldest in the USA and the world.

Life with SCD carved an advocate out of Ernestine, who, in 1985 established an organization known as Sickle Cell Action Through Technology (SCATT) to pursue her vision of encouraging those similarly affected and forewarn others.

Meanwhile, in Africa, another Sickle Cell Warrior, roughly 18 months older, lived in relative obscurity. Only her family and friends knew that she dueled with SCD. Add to that her medical caregivers and co-patients at the Sickle Cell Clinic, Lagos University Teaching Hospital (LUTH). Alhaja Asiata Aduke Onikoyi-Laguda's story would not gain traction and go viral – as the saying goes – until the news-magazine, the *Sickle Cell Journal*, was born in 2008.

A successful trader and owner of several properties in Lagos – apart from being a scion of the Onikoyi ruling family on Lagos Island, she was not formally diagnosed with sickle cell until she got to London in 1960 to study. Her primary care doctor who later became her husband must have known, but he did not divulge much to her. A serial polygamist and a suave ladies' man, Dr. Bolaji Alakija gave her medications to take every day and closely monitored her. Yet he said nothing - it was the norm in the 1940s to disclose as little as possible to the patient or to their relations.

Like Ernestine, no one thought Onikoyi-Laguda would live long, given the torrent of illness and indisposition she was seemingly hexed with.

Yet they both made it to ripe old age, watching their children, grandchildren and great-grandchildren grow. Their survival seemed very much like an affront to medicine.

ADEKUNLE GOLD
KELEGBE MEGBE
- KNOW YOUR LEVEL -

Sickle Cell Took Away My Childhood But Did Not Stop Me From Achieving My Ambition!

*In a stunning revelation on his instagram handle July 2022, popular Afrobeat musician/songwriter Prince **Adekunle Marouf Kosoko,** 35, (better known by his sobriquet Adekunle Gold or AG Gold) looks back on his experience growing up with a poorly-understood health condition. Gold was brutally honest about life with sickle cell but gives out hope of a better life if one does not relent in pursuing one's dreams.*

It feels liberating to finally be able to share this part of my life with you, to finally be able to speak my truth. When I talk about how I struggled to get to where I am today, I need you to know that my struggle was real.

I was born with sickle cell disease. It was life and death, it was physical, mental, financial, you name it and I went through it all. It was tough, painful, and frustrating. I lived with a sickness no one around me understood, I lived with restrictions all through childhood.

I wasn't able to join some of the most minor childhood play and liberating activities like going out in the rain. The times when I insisted and rebelled against my parent's orders and went out in the rain, I would end up having a crisis. The nights were painful and lonely, nights that no one could help me get through. It was just me, God, and my mind. The pains and shivers were unbearable.

They always came in the night, when my family had no means to transport me to a hospital. We simply couldn't afford the constant hospital bills so I had no choice but to endure the pain.

My mum wanted me to be well, she did her best. She took me to all the churches she could find, I'm grateful to her because she saw a future for me. . . A future where no illness or sickness could hold me back from my purpose. From the life, I was destined to live.

Sickle cell disease took away my freedom, my childhood. I lost friends, a lot of them. Some didn't understand the restrictions and rules I had to live by, some just didn't want to deal with my illness or thought it was a nasty or contagious disease that they could catch. I was a burden for some. Living with sickle cell is far from living a normal life!

One of the most intense crises I had was at the age of 20, I remember laying in my bed in the middle of the night asking for an end to it all. I begged God to take my life away because I couldn't understand what I did to deserve the pain my body and mind were under.

'I lived with restrictions all through childhood'

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CATCH ME IF YOU CAN

ADEKUNLE GOLD

Life with Sickle Cell Anaemia ... AG Gold Testifies

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As usual with sickle crisis after some days, the pain subsided and God asked me;

'That end you begged me for, do you still want it?'

Of course, I said no and that's when everything changed for me.

That's when I realized that I had been given another opportunity to live my dreams and to show those that mocked me that sickle cell anaemia was never going to end me, that it was never going to hold me back from my dreams and aspirations.

My body caves in once in a while, and some symptoms come back but what this disease has taught me is resilience. Sickle cell anaemia gave me hope, made me tough, gave me the discipline I needed to be who I am today, and built my character. I went through a whole 5 weeks of back-to-back performances and didn't fall sick.

My mind and body were challenged and I'm stronger, more determined, and ready to take on the world. I'm ready for Adekunle Gold Supremacy, I'm ready to live and enjoy the 5 Star life that I deserve, that my body toiled for.

I'm sharing my testimony with you because I hope that you can find strength in my truth. Some ailments hold us back but I'm thankful this hasn't. I want to encourage you in whatever it is you're going through, know that there is hope. You are strong and you must not give up. YOU CAN DO THIS!

Victory lies at the end for you just as it did for me.

If you know anyone going through any struggle, physical, health, or mental, be kind, and show compassion. In fact, be kind to everyone, you just never know what they're dealing with privately. Be supportive, be gentle, and love endlessly.

If you are a 'sickler', know that the disease does not define you. Don't allow it to limit your dreams or cap your potential. Spread your wings and dream big!

Hope to see you soaring in the big skies.

'I couldn't understand what I did to deserve the pain my body and mind were under'

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 towards the advent of a genotype-aware world. Do send donations to **SCELL MEDIA RESOURCES** account at **GTB** ac no 0015151637, and **SCELL MEDIA RESOURCES** at **WELLS FARGO**, USA Zelle 8178086207, Paypal: **paypal.me/scdjournal**

Sickle Cell/Childhood Cancer Awareness Month:
AFLAC DUCK MOTIVATES CHILDREN BATTLING CANCER, SICKLE CELL

SEPTEMBER 2022.

In collaboration with Aflac Incorporated, the leading provider of supplemental health insurance in the U.S.,1 Nicklaus Children's Hospital hosted a special duck delivery and unboxing event at the hospital's main campus, where patients received a *My Special Aflac Duck,* free of charge, as part of Aflac's philanthropic commitment to support children with cancer and blood disorders.

My Special Aflac Duck is an award-winning social robot designed to be a cuddly companion that helps bring comfort and joyful moments to children with these conditions. In consultation with more than 100 children, families and medical professionals, Aflac, along with Sproutel, a patient-centered research and development company in Providence, Rhode Island, debuted My Special Aflac Duck in 2018 as part of its 27-year, $161-plus million commitment to childhood cancer and blood disorders, including sickle cell disease.

'Aflac is a committed ally to children with cancer and blood disorders, and we continue to make it our mission to expand the reach of *My Special Aflac Duck* to help bring young patients and their families comfort and joy in the moments they need it most,' said Ines Rodriguez Gutzmer, vice president, Strategic Communications, Aflac Incorporated.

Features of *My Special Aflac Duck* include an interactive mobile app that allows children to virtually bathe and feed their duck, customizable soundscapes that provide soothing visuals and sounds, smart sensors that enable touch and awareness of light and sounds, and a calming heartbeat and breathing vibrations. To help children express themselves, the duck also comes with seven feelings emoji discs that, when tapped to a sensor on the duck's chest, prompt My Special Aflac Duck to emulate each emotion. After significant research and development, in early 2022, Aflac introduced *My Special Aflac Duck* with accessories designed specifically for sickle cell patients.

'We are honored to join forces with Aflac and take part in the My Special Aflac Duck program as a way to further support our young patients receiving treatment for cancer and sickle cell disease,' said Jennifer McCafferty-Fernandez, Ph.D., senior vice president of external affairs and chief of staff, Nicklaus Children's Health System. 'We know these fun and cuddly companions are sure to enhance the care experience for the children and families we serve.'

PRNewswire

WHY SIT WE HERE UNTIL WE FAINT? LET'S DO SOMETHING!

Remembering Ernestine Diamond: 1927-2022

By Titi Aladei

Ernestine Diamond's organism manifested all the classical early signs and symptoms of SCD but a proper diagnosis would elude her family until she was 21. Born at a time of overt racial discrimination in America, the first doctor she was taken to refused to attend to her because he did not treat coloured people!

He did cast a glance at the three-month old feverish, sluggish, stiff-necked specimen before him and hazarded a verdict: 'this child has brain fever – take her back home to die!'

At the age of four, Ernestine had a stroke, a sickle cell complication not uncommon in children affected with sickle cell anaemia. It was 1931 and doctors were long away from associating the debilitating cerebrovascular complication with sickle cell. Laboriously, the child learnt to walk again (and lived 90 years thereafter!).

Illness upon illness, crises upon crises, yet there was no treatment except ointment – and prayers! Even after she properly knew what ailed her – sickle cell anaemia – reliance on a Higher Power remained an integral part of Ernestine's self-treatment regimen.

Early in childhood, Ernestine loved to sing. At the age of five, she became a member of her church choir. She would later teach Sunday School. All this helped her to steep herself in worship and prayer to combat an illness many regarded as a demonic possession. She was, after all, growing up in an epoch when SCD was very poorly understood; Clement Noel, the first individual ever to be described with SCD passed away only 11 years before she was born. On days when the pains were unbearable and unresponsive to medication, she resorted to prayer until the pains subsided. Prayer became an armour in the face of an un friendly health condition. The quiet lonesome child learned to pray until she got an answer - she had imbibed Baptist pentecostalism so early in life! It can be said that Ernestine survived as much on prayer and self-care as on medication for the rest of her days.

In 1947, a lover of travel and adventure, Ernestine determined to visit Jerusalem and Israel. Her doctors kicked against her plans, warning she did not have the strength for travel. 'You don't have the stamina for travel stress – you could die!'

For Ernestine, it was one warning of dire consequences after another. Obstinately, she would pray and go ahead with her plans! Thus she visited the Holy Land and 12 European countries.

Ernestine got married to Bradley Jackson and gave birth to four healthy children. After 23 years together, the couple filed for divorce and went their

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MEET THE WARRIOR WHO NEVER GIVES UP

By Abro Onyekwe

***Never Give Up Day** is celebrated worldwide August 18 of every year to highlight the triumph of ordinary humans over adverse conditions and circumstances. It celebrates the spirit of endurance, perseverance and determination without which neither freedom nor achievement is plausible.*

*The life of robotics teacher Raolee, PhD epitomizes the ideals of **Never Give Up Day.** Born in Lagos, Raolee studied Botany/Plant Biology at the University of Lagos and later proceeded to the UK where she earned a Masters in Health Promotion. With yet another masters in Educational Technology , Raolee eventually capped her academic endeavors with a doctorate in Educational Leadership and Management at St. Thomas University, Miami, Florida., USA.*

Despite the ups and downs of life with SCD, the tenacious robotics teacher has lived and worked in many countries in the Middle East and Europe.

In August 2022, the 54 year old Sickle Cell Warrior moved to the Netherlands, where she had landed a contract employment to induct adolescents into the magical world of Artificial Intelligence.

*Below is an excerpt from an interview with Dr. Raolee to mark **Never Give Up Day** 2022.*

DIAGNOSIS

It was discovered I had Sickle Cell Anaemia at age 2. My baby sister was born July 11, 1975, and diagnosed with sickle cell at six months. She died Dec. 31, 1976.

My parents were aware of the disease but since neither of them was sickly, they did not realize they had the sickle cell trait. I don't think any parent will willingly give sickle cell to their offspring!

TRANSFUSION

I have lost count of how many times I have had a blood transfusion, but I am sure I have had nothing less than 50 blood transfusions in my life

COPING WITH SCD

Life is very challenging for most people, and having sickle cell does not give you a pass. I wish it did.

I have a demanding job that does not end at 4:00 pm when the work day ends. I have to do a lot of my work at home and sometimes I work on weekends. I drink a lot of water and I pray to God for healing.

SURGERIES and ANESTHESIA

I have gone under anesthesia at least 20 times: Two cesarean sections, one knee surgery, a cholecystectomy to remove my gall bladder, a herniorrhaphy to remove my hernia, a hysterectomy, colonoscopy, and others.

MY BOOK, *TANWA*

TANWA is actually a spin off of my memoir, so it did not take long to write. The next book in the *TANWA* series is actually taking me longer to write.

As a child with sickle cell, I always felt isolated and different because of my illness. *TANWA* is to help little Warriors. I am currently working on a coloring book as an activity book for kids in hospital with sickle cell or indeed any other acquired or inherited health challenge.

Why Nigeria Can't Perform Liver Transplants For Now

- OOUTH Don

Nigeria is not capable of conducting Liver Transplants (LTs) for now, according to Dr. (Mrs.) Olufunke Adeleye of Olabisi Onabanjo University Teaching Hospital (OOUTH), Sagamu, Nigeria.

Dr. Adeleye was speaking at an in-person/online seminar organized by Max Hospital, India at the Continental Hotel, Victoria Island, Lagos on Saturday 26 August 2022. The online faculty included specialist Indian liver transplant physicians who made presentations on the intricacies of Liver Transplants.

Lack of facilities, the dearth of Liver Transplant specialists and the huge demand for blood in LTs are among the factors militating against LTs in Nigeria. LTs are indicated when liver function is compromised by cirrhosis and other hepatic dysfunction. The risk factors for liver dysfunction include heavy alcohol use, environmental and age-related issues.

Dr. Adeleye urged Nigerians to take health maintenance seriously and not wait until things point towards a point-of-no-return before seeking help. Citing her own example, Dr. Adeleye stated she does yearly comprehensive medical screening for herself and her family.

Max Healthcare is a leading provider of world-class health services with over 4800 doctors and 15000 allied personnel. More than 3.5 million patients from 135 countries access excellent services which includes organ and Bone Marrow Transplants (BMTs), robotic, laparoscopic and weight loss surgeries. Other services include endoscopic surgeries for brain and spine. Max Healthcare is popular with Nigerians seeking BMTs for sickle cell disorder (SCD) cures.

Pharm. Saravanan Arimuthu, Max Healthcare Country Manager, restated the company's commitment to health maintenance and restoration for its patients.

Kids Kicking Cancer Receives $1m From Family To Empower Children in Pain Through Martial Arts Therapy

- PRNewswire

Kids Kicking Cancer announces a $1,000,000 pledge from philanthropists Larry and Jackie Kraft to support the buildout of a new web-based digital dojo for children with cancer and other pediatric illnesses such as sickle cell, hemophilia, and gastro-intestinal issues.

The goal is to connect pediatric patients with Martial Arts Therapeutic Mentors, as well as friends and peers all over the world. Kids will be able to participate in virtual martial arts therapy classes, access the new on-demand library of martial arts technique videos, participate in unique virtual age-appropriate events and engage with other patients through chat, blogs and gamification offerings.

'With the support of the Kraft Family, we will have the opportunity to provide a tool to children in hospitals to help lower their pain, empower them through teaching (the world) and connect them to a community of children who are also experiencing similar challenges', says Rabbi Elimelech Goldberg (Founder and Global Director of Kids Kicking Cancer). 'We are determined to touch the lives of 1,000,000 children within the next several years.'

As a result of the COVID pandemic, Kids Kicking Cancer successfully pivoted to digital program offerings across the United States and globally, resulting in increased demand for its therapeutic product. With daily requests from oncology camps, hospitals and health-based organizations requesting more robust online programming and virtual 'face to face' interaction with their patients, it is evident that creating a means for increased virtual connections is integral to combating pediatric social isolation.

'No sick child should ever suffer the pain and anxiety of serious illness on his own,' said Larry Kraft, a member of the Kids Kicking Cancer Board of Directors and owner of Serta Restokraft Mattress Co.

'That is why we are dedicated to supporting this amazing effort,' said Jackie Kraft. ' We have seen the power of these children teaching. That impact can be significantly replicated with the tools that we are proud to help bring to life.'

Life of Nonagenarian Sickle Cell Warrior

Continued from page 13

separate ways. She later remarried and had 12 years of blissful companionship with Sam Diamond until he passed away.

Advocacy

Ernestine believed that people and families with sickle cell must stand up for themselves and shout their stories loud and clear to the world, hence, her motto, WHY SIT WE HERE UNTIL WE FAINT? LET'S DO SOMETHING!

At the age of 58, Ernestine delved fully into SCD advocacy by establishing the Sickle Cell Action Through Technology (SCATT) to accentuate awareness and reach out to her fellows. She believed diet plays a role in health management and encouraged folks with SCD to eat for health and longevity. For a woman whom the medical profession prognosticated would not survive childhood, she became the friend of doctors in her locality who referred patients to her for mentorship.

Sunset

Ernestine passed away April 27 2022, two months short of her 95th birthday, the oldest documented individual with SCD to live that long. She achieved that milestone despite having to deal with pain most of her life, says grand-daughter, Jasmine Hunter.

Survived by children Donald Jackson, Michael Jackson, Patricia Farr and Bradley Jackson, Ernestine is perhaps the oldest known individual with sickle cell anaemia HbSS) to live to the age of 94 (contender Onikoyi-Laguda. was with HbSC and eight months short of her own 95th birthday).

Ernestine Diamond's memoir, *Learning to Live Well With Sickle Cell, Victorious Living in the Midst of The Storm* will be released any time soon.

'WHY SIT WE HERE UNTIL WE FAINT?

Recommended Children's SCD Awareness Books

Enhance your children's understanding of SCD by getting these books for them.

✓*TANWA* - the story of a five year old living with sickle cell

✓A Dangerous Game | Malorie Blackman

✓A Sickle Cell Coloring Book For Kids: A Creative A to Z guide on growing up with Sickle Cell Disease for Children | Elle Cole

✓ABCs of Sickle Cell Disease | Elle Cole

✓ALEXIA'S WORLD: Thriving with Sickle Cell Disease | Alexia Tennent

✓All About Sickle Cell | Niyoka McCoy

✓Breaking The Sickle: A Snippet of the Life of Dr. Yvette Fay Francis-McBarnette | Louie T. McClain II

✓Chef Marcus Broussard in... The Crescent City Chronicles Part 1 | Cynthia Hall

✓I'm No Different Than You | Jaime Mahaffey & Kristy High

✓My Friend Jen Series | Jenica Leah

MORE BOOKS ON PAGE 35

ON WHOM THE MANTLE FALLS

- Mosunmola Adeniji, Alhaja Asiata Aduke Onikoyi-Laguda's Daughter Steps Into Shoes To Inspire Warriors

By Tosin Fawemida

Mrs. Mosunmola Adeniji (nee Oki) was born in England in 1962 and was Alhaja Asiata Aduke Onikoyi-Laguda's fourth born. Mosunmola and her mom were very close and shared an unbreakable bond.

She was right there at Alhaja Onikoyi-Laguda's deathbed and had the last conversations ever with the 94 year old iconic Sickle Cell Warrior and Advocate. Uppermost on Alhaja's mind was what would happen to the SCD Community in Nigeria when her time was up.

'Mom always felt concerned for the Warrior Community after her exit,' Mosunmola recalls, 'and I used to reassure her I would do my best to fill her shoes.'

That she certainly did. In August 2022 when she turned 60, Mosunmola asked all friends and family to donate her entire cash gifts to purchase medications and equipments for The National Sickle Cell Centre, Lagos. She also obtained one year's health insurance for five hundred Sickle Cell Warriors through Pastor Abiola Awe of the Non Communicable Diseases Alliance Nigeria, Yaba, Lagos,

At every Warrior gatherings to which she was invited, Mosunmola regales the audience with the uncommon character and uncommon determination of Onikoyi-Laguda. Most of her audiences knew some of the uncommon achievements of the late icon - who was born same year, 1925, as Her Majesty Queen Elizabeth II. They were aware of her ever-frequent, severe but undiagnosed SCD crises before she was properly diagnosed; of her having six children, all by normal delivery and of her pilgrimage to Mecca 13 grueling times before, at the age of 75, her children said enough was enough!

At a recent Warrior gathering at the Airport Hotel, Ikeja, Mrs. Adeniji revealed more about Alhaja Onikoyi-Laguda:

Despite her weaknesses as a Warrior and the attendant absences from studies, Alhaja scored one of the highest marks in shorthand in the history of Pitmann's College, London!

'Apart from being very intelligent, Alhaja was also very industrious,' her daughter recalls.

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I DID NOT KNOW I HAD SCA UNTIL I WAS 22!

66-year-old retired typist/stenographer lived in world of pain and ignorance before proper diagnosis and treatment surfaced. From every indication, all his siblings were sickle cell warriors!

By Titi Aladei

Openly or covertly, Sickle Cell makes activists of practically every survivor or family it touches. The same goes for Elder John Owhighohowo Arure, 66. Elder Arure takes interest in SCD events wherever they occur, locally or internationally, online or in-person. He also runs the Success Sickle Cell Foundation, which espouses the lofty ambition to kick out sickle cell disorder from Nigeria. Who blames such lofty ideas of eradication? Experience is its own lesson.

Elder Arure's parents got married by the wishes of their parents in those days when children died only because they were hexed by the evil eye. His mom gave birth to six children, three of whom who died in infancy. Although not specifically diagnosed, their symptoms were similar to what is known as sickle cell anaemia today. Another one passed away at 31 of SCD complications. The remaining two survivors are with sickle cell anaemia: Elder Arure and a 41 year-old sister.

Despite excruciating pain crises and similar indispositions growing up, the young John did not get a diagnosis of what troubled him so cruelly until he was 22 years of age. The repeated illnesses had ensured that he dropped out in secondary Form Three. After training in Pitman's as a typist, he was fortunate to land a job as a typist with Nigeria's National Electric Power Authority.

'I was drowsy and fell fast asleep in an air-conditioned room,' he recalls. 'By the time I woke up, the signs of pneumonia had set in.'

'In 1978 I was employed as a typist with NEPA and the company required that new entrants undergo medical tests,' Elder Arure recalls. And there at the then Sagamu General Hospital, he was found with sickle cell anaemia! For the first time, he was educated about the do's and don'ts of his special health condition - and he began taking folic acid and other routine meds for the first time.

Arure went into study and analysis about the condition that now had a name. He discovered that some foods helped while others hindered; he discovered his aversion to cold.

Despite his carefulness over the years, he yielded to pneumonia in May 2022 after attending a traditional wedding ceremony.

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Onikoyi-Laguda's Daughter

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'She traded everything tradable and built her first property at the age of 58 years.'

Another poignant revelation at the occasion relates to one of the Aduke Onikoyi grandchildren, who carries the sickle cell gene (HbAS).

'My son occasionally manifests symptoms suggestive of carrying sickle cell anaemia genes.'

A worker of the Redeemed Christian Church of God, Mosunmola shares her personal experiences to encourage and embolden Warriors.

'One day, armed robbers came calling in my home,' she says, 'What saved us from being sexually molested was my asthmatic daughter who went into a full blown asthmatic crises.'

The unwanted visitors were so shocked by the spectacle of a severe asthmatic episode that they left the family alone. After dispossessing the family of its cache of jewelry and other valuables, of course. The gang would probably never forget that spectacle of an asthmatic crises.

'This demonstrates that God can use your pain to protect you and others around you - God can make good things out of bad situations.'

Alhaja Onikoyi-Laguda

Having been raised by a Warrior mum and witnessing her mom's groveling in pain and frailty and constant complaints of physical discomfort, it is not surprising that Mosunmola Adeniji would rather not relive such in her own grandchildren.

In the coming years, Mosunmola expects to see enhanced SCD awareness and accentuated research in treatment and management.

'Warriors should never limit themselves in life,' she admonishes her audience, 'We will win the battle together.'

Owhighohowo: SCA Diagnosis at 22

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'I was tired and fell asleep in an air-conditioned room,' he recalls. 'By the time I woke up, the signs of pneumonia had set in.'

He spent two weeks in hospital.

Generally, Elder Arure considers his health nowadays much better than it used to be 30 years ago. He intends to keep it that way while forging ahead to forewarn parents of tomorrow about a 100% preventable health condition the World Health Organization describes as a 'global public health priority'. As for his own children - two girls and one boy, all with sickle cell trait, learning about SCD starts, so to speak, right from the horses' mouth!

Sickle Cell Society, UK Announces Passing Of 89-Year-Old Warrior

Herma Falconer was not diagnosed with SCD until she was 28!

Herma was born in Saint Thomas, Jamaica in 1933. She came to Britain in the 1960s, and was diagnosed with sickle cell disorder in 1971 when she was pregnant.

During the 1970s and 1980s, sickle cell disorder was poorly understood by the National Health Service, with many healthcare professionals ignorant of the condition, and treatments were limited.

Mistakes during Herma's hip replacement in 1973 led to her spending time in a coma, and she had many months-long stays on hospital wards away from her family. Her poor health meant that she had to give up her work at the MacVities factory in Harlesden.

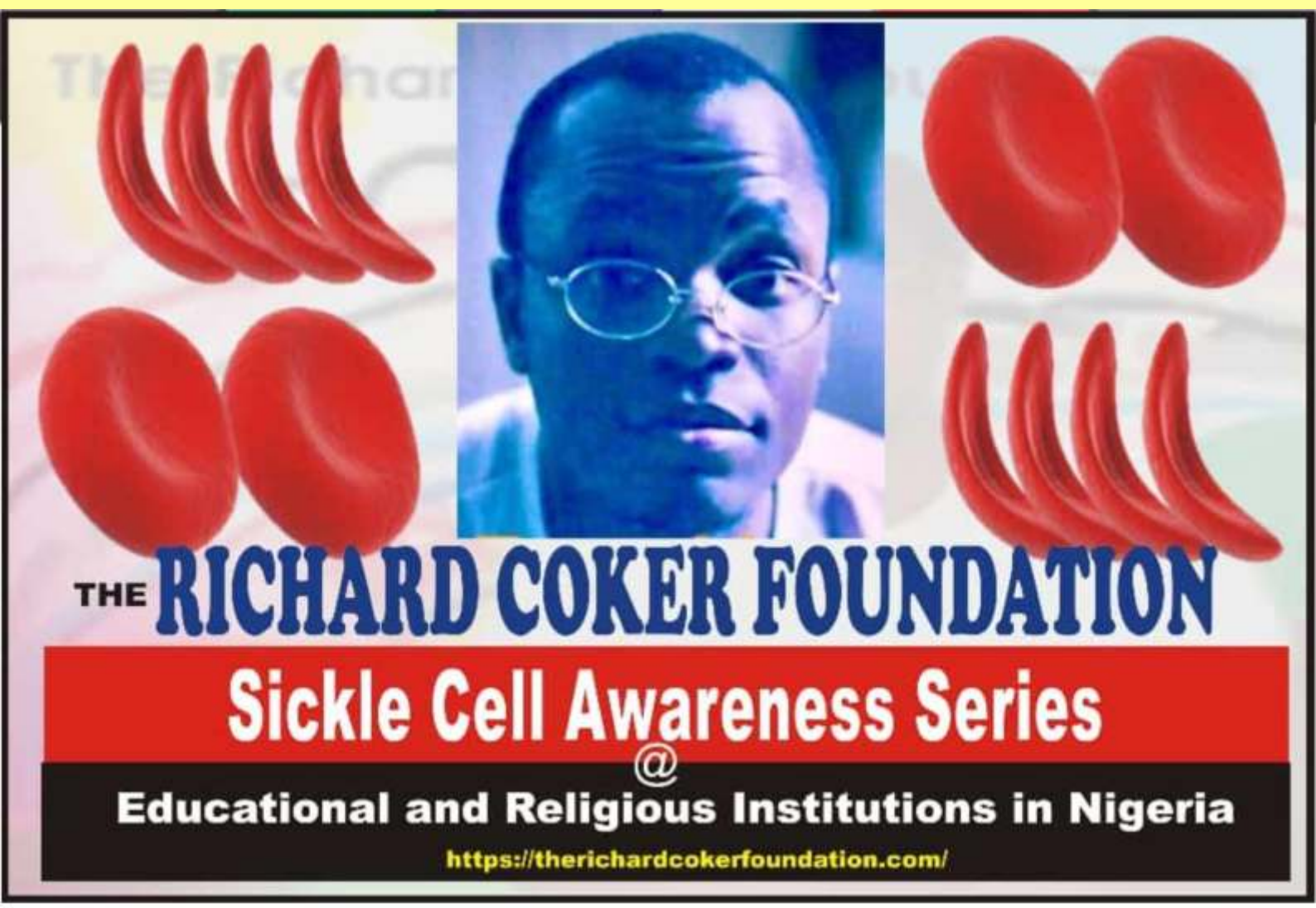
Despite living with such a limiting illness, Herma had a happy family life with her beloved husband and their three children and grandchildren. Her daughter Denise says 'she came to terms with her illness, and how to deal with it'.

In the 1990s, with her health much improved thanks to routine blood transfusions, antibiotics and a healthy diet, Herma mentored young people with sickle cell disorder and did public speaking engagements for the Sickle Cell Society.

Herma gave a speech at the 1993 Sickle Cell Symposium, and said 'I am so happy to have reached 60; I am happy to sit here and say to fellow sufferers – it's not too bad, you can stand it. I can say to all the younger ones, don't give up, there is hope ahead.'

That she lived nearly thirty years after that gives us hope for everyone who lives with sickle cell disorder. We are grateful for Herma's courageous life, and for all she did for the sickle cell community.

- Sickle Cell Society, UK



Lagos Schools Jostle For SCD Awareness

As the 2022 school year rolled to its inevitable conclusion, secondary schools in Lagos seemed to develop a hunger for sickle cell awareness for students. Formal and informal invitations poured in, sometimes right in the middle of promotion exams.

With hundreds of schools to pick from, Richard Coker Foundation selected two public secondary schools and two private in Ikorodu, Lagos State, Nigeria.

Yewa Junior High School

The first port of call was Yewa Junior High School, Aga, Gbasemo, a co-educational public school with a population of 600 students. The sprawling grounds hosted the senior arm of the school (Yewa Senior High School) as well as a primary school, Aga Titun Primary School.

Speaker/RCF representative, Ayoola Olajide took the audience of staff and students round the subject of blood cells, its shape in normal times and in abnormal times. He further outlined a few of the signs, symptoms and complications of SCD, underscoring the grim statistics of SCD/SCT in Africa's most populous country.

The sensitization talk proved to be an eye-opener for Mr. Saliu Bakare, a tutor at Yewa, who recalled having a daughter with a puzzling abdominal protrusion and skin paleness, as described by the speaker.

At the end of the enlightenment session, Principal Mrs. Julie Oluseun Adewale gave kudos to RCF for forewarning her students about SCD. 'A talk like this is crucial for the young ones,' she observed.

Oriwu Senior Model College

Practically the same routine ensued at the next school, Oriwu Senior Model College, Igbogbo, on July 18, 2022. A co-educational government-owned

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6 Signs It's Time to See a Spine Doctor

Endoscopic Spine Surgeon Dr. Kaixuan Liu with Atlantic Spine Center explains back and neck symptoms that should prompt you to visit a specialist.

Coping with back or neck pain might be so pervasive and troubling that it is hard to work or enjoy time off.

But when is the right time to see a spine doctor? Six distinct signs can point the way toward making this important decision, according to Endoscopic Spine Surgeon Kaixuan Liu, MD, PhD, founder of Atlantic Spine Center.

With 33 bony vertebrae spanning the base of the skull to the tailbone, the spine unfortunately offers many opportunities for things to go awry, leading to conditions that can cause pain, stiffness, lost range of motion and other problems.

'Almost all of us have dealt with back or neck pain at some point in our lives, so it can be difficult to know that it's time to seek help,' Dr. Liu explains. 'But pain is the body's way of telling us something is wrong, and many of us, for too long, try to just 'live with it' or even ignore it. It's usually a bad idea.'

According to Dr. Liu, here are 6 of the most common signs that should prompt you to see a spine doctor:

1. Your primary care doctor isn't sure what to do next.

You should tell your primary care doctor about your back and neck troubles. But if they've recommended home treatments such as rest, ice or heat packs, or over-the-counter NSAID pain relievers such as ibuprofen – and all have failed to improve your discomfort – it's time to go to the next level.

2. You've been suffering with back or neck pain for a long time.

What's a long time? A rule of thumb in spine care suggests symptoms should improve in 6 to 12 weeks. If they don't, and you've seemingly tried everything to feel better, seeing a spine doctor just makes good sense,

3. You can't live your days normally.

Can't bend over, stand up straight, or twist sideways without pain? That sure would put a damper on your days, hindering daily tasks such as dressing, bathing, or doing household chores.

4. You can't walk without pain or instability.

Being able to walk steadily is a non-negotiable 'must' that keeps us fully functional in the world. So if you regularly feel unstable on your feet like you might teeter over, or have started falling, read this red flag as a sign to see a spine doctor.

5. You're experiencing weakness and numbness.

Get to an emergency room immediately if you're experiencing dramatic weakness and numbness in your feet and legs and/or signs of accompanying weakness in your bowel or bladder. These symptoms can result from a rare spinal complication called cauda equina syndrome, which requires urgent medical attention to prevent long-term paralysis and other life-altering effects.

6. You need a personalized plan going forward.

Not only will a spine doctor lay out a plan to tackle your immediate back and neck woes, but establishing an ongoing relationship means you'll benefit in the years ahead as well.

PRNewswire

Doris Gbemiloye @60 ... the story of God's own GENOTYPE FOUNDATION

By Fatima Garba Mohammed

Doris Gbemiloye was like the Old Testament prophet who at first refused to obey the command to go and warn the inhabitants of Nineveh of impending disaster. The moment she heeded the call, the floodgates of support - and fulfillment - were flung open..

God indeed works in mysterious ways....

She was a successful accountant and business woman who dealt in diesel oil before she received the call to start a unique ministry in 1997. Hers could have been the first SCD charity in Nigeria, only that haematology Professor Olu Akinyanju beat her to it by a few years.

'My Hb is AA, I knew next to nothing about SCD and had no relations with the condition at the time the inspiration to start Genotype Foundation came from thin air,' Gbemiloye typically tells guests at gatherings organized by her Foundation in Lagos.

Popularly called Mummy Genotype, Mummy Gee or Duchess Genotype, the Itsekiri-born accountant was at a crowded New Year's Eve church programme when she got a revelation to start an organization devoted to genotype awareness. In Nigeria, New Year's Eve is when you see throngs of worshipers at church, a good percentage of whom will not step into a place of worship

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DOES SICKLE CELL WORSEN WITH AGE? DOES AGE WORSEN SICKLE CELL?

A 'Concerned Sister' from Makurdi, Nigeria writes:

DEAR COUNSELOR,

A haematologist once told my sister, a sickle cell warrior, not to expect life to be easy in old age. She was in her late 30s at the time and now 53 years old. My questions:

1. Does sickle cell worsen with age?

As I have stated before, even twins with the same Sickle Cell genealogy present differently. In the past, patients with Sickle Cell Disorder would often have worsening health problems as they got older, and would frequently die early, but there were still exceptions to this rule. In the past also, some people with SCD will experience little or no morbidity and live till a relatively old age.

Currently there is a lot of amazing research taking place across the globe especially in the USA to understand SCD better, and prolong longevity. Again, even in Africa and Nigeria in particular, some drugs are being developed (medical ethics does not permit me to name them), that are helping Nigerians with SCD.

The success of hydroxyurea therapy has ensured that Sickle Cell does not worsen with age, by ensuring improvement in quality of life.

2. Does living with Sickle Cell beyond 60/70 years of age, exacerbate the physical and mental health challenges/decline associated with the twilight years?

In early published works of science in Sickle Cell Disorder, it was stated that, outside childhood episodes, most national median life expectancy of 42 to 47 years, were the peaks in which a person with SCD will reach before facing, challenges,

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Advice given here not meant to replace or supplant interaction with your medical services provider.

A newspaper columnist and Sickle Cell Genetic Counsellor, Dr. Ojum Ekeoma Ogwo is Chief Medical Director, Gregory University, Uturu, Abia State, Nigeria.

Rare Patients With SCD Live Nearly Twice as Long as Average

Longevity Linked to Care Maintenance and Family Involvement

hematology.org

With a national median life expectancy of 42–47 years, people with sickle cell disease (SCD) face many challenges, including severe pain episodes, stroke, and organ damage.

Compounding these complications is that SCD — an inherited, lifelong blood disorder characterized by rigid and sickle-shaped red blood cells that stick to the blood vessels, blocking blood flow — no widely available cure, and many have limited access to appropriate care.

However, a new report published in *Blood,* the Journal of the American Society of Hematology (ASH), shows that some people with mildly symptomatic SCD may live long lives with proper management of the disease, including strong family support and strict adherence to medication and appointments.

This analysis of four case studies details the outcomes of four women with milder forms of SCD who have far surpassed the U.S. median of 47 years old for women with the disease, instead living as long as 86 years.

Report author Samir K. Ballas, MD, Professor Emeritus in the Department of Medicine at Sidney Kimmel Medical College at Thomas Jefferson University in Philadelphia, hopes that this example can serve as a blueprint for others living with SCD.

'For those with mild forms of SCD, these women show that lifestyle modifications may improve disease outcomes,' said Dr. Ballas.

Of the women described in this report, three were treated at the Sickle Cell Center of Thomas Jefferson University, and one in Brazil's Instituto de Hematologia Arthur de Siqueira Cavalcanti in Rio de Janeiro. Though they had dissimilar ancestries (two African American, one Italian American, and one African Brazilian), all led healthy lives bolstered by long-term family support, to which Dr. Ballas attributes their long lives and high quality of life.

'It is very likely that their healthy lifestyles were important contributors to their longevity. All of the women were non-smokers who consumed little to no alcohol and maintained a normal body mass index. This was coupled with a strong compliance to their treatment regimens and excellent family support at home,' said Dr. Ballas.

For this report, treatment compliance was based on observations by health care providers, including study authors. Family support was defined as having a spouse or child who provided attentive, ongoing care.

Another common factor among these four women is that they had what Dr. Ballas called 'desirable' disease states.

'These women never had a stroke, never had recurrent acute chest syndrome, had a relatively high fetal hemoglobin count [which helps to prevent cells from sickling, and had infrequent painful crises. Patients like this usually — but not always — experience relatively mild SCD, and they live longer with better quality of life.'

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Madam Genotype

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for the next 365 days. The year was 1996, the day 31 December. Loud and strident supplication to wean favours from the Almighty was in full gear as the minutes ticked towards 1997. As though nudged to do so, Doris Gbemiloye turned her face skyward and distinctly saw a logo with the word **GENOTYPE** boldly imprinted. In addition, a loud voice boomed in her ears: *'GO TELL MY PEOPLE!'*

It was the logo she would later use for a cause about which, at that time, she knew nothing!

Gbemiloye elbowed a fellow congregant praying beside her to look upward and asked - 'Did you see that?'

'See what?' the fellow responded, looking quizzically at her.

Business Goes Downhill

Not knowing the meaning of what she saw, she continued with her life and business. But things were never the same again. Her diesel supply contracts as well as accountancy consultancy began to fail. Companies where she was VIP began to shun her and finally instructed the security personnel not to allow her into their premises any more. Poverty loomed large on the horizon!

Each time she closed her eyes, she would see the GF logo. In addition, the faces (and names) of people she did not know would display sometimes in full consciousness. Was she going bunkers? Was neuro-psychosis knocking at her door?

Open Doors

Gbemiloye wrote down the names she saw and memorized the faces behind the names. Among the unknown personalities shown to her was the chairman, Cadbury Nigeria, Dr. Christopher Kolade, Dr. Kolade was formerly Nigerian ambassador to the UK.

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AFRICA MOVES TO CURB SCD

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effective interventions for prevention, early diagnosis and management of this condition,' said Dr Matshidiso Moeti, WHO Regional Director for Africa. 'We need to shine the spotlight on this disease and help improve the quality of life of those living with it.'

Due to the absence of newborn screening programmes and surveillance across the region, there is a lack of accurate and reliable data on the disease. Additionally, data collection for SCD is not included in most national population-wide surveys. These data gaps have negatively impacted the prioritization and allocation of resources for the disease.

Beyond its public health impact, SCD also poses numerous economic and social costs for those affected and their families and can interfere with many aspects of patients' lives, including education, employment, mental and social well-being and development.

'We can no longer ignore the significant burden caused by SCD,' said Dr Moeti. 'We must do more to improve access to treatment and care, including counselling and newborn screening by ensuring that programmes are decentralized and integrated with services delivered to communities and at primary health care level.'

Longevity, Care, Maintenance and Family Involvement

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As they had relatively mild disease states, none of the women were qualified to receive treatment with hydroxyurea (HU), the only FDA-approved treatment for adults with SCD. Accordingly, these patients received standard treatment including hydration, vaccination (including annual flu shots), and blood transfusion and analgesics as needed. Patients were encouraged to attend regular follow-up visits, not to smoke, watch their weight, and maintain a support system as needed.

Dr. Ballas was quick to point out, however, that this does not mean these women lived crisis-free lives. Each experienced disease-related complications necessitating medical attention, like occasional acute chest syndrome, a problem that can cause fever, cough, excruciating pain, and shortness of breath.

It is worth noting, said Dr. Ballas, that the report does have limitations. For one, there were only four participants, all of whom were women.

'Adult females with SCD generally live longer than males, but we do not know why. One possibility is that women tend to have relatively lower blood viscosity due to their lower hemoglobin level compared to males.'

That said, Dr. Ballas was quick to point out that this does not mean men cannot benefit from a healthy lifestyle.

To that end, Dr. Ballas hopes that patients who have defied expectations like these four women can serve as positive examples for SCD patients of all ages:

'I would often come out to the waiting room and find these ladies talking with other SCD patients, and I could tell that they gave others hope, that just because they have SCD does not mean that they are doomed to die by their 40s — that if they take care of themselves, and live closely with those who can help keep them well, that there is hope for them to lead long, full lives.'

HEALTH FOREVER

My Incredible Encounter With Jobelyn ...

No Blood Transfusion For 18 Years!

By Ayoola Olajide

Found with sickle cell anaemia at the age of two (Massey Street Children's Hospital, Lagos Island) I remember having my first blood transfusion at the age of six. This was at the then Baptist Hospital Ogbomoso (now Bowen University Teaching Hospital). At that age and by the time I clocked 10, a gloomy interpretation of life had etched itself in my consciousness: life was a drama of pain and health an occasional episode.

Over the years, what with frequent attacks of malaria, I had blood transfused now and then like once in every three or four years. In those days, the cynosure of negative extended family attention, the one for whom the word goes out about being in emergency need of blood, I likened myself to an old lorry, a headache to its driver, a liability to its owner!

I took blood on several occasions at the Baptist Hospital, Ogbomoso, at the General Hospital, Ogbomoso, at Labi Hospital, Ilupeju, Lagos and at Adesola Clinic, Bariga, Lagos.

A lucky introduction to *Jobelyn,* while I was on admission at Adesola Clinic once again, marked a turning point in my proclivity to live on other people's blood.

It was 2004. I was on admission for malaria, typhoid fever and, at a PCV of 11%, dangerously short of blood. I was listless as I heard the doctor tell my wife I needed urgently to have blood.

Prior to my admission, I couldn't take 10 steps without pausing to rest for a few minutes. A bit of exertion left me breathless, heaving and gasping. Extreme tiredness is evil.

My wife offered to donate her own blood, but the doctor refused. Then, speaking her thoughts, she complained half to herself and half to those within hearing range, that she was tired of 'blood today, blood tomorrow'. She had only seen me take blood once but that was once too many times for her.

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'18 Years Without Blood Transfusion!'

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Calling her aside, a woman whose child was also on admission, asked my wife to go buy *Jobelyn* and administer it thrice daily. On the woman's recommendation, my wife insisted I be discharged, which the hospital did, reluctantly, but not before making her sign papers absolving management of responsibility for whatever happened afterwards.

Within 10 days of taking the nutritional supplement, my Hb level rose to 27%. I, that couldn't take more than a handful of steps without being deathly breathless, now took brisk walks and sprinted without a hint of fatigue. It was nothing short of a miracle!

'Jobelyn remains one of the most scientifically-researched ethno-medicines of all time. Research institutions worldwide have endorsed its usefulness for restoring blood to healthy levels not only in SCD but in other conditions of chronic anaemia.'

I took part in the *Jobelyn* clinical trials at the Lagos State University Teaching Hospital in 2012. There, senior nurses at the haematology clinic told of comatose SCD patients with severe anaemia brought back to life within days by the administration of *Jobelyn.*

It is 18 years now and I have not taken anyone's blood - the vampire I used to consider myself. I also experienced much less hospital admissions than were customary with me! Thus, whenever Nigeria's respected SCD czar, the western-trained haematology Professor Olu Akinyanju describes *Jobelyn* as 'absolutely useless' for sickle cell, I used to shake my head at the disservice he is doing to the SCD community and indeed to the continent. We Africans don't value anything African!

HEALTH FOREVER

Jobelyn remains one of the most scientifically-researched ethno-medicines of all time. Research institutions worldwide have endorsed its usefulness for restoring blood to healthy levels not only in SCD but in other conditions of chronic anaemia. It is time for Nigeria - indeed for Africa - to proudly beat its own drum and make the world dance. *Jobelyn* (botanical name - *sorghum bicolor*) is Africa's gift to the world.

HEALTH BENEFITS OF HABITUAL HANDWASHING

October 15 is Global Handwashing Day, a global advocacy day dedicated to increasing awareness and understanding about the importance of handwashing ... as an effective and affordable way to prevent diseases and save lives. The write-up below, adapted from globalhandwashing.org explores the health benefits of regular handwashing

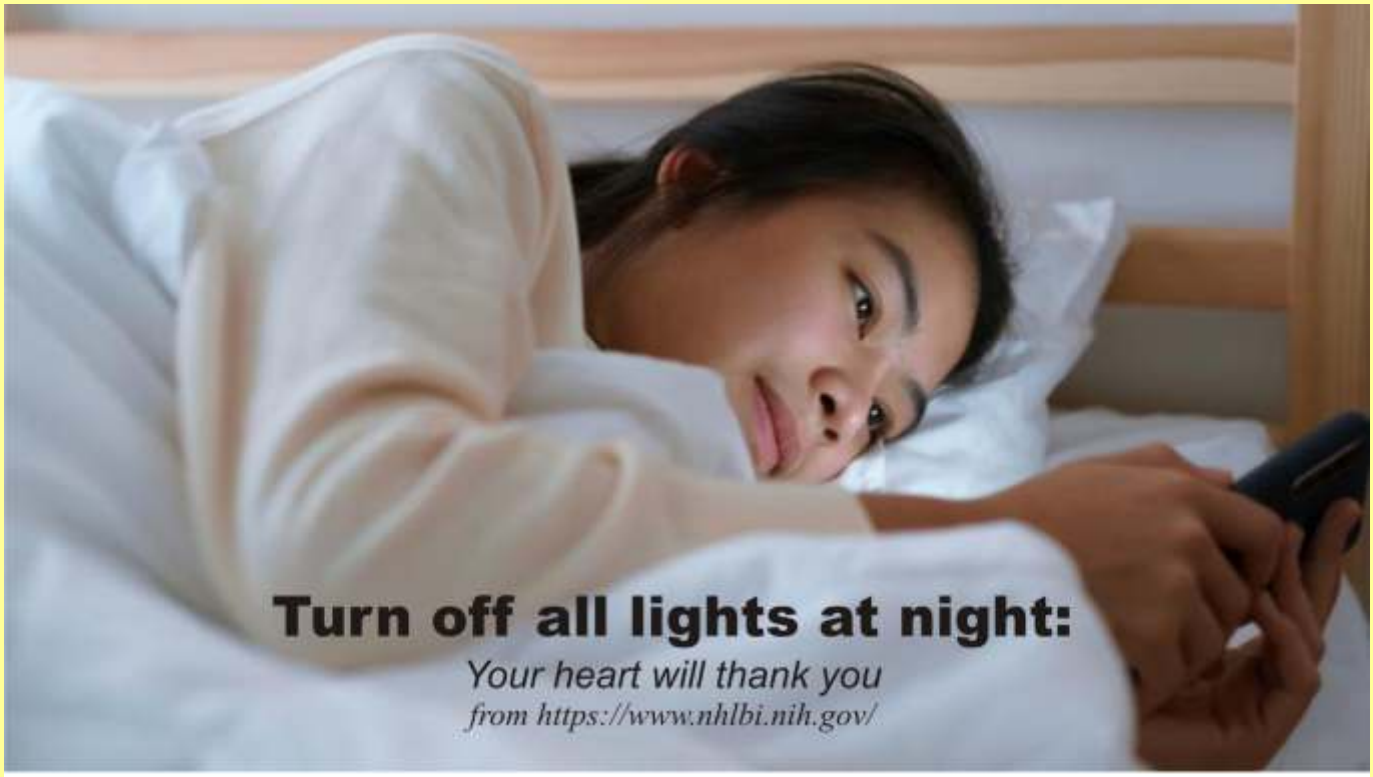
Handwashing with soap prevents many common and life-threatening infections. Many illnesses start when hands become contaminated with disease-causing bacteria and viruses. This can happen after using the toilet, contact with a child's excreta, coughing, sneezing, touching other people's hands, and touching other contaminated surfaces. For example, a single gram of human feces can contain 10 million viruses and one million bacteria, and infant feces are particularly pathogenic.

When hands are contaminated with disease-causing bacteria and viruses, these pathogens can enter the body or pass from one person to another to cause disease. Two major illnesses that are transmitted on the hands are diarrhea and pneumonia. Together, diarrhea and pneumonia cause more than 20% of deaths of children under the age of five. Many of these deaths can be prevented by handwashing with soap.

Handwashing with soap works by removing bacteria and viruses before they can enter the body or spread to other people. Cleaning hands with soap, particularly before eating or preparing food, and after contact with fecal material from using the toilet or cleaning a child's bottom, is one of the most effective ways to prevent disease.

Handwashing also helps prevent or minimize diarrheal diseases - one of the top killers of children worldwide - pneumonia and acute respiratory infections. Handwashing is equally invaluable in preventing and reducing the incidence of eye infections and skin diseases.

Proper handwashing in healthcare settings by medical and associated staff helps prevent hospital-generated infections, a leading cause of prolonged recovery time and hospital stays, increased medical costs, secondary infections and death.



Turn off all lights at night:

Your heart will thank you

from https://www.nhlbi.nih.gov/

You're ready for bed, so you turn off the lights and pull down the shades. Sure, a little light may stream from the sides of the window, or beam from your alarm clock, or TV modem, or cell phone.

No big deal, you say?

Think again. It turns out that even tiny amounts of nighttime light—from any source—may be harmful to your heart.

One recent study found that older adults ages 63 to 84 who were exposed to even moderate amounts of ambient light during bedtime were more likely to be obese, have diabetes, and have high blood pressure – all risk factors for heart disease – compared to adults who were not exposed to any light during the night. The study, supported by the NHLBI, appeared in the journal *SLEEP.*

Another study involving adults in their 20s showed that light exposure during sleep can increase insulin resistance, a risk factor for diabetes, the following morning. That study, also funded by the NHLBI, was published in *PNAS.*

'The link between light at night and cardiovascular disease has been overlooked for a long time. Now, people are beginning to recognize that this is a problem,' said the *SLEEP* study's corresponding author Minjee Kim, M.D., an assistant professor of neurology at Northwestern University Feinberg School of Medicine's Center for Circadian & Sleep Medicine in Chicago.

In her study, the subjects wore a special watch that detects the amount and duration of ambient light while they slept. Although the precise sources emitting the light were unknown to the researchers during the study, Kim suspects that sources as seemingly benign as a streetlight or bathroom light were problematic. 'The good news is that it's a potentially modifiable risk factor for heart disease. People may be able to lower their risk by avoiding or minimizing the amount of light exposure during sleep.'

The exact mechanism behind this link is unclear, Kim said. Studies suggest that light exposure at night can disrupt the body's normal circadian rhythm, the 24-hour internal body clock that controls your sleep/wake cycle. This can trigger a cascade of metabolic or biochemical changes that affect glucose and cardiovascular regulation, boosting the risk of heart disease. Kim noted that some research suggests that not getting enough bright light during the day increases one's sensitivity to light at night and that some people may be genetically predisposed to light sensitivity at night. The specific factors behind the health effects of light at night are the subject of ongoing studies, and Kim said she anticipates more will come.

'We live in a very different world than two hundred years ago,' Kim said. 'There's so much more

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Mrs. Lanre Tunji-Ajayi's family picture taken in 1988 with her two siblings living with sickle cell disease sitting beside each other on the far right

Lesser-Told Sibling Stories

Lanre Tunji-Ajayi, MSM, former CEO, Global Alliance of SCD Organizations (GASCDO) posits that siblings of persons living with SCD have a burden of care to bear ...

The Sickle Cell Awareness Group of Ontario (SCAGO) started as the Seed of Life Philanthropic Organization (SOLPO) in memory of a brave young man — Sunday Afolabi — on June 14th, 2005.

SCAGO is a leading charitable patient organization providing evidence-based support to families with children, adolescents, and adults with sickle cell disease across the four regions of Ontario. It supports clinical research and engages in psycho-social research, health promotion, patient and care providers' education, community awareness, and the development of best practice guidelines.

This Sickle Cell Disease Awareness Month, SCAGO started a campaign of sharing lesser-told stories. These lesser told stories are the stories of siblings who not only witness the pain that their siblings with SCD go through but also support them in conquering the disease.

Mrs. Lanre Tunji-Ajayi, President/CEO, of SCAGO, shared her story as a sibling of two individuals living with SCD. This is her story:

'As the eldest of eight children, I knew from a young age that I needed to look out for all of my siblings, especially my two siblings with sickle cell disease (SCD). My first sibling with SCD was a few years younger, and as such, we were in university around the same time in the Eighties. There were no cell phones then, so to ensure that my brother was well, I would often travel to his school, the University of Ibadan in Nigeria, West Africa (a 3-hour journey from where I attended school), to check on him.

I always felt the need to make sure that he had enough food, that he was not sick, and that his needs were met. I would cook and give him my own upkeep money before leaving his school to go back to mine. Sadly, I lost my brother to preventable complications of SCD in 1999. His death was very painful and has shaped the course of my life. My second sibling living with SCD is alive and well. She currently lives in Nigeria and is the kindest human being I know. Despite her illness, she continues to support those around her.

Though we communicate very frequently, I will double my calls to my sister throughout September Sickle Cell Awareness Month to let her know that she is special and loved.

RCF SCD Enlightenment Talks

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boarding model school, the students gathered at morning assembly to listen to a talk bordering on their role as future spouses and parents. Questions were asked and duly answered about a blood condition that directly or indirectly affects virtually every extended family in Nigeria.

Principal Mr. A O. Bello commended RCF for its outreach to tackle widespread ignorance of genotype and SCD. School Counsellor, Mrs. Adefunke Esan, who doubles as Chairman, Association of Professional Counsellors (APROCON), Ikorodu Zone, pledged to pass RCF's message to her colleagues.

Eunifrance Schools

The management and staff of Eunifrance College, Ikorodu convened an SCD awareness session on the last day of school, July 20 2022. Participants comprised students in Eunifrance's Basic and Secondary School, age ranging from five years to fourteen, their teachers and administrator in tow.

The session at Eunifrance followed the same pattern as at the previous schools with students and teachers asking questions related to genotype and its far-reaching implications. A staff member raised the issue of stigmatization, which the speaker dissected with practical examples. 'What people with SCD need is understanding and acceptance, not pity, not mockery,' the speaker said.

School Administrator Mrs. Toyin Akingbade expressed the school's appreciation at being selected for the RCF SCD awareness chat.

Goskia Group of Schools

It was similarly last day of the school year at Goskia Group of Schools, Benson, Ikorodu on Friday July 22. It was also graduation day. Principal/Founder Pastor Johnson O. Emmanuel invited RCF to minister SCD to staff, students and their parents.

A festive occasion with plenty of dance, music and merriment, you could distinguish the graduating conclave by their customized sashes proudly draped over colorful dresses.

After the short talk on SCD and genotype, Pastor Johnson O. Emmanuel observed that SCD awareness was vital for old and young, married and single. To buttress his stance, he alluded to the experience of a family personally known to him: ignorant of their status as carriers of the sickle cell gene, the husband and wife produced six children, all with sickle cell anaemia.

Pastor Johnson appreciated RCF for helping to bridge the yawning gap in awareness, a major reason for the incidence and spread of SCD in Nigeria.

GAAF CEO, Noble Dotun Alabi and Mom, Mrs. Bernice Alabi

3rd Anniversary, SCD Awareness Week: GAAF Returns To Ekiti State

From October 4 to 7, selected secondary schools in Ekiti State will enjoy visitation by the Gabriel Adewunmi Alabi Foundation (GAAF) on the all-important subject of genotype, sickle cell disorder and sickle cell trait. The schools are Ekiti Government College and Special School For The Blind, both in Ikere; Ekiti Parapo College, Ido, OGS and Eyemota Comprehensive School, Iyin.

In 2021, on the second anniversary of the founding of GAAF and during its SCD Awareness Week, the organization engaged students and staff at Christ School (Boys), Christ School (Girls), Baptist Comprehensive High School Mary Immaculate Grammar School, all in Ado Ekiti in comprehensive conversations about genotype and SCD.

Apart from SCD Awareness on its third anniversary, GAAF will also hand out food products to households at Oloje. The organization runs an organic farm where team members planted various crops in 2021.

Named after Engineer Gabriel Adewunmi Alabi (1940 - 1975), GAAF aims to address the hydra headed challenges of SCD by targeting the young long before emotional attachment sets in. The organization also caters to indigent sickle cell warriors by helping to defray hospital bills.

GAAF operates in Nigeria, Ghana and the United Kingdom.

Recommended Children's SCD Awareness Books

Enhance your children's understanding of SCD by getting these books for them.

- ✓**Dr. Yolanda Landry, Pharm.D. in...The Crescent City Chronicles Part 2 | Cynthia Hall**
- ✓**Keemaya and the Beach: My Journey Living with Sickle Cell | Andressa Hunsel Ambrose**
- ✓**Little Miss Linda Speaks Out About Sickle Cell Disease | Linda J.M. Holloway**
- ✓**My Brother Has Sickle Cell | Erica D. Gamble**
- ✓**My DNA Diary: Sickle Cell Anaemia (Genetics for Kids Series) | Lisa Mullan**
- ✓**Peto: the Boy with C-Shaped Blood | Jarneec' Halsey**
- ✓**Pee Wee Goes to School | Tanya Renee Gentry**
- ✓**Children's Adventure Mystery | Darrellon Prince**
- ✓**So I have Sickle Cell Disease | Agnes Nsofwa**
- ✓**Rainbows | Selena Webster-Bass & F. Anthony Webster**
- ✓**Super Cells | Princess Walls**
- ✓**The Battle of Ottogatz: Super Felix Brothers | Nahomie Acelin**

Night Light

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light at night than in the past when we just had the moon, stars, and candlelight, and it might be contributing to the current epidemic of cardiovascular and metabolic disease.' Her recommendation: 'Don't wait until stronger evidence comes out. Avoid light exposure at night as much as possible.'

To reduce the amount of light in the bedroom, researchers recommend turning off lamps, computers, tablets, cell phones, and other light-emitting electronics before you go to bed. Some of those devices, particularly cell phones, emit wavelengths of blue light that can mimic daylight and interrupt sleep. Studies have also linked blue light exposure at night to increased cardiovascular risks, including obesity. As a result, some health experts recommend using a blue-light filter if avoiding the device altogether is not possible.

Another tip: If you have light coming in from the windows, cover it fully or, at a minimum, move your bed so the light isn't shining in your face. For the safety of older people, researchers do recommend a small, warm-colored nightlight—like red or amber—to reduce the chances of falls at night.

Increasing exposure to natural sunlight during the day is just as critical to protecting your heart and your sleep health as limiting exposure to artificial light, noted Marishka Brown, Ph.D., director of the NHLBI's National Center on Sleep Disorders Research.

'Getting exposure to sunlight during the day, particular early morning sunlight, is important,' Brown said. 'This signal is critical for the regulation of circadian rhythms, which impact many core functions of the body, including blood pressure and metabolism,'

'This daytime light actually helps you improve your sleep at night'—which, in turn, can have a positive effect on your overall health and wellbeing, she said.

Other ways to get better sleep: going to bed and waking up at the same time daily and reducing caffeine, nicotine, and alcohol intake before bed. If you still have trouble sleeping at night, consult your healthcare provider, Brown said.

The bottom line: 'There's a lot you can do to build a healthy heart,' Kim said. 'And keeping your surroundings dark when you turn in for the night is an easy place to start.'

GF: God's Foundation

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Dr. Kolade welcome her like an old friend - although they were meeting for the first time - and readily agreed to be Chairman of the board of the proposed Genotype Foundation.

From that moment, every locked door swung open. Even the companies which sent her away recalled her and gave her juicy contracts as though to make up for lost time. Money rolled in again, most of which she saved to register and launch her Foundation. She studied hard about almost everything related to blood - genotype, SCD/SCT, blood group, and rhesus factor. She met doctors and specialists who helped explain, clarify, and simplify lots of medical jargons.

Fulfilment

Doris Gbemiloye's Genotype Foundation has carried genotype awareness to every nook and cranny in Nigeria, including hard to reach rural and riverine areas.

The little vision that was almost like a hallucination that the Itsekiri-born Mummy Genotype had in church 25 years ago has touched thousands of families and continues to do so. For the petite ebony Duchess who turned 60 on September 15, it has been a life far away from accountancy and business to serving humanity.

'I feel a sense of fulfilment sensitizing young and old about genotype, blood group, rhesus factor *and* the implications thereof,' Gbemiloye says.

How's SCD like in old age?

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including, severe pain episodes, stroke and organ damage.

However, nowadays with improved medical research and care giving a new report published online in 'Blood'- The Journal of the American Society of Hematology (ASH), shows that some Warriors may live as long as 60, 70, 80 years with minimal symptoms. For those with SCD, that have lived beyond 60, 70 & 80, there were certain factors that contributed to their longevity as published by ASH, which include :

Proper management of SCD, including strong family support and strict adherence to medication and appointments.

Lifestyle modifications after 40 also helped improve their health.

Being a non-smoker, consuming little to no alcohol and maintaining normal Body Mass Index (BMI).

Warriors who live beyond 70, hardly experience stroke, recurrent acute chest syndrome, and very infrequent painful crisis. The publication stated that SCD warriors who have lived beyond 60, should serve as positive examples for SCD warriors of all ages. That if they take care of themselves by following some of the examples enumerated above, there is hope for all young SCD warriors to attain their God allotted ages and full lives.

In Memoriam

Fadeelat Adeyemi (1995-2022) Never Stopped Giving Despite All SCD Took From Her!

If there was someone who viewed life as an opportunity to impact lives, Fadeelat was the person. Fadeelat will always be remembered as a soul that gave to her communities unceasingly in all aspects of service. Fadeelat graduated as a Pharmacist in 2019 (Obafemi Awolowo University), and was 27 when we lost her to sickle cell complications. She never stopped giving despite all SCD took from her.

- Ifeoluwa Adeyemi, Sister

Fadeelat Mojisola Adeyemi was the second child of a family of five, and the only one with sickle cell disorder (HbSC).

She was born to a nurse mom and an engineer dad. When she grew old enough to ask questions, Fadeelat asked her mom how a nurse (who should know better) should go and produce a child with SCD!

She learnt that her parents were shocked to find they had produced a child with sickle cell. It was her won diagnosis which prompted them to check theirs again. In reality her mom's was HbAS (she had checked years earlier and told she was AA) while her dad was CC.

Despite the repeated hospitalizations and the many inconveniences of life with SCD, Fadeelat graduated as a Pharmacist at the age of 25.

Upon her sudden passing in July 2022, her friends did what they knew she would love best: an outreach for SCD awareness. With funds raised from her SCD communities, the outreach was conducted in Osogbo, her hometown.

Dr. Samir K. Ballas (1938-2022) Breathed, Ate, and Slept Sickle Cell

- Daughter Nadir Ballas-Ruta

Born in 1938 in Jaffa, Palestine before the creation of the state of Israel, Dr. Samir Ballas passed away on August 12 2022. He was emeritus professor of medicine and pediatrics at Thomas Jefferson University. He earned his MD degree with distinction at the American University of Beirut, Lebanon in 1967 and made many contributions to clinical research on sickle cell pain and lab research on sickle cell shape changes.

Dr. Ballas was attracted to sickle cell like an ant to sugar. As a young medical graduate, he was once offered a job at Saudi Arabia's oil company, ARAMCO. The job came with a lavish salary and perquisites but Ballas rejected this because the job did not involve sickle cell research or patients.

'My father lived, breathed and slept sickle cell,' writes his daughter Nadia Ballas-Ruta in a tribute on Linkednin.

A devoted muslim, Ballas married an Armenian Orthodox Christian woman with whom he moved to the United States at the age of 32.

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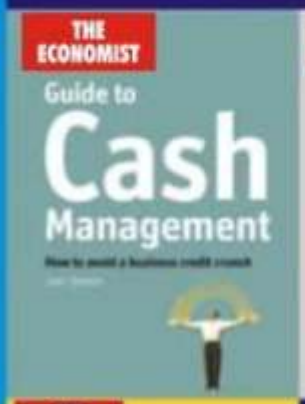

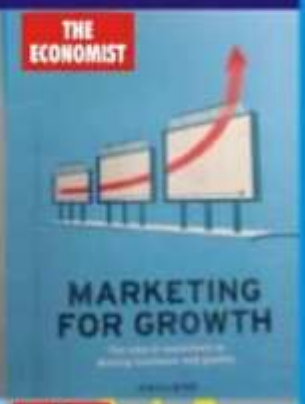

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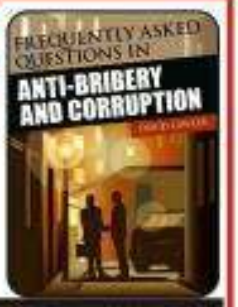

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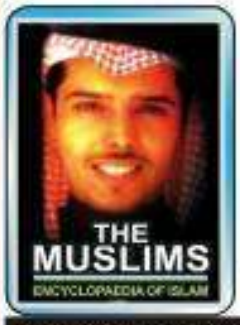

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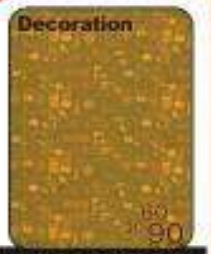

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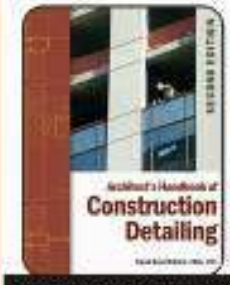

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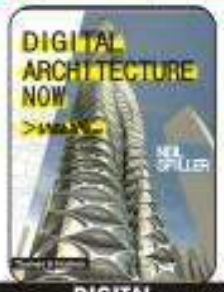

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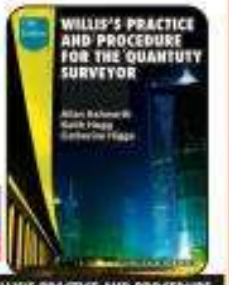

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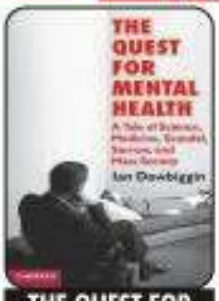

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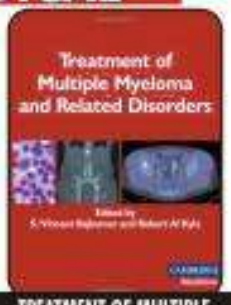

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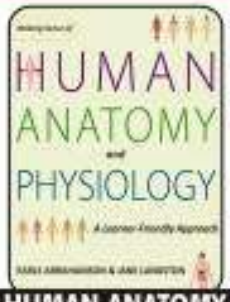

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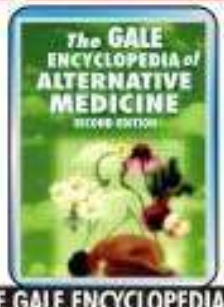

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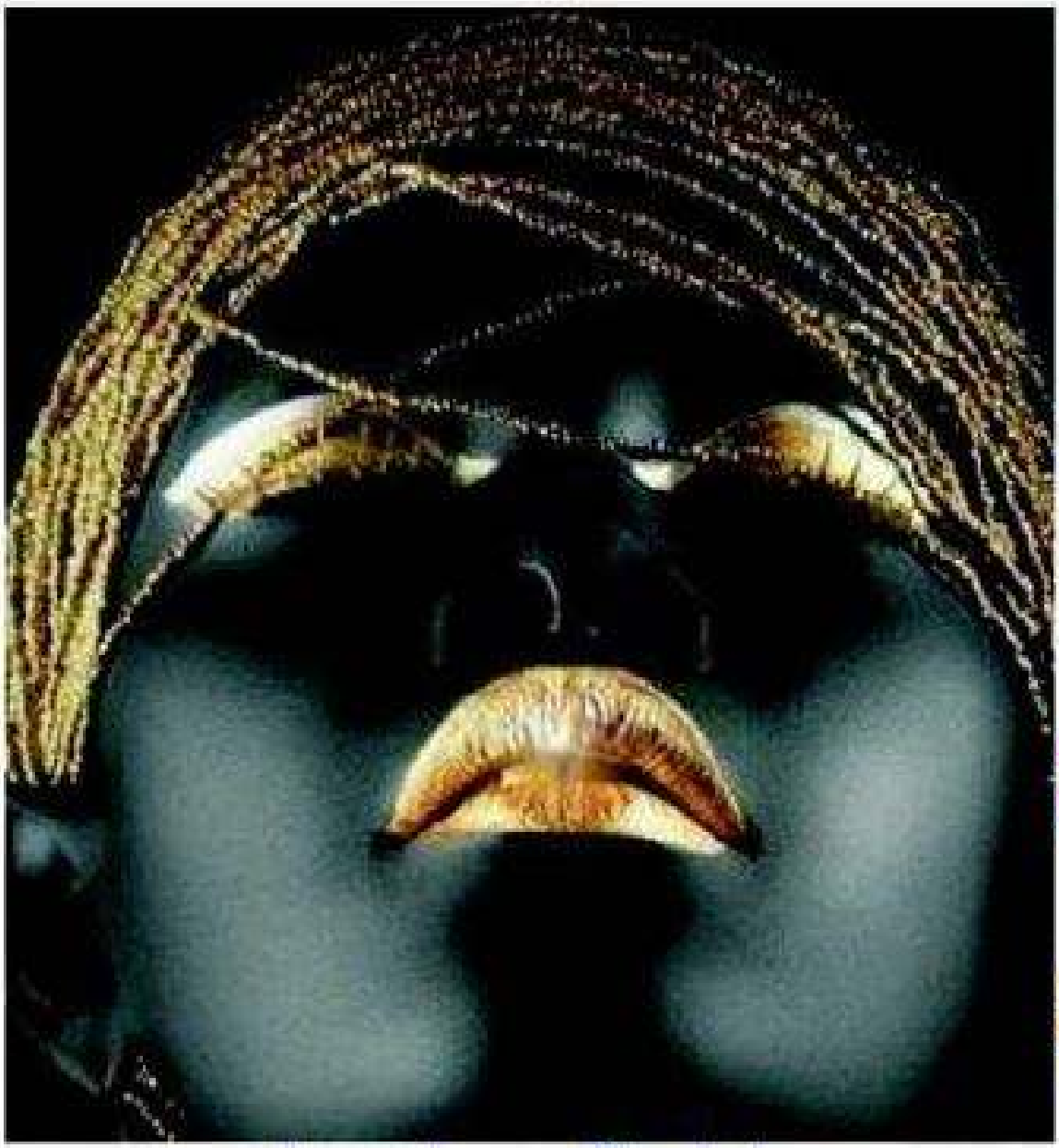

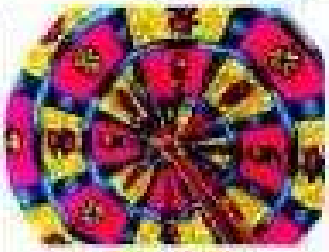

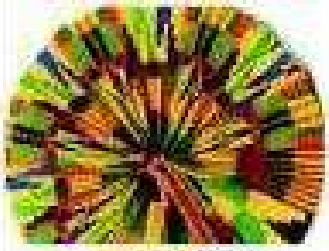

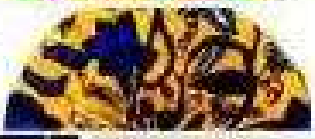

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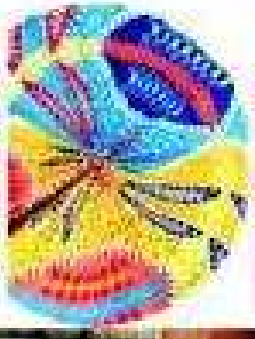

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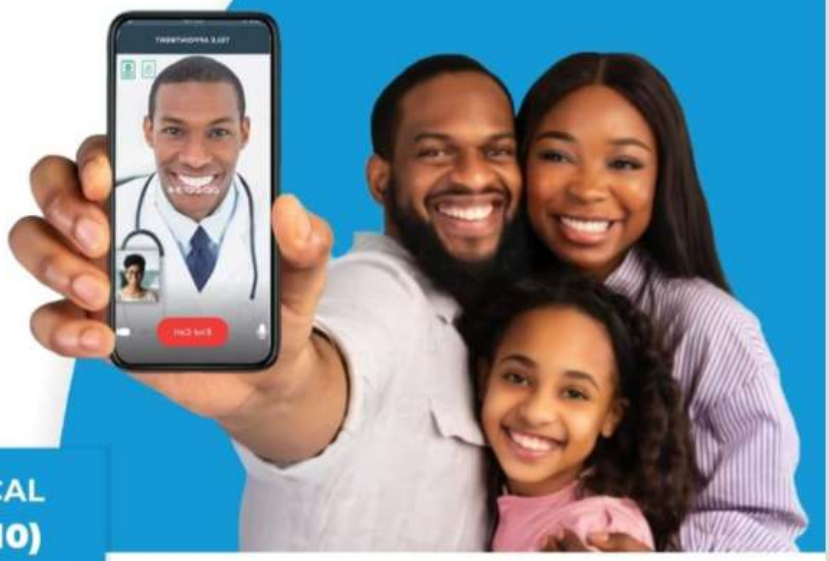

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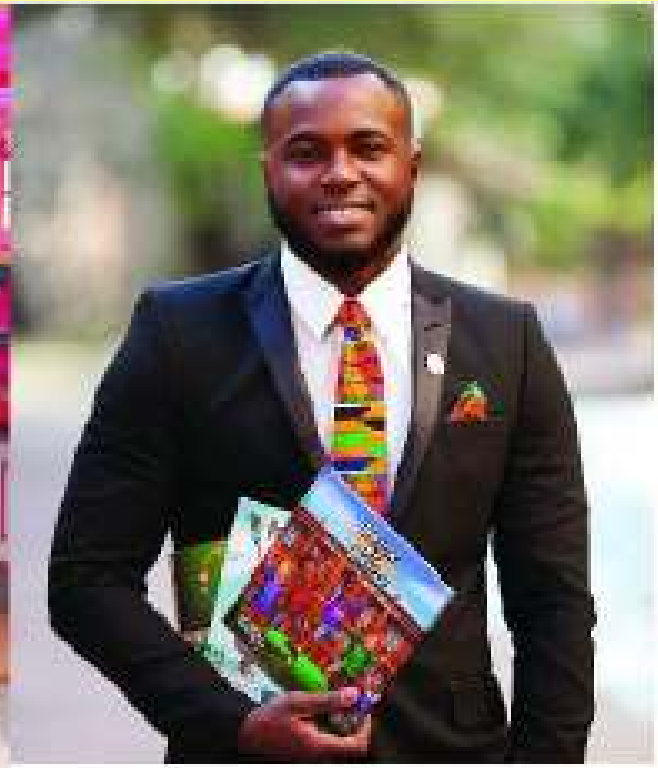

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