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SICKLE CELL NEWS & WORLD REPORT

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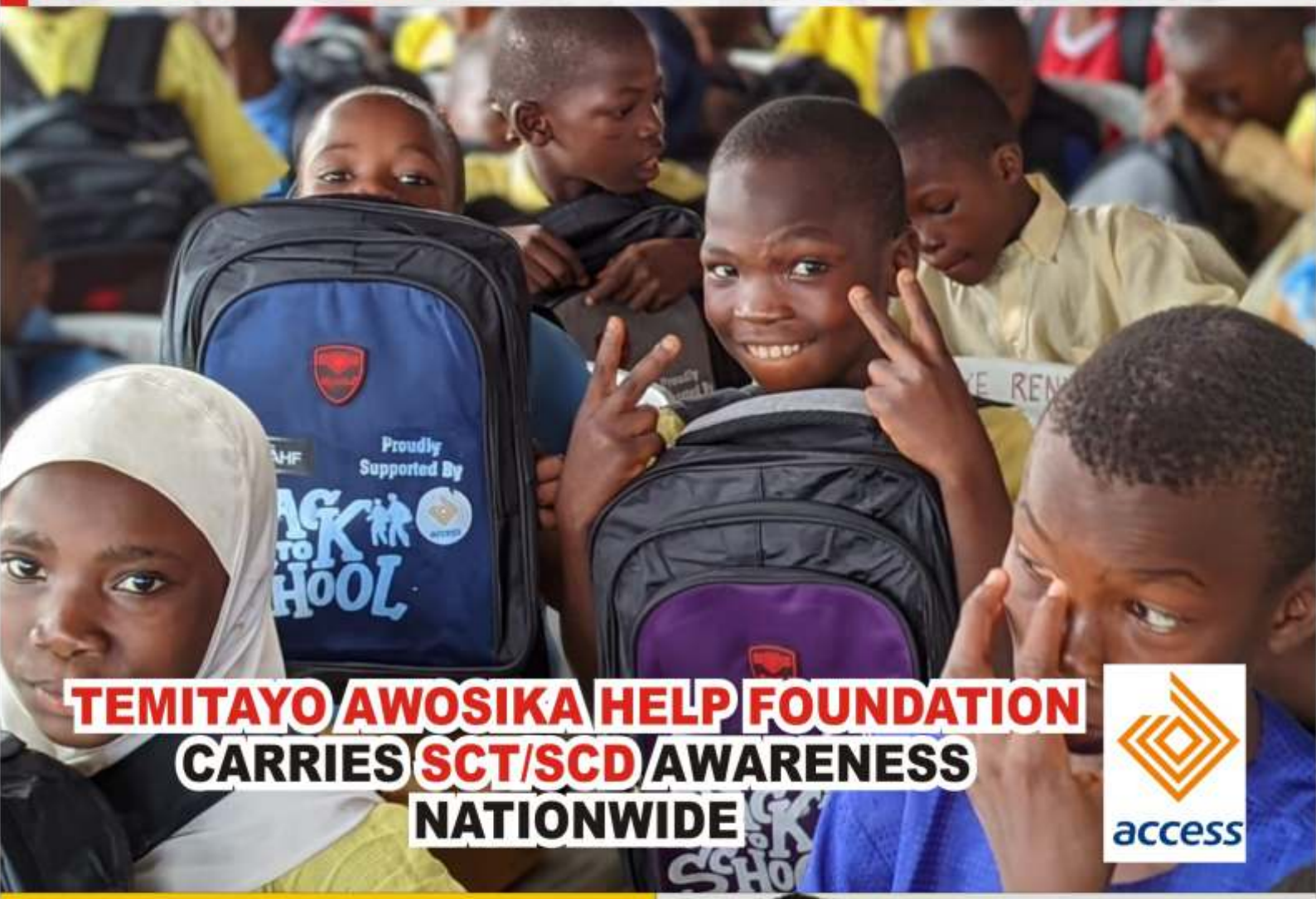

TEMITAYO AWOSIKA HELP FOUNDATION CARRIES SCT/SCD AWARENESS NATIONWIDE

'Sickle Cell is Both a Disease and a Disorder'

- Professor Mrs. Adeyinka Falusi
PhD, FAS, NPOM L'Oreal-UNESCO FWIS Laureate (Africa)

'Most Labs in Nigeria can't detect my genotype'

- Dr. Toyin Oshinowo

HOW I SURVIVED KIDNEY FAILURE

- MY TESTIMONY -

Author Needs N1million monthly to survive

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Contents

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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'My Maternal Grandfather Grappled With Sickle Cell Anaemia!'

Raymond Nathaniel Miller

My name is Raymond Nathaniel Miller III, a general contractor who specializes in the construction of single family homes. I recently took up golfing as a hobby.

I was very young when I first learnt about Sickle Cell. My maternal grandfather was the one who had the condition. His condition meant to me constant illness, regular doctor visits, or hospital trips due to severe pain that would happen suddenly and frequently.

I am not married but will certainly verify the genotype of my partner to prepare us for the potential events that may happen in future regarding our children and the care they may or may not need.

In my opinion, individuals living with SCD should take it with pride and educate others in their environment. The family has a role to play as well: every family member must be knowledgeable about tools to deploy to tackle emergencies in those minutes before help arrives.

Specialized clinics where individuals with SCD can be treated should be established as there is a sometimes an assumption that they may be seeking drugs rather than care.

Society should make it a duty to sensitize youths about genotype.

Miller III graduated from Embry-Riddle Aeronautical University, Florida, USA with a Mechanical Engineering degree, specializing in energy systems

SCT, Unwitting Parent/Sibling of SCD ... ... Kudos to TAHF and Access Corporation

Ayoola Olajide

While sickle cell disorder (SCD) attracts the bulk of global attention and research, the significance of sickle cell trait (SCT) has often been overlooked - even glossed over.

Affecting over 300 million people worldwide, SCT is a genetic condition in which an individual inherits one sickle cell gene and one normal gene. Unlike those with full-blown SCD, people with SCT do not ordinarily experience the debilitating symptoms. However, SCT is nothing to toy with!

Mounting evidence suggests that SCT can increase the risk of certain health complications, including blood in the urine, splenic infarction, and unexplained pain symptoms. SCT can have important implications for one's offspring, increasing the chances of a child inheriting the full condition.

It is time to shine a brighter light on SCT, just as Temitayo Awosika Help Foundation (TAHF), in collaboration with Access Corporation, is currently doing in Nigeria. Through raising awareness and promoting further research, we can empower those living with this condition to make informed decisions about their health and wellness.

Ayoola Olajide, Editor

Letters to the Editor

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

scdjournal@yahoo.com

Welldone, TunMicro

There's perhaps no better way of exercising one's passion than to go public with it. I applaud Dr. Olatunji Sule, CEO, TunMicro Sickle Cell Foundation, and his team for carrying out intensive week-long SCD cum Genotype Education/Verification at a secondary school in Nigeria. The genotype verification was conducted free of cost, which speaks volumes for Dr. Sule's passion.

Please extend your gesture to more secondary schools. These kids must be sensitized about genotype before they become sexually active and long before they fall in - or out of - love!

Mardiyya Abdel-Yussef
Katsina, Nigeria

100% Avoidable, Manageable

Life comes with variegated challenges, some avoidable, many not.

Fortunately, SCD, by its nature, is highly avoidable. Premarital awareness of SCD coupled with action taken accordingly helps minimize prevalence. Again, for individuals and families that are already affected by SCD, the condition is highly amenable to management - lifestyle, diet, exercise and **positive psychology**. Furthermore, there is hope for scientific breakthroughs that will completely disarm SCD.

Oluchi Ajide
Pategi, Nigeria

Richard Coker Foundation's 20th Anniversary

As the parent of an **alumni** of Holy Child College, Ikoyi, Lagos, I was thrilled to learn that the Richard Coker Foundation marked its 20th anniversary at the school. My daughter's time was long after the time of Ms Julie Coker, Richard Coker-Enahoro's mom but we learned of her achievement as a pioneer of TV Broadcasting in Africa.

Losing a child to SCD and casting aside one's sorrow to assist survivors is an ennobling undertaking. Long live RCF!

Louisa Kirkland
Portland, Oregon, USA

Warrior vs Champion

Individuals with SCD may face an uphill struggle to survive the condition, but they are certainly not in a state of war, as the epithet, 'Warrior', seems to imply. (Even in a combat zone, there are interregnums of calm).

I would rather have my kid with SCD referred to as a Sickle Cell Champion rather than as a Sickle Cell Warrior.

All the same, Champion or Warrior, the relegation of the repulsive old word, Sickler, to the dustbin of history (thanks to first Warrior, Tosin Ola-Weissmann) is a milestone in the annals of **psycho-social medicine.**

Adelaide Okunzua
Perth, Australia

Moving From England to Jamaica

Congratulations to author Jenica Leah, who moved from the UK to Jamaica for health reasons and has since enjoyed improved health. My own experience is just the opposite. I moved from Trinidad & Tobago similarly due to SCD. Due to the sudden change of climate, I had it rough in the first few months. Once acclimatized, I began to enjoy significantly improved health.

SCD is a personal drama - what improves one individual's health may just worsen another's.

Marks Peterson
Liverpool, UK

SCDAA Holds 52nd Annual Convention

The Sickle Cell Disease Association of America (Inc) will be holding its 52nd annual convention from October 23 to 26, 2024 in Atlanta, Georgia.

SCDAA's Annual National Convention fosters the exchange of the latest scientific and clinical information through innovative training seminars and educational workshops, interactive panel discussion, advocacy lectures and special events.

Researchers, community-based organizations, physicians, nurses, social workers or anyone working on behalf of people living with SCD and their families to submit their work are encouraged to submit abstracts,

Abstract Topics Include:

- Basic and Translational Research
- Clinical Research
- SCD Global Health
- Community-Based Research
- Psychosocial Research
- Sickle Cell Trait
- Public Health, Policy and Implementing the NASEM Report: Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action
- Gene Therapy Hematopoietic Stem Cell Transplant

The best abstracts in each category will be announced at the Gala on the Friday evening of the Convention.

Since 1972, the SCDAA has been the national voice for SCD, working to resolve issues surrounding sickle cell disease and trait. The organization has been on the forefront of improving the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions.

The SCDAA is the umbrella body for more than 50 member organizations and affiliates spread across 29 US states. The member organizations collectively serve more than 500,000 children and adults living with or impacted by sickle cell alongside their caregivers.

Current medical news affecting SCD gets simplified for stakeholder consumption through the organization's Medical and Research Advisory Committee (MARAC), which comprises world-renowned SCD experts in various fields.

NASCO Holds Workshop in Nandurbar District

By Fatima Garba Mohammed with Gautam Dongre

India's Nandurbar District Health Department held a workshop on June 6 and 7 2024, to train and retrain Primary Health Care medical officers on the accurate diagnosis, treatment and management of Sickle Cell. The workshop was held under the auspices of the National Association of Sickle Cell Organizations (NASCO) at the Nandurbar Jilha Parishad Auditorium.

A pride of place was given to the first drug approved for SCD, hydroxyurea at the august workshop, which brought together Medical Officers and Specialists in-person and online.

Dr. Ashita Singh Ma'am made a well-received presentation on SCD management. Insightful presentations were also made by Dr. Dipty Jain Ma'am and Dr. Giriraj Chandak Sir with ADHO Dr. Amit Patil Sir, ADHO Dr. Sandip Pund Sir, Dr. Khushbu Ma'am and Dr. Madhur Sir (PATH) in attendance.

NASCO was represented by Secretary Gautam Dongre, father of two Sickle Cell Champions, one of them a talented artist and Lalit Kishore Pargi, both of whom spoke from the care-giver and patient perspectives respectively.

India is engaged in serious nationwide efforts to eradicate sickle cell by 2047. If this happens, Prime Minister Shri Narendra Modi, who began a historical third term in office June 2024, will be remembered for lighting the torch to bring SCD to heel in the world's second SCD capital. On a 2014 trip to Japan during his first term in office, he literally pleaded with Nobel Prize-winning scientist, Shinya Yamanaka, to help find a cure for sickle cell.

India's tribal areas are disproportionately affected by SCT and SCD. Ignorance is rife. Lack of access to proper health care and intervention in rural and remote areas has resulted in high mortality and morbidity rates.

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Sickle Cell Treatment Market to Reach $1.6b by 2031

Market Research Report

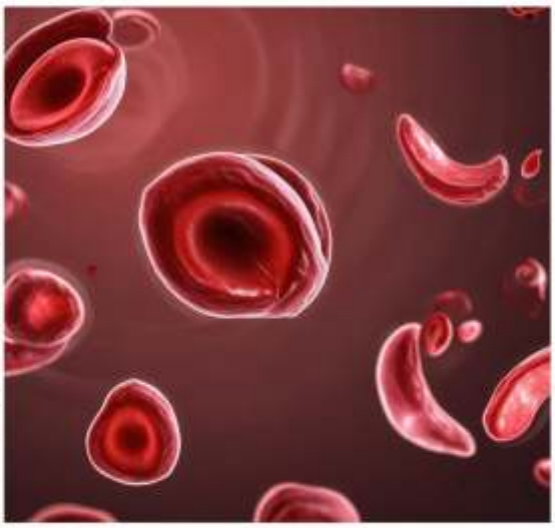
- EINPRESSWIRE

According to a new report published by Allied Market Research, titled, 'Sickle Cell Disease Treatment Market,' 'The sickle cell disease treatment market size was valued at $1.1 billion in 2021, and is estimated to reach $1.6 billion by 2031, growing at a Compound Annual Growth Rate (CAGR) of 4.1% from 2022 to 2031.

The rise in pipeline products, the rise in SCD prevalence, and the surge in demand for SCD medications are driving the expansion of the SCD treatment market. Furthermore, the market for SCD treatments is anticipated to rise at a rapid rate over the course of the forecast period due to the expansion of the research and development pipeline, ongoing medication approvals, and great growth potential in untapped new markets. For example, the FDA authorized Oxbryta (voxeletor) in November 2019 to treat SCD, which is anticipated to accelerate market growth.

Additionally, an increase in government activities to support access programs and broaden the distribution network for SCD medications are other developments in the SCD treatment market that support the industry's growth.

Based on medication type, kind, route of administration, and geography, the market for SCD treatments is divided into



segments. The market is divided by kind of medicine, including hydroxyurea, oxbryta, adakveo, and others. Painkillers, Endari, and other items are included under the others section. Due to the increasing adoption of hydroxyurea brought on by the rise in SCD prevalence, the hydroxyurea category experienced the highest growth in 2021.

The market is divided into sickle cell anaemia, or HbSS, HbSC, and other types based on type. The remaining conditions in the others section are HbS beta thalassemia, HbSD, HbSE, and HbSO. In 2021, the SCD therapy market share was highest in the sickle cell anaemia segment.

Due to factors like the availability of SCD therapies and well-established rules for product approval and distribution, North America held the biggest market share for sickle cell disease treatments in the worldwide SCD market in 2021.

However, due to an increase in SCD cases, Asia-Pacific is anticipated to grow at the highest rate throughout the market analysis for SCD treatments. Moreover, the primary driver of the market's expansion in the area is an increase in investments for the creation of cutting-edge SCD treatments.

The compound annual growth rate (CAGR) is the annualized average rate of revenue growth between two or more given years, assuming growth takes place at an exponentially compounded rate.

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

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Eligibility Criteria and Study Procedures

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

Residency: Must be residents of Lagos State, Nigeria.

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

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

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

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

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

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

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

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

Our Obligations

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

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

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

Jobelyn® is a product of Health Forever Product Ltd,
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TAHF Goes National On SCT/SCD Awareness

By Tosin Fawemida

On the heels of Dr. Olubayode & Dr. Mrs. Dere Awosika losing an HbSS scion to a medical complication being mismanaged in the United States in 1999, the family launched into a mission to help others similarly challenged in every possible manner.

TAHF was inaugurated by the late First Lady Chief Mrs. Stella Obasanjo on October 18, 2000, supported by eminent personalities in medicine, business and politics and civil society. In 2004, when TAHF marked its 5th anniversary at MUSON Centre, Lagos, Mrs. Obasanjo flew down all the way from Abuja with a formidable entourage of Ministers, heads of parastatals and other government agencies. That day, the First Lady encouraged all stakeholders to 'build a solid front' to tackle the inherited health condition in Nigeria.

Twenty years on, building a solid front is exactly what TAHF is doing, reaching out to families affected by SCD, no matter where they dwelt.

In the beginning, Sickle Cell Warrior families which enjoyed TAHF's services mostly lived in metropolitan Lagos and contiguous LGAs in Ogun State. With corporate offices at Association Avenue, Ilupeju, Lagos, the organization held regular meetings with its members at the Lagos State University Teaching Hospital, Ikeja, where counselling, experience-sharing and free distribution of routine meds were provided. Every member had access to free medical treatment at Med-In Specialist Hospital, Ogudu, run by Dr. Olubayode Awosika, TAHF's Founder and proud father of the departed scion, Temitayo. Temitayo was translated to eternity in the United States, on the day following his 19th birthday. Everyone who knew Temitayo attested to his loving nature and strong desire to help the underprivileged.

Twenty years on, building a solid front is exactly what TAHF is doing, reaching out to families affected by SCD...

More on TAHF's Nationwide SCT/SCD Awareness Campaign from Page 19

YES, YOU CAN LIVE TO OLD AGE WITH SICKLE CELL

Alhaja Onikoyi-Laguda (1925 - 2020) was renowned as one of the oldest with SCD. Her genotype was SC.

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

Manage SCD Proactively

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

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

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

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

Maintain a healthy lifestyle

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

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

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Modi: A Pledge To Stamp Out Sickle Cell in India

'We will ensure future generations are safe from Sickle Cell Disease'

India's past, history, present and India's future will never be complete without the tribal community.

Tribal populations in India share a disproportionate burden of SCD. We will usher in a social revolution against this disease and bring in the most advanced science and technology to tackle it.

We are committed to improve the quality of life of people with SCD and ensure future generations are safe from it.'

Living *Looooooong* with SCD

... like A. A. Onikoyi-Laguda

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

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

Prevent infections and complications

- Get recommended vaccinations like the flu and pneumonia shots.

- Promptly treat any infections, as sickle cell patients are more prone to complications.
- Use prophylactic antibiotics if recommended to prevent serious infections.
- Manage chronic conditions like high blood pressure, diabetes, or kidney disease.

Undergo regular screening and monitoring

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

Advocate for your care and participate in research

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

With proactive disease management, a healthy lifestyle, and a team-based approach to care, many individuals with sickle cell disease can achieve a normal lifespan. Early intervention and avoiding complications are key to living well into older adulthood.

India Sickle Cell

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Even so, it is not unusual to find adults in these areas just scraping by, barely managing to survive without the medical intervention they require.

India favours a multi-prong approach aimed at eradicating sickle cell by 2047. However, pundits contend that SCD cannot be eradicated so easily, or so quickly. All India - and indeed any other country - should aim for, they say, is significant reduction in prevalence.

Her Genotype Is So Rare For An African!

Individuals with Dr. Toyin Oshinowo's genotype are more likely to be found in the Mediterranean, throughout the Middle East, the Indian subcontinent, Southeast Asia, and Melanesia to the Pacific Islands

Sickle Cell Warrior Toyin Oshinowo, 44 is an Engineer trained in the UK. She was 9 months old when her family moved to the UK, which was fortunate for her, health wise. Her genotype is so rare that no existing genotype testing machine anywhere in Nigeria can detect her genotype! Even now in 2024, very few labs can pin down her Hb.

With more than 14 years' experience in Product Management, she is currently Head, Product and Programs at 9jaPay, a financial services company based in Lagos.

In this interview with Abro Onyekwe, Toyin relates growing up with a rare genotype and the doctors' reassurances which failed woefully.

How old were you when you were diagnosed with sickle cell disorder?

I have Sickle Beta Thalassemia which is a variant of Sickle which is more prominent in Middle East & India. This form of Sickle Cell does not come up in SCD screening at government or most private laboratories hospitals in Nigeria. Back when my parents were courting they took the tests and my mother was told that she was AA. When they had me and my twin, my mother noticed that I would cry and wouldn't settle. When we moved to the UK for my father furthering his education, I was diagnosed with SCD.

It should be noted that even today - the test for SBThal is still not available at local and national hospitals in Nigeria, but the test is now available at a few private lab facilities.

My mother was tested to be AA - in fact her Hb was ABThal - she was a carrier of the Sickle Beta Thalassemia gene! My father is AS.

What's the nature of your crises - same as classical SS crises?

I typically have vaso-occlusive crisis. I was told that SBTHal is a mild form of SCD and that I shouldn't expect to have crises as bad as someone with 'full blown' SS. I can emphatically tell you that this is untrue. The type of Sickle does not dictate severity but the volume of sickled cells against normal blood cells do. The frequency and severity of my Sickle Cell crises has varied over my lifetime. When I was younger my episodes were severe but far and few between. As I grew older, the frequency increased which led to me looking for different ways to manage my condition - from Hydroxycarbamide to Blood Exchange Transfusions.

I had acute Chest crisis when I was on an exchange program from my UK university to another in the United States. I was admitted into the ICU and had to

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SCD Research Lands Dr. Orkin on *Time's* Most Influential People of 2024

Stuart Orkin, MD, of the Dana-Farber Cancer Institute and Harvard Medical School, has been named as one of Time's *100 Most Influential People of 2024* for his research on fetal hemoglobin and the mechanisms underlying hemoglobinopathies such as sickle cell.

Dr. Orkin's work dates back to 2008 when a genome-wide association study he led showed that the BCL11A gene controls the switch from fetal hemoglobin to adult hemoglobin production—from γ-globin to β-globin. Subsequently, he and colleagues showed that suppressing BCL11A reactivated the production of fetal hemoglobin in mice.

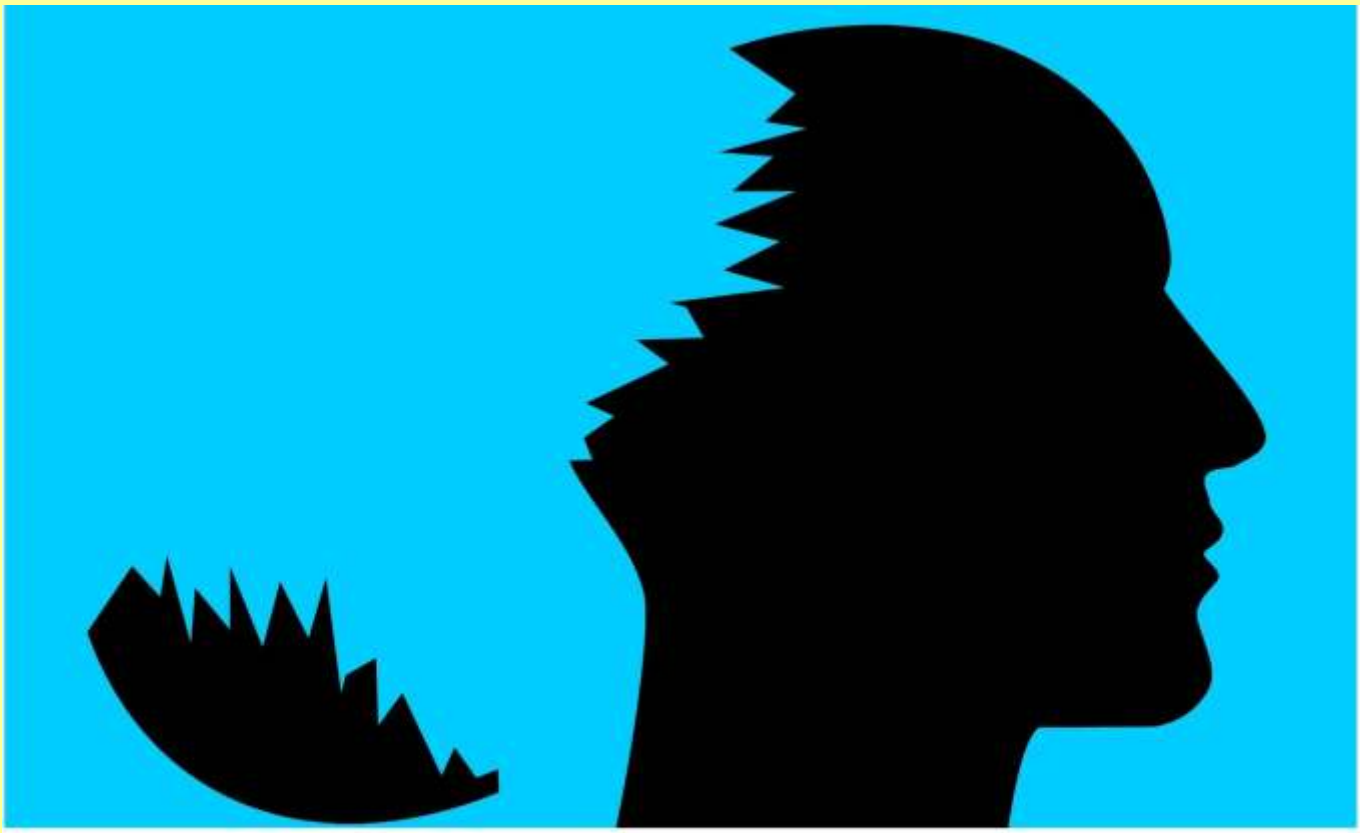
These findings and additional studies led by Dr. Orkin culminated in the development of exagamglogene autotemcel (exa-cel), a therapy that utilized CRISPR/Cas9 gene-editing technology to suppress BCL11A in red blood cell precursors and unlock the production of fetal hemoglobin in patients with SCD.

Following successful phase III trials, exa-cel, codeveloped by CRISPR Therapeutics and Vertex Pharmaceuticals under the name Casgevy, was approved by the US Food and Drug Administration in December 2023 for the treatment of SCD in patients aged 12 years and older with recurrent vaso-occlusive crises.

While exa-cel is a groundbreaking, potentially curative treatment for SCD, it carries a significant cost that currently serves as a barrier to widespread use. To that end, Dr. Orkin told *Time* that, 'we solved some of the problem, but really haven't solved what we set out to solve, which is how to make not just a few people but a lot of people better.'

DocWire News

'we solved some of the problem, but really haven't solved what we set out to solve, which is how to make not just a few people but a lot of people better'



The All-round Emotional & Mental Health Impact of SCD

By Nick Orbido

... Impact of SCD is felt not only by the Warrior but also by family, friends and health care providers

Sickle cell disease (SCD) not only affects the physical well-being of patients but also significantly impacts the mental health of those around them.

Parents & Care-givers

Chronic Stress: The constant worry about their child's health, managing pain episodes, and navigating complex medical systems can lead to chronic stress, anxiety, and even depression.

Burnout: Juggling work, medical appointments, and daily care can cause emotional and physical exhaustion.

Guilt and helplessness: Feeling unable to prevent pain crises or witnessing their child's suffering can lead to guilt and feelings of helplessness.

Social isolation: Focusing on care may limit social interactions, leading to feelings of isolation.

Persons Living with SCD

Anxiety and Depression: Chronic pain, frequent hospitalizations, and limitations on activities can lead to depression and anxiety.

Body Image Issues: Painful episodes, fatigue, and potential for delayed growth can negatively impact self-esteem and body image.

Isolation and Loneliness: Social withdrawal due to pain or fear of pain crises can lead to feelings of isolation and loneliness.

Fear of the Future: Uncertainty about the future course of the disease and potential complications can cause significant anxiety.

Siblings of Sickle Cell Warriors

Feeling Neglected: Parents' focus on the sick sibling may lead feelings of neglect and resentment.

Sibling Rivalry: The extra attention given to the sick sibling can create rivalry and jealousy.

Guilt and Anger: Witnessing their sibling's suffering can cause feelings of guilt or even anger directed at the sibling or the disease.

Fear of Inheriting SCD: The possibility of inheriting the disease can cause anxiety.

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Sickle Cell is as Much a Disease as a Disorder!

- retired Professor of Haematology, Mrs. Adeyinka Gladys Falusi, PhD, FAS,
NPOM L'Oreal-UNESCO FWIS Laureate (Africa)

By Ayoola Olajide

Oyo State Deputy Governor, His Excellency Barrister Abdulraheem Adebayo Adeleke Lawal, stirred up an issue which many Sickle Cell Warriors find vexing - the issue of whether sickle cell was a disease or a disorder, at the recent World Sickle Cell Day celebrations in Ibadan, Oyo State. He said:

'I really don't know what sickle cell is. I think it is a disorder, or a condition - but some say it is a disease. I think we should leave it to the experts to enlighten us.'

Professor Mrs. Adeyinka Falusi possibly did not have that subject in her prepared speech, but had to say something as a preface on the matter. Her organization, the Sickle Cell Hope Alive Foundation (SCHAF), hosted the august day's event, in collaboration with the family of Adeseun Ogundoyin, whose son, Adebo, is the incumbent Speaker of the Oyo State House of Assembly.

Sickle Cell, Prof Falusi stated, is *both* a Disease *and* a Disorder. She later qualified her statement in an interview with *Sickle Cell News* thus:

- The WHO defines sickle cell as a 'genetic disorder';
- The US National Institutes of Health (NIH) refers to SCD as a 'disease';
- The American Society of Hematology (ASH) uses 'disease' and 'disorder' interchangeably;
- As to 'condition' some argue that 'condition' is a neutral term, which emphasizes the genetic aspect rather than the negative connotations of 'disease'.

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TEMITAYO AWOSIKA HELP FOUNDATION

info@tahfoundation.org | www.tahfoundation.org

NATIONAL SICKLE CELL AWARENESS OUTREACH

Back-To-School Program, FHP 1200, World Sickle Cell Day, Free Genotype Verification

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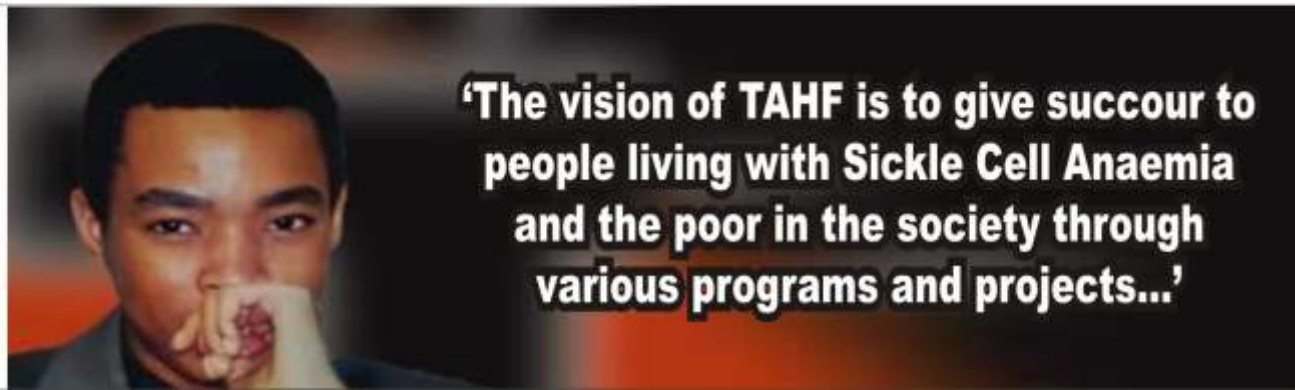
Nasarawa // Ogun // Ondo // Oyo // Plateau // Rivers

access



TAHF Talks Genotype With Leaders, Policymakers, and Parents of Tomorrow

TAHF's striving for the medical, spiritual and psychological welfare of Sickle Cell Warriors continued apace.

In 2023, with the support of Access Corporation, things took a ground-breaking turn with new programmes solidified to impact the sickle cell community: the Free Health Programme (FHP 1200) at which TAHF gave out free health insurance packages to 1200 Sickle Cell Warriors. There was also the Back-To-School package for children and adolescents living with sickle cell, at which thousands of schools bags complete with accessories and exercise books imprinted with SCT awareness information, were distributed free of cost to SCD organizations in mainland Lagos, Epe, Ijede, Ikorodu, Ibadan, Oyo Town.

That was not all. With impetus from Access Corporation, TAHF expanded its outreach to every geopolitical zone in Nigeria. By coincidence, some of these outreaches took place in June 2024, bestowing, on cities like Abeokuta, Ogun State, added significance to World Sickle Cell Day (June 19) celebrations. Before that, from June 18 to 22, free genotype screening took place within the premises of Med-In Specialist Hospital, drawing large crowds of children and adults from the LGA and beyond.

Before and after June 19, for Dr. Sola Adebekun, TAHF's tireless Executive Secretary, along with select staff from Access Corporation, a gruelling itinerary of road and air travel straddling thousands of kilometers across Nigeria ensued. The team was at Bilgade High School, Abattoir Road, Jos, Plateau State with school bags for the SCD communities under Kathy Life Builder Foundation, headed by KLBF's Founder/CEO, Mrs. Catherine Ocholi.

Likewise the TAHF train was at High-Tech International School, Jimeta, Yola North LGA, Adamawa State with same goodies and messages for the communities under the aegis of Badanamu Sickle Cell Foundation. In Ilorin, Kwara State, TAHF partnered with

continued on page 21

TAHF Tackles Crisis of SCT/SCD Ignorance

continued from page 20

Damilola Sickle Cell Foundation to host World Sickle Cell Day 2024 at ECWA Secondary School, Taiwo Road, Oja Iya.

TAHF's indefatigable team is all set within the next few weeks to carry out similar exercises in Port Harcourt (in collaboration with the Society For Healthy Living (SHL) in Ondo (with Ignite Sickle Cell Foundation).

Others planned are Awka, Anambra State (with the Association of People Living With SCD, APLSCD) and Ijibor, Bekwara, Cross River (with Oyiji Odey Sickle Cell Program, OOSCP) and at Ring Road, Ibadan (in partnership with Ibadan Sickle Cell Foundation and Chrisbo Champions Sickle Cell Foundation), all set to be carried out before the end of 2024.

None of the commendable frenetic nationwide pursuit of SCD/SCT sensitization would have been possible without the support of Access Corporation, a banking institution with a high sense of Corporate Social Responsibility. Access Corporation has indeed managed to emblazon its name on the canvass of SCD/SCT education and awareness in the world's heaviest-burdened SCD/SCT country.

The beauty of it all is that TAHF, along with Access Corporation, is taking the message of SCT/SCD to the leaders, policymakers and parents of tomorrow. Most analysts agree that genotype awareness works better when introduced at an early age - long before falling in or out of love becomes the norm - long before emotion overthrows or obscures rationality.

Nigeria - the SCD/SCT Ignorance Fiasco

Left unchecked, non-awareness of one's sickle cell status and its significance for birthing SCD has grave implications for SS prevalence for generations to come. Without SCT, there will be no SCD.

The sheer statistics of SCT/SCD in Nigeria is mind-boggling. Medical statistics suggests that 2 to 3% of the entire population of Nigeria lives with sickle cell anaemia and its variants. This figure tops 4 to 6 million individuals, more than the combined population of Namibia and Estonia!

Similarly, an estimated 25 to 30% of Nigerian citizens harbour the sickle cell trait (SCT). This equates to between 50 million and 70 million citizens, in excess of the combined population of Canada and Australia! Unfortunately, the vast majority of those who carry the sickle cell gene in Nigeria - and indeed worldwide - are unaware of the bomb within their loin, simply awaiting fusion with another carrier to strike - and strike very hard indeed.

People with SCT are generally healthy but carry the blueprint for producing a child with the full-blown disorder. Not knowing - or not being concerned about - one's genotype thus leaves the health, happiness and wellbeing of the unborn to chance.

With TAHF going for the jugular to accentuate SCT awareness nationwide - and sensitize carriers to its meaning - hopefully more Nigerians will take the informed decision to avoid marriage or prevent SCD through various options, among them, prenatal diagnosis (PND), adoption, and so on.

'We Employed Our Back-To-School Programme to Propagate Sickle Cell Trait/Sickle Cell Disorder Awareness Among Students & Teachers.'

- Dr. Sola Adebekeun, Executive Secretary, TAHF

You have been travelling widely within Nigeria with your team to sensitize young people in their communities about SCT/SCD. Have you ever been on the road like this before?

I have never been on the road like this before, not in a long time. Many years ago, when I was running an outdoor advertising company, I had reasons to visit our branches in Kano, Abuja, Kaduna, and Onitsha once or twice, when it was absolutely necessary.

How were you received at the communities visited - do you think there is enough awareness of SCT among the populations?

We had a very warm reception at those communities we have been to so far. The awareness of SCT and its implications is grossly insufficient and in some places, none at all.

What is the rational for combining TAHF's Back-To-School Project with SCT/SCD awareness?

The Back-To-School project was actually a means to an end. SCT/SCD awareness was actually the main agenda, only channeled through the Back-To-School program. We never imagined it was going to be as impactful as it has proved.

What do you think can be done to broaden SCT education in such a vast country as Nigerian?

It's very simple. From our recent experience, collaboration with other SCD advocacy groups is the major and workable solution. It is highly recommended.

Would you describe yourself as passionate about SCT or this is simply part of your job specification as TAHF's Executive Secretary?

I am indeed passionate about impacting lives, particularly the vulnerable people, and in this case, Sickle Cell Warriors. I didn't join TAHF as Executive Secretary - it was my passion for SCD that earned me thet position eventually.

How many kilometers did you log in for WSCD 2024?

I travelled more than 1000 kilometers in June 2024 alone to pursue TAHF's World Sickle Cell Day objectives.

Leda Sweerts (middle), Global Clinical Marketing Manager, Therapeutic Systems, receiving a Certificate of Appreciation on behalf of Terumo BCT

Raising Hope International Friends Hosts 3rd Annual Convention

5 July 2024

Raising Hope International Friends (RHIF) hosted the 3rd Annual Uganda Sickle Cell Convention (#ASCC24) in Jinja. The theme for the 2024 Convention was 'Exploring Innovative Wellness and Preventive Medicine in Sickle Cell Disease in Uganda and Beyond.' The event saw the participation of experts from Zambia, Kenya, Tanzania, South Sudan, Somalia, UK, India, the USA, and Uganda, who shared a wealth of resources and insights on sickle cell disease.

RHIF was able to connect and synergize with various stakeholders, including medical professionals, physicians, researchers, NGOs, advocates, sickle cell warriors, and caregivers. The platform allowed an exchange of experiences, best practices, and challenges, making it an impactful event for the sickle cell community.

Discussions covered a range of topics, including the role of blood transfusion in the care and management of SCD, the progress of the national sickle cell program, ongoing research in Uganda, available diagnostic technologies, life experiences of sickle cell warriors, and perspectives from advocates and caregivers. Best practices, gene therapy, and bone marrow transplantation for sickle cell were also key points of discussion.

Dr. Susan Nabadda, the Commissioner of National Health Laboratory and Diagnostics Services, delivered a keynote address. She emphasized the importance of proper diagnosis in the care of SCD and issued a call to fight sickle cell together.

Isaac Okello, Executive Director, RHIF, host of the convention, expressed gratitude to the sponsors and the Ministry of Health for their technical and financial support in promoting public awareness of SCD in Uganda. Emphasizing the importance of a united effort to combat sickle cell in Uganda and across the globe, he thanked the participants for attending the convention.

High Protein Foods Are Crucial In SCD

By Kemi Oguntimehin, Certified Sickle Cell Genetic Counsellor

Protein is a macronutrient that serves as a building block for tissues throughout the body, including red blood cells. For those with sickle cell, ensuring you get adequate protein is especially important and here's why:

Prevent Anaemia
One of the hallmark symptoms of sickle cell disease is chronic anaemia due to low red blood cell counts and shortened red blood cell lifespan. Protein provides amino acids like leucine, isoleucine and lysine that stimulate the production of haemoglobin, the oxygen-carrying protein in red blood cells. Sufficient protein intake helps maximize haemoglobin levels. In my book, *The Sickle Cell Diet:* I explain in more detail the strategy that I used to stay away and manage my chronic anaemia and was blood transfusion-free for 10 years.

Prevent Complications
Sickle cell disease can lead to various complications like delayed growth, acute chest syndrome, and leg ulcers. Eating enough high-quality protein provides the amino acids needed for proper growth, cell repair, and wound healing. This may help ward off or improve some of these issues.

Energy Booster
Protein foods are also a great source of energy when carbohydrates and fats are used up. This sustained energy can combat the fatigue and weakness many sickle cell patients experience due to anaemia.

Strengthen Immunity
Living with sickle cell raises the risk of infection. Protein malnutrition can weaken immunity further. Getting sufficient protein supports the body's defences by promoting the growth of infection-fighting white blood cells levels.
The right diet looks different for everyone, but aiming for

1.5 grams of protein per kilogram of body weight is a smart target for sickle cell warriors Proteins like chicken, turkey, fish, low-fat dairy, nuts, eggs, seeds, and beans are your best options.

Don't underestimate the power of protein for managing sickle cell disease.

PROTEIN-RICH FOODS

Eggs, dairy products – milk, yoghurt, cheese, nuts and seeds – almonds, pine nuts, walnuts, hazelnuts, cashews, pumpkin seeds, sesame seeds, sunflower seeds. legumes and beans, etc

Lagos State Commissions Paediatric Sickle Cell Centre

Lagos State Governor, Babajide Sanwo-Olu, has commissioned a Paediatric Sickle Cell Centre within the premises of the Lagos State University Teaching Hospital (LASUTH).

The newly built two-storey Paediatric Sickle Cell Centre was donated by the Office of the Senior Special Assistant to the President on Sustainable Development Goals (OSSAP-SDGs) to improve health outcomes for children with sickle cell.

The centre will provide comprehensive care, including diagnosis, treatment, and management for children affected by sickle cell disorder.

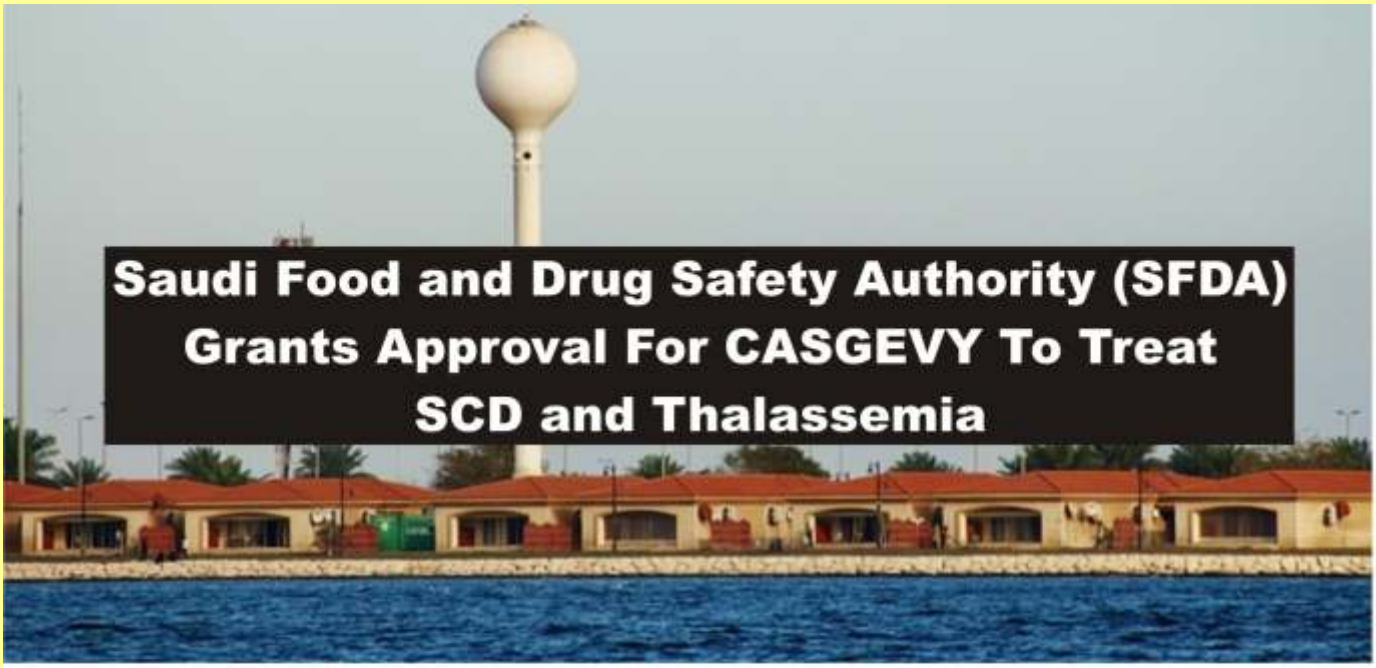
'It is with great pride and a sense of honour that I stand here to hand over this remarkable project in our health delivery value chain: the Paediatric Sickle Cell Centre,' said Governor Sanwo-Olu.

The Governor noted that the centre would offer an environment where children could receive holistic care tailored to their needs, from medical treatment to psychological support.

The Minister of State for Health and Social Welfare, Dr. Tunji Alausa, reiterated the Federal Government's commitment to combating non-communicable diseases and improving healthcare outcomes for Nigerians.

LASUTH's Chief Medical Director, Prof. Adetokunbo Fabamwo stated that the Sickle Cell Centre houses facilities for clinics, wards, daycare centre, laboratory investigation as well as educational and research activities for children living with sickle cell in Lagos State.

The LASUTH Paediatric Sickle Cell Centre is expected to serve as a reference hospital for public and private hospitals in Lagos State and beyond. With state-of-the-art facilities, it demonstrates the commitment of the Federal Government to provide topnotch health services for children. The Centre will treat children aged up to 14 years diagnosed with sickle cell anaemia and its variants.



Saudi Food and Drug Safety Authority (SFDA) Grants Approval For CASGEVY To Treat SCD and Thalassemia

The Saudi Food and Drug Authority (SFDA) has granted Marketing Authorization for CASGEVY™ (exagamglogene autotemcel [exa-cel]), a CRISPR/Cas9 gene-edited therapy, for the treatment of sickle cell disease (SCD) and transfusion-dependent beta thalassemia (TDT).

CASGEVY is approved for the treatment of people 12 years of age and older with SCD or TDT. The Kingdom of Saudi Arabia has among the highest prevalence rates of SCD and TDT in the world, with thousands of citizens living with these genetic blood disorders.

The approval is the first ever given to Vertex Pharmaceuticals in the Kingdom.

'This approval adds to the list of firsts for CASGEVY. It represents the first medicine ever to receive SFDA Breakthrough Designation and be approved through this pathway,' said Reshma Kewalramani, M.D., Chief Executive Officer and President of Vertex.

'Most importantly, with this approval, people living with sickle cell disease or transfusion-dependent beta thalassemia have the possibility of a one-time transformative therapy for their disease.'

ABOUT CASGEVY

CASGEVY is a one-time therapy used to treat people with SCD 12 years and older who have pain crises. It is made specifically for each patient , using the patient's own edited stem cells. It increases the production of a special type of haemoglobin called haemoglobin F (fetal haemoglobin or HbF). Having high HbF increases overall haemoglobin levels and has been shown to improve the production and function of red blood cells. This can significantly reduce or eliminate pain crises.

Before CASGEVY treatment, a doctor will give you a mobilization medicine. This medicine moves blood stem cells from your bone marrow into the blood stream. The blood stem cells are then collected in a machine that separates the different blood cells.

During this step, rescue cells are also collected and stored at the hospital. These are your existing blood stem cells and are kept untreated just in case there is a problem in the treatment process. If CASGEVY cannot be given after the conditioning medicine, or if the modified blood stem cells do not take hold (engraft) in the body, these rescue cells will be given back to you. If you are given rescue cells, you will not have any treatment benefit from CASGEVY.

After they are collected, your blood stem cells will be sent to the manufacturing site where they are used to make CASGEVY.

After they are collected, your blood stem cells will be sent to the manufacturing site where they are used to make CASGEVY. It may take up to 6 months from the time your cells are collected to manufacture and test CASGEVY before it is sent back to your healthcare provider for your transplant.

The treatment can lead to infertility, bleeding, lowered white blood cells and increased susceptibility to infections, severe headache, and so on.

Bahrain Offers Groundbreaking SCD Treatment to Citizens

The Bahrain Oncology Centre (BOC) has achieved a significant milestone, becoming amongst the first centres in the World to offer the ground-breaking CASGEVY (exagamglogene-autotemcel or 'exa-cel') gene therapy for sickle cell disease (SCD) and transfusion dependent thalassemia (TDT). This achievement follows the BOC's successful accreditation, recognising its adherence to international standards for bone marrow transplant and cell therapy services.

The first Bahraini patient with SCD is about to begin the treatment journey, marking a new era of advanced healthcare in the region.

The launch of the CASGEVY (exa-cel) programme is a collaborative effort between the Ministry of Health, the Royal Medical Services, Government Hospitals, and the National Health Regulatory Authority.

This pioneering initiative aligns with the vision of His Majesty King Hamad bin Isa Al Khalifa to elevate Bahrain's healthcare sector and reflects the directives of His Royal Highness Prince Salman bin Hamad Al Khalifa, the Crown Prince and Prime Minister, to provide the highest quality care for all citizens and residents, particularly those with inherited blood disorders.

The Bahrain Oncology Centre submitted comprehensive documentation for evaluation, showcasing the expertise of its team, state-of-the-art equipment, and robust policies adhering to international standards for hematopoietic cell transplantation (HCT) and cell therapy (CT). Following a thorough review of the submitted documentation, there was an on-site audit, culminating in the BOC's recognition as a certified centre for bone marrow transplant and cell therapy services upon meeting all administrative and operational requirements.

The CASGEVY (exa-cel) therapy involves a multi-stage process, beginning with a comprehensive patient assessment. Following a blood exchange transfusion to prepare the bone marrow, stem cells are collected and sent to a laboratory for genetic editing. Rigorous quality checks ensure the safety and efficacy of the modified cells before they are returned to the Kingdom of Bahrain for transplantation. The patient is then closely monitored as the new cells enter the bone marrow and start producing new cells.

The Bahrain Oncology Centre's dedication to advancing healthcare through partnerships with national institutions ensures that the entire community can access state-of-the-art medical technologies. The recent accreditation solidifies Bahrain's position as a regional leader in innovative healthcare solutions.

Saved By The Blood!

Seasoned Nigerian Nurse, Midwife and blogger Martha Ngufan recalls how blood transfusion saved her - and her unborn baby's - life

Living with sickle cell disease, I know the power of donors. Blood transfusions saved my and my unborn baby's life during pregnancy.

At 8 months of my first pregnancy, I was severely anemic and needed blood transfusion urgently. This wasn't the first time anemia plagued this pregnancy, but this time, it felt different. With every passing moment, the stakes felt higher.

After multiple attempts by nurses and even my seasoned nurse-midwife mom, the fetal heartbeat remained silent. The baby had practically died in my womb. Despair choked the air. It was hard for my mom, who, as a nurse, understood the gravity of the situation. She knew how much I had suffered to come this far in the pregnancy. Mom began to pray fervently, a silent plea in a whirlwind of medical protocol.

As the first pint of blood entered my system, a miracle unfolded. The fetal heartbeat, once missing, became a steady drumbeat of life.

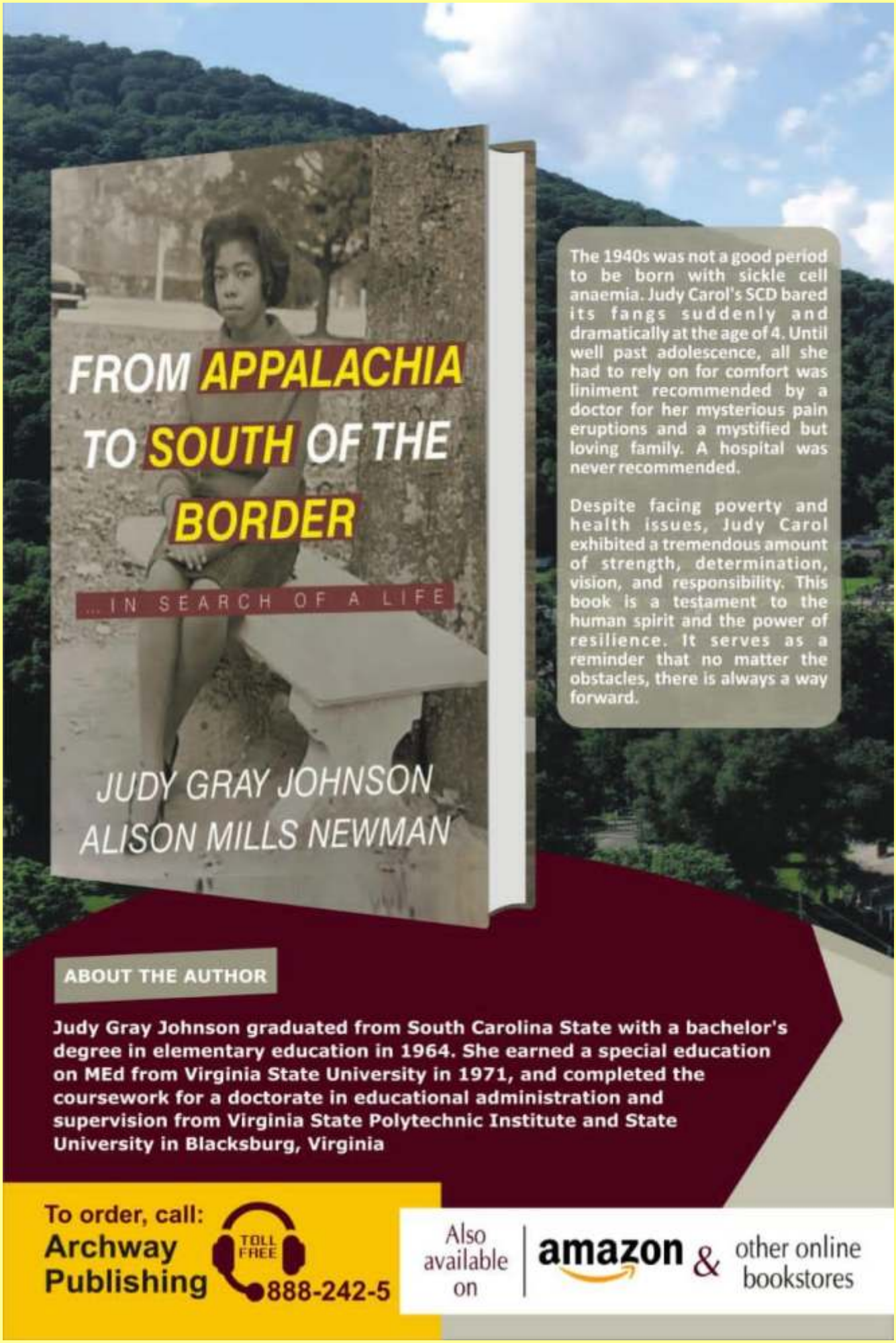
Today, 24 years later, my daughter thrives and has just obtained her LL.B (Law degree), a living testament to the power of modern medicine and a mother's unwavering faith.

Sickle cell disease in pregnancy is high risk for the mother and the baby and can lead to miscarriage, prematurity and more frequent sickle cell crises in the pregnant person.

According to experts, pregnancy in SCD can be complicated as both prospective mother and neonate are at increased risk of adverse outcomes. The physiological changes of pregnancy like increased metabolic demand and increased blood thickness gets aggravated in SCD patients leading to increased incidence of complications like a vaso-occlusive crisis, acute chest syndrome, bone and liver complications, leg ulcers, and other events.

Blood is of essence in SCD and particularly more so for women with SCD in pregnancy.

..., the fetal heartbeat remained silent. The baby had practically died in my womb! As the first pint of blood entered my system, a miracle unfolded. The fetal heartbeat, once missing, became a steady beat of life



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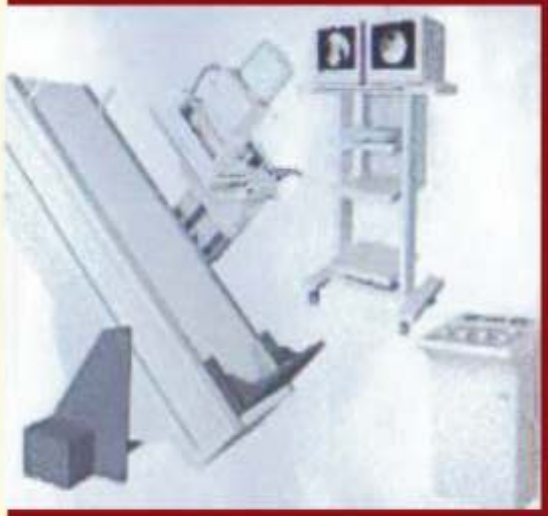

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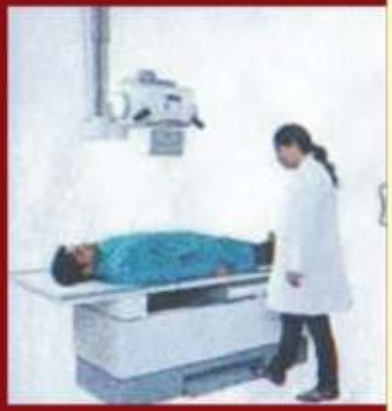

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Hope Gala & Awards 2024

UNVEILING THE SUNDAY AFOLABI SCHOLARSHIP GRANT 2024

MABEL UMOLU

A 3rd year Psychology student at Toronto Metropolitan University, Mabel's experiences with loss and illness have inspired her to become a licensed Grief Therapist. She aspires to support others through their hardships, offering them the understanding and compassion that her own journey has instilled.

KABIBI BOLO

Kabibi Bolo came from a big family of eleven children in the Democratic Republic of Congo, with five of the children lost to sickle cell disease complications. She lost her parents when she was 18 years old and came to Canada in 2019.
Bolo is currently a nursing student at Centennial College.

ROSEMARY OKEIBUNOR

Rosemary Okeibunor is currently attending Algonquin College, where she is enrolled in the Practical Nursing Program. It is her dream to be a nurse advocate for the general population and create a sensitization of sickle cell disease to the public, through creating enlightenment, awareness, and understanding in the rural and urban areas alike.

KARINA KUEVIAKOE

As a black woman living in a predominantly white area, she was told by guidance counselors and peers that her goal of achieving her undergraduate program goal - the McMaster Health Sciences, was too ambitious, and was told to explore other options. She refused to be deterred and became one of the 250 students admitted out of thousands who applied for the program. She is also one of the seven black students in her cohort maintaining a 3.9 GPA and making the Dean's list.

AFEEZ ADEGBOLA

In the face of debilitating experiences with sickle cell disease, Afeez is determined to excel in his academic endeavors. He recently graduated as a postgraduate student of Business Analysis at Fanshawe College. He has also finished an insurance program and currently pursuing a certification in the Chartered Insurance Practitioners (CIP) program.

**** Except for Afeez Adegbola, who received $1000, all others received a Vertex-Sponsored Sunday Afolabi $2000 Grant 2024*

'The way I see it, this genotype is my cross to bear - apportioning blame is pointless'

- Oluwatoyin Oshinowo

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have my first blood transfusion. I was unconscious for three days and recovery took three months!

What limitations would you say SCD placed on you growing up and as an adult?

Physically it has been brutally limiting. I can't keep up with my non-SCD counterparts, but my mother is a force!!! She had this saying that stuck with me and has formed my outlook on life - 'Your legs [enter any other body part] are in pain, but that doesn't mean that your brain has stopped working'. So I compensated by being academic.

As I got older, I've noticed more symptoms - Chronic fatigue, Brain fog, and Chronic back pain. These things have meant that I've had to make adjustments in my life to accommodate these symptoms.

Has sickle cell affected your outlook on life? If 'Yes', How?

Yes, it has though it varies. At the time where my crises were frequent and uncontrollable I was depressed, negative and really hard on myself. I kept comparing myself to my non-SCD family and friends because I wanted to be like them. I felt useless and a drain on my family. Those were some dark times. Ultimately it has knocked my confidence when has come to my career progression and the pressures of rising to the top.

When I got control of my crises, it allowed my mindset to change, I have more of a fighter mindset. I have a running joke with my mum that if I only did what she wanted me to do I wouldn't achieve much in my life - I would only be surviving, not thriving. It's made me fiercely independent because time and time again Sickle has taught me that I am the only one that feels my pain. Yes, I appreciate that family and friends are affected but they *can't* feel my pain. This in turn has forced me to take responsibility for myself and my health.

Have you ever blamed your parents for giving you SCD?

Heck no! My mother she does blame herself - which is ridiculous. My parents did everything they were supposed to do; they got screened and were told they were good to go. The way I see, this genotype is my cross to bear - apportioning blame is a pointless exercise.

Relationships

I'm not married, but in my relationships genotype has always been a factor. As a Sickle Cell Warrior, I know that I can't have a child that has Sickle Cell. I can barely take care of myself let alone take care of someone who has the condition - it wouldn't be fair.

What do you think about sickle cell carriers getting married (to sickle cell carriers) if they knew of the risks to their offspring?

I don't judge - they are free to do as they please. The only thing I would ask is for them to take full consideration of the risks and the life ahead of them if they don't take the measures required to prevent their offspring from having this disease. This is why education is really important. Leaving it to God is a fool's errand - heaven helps those who help themselves. God has given us advances in genetics to prevent having children that are at a disadvantage. Living with Sickle Cell is limiting - it is a

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SCD & Mental Health

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Healthcare Providers

Secondary Stress: Repeated exposure to patients' pain and suffering can lead to secondary traumatic stress, affecting their emotional well-being.

Moral Distress: The inability to completely alleviate a patient's pain can cause mental distress, a feeling of helplessness in the face of suffering.

Burnout: The high workload and complex needs of SCD patients can lead to burnout.

Importance of Mental Health Care

Taking care of mental health is crucial for everyone impacted by SCD. It can improve overall well-being, increase coping abilities, and enhance support systems. Here's why mental health care matters:

Improved Quality of Life: Effective therapy can help manage stress, anxiety, and depression, leading to a better quality of life.

Enhanced Coping: Learning coping skills helps individuals deal with challenges more effectively.

Stronger Support Systems: Therapy can provide tools for better communication and strengthen support networks.

Available Resources

Many resources are available to address the variegated mental health needs of Warriors, their caregivers and medical personnel:

Individual Therapy: Talking to a therapist can provide a safe space to process emotions, develop coping skills, and manage stress.

Support Groups: Connecting with others who understand the challenges of SCD can offer emotional support and a sense of belonging.

Online Resources: Websites and platforms like The Sickle Cell Awareness Foundation offer information and support groups.

Mindfulness Techniques: Meditation, yoga, and deep breathing exercises can promote relaxation and reduce stress.

Mental health is just as important as physical health. Seeking help and utilizing available resources can make a significant difference in the lives of everyone impacted by SCD.

Mr. Orbido is CEO/Chairperson, Sickle Cell Anaemia Foundation, Kenya,

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Thalassaemia International Federation (TIF) Wins Prestigious HemaSphere Award

The Thalassaemia International Federation (TIF) has been cited for its work in thalassaemia advocacy and recognized at the HemaSphere Awards during the prestigious Annual Hybrid Congress of the European Haematology Association (EHA2024).

TIF was awarded for its notable contribution to advancing scientific knowledge in Haematology through its publication, *'2021 Thalassaemia International Federation Guidelines for the Management of Transfusion-Dependent Thalassaemia.'*

The HemaSphere Awards were presented by the official journal of EHA during Europe's most important scientific event in the field of Haematology, held in Madrid, Spain, in June 2024. Among thousands of submissions, the TIF paper was recognized for its impact among scientists, physicians, and researchers worldwide.

Mr. Loris Brunetta, a TIF Board Member, Thalassaemia Patient Expert, and Special Representative of the Federation on European Affairs, accepted the award on behalf of TIF. The ceremony was also attended by the eminent authors of the paper, Professors of Haematology Ali Taher and John Porter.

Dr. Androulla Eleftheriou, TIF Executive Director, remarked on the occasion: 'We are particularly proud to receive this prestigious award. It underscores the international scientific community's recognition of our Guidelines' value and their impact on improving health outcomes for thalassaemia patients worldwide.
'This acclaim also celebrates our ongoing efforts to develop educational tools aimed at enhancing clinical practices for those managing the disease.'

Expressing his gratitude, TIF President Mr. Panos Englezos stated: 'We are delighted to receive this honour and extend our thanks to both the European Society of Haematology and our scientific partners—the authors—whose collaboration made this invaluable Guide possible. Amid rapid advancements in haematology and haemoglobinopathies, we bear an even greater responsibility to expedite our collaborative initiatives in delivering medical innovations' benefits to individuals with haemoglobinopathies.'

Since their initial release in 1999, the TIF Guidelines have been widely-adopted by academics, researchers, and healthcare professionals globally as a definitive evidence-based reference for treating transfusion-dependent thalassaemia patients.

In addition, the Federation has published and distributes specific Guidelines for the management of both a-Thalassaemia and Non-Transfusion Dependent Thalassaemia (NTDT).

TIF Guidelines have been widely-adopted globally as a definitive reference for treating transfusion-dependent thalassaemia patients

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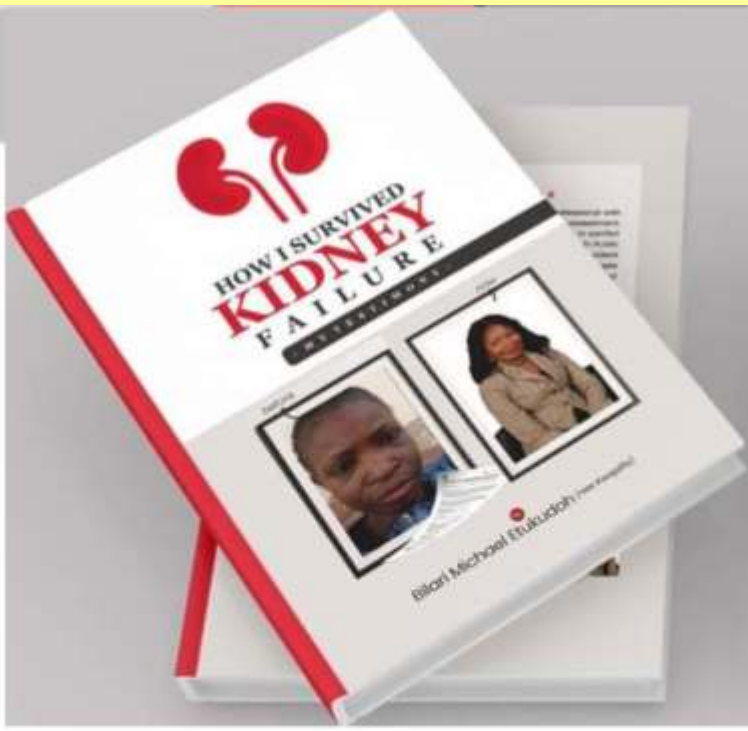

Aliwuya Sadati, 30 graduated from the Mbarara University of Science and Technology with a Bachelor's degree in Medical Laboratory Science. A practiced hand at creative writing, movie scripting and videography, Sadati has produced a film that is certain to amplify empathy, understanding and acceptance of individuals living with sickle cell.

The movie is about a girl struggling to recover from depression as a result of the effects of SCD, who encounters several unforeseen calamities as she tries pursue for her dream as a dancer and sickle cell advocate. Resistance from her father further bogged her down even as she experienced series of sickle cell crises attacks and spends most of her time in hospital. However, with the support of close friends and a support group, she was enabled to keep on pursuing her dreams.

This movie emphasizes the need for SCD screening before marriage and demonstrates that Sickle Cell Warriors can and do live a normal life. This movie should play a role in paving the way for more meaningful conversations on SCD.

The trailer can be watched at https://youtu.be/yXzGNMsQUqg?si=fIpADW_JIaYY-mpw

Read A Book - and Save a Life!

- Sickle Cell Warrior needs nearly N1 million monthly for medications for life

With a kidney donated by her younger brother, Bilari Etukudoh (nee Kwajaffa), 34, survived sickle cell-induced end-stage kidney failure.

The whole kidney issue reared its head after she gave birth to her son - unusual fatigue, rapidly plummeting blood volume, vomiting and the like.

Bilari was not diagnosed with SS until she was past the age of 11. The signs were there from childhood, joint pains during rainy season in particular, but none of the hospitals that treated her thought of verifying her genotype.

With the kidney transplant behind her, Bilari needs to take immune suppressant drugs for life to ensure optimal functioning of the transplanted organ. According to Dr. Ado Theophilus, a member of the multidisciplinary team that managed Bilari at Zenith Medical and Kidney Centre, Abuja, she also needs regular Exchange Blood Transfusion to keep sickle cell from fouling up the transplanted organ.

All in all, Bilari will need close to N1 million every month for life to thrive.

HOW I SURVIVED KIDNEY FAILURE is available for N5000 only. You can pay more, make a gift purchase for others or simply make a donation.

You can reach out to Bilari Michael Etukudoh via Whatsapp at +2347064424546 or email Bilarikwaja130@gmail.com

SCD Both a Disease and a Disorder

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medical management and treatment.

Disorder:

☆Sickle Cell is considered a disorder because it is a genetic condition that affects the normal structure and function of the haemoglobin molecule.

☆The genetic mutation that causes SCD is a disorder in the way the haemoglobin gene is expressed or coded.

☆This genetic disorder is inherited, and individuals with Sickle Cell have received the abnormal haemoglobin gene from both parents.

☆The abnormal haemoglobin gene leads to the production of sickle-shaped red blood cells, which then causes the various symptoms and complications associated with Sickle Cell.

In summary, sickle cell is both a disease, as it is a chronic medical condition with significant health impacts, and a disorder, as it is a genetic abnormality that disrupts the normal function of red blood cells.

To further clarify the issue, *Sickle Cell News* set Artificial Intelligence (AI) to the task. Here is icklewhat it says:

Sickle Cell Disease is considered both a disease and a disorder due to the following reasons:

Disease:

☆Sickle Cell is a genetic blood disorder that affects the haemoglobin in red blood cells.

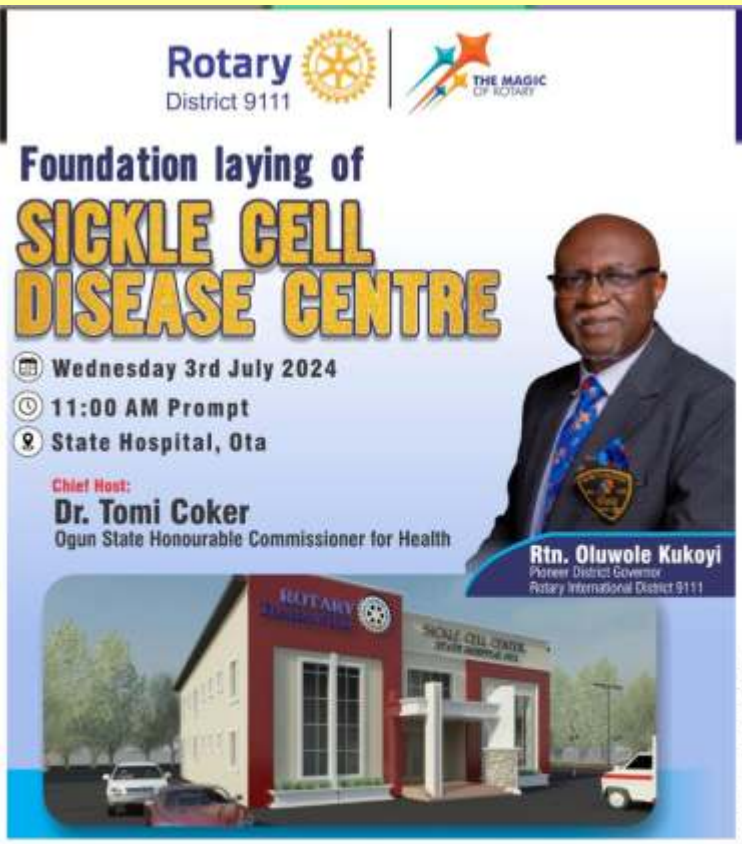
☆In Sickle Cell, the red blood cells become crescent or 'sickle' shaped instead of the normal round shape.

☆This abnormal shape can cause the red blood cells to get stuck in small blood vessels, leading to blockages and reduced oxygen delivery to tissues.

☆This can result in various health complications, including pain, anaemia, organ damage, and increased risk of infections.

☆Sickle Cell is a chronic, lifelong condition that requires ongoing

SCD is a chronic medical condition with significant health impacts, and a disorder, as it is a genetic abnormality that disrupts the normal function of red blood cells



Rotary International District 9111 to Establish Sickle Cell Centre in Otta

... Rotarian Dr. Oluwole Kukoyi installed Pioneer District Governor

The Foundation Stone-laying ceremony of what will become a state-of-the-art Sickle Cell Centre took place on July 3, 2024 at Otta General Hospital, Ogun State, Nigeria.

It was part of the investiture of Rotarian Oluwole Kukoyi as pioneer District Governor of Rotary District 9111.

'Hopefully, this will be completed in time,' an optimistic Rotarian Kukoyi said. His tenure is for just one year; yet the legacy he plans to leave behind will touch generations to come.

The proposed Sickle Cell Centre, for which donations are ongoing, will provide confirmatory tests for newborn screening, treatment and counselling.

The Sickle Cell Centre simultaneously keys into two of the seven cardinal areas of Rotary philanthropic activities: fighting diseases and saving the lives of women and children.

MORE ABOUT SICKLE BETA THALASSEMIA

Sickle Beta Thalassemia (SBThal) Hb S-β-thalassemia is a condition that arises from the inheritance of a β-thalassemia gene from one parent and an Hb S gene from the other.

SBThal is similar to SS although, as in SS disorder, some cases may be unexpectedly favourable.

Oluwatoyin Oshinowo: A Rare Genotype

continued from page 32

disability, if you can prevent it why not? Many have no idea the toll it takes to manage a person living with Sickle Cell. As a parent ultimately you want your children to be able to stand on their own feet, raise their own family and be self sustaining. I can tell you that living with Sickle Cell complicates things and makes it harder to stay afloat, to become, to achieve all those things. I could write a book of how someone like me struggles to compete in this world - but that is a story for yet another day.

How was your genotype traced to Ogun State, Nigeria?

My father is a Consultant Gynaecologist and he took up interest in SBThal when he became aware of my true genotype and my mum's carrier status. Over the course of his career, he took particular interest in mothers who had sickle and those who had it in their families. He was able to trace many sickle cell patients and Thalassemia carriers in Ogun state.

You're ever so busy - what do you do to relax?

I am guilty of watching car crash reality TV, I used to read history books & autobiographies but my workload has limited my bandwidth - so now I listen to audio books.

Some of the children of Adeseun Ogundoyin at World Sickle Cell Day Events, Ibadan, June 19, 2024

Remembering Sickle Cell Warrior, Chief Adeseun Ogundoyin (1940 - 1991)

Birth and Education: Of poor health, later diagnosed as sickle cell (HbSC), Ogundoyin was born into extreme poverty. Trained as a bicycle repairer, he started primary school at the age of 17. After primary school at Baptist Day School, Eruwa, he went on to Modern School. From there he attended Yabatech, Lagos.

He would later earn a degree in Business Administration at the University of Bradford, UK. He was a PhD student at the same university when he passed on.

Business: Ogundoyin resigned his appointment at Steyr, where he rose to managerial level, to venture out in business on his own. At the height of his business success, he had close to 100 expatriates working in his companies.

Farming: He had a 4000-acre oil palm farmland.

Politics: As a councillor in 1974, he donated his entire salary to the Sickle Cell Unit at UCH, Ibadan. As business success rolled in, he sponsored candidates for electoral positions. He was friendly with the top brass of the Nigerian military, including Heads of State. Ogundoyin's son, Debo, 37, is currently Chairman of the Conference of Speakers of State Legislatures of Nigeria.

Philanthropy: Ogundoyin heaped cash gifts on individuals, organizations and causes. He gave huge sums to LAUTECH, Ibadan Polytechnic and what later became Adeseun Ogundoyin Polytechnic, Eruwa. His close friends and associates usually received car gifts.

Every Nigerian who visited London for the first time somehow got wind of where the keys to Ogundoyin's house were kept. Many stayed there until they found their own feet.

'Ogundoyin became as extremely wealthy as he was extremely poor,' Mrs. Gbolagunte, his Headmistress in primary school, once commented.

Women: Women are attracted to money, power, and influence, all of which Chief Ogundoyin had in excess. After his first legal wife, he married three more.

Leisure: A keen sportsman, Ogundoyin founded the Femo Football Fans' Club, which was once on the Nigerian Football League. He also built a stadium, which he later donated to the Oyo State Government.

Ogundoyin was a man to whom wealth meant nothing if not shared.

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SYMPTOMATIC - LIFE OF A SICKLE CELL TRAIT CARRIER

An Invisible Disability - My Story

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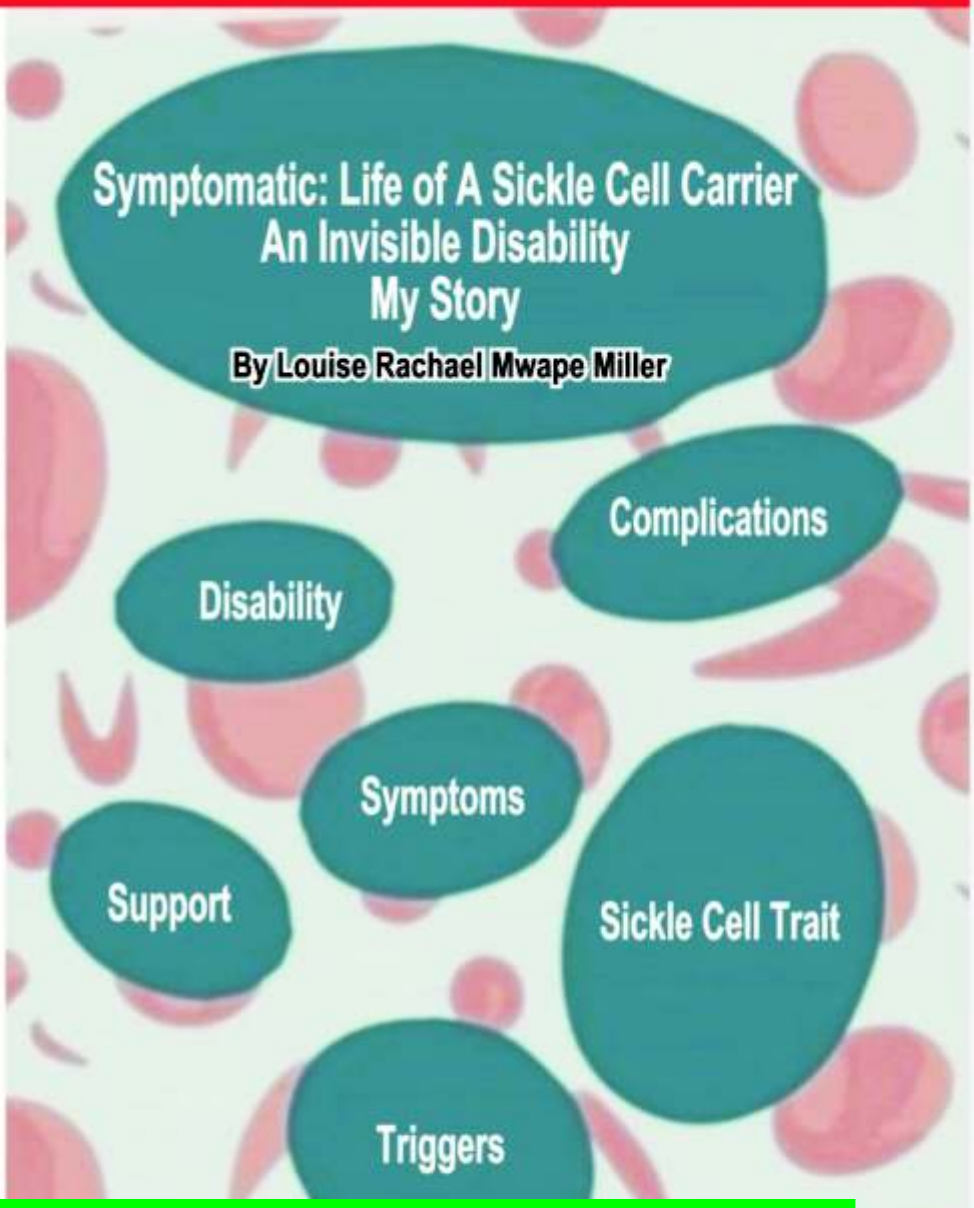
This book provides an intimate, never before disclosed experience with the author, who has been symptomatic all her life.

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 of such gross ignorance



https://www.amazon.com/Symptomatic-Sickle-Carrier-Invisible-Disability/dp/1914442075

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