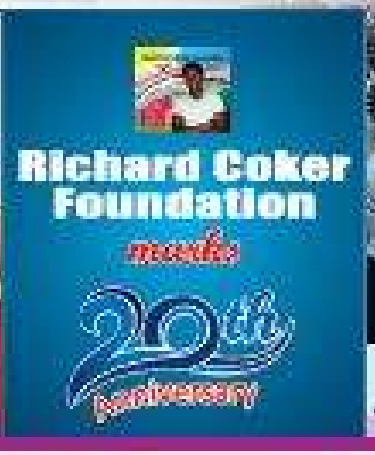
April - June 2024 ISSN 2141-1093 Vol17 no2 N1500 GHC 20 $7 €4.5 £5

SICKLE CELL

NEWS & WORLD REPORT

www.sicklecellnews.com

TunMicro Sickle Cell Foundation along with the National Association of Seadogs and Abeokuta Descendant Union (ADUN) conducts Genotype sensitization at Rev. Kuti Memorial Gram School, Abeokuta, Nigeria



Symptomatic:
Life of a Sickle Cell Carrier, An Invisible Disability

Louise Rachael Mwape Miller

available on amazon & other online bookshops


HAPPY DIAMOND JUBILEE
to a Sickle Cell Warrior, Champion & Conqueror
60th
Birthday
MRS.
MODUPE
OLOKUN
Live long in divine favour and sound health!!!
24th
April
2024

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UK-based **TunMicro Sickle Cell Foundation** (TMSCF) collaborates with **Abeokuta Descendant Union** (ADUN, UK Branch) and **National Association of Seadogs** (NAS/'Pyrates Confraternity') to *catch 'em young* with SCT awareness plus free genotype verification @ **Rev Kuti Memorial Gram School, Abeokuta, Ogun State, Nigeria ...**

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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

AFRICAN SICKLE CELL NEWS & WORLD REPORT is published quarterly by SCELL MEDIA, c/o Trade Trends, 4, Ogunlana Drive, Surulere, Lagos State, Nigeria, West Africa. Email: scdjournal@yahoo.com. Tel. Nos: +2348182721386, +2348170234595, +2348033980521
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'I told my fiancé: Go learn more about SCD, see if you can cope!'

Modupe Olokun

My parents got to know of my special health condition when I was about two years old. Being university lecturers, they sought for help from far and wide. In the 1960s, when there was limited knowledge about sickle cell anaemia, raising a special child was very challenging for them.

Cognizant of my SS genotype, I knew I had to look for a spouse with AA. When I met my future husband, I told him I had sickle cell anaemia. I advised him to go and do research on the subject to know what he was getting into; and determine if he was prepared to travel that road.

Strong psycho-social support is vital in SCD care. A person with sickle cell anaemia needs all the love and support they can get from family, friends, and the community. There is no shame in having sickle cell: it is inherited and no fault of the warrior. Children with the disease need a lot of sensitization and information so that they can carry themselves with confidence.

There should be awareness in the health sector as to the need for the emergency care of acute sickle cell pain episodes. A warrior having crisis should not have to queue to see the doctor. They should be attended to promptly in the emergency unit. Governments and governmental agencies need to provide free medical services for SCD or significantly subsidize our expenses.

Mrs. Olokun is an Advisor with the Indiana Association for the Education of Young Children (INAEYC) Indiana, USA.

Full version of Foreword on PAGE 18

On Nigeria's Sickle Cell Trait Ignorance Conundrum

Ayoola Olajide

From adolescence I had been fascinated about the twin mutated gene that dictated my diagnoses with SS, so long ago, at Massey Street Children's Hospital, Lagos.

In 1987, as part of an academic research, I was confronted with the stark realities of Sickle Cell Trait in Nigeria. The figures for SCT prevalence then remains practically unchanged today: a staggering 25 to 33%.

Tens of millions of Nigerians harbour SCT, the overwhelming majority crassly unaware. This is largely because SCT has virtually no symptoms to alert the carrier. I imagine that more than 90% of parents giving birth to SS children in Nigeria were unaware of their status (just a conjecture, so please don't quote me!).

Without a clear and comprehensive policy to reach out to youths, wherever they dwell, with the SCT message, we are only scratching the surface of drastically reducing the incidence of SCD births. Science can't eliminate SCD as it did smallpox!

Kudos to all organizations reaching out to secondary schools in rural and urban areas, helping to verify genotype and teaching of the implications of SCT. Government should at least empower these organizations doing their best with very limited resources.

Ayoola Olajide

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

scdjournal@yahoo.com

RE: Letter To The Red Cross In Nigeria

I read the editor's *Letter to the Red Cross in Nigeria.* I can testify to the effectiveness of *sorghum bicolor* in the improvement of PCV level. In my nearly six decades living with sickle cell anaemia, this herb is one whose efficacy I know firsthand. The notion that there are no local remedies for SCD has been implanted into our subconscious so much so that if you mention 'herb' within some SCD circles you are likely to be castigated.

There seems to be a well-orchestrated misinformation about plant medicine in the treatment and management of SCD. We have fallen victim of this manipulation, which makes us believe that only orthodox medicines are good for managing SCD.

The earlier health management authorities give deserved recognition to local herbs in the management of SCD - and indeed other ailments - the better for us, considering the current cost of the orthodox medicines.

Mallam Shehu Olaitan Mohammed (FCA),
FCT, Abuja, Nigeria

Miss Africaine Culture Top Model (MACTM) 2023

I salute Mme Viviane Pounguy Tsimba and her associates for organizing the MACTM pageant to promote African culture to Africa and to the world. More remarkable is the fact that a Sickle Cell Warrior was elected winner of the latest (2023) edition of the pageant.

This demonstrates what a lot of people have often commented upon: that women with SCD are often beautiful and intelligent in and out. Queen Kamanga Ntambe exemplifies this.

I suggest you shift the venue from one African country to another to make this a truly pan-African pageant.

Silas Ntangama,
Cape Town, RSA

SCD No Laughing Matter

It was not funny late in 2023, when I watched a skit in which an African-American repudiated a cure for SCD in favour of a doll!

Admittedly it was only a joke but even a joke can be carried to too far. SCD may be classified as a 'rare disease' in the USA but it is rampant in many parts of West Africa. Even in America, how would anyone with this painful condition repudiate a permanent reprieve in favour of fleeting pleasure from a toy?!

Skit makers ought to be more sensitive to the feelings of their audiences.

Mahmoud Sheriff
Bronx, NY, USA

New Cures For SCD

Kudos to medical science for the vigorous march towards a cure for SCD and other inheritable blood diseases. Although at the present time, most of these cures, including effective medications are too expensive for the average family challenged by SCD, it is expected that with the passage of time - and advancements in research - costs will go down.

For the time being, an unaffordable treatment/cure is practically worthless. Governments and scientists must work harder to make these treatments not only available but affordable as well.

Nofisat Alumona

Sickle Cell Disease Association of America Names New Board Members, Promotes Kevin Amado Jr.

The Sickle Cell Disease Association of America Inc., a national nonprofit membership organization that advocates for people affected by sickle cell disease named Katherine Napier, EDB, and Kenneth Thorpe, Ph.D., to its board of directors.

Katherine Napier, EDB, brings over 31 years of experience overseeing financial and business operations. She serves as senior vice president for finance and chief financial officer for Morehouse School of Medicine. Her experience in higher education includes roles as associate vice president of business operations at Kentucky State University, director of internal audit at the University of the Pacific and associate director of audit services at Case Western Reserve University. She received an executive doctorate in business administration from Georgia State University, an MBA from Case Western Reserve University and a bachelor's degree in business administration from Baldwin Wallace College.

Kenneth Thorpe, Ph.D., is a professor and was the chair of the Department of Health Policy and Management in the Rollins School of Public Health of Emory University for over 20 years. He serves as the executive director of Emory's Institute of Advanced Policy Solutions and director of the institute's Center for Entitlement Reform. Additionally, Thorpe is chairman of Partnership to Fight Chronic Disease, an international coalition of over 80 groups focused on highlighting the key role that chronic disease plays in health care spending and high rates of morbidity and mortality. He serves as co-chair of the Partnership for the Future of Medicare. Thorpe received his doctorate from the Pardee Rand Graduate School and his master's degree from Duke University.

... Promotes Kevin Amado Jr.

The SCDAA has promoted Kevin Amado Jr. to senior community impact and education manager. Amado joined the association in 2020 and brings 20 years of experience as a health educator, case manager, community health worker and certified health insurance navigator.

As senior community impact and education manager, Amado

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I Participated in The Lagos City Marathon!

By Ayoola Olajide

I was footsore when I got to the Lekki, Victoria Island, Lagos Starting Point of the Lagos City/Access Bank 10km Marathon. I had trekked all the way from CMS, as the transportation authorities had proscribed movement on that axis.

Thousands of fellow participants were just setting forth. Could they all have trekked to the venue as I did? It was obvious I had missed vital information about getting there. So had Sylvia Roli, who had to hitchhike on courier motorbikes and vans to get there.

Sylvia and I became fast friends. We stayed close together for the next four hours, fellow travellers on that Saturday morning when Victoria Island fell silent for the marathon.

It was supposed to be a run, but we walked, Sylvia and I, as did many others, old and young.. I could not run or even walk at a fast pace without getting fast out of breath, but I could walk at an even pace for hours without any issues.

Sylvia was an experienced runner. At the 2023 Women's Marathon in Lagos, she was among the top 100 to get to the Finishing Line. She even received a medal for that feat.

This time, partly for my sake, she opted to trek. With 10 kilometres ahead of us, we chatted. Sylvia asked about my experience in this sort of thing. I informed her I was taking part in a marathon for the first time, encouraged by fellow sickle cell warriors who were also participating.

At the mention of sickle cell, Sylvia looked more closely at me; and recalled her family's duel with the condition.

'I had two cousins with sickle cell anaemia,' she said.

I was not surprised at the revelation. Practically every Nigerian I have met knows/knew someone with the SCD phenomenon. My companion witnessed many unforgettable episodes of acute, debilitating pain crises.

The streets were devoid of vehicular traffic, save for the few ambulances and other vehicles purposed for the event. Pedestrians and idle youths cheered us on.

We were just turning off Ozumba Mbadiwe Street towards 1004 Estate when a placard tied to a pole displayed *5 KILOMETRES TO GO.* My heart sank.

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GANSID Appoints October Hereditary Blood Disorders (HBDs) Awareness Month

... Oct 18 is Hereditary Blood Disorders (HBDs) Awareness Day

The Global Action Network For Sickle Cell and Other Inherited Blood Disorders (GANSID) has designated October of every year HBDs Awareness Month and October 18 specifically as HBDs Awareness Day.

That day and month have been appointed to shine the light on and celebrate HBDs globally.

'This is truly exciting and the GANSID looks forward to the HBDs community collectively raising the profile of the many diseases under the HBDs banner,' says CEO, Lanre Tunji-Ajayi, M.S.M.

GANSID utilizes a regional network model to advance its global activities. Through these networks, GANSID will provide platforms for sharing, networking, and collaboration that will enable the advancement of public policy priorities through coordinated advocacy. It will also empower the patient organizations through training, capacity building, and mentorship.

Each region is led by a regional lead responsible for identifying regional priorities and elevating same to leadership and advancing the execution of programming at the regional level.

GANSID's eight regions are African Region (AFR), Americas-North, Americas-Central and South, and Caribbean. Others are South-East Asian Region (SEAR), European Region (EUR), Eastern Mediterranean Region (EMR) and Western Pacific Region (WPR).

The organization has a physician-physician mentorship programme in which experienced physicians in various fields help their junior colleagues to hone their skills. This programme is available to interested doctors irrespective of geographical location. All it requires is to fill a form online indicating speciality of interest.

In the area of hematology, GANSID seeks mentors to support it's objective of building capacity among hereditary blood disorders (HBD) physicians.

Designating a 'Day' for HBDs, will help to focus global attention on these health conditions for the purpose of awareness, prevention, timely treatment and management.

... the GANSID looks forward to the HBDs community collectively raising the profile of the many diseases under the HBDs banner,' says CEO, Lanre Tunji-Ajayi, M.S.M.

JOBELYN:

PALPABLE RELIEF AFTER 9 YEARS OF SUFFERING!

*As related to **Ayoola Olajide**, Sickle Cell News Editor,*
*by Nkeirukanma Umeakuekwe***, Port Harcourt, Nigeria*

Surviving a chronic health condition is one thing; having a good quality of life is another matter entirely.

Sickle Cell Warrior Nkeirukanma Umeakuekwe marked her 50th birthday in December 2022. A single mom with a 28-year-old son, SCD prevented her from pursuing her dream of becoming an actuary.

Despite being a Masters degree holder in Statistics, and an MBA in Information Technology, Nkeiru worked various odd jobs including baby-sitting, teaching assistantship, stenographer, petty trader and master of ceremonies at festive occasions.

Not all employers are mean but there is a limit to corporate endurance. Nkeiru's only lucrative employment was 18 years ago at a first generation Nigerian bank. Tolerantly, her direct boss looked the other way whenever she was ill and could not report at the office, sometimes for months at a stretch. There were also countless days of reporting at work but closing early to 'repair home to rest'.

When she needed to go to India to undergo bilateral hip joint replacement surgery in 2004, the bank assisted with 55% of the cost. She also continued to draw her full monthly salary.

Shortly after her return to Nigeria, the bank gave her a handsome severance package, which she did not want, because she knew the implications. But the bank had been very good to her, so she declined the advice to sue proffered by a friend.

Back home to recuperate - she had this constant refrain in her head of being a perpetual convalescent - the money quickly dwindled until she was penniless.

Back Problems

Since 2013, Nkeiru has had unrelenting pains in her spine. The orthopedists and neurologists she consulted diagnosed *spondylosis*. They told her surgery was inevitable. Medications and physiotherapy recommended to stave off the evil day did not provide much relief.

'I bought and administered every supplement touted to improve my health,' Nkeiru told *Sickle Cell News* in an unscheduled interview March 2023.

'Over the years I must have spent more than one million naira - money earned from the bank and a plethora of odd jobs - buying this supplement and saving up for that one, hopeful that one of them would be the Holy Grail for my failing health.

'Despite spending so much, there was no real improvement in my health. I began to resign to a life of reclusive ill-health.'

For two years non-stop Nkeiru took *tramadol* - risking addiction - to cope with the horrible back pains. The Exchange Blood Transfusion the doctors recommended - which she undertook for three years - scarcely helped.

Imagine that throughout a waking day you could not sit or stand for more than 10 minutes. That was the life that Nkeiru lived for 10 years. Because of this sensitivity to standing or sitting without pain, there was little she

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KATHY LIFE BUILDER FOUNDATION

Kathy Life Builder Foundation's slogan, *Save The Next Generation - Suffer Not The Innocent* captures the vision of Executive Director and CEO, Mrs. Catherine Ocholi. Mrs. Ocholi is a Guidance Counsellor and Certified Genetic Counsellor. Headquartered in Jos, Plateau State, Nigeria, the KLBF's SCD awareness outreaches cover what is known as Nigeria's Middle Belt. The pictures depict its most recent outreach at Shendam General Hospital, Jos, Nigeria.

KLBF also advocates for single mothers and offers assistance at orphanages. We need ongoing support to achieve our objectives.

Kathy Life Builder Foundation

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FASTING: Should The Child Sickle Cell Warrior Fast?

Injunctions for fasting at Lent, Ramadan or any other occasion for children/adults with an underlying health condition

By 'Amazing Amazon', Marian V. Lawal, PhD
Dept of Pharmacy, University College Hospital, Ibadan, Nigeria

Parents of sickle cell warriors are sometimes at loggerheads with their children who insist on fasting despite the health risks. Children typically want to follow what they regard as the norm. When they see every other person around them fasting, many feel left out when asked not to follow suit.

What parents can do in this situation is to allow them some 'timed fasting'. Maybe they are able to fast between *sahoor* to 12noon, 2pm or 4pm depending on age and capability. Reward them for this too. This may also test their stamina. As they grow older, they will decide whether they are able to keep the fast or not.

The effect of fasting can be more pronounced in children than adults. It is on record that different warriors have different capacity to withstand the fast. Some do well, while others end up harming practically themselves.

A lot of factors come into play here. Every warrior should critically appraise whether they are doing themselves any good by fasting. Remember, you are

your first doctor.

Warriors who intend to fast should:

- Undergo routine health checks prior to Ramadan, Lent or other fasting occasion to ensure fitness for the exercise;
- Appraise their health and fitness every day before the commencement of each day's fast.
- For Muslims, take a well nourished *sahoor* meal, followed with a generous amount of water. Note the emphasis should be on *quality* of the food, not quantity.
- Ensure to take your regular medication in the morning before commencement of the fast.
- Not engage in any physically-draining activities during fasting hours. You should, however, try to be active, but with non energy-draining activities. If you work in an establishment, you may choose to take your vacation leave during Ramadan/Lent to ease the process.
- Take note of other health conditions they have apart from SCD. It is essential you have a medical clearance from your doctor before you decide to fast. If fasting affects the timing of your medication, see your doctor. Do not stop taking your medication for the sake of fasting.
- Again for Muslims, at *iftar* time (break of fast), take enough fruits and vegetables; then eat another nourishing but modest meal.

Drink a plenty of water at regular intervals through the night to stay hydrated.

NIGERIA: Anambra Police Commissioner Advocates Better Life For People With SCD

By Edozie Maduagwu

Nigeria's Anambra State Commissioner of Police, CP Aderemi Adeoye, has called on the society to provide support towards ameliorating the plight of vulnerable sickle cell children.

CP Aderemi made the call in his office when a delegation from the Sickle Cell Orphanage and Underprivileged Home, Agulu, paid him a courtesy visit to seek his assistance in the fight against sickle cell disorder.

The CP who warmly received the children and their coordinator, Mrs. Aisha Edward Maduagwu, said that the police owe humanity the duty to provide comfort and solace towards underprivileged and vulnerable persons.

'Society owes a duty of care to the underprivileged, and if that responsibility is abdicated, society would have failed.'

CP Aderemi Adeoye urged persons living with SCD to remain positive and steadfast amidst their health challenges.

The Commissioner of police commended the efforts of the National Coordinator of the Association of People Living with Sickle Cell Disorder, and her team for dedicating their lives to the good of others.

In her speech, Mrs. Aisha Edward Maduagwu, said she was in the State Command to seek a working synergy on sickle cell eradication/control. She expressed her profound gratitude for the warm reception accorded to her, and praised the officers and men of Anambra State Police Command for the good work they are doing in providing security to lives and properties.

'Our organization, the Association of People Living with Sickle Cell Disorder (APLSCD) is desirous to sensitize every policeman and woman on sickle cell and genotype,' Mrs Aisha stated.

Recall that APLSCD is on the forefront of genotype education across security formations in Anambra State and Southeast Nigeria in general. The organization previously visited the State Command of the Department of State Service (DSS).

Sickle cell disorder has no place in Anambra State, and the goal of APLSCD is to take this gospel of a free sickle cell society to every man and woman in the State.

Maduagwu is Head, APLSCD Media, Strategic Communications Dept, Association of People Living With Sickle Cell Disorder (APLSCD), Awka, Anambra State, Nigeria

Researcher Receives Prestigious Prize in Health Services Research

*The award presented by the Canadian Institutes of Health Research (CIHR) recognizes Stinson's innovative mobile app **iCanCope** which supports young people living with Sickle Cell Disease*

- eurekalert.org Picture: University of Toronto

Jennifer Stinson, a renowned researcher in the field of chronic pain management in children, has received the 2023 Barer-Flood Prize from the Canadian Institutes of Health Research (CIHR).

Dr. Stinson, a Professor at the Lawrence Bloomberg Faculty of Nursing, Institute of Health Policy, Management and Evaluation, and Temerty Department of Anesthesiology & Pain Medicine, is being acknowledged for her innovative work behind the development of *iCanCope*, a mobile app designed for young people who live with Sickle Cell Disease (SCD) to help them self-manage their chronic pain.

'The app is intended to be an adjunct to the care that young people with SCD receive in hospital. We know we cannot cure or alleviate the pain, but we can empower young people to live well with pain, and to manage it with resources and strategies that are effective, building their confidence in leading a fulfilling life,' says Stinson, who also holds the Mary Jo Haddad Nursing Chair in Child Health and is a Senior Scientist in the Child Health Evaluative Sciences in the Research Institute at SickKids.

The *iCanCope* app includes four key features, which allows users to track their symptoms, set structured goals to improve their function, access a curated library of evidence-based resources, and participate in a community discussion platform, where they can connect with other young people who live with SCD. The app has been intentionally co-designed with young patients and clinicians to ensure it is meeting the needs of this care population.

Stinson notes that because individuals are born with this disease, they often develop persistent pain over-time.

iCanCope uses its validated clinical algorithm to push strategies and resources to a user if they indicate they are having trouble with an issue related to their pain, or if they are looking to set a goal to improve their wellbeing, such as improving sleep. The resource library is another feature that allows users to not only find education about their pain, but also access youth-friendly materials that address mental health, anxiety, and topics related to their transition to adult care.

'These kids will become young adults with persistent pain, and with *iCanCope* we are giving them the tools early in life to be able to manage their pain using appropriate coping techniques and strategies that improve their life satisfaction and well-being,' says Stinson.

'These kids will become young adults with persistent pain, and with iCanCope we are giving them the tools early in life to be able to manage ...'

TIF Marks International Thalassemia Day

As the Thalassemia International Federation (TIF) Marks May 8, ***Nushruth Ebrahim Saib***, 40 shares her story of courage and determination:

When Survival Depends On Blood Transfusions ...

My name is Nushruth Ebrahim Saib. I am 40 years old, and I work as a receptionist/telephone operator in a parastatal organisation in Mauritius. When I was 4 months old, my parents learnt that I had thalassaemia major. Thalassaemia is an inherited (i.e. passed on from parent to child) blood disorder caused by the body not making enough of a protein called haemoglobin, an important component of red blood cells.

No one else in my family had thalassaemia, and my parents did not know that they carried one of the genes that cause the disease. The diagnosis came as a shock to everyone. Since I was first diagnosed as an infant, I was given blood transfusions every four weeks to maintain my level of healthy red blood cells and keep me healthy and alive. Without regular blood transfusions, I feel achy, tired and weak. In fact, my survival depends on these blood transfusions, but that comes with its own challenges:

The main complication associated with blood transfusions is iron overload, which can have a negative impact on several organ systems. Iron overload can lead to heart and liver disease as well as endocrine disorders such as diabetes, low bone mass, etc.

When I was born with thalassaemia, iron chelation therapy did not yet exist; I only started this therapy at the age of 12. For almost 18 years of

Without regular blood transfusions, I feel achy, tired and weak. In fact, my survival depends on these blood transfusions, but that comes with challenges

>>

my life I took a drug called *Desferal,* which had to be administered through a needle into my leg, arm or stomach every night for 12 hours, five nights a week. *Desferal* was used to remove the excess iron that had built up in my body.

This medication was administered via a pump that had to remain strapped to my body. It was uncomfortable and sometimes emotionally difficult because the treatment prevented me from being physically active and doing other things between 7pm and 7am, causing me to miss out on many childhood activities.

Eventually I switched to a newer medication called *Asunra,* which I take in green tea. This greatly improved my quality of life because I no longer had to insert a needle every night and stay hooked up to a pump. Although it was much easier to take *Asunra* by mouth than a *Desferal* injection, I found some aspects of taking it difficult: it had to be taken on an empty stomach, it took time to dissolve in my green tea, and I hate the grainy texture of my green tea after the medication had dissolved. My ferritin level was very high at this point.

Eventually I realized that no one would care about me more than myself, and that without my health I would never be able to pursue my dreams. This realization gave me the push I needed to be consistent with my medication and stick to the treatment plan my doctor had prescribed for me.

- by permission of TIF

MANAGING THALASSEMIA

Thalassemia is a treatable disorder that can be well-managed with blood transfusions and chelation therapy.

Vaccines: Children and adults with thalassemia should get all recommended vaccinations, including a flu vaccination.

Nutrition: Eating nutritious foods is important for everyone to maintain a healthy lifestyle – a diet, high in fruits and vegetables and low in fats is ideal for gaining the essential nutrients our bodies need. For people living with thalassemia, because too much iron may build up in the blood.

Exercise: Exercise is part of an overall healthy lifestyle and helps lead to better health outcomes. Although some people with thalassemia may have trouble participating in vigorous forms of exercise, many people with thalassemia can participate in moderate physical activities including biking, running, and walking

Sickle Cell Kept Me - *and* My Siblings From School!

Her siblings did not have sickle cell anaemia, but when they went to attend to her in hospital, they were captives too!

By Modupe Olokun, Indianapolis, Indiana, USA

My parents received my diagnosis of sickle cell anaemia when I was about two years old. Being university lecturers, they sought help from far and wide for something to relieve me of the burden of the disease.

In the 1960s, when there was limited knowledge about sickle cell anaemia, raising a special child was very challenging for my parents. The frequency of my crisis kept me away from school for weeks on end; and my siblings had to take turns to stay with me in the hospital. So they missed school too!

I had an assigned bed in the children's section of Dala Hospital, Kano because of the frequency of my crisis.

As I got older, my crises became less frequent. I came to understand what works for me, know the trigger signs and understand my limits when it comes to physical exertion. In addition, exposure to extreme weather conditions is a crises-trigger for me.

Cognizant of my SS genotype, I knew I had to look for a spouse with AA. When I met my future husband, I told him I had sickle cell anaemia. I advised him to go and do research on the subject to know what he was getting into; and determine if he was prepared to travel that road.

We have been married for 33 years. We have 3 children.

Strong family support is vital in the care of SCD. A person with sickle cell anaemia needs all the love and support they can get from family, friends, and the community. There is no shame in having sickle cell; it is inherited and therefore no fault of the warrior.

Children with sickle cell need a lot of sensitization and information so that they can carry themselves with confidence.

You are your best doctor, know yourself, know what triggers your crisis, know when your body needs a break, give special attention to your nutrition and hydration, know the medications that work best for you, and always speak up about how you are feeling. It is advisable to use clinics and hospitals that have personnel who are familiar with the treatment of SCD.

I had a bed assigned in Dala Hospital, because of the frequency of my crisis

Mrs. Olokun worked with the National Commission for Colleges of Education (NCCE), and the Pension Transitional Arrangement Directorate (PTAD), Abuja, Nigeria. She currently lives in Indianapolis, Indiana and works as an Advisor with the Indiana Association for the Education of Young Children (INAEYC) Indiana, USA. Mrs. Olokun turned 60 in April 2024.

SCD/SCT Awareness Activists-Advocates, Dr. & Mrs. Olatunji Sule

My Genotype is AC, I Intentionally Went For a Partner with AA!

- Ismaila Olatunji Sule PhD, CEO, TunMicro Sickle Cell Foundation

UK-based Microbiologist Dr. Ismaila Olatunji Sule grew up in a polygamous home in Ibadan, Nigeria, in the early 1970s. He first learnt of his genotype while working as a laboratory technician at the University of Benin, Nigeria. AC. But what did it signify, and what were its implications?

He researched into the implications of his unusual genotype and recalled a sibling whose life was punctuated by frequent illness, pallor, pain, stunted growth and other signs of SCD. The sibling was believed to be under the spell of someone in the close-knit family - an individual who was determined to see her victim go through life miserable!

He had never been ill for a day; but sensitized to the significance of his genotype for the unborn, he deliberately went for a mate with AA.

The Sules have been 31 years now: he was blessed not just with a wife, but with a friend and a passionate Sickle Cell Trait activist to boot. As a phlebotomist, her skills have been pivotal to the genotype awareness vision of TunMicro Sickle Cell Foundation.

Would he have married madam if her genotype was anything but AA? 'No,' he flatly replied.

They began having children while he was a student-worker at the University of Benin Teaching Hospital (UBTH). Four boys in all, all with Hb AC, as though they sourced their genotype exclusively from their disciplinarian dad!

Students of Mafoluku Senior Grammar School received awareness talk on Genotype

TunMicro Sickle Cell Foundation Conducts Free Genotype Screening and Sensitization at Secondary Schools in Nigeria

By Tosin Fawemida and Ayoola Olajide

Thousands of students at two secondary schools in Lagos and Ogun State, Nigeria in March 2024 got the rare privilege of free genotype verification as well as sensitization in their respective domains.

Nigeria's public primary and secondary schools are notorious for making light of the issue of genotype as part of the information required on admission. Yet these are the schools from which the majority of students of higher institutions spring from. In some private schools, a student's genotype constitutes part of the information on their dossiers.

In many instances, public school students are from the lower socio-economic groups, for whom genotype verification is considered a luxury. Cognizant of the need to democratize SCD/SCT awareness, TunMicro Sickle Cell Foundation, in collaboration with the Abeokuta Descendant Union (ADUN), UK Branch and the National Association of Seadogs, Zero Meridian Deck, UK joined hands to provide free SCT screening at the renowned Rev Kuti Memorial Grammar School (Junior/Senior), Abeokuta. The exercise started on Monday March 4 and ended Friday March 8.

The following week, the TunMicro team was at Mafoluku Senior Grammar School to sensitize the students about the imperatives of genotype. Dr. Olatunji Sule, TunMicro's CEO, promised to conduct free genotype screening at the school just as TMSCF did in Abeokuta as soon as arrangements were concluded.

Abeokuta Descendant Union (ADUN), UK Throws Hat SCD/SCT Awareness Ring

Executives and members of Abeokuta Descendant Union (ADUN), UK Branch made it a point of duty to present themselves at the School Hall of Rev Kuti Memorial Grammar School, Isabo, Abeokuta for the students' genotype screening exercise. After all, it was their own turf and the students, their children, figuratively speaking. In addition, they were co-sponsors, co-financiers of the exercise, with a look to the future, for the reduction, if not eradication, of a painful, but highly avoidable, health condition.

Donning their custom Tshirts and caps, they plied the genotype-screening crew with cold drinks and snacks to counteract the tedium of high temperatures.

Some members of ADUN were also old students of the institution named after the gentleman father of the rambunctious Fela Anikulapo-Kuti. They helped maintain discipline among unruly students. Generally, the students were well-behaved and orderly. Bad eggs are inevitable among a student population running into thousands.

As the 5-day event winded to a conclusion, members of ADUN, used to such practices in the UK, got a weekend of respite celebrating Lisabi Day.

Lisabi Day is a popular yearly cultural event that attracts Abeokuta indigenes and other Nigerians from around the world. According to history, the Day marks the exploits of Lisabi, the heroic war tactician who helped free the Egba people from the tyranny of the Oyo Kindgom in those days when intertribal rivalry and wars were rampant in Yorubaland.

NAS Participates in Free Genotype Screening Exercise For Students in Abeokuta

By Fatima Garba Mohammed with reportage by Ayoola Olajide

Similarly with ADUN members and officers, the National Association of Seadogs (NAS) participated actively in the genotype screening and awareness programme at Rev Kuti Memorial Grammar School. Dr. Afolabi Sorunmu and his team members took time off their official duties to help with ensuring a smooth Hb verification process.

In a TV interview, Dr. Sorunmu described NAS as a socially-responsible organization doing all manner of charitable work for ordinary persons and the needy. He acknowledged that many citizens still consider NAS a cult - with all the negative associations of the word - whereas the organization was an open and transparent one striving to contribute its quota to the achievement of a just and progressive society.

More popularly known as Pyrates Confraternity, the NAS was founded by Nobel Laureate Wole Soyinka and six colleagues while they were undergraduates at the University of Ibadan in 1952. The organization, much-misrepresented, much-maligned, much-persecuted in its country of origin has chapters around the world. It also has many arms through which it channels assistance to the poor and underprivileged.

The co-founders of NAS were Ralph Opara, Pius Oleghe, Ikpehare Aig-Imoukhuede, Nathaniel Oyelola, Olumuyiwa Awe and Sylvanus Egbuche.

'I Put My Health First and Migrated To A Tropical Climate'

Same notes, different rhythm. Lots of families have moved from warm climates to the extreme cold of Europe and North America to give their children with SCD a 'better life'.

For Sickle Cell Warrior Jenica Leah, an award-winning author with specialty in rolling out series of books on SCD for children, it was a movement from 'better life' in England to the best life in the Caribbean. Jenica tells Sickle Cell News why she moved to Jamaica.

For how long have you been thinking of leaving England to settle elsewhere?

I've always known that I would eventually leave England. I had 2024 as my deadline to make this transition. My first thought was to settle in The Gambia after spending a bit of time there. But then, after a trip to Jamaica to visit my grandmother, I got stranded due to the COVID-19 lockdown; it felt like a sign as the longer I spent there, the more I noticed a positive influence on my health.

Were your doctors involved in this decision - what was the medical opinion?

My plans to leave England were always purely health-related. England is cold, damp and grey, which was neither helpful for my sickle cell nor for my mental and emotional well-being. It *is* a fact that warmer climates promote good health, which was something I believed I deserved.

When I took the trip to Jamaica to visit my grandmother, I was medically-advised not to travel due to the pandemic and my poor state of health (at the time). My physical health had deteriorated so much during this period. My mental health was at rock bottom.

I was willing to take the risk and go against medical advice - I felt that I had nothing to lose.

Did anyone try to dissuade you from relocating - what were their reasons?

As difficult as it was, family members and friends supported my decision. In that aspect, I count myself lucky. On the other hand, my health team were not so supportive. I practically made my own decision to 'flee' England.

How has life been in Jamaica?

Life in Jamaica has been far better than I expected it to be. The only challenge I've had is missing my loved ones in England as well as special moments that I would normally have been a part of. I had to make the sacrifice and put my health first. Mind you, I would do that time and time again to not experience what I did in England.

Apart from changing location, did you also have to modify other things - diet, daily routines, lifestyle?

Due to being in a warmer climate I definitely had to drink more water, however due to the local produce available it was inevitable that the dietary change could only be positive.

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Jenica Moves to Jamaica

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You are in your early 30s - any plans to marry any time soon? Will genotype be an issue in your choice of a life partner?

Sickle cell is a serious and life threatening condition. Having firsthand experience of this disorder, finding someone who does not carry the gene will be pivotal in my decision to marry and start a family.

How long did it take to heal from your longest relationship yet - a seven-year long romance that ended due to the fact that you live with sickle cell anaemia?

I don't believe in dwelling on situations or painting everyone with the same brush; every life experience is a lesson. I appreciate all of my life's experiences.

Part of my healing, moving forward from a long term relationship, was recognizing what was *and* what was not beneficial to me.

Has moving to another climate afforded you more (or less?) opportunity to pursue your writing career/advocacy?

I've definitely missed out on a lot of opportunities in the UK, as more people became aware of my advocacy work after I had left. However, I have now set up a charity in Jamaica and plan to expand my advocacy work outside the UK and across the Caribbean.

'... finding someone who does not carry the gene will be pivotal in my decision to marry and start a family'

SCDAA Elevates Staff Member

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develops and implements community health worker training programs and identifies community resources for health workers, organizations and members of the sickle cell community. In addition, he coordinates SCDAA's programs and efforts in communities nationwide.

Prior to joining the SCDAA, Amado served as a case manager for Health Care Access Maryland's Certified Navigator Connector Program. He was a community health worker with Healthy Howard and a senior health education specialist with the Virginia Department of Health.

Amado holds a Master of Public Administration from the University of Baltimore and a Bachelor of Science in community health education from Morgan State University.

Doctors told her surgery was inevitable. Medications recommended to stave off the evil day did not provide much relief

Jobelyn ...
Health Forever Product Ltd

Nkeiru, 'Madam Lying Down'

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could do for herself independently. Holding down a job was a dream of ages past.

Thus she had to lie down most of the time to the extent that, to squeeze a little fun out of an odyssey, the family nicknamed her MADAM LYING DOWN!!!

Jobelyn Administration

Nkeiru took her first capsule of *Jobelyn* early February 2023. She noticed within a few days that she could sit for more time without pain. After a few more days, she timed herself and noticed she could sit up for *five hours painlessly*.

The swift improvement in my spine issue is nothing short of a miracle!' Nkeiru says.

Nkeiru now tells every SCD warrior in her circles about the miracle dietary supplement long known in Western Nigeria as a potential 'cure-all'. She has also recommended it to relations, some of them with arthritis. The feedbacks she received from them have been 'very very encouraging'.

She broached the subject of *Jobelyn* to some of her friends in the medical professions. Not surprisingly, skepticism is high, some remarking that anecdotal reports are nowhere of value in science. In so far as they had not been taught in their orthodox curricula that an alternative approach to anything can be of much value, so shall it always be!

Unknown to them, universities and research institutions around the world have tested and confirmed that the dietary supplement known as *Jobelyn* is indeed effective.

Connect with a community of Jobelyn Users on whatsapp at +234 8189576022

Science & Tech Minister Uche Nnaji

Nigerians Should Stop Depreciating Herbal Medicines

- Prof Barth Emeje

The Director-General of the Nigerian Natural Medicine Development Agency (NNMDA), Prof Barth Emeje, has advised Nigerians to desist from looking down on local (herbal) medicines in favour of imported, foreign-exchange-guzzling formulations.

Emeje, a professor of pharmacy, was speaking at the public presentation of four phytoceuticals developed by the natural medicine parastatal for the management of sickle cell, diabetes, upper respiratory tract infections and an

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UK Gene Therapy: Uncertainty Over Approval of *Exa-cel* (Casgevy) for NHS Funding

... Sickle Cell Society calls for public input

Exa-cel (CASGEVY) is a new gene therapy for sickle cell treatment, and is under consideration by the National Institute for Health and Care Excellence (NICE) for potential funding on the National Health Service (NHS) in England. However, in March 2024, NICE released a draft decision not to recommend *Exa-cel* for NHS funding.

'We were very disappointed to hear this,' says the Sickle Cell Society, the umbrella body for SCD organizations in England. in a statement sent to the SCD community.

However, up until mid April 2024, members were urged to make their views known 'loud and clear' to NICE. A robust response pointing towards support for the inclusion of Exa-cel for NHS funding might just tilt a favourable decision towards that outcome.

The community was urged to impress NICE with the challenges of living with SCD and how needed the therapy is for a functional cure for the inherited blood disorder.

'We are working with the Anthony Nolan Charity to get as many voices in the sickle cell community as possible to be heard by NICE,' the Sickle Cell Society said.

NICE's decision comes from concerns around the cost-effectiveness of *Exa-cel*. They have also said that there is too much uncertainty in the evidence about *Exa-cel* they have received. In particular, NICE are not certain about the severity of sickle cell or the magnitude of the long-term benefits to patients of *Exa-cel*.

The Sickle Cell Society recommended that respondents share with NICE the negative impact that severe sickle cell has on the day to day life of people living with the condition, the worsening impact that sickle cell has over time and the impact of SCD on life expectancy and the risk of mortality.

Below is what a respondent living in England, parent of an adult Sickle Cell Warrior, wrote to *Sickle Cell News*:

When SCD is severe, its impact falls heavily on the individual, their family and friends, the health system and society in general.

The fruits of any drug therapy that has the potential to significantly alleviate the symptoms of SCD will be reaped bountifully directly or indirectly by all stakeholders.

People with SCD should be helped by all means available to medical science to live complications-free; and living long and healthy, to contribute their quota to society.

I strongly encourage NICE to recommend Exa-cel (Casgevy) for NHS funding for the benefit of the SCD community. Though still in its infancy, results from experimental gene therapy for SCD shows great promise. People with SCD - and their loved ones - should not have to face a life of uncertainty, or the fear of worsening symptoms as they grow older.

'People with SCD ... should not have to face a life of uncertainty, or the fear of worsening symptoms as they grow older'

Church Donates $7.35M to the American Red Cross

... gift will assist with blood donor engagement initiatives and support for SCD patients

The Church of Jesus Christ of Latter-day Saints, headquartered in Salt Lake City, USA has made a substantial donation of $7.35 million to the American Red Cross. The gift will help purchase blood equipment and biomedical emergency vehicles and will assist with blood donor engagement initiatives and support for patients with sickle cell disease. Church leaders announced the gift as they renewed their commitment to disaster preparedness and relief efforts by signing a new Memorandum of Understanding with Red Cross leadership.

As a current Mission Leader, the Church is part of an elite group of the most generous Red Cross donors — those giving more than $3 million annually to help alleviate suffering in the face of emergencies.

'It's a special day for us to acknowledge the relationship that The Church of Jesus Christ of Latter-day Saints has with the American Red Cross,' said Bishop W. Christopher Waddell of the Presiding Bishopric. 'We know that because of that collaboration and that teamwork, millions of lives have been blessed in some form or another. I'm sure in the future there will be other opportunities to collaborate to serve together to bless millions of lives.'

For more than 100 years, the Church has partnered with the Red Cross, offering financial support, providing in-kind gifts, recruiting volunteers and hosting blood drives. The partnership — dating back to Red Cross founder Clara Barton and Emmeline B. Wells, president of the Church's Relief Society — grew out of their joint efforts building comfort kits for soldiers and resulted in the formation of the Salt Lake City chapter of the Red Cross.

Today, the Church supports several areas of the Red Cross mission. Over the lifetime of the partnership, they have held nearly 40,000 blood drives and collected almost 1.2 million donations across the U.S. — more than any other partner. The Church also offers support in wake of disasters, helps provide lifesaving vaccines for children around the world and supports Red Cross programs serving the military community.

'We are honored by The Church of Jesus Christ of Latter-day Saints' extraordinary generosity year after year,' said Gail McGovern, president and CEO of the American Red Cross. 'Our partner for more than 100 years, the Church supports all facets of our lifesaving mission and leads the way in helping us provide compassionate care and comfort to those most in need. We are so very grateful to continue working with the Church to be a beacon of hope in times of crisis.'

The Church's gift comes during Red Cross Month, an annual celebration throughout March honoring the community heroes that help the Red Cross deliver its lifesaving mission. The donation and new Memorandum of Understanding strengthen a partnership of compassion in action and highlight a shared commitment to helping those in need.

'LCSCF IS THE FIRST NGO TO REFER TO PERSONS LIVING WITH SICKLE CELL AS 'CHAMPIONS'!'

- Olusegun Olajide, CEO,
Life Champions Sickle Cell Foundation

*Although the term **SICKLER** has largely been flung into the dustbin of history, many people are not exactly comfortable with the most popular replacement trending for the past few years: **WARRIOR.***

*Some have coined new terms for themselves - such terms include **OVERCOMER, CONQUEROR** and the like. Some, like the late film-maker Adewale Fanu (1950 - 2022) insisted on being referred to as a **SICKLER!).***

When the Ibadan, Nigeria-based Sickle Cell Hope Alive Foundation (SCHAF) reignited the debate in April 2024, Sickle Cell News received the article published below by permission of LIFE CHAMPIONS SICKLE CELL FOUNDATION (LCSCF), an SCD advocacy NGO founded in 2012.

People living with sickle cell have recently been referred to as 'Warriors', symbolizing their *ongoing battle* against the symptoms and complications of sickle cell disease. Founded in 2012, Life Champions Sickle Cell Foundation (LCSCF) is the first Non Governmental Organization to address its members as CHAMPIONS, rather than as Warriors.

The term 'Warrior' suggests a continuous battle and an uphill struggle, which, while accurate in many ways, can also be a constant, niggling reminder of the challenges and limitations faced by individuals living with SCD. By contrast, the term 'CHAMPION' connotes strength, resilience, and triumph. It celebrates the individual's ability to overcome obstacles and thrive, rather than just survive, in the face of adversity.

The choice between being called a Warrior or a Champion may seem insignificant to folks outside the global SCD community, but the impact of such language on self-perception and identity can be profound. Being labeled a champion can empower individuals living with SCD to see themselves as more than just fighters, but as winners in their own right. It mirrors their ability to adapt, to conquer, and to thrive despite the challenges they face.

The use of the term 'Champion' also has the potential to shift the narrative around SCD in the

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The term 'Warrior' suggests a continuous battle and an uphill struggle, which, while accurate in many ways, can also be a constant, niggling reminder of the challenges and limitations faced by individuals living with SCD

TAHF: Shouldering The Burdens Of More Warrior Families

16 February 2024

Sickle Cell Warriors from various Sickle Cell Clubs along with their coordinators turned up at Med-In Hospital, Gbagada, Lagos to partake in TAHF's first set of humanitarian projects of the year. Every Warrior went back home with a 'Back-To-School' package comprising beautifully customized backpack, a mathematical set, several exercise books and a pack of ballpoint pens.

The aim of this empowerment, according to Dr. Sola Adebekun, TAHF's Executive Secretary, is to lift some of the financial responsibilities of educating their wards off the shoulders of parents. 1500 school bags were distributed free of cost.

From inception, premarital awareness of genotype has been a cardinal vision of TAHF. The organization launched its *Know Your Genotype* (KYG) programme to underscore its genotype advocacy and sensitization effort. This crucial branch of TAHF advocacy is billed to be carried beyond Lagos to other states in Nigeria, particularly among secondary school students. Machines, reagents and other logistics are being warehoused while personnel for the onerous task of free genotype screening/education for youths nationwide are set to hit the ground.

While TAHF's KYG programme looks to the future, its HFP programme focuses on the here and now. In August 2023, TAHF procured free health insurance cards for 100 indigent SCWs; this time, the organization did five times more, with the support of Access Corporation. The cards cater to the health and hospitalization emergencies peculiar to SCD.

A month later, on March 30, TAHF hosted yet another Back-To-School jamboree with many more school bags and accessories given away. Beneficiaries were from Epe, Abeokuta, Oyo Town, Sango and other towns in Southwest Nigeria and as far afield as Adamawa, Abuja and Jos in Central and Northern Nigeria.

A third Back-To-School event is in the pipeline, to be sponsored as usual by Access Corporation.

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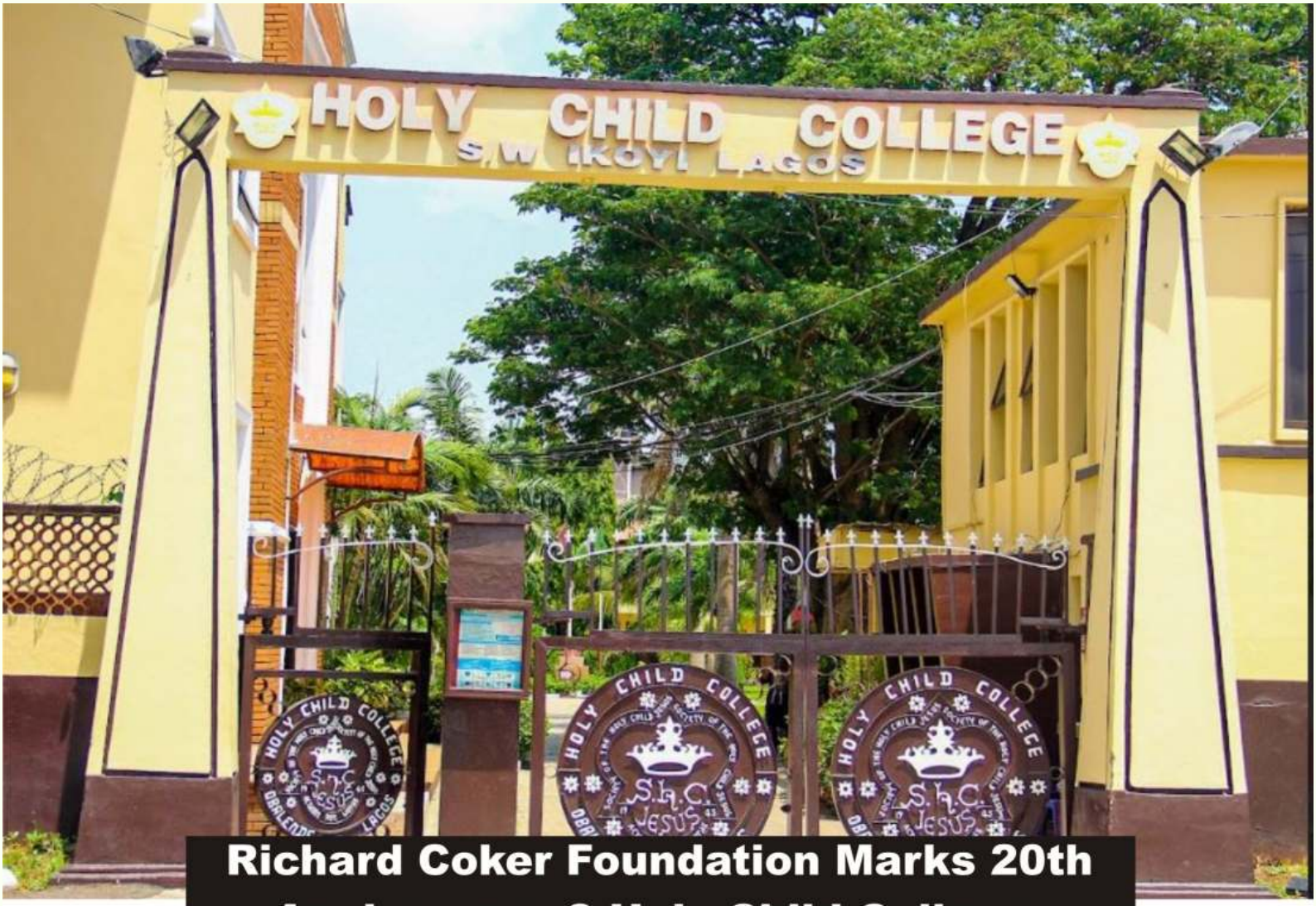

Richard Coker Foundation Marks 20th Anniversary @ Holy Child College, Matriarch's Alma Mater

Ikoyi, Lagos, March 11 2024

Students and staff of Holy Child College (HCC), Ikoyi, Lagos, colleagues, family and friends of Africa's TV Broadcasting icon, Chief Ms Julie Coker gathered at the school hall to celebrate the 20th year since Richard Coker Foundation (RCF) robustly launched into SCD advocacy in the UK and Nigeria.

The event began with Setemi and Semilaanu Adumate, 4 and 7 years old respectively, regaling the audience with a special song, whose theme was Genotype.

'Do you know your Genotype?' the children quipped on and on, emphasizing the importance of that construct in marriage. The college's Drama Club later followed up with a presentation along the same lines.

Similarly, an essay competition on the subject of Genotype had earlier been arranged and assessed by the teachers: the best among the essays were read to the audience, the writers receiving a plaque and cash gifts.

Chief Julie Coker displayed an amazing sharp memory and mental alertness. She was admitted to the school in 1954, six years before Nigeria gained independence and three years before she was crowned Miss Western Region. Along with the students, she sang the school anthem as though she was their schoolmate, which she was, anyway, by a margin of seven decades!

RCF was established in 2004 to keep in memory the life, times and ideals of Richard Coker-Enahoro. His father, Richard Enahoro, just like his mom, Julie, was a pioneer of TV broadcasting in Nigeria. The younger Richard was diagnosed with sickle cell anaemia as a child, and found with leukemia in his late 20s. A talented film maker, Richard passed away in 2002, aged 33.

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Crucial Issues For Girls & Women With SCD

- SCD Coalition, sickle-cell.com/women

Sickle Cell can cause unique problems in women. Along with the major complications of SCD, women may also have delayed puberty and more pain crises during their period. SCD can also cause problems getting pregnant, pain during sex, and complications during pregnancy.

SCD & Puberty

Girls who have sickle cell anaemia (HbSS) may get their period about two years later than girls who do not have SCD. Milder types of SCD, such as HbSC, may only cause a 6-month delay.

Also, girls with HbSS or HbS beta zero thalassemia usually weigh less and are less sexually mature than girls with HbSC or HbS beta plus thalassemia.

Are periods affected?

Many women with SCD experience more pain crises just before and during their period. The frequency of pain crises is also higher during reproductive age.

Heavy menstrual bleeding in women with SCD can lead to iron deficiency anaemia. Doctors may prescribe birth control or hormone injections to reduce heavy bleeding or pain during menstruation. However, some birth control pills increase the risk of stroke for women with SCD.

SCD & Sexual health

Women with sickle cell are more likely to experience pain during sex (dyspareunia). Pain during sex is more common for women who have a history of chronic pain or who experience more frequent pain crises. It may be caused by pain drugs that affect hormone levels. Pain during sex can affect women's:

✓Body image
✓Personal relationships
✓Physical exercise
✓Sexual activity

Women with SCD can use normal birth control methods. Many doctors do not recommend combination hormonal birth control because it increases the risk of blood clots and stroke. Some women with SCD also report that pain crises happen more often with combination hormonal birth control. Birth control that uses only one type of hormone, like progesterone, may lower risk and control pain.

SCD & Pregnancy

Complications from SCD may make it more difficult to get pregnant. Some common treatments for SCD and pain medicines may also affect fertility. This includes hydroxyurea, blood transfusions, and opioids.

If you have SCD and want to have a child, talk to your doctor about how to prepare.

Prenatal care

Your doctor may try to increase your care before pregnancy to reduce complications during the pregnancy. They may advise you to:

✓Stop taking hydroxyurea months before trying to get pregnant
✓Stop taking some other medications
✓Get vaccinations and vaccine boosters
✓Get screened for pulmonary hypertension, liver and kidney function, or iron overload.

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'TAHF is determined to positively impact the lives of Sickle Cell Warriors'

Conversation With Executive Secretary Dr. Sola Adebekun

A graduate of the University of Lagos, Dr. Sola Adebekun is an experienced administrator, astute corporate governance executive, chartered human resources professional, hospital management consultant and public health specialist. He joined Med-In Specialist Hospital in 2019. As TAHF's Chief Operating Officer, Dr. Adebekun has worked tirelessly to help achieve the objective of brightening the lives of individuals and families facing the sickle cell challenge.

What are TAHF's objectives in establishing the Back-to-School Project?

The objective is to assist families with some practical school needs. When parents find a little burden lifted off their shoulders, they are challenged to squarely face the remaining responsibilities. As for the students, when you have a beautiful bag to flaunt to your mates, there's an added incentive to go to school!

What's the HFP 500 all about?

TAHF did this so that no Sickle Cell Warrior will avoid accessing comprehensive health services simply because they have no money.

How about the KYG - Know Your Genotype challenge?

We discovered that many parents become aware of their genotype *not before but after* the diagnosis of an offspring with sickle cell, a clear case of the cart pulling the horse! Similarly, the majority of our youths of marriageable age are ignorant of their genotype and its implications. Genotype sensitivity is crucial to reducing numbers.

TAHF intends to fight until victory is achieved.

Temitayo Awosika Help Foundation

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Named after former medical student/sickle cell warrior Temitayo Awosika (1980 - 1999), TAHF has positively impacted thousands of lives in Nigeria.

As the organization approaches the 25th anniversary of Temitayo's passing, more projects are in the pipeline to touch the lives of Sickle Cell Warriors. Paramount among these is the construction of a dedicated 3-storey hematology clinic within Gbagada General Hospital. By situating the clinic within the ambit of an established and well-equipped public hospital - and collaborating with same - patients stand to enjoy multiple benefits such as access to professional and top notch specialist medical and nursing care.

Richard Coker Foundation's 20th Anniversary

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The Foundation named after Richard is determined to offer a hand of support to folks and families with SCD in Africa. Baba Jallah Epega, RCF's CEO, recalled Richard Coker as a down to earth personality and restated the Foundation's commitment to leave no stone unturned until SCD is defanged. Richard's cousin, Benjamin Awiri described him as 'a very generous and selfless soul'.

Holy Child College (HCC) was founded in 1945 by the Society of the Holy Child Jesus and run by the Roman Catholic Archdiocese of Lagos as a post-primary institution for girls. The girls who witnessed the 20th anniversary of RCF were beside themselves to relate with a fellow student 70 years their senior. Their grand-parents were probably just being born then!

Guests at the occasion included Chief (Mrs.) Ibidun Allison ('Amebo' in *Village Headmaster*), Waheed Olagunju, former NTA newscaster, veteran journalist Pa Bayo Olaoye, Dr. Edugie Abebe and Madam Doris Gbemiloye, among others.

One of the RCF 20th Anniversary essay competition winners poses with Dr. Edugie Abebe (left) and Chief Ms Julie Coker

People Fixing Pain: Anna Belfer, MD, Ph.D
Sickle Cell Pain: A Whole Person Challenge

Picture: US National Institutes of Health

Anna Belfer earned her medical degree from the Moscow Medical University in Russia and is a clinical neurologist who specializes in chronic pain conditions, such as sickle cell disease.

Dr. Belfer's research on mechanistic and translational studies of sickle cell disease pain is helping to develop innovative measures and methods that can be used to study the pain that people with sickle cell disease routinely endure.

The goal is to develop new technologies to identify biomarkers that indicate when acute pain turns into chronic pain or develop new interventions to pain. The researchers investigate using a Whole Person Approach for acute or chronic pain relief.

She currently works for the US National Institutes of Health. There, she is deputy branch chief of the Basic and Mechanistic Research in Complementary and Integrative Health Branch at the National Center for Complementary and Integrative Health.

SCAGO Develops Vaccine Guidance Booklets

Funded by the Public Health Agency of Canada, the Sickle Cell Awareness Group of Ontario (SCAGO) has developed two booklets to support the sickle cell disease (SCD) community in understanding vaccines and how these vaccines may/may not work for people with immuno-compromised illnesses such as sickle cell.

The booklets are *Vaccination Perspectives of People Affected by Sickle Cell Disease* and *Improving Vaccination Understanding.*

Vaccination Perspectives provides an overview of the critical issues surrounding vaccine equity in SCD, offering valuable insights and recommendations to support informed choices and enhance positive health outcomes for individuals and families with SCD. *Improving Vaccine Understanding* provides an approach to enhance vaccine education and promote vaccine confidence within the SCD community.

Health Canada AcceptsVertex Pharmaceuticals' exa-cel for New Drug Submission (NDS) Priority Review

April 2024

Vertex's exagamglogene autotemcel (exa-cel) has been accepted for Priority Review by Health Canada is for the treatment of patients aged 12 years and older with sickle cell disease (SCD) with recurrent vaso-occlusive crises (VOCs) and for the treatment of patients aged 12 years and older with transfusion-dependent beta thalassemia (TDT).

'We are pleased that exa-cel has been accepted for Priority Review by Health Canada and look forward to bringing this therapy to eligible patients,' said Michael Siauw, General Manager at Vertex Pharmaceuticals (Canada) Incorporated.

The NDS will be part of an aligned review with Health Technology Assessment (HTA) organizations, the Canadian Agency for Drugs and Technologies in Health (CADTH) and the Institut national d'excellence en santé et en services sociaux (INESSS) in Quebec.

With Priority Review, the conventional review timeline of 300 days is reduced to 180 days.

About exagamglogene autotemcel (exa-cel)

Exa-cel, formerly known as CTX001, is a non-viral, ex vivo CRISPR/Cas9 gene-edited cell therapy for eligible patients with SCD or TDT, in which a patient's own hematopoietic stem and progenitor cells are edited at the erythroid specific enhancer region of the BCL11A gene through a precise double-strand break. This edit results in the production of high levels of fetal hemoglobin (HbF; hemoglobin F) in red blood cells. HbF is the form of the oxygen-carrying hemoglobin that is naturally present during fetal development, which then switches to the adult form of hemoglobin after birth. Exa-cel has been shown to reduce or eliminate VOCs for patients with SCD and transfusion requirements for patients with TDT.

Exa-cel remains investigational in Canada and the safety and efficacy has not been established by Health Canada. Exa-cel is approved as CASGEVY® for certain indications in the United States, European Union, Great Britain, Kingdom of Saudi Arabia, and Bahrain.

About Sickle Cell Disease (SCD)

SCD is a debilitating, progressive, life shortening genetic disease. The clinical hallmark of SCD is vaso-occlusive crises (VOCs), which are caused by blockages of blood vessels by sickled red blood cells and result in severe and debilitating pain that can happen anywhere in the body at any time. SCD requires lifelong treatment and significant use of health care resources, and ultimately results in reduced life expectancy, decreased quality of life and reduced lifetime earnings and productivity.

About Transfusion-Dependent Beta Thalassemia (TDT)

TDT is a serious, life shortening genetic disease. TDT requires frequent blood transfusions and iron chelation therapy throughout a person's life. Due to anemia, patients living with TDT may experience fatigue and shortness of breath, and infants may develop failure to thrive, jaundice and feeding problems.

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'CHAMPIONS', NOT 'WARRIORS'

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broader public consciousness. It challenges the prevailing view of sickle cell patients as victims, and instead highlights their strength, determination, and accomplishments. This shift in perception has the power to de-stigmatize and humanize individuals living with SCD, and ultimately to foster a more inclusive and supportive society.

The choice between 'warrior' and 'champion' is deeply personal, and individuals living with SCD should be accorded the freedom to define themselves however they deem appropriate. Some may find empowerment in the label of Warrior, symbolizing their ongoing fight against the disease and the strength it takes to navigate its challenges; Others may embrace the term 'Champion', a connotation of strength, ability to thrive and succeed despite the hurdles placed on the tracks by SCD.

In conclusion, LCSCF's action branding its members as Champions rather than Warriors is a significant and meaningful shift in the language and perception of SCD. It challenges the prevailing narrative and provides a framework for understanding and supporting individuals living with this painful and debilitating condition. Ultimately, the power of words to shape our perceptions and identities cannot be understated, and the use of the term 'Champion' has the potential to empower those living with SCD, and to redefine the way we understand and engage with this special community.

... the term 'Champion', is a connotation of strength, ability to thrive and succeed despite the hurdles

Nigerian Natural Medicine Development Agency

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agent for slowing down the ageing process.

The products were unveiled by the Minister for Science and Technology, Uche Nnaji at a ceremony at the Victoria Island, Lagos headquarters of the NNMDA. In the past, the Agency had developed herbal products for hypertension, arthritis, malaria and mosquito repellents, to name a few.

'Nigerians should be celebrating these achievements and patronizing our products, which are proven effective for various ailments.' Nnaji remarked.

Buttressing the Minister's remarks, Prof Emeje stated that Nigeria could develop herbal medicines to manage or cure diseases orthodox medicine finds intractable.

Prof Emeje revealed that at least 11 herbal formulations were in the works, and will be presented to the public before the end of the year by President Bola Tinubu.

According to the pharmacist, Nigeria has the highest bio-diversity in Africa, and should be able to tap into the billions of dollars-worth global herbal industry. This, he affirmed, will not only improve the health of the citizens but also create millions of jobs.

ACCESS BANK LAGOS MARATHON

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I was tired, not dog tired, and told Sylvia I was experiencing pain in my thighs and waist and lower back. Concerned, she asked if I was 'going into crises'. No, I replied, this isn't crises blowing in (I added, matter of fact, that it could easily turn into one).

She too was tired, but we plodded on, wearily lifting one foot after the other. She suggested we rest. I said No, only if she wanted to...

The duo of Peter Oshikoya and Harrison Ojede caught up with us. Big, strong, healthy, and oozing machismo, you wouldn't guess they were of HbSC/SS respectively. After we took pictures, and, asking me to take it easy, they melted away.

Sylvia and I finished the marathon (walk) at our own pace, reaching the Eko Atlantic plain of sand dunes and barren desert.

We had three more kilometers to walk back to the bus stop. In all, I had trekked roughly 18 kilometres that day.

Peter Oshikoya and Harrison caught up with us. Big, strong, healthy, and oozing machismo, you wouldn't guess they were of HbSC/SS respectively. After we took pictures, asking me to take it easy, they melted away

Peter Oshikoya

Vertex exa-cel (CASGEVY)

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Complications of TDT can also include an enlarged spleen, liver and/or heart issues, misshapen bones and delayed puberty. TDT requires lifelong treatment and significant use of health care resources, and ultimately results in reduced life expectancy, decreased quality of life and reduced lifetime earnings and productivity. Stem cell transplant from a matched donor is a curative option but is only available to a small fraction of people living with TDT.

About Vertex

Vertex is a global biotechnology company that invests in scientific innovation to create transformative medicines for people with serious diseases. The company has approved medicines that treat the underlying causes of multiple chronic, life-shortening genetic diseases — cystic fibrosis, sickle cell disease and transfusion-dependent beta thalassemia — and continues to advance clinical and research programs in these diseases.

Pregnancy, Girls & Women With SCD

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During pregnancy

While you are pregnant, you may see different doctors. This may include a hematologist, who specializes in blood diseases. You may need to see a specialist trained in managing high-risk pregnancies. Your doctor may also refer you to other specialists or social workers.

You may need to visit your doctor and change your treatment. Doctors may also monitor you frequently for anaemia and other factors that trigger pain crises. During pregnancy, avoid:

✓Cold temperatures
✓Dehydration
✓Rigorous physical activity

Pregnancy can increase the risk of SCD complications, including:

✓Acute chest syndrome
✓Higher risk of blood clots
✓Higher risk of infections
✓More frequent pain crises
✓Stroke
✓Worse anaemia

Pregnancy complications

Women with SCD in more developed countries do not have a higher risk for pregnancy-related death, but they do have a higher risk of problems during pregnancy.

These problems include:

✓Small Babies
✓Birth defects in the baby
✓Cesarean section (C-section) delivery
✓Going into labor before the expected due date
✓High blood pressure (preeclampsia)
✓Infection
✓Pregnancy loss

GAAF Extends SCD/Climate Change Advocacy to More States in Nigeria

As the Gabriel Adewumi Alabi Foundation (GAAF) celebrates 4th Founder's Day in April 2024, more secondary schools in Nigeria are to benefit from its SCD/Climate Change sensitization program.

For the first 3 years of its existence, GAAF focused on sickle cell. The SCT/SCD sensitization was carried out at various secondary schools in Ekiti State and at Kpere Basic and Junior High School, Upper Volta, Ghana.

Climate Change was added to GAAF's corporate agenda in order to place responsibility for the environment squarely on the shoulders of the leaders and policymakers of years to come. On this note, GAAF Climate Change Schools Campaigns will take place at schools in Ondo, Oyo and Osun State, all in May 2024.

At each school, aside from seminars on climate issues, trees will be planted to underscore the invaluable contribution of trees to a cleaner environment.

Similar tree planting exercises were carried out at GAAF's pioneer Climate Change talks at secondary schools in Lagos.

With an objective to give back to society, GAAF was established to memorialize one of Nigeria's pioneer communications engineers, Pa Gabriel Adewumi Alabi (1940-1975). The organization is registered Nigeria, Ghana and the UK.

https://education.sicklecellnews.com

SICKLE CELL

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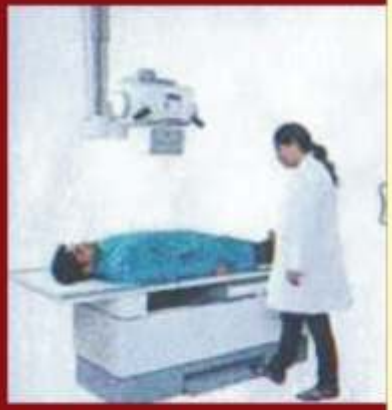

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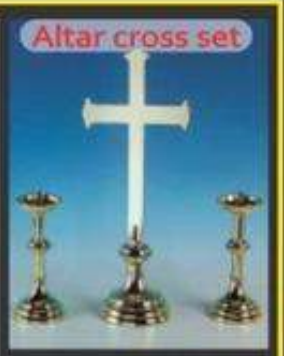

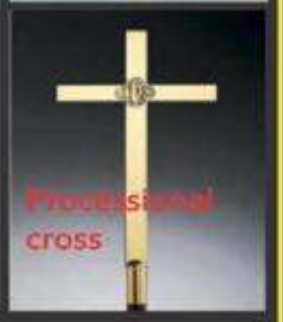

SYMPTOMATIC - LIFE OF A SICKLE CELL TRAIT CARRIER

An Invisible Disability - My Story

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

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

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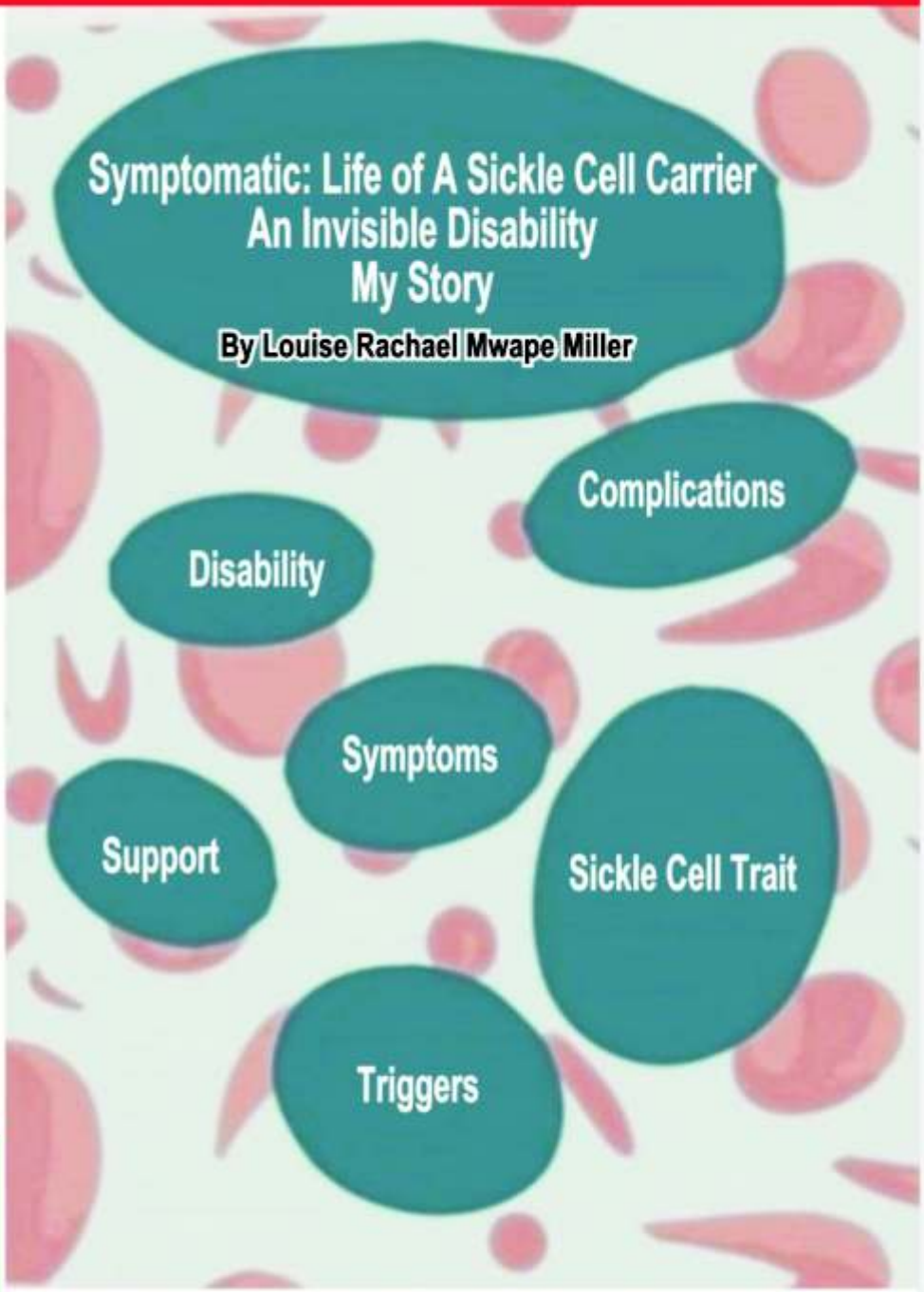
This is her story from a faith-filled perspective! This book aims to spread awareness of the dangers and highlight the risks of such gross ignorance

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



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... in some carriers of the sickle cell gene, it's not nearly as benign as medical science believes

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