AFRICAN
SICKLE CELL
NEWS & WORLD REPORT
Oct-Dec 2018 ISSN 2141-1093 Vol11 No 4 N400 GHC 10 $3.5 £2.5 €3.0

SICKLE CELL & TRAIT
The Good, The Bad, The Deadly ...

Interview with SCT activist
Ritchie Johnson

LANRE TUNJI-AJAYI
honoured by Canadian Senate for work on SCD

Nigeria 2019:
Gubernatorial aspirant promises support for SCD

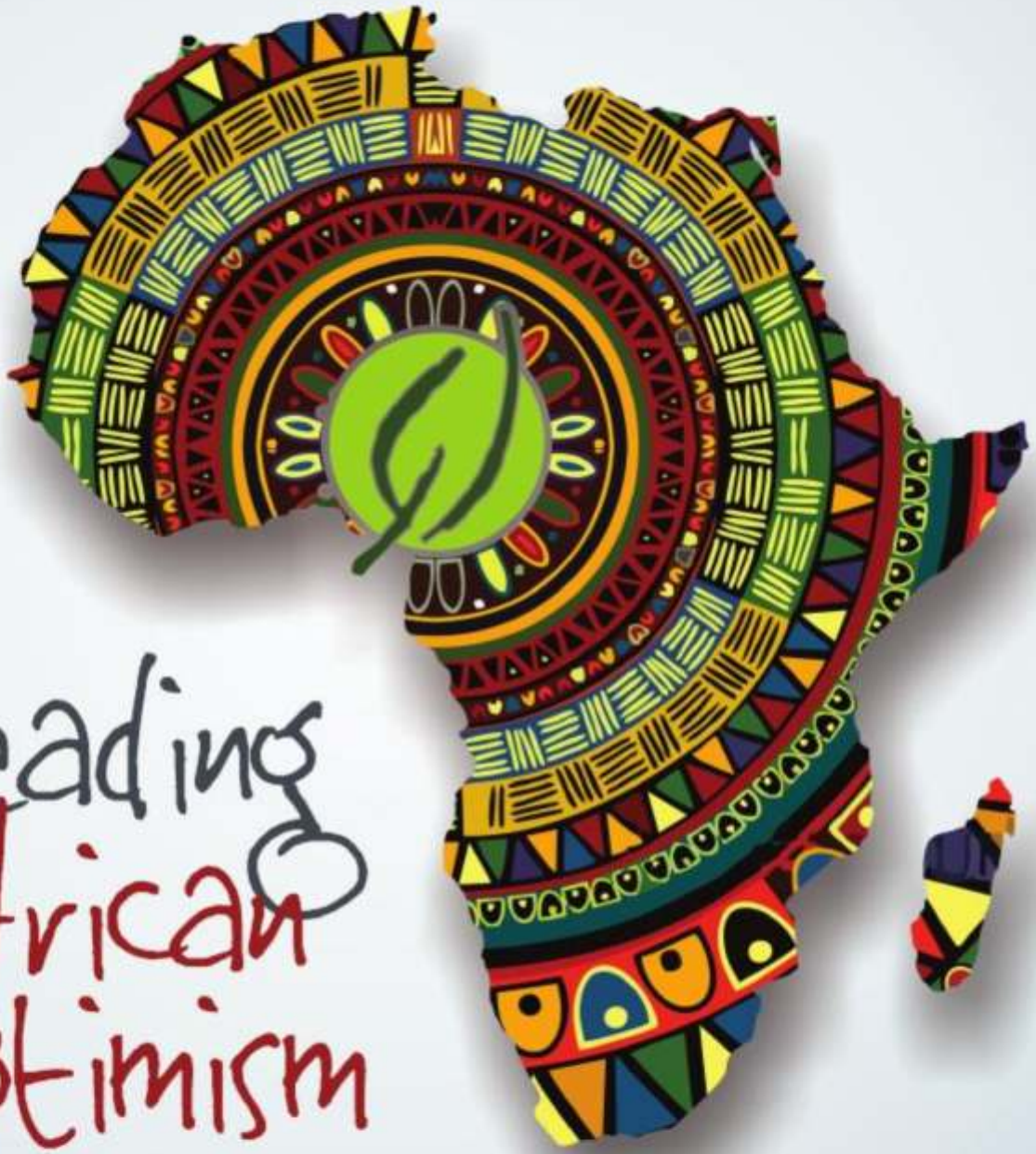
Prof Bernard Odo
Gubernatorial aspirant

I am not ready to pass on sickle cell to the next generation

Dr. Lakiea Bailey
Director, Sickle Cell Consortium

Donald Trump:
'US close to finding cure for sickle cell'

www.verdantzeal.com



Spreading African Optimism

We transform brands by creating value, fulfilling needs, time and again.

follow us on Verdant_Zeal | Verdant Zeal Official | VZ Innovention | verdant_zeal

NIGERIA • GHANA • GAMBIA

Contents

Cover image of magnified blood cells: CDC/Sickle Cell Foundation of Georgia: Jackie George, Beverly Sinclair

CREDITS

Publisher
Scell Media

Editor
Ayoola Olajide

Writers/Correspondents
Titi Aladei
Tosin Fawemida
Fatima Garba Mohammed
Doyin Ojumu
Abro Onyekwe

Contributing Editors
Dr. Ebere Afamefuna
Dr. Fatai Sulayman
Dr. Prince Emetanajo
Dr. Rose Oriolowo
Dr. Rose Ajimatanrareje

Advert & Circulation
Victor Damilola

Canada Rep
Keshia Betty

Ghana Rep
Okyere Baah

India Rep
Dr. Desai Atul

Kenya Rep
Alice Ochieng

Uganda Rep
Ssebandeke Kamulale Ashiraf

UK Rep
Trade Trends Ltd

US Reps
Pastor O. Segun (TX)
La'Veda Wallace Page (GA)

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, 13 Borokini Street, Ikorodu, Lagos State, Nigeria, West Africa.
Email: scdjournal@yahoo.com. Tel. Nos: +2348033199946, +2348182721386, +2348170234595, +2348097901946
Web: www.scdjournal.com. All correspondence to the Editor

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

info@scdjournal.com

Cock and Bull Story
The other day you carried a story about a young lady whose parents and siblings are HbAA while she is SS!
Now you have added yet another incredible tale - a policeman with sickle cell anaemia!
Your stories are beginning to stretch the boundary of credibility.
Onwubiko Achara
Oturkpo, Nigeria

Editor's Note: We stand by our stories.

My Daughter Wants to Join Law Enforcement
My daughter, a final year Sociology student has often expressed a wish to work in law enforcement, especially the police. After reading your story about the Police Sergeant with sickle cell, I made enquiries with the authorities in my country and learnt a former police chief was with sickle cell!
Your story has rekindled my daughter's hope of joining law enforcement in the shortest possible time.
Amanuveve Amposah
Kumasi, Ghana

The Pierre Fabre Interview
The interview with Dr. Beatrice Garrette, Director-General, Pierre Fabre Fondacion, makes thought-provoking reading. I particularly agree with her statement that 'sickle cell has been marginalized by international health agencies' and also that 'African governments have not made

SCD a priority'.
Coming from a non-African, what further call to action do local and international health agencies need to support research and awareness programmes?
Louise Stella Obah
Accra, Ghana

60 million Citizens With SCT!
The revelation by the Lagos State Government – through health commissioner Dr. Jide Idris – that Nigeria may have between 50 and 60 million citizens with Sickle Cell Trait (SCT) is both shocking and alarming.
Going by past records, the Nigerian health authorities are unlikely to wake up to the public health implications of having such large numbers with SCT until it is too late!
The first step is to screen virtually all newborns in this vast country for SCT - and initiate action for massive public sensitization. SCT is a ticking bomb in Africa, particularly in Nigeria.
Chinomso Agbarachi
Enugu, Nigeria

International Sickle Cell Advocate of 2018
Hearty congratulations to Ms Rabi Maidunama for being awarded International Sickle Cell Advocate 2018 by Sickle Cell 101.
Thanks for making Nigeria proud.

Tolude Onome Ogah,
Puerto Rico

Thanks!
Many thanks for highlighting my assumption of office on the July-September 2018 edition.

Beverley Francis-Gibson, President/CEO, Sickle Cell Disease Association of America (SCDAA), Baltimore, USA

Global Education Imperative For SCT

By Ritchie Johnson

At the time I got married (in the late 1960s), no one asked me about my sickle cell status, nor of the status of the man I was to marry. Sure, we had blood drawn, but it was for other reasons.

Having the sickle cell trait (SCT) at that time was not a big deal and never crossed my mind that I needed to know the sickle cell status of my future husband.

I was taught in nursing school that having the trait was not anything to worry about. I can go on and live a normal and healthy life span without medical problems related to SCT. It was sickle cell disease that would cause problems, they said.

I was not told that if I married a person with SCT our children may have SCT or the disease. I did not know that being the carrier of one abnormal gene causing me to have the trait could be passed on to my unborn child.

Needless to say, that gene was passed on to my second child. He had the trait and at the age of 38, my son was diagnosed with renal medullary carcinoma (RMC). This is a rare kidney cancer that predominantly affects adolescents and young adults with SCT. My son passed away 15 months later at the age of 39.

It is imperative that everyone knows their sickle cell status regardless of ethnicity. Global education is critical regarding sickle cell anaemia and trait.

Mrs. Johnson is a registered nurse and President/Founder, Chris 'CJ' Johnson Foundation, Inc. she lives in Sugar Land, Texas, USA

Nigeria's Clueless, Clueless Politicians!

By Ayoola Olajide

If the statistics are anything to go by, 25 to 30% of the entire Nigerian population of roughly 200 million have sickle cell trait (SCT). This amounts to between 50 and 60 something million citizens.

Add to that the estimated 3 to 5 million who have SCD; add to that the unknown millions who have neither SCD nor SCT (their relations, friends, colleagues, caregivers) who will give anything to improve their lives.

From the highest office in the land to the lowest, the aspirants all fall into the categories stated above. Most - if not all - of the aspirants have one thing or another connecting them with SCD.

Not only is Nigeria the nation with the highest burden of SCD/SCT, it is perhaps the only nation on earth where practically every household has or had a member with sickle cell!

How SCD has been forgotten, how it is not a subject of political manifestoes or campaign (though unfulfilled) in this country is baffling to say the least. It cannot be stigma because we all have it one way or another.

Any politician who comes up with a pledge for SCD already has a constituency that would listen - and listen *attentively.* Pledges like free medicare, comprehensive insurance, energetic research, etc are heartwarming messages to a community long overlooked.

Nigerian politicians sure lack clues!

Ayoola Olajide


Jenica Leah

SICKLE CELL NEWS
STARTS WEEKLY ONLINE EDITION

... aptly named **www.sicklecellnews.com**, the site features news, events, interviews, research, arts, personal testimonies, etc for or by the global SCD community

Ikeja, Nigeria 20 August 2018

The publishers of *African Sickle Cell News & World Report* have added yet another feather to their cap by the launch of a new comprehensive sickle cell website.

'Things are always happening in the sickle cell world,' says Hajia Rabo Lawal, a retired medical librarian who unveiled the site on a very rainy day at Maryland Schools Complex, Lagos.

Besides, she adds, while some with sickle cell make it a strictly private and personal affair by not airing their experiences, many in fact are itching to tell theirs.

Dignitaries at the launch included serving and retired education officers, medical doctors and scant members of sickle cell clubs within Lagos.

The incessant rains had kept many indoors.

The following are some of the stories carried so far within the short period of the site's existence:

SCD & S*X
Stunningly beautiful award-winning author, Jenica Leah discloses falling into crises and hospitalization each time she had S*X!
http://bit.ly/2MZa91i

SUPER-ACHIEVER
By the age of 19, he had performed for two US Presidents and shared the stage with Elton John and others.
http://bit.ly/2MuRmWF

HOOLIGANISM
Life as a bus conductor/'Area Boy' living with sickle cell anaemia.
http://bit.ly/2BEPwCv

WHEN BMT FAILS
Complications arose after one year of 'successful' bone marrow transplant to liberate boy from the shackles of SCD.
http://bit.ly/2wWPZdA

HYDROXYUREA
Hydroxyurea is safe to use in malaria –endemic countries
http://bit.ly/2Lcxua1

MURDER!
British SCD advocate murdered at home.
http://bit.ly/2PlA4xC

ADVOCACY
Little Evelyn Islam doesn't even look like she has sickle cell anaemia, yet she has undergone so much... Mother turns into advocate.
http://bit.ly/2Qwveyq

RELIGION
'Sickle Cell Nearly Undermined My Faith in God!' - US Evangelist Narseary Harris
http://bit.ly/2PiJZEl

QUERY
On hospital bed, teenager asks parents (both pastors of the Redeemed Christian Church of God) if they knew their genotype before *leaping* into marriage!
http://bit.ly/2xcerbM

***www.sicklecellnews.com** is updated weekly.

SICKLE CELL TRAIT

- WHAT IT IS, SIGNS, SYMPTOMS, COMPLICATIONS

from cdc.gov

People who inherit one sickle cell gene and one normal gene have sickle cell trait (SCT). People with SCT usually do not have any of the symptoms of sickle cell disease (SCD), but they can pass the trait on to their children.

How SCT is Inherited

If both parents have SCT, there is a 50% (or 1 in 2) chance that any child of theirs also will have SCT, if the child inherits the sickle cell gene from one of the parents. Such children will not have symptoms of SCD, but they can pass SCT on to their children.

If both parents have SCT, there is a 25% (or 1 in 4) chance that any child of theirs will have SCD. There is the same 25% (or 1 in 4) chance that the child will not have SCD or SCT.

Diagnosis

SCT is diagnosed with a simple blood test. People at risk of having SCT can talk with a doctor or health clinic about getting this test.

Complications

Most people with SCT do not have any symptoms of SCD, although, in rare cases, people with SCT might experience complications of Sickle Cell Disease such as pain crises.

In their extreme form, and in rare cases, the following conditions could be harmful for people with SCT:

- Increased pressure in the atmosphere (which can be experienced, for example, while scuba diving).
- Low oxygen levels in the air (which can be experienced, for example, when mountain climbing, exercising extremely hard in military boot camp, or training for an athletic competition).
- Dehydration - having too little water in the body.
- High altitudes (which can be experienced, for example, when flying, mountain climbing, or visiting a city at a high altitude).

More research is needed to find out why some people with SCT have complications and others do not.

SCT and Athletes

Some people with SCT have been shown to be more likely than those without SCT to experience heat stroke and muscle breakdown when doing intense exercise, such as competitive sports or military training under unfavorable temperatures (very high or low) or conditions.

Studies have shown that the chance of this problem can be reduced by avoiding dehydration and getting too hot during training.

People with SCT who participate in competitive or team sports (i.e. student athletes) should be careful when doing training or conditioning activities. To prevent illness it is important to:

- Set your own pace and build your intensity slowly.
- Rest often in between repetitive sets and drills.
- Drink plenty of water before, during and after training and conditioning activities.
- Keep the body temperature cool when exercising in hot and humid temperatures by misting the body with water or going to an air conditioned area during breaks or rest periods.
- Immediately seek medical care when feeling ill.

More research is needed to find out why some with Sickle Cell Trait have complications and others do not

SICKLE CELL TRAIT

The Good, The Bad, The Deadly

By Abu Munir MBBS, Sokoto, Nigeria

Sickle Cell Trait (SCT) arises when a child inherits one normal (HbA) and one abnormal – 'unusual' as Professor Olu Akinyanju, Chairman, Sickle Cell Foundation Nigeria, would have it – (HBS, HbC, HbD, HbE, HbSbthal, etc) from the parents. Thus a child could be HbAS, AC, AD, AE, ASbthal, etc. Over 400 abnormal genotypes have been identified.

The most common SCTs, however, are AS and AC, which occur frequently – but not exclusively - among black Africans and among others who live or whose forebears once lived in malaria-endemic regions of the world.

SCT: The Good

Medical authorities have long underscored the protective advantage of SCT against the worst effects of malaria plasmodium , enabling children to survive a harsh environment of disease-bearing mosquitoes. This protective shield is not afforded those with HbAA, neither for those homozygous for sickle cell (HbSS and its variants such as HbSC and HbCC).

SCT: The Bad

For healthy carriers of the sickle gene, the only downside is that they could pass on the gene to their offspring. And when two sickle cell carriers unite in procreation, the chances are high that not only the trait but also the homozygous condition (HbSS) can be the result.

In a world where most with SCT are unaware of their status – because they are often so perfectly healthy – the danger is that humanity keeps producing the homozygous gene with its heavy burden of pain and other appalling consequences.

The hobgoblin that drives the spread of SCT – and by implication SCD – includes sheer ignorance (due to good health), lust misnamed love and religion (particularly in Africa where zeal for anything foreign, including religion, often overrides common sense).

SCT: The Deadly

For families whose children have been felled by the mere fact of their having SCT, the age-old textbook description of SCT as a 'benign' state of health must evoke melancholy memories - and possibly a reflection that generalizations thwart research efforts.

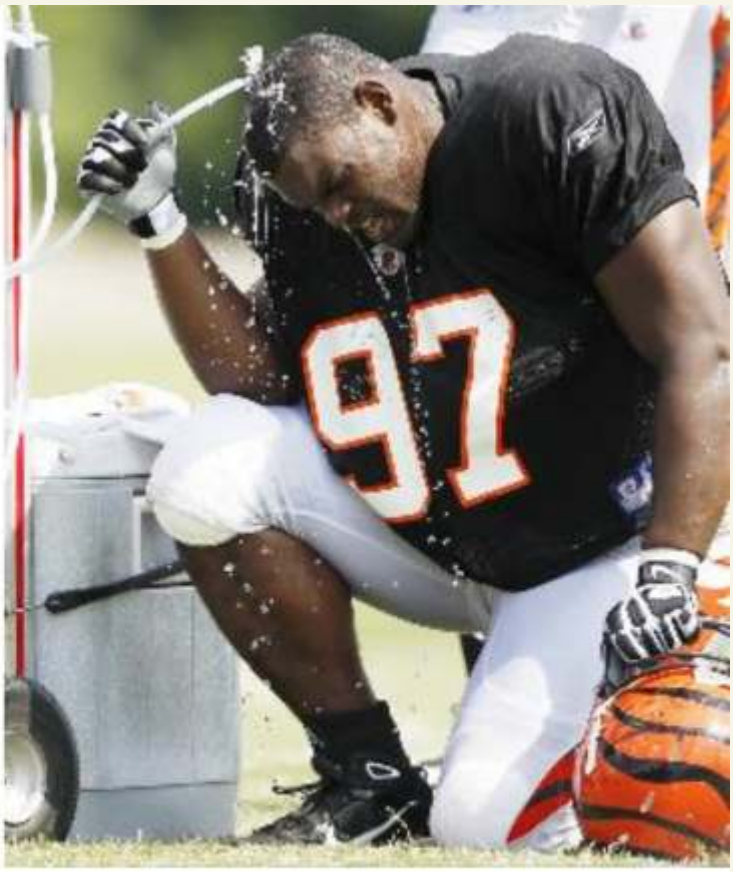
Increasing scientific evidence has shown that a small percentage of folks with SCD will experience SS-like symptoms when faced with triggers such as infection, dehydration, high altitude and extreme physical exertion. More alarmingly, SCT is closely linked with a deadly and yet untreatable form of cancer known as renal medullary carcinoma.

Awareness of SCT – and its implications – is crucial to the realization of the ideal of a sickle cell-free world. Whether that ideal is attainable or not is indeed another matter.

Unfortunately, countries with the highest prevalence of SCT are the very ones starkly ill-prepared to deal with the situation. Epileptic measures at awareness such as occur in Nigeria - a country where one in every three or four citizens have SCT - around June 19 (World Sickle Cell Day) only scratch at the surface of a conundrum.

HOW I COPE WITH SICKLE CELL TRAIT

- Geno Atkins



'My story started when a young man met a young lady on the campus of Florida A&M University. *On their first date* he asked the young woman if she carried the sickle cell trait! That young man became my dad and the young lady is my mother. My dad carries the sickle cell trait and was well aware that if he married someone who also carries the trait, their kids had a 50% chance of being born with full blown sickle cell disease. He discovered that my mother is not a carrier of the sickle cell trait (SCT). The rest is history.

'I am the oldest of three children and the only one with SCT. The first time I learned I carry the SCT was as a freshman at the University of Georgia. I called home and my mother said, 'Your dad has the trait, but I don't recall the doctor saying you had the trait when you were born.'

All newborns are tested for the trait in Florida, yet I had gone my whole life without knowing.

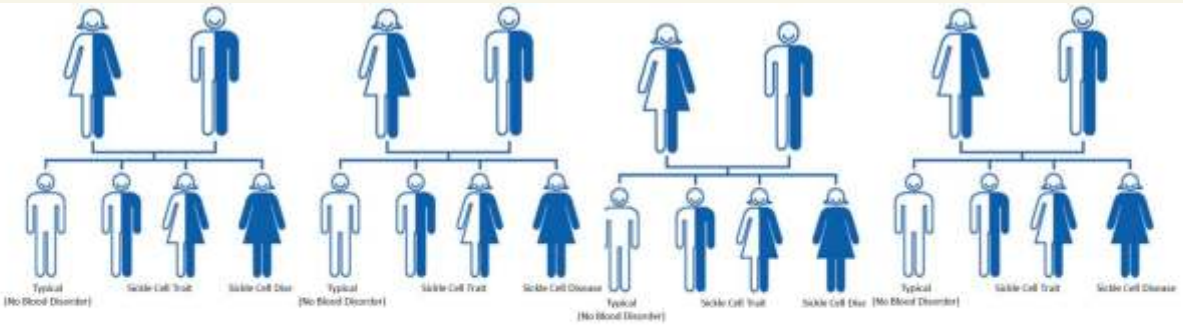
'Once I learned I had the trait, I researched as much as I could and talked with the football training staff. They assured me that the trait would not affect my ability to play. There were four freshmen who tested positive for the trait along with me and we were assigned a trainer who watched us closely during practice sessions and on game day. I was not treated differently by my teammates and went about my life just as I had before. One day I learned that a football player had died from complications of SCT while participating in spring practice at another university. That's when I realized that this is a serious issue and I should not take any chances with my health. I played at the highest level in college and it earned me a spot in the NFL.

'I knew from my research that it would not be good for me to play in high altitude, so I prayed I wouldn't get drafted by Denver, which is at a high altitude. I ended up in Cincinnati and have played at a very high level without any adverse affects of SCT. During the 2011 season we did travel to Denver to play the Broncos and that was the first time I can truly say I felt the effects of the trait. I could not breathe after a 10-play series and had to be given oxygen on the sideline.

'Some of the changes I've made in my life include eating healthy, avoiding drugs and alcohol, not smoking, and most importantly getting a lot of rest. Everyone in my family knows that I have to take my daily nap. I drink more water, sports drinks, and coconut water than ever before because it is important to stay well hydrated before and after strenuous activities.

'Having SCT does not exclude an athlete from participating in sports, however, the training staff and coaches need to take precautions to ensure the athlete is not put in dangerous situations. In high school my coaches would get on me because I was always in the back during running drills and I often got very tired. I think back now and realize that it could have been a dangerous situation for me if over-zealous coaches or I had pushed too much during those hot days in south Florida.

from cdc.gov



EPIDEMIOLOGY OF Sickle Cell Trait

It is estimated that 300 million people worldwide are heterozygous for the mutation in the HBB gene (HBB E6V, also termed HbS mutation or 'sickle gene') that results in sickle cell anaemia (SCA), and are said to have sickle cell trait (SCT). In the overwhelming majority of cases, SCT is a benign entity associated with a normal life expectancy.

The sickle cell mutation arose and remained evolutionarily conserved in those parts of the world where malaria is or was once highly endemic, including sub-Saharan Africa, parts of the Mediterranean, the Middle East and India. Within these regions, the prevalence of SCT may vary widely, with pockets of very high prevalence (30% or more) corresponding to high regional malaria burdens. This striking association was first reported by Allison in a landmark study in Kenya more than 60 years ago. The evolutionary advantage afforded by SCT is presumably related to the fact that, although carriers are not protected from parasitaemia when exposed to falciparum malaria, they are about 90% less likely to suffer the severe consequences of infection. The precise mechanism(s) by which SCT confers this protective effect in red blood cells (RBCs) remains a topic of active research.

The HbS concentration in SCT may demonstrate considerable variability. While typically in the range of 42%, it has been shown to have a trimodal distribution in the African-American population, caused by the interaction with α-thalassaemia. Interestingly, despite the fact that both SCT and α-thalassaemia are individually protective against severe falciparum malaria, the protection is lost when both conditions are inherited together.

The slave trade trafficking and population migrations in recent centuries led to the dissemination of the sickle gene to other parts of the world. In the United States, for example, 6-9% of the African-American population and 0.01-0.05% of other racial/ethnic groups, equating to an estimated 3 million persons, are carriers of the sickle gene. In the French Caribbean Islands, such as Guadeloupe and Martinique, 6-7% of the population has SCT.

SCT AND RENAL MEDULLARY CARCINOMA (RMC)

A very rare complication of SCT is renal medullary carcinoma. This very aggressive malignancy has been reported almost exclusively in individuals with SCT. In the original report of these malignancies, none were limited to the kidney at presentation and many were metastatic. Median survival after diagnosis was approximately 4 months. These tumours often present in young people, with a median age of 26 years, and appear to have a male predominance at younger ages. These tumours appear to have a predilection for the right kidney and are associated with necrosis within the tumour, caliectasis and regional adenopathy. The pathogenesis of renal medullary carcinoma remains unknown but it was originally thought to arise from the calyceal epithelium. Presently, therapy of these lesions includes nephrectomy in the absence of metastatic disease and various chemotherapeutic regimens that have had limited success, with median survival still only six months, although there have been rare case reports of successful treatment. Therefore, early detection of these lesions is paramount and cross-sectional imaging of individuals with SCT presenting with haematuria is important for identifying these and other urothelial malignancies.

from nhlbi

ASTYMIN®

LIQUID | CAPSULE | DROPS

MOST TRUSTED BRAND

INDICATIONS:

- STRESS
- TRAUMA
- DEBILITY
- WELLNESS
- MALNUTRITION
- CONVALESCENCE

DOSAGE

ADULTS
Capsule:
1 or 2 capsules daily
Liquid:
10ml twice daily

CHILDREN
Liquid:
5ml twice a day

INFANTS
Drops:
6 drops twice daily

FIDSON
...we value life

Fidson Healthcare PLC
268, Ikorodu Road, Obanikoro, Lagos.
Customer care line: 0807 700 8888
Head office: +234(1) 3429102, 3429106
E-mail: info@fidson.com, www.fidson.com

...get alert everyday

Jobelyn®

MOST POWERFUL NATURAL ANTIOXIDANT

WITH HIGHEST ORAC5 RATING CERTIFIED BY BRUNSWICK (USA)

Jobelyn scores 37,622 Total ORAC FN Te/g

- HELPS YOU MAINTAIN A STATE OF WELL NESS
- PROMOTES ANTI-AGING
- HELPS THE BODY TO PROTECT AND DEFEND ITSELF AGAINST SEVERAL DISEASES RESULTING FROM OXIDATION AND INFLAMMATION, SUCH AS CANCER, DIABETES MELLITUS, STROKE, HYPERTENSION, ANAEMIA AND ARTHRITIS

Jobelyn is a multifunctional natural product that triggers the body's own immune system to tackle an array of life threatening disease conditions as well as prevent progression of same in healthy populations.

Scientific evidence strongly supports the power of Jobelyn to:

- **RESTORE**
- **REGENERATE**
- **REBUILD**
- **RECREATE**
- **RENEW**

the cells and tissues of your body through the following processes:

Antioxidant protection
Regulation of inflammation
Immune system activation and modulation

AVAILABLE WORLDWIDE
Asia Europe North & South America
+1301 5150139
www.health-forever.com

HEALTH FOREVER
Health Forever Product Limited
11 Dipeolu Street, Off Obafemi Awolowo Way, Ikeja, Lagos, Nigeria
For general inquires & purchase: +23418819666 , +2348035657284, +2348074088101
For distributorship opportunities: +2348078516953, +2348033377787
Fax: +1 240 556 0382
e-mail: getinfo@health-forever.com
www.health-forever.com
www.afritradomedic.com

ALLWORLD NETWORK
NIGERIA FAST GROWTH 50
WINNER

LOW BLOOD IN SICKLE CELL ANAEMIA: STARTLING TESTIMONY FROM A MEDICAL DOCTOR AFTER ADMINISTERING *JOBELYN*

The Blessed Virgin Mary (BVM) Hospital, Apapa, is located in a high density but economically-backward portion of Nigeria's economic capital, Lagos.

Infections are rife and for those with sickle cell, malaria and typhoid are a constant threat. For folks with SCD, characteristically short of blood, malaria parasites plunder the red blood cells, bringing the body to a hair's breadth of heart failure and other complications of severe acute blood shortage.

In this setting, Dr. Titus Okwudili Onyia, formerly of Lagoon Hospital and Tin Can Hospital, performs his medical labour of love. Blood is expensive and in short supply.

Then a sickle cell patient whom the doctor had not seen in months brings him a *sorghum bicolor*-based health supplement known as *Jobelyn*. Uchenna (not her real name) had been taking the supplement and has not reported for crises or other matters as was the norm every one or two months year round. Dr. Onyia couldn't quite believe his eyes.

'Uchenna looked healthy, had gained weight and had clear bright eyes – her health had undergone a transformation!' said Dr. Onyia.

Investigator

Dr. Onyia started giving *Jobelyn* to all his SCD patients – and scientifically monitored their progress or otherwise. One consistent result was a dramatic rise in haemoglobin (Hb) levels from 6 or 7 to 10 or 11 on average. One of the subjects even went as high as 12.6!

All this happened within two months. The subjects' sickle cell crises plummeted.

The doctor proceeded to prescribe *Jobelyn* to pregnant women and other patients experiencing low blood levels. The result was a similar dramatic restoration within a short time.

Dr. Onyia does not bother transfusing women who lost blood at childbirth any more. He gives them mega doses of *Jobelyn*, checks their Hb after a few days and is gratified by the outcome. On one occasion, when Dr. Onyia had travelled for Christmas, University of Benin-trained junior Dr. Ejele tried *Jobelyn* on a 3-day-old who was severely short of blood.

'Within one week,' Ejele later reported to his superior, 'the baby's Hb spiked from 6 to 13.3.'

Campaigner

Having confirmed his results, Dr. Onyia has become something of a campaigner for *Jobelyn* at the Olodi-Apapa branch of the Nigerian Medical Association (NMA). More and more members of the NMA nationwide in public and private setting are testing *Jobelyn* out on their patients - and confirming for themselves nature's healthy substitute for blood transfusion.

When TRAIT mimics DISEASE

the story of ace SCD activist Ssebandeke Ashiraf *(middle)*, whose SICKLE CELL TRAIT Behaves Much Like SICKLE CELL DISORDER

Unlike many who go through life without knowing they have sickle cell trait (SCT) – mostly because it is asymptomatic in the overwhelming majority of carriers – it did not take long for SCT to manifest itself in the life of Ssebandeke Kamulale Ashiraf. At the age of seven, he had his first manifest sickle cell crises and was hospitalized.

The episodes would occur frequently, yet no hospital found him with having SCT (HbAS) until he was 22. Since then he has been placed on a medical regimen suitable for an individual with full-blown sickle cell anaemia (HbSS).

He was 14 years old when he had what he considered his 'worst' sickle cell crises.

'I had become very pale and had unrelenting pain crises,' Ssebandeke recalls. 'At the hospital, the doctors told my relatives I would have died if they had delayed taking me in by just 30 minutes.'

On another occasion, during his final semester exams at Makerere University Business School (MUBS), he had to take all his papers while being treated for SCD pain crises.

'The crises I undergo have never failed to baffle doctors,' said Ssebandeke, who in May received an award from the MUBS for his sickle cell activism. In 2016, he was selected International Sickle Cell Advocate (ISCAY) by a US-based sickle cell non-profit.

Now 29, Ssebandeke intends to make genotype a big issue in his choice of a life partner.

'Sickle Cell carriers like me should beware who they choose to marry and produce children with,' says he. 'We should aspire to bring children into the world, not patients.'

For the SCD campaigner, it is okay to marry from any genotype if one had no intention of bringing forth children.

'Carriers who decide to brave the odds and who produce children with sickle cell should be prepared to handle the burden of life-long guilt'.

A holder of a bachelor's degree in Office and Information Management, Ssebandeke was elected International Sickle Cell Advocate (ISCAY) 2016 and is currently Executive Director, Action Against Sickle Cell, Uganda. He was in Port Harcourt, Nigeria (with stops in Abuja, Lagos and Ikorodu) for World Sickle Cell Day events in 2017 on invitation by the Sickle Cell Interactive & Management Association (SCIMA).

SICKLE CELL TRAIT ... *the story of Chris Johnson*

from cdc.gov

Chris Johnson was born with Sickle Cell Trait (SCT), a genetic condition that occurs when a child inherits one sickle cell gene and one normal gene from the parents. When two sickle cell genes are inherited, the child is born with sickle cell disease (SCD), which can cause pain, acute chest syndrome, stroke, and other serious health problems. SCT is often seen as a less serious condition compared to SCD because people with SCT usually do not experience the painful and life-threatening symptoms of SCD.

After a newborn screening revealed Chris had SCT, the hospital provided little information on the condition. 'I was told that SCT was nothing to worry about and that you could live a long, normal, and healthy life without any problems,' said Ritchie, Chris' mum.

Chris had an active childhood and played sports. He earned a football scholarship from the University of New Mexico. SCT never limited his lifestyle.

At the age of 38, Chris saw blood in his urine. At the emergency room, a CT scan found a tumor in his right kidney. Chris was diagnosed with an extremely rare form of kidney cancer known as renal medullary carcinoma (RMC). Common symptoms of kidney cancer include pain in the lower back, blood in the urine, and weight loss.

RMC has been linked to SCT. RMC is aggressive and typically leads to death. It's especially difficult to treat because of limited research on the disease.

There is no medicine available for RMC. At the time of Chris' diagnosis in 2011, there were no clinical trials (research studies that explore whether a medical strategy, treatment, or device is safe and effective for humans).

Chris and Ritchie were shocked. Before the diagnosis, Chris had lower back pain that continued for several years. He visited a primary care physician, a chiropractor (a doctor who specializes in diagnosing and treating disorders of the musculoskeletal and nervous system, especially in the spine), and even received physical therapy for the pain, but it never went away. Chris thought the pain was a football-related injury received in college or from a previous car crash. He never expected the pain to be a symptom of a kidney cancer linked to SCT. Even his healthcare providers never considered his pain to be linked to SCT or kidney cancer.

continued on page 16

'Hopefully, One Day, We Will Find A Cure For Renal Medullary Carcinoma'

- Ritchie Johnson

The Story of Chris Johnson

continued from page 15

By the time Chris was diagnosed, the cancer was stage 4. Chris needed medical treatment immediately.

At the hospital, he was treated with chemotherapy and additional cancer treatments often used to treat other types of kidney cancer. Treatment was expensive, and at one point, hospital bills reached more than half a million dollars. Chris fought the cancer for one year until his body became de-sensitized to the treatments and rejected chemotherapy.

'The cancer went through his body like wildfire,' said Ritchie. Chris passed away 3 months later in the fall of 2012.

In honour of Chris, Ritchie founded the Chris 'CJ' Johnson Foundation in 2013. While Chris received treatment, he understood the need for awareness and information on kidney cancers, especially RMC and its link to SCT. The Foundation raises awareness and donates funds to advance RMC research, and it provides education and support to families battling RMC. Some progress has been made, including two clinical trials on RMC that help to better understand the condition.

However, more awareness is needed.

'We're working with pediatricians in the Houston area to have them look out for certain symptoms when a child is diagnosed with SCT. We're not trying to scare anyone, but we want people to be aware of any possible symptoms that might be associated with RMC. Awareness is extremely important. We need to get the word out about RMC, and not just in the United States, because we have patients all over. We need to get this information out globally so that we can make a difference, and one day, hopefully, find a cure for RMC,' said Ritchie.

Although the pain of losing a child never goes away, Ritchie finds peace by helping others understand and cope with a devastating diagnosis.

'The main thing is staying positive and not giving up. Even though my son was 39 years old when he passed, it's still scary. People can reach out to us (the Foundation) for emotional support or whatever they need. They need someone to talk to during this time. Think positively, don't ever give up. Stand strong and fight it,' said Ritchie.

Lakiea J Bailey, 39, Executive Director, Sickle Cell Community Consortium, holds a Bachelor's degree in Biochemistry & Molecular Biology as well as a PhD in Molecular Haematology & Regenerative Medicine. The doctor who loves to read, cook and travel says even though she gets to marry a man with sickle cell, she would rather not pass on the sickle gene ....

'I am not willing to pass this disease to another generation!'

By 'Tosin Fawemida

Diagnosis: I was diagnosed with SS at age 5. It was later determined that I carry a rare combination of HbS and haemoglobin Monroe. This presents as SS in the laboratory. I have a distant cousin with sickle cell anaemia, but no other immediate family.
The diagnosis was made by a talented young physician after my parents grew concerned about the amount of pain I constantly experienced. My parents were unaware of their genotype prior to my diagnosis.

SCD Crises: I don't have a crisis that sticks out in memory. Some are worse than others, but all tend to be quite disconcerting.

Blood Transfusions: I have received too many to count. I now only allow myself to be transfused if my counts drop below a certain level and my retic count suggests that it will not rebound on its own.

Medical Specialty: My doctorate is in molecular haematology and regenerative medicine. I have studied the molecular basis of SCD, including the role of cytokines in vaso-occlusive crisis (VOC).

Hospital Admissions: I have been hospitalized too many to count. I estimate approximately 150 – 200 times over the course of my life.

Discrimination and Stigmatization: I've been both discriminated against and stigmatized. People have often doubted my abilities and intelligence. SCD also comes with the unfortunate stigma of 'drug seeker'.

Outlook on life: Sickle cell has a way of sneaking into every aspect of life. Not all of this is bad, however. I strongly believe that sickle cell has made me more determined and focused to accomplish my dreams.

SCT Unions: I am of the opinion that children from such unions should be avoided if possible. In my personal life, if the man I chose to marry and produce children with has sickle cell, we would need to agree to adopt. There are thousands, probably millions of children in the world in need of a loving home. I would gladly become mother to one of them.

Genotype of future life partner: My partner's genotype is of importance to me only if we are considering having our own children. I am not willing to pass this disease on to the next generation.

I'M TIRED, MAMA!

interview with Mrs. Ritchie Johnson, author, Mama, I'm Tired!
Founder/President, Chris 'CJ' Johnson Foundation Inc
By Tosin Fawemida

PHOTO: Mrs. Ritchie Johnson

When did you learn that your son had sickle cell trait?
I knew that my youngest son, Chris, had sickle cell trait based on the results of the newborn state screening.

Sickle cell trait is often thought to be benign – what could have happened in your son's case?
I am not sure what happened in Chris's case. He was perfectly healthy until the invasion of cancer in his body. The etiology of Renal Medullary Carcinoma (RMC) is unknown; however, in the majority of RMC cases, the patients had sickle cell trait.

Do you think rare conditions deserve as much funding/focus as more common disorders?
Currently, millions of people worldwide carry the gene responsible for sickle cell and other haemoglobin diseases. Sickle cell anaemia affects 100,000 Americans and 2-3 million Americans have sickle cell trait (SCT), yet funding lags far behind that of virtually every other genetic illness. It is as critical for funding to become available for rare conditions just as it is for more common disorders. Although SCD research has increased during the past 25 years, it is still not on par with other diseases that affect far fewer people.

So many questions regarding Sickle Cell Trait remain unanswered.

What are the aims and objectives of the Chris 'CJ' Johnson Foundation Inc? What are your achievements so far?
The goals of the foundation are to increase awareness of Renal Medullary Carcinoma (RMC), educate stakeholders, patients, families and health care providers and raise funds to advance RMC research.

As to our accomplishments, we have sponsorships with Houston Methodist Hospital in Sugar Land, Texas, AT&T, Linn Energy, Boon Urology, Life

continued on page 23

Steve Ryan Clark:

Passion For A Cure

By Titi Aladei

Although former National Football League Player Ryan Clark always knew he was with Sickle Cell Trait, he never imagined it would pummel him as it did so dramatically in 2007.

In that year, during a game in Denver, Colorado, Clark experienced sudden unrelenting pain on his left side. His spleen had ruptured due to the high altitude – a typical SCT-induced surgical emergency.

Both his spleen and gallbladder were removed. His career was seemingly over. However, after his mandatory long rest and recovery (he had lost 30 pounds), the talented player returned to the field.

'I am not just lending my name to a cause, I am getting involved in a big way!'

In 2009, Clark's bosom friend lost his wife to sickle cell anaemia, just one year into married life. SCD was even that closer home. His wife, Yonka, had a sister with sickle cell anaemia.

After his fluke SCT 'crises', similar to what occurs in sickle cell anaemia, Clark became an SCD/SCT visionary. He established a non-profit to imprint sickle cell on the American consciousness and put all his weight behind it. Named the *Ryan Clark's Cure League*, the organization is in collaboration with the University of Pittsburgh and the University of Pittsburgh Medical Centre.

'I am always amazed by the strength and resilience I see in people suffering with sickle cell anaemia,' Clark wrote in a Foreword to the Jan-March 2013 edition of *Sickle Cell News,* 'I am not just lending my name to a cause, I am getting involved in a big way!'

One of the Clarks' three children is with SCT. As a little child, her parents have been educating her about her special status – and its implications.

A total cure may still be decades away, but Ryan Steve Clark is intent on shortening those years.

NHLBI Introduces the Cure Sickle Cell Initiative

On September 13 the National Heart, Lung, and Blood Institute (NHLBI), announced the new Cure Sickle Cell Initiative, a collaborative research effort to accelerate the development of promising genetic therapies to cure sickle cell disease.

The initiative fosters a patient-focused research environment that will identify and support the most promising and innovative genetic therapies. This effort builds on the NHLBI's legacy of sickle cell research, which is helping many patients live longer, fuller lives.

ASH, SCDAA Host Sickle Cell Trait Briefing

On Wednesday, September 5, the American Society of Hematology (ASH) and the Sickle Cell Disease Association of America (SCDAA) hosted a briefing on Capitol Hill to educate Members of Congress and their staff on sickle cell trait.

The briefing presented a general overview of SCT and highlighted the importance of knowing what it means to have the trait, and the current state of research. In addition, a family shared their experience with SCT.

How September Became Sickle Cell Awareness Month in America

September was officially declared 'National Sickle Cell Anaemia Awareness Month by President Ronald Reagan in 1983, when the US House of Representatives unanimously passed the resolution, introduced by the Congressional Black

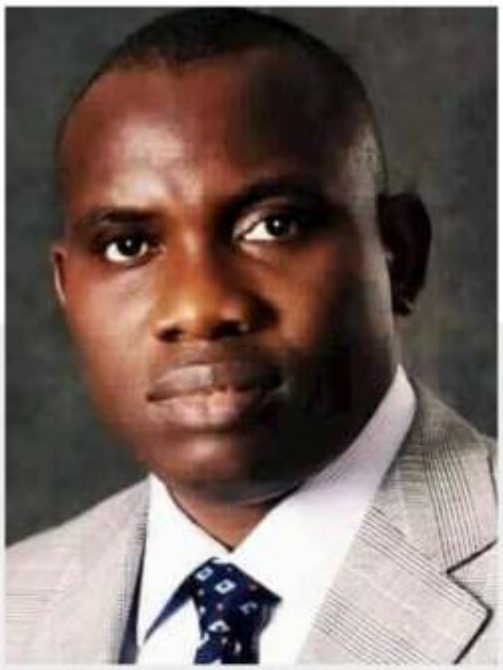
President Trump Restates Commitment To Find Cure For SCD

..... Text of Presidential Statement on National SCD Awareness Month

'During National Sickle Cell Disease Awareness Month, we stand with those fighting sickle cell disease (SCD) and reaffirm our Nation's commitment to finding a cure for this group of hereditary red blood cell disorders.

SCD is a debilitating condition that affects more than 100,000 Americans of all ages by

continued on page 32



Gubernatorial Candidate Pledges Support For SCD Advocacy

Bernard Odo, a professor of Geophysics and a gubernatorial aspirant on the platform of the All-Progressives Congress (APC) in Ebonyi State has pledged to join the SCD sensitization project should he be elected in 2019.

Prof. Odo stated that the decision to wade into the SCD campaign was not a political one, but one borne out of a personal ethos of care and empathy. He stated he will be working hand in hand with the Association of People Living with Sickle Cell Disorder (APLSCD) to bring sickle cell to heel in Ebonyi State.

'SCD is a major contributor to infant mortality in this state,' the geophysicist said, 'and a force in marital failures and broken homes.'

Odo, a former Secretary to Ebonyi State Government, promised that, as Chief Executive, he would ensure that a dedicated SCD Directorate was established to streamline genotype awareness efforts in the state.

SEASON OF HONOURS, DONATIONS FOR MAUREEN AISHA EDWARDS, APLSCD CEO

It was a season of honours and accolades for Mrs. Maureen Aisha Edwards, National Coordinator/CEO, APLSCD, Awka.

First, the Rotary Club of Agbara, District 9110 Nigeria accorded the tireless SCD advocate a Humanitarian Service Award, part of activities marking the installation of Barrister (Mrs.) Tussy Afam-Obi September 8. Rot Afam-Obi is only the 34th President of the District and the second woman to occupy the exalted post. The award took place at the De Santiago Milan Hotel & Suites, Festac, Lagos.

Along with her team, Barrister Afam-Obi has appointed SCD support/awareness one of the cardinal objectives of her term in office.

One week after the Rotary events in Lagos, the centre shifted to Enugu State, where, once again, the APLSCD chief received, on behalf of her organization, the documents and key to a brand new car as well as a N2 million (about US$7000) cash gift.

The donations, which took place at the Ifeanyi Ubah International Stadium, Nnewi, were personally made by Dr. Patrick Ifeanyi Ubah, CEO, Capital Oil and Gas Ltd.

Dr. Ubah emphasized his corporate partnership with APLSCD and enjoined his friends and associates to do likewise.

CANADIAN SENATE CELEBRATES SCD ACTIVIST

... Senate Awards Medal of Honour To Lanre Tunji-Ajayi

..... also nominated one of 100 Most Accomplished black women

By Fatima Garba Mohammed

It all began with trying to immortalize a younger brother and a fallen SCD hero (Engr Sunday Afolabi) when Lanre Tunji-Ajayi established the *Seed Of Life Philanthropic Organization*, SOLPO, to render assistance to people with SCD. SOLPO later morphed into the Sickle Cell Awareness Group of Ontario (SCAGO).

Tunji-Ajayi with Senator Cordy

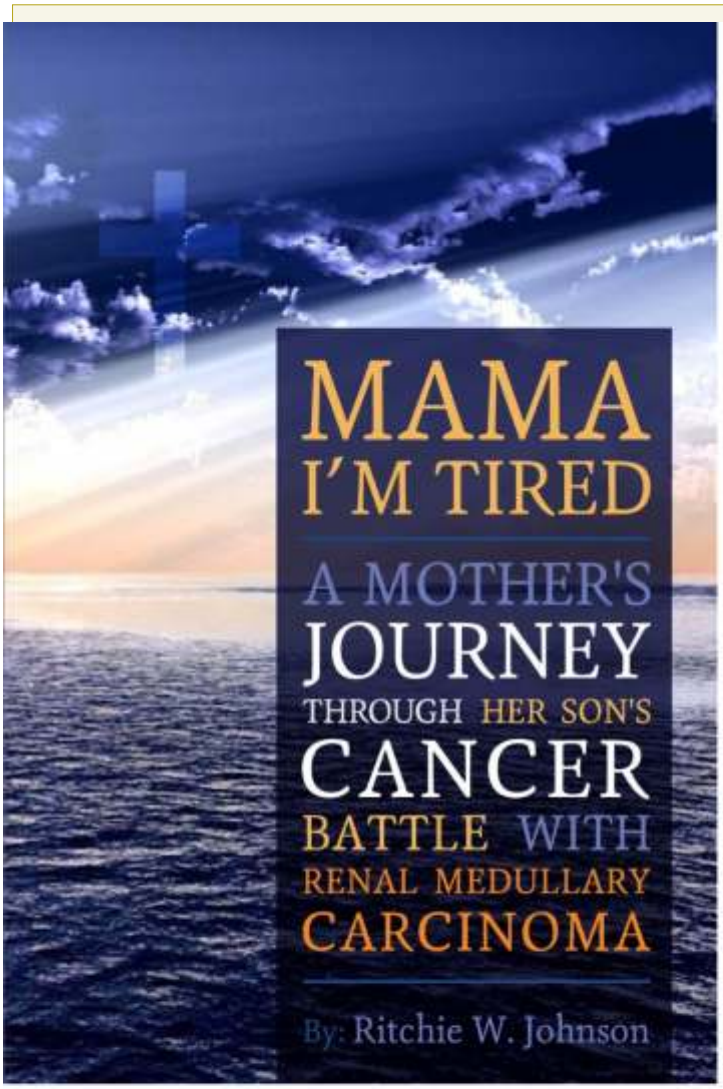
Mrs. Tunji-Ajayi poured all her energy into her project, and began to rally individuals, families as well as organizations in all Canada's provinces with an SCD focus under one umbrella. The result of that singular effort was the formation of the Sickle Cell Disease Association of Canada (SCDAC) with Mrs. Tunji-Ajayi as President. SCDAC is organized along the same lines as the Sickle Cell Disease Association of America (SCDAA) and has the same objectives – assistance to members, awareness and research for a cure.

Then an encounter with Senator Jane Cordy in 2012 and a clear outline of her vision for SCD in her adopted country. The Senator offered her full support and introduced a Bill *'recognizing June 19 as National Sickle Cell Awareness Day'*.The result, just under a year ago, was the recognition of June 19 as Canada's National Sickle Cell Day. For this, Lanre Tunji-Ajayi was in July awarded a Medal of Honour by the Senate of Canada. In 2017, to mark the 150th anniversary of its first sitting, the Canadian Senate created a medal to celebrate the achievements of Canadians who have made significant contributions to their community.

An estimated 5000 Canadians live with SCD.

100 Most-Accomplished Black Women Nomination

Lanre Tunji-Ajayi in September 2018 also received an award as one of the 100 most Accomplished Black Canadian women. Her husband, Elder Timothy Tunji-Ajayi, Founder, SCAGO accompanied her to receive the award. It was also the month of the couple's 25th wedding anniversary.



'CJ' Johnson's Battle With Renal Medullary Carcinoma

continued from page 18

Essential Chiropractic, and others. We have also partnered with As One Foundation, MD Anderson Cancer Center, City of Houston, Sickle Cell of Houston, and RMC Alliance, an organization comprising physicians, scientists and advocates from around the world established to study and understand the biology of RMC.

Keepin' It Renal 5Km Run/Walk, is our major fundraiser. We have donated funds to MD Anderson Cancer Center for the past three years for RMC research. We also distribute SCT educational materials to families and physicians. We give financial and emotional support to patients and families that have either lost or has someone currently diagnosed with RMC.

I visited Washington DC several times with the American Cancer Society - Cancer Action Network to tell my story as to how this rare cancer affected my family.

We have established a scholarship fund for college-bound youth majoring in the medical field.
I am, in addition, a member of the Houston Sickle Cell Collaborative group (HSCC).

What challenges do you see ahead and how do you expect to overcome same?
Disparities in healthcare and funding from the federal government will be the main challenges. We need a surveillance system in each state and eventually centralize all information/data. With awareness and increased advocacy, change will happen. However, we must all learn to work together to make a greater impact.

Chris Johnson Foundation

In his lifetime, Chris wanted to establish a Foundation to spread awareness about SCT and its association with RMC. How does his family feel doing this in his memory?

It was while Chris was receiving his treatment that he noticed a lack of information about SCT and RMC. Despite the fact that RMC has been described in the medical literature for over two decades, many questions remain unanswered. Addressing them is critical in order to optimize the future care of this patient population. The family is very supportive of the foundation and its goals. Chris's legacy lives through this foundation and we will make every effort to fight against RMC and SCT through advocacy, education, support and research.

When did you decide to write about Chris' battle with RMC?
I decided to write the book in the latter part of 2013. Each time I attempted to write about my son's battle with RMC, I became mentally exhausted and would stop and then start again. It wasn't until 2017 that I felt that I was emotionally prepared to complete the book. Reliving our 15-month journey was difficult. I cried and had moments that I felt as if I could not proceed, but God gave me strength to press through the heartache and pain. I knew that

continued on page 32

Sickle Cell Trait and The Eyes

Tips For Eye Specialists to Protect Patients' Vision

from cdc.gov

People with sickle cell trait (SCT) who experience an eye injury are more likely to develop glaucoma post-hyphema. This condition can lead to impaired vision and may even cause permanent eye damage. Therefore, if you have a patient with SCT who has suffered an eye injury, it is important that they are evaluated right away by an ophthalmologist who can closely monitor their care.

What is glaucoma post-hyphema?

Hyphema, the presence of blood in the anterior chamber of the eye, may follow eye injury. It occurs at a rate of 2 per 10,000 individuals in the general population. Glaucoma, or increased intraocular pressure, may occur after hyphema, and in that case is known as glaucoma post-hyphema.

Who is at risk for glaucoma post-hyphema?

People with SCT are at increased risk of glaucoma post-hyphema. Therefore, individuals with SCT and hyphema require urgent evaluation and close monitoring by an ophthalmologist.

What are the signs and symptoms of glaucoma post-hyphema?

Trauma to the eye followed by eye pain, sensitivity to light, and vision changes, such as decreased vision or vision loss, may suggest that a hyphema has occurred. Sometimes hyphema can lead to glaucoma and damage to the optic nerve. So once hyphema has occurred, persistent vision impairment suggests rebleeding or glaucoma. Any trauma to the eye should be treated as a medical emergency, and the individual with SCT should seek immediate medical attention.

What treatments are available for glaucoma post-hyphema in a person with SCT?

Treatment of hyphema in individuals with SCT should be provided by an ophthalmologist. Initial treatment for hyphema includes eye protection to limit further trauma, and might also require bedrest and sedation for those who are found to have an increased risk for rebleeding. Since there is a significant risk for glaucoma post-hyphema, the ophthalmologist must also be familiar with prevention and management of glaucoma. The ophthalmologist should also be made aware that the person has SCT since some medications used to treat increased intraocular pressure might cause sickling complications in individuals with SCT. If intraocular pressure cannot be managed in 24 hours, surgical intervention will be necessary.

What does a healthcare provider who is taking care of a person with SCT need to know about glaucoma post-hyphema?

Any person with SCT who experiences eye trauma should seek immediate attention and care by an ophthalmologist, and he or she should inform the ophthalmologist about having SCT. People with SCT who experience hyphema should be closely followed to monitor any complications. If urgent care is required, they should go to the nearest emergency room.

NABH & JCI Accredited

ARTEMIS
HOSPITALS
OUR SPECIALITY IS YOU

Hematology Oncology, Immunology & Bone Marrow Transplant Centre

ARTEMIS ACHIEVES ANOTHER MILESTONE!

100 BONE MARROW TRANSPLANTS IN ONE YEAR

THE VISIONARY BEHIND

Dr. Gaurav Kharya
Sr. Consultant & Head
Paediatric Hematology Oncology,
Immunology &
Bone Marrow Transplant

OUR ACHIEVEMENTS

- First hospital in North India to be Accredited with National Marrow Transplant Program (NMDP, USA)
- Second in the country to get European Society of Blood and Marrow Transplant Accreditation.
- Transplanted one of the youngest patients (4 months of age).
- Transplanted for rarest diseases like Severe combined immunodeficiency and Congenital erythropoietic porphyria.
- Almost 50% of allogenic transplants being haploidentical.
- Transplanted one of the highest risk patients.
- Maximum number of transplants for Sickle cell disease at a single center in India (both matched sibling and haploidentical) making us center of excellence for SCD BMT.
- Honor of organizing the 1st EBMT Highlights for the APAC region.

CONGRATULATIONS TEAM BONE MARROW TRANSPLANT, ARTEMIS

Email: guarav.kharya@gmail.com
Whatsapp/Phone: +91-921-31-32-168

Pastor Found Guilty Of Fraud

By Abro Onyekwe

….. Sentenced To 2 Years In Prison

….. Counsel Set To Appeal

….. Civil Suit For Hearing October

Abel Olukayode Adewale, 58, the Christ Apostolic Church (CAC) pastor renowned for fathering five children with sickle cell has been found guilty of fraud at Court 20, Magistrate Court, Igbosere, Lagos in the Lagos Judicial Division of Nigeria.

In the suit, *Commissioner of Police vs Adewale Olukayode Suit No P/35/2012*, before Hon. Justice Mrs. A.T Owoyele, Pastor Adewale was sentenced to two years in prison without option of fine for employing electronic means to defraud one of Nigeria's biggest banks of the sum of N1 million.

'To whom much is given, much is expected,' Justice Owoyele commented, saying the clergyman has not lived up to his calling as a 'man of God.'

The fraud suit had lasted 5 years and was brought against the pastor by Wema Bank Plc. The Bank had gone on to file criminal charges on the heels of being found culpable for the infringement of the pastor's fundamental human rights. Justice O. O. Femi-Adeniyi had slapped a N2.5 million damages on the Bank in Adewale's favour.

Wema Bank refused to pay damages although it went the extent of failing to honour it's own cheque hurriedly issued after court bailiffs went to seal up its Marina, Lagos Headquarters. Hearing in the civil suit has been fixed for October 10.

Appeal

Barrister Oluyinka Oyeniji, counsel to Adewale, is set to appeal the judgment. He accused Justice Owoyele of 'bias' for not only not giving room for the plea of *allocotus* but also for not allowing the option of a fine. He stated she erred in finding his client guilty.

Reaction

Similarly, Pastor Emmanuel Dickson Ibekwe, of the Deeper Life Christian Ministry, described the judgment as 'nauseating'. Ibekwe, who is also Chairman/CEO, Dabma Sickle Cell Foundation, said the Bank should have considered the morality of pursuing a case of a mere N1 million to such a conclusion.

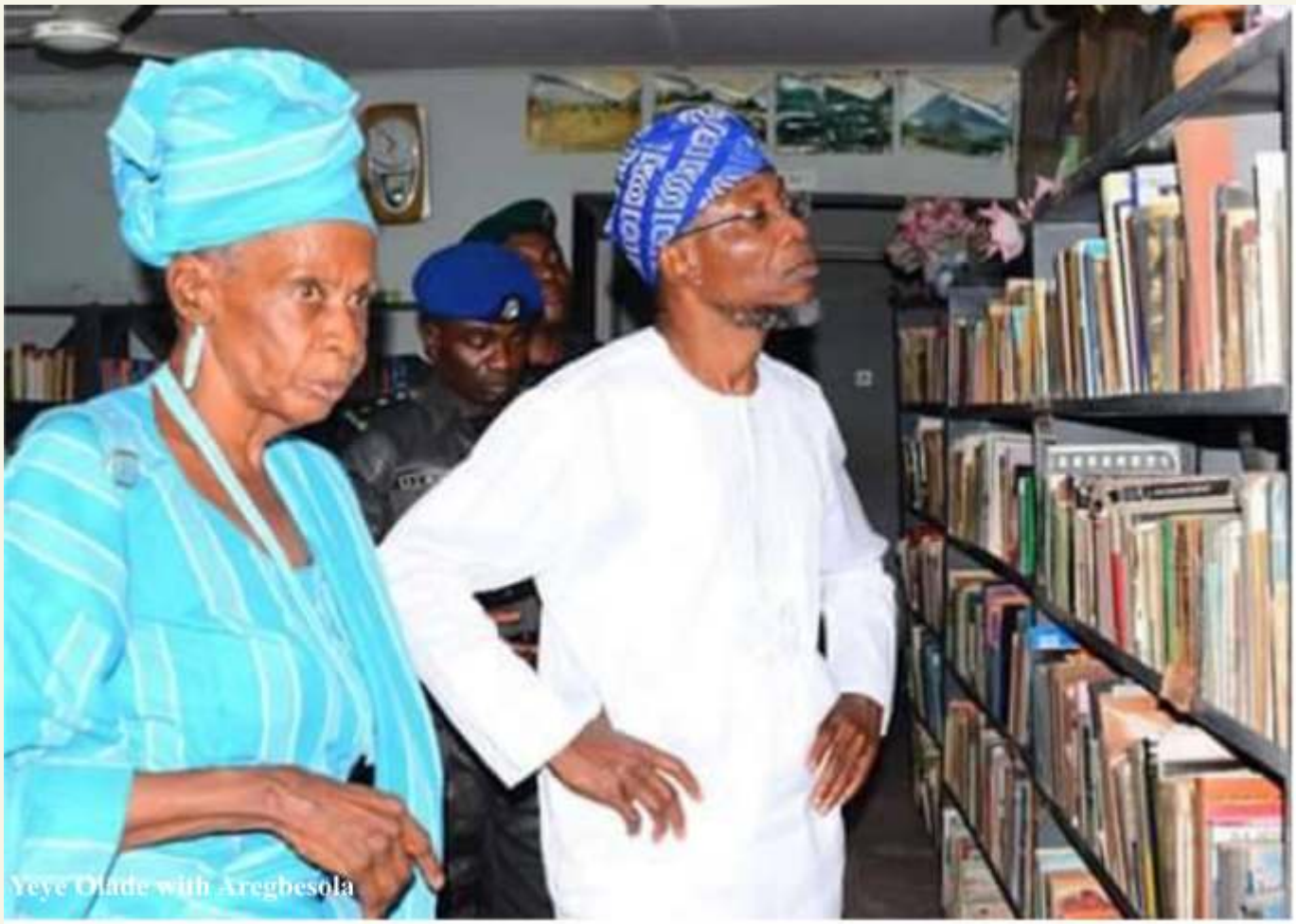
'I am not condoning criminality though,' he said, adding that the judge should have considered the impact of her judgment on the pastor's family.


Adewale

Meanwhile, the pastor's three surviving children with sickle cell anaemia, the youngest of whom is 14 years old, have been left in the lurch, deprived of a devoted father and breadwinner.

WHAT RIGHT HAVE YOU TO SPEND THE MONEY IN YOUR ACCOUNT?

page 30 >>



Yeye Olade with Aregbesola

'Irrespective Of Genotype, Every African Must Do Something About SCD!'

Yeye Akilimali Funua Olade migrated to Africa 40 years ago on the advice of an *Ifa* Priest

By Fatima Garba Mohammed

A chance discussion about sickle cell at one-time Oyo State gubernatorial hopeful Engineer Femi Babalola's Ring Road, Ibadan office got Yeye Akilimali Funua Olade really worked up. Someone at the office had remarked that SCD was not a problem in his family and 'in Jesus' name' would never be one.

Iya, as she prefers to be called, rose up in defence of SCD, saying it was a peculiar Black Race problem, which deserved to be tackled by all Africans irrespective of their genotype.

Anyone who encountered Iya in the street in her *Aso Oke* would be forgiven for assuming she was going to or returning from a festive occasion such as a wedding, naming ceremony or burial. Her friends had told her repeatedly that *Aso Oke* was only worn on special days, but such is her love of *Aso Oke* that she wears them every day. Iya's entire wardrobe comprises only *Aso Oke*! Indeed she has been wearing only that since 1990!

When Iya, now 74, speaks English or Yoruba, you pause for a moment. You know at once she is not a native. Neither the tone nor the delivery of either language is particularly Nigerian.

Born and bred in the United States, her given name, Michele Paul, is but a distant memory. At Oyotunji Village, South Carolina, USA, a *babalawo (Ifa* priest) had advised her husband to go and live in Africa.

Michele studied African History at San Francisco State University, and at the University of California, Berkeley did masters in Librarianship.

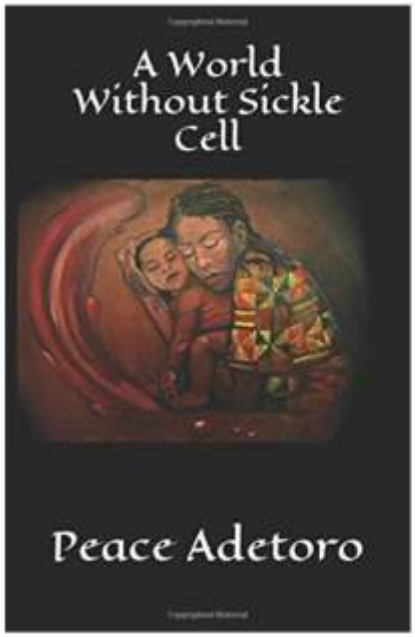
Goodbye, America

In 1978, at the age of 34, Michele packed bag and baggage and moved to Africa; her African-American husband was to join her later. She had applied for and gotten a job with Nigeria's Ministry of Education

continued on page 34

Peace Adetoro's World Without SCD

Sky-diving is not a pastime for the faint of heart - it requires lots of grit, grip and gasp. In 2013, Peace Adetoro went sky-diving to raise awareness for sickle cell.



Writing a book is similarly not for just anyone to dabble into ('a horrible exhausting struggle,' says George Orwell). In 2018, Adetoro released, *A World Without Sickle Cell,* to highlight the myths and stigmas surrounding the disorder.

A World Without Sickle Cell also comes with a hidden homily about the choices people could, should and *must* make before venturing into marriage and procreation.

Share Your Story, Meet Actress Jordin Sparks

Pharmaceutical giant Novartis has come up with a novel story-telling project, *Generation S*, to help rewrite the story of an often misunderstood illness. The project is done in partnership with Grammy®–nominated singer, film and Broadway star Jordin Sparks and the Sickle Cell Disease Association of America, Inc.

NOVARTIS

Sparks herself spearheads the project, sharing the emotional story of her stepsister's battle.

'My stepsister, Bryanna, battled SCD her entire life,' Sparks said.

To enter your story and stand a chance to meet Actress Jordin Sparks in person, visit www.JoinGenS.com.

Adelani Ogunrinade Dedicates *Treasure* To SCD Warriors

Every month – indeed everyday – turns into a sickle cell awareness occasion when you listen to and watch the epic love story, *My Treasure,* penned by songwriter Adelani Ogunrinade. Ogunrinade has been touched by SCD though indirectly and he knows what it is to face the emotional pain and strain of stigmatization.

The lyrics and motions of Treasure (performed by Ogunrinade and Zimbabwean actress Tendai Chitima) are bound to evoke the memories of unconditional love.

(Photo: Ogunrinade with Chitima)

ARE YOU ENTITLED TO EVERY DEPOSIT IN YOUR ACCOUNT?

By Sheu Hassan Maikudi Bsc (Economics) LlB, BL

CBN Governor Emefiele

Most people dream of having lots of money and some would stop at nothing to make that dream a reality.

Having and retaining money requires perseverance, hard work and discipline.

One way you can come into lots of money literally without lifting a finger is if someone makes an unintended transfer into your bank account. You would be surprised that even in this day and age, this can - and does - happen. It happened to Pastor Olukayode Abel Adewale in March 2012 on his savings account with one of Nigeria's biggest banks, Wema Bank Plc.

It requires a micro-second for a bank teller to key the wrong digit when entering an account number during a deposit transaction. Just the same can happen at withdrawals.

In Adewale's case, the transfer did not emanate from human error - a virus in Wema Bank's computer system erroneously transferred the sum of N987000 (about US$6300 at the time). Although he had a history of receiving money from unknowns as a result of media appeals over his children living with sickle cell, he assumed the deposit was a divine answer to his prayers. He went ahead making transfers, making purchases, settling debts, and planning for the future!

It all turned out to be a huge mistake!

ARE YOU ENTITLED TO WHATEVER YOU FIND IN YOUR ACCOUNT?

No, you are not legally entitled to go prodigal with just any deposit into your account. You can only spend money if it was intended to be made into your account. If the deposit was inadvertent - *unintended* - you *can't* keep the money for personal use.

WHAT HAPPENS IF YOU SPEND MONEY SENT TO YOU IN ERROR?

A simple search online would suffice to convince the recipient of an *unintended* windfall of the futility of spending same. People who have received such windfalls have spent part or all of the money on various projects, only to find themselves in deep waters later on. Erroneous deposits have been spent on noble, and charitable causes, yet it has not gone down well with the law. An unwitting cleric who receives unintended financial manna would probably want to build a church or mosque; likewise, a doctor who believes he is entitled to his windfall would want to expand his medical services, etc.

CRIMINAL OFFENCE

Sooner or later a bank would trace where an unintended deposit went and reverse the transaction. If a mere cent is missing, the bank would act as if it was thousands and press criminal charges. Depending on the discretion of management, charges could be dropped with orders to repay.

Should the matter go to court, the offender is left at the mercy of the judge. A judge might decide to fine the offender and/or issue a prison sentence.

A Blood Stem Cell Transplant Study For The Severely Affected

Study Description

Brief Summary:

Blood stem cells can produce red blood cells (which carry oxygen), white blood cells of the immune system (which fight infections) and platelets (which help the blood clot).

Patients with sickle cell disease produce abnormal red blood cells. A blood stem cell transplant from a donor is a treatment option for patients with severe sickle cell disease. The donor can be healthy or have the sickle cell trait. The blood stem cell transplant will be given to the patient as an intravenous infusion (IV). The donor blood stem cells will then make normal red blood cells—as well as other types of blood cells — in the patient. When blood cells from two people co-exist in the patient, this is called mixed chimerism.

Most children are successfully treated with blood stem cells from a sibling (brother/sister) who completely shares their tissue type (full-matched donor). However, transplant is not an option for patients who (1) have serious medical problems, and/or (2) do not have a full-matched donor. Most patients will have a relative who shares half of their tissue type (e.g. parent, child, and brother/sister) and can be a donor (half-matched or haploidentical donor).

Adult patients with severe sickle cell disease were successfully treated with a half-matched transplant in a clinical study. Researchers would like to make half-matched transplant an option for more patients by (1) improving transplant success and (2) reducing transplanted-related complications.

This research transplant is being tested in this Pilot study for the first time. It is different from a standard transplant because:

Half-matched related donors will be used, and
A new combination of drugs (chemotherapy) that does not completely wipe out the bone marrow cells (non-myeloablative treatment) will be used to prepare the patient for transplant, and
Most of the donor CD4+ T cells (a type of immune cells) will be removed (depleted) before giving the blood stem cell transplant to the patient to improve transplant outcomes.

It is hoped that the research transplant:

✡Will reverse sickle cell disease and improve patient quality of life,
✡Will reduce side effects and help the patient recover faster from the transplant,
✡Help the patient keep the transplant longer and
✡Reduce serious transplant-related complications.

INCLUSION CRITERIA

Ages Eligible: 18 Years to 45 years
Sexes Eligible: Both
(The Study is not accepting healthy volunteers).

Eligibility Criteria

Inclusion:

- Confirmed diagnosis of HbSS or S-β° Thalassemia sickle cell disease
- Severe disease status as defined by presence of one or more of the following:
  - Clinically significant neurologic event (stroke) or any neurological deficit lasting > 24 hours; or increased transcranial Doppler velocity (>200 m/s)

continued on page 33

'My Heart Skipped A Beat Each Time My Son Said, 'Mama, I'm Tired!"

- Mrs. Ritchie Johnson

continued from page 23

writing the book would hopefully help someone that may be on or had been on the same journey as me. It is my desire to turn my loss into something positive by being an advocate for RMC and SCT.

What informs the title – '*MAMA, I'M TIRED*'?
I actually changed the title several times as I wrote the manuscript. I remember vividly that Chris would say 'Mama I'm Tired' and was ready to give up because he was in so much pain during the later stage of the disease. Each time he would tell me that he was tired, my heart would skip a beat. So therefore after reading the final manuscript, I decided that *'Mama, I'm Tired' - A Mother's Journey Through Her son's Cancer Battle With Renal Medullary Carcinoma* would be the appropriate title for my book.

As a Nurse, did you ever have to take care of anyone with RMC prior to your son's diagnosis?
As a nurse of 40+ years I had not been aware of any patients with RMC until Chris was diagnosed.

What do you think is the outlook for SCT research in the next 20 years?
I think that as we continue to heighten awareness, medical schools will be mandated to incorporate SCT in their curriculums and have more than a 5-minute discussion. Telling patients that if you have SCT, you can live a healthy life without any problems will be replaced with proper caveat and education. More research funding will be allocated so that researchers will be able to explore and understand the nature of SCT without constraints. It is my prayer that this blood disorder will soon be history.

Trump On SCD Awareness Month

continued from page 20

slowing or blocking blood flow, causing pain and progressive organ damage, and reducing life expectancy.

While the disease disproportionately affects African Americans, other racial and ethnic groups can also be affected.

Bone marrow and stem cell transplants are the only current forms of treatment with the potential to cure this disease. These procedures have a high disease-free survival rate, but it can be difficult to find a matching donor.

My Administration is committed to supporting research to develop a cure to SCD that is available to all people, expanding on the achievements of current treatment options. Clinical trials to accelerate the development of new gene and cell-based therapies within the next 5 to 10 years will be conducted as part of the National Institutes of Health's Cure Sickle Cell Initiative, which will launch this month.

Additionally, we are working to better train healthcare providers to identify individuals with SCD and improve the quality and continuity of their care from infancy through adulthood. As a result of the many advances and medical breakthroughs in genetic therapies and research, we are now closer to finding a cure for all SCD patients.

This month, we celebrate the progress made in treating Americans suffering from SCD and renew our commitment to end this disease.

CLINICAL TRIALS

continued from page 31

A stroke is defined as a sudden neurologic change lasting more than 24 hours that is accompanied by cerebral magnetic resonance imaging (MRI) changes.

- History of ≥ 1 episodes of acute chest syndrome (ACS) in the 2-year period preceding enrollment despite the institution of supportive care measures (i.e. asthma therapy and/or hydroxyurea).
- History of 2 or more severe vaso-occlusive pain crises (VOC)/year in the 2-year period preceding enrollment despite the institution of supportive care measures (i.e. a pain management plan and/or treatment with hydroxyurea). A severe VOC is defined as an episode of pain lasting more than 2 hours severe enough to require care at a medical facility. Note that priapism that lasts more than 2 hours and requires care at a medical facility is also considered a VOC.
- Osteonecrosis of 2 joints despite the institution of supportive care measures.
- Prior treatment with regular RBC transfusion therapy, defined as receiving ≥ 8 transfusions per year for > 1 year to prevent vaso-occlusive clinical complications (i.e. pain, stroke, and acute chest syndrome).
- No HLA matched sibling or 10/10 matched unrelated donor
- Failed prior hydroxyurea therapy or have intolerance to hydroxyurea
- Meets protocol specified organ function criteria
- Women of childbearing potential or sexually active male: Agreement to use adequate contraception prior to study entry and 6 months post-transplant.

Exclusion Criteria

Those who are or who have had a ---

- Prior stem cell transplant.
- Prior bone marrow transplant
- Concurrent other investigational agents, chemotherapy, biological therapy or radiation therapy.
- Planned use of moderate and strong CYP3A4 inhibitors.
- Active infection.
- Major surgery within the last 30 days.
- Clinically significant liver fibrosis or cirrhosis if on chronic transfusion therapy > 6 months.
- Active malignancy (other than non-melanoma skin cancers).
- History of allergic reactions attributed to compounds of similar chemical or biologic composition to any in the pre- or post-transplant regimen.
- Women of childbearing potential: pregnant or breastfeeding -

are not eligible to participate in the study

Sponsors and Collaborators

City of Hope Medical Center, California Institute for Regenerative Medicine

Contacts

Joseph Rosenthal, MD
626-218-8442
jrosenthal@coh.org

Teresa Kim, RN
Phone: 626-218-0263
Email: teresakim@coh.org

Responsible Party:
City of Hope Medical Center

Clinical Trials Identifier:
NCT03249831

'Getting my African name on my passport is my final repudiation of my slave name, Mitchell Paul,'

- Yeye Olade

continued from page 28

Picture: Yeye with Osun Gov Aregebsola

and assigned to the Federal Government Girls College, Ilaro.

It was the perfect setting in which to raise her children (the oldest of whom was 12 at the time), away from what she considered the decadent culture of her birthplace.

'I think being raised in America is the worst thing that could happen to a child,' Iya asserts.

English is a forbidden language in her home. She hired locals to steep her children in Yoruba language and culture. Needless to say, all Iya's children speak Yoruba fluently. And they bear Yoruba names too. For herself, she picked a combination of Swahili, and Yoruba names to answer to. Her American passport bears her African names.

'Getting my African name on my passport is my final repudiation of my slave name, Michele Paul,' Iya submits. Her husband, formerly Christopher Leon Williams transformed to an *agbada*-donning Ayantuga Olade.

The children are all back in the US and married to Yoruba spouses. Yam pounding in a traditional mortar is nothing to them!

Life in Retirement

Iya is now Chief Librarian at Dr. Bayo Adebowale's African Heritage and Research Library and Cultural Centre, perhaps the biggest privately-owned African Studies library in Africa. The library is located at Adeyipo Village, Igbo Elerin in Lagelu Local Government Area, Ibadan.

An adherent of the teachings of Mary Baker Eddy (Christian Science), Iya says she has not taken any medication since she was 11. 'Christian Science helps me to keep healthy,' she asserts.

Politics

Iya has wormed her way into the political ring in her adopted country, particularly in southwest Nigeria. She is well known to governors and the powers that be in every notable political party.

Iya is also known to monarchs – and to people monarchs want to know! She has visited with and has been visited by the cream of Yoruba society including Ogbeni Rauf Aregbesola, outgoing Governor of Osun State and Gani Adams, *the Aare Ona Kakanfo* (Generalissimo) *of Yorubaland.*

Sickle Cell

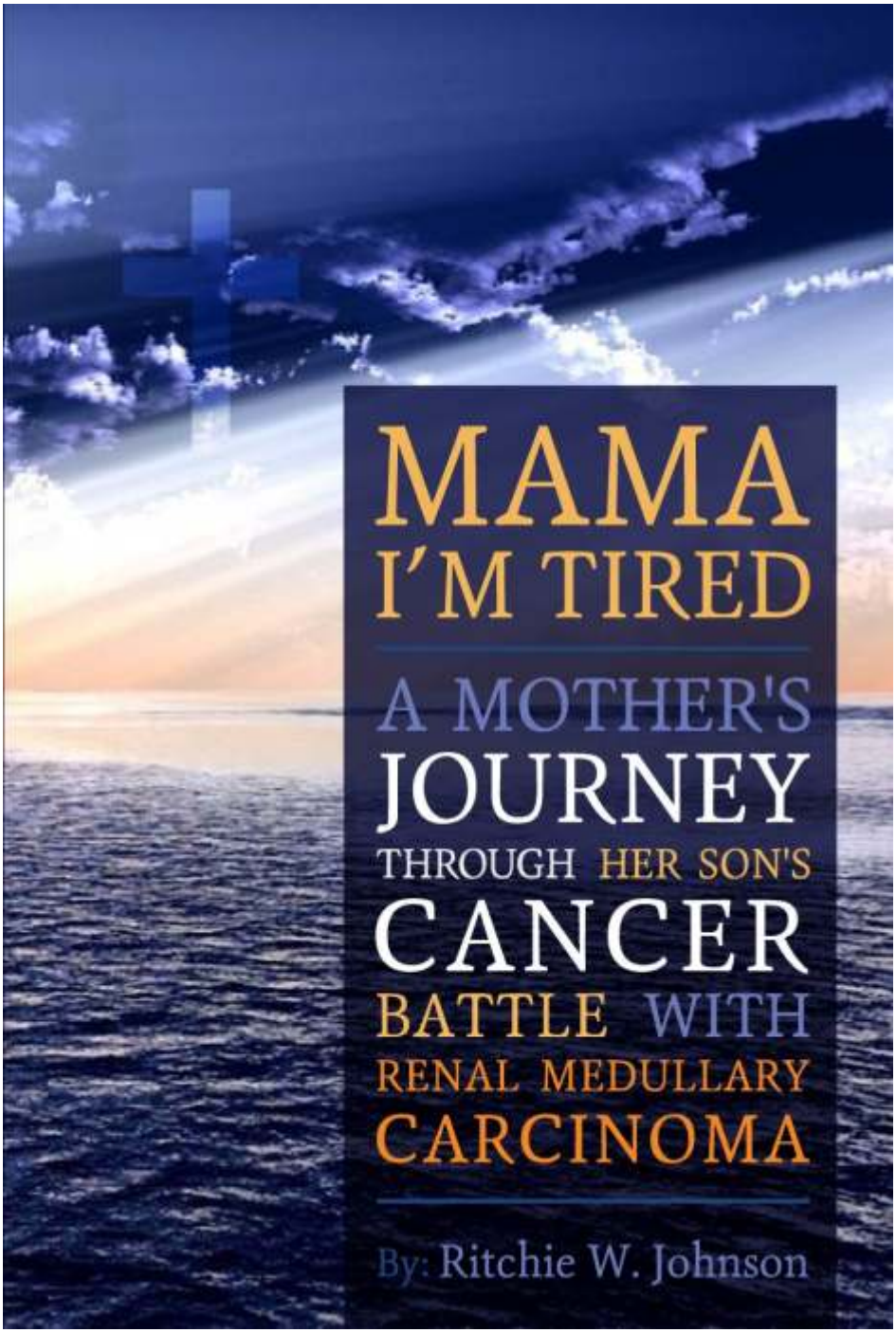
The septuagenarian is not particularly impressed with the way Africa has been handling the SCD crisis of ignorance, myth and misconception.

'Sickle Cell is predominantly a Black Race problem,' she posits, 'and Nigeria must take the lead in finding a solution.'

No Regrets

Iya has never regretted her decision to settle down in Nigeria. In 40 years since migrating to Africa, she 'very reluctantly' visited the United States twice – in 1998 when she went to collect a poetry prize, and in 2007 when her mother was gravely ill. Her mother passed away two years later.

Iya Funua Olade considers African culture far superior to any other and enjoins Africans to celebrate their own history by giving meaningful African names to their children.



Thirty-nine years into her nursing career, Ritchie Johnson was making plans to retire soon.

She dreamed of relaxing and traveling around the world. Until her youngest son, Chris, was diagnosed with a rare, aggressive, and fatal kidney cancer, known as Renal Medullary Carcinoma (RMC).

Ritchie placed her nursing career on hold so that she could fully care for her son. She and Chris had many questions and few answers.

They both faced untold challenges and difficulties, but, nonetheless, held on to their faith in order to overcome the obstacles.

Mama, I'm tired is a reflection of the unconditional love that Ritchie demonstrated towards Chris while he endured this catastrophic illness that eventually led to his death.

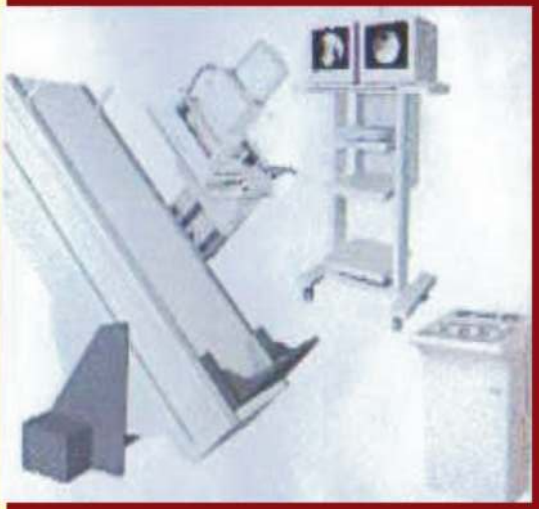
After losing her son 15 months after his diagnosis, she turned her tragic loss into something positive by becoming an advocate for RMC.

Order your copy:

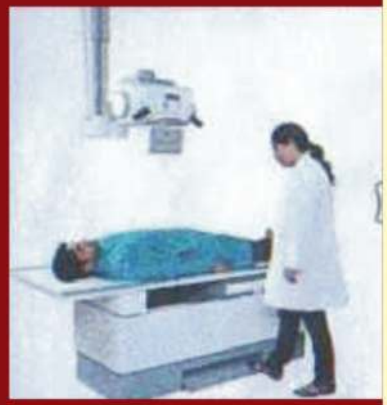
www.amazon.com/Mama-Im-Tired-Medullary-Carcinoma/dp/1718882408

WHEN IT'S ABOUT LIFE...

• SALES • REPAIRS • MAINTENANCE



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



BAATS

CLINICAL ENGINEERING NIGERIA LIMITED

QUEEN ELIZABETH ROAD, BESIDE THE CASTEL HOTEL, AYANNA HOUSE, TOTAL GARDEN, IBADAN, OYO STATE.

Tel: +234 (0) 8035030935, +234 (0) 7031549936,

baats2000@yahoo.com, www.baats.org

DELIVERING VALUE

Our driving force is to ultimately satisfy and exceed the expect ations of our clients. Therefore, at SIFAX Group, we deploy the latest technology and equipment, first-class workforce, creative processes and standards in the provision of prompt, effective and qualitative services and solutions in all our areas of operations.

OUR SERVICES:

- Port Operations
- Airport Ground Handling
- Bonded Terminal
- Freight Services (Air & Sea)
- Haulage & Logistics
- Shipping
- Stevedoring

SIFAX GROUP

54, Warehouse Road, Apapa, Lagos
+234 8105376814, +234 8105364016,
+234 9097970403, +234 -1-7120041
E-mail: info@sifaxgroup. com, www.sifaxgroup.com

GHANA: G9 Community 8 (Opposite Community 8 Market)
Tema
+233 303 305258, + 233 303 305259
sifaxltd@yahoo.com

USA: 8180, Southwest Freeway,
Houston, TX 77074
+ 1-281 820 9000, +1 832 230 2677

SCELL MEDIA RESOURCES

Publishers of African Sickle Cell News & World Report

Like this magazine? Appreciate this free e-copy?

Do make a donation to support our work!

Account Details:

NIGERIAN/WEST AFRICAN DONORS ONLY

Name of Account: Scell Media Resources

Bank: First Bank of Nigeria Plc

Ac No: 2011666024

OR

Name of Account: Scell Media Resources

Bank: GTBank Plc

Ac No: 0015151637

OVERSEAS DONORS ONLY

Name of Account: Scell Media Resources

Bank: First Bank of Nigeria Plc

Ac No: 2011666055 (US Dollar)

OR

Name of Account: Scell Media Resources

Bank: GTBank Plc

Ac No: 0210773919 (US Dollar)

SCELL MEDIA RESOURCES

Publishers of African Sickle Cell News & World Report

We're lost without adverts!

Without advert, we will not be able to keep up producing this magazine, much less provide it for free!

Your advert goes a long way not just in publicising your products/services, but also in shaping and intensifying global sickle cell awareness.

To advertise, please send an email to **sicklecellnews@gmail.com** OR **scdjournal@yahoo.com.**

Ghana, Canada, USA, UK, Nigeria, India, Uganda