SICKLE CELL
NEWS & WORLD REPORT
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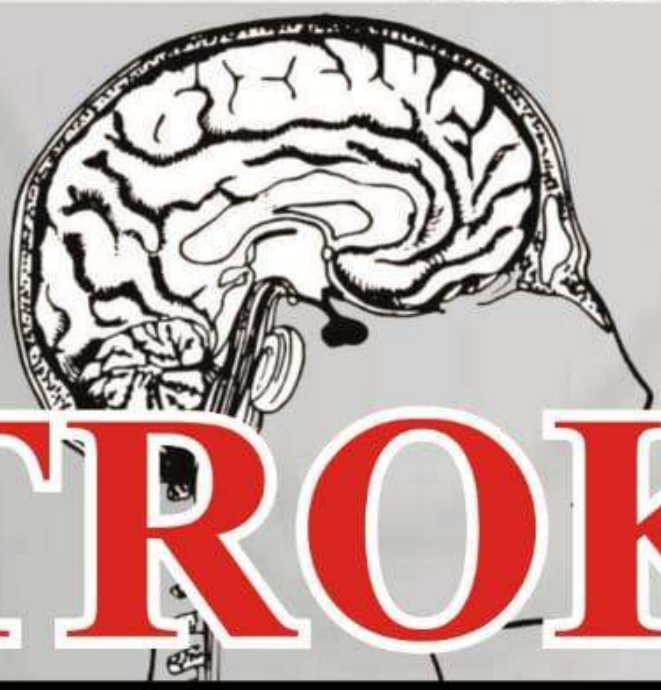

STROKE

IN SICKLE CELL ANAEMIA

'Brain Attack'/'Cardiovascular Accident'

WARNING SIGNS - MANAGEMENT - PREVENTION

'MY SON HAD FIVE MAJOR STROKES, COUNTLESS MINI-STROKES - AND BOUNCED BACK!'

- Carol Nwosu, CEO, Sickle Cell & Young Stroke Survivors, UK

FROM AUSTRIA WITH LOVE

Sulzner Sickle Cell Anaemia Foundation Begins Work in Uganda

New Medications Coming That Would Revolutionize SCD Treatment and Management'

PROF. LEWIS HSU

Director, Children's Hospital - University of Chicago

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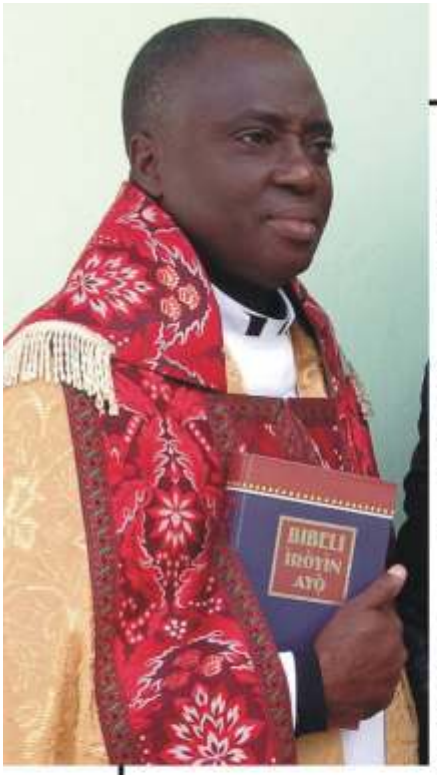

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Mission:
To inform, teach and help reduce the burden of sickle cell on family and society

Vision:
To be the world's best-known resource magazine for the world's most commonly-inherited blood disorder

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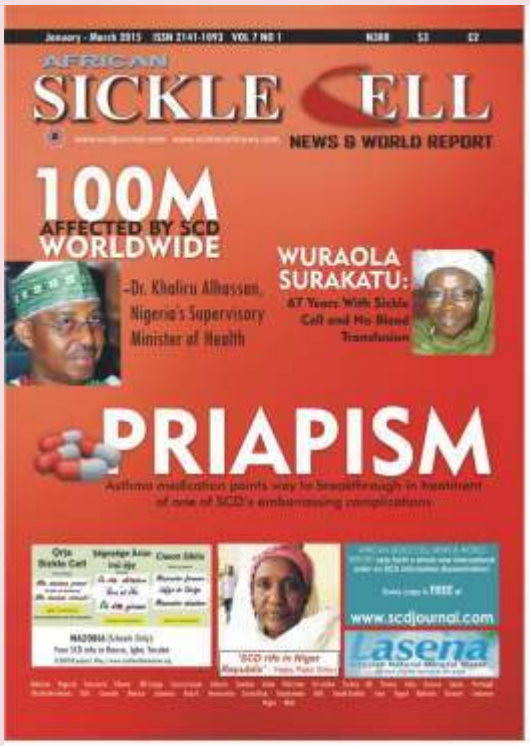


FEEDBACK

Letters, comments bearing date, full name and address of author should be sent to **feedback@scdjournal.com**

It's Awesome!

I came about this magazine by chance online. It's simply awesome. I agree with the editorial statement that what Africa cannot achieve in research, it can at least achieve in sensitization.

With this magazine, Nigeria Africa is truly playing a leading role in global education about one of the world's challenging public health phenomenon.

I will keep watching out for your Portuguese translation. Welldone!

Gabriel Pereira PhD, Rio De Janeiro, Brazil

67 Years Without Blood Transfusion

Blood shortage is a common problem in SCD generally. The worst affected are those with homozygous SS, who must now and then have blood transfusion, some more frequently.

It is certainly amazing that Alhaja Koiki-Surakatu has never received blood in her 67 years, not even at any of her five childbirths. Although her genotype is SC, it is no less remarkable.

Dr. Iyere Okoronkwo, Kumasi, Ghana

Pria-What

I am in my late teens with sickle cell. I prefer to keep to myself rather than mix with fellow-sufferers. Until I came across your January-March 2015 edition at Ikorodu Town Hall Library, I had never heard of the word *Priapism*.

I have since decided to join the Sickle Cell Club in my area and pass to others whatever I read in this magazine. I can't hide anymore!

Majaro Areo, Ijede, Ikorodu, Nigeria

The Boy Who Would Take A Recording

I read the touching story of the boy who wanted surgeons to take a video recording of his surgical treatment for priapism (*A Patient's Unusual Request*). He wanted the video taken so he could teach his wealthy father a lesson.

I commend the patient's perceptiveness. No amount of money thrown at an illness such as SCD can compensate for lifelong discomfort.

Florence Idia-Ngumoha, Owerri, Nigeria

How Does One Obtain The Print Version, Past Editions

Having this magazine online is a great contribution to the socio-medical aspects of SCD. All the same, I would like to obtain the hard copies, including past editions for my neighbourhood public library. I would also like to subscribe to the print edition.

How do I go about this?

Harry Winnecker, Bolton, UK

https://sicklecellnews.com

Welldone!

Sickle Cell News makes for very interesting reading. I am glad you have been able to draw the attention of your readers to the availability of free SCD resources in Yoruba, Hausa and Igbo.

Simon Dyson, Professor of Applied Sociology, De Montfort University, Leicester LE1 9BH UK

My Interaction With SCD

By Olumide Akintayo

My first experience with sickle cell was about 31 years ago. I was an undergraduate at the Faculty of Pharmacy, University of Ife (Now Obafemi Awolowo, University, Ile-Ife). The Drug Research and Production Unit (DRPU) of the Faculty was neck deep into research on the now famous *fagara* plant headed by the late Professor Abayomi Sofowora who identified the anti-sickling properties of *fagara*.

Sickle cell anaemia remains a torturous and painful clinical disease state disproportionately peculiar to the black race.

From a practical perspective sickle cell disorders are completely avoidable through counselling and advocacy. These procedures are best handled by individuals and families with SCD, social organizations and healthcare providers.

Professional body platforms like the Pharmaceutical Society of Nigeria (PSN) can facilitate collaboration between research bodies like the National Institute for Pharmaceutical Research and Development (NIPRD) and the pharmaceutical industry.

The PSN can also organize regular train-the-trainer workshops on the treatment and management of sickle cell disorders.

Pharm Akintayo FPSN, FPCPharm, FNAPharm, FNIM is President, Pharmaceutical Society of Nigeria

Strokes of Luck, Strokes of Blessedness

Two specialists on opposite sides of the globe gave strikingly similar answers to our reporters' questions last month.

In an interview with Professor Lewis Li-yen Hsu of the University of Illinois, Chicago, our reporter asked why some in the most developed countries get a disappointing deal from SCD while some in resource-poor circumstances seem fairly fortunate.

'It's probably the result of good genes that modify disease severity or *just being blessed*,' says Professor Hsu.

The second reporter, in an interview with Dr. Biodun Ogungbo, a popular neurosurgeon in Nigeria, asked why some who are perceptibly at risk for CVA or stroke never experience it while the apparently healthy ones do.

'It's probably due to *luck*', Dr. Ogungbo says.

The specialists' response underline the fact that in life the sums are not always what the quantities suggest.

Ayoola Olajide


Adewale

No End in Sight to Adewale-Wema Bank Tussle

The protracted legal wrangling between Pastor Abel Olukayode Adewale and Nigeria's first indigenous bank, Wema Bank Plc rages on.

Pastor Adewale, 55, the celebrated father of five children with sickle cell anaemia (now down to three), is accused of stealing N1m by electronic means from the bank. The bank, under the headship of Segun Oloketuyi, continues to pursue a criminal case against the pastor and refuses to pay damages (N2.5m) or issue a public apology two years after being found guilty of violating the pastor's fundamental human rights. In February 2015, Adewale escaped being issued a bench warrant after he appeared in court despite instructions not to so do. It would have been the second time he would unwittingly not show up in court for a hearing - and the second time a bench warrant would be issued against him.

'Wema Bank can afford the best attorneys and wait till kingdom come for a judgment.' Adewale says, in reference to the financially costly and morally sapping adjournments the protracted matter had spelt for him and his family. So far the case has witnessed 42 adjournments within 3 years.

Meanwhile, a video released on Youtube about the plight of the Adewales is making huge waves online and generating renewed interest in the Family. *A Family's Challenge* can be watched at **https://www.youtube.com/watch?v=Nq8iwSoCgzw**. By this video, *Sickle Cell News* has received a number of donation enquiries for the family from public-spirited Nigerians.


Oloketuyi

Surgeons Perform World's 1st Penis Reduction Operation

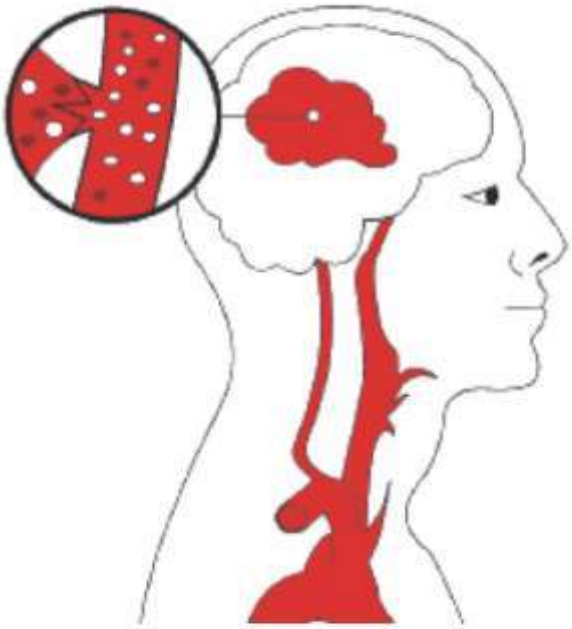
Demand for penis enlargement is the norm for doctors by men dissatisfied with the size of their organ. A request for reduction is unheard of. However, a 17-year old boy has become the recipient of the world's first ever penis-shrinking surgery. Several episodes of ischaemic priapism from the age of 10 had left the boy's organ bloated, fibrous and misshapen.

There was no surgical precedent for urologists to follow; so they adopted a technique learnt from the treatment of Peyronie's disease, a condition that causes the male organ to bend.

Prior to the historic surgery, the boy's penis was described as being as big as an American football or grape. The boy, who has sickle cell anaemia, is a keen footballer. At its flaccid state, the organ was seven inches in length and an unmanageable 10 inches in circumference. When erect it does not increase in size, it only becomes firm.

The operation took place in November 2014 but the report only emerged in February 2015 in the *Journal of Sexual Medicine*.

The operation was pioneered at the University of South Florida by urologist Dr. Rafael Carrion, director of USF's Sexual Medicine Program.



BRAIN: Master Organ, Comptroller Of The Body

Without Brain, Body can't feel, taste, swallow, smell, love, see, hate, plan, reproduce, grow, drive, think or sin ...

By Titi Aladei with input from The Stroke Association, UK. Image: Stroke Association UK

The human brain is one of the most complex objects in the universe. Although it weighs less than 3 pounds, it manages everything from our heart rates to our thoughts and feelings.

Scientists have studied the brain for centuries. By the 1800s, they could still make out only the regions visible to the naked eye. Today scientists know much more about the brain and its functions. The brain's many regions are connected by some 100,000 miles of fibers called white matter enough to circle the Earth four times. Thought, feeling, sense, action, behavior - all derive from complex interactions among billions of nerve cells in the brain.

Like every organ, the brain needs nutrients to perform well. The nutrients are carried by circulating blood. A diminished supply of blood from whatever source deprives the master organ of its basic requirement to keep the human frame going.

A stroke is a brain attack. It happens when the blood supply to part of the brain is cut off.

Blood carries essential nutrients and oxygen to the brain. Without blood, brain cells can be damaged or destroyed and they won't be able to do their job.

Because the brain controls everything the body does, a stroke will affect the way the body functions. For example, if a stroke damages the part of the brain that controls the right leg, then the individual may experience weakness or numbness in that leg.

The brain also controls how you think, learn, feel and communicate.
A stroke is sudden and the effects on the body are immediate. Your doctor may use the following terms:

CVA – this stands for **cerebrovascular accident** (the medical name for a stroke).
It is better to say 'stroke' as strokes are not accidents – there is always a cause.

Infarction – this means an area of brain tissue hasn't received its blood supply and as a result it has been damaged.

Every year there are about 152,000 strokes in the UK. That's more than one every five minutes. Most people affected are over 65, but anyone can have a stroke, including children and babies.

Strokes are not accidents as there is always a cause

STROKE

By Fatai Sulayman, MB.BS

Normally, stroke of any type is rare in the young, but it can and does happen. In March 2015, Nigeria's biggest radio network, *Radio Nigeria*, reported the case of Enikejimi Olayide, a two-year old child who came down with stroke. The child was not with sickle cell. Specialists at the Federal Medical Centre, Abeokuta told the child's perplexed father the stroke was caused by an 'infection'.

In sickle cell anaemia, where blood cells can clump together to block any blood vessel, such an event can happen within the brain, leading to what is called an *'ischaemic stroke'*. Depending on what part of the brain is affected, the effect is seen in distortions of speech, sight, movement, thinking, taste, perception, and so on.

At LAUTECH Teaching Hospital, Oshogbo, a woman is seen tagging along a six-year-old boy, her son. She held his hand tightly as one would that of a one or two year-old child who was not yet confident on his own feet. If she lets go of him for one second, the boy would fall flat on his face. Ischaemic stroke had taken away his sense of balance. It had also affected his speech and there is a permanent crease at the corners of his mouth as though something he had heard was not funny enough for a full laugh.

Mrs Peace Elemele*** faithfully attends the monthly meetings of the Sickle Cell Club at the Federal Medical Centre Ebute-Metta, Lagos. She is anxious to learn as much as she could about a disorder that affects two of her three children. Occasionally she tags them along too: her four year-old looks so healthy and active you would dispute he was with sickle cell. His seven year-old sister is rather austere in body build and pale: she had a mini-stroke, which rendered her right arm too weak to grab anything. At school and at home, she is learning the very difficult task of applying the unaccustomed left hand to her assignments.

According to *Wikipedia*, a stroke is the second leading killer of people under 20 who suffer from sickle cell anaemia. In Africa, reliable statistics for stroke casualties in SCD are lacking; in England, experts state that of the 350 children born with sickle cell anaemia every year, 100 (28.5%) will suffer a stroke by their 9th birthday.

Strokes occur because of a problem with the blood circulation to the brain. In children, strokes usually result from narrowing or closure of the vessels that take blood to the brain. If the blood flow is decreased, parts of the brain do not get the oxygen that is necessary for the brain to function, and may result in problems such as weakness in an arm or leg, difficulty talking or understanding what others are saying, memory problems, or other losses of function. These problems may be temporary or permanent.

How Can You Tell If Someone Is Having A Stroke?

Give The FAST Test

This simple test can help you recognize the signs of a stroke.

F–Facial weakness: Can the person smile? Has their mouth or an eye drooped?
A – Arm weakness: Can the person raise both arms?
S – Speech problems: Can the person speak clearly? Can the person understand what you say?
T – Time to call the emergencies services for prompt attention

Facial drooping
Stroke Assn, UK

*** not her real name

Gloria and her mother

COVER

STROKE: Signs Missed, Signs Overlooked, Signs Misconstrued

By Tosin Fawemida

Titilayo Abolarin, 38 remains optimistic about the future of her children, the both with sickle cell anaemia. The elder, Gloria, 14 looks like your normal prepubescent, only that she still bears the stamp of a stroke she had when she was nine. The stroke affected her right side.

Her brother, Victor, 11 was found to be borderline for stroke by Trancranial Doppler (TCD). Both are on different doses of hydroxyurea to manage and prevent one of SCD's most damaging complications.

Their father is in Lagos. Both he and Titilayo knew about sickle cell but not about their own status - he, a university graduate, she a First School Leaving Certificate (Pry 6) holder. His influence has been so profound that his wife speaks English as though she had been to university herself.

Gloria was scarcely more than 3 years old when she fell ill with malaria. Within days, her urine and eyes turned yellowish. At St, Mary's Hospital, Eleta, Ibadan, the doctors diagnosed SS. That week, the parents knew their own status as carriers of the sickle trait as well as the genotype of their baby son, Victor.

Signs Missed

With the benefit of hindsight, perhaps Gloria's stroke could have been nipped in the bud. Subtle signs manifested, but having no previous knowledge or forewarning about the complication, the signs were put down to external sources.

First, Gloria complained repeatedly of a headache. Second, hitherto a brilliant student, the child began to fall academically, falling to near the bottom of the class. Her handwriting deteriorated to an illegible scrawl. Sometimes the muscles of her hands became so weak she couldn't grab or hold things. Sometimes while walking her legs would tremble momentarily. *What was the matter with the child?!*

Friends, family and neighbours attributed the events to the machinations of the 'enemy' and recommended the parents to seek divine or native help.

Chronic Blood Transfusion

For several months after her stroke, doctors at the University College Hospital managed the child with monthly blood transfusion. The blood had to be freshly donated. Blood procured from a blood bank was not acceptable.

'It was very difficult getting friends and relatives - two every month - to donate blood for my daughter,' recounts Titilayo.

After a while, friends, relatives stopped picking her calls, knowing she was going to ask them for money - or for blood! Not a few pondered how an illness could strike a child and turn her into a blood-guzzlet.

Return To School

The stroke pulled Gloria back many years. A right-hander, she had to learn to use her left hand - a slow, painful and frustrating

Continued on page 29

I started to notice behaviour quite out of character for my son. He became clumsy, always tripping over and hurting himself, forgetting things. His beautiful handwriting became illegible

(Left) Danny, flanked by loving parents (Right) Carol and Danny, aged 17 Source: scyss.org

'MY SON SURVIVED 5 MAJOR STROKES AND COUNTLESS MINISTROKES!'

-Carol Nwosu

Carol Nwosu *(left),* Founder, *CarDan Sickle Cell Centre*, Owerri, Nigeria and *F*ounder/CEO, *Sickle Cell and Young Stroke Survivors,* London, UK, is concerned that many parents are unprepared for the possibility of a Stroke occurring in their children with SCD. Here, she relates her family's experience in the aftermath of her son's affliction

My name is Carol Nwosu, a Nigerian born and bred in the UK. I am married to Ranti Nwosu and have three children: Obi, Danny and Ruth. I live in England. My second son, Danny, has sickle cell anaemia, and has had several strokes as a result. I run a charity here in London called *Sickle Cell and Young Stroke Survivors (SCYSS)* and the *CarDan Sickle Cell Centre* in Owerri, Imo State, Nigeria.

Danny was always in and out of hospital with crises and other things. We were used to running down to the hospital at 3 am, the time his crises usually starts.

The Signature of A Stroke

When Danny was 6, there was a lull in the disease and we were happy that he had stabilized.

But one day, out of the blue, I started to notice behaviour quite out of character for my son. He became clumsy, always tripping over and hurting himself, forgetting things. His beautiful handwriting became illegible as the days went on. He behaved badly and was hyperactive. Though worried, I put it down to boys being boys.

I knew a child with sickle cell could have a stroke, but I always thought it wouldn't happen to my family.

Stroke

One day he came back from school and couldn't undo his buttons. He was fiddling with them and getting frustrated. I looked at him and instinctively knew something was wrong. I took him to the hospital and they told me he had a virus. We were told to go back home, the virus would dissipate in a matter of days. How wrong they were!

Still dissatisfied, I decided to take Danny to the next Sickle Cell Clinic but it was too late. On

Continued on page 29

NeuroAID™ Enhances and prevents Vascular Outcome After a Stroke

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NeuroAID™

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- NeuroAID™ Has a very safe profile

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- Take 2 capsules, 3 times a day, for 3 months, and up to 6 months if insufficient recovery.

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DREPANOSTAT

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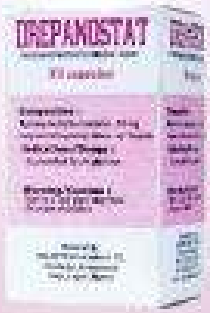
A new original molecule specifically inhibiting the formation of sickled red blood cells brings hope to sickle cell disease sufferers.



- Aids in the production of fetal haemoglobin, which is a disease protective factor is increased during treatment with DREPANOSTAT
- It specially inhibits the formation of sickled red blood cells and prevents destruction of blockformed red cells
- Prevents major complications of SS, SC, SB Thalassaemia
- Rapid onset of action and well tolerated by all ages
- Good tolerance, therefore suitable for long term maintenance treatment
- Lessens pain

DREPANOSTAT: Provides an opportunity to enhance the quality of life in sickle cell anemia patients. It substantially reduces the number of recurrences, absenteeism and hospitalization due to pathology.

INDICATIONS: Treatment and prevention of sickle cell disease acute crisis in SS, SC, associated or not with haemolytic anemia linked to a thalassaemia.

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bolar Pharmaceuticals Ltd

Contrary to perceived ideas, viral hepatitis can be fatal. Viral hepatitis must be treated and on time. Viral hepatitis is probably responsible for most wrong diagnosis of malaria and typhoid.

HEPANTIVIR

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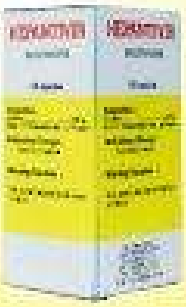
A new original molecule which is a specific antiviral agent actively inhibiting the replication of viruses A, B, C, D, E



- Clear and constant improvement of cytolysis syndrome
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- REAL NOTICEABLE IMPROVEMENT IN PATIENTS:
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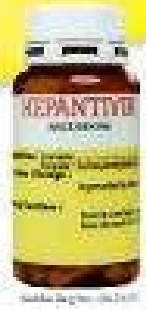
- Excellent tolerance



INDICATIONS: Antiviral treatment of acute (A, B, C, D, E) or chronic (B, C) hepatitis with or without jaundice.

HEPANTIVIR: Should become a standard of care for HBV related chronic liver diseases, as current treatment options for HBV are less than satisfactory or far too expensive.

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NEUROAID: HELP FOR STROKE PATIENTS

Pharm Soremekun

NeuroAiD™, a natural multi-modal stroke recovery treatment was recently approved by NAFDAC, as a natural-based Complementary Medicine. It was developed by Moleac, the innovative Singapore-based company. It was introduced in Nigeria in January 2015, and is now available from **Bolar Pharmaceuticals Ltd**, Lagos, Nigeria. This unique, extensively researched ground-breaking treatment first brought to the international market in 2006 is now available in more than 30 countries worldwide.

According to Pharm Bolade Soremekun, MD/CEO of **Bolar Pharmaceuticals**, Stroke is one of the leading causes of death worldwide and occurs every 2 seconds. Each year 20 million people suffer from the devastating disease. In Nigeria, The WHO and The World Bank estimate that over 196,000 Nigerians suffer stroke every year, and 60% of these die within 6 months of the stroke. The remaining end up with severe disabilities.

While there are generally accepted treatments for acute stroke management such as thrombolytic therapy, they only apply to selected patients. Therefore, it has become imperative to find appropriate therapies to lower the risks of suffering a stroke and increase chances of recovery afterwards. The Nigeria Society of Neurological Sciences (NSNS) dedicated a symposium to the topic as part of its 2014 Annual Congress held in Lagos in which 'New Developments in Neuro-restorative Therapies' and the use of medicines such as **NeuroAiD™** in stroke recovery was discussed.

NeuroAiD™ improves functional outcome and neurological rehabilitation when taken up to six months post stroke.

NeuroAiD™ has undergone extensive double blind clinical trials in Europe and Asia, and is probably one of the most researched natural compounds ever. The product is endorsed by neurosurgeons and neurologists worldwide.

Scientific review has also confirmed the excellent safety profile of **NeuroAiD™** in a cohort of 915 patients. Using the Fugl-Meyer Assessment score, the research concludes that patients on **NeuroAiD™** achieved significantly better results than those on placebo.

On its own, and as an add-on to standard treatment, **NeuroAiD™** improves functional independence and motor recovery and is safe for patients with primarily non-acute stable stroke.

Bolar Pharmaceuticals is an innovative pharmaceutical marketing company based in Lagos, Nigeria. **Bolar's** portfolio includes products like **Hepantivir** for hepatitis, **Drepanostat** for sickle cell, **Edotide** range for diabetes, breast cancer, and enlarged prostate/prostate cancer, **Immiflex** for Immune system, **Hunza** for cancer prevention, and now **NeuroAiD™**.

NeuroAiD™ is now available in more than 30 countries worldwide, including France, Belgium, Spain, Portugal, New Zealand, Greece, South Africa, and Nigeria.

CEREBROVASCULAR ACCIDENT
'Stroke Of God's Hande'

BAMISHE OYEDELE'S FAMILY NEEDS HELP

The Oyedele Family of Abeokuta, Nigeria, is on the verge of penury as mounting cost of treatment for 10-year-old Oluwatibamise puts pressure on family income.

'Bamise', as he is fondly called, was diagnosed with sickle cell anaemia close to his first birthday, and since then has received medical attention at the Federal Medical Centre, Abeokuta. In 2019, when he was six, he suffered his first stroke attack, which affected his right hand and leg. He was placed on chronic blood transfusion and physiotherapy, which quickly drained the family purse.

A year later, he had another stroke, which practically took away functioning in his other leg and left the arm very weak.

For the past seven months, all treatment had stopped for lack of funds.

'Since October 2022, we have had to stop his medications, blood transfusion and physiotherapy - We have simply run out of funds,' laments his doting dad, Hezekiah.

Relations and friends who have been helping are all but worn out - they have their own sea of unmet needs to attend to.

Hezekiah has borrowed massively from the myriad of online loans companies, bait loans he has no means of repaying.

Bamise is the second of four children and the only sickle cell warrior. His father had to quit his job at a private school to attend to his needs 24/7, leaving his wife, a civil servant to fend for the family. He has himself developed health issues spawned by the physical demands of having to lift the child unaided.

Stroke is one of the most-challenging complications of sickle cell. A child with sickle cell is 333 times more likely to have a stroke than a child without SCD. A stroke happens when blood flow to or in the brain is blocked by sickle cells. This blockage slows down or blocks oxygen delivery to the brain.

A child with special needs must have proper medical attention and good feeding. In particular Bamise needs to go back to Exchange Blood Transfusion and physiotherapy. The Oyedeles lack all these luxuries.

Account Details:
Bank Name: FCMB Plc
Account Name: Oyedele Hezekiah Oluwasegun
Account No: 0194247019
Phone no: +2348064104106

Kaka's Friend Encounters Sickle Cell Crises

By Fatimah Garba Mohammed

What with his parents retired, Abimbola Adekunle Kaka, 24, has been working and earning a living for himself for the past five years.

Second-born of three children and the only one with SCD, Kaka recalls always asking his parents about the special condition that marks him out from his peers.

'Mother told me that as an infant I used to cry a lot.'

No one could fathom why he cried endlessly but when, at six months, he presented with swollen hands and feet, doctors immediately diagnosed sickle cell.

Two years after completing secondary school, Kaka was fortunate to get a job at the University College Hospital, Ibadan. On the heels of that, he registered for a part time course in Purchasing and Supply at The Polytechnic, Ibadan.

Away From Home

If for any reason he was not going to spend the night at home, Kaka always ensured to have his medications, especially the painkillers, on his person. Unfortunately, during an unforeseen busy period at The Polytechnic, Kaka had no option than to stay overnight with a course-mate who lived off-campus.

At 1 am, Kaka erupted in excruciating pain crises. His course-mate, like most Nigerian urban dwellers, had heard of SCD, but had never witnessed the aptly named *pain crises*. That night, Kaka's friend had an encounter with sickle cell he would never forget.

'My friend was so scared,' recalls Kaka. 'He thought for sure I was going to die and he would be suspected of the crime.'

Luckily, so late, Kaka's course-mate was able to fetch a taxi, which rushed the patient to emergency at UCH. Despite the extra effort of doctors after learning the patient was a colleague, for the first 24 hours or so, every painkiller administered failed to work.

Rejection

A few months later, Kaka needed to bide overnight again with his friend. But this time around, something seemed rather hostile. Something was amiss.

'Is anything the matter?' Kaka asked.

Averting his eyes, the course-mate replied, 'My mother warned me not to take in overnight visitors anymore.'

There and then, though it was rather late, Kaka packed his things and returned home.

His course-mate would later make overtures of friendship but things were never the same again. To insulate himself from the possibility of rejection, Kaka stopped making friends.

'It was depressing to realize that close friends can desert me on account of my unpredictable health.'

The clerical officer eventually shook off his sense of isolation, but nowadays, work and study are his only family.

Register for the Global Action Network of Sickle Cell and Other Inherited Blood Disorders (GANSID) Congress

@

https://inheritedblooddisorders.world/registration

Foundation Presents 3rd Edition of *Genotype Insight*

2014: Madame Genotype displaying maiden edition of *Genotype Insight* to the public

The accountant-turned Nigeria's foremost genotype activist, Duchess Doris Gbemiloye (aka Mummy Genotype), has celebrated the 2015 International Women's Day in her accustomed style. The Genotype Foundation, of which Gbemiloye is founder and CEO, conducted a one-day public seminar 27th March at the MRC Hall, Lagos State University Teaching Hospital (LASUTH), Ikeja, with a lecture on *SCD, Hb Genotype, and the Nigerian Woman - the End-Receiver.*

The Foundation used the occasion to present the third edition of its quarterly publication, *Genotype Insight.* As the name suggests, the magazine is suffused with insight into the essence of genotype awareness among youths and singles. It features an interview with African-American author Mrs. Judy Johnson, a septuagenarian living with sickle cell disorder.

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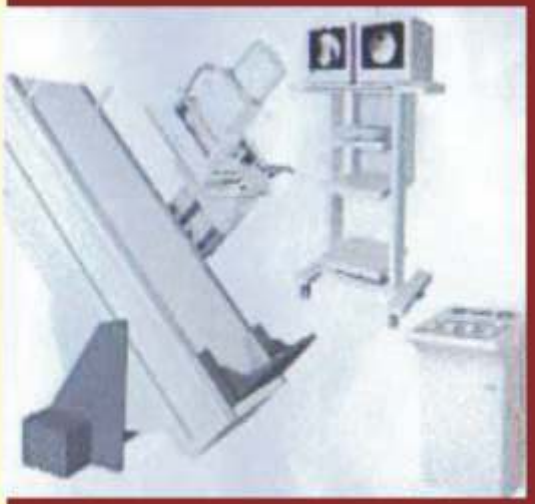

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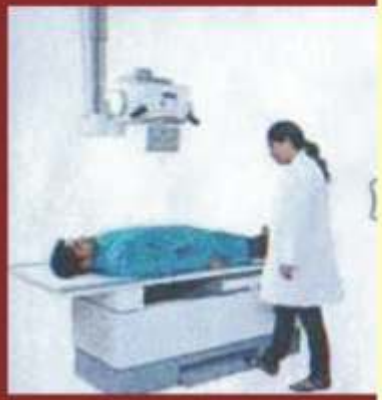

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Jobelyn & The Treatment and Prevention Of Stroke

By Otunba Olajuwon Okubena

Jobelyn is a herbal product derived from *sorghum bicolour.* For centuries, the people of the South Western part of Nigeria have been using this plant in its raw form to treat and manage many diseases including anaemia and stroke. The impression that I was given that this product is good for managing diverse other conditions such as hypertension, diabetes, arthritis, HIV, Parkinson's disease and sickle-cell anaemia seemed too good to be true.

In an attempt to find out the truth or otherwise, I have been engaged in carrying out scientific investigations into *sorghum bicolor* for the past 20 years.

My initial focus on the remedy as a blood boosting agent was successful and two publications in the *African Journal of Biotechnology* (September 2003) confirmed that *Jobelyn* has the potential to be a substitute for blood transfusion except in an emergency.

Still, this finding gave no assurance of its efficacy in so many other conditions. The whole thing became clear when we realized the ultra-high antioxidant properties of

Dr. Abia-Okon

sorghum. Several studies in the United States and Germany confirmed that *Jobelyn* is one of the most powerful antioxidants in the world.

Antioxidants help reduce or prevent damage done to the human system by free radicals from various sources: air pollution, cigarette smoke, radiation, ultraviolet light, food chemicals/additives and so on. These agents weaken the body's natural resistance and open the door to illnesses of every sort.

Having realized the fact of *Jobelyn* as a powerful antioxidant, we have used it for the treatment of many diseases including stroke. It is, however, more advantageous to use *Jobelyn* to *prevent* stroke and many other diseases by taking a daily dose. The old adage that prevention is better than cure applies in this case.

A Doctor's Testimony On The Use Of *Jobelyn* For Stroke

David Abia-Okon, Medical Director, Lindabell Medical Centre, Surulere, Lagos has been using *Jobelyn* for many years to remarkable effect among his patients with ischaemic stroke.

'Prompt and early treatment with *Jobelyn* - say within hours of the visible onset of the event brings excellent results.'

Dr. Okon, however, warns that the dietary supplement, as a blood thinner, is not recommend in the very early stages of a hemorrhagic stroke event.

Several years ago, when the Hungarian-trained general surgeon first came across *Jobelyn*, he was the most irate of sceptics. Today, he gives lectures to groups of patients and medical doctors about the health-giving, immune boosting properties of a product gradually worming its way into the pharmacopoeia of modern medicine.

ANY REMEDY FOR (CHRONICALLY) YELLOW EYES?

- Enquirer from Banjul, The Gambia

I am in my late 20s with HbSS. From as long as I can remember, the whites of my eyes have always been yellowish. My schoolmates in primary school nicknamed me 'Yellowman' while in secondary school I was called 'Bottle-Green'.

I was advised to take lots of fluid to clear the yellow. This helped a little; but my eyes remain light greenish-yellow. I am no end embarrassed by this.

Isn't there any permanent remedy for yellow eyes?

Tinted Eyes, Banjul, The Gambia

In SCD, Yellow Eyes Is Not An Illness. It's Ok If You're Otherwise In Good Health

Dear Tinted Eyes,

I shall start with a statement of fact: Yellow coloured eyes or jaundice in a person with SCD is usually a harmless component of the sickle cell syndrome, which can be expected to appear or disappear from time to time.

Let me explain. The life span of normal Red Blood Cells (RBC), in people with HbAA is 120 days, but that of SCA HbSS is only 10 days. This is because they are shaped like a sickle (or knife or banana) and are regularly destroyed, releasing iron, folate and bilirubin (yellow byproduct).

When there is an unusually high amount of bilirubin in the blood, the white of the eyes (sclera) and the skin turn yellow. In Africans and other dark-skinned folks however, only the whites of the eyes manifest the yellow colour. The dark pigments (melanin) of the skin does not allow it to show.

I am happy that Tinted Eyes passed through primary and secondary school with only name-calling, and no serious health challenge.

My advice is, soldier on. Consult your doctor to rule out external agents, such as infection, drugs, chemical reactions or Glucose-6- Phosphate-Dehydrogenase Deficiency (G6PD), which could lead to excessive breakdown of red blood cells.

After that, as long as you are certified to be in good or fairly good health, you should care less about the colour of your eyes - and about what people say, or how they react.

You must continue to take your medications and ensure you are well-hydrated. Take generous amounts of water and other liquids on a regular basis. Eat a balanced diet.

Now, if you prefer, add style to your looks by wearing a good sun shade or designer eyeglasses.

Good luck!

If you are in good health, you should care less about the colour of your eyes - or about how people react

A Permanent Secretary in the government of Abia State of Nigeria, Ekeoma Ojum Ogwo is a genetic counsellor and medical doctor.

Parents and the Child With SCA/Stroke

A Stroke Exacts A Very Heavy Toll On The Family As A Whole

Engineer Oluseye Ogunrinde, Vicar/Archdeacon, St Paul's Church Odo-Ona, Ibadan, recalls the cataclysm of his daughter, Oluwatoki Adunni's stroke 23 years ago. He once commented - with a touch of hyperbole, no doubt - that he wouldn't wish the worlds then no1 enemy, Osama Bin Laden, to go through what his family underwent in its battle with sickle cell anaemia

By Tosin Fawemida

When a child is diagnosed with sickle cell anaemia, the parents are confused, knowing this here is a lifelong illness with no cure. You start to educate yourself about the disease, trying to hit upon something, anything that will shield your child from the worst effects of a dreaded disease.

When the child now has a stroke, a Pandora's box of troubles is let loose upon the family. My daughter, Oluwatoki (Tee-Kay) Adunni Ogunrinde had a stroke at the age of six in 1992. It seriously affected her on the right side. A brilliant talkative, a loving child suddenly went numb and dumb. It was devastating. She lost control of her bowels and bladder. She could not tell you she is hungry or that she is in pain …

Tee-Kay: A Stroke At Six

My daughter was six years old when she had a stroke. We woke up that fateful morning, preparing to go to work, and the children preparing for school. Tee-Kay suddenly started to cry, I tried to pacify her but she wouldn't stop crying. Her mother asked whether she did not want to go to school but she replied she would go as weekly tests were to begin that day. When all efforts to make her stop crying failed, the mother left for her office. I was at home to take charge. When the crying subsided and she was able to eat, I asked her whether she was ready to go to school. She replied in the affirmative, so I told my driver to drop her in school and inform the mother (she was vice-principal at a school nearby).

While Tee-Kay was standing in the assembly, the teachers noticed that she was crying and sent for her mother.

When she got to her school, she found that Tee-Kay could not recognize her. She quickly rushed her to the University College Hospital (UCH), which was actually our daughter's second home. She was always in and out of UCH.

At UCH, a mother who had also brought her own child for treatment urged Tee-Kay to be quiet.

'I will beat you, leave me alone,' my daughter retorted and suddenly became numb. She was unable to speak again till she passed away eight years later.

Continued on page 25

Complete Recovery Is Possible After A Stroke

... but the likelihood of recurrence are high

- Biodun Ogungbo MBBS, FRCS, FRCSEd, MSc
Consultant Neurosurgeon, *Spine Fixed In Abuja,* Nigeria

Is Stroke a common problem among children with sickle cell anaemia?

Stroke is a common problem in patients with sickle cell anemia in general. Stroke occurs due to the obstruction of the blood vessels carrying blood to the brain. Sickle cell disease causes clumping of blood and this predisposes patients to blockage of the blood vessels to vital organs including the brain.

What is the youngest age at which you have come across anyone with Stroke?

I have seen a 2 year old with SCD who suffered an ischemic stroke.

If in theory infections can cause stroke, what specific pathogens are responsible?

There are no specific pathogens closely related to stroke. But, blood borne infections can lead to damage to blood vessels and stroke. Both hemorrhagic and ischemic strokes can occur in patients with raging infections.

Is complete recovery possible after an hemorrhagic or ischaemic episode?

There are many reports of stroke survivors. Many patients (we calculate about 33% of victims of stroke) return home,

For survivors, secondary stroke prevention is the key treatment

hale and hearty after stroke. We recently reported a case in the newspapers of a man in Abuja who survived death following stroke. He remains well today and has resumed his role as a family man.

The problem with stroke survivors is the real need to prevent another stroke. For survivors, secondary stroke prevention is the key treatment. They must do all they can to prevent recurrent strokes since they have a confirmed risk factor for developing stroke!

An elderly man who can't stop smoking or drinking does not have a stroke. A young adult in sound health comes down with devastating stroke. How can this be explained?

This is unrelated and everyone is different. For example, not everyone who smokes heavily develops lung cancer yet someone who lives with a smoker can come down with the often fatal disease. It may have something to do with luck, genes and the environment in which each person lives.

Is stroke preventable or is one at the mercy of happenstance?

We must not relent in efforts to prevent stroke. These entail real permanent life style modification. Smoking must be avoided at all costs, alcohol must be reduced to the barest minimum, drugs such as amphetamines and cocaine must be avoided, weight control and physical exercise must be encouraged.

Finally, treatment of diabetes, hypertension, sickle cell crisis and cardiac diseases must be optimal. Prevention is really better than treatment when it comes to stroke.

Boy George Helps Stroke Survivor Release Musical

A stroke survivor who is also battling sickle cell anaemia is finally living her dream to become a singer - with the help of Boy George. Leesha McIntosh had to re-learn how to walk and talk after she suffered a stroke when she was just 12 years old.

Now aged 22 Leesha she has just recorded her first song, which she has dedicated to sickle-cell sufferers, after her close friend Imani passed away from the genetic blood disorder. And Leesha's debut record *New Love* is being backed by lead singer Boy George. The internationally acclaimed star took time out from his USA tour to back Leesha's song.

'I wish Lisa all the luck in the world,' said 52 year-old Boy George.

Leesha, from Handsworth, Birmingham, continues to have monthly blood transfusions to prevent another stroke and manage sickle cell. Her illness often leaves her extremely tired and in pain.

'This single is dedicated to all Sickle Cell and Thalassemia sufferers. I am grateful to God that I'm living proof that we can live with this dreadful disease and still achieve so much in life.'

Leesha was rushed to Birmingham Children's Hospital when she suffered a stroke in 2004. She was left unable to walk and talk and her family feared she would never recover.

For more on this story, visit **www.birminghammail.co.uk/whats-on/music-nightlife-news/boy-george-backing-leesha-macs-7102068**

Stopping Silent Strokes With Regular Blood Transfusion

Alexis Haynes, 12, has come a long way. At age 6, a sudden stroke put her in a coma for a full month.

'The doctors told us that she wouldn't be able to walk, she wouldn't be able to talk, she wouldn't remember us,' Kelvin Haynes, Alexis' father told ABC30.

Every six weeks, Alexis spends hours getting her blood transfused. New red blood cells replace her sickle-shaped ones.

While Alexis' stroke was apparent, experts say one in three children with sickle cell suffer silent strokes.

'These are injury to parts of the brain that don't control speech, they don't control movement in an arm or a leg, so they typically go unnoticed,' Michael Noetzel, M.D., and Paediatric Neurologist at Washington University School of Medicine, St. Louis, told ABC30.These kids have a higher risk of memory problems. Many have trouble at school. They're also at much higher risk for having a major stroke.

Researchers found the transfusions reduced the risk of strokes of any kind by 58 percent.

Risks from transfusions include infections, reactions to donated blood and buildup of iron in the bloodstream. Researchers are planning longer-term studies to see whether transfusions, in combination with other sickle cell treatment options -- like stem cell transplantation -- can help prevent kids from losing cognitive function.

For more on this story, visit **www.abc30.com/health/sickle-cell-stopping-kids-silent-strokes/479720/**

Preventing Stroke With

TRANSCRANIAL DOPPLER (TCD)

From www.scinfo.org
Photo Source: STOP study group MCG Dept Neurology, Agusta GA, USA

What is Transcranial Doppler (TCD)?

TCD is a machine that uses ultrasound (similar to the ultrasound that is used during pregnancy) to detect areas of increased blood flow in the blood vessels of the brain. When blood vessels are narrowed due to sickle cell damage, the blood makes a louder noise as it travels through the narrow area. This is like the noise in a water hose when you make the hose bend. If there is faster flow, that means the blood vessel may be narrower, and there is a greater risk of possibly having a stroke in the future.

Why test children with sickle cell for stroke?

Strokes are very uncommon in childhood, but sickle cell disease is one of the few conditions associated with a high possibility of strokes in children. Strokes occur in about 5 to 10% of children who have sickle cell disease (SS) or one type of sickle-beta thalessemia disease (Sb 0). In other words, we can expect that out of 100 children with sickle cell disease, about 5 to 10 may be at risk for having a stroke before the age of 15. This is 300 times more likely than in children without sickle cell disease.

What happens when my child has TCD screening?

The test takes about 30 minutes, although it may take longer in some situations, especially with younger children. The test is painless, but your child needs to be relaxed and still during the test. He or she will be awake and lying on a table during the test. You will be able to stay with him or her.

What happens after the test?

If the test is normal, nothing needs to be done, although the test may be repeated every 6 months or so. If the test results are positive (findings of fast blood flow, indicating possible blood vessel narrowing) or questionable (either because the test was difficult to do, or because the results are only slightly positive), another TCD screening is scheduled within the month.
It is important to understand that TCD is a test that tells if a child may be at risk for having a stroke in the future. If your child ever displays any of the symptoms of having a stoke (weakness in an arm or leg, difficulty speaking or understanding, memory problems), you need to contact your health centre immediately so that other tests which are better at diagnosing whether a child is having a stroke at that time can be run.

What if the results show that my child is at high risk for having a stroke?

If the test is abnormal two times in a row, then regular transfusion therapy may be offered to lessen the likelihood of your child having a stroke.
Regular transfusions are the giving of non-sickle cell blood regularly every 4 weeks or so. This decreases the amount of sickle cells in the blood. It has been shown that once a child has had a stroke, regular transfusions prevent more strokes in the future. A new study has also shown that regular transfusions in children who have had abnormal TCD tests decrease the risk of getting a first stroke in the future.

Children with sickle cell disorder are 300 times more likely to have a stroke than children without the disorder

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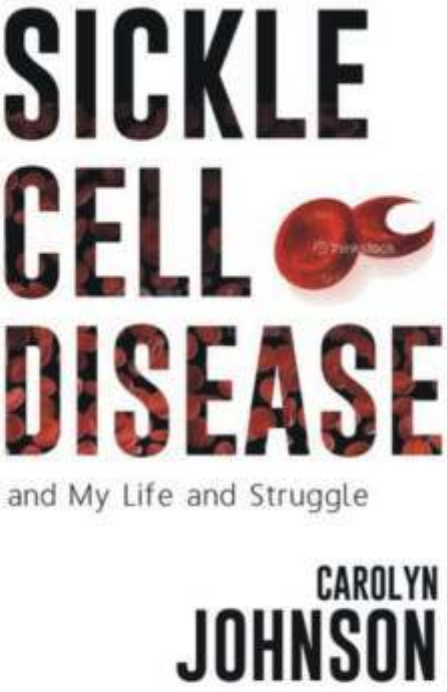
Carolyn Johnson

The Author From Kansas, no symptoms for 23 years, then the strangest sickle cell crises episodes

By Abro Onyekwe



Although she had been diagnosed with sickle cell anaemia at age 13, Carolyn Johnson did not experience *any* SCD-related illness till she was 23. Of Carolyn's 11 siblings, four had SCD with varying degrees of severity. Her immediate younger brother was always the one with the hallmark frequent pain and repeated hospitalization.

In her memoir, *Sickle Cell Disease and My life Struggles* (released in January 2015), Carolyn states that one year after her first baptism of pain, she had yet another excruciating episode requiring emergency room visit and hospitalization. Upon discharge, the patient was given a handbill with a set of rules to live by for good health (increased fluid intake, lots of rest, good personal hygiene and keeping away from infections, including sexually transmitted infections, *STIs*).

Taking to heart the matter of STIs, Carolyn abstained for years. Ironically, it was the very day she let down her guard to have intimacy with a boyfriend that she experienced crises again. The pain barged in not before or after the act, but *during* intimacy! The damsel abruptly discharged her confused paramour and called emergency services. *Lesson: sickle cell pain can occur at any time, even while having fun!*

On yet another occasion - after another prolonged holiday from crises - the author learned yet another lesson about an illness that still puzzles medical science. It was sub zero, bitingly cold, and snowing heavily. Suddenly, Carolyn began to feel chilly and hot, very hot. She broke into a sweat, her clothes soaked in minutes.

'I was burning up and midway to hospital, my whole body started to ache.'

Carolyn gives many other instances of when her sickle cell troubles give no warning but burst in (rudely).

Carolyn, along with her brother, became executive members of the sickle cell chapter in Kansas. She would often attend meetings and seminars, sharing her experience with her fellows. She would advise patients that screaming and yelling while in pain was bound to worsen the pain. A tactic she had learned was to modulate her breathing. She admits, however, that breath control was impracticable with severe pain episodes.

With this interesting memoir, the 53 year old author has signaled her international sickle cell advocacy. Carolyn wants to see SCD get similar media attention as did cancer, HIV, and other medical conditions not just in America but globally.

Left (1996) and Right (2000) Tee-Kay, aged 10 and 14 (Below) Parents Engineer (Venerable) & Mrs.Oluseye Ogunrinde

'I Never Tried To Hide My Daughter From Anyone' - Venerable Ogunrinde

Continued from page 19

Stroke does not often signal you to prepare for a visitation. Since the blood of a sickler can sickle anywhere - anytime - there is probably little you can do to prevent such happening.

Family Cohesion

A stroke in the family can be disastrous if either spouse does not believe in God. We cast our burden upon Christ, trusting Him to give us the moral and financial provision to take care of our daughter. We have seen cases where spouses have abandoned the home, claiming that the family is hexed by demons and principalities. Taking care of a child with SCD involves heavy financial commitment, uncommon patience and mental balance.

The Child and The Society

Parenting a child with sickle cell stroke is not easy at all. In our own case, our daughter's speech was affected and after engaging the services of a speech therapist for thousands of naira, she could only say, *'Daddy'*, *'Mummy'* and *'Tope'* (her elder brother). After spending so much on physiotherapy, she was able to walk in that pathetic way of people with strokes.

Wherever we took her, she was the object of glances and comments. People who knew Teekay before the incident asked embarrassing questions. Some would even accuse you and say, what were you preoccupied with when this 'thing' happened? To them you must have been careless.

Parents with severely handicapped children often locked them in when they have visitors. I never did that to my daughter.

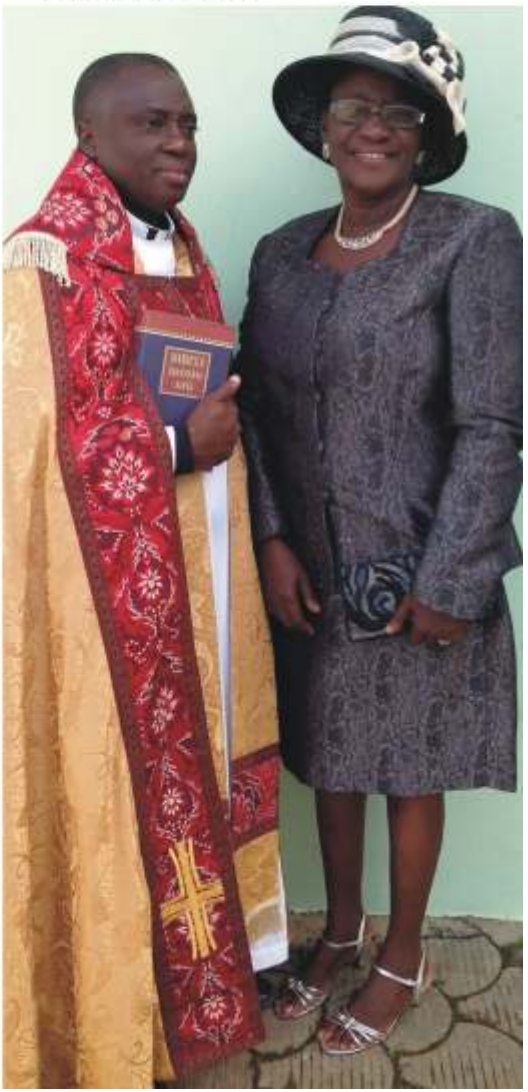
Tee-Kay Foundation

Tee-Kay passed away June 10 2000. We had spent millions on her since she first presented at 4 months with swollen hands.

We started an NGO in her name, the Oluwatoki Oluseye Foundation. Among other activities, we do free genotype verification for students in Senior Secondary School. We sensitize them about the implications of the carrier state, arming them for the future to make informed choices.

At Tee-Kay Foundation, our slogan is, *If your Genotype is not AA, find AA to marry. Bring Happiness Home!*

Tee-Kay's last coherent words were, 'I will beat you, leave me alone!'



Lewis Li-yen Hsu: **From Engineering To Medicine**

By Tosin Fawemida

Chinese-American Lewis Li-yen Hsu MD PHD began his academic career as a Chemical Engineer, having received first degree at the Cornell University, Ithaca, NY in 1981. He attended the University of Rochester, NY from 1981 to 1988 for his medical degree and same year obtained PhD in Biophysics from the same university.

Today, the 55 year old is a renowned paediatric oncologist/haematologist. His clinical and research experience include multi-center trials of sickle cell stroke prevention and bone marrow transplantation. Since 2011 he has been Director of the Paediatric Sickle Cell Programme, Children's Hospital, University of Chicago.

Professor Hsu believes the next five to 10 years will witness seminal advances in the treatment and management of SCD. He spoke with **Tosin Fawemida.**

What triggered your interest in SCD in the first place?

It was the contrast between how much is known scientifically about sickle red blood cells and how little effective treatments were available to people suffering severe pain that drew me to dedicate my career to sickle cell. I felt it was unacceptable that medical science had not come to grips with SCD.

You are described as a haematologist dedicated to finding cures for SCD. What kind of cures are we talking about?

Cures for sickle cell have been accomplished with transplant of donor cells from bone marrow or blood. The first successful transplant was reported in 1984 when a child was cured of both leukemia and sickle cell disease with the same bone marrow transplant. Transplant techniques for children were developed more fully in the 1990s. Now, over 500 children have been cured of sickle cell from cells donated by a matched brother or sister. These transplants for children use an approach similar to transplant for the cure of cancer: strong chemotherapy to wipe out the host's bone marrow cells and then replace it with bone marrow cells from the donor. The success rates for these transplants are about 90% to 95%.

New approaches in the past 6 years now show successful transplants to cure adults with SCD, even one as old as 62 years at the National Institutes of Health (NIH) in the USA. Our hospital, the University of Illinois at Chicago, and the NIH have 86% to 93% rates of success for adults transplanted with cells donated from a matched brother or sister.

People with transplant for sickle cell might take a few weeks to really feel better, but eventually they find that no more new sickle cell problems are occurring. They might still have the bone and organ damage from sickle cell before transplant, but studies have shown no new stroke, for example, after transplant. Quality of life improves, no more unscheduled absences from school or work.

However, these generally require having an HLA-mached siblings. What about people who do not have a matched sibling? Transplants were not possible, because transplanting cells that were not well-matched led to rejection and failure.

New techniques for immune suppression are being tested to see whether transplant can be successful for people whose donor is not a perfect match. The success rates for this are around 60%.

Another new technique for cure is 'gene therapy.' Bone marrow or similar cells are removed from the body, the genes for

Continued on page 30

Getting SCD out of the Shadows

By Tom Williams
Picture: globalsicklecelldisease.org

'Globally 312,000 children were born with SCA in 2010, half being born in just three countries: Nigeria, the DR Congo and India'

Few Non-Communicable Diseases (NCDs) could be more neglected than sickle cell disease (SCD). Despite the fact that, with early detection and an inexpensive package of basic care, the majority of those born with the condition can expect to lead a good quality of life into adulthood, most patients with SCD are born in resource-limited settings (RLS) where the vast majority continue to die undiagnosed in early childhood. Despite its recognition by both the UN and the WHO as a disease of major importance, for the most part, SCD remains virtually invisible on the global health agenda.

Because the carrier state for SCD (sickle cell trait; HbAS) is associated with a strong survival advantage in malaria-endemic areas, the global burden of SCD is aligned to that of malaria. The vast majority of children with SCD are born in resource-limited settings (RLS) (particularly sub-Saharan Africa) where routine data are least reliable.

Because official statistics are so poor, basic parameters such as the global number of births and SCD-specific morbidity and mortality can only be measured using indirect approaches. Estimated birth rates for Sickle Cell Anaemia (which accounts for approximately 70% of SCD) by country, shows that globally 312,000 (294,000 – 330,000) children were born with SCA in 2010, half being born in just three countries: Nigeria, the DR Congo and India.

Resource-endowed countries have adopted universal screening for SCD and provide comprehensive care for affected individuals. As a result, mortality is rare among children born with SCD in Europe, the USA and the Caribbean where the majority of affected children can expect to live a relatively normal life into their 40s and 50s. Providing such services is within reach in many RLS. In comparison to diseases of higher priority (such as HIV, TB and malaria), the provision of basic care in specialist clinics for SCD is not expensive. If widely implemented, such approaches could save the lives of almost ten million children worldwide between now and 2050.

So how can SCD be brought 'out of the shadows' of its current status as a virtually invisible NCD? Most importantly, we need better data, without which it will remain difficult to persuade ministries of health, policy makers and the pharmaceutical industry to devote appropriate resources to the condition. One essential component is better data on the birth frequencies and survival of children with SCD at the micro-epidemiological level, potentially through investigations using large-scale sample sets collected for other reasons, such as national surveys of micronutrient status and HIV prevalence. Better data will lead to better advocacy for SCD at every level: from education in schools and colleges, through to groups of affected patients, the media, politicians, funders and health agencies internationally.

Williams is professor of Haemoglobinopathy Research at Imperial College London

Danny's Many Strokes

Continued from page 10

Carol speaking to His Royal Highness Prince Edward, Duke of Kent about sickle cell and the link to childhood stroke. Source: scyss.org

that morning, I woke him up to find that his whole left side was paralysed. His mouth and eyes drooped, he could not move his arm, fingers or leg. That was the beginning of our journey in stroke.

The MRI scan showed that he had old infarct, meaning that he had been having strokes but we did not know till the first massive stroke that day in September 2003. It was then that we also knew he had a condition called *Moya Moya disease,* which can also cause strokes of a different kind: brain hemorrhage.

Danny had a brain hemorrhage in September 2006 after going on a ride in a theme park. He was in a coma for three days. Doctors just told us to wait and see - they did not know if he would come out of it. It was a horrible waiting game. In true Danny style, he got up on the fourth day and asked to go to the toilet! By the time the doctors came in next, he was busy in the playroom.

Lessons Learnt

My son's case has taught me a lot. I have used my family experience to teach the world about SCD. Danny has had more than five major strokes, countless mini-strokes and bounced back. He is on a chronic blood transfusion program, which has resulted in iron overload and other problems. My son is a fighter and so is every child that has sickle cell.

Here in England, about 10% of all children between the ages of 2 and 16 who have sickle cell will go on to have a stroke. This is not widely publicized; as a result, most parents do not know this until it happens to their child as it did mine.

A stroke can happen. It is real.

My son is a fighter and so is every child that has sickle cell

Stroke Signals

Continued from page 9

process. Sometimes she would voice sadness at the way things have turned out for her. She is conscious of the fact that her classmates are now in Junior Secondary Class 3 or Senior Secondary Class 1 while she lags behind in Primary 3.

At one time, her parents placed her in a school for special children - the deaf, the blind, the physically and mentally challenged - which suited her well. Since everyone had their own handicap to mind, no one would laugh at another's as they do in the institutions of normals (so-called).

Family Against The Sickle

Titilayo and her siblings have begun a kind of sickle cell campaign right within their own family. One of her sisters also has a child with sickle cell anaemia and knows firsthand the challenges involved in raising a special charge.

When their younger brother brought in a girlfriend, the first thing they wanted to know was the Hb genotype of the girl. At their

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'Some survive because they avoided or promptly treated infection, some have better economic resources, some have good genes that modify the sickle cell disease severity, or are just blessed'

Continued from page 27

sickle cell are corrected in the lab, and then transplanted back into the person to cure the disease. These research studies on gene therapy for sickle cell began just a few months ago and no results are available yet.

How many years more before we get a standard cure for SCD?
Cures will become available in more ways within the next 5-10 years: transplant, gene therapy, and new medications.

More medications are now being tested for SCD than ever before. The pharmaceutical industry has become very interested in SCD, for complex reasons that include incentives to work on 'rare diseases.'

Which do you think pays society better - cure or prevention of SCD?
Both. Prevention of SCD means regulating or limiting people's reproductive choices. I think couples with sickle trait must be informed they have a probability of producing children with SCD. However, I do not think that these couples must avoid marriage or have mandatory abortion, because the course of SCD is so variable.

People with SCD can be productive members of society even with limited treatment options. I believe that coping with the disease strengthens their character.

Why do some countries have high survival rates and others poor? Still, why do some in poor resource countries survive (and vice versa)?
Preventing infection with immunizations and preventive antibiotics after newborn screening is the foundation of sickle cell care in the US, Canada, Western Europe, Brazil, and other well-resourced countries. A delay in antibiotic treatment for some infections can be rapidly fatal for SCD.

Some survive because they avoided or promptly treated infection, some have better economic resources, some have good genes that modify disease severity, or are just blessed.

Stroke Sirens *continued from page 29*

insistence, every family member, married or unmarried knew their genotype.

Upon verification, the girl's genotype turned out to be AS, the same as her lover's. Warned of the family history of having children with sickle cell, the girl flat rejected the notion that she might produce offspring with the disorder. She boasted she would marry their brother, who in turn seemed rather unwilling to break off the relationship.

'We rose up against her and practically tore them asunder,' says an unrepentant Titilayo. 'We absolutely don't want to see any more sickle cell mischief in our family.'

'Will I Be Like This In Heaven?'

A highly perceptive child, Gloria occasionally queries her mother if she would ever be well again. She keeps inquiring why God - who she is told can do all things - does not restore her health.

Titilayo assures her daughter God *can* do all things but never fails to warn her He just might not do anything in this particular instance.

'His grace would have to be sufficient for you - for us - if He doesn't do anything now.'

Sometimes, perhaps in the angst of waiting for Godot, Gloria would jerk out of a reverie and ask, 'will I be just like this in heaven?'

No, Titilayo steadfastly reassures her daughter, in heaven, no one will be handicapped.

Public Healthcare Disparities in Iowa, USA

By Tessa Lengeling

Photo: Tessa Lengeling

Isaiah Newsome likes to play sports and hang out with friends, like any 17-year-old. But most of the time these activities are cut short as his body, stricken with sickle cell anaemia since birth, fills with pain.

'It just randomly happens,' Newsome of Des Moines said. 'There's no really preventing it or seeing it coming.'

Getting insurance to cover his health care adequately all of these years has not been easy, but at least he has had insurance the past year. Some other African-American families in Iowa with low incomes do not, adding to difficulties they face getting health care.

A University of Iowa Public Policy Center study in December 2013 put the problem into perspective, showing that African-American and Latino Iowans do not have the same access to adequate health care that Asian and white Iowans have.

The Public Policy Center went on to say in its report, which used data from a child and family health survey conducted in fall 2010 and spring 2011, that Iowa's African-Americans and Latinos are more likely to need medical care, even though they are more unlikely than Asian or white Iowans to receive it.

Newsome's mother, Charice Williams, did not have health insurance for herself or her children until she signed up under the Affordable Care Act in 2013.

Williams works part time for the city of Des Moines so she can spend time caring for her son.

Newsome was 3 years old before Williams learned that the seizures he was suffering from were related to sickle cell anaemia, a genetic disease that primarily afflicts African-Americans.

'Usually I start hurting in my legs, arms or back, and the pain just progresses,' Newsome said. 'I try to handle it as well as I can at home, but it usually gets to a point where it's intolerable, so we go to the hospital.'

No cure exists. Sickle cell anaemia is treated with strong pain medications and fluids. Newsome takes a minimum of 22 pills a day, although that number can go up depending on how persistent and extreme the pain is.

Newsome recently graduated from a Des Moines Public Schools-run accelerated program for students with chronic illnesses, and is looking forward to a bone marrow transplant this year.

Iowa Center for Public Affairs Journalism (IowaWatch.org)

Sulzner (middle) listens to a parent at the launch of Sulzner Sickle Cell Anaemia Foundation

SULZNER FOUNDATION LAUNCHES IN UGANDA

By Ssebandeke Ashiraf, Ugandan Correspondent, Sickle Cell News

At the tail end of 2014, a new sickle cell organization blossomed and launched in Uganda. The launch took place at Uganda National Theatre, Kampala amidst the hustle of Christmas and the New Year.

The Sulzner Sickle Cell Anaemia Foundation was started in September 2014 in Austria by Sulzner Sylvia Amasse, a Ugandan dietician living in Austria.

Sulzner was galvanized into start a sickle cell charity when her classmate at Medizinische University, Graz, informed her of the poor state of sickle cell services in Uganda.

'I didn't know anything about SCD till that moment. No-one in my family has the disease. My colleague piqued my interest in the disease, particularly in my country.' she narrated.

With support from the Austrian government, Sulzner is going to build a sickle cell clinic. The clinic infrastructure will include a state of the art laboratory, library and pharmacy.

The educational arm of the Sulzner Foundation will grant overseas scholarships for students with SCD to pursue their dream outside Uganda.

Sulzner pledged to work with the Sickle Cell Association of Uganda - under the leadership of Mrs. Ruth Mukiibi in providing humanitarian services to people living with SCD.

Mrs. Mukiibi welcomed Sulzner's initiative and thanked the Ugandan government for adding sickle cell on the priority list of non communicable diseases.

SAU was the first organization to advocate for the rights of people with sickle cell. The organization has 14 years of vibrant championing of SCD issues behind it.

Kanakulya John, parent of a son with sickle cell welcomed Sulzner's plan of constructing a free sickle cell clinic in Uganda.

Another parent, simply called Mariam, mother to a second-year university student with SCD urged Sulzner to give people with the disorder as well as their care-givers priority when staffing the organization and clinic.

Sulzner is the 4th sickle cell organization to set up shop in Uganda in 2014. It comes after Sickle Cell Network Uganda, Uganda Sickle Cell Rescue Fund and another organization in the Iganga district of Eastern Uganda.

A VEGETABLE BLEND THAT RESTORES HEALTH

For cancer or hypertension, for sickle cell or diabetes, for arthritis or poor vision, science knows the value a diet of fruits and vegetables in health restoration

By Ebere Afamefuna PhD

Ugu, (Pumpkin, Wole Soyinka, African Spinach

Four cheaply available vegetables, clean water, salt and an electric blender may be all you need to reverse a plummeting state of health.

1. **African Spinach** (Yoruba, E*fo Tete)*
2. **Water Leaf** (Yoruba, G*bure*)
3. **Pumpkin** (Igbo: U*gu*)
4. **Long-fruited vegetable** (Yoruba: E*wedu)*

How To Prepare

Buy N100 worth of Long-fruited Vegetable, N100 worth of Pumpkin, N100 worth of African Spinach and N50 worth of Water Leaf. You may double the amount purchased for a family of three or four members. The vegetables must be fresh.

Pluck the leaves and rinse thoroughly in lightly salted water. Drain the water. Add a cup of potable water to the leaves and blend. The resulting mix is green liquid pulp. Add some more water and stir. Drink liberally.

Reports

Positive reports abound from families that have used this vegetable mix to boost and improve health. Titilayo Abolarin *(mentioned on page 9)* uses the drink for her son and daughter with SCD and testifies to their improved appetite, weight gain and a marked decline in their complaints of a headache. They continue, of course, to take their daily dose of hydroxyurea. Titilayo also knows a neighbor who gave the drink to a teenager showing signs of cataract in one eye. The doctors at UCH, Ibadan were on strike. The teen took the drink for one month. The cataract vanished.

Mrs Fusetu Esangbedo, a 56-year old teacher in Agbor was placed on a diet with this vegetable drink for 2 months. She was not allowed any cooked food, but took fruits and vegetables liberally. The tumour found to be developing in her brain (by Magnetic Resonance Imaging) shrank. She also reports looking and feeling younger than ever.

When Dr. Lorraine Day was diagnosed with breast cancer, she turned away from the chemos (drugs) medical science commonly prescribed for the disease. 'Those medications are killers,' she says, Dr. Day took lots of water, fruits and vegetables. She was cured.

In November 2014, Africa's literary icon, Professor Wole Soyinka disclosed that for ten months he had fought prostate cancer with 'lots of water, fruits and vegetables'. The Nobel Laureate is now free of cancer.

Clearly, fruits, vegetables, herbs and roots from nature's pharmacy hold the key to restoring and maintaining good health. However, the blend mentioned in this article is not meant to replace whatever your doctor has prescribed for you. Do not stop taking your medically prescribed drugs. Remember to consult your doctor before launching on a new dietary or medicinal regimen.

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Steps to obtain Tax Clearance Certificate (TCC)

Tax Clearance Certificate, TCC is a document, issued by the Tax authority, confirming the holder has been cleared (discharged) of his tax liabilities in the past three (3) years or for a defined period of time.

TCC Issuance Process

- A taxpayer who has registered a taxpayer and has obtained his Taxpayer Identification Number will apply for TCC by submitting three copies of the standard application form for TCC.
- A taxpayer or company who has not registered with any tax authority will register with a tax office contiguous with his residential address or the residential address of his/her company's office;
- The completed form and submitted account - that is returns- will be examined to ascertain if a taxpayer has paid all his taxes. Once the Tax Controller is satisfied, the applicant (taxpayer) will be issued his Tax Clearance Certificate **WITHIN TWO WEEKS** of application
- The taxpayer could also be given a letter of regret if the application fails.

Under Section 85 of the PITA, a taxpayer must do the following:

- Completion of application form for Personal Income tax clearance certificate
- Completion of Form A (Income tax form for return of income and claims for Allowances and Relief)
- Completion of Form H2 (Certificate of pay and tax deducted)
- Submission of evidence of payment of tax for the period (for employees, the tax authority may request for copies of pay slips to confirm that the correct tax was paid);
- Submission of identification card of the applicant under PAYE
- Where the tax authority is of the view that the correct tax was not paid, it may request the taxpayer to pay the difference;
- The application would be assessed along with the documents submitted by the taxpayer and where the tax authority is satisfied, it would approve the application and the TCC would be issued under the authority of the Tax Controller of the office to which the application was submitted.

Companies/Individuals

At the Federal Capital Territory, FCT, the FIRS collects Personal Income Tax for employees, individuals and members of the Armed forces.

- Must be registered with an office of the FIRS and issued with a unique Taxpayer Identification Number (TIN);
- Must submit a self assessment returns through an appointed tax professional;
- Must settle all its tax liabilities, as established on any self assessment form filed by the taxpayer or any assessment issued on the taxpayer, as at the date of the application for TCC (subject to relevant exceptions).
- Must submit an application for TCC (in triplicate) by itself or through its representative.
- A TCC must be issued by a designated Tax Office, having jurisdiction over residence/ office of the applicant. (See a complete list **FIRS Offices & Jurisdictions**

Employees of the Federal Government/States

For employees of the Federal Government, in the Federal Capita Territory, FCT, they will visit FIRS Large Tax Office, LTO Abuja. Employees of state Governments will make similar application from the State Board of Inland Revenue Service,

They will obtain, fill and return Form H2, and submit evidence of their payment and deductions.

Steps to obtain Taxpayer Identification Number (TIN)

* Visit the nearest FIRS office.
* Present necessary Company Registration Documents.
* Collect and fill TIN form.
* Obtain your TIN

for further information please call or SMS : 08159490000-2

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