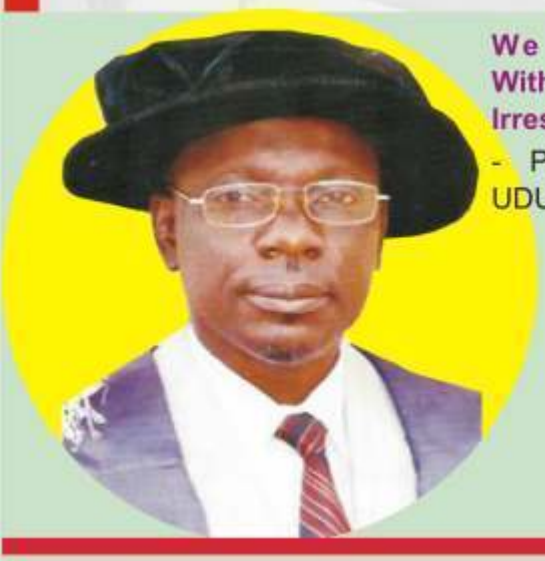
Sujimoto Construction Throws Hat Into Awareness Ring

AFRICAN SICKLE CELL NEWS & WORLD REPORT



We Recommend Everyone With SCD To Take Hydroxyurea Irrespective Of Symptom Severity

- Prof Nma Mohammed Jiya, UDU Teaching Hospital, Sokoto, Nigeria

Many Children At My Clinic Have Forgotten What Sickle Cell Pain Feels Like...

- Dr. Russell Keenan, Paediatric Haematologist, Liverpool, UK



Hydroxyurea

Hydroxyurea therapy is a Breakthrough in the Management of sickle cell

- Dr. Susanna Bortolusso Ali, former Head of Clinical Services, Sickle Cell Unit, Univ. Of West Indies, Jamaica





On hydroxyurea, my son moved from hospitalization twice in one year to twice in 10 years!

- Ms. Andrea M. Williams, Children's Sickle Cell Foundation, PA, USA

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Contents



Hydroxyurea: the miracle of serendipity - 14-year-old with avascular necrosis (AVN) recovers speedily **Page 19**

- Children forget sickle cell pain **Page 14**
- Hospitalization down to few or none per annum **Page 35**
- **Side effects** - transient, reversible, dose-dependent **Page 15**



Dog Breeding: How tending man's best friend helps 'Dogfather' Babajide Olusegun Ajayi cope with Sickle Cell **Page 23**

Speaking Up: for 6 years, Nurse kept daughter's diagnosis from the outside world - now she breaks forth from cocoon of silence... **Page 25**





CSR: Sujimoto Construction wades into crises of ignorance **Page 28**

Diary: An incredible tale of well-educated folks seeking cures at the hands of well-educated alternative medical practitioners **Page 37**

Regulars: *Letters, Help & Advice, Letters*

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

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

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

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Letters, comments bearing date, full name and address of author should be emailed to
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Well-done
I commend your effort in disseminating information about sickle cell. Your passion about educating the public regarding this condition is palpable.
Keep it up!

Dr. Oluwole Kukoyi
MD/CEO, Medicare Clinics, Founder, Medicare Sickle Cell Club, Otta, Nigeria

A Commendable and Worthwhile Project
Awareness creation on Sickle Cell Disease, which your organization has chosen to engage in, is commendable and worthwhile. The Ministry also wishes to appreciate the donation of a copy of the memoir, *Menace In My Blood - my affliction with sickle cell anaemia* made by your organization to our library.
Such endeavour, while educating readers on the plight of those living with the disease and creating awareness about what can be done to alleviate the suffering of those carrying the defective sickle gene, spurs policy discussion and also adds value to the efforts of government on controlling the disease in Nigeria.
We look forward to collaborating with you on this endeavour in any way feasible; please accept the highest regards of the Honourable Minister of Health.

Dr. Evelyn Ngige
For: Honourable Minister of Health, Federal Ministry of Health, Department of Public Health, Federal Secretariat Complex, Abuja, Nigeria

SCD Pain Is Still An Enigma
The article about the 'Matriarch of Sickle Cell', Venice Joyner-Hopkins makes interesting reading. Her effort to accentuate sickle cell awareness in America shows that suffering ennobles the mind.
It is noteworthy that sickle cell pain remains an enigma nearly a century after the birth of Joyner-Hopkins. SCD's commonest complication remains a thousand steps ahead of the strongest narcotics ever deployed.

Versa J. Tyle
Michigan, USA

The Anifowoshes
That SCD is not a death sentence is demonstrated in the lives of father and daughter, Mr. Agboola Anifowoshe and Agnes Anifowoshe-Odunsi. Both American citizens, Mr. Anifowoshe recently celebrated his 80th birthday in Nigeria while Agnes clocked 55.
I congratulate the duo on their milestone and wish them many more years in good health. I fully agree with their calls on folks with SCD to come out into the open *and* talk about the disorder.

Onejeme Owutu
Dublin, Northern Ireland

The Buharis and Sickle Cell
Nigerians are well-aware of the role of direct SCD experience SCD in the family of President Muhammadu Buhari. His daughter, Hadiza's revelation that the Buharis are considering doing Bone Marrow Transplant (BMT) for several children in the family highlights the need to intensify awareness of this costly-to-manage, expensive-to-cure but preventable health condition.
Many Nigerians are unable to afford basic drugs not to talk of BMT. To assist middle-income earners who wish to rid their children of SCD by similar means, I suggest government establish BMT centres locally. This will, in addition, help to conserve foreign exchange at a time of economic recession.

Patricia Francis
Ontario, Canada



Why I founded the Queens Sickle Cell Advocacy Network (QSCAN)

By Gloria Rochester

I am the mother of two boys and two girls. My youngest daughter Tyeisha, was diagnosed with Sickle Cell Anaemia at 18 months. In order to handle the responsibilities of caring for my daughter, I embarked on a quest to acquire the knowledge to enable me make informed decisions about treatment and care.

It was not long before I realized that SCD was not high on the list of either the medical institutions or the legislative authorities. Families were overwhelmed by the psychosocial, medical and economic impact of this chronic condition. This moved me to commit myself to making a difference in the life not only of my daughter, but also others affected by sickle cell.

In 1978, from the basement of my home, I started a parent support group known as the Queens Sickle Cell Community Network. The organization grew and became incorporated in 1997. Subsequently, its name changed to the Queens Sickle Cell Advocacy Network Inc, (QSCAN).

In 2009, QSCAN was recognized as the New York Chapter of the Sickle Cell Disease Association of America (SCDAA).

More about QSCAN at www.qscan.org

HYDROXY YOU RARE: Sickle Cell meets it match

By Ayoola Olajide



For a disorder about which so much is known - and which has taught medical science so much - progress towards a universally - and cheaply available - remedy has been slow.

The medication, hydroxyurea, represents a major advancement in the treatment and management of sickle cell.

To paraphrase many parents whose children are on this medication - and some of whom are taking it for themselves, 'hydroxyurea helps to live well while waiting for a cure'.

Please consult your doctor before embarking on an HU journey (not obtainable without doctor's prescription anyway). If your doctor knows little or nothing about it - as experience shows - advise him/her to go check it out!

**** Disclaimer: the information in this magazine is meant for information purposes alone and is not meant to displace, replace or supplement sound medical advice.*



Timi Edwin, CEO, CrimsonBow, with a parent during the launch of *Keep A Warrior Warm* project

CrimsonBow Flags Off *'Keep A Warrior Warm'* Project

As in America, September is fast becoming the focal month for sickle cell awareness in Nigeria - apart from June 19, World Sickle Cell Day. Various SCD charities in Nigeria, including CrimsonBow Sickle Cell Initiative, Genotype Foundation, Marvel Sickle Cell Foundation, and Maidunama Sickle Cell Foundation held major sensitization events in September.

CrimsonBow inaugurated the first phase of the '*Keep A Warrior Warm*' project. The event took place at Ijaye Low-cost Housing Estate, Agege, Lagos. The audience included families and individuals with SCD, particularly children, the press as well as the public.

Dr. Opeyemi Emoruwa of the University of Lagos Medical Centre was on hand to give hints on the management and prevention of a health condition inappropriately dubbed the 'blackman's scourge'.

Speaking at the event, Hon. Shade Shinkaiye, former two-time Commissioner in Kogi State (Women Affairs & Social Development, and Local Government & Chieftaincy Affairs) forecasted that within the next few decades, SCD would have been much defanged.

'Genotype would no longer be a stumbling block by the time your children are having babies in the next 25 or 30 years,' she assured parents at the occasion.

CEO of CrimsonBow, Miss Timilehin Edwin, 29, stated that the organization is out to give succor to the underprivileged, with or without SCD.

Medications and warm clothing worth over N0.5m were distributed gratis to participants.

Mrs. Bimbola Edwin, 56, praised 'Timi for helping to actualize her pledge of reaching out to people with SCD in Nigeria. Both the Edwins are with sickle cell anaemia.

6Th International African Symposium on Sickle Cell Disease

.... endorses Hydroxyurea (HU) for SCD in Africa

By Ayoola Olajide, Accra, Ghana


Dr. Baba Inusa

Labadi Beach Hotel is a sprawling 5-Star comfort zone fronting the Atlantic Ocean on the Osu Expressway. For four days in July 2016, it hosted the 6th International African Symposium on SCD.

On the final day of the Symposium, attention turned to Hydroxyurea (HU), the medication recognized as a significant advancement in SCD treatment and management. Several clinicians stepped out to report their experience:

Dr. Bazuaye said HU therapy was a requisite for undergoing stem cell transplant at the University of Benin Teaching Hospital.

'The patient must have been on HU for at least six months prior to transplantation.'

Prof Jiya reported the case of a teenager with sickle cell anaemia whose restoration to good health after taking HU for a few months could only be described as miraculous (*see page 19*).

Prof Adekile stated that in the Arab world, patients on HU showed phenomenal increase in HbF levels (40-50%), living as though they no longer had sickle cell. He reflected that the main issue in the prescription of HU in Africa was the inability of clinicians to overcome their fear of the medication.

Commenting on the notion that HU reduced sperm count, Prof Ohene-Frempong said the decrease was not significant enough to cause sterility. Men on HU can - and do - bear healthy children, he stated. He urged clinicians in Africa to prescribe HU to their patients to help them the reach survival and quality of life levels comparable to those seen in Europe and America.

Prof Odame, who doubles as Director, Global SCD Network, declared that HU was a WHO-recognized medication for SCD and should be offered to patients with confidence.

A formidable roll-call of SCD specialists from around the world attended the event, among them, retired haematology Prof Fola Esan, lately of the University College Hospital, Ibadan, Prof Nma Mohammed Jiya, Usmanu Danfodiyo University Teaching Hospital, Sokoto, Prof Kwame Ohene-Frempong, Children's Hospital of Philadelphia, Prof Isaac Odame, Hospital For Sick Children, Toronto, Prof Adekunle Adekile, University of Kuwait, Dr. Solomon Ofori-Acquah, Centre for Translational and International Hematology, University of Pittsburgh and Prof Oby Nnodu, Centre For SCD Research and Training, University of Abuja.

Others included Dr. Nosa Bazuaye, Head, Stem Cell Transplant Unit, University of Benin Teaching Hospital, Dr. Drew Campbell, University of Michigan, Dr. Stephen Obaro, University of Nebraska Medical Centre, Prof Kwadwo Koram, Noguchi Memorial Institute for Medical Research, University of Ghana, and Dr. D.A Okoh, Rivers State Hospital Management Board, Port Harcourt, Nigeria

Other participants included Dr. Jemima Dennis-Antwi, Board Member, International Confederation of Midwives, Dr. Ebenezer Appiah Denkyira,

Continued on Page 38


Dr. Russell Keenan

HYDROXYUREA

Paediatric haematologist **Dr Russell Keenan,** explores the stark effectiveness of the only approved drug for Sickle Cell Disorder

Hydroxyurea, also known as hydroxycarbamide is a medicine that has been around for nearly 150 years. In the early 20th century, it was used to treat some rare leukaemias and skin conditions but it is not often used for these conditions today. Hydroxyurea has been used with increasing evidence in sickle cell disease for almost 25 years now.

How does it work?

Parents may remember that when their child was born they had no sickle cell problems in the first 6 months and very few in the first year. This is because in babies' blood there is a special haemoglobin called haemoglobin F (HbF), which protects the sickle haemoglobin (HbS). This is nature's protection against sickle cell problems. HbF carries oxygen around the body, preventing the fundamental process that causes almost all the problems in SCD.

Hydroxyurea mainly works by reducing the amount HbS made and increasing the amount of this baby blood HbF back towards levels seen in babies.

Have we underestimated Sickle Cell Disease?

In the past there hasn't really been any effective treatment for SCD. Doctors and nurses have not always talked enough about the seriousness of sickle cell, the long term complications, or the risk of dying from its complications.

Now, with hydroxyurea, this is all very different. We now have an effective treatment to prevent sickle cell problems. While hydroxyurea is not a cure, when taken regularly, it certainly is having a massive impact on the quality of life of patients and families.

What is the evidence?

We have known since the early 1990s that hydroxyurea treatment works in adults. It prevents crisis and reduces the frequency of crisis. It also was known early on to reduce hospital admissions and reduce the need for blood transfusions. Very importantly, it was proven early to reduce acute chest crisis which is the commonest cause of death in children with SCD.

As hydroxyurea prevents the fundamental disease process of sickle cells from sickling, it was always probable that all complications would be reduced. Clearly, it was going to take time to prove long term safety and a beneficial effect on chronic sickle cell problems.

There have been 4 large studies published between 2010 and 2015 that prove that hydroxyurea should be used in

Continued on page 9

1995: The anti-cancer drug, hydroxyurea (HU), was shown to reduce the effects of SCD

1998: The US FDA approved HU as the first drug proven to be effective in the treatment of adults with SCD

In parts of Africa, 90% of children with SCD do not survive beyond childhood

HYDROXYUREA

Continued from page 8

almost all patients from a young age.

Studies On Hydroxyurea

Steinberg 2010 (USA)
299 adults with SCD and 17.5 years follow-up.

Patients on hydroxyurea benefited with:
43% overall reduction in death
Less stroke, less kidney disease, less liver failure
This study also looked at theoretical concerns about hydroxyurea: (1) can it cause cancer? or (2) can it cause damage if taken by parents having a baby?

No increased cancer was seen.
No abnormalities in babies seen in mums or dads taking hydroxyurea.
No serious side effects seen.

Limitations: No children were in the study and it wasn't a formal clinical trial. It was simply a long term detailed observation of the outcome in a large number of adults.


Source: American Society of Hematology

Baby HUG Trial 2011 (USA)
This is a large American research trial of using hydroxyurea in all children with SCD from about 1 year of age.
193 children aged 9-18 months.

Hydroxyurea gave benefits of -
52% fewer crisis
Fewer acute chest syndromes
Fewer hospital admissions
Fewer transfusions
No serious side effects seen.

This is the first major trial in young children. The limitations are only short follow up but many further publications have followed this and all have been positive.

Lobo 2013 (Brazil)
Total 1760 children.
The most severe 267 were put on hydroxyurea.
The 1493 milder affected children were given standard treatment.

These are the findings after a 7 year follow up:
Death rate in hydroxyurea patients 1 in 267 (0.37%)
Death rate in standard treatment patients who were clinically less severe was 82 children (5.5%)

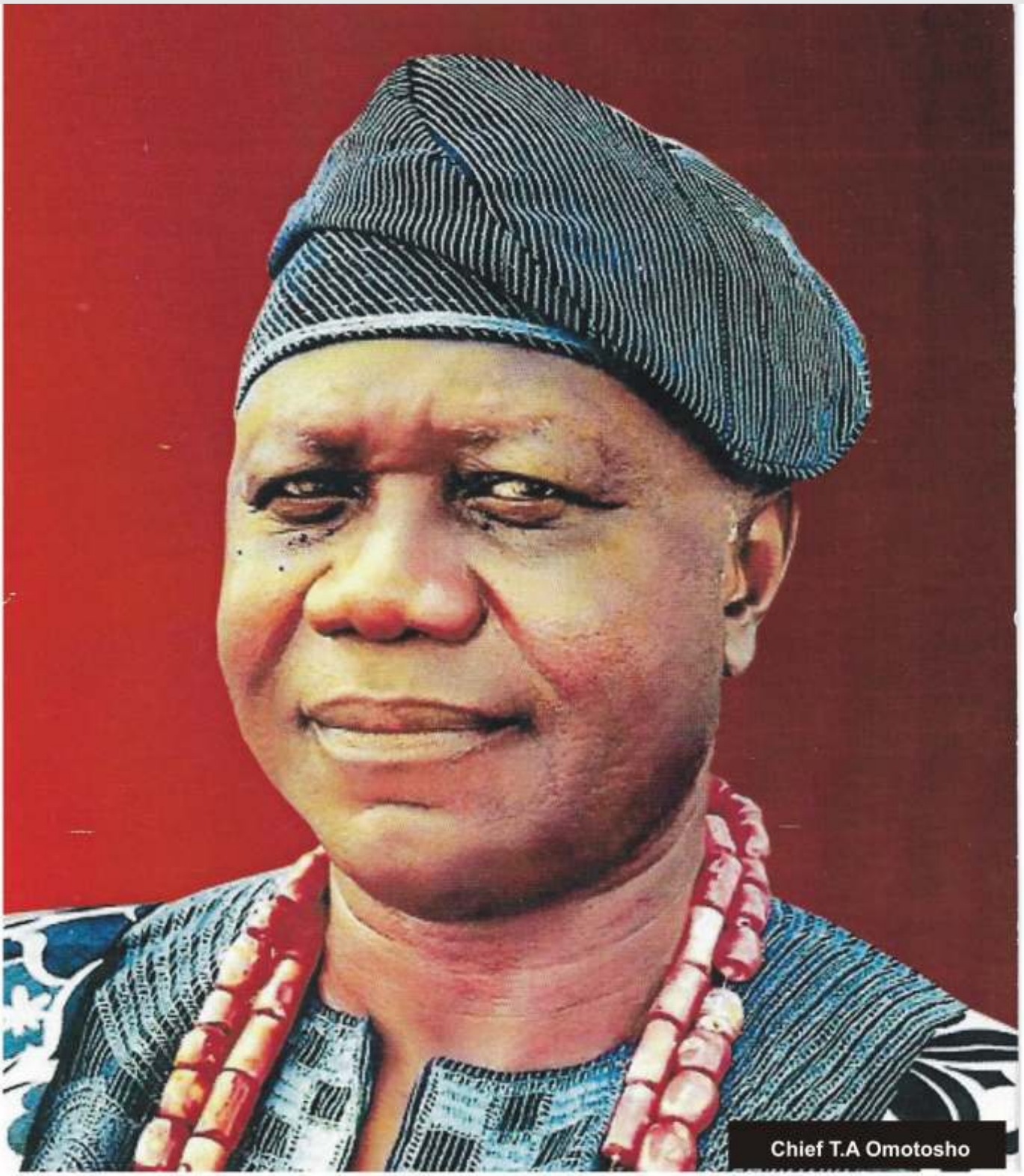
It would have been expected that more deaths would have been seen in the most severe patients.

Hydroxyurea then has prevented more than 90% of deaths from sickle cell disease in childhood.

1 child got cancer and they were in the standard treatment group. No child on hydroxyurea got cancer.

Le 2015 (Belgium)
Used the Belgian national

Continued on page 13



Chief T.A Omotosho

Father of Hydroxyurea Pharmacopoeia in Sub-Saharan Africa Celebrates 80th Birthday

By Tosin Fawemida

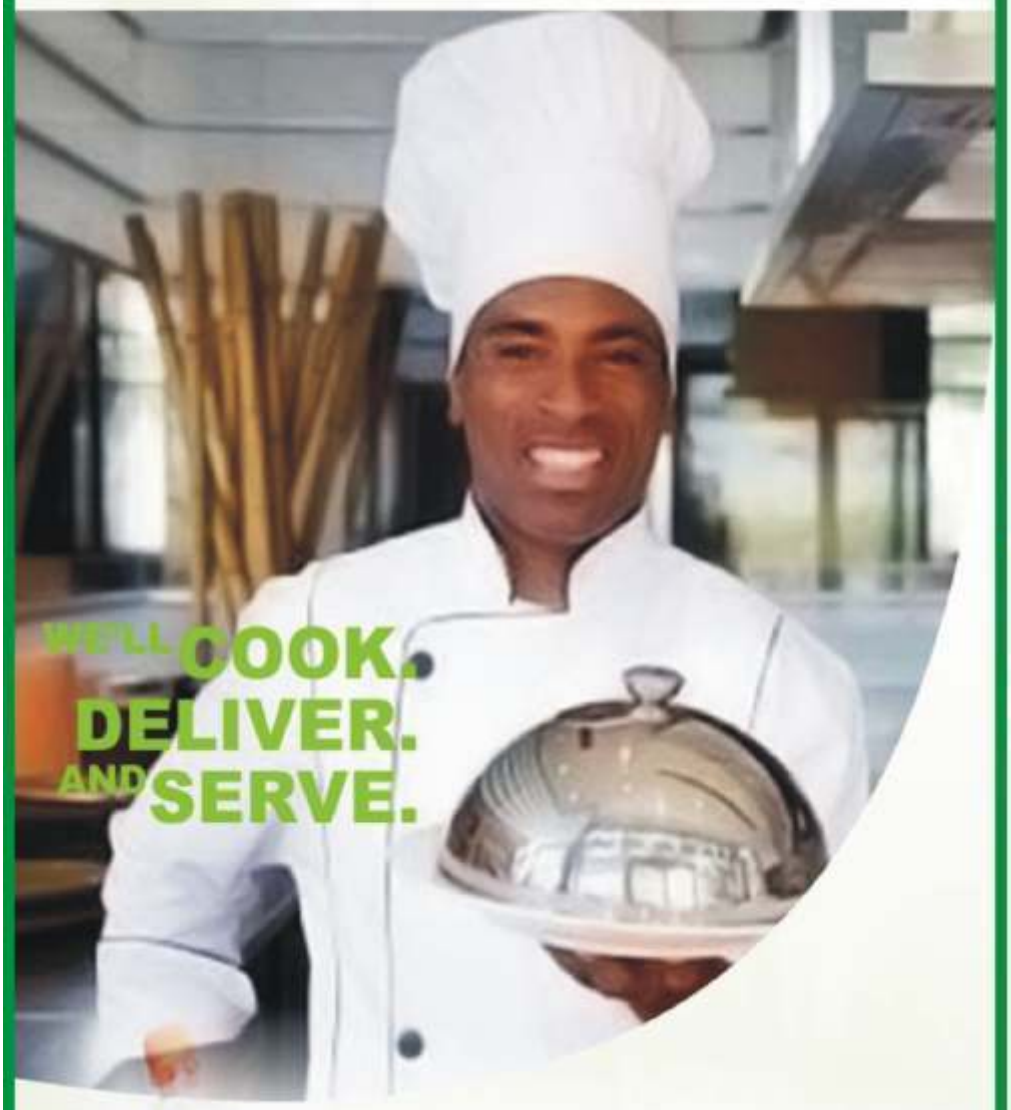
The Hall of Protea Hotels, Ikoyi, Lagos was filled to the brim with guests on August 24, 2016. The guest list consisted of senior and veteran pharmacists from across Nigeria, delegates from Sickle Cell Clubs in Lagos State, officials from various interest groups in the manufacturing industry, a handful of expatriates, and journalists from the print and electronic media. The pharmacist who brought Hydroxyurea to West Africa, Chief Theophilus Adebowale Omotosho, was celebrating this 80th birthday.

Born 29th July 1936 in Kano, Chief Omotosho attended primary and secondary school in

Continued on page 32

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Hydroxyurea

Contiuned from page 9



Picture: American Society of Hematology

registry data of 469 patients over 5,110 patient years.

This large study showed that patients on hydroxyurea had a better survival than patients who were transplanted or did not have disease modifying treatment.

15 year survival with hydroxyurea 99.4% compared to bone marrow transplant 93.8% or no disease modifying therapy groups 95.4%.

Limitations

Very few as this is a whole country's real registry data rather than a research study. The average length of time on hydroxyurea was just over 10 years.

I have not selected these studies to show a positive message. All published studies have shown a very positive effect of hydroxyurea.

In 2014 the United States National Institutes of Health published Evidence-Based Expert Panel Report on the Management of SCD.
This report looked at all evidence relating to all management of SCD.

One of the strongest recommendations of the report is that every child with SCD should be offered hydroxyurea from the age of 9 months .The evidence is overwhelming that hydroxyurea gives benefits that far outweigh any minor side effects.

Hydroxyurea takes time to give the full benefits in the blood and time to get the dose right in an individual. Also, hydroxyurea works by affecting just the blood made in the bone marrow that day. So as a guide any dose started will take months to have a full effect on the blood. It can take up to a year to get the right dose established and see and feel the full benefits.

In conversation with some clinicians and families, I think some people are giving up on hydroxyurea far too early after taking it for a month or so.

I have heard statements like:

Hydroxyurea doesn't work for everyone, so no point taking it.

1. This doesn't make sense to me as there is no medicine for any disease that works for everyone.

My personal experience is that hydroxyurea works for everyone who takes it every day. The only children I have seen who don't get an excellent response to how they feel are the children and families who tell me they are not taking it regularly. My experience is if you take hydroxurea as prescribed it will work.

2. This also doesn't make sense to me as we might be waiting a long time for an even better medicine. Why get ill or deteriorate in the meantime?

More on page 14



Picture: American Society of Hematology

Hydroxurea:
Our Experience in Liverpool, Merseyside, Cheshire and North Wales, UK.

By Russell Keenan, Consultant Paediatric Haematologist and Lead for Clinical and Laboratory Services for Haemoglobinopathies



In the last 5 years, we have been putting more of our children with SCD on hydroxyurea.

At Alder Hey Sickle Cell Clinic, around 70% of all patients with SCD are on hydroxyurea. We have not seen any serious problems and we have seen many lives massively improve.

Many of our children have forgotten what sickle pain feels like ...

Hydroxyurea must be closely monitored to ensure the dose is effective and safe for the individual child. The drug is potentially dangerous if it is taken carelessly or intermittently.

We reviewed our patients on hydroxyurea and found that their blood test parameters are much better. On average our patients who take hydroxyurea have HbF levels of over 30%. Many of our patients have blood parameters that are close to sickle cell trait.

Many of our children have forgotten what sickle pain feels like and don't need to take any pain killers.

Admission to hospital with a crisis is now very unusual. The number of days patients have needed to be in hospital when they are on hydroxyurea is 0.9 days per patient per year. Children are missing very little school.

We have seen sickle problems including mildly abnormal TCD results improve to normal.

We have seen proteinuria, an early sign of sickle cell kidney damage, get better.

We have seen low blood oxygen levels improve on hydroxyurea.

We now have no children in Liverpool who are on regular transfusions as all have converted to hydroxyurea.



Picture: American Society of Hematology

Hydroxyurea: Concerns About Side Effects

Studies report only very minor side effects. My view is that untreated SCD is a worse disease for a child to have than acute leukaemia. My observations are that life expectancy and quality of life is worse for most children with SCD compared to children today with acute leukaemia. When treating leukaemia, patients and doctors accept very severe side effects because the benefits outweigh the side effects.

I've heard of people with sickle cell stopping hydroxyurea for very minor effects such as nail bed discoloration. It doesn't make sense to me to risk strokes and kidney failure and pain because of nail bed discolouration.

Concerns about fertility

There are real concerns about possible effects of hydroxyurea on fertility and these have not been fully answered yet in the medical literature.

However, the concern about fertility is at least in part a theoretical one. We know that SCD itself can affect fertility and the evidence that hydroxyurea makes it worse is not really there.

It is known that some medicines used to treat cancer can cause infertility. It seems to me that hydroxyurea is guilty by association as it was used to treat cancers in the past.

Some medicines that treat cancer cause infertility but many in fact do not. There is no evidence that hydroxyurea causes infertility.

There is some evidence in animals that hydroxyurea can reduce sperm counts. SCD on its own can reduce sperm counts.

One study was in rats. Rats given 100mg/kg had no effect on sperm count. This is 3 times the normal maximum dose we give to humans with SCD. Rats given 200mg/kg had reduced sperm counts which recovered on stopping the medicine. The same study also reported a reduction in sperm counts with a medicine many of us use every day. It was paracetamol.

I don't hear clinicians or patients getting worried about fertility with paracetamol.

The complication of sickle cell disease that is rarely talked about is impotence in men. Some men with SCD do experience a devastating problem of impotence following a sickle crisis called priapism, which often starts in childhood. In talking to young men most are more scared of a real risk of impotence rather than a possible risk of reduced fertility.

We know that poorly managed SCD can make pregnancy difficult and gives increased risks for women with SCD and their babies. I hope that in future our current generation of girls treated on hydroxyurea will get to adulthood well and pregnancy will be much less of a concern.

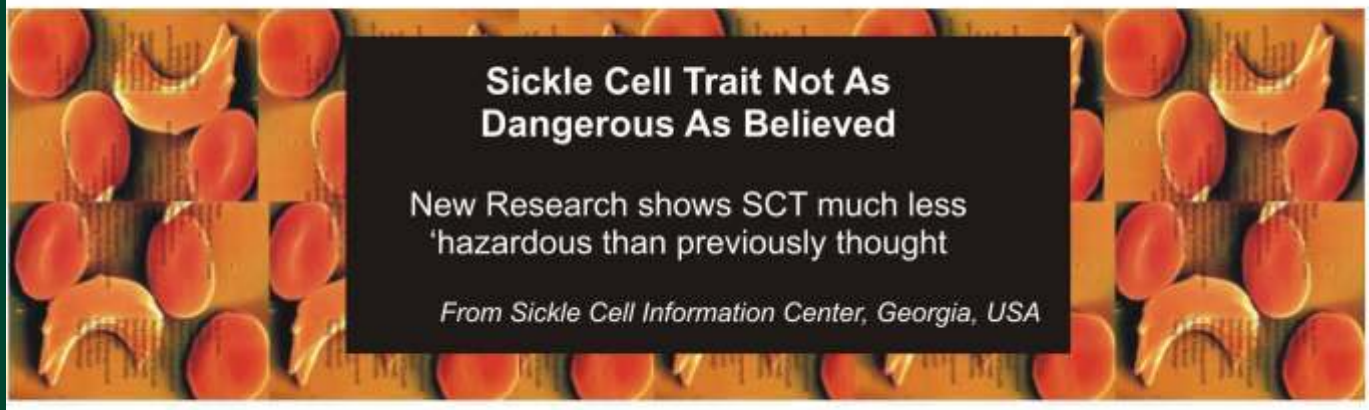
Doctors generally avoid all medicines in pregnancy if possible and the current advice to any woman trying to get pregnant would be to stop hydroxyurea for the pregnancy and the time running up to conception. However there is no evidence in humans at this point that hydroxyurea is harmful to the baby in pregnancy.

Concerns that hydroxyurea may increase the risk of cancer

There is no evidence in the literature that hydroxyurea causes cancer. The evidence we have so far is that it does not. However, it is true that we've not given hydroxyurea for 50 years to anyone yet; so no one can be certain of a possible very long term effect.

In my view, it is extremely unlikely that any side effect that we don't know about will outweigh the benefits.

Russell Keenan, MB ChB, PhD, MRCP, MRCPath



Sickle Cell Trait Not As Dangerous As Believed

New Research shows SCT much less 'hazardous than previously thought

From Sickle Cell Information Center, Georgia, USA

Health experts have long believed that sickle cell gene variants, which occur in about 1 in 13 African-Americans, increase the risk of premature death, even when people carry only a single copy of the variant. But health records of nearly 50,000 active-duty U.S. Army soldiers between 2011 and 2014 shows that's not the case, according to a study led by researchers at the Stanford University School of Medicine.

People who carry two copies of the sickle cell gene variant have sickle cell anaemia, which brings a drastically shortened life span of only 40 to 60 years, as well as lifelong bouts of intense pain.

In contrast, those carrying just one copy of the gene variant have what's called sickle cell trait. Earlier studies have suggested that the health consequences of sickle cell trait might be dire, including higher mortality from a potentially fatal condition called exertional rhabdomyolysis (ER), which occurs when molecules from the breakdown of muscles end up in the kidneys, has been known to fell football players, often when they are practicing too hard in the hot sun without drinking enough water. (ER is distinct from heat exhaustion.) Likewise, ER is a risk for soldiers on active duty.

Yet, in the first-ever longitudinal cohort study of sickle cell trait -- which included African-American soldiers of all ages -- researchers have found they suffered no increase in mortality. Lianne Kurina, PhD, an associate professor of medicine at Stanford, and a team of medical researchers found that having sickle cell trait does not increase the risk of death. A paper describing their findings was published in *The New England Journal of Medicine.*

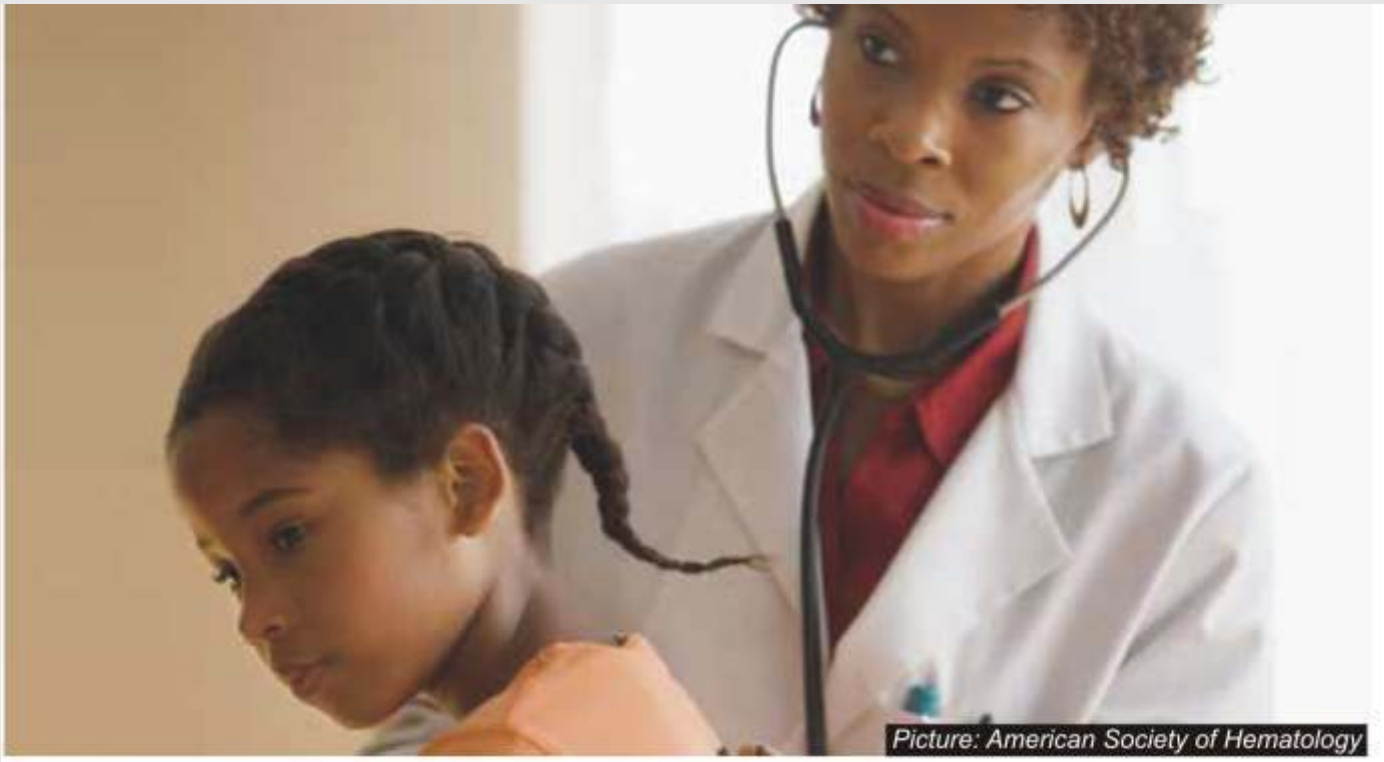
Inconclusive studies

Case reports suggesting a connection between sickle cell trait and deaths of individual patients have dominated the medical literature, according to the new study. A paper published in 1987 reported a 2,800 percent increase in the risk of exertion-induced sudden deaths among African-American military recruits thought to have sickle cell trait. But the actual sickle cell status of every individual was not known.

Despite relatively weak evidence, Kurina said, it's been assumed that sickle cell trait increases the risk of death, of exertional rhabdomyolysis and of heat stroke. This assumption has led to mandated screening by organizations such as the Air Force, the Navy and the NCAA. But the American Society for Hematology and other organizations have argued that screening programs raise questions about job discrimination. The Army typically screens only before combat deployment and high-altitude activities, the study said.

For the study, the researchers reviewed the health records of 47,944 African-American soldiers who served on active duty between 2011 and 2014 and for whom sickle cell status was known. The researchers got the

Continued on page 18



Picture: American Society of Hematology

'HU Therapy is More Practical For Resource-Poor Countries'

*In this interview with **Abro Onyekwe**, Dr. Russell Keenan says Hydroxyurea is the first scientific disease-modifying treatment for SCD*

What do you think can happen to the organs of an SCD patient on hydroxyurea for 20, 30 or 40 years?

This is unknown; however, there is no evidence so far that many years of hydroxyurea use causes organ damage.

It is very important to state that untreated SCD causes severe organ damage of the brain , lungs and kidneys. We have concrete evidence this SCD organ damage can be prevented by hydroxyurea.

Some studies say hydroxyurea works only in 50% of cases - why all the hype about its effectiveness?

My experience is that hydroxyurea works in everyone who takes it.

The hype about effectiveness is that it is the first disease-modifying therapy we have for SCD and it is having a massive impact.

It is 50 years since hydroxyurea first appeared on the scene – is it any safer to take now than at any other time in its history?

The medicine is intrinsically just as safe as it has always been. What continues to improve is the experience of using the medicine. Side effects are rare.

Some authorities say hydroxyurea should be prescribed to all children and adults with SCD irrespective of symptom severity. What is your opinion?

What is clear to me is that all patients adults and children with sickle cell disease should be considered for either stem cell transplant, regular blood transfusion or hydroxyurea.

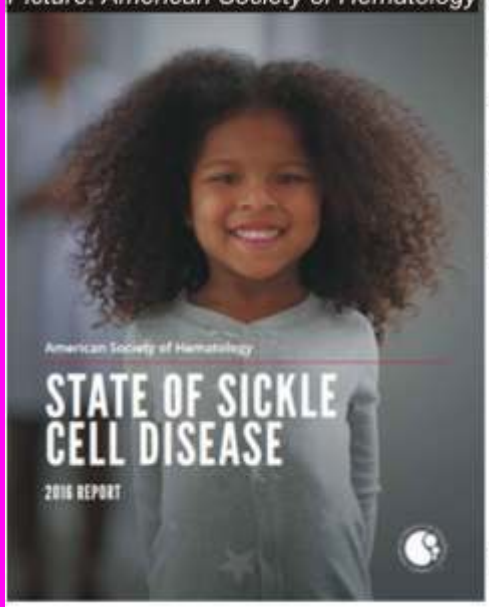
In resource-poor countries, hydroxyurea is going to be the most practical.

For many in the UK, hydroxyurea will be the preferred option even when other treatments are available.

Children not treated with hydroxyurea accrue over $500,000 more in health care costs than those who receive the medication

In many countries, hydroxyurea is not regularly prescribed; where prescribed, adherence to therapy is poor

Picture: American Society of Hematology



ASH Releases *STATE OF SICKLE CELL 2016* Report

From a range of partners including government agencies, patient advocacy groups, healthcare providers, public health organizations, researchers, pharmaceutical and biotech companies, and other stakeholders, the American Society of Hematology (ASH) has emerged with a report, 'The State of Sickle Cell in 2016'.

The document identified four priority areas: access to care, training and professional education, research and clinical trials, and related global issues.

The report states that alleviating the pain and suffering caused by SCD, as well as its socio-economic burden, is entirely within grasp.

Sickle Cell Trait

Continued from page 16

health records from the Stanford Military Data Repository. The repository includes all digitally recorded health encounters at military medical facilities or civilian institutions, general health information and official records of physical performance and mortality of all active-duty U.S. Army soldiers.

Kurina and her colleagues found that the risk of exertional rhabdomyolysis was only 54 percent higher among African-American soldiers with sickle cell trait than among those without it. A 54 percent increase might sound like a lot, but it's far less than the 300 percent increase caused by some ordinary prescription drugs.

Why the difference?

A major reason for the difference between the current study and previous ones, Kurina said, may be better safety for active-duty soldiers. As of 2003, soldiers who are engaged in strenuous exercise are required to drink plenty of fluids, build up to strenuous exercise gradually and take regular rests when it's hot. All of these measures are known to reduce exercise-related fatality rates, regardless of whether individuals have sickle cell trait, the study said.

'Another critical difference between our study and the earlier, population-based studies is that in our study, we knew the sickle cell status of everyone in the population,' said Kurina. She and her team looked only at soldiers whose sickle cell status was confirmed by blood tests taken during their years of service, instead of from self-reported sickle cell status or past medical history, as had been done in the other studies.

The study's results call into question the need to screen service members with sickle cell trait, especially with better safety precautions during intense exercise.

The Brazilian government supplies hydroxyurea free of charge to SCD patients

Providers who are not knowledgeable about the use of HU in SCD may be reluctant to prescribe it

More than 75 percent of adults with SCD with frequent pain crises fail to get hydroxyurea



HYDROXYUREA

An Astonishing Experience at Uthman Dan Fodiyo University Teaching Hospital, Sokoto, Nigeria

By Professor Nma Muhammed Jiya MBBS (ABU), MMCPaed, FWACP, Professor of Paediatrics/Chief Honorary Consultant Paediatrician/DCMAC (Research)

Early in 2014, a 12-year-old boy with sickle cell anaemia was referred to the Paediatric Clinic of the Uthman Dan Fodiyo University Teaching Hospital, Sokoto. He presented with complaints of bilateral hip joint pain and had been bedridden for several weeks.

He was not jaundiced, was fully conscious. Assessment of power of the lower limbs was grade 3/5. Liver function tests and Full Blood Count were normal except for the mild anaemia (PCV of 22%). X-Rays of the hip joints revealed bilateral avascular necrosis of the femoral heads (ANFH) grade 3.

The boy's parents were worried that his education would be adversely affected - he had been missing school for months.

The parents were counseled about the possibility of commencing their son on hydroxyurea. We told them that we started using hydroxyurea for our sickle cell patients in 2012.

We informed them that preliminary results showed significant reduction in the number of crises and visits of our patients into emergency paediatrics unit (EPU) of the hospital.

The parents assented and the child was started on hydroxyurea. The parents were warned to comply fully with doctor's advice on dosage and to report any adverse reactions promptly. They should not stop the medication on their own for any reason.

Six weeks after the commencement of hydroxyurea, the patient's complaints of hip and joint pain subsided significantly and he started walking without support. Thereafter, he returned to school. His PCV rose to 33% and has since remained steadily above 30%.

Six months after the commencement of hydroxyurea, X-Rays of the hip joints showed reversal to normalcy

Six months after the commencement of hydroxyurea, X-Rays of the hip joints showed reversal to normalcy. The ANFH was gone! Repeat X-rays after one year on hydroxyurea showed the same results.

The boy started playing football and resumed riding his bicycle! The whole neighbourhood was astonished!

For two years running, the patient has remained stable and without any complication from the use of hydroxyurea. If hydroxyurea is used at the recommended dosages, the side effects are either absent or minimal.

We recommend the prescription of hydroxyurea to adults and children with SCD irrespective of the severity of their condition.

Biogen Partners CDC Foundation to Develop Longitudinal Data Collection System for SCD

Affecting some 100, 000 Americans, Sickle Cell Disease is the most common inherited blood disorder in the United States. The estimated cost of care for people with the disease is approximately $1.1 billion dollars annually. The CDC Foundation announced a new partnership in 2015 with the U.S. Centers for Disease Control and Prevention's (CDC) Division of Blood Disorders within the National Center on Birth Defects and Developmental Disabilities and other partners to support the development and operation of a longitudinal data collection system for Americans with SCD. Biogen is joining this partnership to help address the health problem. Data from the system will provide states, healthcare provider networks and pharmaceutical and insurance companies with the information needed to establish cost-effective practices to help improve and potentially extend the lives of people with SCD.

'Understanding the clinical history of individuals living with SCD continues to be of great importance,' said Coleen Boyle, Ph.D. director of CDC's National Center on Birth Defects and Developmental Disabilities. 'The partnership fostered between Biogen and the CDC Foundation will further enable critical support for the collection and study of information leading to advances in sickle cell disease treatment.'

Other organizations participating in the partnership include the California Rare Disease Surveillance Program and Pfizer Inc. Although the initial stage of the project will be developed in California, the system will have the capacity to include information on every individual diagnosed with SCD in the United States.

Data will come from a combination of sources including newborn screening, administrative data sets (hospital discharge, emergency department, and Medicaid data), medical charts, and may include personal interviews. The information gathered through this system will allow for a better understanding of medical and educational interventions for SCD, as well as improved patient outcomes over time. The goals of the program are to ensure better care for individuals with SCD and better data for healthcare providers.

'We are grateful to Biogen for joining this important partnership,' said Dr. Judith Monroe, president and CEO of the CDC Foundation. 'This longitudinal data collection system will be the first system of its kind for SCD in the United States.'

Tanzania: Sickle Cell Exhibition Holds at *Sabasaba Fair*

The *Sabasaba Fair* is the most popular national exhibition in Tanzania, attracting over 1,000,000 people who visit the booths of manufacturers, government departments, and research and higher education institutions.

To tie in with 2016 theme of '*linking production to the market*', a novel Sickle Cell Exhibition took place, the aim of which was to engage more closely with the public.

The public got to see blood slide preparations and witnessed first hand on the microscope the different cells including a sickled cell. The aim of this was to make the disease 'real'.

The attending public had their haemoglobin levels checked - of particular importance for those with SCD at the exhibition. It also raised awareness on the importance of blood donation, crucial in SCD management.

Testing for blood group is not a common practice in Tanzania, leading to delays when one needs blood transfusion. Testing helped highlight the fact that blood group is an inherited factor just as SCD is purely an inherited blood disorder.

Along with the hands-on activities, a nurse was on hand to give education and engage with the public on genetic disorder.



The Hype About Hydroxyurea is Justified

Susanna Bortolusso Ali *MB BS, DCH (Lond), DM (Paediatrics) is a 'semi-retired' paediatrician and the Executive Lead at Sickle Cell Awareness Group of Ontario (SCAGO), Canada.*

An honorary senior lecturer at the University of the West Indies, Kingston, Jamaica, she was Head of Clinical Services at the Sickle Cell Unit.

Dr. Ali's areas of interest are neurological complications and pain management in Sickle Cell Disease.

She has to her credit numerous scholarly publications on seizures, stroke, pain and the use of hydroxyurea in SCD.

In this interview with ***Fatima Garba Mohammed,*** *Dr. Ali says Hydroxyurea Therapy is a major breakthrough in the management of sickle cell.*

What makes hydroxyurea more effective than any other drug for sickle cell?

In many developing countries, children with SCD are likely to die before their fifth birthday, especially if they are not diagnosed early.

Continued on page 24





What is the cause of - and remedy for - Persistently High Temperature?

I am the mother of 4-year-old twin girls with sickle cell anaemia. Four months ago, one of them began to have a high temperature – I detected this with our home thermometer. So I took her to Kirrudu Hospital. She was found with malaria and admitted.

A few days after she was discharged, her temperature began to soar - 40◦ Centigrade or more at every reading. She was admitted again, the temperature fluctuating between high and very high.

It is four months now and my daughter's temperature remains high, despite a mélange of antibiotics she had ingested.

Discharged after 3 weeks, the doctors said we have to be patient, that the temperature would normalize 'in due course'.

I am not only impatient, I am worried to the bargain. What is the meaning of temperature that goes up and doesn't come down?

Pauline, From Uganda

Dear Worried Mother,
Fever, an elevation of body temperature, sometimes to above 100*F, is actually a protective response to infection and injury. The elevated body temperature enhances the body's defence mechanisms, while causing relatively minor discomfort for the person.

As the medical team attempts to discover the cause of your child's fever, be rest assured that your baby girl is equal to the task of fighting the fever and protecting herself, since she still generates temperature.

Normal body temperature, also known as normothermia, is 98.2*F or 36.8*C.

The investigation of any child with prolonged fever, follows the standard procedure established by Oxford University.

The child should be taken to a tertiary hospital with a facility for blood culture, where the following steps will be taken.

History -
A thorough history of the child would be taken, where special note would be taken on foreign travels, contact with animals, bites, cuts, surgery, rashes, occasional mild diarrhoea, drugs taken, immunisation, excessive sweats, weight loss, lumps, itching and so on.

Examination
This should be thorough, and repeated - note skin lesions, lymphadenopathy, enlarged liver and spleen, rectal examination. Oro-pharyngeal examination is also done.

Investigations
Full Blood Count(FBC - Total and differential), ESR, U & E, LFT, blood cultures, baseline serum for virology, swab nose and throat, stool sample for analysis and culture, chest X-ray.

Evaluation
If the results of all these investigations come out negative, wait for 7 days and repeat the whole process. Now add tuberculin test, ultrasound or MRI. If nothing still, keep the child under observation and tepid sponge when temperature spikes. Usually after the repeat of the steps, 95% of all fevers are diagnosed. Good luck.

- Dr. Ojum Ekeoma Ogwo



Dr. Ogwo is a genetic counsellor and former Permanent Secretary, Ministry of Mines and Power, Abia State, Nigeria



His email address - jdogfather@gmail.com - says it all. Ajayi Babajide Olusegun loves his canines the way doting parents love their children. The dogs are not only his children but are also his doctors at moments of illness - and depression.

'Breeding dogs gives meaning to my life,' Jide says.

When the business side of his consuming hobby takes over, the dogfather feels as though a part of him had gone with the canine. It's the same feeling when, on impulse, he gives away a puppy to an admirer.

Whether he has lots of money or little of it, the dogs come first. They get their meals and grooming before he does his own. Jide's dogs have it better than human beings in North Korea!

Babajide Ajayi, 26 holds a Bachelor of Science degree in Architecture from the University of Lagos. No one knew he had sickle cell anaemia until he was 11, when, during a routine testing prior to admission to secondary school, the result showed his Hb was SS.

'My parents were shocked because they had believed my Hb was AA based on a lab report when I was still a baby,' says Jide.

Well, maybe the parents need not have been shocked. A year before his admission to secondary school, their child had a horrible horrible bout of pain crises.

'My parents were shocked because they had believed my Hb was AA based on a lab report when I was still a baby'

'The pain was so awful,' he recalls, 'that - at the age of 10 - I prayed for Death to end it all!'

Even as he prayed for death, he remembered his dogs - the dogs actually belonged to a neighbour - and found reason to live.

'I wanted to live to cuddle the dogs some more and run around for a bit more time with them,' he says. 'So I fought hard - very very hard - to get my life back.'

Leaving hospital, he got his own dog - and more afterwards - and launched into a lifelong obsession with man's best friend.

Left to Jide, the pets could roam freely *anywhere* in the house; but his father could not stomach

Continued on page 34

HYDROXYUREA

there is no other drug available that can actually prevent red cells from becoming sickled ...

Continued from page 21



Picture: American Society of Hematology

Up until about 25 years ago, there was no drug that could prevent sickle cell complications. For many people still, the treatment of SCD is limited to managing the complications *after* they occurred. Then in the 1980s a number of studies showed that the drug hydroxyurea, could increase haemoglobin F (HbF) or baby haemoglobin in the red cells of persons with SCD.

Haemoglobin is the red pigment inside red blood cells that gives blood its color. When babies are born, their red cells contain HbF or baby haemoglobin. Over the next six months, HbF changes to the adult type of haemoglobin. In persons with SCD, this means it changes to sickle haemoglobin or HbS. Unlike normal adult haemoglobin (HbA), HbS causes red cells to become rigid and sickle shaped. These rigid red cells are not able to flow easily through small blood vessels and these vessels become blocked. When this happens, tissues are deprived of oxygen and nourishment. Pain and swelling results.

The finding that hydroxyurea increased the amount of HbF and decreased the amount of sickle haemoglobin in the red cells was a breakthrough. Other than hydroxyurea, there is no other drug available presently that can actually prevent red cells from becoming sickled and hard.

Hydroxyurea is a cancer medication. Is sickle cell - at one level - a form of cancer?

Not at all! SCD is a disease inherited from parents if they have the sickle gene. Although hydroxyurea is sometimes used to treat some kinds of cancer, it is the 'side benefit' that we take advantage of in the treatment of



SCD. I'd like to make two things clear: sickle cell disease is not a form of cancer and there is no evidence that hydroxyurea causes cancer.

Some studies suggest hydroxyurea works only in 50% of cases - why all the hype about its effectiveness?

I have to say I am surprised by that figure. Now let us be clear, there are some situations where hydroxyurea will not work. If a patient has had severe damage to any organ or bone, hydroxyurea can't reverse that damage.

The hype about the effectiveness of hydroxyurea is justified in my opinion. Not only does hydroxyurea prolong life in people with SCD, but also it has the potential to dramatically improve the quality of that life so that people can look forward to fulfilling their potential.

Having said that, there are a few people who continue to have frequent pain crises and other complications despite ensuring they are taking the highest recommended dose. They are the unfortunate exceptions. The decision to continue or discontinue hydroxyurea in these people must be evaluated with their doctor.

Why would a doctor prescribe Hydroxyurea for one patient and not the other?

There are some circumstances where hydroxyurea is not recommended. The obvious one is if a patient is allergic to the drug. Another important exclusion criterion is if the patient wishes to start a family.

Continued on page 26



'For 6 Years, I Kept My Daughter's Diagnosis From The Outside World,'

says Shaniquia Nurse as she breaks out of her comfort zone of silence ...

Two weeks after the birth of my little angel, we heard the words no parents want to hear 'Abnormal Test Results'. My journey with Sickle Cell Anaemia began when my daughter, Morgan, was born in 2009. I had heard of SCD, but never knew anyone with it - I never knew it could be so close to skin! My information regarding it was zero. I did not even know my own status.

Keenly going ahead to seek information about the disease affecting my daughter was like learning a foreign language. The medical terminology - PCV, WBC, Hb, FBC, ESR, etc and many other jargons pertaining to her health all but overwhelmed me.

How am I ever going to explain to my daughter that I was ignorant of my sickle cell trait? She is 7 now and ever so inquisitive.

I do not have SCD. My knowledge of sickle cell anaemia comes from books, not from direct experience. My daughter would need real answers from real people to her real life situation.

So this year (2016), I made the decision to seek the support of the outside world and social media. For the first 6 years of her life, I kept my daughter's diagnosis from outsiders. I have begun to understand that there is a whole community of warriors out there, people not only dealing with this disease but living with it and leading amazing lives.

That is exactly what I wish for Morgan - to have an amazing life in spite of having this disease. SCD may be a part of who she is but it is not all she is.

Nurse lives in California, USA



Dr. Bortolusso

HYDROXYUREA

Continued from page 24

By international standards, HU is not an expensive drug, but in resource-challenged countries, the cost of the drug and the cost of blood tests for monitoring can put a strain on the health care system ...
- Sussan Bortolusso Ali

There is some evidence in animals that hydroxyurea taken by the mother may harm the baby. There is no evidence of this in humans but it is always best to be cautious. Finally, in people who already have significant damage to their kidneys or liver, extra care needs to be taken.

Will a patient have to take Hydroxyurea for life?

Once a patient starts hydroxyurea, the improvement in their blood count and health will persist only if they continue to take the drug daily. If they choose to stop taking HU, they will, in two to three months, return to their baseline. Their red cell HbF level will fall and their red cell HbS level will rise. Eventually more of their red cells will become rigid and sickle shaped; they will start having more painful crises and may experience any of the complications seen in SCD such as acute chest syndrome. In order to maintain health and prevent organ damage in the long term, we recommend that HU be taken for life, with breaks only to facilitate pregnancy.

However, if a patient continues to experience frequent complications despite being on HU at the maximum recommended dose daily, a decision should be made whether to continue or not with their doctor.

What challenges do doctors prescribing Hydroxyurea in resource-poor countries face? What should they do to help the SCD patient on Hydroxyurea?

There are two broad challenges. On the one hand, there is the need to overcome the misinformation that people have about this drug. Much of the fear is related to a misconception that it causes cancer. Hydroxyurea has been used in people with SCD for over 25 years and there is no evidence that it causes cancer.

The other challenge is access to care. Like all medications used to treat chronic disease, monitoring for side effects is important and people on hydroxyurea should have regular blood test.

By international standards, HU is not an expensive drug, but in resource-challenged countries, the cost of the drug and the cost of blood tests for monitoring can put a strain on the health care system especially where there are other competing diseases, especially infections disease such as malaria.

Given a stark choice, which would you opt for - better treatment OR prevention through avoidance of SCD?

This is a difficult question to answer. Even with the best care, a child with SCD will need lifelong medical attention and, like all chronic disease, there will be emotional, social and economic consequences. If I believed it possible, I would choose avoidance, but I am a realist. I am optimistic that better treatments are on the horizon, perhaps even a cure.

HU is underused by health care providers and not taken consistently by individuals with SCD

Of the millions of Nigerians with Sickle Cell Anaemia, less than 1% are on HU

In Jamaica, USA and UK, 84%, 94% and 99% with SCD respectively reach adulthood


Judy Grandison



For two weeks every summer, at no cost to their families, children with Sickle Cell go to the picturesque Camp Wenonah, Bracebridge, Ontario, to have fun canoeing, hiking, participating in fireside sing-alongs and meeting new friends

Established 22 years ago, Camp Jumoke is a registered sickle cell charity in Canada. The organization conducts annual summer camps for children and adolescents with SCD. 'Jumoke' comes from a Yoruba name, meaning, join hands together to tend'.
Through education and recreation, the charity charts a path whereby children with SCD can lead healthy, productive lives.
Long-time volunteer Judy Grandison, 42 is currently president. She speaks with ***'Tosin Fawemida****.*

What is *Camp Jumoke* out to achieve?
Camp Jumoke's mission is to provide a medically supervised camp experience as well as provide access to educational support (annual scholarship) to children living with sickle cell disease.

What is your role as president of the charity?
I am a volunteer with *Camp Jumoke*. Currently, I serve in the role of president. I represent *Camp Jumoke* in various forums in order to continue to raise awareness about SCD and the work we do.

What are the challenges facing the organization?
Camp Jumoke faces the same struggles as many other charitable organizations. Our challenges are a lack of volunteers and a lack of funding. Both of these issues have a direct impact on the number of children we can send to camp each year. *Camp Jumoke* receives no government funding and relies entirely on volunteers to execute our initiatives.

What is the age range, racial groupings of those who enjoy your annual camp jamboree?
The age range for our campers is 8 to 16.
While we are available to all children with SCD, our campers are primarily from African and Caribbean countries.

Do you plan to set up similar programs outside Canada - in Nigeria for instance?
It would be wonderful to set up this program in other countries. Perhaps we can explore ideas on how we can help get this going in Nigeria. That would be amazing for the children.

What informs your passion for SCD?
I am a single mom. I have sickle cell trait. My son has sickle cell disease. I parted ways with my partner for fear of producing yet another child with SCD.
I believe that with improved awareness, sickle cell can be prevented or avoided.

More about Camp Jumoke at: www.jumoke.org

Sujimoto Construction Moves To Energize Sickle Cell Awareness

By Abro Onyekwe



Sijibomi Ogundele, MD/CEO, Sujimoto Construction

Sujimoto Construction has thrown its weight behind the fight to stamp out ignorance of sickle cell disorder in Nigeria. The company hoisted its SCD-awareness flag by sponsoring *SCAFLYMPICS,* a sporting event aimed at intensifying awareness of a condition affecting - in its full form - between 3 and 5 million Nigerians.

In its carrier form, sickle cell affects 50 million Nigerians, according to recent estimates given by Professor Michael Kehinde, a haematologist-oncologist at the University of Lagos.

SCAFLYMPICS is a project of the Sickle Cell Aid Foundation (SCAF). Participants engage in sporting and other health-enhancing activities while verifying their genotype.

In September, Sujimoto Construction helped carry out free blood tests for Abuja residents and sponsored sports competitions for sickle cell folks, care givers and members of the public.

Sujimoto Construction Limited is a subsidiary of Sujimoto, a real estate development, energy and finance company.

WHY WE ARE SUPPORTING SICKLE CELL AWARENESS, explains Christycole Popoola, General Manager, Corporate Communications, Sujimoto Construction, in an interview with **Ayoola Olajide**.

Why did you make SCD advocacy a part of your CSR?

Sickle Cell Advocacy is one of the core activities that make up our Corporate Social Responsibility Programmes. Research says 75% of the global incidence of sickle cell occurs in Africa. A recent WHO report referred to about 150,000 babies being born with sickle cell anaemia yearly in Nigeria alone. If these statistics are accurate, why should a socially-responsive business organization not show interest in advocacy? SCD is 100% preventable.

Is this your company's first incursion, so to speak, into SCD awareness in Nigeria?

At Sujimoto Construction, we have always been passionate about CSR Programmes that directly impact human lives. The Sujimoto Principle was at work when we fed 10,000 poor Nigerians, when we renovated the Sujimoto Ward at the Lagos University Teaching Hospital (LUTH) - everything we do is borne out of the need to reach out to society.

Helping with SCD awareness in Nigeria was always something that was going to happen to Sujimoto at one point or another. If all it takes to protect unborn children from the pains of SCD is to join the advocacy and sound the alarm, we will do it wholeheartedly.



Christycole Popoola, GM, Corp Comms, Sujimoto Construction

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WHICH WOULD YOU RATHER BE:

HEALTH FOREVER

A SICKLER,

A WARRIOR,

OR

A CONQUEROR

?

TURN YOURSELF INTO A

CONQUEROR

With Jobelyn ....







If You Are On Hydroxyurea ...

Research suggests combining hydroxyurea therapy with antioxidants heightens drug effectiveness. As the world's leading plant with the highest antioxidant values (United States Department of Agriculture), *Jobelyn* (*sorghum bicolor*) aptly fits in with hydroxyurea SCD therapy

Research carried out by a horde of independent investigators, including the US *National Heart Lung and Blood Institute* (NHLBI) show that sickle cell anaemia patients have high oxidative stress and, conversely, increased antioxidant activity.

Other research studies on the interaction between sickled cells and hydroxyurea therapy found that combining hydroxyurea therapy with antioxidants heightens drug effectiveness.

Jobelyn provides strong antioxidant support for red blood cells (RBCs). Understanding the oxidation process, it's easy to see how RBCs might be vulnerable to the damaging effects of oxygen radicals.

RBCs are the body's oxygen carriers. In the course of their normal 120-day lifespan, they are constantly in contact with this double-edged sword - the element that we require for life, which is also the origin of oxidation. (In Sickle Cell, the RBCs have a severely shortened lifespan of between 10 and 20 days). One way to support RBC health is to prevent oxidation through strong antioxidant supplementation.

Antioxidant supplementation is especially important for people whose RBC health is compromised due to sickle cell anaemia. Recent scientific studies have looked specifically at the effects of *Jobelyn* on anaemia and found that it effectively increases packed cell volume (PCV - the sheer number of blood cells) and haemoglobin concentration. Human clinical research in Nigeria has confirmed these results, showing beneficial effects after just a week of supplementation and significant improvements for 102 of 113 patients after 6 weeks.

In the case of SCD, not only does *Jobelyn* help in its antioxidant activity, but its anti-inflammatory properties may be of benefit too. Some researchers believe that sickled red cells can provoke inflammation throughout the circulatory system because the deformed cells physically hinder smooth blood flow.

Jobelyn protects the RBCs from oxidation and *also* protects the circulatory system from the inflammation state that *often* creates more free radicals. *Jobelyn* cuts off the cycle of oxidation and inflammation that aggravates sickled cells.

Antioxidants: Comparison of *Jobelyn* With Other Fruits and Plants

TABLE OF -ORAC5.0™ FOR FRUITS & VEGETABLES

FRUITS	ORAC (µmol TE/g)	VEGETABLES	ORAC (µmol TE/g)
Cantaloupe	50	Tomatoes	45
Pineapple	100	Sweet Onions	140
Kiwi	150	Celery	20
Red Grapefruit	160	Iceberg Lettuce	55
Oranges	220	Romaine Lettuce	55
Apples	140	Radishes	35
Cherries	200	White Potato	50
Strawberries	420	Broccoli	85
Blueberries	420	Red Leaf Lettuce	80
Plums	160	Broccoli Raab	125
Acai Berry	24,000	Jobelyn	37,622

Brunswick Labs

Jobelyn is a product of Health Forever Products Ltd, 11 Dipeolu Street, Off Obafemi Awolowo Way, Ikeja, Lagos State, Nigeria.
Telephone: 08033376135, 08070516853 website: www.afritradomedic.com

How Hydroxyurea Came To sub-Saharan Africa

continued from page 10

Jos and Keffi respectively. He studied pharmacy in Zaria and proceeded to the Technical College, Bradford, England for further studies. He gained experience at various organizations including St. James's Hospital, Leeds; Hundersfield Cooperative Chemists and UAC/Kingsway Chemists. In 1976, he established Bond Chemists (now Bond Chemical Industries Ltd).

A widely travelled man, Chief Omotosho has visited virtually every major city on earth and has friends and connections all over.

Hydroxyurea

On one his travels to the United States, Chief Omotosho met Professor Kwame Ohene-Frempong, the Ghanaian haematologist and head of the Children's Hospital of Philadelphia.

'We got talking about hydroxyurea, the only USFDA-approved drug for SCD,' he recalls. 'At the end of the day, I made up my mind to go into its production right here in Nigeria.'

His friend, Professor Olu Akinyanju, Chairman, Sickle Cell Foundation, Nigeria, gave his nod. With millions of West Africans having sickle cell anaemia and hundreds of thousands more being born willy-nilly every year, there was a screaming need for an effective medical superintendent such as hydroxyurea.

Symposium

Indeed, during the recent 6th African SCD Symposium held in Accra, Ghana, delegates expressed gladness over the availability of hydroxyurea locally (Nigeria). Convener of the Symposium, Professor Ohene-Frempong, Professor Isaac Odame of Sick Kids Hospital, Canada, and Director, Global Sickle Cell Disease Network (GSCDN) along with other specialists, were fulsome in their recommendation of the medication. The Symposium tasked doctors in Africa to learn more about it to help their patients.

'Fantastically Corrupt'

First guest speaker at the occasion, Professor Fola Tayo, pharmacist and Vice-Chancellor, Caleb University, eulogized the celebrant for holding his head high in the midst of a putrid and corrupt system. A soft-spoken but bitter man, Professor Tayo is the sort bad government catapults into the whirlpool of revolutionary nationalism. He is indeed fortunate that democracy had replaced military dictatorship in Nigeria. A self-confessed born-again Christian, his utterances portrayed the deep frustration of a man let down by a country he so much loves.

'We are indeed a Fantastically Corrupt nation,' he lamented, echoing the words of former British Prime Minister, David Cameron.

Second speaker, Prof Akinyanju gave a lecture with the theme, *Sickle Cell Disease: Innovation and Philanthropy Perspectives.*

With President Mohammadu Buhari in power, Prof Akinyanju veered away from taking a swipe at government SCD policy, as was his custom in previous years. As military ruler or civilian, Buhari has always been sympathetic towards the sickle cell cause.

With millions of West Africans having sickle cell anaemia and hundreds of thousands more being born willy-nilly every year, there was a screaming need for an effective medical comptroller such as hydroxyurea



Duchess Joy El

ADVOCACY: WHEN YOU HAVE A SPECIAL-NEEDS CHILD

By Duchess Joy El

A **mother carries** her baby from the time he or she is as small as a pea until the baby is ready to take his or her first breath. This is a big responsibility. A mother's love for her child starts before they are even born.

When a mother or father holds their baby in their arms for the first time, it is an experience like nothing else. I believe it is bigger and better than any feeling, emotion or thought. It is a blessing - pure magic!

As a parent, you hold that baby in your arms and you make a vow. You promise God to protect this child from hurt and pain, because this child came from you - your very own creation, the greatest thing you've ever made. There is *no* other love like this.

You love your parents, and you love your spouse or significant other, but I don't think it will compare to the love you have for your beautiful creation. This child you carried, this beautiful being for whom you would lay down your life in an instant - that kind of love, that is a parent's love.

What if your creation came into this world even more special than you could ever imagine? What if your child was as fragile as an egg?

As a parent and as an advocate, when you have a medically fragile child or one with disabilities, you might need not only to be their mum and dad but also their first and last health minder, so to speak. You still have and will always have that indescribable love, that fiery passion for your offspring.

You fight for your child to get the treatment or therapy they need. You use your voice to fight for your child. Until they can and do speak for themselves, you are not going to stand idly by while your child needs you to press ahead for him or her.

As you do this, you are teaching this child that he or she is loved. You are showing them the ropes so they know how to do it themselves. By not giving up, you are showing them how to be strong.

As a parent or advocate, you are propping up your child ahead of that day when you are no longer there for them. You prepare them for the world, and you give them every single tool they will need, because if you don't, you might just be setting them up to falter, to fail.

Duchess Joy El lives in Florida, USA



Ajaajide Kennel

Continued from page 23

having dogs take over the family dining room, living room, bedrooms - everywhere!

Jide has had many bouts with SCD-triggered illnesses, but the thought of dogs has always been ever-present to pull him through.

'Breeding dogs has brought me closer to God than any religion could,' he says.

With his looks, you wouldn't believe the dark handsome dog lover is with sickle cell anaemia.

A vegetarian, he was perceptive enough - during his meat-eating days - to note the connection between his diet and health. He takes no carbonated drinks either.

Jide loves to do things for the sickle cell family. Out of pocket, he procures medications and food supplements and gives out to Sickle Cell Clubs at no cost. He also gives talks to inspire families and individuals facing the sickle challenge.

Jide encourages individuals with SCD to take up a hobby and get consumed by that hobby - just as he is with man's best friend.

'Any hobby - any sound hobby - can be both cathartic and therapeutic', says the Dogfather. 'See what loving dogs has done for me!'

Still single, the architect's dream partner would be without sickle cell trait or anaemia ('I don't want my offspring to go through a similar experience') and must, of course, have overwhelming passion for canines of every breed and temperament.



Jonathan and Andrea Williams

Hydroxyurea:

One Family's Choice for Living Well With SCD - *until there is a CURE*

By Andrea M. Williams, Pittsburgh, USA

When my youngest son was diagnosed at birth with sickle cell anaemia, I was told that a cure could come in his lifetime, maybe in the next twenty years.

Every person with sickle cell has a disease course that is unique to them. That's one of the reasons SCD is so difficult to manage. Some with the disease are coping well because their parents decided to give them Hydroxyurea (HU). They have made the choice that has made a huge difference between being very sick and being very well.

When Jonathan was just 2 years old, his lungs began to be affected by SCD. This is known as Acute Chest Syndrome (ACS), one of the most serious complications of SCD. Despite following his treatment plan, he continued to suffer, hospitalized for 6 days at a time, twice a year. The ACS pain was horrible, the treatment was often blood transfusion and strong medicines for the pain.

He also had pain crises in his arms, back and legs, along with random fevers and pneumonia, which would account for more hospitalization.

Living in and out of the hospital continued for 3 years until his doctor presented two treatment options; bone marrow transplant (BMT) and Hydroxyurea (HU). Each of these treatment options had its own set of precautions, risks and potential side effects. We listened intently to the bone

Continued on Page 36



Jonathan Williams

Living Well, Very Well, With Hydroxyurea

Continued from Page 35

marrow transplant option because the requirement was that he have a sibling donor. He has 3 siblings. A CURE? Wow!I don't remember giving much thought to the risks of BMT or hearing anything about HU. All I wanted was a cure for my son.

We had several conversations over the next 2 months, then decided to move forward with the BMT. The first step was talking to my other children to help them understand what was being asked of them. All 3 siblings were tested. A few weeks later the results were in. 'No match.'

I wept uncontrollably, feeling the pain, hopelessness and loss because the only CURE was suddenly unavailable for my son. Our hematologist left the room so that I could collect myself.

When he returned, he asked if I remembered the conversations we had about HU. I had not. Though he reviewed it carefully, I left disappointed and without making a decision. The risks and side effects sounded awful and ranged from upset stomach and hair loss to sterility. I was deeply worried.

'Sometimes I forget I have sickle cell - until you remind me to take my medicine.'

At our primary care visit, I shared my concerns about HU and my disappointment with BMT with Jonathan's physician, Dr. Amy Nevin. Dr. Nevin explained that most HU side effects were dosing dependent and can be reversed. She also informed me of dramatic reductions in the number of ACS and pain for persons taking HU properly.

One thing weighed heavily on my mind. The possibility of infertility. *Infertility!* The word kept echoing in my head. After spending some time in prayer, I had a clarifying thought, 'If Jonathan doesn't start taking HU now with such a difficult course of disease, he may not live long enough to become a Dad, so worrying about him having children has to take a back seat to his becoming well.'

In addition, I spoke to a close friend who reminded me that if I chose not to give him HU, I was allowing SCD complications to continue to damage his body.

She explained that most HU side effects were dosing-dependent and can be quickly reversed

Jonathan started taking HU a few months after his 6th birthday. About 8 months later he was running around, jumping and was more active than he had ever been. I could hardly believe it. One day, when he was about 13 years old, he said to me, 'Sometimes I forget that I have sickle cell - until you remind me to take my medicine.' That's one of the best things I ever heard.

Now, 10 years after starting on HU, he is a typical 16-year-old, playing basketball and hoping for that NBA try-out someday. He has had only one ACS episode and one SCD pain episode resulting in hospitalization. Our lives changed completely from the 6-day hospital stays to years without pain and hospitalization.

We have shared this story many times. We feel so blessed by parents who hear of our experience and want to make HU their choice. We still believe a cure is coming and, with HU, we will be living well, very well, with sickle cell, when it does.

Doctors in Africa need to overcome their fear of HU - Prof Adekunle Adekile, Univ of Kuwait

In Nigeria, candidates for stem cell transplant are placed on HU for at least 6 months

Being on HU did not prevent any of our patients from having babies - Dr. Nosa Bazuaye, Univ of Benin Teaching Hosp, Nigeria



Medical Doctor, Geneticist, Politicians, Academics, Others Seek Cure For SCD With Alternative Medicine

July 11 - July 14: in Accra and Kumasi, Ghana, to cover the 6th African Sickle Cell Symposium. *Sickle Cell News* was the only media organization present. Shows how dearly Africa holds its own health challenges.
I met SCD experts, medics and paramedics from around the world.

.....

July 30: at Newgate Hospital, Ikorodu to visit Mrs. G. Her 3 year old first born with SS has serially been on admission at various hospitals in town. Mrs. G tells me she is planning to travel to Ijebu-Ode to see an Engineer who would cure her daughter of SCD within one or two months.
I collect the Engineer's phone number. Though I don't believe such nonsense about cures, I would pay the man a visit all the same (*see September 2*).

.....

August 3: Mrs A. came from Abeokuta to see me. We met on Facebook. She had been in touch with an **Ahmadu Bello University, Zaria-trained pharmacist** who claims he can - and has - cured two dozen patients of sickle cell. The pharmacist is known to me. I had tasked him to present just one patient he had cured. He is yet to oblige, claiming confidentiality. His regimen would cost quite a sum. He agrees to treat Mrs. A's 4-year old for free. He has no need to worry about publicity once the child is cured.

.....

August 26: Surprise, surprise! It was quite a surprise to see a signpost bearing the legend, *Tope Sickle Cell Awareness* in Oko of all places. Oko is a sleepy settlement near my hometown, Ogbomoso, with perhaps 5000 inhabitants. I was in Ogbomoso for a family event.
Amazing! I begged the driver to turn back so I could note down the phone no.
Africa's rural areas are a hotbed of ignorance and myths about SCD. This organization deserves support (routine medications, medical volunteers). Their phone no: 08145348637

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September 2: in Ijebu-Ode, Ogun State to see Prince Adedeji Adesanya, 72. Prince Adesanya studied Automotive Engineering in Koblenz, Germany, graduating 43 years ago. He claims he cured his two children of the disorder (since 1985) using local herbs. None of the children has allegedly fallen prey to SCD crises or complication of any sort since then.
At his home, I met a few parents and patients who spoke of tremendous health improvements. Unfortunately, none of them has taken time to confirm they have been cured (by blood test)!
To me, improvement is not in the same league as a cure.

'My medication does not only improve,' the prince insists, 'it CURES!'

Adesanya reels out the names of top politicians, Ministers, academics and medical practitioners whose children he had cured of sickle cell.

One of Adesanya's clients, Dr. Y, a surgeon, disclosed 'CURED' was too big a word to use for his son, but that the child seems to have 'wrenched his life back from the shackles of SCD'.

.
I call yet another medical doctor whom Prince Adesanya says can attest to his claims.

'The old man is clearly on to something,' Dr. K says, 'I am working with him to come out with a scientific report.'
Dr. K is with the Ministry of Health in Ogun State and also runs a private clinic.

Continued on Page 38



Mrs. Rhoda Adebayo, a university graduate, one of Adesanya's clients: 'My son's health improved dramatically though I haven't re-done his genotype'

Nigerians Seek Cure At All Costs

Continued from Page 37

Later, Prince Adesanya called a professor at the Tai Solarin University of Education (TASUED) in the same town, would the professor like to talk to a journalist about his son whom he (Adesanya) treated for sickle cell?

The professor went berserk. No! How can Adesanya go so low as to disclose the medical particulars of his son to a third party?

.....

September 12: Pastor O. adds me to his *whatsapp* chat group. Pastor O's signboard is all over the country, screaming in bold lettering, **WE CURE SICKLE CELL**. Officers of the various regulatory agencies of Federal and State Ministries of Health, the zonal offices of the Nigerian Medical Association, etc see this board everyday, but look the other way. I won't be surprised if they themselves are patronizing this man in hopes of having their relations cured!

Anyway, on *whatsapp*, two weeks after I was added, a woman in Ilorin, Kwara State claims her 13-year-old son was cured of SS (Hb changed to AA). From her speech when I called her, I discerned she is well-educated. The child had been diagnosed SS at the University of Ilorin Teaching Hospital (UITH). Now, at the same hospital, he had been found with AA!
Laboratory error again! I thought.

Another woman calls me today **29th September**, a geneticist. She wants to know if I have heard of Pastor O - should she submit her 11 year old under the regime of concoctions and austere dietary discipline that would lead to a cure?

Of course I have known Pastor O for four years. 3 years ago a Colonel in the Nigerian Army categorically told me his son was cured of SCD. I have also interviewed some of the pastor's clients but can't say I have personally seen one cure.

'I know the books say SCD is incurable,' she says, 'but I think there's no harm sticking our neck out for a cure. With God, nothing shall be impossible!'

Well, would madam be willing to share her story whatever the outcome?

Absolutely not, she says, SCD is strictly a private affair for me and my husband. None of our relatives are aware we have a child with sickle cell.

Hydroxyurea For Africa

Continued from Page 7

Director-General, Ghana Health Service, Dr. Ambrose Wonkam, University of Cape Town, Dr. Dapa Diallo, from Mali and Dr. Baba Inusa, Evelina Children's Hospital, London.

World pharmaceutical giant, Novartis was represented by Dr. Jonathan Spector, Head, Global Services while Pfizer was represented by Mrs Margaret Olele, Director, Corporate Affairs, Nigeria and East Africa Region (NEAR). Frederick Meindl represented PekinElmer, world's biggest producer of newborn screening equipment.

Individuals and families with sickle cell from Nigeria, Togo, Brazil and the host country, Ghana were also there.

The theme of the Ghana Symposium was *'Filling in Gaps in Knowledge For Improved Care'.*

The next global SCD gathering takes place in Bhuneshwar, India (February 21 - 24 2017).

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'MY SON HAD NO COMPLICATIONS ON HALF-MATCH BONE MARROW TRANSPLANT'

- Sarah Namugwanya, Kampala, Uganda



December 2019, India

One year after his Bone Marrow Transplant, Elisha Isaiah Muleme and his mom, Sarah Namugwanya, returned to India for a checkup. He was talkative, bubbly and restless like any 3-year-old with an oversupply of native energy. Just a year earlier – in the run-up to the transplant, he was flaccid, lethargic and in a world his own, the result of niggling sickle cell complications. At first the family was discouraged as there was no full match for the boy within the family and even in the Worldwide Bone Marrow registries for unrelated donor. Dr. Vikas Dua and his team decided to go ahead with the Haploidentical (Half-match) Transplant with the boy's father, David Lubowa Kalyango as the donor.

Elisha's transplant went very well, despite the fact that it was a half-match - a testimonial to his doctors' expertise. 'The child suffered no untoward effects,' Sarah says, 'For the past year he didn't have any infections, no pains, no crisis – he is like any other normal child now.' The happy mum now encourages every family that has a child with sickle cell and other blood conditions to submit their children for a transplant.

Dr Vikas says, 'Sickle cell or any other blood condition patient having frequent pain crisis, history of stroke, acute chest syndrome, avascular necrosis, priapism, kidney dysfunction or other major complication warrants a BMT at the earliest. All families are not lucky to get the matching donor or even unrelated donor as few African volunteers have enrolled in the worldwide bone marrow registries. However, there is at least one of parent who is a 50% match. Half match transplant is the best option available to get the chance to live a healthy, pain free life.

These transplants were previously associated with a relatively lower rate of success; but better knowledge of transplant immunology and advanced techniques of T cell depletion has led to dramatic improvements in Half-Match Bone Marrow Transplants.

The aim of BMT Clinic, an initiative of Dr. Vikas Dua and his team is to guide and cater to the needs of patients and their families suffering from various blood disorders and blood cancers, which can be successfully treated by Bone Marrow Transplant (BMT). BMT Clinic gives clear guidance on how to plan your hassle-free travel to India, BMT procedure of your loved one, Hospital Stay, affordable accommodation, follow up checkups and return to your country, happy and healthy.

For details/enquiries, contact Dr. Vikas Dua directly on Tel/WhatsApp no: +917015677759. Or email: drvikas.bmt@gmail.com. Visit www.bmtclinic.com for detailed info.



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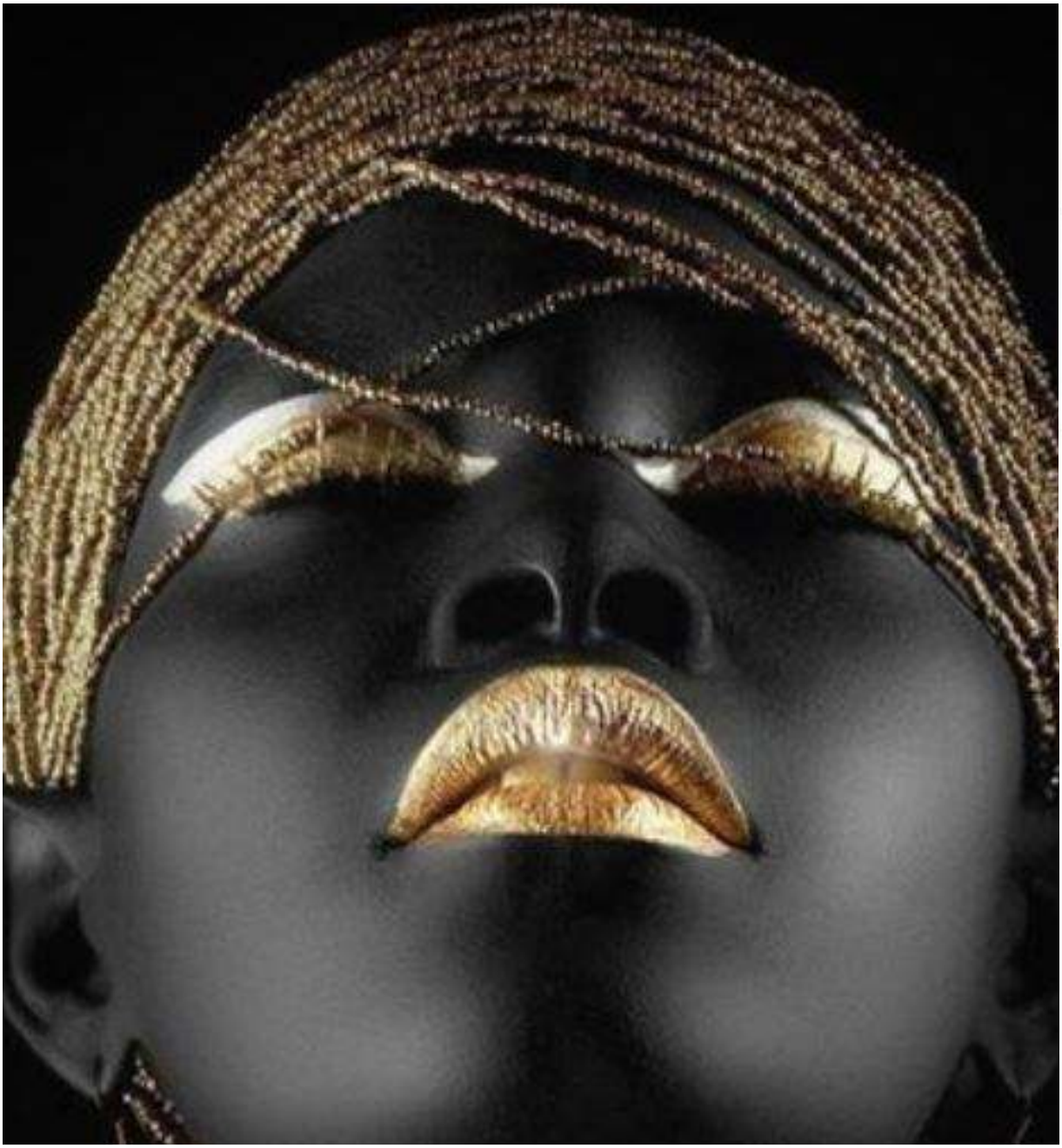
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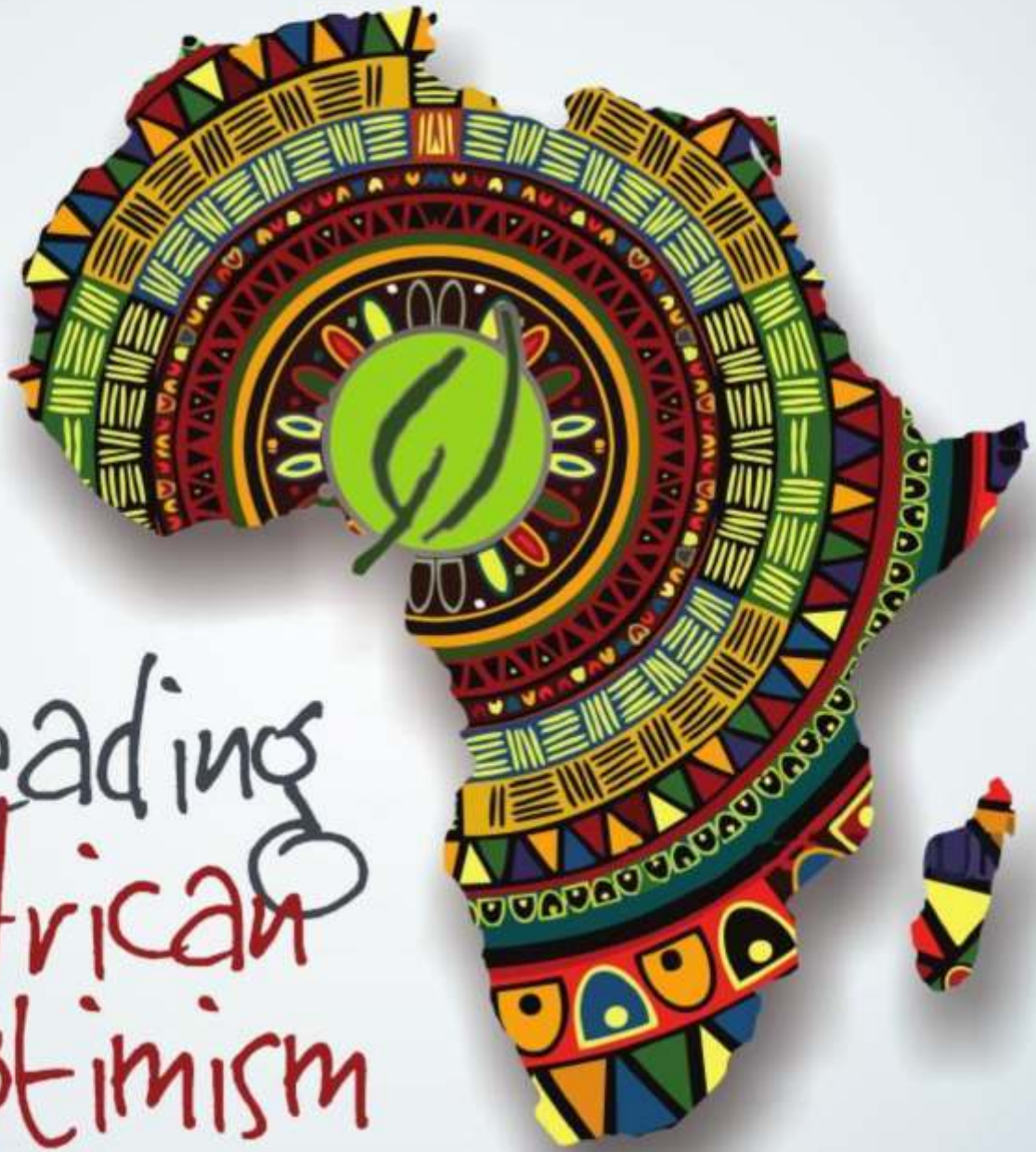
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