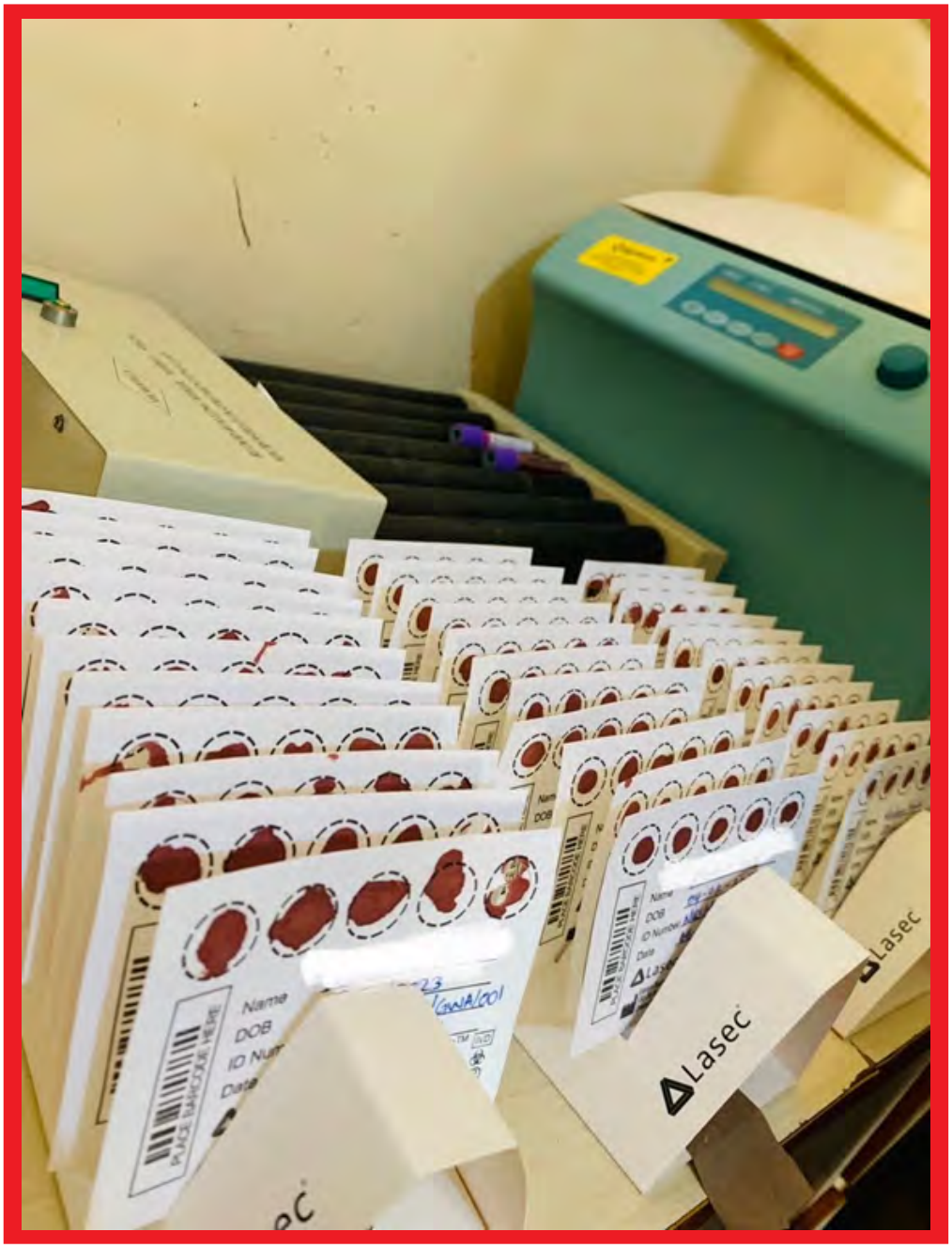
JANUARY



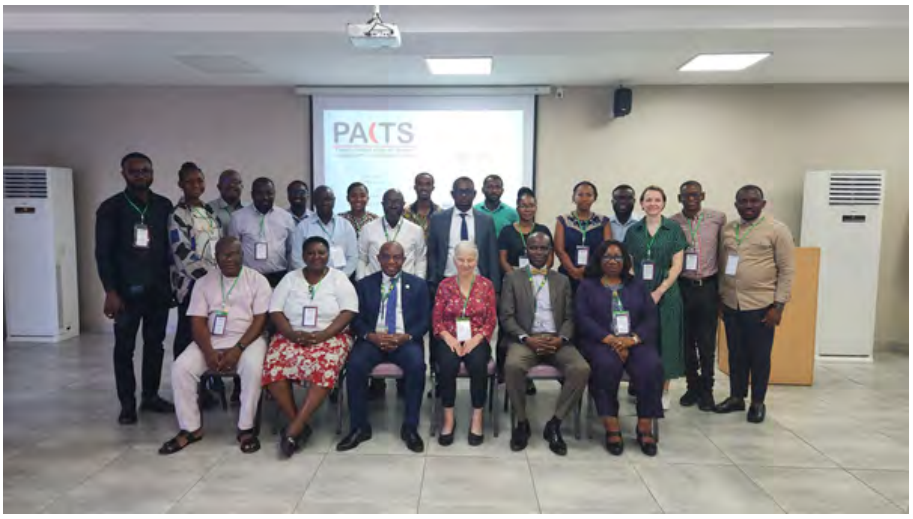
January ushered in a pivotal phase for our Newborn Screening initiative, with the Quantitative Phase 1 implementation kicking off. This project aims to validate point-of-care testing (POCT) using dried blood spots (DBS) against conventional methods like isoelectric focusing (IEF). The goal? Ensuring a sustainable, cost-effective newborn screening program that guarantees diagnostic accuracy.

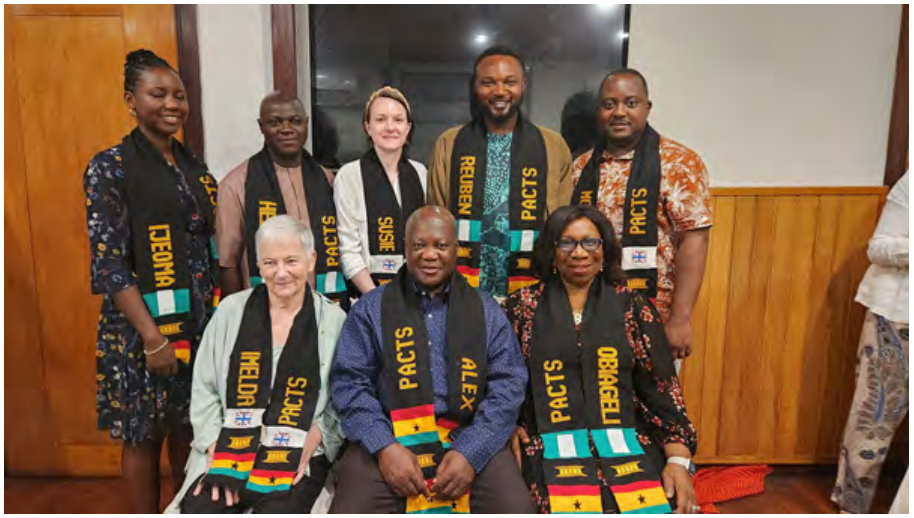
Going beyond just research, we took proactive steps to empower primary healthcare facilities. Our team conducted training sessions to equip staff with the skills needed to utilise DBS POCT effectively for screening and diagnosis at the grassroots level.
Early and accurate detection is crucial for managing sickle cell disease from birth. By validating DBS POCT against gold-standard techniques, we can pave the way for a decentralised screening model. This increased access can revolutionise timely interventions and improve outcomes for countless newborns across communities.

> ***"Going beyond just research, we took proactive steps to empower primary healthcare facilities."***

FEBRUARY

In February, members of the Participatory Approaches to Support Patient-Centred Sickle Cell Disease Management in Africa (PACTS) project gathered for their inaugural in-person meeting at Kwame Nkrumah University (KNUST) in Kumasi, Ghana. This marked a significant milestone as it was the first time all members from the three project sites - Ghana, Nigeria, and Zambia - convened face-to-face after collaborating online for over a year.





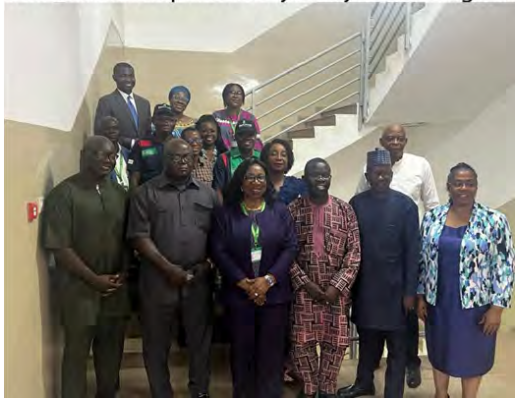
The meeting was structured into two phases. During the first phase, the focus was on the leads of the Standards-Based Audit and the Participatory Action Cycle Lead, along with the PhD students. In phase two, Program Managers from all three sites and other key administrative personnel came together to refine crucial documentation.

The gathering offered a refreshing sense of camaraderie and collaboration that is uniquely fostered by in-person interactions. Meetings like these emphasise the importance of the human element which remains integral to our collective efforts in advancing patient-centred sickle cell disease management in Africa.

MARCH

The month opened on a high note with the inauguration ceremony and stakeholders' workshop for our "mAnaging siCkle CELl disEase through incReased AdopTion of hydroxyurEa in Nigeria"

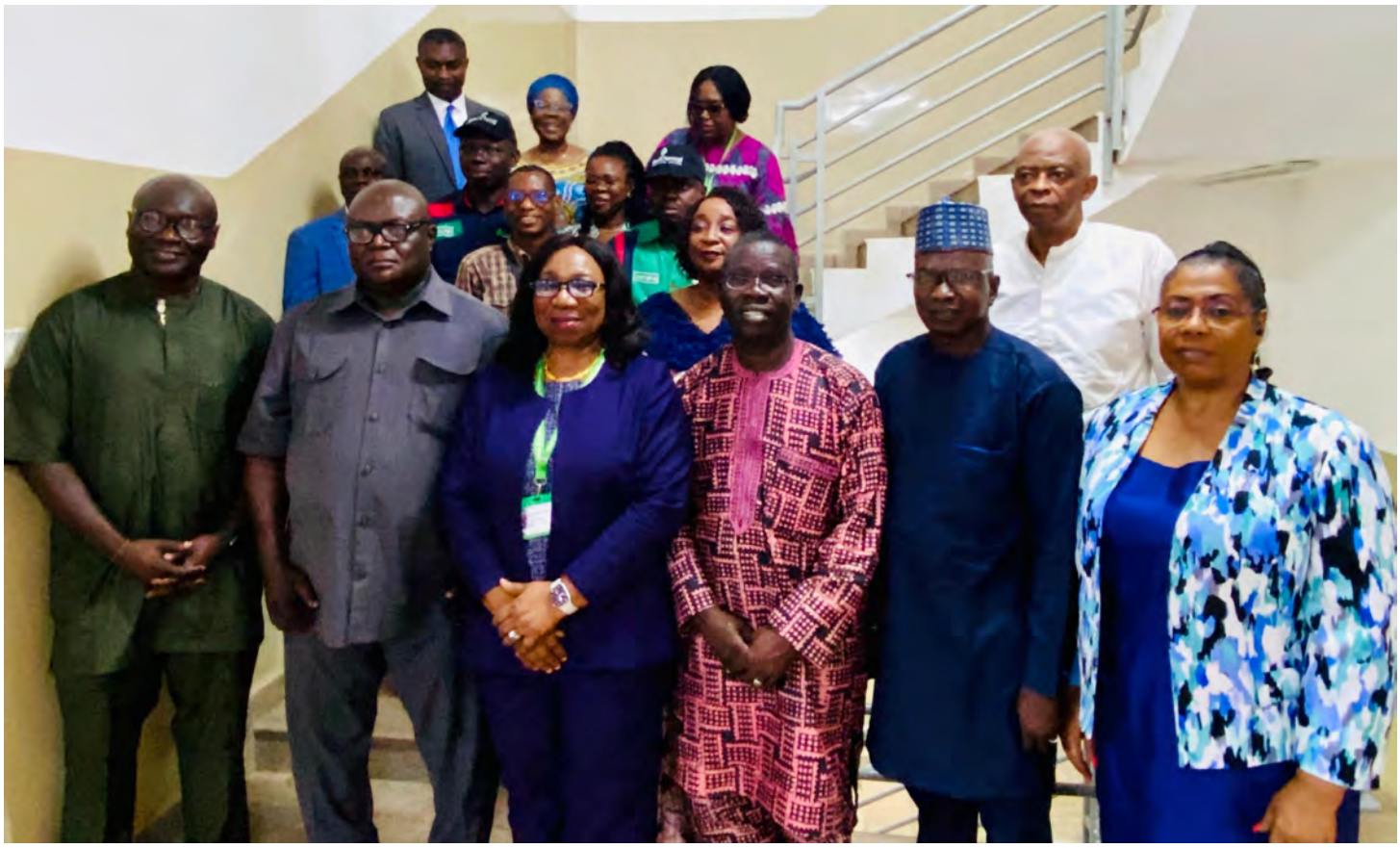
Accelerate
mAnaging siCkle CELl disEase through
incReased AdopTion of hydroxyurEa in Nigeria



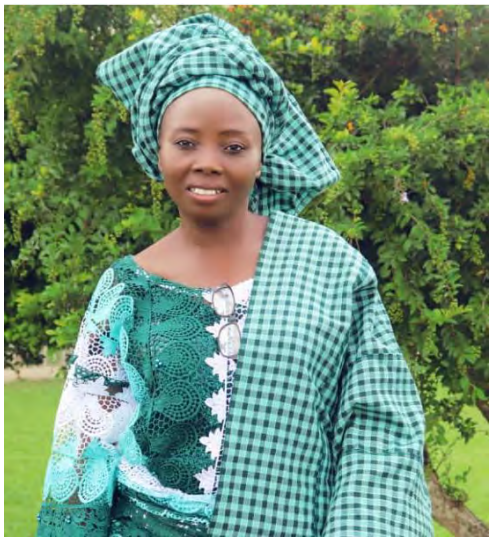
(ACCELERATE) project. This groundbreaking initiative will conduct the first large-scale implementation research study for assessing hydroxyurea adoption in sickle cell disease (SCD) management across clinical sites. The project emerges from a collaboration between NYU's Dr. Peprah (School of Global Public Health) and our esteemed director, Prof. Nnodu. The workshop was a resounding success, arming healthcare professionals, policymakers, and SCD patients with comprehensive insights on hydroxyurea therapy - its importance, efficacy, and potential side effects.

We are immensely excited about ACCELERATE's potential to transform clinical practice and improve outcomes for over 4 million Nigerian SCD patients and countless others across Africa. By driving increased hydroxyurea adoption through evidence-based strategies, we can positively impact millions of lives affected by this disease.

The high-impact workshop set the stage for progress by fostering a shared understanding among all stakeholders. As recruitment and study implementation progress, we will share regular updates in this bulletin. This initiative marks a pivotal step towards improving SCD care in our communities through collaborative research excellence.



International Women's Day and Sickle Cell: CESRTA's Ifunanya Achigamonye chats with Victoria, the Victorious Warrior



Mrs. Victoria Joseph

May we know you?

My name is Victoria Joseph. I am from Kogi state. I am 53 years old, a civil servant and a mother of three children.

Victoria, can you tell us a bit about your experience living with sickle cell disease? How has it impacted your life?

Sickle cell is not a disease I would wish anyone has. Growing up I did not know that I had this disease. My parents didn't know either because they where not educated or enlightened. I was ill on a daily basis due to the excruciating pain and the hospital became my second home. Part of this was caused by a reluctance to observe a different life from my peers. I, like most children did not like to constantly take medication, dress warm and stay indoors when my friends did not live that way. This made the condition worse than it needed to be.

How did you first discover that you had sickle cell disease, and how were you diagnosed?

When I was young I didn't know much about the disease neither did my parents. However, they always advised me to take enough water, avoid being outside late at night, wear clothes that cover my body and take my routine drugs, because the hospital told them so.

As a woman living with sickle cell disease, have you faced any unique challenges or experiences that you would like to share?

No, I have not encountered any. The reason is that a lot of people are not aware of my status unless I tell them. This has really helped me in combating a lot of challenges.

How have you managed your symptoms and pain associated with sickle cell disease? Have you found any particular treatments or coping strategies that work well for you?

In my teenage years the pain was intense, especially during my menstruation. I often missed school because of the pain. However, the pain was greatly reduced when I got married and throughout my child bearing stage. During my pregnancies I supported my health by taking folic acid, iron-free blood tonics and my other medications unfailingly. By God's grace, these had a desirable effect on me and I was able to deliver my children without the need for blood transfusions.

Can you speak to the impact of sickle cell disease on your relationships and family life? Have you found it challenging to maintain close connections with others?

Not at all. This disease did not stop me from having a good relationship with my family and friends. I grew up in a wonderful and supportive family. I am the last child in a family of 3. I had 2 older brothers and they took care of me and made me feel special. They constantly empathized with me and they helped me with my workload especially during my crises periods.

How have you advocated for yourself and others living with sickle cell disease? Have you been involved in any advocacy or awareness campaigns?

Yes, I created awareness especially in my locality and in my workplace. I discovered younger people in my area who have sickle cell disease. Some of them have had tertiary education. I reach out to them and I let them know that this disease is not a death sentence. I tell them that with regular adherence to medications and other safety practices, they can live long and healthy lives. Parents of warriors also come to inquire from me about what I do to keep healthy. As a school teacher, I constantly encourage my students who are sickle cell warriors and I educate them on combating inferiority complexes.

How do you see the future of sickle cell disease treatment and management? Are there any promising developments that give you hope for the future?

Me I no see anything o. I've been in this situation for more than 50 years and I have not experienced any marked improvements in our care. Our medications are quite costly and stem cell transplant remains very expensive to carry out. My greatest hope lies in increasing community awareness to the most remote areas of the country. This will reduce intermarriage between AS genotypes and would totally eradicate this disease. This is where my hope lies.

How do you stay positive and resilient in the face of the challenges associated with sickle cell disease? Are there any particular sources of inspiration or support that you rely on?

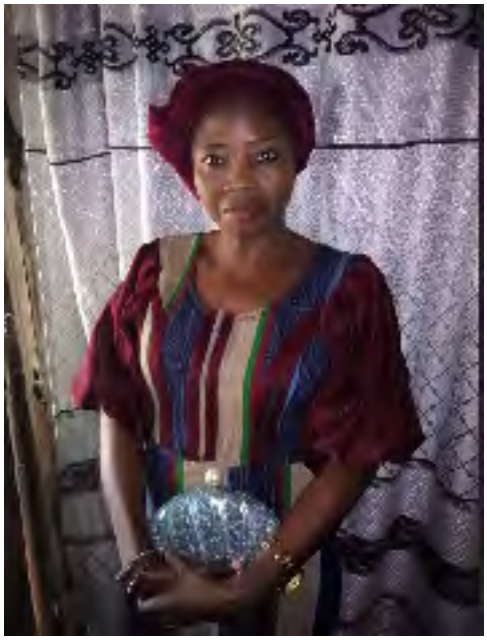
I rely solely on God and indeed He has helped me. I am able to do things that some healthy people cannot do. I earned my degree and I do not miss work. When I have crises, I take analgesics and I pray. Soon after, I am back to my feet. God is my strength.

What advice would you offer to other women living with sickle cell disease?

Are there any specific steps they can take to manage their condition and improve their quality of life?

I recognize that life may be harder for many younger warriors. They may face discrimination in employment with many employers choosing not to hire them because of possibly frequent sick days. Many also face discrimination

in marriage due to their status. To all of this, my advice is that they should turn their focus on improving themselves in any way possible. If it has been difficult to get a regular job, consider learning a skill so that you can be self-employed. Keep a positive mindset in all situation,and above all, maintain faith in God



Mrs. Victoria Joseph

Finally, is there anything else you would like to share about your experience with sickle cell disease, or any message you would like to convey to the wider public about the realities of living with this condition?

I believe people with sickle cell disease have an above average level of intelligence. I am convinced of this. Therefore my counsel is that we should refuse to let our situation limit our capability. Refuse to be sorry for yourself. Refuse to be bullied or intimidated. You are God's creation. Look to God and be ready to be industrious. You will get to the heights you wish.