

# HIGHLIGHTS OF 2023



Photo of CESRTA Staff and Warriors

## FEBRUARY

This month, following the national elections Nigeria's fuel subsidy deregulation sparked widespread price hikes, industrial action and economic uncertainty. Day-to-day life became difficult for many, including our Warriors.

As transportation and medication costs rose, CESRTA banded together to support the most vulnerable fami-

lies. Our staff contributed funds to subsidise expenses, working to avoid treatment gaps. We are grateful to our sponsors for accommodating unexpected needs.

The turmoil impacted our Centre's operations, yet resilience prevails. Our team remains firmly rooted in serving families relying on us now more than ever. And our Warriors continue exemplifying the cour-

age to persist through life's storms. Challenging times reaffirm why our work matters. As Nigeria progresses down the path to reform and recovery, CESRTA will remain a constant support system empowering our community.

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# MAY

This month we brought the future of health-care into focus by taking medical students on an impactful experience to a primary health centre in Gwagwalada Area Council on a hands-on outreach using point of care test (POCT). The students gained firsthand experience with this low-cost screening method for infants. They witnessed for themselves the rapid sickle cell detection at the primary level, they attested to the power of early screening and grasped



practical skills to take home. We believe that this demonstration will inspire these young leaders' zeal to continue in the footsteps of

our centre, in bringing learning about early detection of sickle cell Warriors around the globe.

# JUNE



June was filled with tremendous activities as we commemorated World Sickle Cell Day with the theme 'The Role of Stakeholders in the Management of Sickle Cell Disease'. Members of the team



had interviews, discussions and panel sessions on media outlets such as African Independent Television (AIT) Kakaaki, The African Voice, Aso Radio and Television, Trust Television, Hot FM and

Classic FM. In these visits, there was dissemination of information about the newborn screening program funded by the Consortium on Newborn Screening in Nigeria (CONSA), addressing myths about Sickle Cell Disease and some of the challenges faced by the caregivers of Warriors.. The overall objective was to highlight the role of stakeholders in the holistic management of SCD and the significance of universal newborn screening and early intervention as the key to the management and control of SCD.

# JULY

The Director participated in the Launch of the Lancet Commission on Sickle Cell Disease at EHA in Frankfurt and in Tanzania where she made presentations as one of the Section Leads in the Commission.



# AUGUST



This month, CESRTA welcomed dedicated teams from 7 nations as we hosted the SickleInAfrica Consortium Newborn Screening Study technical meet-

ing. We reviewed pilot data, protocols, NBS tools, pretesting and implementation plans. There were hands-on sessions in the use of research tools includ-

ing informed consent documents, sample collection, in depth interview and focus group discussion guides.

# SEPTEMBER

*Happy Birthday*

September was a special month with the surprise celebration of our Director's birthday; honouring her for her visionary leadership and inspiration and constant admonition to us to always do our best and for providing us with opportunities for growth. We are



grateful for the achievements she has had and always for

being a great support for the team as a whole.

## Training Workshop on Standard of Care Guideline on Sickle Cell Disease



We also had a training workshop on the Standard of Care Guidelines for Sickle Cell Disease Management which was organised for healthcare workers

at the primary health care level. Specialists from both secondary and tertiary levels were present. It was an interactive session in which the community

health extension workers participated and received specialised knowledge and practical skills in the management of Sickle Cell Disease at the primary level.

# OCTOBER

## Special outreach by CESRTA to the PHCs of Gwako and Old Kutunku



This month, CESRTA extended a helping hand to the frontlines of healthcare access by providing much-needed

ed upgrades for local clinics. We champion early screening for sickle cell disease, which relies on community partnerships with primary health centres. CESRTA staff noticed deteriorating seating in the waiting areas of two such clinics. To uplift and empower these invaluable partners, our Centre refurbished furniture for mothers and babies at the Gwako PHC. We also constructed additional office seating

and tables for stretched staff at the old Kutunku PHC. These simple yet essential upgrades help create a professional atmosphere and improve experiences for staff and families seeking care. By assisting with such infrastructure, we hope to register these clinics as trusted places of collaboration to identify vulnerable newborns. Uplifting PHCs enhance access to community health care.

## CESRTA'S Director is appointed Special Advisor (SA) to Nigeria's Coordinating Minister of Health and Social Welfare



This month, Professor Nnodu, Center Director, was appointed Special Advisor to the Coordinating Minister of Health and

Social Welfare. During an advocacy visit, with characteristic passion, Professor Nnodu presented critical needs: the establishment of

daycare centres for Warriors in secondary and tertiary health care centres, , integrating newborn screening into routine healthcare, Ni-

geria's role in the advancing SCD prevention and management programs. As Chair of the Sickle Cell Support Society of Nigeria and Director of the only government owned research centre focused on SCD research, Professor Nnodu can uplift patient outcomes by directly advising national policy. We celebrate this immense honour, knowing Nigeria's sickle cell community has gained an ally guiding strategy with their best interest at heart. We celebrate this hard-earned influence to shape a future where patients and science command attention

## DECEMBER

### Our Director is Golden!

We wrapped up 2023 with a golden celebration of our luminous Director. The Vice Chancellor of the University of Abuja (where CESRTA domiciles) hosts an annual Recognition Award to honour exemplary researchers and authors, and our own Professor Nnodu struck gold twice over! CESRTA staff were on hand to cheer her well-de-



To foster community and resilience amongst our incredible Sickle Cell Warriors, CESRTA hosted an uplifting End-of-Year Celebration for newborns identified through CONSA screening alongside Adult Warriors from UATH. The festivities commenced with a lively dance session sparking joy. Professor Nnodu then welcomed all, emphasising our 'Hope to Cope' theme. By showcasing thriving adults, mothers of Golden babies would receive encouragement, knowing that

served accolades. Her humble, indefatigable spirit drives excellence at CESRTA and in lecturing university students. Even amidst leading the Centre's urgent work, Professor Nnodu re-

their babies' futures were not bleak. Interactive sessions allowed Warriors to gain understanding from shared experiences. To further encourage these forms of informal support, two Warriors were elected to chair the Warrior Support Group on WhatsApp. The celebration brought fun through dancing, networking and even a Warrior pop quiz! The party ended with CESRTA distributing transportation stipends and cute souvenirs to encourage a lifestyle of staying hydrated. It was a memorable way to end

lentlessly contributes scholarship to her students.. Prof's gold medals are the fruits of the seeds of her dedication. Her example of service with heart inspires our entire community. We

beam with pride at her accomplishments and model ourselves after her selfless commitment to our community. Congratulations Professor! Here's to continued celebrations for



## CESRTA will be hosting Visitors!



After Professor Nnodu's winning ASH proposal, CESRTA will host the prestigious African Visitor Trainee Program in 2024. We are honoured to be selected as a global destination for haematologists to learn state-of-the-art sickle

cell disease diagnosis and management. Our centre looks forward to sharing hard-won knowledge from years of empowering Warriors. As we blaze a trail and illuminate the path ahead, we take pride in paying progress for-

ward. By equipping more practitioners with evidence-based techniques, even more Warriors can access life-transforming treatment. CESRTA is going all out in preparing to warmly welcome our esteemed visitors. Here's to culti-

vating connections across borders to save lives! The future of healthcare is global collaboration.

## Warriors as Partners in Healthcare



The year closed on an uplifting note with photos arriving from our research nurse Ibrahim and a dedicated Warrior representing CESRTA at an international conference on patient partnership. They attended the PAPIR (Patients as Partners in Research) meeting sponsored by our collaborators Sickle Data Coordinating Center, University of Cape Town. PAPIR spotlights the immense value of posi-

tioning patients as frontline partners in their own healthcare journeys. The sessions explored tangible ways providers can empower Warriors with more ownership and voice in treatment decisions. Attending this conference reinforces our centre's commitment to ensuring services meet patients' humanity and dignity - not merely medical needs. Our shared quest is not for data points, but for human flourish-

ing. We consider it a privilege to learn ways we can continue improving support services hand-in-hand with the community we serve. As we head into 2024, this conference keeps us grounded in the ultimate purpose of our work - walking hand in hand with Warriors toward fuller, healthier lives. Here's to keeping partnership, empathy and hope at the heart of healthcare in the year ahead!

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### Editorial Team

Ijeoma Udeozo

Dr. Ayomide Fasina

Chidume Jacob