ARISE

African Research And Innovative Initiative For Sickle Cell Education

Existing Programmes to Enhance NBS for SCD in Africa

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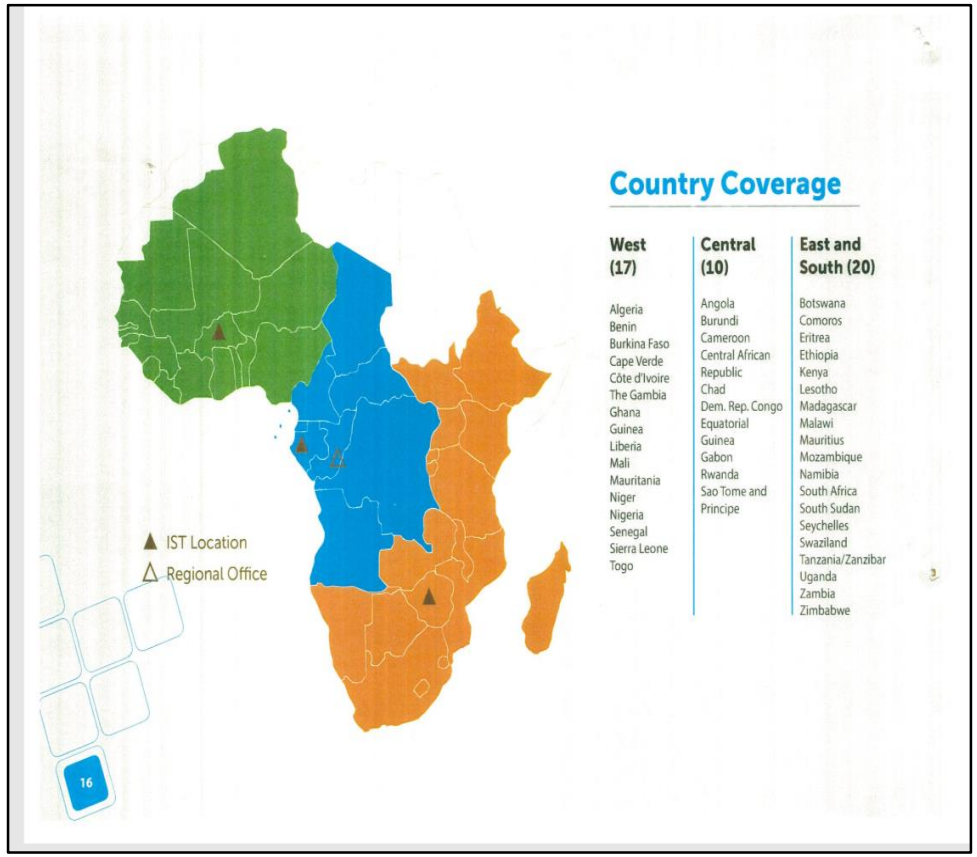
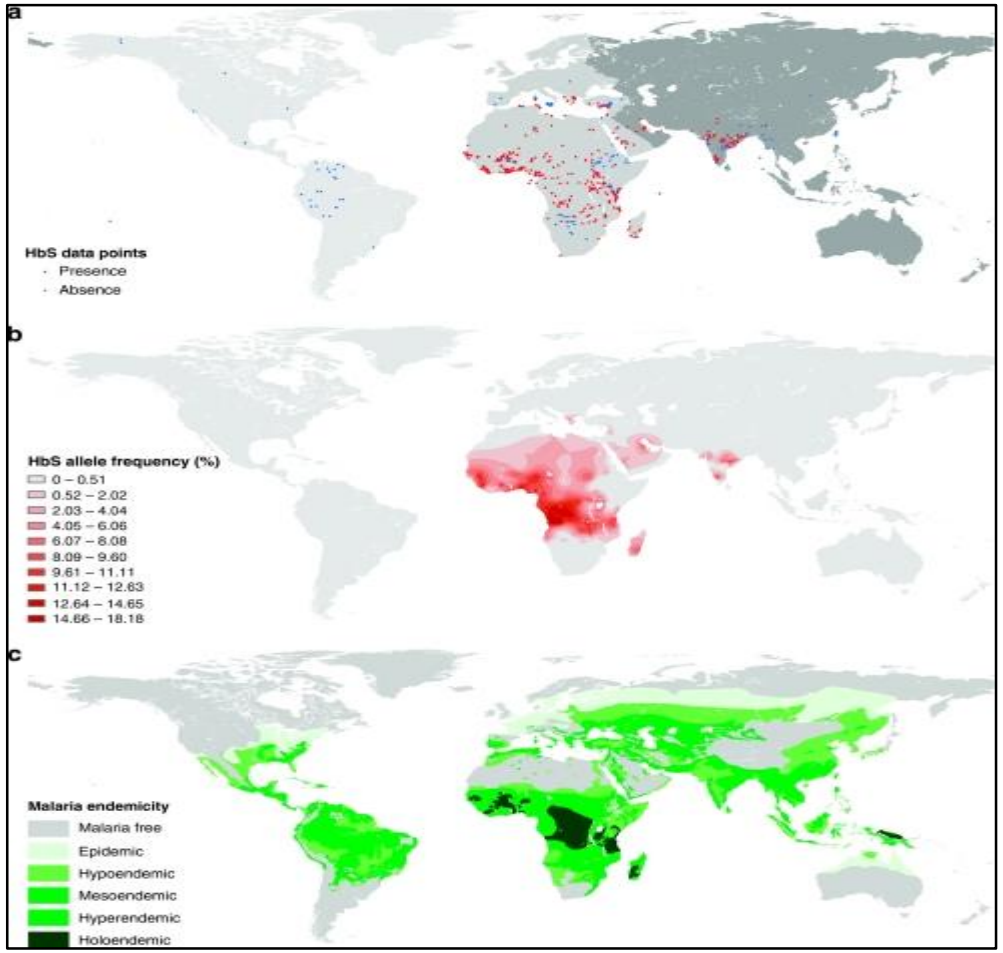
Existing Programmes to Enhance NBS for SCD in Africa

- Background
- Status of NBS for SCD programmes in Africa
- Barriers to escalation of NBS for SCD programmes in Africa
- Existing programmes to enhance NBS for SCD in Africa
- 1st Pan African Workshop on newborn screening
- The Morocco Declaration
- WHO AFRO RC69 High Level Meeting on SCD
- Take Home Message

SCD High Burden Countries in Africa



Countries in WHO African Region



Piel FB, Patil AP, Howes RE, et al. Global distribution of the sickle cell gene *Nat Commun*. 2010;1:104

Background

1. **New-born screening**
2. Raising public awareness about SCD
3. Registry of patients with SCD for prospective follow up
4. Prophylaxis for infection, pneumococcal vaccines, oral penicillin, use of insecticide treated bed nets and anti-malarial
5. Health maintenance at PHC (comprehensive care through integration into Secondary and Tertiary Health Care Centres)
6. Genetic counselling of individuals with abnormal haemoglobin i.e. **AS, AC** SS, SC.
7. Nutrition
8. Education of patients and care givers about sickle cell disease including what to do in acute conditions before coming to the hospital.
9. Optimal hydration by teaching the patients to drink enough fluids to make their urine clear and whitish without yellow colour

Background

Year of publication	Country (city)	Duration	No. of Babies	SCD frequency (%)	Test	Type of sampling	Sample type
2008	Nigeria (Benin)	3 months	644	3.0%	Isoelectric focusing confirmed with citrate agar	Systematic	Heel prick on filter paper
2016	Liberia (Monrovia)	13 months	2785	1.2%	IEF	Systematic	Heel prick on filter paper
2009	Burkina Faso (Ouagadougou)	4 years	2341	1.8%	IEF confirmed with HPLC	Systematic/targeted	Cord blood/ filter paper
2008	Ghana (Kumasi)	Over 10 years	202244	1.9%	IEF	Systematic	Not stated
2009	Republic of Benin	3 years	1189		IEF	Targeted	Heel prick on filter paper
2003	Senegal (Dakar)		478	2.1%	IEF Confirmed with citrate agar	Systematic	Dried blood spots

Table 1: Neonatal Screening for sickle cell disease (SCD) in Africa: countries, techniques and frequencies of SCD.

Hsu L, Nnodu OE, Brown BJ, Tluway F, King S, et al. (2018) White Paper: Pathways to Progress in Newborn Screening for Sickle Cell Disease in Sub-Saharan Africa. J Trop Dis 6: 260. doi:10.4172/2329-891X.1000260

Status of NBS in African Countries

- Newborn Screening for sickle cell disease is being practiced in 12 countries (Benin, Nigeria, Uganda, DRC, Mali, Senegal, Ghana, Liberia, Tanzania, Kenya, Burkina Faso and Cameroun) but not as a national programme in any of the countries.
- The effort is concentrated in tertiary health care facilities where most of the samples are collected.
- In Mali, DRC, Uganda and Ghana, sample collection is carried out at all levels of health care by a variety of health care workers (Nurses, midwives, laboratory personnel and doctors).
- In Democratic Republic of Congo, Mali, Ghana and Niger NBS at PHC

Status of NBS in African Countries

NBS Practice	Countries Involved
Screening test in dedicated NBS Facility	Ghana, Nigeria, Senegal, Mali, Burkina Faso and Uganda
Screening carried out in the same facility where blood is collected	The Republic of Guinea, Liberia, Tanzania and Kenya
Payment for tests by patients	Most countries
Government pays for test	Uganda
Combination of the government, insurance companies and patients.	Kenya
Variety of methods for primary screening and confirmatory testing	Most countries
Point of care tests	Congo, DRC, Guinea, Liberia and Kenya

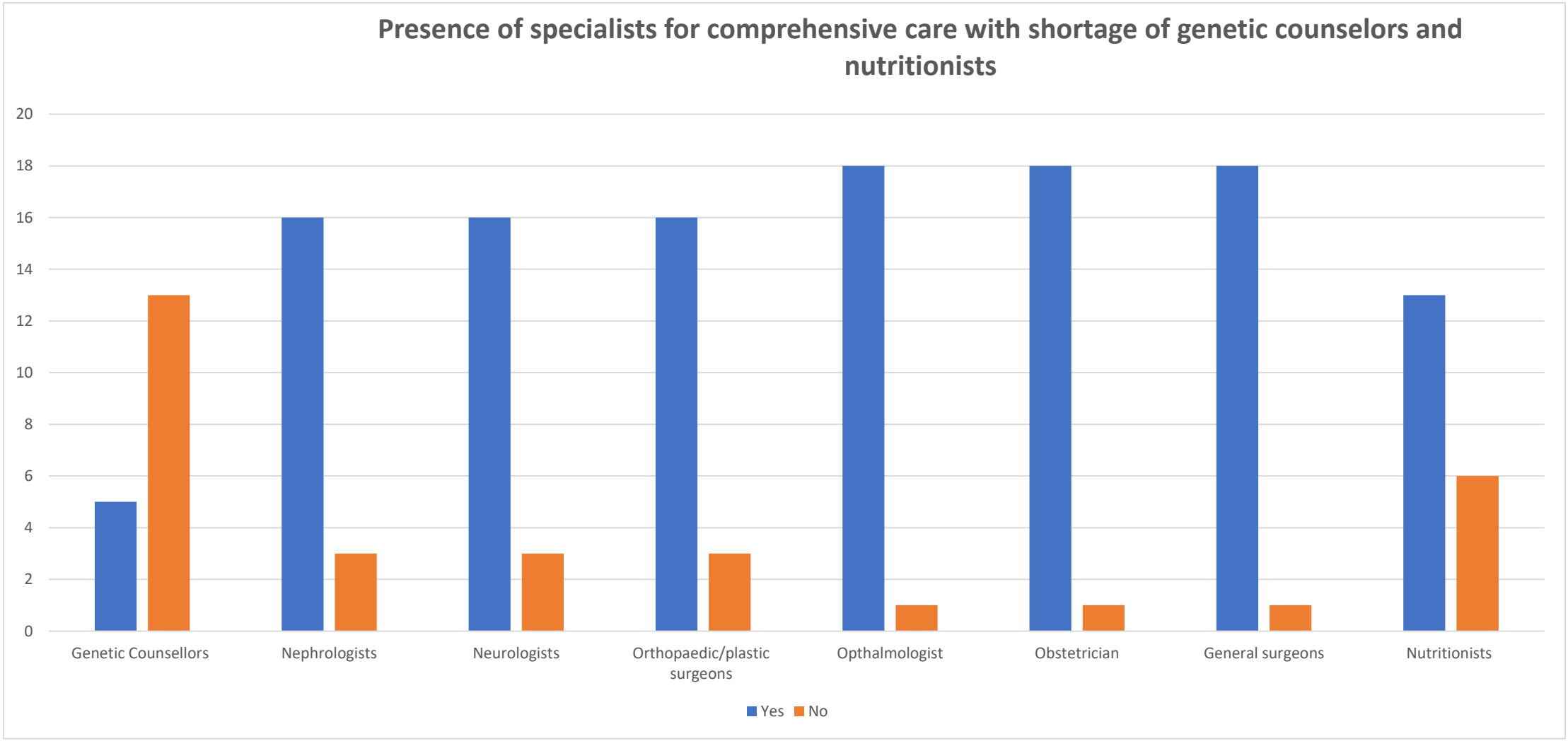
Status of NBS in African Countries

NBS Practice	Countries Involved
Linkage of SCD programs with HIV screening	Burkina Faso and Uganda
Linkage of maternal and newborn screening	Uganda, Democratic Republic of Congo, Republic of Guinea, Ghana, Gabon and Tanzania
Follow up of diagnosed babies	In paediatric or sickle cell clinics (general OPD in Zimbabwe DRC)
Access to pneumococcal vaccines, Haemophilus influenza B vaccine, oral penicillin and malaria prophylaxis.	Most countries

Status of NBS in African Countries

NBS Practice	Countries Involved
Presence of transition clinics	Few countries
Standard package for follow up: folic acid +anti malaria medication +oral penicillin	Benin, Nigeria, Uganda, Republic of Guinea, Mali, Senegal, Liberia, Tanzania, Kenya, Zambia
Folic acid+ oral penicillin +insecticide treated bed nets	Benin, Uganda, Republic of Congo, Democratic Republic of Congo, Mauritania, Senegal, Ghana, Kenya
Access of diagnosed babies to hydroxyurea	Nigeria, Uganda, Republic of Congo, Togo, Mali, Mauritania, Senegal, Ghana, Tanzania, Kenya, and Mauritius
Presence of guidelines for HUT	In only a few countries

Status of NBS in African Countries



The NBS Programs in Nigeria

Description	National (MDG Sickle Cell Centres)	State Screening Programs	SCORE	Local Government Area (University of Abuja)
Location	6 Biorad nbs HPLC machines in each geopolitical zone.	Anambra, Delta State (Kaduna, Oyo)	(North Central Nigeria)	Immunization Clinics in Gwagwalada Area Council of the Federal Capital Territory Abuja
Primary screening method	HPLC	IEF	HPLC	Point of Care. Has acquired IEF platform
Confirmatory method	HPLC	IEF	HPLC	HPLC
Year Started	Installed between 2011-2013	2013-2017	2010-2011	2017 November
Level of activity	Only one centre functioning (Keffi)	Ongoing for Anambra and Delta States	-	Ongoing
Numbers screened	3,424	4,961	10,001	6,219
Prevalence of SCD	1.46%	0.32%.	2.69%	1.83%
Main challenge	Staff not trained in some centres, machines not used, reagents expired.	No data from Kaduna and Oyo state		Delays in obtaining confirmation of result from NBS Laboratory in Keffi

Barriers to Escalation of Pilot NBS

Setting Up A Program

1. **Where will samples be collected- health care facilities**
2. **When will samples be collected-**

- At birth at participating institutions
- At postnatal clinic, usually at 2 weeks and 6 weeks
- At first immunizations (6wks - 14 weeks), measles @ 9months

3. **Screening Laboratory**

- Tests to be used for screening and confirmation
- What happens to the results
- . Person responsible for parental follow-up and scheduling clinical visit
- When/Where is confirmatory testing will be conducted
- 4. **Clinical Network for follow up and care of screen detected babies**
- **5. Drugs and Immunizations**
- **6. Data Management Workflow**
- **7. The personnel charged with data management and quality control**

Barriers to Escalation of NBS Programs Beyond Pilot Projects

- Diagnosis of SCD is by cellulose acetate electrophoresis, (CAE), iso-electric focusing (IEF), capillary electrophoresis, high performance liquid chromatography (HPLC) at different levels of the health care system.
- Apart from CAE, these investigations are expensive, have long turnaround time, require well trained technical personnel and are beyond the reach of majority of people.
- The costs of the diagnostics tests vary widely between countries

Barriers to Escalation of NBS Programs Beyond Pilot Projects

- Government policies recognizing SCD as major NCD and NBS as priority intervention for SCD
- Financial- poor budgetary allocation to SCD prevention and management
- Cost of equipment and reagents and consumables for screening
- Availability of well-trained health workers
- Laboratory infrastructure and associated systems, such as sample transport and laboratory information management systems, to enable testing and dissemination of results.
- Data management infrastructure

Existing Programmes to Enhance NBS- Resources for Follow Up & Treatment

- WHO PEN PLUS- (Program of Intervention for Non-communicable Diseases) at Primary Health Care
- National Guidelines
- SPARCO Multilevel Standardised Guideline
- ASH Protocol on NBS -Family Education

Existing Programmes to Enhance NBS

- WHO- AFRO Strategy for SCD. Regional Committee 60 –Member States
- WHO is technical partner to member states in health matters.
- SCD included in the program of interventions for NCDs (WHO PEN) Nigeria
- Inclusion of SCD in the First National Multi-sectoral Action Plan (NNMSAP) for the Prevention and Control of Non-communicable Diseases for Nigeria
- High level meeting at the sides of WHO AFRO RC69 to urge member states to scale up NBS and package of interventions at PHC level by integration into existing public health services in order to reach the health-related SDGs.

Examples of Best Practices in NBS from the African Region

Ghana

- Newborn screening program started in 1995 as a pilot in the greater Ashanti region and became a national program in 2015

Nigeria

- Screening Method - Designated NBS Centre with HPLC machines
- More recently- point of care testing of babies in immunization clinics in primary health care centres

Democratic Republic of Congo, Republic of Guinea and Tanzania

- Newborn screening for SCD is integrated into the maternal & childcare programmes

Uganda

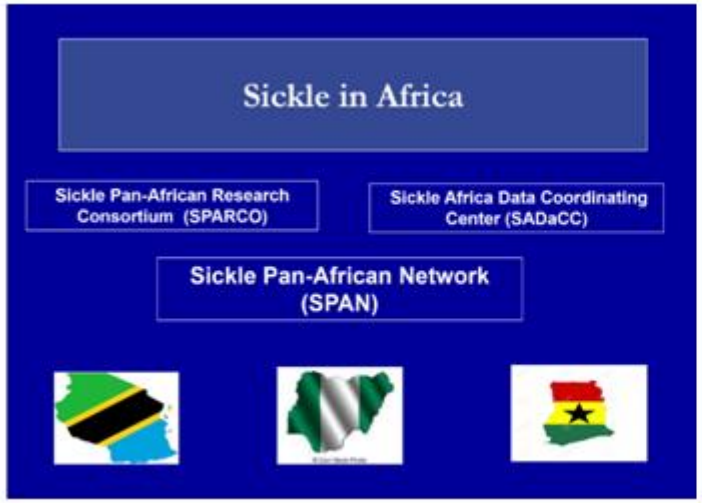
- Started as pilot linked to the HIV screening using dried blood spots collected from PMTCT program

Angola

- Texas Children Hospital SCD Initiative in NBS program

SCD Networks in African Region

1. ***Sickle Pan African Research ConRéseau d'Etude de la Drépanocytose en Afrique Centrale (REDAC)***
2. ***Sickle Pan African Research Consortium (SPARCO) 3. SickleGenAfrica***



Leadership of SickleGenAfrica

GWAS of haptoglobin, hemopexin, alpha-1-macroglobulin, heme oxygenase-1 and ferritin levels in large SCD cohorts in Africa

Role of GWAS variants in acute organ damage in SCD.

Functional validation of GWAS findings in transgenic sickle mice.

SickleInAfrica

Sickle Pan-African Research Consortium (SPARCO)

Sickle Africa Data Coordinating Center (SADaCC)

Sickle Pan-African Network (SPAN)

SPARCO:

- **Tanzania: Muhimbili University of Health and Allied Sciences**
- **Nigeria: University of Abuja**
- **Ghana: Kwame Nkrumah University of Science & Technology**

SADACC

- **South Africa: Sickle Africa Data Coordinating Centre: University of Cape Town**

SPAN: 22 Sites in 17 Countries

SPARCO

Methods

A 4 year project
3 sites and 1 Data Coordinating Centre

- ❖Years 1 & 2 – planning phase
- ❖Year 3- Pilot phase
- ❖ Year 4 -Implementation
- ❖Beyond Year 4
  - ❖To include other SSA countries
  - ✓Sickle Pan African Network

Project Period: 04/01/2017 – 03/31/2021
Project Activated: 05/01/2017

Outcomes

•Infrastructure that will advance SCD-related research in Africa

•Contribute to scientific knowledge to find a cure for SCD

•Reduction of the public health burden (mortality and morbidity) of SCD in Africa

- ❖Improving quality of care
- ❖Increase in skilled HRH
- ❖Standardised management guidelines

SPARCO Aims

Aim 1:

- To develop ethically and legally approved, patient consented, centralized, secure, web-based database for health services and research. (With SADaCC)
- Establish a SCD Registry (n=13,000) which will be embedded/inter-phased with the institutional health information management system

Aim 2:

- To develop, implement and evaluate a resource-based, multi-level, "Guidelines for Management of SCD in SSA", in order to standardize the care of individuals with SCD
- Set minimum standards for management of SCD based on institutional technical and human capacity for each level of healthcare

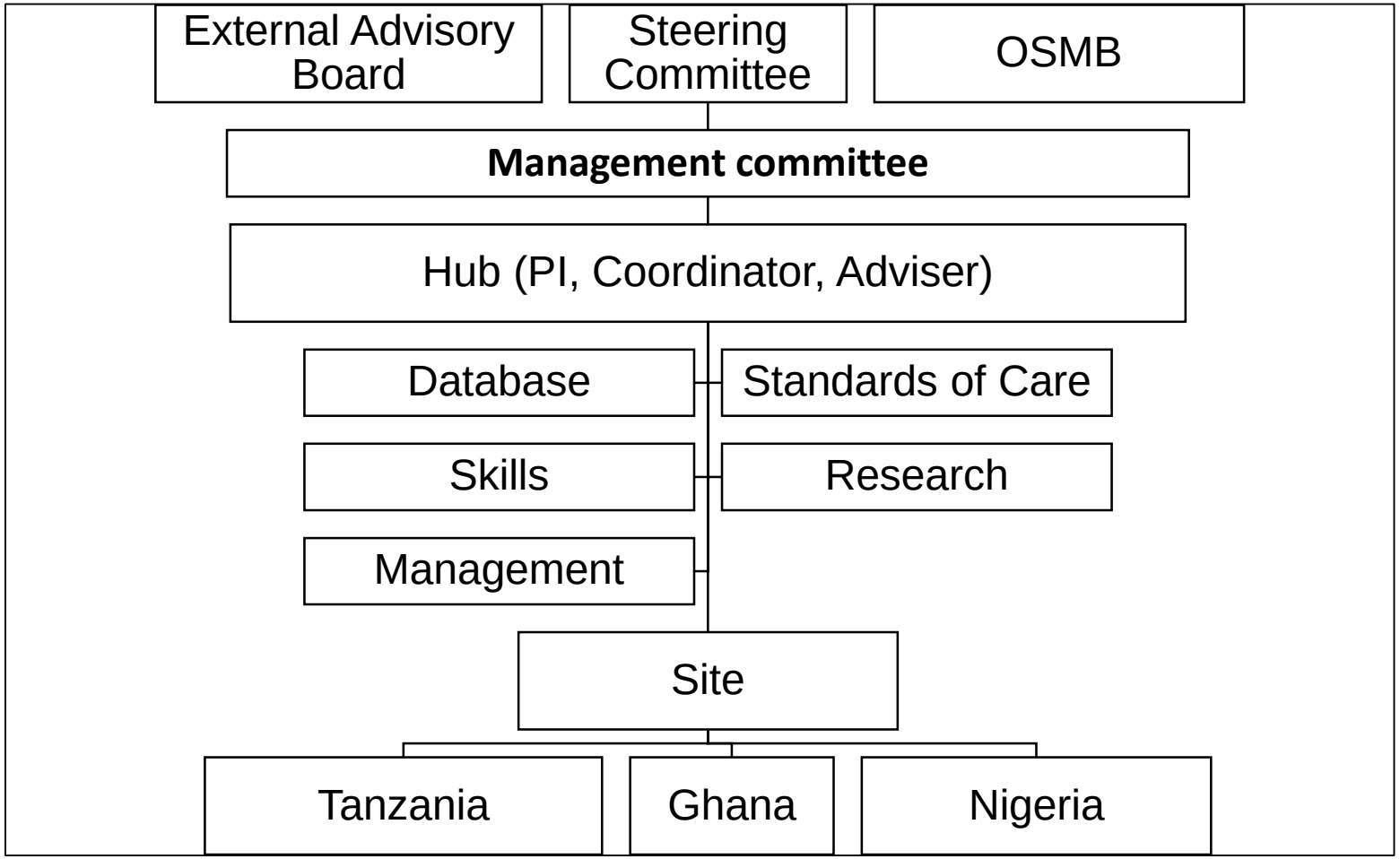
Aim 3:

- To organize short, medium and long-term training programs to strengthen skills in SCD health services and research
- Human resource (HR) capacity for SCD in
  - ❖ 4 areas: Database, Health, Skills and Research

Aim 4:

- **To develop plans for future research by establishing SCD cohorts in SSA in order to create a platform to conduct SCD-related epidemiologic, translational and clinical research.**
  - ➢ **Clinical research: Cohort (n=1500, 500 per site)**
    - ❖ **Clinical epidemiology (n= 1500, 500 per site)**
    - ❖ **Disease modifiers**
  - ➢ **Implementation Research**
    - ❖ **NBS (n= 30,000, 10,000 per site)**
    - ❖ **Infection prophylaxis (n=600, 100 individuals each arm, 200 per site) : Pneumococcal**
    - ❖ **Hydroxyurea (n=1500, 500 per site)**

SPARCO organization



Key Personnel
Consortium Hub (Tanzania): Julie Makani (PI); TBC (Consortium coordinator); Solomon Ofori-Acquah (Consortium advisor); * Kisali Pallangyo (PK)

Tanzania: Emmanuel Balandya (Consortium Site PI); Lucio Luzzatto (Consortium Site advisor);

Ghana: Alex Osei Akoto (Consortium Site PI); Kwaku Ohene-Frempong (Consortium Site advisor)

Nigeria: Obiageli Nnodu (Consortium Site PI); Olufunmi Olopade (Consortium Site advisor)

The SCSSN Centres

Collaborating Centres in the Nigerian Sickle Cell Disease Network

Collaborating Centres

1. Ahmadu Bello University Zaria, Kaduna State
2. Aminu Kano University Teaching Hosp, Kano, Kano State
3. Benue state University, Makurdi, Benue State
4. Bingham University, Karu, Nassarawa State, Nigeria
5. Ekiti State University, Teaching Hospital, Ado Ekiti, Ekiti State
6. Enugu State University of Science and Technology Teaching Hospital, Parklane, Enugu State
7. Federal Medical Centre, Asaba, Delta State
8. Federal Medical Centre Bida, Niger State
9. Federal Medical Centre Ido-Ekiti, Ekiti State
10. Federal Medical Centre Keffi, Nassarawa State
11. Federal Medical Centre Birnin Kebbi, Kebbi State
12. Federal Medical Center, Owerri, Imo State
13. Federal Teaching Hospital, Abakaliki, Ebonyi State
14. Federal Teaching Hospital, Gombe, Gombe State
15. Gbagada General Hospital, Lagos, Lagos State
16. General Hospital Katsina, Katsina State
17. Ifako-Ijaiye General Hospital, Lagos, Lagos State
18. Ladoke Akintola University of Technology, Ogbomoso, Oyo State
19. Lagos State University Teaching Hospital, Lagos, Lagos State
20. Lagos University Teaching Hospital, Lagos, Lagos State
21. Massey Street Children's Hospital, Lagos, Lagos State
22. Murtala Muhammed Specialist Hospital, Kano, Kano State
23. National Hospital, Abuja
24. Nnamdi Azikiwe University Teaching Hospital, Nnewi, Anambra State
25. Obafemi Awolowo University Teaching Hospital Complex, Ile-Ife, Osun State
26. Sickle Cell Foundation, Lagos, Lagos State
27. University College Hospital, Ibadan, Oyo State
28. University of Abuja Teaching Hospital
29. University of Benin Teaching Hospital, Benin, Edo State
30. University of Calabar Teaching Hospital, Calabar, Calabar State
31. University of Ilorin Teaching Hospital, Ilorin, Kwara State
32. University of Maiduguri Teaching Hospital, Maiduguri, Borno State
33. University of Nigeria Teaching Hospital Enugu, Enugu State
34. University of Nigeria Teaching Hospital, Ituku-Ozalla, Enugu State
35. University of Port Harcourt, Port Harcourt, Rivers State
36. University of Uyo Teaching Hospital, Akwa Ibom State
37. Uthman Danfodio University Teaching Hospital, Sokoto, Sokoto State
38. Wesley Guild Hospital, Ilesa, Osun State
39. Zankli Medical Centre, Abuja

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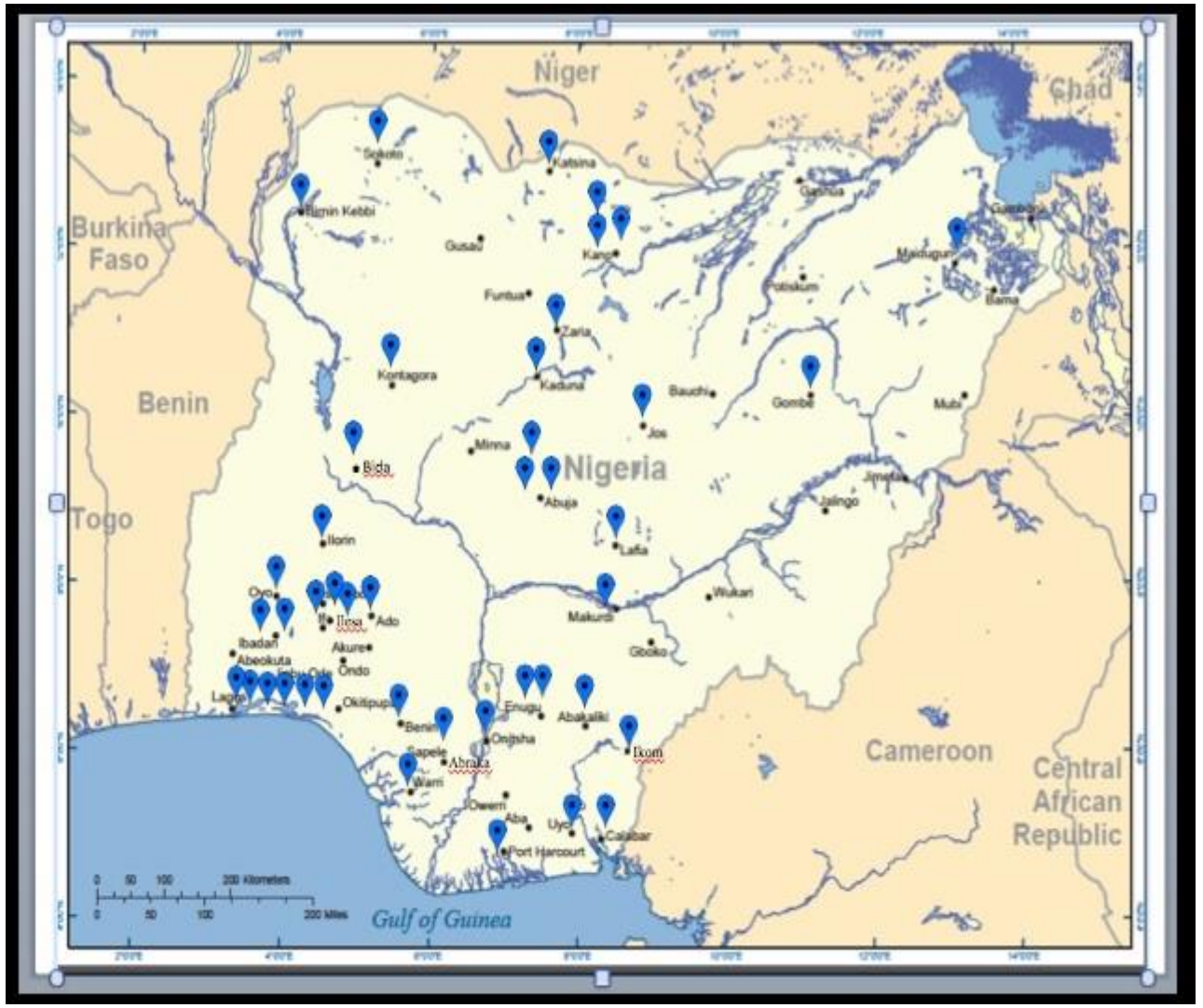
39 Collaborating Centres Offering of the SCSSN Tertiary Health Care Services



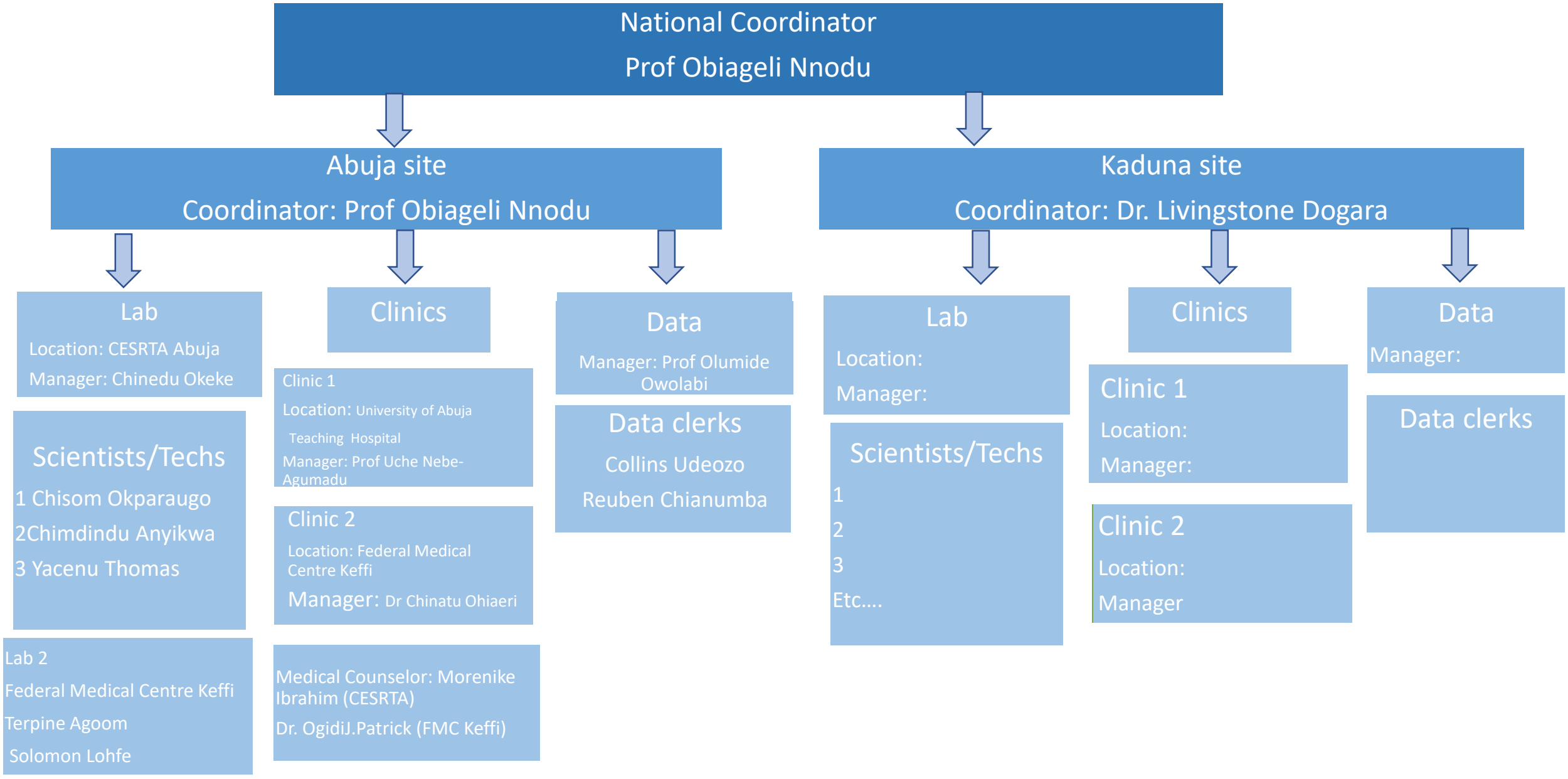
SPARCO –Nigeria Through SCSSN

Initiatives to Enhance NBS

Countries in Consortium
Ghana- Prof Ohene-Frempong
Nigeria –Prof Obiageli Nnodu
Tanzania-Dr Siana Nkya
Other Countries
Liberia- Venee Tubman
Zambia- Catherine Chunda

The Consortium is a collaboration between the American Society of Hematology (ASH) and hematologists across Africa to demonstrate the effectiveness of newborn screening and early therapeutic interventions for babies with SCD in sub-Saharan Africa.
The Consortium has been able to negotiate lower equipment and reagents costs for NBS on the IEF platform

ASH SCD Consortium: Organogram for Nigeria



SPARCO Nigeria Sites

SPARCO Collaborating Centres

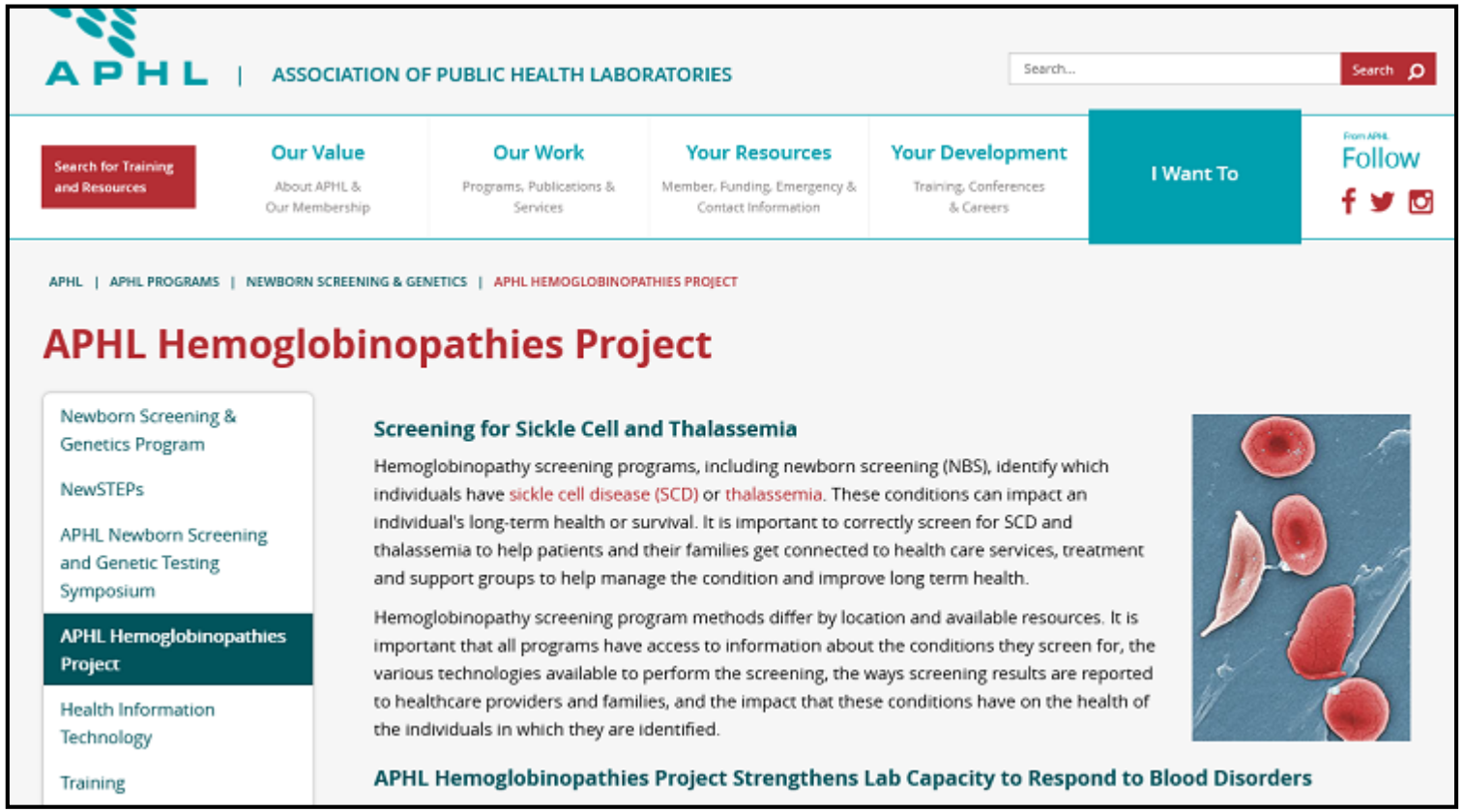
S/No	Centre	Site Lead
1	University of Abuja Teaching Hospital (UATH)- Adult	Professor O.E Nnodu
2	University of Abuja Teaching Hospital (UATH)- Paediatrics	Professor U. Nnebe-Agumadu
3	Zankli Medical Centre, Abuja	Dr Funke Lawson
4	Maitama District Hospital, Maitama	Dr Dominic Umoru
5	General Hospital, Nyanya	Dr Lilian Ekwem
6	Federal Medical Centre, Keffi	Dr Chinatu N Ohiaeri
7	Obafemi Awolowo Universty Teaching Hospital, Ile-Ife- Paediatrics	Dr Samuel Adegoke
	Obafemi Awolowo University Teaching Hospital, Ile-Ife- Adult	Professor Nora Akinola
8	University College Hospital, Ibadan	Dr Biobele Brown
	University College Hospital , Ibadan	Dr John Olaniyi
9	Kaduna State University Teaching Hospital, Kaduna	Dr Dogara Livingstone
10	University of Nigeria Teaching Hospital, Enugu-Adult	Dr Anazoeze Madu
	University of Nigeria Teaching Hospital, Enugu-Paediatrics	Dr Osita Ezenwosu
11	Nnamdi Azikiwe Teaching Hospital, Nnewi- Adult	Dr Emmanuel. Okocha
	Nnamdi Azikiwe Teaching Hospital, Nnewi-Paediatrics	Dr John Aneke
12	Federal Medical Centre, Asaba, Delta state	Professor Angela Okolo
13	Lagos State University Teaching Hospital, Lagos	Dr Ije Diaku-Akinwumi
14	Lagos University Teaching Hospital	Dr Titilayo Adeyemo
15	Federal Medical Centre, Birnin Kebbi	Dr Garba Umar Kangiwa
16	Aminu Kano University Teaching Hospital, Kano	Professor Aisha Gwarzo
17	University of Maiduguri Teaching Hospital	Professor Usman Abjah
18	Federal Teaching Hospital, Abakaliki	Dr Ngozi Ugwu
19	Irrua Specialist Hospital, Delta State; Ambrose Ali University	Dr David Olaniyi Olanrewaju
20	Federal Medical Centre Gombe	Dr Ahmed Girei
21	National Hospital Abuja – Adult	Dr Tambi Wakama
	National Hospital Abuja – Paediatrics	Dr Seyi Oniyangi
22	Ahmadu Bello University Teaching Hospital, Zaria	Dr Abdul-Aziz Hassan

Initiatives to Enhance NBS- Rabat Declaration

First Pan African Workshop For Newborn Screening in Rabat Morocco

- Develop focused groups to address important issues (e.g. training)
- Participate in increased communication efforts across the continent including website and biennial meetings
- Initiate periodic meetings to assess each country's progress
- Establish a local advisory committee for newborn screening planning.
- Work with the MOH to gain national support and to address other important issues (e.g. finances, integration with other MOH programs, etc.)
- Ensure standardization of data through the encouragement of the implementation of the common data elements for newborns to facilitate sharing and exchange of data
- Train the next generation of health professionals in new technologies as applied to newborn screening (e.g., molecular genetic methods)

Existing Programmes to Enhance NBS



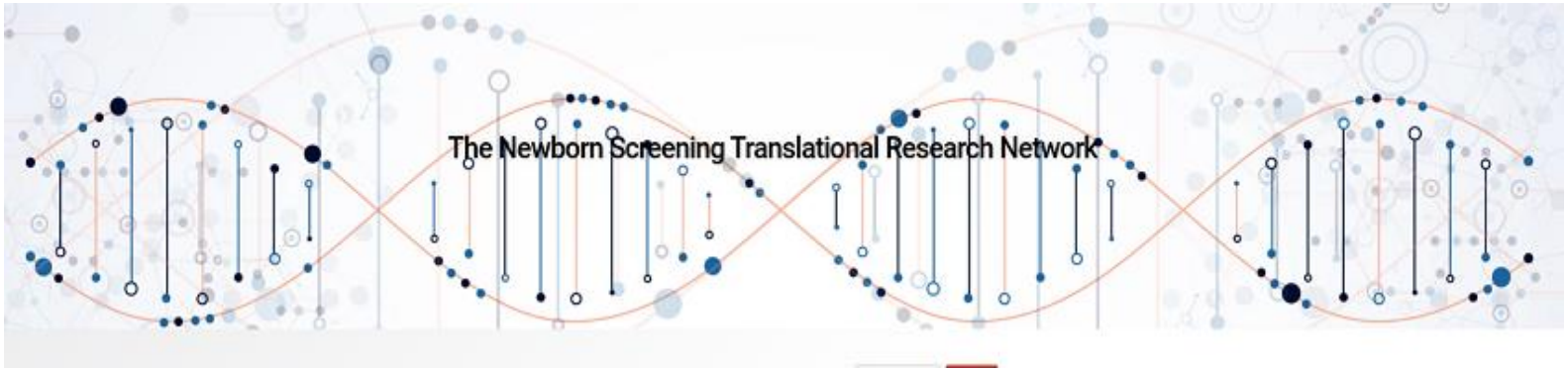
NBS is supported by the newborn screening and genetics (NBSG) program at APHL.

Existing Programmes to Enhance NBS

https://genes-r-us.uthscsa.edu/.

Newborn Screening Technical assistance and Evaluation Program (NewSTEPs)

Existing Programmes to Enhance NBS



http://nbstrn.org/

The Newborn Screening Translational Research Network (NBSTRN) facilitates ground-breaking research in newborn screening as an important part of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Hunter Kelly Newborn Screening Research Program.

Pathways to Progress for NBS

Journal of Tropical Diseases

Hsu et al., J Trop Dis 2018, 6:2
DOI: 10.4172/2329-891X.1000260

Research Article Open Access

White Paper: Pathways to Progress in Newborn Screening for Sickle Cell Disease in Sub-Saharan Africa

Lewis Hsu[1*], Obiageli E. Nnodu[2,3], Biobele J. Brown[4], Furahini Tluway[5], Shonda King[6], Livingstone G. Dogara[7], Crystal Patil[8], Sergey S. Shevkoplyas[9], Guillaume Lettre[10], Richard S. Cooper[11], Victor R. Gordeuk[12] and Bamidele O. Tayo[11]

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[2]Department of Hematology and Blood Transfusion, University of Abuja, Abuja, Nigeria

[3]Centre of Excellence for Sickle Cell Disease Research & Training, University of Abuja, Abuja, Nigeria

Point of Care Tests for SCD

- To overcome the barriers inexpensive, reliable easy to use point of care tests which show high specificity and sensitivity in the discrimination of the different haemoglobin phenotypes are being employed in screening programmes.
- They can be used in very young babies and infants as well as older children and adults.
- Only a pin prick is required for testing
- Do not require electricity nor batteries.

RELATED NEWS

April 30, 2019 | Research Feature

Rapid Result Test On Track to Transform Sickle Cell Disease Screening for Millions

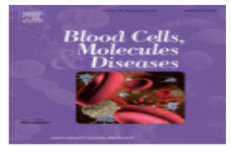
Soon after birth, a baby in the United States is tested for sickle cell disease, the often-devastating genetic blood disorder affecting more than 100,000 Americans and 20 million of people worldwide. If positive, that newborn typically begins a course of treatment that can greatly prolong life and help stave off complications of the disease. But in...

View all news on Sickle Cell Disease

ELSEVIER

Blood Cells, Molecules, and Diseases

Volume 78, September 2019, Pages 22-28



HemoTypeSC, a low-cost point-of-care testing device for sickle cell disease: Promises and challenges

Obiageli Nnodu [a], Hezekiah Isa [a], Maxwell Nwegbu [a], Chinatu Ohiaeri [b], Samuel Adegoke [c], Reuben Chianumba [a], Ngozi Ugwu [d], Biobele Brown [e], John Olaniyi [e], Emmanuel Okocha [f], Juliet Lawson [g], Abdul-Aziz Hassan [h], Ijeoma Diaku-Akinwumi [i], Anazoeze Madu [j], Osita Ezenwosu [j], Yohanna Tanko [a], Umar Kangiwa [k], Ahmed Girei [l] ... Adekunle Adekile [r]

Newborn Screening Programme Summary Gwagwalada Area Council, FCT Nigeria

Screening Method
Point of Care Test- HemoTypeSC SickleSCAN
Confirmatory Testing –HPLC (Keffi)

Screening Centres
Angwan Dodo Primary Health Care Centre
Dagiri Primary Health Care Centre
Gwagwalada Township Clinic
Kutunku Primary Health Care Centre
University of Abuja Health Care Centre
University of Abuja Teaching Hospital
First Baptist church, Gwagwalada
Ledi Community

Take Home Message

•Barriers to NBS for SCD in African countries include inadequate laboratory infrastructure, transport systems and trained health care workers.

• With newer point of care test kits, screening can be undertaken on existing public health programs to detect babies with SCD in resource limited settings.

•The APHL, ASH NBS SCD Consortium, The Newborn Screening Translational Research Network, The National NBS and Global Resource Centre have developed resources and support systems for NBS which can be utilized by all countries.

•Knowledge of available resources will help to deploy them in NBS and early intervention programs to reduce the burden of SCD globally.

Courtesy: Pr Cherif Rahimy : Centre de Prise en Charge Medicale Intergree du Nourisson et de la Femme Enceinte Atteints de Drepanocytose, Cotounou, Republic of Benin

Acknowledgment

Thanks to the Organizers

Team at CESRTA

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