



SickleInAfrica: Sickle Pan-African Research Consortium (SPARCO)

Presentation to Sickle Cell Disease Coalition

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March 2019

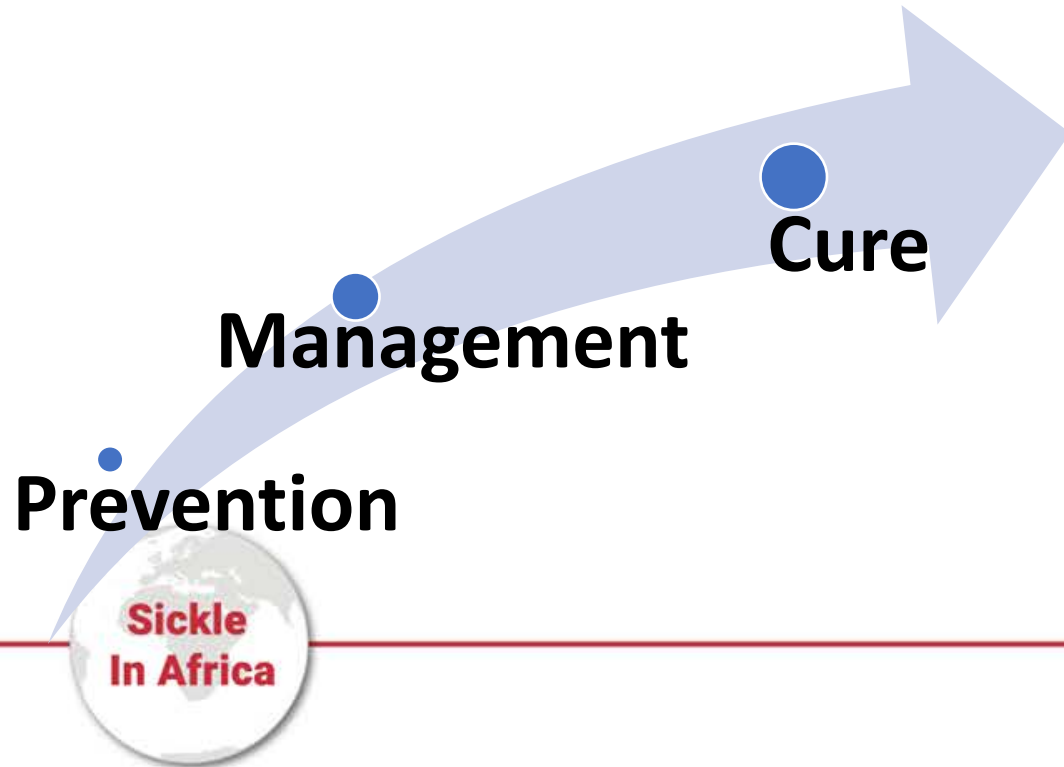


Sickle Cell Disease in Africa

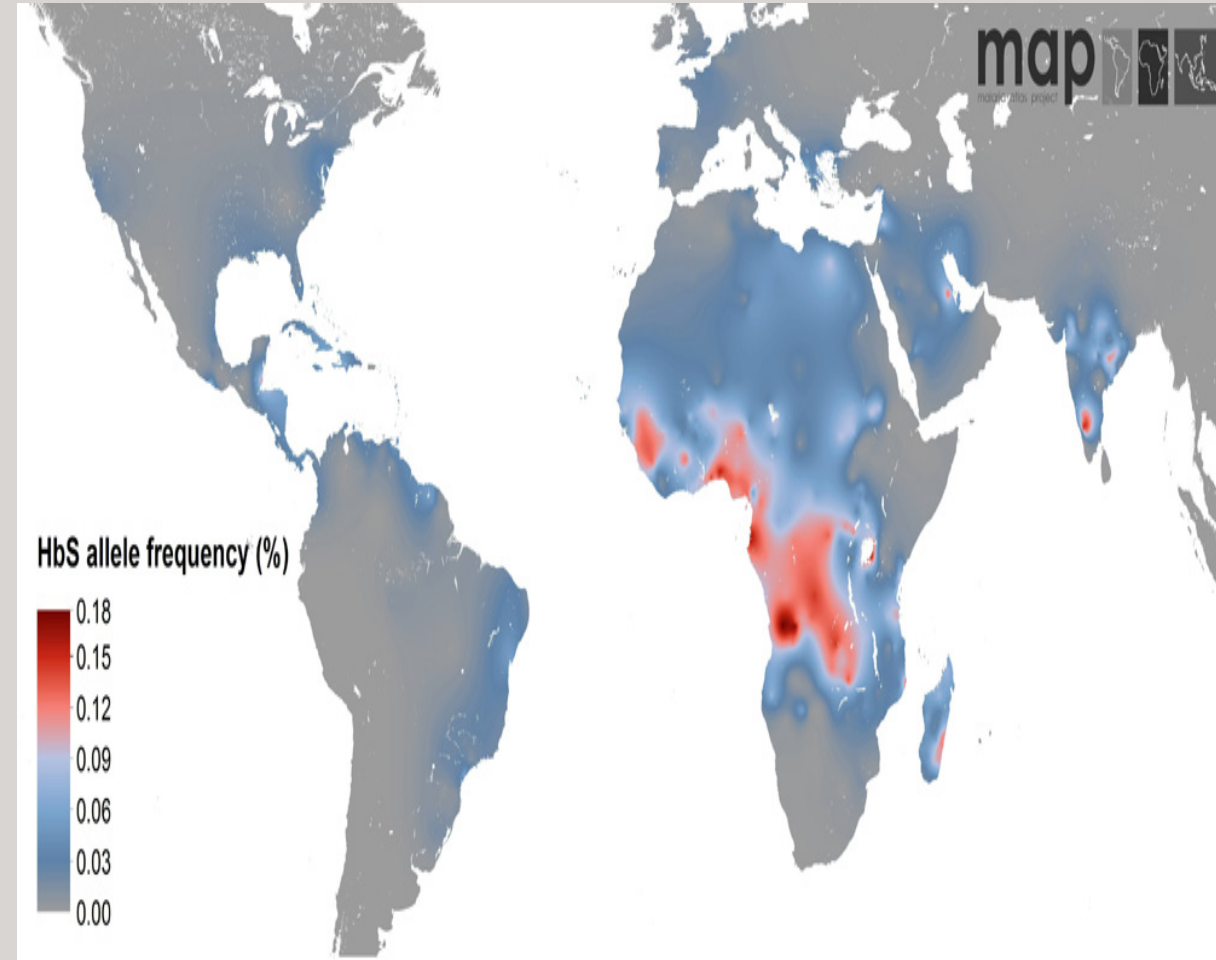


Goal

The goal is to reduce the public health burden (mortality and morbidity) of SCD in Africa whilst establishing capacity for research that will contribute to scientific knowledge to find a cure for SCD.



Burden



SPARCO Introduction



- Over the past 10 years, there have been concerted efforts in Africa to address the burden of SCD
- These efforts have been limited by 4 factors:
 - ❖ Absence of a multi-site, well described cohort of SCD
 - ❖ Failure to deploy consistent standards of care
 - ❖ Human resource capacity that is limited in number and skills
 - ❖ Few programs to explore pertinent research questions to understand SCD in Africa and guide locally-appropriate interventions
- Limited collaboration within Africa to address these challenges has hampered the efforts.

SickleInAfrica

Sickle Pan-African Research Consortium (SPARCO)

Sickle Africa Data Coordinating Center (SADaCC)

Sickle Pan-African Network (SPAN)



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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: 1 April 2017 – 31 March 2021
Project Activated: 1 May 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, Education 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 Progress

Management and administration WG

- Established structures
- 4 consortia meetings (Dar, Accra, Abuja, Tunis)
- Working relationships with stakeholders

Database Development WG

- Database developed (REDCap) and training
- SCD registry
 - 13,000 (Gh: 3,000 Ng: 6,000 Tz: 4,000)
 - 5,354/7,000 (76%) in 2018.

Standards of Care WG

- 12 model guidelines, published not more than 10 years ago, assembled and reviewed, comparing topics covered
- 6 Subject areas with 64 Topics, and sub-topics selected and are now under review.

Skills Development WG

- Review existing training programs in SCD
- Training – Management of SCD, NBS, Research, Data management

Research Planning WG

- Establish ELSI guidelines
- Comparative analysis – Gh, Ng, TZ
- Procedures for conducting research
- Planning research (Cohort, implementation)
 - Clinical research:** Cohort (n=1500, 500 per site)
 - Clinical epidemiology – Hematology and Immunology
 - Disease modifiers - Genomic
 - Implementation Research**
 - NBS (n= 30,000, 10,000 per site)
 - Infection prophylaxis - Pneumococcal (n=600, 100 /arm, 200 /site);
 - Hydroxyurea (n=1500, 500 per site)



Sickle Pan African Network (SPAN)

- SPAN - November 2014
 - Autonomy, Africa

- Link at different levels

- ❖ Programmes - Centers -Institutional
- ❖ National – Regional – African - Global

- ❖ SPAN – 2017: Interim Leadership

- ❖ SPAN Organizing Committee
 - ❖ 4 Chairs of SPAN Working Groups
 - ❖ Health (KOF), Research (AW), Training (JM), Advocacy (ON)
- ❖ SPAN Coordinator
 - ❖ Dr Najibah Galadanci



22 sites in 17 countries

Country of SPARCo Site	African Zone	Integration of additional collaborating sites		
		Country of Institution	SPAN Site	Institution PI
1 DRC	Central (Francophone)	DRC	Kongo University and Medical Institute of Kempese	Charles Mbala Lhemba-Ndongala
2 DRC	Central (Francophone)	DRC	University of Lumbubashi	Shongo ya Pongombo Nick
3 DRC	Central (Francophone)	DRC	University of Lumbubashi	Luboya Numbi Oscar
4 DRC	Central (Francophone)	DRC	Provincial Hospital of Kivu North	Sebastien Matata Ngilima
5 DRC	Central (Francophone)	DRC	Université Catholique de Bukavu	Bruno Mungo Masumbuko
6 Tanzania	East Africa	USA/Liberia	Boston Children's Hospital/JFKennedy Medical Centre	Yenee Tubman
7 Tanzania	East Africa	USA/Ghana	University of Cincinnati	Cheedy Jaja
8 Ghana	West Africa	Ghana	Military Hospital, Accra	Sheila Asamoah-Okyere
9 Ghana	West Africa	Sierra Leone	College of Medicine and Allied Health Sciences, University of Sierra Leone	Sahr Moses Gevao
10 Tanzania	East Africa	Tanzania	MUHAS	Florence Urio
11 Ghana	West Africa	Ghana	Navrongo Health Research Centre	Lucas Amenga-Etego
12 Tanzania	East Africa	Kenya	University of Nairobi	Jesse Githanga
13 Tanzania	East Africa	USA	Duke University	Marilyn Telen
14 Tanzania	East Africa	Tanzania	MUHAS	Siana Nkya Mtatiro
15 Tanzania	East Africa	Mozambique	National Health Institute	Ana Olga Mocumbi
16 Tanzania	East Africa	UK	University of Oxford, National Health Service and Blood Transplant	David J Robert
17 Tanzania	East Africa	Malawi	University of North Carolina	Satish Gopal
18 Tanzania	East Africa	Malawi	University of North Carolina	Ken Ataga
19 Tanzania	East Africa	Malawi	University of North Carolina	Nigel Key
20 Tanzania	East Africa	USA	University of Pittsburg	Enrico Maria Novelli
21 Tanzania	East Africa	Zambia	University Teaching Hospital/ University of Zambia	Catherine Chunda-Liyoka
22 Nigeria	West Africa	Nigeria	Nnamdi Azikiwe University , Nnewi	Emmanuel Okocha
23 Nigeria	West Africa	Nigeria	University of Maiduguri Teaching Hospital	Usman Abjah
24 Nigeria	West Africa	Nigeria	Federal Teaching Hospital , Abakaliki	Nigozi Ugwu
25 Nigeria	West Africa	Nigeria	Ahmadu Bello University Zaria	Sani Awwaku
26 Nigeria	West Africa	Nigeria	Kaduna State University	Halima Bello
27 Nigeria	West Africa	Nigeria	Federal Medical Centre, Keffi, Nasarawa State, North-Central	Chinatu N Ochiaeri
28 Nigeria	West Africa	Nigeria	National Biotechnology Devt Agency	Oyekanni Nash
29 Nigeria	West Africa	Nigeria	Ahmadu Bello University Teaching Hospital	Olufemi Ogunrinde
30 Cameroon	West Africa	Mali	Centre de Recherche et de Lutte contre la Drépanocytose (CRLD)	Dapa Diallo
31 Cameroon	West Africa	Benin	Faculty of Health Sciences. Univ. Abomey-Calavi	Mohamed Chérif Rahimi
32 Cameroon	West Africa	Senegal	Université Cheikh Anta Diop	Ibrahima Diagne
33 Ghana	West Africa	Sierra Leone	University of sierra Leone	Sahr Gevao



SPARCO – Partners



SPARCO

- College of Pathology of East, Central and Southern Africa
- H3ABioNet
- American Society of Hematology
- Global Sickle Cell Disease Network

Others

- WHO – Country, AFRO, HQ
- Other SCD partners and networks
 - SickleGenAfrica
 - REACH
 - REDAC
 - AfroSickleNet

Funders

- NIH

Tanzania

- Muhimbili University of Health and Allied Sciences
- Muhimbili National Hospital, Dar RHMT
- Ministry of Health

Nigeria

- University of Abuja
- University of Abuja Teaching Hospital
- Federal Ministry of Health
- National Biotechnology Development Agency (NABDA)
- University of Chicago
- Institute of Human Virology, Nigeria

Ghana

- Kwame Nkrumah University of Science and Technology (KNUST), School of Medicine
- Komfo Anokye Teaching Hospital (KATH)

SCD in Africa – Present and Future

Sickle cell disease: tipping the balance of genomic research to catalyse discoveries in Africa



Makani, J., S. F. Ofori-Acquah, F. Tluway, N. Mulder and A. Wonkam (2017). "Sickle cell disease: tipping the balance of genomic research to catalyse discoveries in Africa." *Lancet* **389(10087): 2355-2358.**



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Thank You!

