

Terms of References

1. Name:

- Sickle Cell Disease Knowledge and Intervention to Deter Stroke: SCD-KIDS

2. Objective:

- To eliminate preventable strokes in children with sickle cell disease by implementing comprehensive, evidence-based screening, early intervention, coordinated care systems, universal access to life-saving therapies, improving provider awareness, and supporting families through education and transition to adult care.

3. Goals:

- Standardize and Expand TCD Screening: Enhance and ensure mandates for annual Transcranial Doppler (TCD) screening for all children with Sickle Cell Disease between ages 2-16 to identify high-risk individuals, thereby addressing poor implementation rates.
- Promote Evidence-Based Therapies: Drive adoption of chronic transfusions for abnormal TCDs and hydroxyurea (HU) for conditional TCDs or after transfusion therapy, with clear guidelines for transitioning between them.
- Improve Health System Infrastructure: Develop comprehensive care centers, integrate SCD care into existing public health programs, and establish country-level data systems for surveillance and quality measurement.
- Enhance Education and Awareness: Launch multi-level campaigns for parents, providers, policy makers and the public to recognize stroke symptoms and the importance of preventive care.
- Bridge Care Transitions: Create robust programs to smoothly transition youth from pediatric to adult SCD care, thereby addressing provider shortages and psychosocial needs.
- Address Systemic Barriers: Tackle issues like healthcare access, provider training, socioeconomic factors, and racism that hinder effective SCD management.
- Convene Stakeholders: Establish avenues for multi-, inter-, and trans-disciplinary collaborations between researchers to move the science of stroke prevention forward and improve outcomes for children with sickle cell disease. Seek and obtain research funding support from governments, non-governmental agencies, industry, institutions, and philanthropists.

4. Membership:

- Number: 10
- Mechanism of selection: Network, relevant publications, relevant grants, referrals
- Eligibility: WSO members with relevant experience and expertise. Composition will reflect geographical representation and gender balance
- Terms of Appointment: Two years. Task force Co-chairs and members will serve for the entire mandate of the task force

Co-chairs:

Bruce Ovbiagele, United States
Fred Stephen Sarfo, Ghana

WORLD STROKE ORGANIZATION

Members:

Arvind Sharma, India
Yogesh Kolkande, India
Gisele Sampaio Silva, Brazil
Kristina A. Rankine, United States
Joseph Kamtchum Tatuene, United Kingdom/Cameroon
Abd-Allah, Egypt
Sara Mazzucco, United Kingdom
Adriana Bello, Venezuela

5. Organizational Structure:

- Two co-chairs from distinct geographic regions including a co-chair from Africa given endemic nature of SCD in the region
 - **Bruce Ovbiagele and Fred Stephen Sarfo**
 - **Fred Stephen Sarfo** is Professor of Medicine, Head of Department, and Vice Dean at Kwame Nkrumah University of Science and Technology. He is a neurologist and PI of the Sickle Pan-African Research Consortium (SPARCo), a registry across multiple sites in three countries: Ghana, Nigeria, and Tanzania. He is also PI of the Sickle Pan Africa Research Consortium TRAINing (SPARC- TRAIN) Program, which recruits 4-6 diverse talented scholars per year (20-35 total) in Nigeria, Ghana, and other West African countries who aspire to become leaders in hemoglobinopathies and implementation science research utilizing a Team Science approach.

6. Meetings:

- A virtual meeting every other month lasting one hour in duration.
- An onsite meeting once a year, the World Stroke Congress.
- Meeting minutes will be routinely sent to the WSO Secretariat.

7. Reporting Mechanism:

- The Task force Co-chairs will report to the Executive Committee and full Board of Directors.
- The task force Co-chairs will submit a report of activities to the Board, via the WSO Secretariat, at least once a year.

8. Deliverables

- A Round Table Discussion to take place in Africa or India in 2026 or 2027 (potentially supported by industry)
- A Position Statement for prevention of stroke in children with sickle cell disease to be published in International Journal of Stroke in 2027 or 2028
- A Scientific Session at the World Stroke Congress (2026 or 2027) or International Stroke Conference (2027) or African Stroke Organization Congress (2026)
- A World Stroke Academy Webinar in 2026 or 2027
- A WSO Call for pilot funding of a research project based on the Round Table discussions

9. Required Resources:

- Coordination of discussions, meetings, webinar, publication, and funding call

10. Procedures:

- Task force will be constituted no later than March 1, 2026

- Task force will develop a set of measurable and time-based outcomes aligned with its seven listed goals and deliverables by July 1, 2026, and presented to the WSO Executive Committee for input and approval at July 2026 meeting
- Task force will provide an interval update to the WSO Executive Committee at its July 2027 meeting
- Task force will provide a near final/final update to the WSO Executive Committee at its July 2028 meeting
- An evaluation of the task force will be carried out annually to assess its effectiveness.
- This evaluation will be conducted by the Executive on an annual basis and include performance against the approved outline for the task force.
- Expenses incurred by the task force in the course of its duties will require approval by the Executive committee with input from the Finance Committee and Treasurer.
- The task force will liaise with any relevant existing committees which may be engaged in similar activities.

One World Voice for Stroke

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