

2025

World Sickle Cell Day Celebration

Program Report

Organization: Shem Sickle Cell Advocacy Foundation (SSCAF)

Event Theme: *Law, Medicine, and Sickle Cell Burden: A Shared Responsibility*

Date: 19th June, 2025

Venue: University of Jos, Plateau State

Program Duration: 11:02 AM – 02:32 PM

Prepared by:
Shem Sickle Cell
Advocacy Foundation.

1.0 Executive Summary

The Shem Sickle Cell Advocacy Foundation (SSCAF), in partnership with the Student Union Government (SUG) and other stakeholders, organized the 2025 World Sickle Cell Day Celebration in Jos, Plateau State. The event brought together medical experts, legal scholars, religious leaders, government representatives, traditional authorities, students, and civil society organizations.

The program featured paper presentations, poetry and musical performances, a roundtable discussion, and public health advocacy. Key issues discussed included genotype testing, premarital counselling, constitutional and legal perspectives on mandatory testing, and the mental health burden of sickle cell disease (SCD).

More than 250 participants attended. The event generated strong advocacy messages on the need for a legal framework for genotype testing, nationwide screening, and improved healthcare support for sickle cell warriors.

1.1 Introduction

World Sickle Cell Day, commemorated every 19th of June, provides a global platform to raise awareness on sickle cell disease, a genetic condition affecting millions, particularly in sub-Saharan Africa. Nigeria, often described as the sickle cell capital of the world, records the highest number of births of children with the condition annually.

The 2025 celebration, themed “*Law, Medicine, and Sickle Cell Burden: A Shared Responsibility*,” was designed to foster interdisciplinary dialogue between law, medicine, and community stakeholders to combat the persistent rise of SCD in Nigeria.

1.2. Objectives of the Program

- To raise awareness about the burden of SCD and preventive measures.
- To discuss medical, legal, and ethical perspectives on genotype compatibility and marriage.

- To promote nationwide screening and premarital genotype testing.
- To advocate for a comprehensive legal framework addressing SCD prevention and management.
- To strengthen collaboration between government, NGOs, faith-based organizations, and traditional institutions in combating SCD.

2.0 PROGRAMME IMPLEMENTATION

2.1. Opening & Context

The programme opened at **11:02 a.m.** with the National Anthem, followed by a welcome address from the Plateau State Coordinator, who recognized dignitaries from the Faculties of Law and Medicine, religious leaders from Christian background, NDLEA officials, and other stakeholders. He introduced the day's theme and welcomed all guests. A representative of the SUG urged students to invite friends to get tested and help spread genotype awareness. The agenda featured academic presentations from the Faculties of Law and Clinical Sciences, a poem by **Japhet**, and a musical performance by **Illtraq Acton Jos** ("Dirty Water"), encouraging warriors to "keep up the fire."

2.2. Detailed Presentation Summaries

2.2.1 Clinical Perspective: Regulating Marriage by Genotype Compatibility

Presenters: *Adenu Joy Oreoluwa & Degal Alazif* (College of Clinical Sciences)

Focus: Genetics, inheritance, individual choice vs. public health, and the ethics of autonomy vs. non-maleficence.

- **Global & Nigerian Burden:** The presenters cited WHO figures: **~120 million** people live with SCD globally (about **66%** in Africa), with **300,000 children born annually** with SCD and **1,000 babies daily at risk**. Without intervention, **50–90%** of affected children die before age five. They also noted **34,403 SCD deaths in 2019** and a **26% rise** in SCD mortality from 2000–2019—despite awareness and counseling—linking

persistence to inadequate screening, cultural/religious norms, and insufficient public health actions. Nigeria remains the “**sickle-cell capital**” due to its contribution to global burden.

- Policy/Service Gaps: Persistence of SCD is tied to poor screening capacity, norms that override medical guidance, and weak public-health interventions.
- **Recommendations from the presenters:**
 1. Nationwide premarital screening for genotype;
 2. Public awareness campaigns like this event;
 3. Integrate genotype testing into routine healthcare interactions (“one of the tests recommended by the doctor”);
 4. Legislative support to require genotype compatibility for marriage.

2.2.2 Legal & Ethical Dimensions of Regulating Marriage by Genotype

Presenters: *Jeremiah, Tumba & Fortune* (Faculty of Law)

- **Rights Framework Raised by the Students:** They referenced Article 18(1) of the African Charter, Section 37 of the 1999 Constitution (as amended), and Article 23 ICCPR (1966/1969) as protecting privacy/family life and the right to marry, arguing any outright prohibition on marriage based on genotype may be seen as an infringement.
- **Countervailing Public-Health Duty:** They emphasized the State’s constitutional obligations under **Section 17(3)** to protect public health and provide adequate medical facilities. They set out a constitutional argument to justify restrictions on incompatible marriages through: Right to Life (S.33), Dignity (S.34), and public interest limitations (S.45) positioning genotype-compatibility rules as preventive legislation consistent with the maxim *salus populi suprema lex*.

2.2.3 Guest Lecture: Balancing State Interest and Personal Autonomy (Comparative Law)

Speaker: Barr. Tobias Ngufwang, Faculty of Law, University of Jos

- **Complex Drivers:** He linked SCD patterns to malaria prevalence, migration, and consanguineous marriages, arguing that effective response must address medical, social, economic, and infrastructural layers plus cultural barriers where SCD had historically been attributed to witchcraft.

1. Comparative

Jurisdictions:

United States – Sickle Cell Care Expansion Act (May 2023): Sickle Cell Care Expansion Act. It's a law that was enacted by the Congress of the United States of America. And the aim of that law basically is to advance treatment and research pertaining to sickle cell disease. And there are three components of the act.

- **Scholarships/loan repayment** to expand the SCD physician pipeline **\$150M/year (2024–2029)**; The first component of the act dwells on scholarship and loan repayment programmes. Scholarship and loan repayment programme, that's provided for by the act. And so for purposes of advancing learning regarding sickle cell disease and enhancing the supply of physicians to treat the disease, the U.S. government instituted what they call a scholarship scheme, where they award a scholarship or they either make, they give a loan to individuals for purposes of enhancing learning. The scholarship component targets students, students in the medical field particularly, so that if you're undertaking a study in a medical institution, scholarships are awarded to you with the aim that you study sickle cell disease. From 2024 to 2029, the U.S. government will be spending 150 million dollars every year on such scholarships and loan repayments.

- **Community-based grants** for education/advocacy **\$50M/year**; The second component of the law is community-based grants to engage sickle cell population through education and advocacy. On this, the target is to look at entities, groups, particularly faith-based (16:59) community-based organisations that are interested in awareness advocacy. So the target is to ensure that these entities have access to funding, funding that will now enable them to be able to carry out their awareness

activities amongst the populations or within the populations of the United States of America. And to also achieve this, 50 million dollars is earmarked every year for this purpose. You can see how proactive the U.S. law is.

- **Adult transition grants/therapies—\$70M/year.** And the third is grants for sickle cell disease pejorative to adult transitions of care, people who are already infected

CANADA:

Recognizes Sickle Cell Awareness Day (June 19) but lacks concrete compatibility or screening mandates—“a brief piece of legislation” with limited impact.

INDIA:

No strict “compatibility law,” but the National Sickle Cell Anaemia Elimination Mission (2023) aims to reduce prevalence through awareness, screening, counseling, follow-up care, and prenatal/marriage counseling—addressing communities with close-kin marriages.

Nigeria (National policy context): The **2014 National Guideline** on SCD (diagnosis, management, pregnancy, counselling/testing, and new-born screening) remains under-implemented due to funding, manpower, and communication barriers. National comprehensive legislation has faltered **a 2017 Senate bill** died after second reading; **a 2021 bill** remains stalled.

NIGERIA (STATE-LEVEL LAW):

1. **Anambra (2019):** The **Sickle Cell Disease Control and Eradication Law** compels **premarital genotype screening** and issuance of a **sickle-cell status certificate**. Proceeding with an incompatible match constitutes an **offence**. Sanctions extend to religious bodies/marriage registries that perform weddings without verified prevention certificates; penalties include **₦200,000 fine or 3 years’ imprisonment or both**. Enforcement challenges persist: **forged certificates** and **unscrupulous labs** undermine compliance.

- **Human-Rights Balancing & “Wrongful Life” Concern:** Tobias argued that **no right is absolute** (see **Section 45** limits), and while **autonomy/family life** are vital, public-health imperatives can justify mandatory testing for intending couples. He warned of emerging **“wrongful life”** claims—children suing parents/doctors for knowingly proceeding with incompatible unions—citing a **recent Canadian case** where courts **recognized the possibility of such a right**, even though the claimant didn’t succeed. He recommended a **comprehensive national law**, stronger **research/advocacy funding**, and even exploring **gene editing** pathways ethically.

2.2.4 Public-Health Briefing

Speaker: *Dr. Kefas Ibrahim* (Consultant Public Health Physician; Technical Assistant to Plateau State Ministry of Health)

- He affirmed Nigeria as a global epicentre, estimating **~300,000 births annually** with SCD, argued that a **legal framework** is now fundamental to elimination, and stressed **individual responsibility** (“people should be held responsible” for deliberate choices).
- **Genotype Basics:** **AA** (normal haemoglobin), **AS** (trait, usually asymptomatic), **SS** (disease with crises).
- **Symptoms & Life Impact:** Frequent **pain crises**, risks to **vision**, **delayed growth**, **infection susceptibility**, **missed school**, and the reality that families enter an implicit **“contract with the hospital”** due to regular visits. He debunked myths (e.g., **witchcraft link**, “only poor people” get SCD).

2.3 ROUNDTABLE: EXTRACTS & ASSERTIONS

2.3.1 Early Detection & Newborn Screening — *Dr. Ofakuri* (Consultant Gynaecologist, JUTH)

- **Newborn Screening Now Possible “Within the Hour of Birth”:** Traditionally, **haemoglobin electrophoresis** confirmed diagnosis reliably at **9–12 months**, but he noted a **Newborns’ Clinic** now operates for **early diagnosis** and **immediate treatment**, improving outcomes by preventing complications.
- **Scale-up & Cost:** He appreciated Shem Sickle Cell Advocacy Foundation for Organising the program and made a clarion call to the **Ministry of Health for partnership to subsidize the cost of the screening**, citing **Lagos State** adoption as precedent, and posits that the cost of **newborn screening** at a **minimum is ₦6,000**, but urged for **government subsidy**.

2.3.2 Role of Faith Institutions — Rev. Fr. Charles (St. Kevin Catholic Church, Angwan Rogo, Jos Plateau State)

- According to the Rev. Fr. Charles, Churches run marriage courses and refer couples for genotype, HIV, and even mental-health tests, insisting on thorough screening (“you cannot, for example, marry people who are mentally ill...or madness will proliferate”). Where genotypes are incompatible, clergy **“seriously advise”** but **do not force** be we always following the master Jesus, who does not force anyone to do anything.

2.3.3 Pain Management vs. Opioid Misuse — Mrs. Grace Goyol (Deputy Commander In Charge Of the Drug Demand Reduction Unit Of The NDLEA Plateau State Command)

Referencing a **2018 UN survey**, she warned Nigeria is among the **highest abusers of pharmaceutical opioids** (e.g., **tramadol, codeine, and pentazocine**) agents used legitimately for severe SCD pain but prone to **tolerance and dependence**. She urged her audience to draw a balance compassion in pain treatment with vigilance against substance

abuse She urged communities to report illegal sales of **controlled drugs** via **QUADRA** (Community War against Drug Abuse, launched 2021).

2.3.4 Traditional Councils & Enforcement Mr. *Dafiak M. Tanko* (Secretary, Jos North Traditional Council)

- He outlined how policies filter **from the Ujah through clans towards (“angwa”)**, and affirmed willingness to **carry State policy to the grassroots**. Since **marriage is between families** (no king’s approval required), traditional rulers’ role is to **translate and enforce any State-mandated pre-marital testing** down the chain.

2.3.5 State Implementation Pathways — *Dr. Kefas* (Ministry of Health)

- The Ministry will explore **collaboration with PLASCHMA** on **newborn screening** and praised recent State support for testing during World Sickle Day activities, while urging **more awareness** (e.g., **radio/TV jingles**). He stressed creating a **policy framework** that enables **traditional councils** to help local governments implement testing before traditional marriages, which are often unregulated today.

2.3.6 Human Rights, Mandatory Testing & Anti-Discrimination — *Barr. Tobias*

- **Mandatory Testing vs. Autonomy:** He reiterated that **Section 45** allows **derogations for public health**, making **mandatory genetic testing** for intending couples **legitimate** in principle, but he also flagged **unregulated relationships, unplanned pregnancies**, and the limits of “legislating ignorance,” hence the need for **paired legislation + advocacy**. He invoked **Section 42** to insist people with SCD must not face discrimination in employment, education, or healthcare.

4) Legal/Policy Case Study: Bauchi & Anambra

- **Bauchi State in (2017) enacted the: *Compulsory Genotype & HIV Testing; Anti-Discrimination Law*** an example of State-level attempts to **mandate tests before marriage** and **prohibit stigma**.

- **Anambra State in (2019):** Requires genotype screening and prevention certificates before marriage; religious bodies/registries must verify certificates; **offences** attract **₦200,000 fine/3 years' imprisonment**. **Low compliance** noted, including **forged results** by unscrupulous labs; highlights difficulty of **enforcement in rural/traditional settings** and **pre-marital pregnancies** outside formal processes.

5) Consolidated Recommendations (from speakers & discussants)

1. **Scale newborn screening statewide** with **subsidy (~₦6,000/test)** and **MoH-PLASCHMA** collaboration; take cues from **Lagos**.
2. **Legislate mandatory premarital genotype testing** (with **Section 45** public-health justification), and consider **compatibility requirements** with **human-rights safeguards** and strong **anti-discrimination** protections (**Section 42**).
3. **Integrate genotype testing** into routine care (make it a **default test** during clinical visits), and **expand public education**—radio/TV jingles, campus drives, and **faith-based channels**.
4. **Engage traditional councils** to operationalize policies for **traditional marriages**, ensuring **testing precedes ceremonies**.
5. **Strengthen enforcement & integrity:** deter **certificate forgery**; accredit labs and tighten verification for **prevention certificates** (learning from **Bauchi State's** challenges).
6. **Balanced pain management protocols:** clinical pathways that minimize **opioid misuse**; empower communities to report illegal sales through **QUADRA**; train clinicians on **dependence risk** in SCD pain care.
7. **National framework:** revive comprehensive **national SCD legislation** (beyond the 2014 guideline), with **funding for research, services, and advocacy** learning from

the **U.S. model** on **workforce**, **community grants**, and **adult transitions** with an Annual Budget to ensure compliance.

3.0 Free Genotype Testing

- A total of **166 individuals** underwent free genotype testing and counselling.
- The initial target was **200 beneficiaries for the genotype testing**, but resource limitations prevented us from reaching the full target as well as the availability of students that would undergo the genotype testing.
- Testing was conducted by certified medical volunteers with post-test counselling provided.

4.0 Distribution of Relief Materials

The Jos North Primary Health Care Provided us with 50 pieces of Mosquito nets of which 20 were distributed to the 20 Sickle Cell Warriors that were in attendance. and Ministry of Health made available 5 pieces of Hot Water Bags.

- SSCAF distributed **20 mosquito nets and 5 hot water bags** to **5 sickle cell patients**.
- The items were chosen to support patients in malaria prevention and pain management.
- Beneficiaries expressed gratitude, with feedback highlighting the need for expanded support to more warriors in future programs.

6. Outcomes and Achievements

- **250+ participants** attended, representing students, religious leaders, medical professionals, traditional councils, and warriors.
- **166 individuals tested and counselled** on genotype status.
- **20 warriors supported** with mosquito nets and 5 warriors supported with hot water bags.
- Stakeholder commitments for advocacy and policy reform were secured.

5.0 Challenges Identified

5.1 Challenges in Implementing Genotype Laws

- **Forgery of Certificates:** *Punch (2024)* exposed the circulation of forged genotype certificates in Bauchi State, undermining the effectiveness of premarital testing laws.
- **Low Compliance in Rural Areas:** Traditional marriages bypass medical checks.
- **Pre-Marital Pregnancies:** Many unions form outside legal oversight, making regulation difficult.
- **Cultural & Religious Resistance:** implementation of the any law or policy in the rural areas is said to pose a great challenge.
- **Weak Monitoring:** State committees are often underfunded.

5.2 Challenges during the Programme

- Could not achieve full target of **200 genotype tests** due to limited resources but 166 free genotype blood group and PCV test were carried, 150 were sponsored by the ministry and 16 Sponsored by Shem Sickle Cell Advocacy Foundtion though Shem's Initial plan was for 50 people but was constrained by finance.
- Distribution of relief materials reached only **5 warriors**, though demand was higher as the initial plan was for 20 people.
- Limited funds constrained wider community mobilization.
- Time pressure led to shortened presentations.
- Volunteer coordination was difficult due to transport and welfare issues.

6 POLICY RECOMMENDATIONS

1. Nationwide Premarital Genotype Screening

- **Action:** Enforce mandatory genotype testing for intending couples as part of marriage registration.
- **Justification:** Prevents incompatible unions, reducing SCD births.

- **Implementation:** Joint responsibility of Ministries of Health, Justice, and Religious/Traditional Institutions.

2. Integration of Sickle Cell Care into Routine Healthcare

- **Action:** Ensure that all hospitals integrate Sickle Cell services into routine healthcare. This includes not only genotype testing during antenatal and postnatal visits but also **specialized care packages for warriors** under the National Health Insurance Scheme (NHIS). In Plateau State, strengthen and expand the intervention of the **Plateau State Contributory Health Management Agency (PLASHEMA)** to provide subsidized treatment, medications, and emergency care for warriors.
- **Justification:** Embedding Sickle Cell care within NHIS and state health insurance systems guarantees that warriors have sustained access to affordable treatment, while routine genotype testing for mothers and newborns improves early detection and prevention.
- **Implementation:** Federal Ministry of Health through NHIA, in collaboration with State Ministries of Health and agencies like PLASHEMA, supported by tertiary hospitals and primary health care facilities.

3. Establishment of Sickle Cell Desks in All Hospitals

- **Action:** Create dedicated Sickle Cell Desks in all public and private hospitals to coordinate newborn screening, counseling, and follow-up. Mandate **every woman attending postnatal care** to present her newborn for genotype testing.
- **Justification:** Institutionalizes newborn screening, ensuring no child leaves the hospital without early detection.
- **Implementation:** MoH in collaboration with hospital management boards.

4. Large-Scale Public Health Campaigns

- **Action:** Develop sustained awareness campaigns using radio, TV, social media, and community outreach.
- **Justification:** Demystifies SCD, combats stigma, and encourages genotype disclosure in relationships.
- **Implementation:** NCDC, NOA, and civil society partners like SSCAF.

5. Legislative and Policy Backing

- **Action:** Pass a **National Sickle Cell Control Act** to harmonize state laws, criminalize genotype certificate forgery, and fund preventive programs.
- **Justification:** Provides a legal framework to enforce mandatory screening and protect the rights of warriors.
- **Implementation:** National Assembly, State Assemblies, and MoH.

6. Psychosocial and Family Support Systems

- **Action:** Provide counselling services, warrior support groups, and interventions addressing opioid misuse among patients.
- **Justification:** Reduces stigma, improves mental health, and prevents drug dependency.
- **Implementation:** MoH, NGOs, NDLEA, and community-based organizations.

8. Conclusion

The 2025 World Sickle Cell Day Celebration demonstrated the impact of cross-sector collaboration in tackling SCD. With over 250 participants sensitized, 166 free tests conducted (with critical support from the Plateau State Ministry of Health), and relief materials distributed to warriors, the event underscored the importance of awareness, testing, and policy advocacy.

While financial constraints limited SSCAF's capacity to meet its full target, the programme nonetheless achieved significant milestones and reaffirmed the urgent call for nationwide mandatory testing, newborn screening, and warrior support mechanisms.

9. ANNEXES

8.1.1 ANNEX 1: PROGRAM PHOTOS

A. Awareness Walk To Faculty Of Art And Engineering





These are members of Shem Sickle Cell Advocacy Foundation sensitizing students on the need to know their genotype as well as normalize making genotypes a first date question.

B. GENOTYPE TESTING



• SSCAF •

RC: 7212807



A total of **166 persons** underwent free genotype and blood group testing during the event. Out of this number, the **Plateau State Ministry of Health sponsored 150 tests**, while SSCAF sponsored **16 tests** out of its initial plan to cover 50, due to financial constraints. The testing was conducted by trained laboratory scientists from the Ministry of Health.

SSCAF
RC: 7212807

C. PAPER PRESENTATIONS/LECTURES



SSCAF

RC: 7212807



• SSCAF •

RC: 7212807



• SS CAF •

RC: 7212807



RC: 7212807



• SS CAF •

RC: 7212807



The presentations during the program underscored the **urgent medical, legal, and ethical rationale** for regulating marriage based on genotype compatibility, highlighting Nigeria's position as the global epicenter of Sickle Cell Disease. Speakers emphasized that while **autonomy and family rights are constitutionally protected**, public health imperatives justify nationwide premarital screening, newborn testing, psychosocial support, and legislative backing to reduce the disease burden. Collectively, the session reinforced that **SCD is 100% preventable** if policies, awareness, and cultural practices align with medical and legal frameworks.

RC: 7212807

D. ROUNDTABLE DISCUSSION



This is a picture from the Round Table discussion. The roundtable discussion underscored the need for a **multi-sectoral approach** to sickle cell prevention and support, with health experts, clergy, traditional rulers, and legal practitioners each highlighting their unique roles. It emphasized **policy, cultural, and institutional collaboration**—from newborn screening and subsidized tests to premarital counseling, awareness campaigns, and traditional council enforcement. Collectively, the speakers reinforced that sustainable solutions require both **legal frameworks and community-driven advocacy** to balance prevention with protection of the rights of warriors.

E. PRESENTATION OF RELIEF MATERIALS





The Plateau State Ministry of Health, Provided 5 Hot Water Bags to be presented to indigent Sickle Cell Warriors and the Jos Primary Health Care Provided 50 oieces of Mosquito Nets Which 20 pieces were distributed on spot to available Sickle Cell Warriors.

SSCAF

RC: 7212807

F. VOTE OF THANKS



Vote of thanks by Barr. Gabriel Ochai Achadu, the acting State Coordinator, Shem Sickle Cell Advocacy Foundation.

RC: 7212807



Vote of thanks by Mr. Kefas Nantok, SUG representative, University of Jos.

SSCAF

RC: 7212807

G. GENERAL PICTURES



• SSCAF •

RC: 7212807



• SS CAF •

RC: 7212807



SHEM



ATION

SSCAF

RC: 7212807

8.1.2 Annex 2: List of Participants

SN	NAME	PHONE NUMBER	SN	NAME	PHONE NUMBER
1	Amir Yousuf Kaka	0116748558	41	David Tazaka	0940024944
2	Mwajuma L. Ligon	0704772290	42	David Oduo Oduo	0900028325
3	Victor Koko	0705033224	43	David Oduo	0112211545
4	Samson Ochieng Ochieng	0701544760	44	David Oduo Tazaka	0701544760
5	Samson Ochieng Ochieng	0707777649	45	David Oduo Tazaka	0704444570
6	Samson Ochieng Ochieng	0711867716	46	David Oduo Tazaka	0704444570
7	Samson Ochieng Ochieng	0711867716	47	David Oduo Tazaka	0704444570
8	Samson Ochieng Ochieng	0711867716	48	David Oduo Tazaka	0704444570
9	Samson Ochieng Ochieng	0711867716	49	David Oduo Tazaka	0704444570
10	Samson Ochieng Ochieng	0711867716	50	David Oduo Tazaka	0704444570
11	Samson Ochieng Ochieng	0711867716	51	David Oduo Tazaka	0704444570
12	Samson Ochieng Ochieng	0711867716	52	David Oduo Tazaka	0704444570
13	Samson Ochieng Ochieng	0711867716	53	David Oduo Tazaka	0704444570
14	Samson Ochieng Ochieng	0711867716	54	David Oduo Tazaka	0704444570
15	Samson Ochieng Ochieng	0711867716	55	David Oduo Tazaka	0704444570
16	Samson Ochieng Ochieng	0711867716	56	David Oduo Tazaka	0704444570
17	Samson Ochieng Ochieng	0711867716	57	David Oduo Tazaka	0704444570
18	Samson Ochieng Ochieng	0711867716	58	David Oduo Tazaka	0704444570

8.2 Annex 3: Media Coverage Links

facebook: <https://www.facebook.com/groups/698973490513087>

Instagram: <https://www.instagram.com/shemsicklecelladvocacyfoundati/>

Thank you.



**SHEM SICKLE CELL ADVOCACY FOUNDATION (SSCAF)
STANDARD REPORT OF SICKLE-TEMBER 2025 PROGRAMS HELD IN
KADUNA AND PLATEAU STATES**

1.0 INTRODUCTION

The month of September, recognized globally as *Sickle Cell Awareness Month*, provides a strategic platform for advocacy, education, and community mobilization around sickle cell disease (SCD). In line with this, the **Shem Sickle Cell Advocacy Foundation (SSCAF)** implemented a series of impactful programs tagged “**Sickle-Tember 2025**” across **Kaduna and Plateau States**.

These activities were carried out in collaboration with partner organizations including **Sylaz Farm Ventures, Angwan Rukuba Update Limited**, and the **Kaduna State University Students Union**, among others. The objective was to deepen awareness, promote genotype testing, and encourage community-level prevention and support for individuals living with sickle cell disease.

2.0 OBJECTIVES OF THE PROGRAMS

- To raise awareness on the causes, prevention, and management of Sickle Cell Disease.
- To provide free genotype testing and counseling to promote informed marital and reproductive decisions.
- To engage students, community members, and stakeholders in proactive advocacy.
- To strengthen community partnerships for sustained SCD prevention and care initiatives.

3.0 SUMMARY OF ACTIVITIES

3.1 Warriors' Round Table 3.0

Date: 14th September 2025

Venue: Google Meet

The *Warriors' Round Table 3.0* marked the commencement of SSCAF's 2025 Sickie-Tember events. The session brought together SCD warriors, caregivers, advocates, and healthcare professionals to discuss lived experiences, coping strategies, and collective advocacy for better support systems. Participants shared impactful stories, reviewed community challenges, and proposed actionable solutions to improve the welfare of persons living with SCD.



**SHEM SICKLE CELL
ADVOCACY FOUNDATION**

Presents

WARRIORS ROUND TABLE 3.0

Topic

*Inequities in Sickie Cell Outcomes:
The Role of Race, Socioeconomic
Status and Geographic Disparities*



Offikwu Daniel Oche
*National Director Sscaf
Host*



Dr Akinyemi Ofakunrin
*Pediatrician/Haematologist
Speaker*



Gongu Jiritwa Patrick
Moderator



Immaculate Onyema
*Biotechnologist
Speaker*

 **14th Sept.
7:00pm**

 **Google Meet**

 <https://meet.google.com/ngj-ekrd-dnx>  **234-913-6895-054**



3.2 Sickle-Tember Kaduna State University Awareness Event – Kaduna State

Date: 17th September 2025

Venue: 500-Seater Pharmacy Hall, Kaduna State University (KASU)

Theme: *“From Awareness to Action: Building a Future Free from the Sickle Cell Burden”*

In collaboration with the **KASU Students Union** and the **KASU Medical Center**, SSCAF hosted a large-scale campus awareness program focused on preventive education and youth engagement.

Highlights of the Event AND PICTORIAL REPRESENTATINOS:

- **Free Genotype Testing:** 200 free genotype tests were conducted in partnership with the KASU Medical Center.





- **Health Education:** Medical professionals and SSCAF advocates delivered lectures on genetic inheritance, prevention, and lifestyle management for individuals with SCD.





- **Interactive Sessions:** Students actively participated in Q&A sessions, advocacy pledges, and volunteer enlistment for future outreach programs. The event was well-attended by students, and community leaders, reinforcing the message of informed decision-making and youth-driven advocacy.

3.3 Angwan Rogo Community Outreach – Plateau State

Date: 20th September 2025

Venue: Angwan Rogo Primary Health Centre, Jos North

The outreach program at Angwan Rogo focused on community-based sensitization and healthcare access.

Highlights of the Event AND PICTORIAL REPRESENTATINOS:

- **Health Sensitization:** Participants were educated on sickle cell prevention, early diagnosis, and lifestyle management.





- **Free Genotype Testing:** 200 individuals benefitted from sponsored genotype testing.





- **Relief Support:** 20 vulnerable participants received relief materials and health support items.





The outreach deepened genotype awareness within the Angwan Rogo community and strengthened SSCAF's grassroots presence.

3.4 SICKLE-TEMBER COMMUNITY OUTREACH – ANGWAN RUKUBA, PLATEAU STATE

Date: 27th September 2025

Venue: BMC Primary Healthcare Centre, Nasarawa Gwong, Jos North

This concluding program in Plateau State featured a vibrant **awareness rally** from Angwan Rukuba Junction to the BMC Primary Healthcare Centre, drawing the participation of residents, volunteers, and advocates.

Highlights of the Event AND PICTORIAL REPRESENTATIONS:

- **Awareness Rally:** A public march promoting the importance of genotype awareness and preventive marriage counseling.





- **Free Genotype Testing:** Dozens of residents received free testing and counseling.





- **Health Talks:** SSCAF's medical team provided education on SCD symptoms, crisis management, and community roles in supporting affected individuals.





The event reinforced SSCAF's commitment to community-based engagement and public enlightenment.

3.4 Media Advocacy and Radio Talk Shows

Dates & Locations:

1. 26th September, 2025 – Brothers FM 90.5, Makurdi (Benue State)





*The Benue State Chapter of SSCAF hosted a **30-minute radio talk show** at Brothers FM, Makurdi, where medical experts and advocates discussed the causes, complications, and preventive measures of Sickle Cell Anemia.*

- **27th September, 2025 – Unity FM 93.3, Jos (Plateau State)**





On 27th September, 2025, SSCAF and Sylaz Farm Ventures featured on Unity FM Jos, delivering similar advocacy content to thousands of listeners across Plateau and neighboring states. These radio programs enhanced SSCAF's reach and strengthened its public health education mandate, leveraging media as a tool for awareness and behavioral change.

4.0 IMPACT SUMMARY

Activity	Location	Beneficiaries	Key Outcomes
Warriors' Round Table 3.0	Plateau State	50+	Experience sharing and advocacy development
KASU Campus Event	Kaduna	300+	200 genotype tests, youth awareness
Angwan Rogo Outreach	Plateau	250+	200 genotype tests, 20 relief beneficiaries
Angwan Rukuba Outreach	Plateau	300+	Community rally, free testing, counselling, 200 genotype tests, 20 relief beneficiaries

Total Beneficiaries: 700+ individuals reached directly through all programs.

5.0 PARTNERSHIPS AND SUPPORT

SSCAF acknowledges the contributions of the following partners and supporters:

- Sylaz Farm Ventures
- Baulah Sickle Cell Foundation
- Angwan Rukuba Update Limited
- Kaduna State University Students Union & Medical Center
- Community Volunteers and Healthcare Workers

Their collaboration and generosity made the Sickle-Tember 2025 programs a resounding success.

6.0 CHALLENGES ENCOUNTERED

- Limited resources to extend free testing to all interested participants as people kept coming for the genotype test but where told that the budgeted number have been exhausted.
- Need for additional logistics support during rallies and outreach activities.
- Inadequate availability of medical consumables for larger-scale health interventions.

7.0 RECOMMENDATIONS

- Strengthen partnerships with state health ministries to scale genotype testing.
- Increase donor and sponsor engagement for resource mobilization.
- Expand advocacy to rural communities through continuous community sensitization.
- Institutionalize *Warriors' Round Table* as an annual national forum for SCD discourse.

8.0 CONCLUSION

The *Sickle-Tember 2025* programs organized by the Shem Sickle Cell Advocacy Foundation in Kaduna and Plateau States significantly advanced awareness, prevention, and community participation in the fight against sickle cell disease. The success of these initiatives underscores SSCAF's unwavering dedication to achieving a *future free from the sickle cell burden* through education, testing, and advocacy.

Prepared by:

Shem Sickle Cell Advocacy Foundation
2025.

SSCAF

RC: 7212807