



S C D E I

ANNUAL REPORT 2021

Sickle Cell Disease Eradication Initiative

Malari, Gujba Maiduguri By-pass Damaturu, Yobe-State, Nigeria.

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Vision:

An empowered society free of Sickle Cell Disease.

Mission:

To empower Sickle Cell Disease warriors and the community with knowledge, services and skills for self-sustenance in order to achieve community development & peaceful co-existence.

Objectives:

1. To provide health education and raise awareness on Sickle Cell Diseases (SCD) within the community and encourage Pre-marital counselling and testing for Sickle Cell Diseases (SCD) using HB Genotype or any other recommended test for SCD
2. To promote early screening for SCD amongst children for timely management of affected children.
3. To carry out routine meetings with parent, caregivers, patients and care providers for updates and experience sharing for effective management of SCD patients.
4. To establish special blood bank for SCD patients in collaboration with strategic partners and provide unique identification to registered members for easy access to emergency healthcare services.
5. To advocate and champion the establishment of special clinics for SCD patient across the state for effective management and lobby through relevant stakeholders, the provision of accessible and affordable testing and treatment for SCD Patients.
6. To advocate and lobby for legislative laws on compulsory pre-marital testing for SCD and banning marriages between high risk spouses such as; AS and AS, SS and AS, SS and SS and sensitize communities and the community populace through drama, radio jingles and sharing of posters and Information, Education and Communication (IEC) materials on the need to eradicate SCD.

MESSAGE FROM THE C.E.O

To all our Executive leadership, Community Focal Persons, Registered members, friends and strategic partners, we count the joyful moment of sharing with you the Sickle Cell Disease Eradication Initiative (SCDEI) successes, challenges and opportunities during the year 2021.

Your support, goodwill and generosity made it possible for us to continue reaching out to the communities and key stakeholders in our efforts to eradicate sickle cell disease in our society and improve the quality of care for sickle cell disease patients and improve on the livelihood of patients, their families and caregivers.

Nigeria has the highest global burden of sickle cell trait (Healthy Carriers) with approximate mean incidence of 20%. According to study done in Maiduguri University Teaching Hospital in 2013, Borno and Yobe States had the largest number of sickle cell trait in Nigeria with prevalence of **27.9%** and **32.6%** respectively. **This implies Yobe State has the highest prevalence of Sickle Cell Disease in the world!!!**

Sickle Cell Disease Eradication Initiative (SCDEI) is guided by three (3) thematic areas for its operation, these include (a) awareness raising, (b) medical care (c) psycho-social & economic support. We had so far registered over 500 sickle cell disease patients within Damaturu Local Government Area for the ongoing member registration lead by our community focal persons.

Together we can build a society free of sickle cell disease



Dr Aliyu Usman Muhammad (RN, MBChB, MPH)

CEO/CO-Founder, SCDEI

PLANNED ACTIVITIES -2021

No.	Activity
1.	Registration with relevant authorities
2.	Stakeholder Engagement – Yobe State Ministry of Information, Home Affairs and Culture
3.	Stakeholder Engagement – Saving One Million Lives for Results Yobe-State
4.	Stakeholder Engagement – Yobe-State Primary Healthcare Management Board
5.	Stakeholder Engagement – Yobe State Ministry of Health and Human services
6.	Stakeholder Engagement – Yobe State Ministry of Religious Affairs
7.	Stakeholder Engagement – Yobe State Broadcasting Corporation
8.	World Sickle Cell Disease Day 2021
9.	Community Engagement and Recruitment of Volunteer Focal Persons
10	Registration of Sickle cell Disease Warriors
12	Registration of SCDEI Volunteers

IMPLEMENTED ACTIVITIES 2021.

REGISTRATION WITH RELEVANT AUTHORITIES

Sickle Cell Disease Eradication Initiative (SCDEI) was registered as a humanitarian Community Based Organisation (CBO) in Yobe State, committed to eradicating Sickle Cell Disease. The ideation and concept development planning meeting held at The Red Cross Office Damaturu.

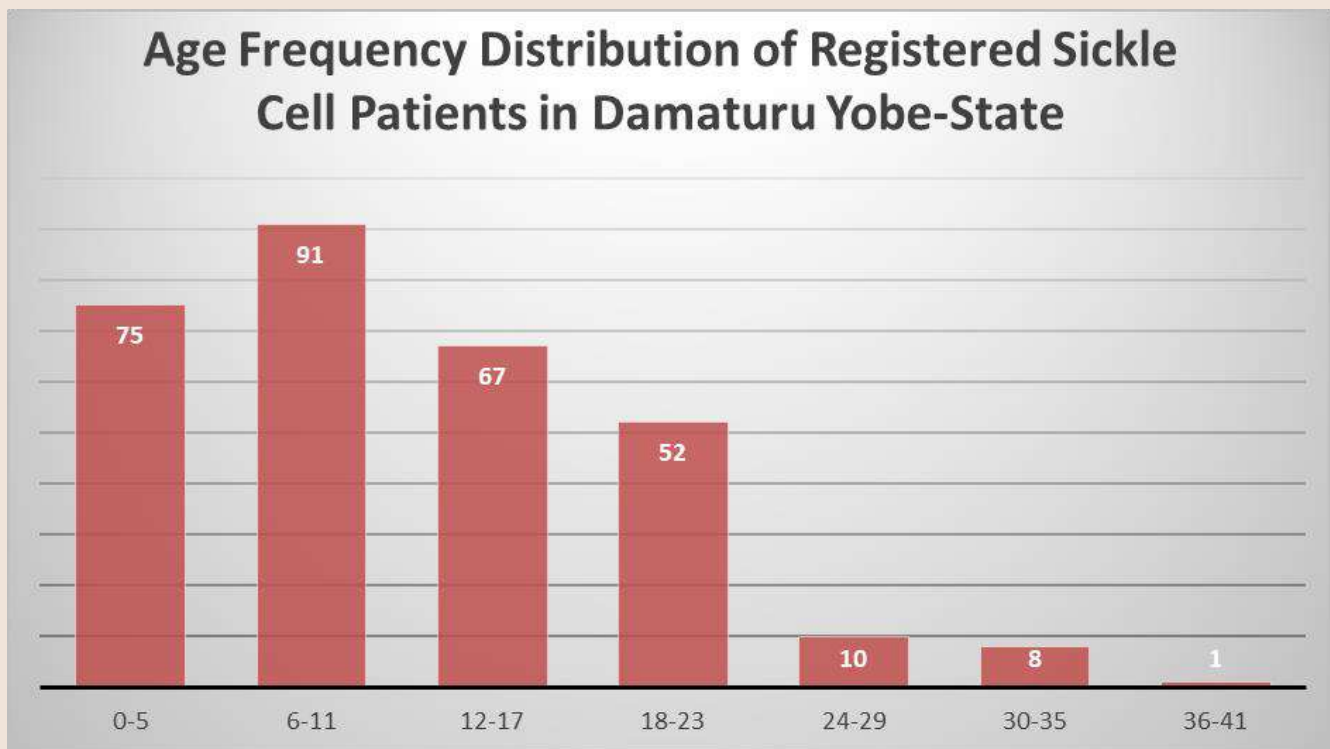


SCDEI Members with community volunteers having strategic planning meeting



MEMBERSHIP REGISTRATION PROJECT

The membership registration exercise is an ongoing project being piloted in Damaturu Local Government area of Yobe-State. SCDEI's interventions are based on researched facts and information, Organisation Capacity Assessment (OCA), and Sickle Cell Disease control programs. A hybrid data collection model was adopted using paper forms and Open Data Tool Kit called Kobo Toolbox. Three Hundred and Four Members were so far digitally captured in our system (304) showing 54% and 46% male and female ratios respectively. However, 77% of the registered clients are below the age of 18 years.



STAKEHOLDER ENGAGEMENT – YOBE STATE MINISTRY OF INFORMATION, HOME AFFAIRS AND CULTURE

Sickle Cell Disease Eradication Initiative (SCDEI) introduced a holistic Sickle Cell Disease (SCD) Eradication strategy through awareness raising, healthcare support and improved livelihood skills. The Yobe State Ministry of Information, Home Affairs and Culture was reached out for strategic partnership and project collaborations. However, the Ministry expressed its interest in the collaboration with SCDEI through support on IEC materials, public awareness campaigns and entrepreneurship skills.

*The Honourable
Commissioner,
Yobe State Ministry of
Information, Home Affairs
and Culture addressing the
officials of SCDEI*



*The officials,
Yobe State Ministry of
Information, Home Affairs
and Culture.*

STAKEHOLDER ENGAGEMENT – SAVING ONE MILLION LIVES FOR RESULTS YOBE

SCDEI officials paid advocacy visit to Yobe State Program manager, Saving One Million Lives for results Dr. Babagana Abba at his office in Damaturu. The visit centered of exploring various collaborative options towards reducing maternal and child morbidity and mortality caused by sickle cell disease. However, the SCDEI's team lead by its CEO Dr Aliyu Usman Muhammad reiterated their commitment towards eradicating sickle cell disease in the society. The Program Manager, pledged his support in the areas of research and development, capacity building, awareness, empowerment, skills and partner networking amongst others.



STAKEHOLDER ENGAGEMENT – YOBE-STATE PRIMARY HEALTHCARE MANAGEMENT BOARD

A high level engagement meeting was held at the office of Executive Secretary, Primary Healthcare Management Board Yobe-State. The need for inter-sectoral collaborations and leveraging on existing infrastructures and manpower were discussed and possible areas of partnership were highlighted. The existing health facilities with over 178 health workers under the PHMB were made available for SCDEI to pilot some of its initiatives. The Executive secretary further cited services and programs that could be leveraged by SCDEI in piloting its activities, namely; Health Promotion Unit, Risk Communication Network and Routine Immunization among others.



The meeting chaired by the Executive Secretary, flanked by the officials of the Board and SCDEI

WORLD SICKLE CELL DISEASE DAY 2021

The World Sickle Cell Awareness Day was celebrated on June 19th 2021 to raise the public awareness about the sickle cell disease and its management. Its history dated back to decades of advocacy that prompted the United Nations in December 2008 to resolve and recognise sickle cell disease as a public health problem and to mark the World Sickle Cell Day (WSCD) on June 19 every year, starting from 2009. The year 2021 marks the 12th anniversary of the World Sickle Cell Disease Day. However, The World Sickle Cell Awareness Day was organized by Sickle Cell Disease Eradication Initiative (SCDEI) in collaboration with Yobe State Ministry of Health and Human services. With the theme ***“Empowering the Society to Eradicate Sickle Cell Disease”***.



*The Theme of the 2021
World Sickle Cell Day
was*

*“Empowering the Society
to Eradicate Sickle Cell
Disease”*

Health awareness rally marking the World Sickle Cell Disease day 2021



The special guests of honour commemorating the occasion with key note address by the representative of Honorable Commissioner, Yobe-State Ministry of Health



A group photograph of invited guests, participants and members of SCDEI

COMMUNITY ENGAGEMENT AND RECRUITMENT OF VOLUNTEER FOCAL PERSONS

Sickle Cell Disease Eradication Initiative inaugurated its community volunteer focal persons on Wednesday 22nd September, 2021 at Nayinawa Primary School. However, the appointees were charged with the following guidelines:

1. The community focal person under the directives of the Chief Executive Officer (CEO), identifies problems, plans, coordinates, facilitates all project activities and reports periodically on the progress of the project and guides problem solving on SCD issues within his/her catchment area.
2. To coordinate SCDEI volunteers at wards level.
3. To collect field data on Sickle Cell Disease (SCD).
4. To create awareness and enhance community outreach activities.
5. To support in community mobilization for SCD Eradication programs.



Community Focal Persons receiving their appointment letters and field kit from the CEO SCDEI Dr Aliyu Usman Muhammad



Community focal person with a client during community outreach activity.

Sickle Cell Disease Eradication Program

INTERVIEWER DETAILS

Whom are you interviewing?

☐ Myself

☐ Others

Date of interview

RESPONDENT'S DETAILS

Name of Sickle Cell Disease Warrior

Name of SCD patient

Gender

☐ Male

☐ Female

How old are you?

☐ Greater than 1 year

☐ Less than 1 year

Educational level

Highest level completed

☐ Informal Education

☐ Primary School

☐ Junior Secondary

Kobo Toolbox used by community focal persons during the registration exercise.

STAKEHOLDER ENGAGEMENT – NORTH EAST DEVELOPMENT COMMISSION

SCDEI representatives paid a courtesy visit to North East Development Commission (NEDC) Damaturu. The organizational activities were discussed and possible areas of collaboration identified. This meeting lead to high level engagement with the commission's headquarters in Abuja. Several correspondence were raised and a proposal concept submitted for further evaluation by the commission.



Photograph of the zonal coordinator NEDC with officials of SCEDI

STAKEHOLDER ENGAGEMENT –YOBE STATE MINISTRY OF RELIGIOUS AFFAIRS

In an effort to reach out for key strategic partners in the campaign to eradicate Sickle Cell Disease in the society, the Ministry of Religious Affairs was approached for moral and spiritual guidance. The SCDEI officials were welcomed and important strategies were highlighted.



A group photograph with the Honorable commissioner, permanent secretary, directors and officials of SCDEI during the courtesy visit.

STAKEHOLDER ENGAGEMENT –YOBE BROADCASTING CORPORATION

Yobe Broadcasting Corporation is one of the key partners in the campaign for the eradication of Sickle Cell disease in Yobe-State and beyond. Several awareness programs were rolled out including live interactive call sessions with listeners in Hausa and English Languages.



Courtesy visit to the management



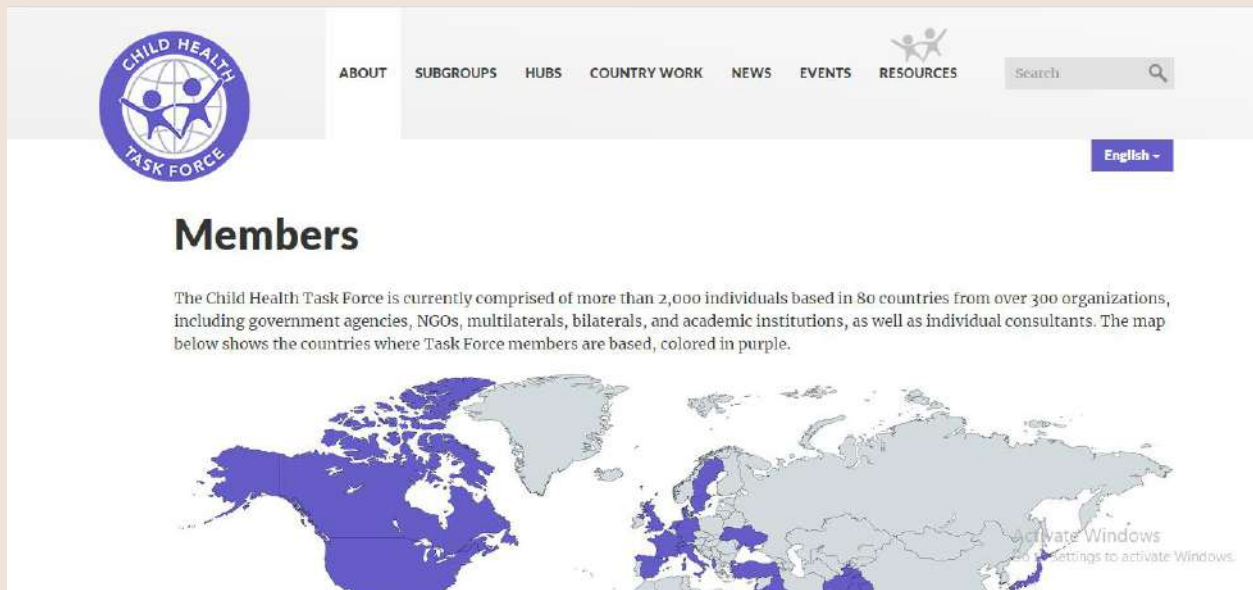
One of the awareness programs at YTV



SCDEI Awareness programs aired on radio

INTERNATIONAL COLLABORATION – MEMBERSHIP WITH CHILD HEALTH TASK FORCE

Sickle Cell Disease Eradication Initiative (SCDEI) has secured the membership of The Child Health Task Force. It's a network of global and country-based organizations and individuals working to design and implement child health programs that take a life-course approach. Aimed at generating and sharing evidence on how to implement equitable, comprehensive, and integrated programs that will translate into better outcomes for children.



Objectives of the Child Health Task Force

In order to achieve strong programming for child health, the Child Health Task Force focuses on the following objectives:

1. Strengthen the community health platform to deliver a comprehensive package of health promotion, prevention, and curative interventions, and support the building of strong linkages to primary health care facilities and first-level hospitals.
2. Support delivery of high-quality case management:
 - Integrated Management of Newborn and Childhood Illness (IMNCI); and,
 - Integrated Community Case Management (iCCM), including community-based management of malnutrition.
3. Support strengthening of Emergency Triage Assessment and Treatment (ETAT).
4. Strengthen referral and counter-referral from community to the primary care facility, the first-level referral hospitals, and back to the appropriate level.

<https://www.childhealthtaskforce.org/about/members>

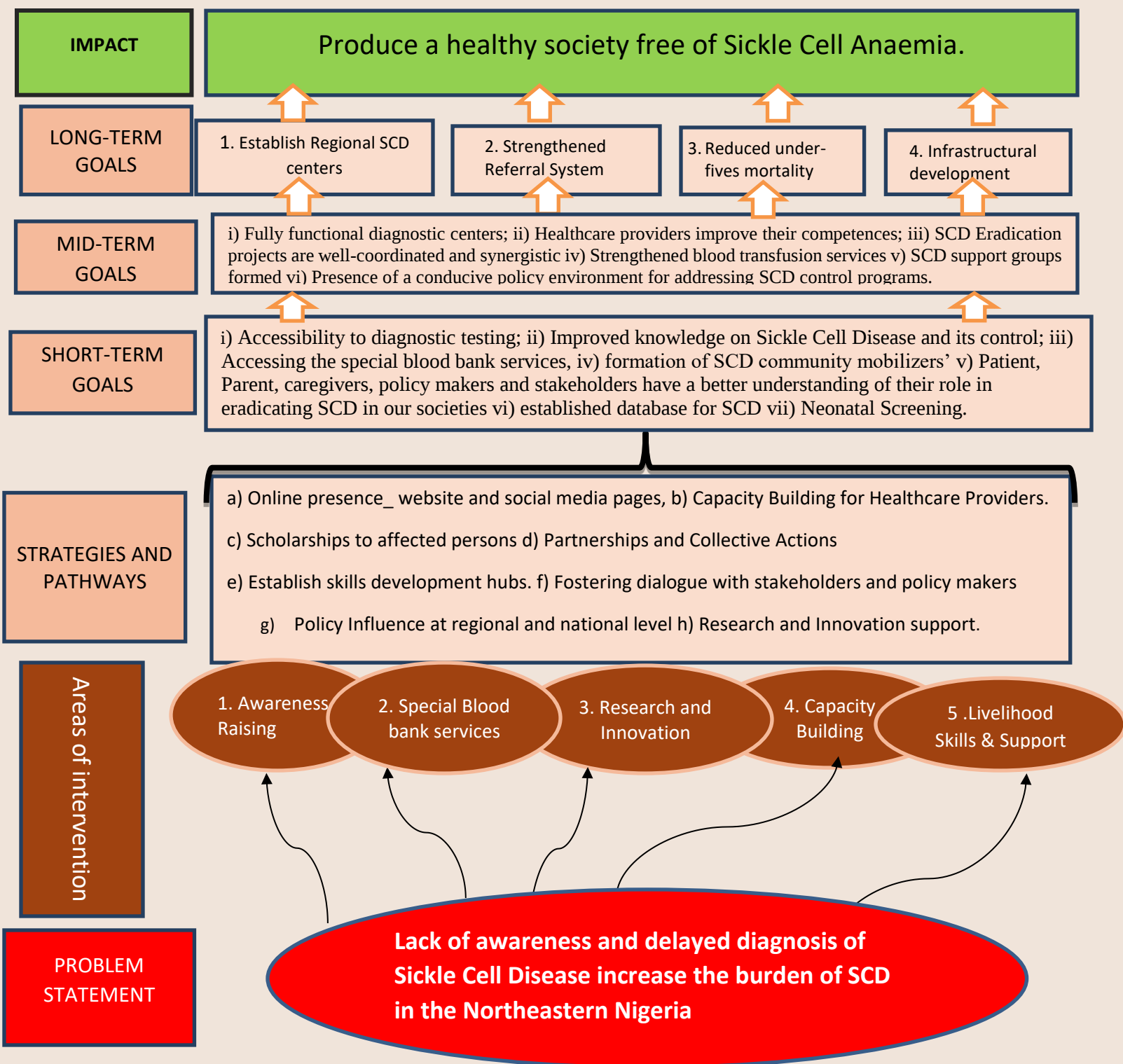
SPECIAL APPRECIATION TO OUR ADVISORS, SPONSORS AND STRATEGIC PARTNERS

1. Professor Muhammad Garba Ashiru
Department of Paediatrics
University of Maiduguri Teaching Hospital
2. Dr Babagana Abba
Program manager, Saving One Million Lives Program for Result Yobe-State
3. Dr Hassan A Elechi
Department of Paediatrics, Yobe-State Specialist Hospital Damaturu
4. Dr. Abdulhamid Gulani
Director Medical Services, Hospital Management Board Yobe State
5. Malam Muhammad Bashir Kukuri
Imam, Abbari Jummah Masjeed
6. Reverend Ibrahim Abako,
ECWA Good News Church Damaturu.
7. Hajiya Fatima Maina Bukar,
Asst. Director Partners Coordination,
Yobe State Primary Health Care Management Agency
8. Dr Hauwa Larai Gwani
Director Public Health, Ministry of Health and Human Services Damaturu Yobe State
9. Alh Abdullahi Ali Danchua,
Director Nursing Services,
Yobe state Ministry of Health and Human Services.
10. The Management, Yobe Television
11. The Management, Yobe State Broadcasting Corporation
12. Channels Television Nigeria
13. News Agency of Nigeria
14. The Red Cross Society
Yobe-State.
15. The Coordinator
North East Development Commission,
Yobe-State Damaturu.
16. Child Health Task Force UK
17. Community Focal Persons
18. Registered Volunteers

PLANNED ACTIVITIES -2022

No.	Activity
1.	Registration of members continue with Damaturu and Other Local Government Areas of Yobe State
2.	Digitization of Registered Members
3.	Full Automation of Organization's Programs- Awareness raising, Patients care, Blood Bank and Transfusion Services, Entrepreneurship and Financial Literacy Skills
4.	Radio and Television Awareness Programs
5.	Community Sensitization and Outreach Programs
6.	Baseline Demographic Survey- Membership Profiling
7.	Epidemiological Study- Burden of Sickle Cell Disease in the society
8	Sickle Cell Disease Eradication – KAP Study among healthcare providers
9	Research study- Prevalence of Sickle Cell Disorder among school pupils
10	Neonatal Screening Services
11	Blood Donation and Transfusion Services
12	Entrepreneurship and Financial Literacy Training
13	Psycho-social support programs
14	World Sickle Cell Disease Day 2022
15	Research Report and Publications

Vision: An empowered society free of Sickle Cell Anaemia. **Mission:** To empower Sickle Cell Disease warriors and the community with knowledge, services and skills for self-sustenance in order to achieve community development & peaceful co-existence.



Support the Sickle Cell Disease Eradication Project

ACCOUNT NAME: SICKLE CELL DISEASE ERADICATION INITIATIVE

ACCOUNT NUMBER: 1024784516

BANKERS: UBA PLC DAMATURU BRANCH

Sickle Cell Disease Eradication Initiative

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