



Fr John Kolkman Foundation

Strategic Plan

ACTS

*towards sustainability and maturity
to improve quality of care and life*



2018-2022

Mission Prayer

Almighty Father, through the most Precious Blood of your Son, grant the Fr John Kolkman Foundation, the resources, and the wisdom to effectively use them, in assisting those with sickle cell anemia.

Inspire in sponsors, the firm hope that, with your protection, the work begun and supported by their generosity, will come to a fruitful completion. Look with favor on their offerings; fulfill their plans. Amen.

April 2017

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A. Introduction

ACTS is Fr John Kolkman (FJK) Foundation's 5-year strategic plan – its roadmap and scope of activities in managing sickle cell disease (SCD) in Cameroon. This plan articulates FJK Foundation's vision and mission, goals, strategic priorities and performance matrices of achievement. It reflects the Foundation's innovative and analytical thoughts, creed and core values, in light of reviewed strengths, weaknesses, threats and opportunities.

ACTS is a call to action, with a sense of urgency, on a neglected public health need. It is an invitation to stakeholders, healthcare providers, community leaders, families and individuals affected by SCD, to collaboratively develop and implement a sustainable SCD program through its Community-Targeted Sickle Cell Initiative (CTSCI).

CTSCI has five objectives: 1) improve health outcomes for persons with sickle cell disease, 2) increase community awareness and knowledge of SCD, 3) promote early detection, counselling, and education of families, 4) identify persons with SCD and SCT (Sickle Cell Trait) through screening; 5) provide follow-up and counseling of patients and family members/care givers.

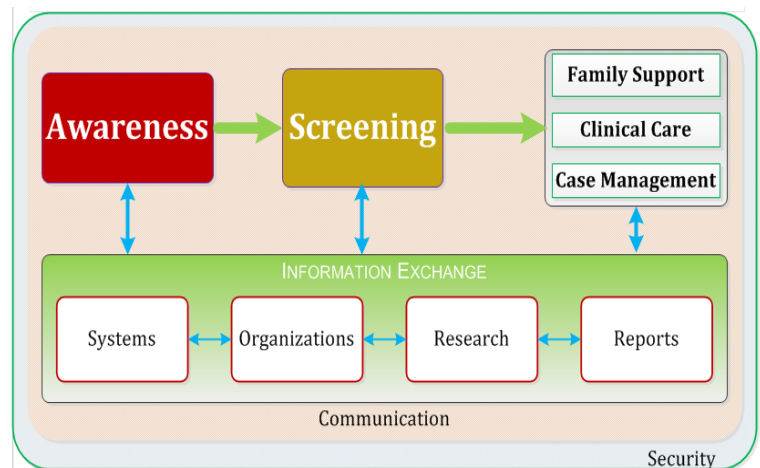


Figure 1 Conceptual framework of the Community-Targeted Sickle Cell Initiative

The initiative is a collaborative approach in which partners and collaborators carry out health promotion activities in rural communities and provide the required services to the affected. Sponsors and provider organizations support the planning, development and implementation of the projects and services.

Key monitoring aspects of the initiative include quantitative and qualitative data collection and analysis, tracking of outreach activities and outcomes through patient satisfaction surveys, events attendance records, number of person counselled and treatment responses as a measure of program success.

ACTS is intended to be a resource tool to secure the needed resources to fulfil FJK's mission.

A.1 Purpose

This plan provides, for the 2018-2022 years, the direction and scope of FJK activities and a set of public health interventions to reduce the burden of SCD in affected communities. The ultimate goal is to establish a sustainable structured sickle cell program that will restore wholeness to the sickle cell child.

A.2 Scope and Beneficiaries

ACTS is bound by the FJK Sickle Cell Management Paragon and covers the health districts and communities beyond the region where FJK has established partnerships and memoranda of understandings. ACTS targets, especially, rural areas where healthcare availability, accessibility and affordability are dismal or non-existent.

Expected beneficiaries include those affected by SCD and SCT: newborn babies, children under five, pregnant women, school children, nursing mothers and pre-nuptial/engaged couples.

A.3 The North-West Region

Cameroon's North West Region covers a surface area of 17,812 sq. km (6,977 sq. miles). There are seven administrative divisions that are home to 21 health districts. A health district is the basic fundamental administrative unit of care. Health districts were created in an effort to decentralize Cameroon's healthcare system¹.

It has over two million inhabitants of a wide range of ethno-linguistic groups. Growth rate is eight (8) percent in the urban area and three (3) percent in the rural communities; 62% of the population is under 20 years.

Like any other part of the country, the NWR's health care system comprises the public and private sectors. Hospital and clinics, which are almost nonexistent in rural areas, with traditional healing houses provide healthcare services. The main sources of healthcare funding are the Government, public enterprises, foreign aid donors, private enterprises, households, religious missions and Non-Governmental Organizations (NGOs). In the private sector, patients are expected to pay cash (payments before service) on demand for healthcare services. Patients often rely on family members and friends (from abroad for the most part) for the purchase of their medications and even needed medical supplies.

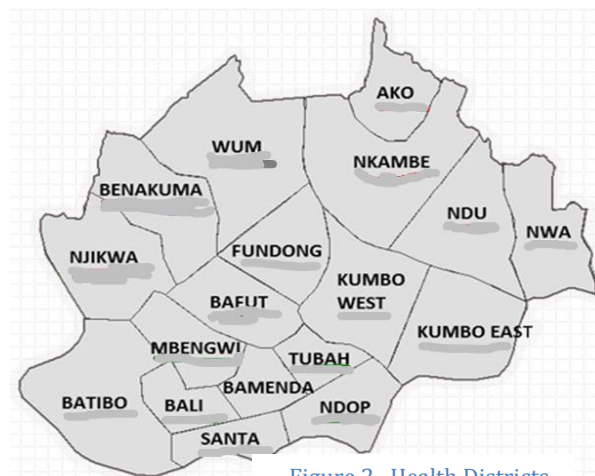


Figure 2. Health Districts

¹ A recommended healthcare framework of the African Regional Office of the World Health Organization to its member countries with the goal of bringing healthcare services closer to the rural community.

A.4 Development of the Plan

ACTS is a patient-family-centered and community-targeted plan.



Figure 3. 2015 World Sickle Cell Day workshop

Since its launching in 2007, FJK Foundation has organized conferences, conducted workshops, held seminars throughout the region and other parts of the country to understand the needs of the sickle cell community. Participants included sickle cell patients and family members or care takers, community and business leaders, civil and traditional rulers, health care providers and donors. In workshop sessions, workgroups focused and discussed on a variety of topics, identified and prioritized critical issues, then made recommendations in their respective reports.

In 2013, FJK Foundation conducted a *Needs Assessment* of all the health districts of the region in an effort to understand the burden of the disease on the community and its members. SCAF, a Sickle Cell Action Framework was developed from the findings of that assessment and constitutes one of the pillars in the development of this strategic plan.²

A body of relevant literature and other sickle cell organizations' strategic plans were reviewed to formulate the outline and content for this plan. Recurring themes, issues, priorities, recommendations from workshop/seminar and conference reports were identified and used to build the strategic objectives, proposed projects, programs and activities.

In developing the plan, care has been taken to align with the public health objectives of the Ministry of Public Health and the WHO recommended priority interventions for managing SCD.

A.5 Funding for Implementation

FJK Foundation relies on public support and internal resources to realize the strategic objectives of this plan. In the course of the years, FJK Foundation has had a number of collaborators, sponsors and partners, but cannot continue to rely solely on them. The Foundation will continue to work with existing supporters while actively seeking both short and long term collaboration with individuals, organizations and institutions to work towards the implementation of this plan. Additionally, we will develop, as part of this plan, sustainable income generating projects.

² Activities, objectives and initiatives of this strategic plan are within the boundaries of FJK's Sickle Cell Paragon. The model was developed to meet an identified need for collaborative planning for a successful health care delivery program. A primary goal of the paragon is to synergize communication during the health care delivery process and reduce patient fatigue from multiple visits.

A.6 Critical Success Factor

An annual review of ACTS is a requirement to ensure the plan is on track and corrective measures taken where and when necessary. FJK will put forth an annual activity or task plan based on the current year activity evaluation, to formulate the coming year's annual work plan. An annual review of ACTS and evaluation of the annual work plan and finances are critical success factors to its implementation.

A.7 ACTS Distribution

Hard and electronic copies of ACTS will be distributed to stakeholders, sponsors, collaborators, partners, community leaders, and potential funders. Wide distribution of this plan is encouraged and appreciated. ACTS is also available on the internet at <http://jkolkman.org/strategic-plan> for download or share via social media outlets.



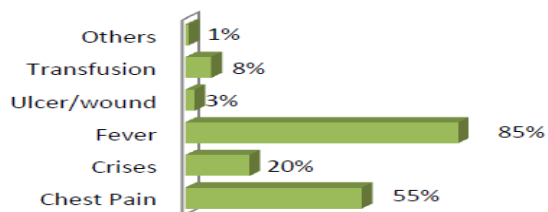
Figure 4. 2015 Community Workshop ³



Our full potentials are realized when we share our lives with others and cooperate on projects that hold the promise of mutual benefit.



³ Source: FJK Foundation Photos



B. Our experience

Our experience in the NWR and around the country validates the situation analysis outlined in the WHO Regional Committee for Africa report.⁴

B.1 What we Know

- The United Nations and World Health Organization declared SCD as a public health priority;
- Cameroon is among the countries whose SCD estimated prevalence is between 20 and 30%.
- WHO estimates that 70% of SCD deaths in Africa are preventable with simple interventions as screening. A sharp decrease in SCD mortality and morbidity rates in children has been reported in countries with implemented screening programs.
- SCD knowledge and awareness among health professionals is low and lacks government financial support.
- Little or no scientific/medical data accounts for an uncharacterized sickle cell population.
- Children make 4 to 6 hospital visits a year for preventable SCD related complications.
- Affected individuals and families suffer a burden of anxiety, financial cost and social outcast.

B.2 Challenges

- No established policies and protocols for SCD diagnosis, prevention and management.
- Testing for sickle cell disorder and carrier status is not a routine clinical practice.
- No health promotion to increase awareness; minimal interest in SCD cause at all levels.
- Financial and material support is low, slow in coming and unpredictable.
- Lack of a data collection (storage, reporting and dissemination) system.
- Inability to provide evidence based information to the public and families.
- Weak governance structure and specialized personnel.
- Poverty of the affected families and limited funding to support their needs.
- Balance between compassion and service provision to affected persons at no cost.

Know Your Sickle Cell Status

Do not pass down a genetic disorder!

Take Action, Get Screened

⁴ Sickle Cell Disease: A strategy for the WHO African Region, AFR/RC/60/8, 22 June 2010.

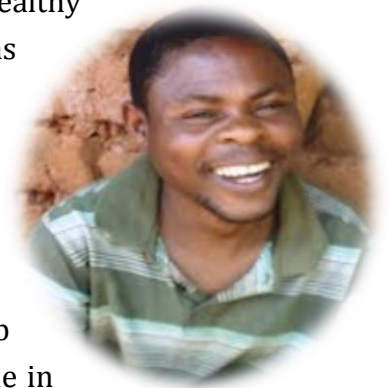


C. Fr John Kolkman Foundation

Fr John Kolkman (FJK) Foundation is a United States based non-profit organization, endorsed by the competent authorities in Cameroon to carry out prescribed services as a non-Governmental Organization. FJK Foundation is committed to the prevention, early detection and management of sickle cell disease in the Rural Health Districts of Cameroon. It is the first structured organization to: 1) raise public awareness and education in the region; 2) introduce and implement intervention measures; 3) promote health activities for SCD control and management⁵.

FJK Foundation was founded in 2010 by Deacon and Mrs. Neba to assist families with sickle cell disease in Bafut. The Foundation has since stretched its circumference of operation and services to over 1,000 families in and beyond the North West Region. FJK's operations and services to those in need regardless of creed, ethnicity and culture are based on Catholic Social teachings..

June 1975: Within a few months of birth in Bafut, Engelbert, the healthy looking baby, developed swellings in his wrists and arms. He was taken to the local health center where pain medications were administered. His symptoms resurfaced within a month accompanied by fever. He was anemic and received his first blood transfusion. At six, he developed a squinting eye; then suffered a stroke (and lost speech and partial movement in the right arm) at seven. At eight he developed a very high fever and was sent to the lab to be screened for Malaria. The result was sickle cell anemia. No one in the family knew what sickle cell was.. People in the community describe cases of children, like Engelbert, who have died from similar preventable SCD related complications (without knowing what they were dealing with). Engelbert's elder brother, a teenager in 1975, determined to find a solution to the problem when he grew up. FJK Foundation is the outcome of years of determination and persistent pursuit to address the sickle cell problem.



FJK Foundation has impacted many families and affected persons. Public awareness and sensitization levels have increased through organized conferences, workshops, seminars, media coverage and presentations. Hospitalization rates for children in the FJK SCD management program have reduced or been eliminated in some cases. School attendance for children and

⁵ Awareness and education through organized conferences, seminars, family and community workshops, and seminar, and interventions as screening, counselling, nutritional supplementation.

self-esteem for affected teenagers and even parents has increased. The perception of sickle cell affected families in the community is changing. There is a developed interest among young people and parent-teacher-associations in learning about the disease⁶. A sickle cell center facility has been erected with the vision of providing comprehensive sickle cell services.

C.1 Vision and Mission

FJK's tenets constitute the building blocks of its holistic approach to managing SCD.

Vision: Restore wholeness to the sickle cell person and family to live a normal and productive life.

Mission: Ensure the early detection, prevention of SCD, proper management and treatment of SCD related complications; promote and improve the quality of life of sickle cell patients through targeted services; provide outreach, awareness, case management, screening, nutrition and counseling services.

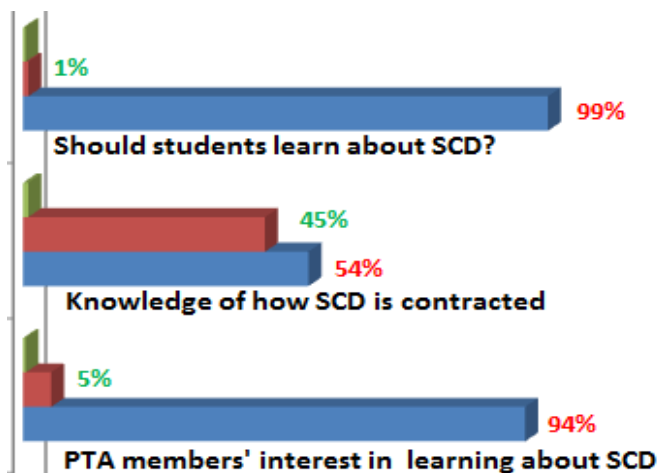


Figure 5. PTA opinions on SCD, 2014

C.2 Goals

- Implement strategies to assist SCD affected individuals and families
- Provide accurate, valuable, and current SCD information to healthcare providers, patients and their families, schools, social service agencies and the general public.
- Provide leadership in raising awareness, establishing standard protocols for patient services and supporting basic research initiatives.
- Offer opportunities to advance the sickle cell cause and focus on health promotion activities.
- Advocate for the implementation of preventive interventions that include sickle cell testing and screening (for new born babies, expecting mothers and engaged couples).
- Develop and implement a centralized sickle cell registry.
- Build and equip a SCD infrastructure, and establish a network of collaborators and partners to support programs and services.

C.3 Value Statements

- All humans have a right to health care and to secure the basic necessities of healthcare.
- Our expressed concern is the well-being of person and family.

⁶ Attitudes of Parents Teachers Association Members in Cameroon's North West Region towards students learning about SCD. A 2014 survey eight PTAs in Bafut and Bamenda health districts.

- c. Our full potentials are realized when we share our lives with others and cooperate on projects that hold the promise of mutual benefit.
- d. We have a moral obligation to health care initiatives.
- e. Our experience, environment and those we encounter shape our decisions.
- f. We take responsibility for our every action.
- g. We recognize the family as the primary caregiver, center of strength and support for the human being.

C.4 Creed

We take to heart and strive to main our creed and values as stated:

- a. Human life is a precious gift from God; we are stewards of this gift.
- b. We enter into a mutual respect, trust, and honest relationship with our clients.
- c. Human wholeness constitutes the physical, psychological, social and spiritual dimensions.
- d. We have an opportunity to share in the suffering and healing ministry of Christ.
- e. We are not capable of curing sickle cell disease; we are capable of caring for each sick person.



Figure 6 A cross section of activities at the Sickle Cell Center, Bafut

C.5 Relationships

- Recognized as *True Partner of Ministry of Health in SCD Management*, 2012.
- Memorandum of Understanding (MoU) with Diocese of Mamfe, 4th September 2013.
- MoU with Regional Delegation of Health, Bamenda, 29th May 2013.
- Endorsed Community-Targeted Sickle Cell Project, Minister of Health, 19th November 2013.
- Endorsement of the Archbishop of Bamenda, 30th January 2015.
- Endorsement of the Senior Divisional Officer for Mezam, 14th June 2016.
- Letter of Collaboration, NWR Delegate of Health, 7th October 2016.

C.6 Governance

Board of Directors

Most Reverend Francis Kane, D.D.
 Auxiliary Bishop of Chicago
 Vicar for Vicariate II
 Archdiocese of Chicago

Linda Drawhorn, MS, RN,
 Executive Director,
 LDR Healthcare Consulting, LLC

Florence Ayafor Neba, BSW
 Cofounder & Social Services Coordinator
 Patient Care Technician, UIC Hospital

Rev. Richard Apongnde, Administrator
 Cameroon Baptist Convention, Bamenda.

Solomon Oranu
 Business Manager Bamenda
 Shed 11, Main Market

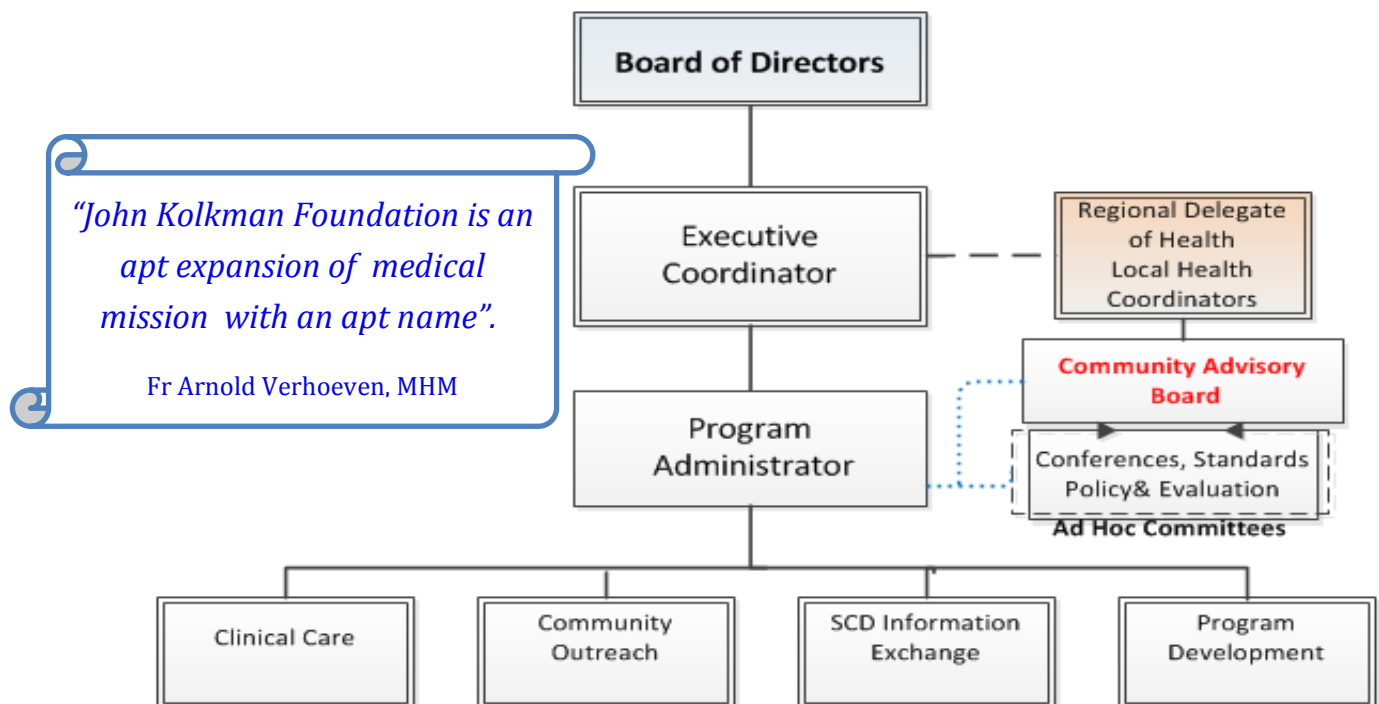
Christina Ngong
 Educational Services, Bamenda

Karen Spruyt, Ph.D.
 Behavioral Sleep Research & Developmental
 Neuropsychology

Robert E. Molokie, M.D.
 Comprehensive Sickle Cell Center
 University of Illinois College of Medicine

Ivonne Kanko, Ph.D., MPH, MBA
 College of Health Sciences
 Chicago State University

Michael Neba Ambe, Ph.D.
 Executive Coordinator & Cofounder
 Archdiocese of Chicago.





D. SWOT Analysis

D.1 Strengths

- a. Mobility into rural areas to make accessible and available, basic health care services.
- b. Possession of a low cost rapid point of contact (RaPoC) SCD screening and diagnostic tools.
- c. Knowledge of the region's sickle cell landscape and ability to adapt to local situations.
- d. Ability to quickly introduce new initiatives and interventions.
- e. Own and operate a sickle cell center for service delivery with uninterrupted water supply.
- f. Own Mobile Clinic utility vehicle and adequate land for expansion.
- g. Good working relationship with families, community and traditional leaders.
- h. Pioneer leader in the development of a comprehensive SCD management program.
- i. Actively developing a sickle cell screening program.
- j. Constant availability of Hemoxide supplementation.
- k. Dedicated and compassionate staff to provide therapeutic support.
- l. Gained public confidence in sickle cell disease management.
- m. Welcoming environment for volunteers and interns.
- n. Environmental development of the community where the sickle cell center is located.
- o. Weekly radio broadcast and presence of a website.
- p. Continuous public awareness and education.

D.2 Weaknesses

- a. Immature and fragile programs in place.
- b. Lack of an established hematology laboratory, and the capacity to build and monitor services.
- c. Inability to expand the current team to meet service demand.
- d. Inadequate funding and resources to develop and implement effective programs and services, promotion materials and to reach out to rural areas where services are needed.
- e. Inadequate operational documentation, management resources, and specialized staff.
- f. Infrequent communication to follow up and maintain contact with clients.
- g. Inability to sustain consistent services and interventions delivery at an affordable cost.
- h. No resources to address malnutrition cases or prevent malnutrition causing factors.
- i. Undocumented administrative and operational policies, standards and procedures.

D.3 Opportunities

- a. Integrate with community-faith-based and current health systems and structures.
- b. Build partnerships and collaborations with institutions and organizations.

- c. Develop and establish a SCD nutrition prevention/management program.
- d. Develop a system to identify and encourage use of local foods with high nutrition values.
- e. Work with families and community on strategies to avoid identified preventable causes of child-maternal SCD complications.
- f. Work with Regional Delegation of Public Health to develop a SCD public health agenda.
- g. Promote the use of Hemoxide supplement and Sicklescan for screening of newborn children.
- h. Erase the social perceptions and implications of SCD in the community.
- i. Bring awareness and education programs into secondary and post-secondary schools.

D.4 Threats

- a. Reluctance of some health care providers and professionals to collaborate in health promotion activity campaigns without compensation.
- b. Non-integration in current healthcare system.
- c. Unknown full extent of the burden of sickle cell diseases in the region and country.
- d. Lack of data on sickle cell poses a challenge to program development.
- e. Notion that FJK Foundation is a rich non-for-profit with unlimited resources for free services.
- f. Government bureaucracy and slow pace of processing documentation.
- g. No steady cash flow or revenue source to cover operational and service costs.
- h. Worsening conditions of clients due to deceit by purported healers of sickle cell disease.
- i. Loosing clients to providers who promise "better" hope for non-helpful incentives.
- j. Not viewed as a collaborator by health care providers.
- k. Downplay of the effectiveness of FJK Foundation's efforts by some healthcare providers.



Figure 7. FJK Experimental Garden

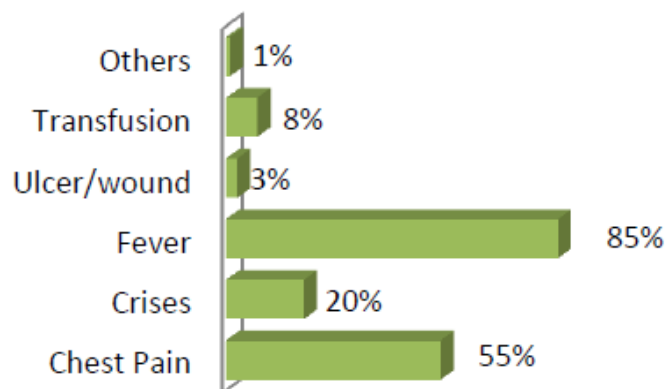


Figure 8. SCD related complications (Source: FJK Foundation)



E. Strategic Priorities

Our strategic priorities are geared towards improving the quality of life and care of the affected person, and developing a matured and sustainable SCD management program.

E.1 Awareness and Education

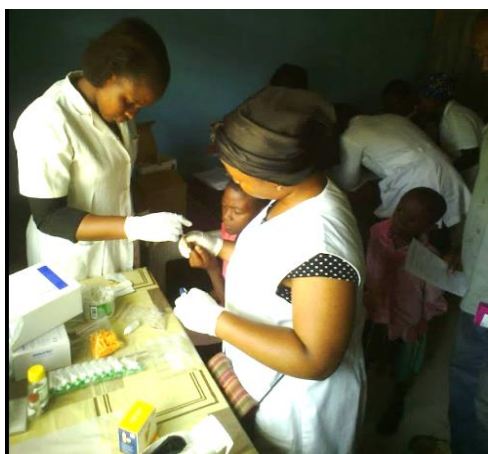
Be a point of contact for first-hand information and encouragement for affected persons.



1. Develop five community- awareness and education courses.
2. Educate the affected, care givers in communities, medical students and others in contact with SCD persons/families.
3. Promote and distribute educational SCD materials.
4. Train Trainers for midwives, school nurses and teachers, health professionals, patients and parents/care givers.
5. Make available and provide accurate appropriate-level SCD and SCT information and educational materials.
6. Promote the use of SickieScan and Hemoxide.
7. Conduct rotational annual regional conferences/seminars.
8. Media broadcasts.
9. Write abstracts on SCD for publication and conferences.

E.2 Patient-Family-Centered Health Care Improvement

Become a model for innovative health care service delivery at the rural door steps.



1. Develop and implement a standardized clinical and counselling protocol for SCD management.
2. Develop and implement a case management program for SCD identified children.
3. Introduce and promote local nutrition recipes to improve quality of care and life for affected persons and families.
4. Review and adopt best practices in SCD clinical care.
5. Establish and operate a functional hematology laboratory.
6. Equip the Mobile Clinic van with medical supplies and accessories.
7. Implement the FJK SCD Management Paragon.

E.3 Early Identification/Screening

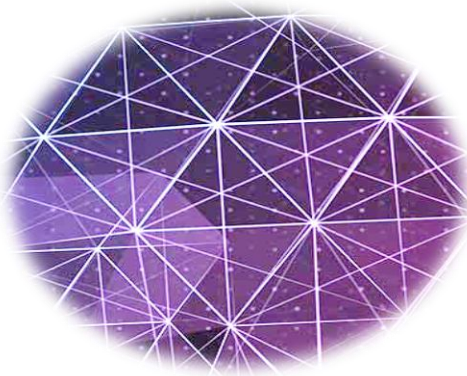
Know your sickle cell status; do not pass down a genetic disorder.



1. Promote and implement the Rapid Point of Contact (RaPoC) screening program.
2. Establish a functional SCD screening Network.
3. Make available SickleScan kits in maternity delivery rooms.
4. Advocate for RaPoC screening as routine for children less than 5 years and newborn babies.
5. Advocate for premarital SCD screening and counseling as a requirement for marriage.

E.4 Partnerships and Networks

Build and maintain a broad network of partners and collaborators.



1. Implement NWR Delegation of Public Health's Letter of Cooperation; operationalize MOU with Diocese of Mamfe.
2. Network with: Association of midwives, PTAs, Health districts, Media, Faith/Cultural-based groups, government agencies, corporations.
3. Continue to solicit, cultivate and update donors.
4. Organize two (2) Medical Missions.

E.5 Capacity building

Enhance the ability to accomplish FJK's mission and sustain its programs.



1. Complete infrastructure development of Sickle Cell Center.
2. Develop and implement a student internship and Sickle Cell Missionary programs.
3. Identify and develop sustainable income generation programs/projects.
4. Establish an online store.
5. Create functional advisory and ethical review boards.
6. Provide current staff with advance training and skills for patient care, data collection, analysis and reporting.
7. Expand current staff to include a medical director.
8. Develop SCD care, management and support manuals.

E.6 Primary Prevention

Decrease incidence of affected births, prevent crises and complications before they occur; reduce disorder health burdens.



1. Develop a screening-counselling program and course for premarital couples.
2. Advocate for engaged couples to complete a pre-SCD screening/counseling as a marriage requirement.
3. Engage women in cultural and social groups to promote identified preventive interventions.
4. Integrate screening and health promotion activities into existing health delivery services across institutional boards.

E.7 SCD Communications

Build and maintain consistent tools for SCD information collection, storage and exchange.



1. Develop and establish a SCD registry.
2. Annalise collected data and report on various performance indices.
3. Produce syndicated programs for distribution to local media outlets..
4. Install a broadband internet connectivity to support a Telehealth System.
5. Enhance and expand the SCD Community Voice program at Radio Abakwa.
6. Write/develop abstracts on activities for presentations and publications.
7. Manage and expand (as needed) websites' contents and maintain acts.jkolkman.org blog.

F. Envisioned Short Term Projects

Expansion and enhancement of current staff skills

Expand current staff to include a medical doctor (0.25 FTE) and social worker. Provide 80 hours of professional training to enhance skills and update management protocols.

FJK Water System Filtration

Implement an inline filtration system to reduce to eliminate contaminants, and presence of any heavy minerals in the current water supply system.

Solar Power Electrical System for FJK Center

Implementation of a 4KW off-grid solar powered electrical system. This is an expansion of an existing solar energy in use for water supply in the sickle cell clinic.

RaPoC - Rapid Point of Care SCD Screening

Universal newborn screening for babies within 48 hours of delivery, or in subsequent visits: focus on children under 5 years and premarital couples, at risk secondary and high school students.

Observational evaluation of Hemoxide SCA

Review hematology parameters of SCD patients on Hemoxide, per FJK management protocols, and analyze data to determine the efficacy of Hemoxide supplementation on SCD management and crisis prevention.

Development of a functional hematology lab

Develop and equip a basic laboratory to include training of laboratory technician, for the assessment of complete blood count, blood disorders and pathologies.

Dove Mobile Clinic

Equip a mobile clinic van with medical supplies and competent skilled staff, to make routine and on demand healthcare visits to various rural communities.

Sickle Cell Disease Registry and Surveillance System

Develop and maintain an up to date sickle cell disease registry for data collection, patient outcome monitoring and reporting.

SCD Educational Materials

Resources manuals, flyers and brochures for parents and families with SCD. Handbook for educators, healthcare providers, etc.

SCD in the educational setting and curriculum development

Develop SCD courses for midwives, secondary and high school students, school nurses and teachers.

FJK Administrative and Operation Manual

Review, update and develop, where lagging, administrative and clinical policies and procedures, and financial management records.

SCAF Implementation

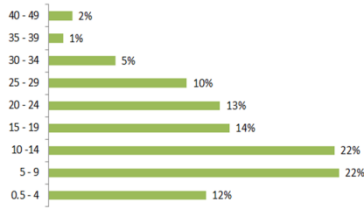
Promotion and implementation of SCAF in collaboration with the NWR Regional Delegation of Health.

Inside the NWR Delegation of Health-FJK collaboration initiative

Strategic Integration of SCD management paragon with the NWR health system.

SCD Maternal Child Health Maintenance Manual

Identify and document routine health maintenance issues important in the care of children with sickle cell disease and related complications.



G. Plan Evaluation

As an organization, we believe in measurable success and accountability, hence an active evaluation component of this plan. Each program and project will be evaluated using the following suggested guidelines in SCAF.



Additionally, questionnaires will be formatted and distributed to program participants at various outreach locations in order to evaluate the success of the program.

Evaluation forms will be made available for program participants to provide valuable feedback.

Participants will be evaluated at the end of each organized conference, seminar and workshops

Interviews will be conducted to receive feedback from patients and their families. An evaluation report shall be prepared and disseminated to stakeholders and made available online.

Know Your Sickle Cell Status

Do not pass down a genetic disorder!
Take Action, Get Screened

Rapid & Easy Procedure

Results

HbAA	HbAS	HbSS	HbSC
Normal	Trait	SCD	HbSC Disease

Applications

- Newborn screening
- Premarital Counselling
- Universal Screening
- Blood bank screening



H. Special Projects Sponsors

 <p>Servants of Mary</p> <p>Mary Alphonse Bradley Fund</p> <p>https://servitesisters.org/index.php</p>	<p><i>dear sponsors!</i></p> <p>our hearty</p> <p>Thank You</p> <p><i>blessings on all you do do!</i></p>	 <p>http://yongenterprises.4t.com/abakwa%20fm/home.htm</p> <p>Abakwa Radio FM 99 MHz</p>
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I wish to testify that my son has been on Hemoxide for 5 years. I have not been to the hospital during this time. I did not know my son will live to this day. [Mother of 14 year old, 2016]

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