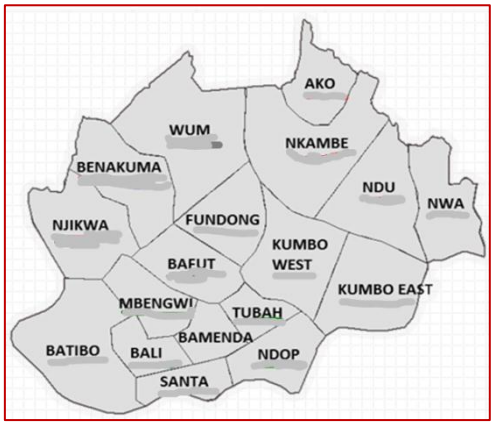
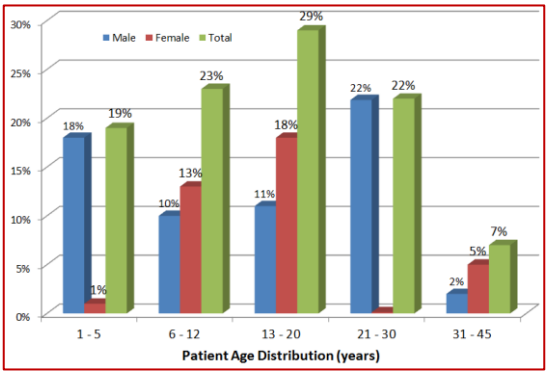
FJK
Sickle Cell Foundation

Inside Cameroon's Sickle Cell Community

an assessment of the North West Region





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1 Introduction

The voice of the sickle cell person is not always heard amidst the notable challenges in providing health care services. Since its founding in 2007, the Fr John Kolkman Sickle Cell Foundation has been leading the initiative to establish a structured program and infrastructure for controlling sickle cell disease in the North West Region. Organized workshops, seminars conferences, surveys and interviews have given sickle cell persons and their families a platform to tell their stories in the hope, as one participant put it "*will be presented to the Minister of Health*", and express what changes the community and healthcare system can make to improve the quality of their lives.

This report, the first of its kind to focus on sickle cell disease in the region, is the voice of the sickle cell community. The report:

- is based on data gathered from a pilot outreach mobile clinic project, discussions with sickle cell patients and families in the rural community, reports of workshops, surveys, seminars and conferences held in Bamenda, Yaoundé, Limbe and Douala;
- presents key findings, community reactions, demands that include free and or subsidized services and medication;
- outlines a bare exposure of the burden of the disease, the challenges and recommendations to manage the disease.

Conducted as part of its service provision, constrained by resources, the assessment was not designed as a full pledge *Community Needs Assessment* study. A needs assessment of a greater depth is required to get a deeper understanding of the magnitude of the problem.

Acknowledgement is given to the Field Staff: Mrs. Grace Fontawa, Ms. Violette Kininla, Mr. Emmanuel Che for gathering the data, conducting interviews and focus meetings; Administrative Staff: Mrs. Magdalene Tamnjong (Informatics); Mrs. Rose Achidi, Pastor Richard Apongnde, Dr. Tamara Bugembe, VSO Fellow at the Bamenda Regional Hospital, Waa Musi, staff of Radio Abakwa.

Staff of the Regional Delegation of Public Health and District Medical Officers and their Coordinating Staff.

2 Background

It is known by various names in Cameroon's North West Region depending on the variety of complications or symptoms experienced. Many have died from it before their fifth day, most of them undiagnosed. Broken families have emerged because the newest birth in the family had the disease. Children in pain from its complications have been beaten to cast out the demon causing the ailment in them. Herbalist and medical doctors have been consulted. No one seems to have the answer. It dates back to the time before Christ, as a German team recently reported that a Pharaoh, King Tut died of it in 1324 BC[1]. A century has gone by since a Chicago based physician in 1910 first "published a description of oddly shaped blood cells termed sickle cell anemia".

As of date, there is no cure for this inherited blood disorder. There is agreement, however, that effectively managing the disease can and does restore normalcy in the lives of the affected and their families. This presupposes an available, accessible and affordable healthcare system.

In the North West Region of Cameroon, there are notable challenges in the provision of healthcare services, from a centralized location, to affected persons in rural communities with diseases like sickle cell anemia, that require specialty care. Among them, availability and accessibility of healthcare providers, transportation, and the distance to and from health care facilities. FJK Foundation analyzed 174 records of its patients who had not returned to the clinic for more than three conservative months over a three year period. About 36% were identified as from a rural community, 19-32 km (12-20 miles) beyond the Bamenda municipality; 16% came from a rural distance of 32-48 km (20-30 miles).

72 families (45%) of the reviewed cases missed their appointments for three or more months. They blamed among others, long distances to travel, cost of transportation, lack of a good means of transportation even when they can afford the cost. About a third of the 72 indicated they knew at least one family with a sickle cell condition, in the rural area, who has not registered in the clinic, is willing but cannot afford to come to town. Five families in the metro area when interviewed said they would not be able to come to the clinic on a regular basis if they lived further away.

That experience initiated the Community-Targeted Sickle Cell Project with a Mobile Clinic component, designed to bring routine and on demand, health care services to the doorsteps of the affected in the rural communities. In order to establish a meaningful program, it was necessary to get input from those who will utilize the service. In 2014, FJK Foundation engaged members of the sickle cell community in the health districts of the North West Region to: 1) get input from the affected families in what ways a mobile clinic will benefit them; 2) understand the health care needs of persons and families affected by SCD and the community in which they live; 3) document the burden of the disease on families and the communities.

[1] http://www.newscientist.com/article/dn19094-tutankhamen-killed-by-sicklecell-disease.html#.VPJ47NLF8XE

3 Usefulness of Community Input

Community input will provide information useful for determining issues of great concern, decisions on what areas resources can be committed with the greatest impact on community health quality of life.

- Identify areas of priority interventions in its effort to develop and implement programs and services for SCD prevention and management;
- Set priorities for the development of resources and interventions for a mobile clinic.
- Validate the components of a FJK-developed regional sickle cell health care delivery model.
- Formulate a framework and a strategic action plan for managing sickle cell disease.

4 About FJK Foundation

FJK Foundation's mission is to ensure the early detection, prevention, management and treatment of sickle cell disorder, promote and improve the quality of life of sickle cell patients. It was established in 2007 for the primary purpose of addressing the healthcare needs, in the most complete form, of the sickle cell community in the Region. Its client base has extended beyond the region with satellite representations in in Bafoussam, Yaoundé, Douala, Limbe and Mamfe. The Foundation has since been leading initiatives to establish a functional structured program and infrastructure to provide services to all affected persons regardless of ethnicity, creed, outlook or age.

FJK Foundation takes a holistic approach that stresses preventive care to managing sickle cell disease. Services offered (and anticipated) include:

- Clinical Care
- Public Education
- Case Management
- Family Support
- Counseling
- Information Exchange
- Testing and Screening (not implemented)
- Mobile Clinic (pilot project)

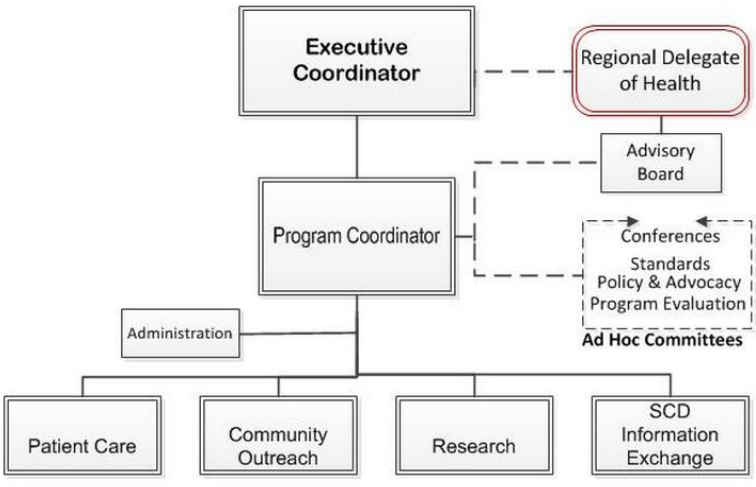

Figure 1: FJK Foundation functional chart

The impact on children has been visibly noticed: reduced sickle cell episodes, increase school attendance, healthy appetites, reduced hospitalization, and a good feeling in families of the affected.

5 Regional Information

The North-West Region is located in the western highlands of Cameroon characterized by rolling mountain chains over a surface area of 17,812 sq. km (6,977 sq. miles). There are seven administrative divisions that are home to 18 health districts in the region. A health district is the basic fundamental administrative unit of care. The health districts were created in an effort to decentralize Cameroon's healthcare system – 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.

The region, like the rest of the country, does not have a structured sickle cell program in any of the health districts (both public and private). The Foundation intends to provide mobile clinic services to the entire region.

It has a population of 2,149,971 inhabitants of a wide range of ethno-linguistic groups. Growth rate is eight percent in the urban area and three percent in the rural communities. 62% of the population is under 20 years.

Figure 2: Health Districts of the North West Region, Cameroon

6 Approach

Against the backdrop of a Memorandum of Understanding (Page **Error! Bookmark not defined.**) the Regional Delegate of Health convened an informative meeting with representatives of the various health districts of the region on 13 December 2014. Prior to the meeting, senior members of FJK Foundation and the Regional Delegate of Health met on December 9th and FJK Foundation presented considerations to be conveyed to representative of the various Health Districts:

- The Ministry of Health takes the management of the disease seriously and invites all members of the Public Health team and community organizations to collaboratively address the problem.
- The Honorable Minister of Public Health endorsed the *Community-Targeted Mobile Sickle Cell Clinic Project* on November 19, 2013.
- The project is aligned with the WHO African Region recommendations and 2020 Targets for member countries on managing sickle cell disease.
- SCD is a neglected community disease that has not received the attention it deserves and requires a community effort to address it.

- SCD has no cure, but can be prevented and managed for affected persons and families to live a normal live.
- There are many undocumented cases and the magnitude of the burden of the disease is not understood.
- FJK Foundation, as health care provider, is an integral part of the Public Health System.
- The Ministry of Health has not allocated funds for this project nor did FJK Foundation receive any funds from abroad specific for this project. The assessment as such was funded by good will donation of the Neba Family, Founders of the of the Foundation

6.1 Team Members

The Health Districts personnel at all levels will participate as the need arises. An appointed coordinator from the Regional Delegation of Health will liaise with the health districts and FJK Foundation.

6.2 Role of Health Districts

Each health district will assist in the dissemination of information to the community regarding when the FJK team will visit, facilitate a meeting and provide a "Sickle Cell Facility" for the team members to meet with participants. They will also assist in the collection and compilation of data on sickle cell in their district.

7 Collaborative Objectives of a Community-Targeted Sickle Cell Project

a. Bring sickle cell healthcare services closer to the community.
b. Work with District Health Personnel to develop and implement the necessary interventions.
c. Collect data on sickle cell cases in order to establish a sickle cell surveillance program.
d. Improve the quality of life of the affected persons and families through identified and implemented interventions.
e. Raise the level of awareness of the disease and educate the community on its management.

Figure 3: Focus Group at Akum Health District

f. Validate components of the Foundation's SCD care delivery model for regional implementation.

8 Methodology

Residents in the community health districts (page 17)had a chance to participate in meetings in which they expressed their views and concerns. Visits were scheduled (one per district) for all community district health centers in the Region between January 20 and March 31, 2014 from 8:30 AM to 4:00 PM. The typical agenda was as follows:

- Opening prayer with a scriptural reflection.
- Registration of clients (through the completion of a Mobile Clinic Registration Card, (page 16). The card was designed to collect demographic and some basic health indicator data. Parents or guidance, who could read, filled out the cards for their children with assistance where necessary. Those who could not read were assisted through a local interpreter.
- Health promotion lecture with focus on sickle cell management: recognizing and handling symptoms, what to do to prevent a crisis from occurring, nutrition counseling, coping strategies, maintaining a high self-esteem.
- Question and answer session.
- Refreshment and distribution of gifts to participants.

Health promotion brochures that included coping strategies and crises prevention measures, and prayer booklets were handed out. In some districts where patients were hospitalized, the team visited them in the hospitals and spoke to the parents and or health caretakers and gave them health promotion materials as well.

Additional information was collected from surveys, reports of past workshops organized in the Region and around the country (page Table 2: Workshops, Seminars and Conferences (Table 2: Workshops, Seminars and Conferences).

A total of 1,206 miles were covered. The operational cost, fuel, staff feeding, gifts and refreshments for patients was cfa 411,250 excluding personnel salary and cost of supplements. 382 pieces of educational materials were handed out.

Figure 4: Participants at Guzang Health District

9 Findings

Demographics:[2] Client demographics were 47.75% female and 51.25% male. Figure 5 shows the age distribution of the SCD population. The youngest and oldest registered patients were respectively one year and 31 years. The distribution is consistent with an earlier finding in data analyzed from FJK Foundation clinical records. The mean age of the population was 11 years. Household size ranged from one to nine children.

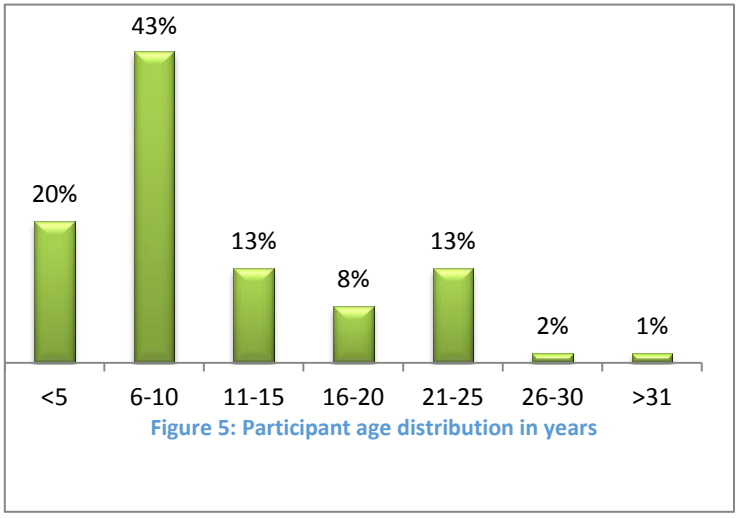

Figure 5: Participant age distribution in years

Communication: Texting via mobile phones is a common means of communication. We found that 86.25% of households had a functional mobile phone; 27.5% a second mobile phone or functional (SIM card) number on the same device. Only 13.75% of the households did not have a house or mobile phone.

SCD Testing: All 18 district health centers had a laboratory. Five (5) of those reported doing sickle cell disease testing though not on a routine basis. Lack of a steady supply of consumables, cost of the test, electrical outage, and malfunctioning machines were some of the reasons for the irregularities in testing. Some patients indicated they had to repeat a test because the first sample was bad due to electricity failure. Others indicated it took too long to get the results, so they never came back to check on them.

Health Education: People are very interested in learning about their welfare and the disease that affect them. In a survey of 370 secondary school students in Bamenda, Foundong, Bafut and Mbengwi health districts, 94% of the students showed an interest in learning about sickle cell disease. There is an expressed willingness to learn and try out new things that will improve their lives. Some who naturally did not like okro (okra) or black beans were willing to eat once they understood its nutritional value was of a medical benefit. One household, on a follow up had produced huckleberry "njamajama" juice[3] after attending a nutrition seminar.

[2] Cognizant of ethnic sensitivity, the distribution per district is not reported.

[3] The common method of preparing huckleberry vegetables: after boiling in water, the vegetables are squeezed, the water, the dark greenish water is through away and the sqeezed leaves are fried in oil and eaten with cocoyams or fufu. At the seminar particpats were told they were throwing away the nutrients in the water and eating the chaffs. Hence the Njamajama juice concept.

Data Collection: This is a serious challenge. Patients have health records with missing pages, illegible entries either from poor handwriting or faded out by water, smoke, grease from food, etc. Various dates (of birth especially) are missing and for the most part can only be estimated. Information, sometimes, is deliberately withheld especially if is suspected that it will not be of benefit to them. For example, reporting a high household income may not get them free service or medication.

There is no centralized record keeping (registry) to refer to in the event the card or hospital record is missing. The patient's "hospital book" is the sole record, kept and managed by the patient and to be taken to where ever they go. Each health institution issues its own "hospital book". Consequently, patients who have visited multiple institutions may have multiple books, especially if they show up in new institution without their hospital book from the previous institution that attended to them.

In General: There were 362 encounters in all. 33% of these were sickle cell persons. Others were family relations who had come out of curiosity to know more about the disease. A third category came to consult because they had heard "doctors" were coming to consult and offer treatment. They had wounds (fresh and old), rashes, insect bites, common cold, cough, fevers, stomach upsets, headaches, malnutrition were among the cases they presented. This category was disappointed that the team had nothing to offer to immediately address their needs. People suffering from sickle cell disease have other diseases that need to be taken care of. Participants were keen in getting information (including extra handouts) to take to those who were absent.

Canceled Visits: The scheduled meeting for Big Babanki was cancelled due to inclement weather. Bambili was canceled because of Youth Week activities in the region.

In Mambu, after the team arrived the Matron of the institution indicated she had forgotten to inform the population, despite confirmation to the team lead the previous day that the center was ready and the patients had been communicated. According to the team, she hastily excused herself to go to a meeting.

9.1 Burden of the Disease

All clients interviewed reported experiencing symptoms or complications in 2013 (Figure 6). "Crises" is a wide use term in the community when a sickle cell patient is in pain, which can be in any part of the body. In this report, crises, is used to describe those situations that lack specificity in the point of pain, like chest pain. None of them had more than one transfusion in the reported time. Some indicated they needed transfusion but were not fortunate to have a donor. Cost was prohibitive for others.

Fever was the most reported symptom. Patients could not pinpoint what type of medication they were using as remedies for their fever or pain other than "what the doctor gave". Some reported concurrent use, during a crisis, a combination of prescribed and traditional medications.

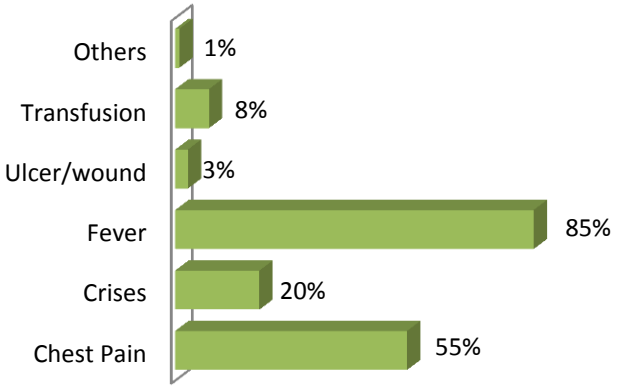

Figure 6: Reported symptoms and complications in 2013

33% of those experiencing complications did not go to the hospital or health center. Cited reasons were: lack of money to cover a previous unpaid bill and/or an anticipated medical bill; long distance to the health center or hospital; cost of transportation. The alternative in those circumstances: reliance on God; resort to self-administered or traditional doctor herbal treatment; share with somebody else's left over medication from a previous prescription. It is a common phenomenon that most patients do not complete their prescribed dosage. As soon as they experience a relief in the symptom, they stop taking the medication and save it for the future should the event re-occurs. Others will transfer to a family member or friend experiencing the same ailment.

89% (48 of 60) who went to the hospital in 2013 were admitted multiple times (Figure 7). Many should not be interpreted as greater than six (6). No confidence level can be associated with the number of times said to have been admitted as participants relied on memory and no hospital records to validate.

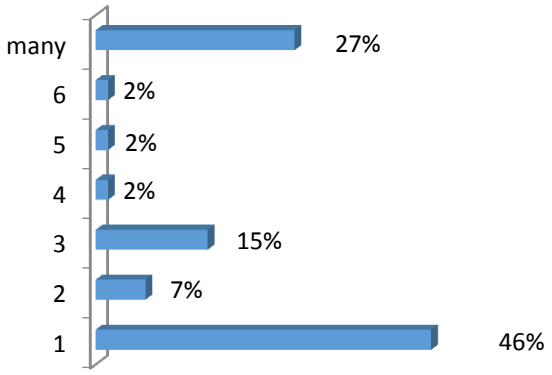

Figure 7: Number of hospital admissions in 2013

Participants did not indicate nor remember the length of stay in the hospital other than "it was many days". Cost of admission was from cfa 1,666 to 150,000 with a mean of cfa 53,295.

9.1.1 Family Deaths

Participants reported 18 deaths from sickle cell complications. It is not clear when the deaths occurred. Eight households each reported one death. Three households each reported 2 deaths in the family. One family reported 4 deaths in a family of six stating all deaths were sickle cell related. The exact ages at death were not reported.

9.1.2 Occupation and Household Income

Occupation ranged from teachers, farmers, "business" (type not specific) and unemployed. 80% reported they had a job. Of this number 17% did not specify the

type of job. Subsistence farming was the number one occupation reported, with no specifics to the type of crop cultivated. Some (5%) reported having two jobs. Combined monthly income from both jobs was under cfa 50,000 cfa.

Monthly household income ranged from cfa 1,000 to cfa 200,000. The mean reported income was cfa 21,377. The cost of a month's dose of supplement (cfa 15,000) is not affordable). For a family with two sicklers , this could be worse. 38.75% of the population did not reveal or report household income. There was some reluctance on the part of some to reveal income, most likely for fear they may not receive free service or supplements.

The minimum cost of a single admission was cfa 16, 667 and the maximum was cfa 350,000. Cost of hospitalization could not be normalized as the length of stay in the hospital was not reported. The problem is further compounded by the fact that some clients reported they did not have enough to eat.

9.1.3 Children Education

a. Children miss a lot of school because of frequent hospital admissions and teachers do not make a focused effort to help them catch up, so they often find themselves tagging behind their classmates.
b. Because their families believe the children with sickle cell will not live into adulthood they do not encourage them to study hard, nor do they invest in their education. Similar stories were told to hundreds of audience during the Bamenda International Sickle Cell Conference.
c. Ability to focus in school is diminished by poverty, further aggravated by the cost of frequent admission and medications, and not enough to eat.
d. Lack of specialist nurses and trained counsellors, special education teachers who can speak with these families and students face to face.

9.2 Patient Creed

Studies of sickle cell patients show a correlation between patient/family spirituality and life control. Spiritual wellbeing is important to the patients we encountered as observed from their full partipcation in the opening prayers and scriptural reflection. Figure 8 shows the religious breakdown of participants.

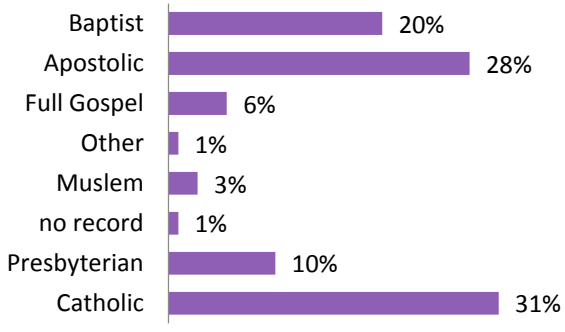

Figure 8: Patient Religious background distribution

10 Lessons Learnt

1. Sickle cell disease cannot be managed in isolation. Sickle cell patients also have other complications that need to be addressed as a package.
2. Community members in the search for health care services will approach any health delivery agent. Non sickle cell patients came because they knew a team of doctors was coming to address their health needs. Others came out of curiosity to learn.

3. Literacy is a big problem amongst children for various reasons. Top among them absenteeism. Due to frequent admissions children find themselves tagging behind classes. There is no focused effort on the part of the teachers to help them catch up.
4. Families believe that their children will not live into adult hood. As such, they do not encourage them to study, nor do they invest in their education.
5. Affected persons have self-confidence and do not see the disease as an obstacle to living a normal life and pursuing life's goals (section 11.1 below).
6. Children, especially, are routinely given carbonated drinks ("top" and coke). Water intake is minimal and should be highly encouraged. Some sickle cell teenagers and adults admitted drinking alcohol.
7. Routine childhood vaccinations that can help to avoid infections are absent.
8. Men, who feel their manhood or reputation threatened, have abandoned their wives and children because their child has a genetic disease.
9. FJK Foundation integration is a challenge: In the private sector the organization is viewed a threat that has come to "steal our patients". In the public sector some civil servants view integration as a secondary source of income and therefore expect a check from the Foundation. This was evident in the lack of interest showed in some of the districts where their leaders walked away from the team saying they were not aware of the scheduled meeting despite repeated confirmation calls even up to 24 hours to the event. It is not unusual for health providers (especially in the public sector) to ask for a per diem from the Foundation as prerequisite to attendance, when invited to participate in a workshop or seminar.

11 Community Voices

On June 13, 2013 Cameroon Sickle Cell Organization, Bamenda Regional Hospital and FJK Foundation, organized a seminar in Bamenda as part of the 2013 World Sickle Cell Day celebrations. 100 patients and families participated. Patients and parents were happy and expressed satisfaction that at last someone was beginning to listen to them. Notably were:

11.1 Exemplary Reactions

a) A 49 year old teacher, wife and mother who walked with a cane because of *avascular necrosis* of the femoral head (a common sickle cell complication) but she didn't let this slow her down!

b) Another teacher who is a sickle cell activist, teacher and radio presenter who passionately begged the participants to stop referring to their sickle cell status as a disease but see it as a disorder instead.

c) A young screen writer presented "On the Brim" a movie on Sickle Cell Disease, as a way to educate the public about the daily struggles of persons living with and managing the disease.

d) A 22 year old who was still in high school because frequent admissions had held her back defied the disease: "sickle cell is the least of my worries, I have so much to

look forward to". She had recently become engaged to her boyfriend who proposed to her whilst she lay in a hospital bed.

11.2 Suggestions

a) Health

i. Separate units in a hospital admission ward for sickle cell patients
ii. Nurses to be trained to know when a sickle cell patient is in a crisis and handle the situation. One parent noted with emphasis and demonstrated how a nurse once scolded her child who was in pain.
iii. Free or subsidized drugs
iv. A special (cheaper) blood bank for sickle cell patients
v. Urgent attention to be given to sickle cell patients when they are presented to a health facility during a crisis.

b) Schools

i. No corporal punishment, as a result of poor academic performance, should be administered to sickle cell patients who are struggling at school.
ii. No manual labour and excessive sports
iii. Sickle cell patients are allowed make-up test and extra tutoring.
iv. School should be informed about sickle cell crisis, teachers should know how to recognize it and notify parents
v. Classmates should be reprimanded for bulling or teasing sickle cell patients

c) Government

i. Encourage sickle cell patients by giving them free education
ii. Government to fund special training for doctors and nurses treating sickle cell patients.
iii. Government to subsidies drugs and supplements
iv. Smaller health units should be able to handle sickle cell patients, so that during a crisis treatment can be received promptly.
v. Regular media shows to educate the general public and improve the image of sickle cell.

12 Recommendations

12.1 Implement the Memorandum of Understanding

1. Socialize the Memorandum of Understanding (MOU) for health districts to understand its implication.
2. Set up an advisory council board to oversee the implementation of the MOU. The council will also define the monitoring mechanisms and evaluation matrices.
3. State Assistance is needed to develop a Regional comprehensive sickle cell program via the Community-Targeted Sickle Cell Project.

12.2 Integration and Service Provision

1. Hemoxide supplement is a proven promising effective therapy for controlling and preventing SCD episodes, but needs state subsidy due to its expensive nature.
2. Conduct a clinical evaluation of Hemoxide Supplement to quantify its efficacy and dosage. It is currently used per manufacturer's recommendation.
3. Integrate FJK and other sickle cell organizations into the existing structures of the public and private health care sectors. An area of immediate integration is the current vaccine program.
4. Train and equip the FJK Team as an agency of the vaccination team, to handle such identified cases they encounter.
5. Organize a Regional workshop on integration. Use the Memorandum of Understanding as the foundational document for the workshop.
6. Educate health care professionals (private and public sectors) on the efficacy integration of healthcare delivery services.
7. Expand the mobile clinic to include other general primary health care needs – that will draw from and utilize existing medical supplies in the Ministry of health.
8. Establish a mutual referral program – identified persons with SCD or trait by the vaccination team are referred to the FJK Team, and persons who are not current on the vaccines identified by FJK team are referred to the vaccination team.

12.3 Public Health Education and Campaign

1. Hire a full time SCD Educational Outreach Coordinator with a Delegation of Health Mandate to help districts
2. Employ and train specialist nurses, counsellors, social workers who can speak face to face with affected persons and families especially in support groups.
3. Design awareness and educational messages to utilize SMS messaging reliability. Almost every household has a mobile phone.
4. Engage with Mobile phone companies as partners in the public education campaign in to disseminate some of these messages on periodic basis.
5. State media (television, radio, newspaper, etc.) should not charge for running public service spots about sickle cell and health education in general. At the moment it is a fee for service even for free public health promotion events.
6. Targeted health education programs and courses, especially in Secondary and High Schools should be encouraged. This could be beneficial to increasing the knowledge level of the disease. Such education is vital for the young population given that in a previous data analysis over 75% of registered patients in the Foundation's clinic affected by the disease were between 13 and 15 years.
7. Develop manuals about care, management and support of the affected person
8. Develop and distribute educational materials that include: facts sheets with general information for educators, parents, healthcare providers, frequently asked questions.

12.4 Focus Groups

1. Develop a men's focused support program whose goal is to elevate them as community heroes (and among their peers) for supporting their child and family as they maze through this genetic disease.
2. There needs to be a special education track developed for children with sickle cell disease who miss out on classes. For the most part educators cannot recognize and do not know how to handle children with sickle cell disease in the class room.

12.5 Partnerships and collaborations

3. SCD is a community disease. It is everyone's disease and requires the attention of everyone. Any scale of partnership and or collaboration makes a difference.
4. Ministry of Health is already a partner but could bring other ministerial partners, e.g., Social Welfare, Women Affairs, Youth, Education, Sports.
5. Established partnerships/collaborations with cultural and social clubs, community and faith-based organizations, media, and local business, Mayors and Councils.

12.6 Capacity Building

1. Support for the FJK Foundation initiatives in project development, capacity building.
2. Utilize FJK Foundation as the SCD Lead and program anchor for the region.
3. Train professional in the area of sickle cell disease
4. Expand the current Radio program and syndicate the content for distributions to other stations.

12.7 Information Exchange

1. There is no data system to collect, store and analyze SCD data in order to understand the impact of the disease.
2. Create regional comprehensive sickle cell registry that will collect the appropriate information required for determining the prevalence of the disease, identify risk factors for complications, a better understanding of the burden of the disease, those who need and are (not) receiving care, and ultimately for managing the disease.
3. Identify those with SCD and bring them into the registry, collect health outcomes and health impact of living with SCD over the course of life.
4. Develop a Sickle Cell Screening program include newborns, pregnant women, prenuptials and implement in all health districts. Countries with SCD prevalence that have implemented screen programs especially for newborns have characterized the program as one of the most successful and health promotion and disease prevention systems.
5. Mandatory reporting into a regional sickle cell regional by those institutions that currently do sickle cell disease testing.be included in the registry.

13 Appendix

Table 1: Registration Card

FJK Dove Mobile Clinic Registration Card ~ District:				Date:
Family Name	**First**	**Middle**	**Sex**	**Religion**
Date of Birth (dd/mm/yyyy)	**Place of Birth**	**No of Siblings**	**With SS**	**Any Died w/SS**
			1	Yes: if yes, how old?
				No
Address	**City/Town**	**Division**		
			Complications in 2013, check all that apply	
email	**Phone 1**	**Phone 2**		crises:
				ulcers
				chest:
Parent Occupation	**Income/Month**			blood transfussion
				fever:

No of crises in 2013	**Did you go to the hospital**	**Admitted in hospital**	**cost**
	Yes	Yes:	
	No	**No**	

Table 2: Workshops, Seminars and Conferences

Date	Topic	Location	Organizer
June 13, 2013	Seminar and Workshop	Ayaba Hotel, Bamenda	Cameroon Sickle Cell Association, Bamenda Regional Hospital, FJK Foundation
July 14, 2012	Light In Darkness Seminar	Limbe	FJK Foundation
July 12, 2012	Light In Darkness Seminar	Sts Peter and Paul Cathedral Hall, Douala	FJK Foundation
July 6, 2012	Light In Darkness Seminar	John XXIII Pastoral Center, Yaoundé	FJK Foundation
June 28, 2012	Light In Darkness Seminar	Conference Hall, Bamenda Regional Hospital	FJK Foundation and Regional Delegation of Public Health
August 4-6, 2011	First International Sickle Cell Conference	CATUC Auditorium, Bamenda	FJK Foundation and Catholic University of Cameroon, CATUC
October 4, 2010	Workshop on Sickle Cell Sensitization Year in NWR	St Therese Parish, Small Mankon, Bamenda	FJK Foundation
March 2, 2009	Workshop, Opening of Sickle	St Therese, Small Mankon Bamenda	FJK Foundation

Table 3: Regional Health Districts

Visit Date	Health District
20-Jan-14	Bafanji
24-Jan-14	Akum
29-Jan-14	Fundong (Urban)
31-Jan-14	Alateneng
3-Feb-14	Wum (Urban)
6-Feb-14	Bafut (Manji)
10-Feb-14	Bambili
14-Feb-14	Batibo (Guzang)
24-Feb-14	Mbengwi (Urban)
27-Feb-14	Kumbo (East and West)

Visit Date	Health District
3-Mar-14	Big Babanki
7-Mar-14	Santa (Urban)
10-Mar-14	Pinyin
14-Mar-14	Mambu
17-Mar-14	Ndop (Urban)
20-Mar-14	Njinikom
24-Mar-14	Balikumbat
27-Mar-14	Nkambe (Urban)
28-Mar-14	Ndu (Urban)
31-Mar-14	Bali