REPORT ON THE DATA COLLECTED BY SCCAN IN THE SCOOPING SURVEY/SCREENING FOR SICKLE-CELL

Introduction:

My name is Sia Evelyn Nyandemo the founder of Sickle Cell Carers Awareness Network commonly known as **(SCCAN**.)

The Sickle Cell Carers Awareness Network **(SCCAN)** is a charitable organisation currently helping carers of children and adults suffering from Sickle Cell Anaemia. This was in response to the need for communication, awareness raising and support for sickle cell sufferers and carers. The project started in January 2008 in Jaiama Nimikor in the Kono District of Sierra Leone with the aim of raising awareness about sickle cell anaemia, how to treat it, its prevention as well as providing practical support and care to people who care for sufferers (carers). The aim is to extend our services throughout Sierra Leone and the Mano River Basin in the not too distant future.

My passion to set up Sickle cell carers awareness network **(SCCAN**) was born out of the loss of our two lovely children Tennema and Miatta, they both died at the tender age of 5 back in our little village called Jaiama Nimikor in the eastern part of Sierra Leone.

Having lived in England with our other daughter who is a sufferer and seen all the facilities and care that is available for sufferers, it gave me the inspiration to set up something that will benefit sufferers in Sierra Leone especially in Kono where sickle cell is seen as the work of witchcraft or bad omen. I wanted to give them hope and to let them believe that there is light at the end of the tunnel for sufferers. With awareness and proper management sickle cell suffers can live life to the maximum.

I have carried this vision with me for almost 30 years. I say this- "when our children died, I could not bury them; they were buried in my heart" and because they stayed in my heart, it was difficult to let go. My husband, our children and myself decided in January 2008 to finally lay them to rest by setting up Sickle cell carers awareness network what we call for short **SCCAN** to bring awareness about this dreadful disease called sickle cell anaemia to the whole of Sierra Leone and beyond.

Our surviving daughter who is so lucky to beat all the odds in Africa, considering the lack of facilities and the know how to deal with sickle cell anaemia. Caring for our daughter for all these years on a daily basis, also going in and out of hospitals, working with professionals and researching more about the disease has made me come to the realisation that it is about time we put all that caring knowledge into action by educating other carers and sufferers that have no knowledge of how to manage or deal with the problem called "**SICKLE CELL DISORDER**".
Since it's inception in 2008 sickle cell awareness network (**SCCAN**) has undertaken a number of projects in service delivery to the Kono District **SCCAN** has been providing medication – penicillin, folic acid and pain killers to sufferers and carers accessing our services. In addition, awareness campaigns have been undertaken to educate, sufferers, carers, students, teachers as to how to prevent and manage this deadly disease.

ACHIEVEMENTS:

We have been able to achieve so much in a very short space of time.

- School children who were absent from school for most of the year can now boast of good attendance record
- A lot of people are now aware of the disease

- One of our sickle cell patients had a successful delivery in Kono where mother and baby are doing fine.
- Screening for ante-natal mothers is now in progress in Kono –
- We were able to undertake a capacity and monitoring trip to Sierra Leone, the benefits were awesome.
- We met with the President of Sierra Leone Dr Ernest Bai - Koroma and the outcome is promising.

Recent awareness campaign undertaken by **SCCAN** commenced from, the 28th of August 2010 to the 4th of September covering five chiefdoms in the Kono District. This was done in collaboration with the Kono Student Union (**Konsu**). During this campaign **SCCAN** was able to reach key stake holders in the communities like Paramount Chiefs, politicians, Carers and sufferers. Various methods of reaching the people were employed like street meetings, megaphone P.A systems and town hall meetings. At these meetings leaflets and booklets were distributed including water. Which we encourage sufferers to drink adequately.

Key challenges:

1. We found out from the areas visited during the last campaign that there is an urgent need for us to partner with the various Primary Health Centers (**PHC**) and equip them to be able to handle the large influx of patients which could not come to Koidu because of transportation.

2. We reckon from the survey and data collected that in the areas visited, there is an estimated total of 500 sufferers.

3. There is a need for a constant supply of drugs to the health centers for patients

4. Empower the mobility of field workers by way of motor bikes, stipend and computers.

5. Capacity building for the field workers (qualified staff are to expensive maintain because of lack of finance) reporting needs a lot of training)

6. Urgent need for an Electrophoresis machine.

7. A well equipped 5-6 bedded respite centre

Our aim is to leave Sierra Leone better than we found it.

This is our message to you our brothers and sisters. We will encourage you to visit our website www.sccan.org.uk

The executive Summary

Report on Sickle Cell Awareness Network (SCCAN) Mobile Clinic Exercise in the Jaiama Nimikoro Chiefdom – Monday 18th to Friday 29th July, 2011

The Chief Executive Officer(CEO) and Founder of SCCAN Mrs. Sia Evelyn Nyandemo arrived in Sierra Leone from London United Kingdom on 26th June, 2011. The early arrival was to allow ample time to liaise with government officials and other organizations about the above exercise to be undertaken. This mobile clinic was organized with the help of Dr Charles Senessie of the Afro European Medical Research Network (AEMRN) who was supposed to lead with Sia Nyandemo during this exercise.

The first point of contact was H E His Excellency, Dr Ernest Bai Koroma who summoned a meeting with the Minister of Health, Mrs. Zeinab Bangura during which she was requested to assist SCCAN and the CEO by supporting this venture by sign posting SCCAN to donors. After Presenting her case, the CEO was handed over to the Ministry of Health by the President to work together to achieve the aims and objectives of the Mobile Clinic. Dr. Yaya Conteh of the Ministry of Health was appointed by the Minister of Health to assist and direct me to various donors for assistance with my work.

The aim of the mobile clinic in the Kono District is not only to bring awareness to the people of Kono, especially Jaiama Nimikoro about the how to detect Sickle Cell and also how to manage it but to introduce awareness of this disease to the whole world so that it can be included in the Millennium Development Goal for discussion at the next conference in 2015. SCCAN is aiming to assess the prevalence of Sickle Cell in general in the community and also warn them about the dangers of neglecting patients or confusing sickle cell with Malaria. Even though, SCCAN did not cover the whole of Kono for this exercise, the Kono people accessed information through radio transmissions and leaflets. The need to cover the whole of Kono and the Nation is the primary aim of SCCAN and with government, World Vision and other donor's backing, this is possible.

Mrs. Nyandemo also contacted the School of Nursing and the Medical school in order to bring volunteers along to work with the SCCAN National volunteers to form the mobile team for the exercise. Sia contacted World Vision, and was also in constant touch with AEMRN.

On Sunday 10th of July, 2011, Mrs. Agnes Kumba Dugba Macauley, one of the Trustees arrived in Sierra Leone to assist Sia with the numerous tasks and organizing relating to the Mobile Clinic. On Thursday 14th July, 2011, Dr. Tom Kollars arrived in Sierra Leone from the United States of America to support the cause. Dr Kollars later informed the Sia, Agnes at a meeting on Friday 16th July, with the Nursing Students and medical students that Dr Charles Senessie was not able to make the trip to Sierra Leone and that he, Dr. Kollars came in his stead. Dr Kollars was in the company of Mr. Tamba Abu, Community Health Officer and the National Liaison officer for AEMRN.

On Sunday, 17th July, 2011 we set out in a convoy of three vehicles heading for Kono, Jaiama Nimikoro. World Vision having seen SCCAN proposal was attracted by the presentation and vision of the CEO. World Vision therefore donated two vehicles to take the team to Kono. Dr Kollars traveled to Jaiama with Mr. Tamba Abu.

The first stop was Makeni to collect some medicines (Penicillin and Folic Acid etc) from Doctor Patrick Turay who lost his brother to sickle-cell at the Holy Spirit Hospital.

The convoy arrived at Jaiama Nimikoro at about 6pm on Sunday 17th July, 2011. The team was greeted with enthusiasm by the Chiefs and the people of Jaiama. Prior to the trip the Kono Radio has been briefing people about the mobile clinic. In short, everyone was expectant and in readiness to access the mobile clinic.

On Monday 18th July, 2011, SCCAN and team had its first meeting with the Speaker, Town and Section Chiefs to brief them about the mission at hand. The meeting commenced with Christian and Muslim prayers. The meeting was chaired by Agnes K D Macauley. Introductions were made and the CEO briefly explained how the mobile clinic will work and on which dates the visits will take place to each town or village. That The CEO enlisted the agenda thus: Jaiama Town, Tuesday 19th, Wednesday 20th and Thursday 21st July. Bumpeh and Senjekor, Friday 22nd and Saturday 23rd July. Sunday 24th July was chosen as a day to rest. Monday 25th Seidu town and Tuesday 26th Seidu Town and Njagbwema and Wednesday 27th Njagbwema because of the demand. While Thursday 28th and Friday 29th were allocated to Bandafafeh, Yengema town.

Prior to the start of the programme, the team met and divided themselves into 2 groups – group 1 and group 2. The teams further divided themselves into sub-groups as follows:

a) **The organizing Group**: responsible to making people stand in a queue.

b) **Registration team**: responsible to taking details of all those who wanted to be screened for the Sickling Traits.

c) **Blood sample group**: responsible for pricking the thumb in order to have the blood on the slides for testing.

d) **Lab Team**: responsible for checking for the sickling traits under the microscope.

e) **The Result and Counseling Team**: responsible for reading of results to attendees. This group dispatched the people without the traits (negatives) and then counseled those with the traits about how to manage the illness and to make informed choices when planning to have children. They were also responsible to inform all the positives that being positive did not mean that they are ill as this was only a test for the traits and not the disease. The were told that only the Electrophoresis machine can give detailed information about whether people had the actual disease. Those that showed evidence of having the disease were advised to follow the 10 vital points about to manage their lives in order to avoid crisis.

f) **The Medication Team:** Those who were actually visually identified as being seriously affected were given medication: Folic Acid and Penicillin tablets to be taken once a day with some vitamins. That these set of people should take the above medicines on daily basis. They were also advised to take malaria tablets in order to prevent a more serious case.

g) **Other Services:** In most of these towns and villages; very serious cases were identified for sickle cell patients who were referred to Jaiama hospital to be referred to the main Koidu Hospital. One particular sickle Cell Child was so neglected that one could only see her bones. It was found out that her parents called her a "witch" and left her to die. She is currently in the care of World Vision who is assisting with her treatment. Similar less serious cases were also directed to Hospital for admission.

On the whole, this exercise opened the eyes of SCCAN and World Vision to work together as Malaria and Sickle Cell Anemia have similar symptoms. On this premise, World Vision has seen the need to work with SCCAN to eradicate or reduce child and community mortality. The age group targeted for this exercises was from 6 months to 50 years old. The age cut off was explained to older people who came for testing as not necessary, especially when they looked well with minor complaints of aches and pains. They were told to continue with pain killers and also to look after themselves in

counseling. Most were satisfied with the explanations. Those who really looked unwell with pains and aches were given some medication and advised accordingly to seek medical advice.

World Vision Contributions: has been there throughout the exercise and without them, SCCAN would have had challenges which could have derailed the planned activity. The Head Office Freetown in collaboration with the WORLD VISION-S/L Nimikor APD team provided transport to convey the team from Freetown to Jaiama and back. World Vision continued to provide vehicles, office space, computers and staff to assist SCCAN all the way. The United Methodist Church Mission Hospital staff also was invaluable contributors. Their vehicle was also at our disposal and WORLD VISION fueled any such vehicles that were used for SCCAN work from start 18th to 29th July, 2011. The financial support for the exercise also came from WORLD VISION SIERRA LEONE (NIMIKORO APD)

SCCAN Responsibilities to Volunteers: All volunteers; forty four (44) people were catered for by SCCAN as follows: accommodation, feeding, transport and other logistics like purchase of medicines for some who were affected by malaria and those with special needs like buying of phone chargers, units for use of their phones and various assistance according to individual needs.

Overall, SCCAN is very pleased with the performance of the team who soon learned to master their allocated team activities. SCCAN appreciates them and would put them first should there be any vacancies in future where SCCAN wished to employ people on permanent basis. SCCAN also reiterated that should they have further exercises like the just ended one (Mobile Clinic), this group will be the first point of contact.

The group spent fifteen (15) days in Kono and World Vision crowned it all by funding the proposal to fund the event to the tune of Le6,600,000 (six million six hundred thousand Leones). This was divided amongst the volunteers as a token of Thanks for their kind assistance. This being the first big exercise undertaken by SCCAN, obviously, there would be lapses but the CEO and SCCAN team have learned a lot from the challenges they faced and hope to do things better the next time round….this is only the beginning.

SCCAN takes this opportunity to thank the Following Donors and Partners:

- Mrs. Rukiatu Kamara and Co. who donated four thousand pounds sterling equivalent to $5,000 (five thousand US dollars) equivalent to Le27,000.000 (twenty seven million Leones)

- Dr Kai Ngegba, Pastor Samura, Mrs. Bondu Saffa and co, Kono District Development Association (KDDA), Mr. and Mrs. Simpson whose contributions totaled three hundred and seventy pounds sterling (370).

- Dr Charles Senessie of AEMRN - $500 dollars; equivalent to Le2, 000.000 (two million Leones).

- H E Sahr Yambasu, Ambassador of the Republic of Sierra Leone to Russia. He donated $500 (five hundred U S dollars) which is equivalent to Le2, 000.000 (two million Leones).

SCANN has special thanks for His Excellency Dr. Ernest Bai Koroma, for the opportunity accorded them to meet him in person despite his heavy engagement and tight schedule.

Dr Yaya Conteh of the Ministry of Health should not be left out in this acknowledgement. Dr Conteh made recommendations and signposted SCCAN to World Vision and the Sierra Leone Broadcasting Corporaton (SLBC). Many thanks also to the Eastern Radio FM 96.5 and the Sierra Leone Broadcasting Corporation teams for their part in disseminating information to the nation.

SCCAN extends Very Many thanks to the Jaiama Nimikor Paramount chief, P C Aiah Denton Bona, the Very Disciplined and Professional Speaker, Sahr Matturi and all town and section chiefs for their embrace and hospitality extended to us. Thanks to the World Vision staff in Freetown and Jaiama ADP, Kono District; the community and all those whom we could not name. All your efforts were very much appreciated. This exercise left an imprint on the minds of the SCCAN team and we hope those, we touched will live to tell the story.

Many thanks to all those who made anonymous financial contributions, in time, their expertise and otherwise to make this exercise viable not forgetting our catering team, without whom, we would not have been energized to continue our work.

Attached is the methodology and the process used to carry out the exercise and Developed countries to invest in finding a cure for Sickle Cell. Sickle Cell should be included in the Millennium Development Goal.

THE SCREENING EXCERCISE

With this Screening clinic SCCAN has moved from high hopes to great expectations-and to the realization that a uniquely productive relationship was proving possible between us and development partners.

"The Screening clinic shows what happens when two organizations – WV-S/L (NIMIKOR ADP) and SCCAN- work together. " The screening exercise is a story of cooperation, mutual understanding and impressive accomplishments that result from partnership.

It is our hope that the WV-S/L (NIMIKOR ADP) will in their annual report capture the SCCAN partnership in a special section to be referred to as "REPORT FORM THE FIELD-ALONG THE LINE OF LIFE" which will lead to strengthening later SCCAN-WV partnership to support us to stand on our own but with WV as the main pillar. The Screening clinic comes in when the world's attention is focused on HIV/AIDS and Malaria forgetting about Sickle-Cell anemia; another blood disease with no cure as it is hereditary. No body seems to think of Sickle-Cell anaemia.

In retrospect, it is remarkable that SCCAN has taken a bold step and has laid a foundation so sound at this stage.

The results of the scoping survey, uncovers the issue of Sickle-Cell to the rest of the world and development actors. This will make everyone aware of the disease and appreciate its status.

Below is the data collected for the exercise.

SICKLE-CELL CARERS AWARENESS NETWORK

MEDICAL CAMP AND CLINIC IN NIMIKORO CHIEFDOM (17TH TO 30TH JULY 2011

WITH SUPPORT FROM WORLD VISION SIERRA LEONE (NIMIKORO APD)

	JAIAMA SECTION	MANSAYIFEH SECTION	BAFINFEH SECTION	GBOGBORAHFEH SECTION	BANDAFAFEH SECTION	TOTALS
PARAMETRS	(19TH-23RD JULY 2011)	(22ND & 23RD JULY 2011	(25TH & 26TH JULY 2011)	(26TH JULY 2011)	(28TH & 29TH JULY 2011)	(19TH - 29TH JULY 2011)
TOTAL SCREENED	**1223**	**273**	**559**	**563**	**576**	3194
TOTAL +VE	**214**	**46**	**120**	**107**	**145**	632
% POSITIVE	**17.50**	**16.85**	**21.47**	**19.01**	**25.17**	19.79
POSITIVE CLIENTS THAT RETURNED FOR COUNSELING	141	36	106	97	135	515
%THAT RETURNED FOR COUNSELING	65.89	78.26	88.33	90.65	93.10	81.49
(FEMALE+VE) COUNSELED	69	15	51	61	70	266
(MALE+VE) COUNSELED	72	21	55	37	66	251

This scooping survey was carried out in the filed: i.e. blood sample collected from the client and examined under a binocular compound microscope on-the-spot.

On Thursday 4th August, 2011, a cross section of the SCCAN Team in company of the CEO Mrs Sia Evelyn Nyandemo went to Bo on the invitation of World Vision Action ADP Manager, Bo town Mr Ambrose Fomba. On Friday 5th August, the team met with some members of staff of World Vision including Mr Fomba, a representative from the Ministry of Health, and a representative from SLBC. SCCAN facilitator, Mrs Sia Nyandemo introduced the SCCAN organization and why and how it came about. World Vision also gave a brief of what they do and emphasized on the need to work with SCCAN as they shared a common goal of working with families to eradicate the spread of malaria and for the general wellbeing of children. Plans were discussed on sentisizing the people of Jimmi Gbagbo the following day which was Saturday 6th August.

The following day, the SCCAN team in company of the world vision team, SLBC rep. and also Mr Massaquoi the Ministry of Health rep visited Jimmi Gbagbo and Lugbu. At the world vision conference in Jimmi Gbagbo, after introductions, Mrs Sia Nyandemo, CEO for SCCAN gave a background of why and how the organization came about. The people of Jimmy Gbagbo and Lugbu were very enthusiastic to know about Sickle Cell Disease and how it is contracted. After the presentation, questions were asked and answers given by SCCAN and world vision staff. What has been proven so far is that Sickle Cell and Malaria symptoms are

very similar and if the two organizations work in unison, there is no doubt that children will be saved from these two deadly diseases.

Looking at the wider picture, SCCAN plans to establish a national secretarial and a well equipped laboratory for further screening. A medical centre will also be established to support follow up activities and attention to positive clients. The laboratory will create a mobile unit that will travel to population centers for Free Screening. A three to four year strategy paper and proposal will be designed for the attention of all development actors and partners for assistance. This will be part of this report. There is urgent need for everyone to support sickle-cell activities; an initiative designed by the Chief Executive Officer of SCCAN, supporters and partners.

Clients that prove to be living with the condition are required to make follow up screening every six months to establish their HB count and receive further counseling to avoid complications. However, where complications set in, clients are referred to the hospital for special care and attention.

Children in schools miss classes when they fall ill. SCCAN will organize remedial classes in the education programme for pupils to cover the classes they miss. Also camping session would be an activity in the programme. This will give assistance to parents when the children would be collected for some time and taken to counseling clinics for at least one week. The motive is for careers and parents to have a break from the tedious caring role for clients. This will also give the clients time to socialize with others thus improving their dignity and building their confidence. This will be with a bid to improve the longevity of clients beyond the mythical age of 21 years.

METHODOLOGY

PERSONNEL

The methodology of carrying out the scooping survey was to set up a medical camp, engage a team of medical students, experienced nurses and technical support staff, train them and undertake the screening exercise. A large team was set up to be able to complete the work within the short time frame available. All the personnel that participated in the survey came on board as volunteers. Only very small living expenses were paid directly in cash. Food, lodging, medication and transport fare was paid by SCCAN. For this gesture the entire SCCAN team appreciated their effort in working for humanity.

LOCATION

Since the support came from WORLD VISION SIREEA LEONE (NIMIKORO ADP), and the first pilot survey ever undertaken was carried out by SCCAN in Jaiama the chiefdom head quarter town of Nimikor, it was but sound to come back with an expanded survey to the same location. This time around, the survey was carried out in the five sections of Jaiama, Mansayifeh, Bandafafeh, Gbogborafeh and Bafinfeh in the chiefdom. Also the WV – S/L (Nimikoro ADP) operates in this same location. The time and financial resources could not allow us to go beyond what we did.

THE SCREENING FOR (HBS) SICKLE HAEMOGLOBIN
The principle;
Unger low O2 tension the sickle Hb assumes the shape of a sickle due to tactoid formation. Using a reducing agent such as Sodium Meta bi Sulphite (NaS_2O_5), drop of blood from the client is mixed with two drops of 3% NaS_2O_5, on a microscopic slide, covered with a cover glass of $2mm^2$. This "wet preparation" is allowed to seat on a flat surface for 30 minutes. The specimen is then examined under the 40mm lens of a microscope.

ANALYSIS OF THE RESULTS

From the data collected, 3194 clients were screened in ten days. Further analysis shows the following:

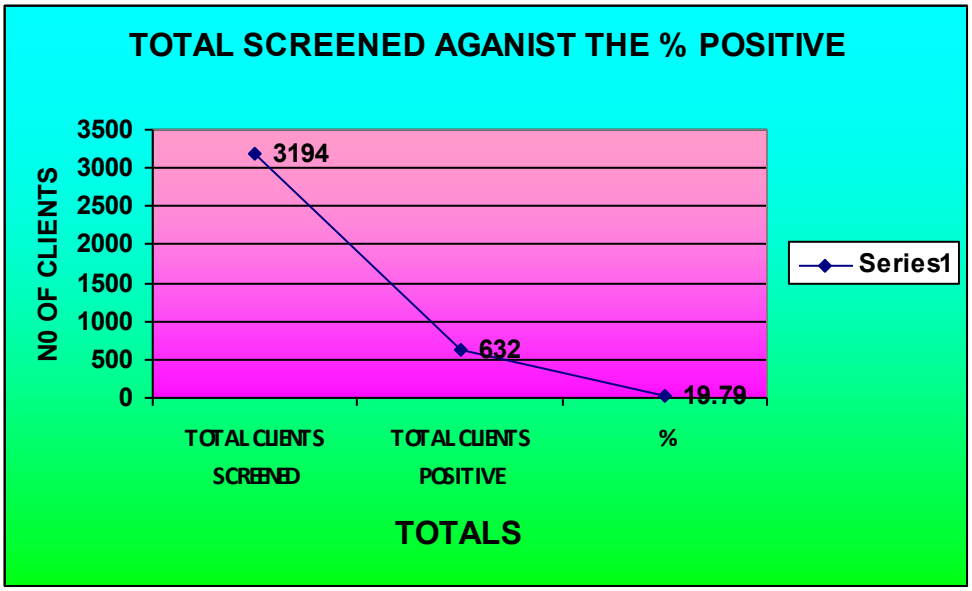
SICKLE-CELL CARERS AWARENESS NETWORK
MEDICAL CAMP AND CLINIC IN NIMIKORO CHIEFDOM (17TH TO 30TH JULY 2011
WITH SUPPORT FROM WORLD VISION SIERRA LEONE (NIMIKORO APD)

	JAIAMA SECTION	MANSAYIFEH SECTION	BAFINFEH SECTION	GBOGBORAHFEH SECTION	BANDAFAFEH SECTION	TOTALS
PARAMETRS	(19TH-23RD JULY 2011)	(22ND & 23RD JULY 2011	(25TH & 26TH JULY 2011)	(26TH JULY 2011)	(28TH & 29TH JULY 2011)	(19TH - 29TH JULY 2011)
TOTAL SCREENED	**1223**	**273**	**559**	**563**	**576**	3194
TOTAL +VE	**214**	**46**	**120**	**107**	**145**	632
% POSITIVE	**17.50**	**16.85**	**21.47**	**19.01**	**25.17**	19.79
POSITIVE CLIENTS THAT RETURNED FOR COUNSELING	141	36	106	97	135	515
%THAT RETURNED FOR COUNSELING	65.89	78.26	88.33	90.65	93.10	81.49
(FEMALE+VE) COUNSELED	69	15	51	61	70	266
(MALE+VE) COUNSELED	72	21	55	37	66	251

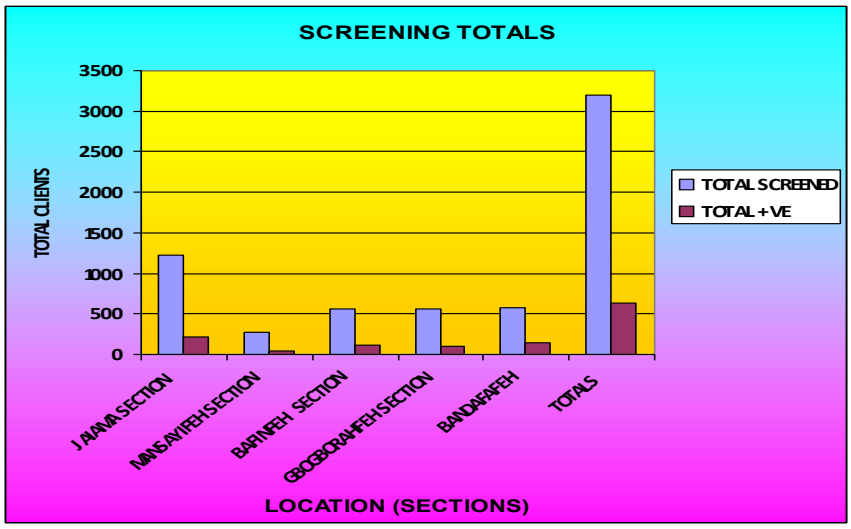
The above table shows that of the 3194 clients screened, 19.79% tested positive for the 'S' Hb. Further analysis using the electrophoresis machine is required. However, in the absence of the equipment SCCAN made use of the available to achieve the above results.

2. TOTAL CLIENTS SCREENED AGAINST THE PERCENTAGE POSITIVE

TOTAL CLIENTS SCREENED	TOTAL CLIENTS POSITIVE	% Positive
3194	632	19.79



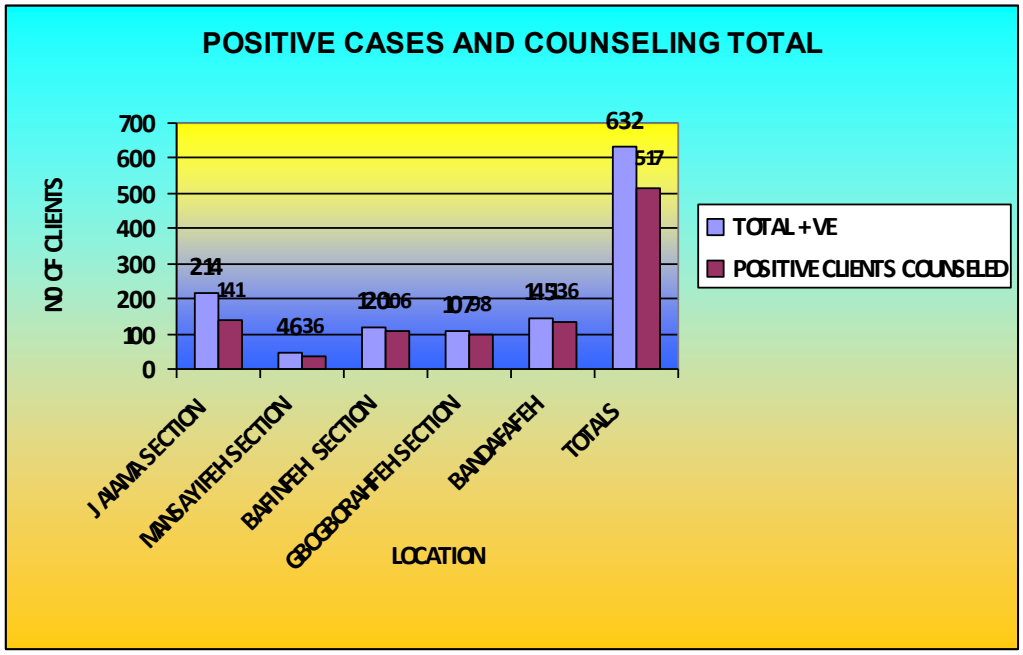
LOCATION	TOTAL SCREENED	TOTAL +VE
JAJAMA SECTION	1223	214
MADIYATA SECTION	273	46
KAJIJIKA SECTION	559	120
GROGRAMA SECTION	563	107
BANDAKA	576	145
TOTALS	**3194**	**632**



COUNSELING AND TREATMENT SESSIONS

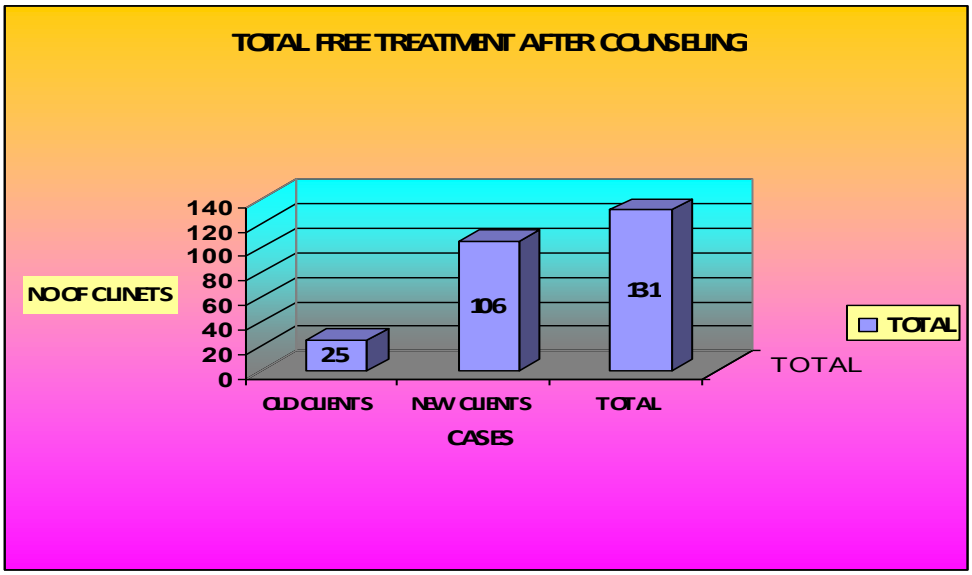
All positive clients were further screened using an observation approach to differentiate the needy clients for treatment and /or counseling. Though the screening was done on the spot, some positive clients were not available for the exercise. This required the team to change the method of releasing the results the next day so the more positive clients could be interviewed. Counseled and treated. There were some clients that really showed signs of sickle-cell aneamia.

	TOTAL +VE	POSITIVE CLIENTS COUNSELED
JAJAMA SECTION	214	141
MANGAYIREH SECTION	46	36
BARNFEH SECTION	120	106
GBOSBORAHFEH SECTION	107	98
BANDAFAFEH	145	136
TOTALS	632	517



FREE TREATMENT AFTER COUNSELING

	OLD CLIENTS	NEW CLIENTS	TOTAL
TOTAL	25	106	131

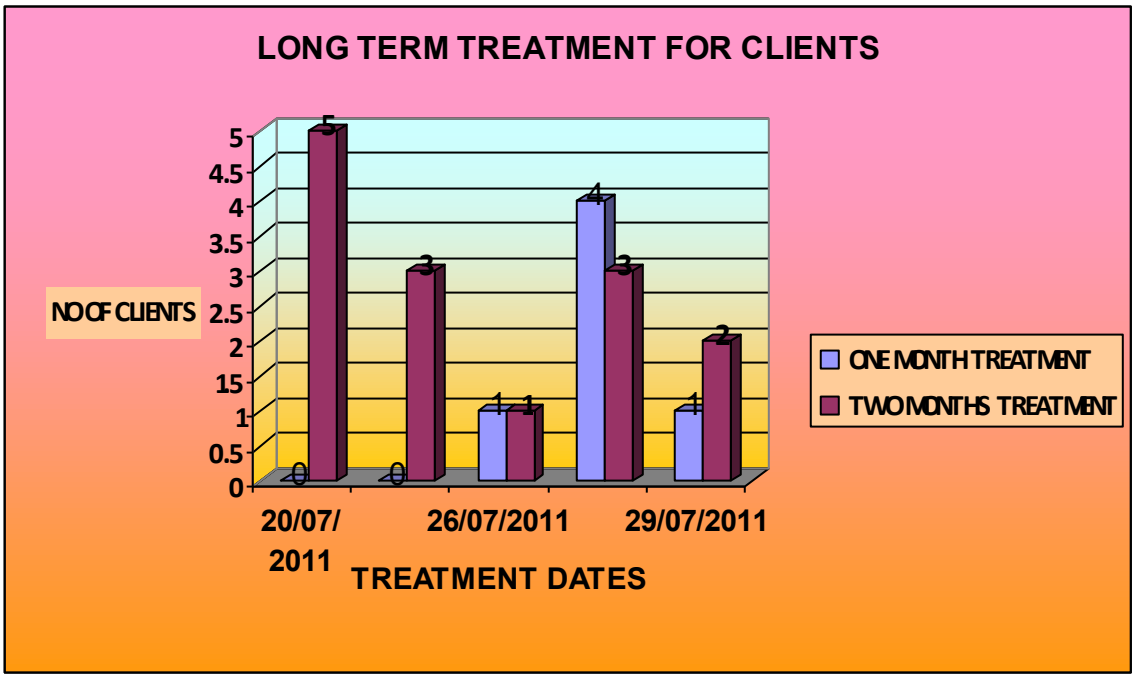


SCCAN had undertaken a small screening exercise three years ago. The sufferers screened were on treatment ever since purely with SCCAN resources through fund raising activities. During this clinic, some turned up and those in need of medication were treated free along side the new cases. Serious conditions observed by the experienced nurses that came to the medical camp to assist were able to refer such serious cases to the Koidu Government Hospital. The counseling sessions were good but some of the clients required treatment. "Technical leaflets" were printed and distributed to the clients as daily reference material for crisis management any time there is an attack.

Treatment was administered to only very 'needy' clients and the drug supply was limited. Other positive clients that looked apparently healthy and fairly good looking were counseled and sent home with the leaflet.

FREE TREATMENTAFTER COUNSELING			
DATE, SECTION & CENTER	OLD CLIENTS TREATED	NEW CLIENTS TREATED	TOTAL
19TH -22ND JULY JAIAMA, JAIAMA& BUMPEH	21	27	48
22ND-23RD JULY MANSAYIFEH SENJEKORO	2	5	7
25TH-26TH JULY BAFINFEH SEIDU	1	21	22
26TH-27TH GBOGBORAHFEH NJAGBWEMA	1	15	16
28TH-29TH BANDAFAFEH YENGEMA	0	38	38
TOTAL	25	106	131

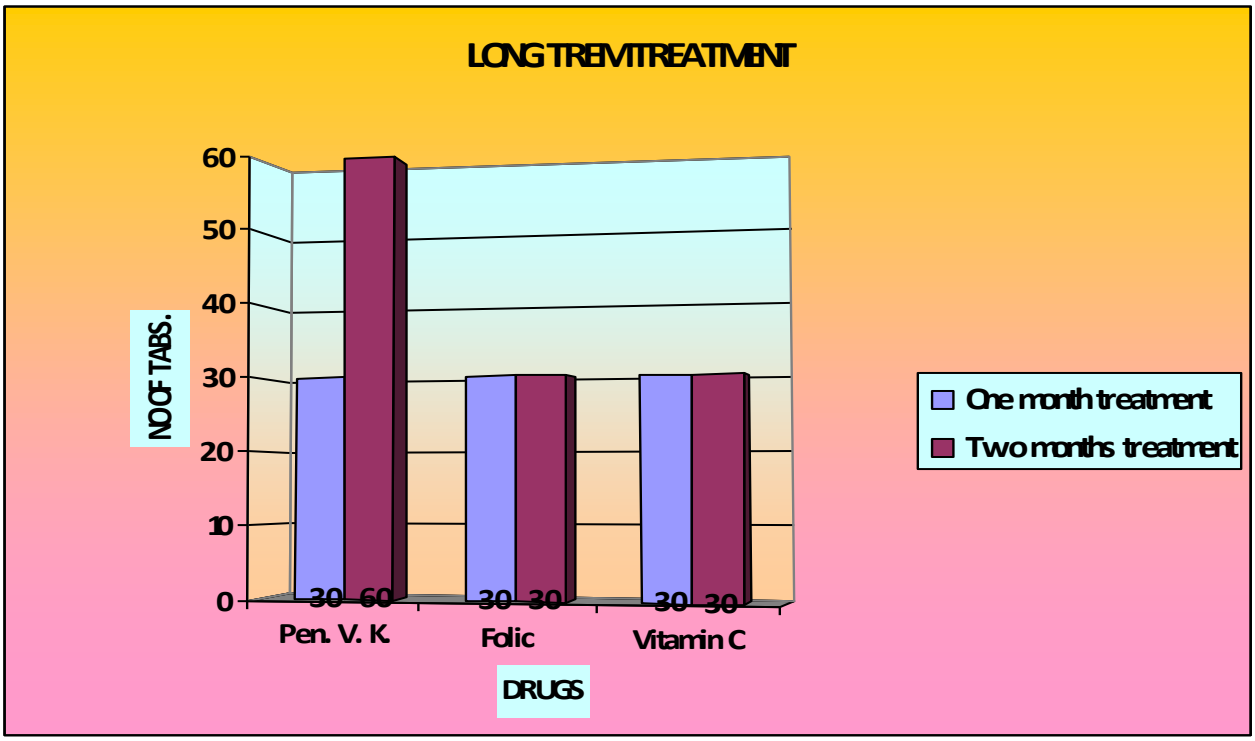
LONG TERM TREATMENT FOR CLIENTS WITH SERIOUS CONDITION		
DATE	ONE MONTH TREATMENT	TWO MONTHS TREATMENT
20/07/ 2011	0	5
25/07/2011	0	3
26/07/2011	1	1
28/07/2011	4	3
29/07/2011	1	2
TOTAL	6	14



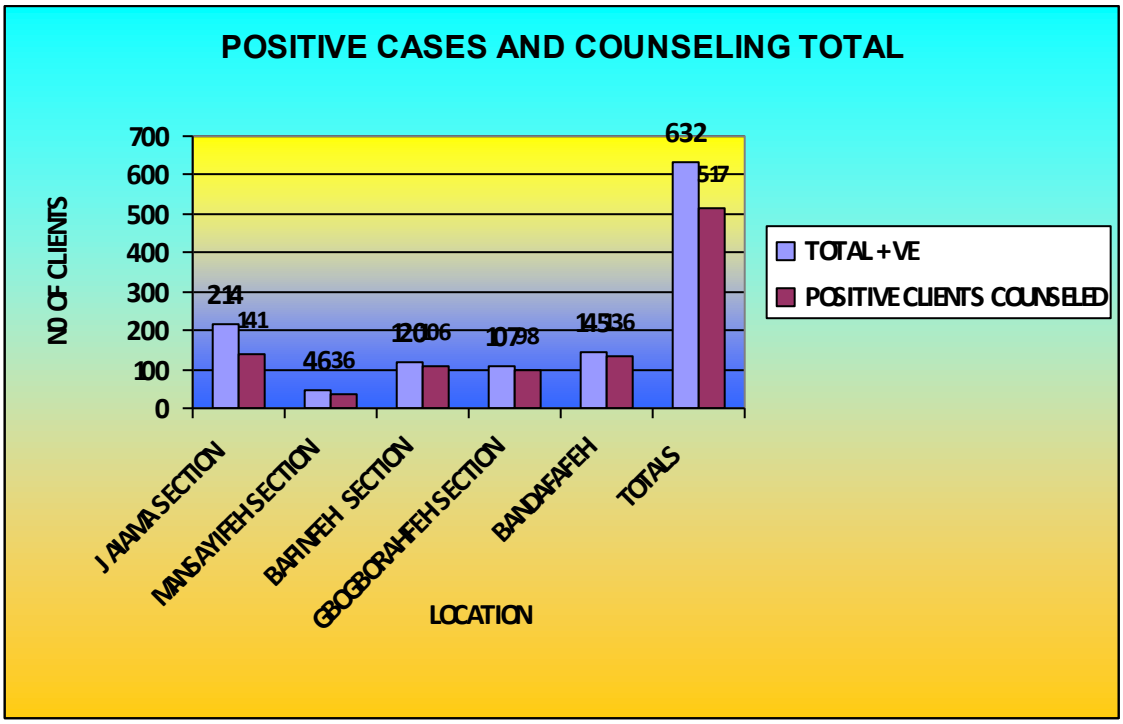
Since the exercise was a scooping survey which will continue only after some more support from good will caring donors like WORLD VISION S/L (Nimikoro ADP), The experienced nurses asked that prolong treatment be administered to clients with very serious conditions. This will help them through for some time.

The treatment consisted of:

N0	Length	Pen-V. K.	Folic	Vitamin C
1	One month treatment	30	30	30
2	Two months treatment	60	30	30



The main treatment administered was purely anti-biotic, vitamins and. For prophylactic care, some clients were supplied with Fansider. Clients with red itchy eyes were treated with tetracycline eye ointment. Pain relievers were also supplied to clients reporting serious pain in the joints.



IMPACT: OUTCOME OF THE SURVEY AND EFFECTS ON FUTURE PROGRAMMING

This is very important for stakeholders for future planning especially for the health sector. The out come is very serious for ages 6 months – 19 years with 16.05% with Haemoglobin **S**. These are the under five, the children of schooling going age and the teenagers. This percentage tends to agree with various notions/facts of which two are worth mentioning.

1. Clients with sickle-cell condition never grow beyond age 21 years.
2. Children with sickle-cell condition in rural areas of Africa hardly reach their fifth birth day.

The SCCAN Supporters: ***World Vision Sierra Leone (Nimikoro ADP)*** supports children in all the sections of Nimikoro chiefdom in their **Child Sponsorship Programme**. The age range of these children happen to fall within the highest percentage of 'S' cases This could impact negatively on the programme if the sponsored children fall within this group. The school going children within this group are affected. They often skip classes due the illnesses. This leads to poor performance of the children and a possible drop out of school and the programme altogether. The supporters need to be aware of this sad result and act by screening the sponsored children. Those with Haemoglobin **S** will need further screening for earlier detection for proper counseling and management. This will serve as an effective tool for the reduction of early child death and the prevalence of sickle-cell thereof. The informed choice made for the child will go a very long way in the management process.

THE LOCAL GOVERNMENT ACTORS:
The chiefdom authorities and the ward development committees that are the entry points in development will be able to plan health promotions programmes addressing sickle-cell like any other disease listed as one of the killer disease for children.

THE DISTRICT HEALTH MANAGEMENT TEAM (DHMT):
If they are aware of the condition in the district, they will b able to map out a coping strategy to raise awareness at the appropriate quarters for support for child survival health programmes with particular reference to sickle-cell

CHALLENGES

1. Time limitation was one of the major challenges which could not allow the team to do extensive work. The CEO and the rest of the team had limited time.
2. Financial limitation: Though all partners and stakeholders supported the exercise whole heartedly and even came up with the project operational budget and provided word processing facility, vehicle, office space from where the team carried out all clerical duties, finance was one of the major challenges. The management had to move the technical team from Freetown. The contributors who were medical students came on board on voluntary basis. This was also true for the highly trained, qualified and experienced medical personnel that consented to offer their services.

3. Equipment and medical supplies: These were in short supply or not even available. The medical staff from the Koidu Government Hospital assisted with almost what they have and could offer; their time inclusive.

STORIES FROM THE FIELD

1. The ignorance about sickle-cell was clearly manifested during this exercise. During the counseling sessions, clients came out with a concept that they fell ill when they took bath under the rain and that was how they got sickle-cell.
2. A mother was very confused. She stated that she has not got sickle-cell. Even her husband did not have sickle-cell she claimed, but her son lives with the condition. She stated that her cousins have sickle-cell. She could not be convinced that they both have the Haemoglobin **S** and that is the reason why the child has sickle-cell.
3. Treatment with elephant bone used as bracelet tied around the joint could ease the pain.
4. Most people beg their loved ones to tie them to ease the pain. They even beg to be tied stiffly.
5. The first day was not very encouraging. As the radio sensitization took effect, more people came up even when the exercise was about to close. They saw the importance of screening to know their condition and receive counseling and to make informed choices in their later life or in choosing partners.
6. Questions were asked about follow up screenings exercises. That was a sign of some understanding of the programme. In reality, such follow up screenings take place every six months to know the HB count for further counseling.
7. Men were asking questions why only one child could have sickle-cell and not the other children. There was doubt in their minds as the legitimacy of that child. The end result was that after the counseling exercise, the man was pleased.

SUGGENTIONS

1. **Further Screening Classification:** Heamoglobin Electrophoresis Machine (HBM) which will differentiate double homozygous for example HbSc and HbSd. This could be part of the free health care delivery service in Sierra Leone To reduce child mortality and improve maternal survival during child birth.
2. There should be free screening for mothers, newly born babies, school leavers which could help reduce the death rate in Sierra Leone
3. Marital counseling should be encouraged. This should be a matter of must to cut down on the prevalence sickle-cell. This is a success story in some countries like Saudi Arabia. Where marital counseling is compulsory.
4. **Extension/Expansion of the exercise:** Further screening exercises in other regions as an expanded medical camp for sickle-cell screening is required. This should be done with the Ministry of Health and Sanitation (MOHS)
5. **Quick release of results:** On the spot screening of clients to quickly know their status is very important. It was notice that sending clients to come back for the test results on the following day leads to poor turn out and counseling. Clients may not have the chance or time to turn up for their results Portable field equipment is required to do on the spot test and release the result after 30 minutes.

6. **Staffing:** Staff may be qualified but they would require training and orientation for the screening job to be able to handle difficult cases in terms of client's attitude and perception of the screening exercise. Specialists should be assigned to handle emerging issues and critical matters.

7. **Logistics:** For SCCAN to effectively carry out implementation of projects and programmes in the field of sickle-cell a lot is required.
    a. Vehicles
    b. Motor cycles
    c. Office space
    d. Field/out reach offices
    e. Respite centers
    f. Trained staff
    g. Medical supplies and equipment to diagnose (Electrophoresis Machine, field/portable microscopes, reagents, standby generator sets echo scanner
    h. Programme and office supplies like (word processing and publishing equipment, recording and reproduction equipment,
    i. Beds for respite center
    j. Communication equipment (LAN satellite v-sat, phones)

The above logistics items were identified as the key challenges that affected the work. They could hinder a sickle-cell programme in future if an extensive programme on sickle-cell covering the entire country is to be undertaken.

CONCLUSION

The few days screening exercise undertaken by SCCAN was very challenging, yet it served as an eye opener for all especially the volunteers that were drawn from all over the country. Such an exercise had to come from a team with the determination to serve mankind.

It is our hope that the government will consider this project. The president has taken the bold initiative in addressing the UN MDG with the free health care delivery service. Now the next initiative should be in the area of sickle-cell where no one has ever ventured into. SCCAN chief executive officer is calling on all development actors, stakeholders and partners to come together to roll back sickle-cell from Sierra Leone and copy the example of Saudi Arabia and Ghana. For the information of all partners, Ghana has the best sickle-cell center in Africa why not Sierra Leone if SCCAN team should ask?