

**WORLD SICKLECELL DAY CELEBRATIONS' REPORT BY  
SICKLECELL ASSOCIATION OF UGANDA (S.A.U)**

**VENUE: KASANA HEALTH CENTRE IV, LUWERO DISTRICT**

**DATE: 10<sup>th</sup> JULY 2013**

**THEME: KNOW YOUR SICKLECELL STATUS**



**PARTNERS: Ministry of Health, World Health Organisation, Bank of Africa Uganda,  
Media, Luwero District and Holly Foundation Luwero**

## INTRODUCTION

Sicklecell Association of Uganda is a non-profit, non-governmental organization (NGO) that was founded by a patient in 2000 to represent the interests of sickle cell patients and their families. It advocates for the rights and responsibilities of affected persons. We work hand in hand with different stake holders to improve the quality of care for sickle cell patients. We also provide education and counseling to the sickle cell patients and their families about home care management.

In the year 2008, the General Assembly of the United Nations adopted a resolution which determines sickle cell disease as a public health problem and one of the world's foremost genetic diseases, requiring heightened awareness and activism, diagnosis and management. The result of the resolution was that June 19th was declared World Sickle Cell Day to increase awareness of the condition all over the world. The World Health Organization (WHO) has started work on a war footing to promote a worldwide agenda to address hemoglobin dysfunctions.

Sickle Cell Disease (SCD) is the most frequent genetic disease worldwide. It is present on four continents: in Sub-Saharan Africa and in the Maghreb, in Asia (Middle-East, Arabic Peninsula, India), in the Americas, on the North (USA), centre (Guatemala, Caribbean Islands), and on the South (Brazil, Surinam, and Guiana), in Southern Europe (Southern Italy and Sicily, Greece, Turkey). It is estimated that 500,000 are born every year with this severe and invalidating condition and that 50% of them will die before the age of 5 years. Trans-continental, SCD is also trans-ethnic and affects black populations from African origin and Arabic, Indian and Caucasian populations from Southern Europe.

It therefore upon this background that Sicklecell Association of Uganda started commemorating this day in 2010. This year Sicklecell Association of Uganda developed a proposal to Ministry of Health and was accepted with all proposed activities and theme and thus the Ministry of Health spearheaded the preparations and SAU brought on board her partners like Bank of Africa and her sister organizations working in Sicklecell disease such as Holly Foundation, Sicklecell Initiative, Uganda-American Sicklecell Rescue Fund, Sicklecell Information and Management, Joy for Joy foundation Luwero to Ministry of Health to be invited for involvement.

## **PLANNING FOR THE WORLD SICKLECELL DAY EVENT**

Since this was a National event, Ministry of Health started preparatory meetings and brought on board World Health Organisation and Luwero District Local Government. We had weekly preparatory meetings from 8<sup>th</sup> May to 4<sup>th</sup> July 2013.

Sicklecell Organisations were charged to bring Sicklecell counselors to all the three Health Center IVs - that is Kalagala, Nyimbwa and Kasana for Sickle cell education, interpretation of results and counseling.

### **ACTIVITIES TO BE CONDUCTED INCLUDED:**

- Sicklecell screening... the carrying out of a sickling test in Health Center IVs of the host district - that is Nyimbwa, Kasana and Kalagala for the three days from 8<sup>th</sup> – 10<sup>th</sup> July 2013.
- Health education about Sickle cell disease in the communities of Luwero District.
- Counseling to be provided for the screened people.
- Sicklecell football tournament for mass mobilization.
- Media engagement - press release, press conference, radio and TV talk shows.
- Charity walk around Luwero town.
- Blood donation drive.

### **PARTNER'S COMMITMENT FOR THE EVENT:**

- Ministry of Health was to pay 4 million for a pullout in newspapers, and 2 Million for a talk show on WBS television, provide technical support and facilitation to the Laboratory technologists in Luwero, provide reagents from National Medical Stores for Sickle cell screening for three days - food, chairs and tents, and to contact Nakasero Blood Bank
- Bank of Africa to cater for trophies for the tournament, T-shirts and brochures on Sicklecell disease.
- Luwero District to host the event and mobilize the public to effectively participate in the activities.
- Each of the Sicklecell Organizations to provide five counselors for the provision of health education concerning Sickle cell disease, interpretation of the screened results and counseling.

- Holly Foundation to conduct mobilization and to make a speech on behalf of all Sicklec cell organisations since it was based in the host District.

## **ACHIVEMENTS FOR THE WORLD SICKLECELL DAY EVENT 8<sup>TH</sup> - 10<sup>TH</sup> JULY 2013**

- **Ministry of Health commemorated World Sicklec cell Day for the very first time in Uganda.**



### **The Minister of State (Primary Health Care) Sarah Acheng Opendi.**

- She committed that Annual World Sicklec cell Day celebrations will be held to carry out awareness of Sicklec cell disease.
- She apologized on behalf of the Ministry that Sicklec cell disease has received little attention and more effort will be given in future.
- Sicklec cell clinics already established include; Mulago National Referral Hospital, Jinja regional referral Hospital, Kasana Health Center IV and Nsambya Hospital which is private.
- To start up Sicklec cell clinics in regional referral hospitals followed by Health Center IVs
- She advocated for couples to test for Sicklec cell disease before marriage and make informed decisions.



- She further advocated for outreaches on Sicklecell disease to be conducted.
- She thanked us for the free airtime that was provided by media houses - WBS Television, UBC Television and NBS Television.
- **The Director General on behalf of Ministry of Health made a commitment to the following;**



**Dr. Aceng Jane Ruth Director General Health Services Ministry of Health**

- To commemorate world Sicklecell day every year.
- To test for Sicklecell disease nationally and this will be done in the public laboratory by collecting blood samples beginning this financial year.
- A prevalence study on Sicklecell disease to be carried out this financial year for new data to be availed.
- To conduct a research on pneumococcal vaccine.

- She emphasized that Sicklecell clinics will be opened in regional referral Hospitals.
- World Health Organisation gave financial support to Ministry of Health in preparation for World Sicklecell day.



■ **Dr. Hafsa Kasule** represented the WHO Representative to Uganda who is **Dr Wondi Alemu**, and advocated for the following;

- New-born screening, early treatment for Sicklecell patients, immunization, sensitization and nutrition should be emphasized.
- To provide pneumococcal vaccines.
- Sicklecell disease should be integrated in research and this will reduce child mortality rates.



**Professor Christopher Ndugwa a Sicklecell disease specialist giving a speech at the World Sicklecell Day celebrations.**

- Sicklecell screening (sickling test) was held at Kasana and Kalagala Health Center IVs.
- 20 Sicklecell bursaries are given by our Lady Parents School Luwero under leadership of Director Nambakire Catherine.
- Sicklecell Association of Uganda was able to pattern with Ministry of Health, World Health Organization, Bank of Africa, Luwero District local Government and other Sister organisation to commemorate World Sicklecell day 2013.





**Sicklecell Association of staff (From L-R) Ms. Annet Nakanyike Counselor and Mrs. Ruth Nankanja Mukiibi Executive Director/ Founder giving an explanation to the VIPS (R-L) LC V Chairman- Luwero, Minister of State (PHC) and WHO representative during the exhibition.**

- Sicklecell Association brought the five counselors to Luwero to give health education on Sicklecell disease, interpretation of results and counseling from 8<sup>th</sup> – 10<sup>th</sup> July 2013.



**Mr. Edward Sentamu Program Officer and Counselor, Ms. Annet Nakanyike Senior Counselor, Ms. Naluwagga Phoebe Counselor, Mrs. Ruth Nankanja Mukiibi Executive Director/ Founder, Mr. Solomon Wasswa Counselor, Ms. Naggita Rosette Counselor.**

- A Sickle cell patient testifying that with proper care and management they can grow up to any age.



**Mrs. Luyombo Catherine 62 , a retired Senior Nursing Officer, a Sickle cell patient and mother of three sickle cell patients and advocates for sickle cell screening before marriage . Board member Sickle cell Association.**

- Bank of Africa initiated a Sickle cell Tournament that will be annual.



**Above : Bank of Africa representative Mr. Billy Bisanga awarding a trophy to Green Valley High School Luwero the third runner up.**





**The first winning team for the Sicklecell trophy was from Everest College Luwero.**

- Awareness about Sicklecell disease was carried out in Luwero.



- SAU's UAPO partners from Community Health and Information Network (CHAIN), and Epilepsy Support Association Uganda (ESAU) attended and exhibited to promote patient solidarity.



**(From L-R) Mrs. Regina Namata Kamoga country Director CHAIN, Mrs. Ruth Nankanja Mukiibi Executive Director/ Founder SAU and Ms. Dorcas Amondong Focal person African Regional Patient Solidarity day 2013.**

## **CHALLENGES AND GAPS**

- The District and Ministry did not carry out the capacity building to the three Health Center IVs laboratory technologists.
- Reagents were not bought because National Medical Stores was closed for stock taking and claimed that they had supplied all facilities for two months.
- 98 people were turned away on Monday at Kalagala Health Center IV because of no reagents Ministry of Health bought reagents privately on Tuesday and 28 people were screened at Kalagala Health Center IV and 5 people at Kasana Health Center IV. On Wednesday 15 people were screened at Kalagala.
- Nyimbwa Health Center IV by 8<sup>th</sup> July 2013 was not aware about the Sickcell screening program and referred SAU counselors to the district for clarification and thus counselors left frustrated.
- There are no established figures for Kasana on Wednesday 10<sup>th</sup> July, 2013.

- Mobilization was poorly done by the committed partners such that SAU had to put announcements on Tuesday night on community radios namely; radio Kalaso, Malaika and Wobulenzi to inform the public about the Sicklecell function on 10<sup>th</sup> July 2013.
- It was only Sicklecell Association of Uganda that brought Counselors from 8<sup>th</sup> to 10<sup>th</sup> July 2013. Most Sicklecell organizations did not even attend the event.
- SAU counselors received a negative attitude from Kasana Health Center IV staff on Tuesday to the extent that they had to counsel clients while seated on the grass yet counseling rooms were empty.
- T-shirts were selectively distributed to only Luwero district officials, a few patients and parents. The dignitaries for example State Minister, Director General, Commissioners, Professor, WHO representative, the exhibitors and the football teams did not get a single T-shirt yet they were very key.
- It was unfair that counsellors were not facilitated by Ministry of Health.

## **WAY FORWARD**

- Transparency and accountability is ideal for all partners if we are to fight this dreadful disease in future.
- Next time Ministry of Health should facilitate active partners in terms of out of pocket allowances, transport and accommodation.

## **CONCLUSION**

Despite the gaps Sicklecell Association of Uganda salutes Ministry of Health, World Health Organisation, Bank of Africa, Luwero District and Holly Foundation for the wonderful World Sicklecell Day.

In a special way SAU Management and Staff appreciates the following persons for coming to our rescue with their financial and moral support. Mr. Desmond Owino (600,000/=) Mrs. Joan Kigundu (50,000/=) and Watoto Medical Department (200,000/=). Your support was spent on facilitating the counselor's accommodation, meals, transport, still photos and video coverage. Also special thanks go to Mrs. Luyombo Catherine, Ms. Jacqueline Nampijja and Mrs. Dorothy Nakimera Mugagga for their tireless effort.

Let us keep fighting against the forgotten enemy Sicklecell disease.

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