



A speech on the Launch of the National sickle cell survey and Testing Laboratory by Mrs. Ruth Nankanja Mukiibi BA/Educ Muk, Executive Director & Founder Sickle Cell Association Of Uganda, Email: joansempa@yahoo.com / Mob: 0712 815978 18th February 2014

Honorable Minister of Health, Honorable Minister of State (Primary Health Care), Honorable Minister of State (General Duties), Permanent Secretary, Director General Health Services, Ministry of Health Head Quarters Staff, Regional Hospital Directors, Directors of Mengo, Nsambya, Rubaga, IHK, Kibuli Hospitals, Senior Staff National Referral Hospitals, All Chiefs of Party/ Country Directors, Health Development and Implementing Partner Organizations Ladies and Gentlemen,

It is my pleasure to be one of the guest speakers today. I extend my appreciation to Ministry of Health and partners who granted me this great opportunity to make a speech to all the invited guests. I am going to give an overview on Sickle Cell disease in Uganda and Sicklecell Association of Uganda where I am the Founder and Executive Director.

A. SICKLECELL DISEASE IN UGANDA:

It is an inherited blood condition common in, but not confined to, the people of African origin. It occurs when abnormal genes are inherited from both parents. Persons inheriting the sickle cell gene from one parent have the harmless sickle cell trait (AS): those inheriting the sickle cell gene from both parents have sickle cell disease (SS). When both parents have the trait, there is a 1 in 4 chance at each pregnancy that the child will have Sicklecell disease (SS). In Uganda... 45% is the highest trait frequency in the world and it's among the Bamba. It is estimated that 20% of the Ugandans are at a risk of having a child with the sickle cell disease. It is also estimated that 33,000 babies with SS disease are born in Uganda each year. 70 - 80% of these babies never live to celebrate their 5th birthday. Unfortunately this data was generated in early 70's.

Much of the morbidity of the disease may be prevented by awareness, social support of families, early diagnosis & management which the Ministry and her partners are trying to implement today. The launch of the National Sicklecell Survey and testing Laboratory, to me as an advocate for Sicklecell patients and the entire community in Uganda this has been my dream all along.

B) Sicklecell Association of Uganda

Sickle cell Association of Uganda (S.A.U) is a charity organization that was founded in July 2000 by a concerned patient. It is registered as a Non-governmental organization. It advocates for the rights of sickle cell patients, awareness of the disease and the improvement of the diagnostic and clinical services for patients.

It's headquarters are located at Kawanda-Namalere off Bombo road. Membership ranges between patients, families, well wishers and cooperates.

Over the years SAU a new Sickle cell prevalence study has been one of the biggest advocacy issues. Therefore this launch is timely and SAU counts it on one of her achievements.

Therefore I once again congratulate and thank Ministry of Health and her partners for this big achievement as a country on behalf of the entire Sickle cell community in Uganda. We pledge our support.

Other issues and their interventions to be carried out by Ministry of Health in particular and the Government at large.

a) Sickle Cell Clinics should be established in all regional referral hospitals and health centers IVs.

- Establish partnership and strengthen collaboration with key stakeholders for example Ministries, Health development partners, CSO's, NGO's, the private sector, professional organizations to create an enabling environment for Sickle cell prevention and control activities.

b) The only available sickle cell clinic has no special fridge for keeping blood yet sickle cell patients suffer from severe anemia regularly and hence need it often.

Intervention

- A special fridge for keeping blood should be allocated to the Sickle cell clinic Laboratory at old Mulago.

c) The available sickle cell clinic is a day care center yet attacks commence at night.

Intervention

- The sickle cell clinic should work 24 hours.
- Strengthen in service training on Sickle cell disease.

d) Patients with Sickle cell disease are more prone to infections yet they do not have their special Ward and therefore are admitted on General wards where they pick other infections.

Intervention

A special ward for sickle cell patients should be established and be equipped with specialized sickle cell health workers.

e) Build capacity of health workers to improve quality of Sickle cell care.

f) Train health workers on Sickle cell issues and management of Sickle cell disease.

Finally, dear all partners in Health, I congratulate Ministry of Health in partnership with Cincinnati Children's Hospital in the US for this wonderful campaign of the National Sickle cell survey and testing Laboratory, it's our prayer that the campaign will benefit all the key beneficiaries to find a solution for this long term disease to save the future generations.

May God bless you all. For God and My Country.