

A REPORT ON THE LAUNCH OF THE NATIONAL SICKLECELL SURVEY AND TESTING LABORATORY ON TUESDAY 18TH FEBRUARY 2014 AT CPHL PLOT 7/11 BUGANDA ROAD

1.0 Introduction

In Uganda, approximately 25,000 children are born with Sickle cell disease every year, but unfortunately 70 – 80% die before their 5th birthday. However, this data was very old because it was generated in the early 70's. There has been no newborn screening program in the country and children are often diagnosed after the development of a crisis. Due to lack of newborn screening and lack of pre-marital genetic counseling, individuals with the Sicklecell Trait and Sicklecell Disease are intermarrying ignorantly, compounding the problem. With lack of screening programs, diagnosis is usually made late and many children die before they are diagnosed. This has been the top priority advocacy issue for Sicklecell Association of Uganda for government to do a new prevalence study for the last 13 years.

1.2 National Sicklecell survey and testing

A team of researchers from Cincinnati Children's Hospital in the US has helped MOH to set up a Laboratory based at CPHL, through which we are to conduct a surveillance study to map the prevalence of sickle cell across the country for one year.

The launch was chaired by the Director General Health Services Dr. Jane Ruth Aceng Ministry of Health, other participants included; Honorable Minister of Health (PHC) Sarah Opendi, Members of Parliament, Ministry of Health staff, Directors of Regional Referral Hospitals, District Health Officials, Civil Societies and Media.

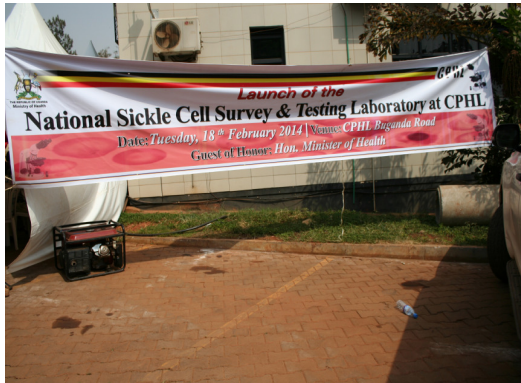
We had speeches from the Director General Health Services, Director CPHL, Prof. Ndeezi, Founder/Executive Director Sicklecell Association of Uganda, Cincinnati Children's Hospital US and the Hon. Minister of Health (PHC) Sarah Opendi who declared the Laboratory officially opened.

2.0 Key highlights

- CPHL will use HIV samples from around 2000 Health facilities in all Districts in Uganda.
- They will conduct 9000 samples every month.
- They will also use the samples collected from babies across the country.
- The machine will work on 160 samples a day.
- After the study they will use the geo mapping method for each District.
- A District with the higher Burden shall be given priority.
- Preliminary results will be read on World Sicklecell day 2014.
- The Government earmarked 400,000,000/= this year through the National Medical Stores to procure Sicklecell testing reagents, such that during the survey, testing for patient care may go on.
- The Government pledged to continue allocating more resources towards Sicklecell burden.

Attached are the speeches from Hon Minister and ED/ Founder SAU

3.0 Photos for the Launch



Dr. Jane Ruth

Aceng Director General Health Services chairing the Sicklecell testing launch at CPHL



Ruth Nankanja Mukiiibi ED/ Founder SAU

Hon Minister of Health (PHC) Sarah Opendi



ED/Founder SAU and delegates from Cincinnati Children's Hospital USA.

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