

**WORLD SICKLECELL DAY INTER – RELIGIOUS SERVICE REPORT
BY SICKLECELL ASSOCIATION OF UGANDA (S.A.U)**

VENUE: NAMIREMBE DIOCESE (HOST)

DATE: 28TH AUGUST 2014

**THEME: “SICKLE CELL IS EVERY RACE, THAT’S WHY IT’S CELL – A –
BRATED ALL OVER THE PLACE”.**



Rt. Rev. Wilberforce Kityo Luwalira (Bishop of Namirembe Diocese Patron SAU)

INTRODUCTION

2nd Corinthians 12:9 -10

9 “but he said to me, “My grace is sufficient for you, for my power is made perfect in weakness”.
“ I will all the more gladly boast of my weaknesses, that the power of Christ may rest upon me.”
10 “For the sake of Christ, then, I am content with weaknesses, insults hardships, persecutions, calamities, for when I am weak, then I am strong.”

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 disease, requiring heightened awareness and activism, diagnosis and management. The result of the resolution was that June 19th was declared as 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.

In Uganda the preliminary findings of the on-going study conducted this 2014 by ministry of health together with Makerere College of health Sciences and Cincinnati Children’s hospital in the US have indicated that the Northern region has the highest prevalence of 18.6 % sickle cell trait. According to the study, the region also has the highest malaria parasites prevalence of 63% and highest anemia prevalence of 74%.

In the second position is East-Central with a sickle cell prevalence of 16.7%, malaria prevalence of 56% and anemia at 70%. This is followed by Mid-Eastern Uganda with a sickle cell trait

prevalence of 16.5%, malaria at 36% and anemia prevalence and 57%. South-Western region has the lowest sickle cell trait prevalence of 4.1%, 12% malaria and 40% anemia.

Professor Ndeezi estimated that of the 1, 600,000 births per year, over 20,000 babies are suspected to be born with the sickle cell gene in Uganda annually.

She said out of the 23, 000, children's specimen that was tested in the different regions during the study, it was discovered that 2,800 babies were carrying a sickle cell gene a proportion of 12%. This implies that one in every ten babies born in Uganda carry the gene. 3,960,000 Ugandans are at a risk of producing a sickle cell child in Uganda.

We have been quoting out dated figures of a study that was conducted in 1949 indicating the Bamba having the highest sickle cell trait at 45%.

PLANNING FOR THE INTER – RELIGIOUS SERVICE

It all started with lobby meetings at the Inter – religious Council from May 2014. SAU also partnered with the Namirembe Diocese Administration specifically the Bishop and the Dean who was very instrumental in the planning process for this Inter – religious service and pledged to draft the Order of service for the Day.

SAU approached the Bishop of Namirembe who accepted to work hand in hand with them for a successful service. SAU was advised to write to all the presidents of the different denominations in Uganda such as the Anglican Church, Catholic Church, Adventist Church, Orthodox Church and Pentecostal church.

Prior to the service, SAU held a press conference on 26th August 2014 at her offices Namalere – Kawanda where we hosted Voice of Africa Journalists who passed this information to the public concerning Sicklecell disease and also encouraging the people to attend this service.

It was therefore agreed between SAU and the Bishop that this service will be held on 28th August 2014 and the main host was to be Namirembe Diocese.

THE INTER – RELIGIOUS SERVICE 28TH AUGUST 2014

The main participants included; the Clergy, Health Workers, Private Sector, Ministry of Health, Buganda Government officials, Media and the congregation from different religions in Uganda.

The Order of service was distributed among the congregation; the Dean of Namirembe Diocese Cannon Kityo Samuel was the leader for the service. He gave out an introduction message that; We have come together as a family of God, In our Father's presence to ponder about Sicklecell problem in our community and to pray for the sickle cell patients and families that are engaged in caring and supporting those who are suffering. We are also here to bring awareness of this problem to those who are still ignorant of this case.

He read out An African parable entitled “**The Problem of Lions.**” (See pg 3 of the Order of Service)

In thanking God and praying for those who are still living with the disease, he said that; “**Let us think about our unique creation. You did not just happen to come into being. You were planned in the mind of God long before you were born. He watched over you as were being formed in the womb. You are uniquely designed - a very special person. He has given you certain strength. He even allowed some negative things in your life. He wants you to see these strengths for him and let your weakness work for Him and for you. Learn to glory in your infirmities, not to hate or despise yourself because of them**”.

Special readings were cited from the Bible and these included; Psalms 139: 13 – 18 and Psalms 38: 1- 22

Solomon’s Choir from Busega Seventh Day Adventist Church blessed the Congregation with their inspirational songs.



Solomon’s Choir

The Rt. Rev. Wilberforce Kityo Luwalira gave his sermon where he emphasized that as religious leaders we have a greater role to play in saving the lives of sickle cell patients, creating awareness and also encouraging couples to test for Sickle cell disease before getting married this will reduce on the marriage breakups due to sickle cell disease.

Communication from the Founder / Executive Director Sickle cell Association of Uganda.

Mrs Ruth Mukiibi explained to the congregation why SAU decided to organize this Inter – religious service this was mainly to bring on board all religions in the fight against Sickle cell disease. To involve all religions in the awareness programs for example as they prepare couples for weddings they should encourage them to test for sickle cell disease in order to make informed decisions and to Fundraise for the construction of a sickle cell center which will be constructed at Kawanda Namalere within the service so that sickle cell patients could have quality Health Care in Uganda.



Mrs. Ruth Mukiibi giving her remarks during the Inter – religious service to mark the World Sicklecell Day event at Namirembe next to her is Mr. Lasito Mukiibi.

She highlighted on some achievements done by SAU;

- We are able to reflect on the progress of SAU by playing a vital role by being part of team of Ministry of Health NCD Technical working committee that drafted the Non Communicable Disease Policy, the National Chronic Non Communicable Disease Prevention and Control Strategic Plan , Clinical guidelines and training manuals.
- SAU owns land at Kawanda Namalere where she wants to construct a 24 hour Sicklecell Center.
- Sicklecell Association of Uganda partnered with Bank of Africa last year and did a car boot sale that fundraised for a hemoglobin electrophoresis machine for the Association.
- SAU has achieved her advocacy goal of a new sickle cell prevalence study which is ongoing by Ministry of Health funded by Cincinnati Children’s Hospital USA

She welcomed Ministry of Health official Ms. Margret Nagawa from the Non Communicable Department who read out the current statistics from the ongoing sickle cell prevalence survey by Ministry of Health in support from Cincinnati Children’s Hospital USA.



Ms.Margret Nagawa represented

Ministry of Health NCD Department.

Fundraising for the construction of a Sicklecell Center at Kawanda – Namalere

Mr. David Mubanda was the chief fundraiser who managed to raise 1,724,000/= from the congregation who attended the Inter – religious service that day. He also gave out some pledge cards for those who were willing to contribute towards the construction of the Sicklecell center.



Mrs. Agnes Sempa in glasses

(Deputy Kaggo, Kyadondo County) represented the Buganda Government

ACHIVEMENTS FROM THE INTER – RELIGIOUS SERVICE

- SAU managed to bring on board all religious leaders to create awareness to their masses about sickle cell disease, to have a positive attitude towards sickle cell disease. This awareness will reduce marriage breakups due to sickle cell disease.
- The Bishop encouraged all corporate agencies, private sector, civil society organizations, cultural institutions, and media and Government agencies to join in the cause of increasing awareness to the public about sickle cell disease.
- The Bishop also emphasized that all religious leaders before marrying couples it should be mandatory to talk about sickle cell disease if possible to encourage these couples to test for this disease.
- He pointed out that the public must be made aware of sickle cell disease so as people before giving birth to children they should have an informed decision.

CHALLENGES AND GAPS

- Some people failed to turn because of the rainy seasons in Uganda, since most sickle cell patients are affected by the cold environment.
- Limited support from the Inter – religious council of Uganda due to funding cuts from their donors.
- There is still limited information about sickle cell disease, management of the disease by the medical professionals.
- SAU has registered a number of deaths of its members due to inappropriate management.

WAYFORWARD

- SAU is planning to construct a 24hour Sicklecell center at Kawanda – Namalere.
- We need to strengthen partnerships with all stakeholders such as Ministry of Health, Civil Society organizations, religious leaders, cultural institutions and media.
- We also need to lobby regional referral Hospitals to run sickle cell clinics.

CONCLUSION

SAU would like to appreciate all those who partnered with her to make this inter – religious service a success, special thanks go to the Bishop of Namirembe and his administration, Mr. Desmond Owiyo SAU's Chairperson Board of Directors, SAU's Board of Directors, Wavah Water, Mr. Ggayi and SAU staff. **Let us keep up the fight against Sicklecell disease.**

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