REPORT FOR THE FIRST ANNUAL SICKLE CELL CONFERENCE HELD IN UGANDA. THURSDAY 11TH JULY 2013. AT NILE HALL, HOTEL AFRICANA

Master of Ceremonies: Mr. Hasaan Nakabale, Ms. Mariam Ndagire, and Daniel Omara.


Introduction

This event was organized to create a national dialogue: a way forward to recognize the need for a National Sickle Cell Disease policy framework in Uganda, involving the Ugandan government, and the urgent need for scientific research, and the challenges along way among those caring and living with sickle cell disease. This marked the beginning of many other conferences that will emphasize the need to save the Ugandan children whose lives are claimed by sickle cell disease in Uganda. This conference targeted government health care policy makers, medical schools, nursing schools, universities, hospitals and the community. The conference also targeted non-government organizations such as local Sickle Cells organizations, International Agencies and the media.

Conference attendance

The hotel records indicate the attendance of four thousand people (4,000) although about one thousand nine hundred and sixty people (1,960) registered. By 0800am half of the conference room was already full and by the time the chief guest arrived at 11am people were sitting on the floors of both the upper and lower levels. All seats were filled including the several hundreds of extra plastic seats that the hotel added into the hall leaving several sitting on the hotel carpet.

Morning Session Presenters

The floor was opened by a Video session of a play written and directed by Singer and Music Director Ms. Mariam Ndagire. Dr Oyella and Dr. Sebunya both from St. Joseph's Hospital Nsambya presented on the issues affecting sickle cell children at Nsambya sickle cell clinic. Dr Namiro a pediatrician from Mulago referral hospital, sickle cell center presented on the need of pre-marital sickle cell counseling as a means of preventing. All physicians participated in a 30 minutes Question and answer session.

a). During the Question and Answer sessions

Participants were eager to know the myths and beliefs about sickle cell disease. Several participants also gave testimonies as well as seek to be clarified in certain issues especially the disease management in Uganda. For example, "a participant inquired whether it was right not to
give the sickle cell patient fluids or decline blood transfusion when hemoglobin is 2 or 3 as she was advised by her colleague".

b). The Miss Uganda fraternity

Led by Miss Uganda East Margaret who delivered the address and pledged to support and work hand in hand with Uganda-American Sickle Cell Rescue Fund (UASCRF) to make sure that Sickle cell disease gets the attention it deserves in Uganda.

c). Refreshments and Entertainments

The All Stars of Uganda Music industry lead by their leader Mr. Shafik presented a song that was composed to increase Sickle Cell disease awareness among the people of Uganda and to bring hope to those affected by it. Among singers were Tuff B, Rena, and Kalifa Aganaga etc.

d). Parental Testimony

Mr. Benard Sembatya a father to a 4 year old sickle cell twin boy gave a parent testimony; he specifically talked about the challenges he face raising a son with sickle cell disease. Mr. Sembatya advised the parents stating, "it is always a blessing to care for our children, so no one should feel like they have been outlawed or punished by God".

e). Patient testimony

Mr. Majara a 51 year old sickle cell patient living 40 miles away from the city and living with sickle cell disease assured the participants that, "it is always about knowing and understanding your body and living with sickle cell, it becomes just like having flu or any other ailment".

**Mid Morning Session (11:00-12:00)**

a). Guest of honor- Uganda

The event was graced by the Honorable Speaker of the Uganda Parliament Rebecca Kadaga. The Hon speaker delivered to the nation what the government of Uganda will do, she informed the members that when the august house comes back out of recess she will make sure the issue of sickle cell will be number one on the agenda/table. And that she will sure the nation is informed and involved as the health care policy makers tackle the issue of sickle cell in Uganda. The speakers promised to 100% support the sickle cell cause and ensure that it gets the attention it deserves. The speakers echoed the concern that research needs to be done so that the country can actually know the status of sickle cell disease across the country other than quoting statistics done in 1940's during the colonials. She highlighted a dire need for government’s financial and moral commitment to this cause especially development of a National Policy Framework that deals specifically prevention, treatment and eradication of the disease in the country.

b). Key Note Speaker- United States
Ms. Lukiah L. Mulumba, The event organizer, a Ugandan American, delivered the long awaited presentation entitled ‘Management of sickle cell disease, coping, caring and living with sickle cell disease. A national dialogue; way forward. The need for a National Sickle Cell Disease policy framework in Uganda, involving the Ugandan government, and the urgent need for scientific research, and the challenges along the way’. Her presentation and her personal story emotionally touched so many hearts including the chief guest. She also supported the speaker’s call to enhance research about the disease in the country. “I did search for articles on sickle cell disease for my graduate project recently and I was surprised to find that multiple research work on different topics on sickle cell had been conducted in neighboring Kenya and Tanzania but nothing on Uganda.” She also called for government’s increased reinforcement to fund countrywide programs including early diagnosis, community education outreaches, research and development of evidence-based management.

c). Foreign Delegate- India

Dr. Sushi Methaa, a consultant from India spoke about sickle cell management, the need for collaboration with Uganda and donating sickle cell screening machines to sickle cell health care centers. Dr. Methaa talked about the Nova specialty centre in Mumbai, India which specializes in facilities that handle all surgical procedures. Dr. Sushi assured the participants that his centre is ready to support sickle cell disease in Uganda by donating and offering surgeries at a discount rate or donated.

d). Foreign Delegate - Nigeria

Mr. Desmond Elliot, Nigerian Sickle Cell Ambassador, Nollywood actor and film director, called upon government of Ugandan and all other African governments to accord as much attention to Sickle Cell as HIV and malaria. He emphasized that “you only need to have had a close person suffering from this disease to be able to understand its gravity. It is more or less like AIDS, Polio Hepatitis or any other feared ailment; hence it should be treated with the same kind of force.” He added, “We in Nigeria are lucky to speak directly to government. Other African countries including Uganda might need to borrow a leaf and call for say the Ministry of education to have a complete department dedicated to inclusion of Treatment prevention and eradication of Sickle Cells in national curricular”

e). Foreign Delegate - Burundi

Mr. Eric, Director Burundi Association presented about the issue of sickle cell disease in Burundi. He emphasized how the Sickle Cell Association works tirelessly to increase awareness and suffering in the Burundi community.
f). Local Delegate

Mr. Bulaim Kibirige Muwanga, CEO and 100% funder of the sickle cell conference, educated the audience about the need for social corporate responsibility and the role it plays in support of noble causes such the sickle cell cause.

**Mid Morning Session (11:00-13:00)**

a). Mulago referral sickle cell clinic

Dr/Prof. Christopher Ndugwa presented about sickle cell disease in Uganda and highlighted the major issues facing the sickle cell clinic of Mulago referral hospital. He indicated that there are more than 9000 sickle cell patients registered with the clinic with more than 3000 actively being followed or receive treatment at the clinic.

b). Ministry of Health of Uganda

Dr. Mwesigwa, assistant ministry of Health assured the people that the Ministry of Health is together with them and it will ensure they get the proper attention and medication. He hinted that the conference has come at the right time when the Ministry of Health is setting priority areas. He promised that Ministry of Health will do all it can to ensure that Sickle Cell disease gets the attention it deserves.

c). Sickle cell testing/Blood drive

The Wandegeya sickle cell testing on site tested 50 people free of charge. The Nakasero blood bank on site all day. Several people donated blood.

**Afternoon Session (13:00-18:00)**

a). Lunch /Question & Answer

A working lunch and bottle of water were served. Participants continued to ask questions from a panel of doctors.

b). Entertainment

Local Singer and organizer Sarah Short entertained the participants. Local singer Meseach Semakula gave a personal testimony and also donated his time to sing for free of charge for the participants.

c). International Diagnostic center

Dr. Macrine Nyisomeh from the International Diagnostic Center presented on sickle cell screening using the electrophoresis machine.
d). Testimony/Sickle Cell Association of Nigeria/Sickle cell patient

A 41 year old, Director of Sickle Cell Association of Nigeria, gave a testimony about living with sickle cell and encouraged participants to hopeful live a healthy life with sickle cell.

e). Parental testimony

Ms. Nakiyma Florence gave a testimony about caring for sickle cell child and the struggles she face on a daily basis.

f). Sibling testimony - Boston United States

Ms. Faridah Sekabembe, a nurse and a sister of Lukiah Mulumba gave a sibling testimony and how her family watched her sister Lukiah struggled raising a child with sickle cell disease.

g). Entertainment

Kitara Troupe, a traditional/cultural show entertained at free of charge. Participants loved the show and interacted with the dancers. Kitara Troupe donated the show to the sickle cell conference for the entire evening.

h). Video- United States

The sickle cell story video by Lukiah Mulumba's daughter how her daughter battled sickle cell disease through cure by bone marrow and cord blood transplant.

i). Question & Answers/Entertainment

A panel of doctors, nurses and health policy makers answer several questions from the participants.

j). Award/Certificates of attendance

Participants were awarded certificate of attendance and those with children departed

k). Social Networking Cocktail

Entertainment and socializing event free of charge until late.

Organizers-USA:

The conference was organized by Lukiah Mulumba of Uganda-American Sickle Cell Rescue Fund, California, and United States.

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