Ministry of Health, Uganda

Central Public Health Laboratories

Minutes of the 6th International Symposium on Sickle Cell Disease in Central Africa

At Hotel Africana Kampala (Uganda) from 25th to 27th May 2016

Programme

1. Welcome remarks from the Permanent Secretary of Ministry of Health (Uganda)
2. Remarks from the Head of Central Public Health Laboratories (CPHL), MOH Uganda
3. Opening Ceremony, Master of Ceremonies, and Prayer Sessions
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5. Remarks from the REDAC President
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22. Highlights from Parallel Sessions on Research and Free Communications
23. Closing ceremony and Presentation of Kampala Communiqué

Agenda items	Key Highlights and Best Practices
MIN 8	1. Ministry of Health (CPHL) to follow-up with the Rt. Hon. Speaker of Parliament about passing a motion in parliament calling for government intervention in facilitating the procurement of sickle cell screening equipment for all hospitals in Uganda, in order to support the new-born sickle cell screening initiative. 2. The national sickle cell programme to organize a nation-wide survey to investigate the prevalence of sickle cell disease in all districts in Uganda 3. The national sickle cell programme to scale up new-born screening services to other high burden districts, introduce Hydroxyurea, and

	implement a policy to administer pneumococcal vaccine to children. 4. The national sickle cell programme to devise a mechanism of encouraging religious leaders to participate in enhancing awareness on sickle cell disease
MIN 12	5. The national sickle cell programme to consider adoption of the following recommendations from conference guest speakers: • There is need to develop policy guidelines on improved pre-transfusion testing and limited phenotype matching in order to improve the management and prevention of erythrocyte alloimmunization among sickle cell disease patients in Uganda • There is need for systematic screening for Hepatitis C Virus in sickle cell disease patients especially those multi-transfused, to ensure early detection and management. • There is need to educate and sensitize sickle cell disease patients on Hepatitis C Virus risk factors and safe sexual practices
MIN 16	6. The national sickle cell programme needs to seek discussions with governments, drug authorities, and pharmacists geared towards making Hydroxyurea affordable and available.
MIN18	7. The national sickle cell programme to consider merits of rapid point of care devices for sickle cell testing and assess possibilities of adopting them in Uganda.
MIN19	8. The national sickle cell programme to devise mechanisms or strategies of: • Increasing awareness of sickle cell in communities, • Empowering sickle cell disease patients with knowledge on ways of living with sickle cell disease, • Enabling early diagnosis (ideally in neonates), • Enabling prevention from infection including malaria, definitive treatment and networking, and • Lobbying for increased funding of research in sickle cell disease management
MIN22	9. The national sickle cell programme to explore possibilities of adopting the pneumococcal and malaria vaccines innovated by PATH. 10. The national sickle cell programme to consider developing and periodic review of policies and guidelines for screening, treatment, and follow-up and general managing of sickle cell disease.
MIN 23	11. Uganda's Ministry of Health to devise mechanisms of collaborating with the Ministry of Health in Nigeria in curbing prevalence sickle cell disease.

MIN 1: Welcome remarks from Permanent Secretary of Ministry of Health (Uganda)

- The 6th REDAC symposium was called to order at 9.00am by Dr. Asuman Lukwago, the Permanent Secretary of Uganda's Ministry of Health (MOH).
- Dr. Asuman Lukwago:
    - Welcomed all conference speakers and delegates to the 6th symposium on Sickle Cell Disease

- Acknowledged the presence of: the WHO country representative; the REDAC President; Prof. Anthony Mbonye (the Director Clinical Services); Dr. Jessica Nsugwa (the Commissioner of Community Health Department); Prof. Christopher Ndugwa (a retired professor of pediatrics and founder of the Mulago Hospital Sickle Cell Clinic); guest speakers and research experts from several countries.
- Informed delegates that the president of Uganda, the chief guest, will be represented by the Hon. Speaker of Parliament.
- Thanked all guest speakers for their research efforts in sickle cell disease diagnosis and treatment.
- Informed delegates that lab services in Uganda started in 1926 at Nakasero Hospital but for only a selected group of the community, and were strengthened in 1962 when the British constructed Mulago National Referral Hospital, the biggest hospital in Uganda as a gift to Ugandans.
- Encouraged conference delegates to consider visiting other historical sites in Uganda.
- Requested the Head CPHL, the host institution of REDAC2016, to brief conference delegates with an overview on laboratory services in Uganda.

MIN 2: Remarks from the Head of Central Public Health Laboratories, MOH Uganda

Mr. Aisu Steven, the Head of CPHL, welcomed delegates and briefed them as follows:

- CPHL was initially established to provide laboratory support to vertical disease programs, but the proliferation of health programs increased demand for lab services and resulted into the current network of 1500 Public and Private Not for Profit laboratories and 1500 private laboratories.
- The **mission** of CPHL is to ensure sustainable health laboratory services to support the delivery of Uganda Minimum Health Care Package at all levels
- The **vision** of CPHL is to contribute to the Ministry of Health vision of ensuring a productive population through the provision of acceptable, affordable and quality laboratory services to all persons
- The **goal** of CPHL is to establish coordinated health laboratory services that function according to national and international standards
- Currently the **functions** of CPHL fall under two categories:
    - **Provision of reference laboratory services:** for Surveillance and outbreak confirmation, HIV early infant diagnosis, Viral load monitoring for ART, and Sickle cell diagnosis and surveillance
    - **Coordination or providing guidance and support to sub-national level laboratories in the areas of:** lab supplies chain management, equipment management and maintenance, laboratory information management system, human resource capacity building, bio-risk management and infrastructure, public health lab based research, financing laboratory services and accountability, regulatory framework for lab services, and monitoring and evaluation
- The increasing complexity and scope of lab services and the escalation of emerging and re-emerging disease conditions, have underlined the need for a comprehensive legal framework for health laboratory services.
    - Therefore, the Uganda National Health Laboratory Services (UNHLS) Bill was developed and is currently undergoing approval processes.

MIN 3: Opening Ceremony, Master of Ceremonies, and Prayer Sessions

- On day 1, the Master of Ceremonies was Dr. Jessica Nsugwa, the Commissioner of Community Health.
- On days 2 and 3, the Master of Ceremonies was Dr. Nicholas Nanyeena, a medical doctor at Lubaga Hospital.
- Prayer in the opening ceremony on day 1 and day 2 was led by Mrs. Rita Eragu Nabukenya, the Program Secretary of CPHL.
- Prayer for other break-out sessions and closing sessions for day 2 and day 3 was led by a volunteer from the conference delegates.

MIN 4: Remarks from the National Sickle Cell Coordinator (Uganda)

Mr. Charles Kiyaga, the National Sickle Cell Coordinator:

- Welcomed chief guests, guest speakers, and conference delegates.
- Appreciated the leadership of Uganda's Ministry of Health, and support from the Ministry's Permanent Secretary, the Director General health Services, and the State Minister of health.
- Informed delegates that the idea of conducting a survey on sickle cell prevalence in Uganda was conceived in 2011/2012 by a team of four comprising, Mr. Charles Kiyaga, Prof. Russell Ware, Prof. Grace Ndeezi, and Dr. Jane Ruth Achieng (the Director General health Services).
    - Cincinnati Children's Hospital Medical Center, Cincinnati (Ohio, USA) sponsored the survey and the new-born screening initiative in 8 sites in Uganda, which has so far screened 50,000 babies.
- Appreciated the REDAC board for accepting Uganda to host the 6th REDAC symposium in May 2016.
- Appreciated the Director General health Services for appointing a hardworking team of 30 members to organize the symposium.
- Informed delegates that the major challenge in curbing sickle cell prevalence is the very limited awareness of sickle cell disease burden.
    - Therefore, REDAC 2016 invited ministers of health in Sub-Saharan Africa to pass a declaration or communiqué on sickle cell disease.

MIN 5: Remarks from the REDAC President

Prof. Léon Tshilolo, the REDAC president:

- Appreciated guest speakers and delegates for honoring the REDAC invitations to the 6th Conference.
- Informed members that:
    - REDAC occurs every 2 years in a chosen country, and that it was first hosted in Kinshasa and subsequently hosted in Angola, Burundi, and Uganda.
    - REDAC is a French abbreviation for "Reseau D'etude Sur La Repanocytose En Afrique Centrale", translated as the Central Africa Network of Sickle Cell Disease Study.

- REDAC's mission is to develop collaboration towards promoting the struggle against sickle cell disease among concerned countries (i.e. Angola, Burundi, Cameroon, Gabon, Equatorial Guinea, Kenya, Uganda, Central African Republic, Republic of Congo, Demographic Republic of Congo, Rwanda, South Sudan, Chad and Tanzania) and the scope of the association's activities is in the countries.
- REDAC is a platform for exchanging and disseminating knowledge about sickle cell disease among member countries, in order to reduce the disease burden.

- Appreciated Uganda and the organizing committee in Uganda for hosting the 6th conference.

MIN 6: Remarks from WHO Country Representative (Uganda)

Dr. Alemu Wondimagegnehu, the WHO Country Representative:

- On behalf of the WHO Director General (Dr. Margaret Chan) and the WHO Regional Director (Dr. Tshidi Moeti), appreciated the invitation of giving opening remarks at REDAC 2016 under the theme: "accessible treatments, new technologies and break the silence"
- Congratulated REDAC and researchers/experts for the immense work accomplished in the field of sickle cell disease, which has built momentum for providing quality prevention and control services to those affected by sickle cell disease in the African region.
- Informed delegates that:
  - Sickle cell disease is a major genetic disease that affects red blood cells in most countries in Sub-Saharan Africa with about 240,000 born with sickle cell disease annually, and 50% to 80% of these die before their 5th birthday.
  - Uganda is one of the countries with the highest prevalence of sickle cell trait in the world at 45% in some parts of the country, which increases chances of getting children with sickle cell disease. Other countries in the region with high burden of sickle cell trait include Cameroon, Republic of Congo, Gabon, Ghana and Nigeria, where the prevalence is between 20% and 30%.
    - The geographic distribution of the sickle cell trait is very similar to that of malaria due to its partial protective effect against malaria.
    - However, those who inherit the gene from both parents do not have this protection and suffer from severe effects of sickle cell disease.
  - In countries where sickle cell trait prevalence is above 20%, the sickle cell disease affects about 2% of the population, which would translate to about 700,000 people in Uganda with sickle cell disease. This is huge burden to the health system given the level of care that these patients need.
  - Sickle cell disease has major social and economic implications for the affected individuals and their families. Recurrent sickle cell crises interfere with the patient lives especially with regard to education, work and psychosocial development and lead to disability and premature death.
  - Despite the big burden of sickle cell disease in the African region, prevention and control programmes face challenges in many of these countries including Uganda. These challenges include:
    - Insufficient allocation of resources to match the commitment to tackle the prevention and control of sickle cell disease

        - Lack of systematic genetic counseling and screening, especially pre-marital, which could lead to a substantial reduction in the number of children born with the trait.
        - Inadequate capacity of the health system for management of the affected, including not proving the necessary information to the patients which would ease the burden of the disease on them.
        - Inadequate surveillance systems and registries for sickle cell disease and other genetic disorders.
        - Lack of good quality local data and research on genetic diseases to inform appropriate policy and planning.
- Congratulated Uganda for conducting the first national sickle cell survey in 2014, which provided information on the magnitude of the problem to guide the Ministry of Health to design appropriate interventions.
- Informed delegates that although there is currently no cure for sickle cell disease, treatments exist got the pain and other aspects of the disease. There is sufficient evidence that new-born screening, when linked to timely diagnostics testing, parental education and comprehensive care greatly reduces morbidity and mortality in infancy and early childhood.
- Informed delegates that research in some countries in the region (Benin, Burkina Faso, Nigeria, Togo) has indicated some agents like Hydroxyurea are effective in preventing or reducing the frequency and severity of crises, even in African countries with high burden of malaria.
- Emphasize that more research needs to be done to advance the treatment of sickle cell disease.
- Reminded delegates that:
    - At the global level, the 59th World Health Assembly (WHA), composed of Ministers of Health of all WHO member states, adopted a resolution on sickle cell disease. The resolution calls upon affected countries and WHO to strengthen their response, by:
        - Increasing awareness of the communities regarding the burden of sickle cell disease;
        - Promoting equitable access to health services; and
        - Supporting research to improve quality of life of the affected persons.
    - A resolution on the prevention of birth defects including sickle cell was adopted by the 63rd WHA in May 2010.
- Assured delegates that:
    - WHO mainly focus on supporting primary prevention initiatives including genetic counseling, general public knowledge, early detection, chemoprophylaxis, vaccines against common infections, clinical care of special groups (children and pregnant women), capacity building of human resources and strengthening partnerships to tackle the disease
    - WHO in Uganda will continue supporting the Ministry of Health to strengthen the interventions for prevention and control of sickle cell disease
- Commended the Government of Uganda for hosting the important REDAC symposium for the first time, and indicating commitment to tackle the sickle cell problem.

- Wished delegates fruitful deliberations towards enriching and advancing the agenda on prevention and control of sickle cell disease in Ugandan and in the African region.

MIN 7: Remarks from Honorable State Minister for Primary Health Care (Uganda)

Hon. Sarah Achieng Opendi, Uganda's State Minister for Primary Health Care welcomed REDAC delegates and addressed them as follows.

- Informed delegates that:
    - The United Nations, World Health Organization (WHO), and African Union declared sickle cell disease to be a major public health problem in Sub-Saharan Africa.
    - WHO further reported that sickle cell disease contributes substantially to under-five childhood mortality in Africa, and therefore sickle cell disease impedes efforts toward achieving Millennium Development Goals 4 and 5.
    - At its 56th session for the WHO regional committee for Africa, countries with high sickle cell prevalence were challenged to develop and implement comprehensive national sickle cell disease control programmes, within the context of their national health strategic plan.
    - To support the global agenda of combating sickle cell disease in high burden countries where Uganda is part, in February 2014 the Ministry of Health working in collaboration with Cincinnati Children's hospital (based in the USA) and Makerere University launched a national baseline survey to assess the prevalence of sickle cell disease in the country.
    - The survey ended March 2015, having tested close to 100,000 babies.
    - Results depicted a high prevalence of sickle disease and trait across all districts of Uganda, which was the objective of the survey.
    - Survey results motivated a pilot initiative of neonatal screening in 8 out of the 47 high burden districts.
    - The pilot that has run since April 2015 and punctuated by several outreach-screening campaigns has so far resulted in testing over 35,000 individuals, of whom over 7000 were trait and over 500 were diseased. Most of these were individuals and families who did not know they had sickle cell. The identified patients had the opportunity of being put on a care plan, which has improved the quality of their life.
    - Despite the challenges faced, the pilot has proved the feasibility of setting up a national sustainable sickle cell program, which is a complex task that needs collaborative efforts if it is to be handled effectively.
    - Sickle cell disease is not just a killer, but is costly for the health system, often requiring repeated blood transfusions and is a common reason for school absenteeism. Families with affected children also invest a lot of time, resources, and emotional energy for the health of their children.
- Appreciated:
    - Health development partners (like PEPFAR, Global Fund, WHO, UNICEF, and many others) for supporting efforts towards combating the major communicable diseases.

- Cincinnati Children's Hospital (USA), for partnering with Uganda on this survey and for building laboratory capacity for the ongoing neonatal and outreach based screening efforts.
    - Our current laboratory capacity can run about 500,000 tests in one year. This capacity is not small by any standards and is a good starting point for our efforts, though there is a lot more that is needed on top of the lab capacity.

- Acknowledged that sickle cell being a genetic disease is not curable but preventable. Therefore screening and counseling is the strategic intervention that will eventually reduce the incidence of the disease, and this is where Uganda wants to focus all efforts.
- Advised that the neonatal screening that started in the 8 districts should be expanded to cover the entire 47 high burden districts, and later cover the entire country, as there is no district spared according to the survey results.
- Informed delegates that Uganda government has earmarked 400,000,000/= this year through the National Medical Stores to procure sickle cell testing reagents and the procurement process is underway.
- Assured delegates that Uganda shall continue to allocate more resources to this critical but neglected service area.
- Acknowledged that the burden for sickle cell burden is so big for a single player like government, and calls for combined efforts between public, private and development partners, to effectively handle the problem.
- Appealed for concerted efforts through partnerships to combat the sickle cell health challenge, which besides putting demand to the meager health resources, it renders the victims unproductive, leave alone the pain, discomfort and eventual death.
- Appealed to all stakeholders to join hands with government to effectively handle the sickle cell problem.
- Acknowledged that there is need to break the silence at the national level and at the lowest levels in order to save children.
- Urged politicians, health workers, school teachers, the corporate world and the general public to support the sickle cell program by: increasing awareness, encouraging screening, health seeking behavior, counseling of affected families, and providing quality care to the patients in individual and collective capacities.
- Appreciated the technical team in Uganda's Ministry of health (led by the Director General of Health Services) for all efforts made towards addressing the sickle cell challenge.

MIN 8: Remarks from Rt. Honorable Speaker of the Ugandan Parliament

The Rt. Hon. Rebecca Kadaga, the Speaker of Parliament (Uganda), welcomed conference delegates, conveyed greetings from the President of the Republic of Uganda, and addressed delegates as follows.

- Appreciated REDAC board for choosing Uganda as the host of the 6th Symposium.
- Acknowledged that many Ugandans are ignorant about sickle cell disease, and urged the Ministry of Health to plan and implement all measures towards increasing sickle cell awareness.

- Assured delegates that she will pass a motion in parliament calling for government intervention in progressively facilitating the procurement of sickle cell screening equipment for all hospitals in Uganda, in order to support the new-born sickle cell screening initiative.
- Informed delegates that after WHO declared sickle cell disease as a major public health problem for Sub-Saharan Africa, several tremendous efforts have been taken in Uganda towards the management and treatment of the disease as a means to rid the country of the burden.
    - Findings from the 2013/2014 Uganda sickle cell prevalence survey indicated a high sickle cell burden, with a national trait average of 13.3%, and disease burden of 0.73%. However, the distribution is not uniform across the country. In some high burden districts the prevalence of the trait is above 20% and that of the disease above 1.5%.
    - Consequently Uganda started targeted new-born screening in the high burden districts of Gulu, Lira, Kitgum, Dokolo, Oyam, Tororo, Jinja and Kampala (covering a total of 274 health facilities). So far over 50,000 new-born babies have been tested.
    - Health workers in these facilities have been trained in sickle cell management and sickle cell clinics have been opened up. These clinics have been availed with prophylactic drugs like penicillin, anti-malarials, and folic acid etc.
    - Also mass sensitization campaigns and counseling have been conducted in several districts to create more awareness about the disease amongst communities.
    - Pre-marital counseling and testing is being promoted in collaboration with religious leaders.
- Informed delegates that Uganda's Ministry of Health plans to:
    - Scale up new-born screening services to other high burden districts
    - Introduce Hydroxyurea, which is a disease transforming drug. Some children are on it privately and are doing very well.
    - Implement a policy to administer pneumococcal vaccine to children with sickle cell disease above 2 years to protect them from recurrent infections.
- Indicated that:
    - Uganda's efforts towards building and strengthening sickle cell research and clinical capacity encouraged REDAC to nominate Uganda as a host of the 6th International Symposium on Sickle Cell Disease.
    - REDAC raises the profile of sickle cell disease that has been largely neglected over the years in Sub-Saharan Africa, by bringing together distinguished scientists, clinicians, policy makers, researchers, advocacy groups, technology and pharmaceutical companies.
    - It is also a great opportunity for Uganda to build collaborations and generate the momentum needed to adequately address the big burden of sickle cell disease in the country.
- Wished delegates fruitful deliberations and successful efforts in: raising the profile of Sickle Cell disease in Africa; sharing new knowledge and technological advances in sickle cell management and diagnosis; and building collaborations necessary for resource mobilization to advance the cause of sickle cell disease in Africa.

MIN 9: Entertainment Sessions at REDAC 2016

- Performances during the opening ceremony, interlude sessions, and closing ceremony at REDAC 2016 were done by the following:
    - Percussion Discussion Performance Group
    - Children from Zainab Baby School, Kampala City
    - Children from Our Lady Parents School, Luwero District

MIN 10: Highlights from Session 1 – Sickle Cell Disease in the Republic of Uganda

Chaired by Prof. Russell Ware and Prof. Jacques Elion, this session involved presentations and discussions on the following topics presented by the following guest speakers:

- Prof. Christopher Ndugwa provided a chronological perspective of initiatives on sickle cell disease in Uganda since 1945, including the establishment of: the Sickle Cell Clinic in the Department of Pediatrics and Child Health at Mulago Hospital in 1971; and other sickle cell clinics at Nsambya Hospital, Lubaga Hospital, Jinja Hospital, Soroti Hospital, Lira Hospital, and Lucor Hospital since 1986.

- Dr. Irene Lubega provided insight into completes research on sickle cell disease in Uganda, ranging from the first sickle cell survey in 1949 through the past research efforts on sickle cell disease, to the current need for collaborative efforts on research initiatives of curbing sickle cell disease.

- Prof. Grace Ndeezi presented findings from a sickle cell surveillance study that was funded by Cincinnati Children's Hospital, in order to explore prevalence and mapping of sickle cell trait and disease in Uganda.

MIN 11: Highlights from Session 2: International Networks

This session, chaired by Prof. Thomas Williams and Prof. Leon Tshilolo, involved presentations and discussions on the following topics presented by the following guest speakers:

- Prof. Leon Tshilolo (on behalf of Dr. Baron Ngasia) presented highlights on: the prevalence of Hemoglobinopathies in Africa, origin of sickle cell disease and its associated forms of prevalence, social problems of children with sickle cell, the motivation of REDAC and its inception in May 2010, REDAC member countries, policies, funding members, and member subscription fees.

- Prof. Marvin Reid presented key highlights on the motivation for establishing the CArribean network of Researchers on Sickle cell disease and Thalassemia (CAREST) to advocate for sickle cell disease in the Caribbean, CAREST objectives, collaborating programmes and strategies, CAREST achievements and research contributions, its resources, and its governance board.

- Prof. Jacques Elion (on behalf of Dr. Isaac Odame) presented highlights on the motivation, achievements and research contributions of the global sickle cell disease network, and emphasized the need to strengthen support for sickle cell research collaborations.

MIN 12: Highlights from Session 3: Blood Transfusion Part I

The session was chaired by Prof. Marvin Reid and Dr. Françoise Bernaudin, and it involved presentations and discussions on the following topics presented by the following guest speakers:

- Assoc. Prof. Mariane de Montalembert discussed key findings on iron pathways in sickle cell disease, introduced the concepts of iron metabolism, iron absorption, hepdicin; and underlined the critical challenge of diagnosing iron deficiency in Sickle cell disease children and the frequent challenge of iron overload in sickle cell disease patients.

- Dr. Bernard Natukunda introduced the concept of erythrocyte alloimmunization among transfused sickle cell disease patients in Uganda, risks and consequences of erythrocyte alloimmunization; and recommended the development of a policy on improved pre-transfusion testing and limited phenotype matching in order to improve the management and prevention of erythrocyte alloimmunization among sickle cell disease patients in Uganda

- Dr. Philip Kasirye presented NIH/NHLBI transfusion guidelines and their customization in the Uganda setting to guide blood transfusion geared towards reducing the sickling of cells.

- Prof. Heather Hume discussed the concept of transfusion support and safety in sickle cell disease, articulated the 3Rs of blood transfusion (i.e. Right unit, Right person, Right time); and asserted that for success to be attained in providing adequate treatment to sickle cell disease patients in Africa in the coming years, there is need to pay much more attention to blood transfusion therapy.

- Dr. Bérengère Koehl discussed the procedure of performing a Manual Exchange Transfusions (MET) in children with sickle cell anemia without causing iron overload; highlighted benefits of the three forms (i.e. Simple Chronic Transfusion, Manual Exchange transfusion, Erythrapheresis) of blood transfusion in sickle cell disease patients; emphasized that Erythrocytapheresis is the safest and most effective method for chronic transfusion therapy in sickle cell anemia, but not widely implemented due to technical and financial reasons. Concluded that MET method can be widely utilizable for all children with no specific equipment and that may be efficient, safe and effective in limiting iron overload.

- Dr. Nitcheu Diego Tchouakam discussed the concept of Seroprevalence and risk factors of hepatitis C virus infection in patients with sickle cell disease, and how it was explored in Douala Laquintinie Hospital; and recommended the need for:
    - Systematic screening for Hepatitis C Virus to sickle cell disease patients especially those multi-transfused, to ensure early detection and management.
    - Educating or sensitizing sickle cell disease patients on Hepatitis C Virus risk factors and safe sexual practices

MIN 13: Highlights from Session 4: Blood Transfusion Part II

Chaired by Dr. Bernard Natukunda and Prof. Heather Hume, this session involved presentations and discussions on the following topics presented by the following guest speakers:

- Dr. Mohamed Cherif Rahimy discussed challenges of blood transfusions in sickle cell disease patients in Africa, and highlighted the feasible progress in transfusion therapy in sickle cell disease patients in Sub-Saharan Africa pointing out the adverse effect of resource-constrained working environment on therapy.

- Dr. Asaah Nkhokwo discussed the Pan-African blood safety perspectives towards improving blood supply safety and adequacy in Sub-Saharan Africa; highlighted public health challenges in blood supply adequacy & safety in Africa, and technological perspectives towards improving health care provision for people who may need the transfusion of blood and its products in Africa

- Dr. Franck Nzengu presented highlights on the role of iron deficiency in blood donors and iron status in sickle cell patients in Kinshasa

- Dr. Olivat Rakoko Alson presented highlights on initiatives on blood transfusions of Malagasy sickle cell disease patients.

- Delegates also received highlights by Dr. Gylna Loko on the four-year experience on Erythrapheresis in Martinique.

MIN 14: Highlights from the Poster Session and Sponsor Expo

These sessions were held on all conference days in two halls, i.e. Nile hall and Katonga hall at hotel Africana, Kampala, with the following events:

- Parallel discussions on posters that exhibited new advancements and ongoing research in sickle cell disease diagnosis and management (in Nile Hall).

- A laboratory demonstration or satellite presentation on the application of Hb Electrophoresis and ISE focusing by PerkinElmer (in Katonga Hall).

MIN 15: Highlights from Session 5: Co-Morbidities of Sickle Cell Disease

The session was chaired by Prof. Marina Cavazzana and Dr. Ezekiel Mupere, and it involved presentations and discussions on the following topics presented by the following guest speakers:

- Prof. Thomas Williams discussed the relationship between sickle cell disease and malaria in East Africa, indicating that it is cost-effective to prevent malaria than treating it among sickle cell disease cases (especially children).

- Prof. Grace Ndeezi discussed the burden of sickle cell disease and HIV, indicating that HIV and sickle cell disease tend to overlap in terms of geographical distribution; about 50% of HIV(+) babies die before age 2 years, and that the low prevalence of sickle cell disease among HIV positive infants could be explained by early mortality.

- Prof. Yves Colin Aronovicz introduced members to Fy-null (Fya-b-), the most common Duffy blood group phenotype in sickle cell patients and the African general population; and indicated that this is a selective advantage of protection against Staphylococcus aureus by iron deprivation of Iron.

- Dr. Valentine Brousse of discussed the concept of the sickle (led) spleen, the spleen and its functions, association between sickle cell disease and the spleen, a comprehensive

perspective of spleen dysfunction in sickle cell anemia; and indicated that the spleen is the first organ injured in sickle cell anemia.

- Prof. Lucio Luzzatto discussed intravascular hemolysis in G6PD deficiency and sickle cell anemia in malaria-endemic regions, reporting that malaria parasites cause oxidative stress.

- Prof. Jean-Paul Gonzalez discussed the impact of infectious diseases and chronic diseases on beta S gene carrier, indicating that there is an increase in synergistic condition for HCV or HBV hepatitis, Pneumococcal and Meningococcal.

- Delegates missed the presentation by Dr. Jesca Nakibuuka on malaria prevalence among children with sickle cell anemia and fever attended to at Mulago Hospital.

MIN 16: Highlights from Session 6: Sickle Cell Disease Therapy: Hydroxyurea

This session was chaired by Dr. Henry Ddungu and Prof. Caroline Le Van Kim, and it involved presentations and discussions on the following clinical trials:

- Dr. Robert Opoka presented ongoing collaborative research on the Novel use Of Hydroxyurea in an African Region with Malaria (NOHARM) using clinical trials.

- Prof. Marvin Reid presented highlights from a clinical trial of the EXTEND (EXpanding Treatment for Existing Neurological Diseases) initiative, indicating that stroke is a common incidence in sickle cell disease cases and chronic transfusion is paramount in sickle cell disease management.

- Prof. Russell Ware presented highlights from a clinical trial of the REACH (Realizing Effectiveness Across Continents with Hydroxyurea) initiative undertaken at Cincinnati Children's Hospital Medical Centre in Ohio (USA). He emphasized that Hydroxyurea is a potent disease–modifying therapy and works in all ages, and that data from REACH will inform evidence-based guidelines for safe and effective use of Hydroxyurea treatment.

    - He recommended that there is need to seek discussions with governments, drug authorities, and pharmacists geared towards making Hydroxyurea affordable and available.

- Dr. Peter Olupot-Olupot further presented highlights from the REACH study, about baseline characteristics of children with sickle cell anemia across Africa, emphasizing that a knowledge gap exists in the use of Hydroxyurea in Africa despite its 30 years of safety and efficacy; and the challenge of Hydroxyurea treatment is monitoring dosage

- Dr. Abel Makubi, discussed the rationale and design of a trial conducted at Muhimbili National Hospital (Tanzania) on the effect of Mobile-Directly Observed Therapy (mDOT) on adherence to Hydroxyurea treatment in adult HbSS patients. He indicated that sickle cell disease is a major public health problem and is associated with significant morbidity caused by pain, crises, acute chest syndrome, stroke and hypertension; yet data on adult sickle cell anemic patients is also largely unknown particularly in Sub Saharan Africa.

- Delegates missed the presentation of Dr. Patrick McGann, which was about a clinical trial on Therapeutic Response Evaluation and Adherence Trial (TREAT), which resulted in a personalized dosing strategy of Hydroxyurea that has the potential to individualize

therapy and optimize the dose titration of Hydroxyurea therapy for children with sickle cell anemia.

MIN 17: Highlights from Session 7: Stroke and Vasculopathy

This session was chaired by Prof. Russell Ware and Prof. Lucio Luzzatto, and involved presentations and discussions on the following topics:

- Dr. Munube Deogratious discussed findings from a study on prevalence of stroke in children admitted with sickle cell anemia in Mulago Hospital, and indicated that: stroke in children with sickle cell anemia is low and present in our population of children with sickle cell anemia; and it commonly presents as a single disease entity or can present with other co-morbidities such as severe anemia, bacteremia and vaso-occlusive crises.

- Dr. Françoise Bernaudin presented findings from a study on management of cerebral vasculopathy in sickle cell anemia, detection of patients at risk of Stroke, silent cerebral infarcts, primary stroke prevention, and secondary prevention of silent cerebral infarcts. He indicated that chronic transfusion remains the referral treatment for secondary stroke prevention, initial management of patients with abnormal velocities and patients with severe stenosis.

- Prof. Brigitte Ranque discussed the epidemiology of vascular complications in Sub-Saharan African among patients with sickle cell disease, indicating that life expectancy is increasing in Sub Saharan Africa; and mentioned some complications such as pulmonary hypertension, cerebro vascular disease, vascular complications included leg ulcers, priapism, stroke, osteonecrosis and glomerulopathy.

- Dr. Gisele Kazadi presented findings from a study experience of using transcranial Dopier among sickle cell disease patients in Kinshasa (in DRC).

- Dr. Jacques Aimé Bazeboso presented findings from a study conducted (in DRC) on the contribution of Doppler Ultrasound in the assessment of early changes in renal vascular resistance in sickle cell disease.

MIN 18: Highlights from Session 8: New technologies and Nouveax outils

Chaired by Dr. Eliane Gluckman and Prof. Grace Ndeezi, this session involved presentations by the following guest speakers on new technologies:

- Dr. Patrick Ducoroy discussed merits and demerits of: conventional methods that focus on proteins, rapid paper-based test for quantifying sickle hemoglobin in blood samples from patients with sickle cell disease, rapid point of care sickle cell test; and introduced the method of diagnostic screening using Mass spectrometry – MALDI-MS and the dual use of MALDI-TOF Mass spectrometry for clinical microbiology and newborn screening of sickle cell disease. He indicated that:

    - Despite merits of rapid point of care sickle cell test (i.e. it requires no equipment and electricity, generates results within 10 minutes, easy to use without specific qualification, and costs approximately 5$), it can be difficult to track and inform families of infants with positive screening results in limited-resource settings with unreliable telephone service and no definitive street addresses.

- Prof. Caroline Le Van Kim discussed new tools for investigating blood cell properties in sickle cell disease towards drug efficacy, contributing factors to sickle cell disease vaso-occlusive crisis, and integrated analyses of red blood cell properties. She indicated that Poloxamer significantly reduces blood viscosity and RBC adhesion to endothelial cells in normoxia and in hypoxic conditions, which makes it a safe molecule for use in sickle patients during acute events.

- Dr. Xavier Dubois introduced the Spectra Optia system, an innovation by Terumo BCT agency, as a state of the art therapeutic apheresis device that supports automated red blood cell exchange in patients with sickle cell disease who need regular transfusion.

- Prof. Russell Ware, on behalf of Dr. Patrick T. McGann, introduced and discussed innovations on Point of Care devices for the rapid diagnosis of sickle cell disease.

- Dr. Robert Kitenge presented findings from an experience of using SysToe to explore peripheral vasculopathy in sickle cell disease patients.

- Dr. Suzanne Belinga presented findings from a pilot project conducted in Cameroon on neonatal screening for sickle cell disease.

MIN 19: Highlights from Session 9: Innovative Treatments

Chaired by Prof. Brigitte Ranque and Dr. Baron Ngasia, this session involved the following presentations on innovative treatments for sickle cell disease:

- Prof. Jacques Elion presented findings on Pathophysiologically-based development of new drugs in sickle cell disease; indicating that hydroxycarbamide that is used in sickle cell management is highly effective in reducing pain, but is less effective than chronic transfusion in preventing stroke recurrences.

- Prof. Marina Cavazzana presented findings from an investigation on Gene therapy for sickle cell disease, indicating that a promising approach for treating patients with hemoglobinopathies is gene therapy (using autologous hematopoietic stem cell transduced with LentiGlobin BB305 lentiviral vector).

- Prof. Lucio Luzzatto discussed issues of ethics, science, and public health of in the management of sickle cell disease; indicating that sickle cell anemia is a molecular disease that involves substitution of gluconic acid and has a 3 dimensional shape of hemoglobin, which requires the injection of urea in sicklers in order to undo the polymerization of hemoglobin. He urged delegates to:
    - Increase awareness of sickle cell in communities,
    - Empower patients with knowledge resources or practical ideas such as those documented in the book titled "**How to live with Sickle cell disorder**" by the late Olu Akinyanju Adebayo Olujohungbe (who was his student and a sickler).
    - Establish mechanisms of enabling early diagnosis (ideally in neonates), prevention from infection including malaria, elimination of malaria, definitive treatment and networking.
    - Increase funding of research in sickle cell disease management.

- Dr. Eliane Gluckman discussed findings from a critical assessment of an international survey (from 1986 to 2013) on Hematopoietic Stem Cell Transplantation (HSCT) from HLA identical siblings for sickle cell disease; indicating that HSCT is the only curative therapy

for sickle cell disease, and therefore there is need to increase awareness to early referral to HSCT of patients with severe sickle cell disease. She however highlighted that HSCT is offered to relatively few patients with sickle cell disease due to:
    - Lack of a suitable HLA- matched donor,
    - Lack of consensus on indications for HSCT,
    - The potential risk of trading one chronic condition for another, such as chronic graft-versus host disease (GVHD), and
    - The mortality associated with the procedure.

- Delegates also received highlights by Dr. Jacques Aimé Bazeboso on the treatment of Hypersplenism by arterial embolization in sickle cell disease patients.

MIN 20: Highlights from Session 10: Newborn Screening

This session (conducted in parallel with the ministerial session in MIN 21) was chaired by Dr Patrick McGann and Dr. Mohamed Cherif Rahimy, and it involved the following presentations on experiences in newborn screening for sickle cell:

- Prof. Russell Ware discussed the characterization of hemoglobin variants identified in the Uganda Sickle cell surveillance study; indicating that:
    - Numerous hemoglobin variants were identified in the Uganda Sickle Surveillance Study, including previously described variants and potentially several novel ones.
    - As newborn screening efforts are developed in Sub Saharan Africa, recognition and correct identification will reduce repetitive testing and streamline clinical practice.

- Dr. Danielle Lena discussed findings on screening and managing children with sickle cell syndromes in developing countries, indicating that: effective intervention in children with sickle cell disease provides a major impetus for neonatal screening; and for effectiveness, neonatal screening must be part of a comprehensive program for the care of sickle cell patients.

- Delegates were briefed with highlights, from Dr. Deogratius Munube, on a cost effective analysis of new born screening and prophylactic interventions for sickle cell disease in Sub Saharan Africa.

- Delegates missed the detailed presentation by Mr. Charles Kiyaga on findings from the experience of newborn screening for sickle cell disease in Uganda.

MIN 21: Highlights from Ministerial Session on the Kampala Declaration/Communiqué

This session occurred in Zambezi Hall (in parallel with the session in MIN 20) as follows:

- The session was attended by: the Hon. State Minister for Primary Health Care in Uganda (as Chair of the session), the Hon. Minister for Health of Nigeria, the Acting Director General Heath Services (Prof. Anthony Mbonye), REDAC President, and selected distinguished conference delegates from countries in Sub Saharan Africa.

- The session involved reviewing and discussing observations and declaration statements on sickle cell disease prevalence, screening, and management that constituted the

Kampala Declaration on sickle cell disease. Several edits were suggested and agreed on in order to effectively communicate the need for interventions on sickle cell disease.

- It was noted that since several Ministers for Health (of countries in Sub Saharan African) who had confirmed to attend REDAC conference had not made it, that the resultant product of this session be referred to as the "Kampala Communiqué" rather than Declaration.

MIN 22: Highlights from Parallel Sessions on Research and Free Communications

Below are highlights of events (on research and free communications on sickle cell disease) that simultaneously occurred in two halls, i.e. Nile Hall (chaired by Prof. Jean-Paul Gonzalez) and Kagera Hall (chaired by Dr. Philip Kasirye).

In the session chaired by Prof. Jean-Paul Gonzalez:

- Mr. Charles Andriajara discussed ongoing research efforts on a combined approach of traditional medicine with scientific methods to search new phytodrugs (such as ARR 033 AND ARR 035) for the follow-up of patients with the sickle cell diseases, indicating that the sickle cell disease patients from low income countries cannot afford some drugs that treat sickle cell disease symptoms.

- Mr. B.C. Tendobi discussed an experience on monitoring a pregnancy case with sickle cell disease at Monkole Hospital in Kinshasa (DRC); and indicated the need to conduct regular biological and sonographic checkups by a hematologist and a gynecologist, and to involve an anesthesiologist to conduct intra operative procedures to avoid hydration, cold and hypoxia.

- Dr. Patricia Coffey discussed technology needs assessment for sickle cell disease in Sub Saharan Africa; indicating that the main aim of PATH is to harness the entrepreneurial insight, scientific and public health expertise (across five platforms of vaccines, drugs, diagnostics, devices, and system and service innovations) and passion for health equity in order to save the lives of women and children. She further reported that:
    - Transformative PATH innovations include safe, effective and affordable pneumococcal and malaria vaccines, semi synthetic malaria treatment, and point of care diagnostic for G6PD enzyme deficiency.

- Delegates were briefed by Dr. Paul Nguewa about the Institute of Tropical Health (Instituto de Salud Tropical Universidad de Navarra, ISTUN), indicating that it is a partner for research in Africa.

- Delegates were given insight into existing literature on sport activities and sickle cell disease by Dr. Constant Vodouhe.

- Dr. Gylna Loko presented a proposal to REDAC prompting for the establishment of a common database for a multi centric study of pregnancies.

- Dr. Olivier Mukuku presented findings from an experience of evaluating serum albumin values and trace elements in sickle cell homozygotes SS.

- Dr. Lydie Ngole't presented a report from about a follow up investigation of the proportioning lactate dehydrogenase serum level for sickle cell disease patients in a low income country, specifically the Republic of Congo.

In the session chaired by Dr. Philip Kasirye:

- Dr. Jerome Sulubani briefed delegates with efforts taken towards managing sickle cell disease in Zambia; indicating that the country developed a national policy and treatment guidelines for sickle cell disease, but newborn screening has not yet been initiated and no electronic database exists to provide accurate data on sickle cell prevalence.

- Delegates were briefed by Dr. Muntaser Ibrahim on the Beta S gene haplotypes in an African setting.

- Mrs. Ruth Nkanja Mukiibi shared her experience with sickle cell disease since childhood in an effort to break the silence and enhance community education and outreach on sickle cell disease.
    - She indicated that over the years many countries tend to focus efforts on children with sickle cell disease than adults, and appreciated that emerging trends of research and innovations have hope for solutions to support adults with sickle cell disease.

- Prof. Nancy S. Green discussed factors that need to be considered by families, community, and the health-system in order to reduce the burden of pediatric sickle cell disease in Uganda; and emphasized the need to partner with program leadership, professionals, patients and families, multinational stakeholders, and leverage resources from existing programs in Uganda and elsewhere in Sub-Saharan Africa.
    - She recommended that the Ugandan infant screening system needs to consider: adapting the infrastructure originally developed for HIV in order to build the public health capacity needed for sickle cell disease; implementation of policies and practices to address these issues is critical for linking affected children and their families to effective care.

- Mr. Charles Alule discussed findings from an exploratory study on knowledge, attitude, and practices regarding sickle cell disease among children below 5 years that are attended to at Lira Regional Hospital in Northern Uganda; and reported that there is high incidence of sickle cell disease in Lira district, which underlines the need to scale up appropriate health programs on sickle cell disease to Lira region.

- Prof. Heather Hume discussed reasons leading to the failure to follow-up sickle cell disease patients attended to at Mulago Hospital Sickle Cell Clinic; and reported that a number of Ugandan sickle cell anemia patients experience extended periods of stable health and the number of deaths was smaller than anticipated/ estimated death rates for sickle cell anemia patients.
    - She emphasized that the large number of patients who could not be reached by telephone or sought treatment elsewhere and the unreported deaths, underline the importance of encouraging families to inform clinic staff of changes in their contact details and status.
- Dr. Musa K. Waiswa discussed matters of bacterial infections, susceptibility and the use of leukocytosis in predicting infections among sickle cell patients in Uganda; and indicated

that enhancing rational use of antibiotics in sickle cell anemia patients, calls for improved access to blood cultures because there is currently no known leucocyte count that is predictive of positive blood cultures.

- Dr. Odong Ochaya discussed matters on prevalence, aetiology, and clinical characteristics of Acute Chest Syndrome in children with sickle cell anemia attended to at Mulago Hospital; and emphasized that Mycobacterium tuberculosis and Chlamydia pneumoniae need to be considered seriously in Ugandan children with Acute chest syndrome.

MIN 23: Closing Ceremony and Presentation of Kampala Communiqué

The closing ceremony of REDAC 2016 was attended by the Hon. State Minister for Primary Health Care in Uganda, the Hon. Minister for Health of Nigeria, the Commissioner of Community Health Department (MOH), the REDAC President, the Head of Central Public Health Laboratories, the national coordinator for sickle cell, all conference guest speakers and delegates.

- **Mr. Charles Kiyaga, the national sickle cell coordinator:**
    - Briefed the Ministers with remarkable events that have occurred before (i.e. the sickle cell awareness walk or campaign) and during the conference
    - Informed delegates that the Kampala Communiqué is one of the key outputs of REDAC 2016; and urged them to internalize it and perceive it as an authoritative document as well as point of reference for stakeholders (i.e. development partners and non-governmental organizations) to combat the sickle cell scourge.
- **Prof. Léon Tshilolo, the REDAC President,** appreciated delegates and guest speakers for their research efforts and attendance throughout all the conference events.

The Honorable Minister for Health of Nigeria:

- Appreciated REDAC2016 organizers for inviting Nigeria to join the symposium, although it is part of West Africa and therefore not part of REDAC member states.
- Introduced a team of three distinguished delegates that accompanied him, i.e.: the technical advisor on sickle cell disease management in Nigeria, the coordinator on sickle cell disease initiatives in Nigeria and the administrative secretary.
- Congratulated delegates upon the achievement of advancing knowledge on sickle cell disease via REDAC.
- Updated delegates with statistics on sickle cell disease in Nigeria as follows:
    - Sickle cell disease is one of the top 10 Non Communicable diseases in Sub Saharan Africa and affects nearly 100 million people globally; but Nigeria ranking first with about 200,000 babies born annually with sickle cell disease, of which 100,000 babies die before age of 5 years and 90% of sufferers do not attain adulthood.
        - Sickle cell disease prevalence is sustained by the high circulation of sickle cell trait in the population, with about 24% prevalence in Nigeria.

- Expressed concern that we have lived with sickle cell disease for long and we are at a risk of taking it as a fact of life that we have to endure, and we haven't tackled sickle cell disease with the seriousness we have used in tackling other diseases, and this is not correct.

- Assured delegates that this is one of the reasons why the government of Nigeria wants to join hands with those who are working on this subject with renewed energy

- Updated delegates with the various efforts that the government of Nigeria has taken towards curbing the sickle cell disease burden in Nigeria as follows:

    - Nigeria's National Communicable Diseases Control Division in Ministry of Health developed comprehensive national guidelines for control and management of sickle cell disease, indicating specific guidelines for managing specific clinic problems and protocols for various therapeutic procedures, in order to facilitate uniformity and standardization of care.

    - Nigeria's National Policy and Strategic plan of action for the prevention and control of non communicable diseases was revised in 2015 to include sickle cell disease. This was done to:
        - Ensure comprehensive care for all sickle cell disease patients to provide evidence-based information;
        - Institute a database for universal newborn screening and genetic counseling;
            - Strengthen structures and capacities of patient management, and
            - Conduct research.
        - Some institutions in Nigeria demand for genotype testing as part of marriage counseling.

    - Nigeria's MOH has established and is developing the national blood transfusion service with a mandate to provide safe, quality and adequate blood at in equitable and cost effective manner.

    - Nigeria's Ministry of Health operates six medical centers as sickle cell centers equipped with quality equipment for diagnosing sickle cell disease in newborns.

        - The six centers develop the most acceptable, affordable and accessible ways to prevent, control, and manage sickle cell disease; and boost community participation for sustainable outcomes.

        - The sickle cell center in Lagos was recently recognized by WHO as a reference center for sickle cell disease treatment in Nigeria, and a center of excellence for sickle cell disease research has been established in Abuja

    - The Nigerian Institute for Pharmaceutical Research and Development has developed a sickle cell disease management drug, clinical trials on this drug have been successfully conducted, and the drug was licensed for commercial production.

    - Nigeria's Ministry of Health plans to:

- Intensify public awareness and education programmes correct ancient erroneous beliefs and misconceptions.
- Adopt use of mobile telephone messaging and social media to enhance information dissemination on sickle cell disease.
- Support all those who call for routine screening for sickle cell disease traits and the Know Your Genotype Campaign (in order to increase awareness as it is done with HIV).

- Noted that although care of sickle cell disease currently includes various interventions, evidence indicates that one future option of sickle cell disease management lies in born marrow transplant surgery despite the risks and side effects.
    - Two such transplants have been performed in Nigeria's tertiary and health institutions and they continue to explore the possibility of offering routine bone marrow transplant surgery, and emphasized the need for Nigeria to upgrade human and infrastructure capacity to meet the needed skill

- Urged African governments to:
    - Closely cooperate and collaborate towards developing a strategy to confront the significant genetic sickle cell disease burden in Africa, which also afflicts persons of African origin in the Caribbean and other countries
    - Take ownership of the sickle cell disease problem, and not to depend on getting the same amount of support from developed economies, which would be expected if sickle cell disease was a communicable disease that would affect the rest of the world easily.

- Collaborate in a coordinated action especially in all areas of research, health systems strengthening, sickle cell disease education, prevention, and management.

- Assured delegates that Nigeria, the country with the highest sickle cell disease burden in the world, is prepared to play a role in bringing all actors together towards a concerted response to sickle cell disease

- Commended REDAC for the initiative and thanked Uganda for hosting the REDAC 2016 event

- Encouraged delegates that Nigeria looks forward to sustainable interactions towards curbing sickle cell disease.

Hon. Sarah Achieng Opendi, Uganda's State Minister for Primary Health Care in Uganda:

- Acknowledged the Hon. Minister for Health of Nigeria for showing commitment by attending REDAC 2016.

- Noted that inadequate attention has not been paid to sickle cell disease, and urged other Ministers for Health from REDAC member states to support the REDAC initiative.

- Presented the Kampala Communiqué

- Assured delegates for her support in initiatives towards increasing awareness and management of sickle cell disease and curbing sickle cell disease prevalence.

REDAC 2016 events ended at 6:00pm on 27th May 2016.

Chairperson(s)	**Secretariat**
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Date	**Date**