MUCU ADOLESCENT HEALTH NEWSLETTER

Sickle Cell Disease: Overview and Interesting Facts

May 2018 Issue 11

Dear Partner,

Makerere University and Columbia University (MUCU) are pleased to publish the 11th issue of our newsletter dedicated to Sickle Cell Disease. We are excited to update you on interesting things that have occurred in the area of adolescent medicine. We are delighted that you have continued interest in the care of the adolescent patient and look forward to hearing about **THE WORK THAT YOU ARE DOING** related to adolescent health.

Our mission is to provide a forum to discuss the latest in "hot" adolescent topics

Uganda has a young population, with 52% of its population under the age of 15 years, and 25% ages 10-19 years. In order to help optimize the health of adolescents, reduce their risk-taking behaviors and guide them into thoughtful decision-making that can capitalize on their strengths, access to comprehensive health education and reproductive, physical and mental health care is essential.

The Society of Adolescent Health in Uganda (SAHU) was launched November 2012, following a regional training in Kampala, Uganda led by experts from Columbia & Makerere Universities & the Naguru Teenage Information & Health Centre.
SAHU is now a register Non- Governmental Organization.

SAHU's Mission:

To promote comprehensive adolescent health, growth and development in Uganda through knowledge dissemination, research, advocacy and affiliation with other societies and bodies involved in adolescent health.

The Vision of SAHU:

Each & every adolescent will be provided the opportunity to access his/her potential and grow into a healthy, responsible and independent adult. **Website:** **www.sahu.ug**
SAHU membership is $10 (ugx 30,000)
Become a member by e-mailing:
adolhealthuganda@gmail.com or info@sahu.ug
Include the following information in your e-mail:
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Become A Member

Meet the Newsletter Editorial Board

Co-Editors in Chief

Sabrina Kitaka M.D., *Senior Lecturer & Paediatric & Adolescent Health Specialist, Department of Paediatrics and Child Health, Makerere University College of Health and Sciences Kampala, Uganda and acting President of SAHU. Dr. Kitaka is passionate about promoting adolescent health and medicine in East Africa. For the past 15 years, she has taught Adolescent Medicine at Makerere University College of Health Sciences. Since 2006, she has collaborated with Dr. Betsy Pfeffer and her colleagues at Columbia University, and since 2010, they have conducted three annual in-service adolescent health workshops for East African health providers and four clinical and scientific meetings. She is the director of the Adolescent Program at the Paediatrics Infectious Diseases Clinic at the Mulago National Referral Hospital.*

Betsy Pfeffer, M.D., *Associate Professor of Pediatrics at Columbia University Medical Center and New York Presbyterian Hospital, New York, U.S.A. Dr. Pfeffer is an adolescent medicine clinician who sees teens in an outpatient and inpatient setting, teaches medical students and residents and lectures internationally on multiple topics related to adolescent health care. She has been working together with Dr. Kitaka for over ten years and is committed to their efforts to help improve health care delivery to teens in Uganda. She is a lifetime member of SAHU and the Director of International Relations.*

Editorial Team

Denis Lewis Bukenya *BSWSA, MPA is a social worker and an Adolescent Health Training Specialist and the Training Manager at the Naguru Teenage Information and Health Centre, a pioneer Adolescent Sexual Reproductive Health and Rights program in Kampala, Uganda, that provides advocacy and youth-friendly reproductive health and related services. Denis has nine years of progressive involvement in Adolescent Sexual Reproductive health services' delivery and trainings, psychosocial and behavioural support for children and youth, specifically on Adolescent Sexual Reproductive Health and Rights and HIV/AIDS. He also is the Vice Chair of SAHU.*

Godfrey Zari Rukundo M.D., *Child and Adolescent Psychiatrist, Senior Lecturer and Head of the Department of Psychiatry at Mbarara University of Science and Technology University (MUST). Dr. Rukundo is also the General Secretary of SAHU and the programme Director for MMed Psychiatry Training program. He has expertise in psychiatry through his research in schizophrenia, depression, and mental disorders secondary to general medical conditions. He has been an investigator in a number of funded research grants, with a number of publications coming out of this work. He has interest in quality improvement and has been the chair for the committees of Quality Assurance and Strategic Planning of the Faculty of Medicine at MUST for. He is the National Coordinator of Training in Child and Adolescent Mental Health. He is the Key Personnel for Mental Health Research Training in the ongoing NIH five years Research Training Grant (MURTI).*

Charles Emma Ofwono, *SAHU Web Administrator and Network and Systems Administrator, the B.Sc. degree in Software Engineering from Makerere University, Kampala, in 2012, and currently is pursuing his M.Sc in Information Technology from Walden University, Minneapolis, USA. In2007, he joined Naguru Teenage Information and Health Centre, as a peer leader in the Post Test Club, and in 2010 became the club coordinator. Since March 2013, he has been with the Department of Advocacy and Research, where he coordinates youth programs and ICT/Data. Emma is also the IT manger of SAHU.*

Hot News

ICATCH 2018 Funds Adolescent Health Project in Laos

Ms. Sally Piper Pillitteri and Madame Bai Soulithan are the proud recipients of a three-year grant from the American Academy of Pediatrics' International Community Access to Child Health (ICATCH) Grant Program.

Ms. Sally Piper Pillitteri is British and the Program Director. She qualified as a registered nurse in London and worked in the Emergency Department before moving to France and working in General Medicine, and Palliative Care. In 2010, she founded the French Non-Governmental Organization, "Eau Laos Solidarité".
Madame Bai Soulithan is from the Lao Leum ethnic group and is the Program Co-Director. She has been the director of Pakseng Community Learning Centre for six years.

Their project is entitled ***"Engaging Ethnic Communities in Rural Adolescent Health Knowledge in Laos"***. The goal of this project is to build capacity for a mobile hygiene knowledge team to enable this team to deliver information related to adolescent reproductive health to five mountain villages a year, 15 over three years. Their project will help parents and teenagers understand the changes that occur during adolescence, encourage related hygiene practices, and motivate community support for adolescent reproductive health.

Dr. Sabrina Kitaka was a previous recipient of an ICATCH grant in 2014. Her project ***"Promoting Adolescent Medicine in Uganda"*** was successful in achieving its aims with the support of ICATCH.

The aims included:

- Enhancing the Makerere-Mulago-Columbia-Adolescent-Health-Clinic (MMCAHC) by creating an adolescent friendly space and expanding services provided
- Providing a training experience in adolescent medicine for the clinic staff and Makerere University post graduate trainees
- Creating and implement ongoing program evaluation tools to improve MMCAHC programs
- Serving as a model adolescent clinic

Over 2300 unique clients have been serviced to date.

ICATCH grants provide both financial and technical support to grant recipients who are developing and implementing a program or project that improves child health in their community. Priority is given to applicants from low-income and low-middle-income countries. Funding is $2000 per year for 3 years. ICATCH grants emphasize:

- Partnerships with governmental and/or nongovernmental agencies or groups (such as public health centers, schools, faith-based groups or local businesses)
- Sustainability and growth of the program beyond the funding period
- Expansion of successful strategies to other communities or regions

FOR MORE INFORMATION ABOUT ICATCH GRANT APPLICATIONS & FOR A LIST OF OTHER ADOLESCENT PROGRAMS FUNDED PLEASE VISIT

www.aap.org/icatch

Sickle Cell Disease

Submitted by Dr. Nancy Green, Dr. Deogratias Munube , Dr. Mindy Brittner and Miriam Kwarteng-Siaw

Overview of Sickle Cell Disease

Intro

Sickle Cell Disease (SCD) is an inherited blood disorder that is a significant public health problem worldwide. Sub-Saharan Africa bears the highest burden of the disease.[1] Mortality estimates in communities without newborn hemoglobinopathy screening and access to standardized health services for SCD are between 50 to 90% in affected children by 5 years of age.[2] The prevalence of SCD in Ugandan newborns is 1-2%.[3]

SCD survival beyond childhood is over 95% in countries with well-resourced health services. Although previously considered a disease of childhood in Africa, more children are surviving into adulthood with increase in disease awareness, newborn screening, and interventions. This increase in survival beyond childhood has increasingly created the need for transition services to adult care.[4,5] In the U.S., transition to adult care usually occurs between ages 18-21 years. Successful transition from pediatric to adult care requires that patients adapt to addressing life-skill and growing medical challenges. In addition, transitional requires that psychosocial issues are addressed to support the shift of responsibility to self from prior responsibility based on family and medical staff.[6-8] Adolescent and young adult patients must adopt the necessary skills to minimize disease-associated complications, attend medical visits, and engage in disease self-management.[7,8]

Among low income countries in Sub-Saharan Africa, infant screening for SCD and improving services are expected to enhance disease survival.[9,10] As elsewhere, challenges associated with transition from pediatric to adult care may be magnified by the African practices of transition to adult care during mid-teen years.[6,11,12] Traditionally, high childhood mortality had minimized need for adult-directed medical care. Improved SCD patient survival in Uganda and elsewhere in the region is predicted to expand, as are the needs for providers and health systems suited to adult patients.

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SSD in Uganda and Recommendations for Care

Sickle cell disease (SCD) is a major non-communicable haematological disease throughout sub-Saharan Africa. Globally, recommendation for the treatment of sickle cell disease include early diagnosis. This leads to improved health care and quality of life for people affected by SCD (Makani 2017, WHO 2006). With support from the Uganda Ministry of Health, the Uganda Sickle Cell Disease management guidelines are being developed. This will ensure specific interventions for sickle cell disease and as well as the training of all medical and nursing health professionals. It has also included the public health approach to disease control.

Recommendations include adequate clinical, diagnostic, laboratory services and transfusion services. National referral hospitals are Mulago Hospital in Kampala and the Muhimbili National Hospital in Dar es Salaam. Patients undergo diagnostic testing, are assigned unique identity number for tracking care and disease complications. In both SCD clinics, the vast majority of patients with SCD have homozygous sickle disease (HbSS). Universal infant screening and early entry into preventative care for SCD, as practiced in high sickle cell trait prevalent districts of Uganda, is a critical aspect of reducing morbidity and associated mortality in young children.

Patients are seen in a dedicated SCD clinic for follow-up and urgent care. For those diagnosed with SCD, routine care includes daily folic acid, penicillin prophylaxis and antimalarial prophylaxis. Due to high mortality associated with malaria infection in these patients, regular malaria prophylaxis is a key part of care. Care includes daily anti-malarials and/or treated nets, as well as prompt diagnosis and treatment of malaria infections. Pneumoccocus is another serious infection for people with SCD. Since 2014, vaccination is now available in Uganda for children up to age 2 years. For children up to age 5 years, twice daily penicillin prophylaxis for prophylaxis is another key approach to preventing pneumococcal infection. For acute fevers, empiric antibiotics and malarial diagnosis and treatment are critical aspects for reducing mortality in children with SCD. Hospitalization, parenteral antibiotics and antimalarials, antipyretics and analgesics (e.g. opioids), as well as supportive care, sometimes including oxygen, are essential aspects of SCD care.

Blood transfusion is another key aspect of care capacity for SCD. Transfusions are often needed for acute severe anemia, acute stroke and acute chest syndrome (a combined pneumonia and lung crisis). Surgical needs include management for treatment of splenic sequestration, cholelithiasis with cholecystitis and other abdominal emergencies.

Where available, hydroxyurea (also known as hydroxcarbamide) should be available for daily use. This medication is highly effective for chronic prevention of many of the disease complications, including acute pain episodes, severe anemia and acute chest syndrome. When used at standard dosing, complications are rare. A key impediment for use in young children is the frequent lack of low dose liquid preparations and most pharmaceutical preparations are in a capsule form.

As with any serious complicated chronic condition affecting children, adolescents and surviving adults, health education to patients and their families is vital for appropriate urgent care, long-term health management and reducing associated stigmatization. As for all major non-communicable diseases, limited social and personal burdens requires the recognition of the importance of availability for the medications and services described above and appropriate integration into society. Medical training and capacity-building in SCD, along with public advocacy, must continue to flourish to meet the demands of the disease burden. Several advocacy groups are successfully aligning with Ministry of Health efforts. The Ministry is also developing regional capacities to expand the availability of care throughout Uganda.

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Risk Taking in Adolescents with Sickle Cell Disease:

Risk taking is a normal part of adolescent development, but one that can expose young adults to adverse psychological and health outcomes. Risk taking in adolescents often involves experimentation with tobacco, alcohol, drugs and sexual activity. Clinical encounters with adolescents must anticipate and screen for these behaviors in order to provide appropriate counseling and treatment. When caring for young people with chronic diseases such as Sickle Cell Disease (SCD), there can be a tendency to focus on disease specific issues such as pain control, infection prevention, and medication adherence. Perhaps it seems some of these patients hardly have time to be "normal teens" with the stress of pain crises, infections and vascular events. In reality, we do our patients with SCD a disservice when we neglect to screen for risky behavior.

There is frustratingly little research on the risk-taking behavior patterns of adolescents with chronic diseases including SCD. The few studies that have evaluated risky behavior in adolescents with SCD were conducted in the Americas. These studies, though small, show the importance of screening for tobacco, alcohol and drugs, as well as sexual activity in adolescents with Sickle Cell Disease. An older study, published in the US Journal, Pediatrics in 1998, looked at the timing of risky behavior in adolescents with SCD living in the US state of North Carolina. The authors found that while adolescents with SCD were less likely than their peers without chronic illness to engage in sex, drugs and alcohol, risky driving, and weapon carrying, and did so at a later age than their peers without chronic illness, they still took part in all of these behaviors, with 30% of adolescents with SCD reporting having smoked and 51% of adolescents with Sickle Cell Disease reporting having had sex.[1] Similarly, a 2014 study of risk behaviors in Jamaican adolescents with SCD found that almost 50% of Jamaican adolescents with SCD had sex (compared with 58% in the national sample) but were less likely than teens without SCD to have used contraception during the last sex, and that adolescents with SCD were more likely to have used alcohol and tobacco and equally likely to have smoked marijuana.[2]

Next time you are in an exam room with an adolescent with SCD, be sure to screen for risky behaviors as you would with any other adolescent. Screening may in fact be of even greater importance for patients with SCD, as the sequelae of behaviors such as smoking and unprotected sex may be more serious for these patients when it complicates their pre-existing illness. A qualitative study of adolescents with SCD conducted in the US state of Washington, showed that adolescents with SCD often have unmet sexual health education needs. Housten and colleagues found that 60% of the adolescents they interviewed were having sex, and 35% in risky sexual behaviors, while 95% showed deficits in sexual health knowledge or requested sexual health education.[3] A useful way to approach the psychosocial interview for all adolescents is using the HEEADSSS method. The HEEADSSS interview focuses on assessment of the Home, Education/Employment/Eating, Activities, Drugs, Sexuality, Suicide/Depression, and Safety.[4] When use of this screening tool and counseling are provided in an open and non-judgmental fashion, your adolescent patients are likely to be very receptive to your inquiries and advice.

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Interesting News about Care for the Adolescent Patient with Sickle Cell Disease in Ghana

1. **What are the current resources available for patients including adolescent's with SCD in Ghana?**

Patients with SCD in Ghana who are able to access one of the few sickle cell clinics in the country (17 established, 12 functional[1]) receive standard SCD care which includes clinic appointments every 3 - 4 months, vaccinations, particularly the conjugated pneumococcal vaccine, folic acid supplementation, penicillin prophylaxis, and in select cases, hydroxyurea[2]. Between the ages of 12 and 15, adolescent patients with SCD are transferred from a pediatric SCD clinic to an adult SCD clinic or more commonly, a general adult clinic depending on the location[2]. At the sickle cell clinic at Korle Bu Teaching Hospital in Accra, the capital of the country, there is a transition program for adolescents in the summer months that focuses on patient education on SCD, addressing psychosocial challenges adolescents may face, and assisting with making the transition to adult SCD care.

2. Where should an adolescent with acute pain/fever go for care?

Adolescents with acute pain/fever usually go directly to the emergency department (ED) of tertiary referral centers in the country for care. Occasionally, patients with acute pain first present to private hospitals or the sickle cell clinics and are referred to the ED from there. Showing up to the sickle cell clinic first sometimes proves beneficial as adolescents, if fortunate, may be accompanied by nursing staff from the clinic to the ED to ensure that their care is expedited. Unfortunately, there are not many EDs in the country equipped with the staff and resources to care for patients with SCD and thus adolescents who live far from a hospital with an equipped ED, tend to travel long distances for acute care. In the ED, patients are tested for malaria and other opportunistic infections with initiation of antibiotics and antimalarial medications in cases of confirmed infection or high suspicion for infection. Patients also receive IV fluids and analgesics with nonsteroidal anti-inflammatory drugs as first line with addition of narcotics such as tramadol or morphine depending on the severity of pain and cost of medications. Those with a hemoglobin level below 6 receive blood transfusions.

3. Where are adolescent patients admitted?

Starting from age 12 years, adolescent patients who require admission for further management of symptoms related to SCD are admitted to the general adult ward after stabilization in the ED. Here they are seen by general internists and receive continual management for pain and infections. Patients are either discharged home after recovery, sent back to the ED should symptoms worsen (e.g. require more blood transfusions), or unfortunately pass away while admitted.

4. What are some of the current challenges to delivery of care to adolescents with SCD?

Challenges to delivery of care to adolescents include a lack of national policy or guidelines for management of acute vaso-occlusive episodes and complications associated with SCD. Another challenge is the shortage of adult hematologists and healthcare workers trained to care for patients with SCD[3,4]. Due to the shortage of adult hematologists in the country, once adolescents transition out of specialized SCD pediatric care, they are usually seen by general adult internists who may not be as familiar with SCD. This is the case at the Komfo Anokye Teaching Hospital, the second largest tertiary hospital in the country. Additionally, there are only a few hospitals that offer SCD specific care in the country and most of them are located in urban cities which are inaccessible to those living in rural areas. Many families are unable to afford the cost of medications such as hydroxyurea and/or the frequent lab tests required at the initiation of the medication making it difficult for adolescents to have access to the necessary medications. Adolescents with SCD experience emotional and psychological stress including stigmatization with SCD[2,3,4] but there are unfortunately limited psychosocial resources, support groups included, available.

5. Future goals related to care of the adolescent patients with SSD?

Future goals related to care of adolescent patients with SCD include the training of more healthcare professionals in the provision of specialized SCD care[3,4]. Another future goal is the establishment of a national policy or guidelines for the management of acute vaso-occlusive episodes and complications associated with SCD. At the 59th annual American Society of Hematology Conference in December 2017, Dr. Ohene-Frempong, a pioneer in SCD Newborn Screening in Ghana gave an update on the creation of national guidelines for acute SCD care in the country[1]. It is the hope that these guidelines will be ready for national use in the country soon. Establishment of resources and programs that can facilitate the transition process for adolescents transferring from pediatric to adult care is also an area of future interest[2].

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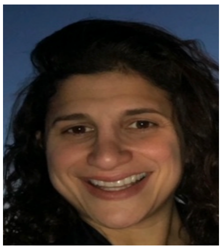
AUTHORS

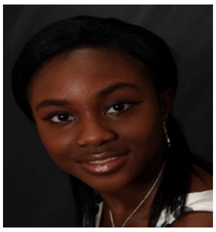
Dr. Green is a Professor of Pediatrics in pediatric hematology-oncology at Columbia University. She has been engaged in clinical and translational research for over 25 years. Her primary research and clinical emphasis is on pediatric sickle cell disease, emphasizing biological, neurological, cultural, behavioral and genetic aspects of disease heterogeneity and variability in response to therapies. She has been collaborating with senior Paediatric faculty at Makerere University on sickle cell disease since 2014. She is currently co-Principle Investigator of the NIH-funded BRAIN SAFE program, which aims to understand and reduce the impact of sickle cell disease on children in Kampala.

Deogratias Munube is a Consultant Pediatrician, Honorary Lecturer and PhD Fellow in the Department of Pediatrics and Child Health Mulago Hospital/Makerere University Kampala currently completing his PhD in neurology and involved in research in children with sickle cell disease evaluating children with stroke. He also has a position as a Paediatric Haematology/Oncology Fellow under the Makerere University/Baylor College of Medicine HOPE program in East Africa and serves as a co-investigator for BRAIN SAFE, with oversight responsibilities for the transcranial doppler and clinical link to care in the sickle cell anemia clinic.

Part of his PhD training has included Transcranial Doppler (TCD) recordings with additional training as part of the R21 capacity building program. He has led the performance of TCD for the R21, trained and supervised the study physician and nurse in carrying out these tests and provided quality control. In the proposed study and as Co-Inv, he will continue to perform these roles, train the new study staff, oversee participant recruitment and care during acute sickle cell events including incident strokes.



Mindy Brittner MD, MS is a family doctor with sub-specialty training in adolescent medicine. She completed her medical degree at Rutgers University- Robert Wood Johnson Medical School. She trained in Family and Social Medicine at Montefiore Medical Center in the Bronx, NY. She is currently a 3rd year adolescent medicine fellow at Columbia University Medical Center.



Miriam Kwarteng-Siaw is a 4th year medical student at Columbia University Vagelos College of Physicians and Surgeons with an interest in sickle cell disease & global health. She plans to apply into Internal Medicine for residency & Hematology for fellowship in order to better understand the pathophysiology, diagnosis, management, & hopefully treatment & complications of sickle cell disease. She conducted a summer research study on transition of care issues for patients with sickle cell disease in Ghana & is excited about contributing in multiple ways towards further research in the area of sickle cell disease in the U.S and African countries.

Highlights from the 5th Annual Clinical and Scientific Meeting of the Society of Adolescent Health in Uganda

Submitted by Dr. Sabrina Kitaka

The Society of Adolescent Health in Uganda held its 5th Clinical and Scientific Meeting at the Hotel Africana in Kampala, Uganda from April 11th -12th, 2018. This was also the 8th Annual Adolescent Health Conference in Kampala sponsored by the Makerere University-Columbia University (MUCU) Collaboration.

Theme:

Transitions in Care: Children to Adolescents to Young Adults

Sub Themes:

- **Transitioning Adolescents with Chronic Conditions**
- **Educating Providers and Parents about Developmental Transitions**
- **Adolescent Responsive Programing in Schools**

Conference Objectives

The aim of this meeting was to provide health care providers with up to date evidence-based information related to transitioning of children to adolescents to young adults. Adolescence (ages 10-19 years) and young adulthood (ages 20-24 years) are periods in an individual's life highlighted by significant physical, social, behavioral and psychological changes. During these pivotal periods, adolescents and young adults establish behavioral patterns that determine current and future health outcomes. Moreover, these periods are windows of opportunity for healthcare providers and parents or caregivers to teach, support, and foster healthy behaviors, encourage independence and active decision making, and usher adolescents into the adult-centered healthcare system. To appreciate the magnitude of this challenge, every year in Uganda nearly 4 million people become 18 years of age. In fact, nearly 1/3 of Uganda's population is aged 10-19 years, a key reason why we should understand how best to take care of this population.

Globally, adolescents constitute approximately 20% of the population, with 196.5 million adolescents in Africa. Uganda has a predominantly young population with adolescents (10-19 years) constituting 25% (8.48 million). A young population is highly dependent and vulnerable and also presents serious challenges of addressing their sexual and reproductive health and rights and other conditions. If the needs of the young population are not addressed, they undermine social transformation and sustainable development. Another important aspect of adolescent health that has largely been neglected is oral health. It is a public health concern that affects every person. There is therefore a need to discuss the importance of improving the oral health of both the population and the individual.

Participants

A total of 183 participants attended this meeting including paediatricians, social scientists, psychiatrists, obstetricians, nurses, parents and parent groups as well as young people.

Key Highlights

The meeting was opened by Professor Lawrence Stanberry of Columbia University, and Dr.Ezekiel Mupere from the Department of Paediatrics at Makerere University, College of Health Sciences. There were many insightful and interesting key note speeches made by Columbia University faculty, as well as local faculty from Makerere University and the Naguru Teenage Center. Exciting oral abstracts were also presented and discussed and a fabulous youth group from Baylor Uganda presented a skit on the Triple 90 UNAIDS Campaign aimed at eliminating AIDS related deaths by 2030. Please visit the SAHU website to view all of the conference presentations and see a detailed report **www.sahu.ug**.

CONFERENCE PICTURES

Drs. Ezekiel Mupere and Lawrence Stanberry

All Participants

Dr. Sabrina Kitaka

Dr. Sabrina Kitaka and Ms. Nasolo Divine Christine (Volunteer at the Makerere-Mulago-Columbia-Adolescent Health Clinic)

Moderators

Dr. Godfrey Zari Rukundo and Dr. Barbora Silharova

OUR NEXT NEWSLETTER WILL BE PUBLISHED NOVEMBER 2018

TITLE

Positive Parenting: An Effective Approach to Address the Challenges of Adolescent Parenting in Uganda and Beyond

SAHU MEMBERS

please submit member news, program updates and interesting cases with all patient identifiers removed

The editorial board will conduct a peer review process for all submissions. Submissions will be accepted from September 1st-October 15th, 2018. Please e-mail all submissions to: sabrinakitaka@yahoo.co.uk. Thank you in advance for your participation