Newsletter

Baylor College of Medicine Children's Foundation - Uganda

April 2011 Newsletter

Inside This Issue

- The Near death Experience 3
- Creating Better opportunities for Paediatric HIV/AIDS Care 4
- Real Cartoons, Real Information 6
- Strategic Positioning for Greater Impact 7
- Our youth client's dream of a Medical degree 8
- Sanyuka 2011, A unique Camp 11
- When the Saints Come Matching In 13
- Sweet, Sweet Melodies 14
- Baylor-Uganda in the Media 15

BIPAI Baylor International Pediatric AIDS Initiative

BCM Baylor College of Medicine

Texas Children's Hospital

Editorial

My favorite football team slogan 'You never walk alone' is every player's pride and can change a dead game instantly. That is called team spirit.

Our team spirit, with each member having a part to play, is here presented under a roving lens.

In here, you can read about our work and related excitements events that have occurred during our work, our visitors, weddings, children and fun. Meet Angel patiently counting down towards realizing her dream of a medical degree and enjoy a hilarious read about Sanyuka Camp 2011. The camp almost became 'Camp David' as Daudi celebrated his 11th birthday.

And now close your eyes and feel the SAINTS 'marching in'; know who they are, where they come from and where they are going. Enjoy cartoon time with the children!

Take some time to learn about our services too and follow us in the media.

Paul Mayende Nicodemus
Editor

Editorial Team:

Dr. Leticia Namale, Dr. Betty Nsangi, Dr. Paul Tumbu, Mr. Nghania Frehd and Mr. Mayende Paul

Note from Executive Director

The year has just started and the quarter is gone. We have had very close deadlines to observe, several partners expectations and appointments to honor; and above all offer our commitment for provision of free, high quality, high impact and highly ethical family based Pediatric HIV/AIDS care and treatment services to our clients. This desire has driven some of the team to deploy their much valued efforts in new strategic areas of operations such as Rwenzori, West Nile, Eastern and Karamoja regions. To those we say bravo.

For the new staff, some have settled in completely while others are settling in, welcome to Baylor-Uganda. I am optimistic that this kind of team will deliver our mandate as we can read what each of you is doing and how lives are being impacted. Congratulations to those who have entered long term commitments to serve the children and their families. Learn a thing and have fun as you read.

Dr. Adeodata Kekitiinwa
Executive Director

The Near Death Experience

By Sharon Kesande Waisadha

It was on a cold Thursday morning at around 8.30 am when I received a call from the caretaker to one of our patients NJ, informing me that NJ was critically ill. He said that she could not speak, hear or move any part of her body. She had also been vomiting since 2.00am the previous night.

I told him to rush her to the nearest hospital but he said that they didn't have enough money to hire a car to take her to the hospital! After a second thought, I came up with an idea, immediately asking him to get prepared and I pick them for review at Baylor-Uganda clinic.

The 60 Km journey to NJ's home took us close to two hours due to the heavy traffic on the highway often caused by the many big trucks that using the road.

On arrival at NJ's home in Najjembe village, Mabira forest, I was shocked to see many people somberly gathered. Literally the whole village had gathered there for an overnight vigil and even lit a bonfire. Probably they came over, expecting the worst, to support her family at night when her situation worsened. Thinking that she had passed on during the night, I got so scared and my heart started beating fast.

My Social Work background notwithstanding, I was particularly challenged with the situation at hand. "What was I to do next?" I mused.

NJ lay stiff on a dirty mat in the banana plantation, surrounded by many people, mostly women, all weeping loudly. Upon seeing me, they all kept quiet; perhaps because they had finally seen this 'Musawo' (doctor) coming from the city to arrest the situation; "*Thank God you have come Doctor*" said the grandfather. I went straight to the patient and touched the stomach to feel whether she was still breathing. Fortunately she was. The driver and I then lifted and placed her in the car. While doing this, I overheard somebody remark '*I don't think she will reach Mulago*". That statement scared me so much that I kept praying throughout the journey. After a brief encounter with the traffic police, we arrived at the clinic and found our team ready to offer NJ emergency care. In the treatment room, NJ was examined and found to be deeply comatose with a modified coma score of 7/15. Emergency tests for blood sugar and malaria were done. She was resuscitated with intravenous fluids and given anti-malaria treatment after testing positive for malaria. NJ was admitted into the intensive care unit. Three days later, NJ's condition greatly improved and she was due to be discharged. Seeing NJ strolling in the clinic corridors with her usual wide smile was simply unbelievable to all of us in the ARROW team! We were thrown into a frenzy of joy and excitement at her remarkable recovery!

My special thanks to the doctors and the broader ARROW team.

BRAVO TEAM!

Bristol Myers Squibb Foundation and BIPAI teams in a group photo with Baylor Children's Choir and some of the Baylor-Uganda staff.

Creating better Opportunities for Pediatric HIV/AIDS Interventions

BIPAI and Bristol Myers Senior Leadership in Uganda

By Baylor Uganda Staff

The Senior leadership of Bristol Myers Squibb Foundation and Baylor International Pediatric AIDS Initiative have visited Uganda and witnessed the efforts made to support pediatric HIV/AIDS in the country by the Baylor College of Medicine-Bristol-Myers Squibb-Texas Children's Hospital-Children's Clinical Centre of Excellence.

Mr. John Celentano, Mr. John Damonti, Phangisile Mtshali, Mr. Mike Mizwa and Dr. Wanless Sebastian held meetings with several senior health practitioners, HIV/AIDS partners and activists in the country.

During the meeting with Dr. Edward Ddumba, the then, director of Uganda's main and largest referral Mulago hospital, the team appreciated the work and commitment of the partners through Baylor Uganda towards the children and families affected with HIV/AIDS.

"We are happy that Baylor Uganda has moved these steps with your help and we look forward to strengthening these interventions", said Dr. Ddumba. The director was briefing the team on various departments and engagements of the hospital, challenges and the opportunities in the next two years.

The team also held discussions with CDC-Uganda Country and Programme Directors and the Baylor Uganda Senior Management staff and Board of Directors.

Bristol Myers Work in Mulago Hospital

The foundation funded the construction and equipping of the Baylor College of Medicine-Bristol-Myers Squibb-Texas Children's Hospital-Children's Clinical Centre of Excellence (COE) at Mulago hospital. The facility houses the clinical and administrative units of

Baylor College of Medicine Children's Foundation Uganda. Inaugurated in October 2008, the Centre currently provides HIV/AIDS prevention, care, treatment and support services to 4,709 children with funding from PEPFAR through *Centers of Disease Control*. Other partners include the *Ministry of Health*, *Abbot Fund*, *Canadian Feed The Children*, *UNICEF*, *Clinton Foundation*, *Paediatric AIDS Canada*, *Elton Johns Foundation*, *KOICA* among other partners.

Left-Right: Bristol Myers Squibb Foundation President-John Damonti, the Foundation's Senior Vice President - John Celentano, the then Mulago Hospital Director - Dr. Edward Ddumba and the Baylor-Uganda Executive Director Dr. Adeodata Kekitiinwa during a courtesy call to Mulago Hospital Director's office.

BIPAI's Dr. Wanless greets CDC-Uganda Director, Dr.Tadesse as Baylor-Uganda Executive Director, Dr. Kekitiinwa talks to Bristol Myers Mr. Celentano

Real Cartoons, Real Information

Mwanawengo creations ©2010
mwanawengo@gmail.com

Strategic Positioning for Greater Impact

By Barbara Sentiba & Emily Ayik

Baylor - Uganda has grown further in terms of programs and geographical scope, which has resulted in the recruitment of new staff both at the COE and across the country in Baylor-Uganda supported regions and facilities. Several staff have been deployed to new operational areas both in recognition of performance and promotion of efficient service delivery. Specifically seasoned staff have moved to support the new regions and these include.

Dr. Fredrick Twebaze

Joined Baylor-Uganda as Head of Strategic Planning and Development and worked with the Senior Management Team to oversee the implementation of Baylor-Uganda's five year strategic plan, the National Expansion of Paediatric (NEP) HIV/AIDS prevention, care and treatment in 144 health facilities. Fred was part of the team that wrote the grant application, for West Nile and Soroti regions that Baylor-Uganda victoriously won. Under this new grant from CDC/PEPFAR Fred was appointed as Program Manager for West Nile and Soroti regions with responsibilities to implement and monitor planned activities towards meeting the program objectives and achieving the Baylor-Uganda mission.

Kahungu Muhindo Methusela

Started at the Paediatric Infectious Diseases Clinic (under the Infectious Disease Institute) as the clinic manager. He later joined Baylor-Uganda in and was transferred on promotion to Fort Portal as the HIV Counseling and Testing (HCT/PMTCT/EID) Coordinator for the Rwenzori Region. He has an overall responsibility to provide technical support to the districts and health facilities on HCT/ PMTCT/EID in accordance with Baylor-Uganda and the Ministry of Health policies and procedures.

Robinson Mukisa

The two have served diligently as drivers, with a lot of enthusiasm on their job. They are committed to their work and are hard working. Robinson worked with the Baylor-Uganda team in Hoima District for two years before transfer to the new Rwenzori region. James moves from the COE to work in west Nile and contribute to improving access to services in this largely underserved region.

Ofoyuru James

Baylor- Uganda Senior Management Team

It is widely recognized that efficient Management is a key determinant of independence and sustainability. Baylor-Uganda's Senior Management Team welcomes three new members who have joined the organization.

- **Mr. Samuel Lubulwa Mpiima** is a chartered Accountant with over two decades experience in Finance, Accounting and Management.
- **Mr. Stephen Opio** is an Internal Auditor with ten years' experience. He is charged with setting up the Internal Audit department.
- **Dr. Leticia Namale** is a Clinical Epidemiologist with 7 years experience in clinical and program management of HIV/AIDS. She is the Program Manager for the A healthy and fulfilled life for every HIV infected and affected child and their family in Africa Supporting And Improving National Training Systems for health workers project (SAINTS).
- **Albert Koma Maganda** joins the team after several years of work with Baylor-Uganda. Rising through monitoring and Evaluation ranks coupled with trainings, he heads the Directorate of Strategy Development, Monitoring and Evaluation.
- **Dr. Robert Iriso** is a seasoned paediatrician with new assignment of overseeing up-country programme implementation in Rwenzori, Karamoja, West Nile and Eastern Regions. He now heads the Directorate of Medical and Psychosocial programmes.

Step by Step towards a Medical Degree

By Paul Mayende & Fred Sebuma

"I never cared about life or death. I was taking some drugs, sometimes with beating from my mother. The drugs were very bitter and I was taking them either for sickle cells, heart disease or TB", says 18 year old Angel.

That was 2001 and for a 9-yr old girl, nearly all her questions went unanswered; the government policy on HIV status disclosure for minors was still in strict enforcement.

A year later, Angel leant that she was HIV positive and had lost her dad to HIV/AIDS. The boy child before Angel also died of HIV related illnesses later.

Angel, her mother, and a younger brother, also living positively, reside in a Kampala suburb, in one of the communities worst hit with HIV/AIDS. Her two younger sisters have undergone HIV counseling and testing and are HIV negative.

Angel says *"so many things have happened at our clinic (Baylor) and I am happy to receive care. Ever since I started taking ARVs, around 2004, I have changed a lot. I remember in the beginning taking the drugs was so difficult for me. The drugs made me look funny, people around our home made fun of me and I became fearful that I was soon going to die. This was because I used to remember what my late brother went through during his illness. I overcame that and now I am used to taking my drugs daily because they are not bitter and I can see a bright future."*

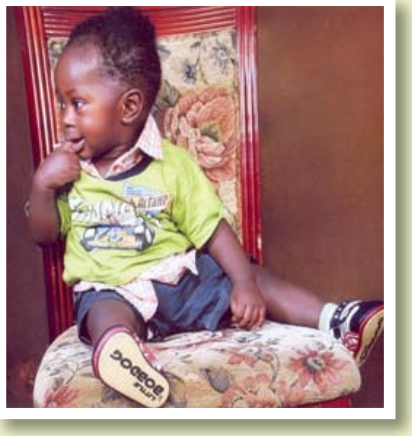
Seated comfortably at home, dreamily stroking her beautiful curly hair, she says, *"I have seven years left to become a doctor."* Angel sat her senior four (Grade 11) final examinations at the end of 2010 and hopes to join advanced high school level for another two years and thereafter university to study human medicine.

"I have changed and put on weight. I look beautiful and can express myself. The greatest challenge I have is to keeping boys off; they can't believe that I am living with HIV whenever I tell them while turning down their love and sexual advances", says Angel adding "sometimes, I really quarrel with them". She says on several occasions in her former school, her peers have been seeking assistance on how she manages to be firm and say "NO" to pre-marital sex.

The Roving Lens

Now We Are One: Baylor-Uganda's Andrew Mujisi Butusibe during their wedding at Kashari Mbarara

The Japan team with Baylor-Uganda staff and youths, April 2011

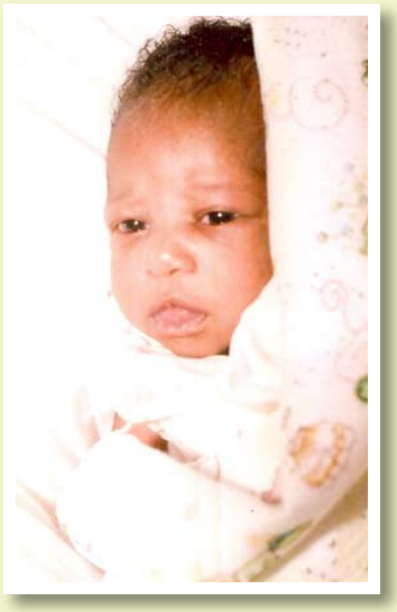


Baby Nathan

Esther

Eliana Ampiire

Vivianne



Destiny

Peter Korooma

Clever

Sanyuka 2011, a Unique Camp

By Cissy Ssuuna

Sanyuka: *Youth having a fun ride during the camp.*

This year's Sanyuka Camp has seen the largest number of participants so far with 114 campers, an increase of 17 from the previous year. With several innovations such as medical point persons, Question and Answer sessions and entertainment, the campers had life changing moments. One of those moments was the surprise birthday party for one camper who turned 11 years at camp. During the final camp banquet, Daudi screamed with happiness, "is all of this for me'. For that brief moment it was reminiscent of 'Camp David!

With 'Happiness: Our Treasure' as the theme, the Camp was uniquely packaged bringing together various partners, teams and Baylor-Uganda personnel. In a bid to improve on the management of Sanyuka Camps this year, two Right To Play (RTP) representatives on the camp leadership team, one Sanyuka staff member on the leadership team and one Baylor representative on the medical team participated in the Hole in the Wall (HITW) Staff Exchange Program, visiting similar HITW programs in both Ireland and Swaziland. Other innovations came from the Camp Program

Coordinator and Camp Manager who had attended the Global Partnership International (GPI) Network Meeting in South Africa in November 2010.

New innovations such as the creation of colour group communicator within each color group helped in easy communication and feed back during the daily meetings while the creation of an entertainment coordinator on the Leadership team brought in a great deal of enthusiasm and new ideas. Children were grouped and given names, each based on a particular colour.

The introduction of a "Free Choice" period into the camp schedule allowed campers to make independent decisions about what activities they would like to participate in during this time. This was a positive addition to the program and it allowed children to spend time with campers from other colour groups.

The camp's top priorities were the values of safety, love, and respect for children living with HIV and all campers who participated in Sanyuka Camp 2011 were given a safe, empowering, and fun camping experience they will not soon forget.

Present were three consultants from HITW facilitating staff trainings, leadership trainings as well as supervising daily camp program and supporting the local leadership team.

Hands Together: Campers in a social

An *HIV Question Box* was made and placed in a central location at the beginning of camp to allow campers to anonymously "drop-off" their HIV related questions which were answered at the end of the week. This allowed the medical team of two Doctors and three Counselors ample time to prepare for the HIV Q&A session in a group discussion at the end of the week. This new intervention triggered children to share their feelings, thoughts and fears regarding HIV in general.

About Sanyuka Camp

Sanyuka, a local word for 'be happy' resulted from a partnership between Association of Hole in The Wall Camp (AHITWC) and Baylor-Uganda in 2007, leading to launching and piloting the first Sanyuka Camp in January 2008 serving 28 children. Other partners such as Right To Play have since joined in.

Sanyuka Camp is an annual event, which is held in January. It involves recruiting children attending Baylor-Uganda clinic aged 9-11 years, to whom their HIV status has been disclosed and whose caregivers have consented to their participation in the Camp.

Congratulation

SANYUKA TEAM 2011

When the Saints Come Matching In

By the SAINTS Team

Did you know that 'SAINTS' do not only reside high up in the heavens? As of October 2010, thanks to a 5-year grant from CDC/PEPFAR, they came to Baylor-Uganda to **S**upport **A**nd **I**mprove **N**ational **T**raining **S**ystems for health workers in Uganda (SAINTS). Their coming is timely to contribute to the availability and equitable distribution of well trained health workers in Uganda and will focus on the following objectives:

- To support existing pre-service training institutions to increase the production of new health workers;
- To strengthen national systems for planning, coordination, standardization, certification, accreditation and supervision of both pre and in-service training of health workers;
- To support in-service health worker training and integrate standardized HIV training curricula into in-service programs.

Being the actor that Baylor-Uganda has always been and having realized the shortages of critical staff in health facilities, insufficient training capacity, non demand driven trainings as well as limited regular review and update of training curricula: support was sought from CDC/PEPFAR to address these gaps. SAINTS is implemented in partnership with the Ministries of: Health, Education & Sports, Public Service, Local Government, Gender, Labour & Social Development and other capacity building and development partners.

SAINTS bursary recipients with some of their instructors and one of Baylor Uganda 'SAINTS'

The SAINTS presence is already being felt with a secretariat at Baylor–Uganda, Mulago Hospital as their activities are being rolled out. A Technical Working Group (TWG) with representation from the line ministries and selected development partners has been constituted to promote a broad understanding and acceptance of the project as well as provide technical guidance on policy and advocacy issues concerning the project.

The first beneficiaries of SAINTS are 10 laboratory teaching staff from selected laboratory training schools. Baylor-Uganda has provided them with SAINTS bursaries to undertake the 9 months modular diploma course in Clinical Mentorship offered by Uganda Martyrs' University, Nkozi.

Sweet, Sweet Melodies

By Jane Beyeza

These are fearfully and wonderfully made girls and boys! Their physical appearance gives you hope and joy that the therapy offered at Baylor Uganda is paramount.

The news that we are having a presentation at the National Paediatric HIV/AIDS conference at Hotel Africana in Kampala is broken to us. The most interesting part is that we are residing in Sports View Hotel, Kireka.

This is our first time to go and sleep out!!! What an experience! We have a lot of quality time together. That's when most children open up and talk about their life at home.

It is all joy as we go singing in the Van all the way. In between the singing, we talk about the food and the sleeping rooms.

A warm welcome is offered to us. Talk about eating good food (chicken and chips)!! It is at the right time as we had earlier discussed it on our way.

We are shown where to put up, wooooooow, and very nice self contained rooms.

Having seen all this and says, one child kneels down and exclaims "God! Who in life knew that I would sleep in such an environment!!!!!"

We go for the presentation and it is so interesting in the way the singing is done and our audience is touched.

One thing that I know when you show love to these children, they will open up and you can help them overcome so many issues including stigma. We are one inseparable family!!

We have so far 2 audio CDs and we are yet to continue exercising our talents. We intend to launch the music in order to help other children in the community overcome stigma, keep themselves safe and encourage their friends not to lose hope.

Baylor Uganda in the Media

On 27th December 2010, a story **'Search for miracle healing a big blow to HIV kids clinic'** featured an interview with the Baylor-Uganda Executive Director (Dr Addy Kekitiinwa). The issue of concern was that some clients, with promises of miracle healing in their places of worship, were not fully adhering to their treatment hence putting their lives in danger.

January 20, 2011 In response to the story **'Mother of defiled girl seeks justice'** Baylor-Uganda published a letter of the week entitled, **'How did a criminal case become civil?'** Above all, working with the New Vision, Baylor-Uganda contacted the family to access services and the mother and child were registered for services on January 24, 2011

January 13th 2011 a guest appearance slot was given to Baylor-Uganda on the popular **Simba Taxi.** Baylor-Uganda used this opportunity to re-affirm her commitment to the clients with regard to provision of *free, high quality, high impact and highly ethical family based Paediatric HIV/AIDS care and treatment services.*

27th January 2011, Baylor-Uganda clients and counselor featured on **'Ddoboozi ly'abakyala'**, Women's Voice, on Radio Star. Two clients, both female, shared their testimonies on how ART had helped them achieve their dreams of caring for the family for one and staying in school for another. They also emphasized the importance of early diagnosis and treatment for children for improved survival.

Sunday March 13, 7-8 PM **'Ddoboozi ly'abakyala'** Women's Voice programme of STAR TV featured a teen mother. The intention was to highlight how young girls living with HIV/AIDS are accessing services for healthier lives; and also encourage young girls to practice safer living habits as part of their empowerment and rights. The programme featured again on **Monday 14th March at 2.30 PM.** In response to this, gift collections to support the teen mother have been brought to UBC by the public..

Disclaimer: The logos appearing here have been got from partner websites and may not represent the actual sizes and other dimensions as used by the respective media houses. The use is limited to the flip attached.

***Tuesday March 29, 8-9 PM*, Capital Doctor,** featured two Baylor-Uganda paediatricians. The programme was to create awareness for HIV/AIDS services for children specifically Early Infant Diagnosis and highlight the role of various stakeholders in promoting access to Early Infant Diagnosis. The doctors presented on the situation of Paediatric HIV/AIDS in Uganda, HIV effect on the child's growth, What Early Infant Diagnosis (EID) is about, why it is necessary among other issues.

Our Contacts:

Baylor College of Medicine Bristol Myers-Squibb
Children's Clinical Centre of Excellence-Uganda
Block 5, Mulago Hospital, P. O. Box 72052, Clock Tower
Tel: +256 -417-119100/200/125, Fax: +256 -417-119166
E-Mail: admin@baylor-uganda.org **Website:** www.bayloraids.org/uganda