

PATA Newsletter Volume V Issue 5

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1. 2010 East Africa Regional Forum to be held at Hotel Africana, Kampala

PATA is pleased to announce that our East Africa Regional Forum (11 to 15 October) will be held at Hotel Africana in Kampala, Uganda. The hotel will serve as both the conference and accommodation venue for treatment teams and guest speakers.

Hotel Africana is located just two minutes from the centre of Kampala and a short bus transfer from Entebbe Airport. For more information on Hotel Africana, please see their website: www.hotelafricana.com.

2. Uganda Paediatric Association to be implementing partner

The Uganda Paediatric Association (UPA) is PATA's East Africa Forum implementing partner, which means that they will help to host and facilitate the forum.

UPA was established 17 years ago to improve the health and welfare of all children in Uganda. Their vision is for "all children in Uganda to grow up and reach their full potential". The president of UPA, Dr. Sabrina Bakeera-Kitaka, will be presenting on Day Two of the Forum.

PATA will be assisted by Mrs Stella Bakeera-Ssali. Stella has a Bachelor's degree from Makerere University and has worked as a consultant for a number of health organisations. She most recently organised the WHO-UNICEF Global Consultation for Adolescents living with HIV.

We are incredibly lucky to have this self-motivated and enthusiastic individual as part of our team for the East Africa Forum.

For more information on UPA, see <http://www.upa.or.ug/>

3. Day One's keynote speakers in the spotlight

The first day of the PATA East Africa Regional Forum will focus on Advanced ART. Foremost experts in this field will be presenting, such as Prof Peter Mugenyi from JCRC and Mbarara University of Science and Technology. He is at the forefront of HIV research in Uganda and will discuss 'Current issues in paediatric ART'. Thanks to Prof Mugenyi, JCRC is currently the largest specialised AIDS research centre in Sub-Saharan Africa.

Dr Leon Levin will be presenting on ART toxicity and fragile regimens as well as giving a case-study based masterclass. Levin's primary concern is to get antiretroviral therapy to all children and infants who need it. He believes that if these children are initiated on ART early, they can have a normal lifespan and an excellent quality of life. The prevention of vertical transmission of the HIV virus is also high on his agenda. "As good as antiretroviral therapy is in children, I would rather deal with a negative child," Levin says.

Hailing from the Makerere University-John Hopkins University research collaboration in Uganda, Dr Eric Wobudeya will be talking about TB in HIV-infected children.

PATA is privileged to have these and others speakers at the East Africa Regional Forum.

4. Interview with Prof Dorothy Mbori-Ngacha

Prof Dorothy Mbori-Ngacha (Chairperson of the Department of Paediatrics and Child Health at the University of Nairobi and Senior HIV Specialist at UNICEF ESARO) will also be presenting on Day One. We asked her a few questions on her presentation.

Has there been any recent shift in the approach to PMTCT?

Yes. The new WHO guidelines released recently have introduced regimens that can reduce MTCT HIV transmission to less than 5% even amongst breastfeeding populations in resource constrained settings. The new guidelines recommend treating all pregnant women with CD4 < 350 and using combination ARVs for prophylaxis in women with CD4 > 350. The guidelines also make breastfeeding a safe option for babies by introducing postnatal prophylaxis during breastfeeding. This recent shift makes elimination of new cases of paediatric HIV a real possibility.

What is the major challenge still facing HIV in paediatrics?

The early identification of HIV infected children remains the main bottle-neck.

Where do you think resources should be concentrated for research into paediatric HIV? And is this happening?

Given that children will have to take the drugs for a much longer period than adults, we need to address toxicity and drug side effects. We need safer and easy-to-take formulations for children. We also need to explore if children who have started therapy in early infancy can safely interrupt treatment once their immune system has matured. Preventive and therapeutic vaccines for children are another area which should be researched. In my opinion, paediatric HIV research isn't adequately funded.

5. Feedback from the International AIDS Conference held in Vienna, Austria

PATA's Taru Jaroszynski attended the 'Children and HIV: Family Support First - Working Together to Achieve Universal Support and Access to Treatment' pre-conference (16 – 17 July) in Vienna, Austria. This is a symposium held in the lead-up to the International AIDS conference. It aims to present the latest evidence and share the latest models on family-centred care and services for children affected by HIV and AIDS.

Natalie Kanem from ELMA Philanthropies opened the symposium by noting that "HIV/AIDS is a medical and social disease that brings us all together" in order to meet "the urgency of these times". Several keynote speakers extrapolated on these comments. Michael Sidibe from UNAIDS commented on the timely nature of the Symposium calling for "universal access: zero new infections, zero discrimination, zero HIV-related death". "It's not a time to scale down, it's a time to scale up," he emphasised. He also reminded the delegates that programmes, advocacy, policy and planning must be concerned with what is really happening in communities.

A very interesting CIFF-funded pilot project in the Tamil Nadu district in India was presented. It showed the positive and persuasive effects on the effects of a family-centred programme of HIV/AIDS treatment and care.

Theresa Betancourt presented research done in collaboration with Partners In Health, Rwanda, on mental health and family-centred support and treatment. This research is highly attuned to the culturally dependant constructs of health and advocates a "family strengthening intervention" to mitigate the effects of HIV/AIDS on families and children.

One workshop session was dedicated exclusively to looking at the role of men and fathers in clinics. Patrick Godana from the Sonke Gender Justice network spoke passionately about involving men in treatment and care.

The plenary session on CEPA (Campaign to End Paediatric HIV/AIDS) resulted in a passionate and enthusiastic crowd of delegates standing up and swearing that they were committed to ending paediatric

HIV/AIDS. The key issue that emerged from this session is the need to forge links between service providers, clinics, community organisations and international advocacy and aid organisations.

A session titled 'Supporting families and caregivers to tell children they are HIV positive' was particularly useful in light of the fact that this is a topic for 2010 PATA East Africa Forum. Dr Felix Rwabukwisi Cyamatare (who will be in attendance in Uganda) discussed the Partners in Health experience. Dr Susan Strasser from EGPAF Zambia presented a training programme for 'Psychosocial Care and Counselling for HIV-Infected Children and Adolescents'. If you would like these resources please contact Taru at taru@teampata.org.

The symposium called for a channelling of the passion and energy of the participants towards promoting family-based approaches to the prevention, treatment and care of paediatric HIV/AIDS. This involves empowering people and services to do what is needed to link the health, educational, social and community responses to HIV/AIDS.

6. Request for 2011 XVIII International AIDS Conference Feedback

Delegates from all over the world met in Vienna in July 2010 for the International AIDS Conference. We understand that many PATA-affiliated clinics and organisations attended the conference. We would love to hear about your experiences. Please send any papers or comments that you think will be useful to your PATA peers to Taru at taru@teampata.org.

For more information on the IAS you can check the IAS website: <http://www.aids2010.org>. Alternatively check the NAM website with updates on the IAS: <http://www.aidsmap.com/page/1448242/>

7. Experts Patients' involvement in Wits ECHO Defaulter Tracing

PATA recently received a report from Wits ECHO (Enhancing Children's HIV Outcomes) detailing the successes and challenges of their home visit and defaulter tracing programme of which several PATA Expert Patients are integral.

The clinic reports that for the month of June, 68 out of their total number of 1247 patients defaulted. Of those defaulters, 57 were on treatment and 11 were not. By the end of the month, 31% of the defaulting patients had been traced, leaving 47 patients still as a loss-to-follow-up (LTFU).

The Wits report outlined the many reasons that their patients defaulted. The reasons included a caregiver being sick, the patient being out of town, the lack of a committed caregiver, a misplaced appointment card as well as practical matters such as a taxi strike and the writing of exams.

Wits ECHO indicated that of the 37 home visits assigned due to defaulting patients, 21 were completed by seven defaulter tracers. The report states that their goal is to complete home visits every day to reduce the number of defaulters in general.

Wits ECHO has strong protocol for defaulting patients, yet the report highlighted the many obstacles in the way of ending LTFU. This kind of data gathering and research is very useful for designing responses and systems to defaulting patients. PATA is grateful to Wits ECHO for sharing this in-depth report.

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