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### 1. JCRC Uganda – Improving disclosure and adolescent care

After a suggestion by the JCRC team who attended the 2010 PATA forum, JCRC Clinic Kampala now notes down in a patient's file whether a child has been disclosed to or not. The team also organised a special workshop for parents who need to disclose to their children but felt that they lacked the skills to do so. Their aim is to have all 13 year-olds in treatment fully disclosed to before entering secondary school.

An anonymous suggestion box for adolescents has enabled the team to gauge the effectiveness of their services. In order to specifically address boys' issues, such as reproductive health services, four male staff members have been appointed 'male contact persons'. The team also started a transition clinic for 17 year-old boys to prepare them for adult services.

The pharmacy team also instigated changes as a result of the forum. Clients now receive correct dosage counselling after their pharmacy visit, helping those patients whose dosages have changed.

### 2. FACES Patient Adviser Groups bring home the right to participate

TeamPATA met up with the FACES Expert Patients in Kisumu during a recent visit to Kenya. We were very excited to learn about their formation of Patient Advisor Groups (PAG).

These groups are made up of men and women spanning the professional, unemployed and youth populations served by the FACES clinics. Each PAG also contains two representatives from their social support groups. A PAG meets once a month to discuss the clinic's services. This is an example of best practice which gives clients the right to participate in their own health care.

### 3. Talk and play: Kiwoko local forum draws multi-sectoral stakeholders and children together

*"HIV isn't treated with just pills, there is so much more. Children are not little adults. They may be dependant but medically, socially and spiritually each child has their own needs."* – Dr Rory Wilson, Kiwoko Hospital Medical Director

The PATA Kiwoko forum (Uganda) was the first PATA forum to involve local community based organisations and small NGOs. These multi-sectoral stakeholders were brought together to support a more integrated

approach to paediatric HIV/AIDS care and treatment in the area. Together these organisations care for over 1500 HIV+ children.

Prof Claire Penn opened the forum with an overview of communication in the clinical setting, emphasising that the health care workers' role was to help patients negotiate the world of medicine. This involves interpretation, translation and a revision of medical language to help clients understand their role in their own health care.

On Day Two, the twelve organisations attending the forum shared their successes, challenges and expectations.

Alison Fletcher, physiotherapist and head of the Children's Clinic at Kiwoko, spoke on the importance of care in child development.

Barbara Nazziwa from Mildmay Uganda said that "the language of children is play". To prove her point about how play can start conversations, she asked participants to draw pictures and play in sand.

Participants were then joined by over 30 children and teens from the Kiwoko Kids Club. Participants practiced their newly acquired strategies of communication with children. A debriefing session looked at what worked, allowing participants to reflect on their own strengths and challenges.

Day Three started with yoga exercises to help participants become more aware of their body and breathing. Claire Penn presented on child friendly communication and provided tips for communication with children. Taru Jaroszynski built on this by introducing PATA resources such as the [child friendly clinician poster](#), Project Concern's [Say and Play](#) toolkit and three [South 2 South disclosure booklets](#).

Finally, team grids were developed, setting out the respective teams' activities for the upcoming year. Most of the goals focused on staff training and developing child-friendly clinics.

PATA would like to welcome these new teams to the PATA network!

#### 4. Journeys of many kinds: The Vihiga local forum and disclosure to children

*"Having worked in HIV management for a long time, I have realised that it's often the small things that make the greatest impact on HIV outcomes." – Dr Sultani, Vihiga District Hospital*

The Vihiga PATA forum brought together teams from five facilities in the district who volunteered their time to learn about disclosure to children.

Together these clinics care for 885 HIV+ children (under 18 years old). The facilities face several common challenges, such as insufficient human resources, poor defaulter tracing, drug shortages (especially opportunistic infection drugs) and transport problems.

Despite these often oppressive challenges, all the hospitals cited the improved quality of life as children gain access to care and treatment. Three teams cited successful PMTCT programmes which have prevented the spread of HIV from mother to child.

Marnie Vujovic, a psychologist and researcher, provided the main academic content. She looked at strategies with which care workers can encourage communication with children in order to introduce disclosure. Participants had the opportunity to role-play with dolls and puppets and learn about ways to use drawing, sand and natural opportunities for disclosure.

A discussion on the “right” age to disclose was lively with participants expressing concern that discussions on HIV/AIDS means evoking conversations on the means of transmission – thus having to talk about sex.

Marnie helped the teams to see that disclosure is “a process, a journey that the health care professional undertakes with the caretaker of an HIV + child from a very young age”.

The right of children to participate in their own health care was also a subject of discussion. Taru Jaroszynski looked at two case studies of effective child participations and noted the importance of including the voices of children in clinics plans and projects.

By the end of the forum, teams reconvened to devise a set of 12 team goals which they will implement in their clinics over the next year. The common themes were clear: dissemination of information and the development of child-friendly clinics.

We wish the teams all the best with their journey in implementing their team goals.

Visit [www.teampata.org](http://www.teampata.org) for the presentations from our local forums.

## 5. Run-up to the PATA Summit: Meet Dr Sello from Baylor Botswana

Dr Refilwe Sello is the Programme Manager for Adolescent Services at Botswana-Baylor Children’s Clinical Centre of Excellence. Baylor Botswana is co-hosting the PATA Summit in November 2011 and Day Two will focus on care of the adolescent girl. We asked Refilwe a few questions:

### **What makes you passionate?**

I love working with children born with HIV. I am a local Motswana doctor who knows our epidemic very well and am excited to be an agent of change in Botswana and globally. Adolescents are a special population at a critical ‘make or break’ stage. They are not children and not yet adults either. Working with adolescents, one has to be energetic, warm, approachable, open-minded, sensitive, and compassionate to allow them to open up.

### **Tell us about the Botswana-Baylor Teen Club.**

Teen Club is a peer support group intervention for HIV+ adolescents whose mission is to empower these teens to build positive relationships, improve their self-esteem and acquire life skills. The idea is that a healthy transition into adulthood is secured. Our Teen Club’s international recognition for best practice can be viewed online at [http://www.aidstar-one.com/promising\\_practices\\_database/search](http://www.aidstar-one.com/promising_practices_database/search). More information on Teen Club resources can be found on: <http://botswanateenclub.wordpress.com/>

### **How many adolescents does the Teen Club work with?**

We started in 2005 with only five teenagers in Gaborone. Now over 600 teenagers are registered in the Club. We estimate that by the end of 2011 the Club will have 800 teenagers.

### **What makes it special?**

All members are fully disclosed to; hence it provides a forum for HIV+ adolescents to feel free, safe, and welcome. Every Teen Club session starts with an adherence lecture, which educates teens on the importance of adhering to their medications, which is critical to the success of ART.

### **What are the challenges?**

Our major challenge is to expand and strengthen our current activities to reach all adolescents living with HIV across the country. To do this we need more staff funding and funds to operate satellite teen clubs. Our priority for this year is fundraising for the construction of an Adolescent Centre to meet the demands of rising numbers of teens coming to our clinic. This will be a critical spring-board to reaching out to teens in other parts of Botswana.

## 6. *Yoga for Africa: getting 'bendy' for a focus on self, breath & body*

During recent local forums in South Africa, Uganda and Kenya, yoga classes were held for the participants. These classes proved to be a great team building exercise as well as a way for participants to connect with their bodies. *Yoga for Africa*, a series of yoga exercises (which originated in London prisons!) have been modified for Africa and compiled into a self-help manual by SeraUnite. *Yoga for Africa* enables people of all ages and abilities living in difficult environments to enjoy the benefits of yoga.

For more information on SeraUnite and the Yoga for Africa programme see: [www.servauite .org](http://www.servauite.org).

## 7. PATA has new offices!

We have moved into our new offices as of 1 August. Our **new contact details** are:

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*Our website: [www.teampata.org](http://www.teampata.org)*