

PATA Newsletter: Volume V Issue 7

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1. Day 3 of 2010 PATA East Africa Forum: Spotlight on Disclosure

With expanded access to HIV treatment, increased longevity is becoming normal for children with HIV. The positive outcomes associated with disclosure of HIV diagnosis are well documented. Yet many PATA-affiliated clinics and treatment teams identified **disclosure to children** as a stumbling block for service providers and caregivers.

Disclosure to children and adolescents will be tackled from multiple perspectives at the Forum. Goretta Nakabugo (TASO) will discuss how disclosure fits with the psychosocial needs of children and adolescents. Rose Nasaba (AIDS Relief) will look at disclosure from ethical and legal perspectives. Both the *United Nations Convention on the Rights of the Child* and the *African Charter on the Rights of the Child* make provision for the sharing of information with children. A personal perspective will be provided by an Expert Patient from JCRC who will tell of her experience with disclosure to her own child. Finally, Prof Claire Penn will provide suggestions on how to communicate with children about the “hard stuff”.

Disclosure impacts on clinical outcomes such as adherence and the mental and social health of the child. Many clinics have recognised this and implemented their own guidelines; hence PATA has a new addition to the programme where representatives from five different clinics will share their disclosure protocols. Speakers from Kenyatta National Hospital (Kenya), Beacon of Hope Care Centre (Kenya), Baylor College (Uganda), Arrow Study (Uganda) and Songea CTC (Tanzania) will also share their protocols and discuss their successes and challenges with implementing these guidelines.

PATA will also be distributing CDs with **presentations, documents, book, activities and learning tools** made available by MSF. RIAAT has also allowed us to distribute their materials. ANECCA has a training course for counsellors dealing with psychosocial issues including disclosure to children, which they will distribute at the forum.

Please follow this link for the [full programme](#) for the East Africa Forum.

2. CEPA and PATA to collaborate at the East Africa Forum

In May 2009, the **Global AIDS Alliance (GAA)** and several Africa-based country and regional partners launched the **Campaign to End Paediatric HIV/AIDS**, a three-year local-to-global advocacy campaign to reduce the incidence of paediatric HIV/AIDS. They also want to measurably improve the delivery of treatment to children and mothers. Ultimately, CEPA seeks to increase coverage rates for PPTCT+ and high-quality paediatric treatment services from the current average of 45% to the globally agreed-upon target of 80%. PATA is thrilled to have CEPA at the East Africa Forum where they will give a short presentation on Day 2.

CEPA is a local-to-global advocacy programme with six focus countries: Kenya, Uganda, Tanzania, Zambia, Mozambique and Nigeria. Their work in East Africa makes CEPA well-suited to participate in our regional East Africa Forum.

The CEPA campaign-wide objectives are:

1. Family Centred Care and Nutrition
2. Early Infant Diagnosis and Treatment
3. Access to Appropriate Medicines and Commodities
4. Full Funding (increased national budgets, achieve Abuja Declaration Commitment)
5. Programming to Achieve CEPA Impact
6. Overcoming Human Resource Crisis
7. Overcoming Stigma and Discrimination

Highlights of the initiative thus far include the Kenyan Government committing over \$11 million to life-saving ARVs for the period of 2009-2013 and a pilot of the new WHO PPTCT Guidelines (Option A) in Maputo, Mozambique which aims to be rolled out nation-wide. PATA is proud to be aligned with these objectives and look forward to continued collaboration with CEPA.

Franco Wandabwa, of CEPA and ANECCA, tells us why presenting at the Forum is an exciting prospect: “This provides an opportunity to put forward CEPA campaign objectives to people directly involved in the treatment and care services of children-‘foot soldiers’. It provides a great opportunity to get PATA members supporting the process at the country level.”

Further Campaign to End Paediatric HIV/AIDS triumphs and updates to come at the Forum, so watch this space! For more information on CEPA or to learn how you can get involved, see: www.endpaediatricaids.net

3. Impact of PATA Forums on clinic self-improvement tasks

As we draw closer to the East Africa Forum, it is important to reflect on the effect of previous Forums. PATA has collected data about the impact of the PATA Forums on clinics. These surveys are the beginning of an extensive monitoring and evaluation plan.

The information received from these questionnaires (9 teams from 6 countries responded) strengthened PATA's belief that these Forums are indeed challenging, pertinent and successful.

FACES (Kenya) said that the 2008 Forum was very relevant to their clinic. "The area we work in has the highest HIV prevalence in Kenya and also high levels of poverty. Understanding the relationship between malnutrition and HIV is a must for anyone who works here," they said.

The multidisciplinary 2009 Forum topics resonated with South African clinic, Zoe-Life. "Clinics or sites are not one dimensional. Medical and psychosocial issues are part of our challenges."

Each team that returned a questionnaire plotted their successes and difficulties with their 3, 6 and 12-month self-improvement goals set at each Forum. JCRC, Uganda, set a 3 month goal at the 2008 Forum to assess the nutritional status of all children and to plot growth charts at clinic visits. "This was achieved and now all children have their weights plotted at every visit," JCRC said.

The final part of the questionnaire focused on the Forum process. Chantal Biya clinic (Cameroon) said that they considered the most useful part of the PATA Forum to be the mutual platform it offers – "We shared common goals and exchanged ideas."

Tygerberg Hospital in South Africa thought that the presentations done by the guest speakers were very informative and assisted participants with "re-examining their own hospitals' practices".

FACES said that they thought PATA Forums could be improved by involving more presenters and facilitators from the African countries. The smaller regional forums – such as the upcoming East African Forum – will indeed enable more local experts to participate.

"The forum helps with 'end of year loss of morale'," said Tygerberg clinic. "It gives participants a boost and a sense of renewed energy to continue in this field. It has become an annual event that is seen as an educational treat."

PATA would like to thank all clinics that participated in this questionnaire for their in-depth responses. These answers will be an important part of securing future-funding for summit, regional and local PATA Forums.

You can obtain a copy of this from Rebecca@teampata.org. If you have not already, we encourage you to complete it and send it back to us.

4. Progress at the Livingstone Centre of Excellence Clinic, Zambia

Livingstone COE in Zambia provided PATA with an update on the progress of their team goals, set at the 2009 Southern Africa Regional Forum in Gauteng, South Africa.

The clinic's 3-month goals included integrating tools like *Auntie Stella* and *Say and Play* into group sessions, recruiting peer educators from their adolescent group, separating the paediatric pharmacy from the adult one, and having a paediatric pharmacist.

Livingstone was able to meet all of these goals. "We have recruited five peer educators," the report states. "The objective of recruiting these peer educators is to help other adolescent clients within the COE to understand fully the importance of keeping appointment dates as well as sharing knowledge on HIV and to encourage one another by sharing their experiences. This also helps them to accept who they are."

Livingstone's 6-month goals were to send one staff member for communication training for the physically impaired, start a skills/crafts learning group for adolescents, renovate and equip a new building, and recruit "expert mothers" as follow-up assistants.

The clinic has sent a nurse for communication training and an adolescent group has also been established. The crafts that these teens are producing (bracelets) will be sold to generate income for these adolescents. Two "expert mothers" have been recruited and now help to bring in patients from the community for follow-up visits. Although Livingstone has not been able to secure new space for renovations (which would include a new pharmacy), they have new furniture in the clinic and, as mentioned in the three-month goals, built a paediatric pharmacy in their current space.

Upcoming tasks set for the end of the year are to access more assistance from Faith-Based Organisations and to acquire an outreach vehicle for follow-up in the community.

PATA would like to thank Livingstone COE for their report and congratulate them on their achievements. We look forward to hearing more about their work in the future.

5. SADC/UNICEF collaboration agreement for the Prevention, Care & Treatment of Paediatric HIV, TB and Malaria

Globally the under-five mortality rate has been declining, however almost all of these deaths occur in poor and middle-income countries. Forty-four percent of deaths of children under 5 years of age globally occur in sub-Saharan Africa - the main causes of which include upper respiratory tract infections, diarrhoeal disease, neonatal deaths, malaria and HIV. Access to treatment for HIV is improving, but less than 40% children in need are receiving antiretroviral therapy. The percentage receiving effective treatment for malaria is still low and little progress has been made since 2000 on children receiving correct treatment for pneumonia and diarrhoea.

The Southern African Development Community (SADC) has committed to reducing poverty within its member states and this strategy includes the reduction of HIV and AIDS. In this respect SADC Secretariat is collaborating with UNICEF to standardise and scale up Paediatric Care and Treatment and document and disseminate Best Practices for HIV (including PMTCT), TB and Malaria. This collaboration focuses on the regional integration of control of communicable diseases - specifically HIV, Malaria and Tuberculosis. Assessments for current programmes for the Prevention, Care &

Treatment of Paediatric HIV, PMTCT, TB and Malaria will be conducted in all 14 SADC Member States and partnerships will be made with regional experienced institutions to help the SADC countries formulate policies, guidelines and protocols for the prevention, care and treatment of paediatric HIV, TB and Malaria. UNICEF's role is to mobilise political will and material resources to help countries ensure a "first call for children".

UNICEF is committed to strengthen capacity of regional and national governments and institutions to programme, plan, manage and evaluate development progress in Child Survival interventions including HIV and AIDS. It also supports programmes in health education and protection from HIV. In response to the capacity building needs, UNICEF promotes partnerships between local institutions/organisations and institutions and organisations with strong experience in health policy and programming in this area.

PATA took part in a planning meeting earlier this year regarding the SADC/UNICEF Initiative. We are aligned with the proposed vision and protocols of this plan and are happy to be able to report on this important endeavour.

PATA wishes to thank UNICEF and Dr Guillermo Marquez for assisting with the material for this article and with them every success in this much needed endeavour.

6. Expert Patient Programme Reminder

Important information for all clinics involved in the Expert Patient Programme: six-month reports are due at 4 pm on 1 October 2010.

It is essential that these reports be sent on time, as PATA cannot fund the programme without receiving them. The template has been e-mailed to all Expert Patient clinics and can be downloaded from the PATA website, www.teampata.org. All completed reports should be sent to the Expert Patient Programme Manager, Rebecca, at rebecca@teampata.org. Please do not hesitate to contact Rebecca with any questions or concerns.