

Volume VI Issue 2: Treatment teams take great strides toward better adolescent care & 2011 PATA Forum Applications now open

Contents

1. Important PATA notices
2. Umtha Welanga treatment team develops village health worker system
3. Vihiga District Hospital treatment teams extends psychosocial support
4. Nsamabya Home Care focus on developing adolescent care in their clinic
5. Expert Patient programme applications: new clinics, new goals and hard work ahead
6. Thinking about palliative care in Paediatric HIV care and treatment

“Thanks for the newsletter – it is good to hear the good news about the progress and the PATA effect, quite motivating and encouraging. It makes me believe I too can do something.” – Resty Ingabire, Uganda

1. Important PATA notices

- **The closing date for applications for this year’s pan-African PATA Forum is 20 May 2011.** The application forms can be downloaded from our website (www.teampata.org) as of 20 April 2011 or can be emailed to you upon request. The PATA forum themes for 2011 are **Early Infant Care, Adolescent Girls** and **Adding Value to your Service**. Masterclasses will be held on OVCs, Palliative Care, How to Run a Local PATA Forum and ART Made Simple (Case studies). There is space for 40 treatment teams to attend and teams from 23 different countries have indicated their willingness to participate in this forum. Simultaneous English, French and Portuguese interpreting will be available. Multidisciplinary treatment teams are urged to submit their applications as soon as possible to avoid disappointment.
- Some **new materials** have been added to the PATA website. You can download a useful step-by-step guide to disclosure, view a recent newsletter on PATA’s work and view our updated clinic finder
- **Did your team attend the 2010 East Africa Forum?** Tell us how you are doing with your team goals. Send us an email to Taru at taru@teampata.org

2. Umtha Welanga treatment team (South Africa) develops Village Health Workers’ system

Umtha Welanga treatment team (from Hamburg, Eastern Cape) provided PATA with an overview of their achievements since the 2010 Southern African Regional Forum.

In order to improve **family involvement** in the initiation of ART for children, the team now identifies two family members who are informed on the child’s diagnosis, medication and the support required for adherence. The team also set up a system to follow-up on all positive PCR tests. The nurses in charge of clinics in the area report each positive PCR so that follow-up can be instigated.

The team learnt about **“Say & Play”** and **“Auntie Stella”** at the 2010 Forum. The Auntie Stella kit was well received by their staff and expert patients.

A great achievement has been the development of a **Village Health Workers’ system**. Dr Paul Roux from Kidzpositive and Dr Sara Stulac from Partners In Health have helped the team to develop a plan for training

staff and monitoring and evaluating the programme. With these experts' guidance, team leaders have been elected and more Village Health Workers have been hired.

To address their challenges in caring for adolescents, a monthly **adolescent clinic** was established. Three peer educators were also recruited. The team is now working towards setting up an adolescent centre which will include STI, VCT and family planning services. Their Computer Centre is near completion and will double as an adolescent centre. The team is currently looking for staff to offer counselling services and education at the centre.

In an effort to address the number of **child-headed households and adolescent orphans** on ARVs, the Umtha Welanga team is in discussion with the Community Management Team on the creation of a children's home for orphans. The plan is to fundraise and then renovate a building to be turned into the children's home.

For more information on Umtha Welanga please see their website (www.keiskamma.org/health) or contact Taru at taru@teampata.org with the subject line 'Umtha Welanga' in your email.

3. Vihiga District Hospital (Kenya) treatment team extends psychosocial support

The Vihiga District Hospital team attended a PATA Forum for the first time in 2010. They recently sent PATA their three month report. **"The seemingly small things that we have overlooked over the years,"** they wrote, **"are in fact extremely valuable in the overall results achieved in the care and treatment of our clients."**

The goals undertaken by the team for the first three months following the 2010 East African Regional Forum were:

1. To attach **each child** to the nearest psychosocial support group or social worker
2. **To strengthen psychosocial support groups** through regular meetings
3. **To train** all contact health workers on disclosure
4. To establish an **Expert Patient programme**

Of the 124 children attending the Vihiga clinic, only nine are yet to be attached to a psychosocial support group, but they will be allocated to one of the three groups in the next few weeks. The team has approached the District Health Management Team and the District Nurse to plan and budget so that more than 1000 children attending the hospital's 15 satellite clinics in the district will be attached to a support group. **"Every single child must belong to and benefit from a psychosocial support group,"** the team writes. The team plans to increase the number of support groups to between 20 and 25, as the number of children increases.

Due to logistical and financial constraints, the clinic has held only one out of the three planned meetings aimed at strengthening the psychosocial support groups. They have secured the hospital administration's support and more meetings are planned.

There are five resident clinicians in the comprehensive care clinic. The team plans to train more and to incorporate disclosure training with on-site training through the District Public Health Nurse's facility visits. A 'train the trainer' model will be used so that one health worker per satellite site will train colleagues at each particular site.

The clinic has established an Expert Patient type programme with two Expert Patients currently volunteering at the District Hospital clinic. The Expert Patients care for the children during the paediatric day clinic and are

central to the collection and management of data. They are investigating ways of expanding the programme and making it more sustainable.

If you have any comments or questions for the Vihiga team, please email Taru at taru@teampata.org with the subject line 'Feedback for Vihiga'.

4. Nsambya Home Care (Uganda) focuses on developing adolescent care in their clinic

Nsambya Home Care (NHC) from Kampala joined the PATA network in 2010. The treatment team that attended the 2010 PATA Forum have shared some of their progress since the forum.

The team's first goal was to produce a **monthly newsletter** about their experiences in dealing with adolescents. The first newsletter was printed in March 2011.

Performance review meetings were conducted and subsequently a representative group of staff and adolescents has been formed to initiate improvements in services to adolescents living with HIV.

Eight **focus groups with adolescents** were held to guide the creation of an adolescent transition process manual.

The team also held a meeting to share information from the PATA forum with other health care workers in the clinic.

In addition the clinic has been successful in:

- **Strengthening** the existing five Peer Support Groups and initiating another group in a satellite clinic
- Each group has a constitution, objectives and details of meeting minutes
- **Seeking donations** for recreational materials for children
- Making two **presentations** at the Uganda Paediatric Association conference
- Providing **IEC materials** in the clinic e.g. ART, SRH services, TB, motivation messages and other reading materials from Straight Talk Foundation and Young Positives

If you have any comments or questions for the NHC team, please email Taru at taru@teampata.org with the subject line 'Feedback for NCH'.

5. Expert Patient programme applications: new clinics, new goals and hard work ahead

PATA recently received **49 applications** for clinics who would like to participate in the Expert Patient programme – seven of these applications are from new clinics. The applications are to hire 182 Expert Patients in clinics in 14 different countries. A special welcome to Baylor Botswana who will be the first Botswanan clinic to participate in the Expert Patient programme.

The majority of the Expert Patients conduct **home visits** to community members (26%), while 18% will be involved in **simple clinical tasks** such as anthropometric measurements. A fair number of Expert Patients will be involved as **support group leaders** (8.8 %), **adherence monitors** (7.7%), **health educators** (6.6%) and **nutritional assistants** (5 %).

Telephonic interviews were conducted with Expert Patient supervisors and some of the highlights include:

- Songea Regional Hospital (Tanzania) has **published an article** on the Expert Patient programme in the Tanzanian Regional Referral Health Management newsletter (February 2011).
- Tisungane clinic (Malawi) is working on a **research project** to evaluate the training for and implementation of triage by Expert Patients at the clinic.
- Expert Patients from HAQOCI (Zimbabwe) played a very important role in a **training workshop** where AFRICAID and HAQOCI adapted the generic WHO training materials on Integrated Management of Adolescent Illness (IMAI) to meet local needs.
- Chantal Biya (Cameroon) has created a **patient psychosocial record form** which includes a table to record information such as dates of service, the caregivers' names, the problems identified and the intervention provided by the Expert Patient. These sheets will be used to track the Expert Patient interventions.
- An abstract of the Evaluation of an Expert Patient programme for PMTCT services conducted in Zomba Hospital (Malawi) has been accepted to be **presented for the 2011 IAC in Rome**.

PATA will be working to consolidate and improve the Expert Patient programme so that it becomes an example of best practice in task shifting and better integration of community workers into treatment teams. An Expert Patient Programme Manager will join the PATA office to facilitate this process. PATA will present a paper on the Expert Patient programme at the South African AIDS conference in Durban (June 2011).

We would love to hear your thoughts on the programme. Send us an email to info@teampata.org with comments and suggestions.

6. The role of palliative care in the future of paediatric HIV care and treatment

PATA has recently been looking at partnerships with the **Princess Diana Memorial Fund** and the **International Children's Palliative Care Network (ICPCN)** in order to focus attention on paediatric palliative care.

Palliative care organisations are "concerned with the management of the physical, emotional, social and spiritual manifestations of pain among those living with a life-limiting, incurable disease" (Harding, Sherr & Albertyn 2009).

The aforementioned organisations are working to **integrate palliative care into health care systems**. This is motivated by research that indicates that palliative care improves the quality of life of children living with and affected by life-limiting illnesses. A recent study has shown that a palliative care approach has a role to play in treatment, by helping adherence to anti-retroviral treatment. It is also central to effective pain management and enables patients to live out the remainder of their lives with dignity, and as little pain as possible. Palliative care is multidisciplinary and supports patients AND their families.

Like PATA, the ICPCN and the Princess Diana Memorial Fund are focused on promoting integrated, comprehensive family-centred care and treatment services. The WHO views palliative care as an essential component of the care and treatment of people living with HIV/AIDS.

A **masterclass on paediatric palliative care** will be held at the 2011 PATA Summit. Please let us know if you have examples of how palliative care is already being used in your clinic.

You can join the International Children's Palliative Care Network by signing up online at <http://www.icpcn.org.uk> . Any organisation or individual working in the field of palliative care for children can join ICPCN for free.

The textbook *Children's Palliative Care in Africa* is **free for download** on the website. It aims to 'respond to the enormous and growing need for children's palliative care services in Africa and other resource-poor settings'.

Contributors: Melanie Evans, Toast Coetzer, Taru Jaroszynski, James Millar and Virgile Mahoro