

Volume VI Issue 3: Focus on local forums – the PATA-effect at work

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1. Important PATA notices

- PATA 2011 Summit Applications were due 20 May 2011. For any application queries or late applications, please contact Taru at taru@teampata.org.
- The PATA poster titled *The Child Friendly Clinician* can be downloaded in French, English and Portuguese from our website: <http://www.teampata.org/downloads/Poster-English.jpg>

2. What is a PATA local forum?

At the 2010 PATA East African Regional Forum, teams were introduced to the concept of 'Local Forums'.

The local forum is a means to cascade knowledge and learning from the annual PATA forum to the community level. Treatment teams attending a PATA Summit or regional forum will be taught (during a masterclass session) how to run a local PATA forum. Teams keen to run a local PATA forum (as one of their annual tasks) will be encouraged to submit an application to PATA to access funding and mentorship.

Local PATA forums will closely follow the format of annual PATA forums (ie plenary presentations, intra-disciplinary workshops and inter-disciplinary workshops). The local PATA forum is characterised by the following:

- The local host attended a PATA forum and is inspired by the topics or PATA model
- Topics addressed at local PATA forums are selected by the local host team to address an identified need in their area
- The local forum is multi-disciplinary and is likely to be cross-sectoral; the engagement of other community-based organisations and NGOs is encouraged
- A typical local forum involves 4 treatment teams of 5 people (approximately 20 participants) from the surrounding community/ area, and three guest speakers/ facilitators
- Expert patients and/ or Community Health Care Workers are included as team participants
- Local forums are held within the community of the local treatment team, typically within a local church, school hall or at the clinic itself
- Local forums are of shorter duration (2 days) than regional PATA forums (4 days)
- A dissemination of information plan is created to ensure that information reaches other clinics, government bodies and officials

- Teams set goals aimed at improving the quality of care they provide to HIV infected and affected children and their families

Local forums will be held in countries which had treatment teams in attendance at the preceding annual PATA forum. Local PATA forums are planned:

- For the East African region in 2011 (following the East African regional forum held in Uganda in 2010). 5 local forums are planned for this region, the location of which *will depend on which treatment teams select this as a task*. To date, local forums are confirmed for Vihiga District Hospital (Kenya), Kiwoko Hospital (Uganda) and JCRC (Uganda).
- Following the PATA Summit, 10 local forums are planned. The location of these local forums *will depend on which treatment teams select this as a task*.

If your team is interested in hosting a local forum please email Taru at taru@teampata.org with the subject line 'A PATA Local Forum'.

3. PATA welcomes Tiny Tim and Friends (Zambia) to the PATA network

Tiny Tim and Friends (TTF) is a paediatric care and treatment facility, working in some of the poorest communities in and around Lusaka, Zambia.

TTF provides VCT at community events and is open to the public for testing, care and treatment. The clinic has a special focus on pregnant women and vulnerable women.

“We have a cadre of dedicated women working in fourteen of the compounds literally going door-to-door and following referrals from others in the community, to OVC and pregnant and other vulnerable women needing assistance,” says Thomas Lent, director of TTF. “Those in need are provided with transport to and from the clinic and are escorted by members of the women's support group – some of whom are also HIV+. It is a beautiful programme.”

The clinic works in collaboration with Grassroot Soccer and Elton John Foundation on a project called ‘Bridge the Gap’. Community events are paired with education and training to reduce loss to follow up, enrol new patients in care and provide various forms of assistance such as rental and small business support.

TTF is also pioneering a programme for children at the end of their lives. “The realities are bleak for critically ill children in Zambia,” says Lent. “Often critically ill children die at home and in pain with family members who do not know how to care for them.”

TTF in association with Princess Diana Memorial Foundation are developing a programme to train medical professionals and women's support groups to provide home-based palliative care and assistance in a hospice in a nearby community.

From 21 to 24 November 2011, TTF will be co-sponsoring the International Paediatric Palliative Care Symposium, the first of its kind in Zambia.

If you have any comments or questions for the TTF team or would like to learn more about the International Paediatric Palliative Care Symposium, please email Taru at taru@teampata.org with the subject line 'Feedback for TTF' or see their website at <http://www.tinytimandfriends.org/>

4. Kiwoko (Uganda) reviews their PMTCT protocol and creates teen groups

The team at Kiwoko Hospital in Uganda serve a rural population and provides a range of treatment and care services and as well as a prevention and education programmes.

Before the PATA East African Forum the team identified teen pregnancy, adherence, stigma and sudden changes in caretakers as major challenges. In the 6 months following the forum the team have:

- Shared information with the hospital
- Implemented adherence educational sessions for caretakers
- Reviewed their PMTCT protocol
- Split their adolescent groups so that appropriate information is shared with each group
- Created new age cohorts groups
- Put forward a proposal for basic needs funding for severely disadvantaged clients

The team also plans to develop their disclosure protocol and start a teen mothers' club.

Kiwoko Hospital will be hosting small local forum to involved community groups and local clinics in order to develop an integrated response to working with caregivers.

5. The positive benefits of the Expert Patient programme and PATA's presentation at the 2011 SA Aids Conference

PATA will present a paper at the 2011 SA AIDS conference on the lessons learnt in the Expert Patient programme. The programme is constantly being revised in response to changing challenges. In addition to alleviating some of the human resource difficulties by task-shifting, the Expert Patient programme has had positive benefits for the quality of life of Expert Patients, their families and communities. It has also helped to expand child and adolescent programmes.

Expert Patients testify that they have gained personally from the programme:

"They are provided an opportunity to show their worth to society. They are highly regarded in our community and live an exemplary life for all PLWHA and the programme has also provided an income." (Songea CTC, Tanzania).

"The programme has helped self-confidence among volunteers." (Sunshine Smiles, Kenya)

"Expert Patients feel good, motivated and valued. They feel that they are still people like anyone else and can contribute to society." (Nyangana, Namibia).

"Expert Patients feel more useful, which is vital for PLWHA. Since they are meant to act as models for adherence, it gives them a reason to maintain adherence." (JCRC, Uganda)

Expert Patients are role models to children and the benefits are tangible:

“The fact that Expert Patients are living with HIV makes it easy for the children/adolescents to relate to them. The average age of the Expert Patient is lower than that of other clinic staff and therefore children regard them as older brothers or sisters and they open up to them.” (Songea CTC, Tanzania)

“Adolescents feel free and at home since they always have someone to talk to. Children also feel safe and are able to make good relationships that spread to their schools and families.” (PIH Butaro, Rwanda).

“The increase in psychosocial support has been carried out in part by Expert Patients and the lives of many children have been transformed.” (Sunshine Smiles, Kenya)

“The teen club has been very exciting and empowers children to cope with stigma.” (Dvokolwako, Swaziland)

“During our paediatric clinic, children have time to play with the Expert Patients. Children are now more willing to go to the clinic for follow up.” (Nyangana, Namibia)

Expert Patients have “a profound effect” on the function of the clinics where they work:

“Apart from the specific tasks they are hired to undertake, the Expert Patients have learned to assist in almost every aspect of the running of the CTC.” (Songea CTC, Tanzania)

“Clinicians now have enough time to treat patients holistically. They do more TB screening which means more treatment. The LTFU rate has dropped from 5% to 1.6% due to Expert Patient work.” (Dvokolwako, Swaziland).

“Due to a lot of task-shifting from staff to Expert Patients... Nurses have much more time...” (Nyangana, Namibia).

“They lend a personal and experiential perspective to patient care...offers a personal emphasis on patient management, giving rise to a more holistic and insightful patient care.” (Baylor, Malawi)

Expert Patients also provide an important link with the community:

“They make home visits to patients who are LTFU and bring valuable information back to the clinic.” (Songea CTC, Tanzania).

“Their home visits result in improved care and sensitization to health care, and a reduction in stigma.” (PIH Butaro, Rwanda)

“One community north of Kampala was particularly poorly linked with paediatric HIV services. The Expert Patient has done well to direct and often bring the infected children and their carers to JCRC Kampala. The EP that lives in this community held meetings with other people attending JCRC from the area and explained the services.” (JCRC, Uganda)

It is heartening to learn that the PATA Expert Patient model is providing a standard for the development of similar programmes *“Using PATA Expert Patients as the model, Dvokolwako has been able to enrolled 21 Expert Patients to work in the community.”* (Dvokolwako, Swaziland).

If you or a member of your clinic is attending the SA Aids Conference in Durban, please let Taru know at Taru@teampata.org because we'd love to meet up with you there.

6. A 2011 PATA Summit Taster

The 2011 PATA Pan-African Summit, co-hosted by Baylor-Botswana, will be held at the Phakalane Golf Estate Hotel Resort in Botswana (<http://golfestate.phakalane.com>) from 14 to 18 November 2011. The Phakalane Estate is situated in the suburb of Phakalane, a 20 minute drive from Gaborone airport and 15 km from the city centre. The resort boasts many interesting bird species and wildlife. There is a variety of accommodation options; from self-catering chalets to hotel rooms. The tranquil setting will be ideal for PATA's packed programme of state of the art technical presentations and structured workshops in professional groups and teams. The PATA Academic Committee is working hard to put together a programme that will inspire and challenge participants.

If you have ideas on how we can make this year's forum particularly special for all teams in the PATA network, please email your suggestions to Taru@teampata.org.

7. Update from the PATA office

James Millar, PATA's newsletter rapporteur for the last 3 years, is nearing the end of his medical studies and has expressed his wish to continue writing for PATA, informally, in a volunteer capacity. The PATA secretariat is very grateful to James for his enthusiasm and assistance with the newsletter and PATA forums, and wishes him well with his final exams.

In the PATA office, two new faces are working hard to ensure that PATA organisation is seamless; Glynis Gossman is employed as PATA's Financial and Administrative Associate, and will be supporting Taru in the task of organising the PATA Summit, the five local forums scheduled for 2011 and in all financial matters. Roseanne Turner, who has been contracted to review Expert Patient training, will continue on a contractual basis for PATA until mid-August, managing the Expert Patient programme as a whole. At present, Roseanne is developing the monitoring and evaluation of the Expert Patient programme within the broader PATA monitoring and evaluation framework.

PATA is very pleased to welcome visiting steering committee member, Dr Elizabeth Obimbo, based at Red Cross Children's Hospital for a sabbatical. Fellow Kenyan, Dr Polycarp Mandi is also currently furthering his studies at Red Cross Children's Hospital. We hope that they both have a wonderful stay in Cape Town. If any other PATA network members are visiting Cape Town to further their studies or to gain work experience, please do contact us so that we can arrange to meet up with you.

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