

PATA Newsletter Volume V Issue 1

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1. Clinics achieving goals set at the 2009 Southern African Forum

It is now three months since the Southern African Forum in Johannesburg, at which 25 teams from 10 Southern African countries met to converse around the themes of Advanced ARVs, Adolescent Care and a Clinic Psychosocial Toolkit. On the last day of the PATA forum, clinics set tasks to achieve in the year ahead.

Roughly fourteen different categories of tasks can be identified, reflecting the diverse array of problems the clinics have to deal with on a daily basis. These categories include issues affecting staffing (for example, the Baylor Lesotho clinic intend to provide communication training to key staff members), adolescents (clinics plan to actively look for lipodystrophy in young patients) and caregiver support through an alcohol rehabilitation programme (as put forward by the Robertson clinic).

There were 18 different clinics who planned to set tasks affecting their staffing issues and many also singled out adolescents as a problem area, but other categories, such as nutrition, family-centred care, gardening projects and toxicity attracted only the interest of one clinic each (Job Shimankana Tabane, Tisungane clinic and HAQOCI).

A recurring category for PATA clinics is that of providing child-friendly care centres. The George clinic, for example, wants to build a play area and implement the 'Say and Play' materials. Many clinics also plan to improve their networking with other clinics in order to exchange information – the Baylor Botswana clinic want to improve their collaboration with Mpilo OI clinic by exchange information regarding best practices.

Dora Nginza Hospital planned to set up community meetings to strengthen their foothold in the community and Bophelong, Zoe-Life and Newlands clinics all intend to improve their administration by compiling training materials.

Tygerberg clinic was amongst those who wanted to improve their voluntary testing and counselling (VCT) and planned to do this by identifying undisclosed patients. Infrastructure was a category which six clinics wanted to focus on and a handful also intended to improve the functioning of their pharmacies.

Three months after the forum (there will also be six and nine month report-backs), we are asking teams to report back on the progress that they have made towards achieving these goals. Teams that have not already done so, are encouraged to email Melanie at melanie@teampata.org. We would like to know:

1. What success have you had in achieving your goals?
2. What challenges have you experienced in this process?
3. What additional support do you need from PATA to achieve the goals you have set?

We are waiting to hear from you!

2. Zoe-life amends their team grid

Zoe-life in Durban is an example of a team that amended their grid after reporting back on the PATA forum. The team felt that this allowed them to align and integrate their stated goals with work already going on at the clinic. They spoke to their Maternal Child and Women's Health (MCWH) team so that they knew what goals the clinic had committed themselves to for the year ahead.

Zoe-life has added a column to the PATA grid showing to which programs at Zoe-Life the tasks are linked.

Zoe-life reported that the MCWH team discussed the grid and noted a few changes, for example:

- In researching peer counsellors, the team decided that they should set a longer term goal. Although this fits within the scope of the Zoë-Life Adolescents program, it was felt that it would outgrow the interactions they would be having with schools as well as clinics, so this would need to be ongoing throughout the year.
- In developing caregivers' materials: The team felt it would be important to note the need for the development of caregiver material in the first part of the year and to then pilot and

then roll out caregiver workshops. This would fall within the Zoe-kids/ Paediatrics psychosocial programme for 2010.

- In training the MCWH team: The team that attended the PATA forum felt that the Auntie Stella programme could be considered as a tool for their work. There was a need for Zoe-Life to unpack the tool and identify if there were any amendments to be made to the areas in which they work and also to their understanding of how best to utilise the tool. It was agreed that those who attended the PATA conference would train the MCWH team and would work together to make any amendments if needed.

3. Disclosure materials in the spotlight at East Africa PATA forum

Disclosing HIV+ status to children and their carers has been a much-discussed and debated topic in the field of paediatric HIV/AIDS. At the 2009 PATA Forum in Johannesburg, many PATA teams chose Child Disclosure as something to be worked on in the coming year. At this year's East Africa PATA Forum, a day of the proceedings will be devoted to illuminating this challenging issue. Pre-counselling to evaluate the child and his or her carer and post-counselling for those children found to be HIV+ are both integral steps in the disclosure process.

With child disclosure, there are frequently three parties involved in the disclosure: the child, the counsellor and the care-taker(s). The counsellor must navigate the often complex relationship between the child and his care-taker (who may or may not also be HIV+) while at all times being mindful of the medical and emotional wants, rights and needs of the child.

Médecins Sans Frontières (MSF) recommends in their 2008 guide *Patient Support for HIV Infected Children* that children under the age of six be subject to "gradual disclosure," as they most likely do not have the personal resources and maturity to deal with immediate, full disclosure. Children from six to twelve years of age must be assessed individually and with the help of their carers to formulate a disclosure plan that is best for the child. This plan must take into account, among other things: family situation, the status of the care-taker, and the child's conception of why he is being tested.

Disclosing to an adolescent about his HIV+ status requires yet another approach, with more direct talk and emphasis placed on risk evaluation, privacy, and support services. This approach fluctuates based on whether the adolescent has a trusted parent/guardian with whom he can share his status or not.

Disclosure, when done correctly, can ensure that HIV+ children receive the psychological support and medical services they need. It can also work to eliminate stigma by encouraging open conversation between the counsellor, carer and child/adolescent.

Melanie Evans represented PATA at a Disclosure to Children workshop that was hosted by the Children's Rights Centre in Durban on Thursday the 25th February. Other South African PATA-

affiliated teams that were represented included Zoe-life, Wits Echo and Right to Care. The minutes and resources shared at this meeting will be posted on the PATA website. Also available on the PATA website is a CD compiled by MSF with materials on Child Disclosure.

4. East African Forum update

The East African Forum will be held in October 2010. The original envisaged date of April 2010 was deemed unrealistic given current budget constraints. The programme planning is already advanced and the forum themes have been decided on: Day 1 will focus on Advanced ARVs (e.g. treatment failure, second line regimens, resistance and toxicity), Day 2 on Adolescent Care and Day 3 on Disclosure to Children.

Applications to attend the 2010 PATA Forum will open in April 2010. All teams in the East African region are welcome to submit applications. Please note that there will be no French translation at the East African forum, as there will be a dedicated Francophone forum in Cameroon later in the year. Teams are encouraged to source their own funding wherever possible as there will be limited scholarships available. Scholarship preference will be shown to teams who have regularly reported back on their progress (e.g. about their successes and challenges) to PATA.

5. Expert Patient Programme Funding Renewals

The funding year for the expert patient programme ends at the end of March 2010. Teams wishing to continue with the programme are required to complete an application form available for download on the PATA website.

Teams will only be considered for renewed funding if they have complied with the following:

1. All progress reports up to January 2010 have been sent to PATA
2. All funds received for the expert patient programme in the last year have been acknowledged in writing
3. The bank account details have been completed in full; please note that the bank account given needs to be in the name of the clinic or NGO, and not an individual.

All applications for renewal must be received by 23 March 2010.

6. CEPA Update: Looking at Family-Centred Care

The Campaign to End Paediatric HIV/AIDS (CEPA) is a global initiative launched by Global AIDS Alliance (GAA) in 2008 in an effort to mobilize full funding for paediatric HIV diagnosis, treatment, care, and support, and to expedite scale-up to end paediatric AIDS in Africa.

GAA has identified these objectives for accelerating their action plan: Family Centred Care, Early Infant Diagnosis (EID) and Early Infant Treatment (EIT), Access to Appropriate Medications and Full Funding to Eliminate Paediatric AIDS.

Family Centred Care (FCC) offers HIV/AIDS prevention, testing, care and treatment to the entire family at one location and has been shown to increase service uptake as well as case finding of women and children. National programmes utilizing FCC, with the family as the unit requiring medical and social intervention, have the greatest chance of ensuring long-term adherence. Family Centred Care should be the gold standard for national programs in the prevention and treatment of HIV/AIDS (DeGennaro & Zeitz, 2009).

How family-centred is your clinic? PATA would like to find out about the challenges and successes your clinic is facing in following a family-centred approach.

Please complete the questions below. Thank you for your time and thoughtfulness in answering these questions.

1. Does your clinic/hospital provide routine opt-out (not opt-in) HIV testing when mothers first book for antenatal care?
2. Does your clinic/hospital provide ART to all HIV+ mothers free of charge for life?
3. Does your clinic provide Nevirapine for mothers during labour and AZT for the neonate after birth for 6 months? If not, which drugs (if any) are used?
4. Does your clinic provide mothers with comprehensive education regarding PMTCT for all mothers attending antenatal care?
5. Do you offer HIV testing for partners of HIV positive mothers at the same clinic where the mothers are booked in?
6. Do you encourage testing of partners and children of HIV positive at the booking visits? And do you make this easy for the patient's family to apply for at the booking visit?
7. How is infant HIV diagnosed at your clinic? (Please circle most appropriate a-f)
 - a. Routine PCR on all infants born to HIV+ mothers at 6 weeks
 - b. Routine Elisa at 6 months?
 - c. PCR/Elisa only if infant is symptomatic.
 - d. We do not test infants for HIV because the tests are not available
 - e. We do not test infants for HIV because there is no ART at our clinic
 - f. Other (please specify):

8. If an infant is found to be HIV+, do you start ART immediately?
9. Do you have structures and protocols to test and treat a patient's family if an HIV test is positive?

7. Congratulations to PATA: Health Care award

PATA has received national recognition in South Africa. An award for Excellence in Health care from the Health Professionals Council of South Africa is an acknowledgement of the work of PATA in improving the lives of sub-Saharan children living with HIV and AIDS. The award was received by Paul Roux, PATA co-founder and co-founder of the Kidzpositive Family Fund.

Through One to One Funding, Kidzpositive, a Cape Town based NGO, was able to deliver ARVs to HIV-positive children two years before the South African government started its national rollout of the drugs.

This donation paved the way for a team of health care workers to gain experience in the management of children on ARVs. A 'visiting treatment team' programme was launched in 2004, to assist colleagues in Africa who, at that time were not treating patients with anti-retroviral treatments because they had nowhere to go to gain the necessary experience. This initiative led to the first PATA conference in December 2005 (once again funded by One to One) and the establishment of PATA in 2006.

By reaching out and touching communities and health professionals, and helping to build capacity in Africa, PATA aims to create a ripple effect of treatment action that will give a growing number of children access to life-saving antiretroviral therapy and holistic care. PATA does not tell people what to do, but helps them discover common goals and to collaborate to get things done

PATA is proud of this acknowledgement. We hope that the award will inspire others also to take on challenges and develop new ideas.

8. Changes at the PATA office

PATA would like to welcome Rebecca Norman, an intern from Boston who has been volunteering at One to One Children's Fund. She will be based in Cape Town for the next six months.

James Millar will continue working on the newsletter with our journalist, Toast Coetzer, and our translator, Virgile Mahoro.

PATA will be welcoming Taru Jaroszynski in the position of Assistant Project Director and Advocacy officer from 1 June 2010. Taru will be filling the role briefly occupied by Ashley Petersen. We wish Ashley well in his new career.

Melanie Evans will be expecting her first baby in August and so will be on leave from August until December. Her role will be filled by another assistant project director who will start work on the 15th of July. This position will be advertised in March 2010.

References:

DeGennaro, V. & Zeitz, P. (2009). Embracing a Family-Centred Response to the HIV/AIDS Epidemic for the Elimination of Paediatric AIDS. *Global Public Health*, 99999, 1-16.

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