

Newsletter Vol V Issue 3

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1. Website updates and East African Forum application deadline

We encourage all PATA members to take a look at our recently updated website. You can now download Say & Play (a development tool for children) and child disclosure tools from Medecins Sans Frontieres. The application form for the 2010 East Africa Forum – which will be held in Kampala from the 11th to the 15th October 2010 – is also available on the website. The applications for the East Africa Forum are due before the 31st of May 2010. Teams are encouraged to arrange their own sponsorship for transport and accommodation. Please visit www.teampata.org to download the application form.

2. Feedback from the ‘Disclosure to Children’ workshop in Durban

The Children’s Rights Centre in Durban, South Africa, hosted a workshop entitled ‘Changing the Discourse on Disclosure for Children Living with HIV/AIDS’ in February. Links to the resources that are currently being used by participants to assist in the disclosure process are shared below.

Melanie Evans attended on behalf of PATA and other participants included NGOs, health care workers and the caregivers of children with HIV. Participants explored collaborative options and advocacy actions necessary to enable disclosure to children on a larger scale in South Africa. They also investigated how existing information, approaches and tools can be shared more effectively.

A number of clinics follow the EGPAF, CHIVA and the Open Society Foundation for South Africa guidelines (www.osf.org.za). Many also make use of skills training: basic counselling training, peer education, structured group therapy and one on one counselling sessions. Another recommendation was the use of a multi-disciplinary form for history taking, in which information is obtained from the caregiver, the child and the school.

Other activities described by participants as being helpful in working towards disclosure include: art therapy, Body Mapping, Tree of Life, camps, workshops for caregivers and staff, games (using the Living Positively handbook), Kids

Count (children's resource guide and trainers' guide), training provided by Big Shoes Foundation and Memory Box work.

Participants to the workshop identified a number of challenges around disclosure. These included stigma, caregivers who are reluctant to disclose and the many levels on which disclosure operates – eg if you disclose the child's status, you are also disclosing the mother's status or the status of other family members.

Sometimes children also inadvertently find out from the community if parents have not disclosed to them.

The conclusion of the workshop was that we are still struggling with disclosure to children. This is because every child and family is different and there's no one formula that works for all situations.

Counsellors have their own ghosts from their own pasts in terms of working with children. We need to find counsellors who want to work with children.

Helpful disclosure materials and resources identified by the workshop:

- A chart developed by Kimesh Naidoo (Dept of Paediatrics, University of KZN) and Diane Melvin called 'Step by step guide for disclosing to children regarding their HIV Status'. This chart looks at different age groups (0 to 4 year olds; pre-schoolers aged 5 to 7 years; school-going children between 8 and 11 years; and teenagers between 11 and 14). For a copy of this chart, phone +27 31 260 4111.
- Right to Care has developed a training manual for caregivers. Contact +27 11 276 8850 for more information.
- MSF patient support guideline CD – contact the PATA office +27 21 686 9710, or download it off the PATA website www.teampata.org.
- Regional Psychosocial Support Initiative (REPSSI) table and talking book – mostly targeted at caregivers. See www.repssi.net
- TARSC materials e.g. Say and Play (aged 0 to 6 years) and Auntie Stella (teenagers talking about sex). Visit the PATA website www.teampata.org
- Zoe-Life has an intensive kids' disclosure programme. Visit www.zoe-life.co.za for more information.
- A best practice guide to HIV disclosure (www.osf.org.za)

3. Three helpful MSF disclosure materials

The disclosure materials discussed in this article are now available at www.teampata.org

Counselling Cards: Tools for the counselling of children living with HIV

This set of 32 cards (created by David Goetghbuer, Nazira Nangy, Wania Correia, Zacarias Chemane) is meant for children between the ages of 4 and 16 who are undisclosed, partially or fully disclosed to about their diagnosis, on ARVs or not.

The cards have images on one side and explanations on the other side. The counsellor should show the card to the child (without giving the card to the child) and ask the child about the picture. The counsellor should then explore the theme by following the instructions on his/her side of the card.

Themes covered include the immune system, CD4 cells, adherence to treatment, emotional and physical state, personal hygiene, friends, family, and leisure activities.

Behki

Behki is a children's book written and produced by the infectious diseases paediatrics team of Brussels Hôpital St-Pierre Complex in Brussels, Belgium. The story (available in French, English and Portuguese) follows a lion cub named Behki as he, his father, his mother, and a hippopotamus named Rakou journey from "the Land of the Golden Sun" to "the Land of the Tree of Smiles." Behki's mother is sick and dies during their long walk. Behki begins exhibiting the symptoms of his mother and falls sick.

Using language that children will understand as well as c engaging pictures, *Behki*'s message is that when you are sick (with HIV/AIDS), you must take the medicine that will make you better every day. *Behki* also touches on issues such as the death of a parent and how to tell friends that you are sick.

Thanks ARVs: A Fairytale that Encourages General Well-Being

This story (written by Nisachoul Ounjit and illustrated by Celestine Wamiru) gives children a positive understanding of HIV/AIDS. The narrative follows a village full of animals that become sick when an evil hyena gives them the "Devimon" virus. The animals begin taking ARVs with the understanding that ARVs will not cure them, but will prevent the illness from becoming worse.

At the end of the tale there are questions concerning the characters of the book, health, family and medicine. The second half of the questions explicitly use the term HIV/AIDS, so it is important to note the age, status and disclosure-level of any child who will be reading *Thanks ARVs* and to designate which questions may or may not be appropriate for that child.

4. Family-centred care at Chantal Biya

In the PATA newsletter for February, we sent out a questionnaire regarding Family-Centred Care. Chantal Biya, a hospital in Cameroon, sent the following reply.

Answers provided by Dr Francis Ateba, from the hospital.

Does your clinic/hospital provide routine opt-out (not opt-in) HIV testing when mothers first book for antenatal care? *No, our clinic provides opt-in testing.*

Does your clinic/hospital provide ART to all HIV+ mothers free of charge for life? *No, our hospital refers HIV+ mothers to adult clinics for ART.*

Does your clinic provide Nevirapine for mothers during labour and AZT for the neonate after birth for six months? If not, which drugs, if any, are used? *Our hospital follows and provides AZT+NVP both for pregnant HIV+ women and for neonates. But those women are referred to adult clinics for delivery.*

Do you offer HIV testing for partners of HIV+ mothers at the same clinic where the mothers book? *Yes*

Do you encourage testing of partners and children of HIV+ mothers at the booking visits? And do you make this easy for the patient's family to apply for at the booking visit? *Yes, we do.*

How is infant HIV diagnosed at your clinic?

a) Routine PCR on all infants born to HIV+ mothers at six weeks

If an infant is found to be HIV+, do you start ART immediately? *Routine PCR on all infants born to HIV+ mothers from 6 weeks and above. However, if there is a lack in PCR reagents, we combine arguments based on HIV serology, CD4 count and clinical status to initiate ART.*

Do you have structures and protocols to test and treat a patient's family if an HIV test is positive? *Yes, we do.*

PATA would like to encourage other clinics to share their stories with us.

Please send your responses to Rebecca@teampata.org.

5. Adolescent postcards sent far afield

At the G26 Adolescent Clinic at Groote Schuur Hospital in February this year, the adolescent group wrote on the backs of illustrated postcards depicting their

home province, the Western Cape. These were sent off to the Teen Club at Baylor Children's Foundation in Malawi.

The Western Cape teenagers wrote about their hobbies, favourite foods, their families and the school subjects they like best. Three weeks later, and to their great surprise, the kids at Teen Club in Malawi received the postcards.

The Adolescent Group at G26 are looking forward to fostering their new pen pal friends. They want to learn more about different cultures, countries and ethnicities, traditional foods and lives of people around the world. This exercise was a first, but more are planned. With the support of PATA, the energetic group will continue to connect with other adolescent clinics in Africa. PATA would like to encourage other clinics with adolescent groups to let us know if you would like to participate in similar activities.

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