

PATA Newsletter Volume V Issue 8

SPECIAL WORLD AIDS DAY EDITION

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1. World AIDS Day: A time to reflect ...and be proud of our achievements

The first World AIDS day was held in 1988 to raise funds, increase awareness and fight prejudice against people living with the disease. The 1st of December has since become an annual reminder of the need to reflect on how far we have come and where we are going.

The recently published UNAIDS global report show some signs of progress in fighting the pandemic. New infections among children have decreased by 24% from 2001 to 2009. This suggests that the virtual elimination of mother-to-child transmission of HIV is indeed possible.

Around the world, AIDS-related deaths among children younger than 15 is also declining. In 2009 an estimated 260 000 children died from AIDS-related illnesses which is 19% fewer than the estimated 320 000 who died in 2004.

2.3 million children are living with HIV. An estimated 90% of the world's children living with HIV reside in sub-Saharan Africa, yet ART coverage of children in the region is slightly below the global average, at just 26%.

Globally the number of children under 15 years of age receiving ARTs increased by about 80 000 (or 29%) in 2009, from 275 000 to 354 000. A rough estimate shows that the PATA network reaches a minimum of 20% of the children on ARVs.

The report recommends that ART centres and maternal and child health services work together closely to improve children's access to ART. Better diagnostic tools and ART formulations for children also need to be developed. The PATA network is one key means to help implement these changes to ensure HIV+ children have access to comprehensive care.

It is Michel Sidibé, Executive Director of UNAIDS, who summarised the report perfectly: "Investments in the AIDS response are paying off, but gains are fragile," he said. "The challenge now is how we can all work to accelerate progress."

2. The Expert Patient Update

One of the greatest challenge in dealing with the HIV/AIDS pandemic and ensuring access to comprehensive care and treatment for those affected, is the serious shortage in health care workers. At the 2006 PATA forum in Kenya, a programme was developed to address some of these issues. The idea was to task-shift healthcare tasks from more highly trained individuals to those with less training – expert patients.

PATA's Expert Patient Programme, funded by One to One Children's Fund, was also designed as a way of harnessing the passion and expertise of people living with HIV/AIDS, providing a job, a stipend, and a sense of autonomy in their work.

Since 2007 the programme has grown from a reach of 21 clinics to 47 clinics by October 2010 with a total of 202 expert patients being employed in 14 Sub-Saharan African countries. These clinics alone deliver ARVs to over 45 000 children. On average, an expert patient works for 25 hours per week fulfilling various roles such as a default tracer, clinical assistant, peer educator and counsellor.

The impact of this programme is profound. As well as providing extra human resources for the clinic, the Expert Patients are often said to be a critical link between the community and the clinic, central to community outreach, education and the follow up of defaulters. The clinics say that Expert Patients have aided in creating a more child-friendly clinic, improving patient flow and efficiency while reducing LTFU.

"The in-service training that I have undergone has equipped me with information and helped to boost my knowledge in taking care of children," says an Expert Patient from Baylor Lesotho. "I have learned to be part of the team as this is necessary for organizational cohesiveness. It also helped me in how to deal and handle people with different characters and personalities and how to comfort them too."

A typical example of an Expert Patient success story is the case of SM, a 27-year-old patient at Worcester Hospital in South Africa. SM had a CD4 count of just 8. Expert Patient Theresa fetched SM's file and then helped SM – who was very weak – from her chair to the doctor's room and back. SM needed to start ARV treatment urgently and was admitted to Hospice. Theresa helped getting the relevant history from the patient and helped with translation as well as discussing the patient's options. She walked with her to the X-ray department and fetched her medication from the pharmacy. She assisted SM with her kids as they waited for the ambulance to take her and the children to Hospice. Theresa helped SM with her baggage and answered her questions. She gave emotional support to the patient, as SM was upset about having a fight with her husband and helped her to phone her family. SM has since started taking ARVs and mentioned to the Hospice staff how much she appreciated the service she got from the clinic and Theresa.

Thank you to our Expert Patients for their continued hard work and another thank you to the Expert Patient Supervisors for the 6 month reports and for the incredible work that went into them.

If you would like to apply for the Expert Patient Programme or want to learn more, please contact info@teampata.org. Applications will be opened in February 2011 and will be due back to us March 2011.

3. A tool from the East Africa Forum: Discovering the 'Hidden Agenda' using HANDSS with adolescents

At the recent PATA Forum in Uganda, attending clinic teams got very excited about Goretta Nakabugo's step-by-step approach to counselling adolescents. Adolescents often present with non-distinct complaints such as

headaches or a sore throat which may have atypical or vague histories. In these cases adolescents may actually be hiding a real and often more serious complaint – the “hidden agenda” – that they feel embarrassed or uncomfortable to discuss. Often these complaints relate to HIV. It requires skill and a sensitive technique on the part of the health worker to elicit this hidden agenda from the adolescent.

Nakabugo emphasised the use of a thorough psychosocial assessment to achieve the discovery of adolescents' hidden agenda. She presented a structured interview format called **HEADSS** – an acronym for **Home, Educating/eating/exercise, Activities, Drugs/depression, Sexuality and Suicidality/safety**. As one goes through this format in the interview, it is important to emphasise the adolescents' in each area. This format enables the interviewer to cover – in a non-confrontational manner – the important spheres that impact on an adolescent's life.

Confidentiality and privacy are critically important when dealing with adolescents – often made difficult with concerned parents and the environment of a busy clinic.

If you wish to find out more details on this topic, Nakabugo's [full lecture](#) is available on the PATA website.

4. PATA visits the treatment team at Rustenburg Clinic, South Africa

In October the Rustenburg Paediatric OPD was visited by a representative from PATA to see how they were progressing with their 2009 Team Goals. PATA was able to work with the team to address some of the problems they were facing.

One of the greatest successes at Rustenburg has been the introduction of Abacavir, an oral solution for paediatrics rather than d4T (ABC is recommended by WHO and South African Clinicians Society). This was a direct result of recommendations made by Dr Leon Levin at the 2009 PATA Forum. Previously ABC had to be motivated for on case-by-case basis, but is now considered the first line treatment. Madria Geissler, the pharmacist who championed this intervention, must be applauded for her hard working in making ABC available.

Queen Lebelo, the counsellor and co-founder of the Paediatric OPD, was enthusiastic about the successful use of Auntie Stella especially with the older children and adolescents. She noted that children dislike always talking about HIV and Auntie Stella provides another avenue to discuss pertinent issues. She noted that despite the lack of space at the clinic, their Friday support groups are well attended and the children enjoy dancing, singing and play-acting.

One of the greatest challenges facing the clinic is the fact that some staff salary funding has been pulled. Hence Queen has been without a salary for two months, but she still works an eight hour day as a volunteer, receiving no remuneration. However if she didn't come to work the clinic would not function as she does all the adherence counselling, support groups and is central to running the clinic. We applaud Queen on her dedication and commitment and are working with the management to find a solution to this funding crisis.

Another issue is the lack of space for adolescents who are a problematic group with regards to treatment and adherence. According to provincial guidelines, once a child is 15 they should join the adult HIV clinic, yet Tebogo Tshengiwe, the mainstay and co-founder of the Paediatric OPD department, informed us that most

of the adolescents refuse to do this and want to stay at the 'paeds ward'. Transferring them to the adult clinic is problematic as it destroys their trust in the hospital staff.

A discussion with the Team and the Head of the department led to some fantastic outcomes. PATA would like to thank the team for allowing us to visit the facility.

5. Clinic focus: Mpilo OI Clinic Zimbabwe

Mpilo OI clinic was established in April 2004 in Bulawayo, Zimbabwe. They currently care for 2824 children under 13 years of age ARVs and 1200 adolescents between 13-19 years of age on ARVs. Since the beginning of this year, 156 children below 12 months have been started on ARV treatment.

The clinic currently faces various systemic challenges which include severe human resource shortages, the general failing of the health care system and a huge reliance on NGOs in order to sustain themselves. Yet they work with various partners to make sure that they can continue to serve their clients and are surviving and even thriving in a very difficult and turbulent environment. They proudly note that the OI nurses and doctors have never been on strike and the clinic has never closed.

A team attended the 2009 PATA forum and reported a large number of successes since then:

- The first adolescent case management meeting was held in February 2010
- In order to care for the carers, they now celebrate staff birthdays quarterly
- To address the incorrect self-administration of ARVs, 150 children have been checked to see if they are taking their meds correctly
- 50 adolescents that had not been disclosed to were identified and disclosure has taken place
- 23 adolescents with lipodystrophy have been identified and their treatment modified. Health talks are given to patients and caregivers to enable them to note bodily changes and report them
- 15 teenage leaders have undergone a week of leadership training. These leaders are responsible for the monthly adolescent meetings, which draw an average of 250 young people
- Four teenage leaders did a basic counselling course and now work as peer educators in the adolescent clinic. All of the teen leaders also attended a course on reproductive health.
- A 'Chill Room' has been established with the help of partners. The chill room has been furnished with a TV, DVD player, two computers and reading materials. This room acts as a resource centre, and orientation sessions will teach adolescents how to use a computer and access the internet

PATA would like to congratulate the Mpilo team on their hard work. If you would like some advice or feedback on how they achieved their successes, please email PATA and we will put you in contact with the clinic.

6. Tell PATA how you are achieving your goals

It has now been 12 months since the 2010 PATA Forum in Johannesburg. We would love to hear how the teams that attended the Forum are doing with their PATA goals. Email us at Taru@teampata.org to tell us about your progress.

Contributors: Rebecca Norman, Toast Coetzer, Taru Jaroszynski, James Millar and Virgile Mahoro.