

PATA Newsletter Volume V Issue 4

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1. Opportunity for Expert Patient clinics to access training funding

PATA is pleased to announce that the One to One Children's Fund has made money available for the purpose of training Expert Patients. These funds will amount to 125 USD (or 1000 South African Rands) per clinic and will be given to 25 different Expert Patient clinics on a first-come, first-serve basis.

These scholarships are being provided so that Expert Patients and their supervisors can analyse what challenges their clinics face and what type of training could best meet their needs. Courses must be accredited and related to tasks that Expert Patients currently perform or could potentially perform.

We thank One to One for their assistance and look forward to learning about the training programmes that PATA clinic teams choose.

To apply, please download the application form on our website at www.teampata.org or e-mail Rebecca@teampata.org.

2. East African Forum update

Applications to attend the East African Forum have now closed. All applications will be presented to the PATA steering committee for consideration, and clinics will be notified of the outcome by 20 July 2010. PATA is grateful to the following organisations who have indicated that they will fund the 2010 forum: Miracle Corners of the World, Partners In Health, TASO and ACTS University of Nairobi.

In addition, the following clinics are able to contribute towards the cost of their participation: Bungoma District Hospital, Vihiga District Hospital, Kibong'oto National TB Hospital, Joint Clinical Research Centre, World Wide Orphans, FACES and Children of God Relief Institute. Other applicants are also encouraged to source their own funding for attending the

forum and to keep PATA updated on any progress. The PATA academic committee met on 28 June to finalise the programme, which will be posted on www.teampata.org before the end of July.

3. Help to create an ARV physiotherapist network

Jenna Hutchings is a Paediatrics NDT Physiotherapist working at Newlands Clinic in Harare, Zimbabwe. She is responsible for setting up the neuro-developmental service for children (those children affected by neurological impairment secondary to HIV). Jenna has also identified a need for pulmonary rehabilitation for children with HIV-related respiratory impairment.

She is looking to contact other clinics that provide physiotherapy / occupational therapy / speech therapy to children living with HIV. If your clinic provides these services or is interested in contacting Jenna about her work please email Taru at Taru@teampata.org.

4. New clinics in the PATA network

PATA would like to welcome four new clinics to the network: B.J. Vorster (SA), Nankudu (Namibia), Beacon of Hope (Kenya) and Vihiga District Hospital (Kenya).

B.J. Vorster Hospital is in the small Eastern Cape town of Kareedouw. It also serves the Magisterial Districts of the Koukamma region as far as Bloukrans, The Heights and Zuuranys. Thirteen HIV positive children are currently managed by the clinic.

Nonkosi Ndalasi, the ART coordinator for four hospitals in the area, describes the biggest challenges that B.J. Vorster faces as poverty and hopelessness, which both lead to high rates of defaulting. Sister Ndalasi says that there is a caring attitude at the hospital and that patients always receive a warm welcome. The clinic has some innovative projects to fight malnutrition. They are currently running a raffle for the person with the best vegetable garden in the district.

Ndalasi says that B.J. Vorster decided to join PATA because they “want to share” ideas, information and experience. Ndalasi said that clinics in Africa share many of the same problems and thus can learn from one another.

Vihiga District Hospital has recently joined the PATA network when they applied to attend the 2010 East African Forum. Having heard about the “good things that the PATA effect has brought” to other clinics, Dr. Sultani Hadley Matendechemo is keen to see Vihiga District Hospital benefit in the same way.

Vihiga District Hospital is situated in Maragoli in Kenya. They have 11 satellite clinics and serve 325 HIV+ children under 18 years old and 13 infants under 12 months of age.

Dr. Matendehero describes one of Vihiga District Hospital's successes as their decentralization of ART services to 11 satellite clinics. This has greatly improved access to health care services for HIV+ children. They also have a very active psychosocial support group with peer counsellors and there is increasing male involvement in provision of PMTCT services.

The hospital also faces several challenges, especially due to stock outs of drugs, test kits and reagents. They also struggle to carry out adequate outreach services and to facilitate further training for staff, due to lack of resources. Stigma and discrimination are other issues that hamper the provision of services and result in high defaulter rates.

5. Adolescent care and disclosure challenges: Headline topics for the 2010 PATA forum

The PATA 2010 East African Regional Forum will focus on issues relating to ARVs, adolescent care and disclosure to children. We have asked some of the teams about the challenges they face with disclosure and how they are working with adolescents.

Eleven of the fifteen teams we spoke to mentioned that one of the biggest hurdles faced by clinicians is the **caregiver's reluctant attitude towards disclosure**. Mbeya District Hospital (Tanzania) suggests that caregivers fear that their children will stop taking the medicines and also that they will be blamed by their children for transmission of the virus.

Other clinics mentioned the role of **stigma and denial** and its effect on disclosure as well as the poor communication skills of caregivers. This is in line with previous research that finds that caregivers' reluctance to disclose is because they fear that the child might talk about his or her infection, that the child's psychological state would be affected and that the relationship with the care giver can deteriorate (Children's Rights Centre, 2010).

Half of the teams' responses identified **the need for a standard protocol for disclosure**. The need for **training of personnel** was also cited as a main challenge, especially with regard to counselling and post-disclosure follow up.

It has become increasingly evident that there **needs to be a focus on care of adolescents with HIV**. This group suffers high rates of new infections. Furthermore they have a set of specific issues related to processes of physical, psychological and cognitive changes that occur during this time (Mark, 2009). This has been identified in many PATA affiliated clinics such as the FACES clinics in Kenya which have specifically created an 'adolescent taskforce' to address teen issues.

Nine of the fifteen East African teams we spoke to said that they had **special adolescent programmes**, groups or clubs. ALERT (Ethiopia) has created a 'youth services' program which includes access to a library. Bungoma District Hospital (Kenya) has an adolescent support group which deals specifically with issues like stigma and income generation. Bungoma has identified the need for a separate youth-friendly clinic that will enable confidentiality and better psychosocial support.

Many **challenges** were also identified. **Adolescent adherence** was identified by more than half the respondents as a major issue. There is an identified need for psychosocial, educational and nutritional support for adolescents. **Stigma and religious beliefs** were also seen as challenges to care especially for those adolescents in boarding schools and institutions. Children of God Relief Institute (Kenya) has attempted to deal with these difficulties through educational support and mentorship programs.

Several clinics pinpointed the challenges faced by adolescents with regard to **sexuality and sexual health**. Joint Clinical Research Centre Kampala (Uganda) noted that more information, education, and communication (IEC) materials are needed to aid psychosocial support for adolescents.

The 2010 PATA Forum will hopefully enable teams to work and make plans to address some of the challenges in adolescent care.

6. Play Football for Life

Football fever has swept the continent for the past few weeks. Play Football for Life (PFL) – created in partnership by One to One Children’s Fund, Small Projects Foundation and Africaid – aims to create an AIDS-free generation in a unique and innovative way. They want to provide sustainable HIV/AIDS education and awareness leading to permanent behaviour changes, acquisition of vital life skills and building self-esteem by employing the language of football as an analogy to life.

A pilot programme was launched in 2009 in Rustenburg (North West Province, South Africa). Within a year, over 2 500 children participated in and benefited from the life skills course presented by PFL. One to One Children’s Fund and Africaid have now agreed to extend and develop this programme to the Eastern Cape.

There are four components of the programme: The **Life Skills Course** is taught both inside the schools and outside on the football pitch. Children are empowered with the knowledge and skills they need to practice healthy modes of behaviour. Upon completion of the Life Skills Course, all children and adolescents receive a certificate, medal and get to participate in a **World Cup Football Tournament**; an all day, co-ed tournament modelled on the FIFA World Cup. Teachers choose one boy and one girl who have shown exceptional leadership during the Life Skills Course and they receive additional training to become **Peer Educators**, eventually leading workshops with their classmates. The last component is **Teacher Training**, in which teachers are trained to deliver the Life Skills Course. The training is designed to strengthen the sustainability of the programme by building the capacity of teachers, allowing them to teach the programme independently for years to come.

On 9 June 2010 in London, a six-a-side football tournament was organised to raise funds for One to One Children’s Fund. Sixteen teams participated, all coached by football legends. The final match was refereed by Pier Luigi Collina (regarded by many as the best referee of all

time) and the tournament was followed by a dinner and auction. Much of the proceeds will go towards PFL and its roll-out.

7. Changes in the PATA Office

There have been some exciting changes at the PATA office as we have increased staff numbers and capacity in order to meet the growing demand of the PATA network.

We are lucky that Rebecca Norman has extended her stay and will be working for PATA until 19 November 2010 in the capacity of Fundraiser and Expert Patient Manager. Taru Jaroszynski has been employed in the role of Assistant Project Director. Melanie Evans will be on maternity leave from 1 August until the end of the year.

References

Mark, Daniella 'Psychological support for HIV-positive adolescents' (2009) Paper presented at the 2009 PATA Forum.

Children Rights Centre 'Disclosure Rapid Assessment' Draft (2010) Changing the discourse on disclosure for children living with HIV AIDS.

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