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L'Équipe PATA

Friday 18 November 2011 The Daily Journal of the Paediatric AIDS Treatment for Africa (PATA) Summit, Botswana



**Thank you all
for coming!**

“We want to add life to days, not just days to life...”

On Thursday participants were treated to a morning masterclass from the Bigshoes Foundation on providing palliative care to children.

Palliative care focuses on the “active total care of body, mind and spirit” in ill children. It also involves providing support to their families. Participants were reminded that palliative care is not just for terminal illness and is not a passive process. “We want to add life to days,” shared Michelle Meiring, “not just days to life.”

Addressing both pain and non-pain symptoms, Michelle and Tracy Brand

walked treatment teams through a case study involving an HIV positive 8 year old with extremely advanced symptoms.

Michelle zoomed in on pain, which tools could be used for pain assessment and then encouraged teams to involve children in the pain assessment process. She shared updates on managing pain symptoms, utilizing the WHO three-step ladder for pain management.

On the subject of non-pain symptoms, Tracy spoke about appropriate bedside manner when dealing with children. She encouraged participants to be accessible,

friendly and creative in using tools and toys, and to answer questions in an honest, open, understandable manner.

As treatment teams, PATA members are uniquely placed to provide the holistic approach that palliative care requires. Each team received a palliative care textbook in their team pack that, together with the lessons presented by Bigshoes, can help improve the overall quality of life for their clients.

“When there is nothing more that can be done,” concluded Tracy, “there’s a lot that needs doing.”

INTERVIEW:

Teodomiro Dercio de Ana Chemane

Country: Mozambique

Affiliation: Mavalane General Hospital

Favourite food: Salad with shellfish.

Pastimes: Research, listen to soul music and converse with friends.

Interesting fact: Teodomiro is from Maputo but he spent some time in Beira.

“There were many positive things which came out of the Wednesday sessions for me,” Teodomiro says. “I feel that I have learnt from the other delegates – when I go back home, some things are going to change. I hope to return to the PATA forum on another occasion to report on positive changes which have come about due to this PATA experience.”



Play dough recipe

Here's how you can make your own play dough back home. It's really easy and the kids in your clinic will love playing with it!

Ingredients needed:

2 cups of flour

2 cups of warm water

1 cup of salt

2 tablespoons of vegetable oil

Food colouring (optional)

Method:

Mix all the ingredients together and stir over low heat. The dough will begin to thicken until it resembles mashed potatoes.

When the dough pulls away from the sides of the pan and clumps in the center, you can remove the pan from the stove. Let it cool until it can be handled. If the dough is sticky, continue to heat until it is thicker.

What do you do when people disagree?

Michelle Meiring and Tracey Brand from Bigshoes on what to do when there is a difference of opinion on starting anti-retrovirals or what children should be told (and not told).

We need to understand the rights of the child as expressed in the UN Convention.

These are: Article 3 says the best interests of children must be the primary concern in making decisions that may affect them. All adults should do what is best for children. When adults make decisions, they should think about how their decisions will affect children. Article 12 says that when adults make decisions that affect children, children have the right to say what they think should happen. This does not mean that children can now tell their parents what to do. Article 12 does not interfere with parents' right and responsibility to express their views on matters affecting their children. Children's ability to form and express their opinions develops with age and most adults will naturally give the views of teenagers greater weight than those of a preschooler.

What lies behind the wishes of the parent not to tell the child or let the child receive treatment?

Often the parent may have their own unaddressed personal issues e.g.: Guilt at having passed the virus on to his/her child; or fears about treatment based on previous experience or hearsay. Often the reason behind not wanting to talk to children about things is based on a good intention to protect the child from harm: validate this rather than criticize the parent.

Look at the benefits vs harms of being honest with the child.

Often in their desire to protect their child from

harm, parents may have overlooked the harm that could occur from not telling/treating. A useful framework from Children's Palliative Care in Africa:

Investigate: Find out how much each person in the family knows and would like to know. Ask them in person.

Think: Is this the right time to address this issue or should we come back later? (e.g. recent disclosure/loss/anger/tiredness)
Reflect back: Show that you appreciate all the love and care. Make it clear that you recognise that everyone is acting as they are purely to prevent others from being hurt. But also explain that by not allowing communication, they may be inadvertently hurting their child.

Explain the facts

What parents think they are hiding, the child usually already knows. By not communicating, parents are preventing their child from sharing their fears and concerns and therefore preventing the child from being comforted. Children are mostly very resilient and capable of dealing with bad news. Conversely, children do not deal with feeling isolated or rejected. Open communication tends to reduce anxiety all round.

Balance up the pros and cons

The risks of breaking the collusion versus the risks of holding it. The rights of the child, vs the rights of the parents. Consider the law of the land (in your country). A bit of time spent in hearing everyone's views and addressing fears and misconceptions leads to a favourable outcome that is in the best interests of the child.

What's in your PATA goodie bag?

In addition to their certificates, teams received the following:

- South to South PATA Toolkit
- 2008 Rwandan Proceedings
- 2008 Adolescent Workshop Proceedings
- 'Children's Palliative Care in Africa', Edited by Justin Amery
- Child-friendly Clinician Poster
- Male and Female Condom Packs from Triangle Project
- Kidz Who Test Training and Story DVD (Zoë Life)
- Breastfeeding for Health Care Workers and Mothers DVD (Africa Centre)
- Caring for Mothers DVD (Perinatal Mental Health Project)
- Team flash stick containing all plenary, speaker's corner, and masterclass presentations; WHO Disclosure Protocol; Disclosure Materials (MSF); Adolescent Resources (compiled by Dr Sara Stulac); Infant Feeding Materials (compiled by Dr Max Kroon); Basic Counselling Materials (from Dr Simone Honikman); Quality Improvement Materials (from Dr Melanie Pleaner); A guide to hosting a local forum; and photos.

Teams can initiate the "PATA effect" by sharing these materials with as many teams as possible in their home districts and countries!

INTERVIEW: Tapiwa Nkhwalume

Tapiwa was part of the Baylor Botswana, the hosts of the summit. We asked Tapiwa what her favourite moments were during this PATA summit.

"This is my team's first time at a PATA summit, so that is great. We were all very curious and searched on the internet for information about PATA. So we had been waiting a long time for this to happen!

"Secondly, it has been very exciting to meet new people, the PATA team and all the amazing clinic

teams. It was my 31st birthday on Tuesday and I spoke in the Speaker's Corner that day, which was lovely.

"My favourite sessions were on palliative care and how to approach adolescents.

"In the future I wish to continue to work with PATA and attend coming summits. I really like to share valuable info, exchange ideas and get a wider picture of how to work with paediatrics.

"Let's all meet soon again! Good luck to all the teams and keep the spirit going!"



I hope we can create a social network where we can talk, share ideas and share what we have learnt. We have the same challenges and come from different backgrounds, and we can come together as nurses to create new ideas. **Phoebe Ongadi (Sunshine Smiles, Kenya), newly elected nursing representative to PATA**



Twenty five thousand, twenty five thousand! That is the number of children cared for by the treatment teams in this room. That is what PATA is about, caring for children and that is what we are trying to do better. **David Altschuler, chairman of PATA**



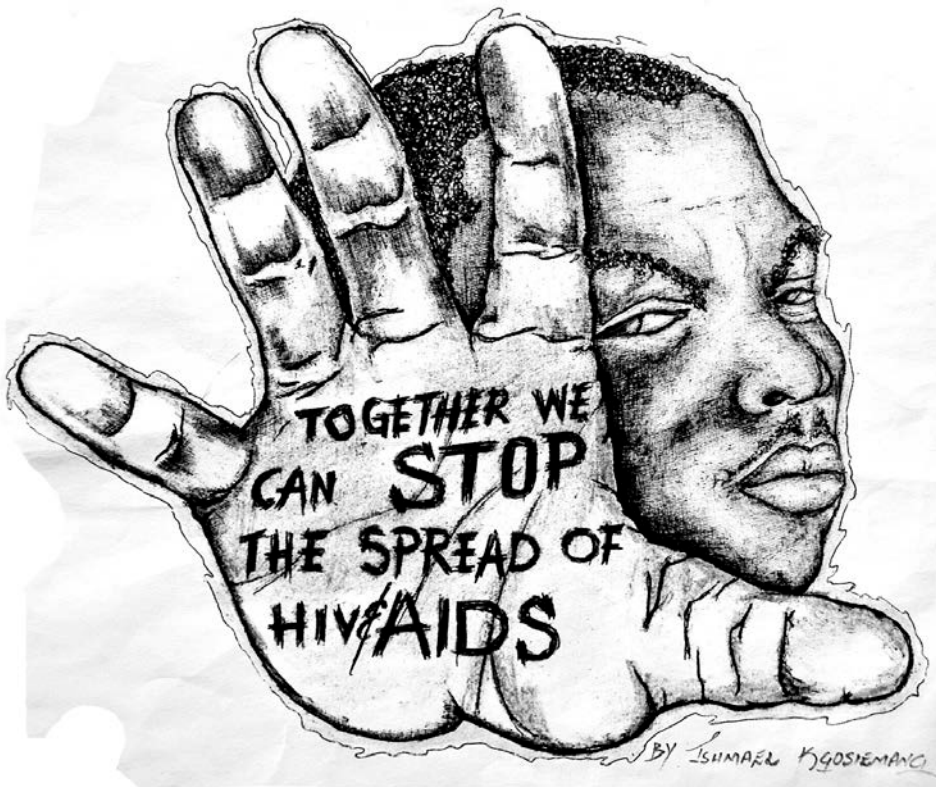
Administrators for PATA in future?

"To achieve a treatment team's potential, we need administrators at the PATA Forums." This is the opinion of Clinton Simelane, an administrator from Baylor Lesotho.

Clinton approached Team PATA to argue to include administrators at summits in future. Clinton argues is that "administrators and the technical team need each other".

"The administrators can frustrate the team," he says. "The administrators must be included into teams and be appreciated and supported. Administrators are the controllers. They can help technical teams develop budgets and plan programmes and activities more effectively. The technical team might be saving the lives, but the technocrats help make sure the path to saving lives is paved. We need to reap their expertise."

Artwork by Ishmael Kgosiemang (cell number: 71 222 946)



INTERVIEW:

Dr Mpho Maraisane

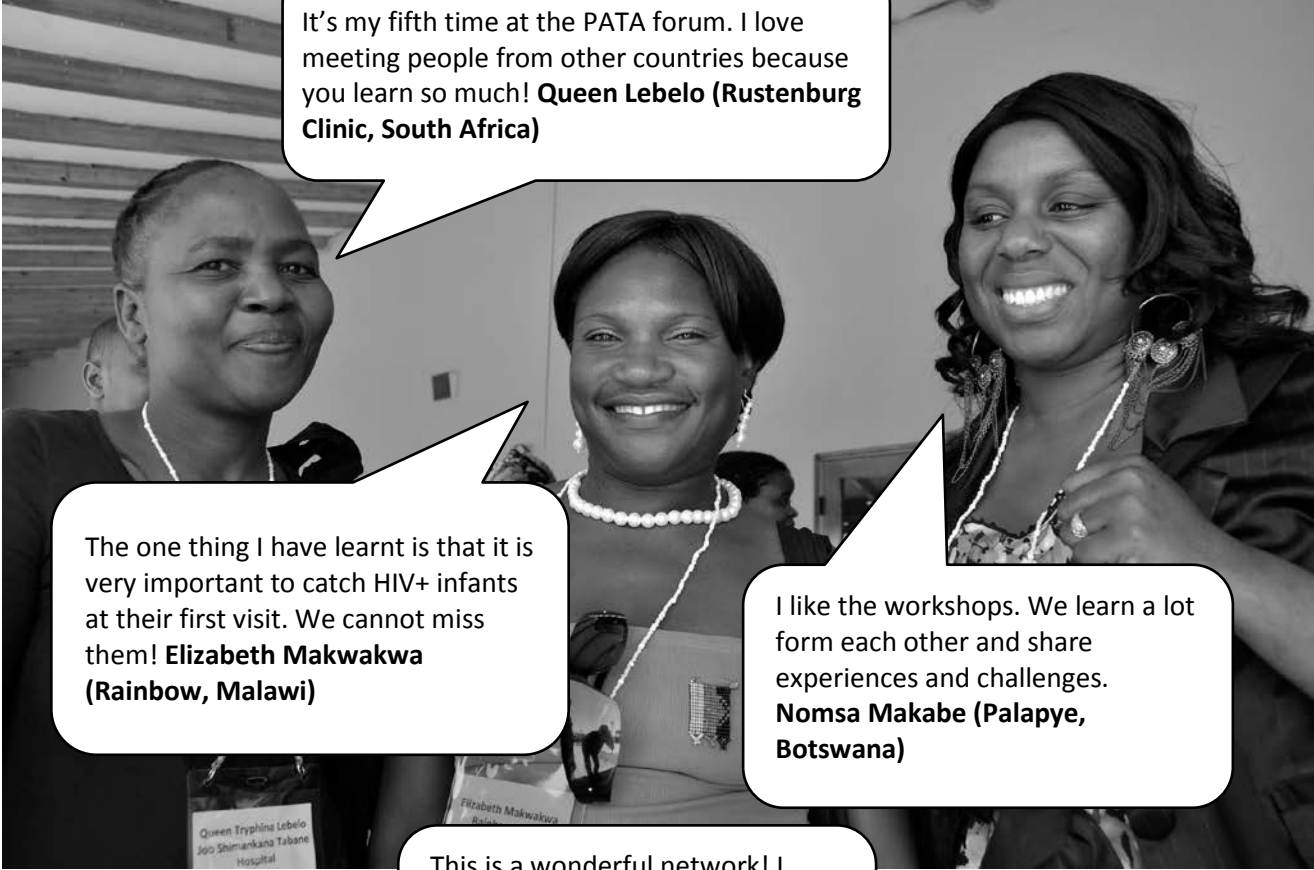
Dr Maraisane is from the AURUM Institute in Johannesburg, South Africa. She shared her impressions on the professional workshop teams.

"It was very vibrant! The good thing was how people from different places got together only to realise that their experiences seemed very much alike," she said. "We share common problems, and when a passionate need or frustration is shared, it brings minds together and brings common solutions – fantastic!"

She was amazed by the innovation and adaptation strategies that peer-professionals from other settings undertook to make the best of their resources and opportunities.

Although she was aware of the strong emphasis on the MDT (multi-disciplinary team) approach that PATA encourages, she was pleasantly surprised to see the emphasis not being on one profession.

"Every professional role had their equal place. Everyone could contribute their individual experiences."

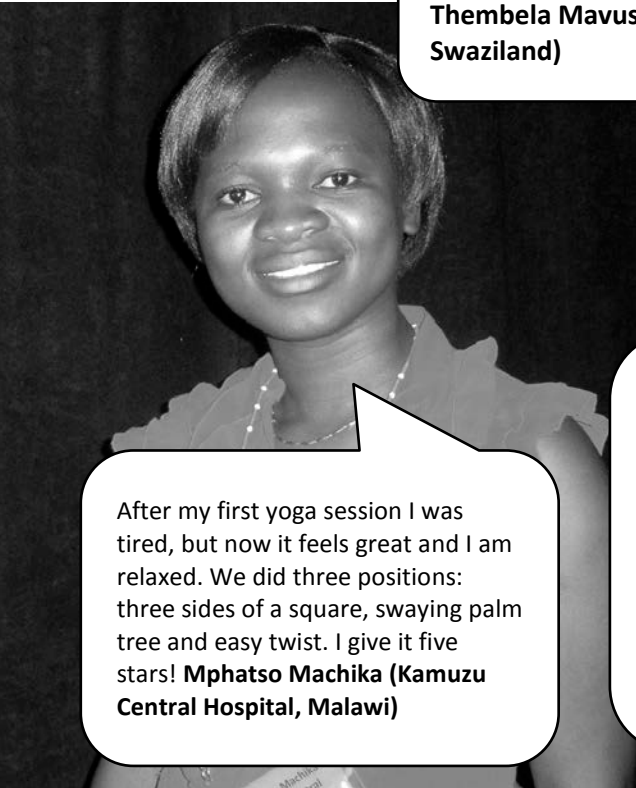


It's my fifth time at the PATA forum. I love meeting people from other countries because you learn so much! **Queen Lebelo (Rustenburg Clinic, South Africa)**


The one thing I have learnt is that it is very important to catch HIV+ infants at their first visit. We cannot miss them! **Elizabeth Makwakwa (Rainbow, Malawi)**

I like the workshops. We learn a lot from each other and share experiences and challenges. **Nomsa Makabe (Palapye, Botswana)**


This is a wonderful network! I enjoyed all the speakers. It's all relevant to what we are doing. **Thembele Mavuso (Baylor Swaziland)**



After my first yoga session I was tired, but now it feels great and I am relaxed. We did three positions: three sides of a square, swaying palm tree and easy twist. I give it five stars! **Mphatso Machika (Kamuzu Central Hospital, Malawi)**



I have a special interest in palliative care for children. I have applied to do a course with Mildmay. My patients gave me a nickname: they call me Nurse High-Five! **Paula Akongo (TASO, Gulu, Uganda)**



Contributors to this newsletter: Melanie Evans, Taru Jaroszynski, Roseanne Turner, Virgile Mahoro, Victor de Andrade, Anne Ferrara, Anna Wiberg, Samantha Oliver, Meghan Dawson and Toast Coetzer. Thanks to all the summit participants for sharing their stories during the past week. Good luck!