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# L'Équipe PATA

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Paediatric AIDS Treatment for Africa (PATA) Forum

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## Adolescents must be respected and listened to



**IN THE MOMENT:** Morney Willemse from the George Hospital (South Africa) in action during a workshop session yesterday.

**Note** - Many of you have asked us about getting access to the presentations from this year's forum. Each team will receive a CD containing all the conference presentations as well as a selection of photographs on Thursday evening. Make sure you get yours!

**Donna Futterman (Albert Einstein College of Medicine, New York) last night urged PATA participants to create teams of people that want to work with adolescents.**

"It is important not to be scared of adolescents; they want us to respect them and listen to them," she said.

"For children who are infected through vertical transmission, their childhood did not prepare them to grow up. This makes working with adolescents challenging. Part of this is normal development as adolescents want to be independent and say 'No'. We know from other chronic illnesses such as diabetes that during this phase, adolescents may refuse to take their treatment."

From Donna's own experience of working with them, she advised that sometimes you have to back away and let them learn from their mistakes. "As much as you can give them, they have to be convinced of the need to be adherent themselves. HIV is as much a psychosocial disease as a medical disease. In transition to adult services adolescents are particularly vulnerable as teenagers are often not ready for adult care.

"Every liberation movement has had the involvement of young people. Young people are willing to put their bodies on the line. The more we partner with them, the more energy we will have," she said.

## Diane Gray: Perspectives from a PATA novice



I have always been impressed with the concept of the PATA conferences and it has been an immense privilege to be part of this, the 5<sup>th</sup> PATA forum and first regional (Southern African) forum. I have been amazed at how smoothly and efficiently the conference has run - congratulations to Melanie and her team.

The PATA concept of on the ground teams meeting, learning and problem solving together has been thrilling to observe. As I walked around

one room I heard: "the workload is overwhelming" met with passionate agreement from the colleagues at the table. Immediately however the group set about trying to find practical solutions for each other by sharing their experience. This form of collegial support is invaluable and provides enormous motivation in addition to the practical help gained.

It is so exciting to witness every voice being heard and the enthusiastic participation

of all the delegates.

The disjunction between policy makers/ researchers and the delivery at the coal face is so often apparent at conferences - here however we have those on the ground who provide the care discussing and solving issues of service delivery. The potential impact on the delivery of quality care for our children is huge. Thank you, Team PATA!

- Diane Gray,  
UCT, GSH-Kidzpositive



## Our fragile regimens

Right to Care's Leon Levin – presenting at his fourth PATA forum – woke us all up yesterday morning with his crash course in deciphering secret codes, mutant (ninja turtles) and (denim) genes.

When a virus makes a copy of itself but it is not an exact copy, it is a mutant. These mutations are weaker if there are no ARVs. But if ARVs are on board, they will suppress the virus but the mutation will not be killed – Leon calls this the “resistance movement”!

Fragile regimens are those which contain drugs with a low genetic barrier to adherence. Some drugs such as 3TC contain fragile regimens but result in a

weaker virus too. In contrast, NNRTIs do not have the same advantages of off-setting the weaker virus and need to be avoided in cases likely to have poor adherence, in young children and when a single dose of Nevirapine has been given to the mother.

Leon urged PATA teams to stick with regimens which have been tried and tested, and to avoid once-daily regimens and strange combinations for which no efficacy has been demonstrated.

**Teams which would like to contact Leon can do so by calling + 27 82 352 6642.**

## Make swallowing pills a core priority

*In her presentation ‘Can children swallow pills?’, Helena Rabie reminded us that advanced HIV medicine is really about getting back to basics. With proper pill swallowing, 71% of children improved adherence within 6 months!*

### Why pills are good

When we look at what people are complaining about in adherence, it is usually flavour, smell or the number and size of pills. The advantages of pills are that they can be used in combination therapy, it is easier to check on adherence and it gets rid of bad taste/ texture and smell (Kaletra can be smelled by children three rooms away!).

They also take up much less space in the pharmacy and this is more cost-effective.

“At the moment many of us are creating suspensions or playing ‘pharmacist- pharmacist’,” Rabie said. “You can actually create behavioural aversion this way.”

### When to start teaching

It is much easier to teach the younger age groups (4 – 7 years) and generally three or four sessions are needed for them to learn how to swallow pills properly.

“Most of the protocols use a technique called ‘shaping’,” Rabie explained. “This involves a placebo or sweets. Sweets are great because you can finish them off after the session! Use candy of an increasing size. Jelly worms are great as they can be cut into different sizes. The whole aim is to create social and behavioural adjustment rather than bribery, coercion and threat. Be patient and teach the skill using gradual steps. The child should not feel under pressure to succeed and it’s best not to do this when they’re acutely ill.”

### Prepare

Remember to take a history beforehand: What is the child’s attention span or intellectual ability? Can they swallow meat or chewy foods? Have they taken pills before and was it successful?

“Some children have had very bad experiences before with taking tablets. Make sure the child can take a sip of water in his or her mouth, hold it there, and then swallow.”

### How to set up

Book an appointment for the pill teaching session. Rabie said that before the session, the child should not eat or drink immediately beforehand and should go to the toilet. It’s best for parents to be absent from the session. Importantly, the trainer must be patient.

“You can show the child what you’re doing. You can be creative with what you use. I usually end with a jelly bean because it is the size of a pretty big pill. ‘Hundreds-and-thousands’ cake decorations are great for small children who’re starting as they can actually dissolve. Tic-Tacs work well because they have a smooth edge.”

### At the session

Start with the smallest pill. Show the child how you can swallow. Use a mirror. Then show them that your mouth is empty. Keep your head in the neutral position. Don’t tip your head back.

Then allow the child to practice. If the child is extending their head, then gently hold the head in the neutral position as this will support their swallowing.

### Don’t intimidate

Only move on to the next size once they have mastered one size. Never mention size. Always say, ‘Let’s try the next one’, not ‘Let’s try the *big* one’!

Don’t say: ‘See if you can do this’. Rather say, ‘Let’s try the next one’.

Sometimes you have to give up – Rabie said she once had a child who swallowed more than a litre of water and not a single pill.

When the parent comes back in, praise the child in front of the parent even if they didn’t swallow a pill at all – then praise them for good behaviour and cooperation.

### Refusal

What action should be taken when refusal occurs? When this occurs, nothing happens. Everything needs to stop. But there is no need to shout or punish.

“Just stop everything until the child does swallow. Sometimes we don’t take this seriously enough and we don’t give parents the tools to manage this at home.”



## Helena Rabie’s general ARV tips for parents:

- Pill taking needs to be a part of the daily routine
- Try to administer pills at the same place at the same time
- Give more control to the child
- Use stories
- Make the process a fun experience
- Do not bargain or bribe the child
- Avoid power battles, punishment and threats
- Avoid tricking the child with food as this will lead to mistrust
- Don’t use thick liquids

## Your essential pill-swallowing toolkit:

- Different size ‘pills’ (sweets)
- A cup of water/ cooldrink
- A mirror



**Manyatso Penane (Bophelong, Lesotho) and Brigitha Namvuhra Kanyengo (Nyangana, Namibia) hard at work during the counsellors' Advanced ARV Therapy workshop yesterday.**

## The true value of counsellors in clinics

*During the workshop on Advanced ARV Therapy yesterday morning it was clear that the counsellors – despite coming from different countries – shared many practical difficulties at their clinics.*

The counsellors covered a range of issues that they grapple with on an ongoing basis. First-priority issues included patient adherence and when to disclose HIV status to a child. These sensitive topics are multi-dimensional in nature and require collaborative efforts from a dedicated team, including doctor, nurse, counsellor and pharmacist.

Adherence issues involved a complex interplay of factors such as the quantity of the daily dosage of ARVs, drug fatigue issues, drug availability, emotional wellbeing, religious affiliations and who the primary caregiver or provider of medication to the patient is. Valuable examples and experiences were shared in small groups and fed back to the workshop with common difficulties being expressed.

The session was an opportunity to sit together and problem-solve difficulties that they face in their clinics with ARV patients. They could also offer examples and grow in their knowledge of the vital role they play.

## Scientific findings must be pushed into practice faster

*Tammy Myers (Wits University) yesterday spoke about the need to develop a proper national ARV programme.*

“Government has been looking at guidelines for some time,” she said, “Discussion has been happening, but it must still be finalised.

“In hindsight, we didn’t have good guidance in treating infants in the past – the suggestion was always that they should be sent to main centres for treatment. This affected who received treatment and who didn’t and thus the overall quality of health care provided.”

She explained that guidelines can also sometimes be a barrier to the expansion of care. “Currently people are afraid to treat unless all the processes are in place. This means that kids often don’t get the care they need. Some clinics do not treat unless there has been three counselling sessions, which means that it could take months for a child to start treatment. If they are very sick, they need treatment.

Myers said that – unlike in the past – there was now more evidence available. “Still, it has taken us five years to respond to this new information. We are waiting too long to push these findings out and use them in practice.”

She said that one of the lessons we’ve learnt thus far was that guidelines need to be enabling. We must ask whether they are practical, explanatory and whether they can be implemented.

“We need to target high risk groups such as infants or TB co-infected patients. Within the new guidelines this has been highlighted which will hopefully bring this to the forefront of upcoming treatment.”

### **A tip from Kenya on keeping up to date with guidelines:**

Elizabeth Obimbo : “In Kenya, instead of waiting for a new guideline to come out, when there is a new development in treatment, an official circular is sent to all of the clinics in the country updating the existing guidelines.”



### **Overheard at the nurses' workshop yesterday:**

**Traumatic disclosure may result in a child not wanting to take his or her medication.**

**As parents, we even have to swallow bitter things, but we must still ensure our children's adherence.**

**When mom dies, the children are given to caregivers who are not ready to administer ARV treatment.**

## Weight band dosing improves adherence



Weight band dosing results in simplified routines and improved adherence.

That was the message from James Nuttall (UCT, Red Cross Children's Hospital, Cape Town). He said that prescribers, counsellors, pharmacists, children and parents can all benefit from weight band dosing.

In the 2008 WHO weight band dosing guidelines, the new weight band chart now includes children from 3kg.

This provides a mechanism for initiation of treatment in young children and initiation of treatment by non-specialists in resource-poor settings.

Surprisingly, the guidelines on dosing for very young infants is high, as very young children need high levels in order for treatment to be effective.

In the doctors' professional workshop, Dr Muzah from Nyangana RC Hospital in Namibia said that inconsistent availability of some paediatric tablets and capsules that are recommended on the weight band paediatric dosage chart is a problem. This forces clinics to make do with adult tablets or different formulations which can confuse caregivers.



"It was good to learn more about how to get children to take pills. At our clinic we use liquid medicines, but we want to suggest to them that we use pills. Most of our patients come from places where use of pills is better, they're easier to keep. We have to look at these things." - **Mlamli Zinto (project manager) and Mlamli Maqungo (pharmacist) from Dora Nginza Hospital, South Africa**

"It was interesting to find out that the problems encountered by pharmacists are somehow common to all of us. I believe that problems are easier to solve when experienced by many. I now hope we will be able to round up the team of the Paediatric Centre of Excellence when we return to develop a comprehensive programme and ensure that we can address problems as a team. Teamwork is key." -

**Msanide Sakala (pharmacist) Livingstone Paediatric Centre of Excellence, Zambia**



DELEGATE FOCUS:

## Pumla Tyulu

Counsellor at Groote Schuur Hospital, Cape Town



"To me, meeting and talking to other counsellors has let me grow, reflect on others stories and learn."

Pumla is passionate about people at the conference coming together and communicating with each other.

The PATA forum, she says, is an ideal place "where you grow and gain information from other people from other countries".

"By talking to people you can find out so much more than you intended."

Having been trained by Lifeline/Childline by a mentor who focused on psycho-social training, assessment and referrals, Pumla reflected that the PATA conference is an ideal place to hone these skills and share with others.

"We have so many things in common in our clinics."

Pumla is passionate about adolescent care and is looking forward to tomorrow's plenary and workshops. Getting to know adolescents, assessing them, reflecting on issues and probing adolescent experiences are fundamental to providing quality, holistic care to patients.

"This is a key role of counsellors in ARV clinics where adolescents often don't know where to go, who to talk to, have no-one they trust implicitly to share their feelings with."

When asked about the major issue facing counsellors in their own jobs, Pumla reflected on how so many counsellors "don't trust themselves and their capabilities".

"Working together, as a team is essential for counsellors – no-one can deal with issues alone – they need to share."