

2006 ZAPHA+ Success Stories

Hi there,

Okay – here we go – first Khamisi Mtumwa –



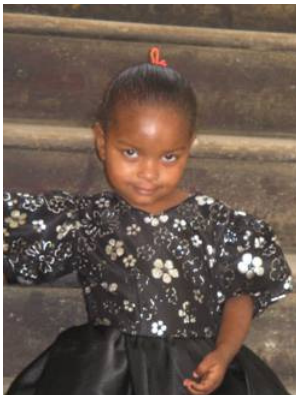
Here is Khamisi the day of the CD4 testing – his first hope that he might have a chance to live. Khamisi Mtumwa has been married to Mtoro since 1994 and they have two daughters, Neema, 12 and Samira 4. He is a policeman and they live in Tomondo district in Zanzibar. In 2001 Khamisi was not feeling well, had lost a lot of weight and he went to the Kmwanchina (spelling?) Street clinic where he tested positive for HIV. After 3 months, Mtoro also tested positive. He thinks that he may have gotten the disease from other women but he was hesitant to go into detail about that. When he told his mother that he was positive she cried and said “You are a very happy man. Everyone must die but God will help you”. Mtoro’s family was very angry with Khamisi blaming him for infecting her and his family claimed that he had been infected by his wife. After awhile they all accepted their plight and tried to move forward. Khamisi’s philosophy was that it was a waste of time to try to find out where they got it from that it was more important to learn how to live with the disease. Mtoro joined ZAPHA+ first in 2002 after her mother had heard about it from a neighbor who was a member. Mtoro appreciated having others to talk with and that the members were able to give each other different opinions about living with HIV. Mtoro was able to go to workshops and trainings and make some money and bought tables and cupboards for their home. Khamisi did not join right away because he was feeling healthy, was busy working and didn’t feel that he had the time to join although he changed his mind and joined in 2003.

When Khamisi started to get sick in late 2004 his mother had him go to an mganga, a traditional healer, but he didn’t get any better. She felt that maybe someone had put a spell on him and wanted to do everything that she could to make him better. He deteriorated and his brain became “very tired and confused”. He couldn’t dress himself or remember his childrens’ names. He was afraid that he was going to die. His biggest fear was that his children would be left without a father to provide for them.

In March 2005 the Clinton Foundation contacted ZAPHA+ and tested some of its’ members for CD4 to see if any of them were eligible for ARV treatment. Khamisi had had a CD4 test in Dar es Salaam the year before and had a count of 19 but the doctors would not give him the medicine because they felt that he wasn’t strong enough and the medicine was very expensive. He went home to try to become stronger – he attempted to eat healthy and take vitamins. So in March 2005 his CD4 count was 30 but he had physically deteriorated and the doctor wasn’t sure that even with ARV treatment that the brain damage would be reversible. Even so Khamisi was one of the first three people in Zanzibar to receive ARVS and today he is a miracle.

It has not been easy for him because he had to cope with various side effects in the beginning. He had nightmares and hallucinations of large snakes coming at him. He had skin rashes that were very uncomfortable. He was not able to follow through on the adherence schedule himself because of his confused state and his wife Mtoro took complete responsibility to make sure that Khamisi took his medication twice a day and ate healthy food with it.

Khamisi's CD4 count is up to 350 today. He is back at work on light duty as a policeman and he is a respected member of ZAPHA+. He was voted to the executive committee during the June elections and is chairman of the relief committee which gives emergency funding to members who are in dire need for food, medicine and housing. He works with other members in helping to strengthen and organize the NGO. Today he goes to English class at ZAPHA+ that is provided by UNDP and he supports and works with new members.



Photos – these are some of the better ones – the two small ones of Mariam and Munira are Julie's – she would need credit for them. The rest are mine.

Mariam Saidi lives in a four room house in Mikanguni with her son Nassir, 14 and her daughter Munira, 3 and 20 other people including her father and extended family. They do not have electricity or running water yet Mariam and Munira always have incredibly clean clothes. (I have to email Nadine to find out if Mariam was divorced from her first husband or what) Mariam was married off as the third wife to a man who knew that he was HIV+ but he was desperate to have children. He infected Mariam before he died in 2004 although she didn't know it yet. When Munira became ill with large sores on her legs Mariam took her to the hospital and she tested positive for HIV. Mariam also tested positive at this time. She has been terrified ever since to let her family know because although she was a good Muslim wife she is afraid that she is bringing shame on

the family. She finally told her mother and father recently but is still hiding it from the extended family. She was afraid that Munira was going to die because there was no treatment available in Zanzibar. In April 2005 Munira had a CD4 count of 2% and because there were now pediatric ARVs available it was decided that she could go on a pediatric dose. President Clinton was urging as many children as possible to be put on ARVs but many of the staff were not experienced with the dosing requirements etc. Yet the staff at the HIV clinic at Mnazi Moja hospital worked together with Heidi Becher of the Clinton Foundation to learn how to prescribe the correct dose.

Munira is alive today but not in good health. Mariam has no money and therefore very little food for them to eat that's healthy. Her father and extended family are all unemployed and the little money that they do have is spread amongst them all. Because she has to keep Munira's condition a secret she has very little grounds to negotiate for healthier foods, such as vegetables and fruit for herself and her daughter. Munira will go through spells where she cannot keep the medicine in her stomach and has high fevers. I spent the day at the CTC clinic with Mariam and Munira last week and it was an overwhelming experience. We arrived at 8:00am and did not leave until 3:00pm. Munira was wonderful and sat quietly the entire time taking everything in. There were many people there for the first time getting tested (it was obvious as they were holding pamphlets on HIV and they were very scared), people getting CD4 tests and others there for adherence counseling and their ARV medication. Mariam and Munira saw the doctor, waited then went for adherence counseling then waited some more then finally saw the pharmacist to receive her monthly allotment of ARVS.

As of November 2005 Munira's CD4 count was only up to 4% and the staff is concerned that her mother may not be dosing her correctly. This only reinforces the idea that home based care is desperately needed here in Zanzibar as follow up. As a mother I would be totally overwhelmed if I had to give my child this medicine. Munira received 10 bottles of Zidovir, 5 bottles of Lamivir and 4 bottles of Viramune. She was given three separate syringes to measure out each dose – sometimes having to measure three times to get the full dose. She must take the medication twice a day and is supposed to eat before she receives it.

I admire Mariam and all of the other parents who do the best they can to keep their children alive under such difficult circumstances. Munira did nothing to deserve the death sentence that she has been given. Even with ARVs available her life is still in jeopardy as she is now susceptible to so many other illnesses that could take her life such as malaria, pneumonia and TB to name a few.

As a Muslim African woman, many like Mariam, have no options but to just try to survive every day. They cannot protest or lobby or email their congressman. They are often at the mercy of others and do the best that they can to take care of themselves and their children. President Clinton has become the voice for so many disaffected people in the world – he has become their advocate. They NEED a voice – please listen to them – listen to their strength and their willingness. Listen to their fears and their pain – listen and respond.

Okay Sandra – there it is – I have no idea if this is what you want and of course you can edit it any way that you like. I hope that this is at least a start. If you'd like I'll do the best I can to have Khamisi, Mariam and Munira at ZAPHA on Tues to meet Ipuge and Deepak – okay??

I'm so glad that you're enjoying Ilula – this work is SO rewarding and we are so fortunate to be a part of this.

K