

June/ July 2005

Almost all the children now at John Hospice Day care are on ARV's thanks to TT and F and our many donors. Some families and caretakers refuse to let their children take ARV's even though they know that the child is HIV+ and we are slowly working on changing that attitude, before the children become too ill.

Saviour, one the newest and littlest of the children at Day Care, is pictured this month in the Faces and Stories Section. He came to Day Care still crying because of his mother's death 2 weeks prior. He is such a small boy and is almost 6 years old! He has a strange lung condition that only occurs in people living with HIV (more commonly in children) called LIP or lymphocytic interstitial pneumonitis. He has some special changes to his fingers and toes, called clubbing, which is seen in this disease. He was treated for pneumonia and started on anti-TB meds and last week we started



him on ARV's. He is doing somewhat better. He stayed at our house for two weeks and when he got back to his auntie's home she was thrilled with how much better he looks.



Sad update from Joshua, who is now struggling for his life in the hospice. He was doing so well after starting ARV's and was smiling and playful when he left our house to return to his grandmother's place. But he developed terrible pneumonia, probably the result of something called immune reconstitution syndrome. This is something that happens when someone with a very low immune system is started on ARV's and as their immune system wakes up and begins to recover, the person becomes very ill. Joshua has the lowest immunity of any of the children at Day Care so it did not come as a surprise when he became very ill two weeks ago. We started him on TB treatment and switched his ARV cocktail around a bit to accommodate this. Then started treating him for pneumonia. He stopped eating and dropped from 22 kg (48.5 lbs.) to about 18 kgs (39.5 lbs.) now and he really looks wasted.



He was so ill that I send him home with our wonderful medical students, Jackie Coloe and Joseph Simonetti, who have been working with me at the hospice and Day Care for the last 4 weeks before resuming medical school at the University of Ohio. What wonderful volunteer work they have done here this past month. I am

not exaggerating when I say that they helped to save many lives in the hospice and also Joshua would not be alive today if it had not been for their help.

Over this past weekend, we visited Joshua in the hospice every day and I brought along Eric, who still lives with me on the weekends but whom we were able to place in school during the week at Lazarus Project. He carried the yogurt for Joshua and helped to feed him both Saturday and Sunday. I was happy to see Eric entering the hospice without fear to help another child; he must well remember, as I do, the terrible experience that he had there when he was a patient himself and almost dead.

Finally, this month, we had important visitors from the UK. Corine Koppenol and Tracy Jones came from UK to visit us for a week. They are paediatric palliative care nurses with the Demelza House Hospice and are investigating linking their hospice to Jon Hospice and the Day Care. It was a wonderful week and they were so helpful in every way, especially with Saviour and Joshua who were quite sick. Tracy stayed an extra week and helped out at the Day Care every day, quickly becoming a favorite with the children. They have already found some donations for TT and F through their visit and we are hoping for a long and cooperative relationship. Paediatric palliative care in Zambia is really in its' infancy, so they have a huge job before them helping us to find our way.

Post Script – August 1<sup>st</sup>

Sadly, Saviour passed away today at his Aunt's home. He will be missed by all of us.