

New Hope Special Needs Programme Newsletter: June 2011.

Dear Friends,

We hope that this letter finds you all well and enjoying life. Here at Kasana, we are well into the 2nd term of the school year and are currently enjoying many juicy mangoes to eat!

The last couple of months have certainly been full of 'ups' and 'downs' as we have rejoiced in the progress that some children have made whilst being saddened as others have deteriorated.

The greatest 'down' happened only last week when, after just 4 days of moving in with Carol and Hassan, Kakiwoko Lydia had to be admitted to hospital. She had come to us straight from the hospital after spending 2 months on the nutrition ward where she failed to add any weight to her 5kg (aged 14 months.) As well as being severely malnourished she also had Downs Syndrome and a heart condition. Her parents had given up hope for her and we had agreed to take care of her until she had gained some weight and strength. However, this was not to be. Sadly, Lydia had a severe un-diagnosed infection and spent her last few days struggling to breathe, despite being on Oxygen and receiving all sorts of treatment intravenously. Thankfully, her Mum arrived on Tuesday and although she didn't seem to take much care with her daughter she did at least stay by her side (along with Auntie Ruth and I) until Lydia passed away early Saturday morning. Several of us were able to attend her burial on Saturday afternoon which was of course a very sad occasion. However, we are comforted by the fact that she is now with her heavenly Father and that one day we shall join her! We will miss her cheeky, stubborn character and her ability to bend in all different ways ☺



LEFT: Kakiwoko Lydia



*RIGHT: Auntie Christine
& Carol*

The other residents of Hassan's house are doing well although this month both the staff and children have battled with a very bad cough and cold that has been doing the rounds! Carol, who was another severely malnourished baby has become rather 'chubby' and although she obviously has cerebral palsy, she is definitely making progress since Auntie Christine (her carer) has been doing a daily physio programme with her. Kakulu continues to stay with us from Mon - Thurs and is bringing us great happiness as his vocabulary seems to increase on a daily basis, as does his ability to get around independently in Hassan's wheelchair!

CLASS NEWS:

Just before the 2nd term started, we were very pleased to be able to appoint a new teacher; Uncle Eric. He himself has had a disability ever since he contracted Polio as a young boy. He has worked with children and adults with various disabilities over the years and is particularly good at teaching people basic craft and carpentry skills.

A couple of weeks ago, we had a class Physiotherapy day when Uncle Sam (the community physio) came and spent a day with us as a class; teaching all of us what exercises we should be doing with each of the children. It was a great help! He also put plaster-of-paris casts on Brian to try and correct some deformities on his feet and to encourage the legs to bend at the knee!



LEFT: Uncle Eric with the boys.



RIGHT: Out and about at the borehole with Uncle Eric

We have really struggled due to staff sickness this last month but have just been given one of the Investment Year students, Fiona who will be helping out for the next few months.

Another disappointment that we have faced recently was the decision of Nalubega's Father to take her away (without informing us!) We kept going to her home to try and find her but no one knew where he had taken her and when we tried calling him, his phone was either off or he refused to answer. Thankfully last week we were able to speak to him and he told us that as we had not 'fixed' his daughter as he had expected, he had decided to go and find his own solutions. Apparently he is convinced that her brain damage and epilepsy was caused by witchcraft which now needs to be undone by other means (we strongly suspect he has gone back to witch doctors to enquire what needs to be sacrificed in order to heal his daughter.) He has promised that he will bring her back soon but we don't know when and are concerned about her safety.

COMMUNITY OUTREACH NEWS:

Our community outreach sessions have continued to be extremely popular and in the last couple of months we have had to make 2 difficult decisions; firstly that we would accept no more new children on the programme until November (we plan to have 4 sessions for new children each year,) and secondly, we need to split the group in two (according to where they live) and each group will come every two months. This is partly due to space in our classrooms but also the costs of transport and food. Prices here in Uganda have been rising

dramatically for the last 8 months or so. A 25kg sack of posho that cost 18,000 back in October now costs 42,000!

In May we gave a talk on Epilepsy and showed a Luganda DVD on the subject which a music & drama group from Kiwoko hospital had made. Hopefully the DVD, talk and discussion that followed, helped to correct some of the false ideas about the disease. Many people here still believe that it is caused by demons or they agree that it is a medical problem but think that they should just take the medicine for a month and then they'll be fine. In June, our new teacher Uncle Eric shared his story with the parents about what it was like to grow up with a disability; the struggles he faced and how he overcame them.

We have not yet been able to provide any more children with equipment and are still waiting for baby Carol's special chair; when we went to collect it (having being told it was ready,) they had made the wrong size which was very frustrating as it is expensive going all the way to Kampala. Uncle Eric is going to try making some basic chairs and other aids from local materials (branches, banana leaves etc) which will be interesting. We still plan to train a local carpenter to make equipment but timber is also very expensive these days so for now, we will make use of the original, un-tampered- with tree!

PRAISE AND PRAYER:

As we did last time, we will finish with a list of things that we wish to praise God for and some things we would like you to pray about:

- **We praise God that nothing, not even death, can separate us from his love.**
- Please pray for the family of Kakiwoko Lydia and those of us who were involved in her care – pray that we will know God's comfort and strength at this difficult time.
- **We praise God that we were able to employ Uncle Eric to be a part of our team.**
- Please pray for Auntie Lydia (Hassan & Kakulu's main carer) who went on leave 3 weeks ago but has not yet come back as she is sick and very weak.
- **We praise God for the progress we have seen each child make over the last few months.**
- Please pray specifically for Allen who lost weight that she cannot afford to lose over the school holidays. Pray that she will overcome her fear of food and eat! Please also pray that Nalubega will come back to us soon and that God will protect her from whatever her Father is planning to do.

We are so thankful for all your support and prayers – together we are making a difference in the lives of some very precious children here in Uganda.

Blessings to you all from all the children and staff on the Special Needs Programme.