

Report from Jane Sibley, cleft nurse specialist.

Visited CoRSU hospital in March 2016 with Marc Swan (plastic and reconstructive surgeon)

I had visited Andrew and Sarah Hodges in Uganda in February 2008 with Tim, Marc, Louise and Carrie (my colleagues from the Spires cleft team, based in Oxford) when I got my first insight into cleft care in Uganda. I had such fond memories of this trip that I didn't hesitate to say yes to be able to have the opportunity again, but this time, being able to get much more involved in the day to day care of the babies with clefts at CoRSU.

I felt privileged to be invited to offer my knowledge of nursing babies with cleft lip and palate. I have worked in Oxford as a cleft lip and palate nurse specialist for the last 20 years. Having worked with both Tim and Marc so closely over many years, their passion for the work that Andrew and Sarah carry out at CoRSU is infectious and I was really excited to be asked to return. We decided that I would join Marc during his first week of a three week trip that he had planned in March 2016. I didn't realise at the time but it was to be one of the most emotive weeks of my life.

Sarah immediately put me in touch with Lorna, the nutritionist at CoRSU and Christine, the ward sister. I asked them for a wish list of items, that in an ideal world, they would like to have access to. I made no promises but decided to see what I could do to help out and planned to take a couple of bits and pieces with me.

I was overwhelmed by the response from my own local friends/ mums network. Within a weekend, I had collected 6 brand new breast pumps, weaning spoons, bottle warmers and steam sterilisers. One of our mums, of a baby who had just had cleft lip surgery managed to raise £1500 by running the Reading half marathon to help provide bottles and teats for the nutrition team at CoRSU (You can read Rebecca's story on The Interface Uganda Website).

By the time that Marc and I were about to leave, we had an abundance of feeding equipment, including 32 special MAM soft bottles and 70 MAM teats as well as all the other items mentioned earlier. This proved quite a challenge when it came to packing and weight restrictions. We certainly heaved a huge sigh of relief once it was processed at the airport check in desk and another when it arrived safely at Entebbe!

After a fabulous welcome by Andrew and Sarah and a relaxing weekend, I was thrown in at the (very!) deep end on my first morning at CoRSU.

Lorna and Bertha (nutritionists) had organised a special clinic for me. They had invited around 30 mums and babies with clefts for me to talk to and assess with regards to their feeding. They all turned up at once and so I was greeted by a room full of mums and babies all waiting to see me! I was absolutely in my element but completely overwhelmed. I was struck by how open the mums were and wanted to share their stories with me. They wanted to show me their babies to see what I had to say and if there was anything I could suggest and more importantly if they could try one of the new bottles that I had brought with me!

During that first morning clinic, I started about 15 babies on the new bottles. I couldn't believe how well they took to them. Even babies that were a few months old, who I wouldn't expect to change so readily. Lorna, Bertha and Maureen (nurse on nutrition team) were very excited about how well the babies and their mothers seemed to adapt to the new bottles. They had never seen the bottles and teats before; they had only heard about them which is why they had asked me to bring them. Every mum who saw another baby with the 'new bottle' wanted to try their own baby on one with my guidance. Lorna, Bertha and Maureen quickly became confident with using the bottles and teats and started to teach the mums themselves how to use them safely and effectively.

Lorna has been in contact with me since my return to the UK to let me know about her success starting two, 4 week old babies on the soft bottles. apparently the babies came in to CoRSU malnourished and they took to the bottles without a problem. Bertha said in an email to me *"The bottles are working exceptionally well for the newborn babies and those of 1, 2 and 3 months."*

Another thing that the nutrition team had hoped I would be able to do was to introduce the use of electric breast pumps to the resident mums at CoRSU. Many mums that have babies with cleft palates struggle to keep their milk supply going because the cleft prevents successful breastfeeding. The babies cannot create a vacuum that is necessary to draw the milk from the breast or to suck strongly enough to increase the breast milk supply in line with the babies growth. Malnutrition is caused by this lack of breast milk or by diarrhoea from feeding young babies on cow's milk (as an alternative to breast milk) whose digestive systems are too immature to absorb it. The use of a breast pump will increase the mother's milk supply because it stimulates the breasts to produce more milk than with hand expressing. It is also quick and efficient, meaning the mothers are more likely to persevere with expressing for longer. The mothers on the ward looked on in amazement at the first mother who used the breast pump. It was a touching moment when a group of mothers crowded around the mum using the breast pump who instantly gained 'celebrity status'! I have since heard from Lorna that the breast pumps are continuing to be used successfully.

I was welcomed on to the ward by Sister Christine and her team of nurses. I spent time in recovery and also on the ward, supporting the nurses in their post operative care. The nurses proved very astute in immediate post operative care and listened intently to a couple of well attended teaching sessions that I gave on the ward.

A simple thing that I introduced was the use of vaseline which we apply regularly to the suture line of a cleft lip repair. The vaseline protects the suture line and softens it making it more comfortable for the baby. It also prevents the area getting scabs on it from blood ooze. Sister Christine and her team are keen to continue using vaseline but might need help with the supply. We find that it is a cheap, simple treatment that makes a big difference to the care of the suture line.

I would like to say a huge thank you to Interface Uganda for inviting me to visit CoRSU and for supporting me with my travel expenses. I would love to be given the opportunity to return to CoRSU in the future to work with the nutrition team and nurses again. I would also be delighted if it were possible to continue the supply of bottles and teats to the unit. If that becomes a reality, I would see it as essential to design a very simple audit form that the nutrition team would fill out for us, so we could monitor the appropriate use and success of the bottles.

The trip would not have been the same without the incredible hospitality of Andrew and Sarah, so generously sharing their home and their lives for a week. I have many fond memories of the Makinde Country Club, sailing on Lake Victoria, the bumpy rides to and from CoRSU in the Landrover, navigating potholed, dusty side streets through Kampala in the dark to find a particular Indian restaurant recommended by Sam Hodges (!), the Hodges' sauna and amazing dinners! All this and getting up every morning to leave the house before 7am to beat the traffic!

I was inspired by the patients, their parents and the staff who were so open and happy to share their lives and their work with me. It has been such a privilege to be invited to work with a truly amazing team that have filled my mind with so many poignant memories.