

Hello from beautiful Fort Portal! We hope 2017 is treating you all well. Our year continues to fly by and keep us all very busy, with over one hundred more referrals since our last newsletter! In the last 3 months we have started an additional 2 new outreaches in local health centres, further away from Fort Portal, so we are able to take our services to where most families would have no access or opportunity to travel to Fort Portal, bringing our total monthly outreach centres to 11. We have also welcomed one Ugandan physio student and 4 UK physio and occupational therapy students learning and working alongside us.

We would like to say a big thank you to St. James Place Foundation for their generous donation towards our therapy outreach programme. This donation will go a long way in supporting newly referred children in receiving on-going therapy assessment and intervention.

We have also had to say farewell to Kaitlin, who was helping us set up our special education programme. She has now returned to the USA and we are struggling on without her. If you know any special education teachers who would be interested in coming out to work with us, please let them, and us, know.

Best wishes,

KCDC team x

### Orthopaedic Services at KCDC by Golden

Last year KCDC opened up an orthopaedic unit to extend our services to children born with deformities, especially those with clubfoot (Congenital Talipes Equino Varus - CTEV).

Golden, our Orthopaedic officer, is using her skills to help correct clubfoot in 11 children who have attended our clinic in the first year of their life.

Many children with clubfoot are sadly brought to us at a later stage of life which makes treatment very difficult and brings to our minds that there is a lack of awareness within the community and amongst health care workers.

In an effort to increase awareness, Golden has been conducting teaching sessions to health care workers especially midwives in 3 health centres on the importance of early identification and treatment, with additional sessions planned in the other health centres that we work in. We hope that this will mean more children are referred for effective treatment at KCDC.

### Dysphagia Training

On 1<sup>st</sup> June 2017, Rehema, a nurse working with KCDC as a speech and language therapy assistant, was given the opportunity to attend a 7 day training on dysphagia (swallowing difficulties) at CORSU Rehabilitation Centre near Kampala. The training was carried out by two British SLTs called Amy Jessen and Lucie and it was sponsored by MAITS (Multi-Agency International Training and Support)



"I was so excited and grateful about the dysphagia training but a bit nervous that it might be a bit complicated for me or I may not fit in with the rest of the group, but the first day when we started, it was amazing. I met a lot of new, loving people who are very eager to help and share information, the trainers were wonderful and lovely people, and were willing to help us in whichever way possible to see that we benefit from the training.

Some of the things I learnt from this training are; what dysphagia means, why is it important to know about dysphagia, dysphagia related to cerebral palsy, anatomy and physiology of swallowing and oral cavity, how to assess and manage dysphagia, advice to give to care takers and parents on how to cope and help their children with dysphagia. The training was carried out through discussion, demonstration and using videos, which motivated everyone in the group to share different information they think is correct and helpful making the training more fun and interesting. I am looking forward to using my new knowledge and skills to help children with dysphagia and train my fellow staff member at KCDC and all the parents/care takers on dysphagia."

### **Early Identification and intervention in Cerebral Palsy**

In the last newsletter we wrote about our programme to run a parents group specifically for under 2 year olds with CP, allowing us to provide education and support to parents at such a crucial time for their development. Last time we wrote we were focused on training health care workers to make appropriate referrals to KCDC and training the KCDC team and 2 of our mothers with older children with CP to run the parents group. And now we have actually started running the groups!

Our first group of 8 mothers are now half way through the programme, so far they have learnt about what is CP, positioning, feeding, communication and how to help your child learn to sit, reach and hold. Golden, our Orthopaedic officer and our 2 expert mamas are doing a fantastic job running the group. The mothers coming to the group are supporting each other with advice and hugs when one of them is struggling and laughter is often heard in the sessions as they learn and discuss together. Last week one of the babies attending the group was unwell with pneumonia and in hospital and after the group, all the other mothers went to visit him and offer support to his mum. A lovely heart-warming testimony to the power of the groups and peer support.

Some quotes from our mamas....

"The group has helped me a lot in improving my son. Before he was not sitting at all, now he is sitting with little support. I have learnt about communication, play and feeding...now he can eat, he can laugh and play and is always happy!"

"I feel very happy finding other mothers here. I was always sad now I don't feel lonely"

"And now I can leave him with my grandmother, sister of his father when I go to school, they take good care of him, my family used to say you are wasting your time with that boy, now they understand and encourage me"



Peer learning during one of the early intervention training sessions

### A little taste of our day to day work by David, Physiotherapist

Irene is a 1 ½ year old girl who had a difficult start to life and was deprived of oxygen during her birth.

At the time of assessment in April this year Irene could sit on her own but was struggling to crawl and could only stand with support and she was depending only on breast milk as she wasn't eating solid foods.

With these findings I and advised mum to start weaning Irene from breast milk onto solid foods, but at first mum could not allow these things, as she was worried about what Irene would eat, and the cost of feeding one more child. We explained that she could be introduced to porridge, rice and mashed potatoes. I explained that her disability doesn't affect her ability to eat and that she needs the nutrition to have the energy to learn to crawl and stand. I also introduced her to a walking frame to practice standing and walking at home. Two weeks later her mother was reporting great progress as Irene was able to push the walker herself and had started to accept solid foods.

Within 2 months I am happy to report what good work the walking frame has done as Irene can now stand and walk on her own, and she is taking solid foods well and putting on weight too!

### Volunteering with KCDC by Alex

Olyota!

With those words, we start our therapy session. I have been here at KCDC for two and half months now and what an adventure it has been so far! People back home ask what life and work here in Fort Portal is. It's interesting, challenging, inspiring, hot and dusty and just simply great! I am learning so much from the lovely children that we see, their families and the staff here at KCDC. It's not always easy but it's what makes you

grow, as therapist and as a person. The challenges of working in a low-resourced country bring out your creative side. Who needs an expensive hand splint when you can make one from a plastic bottle and some left-over fabric?

I have realised how a small thing can make a big difference in a child and their families lives. This is what I love about being a therapist!

I have another month and half left here and am very much looking forward to keep adding new skills to my 'physiotherapy toolbox'.



#### Our Student Placement at KCDC by Mille and Jenny

We are from London South Bank University and are here at KCDC to complete our final student placement as part of a Masters in Occupational Therapy. Since early May we have been working with a number of wonderful children of all ages and abilities. With a focus on progressing the children's ability to participate in daily life within their homes and communities, we have been working on occupations such as washing and dressing, eating and drinking, playing, taking part in school activities and exploring the world around them to grow and develop. For many of our children this includes practicing their hand function so they are able to reach and grasp items they most desire, and thus have more autonomy and satisfaction in their life.

Two children who have been enjoying their therapy sessions are George and Cindy. They have both been working hard towards their goals which are focused on becoming more autonomous and independent in eating and drinking.



Cindy has severe cerebral palsy and is 4 years old. During therapy sessions both Cindy and her family have been practicing strategies to promote Cindy's ability to learn to feed herself (see picture). Teaching feeding can be a slow and sometimes messy process but it has been great to see Cindy's progress as well as the positive impact that increased participation in this activity can have for both Cindy and her family.

George is an 11 year old boy with cerebral palsy and has been working on becoming more independent in his daily activities. Through a combination of practicing his motor skills both in therapy sessions and with his family, along with the use of an adapted cup, he has now reached his goal of being able to drink independently. As you can see in the picture he is very proud of achieving this. As well as reducing the amount of support that his family need to provide, this has increased his own sense of personal achievement which is vital for developing children's motivation and independence.



In addition to supporting children to be autonomous and independent in such activities we have had the pleasure of working with children, their families, and their teachers to understand different conditions and how we can support individuals with a disability to participate in daily life in their communities. It has been an incredibly valuable opportunity to work with the amazing team here at KCDC. We have learnt a huge amount and have had the chance to work with many brilliant children and families. We are looking forward to the rest of our student placement here and working with these children to help them fulfill their potential and enable them to successfully engage in their daily occupations.

### Facts and Figures - Q2 2017

133 - New referrals

1089 - Total therapy sessions

363 - Average number of therapy sessions a month

52.5% - of referrals this year are under 3 years old, which gives us a much better chance to help children reach their full potential

28.6% - of school aged children we work with are in school, we want to support families and schools to increase the number of children able to access school

### Getting Involved

You can get involved by sharing this newsletter with your family, friends and colleagues to let them know about the great work we are doing. You can even come and join the team and work alongside us, share your knowledge and skills, whether it is for short or long term, you would be very welcome. As the demand for our services increases, we are looking for volunteers and additional funding for a long term speech therapist and a special



needs trained teacher.

If you are planning a fundraising event then please consider KCDC as a beneficiary. We are a registered charity on Just Giving [www.justgiving.com/kyanninga-cdc](http://www.justgiving.com/kyanninga-cdc)

If you are able to help in any way, you can make a donation via PayPal on our website [www.kyanningacdc.org](http://www.kyanningacdc.org) or contact us directly

### **Online shopping**

Don't forget that when you are doing your online shopping, whether it is for your groceries, clothes, travel or gifts, going through the Give as you Live website will raise even more money for KCDC, with no additional cost to your shopping bill.

Keep up with the latest KCDC news by following us at [www.facebook.com/kyanningacdc](http://www.facebook.com/kyanningacdc)