

RCS Christmas Charity Campaign 2017: Update for Donors October 2018

Improving Survival from Gastroschisis in Sub-Saharan Africa

Overview

Project plans for the multi-centre study aimed at improving survival from gastroschisis in sub-Saharan Africa are going very well.

Naomi has worked with study team members at each of the seven study hospitals to develop the full study protocol. In total they now have 45 team members at King's College London and across the seven study sites all highly motivated to improve survival from gastroschisis in these settings. The study has been registered on www.clinicaltrials.gov and should be released for public viewing on the website in the coming days. Ethical approval has been gained at King's College London (the host centre) and most of the study sites in sub-Saharan Africa. The last couple of ethics approvals should be cleared by the end of the month.

The pre-intervention component of the study at the Korle-Bu Teaching Hospital (*Figure 1*) in Accra, Ghana was launched on Monday 8 October. This involves collection of data on all patients presenting or referred with gastroschisis to gain an understanding of the current management and outcomes before we implement the new care bundle. The aim is for pre-intervention data collection to commence at all other study centres by the end of November. This information will not only help us to identify key areas for improvement, but will also allow Naomi and her team to determine if the new care package makes a significant difference in survival by comparing the datasets before and after the care bundle is introduced. They will also be able to analyse which components of the care bundle are actually used in practice as planned and which components make a difference to survival so they can then adapt and improve the care bundle going forward.



Figure 1: Korle-Bu Teaching Hospital in Accra, Ghana

Implementing the care bundle

They plan to start implementing the new care bundle into the study centres from May 2019. Naomi will spend four weeks at each of the seven study centres to assist with implementation of the new care bundle. This will involve staff training, provision of key resources and establishment of parenteral nutrition for babies (to allow nutrition to be given via a vein). She will be joined by a Consultant Paediatric Gastroenterologist at each site. This will be vital to help safely and effectively implement the infrastructure and training required for the local teams to give nutrition via a vein to babies.

The Paediatric Gastroenterologist who has very kindly volunteered to come to all sites to help with this is not only highly experienced in these techniques in the UK but also has copious experience working in the sub-Saharan African setting. She will ensure that the system for giving nutrition via a vein to babies is appropriate to each setting and also sustainable long term by utilising and adapting locally sourced resources and working closely with the local team. She will also establish an early and enhanced breastfeeding programme with the aim of assisting some babies with gastroschisis to survive without the need for nutrition via a vein at all. For those that do require a short period of nutrition via a vein, this breastfeeding programme will minimise the amount required.

Two neonatal nurse specialists will be joining Naomi - one for the first five sites and another for the last two. Their input will be vital to help provide training and motivation to the local nurses on how to improve neonatal surgical outcomes and to specifically improve survival amongst babies with gastroschisis. Both nurse specialists are highly experienced in managing babies with gastroschisis and have many years of experience to share with the nurses at the study sites. Empowering nurses to optimally care for babies for gastroschisis on the ward will be key to their survival.

Your generous donations will pay for the Paediatric Gastroenterologist and Neonatal Nurse Specialist to join Naomi for two weeks at each of the seven sites. Undoubtedly Naomi will be able to achieve much more during her visits to each site with their input, expertise and support. Naomi and the RCS cannot thank you enough for making this provision possible.

She has recently written a summary of the current thoughts regarding how to improve the care and outcomes from gastroschisis in low resources settings, which has been published in the journal *'Seminars in Paediatric Surgery'* <https://www.sciencedirect.com/science/article/pii/S1055858618300659?via%3Dihub>. If you are interested in reading the article please email fundraising@rcseng.ac.uk and we can provide you with a copy.

A message from Naomi

Thank you so much for helping to make this project possible. With over 90-95% of babies with gastroschisis dying at the study centres at present, compared to less than 4% dying in the UK, we have a long way to go, but a huge amount to gain from the efforts. An estimated 16,000 babies are born with gastroschisis in sub-Saharan Africa each year, most of whom die at present. If they were born in the UK or other high-income country they would nearly all survive and go on to live a full normal life. With many highly dedicated researchers and children's surgical care providers now behind this project we can make a difference to give babies with gastroschisis in sub-Saharan Africa a chance to survive too.

What's next?

Naomi will write again with an update from sub-Saharan Africa next year.