



Assessing the Impact of Early Surgical Care  
in **Gastrochisis**

Learning about Gastrochisis from Parents and Children



Assessing the Impact of Early Surgical Care  
in **Exomphalos**

Learning about Exomphalos from Parents and Children

Excellent long-term outcomes are what we all aspire to, especially where patients undergo surgical management in the first few days of life. To date, very little has been published on what the long-term future holds for children born with any condition managed by paediatric surgeons. Studies have mostly reported single-centre experience and as such, may refer to a select group of patients often using data collected over a long period and hence including many children who have been managed without the benefit of modern neonatal, anaesthetic and surgical technologies.

AIMES is a new study to try to address this issue across the UK. AIMES stands for Assessing the IMpact of Early Surgical care and the first two proposed studies focus on children born with abdominal wall defects. These studies will look at national cohorts of children born with gastrochisis and exomphalos (previously identified through BAPS-CASS) in order to see what happens to *all* patients across the UK and Ireland when they grow up. In the gastrochisis study, for which we already have funding and ethics committee approval, clinical outcomes as well as parent and patient reported and educational outcomes will be assessed to try to get a holistic picture of how the children are doing at age 7-9.

**We would like to invite trainees from the PSTRN to get involved.** Each centre already has a nominated consultant lead for the study and when we discussed the study at the recent PSTRN meeting in Bristol we felt this was an ideal way to showcase what the PSTRN can achieve by asking a trainee in each centre to help with the study. We plan to report the study as one conducted jointly by the PSTRN and BAPS-CASS. **Trainees who are involved with the study will be acknowledged as part of the PSTRN collaborating group in any publications. They will be able to use the study as an individual audit of local outcomes which can then be compared to the national data when it is published, and this would fulfil the audit requirement for ARCP, etc.** Obviously individual centre data must not be included in any publication until after the national data are published.

The study has two parts, the first simply involves tracing children and putting their address on an envelope which will contain questionnaires for the family. The second part involves reviewing the child's notes and completing a data collection form. The numbers are fairly small from each centre, (the maximum is 36) and many of the children have a very straightforward course so for the majority, this is very quick. I have piloted the form myself to make sure it doesn't take too long!

If you would like to get involved or would like to know more about the study, please email [anna-may.long@npeu.ox.ac.uk](mailto:anna-may.long@npeu.ox.ac.uk)