



The national system to study the surgical management of a range of neonatal conditions – enabling national audit in neonatal surgery

Parent Advisory Group Day

We held our third Parent Advisory group meeting at The Studio in Birmingham on Thursday 11th February. Parents of children with a range of conditions were represented including exomphalos, gastroschisis, Hirschsprung's disease and short bowel. Families were updated on the progress of our research, and future research plans and directions were discussed. The day was highly interactive with parents engaging in discussion around both current and future studies and talking about their experiences. We received excellent feedback from the day; parents were very interested in the progress of our work and felt their viewpoints were listened to and valued. A number of parents expressed an interest in taking part in the BAPS-CASS steering group as a lay member and we are pleased to welcome Janie French and Joanne Shepherd who will be taking part in our February steering group meeting.

Parents - Why do we need you?

- You know your children and what they need
- What happens to babies after they leave hospital?
- How can we undertake research in the best way for children, parents and families?
- What other new research might be important?

Future Studies

- Anorectal Malformations
- Duodenal Atresia
- Surgical Short Bowel

Progress on Studies

- Abdominal Wall Defects

Management and outcomes for infants with Hirschsprung Disease in the UK and Ireland

New study - Duodenal Atresia or Stenosis

The new Duodenal Atresia or Stenosis study is due to start 1st March, running until 28th February 2017. Please report any live-born infant with occlusion or narrowing of the duodenum associated with atresia, stenosis, duodenal web or annular pancreas presenting before 44 weeks post-conception. Exclusions: Occlusion of the duodenum caused by congenital bands associated with malrotation, intestinal volvulus, duplication cyst or malignancy.

Chocolate Box

Chocolates this month go to Dr Atif Saeed from Addenbrooke's Hospital for prompt return of report cards and data collection forms.

Many thanks from the BAPS-CASS team!

Read more online

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*Search your app store for 'qrcode'



Anorectal Malformation Study - reminder

This study commenced in October 2015 and has collected a number of cases already. Following discussion at the UK Paediatric Colorectal Group (UKPCG) meeting last year it was felt that cases with anterior anus who required evaluation or follow-up should be included in the study so please remember to report all such cases presenting during the data collection period. Thank you!

Thanks to the following hospitals who have returned **Exomphalos** cards for the last three months (October, November and December 2015):

Addenbrooke's Hospital, Cambridge
 Alder Hey Children's Hospital, Liverpool
 Birmingham Children's Hospital, Birmingham
 Edinburgh Royal Hospital for Sick Children, Edinburgh
 Hull Royal Infirmary, Hull
 Leicester Royal Infirmary, Leicester
 Queen's Medical Centre, Nottingham
 Royal Aberdeen Children's Hospital, Aberdeen
 Royal London Hospital, London
 The Children's University Hospital, Dublin 1
 King's College Hospital, London
 Leeds General Infirmary, Leeds
 Royal Victoria Infirmary, Newcastle-upon-Tyne
 St George's Hospital, London

Evelina Children's Hospital, London
 John Radcliffe Hospital, Oxford
 Southampton General, Southampton
 University Hospital of Wales, Cardiff
 Bristol Royal Hospital for Children, Bristol
 Chelsea and Westminster Hospital, London
 Glasgow Royal Hospital for Sick Children, Glasgow
 Great Ormond Street Hospital for Sick Children, London
 Norfolk & Norwich University Hospital, Norwich
 Our Lady's Hospital for Sick Children, Dublin 12
 Royal Alexandra Children's Hospital, Brighton
 Royal Belfast Hospital for Sick Children, Belfast
 Royal Manchester Children's Hospital, Manchester
 Sheffield Children's Hospital, Sheffield

Thanks to the following hospitals who have returned **ARM** cards for the last three months (October, November and December 2015):

Addenbrooke's Hospital, Cambridge
 Alder Hey Children's Hospital, Liverpool
 Birmingham Children's Hospital, Birmingham
 Edinburgh Royal Hospital for Sick Children, Edinburgh
 Hull Royal Infirmary, Hull
 Leicester Royal Infirmary, Leicester
 Queen's Medical Centre, Nottingham
 Royal London Hospital, London
 Sheffield Children's Hospital, Sheffield
 The Children's University Hospital, Dublin 12
 Bristol Royal Hospital for Children, Bristol
 King's College Hospital, London
 Leeds General Infirmary, Leeds
 Royal Aberdeen Children's Hospital, Aberdeen

Evelina Children's Hospital, London
 John Radcliffe Hospital, Oxford
 Royal Victoria Infirmary, Newcastle-upon-Tyne
 Southampton General, Southampton
 University Hospital of Wales, Cardiff
 Chelsea and Westminster Hospital, London
 Glasgow Royal Hospital for Sick Children, Glasgow
 Great Ormond Street Hospital for Sick Children
 Norfolk & Norwich University Hospital, Norwich
 Our Lady's Hospital for Sick Children, Dublin 12
 Royal Alexandra Children's Hospital, Brighton
 Royal Belfast Hospital for Sick Children, Belfast
 Royal Manchester Children's Hospital, Manchester
 St George's Hospital, London

Returned all three cards. Returned two cards. Returned one card. No Cards Returned.

Case report summary for cases reported up until February 2016

CONDITION	Cases Reported	Forms returned (%)
ARM	30	11 (37%)
Exomphalos	138	98 (71%)
Exomphalos 1 yr Forms	49 requested	24 (49%)
Meconium Ileus	104	89 (86%)
Meconium 1yr Forms	68 requested	59 (87%)
Necrotising Enterocolitis	321	290 (90%)
Necrotising Enterocolitis 1yr Forms	188 requested	152 (81%)
Posterior Urethral Valves	162	111 (69%)