Minutes of the 2nd meeting of the UK Paediatric Colorectal Group.

8th May 2015

Held at the East Midlands Conference Centre, Nottingham.

Chair – Daniel Colliver – Nottingham
Secretary - Richard England - Norwich

Attendees
Catherine Richards London
Michael Stanton Southampton
Anthony Owen Leicester
Govind Murthi Sheffield
Daniel Colliver Nottingham
Jonathan Sutcliffe Leeds
Ian Sugarman Leeds
Oliver Gee Birmingham
Stefano Giuliani London
Stewart Cleeve London
Silke Wagener Oxford
Richard England Norwich
Sanja Besarovic Hull
Eleri Cusick Bristol
Baia Eradi Leicester
Graham Lamont Liverpool
Ashish Minocha Norwich
Andrew Neilson Birmingham
Irene Miliken Belfast
Paul Jackson Nottingham
Shalinder Singh Nottingham
Manoj Shenoy Nottingham
Nia Fraser Nottingham
Richard Stewart Nottingham
Sandeep Motiwale Nottingham
Claire Clark Edinburgh
Yatin Patel Aberdeen
Kristin Bjornland Oslo
Sarah Almond
Gregory Shepherd
Georgina Malakounides

Apologies
Amulya Saxena London
Ali Keshtgar London
Rick Turnock Liverpool
Niyi Ade-Ajayi London
Richard Lindley Sheffield
Khalid El-Malik Leicester
The chair welcomed all attendees and outlined the programme for the day.

The first part of the meeting was administrative. Richard England discussed the following points / decisions were made.

1. The name of the group was clarified. Following discussions in the first meeting the name has evolved to UK Paediatric Colorectal Group or UKPCG. This name should be used on all correspondence, flyers and documents related to the Group.

2. The next meeting will be on the 19th November 2015 and will be in London. It is hoped the meeting can be held at the RCS Eng. This will be confirmed shortly. The date of the meeting is set to coincide with the BAPS winter meeting on 20th November so members can attend both. A BAPS council meeting will be taking place from 4pm and so our meeting will finish by that time.

Volunteers for a Chair for the meeting from the London consultants was requested. [It has just been confirmed that Stewart Cleeve will be Chair for the next meeting – Thank you for taking this on Stewart]

3. The development of the website for the group was outlined. This is attached to the members section of the BAPS website. Currently it holds meeting agendas, minutes and links to other national and international paediatric colorectal groups and resources.

4. The idea of an online discussion forum was discussed. Initial discussions with the website developers (Mixd) for the BAPS site suggested that a forum attached to that site was not ideal and they asked us to try LinkedIn. This was tried but found not to be user friendly, attracted unwanted marketing and also the site was not supported by many hospital intranets.

Various other options were discussed such as a facebook group, a discussion forum App (Interests) or email discussions. It was noted that a number of email group discussions have occurred very successfully but it was pointed out that this is not an ideal long term situation and lacks control / ability to moderate.

Mr Shenoy raised the comparision with BAPU who use a Yahoo Group forum which is external to their own website.

Ashish Minocha commented that he uses WhatsApp to discuss issues with colleagues internationally. It was noted this is likely to need sharing of phone numbers and is not secure.

Jonathan Sutcliffe commented on a Seattle group who have set up a website. Ian Sugarman commented that he hoped Mixd the BAPS site web developers could still link a forum to the main site and he has agreed to discuss this with them this week. [ACTION – Ian Sugarman to discuss options with Mixd and report back to Secretary]

Eleri Cusick commented that the email discussions that have taken place have been extremely useful and she hoped that further discussions could take place.

The Secretary reported that the LinkedIn group would be closed.
5. CME Points: An application for CME points for the meeting would be put to Joe Curry, who was not present. Certificates of attendance would be circulated as soon as possible. [Secretary to contact Joe Curry]

5. It has been recognised that links with adult surgeons involved in colorectal care would be an important aspect of the UKPCG activities and there are a number of possibilities for interaction.
   - Cross over clinical conditions, e.g. IBD.
   - Adolescent Colorectal Surgery
   - Transition
   - Long term outcome
   - Support for and education of the adult surgeon on congenital colorectal conditions.

The Association of Coloproctologists of GBI (ACPGBI) have noted our existence as a group and the Secretary announced that he has been invited to speak about the interactions between Adult and Paediatric Surgeons with respect to Colorectal Surgery at their meeting next year. Examples of good practice from around the country would be welcome for this talk.

It was announced that Abigail Jones has recently been appointed as a NICE Fellow to investigate the pathway of transition in conditions such as ARM and Hirschsprung’s disease.

6. International Requests

Kenya: The secretary reported that a request for Colorectal Surgery support for a stoma support group in Kenya had come to us via the International Affairs Committee of BAPS. The request was essentially for long term support to help reconstruct and close the stomas of children who had been born with conditions such as ARM and provide training for the local teams. There have been short term missions to the area by other international surgeons although a more sustainable approach is desired.

The topic was discussed at length and the following points were raised:

- Training of local surgeons would be important.
  - However, short visits may not provide good training.
  - Facilitating Kenyan surgeons to visit the UK for training would not provide adequate exposure.
  - Links with local surgeons in nearby cities maybe worth considering and investigating further.
  - South Africa provides training for selected paediatric surgeons and this model may be more appropriate long term.

- Twice yearly visits by a UK team may be possible but would need to be able to provide appropriate back up and follow-up.
  - Anorectal Malformations and Hirschsprung’s disease are conditions that do not lend themselves easily to intermittent visits.
o There was a feeling that the group is still young and we should be careful about taking on such a large project at the current time.

o Ashish Minocha reminded us of the Global Pediatric Surgery Network that can provide international assistance.

- The support of the IAC was welcome and a jointly led project utilising their experience and funding should be discussed further.

[**ACTION: Secretary to discuss with Koikila Lakhoo (IAC) to establish further steps**]

**Romania:** A request for a Surgeon to speak at a Paediatric Surgery Conference in Bucharest has been received. This is to talk about stoma management including gastrostomy. Funding may be available from the local stoma foundation and BAPS. [**Expressions of interest should be directed to Ian Sugarman as soon as possible.**]

7. **Guest Lecture: Dr. Kristin Bjørnland – Endoanal Ultrasound.**  
Associate Professor, Institute of Clinical Medicine, University of Oslo

The Group was delighted to welcome Dr Bjørnland as our first guest lecturer! She gave a very thorough outline of the use of Endo-anal Ultrasound.

Aspects of the technique covered included:
- Methods
- Normal Anatomy (Smooth vs Striated Muscle Appearance)
- Interpretation of scars and differentiation from anatomical structures
- Use in ARM and Hirschsprungs
- Operative outcome and functional correlation

8. **Stefano Giuliani: Transitional Care in ARM**

A survey of transitional care pathways was circulated and then a discussion on current practice ensued.

The idea of risk stratification was presented as a way of identifying patients requiring more intensive management during adolescence and early adulthood.

The emergence of new issues for example, sexual function, gynaecological / obstetric and psychological / body image was recognised.

Methods of follow-up including telephone consultation or selective email correspondence was considered.
The question of natural childbirth or routine LSCS for anorectal patients was discussed. Recognition of the issues and raising awareness with the obstetric team was felt to be important.

Parallels with the new specialty of Adult Congenital Heart Disease was made and the idea of an Adult Congenital Gastrointestinal Specialist suggested.

The difficulties of maintaining the holistic care provided in paediatric surgery once a child is transitioned to adult services was recognised. Relevant specialties may be provided in various separate regional services.

9. Michael Stanton

a) Transition services: An example of good practice was described regarding a new Transition program in Southampton which is now being rolled out nationwide.

www.uhs.nhs.uk/readysteadygo

b) Interferential Therapy: UKPCG Subgroup research report.

Following a small feasibility study in Southampton, a working group looking at emulating the results from John Hutsons group in using Interferential therapy for Slow Transit Constipation (STC) has been formed. This group covers 5-6 centres. They plan to set up a RCT to determine the effectiveness of this intervention.

Mr Stanton asked for opinions on the best outcome measures to use for the study. The use of validated questionnaires to cover a range of symptoms as well as radiological measurements of transit time were discussed.

Easy comparison with the techniques of Professor Hutsons group was felt to be important at this stage of evaluating the technique.

Nuclear transit studies using isotopes with decays slow enough were not felt to be ideal methods for such an RCT.

[Action: The Interferential Therapy Subgroup will consider the methodology further and provide an update at the Nov meeting]

10. Percutaneous Tibial Nerve Stimulation (PTNS)

There was a brief discussion regarding the use of PTNS for patients with faecal incontinence. Potentially this could be of use in patients with sacral anomalies who are not suitable for Sacral Nerve (implanted) stimulation.

The technique is relatively simple but involves insertion of a needle which may limit it’s use in younger children.

Dan Colliver summarised the literature – some of which shows variable efficacy, and emphasised the fact that a Multicentre randomised trial is due to
take place in adults. The results of which perhaps would be useful before considering use in children on a widespread scale. A short video was shown demonstrating the technique.

11. Audit

a) Delayed diagnosis of ARM

Richard England proposed a survey of practice with regards midwife examination of the newborn anus. It had been highlighted there was a change in practice in his local obstetric unit following the delayed diagnosis of ARMs. This led to the re-introduction of rectal thermometers to be used at the initial examination of the baby and when the temperature was taken soon after the first hour following delivery.

The idea of using a rectal thermometer was not felt by any member of the group to be likely to cause harm.

Current NICE guidance on the relevant aspects of newborn care was summarised (CG 190 & CG 37).

A prospective audit of time to diagnosis of ARM was also proposed although the discussion considered it may be difficult to define outcomes suggesting harm was caused by a delay. It was noted that many babies diagnosed after 24 hrs still do very well while other members suggested that any baby who is fed or sent home before an ARM is diagnosed may come to harm.

The type of ARM and degree of spontaneous decompression e.g via a perineal fistula would obviously make a difference in outcome.

[Action: Richard England will construct a survey of newborn examination practice]

Rectal atresia

Richard England used the topic of delayed diagnosis to outline a recent case of rectal atresia. The normal appearance of the anal canal led to a delayed diagnosis but subsequent management was uneventful. A video of the rectal atresia technique was shown which limits resection of the anal canal.

b) VACTERL Screening audit update

The 1st year results of a 2 year multicenter prospective audit of VACTERL screening was presented. Retrospective results showed that the 90% target was met in 4 out of 11 screening criteria, however, the target was reached in 9 out 11 criteria once a screening proforma was introduced to the units. Final results will be available at the meeting in May 2016.

12: Practical Advice for Patients with Stomas
Eleri Cusick spoke about her involvement with focus groups looking at the practical and lifestyle issues facing people with stomas. Ideas on how to take this project forward and develop a questionnaire are welcome.

Development of a stoma care booklet for specifically for our patients and linked to our website was suggested.

13. Case Discussions

a) Govind Murthi presented a case of intermittent GI bleeding. The site of bleeding remained obscure for many years despite numerous forms of basic and advanced GI investigation. Eventually a laparotomy identified a gastric duplication with fistulation into the left colon.

b) Clare Clark asked for advice regarding a post pull through patient who still could not easily stool despite initial EUA and repeat biopsy ensuring no residual aganglionosis.
   - Suggestions:
     - Botox (Dysport preferred but dosage and site of injection variable)
     - Manometry and myectomy (1cm shorter than HPZ)
     - Regular washouts
     - Arbitrary redo pull through at higher level
     - Stoma

c) Eleri Cusick described cases of megarectum with dilated colon presenting in young children rather than a congenital origin. Further similar cases were identified from the group and as these patients were not of European origin and one particularly was South African the diagnosis of Degenerative Leiomyopathy was suggested. Cases seen in South Africa responded poorly to attempts at washout or decompression but had good short term relief following colectomy. A full thickness biopsy is required for diagnosis.


**Comments from the Secretary.**
The evolution of this group is an exciting development for paediatric surgery in the UK. The range of topics, ideas, problems and solutions discussed demonstrates why we need these meetings. Avenues for international work are an unexpected aspect of the group and needs careful consideration but may turn out to be very rewarding. Please let me know what you thought of the meeting and if you have any ideas for futures meetings or projects.

Thank you to everyone who attended

Richard England
Secretary UKPCG