

UK Monogenic inflammatory bowel disease grand round - Transforming the care of patients with complex inflammatory bowel disease

Genomic analysis is a foundation of precision medicine. With a better understanding of the molecular causes of inflammatory bowel diseases (IBD) and enteropathies there are therapeutic opportunities. Increasingly there is realisation of a spectrum of disease where multifactorial and polygenic Crohn's disease, ulcerative colitis, and IBD unclassified, is complemented by monogenic conditions that can present with intestinal inflammation. For those exceptionally rare monogenic conditions, the NHS has commissioned genomic testing. **The diagnostic challenge is to select those patients who might benefit from genomic medicine, to interpret the genetic results, validate the findings and select evidence-based treatments.** The successful implementation and progression of clinical genomics requires multi-disciplinary care, specialist knowledge and establishment of professional networks. **The monogenic IBD grand round series, aims to discuss diagnostics and clinical care for patients with suspected or confirmed monogenic IBD supporting practical implementation of clinical genomics in paediatric and adult IBD.**

Aim is to discuss genetics, immunology, endoscopy, histology, and treatment of complex patients challenging mIBD patients where a clear learning objective is achieved or a national specialist input might be helpful (England, Scotland, Wales, NI). The monogenic IBD grand round is a clinical and educational forum to bridge and support ongoing multi-disciplinary care discussions and specialised clinics in each region.

Audience: Paediatric and adult gastroenterologists, immunologists, geneticists, SHO and registrars / trainees.

Format:

- 3-4 times a year (3 online webinar or in person seminar)
- 1-1.5 hours – 3 patient cases per grand round (10 min case presentation; 5 minute disease mechanisms; followed by interactive discussion)
- Clinicians/fellows submit a case summary online in a standard format for review/selection
- **Cases will be selected based on clinical relevance and predicted educational benefit (clear message and clear questions). One or two local presenter (for instance trainee and/or the local consultant) and one grand round steering group member will present each case and moderate the discussion.**
- The steering group (Uhlig, Kammermeier, Ashton, Jones, Desoki, Haller, Baple, Gilmour) will review the summary in advance and select cases; one steering group member will mentor
- Discussion of patients on a strict anonymised basis (conference setting), the forum aims on maximum educational outreach while avoiding hurdles due to confidentiality, need for honorary contract or formal referral.
- **We encourage patient / parent consent for presentation via the accepted BMJ's patient consent policy** documented in the local patient notes **(consent for adult and children in several languages available).**
- Confirmation of attendance / CPD points for participation will be applied for.

Suggested reading Kammermeier et al. Genomic diagnosis and care co-ordination for monogenic inflammatory bowel disease in children and adults: consensus guideline on behalf of the British Society of Gastroenterology and British Society of Paediatric Gastroenterology, Hepatology and Nutrition. *Lancet Gastroenterol Hepatol.* 2023 Mar;8(3):271-286.

Monogenic IBD – Virtual Grand round submission form

In order to prepare the program, we invite to provide a short summary with anonymised patient information two week in advance of the Virtual Grand round.

Please share the form with Dr James Ashton: J.Ashton@soton.ac.uk

Case submission timeline: 1.12.2023
Meeting: 1st Grand round online
Date: 12.12.2023 4-5.30pm

Meeting link:

https://teams.microsoft.com//meetup-join/19%3ameeting_YTM5ZTA2NTktMzVjYy00NWJiLWFmYWYtNGZhYWMyZjEzM2Fh%40thread.v2/0?context=%7b%22Tid%22%3a%22cc95de1b-97f5-4f93-b4ba-fe68b852cf91%22%2c%22Oid%22%3a%221aac6aed-fd26-4540-bddf-df81b226e13c%22%7d

mIBD Panel member 12.12.2023

- Professor Holm Uhlig, University of Oxford
- Dr Kimberly Gilmour, GOSH, London
- Dr Kelsey Jones, GOSH, London and Kennedy Institute, Oxford
- Dr James Ashton, Southampton
- Dr Jochen Kammermeier, Evelina Hospital
- Dr Rofaida Desoki, Cambridge

Name of the presenter and co-presenter and hospital:

Patient consent for anonymous presentation available and documented in the local patient notes? **Yes / No**

Patient history background:

Patient phenotype (including age of IBD onset, extraintestinal manifestations, previous/current treatments):

Family history:

Genetic investigations and genotype:

Immunological tests and key results:

Discussion, recommendation for patient care and key questions: