

# BSPGHAN

working for children with  
digestive and liver disorders

British Society of Paediatric Gastroenterology Hepatology and Nutrition



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## ANNUAL MEETING 2016

Wednesday 27th – Friday 29th January 2016

Royal Marriot Hotel, Bristol

Local Organiser: Dr Christine Spray, Consultant Paediatric Gastroenterologist | E&OE and CPD Approved

**Thanks to all of our sponsors**

On behalf of the organising committee and council of BSPGHAN, we would like to express our profound thanks to all our sponsors for their generous support provided for this meeting and each BSPGHAN annual meeting.

The annual meeting has gained in significance as a pivotal meeting in our calendar where all specialists looking after children with gastrointestinal, liver and nutritional problems come together and learn from each other. It is a time and place where the senior physicians and trainees present research, audit and case presentations in order to enhance each other's knowledge. It is a place where our AHP's display their particular skills in managing our chronic and complex patients. It is also important to work with our partners in the pharmaceutical industry and scientific commercial arenas. As a result of our annual meetings, we can all learn how to improve patient care and patient experience. Without your support and continuing contribution it would be difficult to develop such opportunities and we hope you will gain from this meeting as well as ourselves.

**Dr Christine Spray**

*Consultant Paediatric Gastroenterologist*

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## Welcome address from the local organising committee

Dear Colleagues,

The inaugural meeting of the society took place in 1987, co-hosted by Professor Sandhu and has grown from strength to strength. Our allied health professionals joined us for the first time at the millennium meeting in Bristol also hosted by Professor Sandhu. The team in Bristol welcomes you all in 2016 to celebrate the 30th annual meeting of BSPGHAN and are happy to have the opportunity to show off our wonderful city. The venue is at one of our best hotels in the heart of the city along the quayside surrounded by theatres, shops and restaurants all within walking distance. Bristol is easily accessible by all forms of transport from all over the UK and I would urge you to extend your stay over the weekend as you will not be disappointed. For more information please visit the website: [visitbristol.co.uk](http://visitbristol.co.uk)

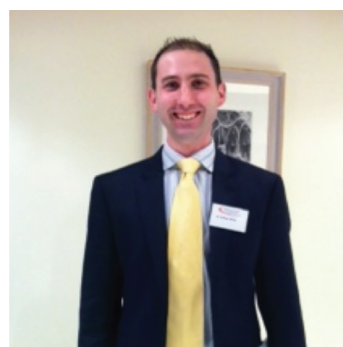
I hope you will find the meeting exciting and stimulating and agree we have arrived at a programme that suits all specialists. It is not only a delight to design such a programme but also a challenge to ensure everyone takes home a new learning point. We have a number of excellent guest lecturers from home and abroad and I would strongly recommend you do stay to the end of the meeting as we are fortunate to have 2 highly distinguished and successful doctors as the finale; Professor Bhupinder Sandhu, OBE will celebrate 30 years of BSPGHAN and Dr Jacqueline Cornish, National Clinical Director for Children and Young People's Services, NHS England will give the final key note lecture to close the meeting on Friday. Although the Wednesday programme is slightly weighted towards post graduates, it is also a full programme with a plenary session that should be as attractive as the subsequent 2 days. There is a good blend of clinical conundrums and research presentations. With your active participation in discussion and questions, the meeting will be enjoyable and a success. The posters this year will be on show for all 3 days so you will have time to read and digest. There is also a little more time this year to visit the posters and our sponsors' stands, all in close proximity. However, the meeting also importantly serves as a time for networking, inspiring new ideas and socialising. Not only do I hope you enjoy the academic programme but will also participate actively in the social programme. On Wednesday night we will be guests at the Cuban restaurant sampling tapas and sipping Mojitos whilst being entertained by a professional display of Latin dancing. Whilst for Thursday's Gala dinner, I have arranged for a superb professional band "The Swingers" who have played at a number of top venues in London to entertain us and ensure we dance the night away.

I would like to thank Carla for her invaluable help and hard work in co-ordinating the meeting and thanks to Rafeeq as the society's education representative in co-organising the abstract selection and other members of the society who have given advice in developing the programme. I would like to thank all of you who have submitted abstracts, agreed to be chairs and my team who will help run the meeting and have supported me in developing the programme.

So welcome again and enjoy your time in Bristol.

Best wishes

Dr Christine Spray  
Professor Bhupinder Sandhu  
Dr Dharam Basude  
Dr Tony Wiskin  
Dr Eleni Volanaki



# POST GRADUATE DAY

## Wednesday 27th January 2016

### Royal Marriott Hotel, Bristol

## Welcome and Introduction

10.20 – 10.30

Dr Christine Spray  
Consultant Paediatric Gastroenterologist  
Local Organiser BSPGHAN Annual Meeting 2016

10.30 – 12.35

## Session I

### Working in partnership

**Chairs:**

Dr Anna Pigott, Consultant Paediatric Gastroenterologist  
City General Hospital, University Hospital of North Staffordshire, Newcastle Road, Stoke-on-Trent  
and  
Ms Kay Crook, Paediatric Gastroenterology CS,  
North West London Hospitals NHS Trust, St Mark's Hospital, Harrow, Middlesex

10.30 – 11.15

### Therapeutic endoscopy - Working with Surgeons

Dr Dharam Basude  
Consultant Paediatric Gastroenterologist  
Bristol Children's Hospital  
Bristol  
&  
Mr Tim Rogers  
Consultant Paediatric Surgeon  
Bristol

11.15 – 11.45

### What's new in radiology?

Dr Nasim Tahir  
Consultant Paediatric Radiologist  
Leeds General Infirmary  
Leeds

11.45 – 12.15

### How to use and interpret impedance

Dr S Perring  
Clinical Scientist, Medical Physics  
Poole Hospital NHS Foundation Trust  
Longfleet Road  
Poole  
Southampton

12.15 – 12.35

### OFG & other oral manifestations of GI disease

Dr Konrad Staines  
Senior Clinical Lecturer in Oral and Dental Sciences  
Lower Maudlin Street  
Bristol

12.35 – 13.25

## Session II

### Why do research?

**Chairs:**

Dr Nick Croft, Consultant Paediatric Gastroenterologist, Digestive Diseases  
Centre for Immunobiology, Blizard Institute, Wingate Building, 26 Ashfield Street, London  
and  
Dr Kornilia Nikaki, GRID trainee in PeGHAN, Dept of Paediatrics  
Bristol Royal Hospital for Children, Upper Maudlin Street, Bristol

12.35 – 12.55

### Current options for an academic pathway

Professor Ian Sanderson  
Consultant Paediatric Gastroenterologist  
Adult and Paediatric Gastroenterology  
ICMS, Bart's and the London  
Turner Street  
London

12.55 – 13.25

### Why I did research, what skills have I learnt and has it influenced my clinical practice

Dr Anthony Wiskin  
Consultant Paediatric Gastroenterologist  
Bristol  
&  
Dr Protima Amon  
Queen Mary, University of London  
Barts & The London School of Medicine & Dentistry  
Blizard Building  
London

13.25 – 14.40

LUNCH AND POSTER VIEWING  
OPPORTUNITY TO VISIT EXHIBITOR STANDS AND MEET THE SPONSORS



14.40 – 15.30

## Session III

### Clinical Problem solving

**Chairs:**

Dr Astor Rodrigues, Consultant Paediatric Gastroenterologist  
Oxford Children's Hospital, John Radcliffe Hospital, Oxford

and

Dr Nkem Onyeador, Senior Clinical Research Associate  
Nutrition Unit, ICH, 30 Guilford Street, London

14.40 – 15.10

#### Clinical problem solving with key Pads

*Dr Rafeeq Muhammed*

*Consultant Paediatric Gastroenterologist*

*Birmingham Children's Hospital, Birmingham*

15.10 – 15.30

#### Preventing infection in patients with short bowel syndrome on TPN (is it bacterial overgrowth, translocation, line infection)

*Dr John Puntis*

*Consultant Paediatric Gastroenterologist*

*Leeds*

15.30 – 16.30

## Session IV

### Plenary Presentation I

**Chairs:**

Dr Ieuan Davies, Consultant Paediatric Gastroenterologist, Dept of Child Health  
University Hospital of Wales, Heath Park, Cardiff

and

Dr Chris Knight, Consultant Paediatrician  
Musgrove Park Hospital, Parkfield Drive, Taunton

15.30 – 15.40

#### New trends in biologic use in paediatric IBD in the UK: significantly less co-immunosuppression, milder disease and more patients!

*R Muhammed, Birmingham Children's Hospital; K Mortier, Royal College of Physicians, London; L Williams, Royal College of Physicians, London; M Auth Alder Hey Children's Hospital, Liverpool; N Croft, Royal London Hospital, London; RM Beattie Southampton University Hospital NHS Trust; et al*

15.40 – 15.50

#### Comparison of efficacy and safety of Biosimilar Infliximab to Originator Infliximab in children with Inflammatory Bowel Disease

*C Legere, Clinical Fellow In Gastroenterology; T Wong; W Haller; S Protheroe; L Whyte; R Bremner; R Muhammed*

*Birmingham Children's Hospital NHS Foundation Trust*

15.50 – 16.00

#### The Impact of "Crohn's Disease-Treatment-with-EATing" Diet (CD-TREAT Diet) and Exclusive Enteral Nutrition on Healthy Gut Bacteria

*Vaios Svolos, PhD Student; Richard Hansen; Katie Hughes Umer Zeeshan Ijaz; Christopher Quince; Daniel Gaya; Richard Russell; Konstantinos Gerasimidis*

*Room 3.84, Level 3, New Lister Building, GRI, 10-16 Alexandra Parade, Glasgow, G31 2ER*

16.00 – 16.10

#### Assessing the colonic microbiome in children: Effects of sample site and bowel preparation

*Naomi Black<sup>1</sup>, Medical Student; Azelea Rushd<sup>2</sup>, Medical Student; Kathleen Sim<sup>1</sup>, Clinical Research Fellow, Department of Medicine, Section of Paediatrics; Simon Kroll<sup>1</sup> Professor, Department of Medicine, Section of Paediatrics; Alexander Shaw, Research Associate, Department of Medicine, Section of Paediatrics; Jenny Epstein<sup>3</sup>, Consultant Paediatric Gastroenterologist, Department of Paediatric Gastroenterology:*

*<sup>1</sup>Imperial College London, London, UK; <sup>2</sup>King's College London, London, UK; <sup>3</sup>Chelsea and Westminster Hospital NHS Foundation Trust, London, UK*

16.10 – 16.20

#### Adalimumab as first line biologic therapy is effective and well tolerated by children with Crohn's disease

*Adalimumab as first Line biologic therapy is effective and well tolerated by children with Crohn's Disease*  
*N Oneyador; T Wong; S Protheroe; W Haller ; L Whyte ; R Bremner; R Muhammed*

*Birmingham Children's Hospital NHS Foundation Trust, Birmingham*

16.20 – 16.30

#### Barriers to implementing the revised ESPGHAN Guidelines for Coeliac Disease in Children – a national cross-sectional survey across the paediatric units in England

*Dr Siba Prosad Paul<sup>1</sup>; 2. Miss Sophie Harries<sup>2</sup>; 3. Dr Dharamveer Basude<sup>1</sup>*

*<sup>1</sup>Bristol Royal Hospital for Children; <sup>2</sup>University of Bristol*

**16.30 – 17.00**  
TEA

**17.10 – 18.10**

**Evening Symposium Hosted by Abbvie**

Real-life considerations for the management of paediatric Crohn's disease  
Interactive case study disc

**18.15 – 19.15**

Professional Group meetings

Associate Members  
Trainee Members

**19.30 – 20.30**

Annual Trainees v Consultants Football Match

**20.00 – till late**

Welcome Dinner

Tapas and Mojitos with Professional Latin Dancing at The Cuban Restaurant  
[www.thecubanbristol.co.uk](http://www.thecubanbristol.co.uk)



Professional Latin Dancing at The Cuban Restaurant  
[www.thecubanbristol.co.uk](http://www.thecubanbristol.co.uk)

**Thursday 28th January 2016**

Royal Marriott Hotel, Bristol

**7.45 – 8.55**

Working Group Meetings  
Please see notice boards for room details

Endoscopy  
Education  
Nutrition  
Motility

**9.00 – 10.00**

## **Symposium Hosted by Mead Johnson**

### **Accelerating Cow's Milk Recovery**

Professor Berni Canani, Dept of Paediatrics  
University "Federico II" of Naples, Naples

**Debate:**

**This believes active tolerance induction should be a key outcome goal in  
management of infants with cow's milk allergy**

Dr Adam Fox, Consultant Paediatric Allergist, Guy's & St Thomas'  
NHS Foundation Trust, The Portland Hospital, London

## **Welcome and Introduction**

**10.00 – 10.10**

Dr Christine Spray  
Consultant Paediatric Gastroenterologist  
Local Organiser BSPGHAN Annual Meeting 2016



10.10 – 11.30

## Session V

### Novel GI / Liver diseases

**Chairs:**

Dr Nadeem Afzal, Consultant Paediatric Gastroenterologist  
Southampton General Hospital, Tremona Road, Southampton  
and

Dr Mona Abdel-Hady, Consultant Paediatric Hepatologist  
Birmingham Children's Hospital, Steelhouse Lane, Birmingham

10.10 – 10.30

#### Diagnosis and Management of Metabolic Liver Disease

Dr Patrick McKiernan  
Consultant Paediatric Hepatologist  
Liver Unit  
Birmingham Children's Hospital, Birmingham

10.30 – 10.50

#### Genetic/phenotypic correlation in patients with Congenital Phenotypic diarrhoea

Dr Lisa Whyte  
Consultant Paediatric Gastroenterologist  
Dept of Gastroenterology  
Birmingham Children's Hospital, Birmingham

10.50 – 11.10

#### Liver disease and congenital disorders of glycosylation

Dr. Jos Jansen  
Translational Metabolic Laboratory and dept. Gastroenterology & Hepatology  
Radboud University Medical Centre  
Nijmegen, the Netherlands

11.10 – 11.30

#### Identifying mitochondrial disorders and impact on transplantation

Professor Robert Taylor  
Mitochondrial Pathology  
Newcastle University and Honorary Consultant Clinical Scientist  
Newcastle upon Tyne Hospitals NHS Foundation Trust

11.30 – 12.00  
COFFEE & POSTER VIEWING

12.00 – 12.30

## Session VI

**Chair:**

Dr Suzanne Davison, Consultant Paediatric Hepatologist  
Children's Liver and GI Unit, Martin Wing, Leeds General Infirmary

12.00 – 12.30

### STATE OF THE ART LECTURE: CHOLESTASIS IN PREGNANCY

Professor Catherine Williamson  
King's College Hospital, Denmark Hill, London

12.30 – 13.10

## Session VII

### PICO Session

**Chairs:**

Professor Stephen Allen, Professor of Paediatrics  
Liverpool School of Tropical Medicine, Room M-215, Dept of Clinical Sciences, Liverpool  
and

Dr Julian Thomas, Consultant Paediatric Gastroenterologist  
Dept of Child Health, Royal Victoria Infirmary, Newcastle upon Tyne

12.30 – 12.40

#### Overview of current research activity in PGHN in UK

Professor Stephen Allen  
Professor of Paediatrics / Honorary Consultant Paediatrician  
Room M-215 Department of Clinical Sciences, Liverpool School of Tropical Medicine  
Liverpool L3 5QA, UK

12.40 – 12.50

#### Funding opportunities

Dr Julian Thomas  
Consultant Paediatric Gastroenterologist, Dept of Child Health, Royal Victoria Infirmary  
Newcastle upon Tyne NE1 4LP

12.50 – 13.10

#### PICO Presentation:

#### What is the effectiveness and cost effectiveness of extensively hydrolyzed formula compared with omeprazole in formula fed infants with GORD?

Dr. Haitham Abul-eis, Locum Consultant Paediatrician  
Royal Alexandra Children's Hospital  
Eastern Road, Brighton BN2 5BE

13.10 – 14.25  
LUNCH AND POSTER VIEWING  
OPPORTUNITY TO VISIT EXHIBITOR STANDS AND MEET THE SPONSORS

14.25 – 15.25  
**Session VIII**  
**Plenary Session II**

**Chairs:**  
Dr Su Bunn, Consultant Paediatric Gastroenterologist  
Ward 10, Royal Victoria Infirmary, Queen Victoria Road, Newcastle upon Tyne  
and  
Dr Patrick McKiernan, Consultant Paediatric Hepatologist  
Liver Unit, Birmingham Children's Hospital, Birmingham

14.25 – 14.35

**Variation in upper GI bleeding service provision for children in the United Kingdom – A nation-wide survey by British Society of Paediatric Gastroenterology Hepatology & Nutrition (BSPGHAN)**

Afzal NA, Lloyd C, Narula P, Gupte G, Croft NM, Baker A

14.35 – 14.45

**Capturing T-Cell receptors. A Potential new modality for targeting hepatic tumours and post-transplantation lymphoproliferative disease (PTLD)**

Dr Nicola Ruth<sup>1,2</sup>, Research Fellow; Professor Deirdre Kelly<sup>2</sup>; Dr David Millar<sup>3</sup>; Miss Lora Steadman<sup>1</sup>; Dr Sarah Penny<sup>1</sup>; Dr Nico Buettner<sup>1</sup>; Dr Paisley Trantham<sup>4</sup>; Prof Donald Hunt<sup>4</sup>; Mr K Sharif<sup>2</sup>; Prof Mark Cobbold<sup>3</sup>

<sup>1</sup>University of Birmingham, <sup>2</sup>Liver Unit, Birmingham Children's Hospital; <sup>3</sup>Harvard University;

<sup>4</sup>University of Virginia

14.45 – 14.55

**Long-term outcome of biliary atresia into adult life**

J Sadiq<sup>1</sup>; A Kumar<sup>2</sup>; H Sohail<sup>2</sup>; C Lloyd<sup>1</sup>; J Ferguson<sup>2</sup>; K Sharif<sup>2</sup>; D Mirza<sup>1,2</sup>; G Hirschfield<sup>2</sup>; D Kelly<sup>1</sup>

<sup>1</sup>Liver unit/Institute of Hepatology, Birmingham Children's Hospital;

<sup>2</sup>University Hospital Birmingham (UK)

14.55 – 15.05

**Hepatic Lesions Associated with McCune Albright Syndrome**

Dr Lauren Johansen, Hepatology Grid Trainee; Dr Wolfram Haller, Consultant Gastroenterologist; Professor Deirdre Kelly, Consultant Hepatologist; Dr Patrick McKiernan, Consultant Hepatologist Birmingham Children's Hospital

15.05 – 15.15

**Paediatric HBV in the East End**

Dr Ramiya Kirupanathan<sup>1</sup>; Dr Patrick Kennedy<sup>2</sup>; Dr Upkar Gill<sup>2</sup>; Dr Sandhia Naik<sup>1</sup>.

<sup>1</sup>Paediatric Gastroenterology, Children's Hospital, Royal London, Barts Health NHS Trust. E1 1BB;

<sup>2</sup>Blizard Institute, Barts and the London School of Medicine and Dentistry QMUL, 4 Newark St. E1 2AT

15.15 – 15.25

**Fermentation capacity of Gut Microbiota in patients with Inflammatory Bowel Disease compared to healthy controls**

Miss Yunqi Koh<sup>1</sup>; Miss Mhairi McGowan<sup>1</sup>; Dr Daniel R Gaya<sup>2</sup>; Dr Douglas Morrison<sup>3</sup>; Dr Richard Hansen<sup>4</sup>; Dr Richard K Russell<sup>4</sup>; Dr Konstantinos Gerasimidis<sup>1</sup>

<sup>1</sup>University of Glasgow, School of Medicine, New Lister Building, Glasgow Royal Infirmary, G31 2ER; <sup>2</sup>Department of Gastroenterology, Glasgow Royal Infirmary, G31 2ER

<sup>3</sup>SUERC, University of Glasgow, East Kilbride, G75 0QF; <sup>4</sup>Department of Paediatric

Gastroenterology, The Royal Hospital for Children Glasgow, 1345 Govan Road, Glasgow G51 4TF

15.25- 15.55  
TEA & POSTER VIEWING

15.55 – 17.40  
**Session IX**  
**IBD**

**Chairs:**  
Professor Bhupinder Sandhu, Consultant Paediatric Gastroenterologist  
Royal Hospital for Children, Upper Maudlin Street, Bristol  
and  
Dr Matthew Thorpe, Consultant Paediatrician  
Dept Child Health, Royal Cornwall Hospital, Truro

15.55 – 16.10

**The IBD Registry - why and how to join**

Mr Richard Driscoll  
Development Lead, IBD Registry  
London

16.10 – 16.30

**Epigenetics in IBD**

Dr Matthias Zilbauer  
University Lecturer and Honorary Consultant in Paediatric Gastroenterology  
Cambridge University Hospitals  
Cambridge

16.30 – 16.50

**Precision IBD therapy**

Dr Tariq Ahmad  
Consultant Gastroenterologist  
Royal Devon and Exeter NHS Foundation Trust  
Devon

16.50 – 17.10

**Transition from paediatrics to adults – what next?**

Dr Tom Creed Consultant Gastroenterologist  
Bristol Royal Infirmary  
Upper Maudlin Street  
BS2 8BJ

17.10 – 17.40

**State of the Art Lecture:  
PIBD mortality & morbidity**

Dr Lissy de Ridder  
Consultant Paediatric Gastroenterologist  
Erasmus MC-Sophia Children's Hospital  
Rotterdam

**17.45 – 19.00**

Annual General Meeting

**20.00 – late**

Pre-dinner drinks with High Sheriff of Bristol  
Gala Dinner and Dancing to The Swingers



**Friday 29th January 2016**

Royal Marriott Hotel, Bristol



**7.45 - 9.00**  
Working Group Meetings  
(Please see notice boards for rooms)

Research  
PeGHANS  
Hepatology

**9.00 – 9.15**

**GRS Update**

Dr Priya Narula  
Consultant Paediatric Gastroenterologist  
Sheffield Children's Hospital  
Western Bank  
Sheffield

**9.15 – 10.45**

**Session X**

**Chairs:**

Dr Eleni Volonaki, Consultant Paediatric Gastroenterologist  
Bristol Royal Hospital for Children, Upper Maudlin Street, Bristol  
and

Dr Keith Lindley, Consultant/Hon Reader, In Paediatric Gastroenterology, UCL Institute of Child Health &  
Great Ormond Street Hospital for Children NHS Trust, London

**9.15 – 9.35**

**Social concerns in children being investigated for Chronic Intestinal Pseudo Obstruction**

Joanne Brind  
Clinical Nurse Specialist – CIPO  
Great Ormond Street Hospital  
Great Ormond Street  
London

**9.35 – 9.55**

**Motility disorders in patients with Cerebral Palsy**

Consultant Paediatric Gastroenterologist  
Gastroenterology Unit  
Institute of Child Health  
London

**9.55 – 10.15**

**Case Presentation: Approach to feeding children with severe neurodisability and intestinal failure – when is PN indicated?**

Dr Huw Jenkins  
Consultant Paediatric Gastroenterologist  
University Hospital of Wales  
Cardiff  
&  
Dr Amar Wahid  
Specialist Registrar  
University Hospital of Wales  
Cardiff

**10.15 – 10.45**

**Guest Lecture:**

**Making a diagnosis and managing patients with fatigue and gastroenterology symptoms**

Dr Esther Crawley  
Chronic Fatigue Team  
Royal United Hospital  
NHS Foundation Trust  
Bath

**10.45 – 11.15**

COFFEE

**11.15 – 13.05**

**Session XI**

**Nutrition**

**Chairs:**

Dr Mark Beattie, Consultant Paediatric Gastroenterologist  
Southampton General Hospital, Tremona Road, Southampton  
and

Miss Lisa Cooke, Dietitian  
Royal Bristol Hospital, Upper Maudlin Street, Bristol

**11.15 – 11.35**

**Long term management & follow up of patient following diagnosis of Eosinophilic esophagitis**

Dr Mark Furman  
Consultant Paediatric Gastroenterologist  
Royal Free Hospital / Centre for Paediatric Gastroenterology  
London

**11.35 – 11.55**

**Dietetic approach to management of chronic diarrhoea in patients post bone marrow transplantation**

Ms Karen O'Connor  
Dietitian  
Bristol Royal Hospital for Children  
Upper Maudlin Street

**11.55 – 12.15**

**Translating evidence into practice to improve the nutritional care of preterm infants**

Dr Mark Johnson  
ST8 Neonatal Medicine  
Department of Neonatal Medicine  
University Hospital Southampton NHS Foundation Trust  
Princess Anne Hospital  
Coxford Road, Southampton

12.15 – 12.35

**Is there a role for FODMAP diets**

Ms Emily Trewella  
Specialist Paediatric Dietitian  
Chelsea and Westminster Healthcare  
369 Fulham Road  
London

12.35 – 13.05

**GUEST LECTURE:  
UNUSUAL ASSOCIATIONS WITH GUT INFLAMMATION**

Professor Athimalaipet Ramanan, Consultant Paediatric Rheumatologist  
Bristol Royal Hospital for Children & Royal National Hospital for Rheumatic Diseases,  
Bath, Upper Maudlin Street, BS2 8BJ  
Joint Lead for Research, Division of Women's and Children's,  
University Hospitals Bristol NHS Foundation Trust  
Associate Director, UK Experimental Arthritis Treatment Centre for Children  
(JIA -Uveitis and Industry workstreams)

13.05 – 14.20

LUNCH

OPPORTUNITY TO VISIT EXHIBITOR STANDS AND MEET THE SPONSORS

9.15 – 10.45

**Session XII  
Plenary Presentation III**

**Chairs:**

Dr Sandhia Naik, Consultant Paediatric Gastroenterologist  
Dept of Paediatric Gastroenterology, Royal London Hospital, London  
and

Dr David Devadason, Consultant Paediatric Gastroenterologist  
Paediatric Gastroenterology, Queens Medical Centre, Nottingham

14.20 – 14.30

**Intestinal Adaptation in Children With Short Bowel Syndrome During Treatment With Teduglutide**

Susan Hill, Consultant Paediatric Gastroenterologist, Great Ormond Street Hospital for Children, The Octav Botnar Wing, Great Ormond Street, London, WC1N 3JH, UK; Samuel A. Kocoshis, Professor of Pediatrics, University of Cincinnati College of Medicine, 3333 Burnet Avenue, Cincinnati, OH 45229, USA; Beth A. Carter, Associate Professor of Pediatrics and Medical Director, Intestinal Rehabilitation Clinic, Texas Children's Hospital, 6701 Fannin Street, 11th floor, Suite 1010, Houston, TX 77030, USA; Simon Horslen, Medical Director, Liver and Small Bowel Transplantation, Seattle Children's Hospital, 4800 Sand Point Way NE, Seattle, WA 98105, USA; Benjamin Li, Manager, SAS Programming, NPS Pharmaceuticals, Inc., 550 Hills Drive, Bedminster, NJ 07921, USA; Sunita Goyal, Clinical Development Lead, Shire plc., 200 Shire Way, Lexington, MA 02421, USA; Robert S. Venick, Assistant Clinical Professor of Pediatric Gastroenterology, Hepatology and Nutrition, Mattel Children's Hospital UCLA, Departments of Pediatrics and Surgery, 200 UCLA Medical Plaza, Suite 265, Los Angeles, CA 90095-1752, USA

14.30 – 14.40

**Diagnostic endoscopy in children with GI symptoms: Indications and Outcomes**

Dr Shuang Wang<sup>2</sup>, ST3 Paediatric Gastroenterology; Mr Osman Younus<sup>2</sup>, Medical Student; Dr Nick Croft<sup>1,2</sup>, Consultant Paediatric Gastroenterologist  
<sup>1</sup>Centre for Immunobiology, Blizard Institute, Barts and the London, Queen Mary's School of Medicine; <sup>2</sup>Dept Of Paediatric Gastroenterology, Barts Health NHS Trust, Royal London Hospital, Whitechapel Road, London E1 1BB

14.40 – 14.50

**Effectiveness of double-balloon enteroscopy-facilitated polypectomy in pediatric patients with Peutz-Jeghers syndrome**

Dr Dalia Belsha, MBCHB, MRCPCH. Paediatric gastroenterology registrar; Dr Arun Urs, MBCHB, MRCPCH. Paediatric gastroenterologist; Dr Mike Thomson, MBCHB, MRCPCH, MD. Paediatric gastroenterologist  
Sheffield Children's Hospital, Western Bank, Sheffield, S10 2TH

14.50 – 15.00

**Validation of malnutrition screening tools in paediatric patients: associations with body composition and clinical outcomes**

Ms Nara Elizabeth Lara-Pompa<sup>1</sup>; Dr Jane Williams<sup>1</sup>; Ms Sarah Macdonald<sup>2</sup>; Dr Jane Valente<sup>3</sup>; Ms Vanessa Shaw<sup>2</sup>. Dr Susan Hill<sup>4</sup>; Prof Jonathan C Wells<sup>1</sup>. Prof Mary Fewtrell<sup>1</sup>.  
<sup>1</sup>Childhood Nutrition Research Centre, UCL Institute of Child Health, 30 Guilford Street, London. WC1N 1EH UK; <sup>2</sup>Dietetics, Great Ormond Street Hospital for Children NHS Foundation Trust. London. WC1N 3JH. <sup>3</sup>Paediatrics, Great Ormond Street Hospital for Children NHS Foundation Trust. London. WC1N 3JH. <sup>4</sup>Gastroenterology, Great Ormond Street Hospital for Children NHS Foundation Trust. London. WC1N 3JH.

15.00 – 15.10

**A review of the Home Parenteral Nutrition cohort over the last 10 years: how have the complexity and challenges of this cohort changed?**

Anna Hughes, Advanced Nurse Practitioner (Trainee); Emily Swallow, Specialist Nurse; Dr Jutta Koeglmeier, Gastroenterology Consultant; Dr Susan Hill, Gastroenterology Consultant, Great Ormond Street Hospital

15.10 – 15.20

**UK National Survey of Methodology and Interpretation of Impedance-pH monitoring in Children**

Ahmed Kadir; Hani Rajab; Nikhil Thapar; Mohamed Mutalib; Nikhil Thapar; David Rawat  
Whitechapel Rd, London E1 1BB

15.20 – 15.40

**Session XIII  
Plenary Presentation III**

**Chair:**

Dr Martin Brueton  
Consultant Paediatric Gastroenterologist (Retired)

15.20 – 15.40

**Celebrating 30 years of BSPGHAN**

Professor Bhu Sandhu, OBE  
Consultant Paediatric Gastroenterologist  
Royal Hospital for Children  
Bristol

15.40 – 16.10

## Session XIV

### Chair:

Dr Alastair Baker, Consultant Paediatric Hepatologist  
King's College Hospital, Denmark Hill, London

15.40 – 16.10

### KEYNOTE LECTURE: STRATEGIC DIRECTION FOR CHILDREN AND YOUNG PEOPLE'S SERVICES IN NHS ENGLAND

*Dr Jacqueline Cornish  
FRCP(Lond) Hon FRCPCH DSc(Hon)  
National Clinical Director Children  
Young People and Transition to Adulthood,  
Medical Directorate  
NHS England*

16.10 – 16.30

### PRIZE PRESENTATION AND CLOSE OF MEETING

#### Previous Prize winners

##### 2008 Southampton

Alex Mowat Prize – Dr Andrew Barclay  
Best Abstract Presentation – Ms Elaine Buchanan  
Best Presentation – Dr Sherina Ross

##### 2009 Sheffield

Alex Mowat Prize – Dr Johann van Limbergen  
Sean Devane Memorial – Dr Jenny Epstein  
Best Allied Health Professional – Ms Jackie Falconer

##### 2010 Liverpool

Alex Mowat Prize – Dr Emer Fitzpatrick  
Sean Devane Memorial – Dr Rachael Taylor  
Best Poster Presentation – Dr Paul Henderson

##### 2011 Edinburgh

Alex Mowat Prize – Dr Paul Henderson  
Sean Devane Memorial – Dr Emer Fitzpatrick  
Best Poster Prize – Ms Helen French

##### 2012 Nottingham

Alex Mowat Prize – Mark Goddard  
Sean Devane Memorial – Anna Gregory  
Challenging Case – Lisa Whyte  
Best Poster – Ms Hannah Williamson

##### 2013 Manchester

Alex Mowat Prize – Dr Protima Amon  
Sean Devane Memorial – Dr Lisa Whyte  
Best Poster Prize – Dr Rana Bitar

##### 2014 - London

Alex Mowat Prize – Dr Vandana Jain  
Sean Devane Memorial – Dr Ed Giles  
Best Poster Prize – Dr Bradley Keller

##### 2015 – Stratford upon Avon

Alex Mowat Prize – Dr Mona Abdel-Hady  
Sean Devane Memorial – Dr Kelsey Jones  
Best Poster Prize – Sarah Macdonald and Dr Katherine Fawbert  
Best PICO Presentation – Dr Huey Miin Lee

##### 2016 Nutricia ELN Awards

Konstantinos Gerasimidis: The Impact of "Crohn's Disease-Treatment-with-EATing"  
Diet (CD-TREAT Diet) and Exclusive Enteral Nutrition on Healthy Gut Bacteria

Anna Hughes: A review of the Home Parenteral Nutrition cohort over the last 10 years:  
how have the complexity and challenges of this cohort changed?

C Smith: Blinded enteral feed rate challenge:  
Application to the child with medically unexplained poor "enteral tolerance"

Mrs Janis Maginnis: Clinical management of treating children with IBD  
by administering Infliximab (Remicade) as a one hour infusion

Joan Gavin: Crohn's Disease: Initial treatment and outcomes at 12 months  
& Maintenance enteral nutrition post induction therapy in paediatric Crohns Disease.  
Does 600kcal more per day keep the doctor away?

Christine Maville: New safer, cost effective system to encourage and ensure compliance  
to thiopurine safety blood monitoring in children with inflammatory bowel disease.

Heather N: Pilot study to consider the feasibility and acceptability of My Health Vault  
– a telemedicine platform, in children with IBD.

Sarah Allen: Hydrogen breath testing in paediatrics:  
A retrospective audit of results in a tertiary paediatric centre.

Ms Nara Elizabeth Lara-Pompa Validation of malnutrition screening tools in paediatric patients:  
associations with body composition and clinical outcomes



## Speaker Biographies



**TARIQ AHMAD, M.B., Ch.B., D.Phil., F.R.C.P. (UK)**

Dr Tariq Ahmad is a Consultant Gastroenterologist in Exeter. He qualified from Bristol University in 1992 and completed higher specialist training in Oxford where he developed particular interests in inflammatory bowel disease and nutrition. Dr Ahmad was awarded a D. Phil in 2002 for his research investigating the genetic basis for disease heterogeneity in IBD, and continues to work in this field at the University of Exeter Medical School. He is a member of the UK IBD genetics consortium and currently leads a series of UK-wide pharmacogenetic studies, PANTS and PRED4, investigating response and side effects of drugs used in gastroenterology. He is currently the PI or CI for a number of commercial clinical trials and is the Peninsula NIHR gastroenterology research lead. He spends his spare time on the phone hassling colleagues to recruit to the genetic studies, much to the annoyance of his family and friends.



**Dr Protima Amon**

Protima is a paediatric gastroenterologist. She completed her medical degree at Imperial College and graduated in 2002. Her early paediatric training was at Guy's and St Thomas' Hospital in London, where she achieved Membership of the Royal College of Paediatrics in 2006. In the same year, she was appointed to the Higher Specialist Training Programme in Paediatric Gastroenterology in The London Deanery. She completed her specialist training in March 2014 and took up her current post as a Clinical Research Fellow within the Centre of Immunobiology, Queen Mary University of London. Protima is a self confessed research enthusiast. She is currently doing a PhD studying the microbiome in childhood Crohn's disease. She is investigating whether enteral diets, used as first line therapy for children with active Crohn's disease, affect the microbiota. If an improvement in the condition of the gut is found to be associated with changes in the bacteria, the aim would be to maintain the composition of bacteria to achieve long term health in children with Crohn's disease.



**Dr Dharam Basude**

Consultant Paediatric Gastroenterologist in Bristol Royal Hospital for Children since 2008, Honorary Clinical Senior Lecturer University of Bristol, lead for Endoscopy, Video Capsule endoscopy and Nutrition. Qualifications MBBS, DCH, MRCP(Paediatrics), MRCPCH.

Graduated from AP University of health sciences, India in 1996. Core SpR Paediatric training in Manchester deanery. Obtained Subspecialist PGHN training in Manchester, Glasgow, London and Edinburgh. Special interest in Diagnostic and Therapeutic Endoscopy, Nutrition, IBD and Coeliac disease. PI for EUROPAC2, PRED4, PANTS and GEM multicentre trials. 7 publications so far.

**Ms Joanne Brind**

Qualifying as RGN 1994 in Glasgow Joanne spent 10 years working in Intensive Care Units internationally, specialising in general ICU, hyperbaric, cardiac, and latterly paediatrics.

After qualifying as RN-Child (2004) worked as Endoscopy Pre-admissions Specialist Nurse, then Clinical Nurse Specialist (CNS) for Nutrition. Completed MSc in Nursing 2009 (London City University), and also obtained Independent Prescriber diploma (London Southbank); published articles on prevention of CVC sepsis in Nursing Standard and Journal of Paediatric Gastroenterology & Nutrition. Dedicated to high standard of patient care Joanne won British Journal of Nursing award in 2008 for recognition of clinical role, and awarded Florence Nightingale Foundation travel scholarship the following year, which she used to visit bowel transplant centres in the USA.

Employed now as the UK's first Chronic Intestinal Pseudo Obstruction (CIPO) CNS since 2012, she has been part of core team setting up National CIPO Diagnostic Service at GOSH, and won Health Service Journal Efficiency award for this initiative in 2013. Throughout the 3 years in post has been conducting independent research, which has been accepted for presentation at specialist conferences nationally and internationally.



**Dr Jacqueline Cornish**

Dr Jacqueline Cornish was appointed to the post of National Clinical Director Children, Young People and Transition to Adulthood in NHS England in April 2013. She is passionate about continuously striving for improved healthcare outcomes in this young group, giving them and their families the best experience and delivering care safely to the highest possible standard.

She is a practicing clinician, having only recently stepped down as Director of Paediatric Stem Cell Transplant (SCT) at the Bristol Royal Hospital for Children. Dr Cornish specialises in the transplant of children with a high risk haematological malignancy, and the Unit has been pioneering in the development of the use of alternative donors, detection of molecular minimal residual leukaemia, and white cell chimerism techniques. The Bristol SCT Unit is a world leader, and published clinical and research outcomes have set a gold standard in the transplant of Childhood Acute Lymphoblastic Leukaemia which has not been surpassed.

Dr Cornish has over 20 years' experience of Medical Management in the NHS, having been Head of Division of Women's and Children's Services at University Hospitals Bristol NHS Foundation Trust for 10 years before taking up the National post. She believes that the strong synergy between clinicians, dedicated managers and commissioners leads to the best result for patients and is a hallmark of high performing organisations and services.

With this clinical and managerial background, she intends to contribute towards making a real impact on the improvement of health and wellbeing outcomes in Children and Young People in England. She believes strongly in Parity, for CYP overall but importantly bringing mental health on a par with physical health. She hopes to secure robust Transition to adult services through multiagency partnership working for all young people with chronic and long term mental and physical health conditions. The goal is to facilitate a positive experience such that they remain engaged as they move from child and young person centred to adult delivered services, and are supported to take responsibility for their own health as they move into adulthood.

Dr Jacqueline Cornish OBE FRCP(Lond) Hon FRCPCH DSc(Hon)  
National Clinical Director Children, Young People and Transition to Adulthood,  
Medical Directorate, NHS England, March 2015



**Esther Crawley BA(Hons), BM BCh, MRCPCH, PhD**

Esther Crawley, is a Reader in Child Health at the University of Bristol, a Consultant Paediatrician and an NIHR Senior Research Fellow. She is the clinical lead for the Bath specialist CFS/ME service for children based at the Royal United Hospital in Bath. This service provides assessment and treatment for over 400 children and young people each year. Esther leads a research team which investigates the epidemiology and treatment of CFS/ME in children and adults. The epidemiological work uses the Avon and Longitudinal Study of Parents and Children (ALSPAC) and a large cohort of patients (~10,000 adults, and 2000 children) to study the causes and different types of CFS/ME. Her team have developed expertise in delivering complex hard-to-do trials. They have just finished trials investigating the Lightning Process in Children and Early Intervention in Adults. Children are currently being recruited into a large trial investigating Graded Exercise Therapy and will shortly be starting a National Trial investigating Internet Delivered CBT. Esther trained in Oxford, did her PhD in London and lives in Bristol when she is not sailing or skiing with her family.

**Dr Tom Creed**



**Richard Driscoll**

Richard Driscoll works as an independent healthcare specialist with a particular interest in patient engagement and quality improvement in health services for long term conditions. He has substantial experience in bringing together patients, health professionals, pharmaceutical companies and National Health Service organisations to collaborate in projects designed to deliver high quality patient-centred care. Having previously been CEO of the patient organisation Crohn's and Colitis UK, he has continuing part-time roles as Development Lead for the UK IBD Registry and Chairman of the Health Quality Improvement Partnership, which manages the NHS Audit Programme in England. Richard co-chairs the IBD2020 Global Forum with Professor Simon Travis.



**Mark Furman**



**Dr Jos Jansen**

Dr Jos Jansen is a PhD candidate at the glycosylation disorders laboratory of Dr. Dirk Lefeber in Nijmegen. He graduated medical school with Honours in 2013 at the University of Amsterdam. Prior medical school he obtained a bachelor's degree in Pharmaceutical Sciences at the University of Utrecht in 2006. His main topic is characterization of two new types of congenital glycosylation disorders with a predominant liver phenotype. In 2016, he will start his GI residency with special interest in liver diseases.



**Dr Huw Jenkins**

Dr Huw Jenkins is a Consultant Paediatric Gastroenterologist at University Hospital of Wales in Cardiff.





**Dr Mark Johnson PhD BM BSc MRCPC**

Dr Mark Johnson is a senior registrar in Neonatal Medicine at University Hospital Southampton NHS Foundation Trust. His research centres around the nutritional care and growth of preterm infants, and the implementation of practice change in order to improve care. He recently completed a PhD which focused on change management in neonatal care in the context of nutritional care, successfully implementing improved nutritional practices in order to improve the growth of preterm infants. His work has also included several systematic reviews looking at the use of early parenteral nutrition in preterm infants, the impact of enhanced nutrition on the neurodevelopmental outcomes of preterm infants, and the effect of preterm birth on body composition and growth. He was successful in gaining a prestigious NIHR Doctoral Research Fellowship to fund his PhD in 2012, is a member of the BAPM working group on parenteral nutrition, and has published over 10 peer reviewed publications.



**Dr Patrick McKiernan**

He qualified in 1983 and trained in medicine and paediatrics in Belfast. He has been a consultant paediatric hepatologist in the Liver Unit at Birmingham Children's Hospital since 1994.

His work involves medical care to children with all forms of liver disease and for those undergoing liver transplantation. He has a particular clinical interest in inherited metabolic liver disease and portal hypertension.

His research interests are in the clinical aspects of inherited metabolic liver disease, portal hypertension, novel endoscopic techniques, non-invasive markers of hepatic fibrosis and immunosuppression following liver transplantation. Outside work his interests are his family and grandchildren and he tries to keep fit by cycling.



**Dr Rafeeq Muhammed**

Steve Perring studied Natural Sciences in Cambridge and completed a PhD Rafeeq is a consultant paediatric gastroenterologist and clinical lead for Inflammatory Bowel Disease services in Birmingham Children's Hospital. Rafeeq is the chair of education committee of BSPGHAN. He is also a member of IBD working group of BSPGHAN and IBD registry board. Rafeeq's research interests include epidemiology and immunology in IBD.

**Karen O'Connor, Paediatric Oncology Dietitian RD**

Karen O'Connor qualified as a Dietitian in 2010 with a BSc in Dietetics from the University of Plymouth. She started work as a Dietitian at the Royal United Hospital, Bath in 2011 as a general adult Dietitian. During her time in Bath she progressed to specialise in Oncology and then into Paediatrics. Early this year she had the opportunity to further develop her career in Paediatric Dietetics at the Bristol Royal Hospital for Children. Whilst at the BRHC Karen has been working in Oncology, Haematology and Bone marrow transplant.



**Dr Steve Perring**

Steve Perring studied Natural Sciences in Cambridge and completed a PhD in image fusion at Southampton in 1993. He has run a GI Physiology service in Poole Hospital since 1994. He is a member of Council of the Association of GI Physiologists (AGIP) and until recently was on the Physiological Measurement Special Interest Group of the Institute of Physics and Engineering in Medicine (IPEM). He has published significantly on various aspects of physiology including upper GI physiology.



**Dr John Puntis**

Steve John Puntis was an undergraduate in Southampton before training in paediatrics in Birmingham under Sandy McNeish and Ian Booth. Appointed as a consultant neonatologist in Leeds in 1990, he also shared general paediatric workload and developed a regional gastroenterology and nutrition service. The nutrition team in Leeds currently provides care for 20 children receiving home parenteral nutrition for intestinal failure.



**Dr Lissy de Ridder**

Dr Lissy de Ridder is specialist in Pediatric gastroenterology at Erasmus MC-Sophia Children's Hospital, Rotterdam. Her current research concerns pediatric inflammatory bowel disease (IBD) with a main focus on clinical and translational studies. She is particularly interested in the safety and efficacy of medical treatment of IBD as illustrated by a large international survey on cancer and mortality within pediatric-onset IBD she is working on. Furthermore, she is principal investigator and project leader of TISKids, a randomised controlled trial on top-down versus step-up treatment in newly diagnosed pediatric Crohn's disease.

She is steering committee member of the ESPGHAN pediatric IBD Porto working group, treasurer of PIBDnet and she is a very enthusiastic faculty member of the Young Investigators Forum (YIF) of the ESPGHAN.

**Credentials and Affiliations:**

Graduated Medical School at University of Amsterdam, the Netherlands 1995.  
 Pediatrician, Academic Medical Center, Amsterdam, the Netherlands 2003.  
 Pediatric gastroenterologist, Academic Medical Center, Amsterdam, the Netherlands 2006.  
 Doctorate at University of Amsterdam, Ph.D. Thesis: "Pediatric inflammatory bowel disease: scoping the future. Genetics, diagnostics and therapeutics", 2007.  
 Pediatric gastroenterologist, Erasmus MC-Sophia Children's Hospital, Rotterdam (the Netherlands) since 2007.

**Mr Timothy Nicolas Rogers**

I am a full-time NHS consultant in Paediatric Surgery and have worked in this role for the past 8 years. I have worked both locally and nationally to deliver and improve high quality surgical care to children. My job includes a major commitment to the surgery of childhood cancer, neonatal surgery and minimally invasive surgery. I take an active role in clinical research with a specific interest in paediatric rhabdomyosarcoma.





**Professor Ian Sanderson**

Ian Sanderson is Professor of Paediatric Gastroenterology at Queen Mary University of London. He leads an internationally recognised unit in paediatric inflammatory bowel disease. He is also on the faculty of Harvard Medical School and is an associate molecular biologist at the Massachusetts General Hospital for Children in Boston. He established the Digestive Diseases Clinical Academic Unit Barts and The London NHS Trust in 2007, the first centre in the UK that incorporated adult physicians, surgeons and paediatricians. As new administrative structures changed in 2011 with the expansion of Barts Health to include other hospitals in the East End, this sense of a community dedicated to diseases of the intestine and liver has remained. He is a past president of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition; on the health advisory committee of Coeliac UK; on the research advisory committee of CORE; and a Trustee of the Barts Charity with particular responsibility for clinical academic training. He is the academic training programme advisor for paediatrics at UCLP, and leads the London paediatric gastroenterology pathway group at NHS England. He is visiting Professor of Paediatric Gastroenterology at University College, London and at the Juntendo School of Medicine, Tokyo. He is co-director of the Wellcome Trust Bloomsbury Centre for Global Health Research and an investigator in the Harvard Nutrition Obesity Research Centre in Boston.

Professor Sanderson was the first to show: (i) that the enterocyte has distinct transporters on the basolateral aspect for the exit of different amino acids (published 1980); (ii) that enteral feeds are as efficacious in treating children with Crohn's disease as high dose steroids, while showing a significant benefit for growth (1987); (iii) that diet can regulate immune gene expression by the epithelium in vivo (1993); (iv) that short chain fatty acids (SCFA) regulate chemokine and IGF binding protein expression in enterocytes through histone acetylation (1997); (v) that breast milk contains VEGF in high concentrations, and that there is a VEGF receptor on the intestinal epithelial cell (1999); (vi) by epithelial cell-specific transgenic techniques, that chemokine expression by the epithelium orchestrates neutrophil and lymphocyte invasion in vivo (2001); (vii) that diet and age interact at the nuclear protein level to regulate gene expression (2004); (viii) that IL-6 mediates growth retardation in Crohn's disease (2005); (ix) with Prof Tom MacDonald that colonic myofibroblasts enhance chemokine activity of the epithelial cell (2006); (x) that non-canonical Wnt signalling from colonic myofibroblasts enhances the repair of epithelial monolayers (2012) (xi) with Prof Petterson in Sweden, that persistent TLR signalling in the epithelial cells reduces the generation of new intestinal tumours in mice (2014). As a clinician he has also published many observations, including being the first to describe four new diseases of childhood, two of which involve inflammation in the GI tract.



**Professor Bhupinder Sandhu OBE, DSc, MD, FRCP, FRCPC.**

Prof. Bhupinder Sandhu graduated from University College and obtained a doctorate from London University. She was appointed a Consultant Paediatrician and Gastroenterologist at the Bristol Royal Hospital for Children in 1988 and subsequently developed a tertiary level Regional Paediatric Gastroenterology Service for the SW.

She is an honorary Professor at the UWE Bristol/Bristol Universities. She is a founder member of BSPGHAN and hosted its inaugural and Millennium meetings and served as its secretary and convenor. She has published book chapters and over 120 papers, chaired ESPGHAN working Group on Diarrhoea and has spoken at many international meetings, and was advisor to the World Health Organization.

She served as: President of Commonwealth Society of Paediatric Gastroenterology, The UK Medical Women's Federation; Board Member of British Medical Association, UK Food Standards Agency, VSO, Bristol Old Vic Theatre School, RMBF, and Chair of BBC West Regional Advisory Council.

She received The Asian Women of Achievement Award in 2002, a DSc in 2008 for contribution to Education and was awarded an OBE by Her Majesty The Queen in the 2013 honours for her contribution to Child Health.

Email: profbksandhu@gmail.com

**Dr Konrad S. Staines**

Consultant & Senior Lecturer in Oral Medicine, Bristol Dental Hospital appointed in 2013 having previously held a position of Consultant in Oral Medicine in Newcastle Dental Hospital.

He is currently Specialty Lead in Oral Medicine, Training Programme Director, Oral Medicine, Southwest Deanery, Specialty Advisor in Oral Medicine, Specialty Advisory Board RCS (Ed), Examiner for Intercollegiate Specialty Exam on behalf of RCS (Ed) and RCS (Ed) nominated member of SAC in Additional Dental Specialties.



**Dr Nashim Tahir, MBChB, MRCS, FRCR**

- Consultant Paediatric Radiologist with 5 years experience
- Subspecialist interest in Paediatric Interventional Radiology
- Trained in Yorkshire with additional subspecialist training in Great Ormond Street Hospital
- Currently working at Leeds Children's Hospital



**Professor Athimalaipet Ramanan**

Professor A. V. Ramanan, FRCPC, FRCP, is a Consultant Paediatric Rheumatologist at Bristol Royal Hospital for Children and Royal National Hospital for Rheumatic Diseases, Bath, UK. Professor Ramanan has published more than 100 papers in peer reviewed journals and authored chapters in textbooks. He is Associate Editor for the Archives of Diseases in Childhood and in the Editorial Board of Rheumatology. He is the Associate Director of UK's only Paediatric Experimental Arthritis Treatment Centre.



**Professor Robert Taylor**

Rob Taylor obtained his first degree in Biochemistry and his PhD (Molecular Biology) from Newcastle University where he was appointed as a Lecturer in 2001. He is currently Professor of Mitochondrial Pathology at the Wellcome Trust Centre for Mitochondrial Research at Newcastle University and is an Honorary Consultant Clinical Scientist with the Newcastle upon Tyne Hospitals NHS Foundation Trust, leading a Highly Specialised Services-commissioned Mitochondrial Diagnostic Laboratory which provides a UK-wide diagnostic service for patients with mitochondrial disease together with colleagues in Oxford and London. His research laboratory focuses on the biochemical and molecular genetic investigation of human mitochondrial disorders, both in terms of determining the molecular mechanisms by which somatic and inherited mitochondrial genetic abnormalities cause cellular dysfunction as well as identifying and characterising new genes associated with both paediatric-onset and adult-onset mitochondrial disease presentations.



**Dr Nikhil Thapar**

Dr Thapar - Academic Lead for Gastroenterology Senior Lecturer (University College London's Institute of Child Health) and honorary consultant (Great Ormond Street Hospital for Children)

Nikhil Thapar undertook his undergraduate medical training at Southampton before completing his postgraduate Paediatric training and subspecialist training in Paediatric Gastroenterology. In 2004 he completed a PhD (University of London) at the National Institute for Medical Research, London studying the enteric nervous system and potential of regenerative medicine. In 2006 Dr Thapar was appointed as honorary consultant in Paediatric Gastroenterology at Great Ormond Street Hospital, where he runs a specialist multidisciplinary clinical service for children with gastrointestinal motility and functional disorders including a national service for children with intestinal pseudo-obstruction. Dr Thapar's research programme focuses on the pathogenesis and treatment of gut motility disorders including molecular mechanisms and regenerative medicine.

Dr Thapar sits on council of the European Society of Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) and chairs its gastroenterology committee. He chairs BSPGHAN's gut motility disorders working group. He is a member of the steering group of the European-wide Paediatric Digestive Diseases Research Network (PEDDCReN). Dr Thapar has published widely and is co-editor of the textbook of Paediatric Neurogastroenterology. Dr Thapar has a keen interest in teaching and is director of the Academy of Paediatric Gastroenterology as well as faculty for the ESPGHAN young investigator's forum and postgraduate training schools.



**Emily Trewella MNutr RD, Specialist Paediatric Dietitian**

Emily graduated with a Master of Nutrition degree from Nottingham University in 2007. She then went to work at Northwick Park Hospital, specialising in paediatrics in 2008. Emily started working at Chelsea and Westminster Hospital in 2010 where she has worked in a number of areas including burns, diabetes and is part of the MDT Prader Willi Service. Currently her time is spent in gastroenterology and diabetes. Her particular area of interest includes FODMAPS and has along with her colleague Claire de Koker been involved in setting up a paediatric service looking in to the efficacy on the low FODMAP diet on GI symptoms.

Emily is HCPC registered and is a member of the Food Allergy and Intolerance and Diabetes Management and Education Specialist groups of the BDA.

**Dr Amar Wahid**

**Dr Lisa Whyte**

I graduated from University of Dundee in 2005 with Distinction. Having developed an interest in paediatric gastroenterology during core paediatric training I was appointed to paediatric gastroenterology GRID training in Cardiff and Birmingham. I was elected to represent my peers on CSAC at RCPCH during this time. Following successful completion of training I was recently appointed as a Consultant Paediatric Gastroenterologist in Birmingham Children's Hospital.

I undertook a part-time MSc in Child Health at University of Warwick during my full time training which has helped me to develop my research portfolio, teaching and management skills that are aiding me in my transition to the consultant role.

I am continuing to add to my research portfolio with a number of ongoing projects including work on the immunology of children with phenotypic diarrhoea. I am also in the process of setting up a pathway for children with neurodisability and feeding difficulties within our region and alongside this, a gi motility service within our centre.



**Dr Anthony Wiskin**

Tony developed an interest in paediatric gastroenterology and nutrition while doing paediatric training in the Wessex deanery. Supported by Crohn's in Childhood Research Association he completed a PhD at the University of Southampton examining nutrition in childhood Crohn's Disease and was awarded the RCPCH Young Investigator of the Year Award in 2013. He completed sub-specialist training in paediatric gastroenterology, hepatology and nutrition working in Southampton, Kings College and Great Ormond Street. In 2015 Tony was appointed to a substantive consultant post at the Bristol Royal Hospital for Children.



**Professor Catherine Williamson MD FRCP**

Catherine Williamson is Professor of Women's Health at King's College London and Honorary Consultant Obstetric Physician at St Thomas' Hospital. Between 2007 and 2013, she was Professor of Obstetric Medicine at Imperial College. She is a leading clinical researcher in maternal medicine in the UK and internationally. Her principal research focus is on the maternal and fetal aetiology and outcomes of a common liver disease of pregnant women, intrahepatic cholestasis of pregnancy (ICP). She is part of the UK team running a clinical trial to find the best treatments. She also runs a research programme investigating gestational signals that influence alterations in lipids, glucose and bile acids in pregnancy. The group also focusses on the influence of intrauterine environment on the subsequent health of the offspring. Catherine uses a large database to study the outcome of tumours of endocrine glands in pregnant women in the UK, with the aim of improving treatment for affected mothers and their unborn babies. She also works on prediction of diseases in pregnant women. Catherine is an assessor of maternal deaths in the UK. Professor Williamson receives referrals to the specialist obstetric medicine clinic at St Thomas' Hospital from colleagues in the UK and internationally and regularly speaks about medical disorders of pregnancy at international courses and conferences.



**Dr Matthias Zilbauer**

Dr. Matthias Zilbauer completed his medical training at Mainz University (Germany) and trained in paediatrics as well as paediatric gastroenterology at a number of tertiary European Hospitals. Following completion of his PhD in mucosal immunology at the Institute of Child Health (UCL, London) as well as clinical training he was appointed as University Lecturer and Honorary Consultant in Paediatric Gastroenterology in 2013. Based at the University of Cambridge (UK), he is leading a translational research programme investigating the role of epigenetic mechanisms in intestinal health and the development of Inflammatory Bowel Diseases. A major focus within this research theme lies on elucidating the implication of DNA methylation in regulating gene expression and cellular function of the intestinal epithelium. Additionally, with an aim to translate these findings into clinical practice, Dr. Zilbauer's group is working on the development of disease prognostic biomarkers using epigenetic signatures. As the current chair of an ESPGHAN epigenetics working group, Dr. Zilbauer is involved in several collaborative international research initiatives and actively promotes basic and translational science in the field of epigenetics in paediatric GI health and disease.



# BSPGHAN 2016 Annual Meeting

## ORAL ABSTRACTS

WEDNESDAY 27TH JANUARY

### **New trends in biologic use in paediatric IBD in the UK: significantly less co-immunosuppression, milder disease and more patients!**

Rafeeq Muhammed, Birmingham Children's Hospital; K Mortier, Royal College of Physicians, London; L Williams, Royal College of Physicians, London; M Auth Alder Hey Children's Hospital, Liverpool; N Croft, Royal London Hospital, London; RM Beattie Southampton University Hospital NHS Trust; JE Fell Chelsea and Westminster Hospital, London; S Loganathan Aberdeen Royal Infirmary; C Charlton Nottingham University Hospital NHS Trust; A Akobeng Manchester Children's Hospital; MA Morris Norfolk and Norwich University Hospital NHS Trust, Norwich; A Willmott University Hospital of Leicester; B Vadamalayan King's College Hospital, London; F Torrente Addenbrooke's Hospital, Cambridge; SG Mitton St George's Hospital, London; A Butt Brighton and Sussex University Hospital NHS Trust, Brighton; H Jenkins University Hospital of Wales, Cardiff; A Rodrigues John Radcliffe Hospital, Oxford; J Puntis Leeds Teaching Hospitals NHS Trust, Leeds; F Kiparissi Great Ormond Street Hospital, London; M Furman Royal Free London NHS Hospital Trust, London; M Cosgrove Singleton Hospital, Swansea; SK Bunn Great North Children's Hospital, Newcastle Upon Tyne; A Pigott University Hospital of North Midlands, Stoke on Trent; W Hyer St Mark's Hospital, London; DC Wilson Royal Hospital for Sick Children, Edinburgh; RK Russell Royal Hospital for Children, Glasgow

#### **Introduction**

The national clinical audit of biological therapies for Inflammatory Bowel Disease (IBD) was started in 2011. Paediatric patients started on biological therapy for the treatment of IBD between September 2011-February 2015 are included in this analysis.

#### **Methods**

Paediatric IBD centres in the UK submitted real time data to the audit web tool. Additional data from the Personalised Anti-TNF alpha Therapy in Crohn's Disease Study (PANTS) have also been included. We ascertained the % of new paediatric IBD (PIBD) biological starters in UK by comparing data from the biologics audit to the data from the national audit of the PIBD service provision (September 2014).

#### **Results**

696 patients are included (579 with Crohn's disease (CD), 92 with ulcerative colitis (UC) and 25 with IBD unclassified (IBDU)) 609 directly via the audit and 87 from PANTS. The number of patients entered into the web tool has increased from 191 patients in 2012 to 235 patients in 2015. 63% of patients with CD were male with median diagnostic age of 13 years with median interval to biologic initiation of 1 year. The indication for starting biological therapy was active luminal CD in 463/570 (81 %) patients. 551/579 (95%) of CD patients were treated with Infliximab. The audit now covers the majority of new starters in paediatrics (62%).

There is a trend for treating milder disease with the median PCDAI score at the initiation of treatment being 25 (IQR 18-38). The pre-treatment PCDAI score is lower compared to the previous 2 years of audit (Table 1). 119/197 (60%) of these patients received concomitant immunomodulatory therapy and 25/197 (13%) were receiving steroids at the initiation of biological treatment; compared to the 1st audit period the rates of co-immunosuppression and steroid usage at initiation are significantly lower 56/67 (84%) cf. 60% (119/197),  $p < 0.001$  and 24% (16/67) cf. 13% (25/197),  $p < 0.05$  respectively.

There have been no changes in safety data. Of the 92 UC patients, 88 (96%) received Infliximab. Median PUCAI score at the time of initiation of biological therapy was 35 dropping to 15 at 3 months follow up. Pre treatment PUCAI score is lower compared to previous years (Table 1). UC patients 40% (26/65) were significantly more likely to be prescribed Infliximab in compliance to NICE criterion compared to 14% (47/337) of CD patients ( $p < 0.0001$ ). Patient related outcome measures (PROM) were assessed using IMPACT-III questionnaire. Median IMPACT-III score at the initiation of biological therapy was 116 (IQR 102-137) and this had significantly improved to 132 at 3 months follow up (IQR 93-146).

#### **Discussion**

The increase in participation of IBD biological audit demonstrates the value of the audit. The audit suggest that biologics are being used to treat milder Crohn's disease compared to previous years, as evidenced by the lower PCDAI score and lower use of steroids at initiation of treatment. The surprising trend of reduced prescription of co-immunosuppressants was seen in this audit; however this is not clearly related to any changes in safety signal. The biologics audit is coming to an end in this form after March 2016; however given the importance of collecting longitudinal data on children, we strongly recommend adopting the IBD registry which combines the role of the patient management system and tool for audit with quality improvement and so will continue this important work.



**Table 1: Analysis of results over the time of the different audit cycles**

Audit period	2011-12	2012-13	2013-14	2014-15
<b>Number of IBD patients added to the register</b>	77	191	193	235
<b>CD patients on Concomitant Immunomodulation % (n/N)</b>	84%(56/67)	80%(124/155)	68%(108/160)	60%(119/197)
<b>CD patients on steroids</b>	24%(16/67)	30%(47/155)	10%(16/160)	13%(25/197)
<b>PCDAI score at initiation of biologics treatment Median (IQR)</b>	(n=51) 20(5,35)	(n=100) 30(20,38)	(n=93) 30(15,40)	(n=102) 25(15,35)
<b>PUCAI score at initiation of biologics treatment Median (IQR)</b>	(n=8) 45(24,69)	(n=29) 55(40,65)	(n=21) 65(43,78)	(n=19) 35(20,65)

**Conflict of Interests Declaration**

RM has received speaker’s fees, travel support, research grants, or has performed consultancy work with MSD Immunology, Abbvie, Dr Falk, Tillotts Pharma, Nestle, Takeda and Pfizer. NC has served as advisory board member, speaker or received research funding from Abbvie, Abbot, Shire, MSD Immunology, Schering Plough. JF has served as advisory board member for Jansen and received conference sponsorship from Dr Falk and Nestle. DCW has done consultancy work with Pfizer and research support from MSD Immunology for investigator initiated study. RKR has received speaker’s fees, travel support or has performed consultancy work with MSD Immunology, Nestle, Abbvie, Dr Falk, Takeda, Napp, Mead Johnson, Nutricia, 4D pharma. Other authors have no conflict of interests to declare.

**Comparison of efficacy and safety of Biosimilar Infliximab to Originator Infliximab in children with Inflammatory Bowel Disease**

C Legere, Clinical Fellow In Gastroenterology; T Wong; W Haller; S Protheroe; L Whyte Birmingham; R Bremner; R Muhammed  
Birmingham Children’s Hospital NHS Foundation Trust

**Introduction**

Biosimilars are biological medicines that are similar to another biological medicine that has already been authorised for use. CT-P13 is the biosimilar Infliximab approved for use in Europe and it is marketed in the UK in two brand names, Remsima (NAPP pharmaceuticals) and Inflectra (Hospira pharmaceuticals). European Medicines Authority (EMA) has approved CT-P13 for all the indications of originator Infliximab (Remicade, MSD Immunology). No clinical trials in paediatric inflammatory bowel disease (IBD) of biosimilar Infliximab are completed till date. We have compared the efficacy and safety of biosimilar Infliximab to the originator Infliximab in our clinical practice.

**Methods**

Clinical and laboratory data of patients receiving Infliximab from January 2015 to date was collected from patient records and electronic case records.

**Results**

We have used biosimilar Infliximab (Inflectra) for all new starters of Infliximab treatment in our unit since July 2015. Prior to that all patients on treatment with Infliximab were receiving originator Infliximab (Remicade). 24 patients (18 with Crohn’s disease (CD) and 6 with ulcerative colitis (UC)) were started on Inflectra this year. 17 patients (14 patients with Crohn’s disease and 3 with ulcerative colitis) were started on Remicade from January to July this year. A total of 72 Inflectra infusions were administered compared to 96 infusions of Remicade. Median number of infusions per patient was 3 and 6 respectively for Inflectra and Remicade. 1 patient receiving Inflectra had a major infusion reaction needing a switch of treatment to Adalimumab. This was comparable to the incidence of major infusion reaction in patients receiving Remicade (1/17). 5/18 (28%) patients with Crohn’s disease on treatment with Inflectra needed dose or frequency escalation of infusions. Clinical remission was achieved in 5/8 (63%) patients receiving Inflectra treatment. 10/14 (71%) children with Crohn’s disease on treatment with Remicade achieved clinical remission. Dose or frequency escalation was needed in 3/14 (21%) patients on Remicade. Co-immunosuppression was used in 15/18 (83%) patients with Crohn’s disease on Inflectra compared to 12/14 (86%) patients with Crohn’s disease on Remicade. 2/5 (40%) patients with UC achieved clinical remission using Inflectra. 2/3 (67%) patients with UC on Remicade achieved clinical remission. Cost of Inflectra is less than that of Remicade (100 mg vial of Inflectra costs approximately £210 and 100 mg vial of Remicade costs approximately £350). Results are summarised in Table 1.

**Discussion**

Biosimilar Infliximab is a safe and effective treatment for children with IBD. Efficacy and side effect profile of biosimilar Infliximab are very similar to the originator Infliximab. The reduction in the cost is another advantage of using biosimilar infliximab. We hope that our experience of using biosimilar Infliximab would encourage other units to adopt similar practice which would result in significant cost savings for National Health Service (NHS).

**Conclusion**

In our clinical practice, the efficacy and safety of biosimilar Infliximab (Inflectra) is comparable to the originator Infliximab with significant cost savings offered by the use of biosimilar Infliximab.

**Table 1**  
**Comparison of patients with IBD on treatment with Remicade and Inflectra**

	Patients on treatment with Remicade	Patients on treatment with Inflectra
<b>Number of patients</b>	17 (CD 14, UC 3)	24 (CD 18, UC 6)
<b>Total number of infusions</b>	96	72
<b>Number of infusions per patient median (range)</b>	6 (2-8)	3 (1-6)
<b>Major infusion reaction</b>	1/17 (6%)	1/24 (4%)
<b>Patients with CD on Azathioprine</b>	12/14 (86%)	15/18 (83%)
<b>Patients with CD needing dose escalation</b>	3/14 (21%)	5/18 (28%)
<b>Patients with CD in remission</b>	10/14 (71%)	5/8 (63%)
<b>Patients with UC in remission</b>	2/3 (67%)	2/5 (40%)
<b>Drug cost of 6 month's treatment</b>	£3500	£2100

**Declaration of Conflict of Interest:**

RM has received speaker's fees, travel support, research grants, or has performed consultancy work with MSD Immunology, Abbvie, Dr Falk, Tillotts Pharma, Nestle, Takeda and Pfizer. Other authors have no conflicts of interests to declare.

**The Impact of "Crohn's Disease-Treatment-with-EATING" Diet (CD-TREAT Diet) and Exclusive Enteral Nutrition on Healthy Gut Bacteria**

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**Introduction/Background**

We have recently demonstrated an extensive modulation of gut microbiome in children with Crohn's disease on induction treatment with exclusive enteral nutrition (EEN) (1,2). This observation offers clues about the potential mode of EEN action and advocates towards the development of novel therapies through dietary manipulation of the gut microbiota.

**Aim**

This cross-over, RCT compared the effect of a novel "ordinary" food based diet (CD-TREAT diet) and EEN on healthy gut microbiota.

**Subjects and methods**

Healthy adults followed two experimental diets for seven days with a 15 day wash out period in between; EEN and CD-TREAT, an "ordinary" food diet which has similar nutrient and food ingredient composition to EEN (e.g. fibre content, fatty acid composition, lactose and gluten free content). Participants were randomly allocated to start with EEN or CD-TREAT first. Fresh faecal samples were collected before and after each dietary intervention (4 different time points) and faecal short chain fatty acids (SCFA), pH, ammonia and sulphide were measured.

**Results**

100 samples were collected from 25 healthy subjects. Faecal concentration of total SCFA, acetic, propionic, butyric and caproic acid significantly decreased during both dietary interventions ( $\Delta$ Median  $\mu$ mol/g, EEN: -167.27, -135.61, -15.47, -21.01, -2.02 vs CD-TREAT: -165.18, -68.92, -25.5, -34.99, -1.36, all  $p < 0.01$ ). Proportional ratio (% of total SCFA) was significantly reduced for butyric and caproic acid ( $\Delta$ Median %, EEN: -2.92%, -0.47%, CD-TREAT: -5.04%, -0.21%, all  $p < 0.01$ ); while did not change for the other SCFA. Faecal concentration of iso-butyric and iso-valeric acid was significantly increased after EEN only ( $\Delta$ Median  $\mu$ mol/g, EEN: 2.33, 2.59), while their proportional ratio increased after both diets ( $\Delta$ Median %, EEN: 1.95%, 2.13%, CD-TREAT: 0.72%, 0.88%, all  $P < 0.001$ ). Faecal pH significantly changed from a neutral baseline level to the alkaline range ( $\Delta$ Median pH units, EEN: 1.39 vs CD-TREAT: 0.97, both  $p < 0.001$ ). Likewise, total sulphide significantly increased during both diets ( $\Delta$ Median  $\mu$ mol/g, EEN: 3.1, CD-TREAT: 0.92, both  $p < 0.001$ ). Faecal ammonia and free sulphide concentration did not differ between the 4 time points.

**Summary and Conclusion**

We have developed an "EEN composition alike" food based diet which induces similar effects on gut microbial metabolites with EEN. Further analysis including high-throughput deep sequencing techniques will provide additional scientific evidence before we move this novel dietary treatment towards a subsequent clinical trial in people with active CD.

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### Assessing the colonic microbiome in children: Effects of sample site and bowel preparation

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#### Introduction/Background

Despite the increasingly recognised importance of the gut microbiota in health and disease, and vast refinements in our technical ability to measure it, there is little consensus as to sample site, pathological interpretation or clinical extrapolation. Considering the invasive nature of a mucosal biopsy, a surrogate method of obtaining an accurate representation of the mucosa-associated colonic flora, such as faecal sample or rectal swab may be more acceptable to patients. Furthermore, little is known about the short and long term effects of bowel cleansing on the colonic microbiota.

#### Aims

1. To establish concordance or difference in the paediatric colonic microbiota as sampled in faeces, rectal mucosal biopsy and rectal swab.
2. To assess the effect of bowel preparation on the colonic microbiota.

#### Subjects and Methods

We recruited 31 paediatric patients (Aged 7 months to 18 years) undergoing a lower gastrointestinal endoscopy in our unit between February-May 2014. To provide a longitudinal representation of the gut microbiota we collected 6 samples at 3 time points; pre-colonoscopy (faecal sample), colonoscopy (rectal biopsy, rectal swab, faecal sample) and post-colonoscopy (rectal swab, faecal sample). We collected the three samples at colonoscopy in 16 patients and successfully sequenced 14. Available samples were split into three groups according to diagnosis, either Crohn's Disease (CD), Ulcerative Colitis (UC) or Other. The samples underwent DNA extraction, PCR amplification of the V3-V5 regions of the 16S rRNA gene and amplicons were sequenced on the 454 platform.

#### Results

In a prepared bowel at colonoscopy (n = 14), paired faecal samples and rectal biopsies were significantly similar (p < 0.001) in microbial diversity and abundance compared with paired biopsies and rectal swabs. Faecal samples were significantly more similar (p < 0.001) to their paired biopsy than biopsies from different individuals were to each other.

Faecal samples from an unprepared bowel (n = 8) were found to be significantly more similar (p = 0.03) to their paired biopsy than biopsies were to each other, although faecal samples taken at colonoscopy were significantly more similar still (p = 0.029). We identified significant differences in the microbial community of CD patients that allowed differentiation of this disease state from others, for example a lower abundance of Clostridia in the biopsies (p = 0.021) and faecal colonoscopy samples (p = 0.012) in CD patients.

Microbial diversity in faeces was significantly lower during colonoscopy than in matched faecal samples both pre-bowel preparation (p = 0.03) and post-colonoscopy (p = 0.0005) (n=6). No significant change in diversity was seen between pre- and post-colonoscopy faecal samples suggesting that the alterations in flora induced by bowel cleansing were transient, although some minor shifts in abundance at genus and phylum level were observed.

#### Summary and Conclusion

The similarity in bacterial diversity and composition between mucosal biopsies and faeces supports faecal sampling as a viable, non-invasive surrogate to a biopsy. We conclude that the mucosa-associated microbiome can accurately be represented by a faecal sample. Measurements of the microbial community demonstrated in the biopsy, and therefore in the paired faecal samples, were able to segregate CD patients. Rectal swabs are not closely representative of the mucosa-associated colonic microbiome and are therefore an unsuitable sample site. Faecal microbiota at colonoscopy differs to pre-procedure, likely reflecting the effects of bowel cleansing, and these effects are largely transient.

### Adalimumab as first Line biologic therapy is effective and well tolerated by children with Crohn's Disease

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#### Introduction

Infliximab and Adalimumab are the two anti Tumor Necrosis Factor (TNF) alpha agents licensed for use in children with Crohn's disease (CD). We have compared the efficacy, safety and patient acceptance of treatment with Adalimumab as first line anti TNF alpha agent to treatment with Infliximab.

#### Methods

We have collected clinical and laboratory data from patient notes and electronic case records of all patients with Crohn's disease who are currently receiving anti TNF therapy.

#### Results

21 patients with Crohn's disease were started on Adalimumab as the first line anti-TNF alpha treatment compared to 101 patients receiving Infliximab as the first line anti TNF alpha therapy. All patients were receiving Adalimumab using a pen device at home. All Infliximab infusions were given in the hospital. Active luminal Crohn's disease was the indication to start Adalimumab in 19/21 (90%) patients. 88/101 (87%) patients were started on Infliximab for active luminal Crohn's disease. 2/ 21 (10%) patients on Adalimumab switched treatment to Infliximab due to patient preference. 20/101 (20%) patients switched treatment from Infliximab to Adalimumab ( 11 due to loss of response, 6 due to infusion reaction and 3 due to patient preference). 3/ 21 (14%) patients receiving Adalimumab as first line anti TNF alpha treatment needed dose or frequency escalation whereas 21/101 (21%) patients on Infliximab needed dose or frequency increase. 16/21 (76%) patients on Adalimumab were receiving co-immunosuppression with Azathioprine compared to 94/101 (93%) patients receiving Infliximab. 17/20 (85%) patients on Adalimumab treatment were in clinical remission compared to 70/81 (86%) patients receiving treatment with Infliximab. Results are summarised in Table 1. Infections needing hospitalisation were recorded in 1 patient receiving Adalimumab compared to 3 patients on treatment with Infliximab. No malignancy was reported in any patients.

#### Discussion and Conclusion

Treatment with adalimumab as first line biologic agent is safe and effective and well accepted by children with Crohn's disease. We hope that this information would be useful for children and parents to make an informed decision about the choice on anti TNF alpha treatment.

Table 1

Comparison of patients with Crohn's disease receiving Adalimumab and Infliximab as first line anti TNF alpha therapy

	Patients receiving Adalimumab	Patients receiving Infliximab
<b>Number of patients</b>	21	101
<b>Patients on co-immunosuppression</b>	16/21 (76%)	94/101 (93%)
<b>Patients needing dose/frequency escalation</b>	3/21 (14%)	27/101 (21%)
<b>Patients needing switching of biologic treatment</b>	2/21 (10%) ( patient preference)	20/101 (20%) (11- Loss of response 6-Infusion reaction 3- patient preference)
<b>Clinical remission</b>	17/20 (85%)	70/81 (86%)
<b>Clinical response</b>	3/20 (15%)	11/81 (14%)
<b>Cost of 6 months treatment</b>	£ 6000 (Adalimumab induction 160/80 mg followed by maintenance dose of 40 mg weekly)	£ 7500 (Infliximab 5 mg/kg for child weighing 40 Kg induction doses at 0,2 and 6 weeks and maintenance doses at 8 weekly interval)

#### Conflict of interest Declaration

RM has received speaker's fees, travel support, research grants, or has performed consultancy work with MSD Immunology, Abbvie, Dr Falk, Tillotts Pharma, Nestle, Takeda and Pfizer. Other authors have no conflicts of interests to declare.



**Barriers to implementing the revised ESPGHAN Guidelines for Coeliac Disease in Children – A National Cross-Sectional survey across the paediatric units in England**

Dr Siba Prosad Paul<sup>1</sup>; 2. Miss Sophie Harries<sup>2</sup>; 3. Dr Dharamveer Basude<sup>1</sup>; <sup>1</sup>Bristol Royal Hospital for Children; <sup>2</sup>University of Bristol

**Background**

In 2012, ESPGHAN guidelines<sup>1</sup> for diagnosing coeliac disease (CD) were modified. In symptomatic children a diagnosis of CD can be made serologically if the child has anti-tissue transglutaminase antibody (tTG) titre over ten times the upper limit of normal (10xULN), and has positive HLA-DQ2/8 haplotype. In selective group of children serological diagnosis without biopsy is advantageous as it is reliable, less invasive and economically favourable. However, there are several tTG assays available suggesting different threshold values, thus fostering potential interpretation error and diagnostic inconsistencies.

**Aims**

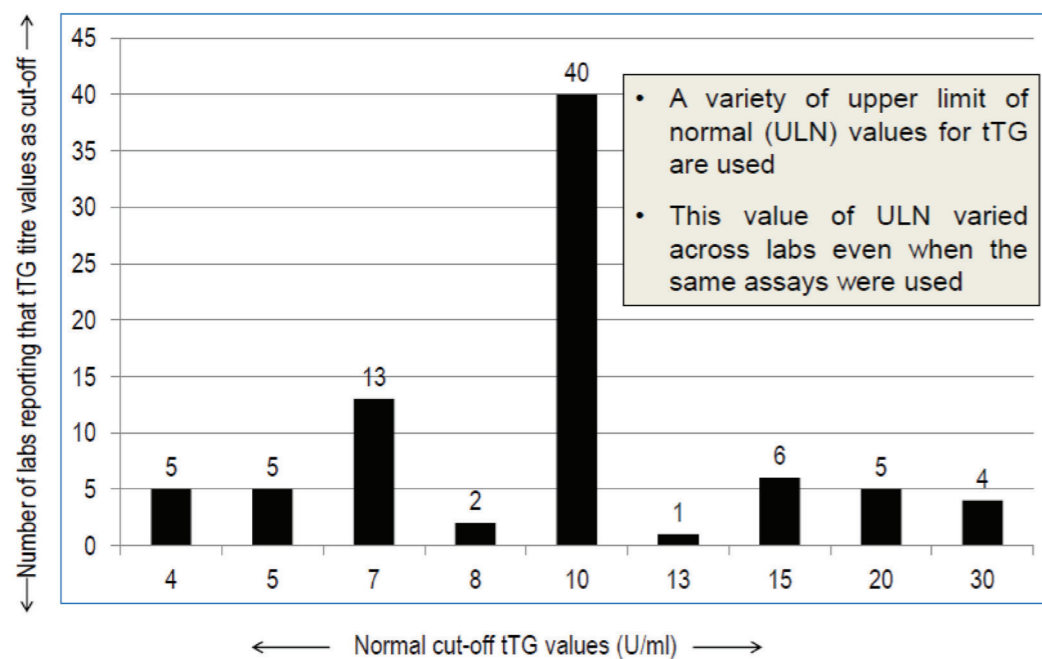
The aim of this study is to explore how tTG is reported by all pathology laboratories in England in order to ascertain current practice and facilitate better implementation of the ESPGHAN guidelines.

**Methods**

A cross-sectional study was conducted in the form of a telephone survey involving all 139 acute hospitals in England providing paediatric services. The respondents were asked what tTG test assays were available in their laboratory, threshold value for normal, availability of anti-endomysial antibody testing, and whether they routinely report the total IgA-levels.

**Results**

135/139 (96.4%) of laboratories responded. 83 (62.6%) of hospitals do their tTG testing in-house and 81.4% (n=) of these also do the IgA-EMA themselves. A range of different tTG assays and 10 different threshold values for normal are being used across England (ranging between 4 – 30 IU/ml [see figure]). Multiple values are being used in each geographical region covered by one or two specialist paediatric gastroenterology centres receiving referrals for diagnosis of CD. 96.3% of laboratories quantitatively reports tTGs. Automatic reporting of total IgA levels occurs in 29.6% of laboratories.



**Conclusions**

Despite calls to standardise, there is still much heterogeneity in tTG reporting in England. Tertiary paediatric gastroenterology centres need to be aware about different tTG threshold values to decide which child can be diagnosed with CD serologically or if biopsies are needed. Standardisation of tTG titres and routine reporting of IgA levels will be beneficial. There is plan to share the findings with all the paediatric gastroenterology units in England with a view to streamlining the diagnostic pathway.

**BSPGHAN 2016 Annual Meeting**

**ORAL ABSTRACTS**

THURSDAY 28TH JANUARY

## Variation in upper GI bleeding service provision for children in the United Kingdom – A nation-wide survey by British Society of Paediatric Gastroenterology Hepatology & Nutrition (BSPGHAN)

Afzal NA, Lloyd C, Narula P, Gupte G, Croft NM, Baker A

### Aims

The CROMES Report (2007) shows significant variability in provision of acute upper GI bleeding services for adult in the UK. With no information available regarding paediatric upper gastrointestinal bleeding services (pUGIBS), BSPGHAN conducted a nationwide survey; the aim to assess the provision of pUGIBS in the United Kingdom.

### Methods

The national survey was conducted, designed and led by the BSPGHAN executive. The questions were finalised after 'face validation' and are in a yes/no and multiple choice question formats with free text space for comments. The questions were direct, relating to provision of services, 24/7 cover, availability of written protocols and presence of local lead. The survey was conducted online and one reply per centre chosen to be representative of services in the hospital.

### Results

25 BSPGHAN members from 15 units in the United Kingdom (England, Wales, Scotland, N. Ireland) participated in the survey. Paediatricians in Paediatric liver (pLiver), paediatric Gastrointestinal (pGI) and paediatric services in district general hospitals (pDGH) participated in the survey. 8/10 of the pGI units offered upper paediatric GI bleeding services with a 24/7 out of hours provision offered only by 5/10 units (2/7 pGI and 3/3 pGI+pLiver centres). 6/10 pGI centres had a designated pUGIBS clinical lead with 5 / 9 of these pGI centers with a protocol for banding for management of bleeding varices. Only 6/15 units of all paediatric centres had an acute upper GI bleeding management protocol.

### Conclusion

Despite limited representation, the survey reflects a country wide variation in paediatric upper gastrointestinal bleeding service, similar to adult services as in the CROMES report. Additionally, paucity of acute upper GI bleeding management protocols highlight the urgent need for developing local and national guidance with standards. The paediatric endoscopy working group (BSPGHAN) is assisting JAG (Joint advisory group on GI endoscopy) to develop a new paediatric endoscopy service assessment tool. This will help to conduct regular annual audits, benchmarking against other paediatric endoscopy units therefore helping to implement quality standards in pGI units in the UK.

## Capturing T-Cell receptors. A Potential new modality for targeting hepatic tumours and post-transplantation lymphoproliferative disease (PTLD)

Dr Nicola Ruth<sup>1,2</sup>, Research Fellow; Professor Deirdre Kelly<sup>2</sup>; Dr David Millar<sup>3</sup>; Miss Lora Steadman<sup>1</sup>; Dr Sarah Penny<sup>1</sup>; Dr Nico Buettner<sup>1</sup>; Dr Paisley Trantham<sup>4</sup>; Prof Donald Hunt<sup>4</sup>; Mr K Sharif<sup>2</sup>; Prof Mark Cobbold<sup>3</sup>  
<sup>1</sup>University of Birmingham, <sup>2</sup>Liver Unit, Birmingham Children's Hospital; <sup>3</sup>Harvard University; <sup>4</sup>University of Virginia

### Objectives and Study

Malignant cells express specific proteins on their cell surface. It is widely believed that it is these proteins that the immune system uses to recognise tumours and eventually eradicate them. When this process goes wrong, a tumour forms.

### Aim

- (1) To identify tumour specific MHC class I phosphopeptide antigens on lymphoblastoid cell lines LCLs (an in vitro model for PTLD) as well as hepatic tumour tissues.
- (2) T-cells are immune cells which are notoriously difficult to maintain in long-term culture and as a result it is difficult to establish an 'off the shelf' T-cell product, however the aim of this project was to explore potential modalities for capturing the T-cell receptor (TCR), important in recognising tumour specific antigens and the resultant product could be used to establish a non patient-specific, but tumour specific product.

### Methods

Paediatric and adult patients were identified with hepatic malignancy and consented as per current policy. Cells were isolated and tumour specific phosphopeptide antigens were identified. These provide the targets for T-cells, and more specifically TCRs. Having identified these antigens, modalities have been explored for expanding these cells. Human Induced Pluripotent Stem Cell (hiPSc) technology was used to immortalise target T-cells of interest. Other modalities were subsequently used to transform these cells into stable T-cell products.

### Results

A number of novel phosphopeptide antigens have been identified both in vitro as well as on patient tissues. This information has been used to identify potential T-cell targets and by formation of hiPSc we have established a method for expanding specific T-cell's in vitro. Following on from this we have developed a technology for expanding these and transforming them into a target cell of interest with potential for future clinical application in paediatric tumours.

### Conclusion

Identifying a modality for expanding cells with a specific TCR repertoire clearly allows us to target tumour specific phosphopeptide antigens and has the potential to be developed as an immunomodulatory therapy in patients with hepatic tumours or PTLD.

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### Long-term outcome of biliary atresia into adult life

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<sup>2</sup>University Hospital Birmingham (UK)

#### Background

Biliary Atresia (BA) is the single commonest cause of neonatal cholestasis leading to cirrhosis, portal hypertension and liver failure and is the main indication for pediatric liver transplant(LT).

#### Aim

Evaluate the long-term outcome of children with BA transitioning to adult life

#### Subjects & Methods

Records of patients of BA managed over a period of 34 years(1980-2014) at a single institution were retrospectively reviewed. Patients with more than 10 years of follow-up were included in the study. Data collection included demographics, age at Kasai Portoenterostomy (KPE), associated malformations, survival with native liver or post-LT, mortality, current education/work/marital/family status.

#### Results

493 BA patients were managed during this period(260 F & 233 M). Median age at kasai was 53 days(range:7-183 days). 92 % had isolated BA while 8 % had BA polysplenia malformation syndrome. 332 patients were included in this study (1980 – 2004). 11 patients were lost to follow-up. Median patient survival is 17.3 yrs (0.32- 34.6) & median survival with native liver is 2.25 yrs (0.07-34.6).

53 patients(16.5%) died in pediatric care; 26 with their native livers & 27 after LT. 135 patients(50.3%) are still in pediatric care(Group A). 57 are surviving with their native liver(A1) while 78 children have been transplanted(A2). 7 patients are awaiting transplant in Group A1. 133(49.6 %) patients were transferred to adult services(Group B); 49 with native livers(B1) and 84 after LT(B2). 28 patients in group B1 had portal hypertension(PH); 20 treated with beta blockers, esophageal banding or shunts. 9 patients transferred to adult services with native liver(B1) subsequently required LT & 7 are listed for LT due to decompensated liver disease. 6 patients in group B2 required retransplant. After transfer to adult care, 3 patients in Group B1 died (one due to ruptured splenic aneurysm; 2 due to decompensated liver disease) while 5 patients in Group B2 died from post-transplant lymphoproliferative disorders (PTLD), Hepatopulmonary syndrome, ruptured psoas cyst and bleeding & chronic rejection). Of 268 patients in this series, majority participated in normal school education while 32 (12 %) required special needs support. 29 transferred went to university, 18 obtained non-vocational qualifications and 33 joined various training courses.

#### Conclusion

Improved medical and surgical techniques have improved the outcome and quality of life for patients with BA, allowing them to live into adult life, complete their education & function as useful members of the society

### Hepatic Lesions Associated with McCune Albright Syndrome

Dr Lauren Johansen, Hepatology Grid Trainee; Dr Wolfram Haller, Consultant Gastroenterologist; Professor Deirdre Kelly, Consultant Hepatologist; Dr Patrick McKiernan, Consultant Hepatologist Birmingham Children's Hospital

#### Introduction

McCune Albright Syndrome (MAS) is a rare sporadic condition with an estimated prevalence of 1 in 100,000 – 1 in 1,000,000. It results from an early embryonic postzygotic somatic-activating mutation in the GNAS gene, which encodes the cAMP pathway-associated G-protein, G $\alpha$ s. MAS classically presents with a triad of café au lait skin pigmentation, polyostotic fibrous dysplasia and precocious puberty. Known hepatobiliary and pancreatic manifestations of MAS include neonatal cholestasis, hepatitis, hepatic adenoma, intraductal papillary mucinous neoplasm and pancreatitis. There have been a number of case reports demonstrating an association between MAS and malignancy; however malignant hepatic lesions have not previously been reported.

#### Aim

To describe the hepatic lesions associated with MAS.

#### Case series

Over a 20 year period, 3 children with MAS have been treated at a National Paediatric Liver Unit. All infants presented within the first month of life with high GGT cholestasis, poor growth, hepatomegaly, raised liver transaminases and progressively acholic stool. An extensive diagnostic work-up was non-confirmatory in all infants. Ultrasonography demonstrated gallbladder abnormalities in 2 of the 3 infants and TIBIDA scans were non excretory. Liver biopsy showed neonatal hepatitis with associated microabscess formation in 2 cases, bile duct paucity in 2 cases, necrosis in 1 and severe cholestasis in 1. Of the 2 infants with bile duct paucity 1 proceeded to ERCP which showed a hypoplastic biliary tree and the other underwent an intra-operative cholangiogram which was normal. All infants were treated with ursodeoxycholic acid, fat soluble vitamins and received nutritional support with a MCT feed. In all cases cholestasis resolved by 1 year but transaminases remained raised.

MAS was diagnosed during infancy in 2 cases and in later childhood in one case. All children had café au lait skin patches, polyostotic fibrous dysplasia, 2 had renal tubular acidosis, 2 had precocious puberty and 1 developed thyrotoxicosis and prolactinoma.

1 child presented with abdominal mass and vomiting at 5 years of age. Imaging showed a large well defined lobulated lesion involving multiple segments of the liver. Alpha fetoprotein levels (AFP) were raised and Hepatoblastoma was confirmed on biopsy. He was treated with chemotherapy, right hepatectomy and cholecystectomy and is currently in remission.

The other 2 children developed hepatic lesions at ages 6 and 7. The lesions are progressive, increasing in both size and number. The lesions distort the liver architecture and exert a mass effect on the hepatic vasculature. On MRI, they show enhancement at the peripheries post contrast, followed by enhancement of the central scar on delayed imaging suggestive of atypical focal nodular hyperplasia. AFP levels are normal.

#### Summary

This case series confirms that MAS is a cause of high gamma GT neonatal cholestasis, which resolves over time. However, the liver does not recover and in our experience all affected children had persistent low level transaminitis and subsequently developed hepatic mass lesions. Focal nodular hyperplasia is a non-specific hyperplastic reaction to vascular abnormalities. Its cause is unknown but it may be instigated by inflammation within GNAS mutated hepatic tissue or by the associated endocrine abnormalities seen in MAS.

The incidence of Hepatoblastoma is 0.5-1.5 cases per million children. Hepatoblastoma is associated with a number of genetic diseases to include Beckwith-Wiedemann syndrome and Familial Adenomatous Polyposis. Co-existent GNAS defects have been reported in individuals with both of these conditions. GNAS mutations have been shown to be pro-inflammatory leading to fibrosis and STAT 3 activation, possibly through cross-communication between the cAMP and JAK/STAT pathways, in hepatic tissue. We theorize that the somatic activating GNAS mutation in MAS is involved in tumorigenesis within the liver.

#### Conclusion

Neonatal cholestasis in children with MAS resolves spontaneously. However, subsequent mass lesions seem common and appear to have a malignant potential. Children with MAS and neonatal cholestasis should undergo regularly ultrasound and AFP monitoring.



## Paediatric HBV in the East End

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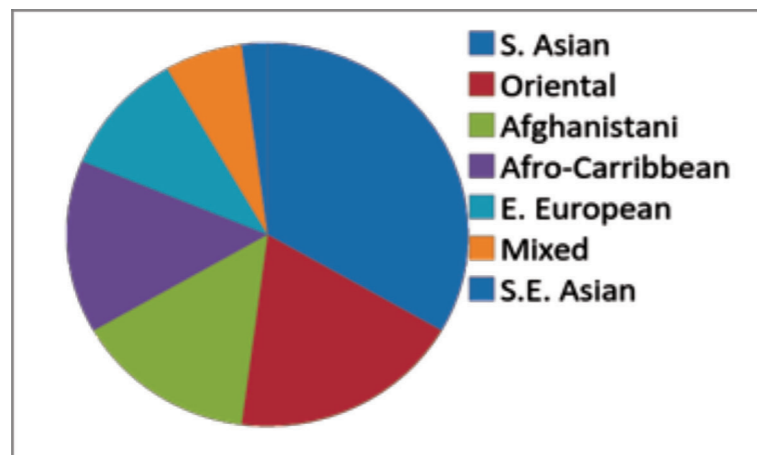
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### Background and aims

Childhood infection with hepatitis B is often asymptomatic however long-term complications of cirrhosis and hepatocellular carcinoma are of significant concern<sup>1</sup>. Our aims were to evaluate an East London population with confirmed hepatitis B who were diagnosed during childhood. We aimed to use HBsAg levels to determine whether the standard criterion of "inactive carrier" is applicable to paediatrics.

### Method

An observational study of Paediatric HBV. Data was obtained from medical notes, electronic healthcare records and CRS. HBsAg titres and HBV DNA levels were measured using Abbott architect and Roche Taqman, respectively.



### Results

48 patients were identified, 29 females. 1 patient moved out of area and 2 spontaneously cleared HBsAg. Data expressed as median (range).

Age (years) at diagnosis 10 (1-18); follow-up 6.9 (0.3- 14.0) years.

39/46 patients had HBsAg >1000 IU/ml. 11930.85 IU/ml (1,466.41 - 174,935.30 IU/ml). 52.1% HBsAg >10,000 IU/ml.

17/21 inactive carriers (normal ALT, viral load <2,000 IU/ml) 2 with HBsAg levels > 1,000 IU/ml identified; 9176.35 IU/ml (1,466.41 to 34,929.55).

11/48 patients had an ALT >35, 25/48 if Prati criteria was applied 3.

6 patients (12.5%) had vaccine escape. All 6 were born in the UK.

9/48 patients could not be genotyped due to HBV DNA <100 IU/ml. Genotype D was most common - 43.1%, C-19.6%, A-8.7%, B-8.7%, E- 2.2%. Genotype D was associated with a higher HBsAg and viral load.

### Conclusion

The ethnic diversity is typical of an inner city population. 0.01-0.03% of chronic HBV carriers will develop HCC before adulthood 4. 25% will have disease progression with increased morbidity in adult life<sup>5</sup>, a significant cost burden for the NHS. In adults a high HBsAg (>1000 IU/ml) indicates increased risk of disease progression to cirrhosis and HCC. Based on these results we question whether the same parameters should apply to paediatric HBV. Further research including detailed immune profiling is required to identify better markers to risk stratify paediatric disease progression in order to target effective earlier interventional treatments.

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## Fermentation capacity of Gut Microbiota in patients with Inflammatory Bowel Disease compared to healthy controls

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### Introduction/Background

Gut microbiota in the colon ferment undigested dietary fibre to produce short-chain fatty acids (SCFA). SCFA have beneficial effects on colonic health. Differences in microbiota composition and metabolic activity have been described between IBD patients and healthy controls.

### Aim

This project explored the capacity of the gut microbiota of IBD patients to breakdown dietary fibre.

### Subjects & methods

Fresh faecal samples were collected from IBD patients in clinical remission and healthy controls (HC). In vitro batch culture fermentations were carried out for 8 carbohydrate/fibres (maize starch, pectin, raitilose, wheat bran, cellulose). Aliquots were taken at 0, 4, 24 and 48 hours. Faecal SCFA (butyrate, propionate and acetate) concentration (umol/g) was measured with Gas Chromatography.

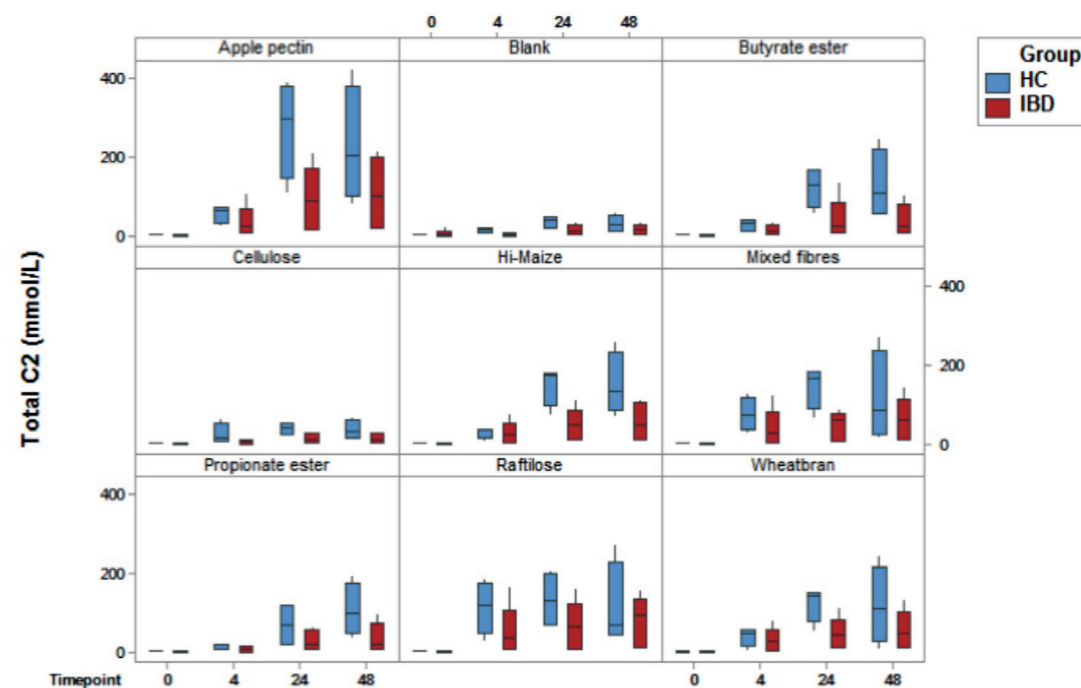
### Results

Five IBD participants and four matched HC were recruited. Following 24h batch cultures, total SCFA, acetate (Figure 1) and butyrate tended (p~0.100) or were significantly lower in IBD participants than in healthy controls (p<0.05) and for the majority of the fibre substrates tested: [Butyrate, umol/g, IBD vs HC; wheat bran: 8.7 vs 36.4, p=0.022; cellulose: 4.0 vs 8.2, p=0.070; raitilose: 18.4 vs 58.3, p=0.048, apple pectin: 15.7 vs 42.6, p=0.066; Maize starch: 13.5 vs 51.2, p=0.044]; [Total SCFA, umol/g, IBD vs HC; wheat bran: 74.3 vs 268, p=0.029; cellulose: 32.3 vs 77.2, p=0.012; raitilose: 133 vs 330, p=0.102, apple pectin: 122 vs 461, p=0.031; Maize starch: 80.3 vs 300, p=0.028]; [Acetate, umol/g, IBD vs HC; wheat bran: 45.8 vs 124.5, p=0.039; cellulose: 15.8 vs 39.7, p=0.055; raitilose: 66.6 vs 135, p=0.176, apple pectin: 91.9 vs 273, p=0.052; Maize starch: 48.2 vs 151, p=0.023]. No significant differences were observed for propionate concentration or the production profile (% proportional ratio) or SCFA.

### Summary/conclusions

This pilot data suggest that the microbiota of IBD patients has a lower capacity to break down fibre, compared to healthy people. The findings of this work should be replicated in larger populations and be complemented with the use of next generation sequencing.

Figure 1: Concentration of acetate (C2) following 48 h fermentation of 8 fibres in people with Crohn's disease and healthy controls.



# BSPGHAN 2016 Annual Meeting

## ORAL ABSTRACTS

FRIDAY 29TH JANUARY

**Intestinal Adaptation in Children With Short Bowel Syndrome During Treatment With Teduglutide**  
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### Introduction

A percentage of children with short bowel syndrome (SBS) remain dependent on parenteral support (PS; parenteral nutrition and/or intravenous fluids) under current standards of care (SOC) for many months with little chance for adaptation. Teduglutide (TED), a GLP-2 analogue, is an intestinal hormone that stimulates small bowel growth and mediates intestinal adaptation after resection.

### Aim

We sought to determine whether TED promotes intestinal adaptation in PS-dependent children with SBS for whom no significant advance in enteral nutrition (EN; oral and/or tube feeding) could be achieved.

### Subjects and Methods

This 12-week, open-label, multicentre, safety and pharmacodynamic study enrolled patients aged 1-17 years with SBS  $\geq 12$  month duration who required PS for  $\geq 30\%$  of caloric and/or fluid/electrolyte needs and who showed minimal/no advance in EN feeds for  $\geq 3$  months before baseline. Patients enrolled sequentially into 3 TED cohorts (0.0125 mg/kg/d [n=8], 0.025 mg/kg/d [n=14], 0.05 mg/kg/d [n=15]) or received SOC (n=5). Data presented are median (min, max).

### Results

At baseline, 42 patients (age, 3.0 [1.0, 14.0] years) received 7.3 (4.0, 16.0) L/week PS and had been PS dependent for 3.7 (0.5, 12.2) years. 40 patients (95%) completed the study; 1 withdrew consent, and 1 discontinued because of protocol non-compliance. Weekly prescribed PS volume decreased between baseline and Week 12 with TED 0.05 mg/kg/d (-1.3 [-11.0, 1.0] L/week [-25%]) and 0.025 mg/kg/d (-2.3 [-6.9, 0.0] L/week [-41%]), and was unchanged with TED 0.0125 mg/kg/d (0.0 [-2.5, 0.0] L/week [0%]) and SOC (0.0 [-0.3, 1.4] L/week [0%]). At Week 12, prescribed PS calories decreased by 45% and 41% in the 0.05- and 0.025-mg/kg/d cohorts, respectively; in the 0.0125 mg/kg/d and SOC cohorts, PS calories changed by 0% and +4%, respectively. Based on patient diary data, EN volume increased by 0.6 (0.0, 3.9) (40%), 2.3 (-0.9, 8.8) (32%), and 1.1 (0.0, 12.5) L/week (22%) in the 0.05-, 0.025-, and 0.0125-mg/kg/d cohorts, respectively, but by only 0.5 (0.0, 1.7) L/week (11%) with SOC. EN calories increased by 62%, 28%, 9% and 46% in the 0.05-mg/kg/d, 0.025-mg/kg/d, 0.0125-mg/kg/d and SOC cohorts, respectively. 4 patients achieved PS independence with TED (0.05 mg/kg/d, n=3/15; 0.025 mg/kg/d, n=1/14), 2 of whom resumed PS 4 weeks after TED ended. Improvements in EN volume were maintained or increased from baseline at 4 weeks after stopping treatment (0.05 mg/kg/d, 0.8 [0.0, 3.5] L/week [38%]; 0.025 mg/kg/d, 3.5 [-1.9, 8.7] L/week [32%]; 0.0125 mg/kg/d, 3.2 [0.0, 10.5] L/week [60%]; SOC, 0.9 [0.0, 1.7] L/week [24%]). Levels of plasma citrulline, a biomarker of enterocyte mass, increased with TED. All patients experienced  $\geq 1$  treatment-emergent adverse event (TEAE); most were mild (95% TED, 100% SOC) or moderate (57% TED, 60% SOC). The most common TEAEs in the combined TED group were vomiting (32% vs 0% SOC), upper respiratory tract infection (27% vs 40% SOC), catheter-related complications (24% vs 20% SOC), and pyrexia (24% vs 40% SOC). No serious TEAEs related to TED occurred. There were no reports of AEs related to fluid overload, intestinal obstruction, hepatobiliary complications, or colon polyps. One patient tested positive for non-neutralizing anti-teduglutide antibodies at Week 16 but was negative at 3 months follow-up; no patient developed neutralizing antibodies to TED. Clinical/nutrition parameters were maintained despite PS reductions with the highest TED doses.

### Summary and Conclusion

TED treatment reduced PS dependence while advancing EN in children with SBS whose intestinal rehabilitation had plateaued. TED 0.05 mg/kg/d achieved PS independence for some patients, and decreased PS and increased EN overall; 4 weeks after TED, 2 patients remained PS independent, and PS reductions and EN improvements were maintained. TED was generally safe and well tolerated. ClinicalTrials.gov: NCT01952080; EudraCT: 201300458830

### Conflict of Interest:

S. Hill, S. Kocoshis, B. Carter, S. Horslen, and R. Venick and have served as study investigators for and received research support from NPS Pharmaceuticals, Inc. B. Li is an employee of NPS Pharmaceuticals, Inc. S. Goyal is an employee of Shire plc. This research was funded by NPS Pharmaceuticals, Inc., Bedminster, NJ. NPS Pharmaceuticals, Inc., is a wholly owned subsidiary of Shire plc.

### Diagnostic endoscopy in children with GI symptoms: Indications and Outcomes

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#### Background:

Paediatric endoscopy is an invaluable diagnostic tool. While there are guidelines from national and international bodies there is little evidence base available to guide clinicians in appropriate selection of patients for endoscopy. Within the UK there is wide variation in paediatric endoscopy rates by postcodes (Atlas of Variation from ChiMAT <http://atlas.chimat.org.uk/IAS/dataviews/view?viewId=152>). This is likely to be due to both variable service availability plus different clinical indications applied. This single centre study aimed to evaluate one unit's use of endoscopy in newly presenting children with the secondary intention of designing and informing a prospective study.

#### Aims

- 1) To elucidate clinical factors leading to endoscopy in a single tertiary referral centre.
- 2) To examine the likelihood of endoscopic abnormalities related to the clinical factors.
- 3) To obtain data for a prospective study of selection of patients for paediatric endoscopy.

#### Subject and Methods

We retrospectively reviewed our unit's practice over a period of 6 months. Patient demographics, clinical indications, past medical and family history, laboratory, macroscopic and histological findings were evaluated by accessing endoscopy reports (Endobase) and electronic patient records (Cerner Millennium). Only first diagnostic paediatric endoscopic procedures were included in the study. We excluded any follow up or therapeutic endoscopies from our study. As a service evaluation ethical approval was not required.

#### Results

218 endoscopies were reviewed in a total of 164 children: 90 having gastroscopy only (median age 8 years 7 months), 20 having colonoscopy only (median age 7 years) and 54 patients undergoing both upper and lower GI endoscopies (median age 12 years 4 months).

Out of all children, 49% had macroscopically and histologically normal endoscopy findings, 45% had macroscopically abnormal findings, and 35% had histologically abnormal findings. Macroscopic and histological abnormalities (respectively) for each group were found as follows: 44% and 28% of gastroscopy patients, 25% and 25% of colonoscopy patients, and 53% and 53% of patients undergoing both upper and lower GI endoscopies.

For patients undergoing gastroscopy alone, the most frequent clinical indications, with percentages found to be macroscopically (M) and histologically (H) abnormal in brackets, were abdominal pain (M: 45%, H: 23%), vomiting (M: 24%, H: 24%), reflux (M: 33%, H: 11%), diarrhoea (M: 50%, H: 31%) and dysphagia (M: 20%, H: 10%), of which diarrhoea led to the highest rate of abnormal histological outcome (PPV = 0.31). For patients undergoing colonoscopy only, top indicators included PR bleeding (M: 13%, H: 20%), abdominal pain (M: 50%, H: 38%) and diarrhoea (M: 50%, H: 33%), of which abdominal pain was the highest predictor of abnormal histology (PPV = 0.38). For patients undergoing both upper and lower GI endoscopies the most common indications were abdominal pain (M: 56%, H: 56%), diarrhoea (M: 64%, H: 59%) and PR bleeding (M: 67%, H: 43%), of which diarrhoea was the highest predictor for abnormal histology (PPV = 0.61).

Reviewing correlations between macroscopic and histological findings revealed that in gastroscopy, the positive predictive value (PPV) of having abnormal histology if the endoscopy was macroscopically reported as abnormal was only 0.4 compared to colonoscopy alone and both upper and lower endoscopy patients (PPV 0.8 and 0.93 respectively).

#### Summary and Conclusion

This study shows that 51% of newly presenting patients undergoing diagnostic procedures have findings at endoscopy. The rate of histological abnormality in gastroscopy alone was only 28% and this included our patients with positive coeliac antibodies. There was more discrepancy between reported endoscopic abnormalities and histological findings in gastroscopy patients than in colonoscopy. Whether this is due to endoscopist experience or local availability of regular histology meetings will need further study. This study shows that the clinical application of predictive models for endoscopy merits further research and may contribute to developing guidelines to select the most appropriate patients for endoscopy.

### Effectiveness of double-balloon enteroscopy-facilitated polypectomy in pediatric patients with Peutz-Jeghers syndrome

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#### Background:

Sizable small-bowel (SB) polyps in Peutz-Jeghers syndrome (PJS) pose a high risk for intussusception, often necessitating laparotomy and intraoperative-enteroscopy (IOE). This series examines the effectiveness of double-balloon enteroscopy (DBE) facilitated polypectomy as an alternative therapeutic option for pediatric patients with PJS.

#### Methods:

Prospective analysis of collected data (6 years) on all patients with PJS referred for DBE-facilitated SB polypectomy at a pediatric tertiary-referral center in the UK.

#### Results:

Between August 2009 to June 2015, 14 patients with PJS (8 males, median age thirteen and a half years; range: 8-16 years) were referred for SB polypectomy by DBE. All patients had at least 1 pre-DBE evaluation by SBCE or diagnostic imaging or both. Four (26%) patients had a history of SB surgery following intussusception. A total of 21 DBE procedures were performed with the number of procedures required per patient ranging from 1 (n=8) to 3 (n=1). Five patients required 2 procedures each. 11 DBE procedures were performed via the oral route and anal route, 10 via the oral route only. Estimated mean depth of insertion was 239(120-420) cm post-pylorus and 69(50-140) cm proximal to the ileo-cecal valve for oral and rectal procedures, respectively.

#### Successful clearance of large polyps by DBE or Lap-DBE

The aim at DBE was to attempt polypectomy of all significant polyps found (as detected by SBCE and/or SB radiology) in all 14 patients. One patient did not undergo polypectomy at DBE as the polyps were considered non-significant due to likely overestimation of size at SBCE. Therefore 13 patients were considered suitable for DBE-facilitated polypectomy. Of these, 10/13 patients (77%) underwent successful polypectomy by DBE alone or else (23%) by Lap-DBE facilitated polypectomy (n=3); for large, sessile duodenal polyps that were deemed high-risk for polypectomy by DBE alone. On average, 3(range 1-7) polypectomies per patient were performed. A total of 43 polyps were resected; the majority of these were pedunculated (86%) while the remainder, were semi-pedunculated or sessile. The median diameter of excised polyps was 22mm (range: 10-45mm). Distribution: 14% were duodenal in origin; 69% of polyps were located within the jejunum; and 14% were located within the ileum. The histopathology of all retrieved polyps confirmed their hamartomatous nature.

#### Need for additional laparotomy with IOE

The only complication identified in the series, occurred in a patient after successful polyp clearance by Lap-DBE, who suffered a pelvic abscess related to an infected laparoscopy-port wound which responded well to conservative management and drainage.

#### Follow-up

At a median follow-up period of 26 months (range: 1-60 months) all patients remain well and have not required further intervention having undergone 2-3 year surveillance by SBCE and/or MRE. During that period, 6 patients had repeated DBE for further polyp.

#### Conclusion:

This series demonstrates that DBE-facilitated polypectomy is an effective alternative to IOE in selected pediatric patients with PJS. DBE offers a less invasive approach and should be considered as an alternative therapeutic option at an early age where possible.



### Validation of malnutrition screening tools in paediatric patients: associations with body composition and clinical outcomes

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#### Background

It has long been recognized that children admitted to hospital have a high risk of malnutrition. National guidelines in the UK indicate children being admitted to hospital should be screened to identify the risk of malnutrition (Brotherton et al., 2010). Available paediatric malnutrition screening tools (MSTs), contrarily to the case for adults, are scarce (Aurangzeb et al., 2011); and more evidence is still needed to validate them in different settings and determine if they can predict clinical outcomes in sick children on admission.

#### Aim

Identify variables predicting the risk of malnutrition in children being admitted to a tertiary referral hospital and evaluate the associations between currently available paediatric malnutrition screening tools (MSTs) and baseline body composition (BC) measurements and clinical outcomes (length of stay-LOS; complications, nutrition status on discharge-NS).

#### Subjects and methods

152 children (mean age 10.7yr; 50% male; 51.3% surgical) admitted to Great Ormond Street Hospital (GOSH) under any specialty and expected stay >3 days were enrolled in the study. 3 MSTs (Paediatric Yorkhill Malnutrition Score-PYMS; Screening Tool for the Assessment of Malnutrition in Paediatrics-STAMP; Screening Tool for Risk of Impaired Nutritional Status and Growth-STRONG) were implemented on admission. Weight (WT), height (HT) and BC measurements (lean (LM) and fat mass (FM) by dual Energy X-ray Absorptiometry) were obtained within 48 hours of admission and SD scores (SDS) calculated using UK BC reference data (Wells et al., 2012). Discharge WT, LOS and complications during stay were recorded.

#### Results

Most patients were identified as moderate risk (MR) by both STAMP and STRONG, and low risk (LR) by PYMS. Patients reporting loss of appetite had a significantly increased risk of being classified high risk (HR) by all MSTs (risk ratio (RR)=1.86, 1.65, 2.17 PYMS, STAMP and STRONG respectively), while dietary restrictions, reduced intake and nutrition support were also predictors of HR using STRONG. Children classified HR by STRONG had significantly lower HT (-1.38 SDS; p=.013), WT (-1.48 SDS; p=0.000) BMI (-0.84 SDS; p=.000), LM (-1.87 SDS; p=.006) and FM (-0.87 SDS; p=.001) compared to LR and MR patients. A similar association was found for PYMS HR patients (WT -0.86 SDS; p=.024, BMI -0.27 SDS; p=0.019 and LM-1.54 SDS; p=.019), while STAMP HR patients only correlated significantly with decreased mean HT, WT and LM. PYMS HR patients had a significantly greater risk of staying longer than predicted (RR=2.53) and having decreased WT (RR=2.02). STRONG HR patients also had a longer than predicted stay (RR=2.31). There was not a significantly increased risk of complications with any MSTs.

#### Conclusion

Paediatric patients admitted to GOSH had a high risk of malnutrition, especially using STAMP and STRONG. HR patients had worst weight, BMI and body composition scores on admission compared to MR and LR patients using most tools, as well as staying longer than predicted. Different MSTs seem to show different strengths and limitations that warrant further validation and study in different settings and populations.

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### A review of the Home Parenteral Nutrition cohort over the last 10 years: how have the complexity and challenges of this cohort changed?

Anna Hughes, Advanced Nurse Practitioner (Trainee); Emily Swallow, Specialist Nurse; Dr Jutta Koeglmeier, Gastroenterology Consultant; Dr Susan Hill, Gastroenterology Consultant, Great Ormond Street Hospital

#### Background

Parenteral Nutrition (PN) is the treatment of choice for children with severe Intestinal failure (IF) that has failed to respond to treatment. This tertiary centre has been discharging children home once clinically stable on PN after extensive investigation and management of intestinal disease when expected to require PN for more than 6 months, for more than 25 years. The aim of homecare is to give the child and family the best possible quality of life. The parents undergo a formal 2-week training programme to manage the PN and have sole responsibility for completing the PN connection and disconnection and over-night care once discharged. As PN as a treatment has become more widely available it is now being used by a greater variety of patient groups, and children with more complex medical problems are being referred for Home PN. This is a patient cohort whom is forever growing alongside the needs of the patients and the treatment they need to carry out at home.

#### Aim

The aim was to discover how the patient group requiring Home PN has altered in the last 10 years and the how the complexity has altered with this increase in population.

#### Subjects and Method

All children at home on PN treatment and managed by our intestinal rehabilitation service in 2005 and 2015 were reviewed. Patient details obtained included age, sex, and underlying diagnosis, hours the PN was infused over, whether there was an underlying life-limiting disorder and whether an ethical review had been required prior to discharging home on PN. Patients were analysed according to their underlying diagnosis and placed into three groups: Gastroenterology, Surgery and Haematology/Oncology. The current patients were compared with the 2005 patients.

#### Results

The current patient caseload of 41 patients in 2015 (16 males and 25 females) age range of patients is 11 months to 17 years 6 months (mean age 8 years and 2 months), 29 patients (70.6%) Gastroenterology, 9 patients (22%) Surgical and 3 patients (7.4%) Haem/Onc. Within the Gastroenterology cohort 4 (13.8%) of these patients are classed as life limited, whom have undergone ethical reviews. 5 patients (17.3%) receive 24 hours of PN as they are unable to tolerate cycling the PN. The patient group include 3 patients post Bone Marrow Transplant, and 1 patient on full gut rest for IBD. In comparison in 2005, the cohort consisted of 22 patients (12 males and 10 females) age range of patients 1 year and 9 months to 15 years 11 months (mean age 7 years and 5 months). 11 (50%) patients with underlying Gastro conditions and 11 (50%) patients with underlying surgical conditions. There were no patients from the Haem/Onc cohort, no post BMT patients and no patients who were living with an underlying life limiting condition and no patients who required their PN over 24 hours. From the 2005 cohort, 8 patients were then transitioned at 18 years old, still on PN, 2 received a small bowel transplant and 2 patients remain part of the 2015 cohort.

#### Conclusion

In conclusion, the complexity of the patients being discharged home with PN has increased dramatically in the last 10 years. With this increase in complexity comes the need for increase in time spent managing the patients. There also need to be more personnel involved in the care of this cohort. E.g the patients who are living on PN for 24 hours, still need to attend school, currently the advice is that they attend alongside a qualified nurse, but this is a great resource and puts added financial pressure on those providing the care. These patients also require a portable pump and a PN bag which can be carried comfortably by a small child, which currently the Homecare companies do not provide. The patient cohort which has grown dramatically are those being referred post Bone Marrow Transplant, in 2014 there was 9 patients in this cohort, these patients can require very frequent changes to their HPN bags, leading to pressure on the PN Pharmacists and Home Care Companies. There is also growing population of children with life-limited conditions; this centre has held individual ethical reviews for this patient group. But this is a patient group that alongside the PN can often require IV pain medication, home oxygen and seizure management, and consideration must be taken to ensure the families have the support required at home to manage all aspects of the care required. The HPN cohort will only continue to grow both in volume and complexity, and our aim as health care professionals should be to continually analyse our HPN programmes to ensure all those who require HPN are able to safely within their own homes with a good quality of life.

**UK National Survey of Methodology and Interpretation of Impedance-pH monitoring in Children**

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Whitechapel Rd, London E1 1BB

**Introduction**

Since its introduction in 2002, multichannel intraluminal impedance (MII) in combination with pH recording becoming the gold standard for reflux detection. MII-pH produces more clinical results than pH monitoring alone because reflux detection is extended to include non-acid or weakly acid reflux. However, there is significant variation in performance and interpretation of MII-pH recording, with inter- and intra-observer reproducibility studies raising concerns<sup>1</sup>.

**Aims**

The primary aim of this study was to analyse the current methods used in the delivery and interpretation of MII-pH monitoring in paediatric gastroenterology departments across the United Kingdom. Secondary aims included analysis of prevalence of MII-pH as a diagnostic tool and awareness of European consensus guidelines on the topic.

**Methods**

A standardised impedance study questionnaire was sent to all paediatric gastroenterology centres across the UK. The questionnaire had tick-box and free text components, and results were collated onto an Excel database.

**Results**

All 17 centres contacted responded to the questionnaire. Two centres did not undertake any impedance studies. Of the remaining 15 centres, 10 performed this test less than 50 times per annum, 3 centres performed it 50 to 100 times per annum, and two centres between 100 to 200 times per annum.

On assessment of impedance study methodology, eleven centres opted to confirm impedance probe position with x-ray radiography, two by fluoroscopy, and two by combination endoscopy and radiography. Four centres used automated settings, five centres used manual settings and six centres used both. Eight centres had a designated gastrointestinal physiology department, of which four had a specific paediatric gastrointestinal physiology department.

On assessment of impedance study interpretation, twelve centres used a consultant gastroenterologist in conjunction with registrars or specialist nurses or physiologists to interpret test results, two used respiratory physicians and one did not answer. All centres claimed to have been trained in interpretation; however location and method of training received varied at each centre. Four centres took less than an hour to interpret results and three centres took up to two hours for interpretation. Three of the twelve centres would refer to gastrointestinal motility units. Twelve centres stated they were aware of the existence of European consensus guidelines on MII-pH monitoring, while three centres were not aware of this publication.

**Conclusion**

This short survey suggests a wide national variation in frequency of use of MII-pH monitoring and methodological approaches to this modality. Compounding this, the differing training in interpretation and its execution, suggests a centralised standardised approach is yet to be adopted in the UK.

Wenzl T, Benninga M, Loots C, Salvatore S, Vandenplas Y et al. Indications, Methodology, and Interpretation of Combined Esophageal Impedance-pH Monitoring in Children: ESPGHAN EURO-PIG Standard Protocol. *J Paediatr Gastroenterol Nutr* 2012;55:230-234

## Poster Abstracts

## Poster Number One

### A single centre paediatric gastroenterology unit experience of use of Peristeen, Trans-anal Irrigation System for Paediatric Faecal Incontinence

Vinod Sharma<sup>1</sup>, Dr, Gastroenterology; Kim Gordon<sup>2</sup>, Paediatric Gastroenterology specialist nurse; Sue Stevens<sup>2</sup>, Paediatric Gastroenterology specialist nurse; Nancy Mew<sup>2</sup>, Paediatric Gastroenterology specialist nurse; Astor Rodrigues<sup>2</sup>, Dr, Paediatric Gastroenterology; Lucy Howarth<sup>2</sup>, Dr, Paediatric Gastroenterology; <sup>1</sup>Great Ormond Street Hospital, London <sup>2</sup>John Radcliffe Hospital, Oxford

#### Aim:

To evaluate the efficacy and safety of Peristeen for the rescue treatment of faecal incontinence in children with chronic idiopathic constipation who have not responded to long term laxative management.

#### Methods:

Peristeen is an established treatment for constipation management in children with underlying neurological or surgical aetiology. This study reports the results of a pilot to trial Peristeen in children with severe treatment non-responsive idiopathic constipation. Prospective data was collected on children who were still regularly soiling despite intensive input and laxative advice from the nurse-led constipation service. Children who started Peristeen treatment between January 2014 to December 2014 were reviewed. All children with faecal incontinence due to idiopathic chronic constipation who began Peristeen trans-anal irrigation at home were included for data analysis. Children referred with neurological and surgical causes of constipation were excluded.

#### Results:

11 children with idiopathic chronic constipation and soiling were included in the study. There were 8 boys and 3 girls. Two children did not tolerate Peristeen and treatment was withdrawn within a few days. Among these two children one child was reported to have Autism Spectrum Disorder (high functioning) and another Attention Deficit Hyperactivity Disorder (ADHD). All 11 children were included for data analysis. Mean age was 12.2 years, ranging from 7 years to 15 years. Duration of constipation was noted to be: 2-5 years in one child, 5-10 years in 8 children and more than 10 years in 2 children. One child was noted to have been soiling for 1 year and 10 children for more than 5 years. 63% (7) of children showed improvement in soiling on Peristeen treatment. 45% (5) of children showed improvement in chronic constipation on Peristeen treatment. In one child Peristeen was successfully stopped. He has been off Peristeen for more than 5 months. He has had no soiling during this period and his constipation has been well controlled. In another case Peristeen has been successfully weaned from once daily to twice in a week regimen. Analysis of data of social activity showed poor school attendance (<85%) in 5 children which significantly improved in 3 children. Out of 3 children with severe impact on their social functioning due to soiling, one child reported significant improvement in anxiety and self-confidence. His academic performance improved and he developed significantly improved relationship with his peers. There were no adverse complications reported related to Peristeen treatment in any of the children studied.

#### Conclusion:

In this small pilot study Peristeen appears to be a safe and effective bowel management system for children with intractable idiopathic constipation and faecal incontinence not resolving with long term specialist constipation and laxative management. In children without significant behavioural problems Peristeen appears to be well tolerated. There appears to be improvement in social activity and school attendance in children on Peristeen treatment.

## Poster Number Two

### A single centre study comparing USS small bowel and MRI enteroclysis in early onset Crohn's disease

Jothisana Srinivasan, Paediatric Registrar; Sian Kirkham, Consultant Paediatric Gastroenterologist; Nandini Kumara Guru, Consultant Paediatric Gastroenterologist; David Devadason Consultant Paediatric Gastroenterologist, Queen's medical centre, Nottingham

#### Introduction:

Small bowel imaging is an important part of the diagnostic work up in Paediatric IBD. In addition to identifying complications such as strictures and fistula, it is often the means by which paediatric IBD can be classified as Crohn's disease. Opinion varies as to the modality and timing of small bowel imaging and MRI enteroclysis has become widely available surpassing Barium studies that were used until quite recently. However access to MRI scanning can be difficult and the actual scan a time consuming process. The utility of Ultrasound abdomen (USS) in small bowel disease has been poorly evaluated in early onset IBD.

#### Aims and objectives:

We aimed to evaluate the adequacy of USS in detecting the presence of small bowel disease at the initial work up of early onset IBD according to the Porto Criteria. We also compared the findings on MRIE to recent small bowel USS, where available, and to historical findings on USS at presentation in a known cohort of patients with early onset Crohn's disease.

#### Materials and Methods:

Data from patients with an established diagnosis of Crohn's disease that had MRI small bowel as part of disease reassessment during a two year period (2013-2014) was collected. Usual practice at our centre is for all patients to have an USS small bowel at the initial presentation, unless surgical complications are suspected. Findings on MRIE performed during the course of disease were compared with historical USS data at the beginning of illness or to an USS done concurrently for disease location, behaviour, and presence/absence of complications.

#### Results:

33 patients (23 males, 10 females) with MRI small bowel study were eligible. The median age at initial diagnosis was 11.2 years. All had USS small bowel at the time of diagnosis. The median time duration to MRIE (as part of disease reassessment) was 31 months. 14/33 patients had abnormalities on MRI small bowel that were previously found on the initial diagnostic ultrasound. 4/28 of patients who had normal initial ultrasound had MRI abnormalities either indicative of small bowel disease progression or the limitation of USS small bowel. Of the 33 patients who had MRI small bowel as part of disease re-evaluation, 9 patients had a preceding ultrasound within 3 months. The concurrent USS was abnormal in 8 patients. 2 patients with USS abnormalities had in fact a normal MRIE and 6 were abnormal. Additional information in terms of disease topography and behaviour was obtained in all 6 patients.

#### Conclusion:

USS small bowel in the hands of a trained paediatric radiologist is useful in detecting small bowel disease. These changes accurately predict changes seen on MRIE. USS as a diagnostic tool appears to have a high sensitivity in the detection of small bowel changes. However MRIE supersedes USS in accurate topographic mapping, definition of disease and complications. Despite the absence of small bowel disease on the initial work up, a low threshold is required for reassessing small bowel disease in early onset Crohn's disease.



### Poster Number Three

#### Childhood idiopathic constipation: Are things flowing right?

Mr Daniel Liu, CT2; Mr Nihal Weerasena, Consultant; Mr Jonathan Sutcliffe, Consultant Paediatric Surgeon; Leeds General Infirmary, Great George St, Leeds, West Yorkshire LS1 3EX

#### Background:

Childhood idiopathic constipation (CIC) leads to 3-5% of all visits to Paediatric clinics and has an estimated prevalence around 6.5%. Regional variations in resources lead to differences in service delivery and service planning.

#### Aims:

The aim of the current project was to quantify the opportunity cost of treating patients with Chronic Idiopathic Constipation (CIC) within a large teaching hospital, where a significant proportion of these patients are seen in a paediatric surgical clinic setting.

#### Subjects and Methods:

Data were gathered from computerised records of all new referrals of children with CIC to a single consultant clinic between 01/06/2013 and 31/05/2014. Patients with CIC referred prior to the study period were excluded. Patients with known Hirschsprung disease or Anorectal Malformations, and those seen primarily for rectal bleeding or a non-constipation related reason were also excluded.

#### Results:

We reviewed 712 individual patient encounters within the study period with 42 new patient referrals for CIC. These patients alone accounted for 90/712 (12%) of clinic spaces within the 1 year period and generated 120 clinic appointments across their pathway. Of these, 23% were non-attendances.

Initial management was mapped to three pathways. Definitive Examination under Anaesthesia (EUA) and biopsies were deemed necessary for 23/42 (55%) of patients with 2 patients proceeding directly to EUA from referral. During the study period, 13/42 patients required medical management alone. This group used a total of 26/712 (3.7%) of total clinic appointments in the study period. A third group 3/42 comprised of patients for whom further medical management was attempted but who subsequently required EUA. 3 patients were excluded (2/42 DNAs, 1/42 admitted for EUA prior to referral).

Although only 15/42 referrals (36%) originated from GPs, they accounted for 8/13 (62%) of "medically managed" patients. Paediatric referrals from clinic accounted 17 of our referrals with the rest referrals after an inpatient admission (4 Surgical admissions and 1 from Paediatrics) and from other specialities such as Paediatric Urology and Gastroenterology (4/42, 1/42).

Waiting times for clinic were variable with GP referrals taking a mean of 53 days, Paediatric referrals taking 71 days and Urology referrals taking 135 days. This was reflected in the referral to treatment (RTT) times with GP referrals taking 64 days and Paediatric and Urology clinic referrals taking 134 days and 150 days respectively. In the UK, the target is 18 weeks (126 days). In addition to clinic spaces, theatre space was also limited. Of those who needed an EUA, 11/23 patients breached the referral to treatment times.

#### Summary and Conclusion:

This service evaluation demonstrates the unintended consequences of a paucity of gastroenterology resource and integrated approach in the management of this common condition. We have demonstrated that at least 3.7% of surgical clinic spaces were used to care for new referrals with CIC who may have been treated as effectively in other clinics. The impact of chronic patients outside of this study are likely to add to these figures. Addressing resource use would streamline the management of children who can only be treated by a surgeon, without compromising the care of children with CIC who require medical management. This would confer clinical and potential cost benefits in terms of referral to treatment times

### Poster Number Four

#### Children newly diagnosed with coeliac disease; symptom resolution on Gluten free diet.

Paul Bellis, Paediatric specialist trainee; Rana Bitar, Paediatric Gastroenterology Consultant; Royal Victoria Infirmary, Newcastle upon Tyne

#### Background and Aim:

Most children with coeliac disease present with symptoms. We usually expect the symptoms to resolve at some point after starting a gluten free diet. However some children continue to have symptoms even after normalization of TTG. We aim to assess the likelihood of symptom resolution and assess the symptoms more likely to persist after adequate treatment on Gluten free diet.

#### Method:

This is a prospective review of newly diagnosed children with coeliac disease over a 12 month period. All patients were diagnosed based on the ESPGHAN guidelines. We review the symptoms and TTG on presentation and 6 months after initiating gluten free diet. We also assessed what was the likely cause of persistence of symptoms.

#### Results:

20 patients (10 M:10F) were newly diagnosed with celiac disease. Median age at presentation was 11 years (Range 1-16 years). Only one patient was asymptomatic at diagnosis. At presentation the median TTG was 139 (Range 21-250) and anti endomysial antibody was positive in all however the median TTG after 6 months of treatment was 13 (range 0.9-87). Six patients (30%) did not have complete resolution of their symptoms; the two symptoms that persisted including abdominal pain (four patients) and lethargy (two patients). All these patients had a TTG in the normal range suggesting compliance to treatment. One patient with lethargy had iron deficiency anaemia and was started on iron supplements, two has dyspepsia and were started on proton pump inhibitors and one was felt to have functional abdominal pain and was started on Amitriptyline. (by January 2016 we anticipate to have 40 patients enrolled in this study with longer follow up period)

#### Conclusion:

Patients with coeliac disease usually present with gastrointestinal symptoms. However a significant proportion of patient symptoms don't resolve 6 months after initiating a Gluten free diet and normalization of TTG. In this group abdominal pain and lethargy were the most common symptoms. Clinicians may need to be aware of this when managing newly diagnosed patients with celiac disease.

**Poster Number Five**

**Clinical management of treating children with IBD by administering Infliximab (Remicade) as a one hour infusion**

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**Background:**

Infliximab (Remicade) is the commonly used biological agent in treatment of paediatric IBD. Infliximab is a monoclonal antibody which inhibits pro-inflammatory cytokine TNF  $\alpha$ . Conventionally the infusion is given over 2 hours. By safely reducing the duration of infusion to one hour, we can make a positive impact on patient experience and improve cost effectiveness of the treatment.

**Aim:**

To assess the outcome and overall safety of patients following administration of infliximab infusion over one hour in children already established on conventional two hourly regimen.

**Subjects & Methods:**

A multidisciplinary team meeting was organised to discuss the proposed change in treatment regimen at the outset. The changes were discussed with parents who readily agreed. It was a prospective study conducted on all paediatric IBD patients already established on 2 hourly Infliximab Infusion (at least 5 infusions). The dose of Infliximab was kept at 5mg/kg/do. As standard, Infusion episode number and infusion rate were documented. Premedication was not given routinely. Regular monitoring of temperature, pulse, respirations and blood pressure every 15 mins was done as standard with a further 1 hour surveillance period post infusion. We recorded PCDAI and PUCAI scores for every patient.

**Results:**

Over a 11 month period, 52 infusions were administered in 10 patients aged 12-17 years. There were no adverse effects noted during any of the infusions. PCDAI and PUCAI scores showed good disease control even on one hourly infusion. Overall we felt it improves patient experience

**Conclusion:**

In patients already established on 2 hourly maintenance infusions of Infliximab, one hour rapid infusions can be safely administered. Short infusions do not affect the efficacy of treatment. It can enhance patient experience and improve efficiency by shortening hospital stay and health care provider time. We recommend more robust randomised control trials to validate the results.

**Poster Number Six**

**Crohns Disease: Initial treatment and outcomes at 12 months**

J Gavin<sup>1</sup>; Dr JJ Ashton<sup>2</sup>; N Heather<sup>1</sup>; Dr LV Marino<sup>1</sup>; Dr RM Beattie<sup>2</sup>; <sup>1</sup>Nutrition and Dietetic Dept, University Hospital Southampton; <sup>2</sup>Dept of Paediatric Gastroenterology, Child Health, University Hospital Southampton

**Introduction:**

The role of exclusive enteral nutrition (EEN) to induce remission in paediatric Crohns Disease (CD) is well established. Only a small number of studies however have investigated the role of energy supplements as maintenance enteral nutrition (MEN) post induction to prolong remission. The aim of this retrospective study was to investigate the use of MEN in paediatric CD and to compare growth data and relapse rates to an unsupplemented group.

**Methods:**

Data from diagnosis, start of MEN, at 3 months and at 1 year were collected retrospectively from dietetic and medical records for 78 patients diagnosed from 2012-14. Patients received either EEN, steroids with partial enteral nutrition (PEN) alongside normal diet or steroids alone as induction therapy. All patients receiving EEN/PEN were offered MEN post induction, alongside patients treated with steroids who had a body mass index Z (BMIZ) score of less than -2 or unintentional weight loss of more than 10% in previous 3-6 months. The 2 patient groups were therefore those who received MEN plus normal diet (MEN=42) and those who remained on normal diet alone (ND=36).

Clinical remission was determined using a physician global assessment and blood biochemistry. Relapse was defined as a required change in medication due to worsening symptoms. Data are presented as median values unless otherwise specified.

**Results:**

Age at diagnosis was 13 years (2-16 years), n=62 (79%) were male. All groups had similar rates of clinical remission post induction therapy. The length of MEN was 3 months (1 month - 12 months). The energy content of MEN consumed was 635kcal (250-1280kcal) representing 33% (12-66%) of the patient's energy requirement. 76% (32/42) MEN patients received EEN as their induction therapy, 17% (7/42) received PEN and 7% (3/42) steroids.

24% of MEN group relapsed within 6 months of diagnosis versus 53% ND (p=0.009). In the MEN group. There were no differences in height-for-age-z scores (HAZ) between the two groups from post induction to 1 year however the BMIZ significantly improved (MEN: p < 0.001; ND: p = 0.02)

**Table 1- Relapse rates, HAZ and BMIZ from diagnosis to 1 year in MEN and ND groups**

	Diagnosis	Post induction	3 months	1 year	No of patients relapsing at less than 6 months
<b>MEN (n=42)</b>					
HAZ	-0.34	-0.23	-0.26	-0.31	10/42* (24%)
BMIZ	-1.63**	-0.56	-0.28	-0.30**	
<b>ND (n=36)</b>					
HAZ	-0.28	-0.32	-0.36	-0.32	19/36* (53%)
BMIZ	-0.63***	-0.08	0.16	-0.20***	

\*P=0.009 \*\*MEN p<0.001; \*\*\*ND p=0.02

**Conclusion:**

CD patients treated with MEN who received EEN or PEN as induction therapy were less likely to relapse within 6 months of diagnosis. There was no difference in HAZ between diagnosis and 1 year in either group. However BMIZ improved towards normal in both groups. These results suggest that prolonged nutritional support from diagnosis may extend length of remission. The precise impact of maintenance enteral nutrition requires further investigation.

## Poster Number Seven

### DQ typing is effective in Coeliac Disease screening in Down Syndrome in South East Scotland

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#### Introduction/Background

The association between Down Syndrome (DS) and Coeliac Disease (CD) was first described in 1975 (1). Screening programmes for CD have utilised DQ typing in a number of studies (2, 3) but new guidance from BSPGHAN (4) suggested that it is should be a key part of assessment of all patients with DS. A negative DQ 2.5, 2.2 or 8 test in a patient would essentially rule CD out and exclude them from further testing.

Aim; We aimed to 'road test' the new BSPGHAN guidelines to assess their utility in clinical practice.

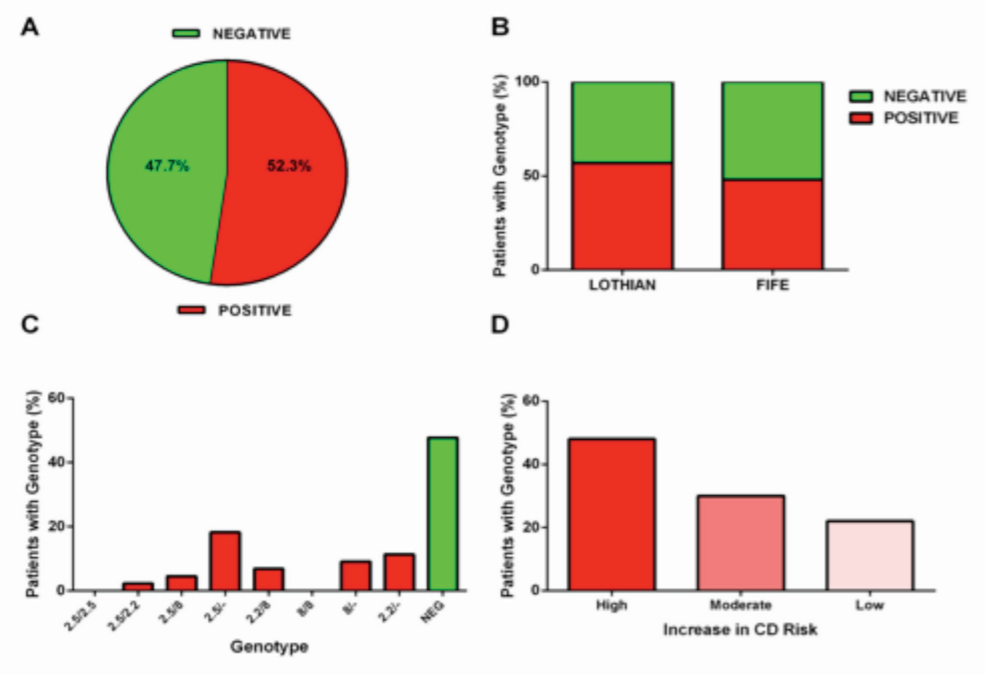
Subjects; We looked at patients with DS under age 16 in Lothian and Fife between October 2014 and October 2015.

#### Methods

We contacted families with children with DS under age 16 in Lothian and in Fife with an information leaflet about CD and offered testing for CD in particular, coeliac disease genetic testing with DQ typing. Anti TTG antibodies were measured in the regional biochemistry laboratory in Edinburgh. DQ 2.5, 2.2 and 8 typing was performed in the BTS national tissue typing laboratory in Dundee.

#### Results

48 patients (27 male and 21 female) were screened, 27 in Lothian and 21 in Fife. Overall 47.7% were DQ negative. No patients were found to be positive on anti-TTG testing. The table shows the breakdown of DQ types in the study and we were able to help risk stratify those who were positive, according to a recent position paper (5).



#### Conclusion

DQ typing is very effective in excluding children with DS from the need for further screening for CD (in nearly 50% of cases). This can be performed at the earliest opportunity in any child and should be accepted as a standard of care across the UK. All patients with the diagnosis of CD should be screened as future therapy is designed for patients with DQ2.5.

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## Poster Number Eight

### Infliximab improves growth in paediatric Crohn's disease only if commenced early in puberty or prior to the onset of puberty

Arundoss Gangadharan<sup>1</sup>, Paediatric Registrar; Joanne Melcalf<sup>2</sup>, Medical student; 3. Sharon Irving<sup>1</sup>, Specialist Nurse; Marcus Auth<sup>1</sup>, Consultant Paediatric Gastroenterologist; Balaji Krishnamurthy<sup>1</sup>, Consultant Paediatric Gastroenterologist; Krishnappa Venkatesh<sup>1</sup>, Consultant Paediatric Gastroenterologist; Joanne C Blair<sup>1</sup>, Consultant Paediatric Endocrinologist; Mohammed Didi<sup>1</sup>, Consultant Paediatric Endocrinologist; <sup>1</sup>Alder hey Children's Hospital, Liverpool, UK; <sup>2</sup>Liverpool University, UK

#### Background

Crohn's disease is a relapsing systemic inflammatory disorder with inflammatory bowel disease (IBD) due to up-regulation of pro-inflammatory cytokines including TNF- $\alpha$ . More than 80% of newly diagnosed children present with growth failure<sup>1</sup>. Paediatric gastroenterology units in the UK submit data to the UK IBD database, which can be accessed when required. One aim of current treatment protocols is to promote growth. Studies on the use of Anti-TNF- $\alpha$  antibodies like Infliximab have produced conflicting results with respect to growth<sup>2</sup>. PCDAI (Paediatric Crohn's disease activity index) score has been validated as a measure of disease activity.

#### Objective

To determine whether Infliximab improves growth in paediatric Crohn's disease.

#### Method

The UK IBD database was used to identify all Crohn's disease patients at Alder Hey Hospital, Liverpool, UK receiving Infliximab. Age, height, weight, Tanner pubertal status and PCDAI score were determined at commencement of infliximab, 9-12 months later or at the latest assessment. The height and weight standard deviation scores (SDS) were calculated. Paired T test was employed to compare height and weight SDS at these time points for patients who were at Tanner stage 1-3 vs those at stage 4-5 at commencement of Infliximab therapy.

#### Results

There were 31 patients (14 females). The median age at commencement of Infliximab treatment was 14.3yrs (range 7.5 -17.4 yrs). The median duration of follow up since commencement of Infliximab therapy was 1.6 yrs (0.3 - 2.0). Twenty patients at Tanner stages 1-3 had median height SDS -0.45 (-1.88 to +1.86) at the second assessment, which was significantly better than at commencement of infliximab (median -0.94 (-2.15 to +1.72), [p= 0.018]. PCDAI score was significantly better in this group (p 0.028). Both Ht SDS and PCDAI score were not significant when the infliximab therapy was started at late stages of puberty (Tanner 4-5).

#### Conclusion

Infliximab improves growth in children with Crohn's Disease who are in early stages of puberty. Pubertal hormones appear to modulate the TNF- $\alpha$  availability for attack by a TNF- $\alpha$  antibody. A larger prospective study confined to the paediatric age group is required.

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## Poster Number Nine

### Insulin like growth factor-1 (IGF-1) a potential biomarker of neonatal gut health in maternal milk and stool.

Dr AR Barclay<sup>1</sup>, Miss E-MTheriou<sup>2</sup>, Dr LM Beattie<sup>3</sup>, Mrs D Barnett<sup>4</sup>, Dr J Simpson<sup>3</sup>, Dr DJ Morrison<sup>5</sup>, Prof CE Edwards<sup>2</sup>, Dr K Gerasimidis<sup>2</sup>; <sup>1</sup>Department of Paediatric Gastroenterology, Royal Hospital for Children, Glasgow; <sup>2</sup>School of Medicine, College of MVLS, University of Glasgow, Glasgow; <sup>3</sup>Department of Neonatal and Perinatal medicine, Southern General Hospital, Glasgow; <sup>4</sup>Donor Breast Milk Bank for Scotland, Southern General Hospital, Glasgow; <sup>5</sup>Scottish University's Environmental Research Centre, East Kilbride

#### Background

Enteral growth factors are known to be protective against necrotising enterocolitis (NEC) and are a potential preventative and rescue therapy in resultant short bowel syndrome. Glucagon like peptide 2 (GLP-2) has been used in previously to treat SBS. However IGF-1 has been identified as a more potent enteral growth factor that works upstream from GLP-2 in the maturation of neonatal gut. However IGF-1 has not been studied in the context of maternal expressed breast milk (MEBM) or infant stool.

#### Aim

We aimed to investigate whether IGF-1 could be reliably assayed in MEBM and stool in a cohort of term, preterm and very low birth weight (VLBW) infants, and to identify any relationship between IGF-1 levels and outcome.

#### Methods

Paired MEBM and stool samples from preterm VLBW infants were available for analysis from previous clinically followed cohort who were all <32wk gestation and <1500gm ('NAPI cohort' (1)) of whom a proportion developed NEC. In addition MEBM from the donor expressed breast-milk bank of Scotland (DEBM samples) were obtained from term and preterm infants. In total 39 MEBM samples were analysed (23 NAPI (10 NEC, 13 Non-NEC) 16 DEBM (11 term 5 preterm)). 30 NAPI stools were analysed (10 NEC pre disease, 10 NEC 2wk after disease, 10 non NEC), paired MEBM and stools were available for 7 infants. IGF-1 was measured by commercially available ELISA kit (Oxford Biosystems), with a modification to protocol to measure lower level IGF-1 in comparison to serum samples. Statistical analyses were performed using Minitab. Data from the NAPI study were compared with paired t-test if samples came from the same subject, either 2-sample t-test if samples came from different subjects and were normally distributed. If results were non-normally distributed Mann-Whitney test was performed. One-way Analysis of Variance (ANOVA) was used to compare 3 groups that were normally distributed. Furthermore, Pearson's correlations were performed when data was normally distributed and Spearman's correlations when data was non-normally distributed. Statistical significance was accepted at  $p \leq 0.05$ .

#### Results:

IGF-1 was present in all MEBM and stool samples. MEBM IGF-1 levels in mothers of pre-term infants, from the NAPI study, were significantly higher (47.41ng/ml, 95%CI [43.65, 51.17]) in comparison to donor breast milk levels in mothers of pre-term (36.29ng/ml, 95%CI [27.27, 45.30]) and full-term infants (33.57ng/ml, 95%CI [27.87, 39.27]) ( $p < 0.001$ ). No significant differences were found between IGF-1 levels in faecal samples of pre-term infants before and after developing NEC ( $p = 0.096$ ), although a trend was observed. Lastly, no significant differences were found between IGF-1 levels in faecal samples of pre-term infants before and after developing NEC and infants that did not develop NEC ( $p = 0.333$ ,  $p = 0.325$  respectively).

#### Conclusions

We report the first clinical study of IGF-1 in MEBM and stool of neonates. Identification of significant changes in MEBM IGF-1 levels in relation to gestation and a trend between infant before and after developing NEC fit with the current working hypothesis enteral factors in the pathogenesis of NEC. IGF-1 shows potential as a modifiable risk factor for NEC and as a trophic factor for SBS and further study is warranted.

#### Reference:

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## Poster Number Ten

### Maintenance enteral nutrition post induction therapy in paediatric Crohns Disease. Does 600kcal more per day keep the doctor away?

J Gavin<sup>1</sup>; Dr JJ Ashton<sup>2</sup>; N Heather<sup>1</sup>; LV Marino<sup>1</sup>; Dr RM Beattie<sup>2</sup>; <sup>1</sup>Nutrition and Dietetic Dept, University Hospital Southampton; <sup>2</sup>Dept of Paediatric Gastroenterology, Child Health, University Hospital Southampton

#### Introduction

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#### Methods

Data from diagnosis, start of MEN, at 3 months and at 1 year were collected retrospectively from dietetic and medical records for 78 patients diagnosed from 2012-14. Patients received either EEN, steroids with partial enteral nutrition (PEN) alongside normal diet or steroids alone as induction therapy. All patients receiving EEN/PEN were offered MEN post induction, alongside patients treated with steroids who had a body mass index z (BMIZ) score of -2 or unintentional weight loss of more than 10% in previous 3-6 months. The 2 patient groups were therefore those who received MEN plus normal diet (MEN=42) and those who remained on normal diet alone (ND=36).

Clinical remission was determined using a physician global assessment and blood biochemistry. Relapse was defined as a required change in medication due to worsening symptoms. Data are presented as median values unless otherwise specified

#### Results

Age at diagnosis was 13 years (2-16 years),  $n=62$  (79%) were male. All groups had similar rates of clinical remission post induction therapy. The length of MEN was 3 months (1 month - 12 months). The energy content of MEN consumed was 635kcal (250-1280kcal) representing 33% (12-66%) of the patient's energy requirement. 76% (32/42) MEN patients received EEN as their induction therapy, 17% (7/42) received PEN and 7% (3/42) steroids.

24% of MEN group relapsed within 6 months of diagnosis versus 53% ND ( $p=0.009$ ). In the MEN group. There were no differences in height-for-age-z scores (HAZ) between the two groups from post induction to 1 year however the BMIZ significantly improved (MEN:  $p < 0.001$ ; ND:  $p = 0.02$ )

Table 1- Relapse rates, HAZ and BMIZ from diagnosis to 1 year in MEN and ND groups

	Diagnosis	Post induction	3 months	1 year	No of patients relapsing at less than 6 months
<b>MEN (n=42)</b>					
HAZ	-0.34	-0.23	-0.26	-0.31	10/42* (24%)
BMIZ	-1.63**	-0.56	-0.28	-0.30**	
<b>ND (n=36)</b>					
HAZ	-0.28	-0.32	-0.36	-0.32	19/36* (53%)
BMIZ	-0.63***	-0.08	0.16	-0.20***	

\* $P=0.009$  \*\*MEN  $p < 0.001$ ; \*\*\*ND  $p=0.02$

#### Conclusion

CD patients treated with MEN who received EEN or PEN as induction therapy were less likely to relapse within 6 months of diagnosis. There was no difference in HAZ between diagnosis and 1 year in either group. However BMIZ improved towards normal in both groups. These results suggest that prolonged nutritional support from diagnosis may extend length of remission. The precise impact of maintenance enteral nutrition requires further investigation.

**Poster Number Eleven**

**New safer, cost effective system to encourage and ensure compliance to thiopurine safety blood monitoring in children with inflammatory bowel disease.**

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**Introduction:**

Thiopurine medication is used commonly in children with inflammatory bowel disease (IBD) as steroid sparing, immunomodulatory agents. Thiopurines are cheap, effective & orally administered but require regular blood monitoring to identify toxicity or side effects. In paediatric practice IBD teams have a safeguarding responsibility not to merely recommend blood testing at specific intervals but to ensure that children have protocol bloods collected & reviewed before further drug is prescribed. We have undertaken serial audits of compliance to thiopurine safety blood monitoring to investigate the effectiveness of practice change.

**Methods:**

For each audit all children taking thiopurines over a 6 month period were identified from paediatric IBD database; the dates the thiopurine protocol blood tests were due plotted (noting start date & dose changes); central / regional laboratory data checked against plotted dates to ensure that blood tests were collected within set time window of predicted dates.

**Results:**

Audit year	Number of children on thiopurine	% children with all bloods taken within time window	System for ensuring blood tests taken	Change in practice after audit
2004	43	0%	Dr advising families verbally +/- letter	Appointment of 1 specialist nurse
2008	78	29%	Specialist nurse overseeing system & reminding families	Appointment of 2nd specialist nurse & change of protocol from weekly to fortnightly blood tests initially
2011	93	72%	Specialist nurses overseeing system & reminding families. Average of 10 hours of band 7 nursing time per week.	Responsibility transferred to band 3 admin staff. Electronic scheduling system developed. SMS reminders (X-on®) sent to family +/- child. Results chased by admin staff & 2nd reminder sent if non compliant. Letter to GP & family to stop drug if non compliant after 2 reminders
2014	118	92% (8% who did not have bloods taken despite x2 reminders)	Average of 7 hours per wk band 3 admin time & 1 hour band 7 nursing time.	

**Summary:**

Concerning audit results indicating that children were at risk through not having thiopurine safety blood tests taken as per protocol resulted in changes to practice & serial improvements in compliance. However by 2011 over a quarter of children missed or had late blood tests, despite two band 7 specialist nurses spending 10 hours per week on service. The appointment of a part time band 3 admin staff member; a diary scheduling system with "replotting" at any dose changes; SMS reminder system (X-on®); admin staff checking blood test taken & reminder SMS sent where necessary - has increased compliance to 92%. Importantly, this system allows the identification of families where blood tests are not taken despite reminders so thiopurines can be stopped & safeguarding procedures initiated, where necessary.

**Conclusion:**

A new, admin staff led system with SMS reminders (X-on®) for thiopurine blood monitoring is more effective, safer & cheaper than previous specialist nurse led systems & allows specialist nurses to focus on their clinical role.

**Poster Number Twelve**

**Not just another Crohn's Disease**

Dr Siba Prosad Paul; Dr Dharamveer Basude, Bristol Royal Hospital for Children

**Background and aims:**

Bowel carcinomas are considered to be extremely rare in children; incidence in the UK between 2009 – 2011 was 0.1 – 0.3 per 100,000 children aged 0 – 14 years with equal sex preponderance<sup>1</sup>. The aim of this paper is to highlight two rare cases of bowel carcinoma diagnosed at endoscopy who presented with initial symptoms suggestive of Crohn's disease.

**Methods:**

Patient #1 aged 14 years male presented with 5-weeks history of right iliac fossa pain, intermittent loose stools and weight loss. Patient #2 aged 15 years male presented with 3-months history of recurrent abdominal pain, occasional loose stool and weight loss. Both patients were initially reviewed by surgeons as suspected appendicitis (patient #1 underwent laparoscopy with normal appendix), had normal blood inflammatory markers and abnormal findings on small bowel MRI scan. Both patients underwent urgent endoscopic assessment with biopsies; these are shown in figures below.



Patient #1 - Pseudopolyps and large lymphonodular lesions seen in terminal ileum



Patient #2 - Abnormal mass protruding from splenic flexure with marked narrowing

**Results:**

Patient #1 was diagnosed with B-cell non-Hodgkin's lymphoma (Burkitt's lymphoma) and underwent chemotherapy with complete cure. Patient #2 got diagnosed with primary colorectal adenocarcinoma. He underwent multiple surgical interventions and resections and chemotherapy. He developed multi-organ metastasis and died 13 months after initial diagnosis. Burkitt's lymphoma is endemic in Africa and has an excellent 5-year survival of 90%. Colonic adenocarcinoma has a dismal prognosis of 2.5 – 7% survival at 5-years and despite radical surgery with 2/3rd of cases die by 1-year.

**Conclusions:**

Significant abdominal pain and weight loss with normal inflammatory markers were the prominent features in both the cases and these should raise suspicion of bowel carcinoma. Although these are extremely rare, they present with unusual endoscopic findings which requires appropriate biopsy samples to process urgently for histological diagnosis.

## Poster Number Thirteen

### Outcomes in a prospective cohort of newly diagnosed children with Crohn's disease treated with exclusive enteral nutrition

Gregory Williams<sup>1</sup>, Final Year Medical Student; Minal Patel<sup>2</sup>, Laura Jellis<sup>2</sup>; Edward Giles<sup>2</sup>; Ian Sanderson<sup>3</sup>; Protima Amon<sup>3</sup>; <sup>1</sup>School of Medicine and Dentistry, Queen Mary University London, UK; <sup>2</sup>The Royal London Hospital, Barts Health NHS Trust, London, UK; <sup>3</sup>Blizard Institute, Queen Mary University London, UK

#### Introduction

Exclusive enteral nutrition (EEN) is recommended as induction therapy for active Crohn's disease (CD). It is well established that enteral nutrition has strong anti-inflammatory effects when given exclusively for 6-8 weeks (1).

#### Aim

This study reports on the efficacy of EEN upon disease activity and growth in children newly diagnosed with CD.

#### Methods

A prospective assessment of all children diagnosed with CD between 1st March 2014 and 31st October 2015 who were commenced on enteral diet for 6 weeks, in a single tertiary paediatric gastroenterology centre. Primary outcome measures were weight change and disease activity (Paediatric Crohn's Disease Activity Index: PCDAI). Secondary outcomes were relapse and the use of immunomodulatory therapy.

#### Results

Thirty children (Females 17; Mean age: 12.5 years) were commenced on EEN with a mean follow-up of 294 days. Twenty-one children completed the prescribed period of EEN (70%) and these all achieved clinical remission. Children responding to EEN all took the feeds orally and gained an average of 4.4 ± 2.4kg with mean PCDAI decreasing from 32.1 ± 11.6 to 8.5 ± 8.9 after 6 weeks. 13/30 (43%) relapsed during follow-up with a mean time to relapse from diagnosis of 5.9 months. All 13 of these children were started on azathioprine during the follow-up period, with a mean starting time of 6.9 months following diagnosis.

#### Conclusions

EEN induced remission in 70% of children with newly diagnosed CD. In addition to inducing remission, EEN improved weight gain. This is in keeping with published data (2, 3). Further studies are required to determine whether these benefits are sustained longer-term.

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## Poster Number Fourteen

### Parent's attitudes to a joint Dietetic / Specialist Nurse led clinic for coeliac disease

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#### Introduction/Background

A joint Specialist Nurse and Specialist Dietetic led clinic has been established within our hospital for 2 years. Children with coeliac disease are seen with their parents by a specialist paediatric gastroenterology nurse and a specialist paediatric dietitian. A 5 day food diary and aspects of dietary compliance are reviewed by the Paediatric Dietitian with a physical examination being carried out by the Specialist Nurse. Clinics are held once a month.

#### Aim

To explore parents' attitudes to different aspects of care provided by the clinic with a view to improving the overall clinic experience and care provided.

#### Subjects and methods

Questionnaires were sent, along with the usual diet diary, to the parents of all patients 2 to 3 weeks before their clinic appointment. The 6 month survey period covered 6 clinics and involved 39 patients and 38 parents. Questions related to preferences of who they would like to see in clinic, the ease of completing the food diaries, their understanding of information provided in clinic and what they considered to be the priorities of their child's review. In addition, parents were asked whether they wanted a copy of the clinic report to be sent to them and for comments on how the clinic might be improved. Questions required answers of yes / no or were categorised as to whether parents felt they had received too little, the right amount or too much information on different aspects of their child's care. Qualitative information was obtained by asking parents to comment on how the clinic might be improved.

Some questionnaires were filled in prior to attendance and others were completed and collected at the clinic.

#### Results

7 out of 38 questionnaires (71%) were completed and returned. The majority of parents felt that they understood the information that they received in the clinic. The 3 areas that parents were most interested in were:

1. Results of antigliadin antibody tests (21/27).
2. Their child's growth (20/27)
3. An update on new gluten free products (18/27)

Of the 24 responses to the clinic satisfaction question 7 (29%) said they were 'very satisfied' and 17 (71%) said they were 'satisfied' with the service provided by the clinic. 25 (96%) of 26 parents who answered the question on receiving a copy of the clinic report said they would like to receive a copy.

#### Resulting changes to clinic format

As a result of this feedback the following changes to clinic format have been made:

1. A 3 day rather than 5 day food diary is now sent out to parents before clinics
2. Patients are given the option of having their blood tests for antigliadin antibodies carried out 2 to 3 weeks prior to their scheduled clinic appointment.
3. Each parent receives a written copy of their child's clinic report.
4. The possibility of company representatives providing nutritional samples in clinic may be explored.

#### Summary and Conclusion

Overall satisfaction with our Specialist Nurse / Specialist Dietitian led clinic is high (100% satisfied or very satisfied). By exploring parents' attitudes to our clinic we have been able to make changes that provide more patient centred information. Reducing the number of days to complete the food diary may help with compliance without affecting quality dietary information received.

loose stools and weight loss. Patient #2 aged 15 years male presented with 3-months history of recurrent abdominal pain, occasional loose stool and weight loss. Both patients were initially reviewed by surgeons as suspected appendicitis (patient #1 underwent laparoscopy with normal appendix), had normal blood inflammatory markers and abnormal findings on small bowel MRI scan. Both patients underwent urgent endoscopic assessment with biopsies; these are shown in figures below.



## Poster Number Fifteen

### Patient perceptions of food-based dietary treatment of Crohn's Disease; A survey of paediatric patients previously treated with exclusive enteral nutrition.

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#### Introduction/Background

Exclusive Enteral Nutrition (EEN) is the primary treatment in active paediatric Crohn's disease (CD) and there is emerging evidence that exclusion diets can treat or prevent disease flare ups (1-2).

#### Aim

The aim of this questionnaire was to explore beliefs/issues around the use of EEN and acceptability of an alternative solid food diet (SFD) by paediatric CD patients and their parents/carers.

#### Subjects and methods

We retrospectively surveyed all the families of the paediatric patients who have been treated with EEN over one year by the IBD team at the Yorkhill Hospital. This was achieved by posting two copies of a questionnaire, which were both very similar, asking the parent/carer and the CD child/young person. A reminder was sent out two months later to encourage response. Questions explored participants' demographic characteristics; opinion on how difficult EEN was and SFD would be; acceptability of an EEN course repeat-if needed; intention to participate in a future clinical trial assessing the therapeutic efficacy of a SFD on CD.

#### Results

Forty-one paediatric patients were identified and a total of 82 questionnaires were posted to them. Of these 58 (71% response) questionnaires were returned providing information on 29 CD children (median age, 13.3; interquartile range [IQR], 4.0 years), of which 20 (69%) were boys. The majority of them completed 8 weeks on EEN (n=23, 79%), while 55% had to use nasogastric tubing during the treatment course. Both patients and their carers rated (on a scale from 1-100) EEN course to be significantly more difficult when compared to an alternative SFD (Median, Patients: 62 vs 23, Carers: 50.5 vs 26.5, both  $p < 0.03$ ). Diet ratings by patients was strongly correlated to those of parents/carers (EEN:  $r = 0.831$ , SFD:  $r = 0.749$ , both  $p < 0.001$ ). Approximately two thirds of the patients and their carers (59%) were positive on completing another EEN course in a further relapse, however a high proportion of participants thought a SFD would be better than EEN (Patients: n=19, 66%, Carers: 21/72%). Participants reported that they would agree to participate in a trial comparing EEN with an alternative SFD in a high percentage (Patients: 52%, Carers: 66%). When they were given further explanation of a hypothetical randomised controlled trial, which would recruit only patients in need of EEN treatment, this percentage was further increased (Patients: 23/79%, Carers: 21/72%). Comments quoted by the participants included: "the liquid-only diet was very isolating at times for my child"; "I would like to try the solid food diet to avoid steroids in future"; "I think being on the other diet may make her feel more normal and part of the family"; and "I am delighted at the proposed solid food diet and we will do all that we can to help this work".

#### Summary and Conclusion

This survey concluded that there is a positive attitude and perception on the use of a SFD, as an alternative to EEN, for the treatment of paediatric CD.

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## Poster Number Sixteen

### The Rising Incidence of Classical and Non-Classical Coeliac Disease in Southeast Scotland

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#### Introduction/Background

The incidence of coeliac disease (CD) is increasing in many countries, including Scotland.

#### Aim

We aimed to update our previous research<sup>1, 2</sup> into the incidence and presentation of CD in Lothian, Fife and Border regions of Southeast Scotland (SES).

#### Subjects

All patients under 16 years of age diagnosed with CD in SES in the 5 years from the 1st of January 2010 to the 31st of December 2014.

#### Methods

All positive anti-tissue transglutaminase (anti-TTG) results from SES are reported to the clinical lead for the regional coeliac service, at the Royal Hospital for Sick Children in Edinburgh and followed up. A centrally held database was cross-checked against local databases within the Region. Depending on antibody level and symptoms, most patients still will have their diagnosis confirmed by biopsy. A retrospective cohort study of electronic case records of CD diagnoses was performed. The number of serology tests requested in under 16's in Lothian and Fife (these go to a central laboratory) was also assessed as a proxy for increasing awareness.

#### Results

224 patients (149 female, 75 male) were diagnosed with CD in Southeast Scotland over the study period. Median age at diagnosis was 7 years 6 months (range: 1 year 65 days to 16 years). In 2010 there were 31, 2011: 37, 2012: 49, 2013: 54 and in 2015: 53 patients identified. Incidence has increased from 2010 to 2014 (13.6 to 23.2/100 000 respectively). Classical cases<sup>3</sup> rose from 6.6/100 000 in 2010 to 14/100 000 in 2014. Non-classical cases showed a similar rise from 3.9 to 8.3/100 000 between 2010 and 2014. In addition, 16 asymptomatic cases were identified by screening individuals with associated conditions, and in 6 cases the presentation was unknown.

Serology testing from Lothian and Fife is sent to a central laboratory (accounting for 72% of the region's population). There has been an increase in the number of anti-TTG requests from 2274 in 2010 to 3489 in 2014. The percentage of positive tests rose.

#### Summary

We performed a retrospective analysis of cases of CD over a 5 year period. The incidence of both classical and non-classical presentations of coeliac disease continue to rise in Southeast Scotland. The proportion of positive results is increasing confirming a true rise in the incidence of coeliac disease. Better awareness and a lower threshold to test is clearly good. Comparison once again with other regions in Scotland would be a key piece of information for clinicians and Coeliac UK to help target awareness campaigns and improve diagnosis.

#### Conclusion

The incidence of both classical and non-classical presentations of coeliac disease continue to rise in Southeast Scotland.

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## Poster Number Seventeen

### A case series of early life conjugated hyperbilirubinemia presented in a District General Hospital: still there are important lessons to learn.

*Tushar Banerjee, Consultant Paediatrician; Tim Lang, Consultant Biochemist; Antima Banerjee, Consultant Paediatrician: County Durham and Darlington NHS Foundation Trust*

#### Aim

To highlight the spectrum of the aetio-pathological variation of conjugated hyperbilirubinemia (CH) presented in a district general hospital and the need for the awareness of CH management in early life among non-paediatricians and general practitioners.

#### Method

A retrospective case-note study was undertaken from June 2012 to June 2015 at County Durham and Darlington NHS Foundation Trust. A total number of 9 cases were identified.

#### Findings

There is a significant variation in age at presentation in this cohort. The spectrum of etiological diagnosis highlights the importance of considering uncommon causes of CH besides biliary atresia at presentation

#### Case 1:

A referral letter from A&E of Ormskirk for a 5 weeks old with CH. The diagnosis of Byler's Disease (Progressive Familial Intrahepatic Cholestasis) was confirmed from Liver Unit. Referral and investigations commenced at 5 weeks.

#### Case 2:

Neonatal jaundice presented in secondary care with CH. The diagnosis was made early on day 15 and the referral was made to tertiary centre.

#### Case 3:

A 46 days old referred to secondary care with bronchiolitis and incidentally found to be mildly jaundiced with clay-white stool. The investigations confirmed biliary atresia. Previously managed as breast milk jaundice and milk intolerance in the primary care.

#### Case 4:

Hepatomegaly and pericardial effusion on antenatal scan, jaundice at birth with associated hypoglycaemia and hypertension. Persistently increasing CH along with hypoglycaemia was investigated. Glycogen Storage Disease Type VI at 3 weeks was diagnosed by enzyme study.

#### Case 5:

Jaundice was noted at day two, followed up in the primary care, not investigated for CH. Biliary atresia was confirmed in secondary care and was referred to liver unit at 9 weeks.

#### Case 6:

A 42 days old with CH, investigations confirmed Alpha-1 Antitrypsin Deficiency – PIZ homozygote. Delayed identification of CH at primary care leading to a delayed referral for further investigations.

#### Case 7:

An ex-preterm on TPN found to have persistent CH secondary to biliary stasis in the special care baby unit, resolved with supportive care.

#### Case 8:

Maternal Anti-Kell antibody and haemolytic disease of new-born presented at day one with CH, resolved with supportive care.

#### Case 9:

Fulminant liver failure on Day 7 secondary to severe perinatal herpes simplex infection leading to CH and poor outcome.

#### Discussion

The above case series highlights the multiple underlying aetio-pathologies of CH presenting in the primary and secondary care in early life. Biliary atresia was commonest pathology in this case-series and 3 cases had delayed diagnosis. This also identifies the lack of awareness of the current BSPGHAN guideline for CH among the non-paediatric trained professionals working in the primary care and A&E. There is an urgent need for generating the awareness among this group of health professionals for a timely diagnosis of CH and its successful management with a better outcome.

## Poster Number Eighteen

### Pilot study to consider the feasibility and acceptability of My Health Vault – a telemedicine platform, in children with IBD.

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#### Background & aims

My Health Vault IBD portal was developed for adults with inflammatory bowel disease (IBD) allowing the healthcare team to flag early warning signs of a flare. The aim of our pilot was to investigate the usability of this telemedicine platform amongst young people with IBD and their families.

#### Subjects & methods

Observational prospective cohort study, 15 patients (and families) with IBD known to the Paediatric Gastroenterology team.

#### Results

33%(n=5) completed the study; 30%(n=3) did not progress to complete baseline data, 60%(n=6) had baseline data collected but did not register online, 10%(n=1) participant dropped out part way through the study. Reasons for not completing the study included; too time consuming and complicated registration. A pre-assessment survey revealed that all participants predicted My Health Vault would be useful prior to completing the study and post intervention assessment interviews revealed a common theme to the benefits including 'monitoring' and having 'easy, rapid contact' with the Dietitian.

#### Summary & conclusion

The use of telemedicine platforms is increasing, but in order for clinicians and families to get the best out of these platforms it is important that their ease of use, feasibility / applicability in addition to impact on health care utilisation is completely understood. The IBD My Health Vault platform was designed for adults and in its current format does not work for children and their families. However, if registration and its use were simplified then it could potentially be a much more attractive tool. Young people and families liked the ease of contact with a Dietitian, even when they weren't having a flare and the sense of being watched over.

#### Funding:

This work was supported by an educational grant from Nutricia-BAPEN 2014.

## Poster Number Nineteen

### Arthropathy- An Early Marker of Anti-Infliximab Antibodies?

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#### Background

Infliximab is a chimeric monoclonal antibody against tumour necrosis factor alpha (TNF $\alpha$ ). Its use in inducing remission as well as maintenance therapy for children and young people with inflammatory bowel disease (IBD) is well established<sup>1</sup>. The development of anti-infliximab antibodies (ATI) precludes the use of Infliximab requiring a change in treatment to control their disease<sup>2</sup>. There is a paucity of clinical features that alert the clinician to the development of ATI.

#### Aim

To describe three patients with early onset Crohn's Disease who developed joint symptoms during the course of treatment with Infliximab not associated with the primary disease process.

#### Subjects and Methods

Case reviews were carried out following the identical presentation on three patients within a short period of commencement of Infliximab. The clinical course of each case was analysed with respect to concomitant Thiopurine treatment, clinical signs of de novo arthropathy and the development of ATI.

#### Results

Patient	Age at presentation (Years)	Disease location	Time from diagnosis to commencement of infliximab (months)	Time from commencement of infliximab to development of joint symptoms (months)	Level of Anti-Infliximab Antibodies ( $\mu\text{g/mL}$ )
1	16	Colon	2	6	22
2	15	Colon and terminal ileum	21	5	>200
3	11	Colon, ileum, perianal and OFG	7	14	>200

**Table 1.** Summary of Clinical Course in three patients with arthropathy

#### Summary and Conclusion

All three patients developed significant arthropathy that was thought to be Crohn's related. In all cases the development of ATI was discovered shortly after presenting with joint symptoms in the absence of gut symptoms. All three cases had recently discontinued Thiopurines during their treatment course. The absence of concomitant immunomodulator whilst on infliximab contributing to development of ATI corroborates with previous studies<sup>2</sup>. This observation does raise the possibility that joint symptoms that occur whilst on infliximab treatment may be a clinical marker for the presence of ATI, and do not necessarily imply extra intestinal manifestation of Crohn's Disease. To our knowledge this has previously not been described.

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## Poster Number Twenty

### Blinded enteral feed rate challenge: Application to the child with medically unexplained poor "enteral tolerance"

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A 15 year old Caucasian girl was admitted to day case unit for a routine Naso gastric (NG) tube change. She was a known patient with Ehlers Danlos syndrome who was well established on supplementary NG feeds. After uneventful replacement she was admitted to the ward with failure to re-establish feeds, reporting pain and discomfort. Over the following 4 weeks as an in-patient her oral intake completely ceased and the enteral pump rate did not progress over 10mls/hr (previously tolerating 100mls/hr) due to consistent reported pain and discomfort associated with intake. There were no physiological changes observed (e.g. heart rate) during reported periods of pain. Various investigations (x rays, video fluoroscopy, barium swallow, gastric emptying studies and endoscopy) were undertaken with no results to explain her situation. Alternative feeding regimens and types of feed (elemental, hydrolysed, different manufacturers) were unsuccessful in alleviating symptoms or allowing for progression of enteral feeds. In addition to on-going management, psychological assessment and input was recommended. However this was declined by the family. At this stage parenteral nutrition (PN) was requested by the family. Prior to the decision for PN, the team decided to conduct a 3 day period of feed challenge where the rate would be blinded to the patient, the family, nurses and medical team.

To achieve this the drip stand, including the pump and the feed bag, were fully covered with an opaque cover and secured by tamper proof plastic ties. A second sham pump was attached to the drip stand and set to run continuously at 100mls/hr to ensure the sound of the pump speed had no influence. The dietitian prepared a random rate plan for 3 days and this was reviewed by an independent colleague to avoid bias. Three clear objectives were set to identify: (1) a correlation of rate of feed with symptoms, (2) if symptoms are specific to time of day irrespective of rate and (3) if daily cumulative volume had an impact. Consent was signed by the child and parents on the basis that this trial would be independent of the medical team and the self-reported symptoms would help us to establish links. The dietitian reviewed the patient 2hrly between 9:00am- 6:00pm to remove the cover and alter the rate as planned (increased, decreased or no change). After each review/change the cover was replaced and new tamper proof ties were attached. During the trial the patient scored their symptoms (pain, nausea) on a self-scale (1-5). If the symptoms became too much it was agreed the pump would be stopped for 2hrs.

After the 3 day trial the rate was un-blinded and matched to the symptom scores. There was no association of symptoms to rate, correlation of time of day or cumulative volume. Symptoms persisted unchanged to rate (ranging from 1mls/hr and 80mls/hr). Following this assessment the family agreed to psychological input and PN was not started.

#### Learning points

This case illustrates the challenge of subjective reported symptoms of unexplained GI origin. It further illustrates the potential escalation of treatment that can occur if all other routes have not been exhausted. Blinding of feed type has been used extensively both for assessment of response in RDBPC research context and in clinical practice to challenging symptoms to feed contents e.g. cow's milk protein. However, the use of blinding the rate of feeds to challenge the reported associated symptoms is largely undescribed in the literature and rarely used in clinical practice.

Care is required in several aspects of this practice. Firstly, in obtaining consent from the families and child as the presentation of such a proposal can be seen as proof of suspicion or disbelief over reported symptoms. Secondly, great care is required in the reporting of the results to the patient to ensure the relationship is maintained, especially if the results do not concur with the patients or families belief. Thirdly, rigorous clinical observations and recording of symptoms is vital. This type of challenge is hugely time consuming but this investment of time is appropriate when it prevents an escalation of treatment to more serious and costly interventions. Blinding the rate should be considered as an adjunct to standard assessment of gut function particularly in the presence of medically unexplained symptoms.



**Poster Number Twenty-One**

**Central Venous Catheter related infections in children on home parenteral nutrition – do patients with ileostomies have a higher infection rate?**

Emily Swallow, Nurse Specialist; Anna Hughes, Advanced Nurse Practitioner; Susan Hill, Consultant Paediatric Gastroenterologist; Jutta Koeglmeier, Consultant Paediatric Gastroenterologist Great Ormond Street Hospital, London

Central Venous Catheter (CVC) related infections are a serious and potentially life threatening complication of children with Intestinal Failure (IF). In our cohort of patients on long term home Parenteral Nutrition (PN), children with IF due to an underlying severe motility disorder appear to suffer from higher infection rates compared to patients whose IF is due to other pathologies. Many children with dysmotility undergo an ileostomy formation raising concern that there may be a link between CVC infections and stoma surgery.

**Aim**

The aim of this study was to understand if the number of CVC related infections is higher in those children on home PN who underwent an ileostomy formation compared to those without a stoma.

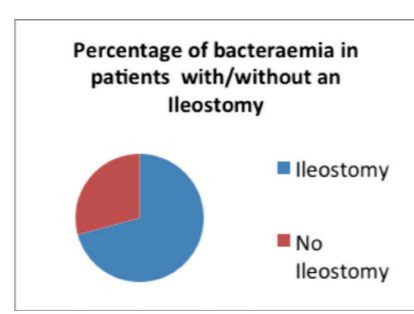
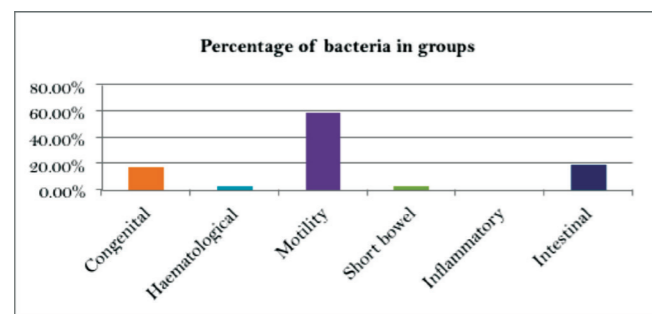
**Subjects and Method**

Patients were identified from the clinic database of a large tertiary centre paediatric intestinal rehabilitation unit.

All 46 children receiving home PN between January 2015 and November 2015 were included in the study and split into the following diagnostic groups: Motility, short bowel syndrome, inflammatory bowel disease, congenital enterocyte defect, haematological/oncological disease, Intestinal failure. The average period on home PN was equivalent to 264 catheter days. The frequency of blood culture positive bacteraemia was documented in each patient.

**Results**

Patients were aged 1-17 years, 20 were male and 26 female. The total number of catheter days studied was 12,158 with an average period of 264 CVC days per patient. CVC related infections were most common amongst children with motility disorders (9 gram negative, 12 gram positive bacteria and 3 fungi). In 17 of the 24 confirmed infections the patient had an ileostomy (8 gram-ve, 6 gram +ve & 3 fungal), whilst only 7 episodes of bacteraemia (1 gram -ve, 6 gram +ve) occurred in children without an ileostomy.



**Conclusion**

This study has shown that patients with an ileostomy go on to develop a higher percentage of line infections. There is a strong correlation between translocating gut bacteria developing into CVC infections in patients with ileostomy's. From this we as a team can advocate the necessary use of preventive measures for patients going home on PN with an ileostomy, for example to start IV Tauorlock from the start of training, as a linelock. Also to advocate covering the end of the central line with parafilm and teaching the importance of keeping the line away from the ileostomy bag. From this we could hope to see a decrease in infections developing in this group of patients.

**Poster Number Twenty-two**

**Evaluation of patient/parent satisfaction of a newly established Paediatric Gastroenterology Ambulatory Unit (PGAU)**

Aikaterini Kakotrichi<sup>1</sup>, Clinical Fellow in Paediatric Gastroenterology; Neil Shah<sup>2</sup>, Consultant Gastroenterologist; Sara Sider<sup>2</sup>, IBD Clinical Nurse Specialist; Sibongile Chadokufa<sup>2</sup>, IBD Clinical Nurse Specialist; Bonita Huggett<sup>2</sup>, IBD Clinical Nurse Specialist; Eleni Volonaki<sup>2</sup>, Consultant Gastroenterologist; Fevronia Kiparissi<sup>2</sup>, Consultant Gastroenterologist; <sup>1</sup>Great Ormond Street Hospital, Gastroenterology Department, WC1N 3JH, London; <sup>2</sup>Great Ormond Street Hospital, Gastroenterology Department, Division of Mucosal Immunology, WC1N 3JH, London

**Background:**

The Paediatric Gastroenterology Ambulatory Unit (PGAU) was established 18 months ago, aiming to provide rapid access and hence improving the quality of care in our patients. It was designed for current patients that are deteriorating and newly diagnosed ones. The ambulatory facilities comprised clinical reviews, laboratory and radiology investigations, as well as dietetic and CNS reviews.

**Aim**

Our aim was to evaluate patient/parent satisfaction for the newly established PGAU.

**Subjects and methods**

A previously validated, modified and anonymous questionnaire was used; it was distributed to the parents/patients for completion after the consultation. The form included 19 questions and the answers provided were either qualitative values (i.e. poor to excellent) or quantitative (i.e. from a numerical scale 0 to 10). It also provided the opportunity to submit free comments. Parameters examined included evaluation of the pre- appointment administration, staff attitude and courtesy, medical and nursing care and overall satisfaction with the service.

**Results**

The data were prospectively collected over a one-month period. 52 out of 60 questionnaires were successfully completed. Out of 52, 15 (28.8%) were completed by patients and 37 (71.2%) by parents, 37 were female (71.2%), 12 were male (23%), and 3 (5.8%) did not comment. The administration booking process scored 5 (very good) on a range from 1 being poor to 6 being excellent. The staff attitude and courtesy was evaluated as excellent for the doctors (5.62), nurses (5.63) and Allied Health Professionals-AHPs (5.60) respectively, on a scale from 1 being very poor to 6 being excellent. On a scale from 1 rated as 'no confidence' to 3 rated as 'yes, definitely confident', the confidence and trust were rated 2.90 for doctors, 2.88 for nurses and 2.89 for AHPs. 94.2% of patients/parents thought that the 'right amount' of information was given to them about their condition, diagnosis and treatment; 5.8% thought that information given was either 'not enough', 'too much' or 'didn't know'. Overall, the average score for the degree of overall satisfaction, with regard to all services provided, was nine 9 (very good) on a scale from 1 (very poor) to 10 (excellent). Lastly, in the friends and family test, 90% were extremely likely to recommend PGAU to other families.

**Summary and conclusion**

The evaluation of the newly established PGAU service revealed high patient and parent satisfaction levels and has been found to be an excellent model of delivering care that could be used within other settings.

## Poster Number Twenty-three

### Hazards of button battery ingestion – Management of oesophageal perforation post button battery ingestion, using oesophageal stent and transthoracic T-tube

*Dr Shishu Sharma, ST7, Paediatric Gastroenterology; Dr Mike A Thomson; Mr Sean A Marvin; Mr Govind Murthi; Dept of Paediatric Gastroenterology, Sheffield Children's Hospital, Western Bank, Sheffield*

There are many household battery-operated items in a modern home that contribute to the availability of button batteries to young children. The children may mistake them for sweets or pills, leading to inadvertent ingestion. Worldwide there has been a recent increase in the incidence of button battery ingestion in this age group sometimes leading to fatal and catastrophic outcomes. The incidence may also be rising in the UK and the recent media coverage of button battery related deaths have attracted a huge public interest and awareness.

#### Case report

A 2 year old girl presented after 1 hour following ingestion of a 20mm lithium ion button battery. This was removed using a rigid oesophagoscope within 2 hours of stipulated time. A 5cm long segment of necrosis and erosive damage to the mucosal surface was noted on the posterior aspect of the oesophagus 15cm from the incisors. She was then admitted for observation and was planned for discharge the following day. Prior to discharge after 22 hours post-ingestion her clinical state deteriorated and a left sided tension pneumothorax was noted which was treated by urgent needle decompression followed by intubation and chest drain insertion. Clinical suspicion of an oesophageal perforation was confirmed by an upper GI contrast, revealing an 8-10mm perforation approximately 20 cm from the incisors. A temporary metallic oesophageal stent (Comvi® fully covered shunt 10mm X 60mm) was placed across the perforation endoscopically with a plan to replace this in a week. Total parenteral nutrition was also commenced on day 3 post ingestion.

Unfortunately her condition was further complicated by a right side pleural effusion and worsening of empyema, needing another chest drain as well as thoracoscopic debridement of the empyema on day 7 post ingestion.

On day 10 post-ingestion it was planned to replace the metallic stent with Polyflex tracheo-bronchial fibre stent, but a contrast chest CT prior to the procedure showed a longitudinally oriented defect extending from the oesophagus into the left pleural space, measuring almost 14 mm in coronal section and approximately 5 mm in AP diameter. This was considered to be unamenable to stent alone. Therefore a decision was made for endoscopic removal of the original stent combined with thoracotomy and insertion of a ZOF® T-tube extending from oesophagus to outside the chest wall. A serratus muscle flap was raised and split to wrap around oesophagus.

Post-operative recovery was complicated by further pleural effusion and drainage and also a paralytic ileus which led to bilious drainage from the T-tube. On day 52 post-ingestion the T-tube was removed under direct endoscopic vision and a tissue repair glue (Tissel®) was injected into the artificial fistula. Subsequently two Instinct® endoclips were also applied to the residual defect in the oesophageal wall. Intraoperative contrast X-ray identified oesophageal integrity and no leak. (Figure)

She was discharged home on day 56 post-ingestion and a repeat upper oesophagoscopy on day 66 post-ingestion showed complete healing of the perforation.

#### Conclusion

The outcome of button battery ingestion is potentially catastrophic and a very high index of suspicion should exist amongst front line medical staff with a very low threshold for radiological examination.

Oesophageal arrest of the battery is an endoscopic emergency necessitating removal immediately.

It would seem intuitive that an urgent review of preventive measures such as education around their storage and safe disposal, and child-proof packaging be advocated on a national level. A case is made for the establishment of a National Helpline, equivalent to the National Battery Ingestion Hotline in the US, to advise general public as well as front line medical staff

## Poster Number Twenty Four

### Histological Characteristics of IBD in Infants and Toddlers.

*Dr Elena Cernat; Dr Neil Shah; Mr Robert Dziubak; Ms Dyanne Rampling; Dr Fevronia Kiparissi; Prof Neil Sebire; Dr Jochen Kammermeier; Great Ormond Street Hospital, Great Ormond St, London WC1N 3JH*

#### Introduction

Infantile-onset inflammatory bowel disease (IOIBD) refers to children with evidence of chronic intestinal inflammation and symptom-onset before the 2nd year of life. IBD phenotypes are stratified according to the revised Porto Criteria (based on the Paris Classification for the diagnosis of paediatric IBD) into: Crohn's disease (CD), ulcerative colitis (UC) and IBD unclassified (IBDU).

#### Aim

In this study, we describe the histological phenotypes and disease progressions of children with IOIBD.

#### Methods

Retrospective histology data from 62 children with IOIBD presenting over the last 15 years was extracted and cumulative histological features and disease extent were determined for all patients. Longitudinal histology data was available for a median observational period of 16 months [IQR 0 to 45].

#### Results

62 IOIBD patients (55% male) were identified. The median disease-onset was three months of age [IQR: 1 to 11]. Conventional IBD classification applied to 15 patients with CD-like phenotype (24%), of whom all developed pancolonic disease (80% at diagnostic endoscopy). Similarly, all three children with UC-like (5%) phenotype developed pancolonic inflammation (67% at diagnostic endoscopy). Forty-four patients (71%) were diagnosed with otherwise unclassifiable IOIBD (IOIBDU). Within this subgroup, only six qualified for the definition of IBDU according to the revised Porto Criteria for diagnosing paediatric IBD (inflammation limited to the colon with features that make the differentiation between UC and CD uncertain). Panenteric IOIBDU (defined as inflammation involving small and large bowel) was established in 31 patients (70%). CONCLUSION: The histological phenotype in children with IOIBD is frequently not classifiable into CD, UC and IBDU according to the revised Porto Criteria. Children with IOIBD often have pan-colonic and pan-enteric inflammation which is already evident at the time of diagnostic endoscopy.

## Poster Number Twenty Five

### Incidence of both Crohn's Disease and Ulcerative Colitis is continuing to rise and is higher in the city population

Dr Siba Prosad Paul<sup>1</sup>, Dr Jim Hart<sup>2</sup>, Prof. Bhupinder Sandhu<sup>1</sup>, <sup>1</sup>Bristol Royal Hospital for Children; <sup>2</sup>Royal Devon & Exeter NHS Foundation Trust.

#### Background and aims

The first prospective national survey<sup>1</sup> of paediatric Inflammatory Bowel Disease (pIBD) in the UK documented an incidence of 5.2/100,000 children per year. A higher incidence was noted in the north (Scotland: 6.5) as compared to the south (England: 5.2) and Ireland (4.4). This prospective study aimed to:

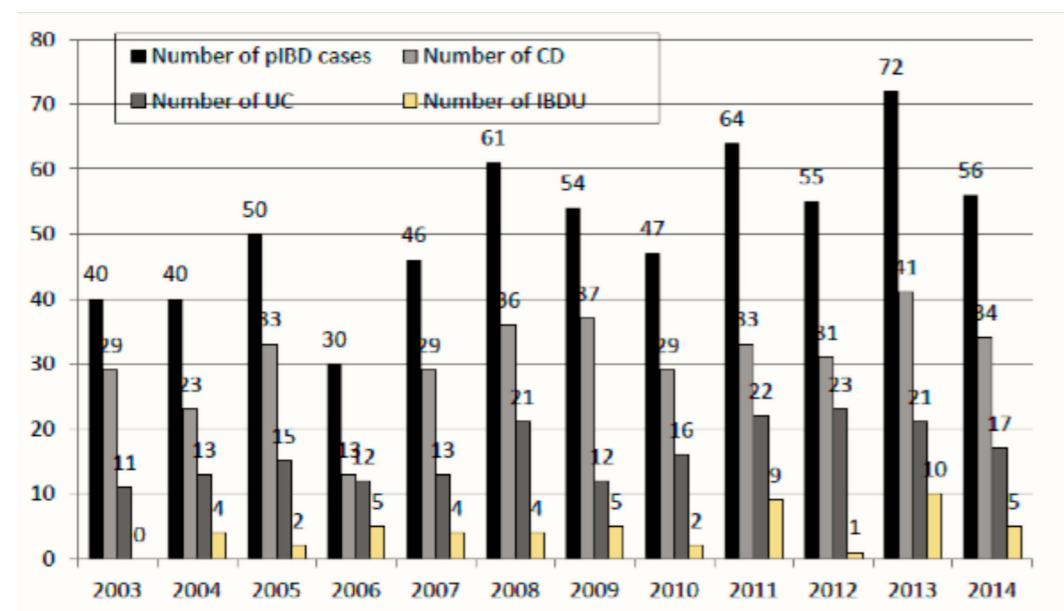
- document any change in incidence of pIBD in the SWE from 2003 to 2014
- document any difference in incidence of pIBD in the city of Bristol population compared to the whole of southwest England (SWE)

#### Methods

Bristol is the single specialist paediatric gastroenterology centre for SWE to which all children (aged 0 – 16 years) suspected of having IBD from the 12 paediatric centres are referred for endoscopy. Prospective data was collected on all new pIBD cases between 2003 – 2014 including types of IBD, gender and postcode address for the City of Bristol.

#### Results

615 new cases of pIBD were diagnosed over a 12 year period (2003 – 2014). Male (n=361) to female (n=254) ratio was 1.4:1. The cumulative incidence rates over two consecutive 6 year periods for the city of Bristol were much higher than the whole SWE: 9.5 per 100,000 versus 5.0 per 100,000 (2003-2008) and this increased to 10.6 versus 6.2 (2009-2014). Cumulative incidence increased for all subtypes of IBD: Crohn's disease (CD) increased from 3.06 (2003-2008) to 3.63 (2009-2014), Ulcerative Colitis (UC) 1.6 to 1.96 and IBD-unclassified (IBDU) 0.36 to 0.57. Figure below shows the overall rising incidence for both UC and CD in SWE.



#### Conclusion

Cumulative incidence of IBD over two consecutive 6 year periods increased from 5.0 (2003 – 2008) to 6.2 (2009-2014) in SWE. This was noted for both CD and UC with male preponderance. This study documents significantly higher incidence in the city population suggesting environmental factors have a role.

Ref: 1. Sawczenko A, Sandhu BK et. al. Prospective survey of childhood inflammatory bowel disease in the British Isles. Lancet. 2001;357(9262):1093-4

## Poster Number Twenty Six

### Normal GGT conjugated Jaundice; a metabolic cause to consider in your differential diagnosis.

Paul Bellis<sup>1</sup>, Paediatric specialist trainee; 2. Alex Kinsley<sup>2</sup>, Consultant Histopathologist; Andreas Janecke<sup>3</sup>, M.D; Rana Bitar<sup>1</sup>, Paediatric Gastroenterology Consultant, <sup>1</sup>Royal Victoria Infirmary, Newcastle upon Tyne; <sup>2</sup>King's College Hospital, Denmark Hill, London <sup>3</sup>Innsbruck Medical University, Austria

#### Background and Aim

Paroxysmal liver disease is an uncommon cause of Jaundice in children. I aim to present an interesting boy with a diagnosis of Paroxysmal liver disorder referred to Paediatric Gastroenterology department with mild Jaundice and was presumed to have Gilbert's syndrome.

#### Method and Results

A 14 year old boy was referred to the Paediatric Gastroenterology Unit with new onset mild conjugated jaundice and possible diagnosis of Gilbert's syndrome. His total bilirubin was 86, conjugated was 34, GGT, ALT and fat soluble vitamins were normal. He had a family history of Gilbert's Syndrome his half-brother and biological brother have a history of recurrent Jaundice. Maternal grandmother and maternal uncle died from liver related disease. The chronic liver workup was normal, urine specific bile acids were normal and metabolic liver workup demonstrated increased excretion of odd-numbered dicarboxylic acids (DC7 and DC9) and the even numbered DC8. His Jaundice persisted so he had genetic testing for Gilbert's syndrome which came back normal. Abdominal USS and MRCP were normal. Because of his persistent Jaundice a liver biopsy was performed which demonstrated very focal pericholangitis and peribiliary sclerosis (not of onion skin type) and minimal steatosis. No evidence of advanced bridging or cirrhosis. The Liver biopsy was sent for more specialist review and staining in a specialized paediatric liver unit. The interesting finding showed marking of three peroxisomal enzymes: alpha-methy acyl CoA racemase, bile acid CoA: amino acid N-acyltransferase and catalase to be substantially deficient throughout the lobule. We therefore concluded that abnormality of this patients organic acids, coupled with normal GGT and lack of pruritis in addition to his biopsy results suggest a peroxisomal defect. DNA samples from this patient and mother and siblings are being tested for whole-exome sequencing to identify the genetic disorder.

#### Conclusion

Mild conjugated jaundice can be caused by peroxisomal disorders. Collaboration between professionals and centres can help in diagnosing the disorder, identify the gene responsible and helping us understand the way it is inherited. This will eventually help in counselling and long term management of this family.



**Poster Number Twenty Seven**

Withdrawn

**Poster Number Twenty Eight**

**Parental perception of their child's Quality of Life in children with non-IgE mediated food allergy**

*Dr. Ru-Xin M Foong<sup>1</sup>; Dr. Rosan Meyer<sup>1</sup>; Heather Godwin<sup>1</sup>; Robert Dziubak<sup>1</sup>; Adriana Lozinsky<sup>1</sup>; Kate Reeve<sup>1</sup>; Neil Shah<sup>1,2</sup>; <sup>1</sup>Great Ormond Street Hospital for Children NHS Foundation Trust, London UK; <sup>2</sup>Institute of Child Health, University College, London UK*

**Background**

Food allergy can have a significant impact on the quality of life of children. Little data is available on health related quality of life (HRQL) in non-IgE mediated food allergic children so the aim of this study was to evaluate HRQL in these children by parent proxy.

**Methods**

A prospective, observational study was performed. Children 2-16 years old with non-IgE mediated food allergy who had symptom improvement after starting an elimination diet were included. Parents of these children completed the Paediatric Quality of Life Inventory (PedsQLTM) questionnaire, which has been validated for parental proxy use. The questionnaire scores were compared to two cohorts, one with functional abdominal pain (FAP) and another with Duchenne's Muscular Dystrophy (DMD).

**Results**

52 children's parents completed the PedsQLTM parent proxy questionnaire. The median age of the children was 70 months (37 male). The domain that had the lowest score was emotional functioning. Factors that had a significant negative impact on total PedsQLTM parental score were the number of foods excluded, comorbidity of nasal congestion and the persistence of flatus following an elimination diet. Our cohort had higher total scores compared to both the FAP and DMD cohorts but had significant lower emotional functioning scores compared to FAP children.

**Conclusions**

This study showed that the quality of life of children with non-IgE mediated food allergy has the most significant impact on emotional functioning, and highlights the need for a specific non-IgE food allergy quality of life questionnaire to better understand the impact on these children.

## Poster Number Twenty Nine

### Parenteral Nutrition Audit

Sue Croucher, Nutrition Nurse Specialist; Lisa Cooke, Head of Paediatric Dietetics  
Bristol Royal Hospital for Children

#### Introduction and Background

Parenteral nutrition has become the mainstay in the treatment of children with intestinal failure and conditions that preclude enteral feeding. Nutrition support teams have improved clinical and economic outcomes by encouraging the appropriate use and monitoring of Parenteral Nutrition (PN) therapy. Within the Bristol Royal Hospital for Children (BRHC) there had historically been no nutrition support team. Following 141 PN related incidents logged at BRHC between April 2012-April 2015 and a long standing risk on the divisional risk register a nutrition team was funded. An audit to assess the current practice around PN therapy was undertaken to assess the current situation. This took place for 6 weeks between 7th July and 25th August 2015

#### Aim

To assess compliance of current practise against national recommendations and divisional PN guidelines. To enable practise change to improve clinical and economic outcomes for children receiving PN within the hospital and receiving tertiary area.

#### Methodology

An audit data collection sheet was produced based on current PN guidelines and used to collect data on the following areas:

- prescribing practise, type of venous access being used to administer PN, nursing practise in handling/connecting/disconnecting PN
- Checking that patients were being adequately monitored whilst receiving PN, checking that adequate and thorough documentation of any line or PN related complications was done.

During the audit period there were; 23 patients receiving inpatient PN at BRHC and St Michael's Hospital (SMH)

#### Results

No	Standard/Criteria	Target	Result
1	Prescribing practise in line with guidelines	100%	65 (15/23)
2	Appropriate venous access is used	100%	96 (22/23)
3	Aseptic technique used	100%	61 (14/23)
4	Patients monitored adequately	100%	70-100 (16/23 - 23/23)
5	Any complications recorded adequately	100%	78-100 (18/23 - 23/23)

#### Summary

Practise varies considerably on different wards and areas and there is no standard practise across the trust. The neonatal unit work very differently to BRHC with managing their PN. Nurses are unaware of certain Guidelines and expectations, when managing children on PN, e.g. when bloods need to be taken, how often weight should be measured. This then has a knock on effect when PN is being prescribed. Due to the increasing numbers of children around the hospital on PN, impacts on capacity issues for both Pharmacy sterile Unit and ward nurses. Although aseptic non touch technique procedure is used, it is inconsistent with either a 1 or 2 person set up. Erratic and ad hoc monitoring, particularly with blood and urine tests. There was no current system, for PN related incident reporting for the appropriate people to review the incident.

More robust monitoring of incidents is necessary.

#### Conclusion

To work on consistency and a uniform approach to practise across both hospitals, BRHC and SMH  
To have consistency on the prescribing of PN  
Updating of Paediatric Parenteral Nutrition Guidelines  
Review of all current PN related Standard Operating procedures  
More in depth training for ward nurses using rolling training programmes  
For Nutrition Support Team to work collaboratively, to improve patient outcomes, in all aspects of PN management

## Poster Number Thirty

### Service Evaluation of Bristol Endoscopy

Dr. Lakshmi Selvarajan<sup>1</sup>, ST6; Dr. Siba Paul<sup>2</sup>, ST8; Dr. Dharam Basude<sup>1</sup>, Consultant Paediatric Gastroenterologist; Prof. Bhupinder K Sandhu<sup>1</sup>, Consultant Paediatric Gastroenterologist,  
<sup>1</sup>Bristol Royal Hospital for Children; <sup>2</sup>Yeovil District Hospital

#### Background

There is a wide variation in the provision of paediatric endoscopy services across units in the UK. Childhood endoscopy is most commonly indicated when the diagnoses of inflammatory bowel disease, coeliac disease or reflux oesophagitis are under consideration.

#### Objectives

The aim of our study was to identify the current provision of paediatric endoscopy services in Bristol, the number of endoscopies performed in the last 7 years, the number of abnormal results and the contribution of Inflammatory bowel disease, Coeliac disease and Eosinophilic oesophagitis to our endoscopy workload.

#### Methods

Data was collected from our endoscopy database from January 2008 to December 2014. Details of all children undergoing endoscopy are prospectively entered with demographic details, indications, macroscopic findings and histopathology results.

#### Results and Summary

On an average, 347 patients underwent endoscopy each year with 476 procedures/year. 66% of our results were abnormal (62-68%), 52% of which, was contributed in diagnosing Inflammatory bowel disease, Coeliac disease and eosinophilic oesophagitis. 10-12% of those with Inflammatory bowel disease had their disease re-assessed. On an average, there were 58 (range 47-72) patients with a new diagnosis of IBD and 8 (range 6-13) with eosinophilic oesophagitis. Endoscopic diagnosis of coeliac disease has reduced from 92 in 2010 to 45 in 2014. We do 15 therapeutic procedures/year on an average.

In 2014, we had 94 elective, 5 extra and 32 emergency lists with an average of 8 lists and 5-6 procedures per month. 35% were from Bristol and the remaining were referred from other hospitals. We had a total of 537 procedures with 159 upper GI endoscopies, 33 colonoscopies and 171 had both the procedures. Our terminal ileum intubation rate was 96%.

#### Conclusion

There is a wide variation in the number of procedures each year and there has been a steady increase. More than half of our endoscopic procedures are to diagnose Inflammatory bowel disease, coeliac disease and eosinophilic oesophagitis although there is a downward trend in the endoscopic diagnosis of coeliac disease.

#### Discussion:

Is there a 'right' rate of testing? Should standards for paediatric endoscopy service in the UK include unified indication criteria for the diagnostic procedures to reduce variation?

## Poster Number Thirty One

### Utility of E-BANS for parenteral nutrition (PN) data collection for children admitted to hospital.

Vinod Sharma, Dr; Jutta Koeglmeier, Dr; Mark Cowles, Mr, Paediatric Pharmacist; Susan Hill, Dr, Great Ormond Street Hospital, London

#### Background

The British Artificial Nutrition Survey (BANS) was launched in 1996. BANS is a multi-professional committee of BAPEN (the British association for Parenteral and Enteral nutrition). E-BANS is a national survey which collects, analyses and reports information about patients receiving Artificial Nutrition Support (ANS) in hospital and the community. A dedicated paediatric e-BANS reporting system was set up in 2015.

#### Objective

To review the utility of E-BANS for parenteral nutrition (PN) data collection for children admitted to hospital.

#### Methods

All paediatric inpatients who and required PN for more than 27 days were registered on E-BANS. Data was collected from patients' notes and put on E-BANS in a pre-set required format. We reviewed and analysed data from E-BANS from June to October 2015.

#### Results

A total of 33 in-patients were registered on The British Artificial Nutrition Survey (e-BANS) from our specialist Children's Hospital over a 5 month period between June and October 2015. The system was simple to access and each patient was easily registered within a few minutes. There were 15 male and 18 female. Mean age of children was 5.4 years. 36%(12) children were under the age of 1 year. The largest group of children was reported with primary gastrointestinal problems. The commonest diagnosis was necrotising enterocolitis (NEC) in 7 neonates. Out of these 2 were extreme preterm and 5 preterm babies. In another 3 children PN was started because of intestinal failure (IF) secondary to inflammatory bowel disease (IBD) with IL10 deficiency in 2, and early onset unclassified IBD in one child. There was one child who required PN for long segment Hirschsprung disease, one with megacystis microcolon syndrome and one tufting enteropathy. One child had duodenal atresia and another child had trachea-oesophageal fistula. One patient was reported with acute recurrent pancreatitis and noted to have multiple acyl-CoA dehydrogenation deficiency (MADD). Another child was reported with congenital hyperinsulinism due to a compound heterozygous ABCC8 mutation who required PN post near-pancreatectomy. The second largest group of children requiring PN had haematology and oncological problems. Eight children were reported with Leukaemia, 2 with abdominal teratoma and one child with Wilm's tumor. Two children were diagnosed with Hemophagocytic lymphohistiocytosis (HLH) and required bone marrow transplant. Two children with post heart transplant end-stage heart failure required PN. One child with cystic fibrosis required PN because of post-lung transplant enteropathy. 31 patients received PN for more than 27 days with more than 50% calories intake from PN. Two patients received PN for more than 3 months. In 8 children PN was stopped and feeding was successfully established. There was no death reported.

#### Conclusion

E-BANS is an effective tool for PN data collection. It is an easily accessible system that is readily available for health professionals to view and audit the Artificial Nutrition Support (ANS) of the children under their care.

## Poster Number Thirty Two

### What Parents Think of Climbing Up a Milk Ladder

Miss Samantha Brock<sup>1</sup>, Medical Student; Dr David Tuthill<sup>2</sup>; <sup>1</sup>Cardiff University School of Medicine; <sup>2</sup>Noah's Ark Children's Hospital for Wales, Cardiff

#### Background

Cows' milk allergy is very common, occurring in up to 2% of infants and normally resolves in early childhood. Previously, strict total avoidance of milk was advised. Now, reintroduction of baked milk initially, followed by progressively "rawer" and "more concentrated" forms is recommended to facilitate oral tolerance. Many "Milk Ladders" exist guiding clinicians in this reintroduction including: the St Bartholomew's (Bart's), BSACI (British Society of Allergy and Clinical Immunology), Cardiff (REACH Team) and MAP (Milk Allergy in Primary care) ones. Despite widespread use, few data exist on parents' views and preferences regarding these ladders.

#### Aim

To compare parents' views and preferences on four milk ladders.

#### Subjects and Methods

A pilot questionnaire was devised exploring families' views and tried for clarity; minor revisions were made. The final version had 9 questions: the first seven questions assessed aspects including layout and practicality through questions such as 'How clear do you think the language and layout is?', 'How clear is it when to progress to the next step of the ladder?', 'How relevant are the examples (of food in the milk ladders) used?' and 1 question asked parents to rate the milk ladder. All of these 7 questions were scored by the parents out of a possible high score of 5, giving a possible total score of 35.

Two further questions assessed parental understanding in using the ladder, through questions, which asked at which stage of ladder items such as yoghurt and milk would be on. The questionnaire was distributed to Parents/Guardians of children of any age on the Wards and OPDs; each participant was given two randomly allocated ladders to assess. SPSS was used for data analysis.

#### Results

150 questionnaires were distributed and 123 returned with 11 non-responders and 16 incomplete. Participants reviewed 252 Milk Ladders.

A one-way Welch ANOVA assessed the mean questionnaire scores with these being statistically significantly different ( $p < 0.0005$ ) between the groups. The BSACI ladder scored worse than the other three ladders, whilst Cardiff scored higher than the Bart's ladder.

	Bart's (n= 62)	BSACI (n= 66)	Cardiff (n= 67)	MAP (n=57)
Mean Total Score	24.7	20.3	26.9	24.8
Parental Understanding	32.3%	77.3%	73.1%	73.7%

#### Summary and Conclusions

Parents found all milk ladders helpful, preferring aspects such as a boxed layout and fewer stages. Overall the Cardiff Milk Ladder was found easiest to use. This preliminary study has highlighted the need for further research on Milk Ladders.



## Poster Number Thirty Three

### A Case of Myotonic Dystrophy with Liver Failure and a Rare Genetic Mutation

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#### Introduction

We report an unusual case of congenital myotonic dystrophy with liver disease, which is not a commonly reported association.

#### Case

A baby with an antenatal diagnosis of Congenital Myotonic Dystrophy (CMD), was delivered at 34 weeks gestation. The newborn required parenteral nutrition from day 1 due to feeding difficulties associated with CMD. At age 2 months, the infant developed conjugated hyperbilirubinemia. Further blood tests for conjugated hyperbilirubinemia did not identify an obvious cause of jaundice. A liver biopsy was not performed due to the associated risks of anaesthesia in children with congenital myotonic dystrophy. At 6 months of age, parenteral nutrition was discontinued and the patient was primarily fed via a nasogastric tube. Although, enteral feeds were established and child was gaining weight, the cholestasis did not improve, which prompted us to do further investigations. A liver biopsy at 10 months showed severe cholestasis and mild sinusoidal fibrosis, features similar to those seen in parenteral nutrition, but also few compressed portal tracts in which bile tracts were difficult to identify. Hence further Immunostaining of the biopsy sample was done which showed MRP2 and BSEP with poorly expressed GGT at the canalicular margin, DNA sequencing confirmed the patient carried 2 different genetic mutations, heterozygous for both ATP8B1 and ABCB4. At the age of 4 years, the liver disease began to progress and the patient required surgery for an orthotopic liver transplant. The explanted liver showed features consistent with progressive intrahepatic cholestasis.

#### Discussion

Initially it was thought that the liver disease was secondary to parenteral nutrition as 40-60% of children on long-term parenteral nutrition will develop IFALD which causes liver failure in a minority. The introduction of enteral feeding for such patients can reverse cholestasis, but did not occur in our case. This led us to do further investigations including a liver biopsy with the associated risks of anaesthesia. The liver biopsy changes (especially bile duct paucity in a child with PN) and immunostaining raised the possibility of familial intrahepatic cholestasis group of condition as a possibility. The genetic tests further raised the possibility of a PFIC like syndrome or the presence of other genes acting to impair the excretion of bile. To our knowledge, this is the first reported case of a paediatric patient with CMD developing progressive liver disease with PFIC like changes on liver biopsy which progressed to liver failure and subsequently required a liver transplant. At the last follow-up the child had normal liver function tests and shown a remarkable improvement in her overall development including motor skills.

#### Conclusion

This is a case of known myotonic dystrophy with symptomatic hepatic dysfunction; with only biochemical abnormalities previously reported. This could suggest previously unreported association of liver problems in children with muscular disorders.

## Poster Number Thirty Four

### Paediatric Helicobacter pylori Practice in the West of Scotland: A Retrospective Audit

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#### Background

Helicobacter pylori is a World Health Organisation confirmed carcinogen, identified as the cause of most peptic ulceration. This has led to widespread eradication in the adult population. Children are colonised with H. pylori in the preschool years and, if untreated, carry the organism long-term. With paediatric prevalence rates falling, and carcinogenesis a long-term possibility, the standardisation of paediatric practice is paramount. Joint ESPGHAN/NASPGHAN guidelines from 2011 promote gastric biopsy as the diagnostic method of choice; describe no role for H. pylori serology; suggest triple therapy for 7-14 days with proton pump inhibitor paired with two antibiotics from amoxicillin/metronidazole/clarithromycin/tinidazole; and recommend confirmation of eradication with faecal antigen or urease breath test in all cases after a minimum of 4 weeks off antibiotics.

#### Aims

To review all cases of H. pylori diagnosed by microbiological or pathological testing in one calendar year within a regional centre and its catchment population, and compare practice against joint ESPGHAN/NASPGHAN guidelines.

#### Subjects and Methods

The results of all positive paediatric (<=16 years) H. pylori serology and faecal antigen testing were generated from microbiology databases, and the results of any H. pylori positive gastric biopsies were generated from the pathology database for the period 1st of July 2013 to the 30th of June 2014. The period was chosen to allow one year of post-test clinical history. The electronic hospital records of the resultant patients were reviewed to complete a proforma focussing on diagnostic method, treatment given and confirmation of eradication.

#### Results

110 patients tested positive within the year (56 male; 54 female. Median age = 13 years). Of these, 56% were diagnosed by serology, 13% histologically, 24% by faecal antigen testing, 5% by a combination of serology and histology and 2% by a combination of serology and faecal antigen. No urease breath tests were performed within the study period. General practice requested 20% of tests, paediatric gastroenterology 15%, all other paediatric specialties 8%, adult gastroenterology 2%, other adult specialties 4%, secondary care 'other' 4%, general practice and paediatric gastroenterology together 4% and unknown 43%. 45 patients (41%) were treated with an ESPGHAN/NASPGHAN approved regime. A further 6 patients were treated but exact drugs were not specified (5%), treatment was unknown for 53 patients (48%), whilst a further 3 patients were told to 'see GP' and 3 patients (3%) were intentionally not treated. Of the 54 patients who were definitely treated, 46% were treated for 7 days, 2% for 10 days and 24% for 14 days. For 28% the duration of eradication therapy remained unknown. Confirmation of eradication was only definitely undertaken for 29 patients, 26% of the total number tested. All of the tests of eradication took place within an appropriate time period.

#### Conclusions

Despite ESPGHAN/NASPGHAN guidance recommending against serology in the diagnosis of H. pylori, this is the mainstay method of diagnosis in the paediatric population in the West of Scotland. Biopsy is the diagnostic method in a minority. Although data on choice and duration of therapy was limited by having no access to GP notes, 72% of those definitely treated had an appropriate course length. Confirmation of eradication was only achieved in less than a third of patients, a concerning figure given the long-term possibility of gastric carcinogenesis. This audit demonstrates variance from consensus guidelines and supports the need for a review of local practice.

## Poster Number Thirty Five

### An Appraisal of the Burden of Giardia Infection in Children <5 Years Old in Low and Middle Income Countries: a Systematic Review and Meta-Analysis

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#### Background

Giardia lamblia is protozoal parasite that is endemic in non-industrialised settings. It is frequently asymptomatic but has been implicated as a potential stunting pathogen. Stunting affects up to 1 in 4 children, and results in diminished cognitive development and a resultant loss in human potential for the affected individual and society. This systematic review and meta-analysis provides a crude baseline estimate of the prevalence of asymptomatic Giardia infection in children under 5 years old, and examines its role as a stunting pathogen.

#### Methodology

Following systematic review of the published literature and extraction of raw prevalence data, a random effects meta-analysis was performed to obtain a pooled proportion of Giardia infection using culture-based detection techniques in under-5s in low- and middle-income countries. Pooled prevalence using ELISA-based prevalence results from the MAL-ED project was performed in order to compare the two detection techniques. A qualitative analysis of data on association between stunting and Giardia infection was performed.

#### Results

The overall pooled proportional prevalence was 20% (95% CI 16% - 23%). There was no difference between the pooled proportion in urban settings and rural settings. The pooled proportion using ELISA-based results from the MAL-ED research project was 16% (95% CI 9% - 24%). The amount of heterogeneity between the papers on the association between Giardia infection and stunting did not allow for a quantitative synthesis of the data. A qualitative analysis revealed conflicting results on this association.

#### Conclusions

This review found a crude baseline prevalence of 20% Giardia lamblia infection in children under 5 in low resource settings. Our paper focused on microscopic-based detection, however, our results were in keeping with those found using ELISA-based detection methods. Despite being so prevalent, this is an extremely under recognised pathogen. There is a need to further understand the risk factors, pathogenesis and clinical sequelae of subclinical Giardia infections in order to understand its contribution to global morbidity in children.

## Poster Number Thirty Six

### Audit on Thiopurine metabolites in children receiving Thiopurines for Inflammatory Bowel Disease

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#### Introduction

Most paediatric inflammatory bowel disease (IBD) centres undertake red cell thiopurine methyltransferase (TPMT) estimation prior to the initiation of thiopurines in children with IBD. Where children have a normal enzyme activity; the full dose may be prescribed from the onset: Azathioprine may be prescribed at 2-2.5mg/kg/day and the prodrug 6-mercaptopurine at 1-1.5mg/kg/day. A dose reduction is usually required for children who are heterozygote for the TPMT gene or have intermediate enzyme activity.

As steady state concentrations are reached between 2-4 weeks of therapy, it is our practice to measure thiopurine metabolites 4-6 weeks after initiation or dose change to allow rapid optimisation of thiopurine treatment.

We aim for an active metabolite (6-Thioguanine Nucleotide (6TGN) ) range of 235 – 450 pmol 6TGN/8x10<sup>8</sup> , and the potentially hepatotoxic 6-methylmercaptopurine nucleotide (6MMPN) level of < 5700 pmol 6MMPN/8x10<sup>8</sup> cells

#### Aim

To examine the relationship between normal TPMT activity, and thiopurine metabolites in children receiving the current recommended dose of thiopurine for inflammatory bowel disease

#### Methods

All children in our unit with inflammatory bowel disease who are currently receiving thiopurines (Azathioprine or 6-mercaptopurine) were identified through the paediatric IBD database.

Retrospective data collection was undertaken from electronic patient records to identify their TPMT status, starting dose of thiopurine /kg and thiopurine metabolites 4-6 weeks following initiating thiopurine therapy

Only children who were commenced on the current recommended doses on initiation of therapy were included in the study.

Children heterozygous for TPMT, or in whom compliance with either medication or blood sampling was poor were excluded from the study

#### Results

There are currently 378 children with inflammatory bowel disease on our data base; 58.9% of which are currently receiving either Azathioprine or 6 MP. The data from 15% of children currently receiving thiopurines was analysed. 24% of children required a dose change within 4-6 weeks of commencing Thiopurines. In 10% of cases this was due to suboptimal levels of 6TGN. The majority of dose changes were due to high levels of 6MMPN

#### Conclusion

Children with normal TPMT activity may require dose alternations to ensure metabolites are at safe and therapeutic levels

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## Poster Number Thirty Seven

### Case report of Posterior reversible encephalopathy syndrome (PRES) in a 15 years old child with diagnosis of Early onset IBD ( IL-10 receptor beta deficiency) on azathioprine and very low dose of prednisolone

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A 15 year old girl with early onset inflammatory bowel disease secondary to IL-10 receptor beta deficiency. At the age of 2 months she presented to her local hospital with bloody stools diagnosed with cows milk protein allergy in view of this she was started on a cows milk protein free formula symptoms improved. At the age of 9 months had fresh bleeding PR, in view of this she had a colonoscopy done which was suggestive of inflammatory bowel disease. Since then she underwent different medical and surgical therapies.

She was initially started on sulphasalazine with no benefit. At this point in time her weight was static. At the age of 10 months she required sigmoid colostomy because of colitis, which got infected and therefore it was changed to ileostomy at the age of 12 months. She also required total parenteral nutrition intermittently. At this stage she was also diagnosed with right sided sensorineural hearing loss and therefore had a cochlear implant which was thought to be secondary to aminoglycoside exposure. At the age of 18 months had caecum and distal ileum resection, with reversal of her ileostomy. She had transient improvement in her symptoms.

At 30 months of age her symptoms started again with bloody stools in view of this had a repeat colonoscopy done which showed colitis – she was then started on azathioprine without any improvement. At 3 years of age her symptoms worsened and therefore required prolong period of TPN and trial of ciclosporin was given for 6 months but there was no improvement. At the age of 7 years because of poor response to the treatment she was referred to tertiary paediatric gastroenterology where she was found to have IL-10 receptor beta mutation.

At the tertiary paediatric gastroenterology unit she had a repeat endoscopy which showed gastritis and inflammation of small bowel in view of this she was started on azathioprine. At the age of 13 years she developed perianal abscess requiring incision and drainage with IV antibiotics. She was then started on EO28 on top of normal diet. She was continued on azathioprine, weaning dose of oral prednisolone and lansoprazole.

At the age of 15 years she presented to her local hospital with a fall and with abnormal behaviour. At this time she was on a very low dose of prednisolone and azathioprine. While in A&E at the local hospital she had a very high blood pressure and subsequently had a seizure for eventually she was intubated and ventilated. Her CT head showed low density signals in subcortical white matter of the right posterior cingulum with preservation of cortex, changes were suggestive of PRES syndrome. It was thought that child had PRES secondary to azathioprine and therefore all her immunosuppressants were stopped. Her repeat CT showed disappearance of changes seen in the initial CT scan.

Child now has had a bone marrow transplant for her IBD secondary to IL-10 receptor beta deficiency

## Poster Number Thirty Eight

### Idiopathic Small Bowel Diaphragmatic Disease in Paediatric Population

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#### Introduction

Small bowel diaphragmatic disease (SBDD) is a rare complication of small bowel enteropathy secondary to the use of non-steroidal anti-inflammatory drugs. Idiopathic SBDD is a rare entity in itself and it has not been widely reported in paediatric population. We present here a 33 month old girl who was diagnosed with SBDD by wireless capsule endoscopy (WCE) and further managed effectively by trans oral double balloon enteroscopy (DBE) and mini-laparotomy-assisted enteroscopy (LAE).

#### Case report

A 33 month old girl presented with a 1 year history of microcytic hypochromic anaemia with hypoalbuminaemia of unknown origin, requiring 5 blood transfusions over this period. No PR blood or melaena were identified. Night sweats and intermittent facial/pedal oedema were seen. The parents were second cousins. Racial background:

Initial normal/negative investigations at the referring hospital included: FBC; LFTs; clotting screen, B12, folate, fat soluble vitamin levels, thalassemia screen, electrophoresis, autoantibody/ANA screen, thyroid function tests, coeliac screen, ASOT, mycoplasma, EBV screen, parvovirus screen, Quantiferon, serum compliments, trypsinase, stool pancreatic elastase and urine neuroblastoma screens. The stool tests were negative for bacteria, ova cysts and parasites on multiple occasions but was positive for faecal occult blood. She also had an echocardiogram to rule out constrictive pericarditis.

The bone marrow aspirate and trephine biopsy at the referring hospital were suggestive of iron deficiency anaemia. She had low serum ferritin (3ug/L) and iron levels (1umol/L), needing intravenous iron infusion. Her urinary iron levels were normal, which ruled out renal iron loss.

Urine dipstick showed intermittent non-nephrotic range proteinuria and abdo ultrasound suggested nephrocalcinosis.

Raised faecal alpha 1 anti-trypsin level raising the possibility of intestinal lymphangiectasia was present. Elevated LDH potentially invoked other small bowel pathologies such as lymphoma. Faecal calprotectin was raised on more than one occasion precipitating the referring hospital to perform oesophagogastroduodenoscopy, ileocolonoscopy and a Meckels' scan, which were all normal except for mild chronic gastritis.

On referral to the gastrointestinal bleeding centre WCE was performed and this showed SBDD with ulceration associated with multiple narrow strictures/bands. Subsequent DBE and then LAE revealed 23 stenosing ulcerated concentric band type lesions over a 70cm span of small bowel 180 cm distal to the pylorus.

In addition a single gastric aphthoid ulcer and multiple terminal ileal aphthoid ulcers were noted and biopsied. The diseased section of small bowel was resected under the same anaesthetic. The infectious disease team review ruled out tropical disease but more information is awaited from the school of tropical medicine. Histopathology showed non-specific superficial ulcers of the mucosal surface with no evidence of vasculitis, CMV or inflammatory bowel disease, leading to a final diagnosis of idiopathic small bowel diaphragmatic disease.

#### Conclusion

To the best of our knowledge this is the second reported case of poorly understood paediatric idiopathic SBDD. Our centre published the first ever case report of SBDD in a 5 year old girl in 2012. The differential diagnosis of SBDD is NSAID-precipitated ulceration, Crohn's disease, vasculitis, intrauterine insults, CMV, tuberculosis and eosinophilic enteritis. This case highlights the importance of WCE and DBE/pan-enteroscopy in managing difficult cases of chronic intestinal blood loss.



**Poster Number Thirty Nine**

**Epidemiology of Inflammatory Bowel Disease in Staffordshire**

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**Background**

We have always noted there appeared to be clusters of paediatric IBD in our catchment area of Stoke-on-trent and North Staffordshire. We looked at the distribution of our paediatric patients with IBD by postcode and found that there was a striking difference in prevalence between different areas.

**Method**

We included all patients cared for by University Hospital of North Midlands Paediatric Gastroenterology team, our data source was the IBD specialist nurse’s database of patients. We included 85 patients ranged in age from 6 to 21. There were 57 boys and 28 girls. 53 patients had Crohn’s Disease, 25 Ulcerative Colitis and 7 IBD-U.

**Results**

Area	Number I	Populatio	Ethnicity	Area	Area Covered	Prevalence	Per 100000
ST1	3	240,306	71.4% White English	Stoke	Hanley, Cobridge, Sneyd Green, Birches Head	0.00001248	1.2
ST2	9	46,769	92.6% White English		Bentilee, Abbey Hulton, Bucknall	0.00019244	19
ST3	9	67,689	93.3% White English		Longton, Meir, Blurton, Weston Coyney	0.00015763	16
ST4	6	57,096	81.9% White English		Shelton, Stoke, Fenton, Penkhull, Trentham	0.00010509	11
ST5	20	82,261	94.3% White English	Newcastle Upon Lyme	Newcastle-under-Lyme, Keele, Chesterton	0.00024313	24
ST6	12	64,695	78.4% White English		Tunstall, Burslem, Smallthorne, Brown Edge	0.00018549	18
ST7	5	53,470	97.3% White English		Kidsgrove, Talke, Talke Pits, Alsager, Mow Cop, Audley	0.00009351	9.35
ST8	5	20,197	98.3% White English	Staffordshire Moorlands	Biddulph	0.00024756	25
ST9	4	11,933	97.2% White English		Werrington, Endon	0.0003352	33
ST10	0	25,399	97.1% White English		Cheadle, Church Leigh, Tean	0	0
ST11	2	9,827	97.9% White English		Blythe Bridge	0.00020352	20
ST12	0	3,597	96.2% White English		Barlaston	0	0
ST13	4	14,387	95.7% White English		Leek	0.00027803	28
ST14	1	20,789	97.1% White English		Uttoxeter, Stramshall	0.0000481	5
ST15	4	16,385	96% White English		Stone	0.00024	24
ST16	2	30,791	90.8% White English	Staffordshire	Stafford	0.00006495	6
ST17	1	39,360	93.3% White English		Stafford	0.00002541	3

Our findings show that there is a variability of rates of IBD in our region, which is not explained by difference in social class or ethnicity.

**Conclusion**

Our findings support the theory that although there are genetic predispositions to IBD, environmental triggers are very important. We would like to work further to identify differences in our populations in order to try and identify possible environmental triggers.

**Poster Number Forty**

**Factors beyond gastrointestinal symptoms in an allergy focused history in children with suspected food protein induced gastrointestinal allergies**

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**Background/Aim**

An allergy focused history remains the cornerstone for the diagnosis of food allergy. We therefore aimed to assess the prevalence of atopic family history, co-morbidities and prevalence of extraintestinal manifestations (EIM) in children with non-IgE mediated gastrointestinal food allergies (GIFA) to aid the diagnosis.

**Methods**

A prospective observational study was performed on patients aged 4 weeks – 16 years with non-IgE mediated GIFA. Only children in whom symptom improvement occurred after the elimination diet were included. A questionnaire regarding atopic family history, co-morbidities and EIM was completed by research nurses before starting the elimination diet to assess prevalence in children that improved on a dietary elimination.

**Results**

Data from 131 patients were analysed including 90 boys with a median age of 21 months [IQR: 7 to 66]. Eighty-three (63.3%) children had atopic co-morbidities: 68 (51.9%) had eczema, 38 (29%) asthma and 27 (20.6%) allergic rhinitis. Nasal congestion was reported in 70% of children. The median number of EIM per patient was 2 [IQR: 1 to 4]. The most commonly reported EIM were poor sleep (74.3%) and atopic shiners (51.4%). After 4 weeks of elimination diet there were a significant decrease in percentage of children presenting with poor sleep, fatigue, night sweats and dark eye rings. The majority of children (95.3%) had a family history of atopic diseases.

**Conclusion**

This study has shown that family history, atopic co-morbidities and EIM are important features in patients with non-IgE GIFA, and therefore taking these symptoms into account may facilitate the diagnosis and treatment.

**Poster Number Forty One**

**HLA typing and coeliac disease, is it being inappropriately used?**

Dr Siba Prosad Paul; Prof. Bhupinder Sandhu, Bristol Royal Hospital for Children

**Background**

The European guidelines (ESPGHAN) for diagnosing coeliac disease (CD) were revised in 2012 and recommend that in symptomatic children with tissue-transglutaminase-titres (tTG) of >10-times of upper-limit-of-normal (10xULN), a diagnosis of CD can be made without small-bowel biopsies provided they have HLA-DQ2/HLA-DQ8 positive haplotype. Approximately 30-40% of white population has HLA-DQ2 haplotype, although only 0.1-1% develops CD. So, vast majority of cases with positive HLA-DQ2/HLA-DQ8 will not develop CD as probability is only increased from 1% to 3%.

**Aim**

To check if HLA-DQ2/HLA-DQ8 testing is being used appropriately and if not, then to clarify its role for health professionals.

**Methods**

Analysis of case referrals where positive HLA-DQ2/HLA-DQ8 has been done inappropriately leading to wrongful diagnosis and/or waste of resources.

**Results**

Table below highlights illustrative cases. 2/4 patients wrongly diagnosed with CD and 2/4 inappropriately managed.

Sl. No.	Patient demographic	tTG-titres	HLA-haplotype	Symptoms	Action taken locally	Outcome
1	15-year/female	5.6U/ml (normal:<4U/ml)	<sup>†</sup> HLA-DQ2/8	Abdominal-pain	Diagnosed CD. Local hospital started gluten-free-diet (GFD)	Normal diet restarted
2	6-year/male	8U/ml (normal:<4U/ml)	<sup>†</sup> HLA-DQ2	Intermittent diarrhoea	Diagnosed CD. GP started GFD	Gluten restarted, small-bowel-biopsies negative. Diagnosis: Not CD
3	5-year/female	25U/ml (normal:<10U/ml)	<sup>†</sup> HLA-DQ2	Iron-deficiency anaemia	Diagnosed CD. Local hospital started GFD	Gluten restarted, small-bowel-biopsies positive. Diagnosis: CD
4	10-year/female	20U/ml (normal:<10U/ml)	<sup>†</sup> HLA-DQ8	Asymptomatic		Small-bowel-biopsies positive. Diagnosis: CD

<sup>†</sup>Inappropriately done (cost: £40/case)

**Conclusion**

This suggests that there is poor understanding of the role of HLA-DQ2/HLA-DQ8 in diagnosis of CD and the need for education. Its use should be limited to cases of tTG>10xULN where biopsy is no longer mandatory. HLA-DQ2/HLA-DQ8 testing should not be done to screen for CD.

**Poster Number Forty Two**

**Hydrogen breath testing in paediatrics: A retrospective audit of results in a tertiary paediatric centre.**

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**Introduction/Background**

Hydrogen breath testing (HBT) is a useful, non-invasive test which can be used to detect the presence of small intestinal bacterial overgrowth (SIBO) as well as intolerance or malabsorption of certain carbohydrates i.e. lactose, fructose, sucrose. SIBO is a condition in which abnormally large numbers of commensal bacteria are present in the small intestine. It is a common cause of IBS and is associated with a range of GI symptoms including abdominal pain, bloating, diarrhoea, constipation and malabsorption. HBT is now increasingly being utilised as a less expensive, alternative modality to quantitative culturing of jejunal aspirate (considered to gold standard for diagnosis of SIBO). Despite this there is a lack of consensus regarding the methodology and interpretation of results for hydrogen breath testing.

**Aim**

To evaluate the current protocol for hydrogen breath testing in a tertiary paediatric gastroenterology centre by retrospectively reviewing our current practise.

**Subjects and methods**

Patients were who were suspected on clinical symptoms, of having SIBO or carbohydrate malabsorption by paediatric gastroenterologists at a tertiary gastroenterology centre were recruited. Bedfont Gastro+ Gastrolyzer device was used for measurement using a standard, departmental protocol for the breath testing and analysis. Data of comorbid, underlying medical diagnosis, clinical presenting symptoms, reporting of symptoms during testing, results and clinical outcomes (resolution or improvement of symptoms) was recorded and analysed. 123 paediatric patients, M:F 54:80, median age 11 years (range 2 to 21) were included in the study. Data was collected over a 28 month period from January 2013 to April 2015.

**Results**

In total 134 hydrogen breath tests were analysed (lactulose n = 93; lactose n = 33; fructose n=5; sucrose n=3). 63/134 (47%) of HBT were positive of which follow-up data was available for 56 patients. 24/ 38 patients (63.1%) with a diagnosis of SIBO had a complete improvement of symptoms and 6/38 (15.7%) had a partial improvement. 2/38 (5.2%) had a deterioration in symptoms and 2/38 (5.2%) patients relapsed following antibiotic treatment. Only 9/134 (6.7%) patients reported symptoms of discomfort or related GI symptoms during HBT using Lactulose or lactose substrate. Abdominal pain (n = 88) was the main presenting symptoms as indication for hydrogen breath testing, followed by constipation with bloating (n = 47), chronic diarrhoea (n= 39). 15/18 (83%) patients with a positive result for carbohydrate intolerance/ malabsorption had complete resolution of symptoms following referral to a dietician and adherence to an elimination diet.

**Summary**

HBT is a useful, differential investigation for children presenting with functional and chronic gastrointestinal disorders. Two thirds of appropriately, clinically selected patients in a tertiary paediatric gastroenterology centre had a clinical improvement following treatment after a positive result using hydrogen breath testing.

**Conclusion**

The lactulose HBT offers an effective method for identifying SIBO and may be useful in management of an increasing population of children with IBS symptoms. As yet there is no documented consensus for the indications, methodology and analysis of HBT in the paediatric population. Moreover there is paucity of good quality, medical evidence for the treatment of SIBO. Further studies are required to validate the investigation protocol for HBT and the treatment SIBO.

**Poster Number Forty Three**

**Hyperplastic gastric polyp in an infant with Menkes disease.**

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A Caucasian infant with Menkes disease (MD) presented at the age of five months, with coffee ground vomiting, melaena with a significant drop of haemoglobin. Urgent endoscopic assessment revealed a friable bleeding trans-pyloric multi-lobulated sessile polyp of around 4 cm in diameter. (Fig.1). Due to further significant upper gastrointestinal bleeding, polypectomy occurred. Tissue lifting was achieved with plasma expander mixed with adrenaline and methylene blue. Piecemeal polypectomy was the procedure of choice (Fig.2). Due to the difficulty in lifting up such a folded and small area, endoscopic mucosal resection was performed with a grasp-and-snare technique using a dual channel operating gastroscope (Fig.3). Haemostasis was achieved by application of argon plasma coagulation where required. (Fig.4). No perforation occurred. Repeated debridement was required 6 weeks after which the growth was excised completely with no further blood transfusion required after that procedure. Histological examination confirmed ulcerated and inflamed hyperplastic polyp.

MD is a rare metabolic disease secondary to copper deficiency. Failure to thrive, neurological deficits, connective tissue weakness and bony changes are classical features of MD. (1) Four similar cases of hypertrophic pyloric gastric polyps in MD were all presented in infancy period (2,3,4), two patients had fatal extensive bleeding and two managed with surgical excision of the pylorus. One case developed multiple gastrointestinal polypoid masses on the gastrointestinal tract. (4)

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**Poster Number Forty Four**

**Microvillous inclusion disease (MVID): A regional centre experience**

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**Background**

Microvillous inclusion disease is a rare congenital enteropathy of the intestinal epithelial cells characterized by severe intractable diarrhoea typically beginning in the first hours to days of life (early-onset form). Rarely, the diarrhoea starts later around 6 to 8 weeks of life (late-onset form). It is characterised by a mutation in the MYO5B gene and is inherited in an autosomal recessive pattern with incidence at 1 in 200,000 in children from United Kingdom.

**Aim**

We describe clinico-pathological features and management of 4 patients diagnosed with MVID at our unit over the past 10 years.

**Methods**

Two children (Patient 2 & 3) were siblings and parents had two other healthy boys. Both of them showed metabolic decompensation, repeated episodes of dehydration, with significant infectious and liver complications. In patient 1 due to significant co-morbidities palliative care was accepted. All the patients demonstrated intestinal failure secondary to diarrhoea. Electron microscopy revealed an increased number of secretory granules in the apical cytoplasm of the enterocytes, vacuolation of the surface enterocytes with apical inclusions containing microvilli, and absence of the brush border. All patients received parenteral nutrition and 3 of 4 were referred for bowel transplant. Two patients died whilst on waiting list for transplant.

**Table1.** Summary of characteristics of 4 patients with MVID

Patient No	Sex	Gestation	Age at diagnosis	Weight	Consanguinity	Genetics (MYO5B Mutation)
1	F		< 1 week		Yes	Negative
2	F		< 1 week		No	Positive
3	M		3 weeks		No	Positive
4	F		11 months		Yes	Not tested

**Table2.** Clinical features, clinical course and outcome

Patient No	Clinical features	Clinical course	Outcome
1	Antenatal scans -dilated fluid filled bowel loops, watery stools, abdominal distension, weight loss, metabolic acidosis.	Cerebral cortical atrophy, schizencephaly, Hyperglycaemia, seizures, DIC, left leg thrombus.	Died at 5 weeks
2	Antenatal scans- dilated bowel loops. Loose watery stools	Recurrent hypoglycaemia, GORD, IFALD, Line sepsis, renal calculi, hypocalcaemia, Haemangioma right lobe of liver. Hypercholesterolemia, hypertriglyceridaemia.	Transplant at 17 months
3	Severe watery diarrhoea since birth, lethargy, worsening acidosis.	Recurrent hypoglycaemia, metabolic acidosis, IFALD, Low IgG, hearing impairment, VUR- recurrent UTI, recurrent line sepsis, Vocal cord paralysis, Atrial septal defect	Died at 11 months
4	Antenatal scans -polyhydramnios. Abdominal distension, chronic diarrhoea, failure to thrive, HLH at 4 months - unrelated cord blood transplant	Conjugated jaundice, delayed development, hepatosplenomegaly, coagulopathy, Vitamin D deficiency, Proximal tubular nephropathy	Died at 13 months

**Summary and conclusion**

MVID is a very rare disorder with generally poor long-term outcome despite diagnosis at specialist centre, early institution of parenteral nutrition and early referral for small bowel transplants. The partial or variant form can be missed till much later in infancy. Early small bowel transplant offers new horizon for disease management and outcome.



## Poster Number Forty Five

### Pica as a presenting symptom in very early- onset inflammatory bowel disease- a case report

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#### Introduction

Pica is an eating disorder defined as the repeated ingestion of non- nutritive substances for more than one month. Here, we discuss a case of pica as a presenting symptom of very early- onset inflammatory bowel disease (VEO-IBD).

#### Case

A 2-year old boy, born to non- consanguineous Bangladeshi parents, presented with a three-week history of per rectal bleeding, increased bowel movements, and abdominal pain. The volume of blood was described as a teaspoonful each bowel motion. His mother also described a 4- month history of pica, where he would eat tissue wipes, carpet, and wood. During periods of illness, he would drink only cow's milk.

Admission blood tests showed severe iron deficiency anaemia with haemoglobin of 48 g/L (normal 115-155), mean cell volume of 47.4 fl (normal 75-88) and ferritin of 2 ug/L (normal 15-300). Initial diagnosis was that of cow's milk protein allergy and he was therefore started on a dairy- free diet, but continued to have PR bleeding. Several investigations including coeliac screen and a Meckel's scan were negative. Subsequent colonoscopy showed chronic, focal pancolitis consistent with early- onset inflammatory bowel disease, following which an elemental diet of Neocate LCP, sulphasalazine, azathioprine and prednisolone were started.

#### Discussion

In our case, the history of PR bleeding, large intake of cow's milk and iron deficiency anaemia led to an initial diagnosis of cow's milk protein allergy. While pica is commonly associated with iron- deficiency anaemia, the mechanism through which this occurs is unknown.

VEO-IBD (defined as IBD diagnosed in children <10 years<sup>1</sup>) is a rare diagnosis, and a database search of Medline revealed only one previously reported case of pica linked with inflammatory bowel disease in 1974. Nevertheless, early diagnosis is crucial for optimal management, as patients tend to follow a more severe disease course and are often unresponsive to immunosuppressive treatment<sup>2</sup>. We therefore recommend that clinicians consider VEO-IBD as a potential differential when managing infants or toddlers with unusual symptoms, especially in the presence of other gastrointestinal symptoms.

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## Poster Number Forty Six

### The use of Alpha-1-Glycoprotein as a screening tool in inflammatory bowel disease compared with standard serological and faecal markers in children.

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#### Introduction/Background

Alpha-1-Glycoprotein (AGP) has been shown to be elevated in patients with inflammatory bowel disease (IBD). Studies have previously focused on other serological and faecal markers of mucosal inflammation to help establish diagnosis and in the evaluation of chronic disease activity.

#### Aim

The purpose of this work was to evaluate the use of AGP as a screening test for paediatric patients referred with suspected inflammatory bowel disease, when compared to routine markers such as C-Reactive Protein (CRP), erythrocyte sedimentation rate (ESR) and faecal calprotectin (FC).

#### Subjects and methods

A retrospective study was performed of all patients under 18 years of age whose AGP was measured from September 2014 to September 2015; analysing laboratory investigations that were simultaneously performed and reviewing medical notes for presenting complaint and diagnosis.

#### Results

A total of 58 tests were performed over a 12 month period. Fourteen results were excluded due to inadequate clinical information, making a total of 44 AGP levels in a patient population of 39 children (average age 12.3 years, male 46%).

Abdominal pain was the presenting complaint in over fifty percent of all children tested. Of these, seven children consequently or had already been diagnosed with IBD, giving a prevalence of 18% in this patient population.

A total of 16 positive AGP were identified (reference range normal  $\leq 1.1$ g/L) with a range 0.07-3.28g/L and median 0.9g/L.

In the diagnosis of IBD, the sensitivity for AGP was 72.7% and specificity 75.8%. Positive predictive value was only 50%, however when focusing on a higher reference range of AGP  $>2.0$ g/L, this improved to 77.8%.

AGP when used in combination with 2 other markers (i.e. ESR/CRP/FCP) improved specificity, sensitivity and positive predictive value to 70%, 94% and 91.4% respectively.

#### Conclusion

Abdominal pain is a common paediatric presentation, with IBD being one of several differential diagnoses. Almost two thirds of the patient's tested had negative AGP levels, with no evidence of inflammatory bowel disease in over 80%. As a general paediatrician or gastroenterologist, the measurement of AGP is a useful investigation in the screening and diagnosis of paediatric inflammatory bowel disease. AGP  $>2.0$ g/L has a higher specificity and positive predictive value than CRP, ESR and faecal calprotectin. The diagnostic value of AGP is significantly improved when used in conjunction with other inflammatory markers.

## Poster Number Forty Seven

### Very Early Onset Inflammatory Bowel Disease – a single centre experience

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#### Introduction

There is evidence to suggest that Very Early Onset Inflammatory Bowel Disease (VEOIBD) runs a more aggressive course when compared to older children with inflammatory bowel disease and may not respond to conventional therapy. We also know that many of these children have monogenic conditions with genetic defects that disrupt intestinal epithelial barrier function or affect innate and adaptive immune function.

#### Aim

To study outcomes and disease course in children with VEOIBD (6 years and under at the time of diagnosis) in the era of established biological therapy.

#### Method

A retrospective descriptive analysis was performed on patients with VEOIBD at the Queen's Medical Centre, Nottingham. These children were identified using the database and corroborated by clinician recall and histopathology records. Diagnoses were based on endoscopic and histological findings. We then analysed the medical notes, documenting diagnosis, histology findings, growth parameters, immune work-up, clinical course and management.

#### Results

We identified 12 patients with VEOIBD diagnosed between March 2011 and December 2014. 7 were male (58%). The median age at diagnosis was 3 years 6 months. Of our cohort: 5 had indeterminate colitis, 4 had a phenotype of Crohn's disease and 3 had a phenotype of ulcerative colitis. None of these children has been lost to follow up and the median duration of follow up is 15.5 months (4mo - 56mo).

Of particular interest 75% of this cohort were born to non-British born parents, possibly indicating that the aetiology of VEOIBD may be related to a rapidly changing microbiome interacting with the innate & adaptive immune system. 3 of the 12 patients were considered to have severe disease (all males), with one of these cases having proceeded to bone marrow transplant and two further cases currently being considered for bone marrow transplant. All three had a slightly earlier age at onset (2.7y) and found to have confirmation of functional genetic defects.

In terms of management 9 children received methylprednisolone at diagnosis to induce remission often followed by weaning of oral steroids. 9 children received Azathioprine. 4 received infliximab, 1 of whom progressed onto Adalimumab and Sirolimus in combination. At latest follow-up 9 out of the 12 children were considered to be in remission.

#### Conclusion

We describe the clinical course of children with VEOIBD. Histopathological diagnosis into Crohn's disease and UC is more difficult in this group and early work up for monogenic disease is recommended for planning individualised treatment. VEOIBD is a distinct and heterogeneous category of bowel inflammation, the incidence of which is rising and more likely to affect children born to recent immigrant families.

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