BSPGHAN
working for children with digestive and liver disorders

British Society of Paediatric Gastroenterology Hepatology and Nutrition

Newsletter

January 2013

President's Report
Dr Mark Beattie

This newsletter is a testament to the society and time and commitment of the membership with reports on the many activities reflecting our mission to improve the care of our patients through education, training and research. There are many challenges ahead. The society has evolved considerably over the last 25 years through the activities of the various sections and working groups, as stakeholders and partners in the delivery of care and is frequently consulted by external groups for our opinion and support. We will need to continue progress responding to the changes in the NHS, developments in information technology, increasing need for health care to be evidence based and quality assured and the challenges of training, appraisal and revalidation. The challenge in the modern NHS is to deliver evidence based care, as close to home as possible, in networks, delivering best quality within the resource available and as a society we need to work with other stakeholders in order to work out how best to achieve this. We are strengthened considerably by the enthusiasm and commitment of the membership, the multidisciplinary nature of the society and the strong patient groups who support us in our role. We will be strengthened considerably by engagement with other specialist groupings, the royal college and NHS commissioners.

At the core of our activities is the annual winter meeting with its educational and social programme and networking opportunities. Each year the meeting attracts record numbers of delegates and scientific papers. I would like to thank Charlie Charlton and the Nottingham team for organising such a successful meeting in January 2012 with its excellent academic programme and most enjoyable social programme, especially Charlie's amazing rendition at the Burn's supper. This was a fantastic start to the year. We have the Manchester meeting to look forward to this year and the annual meeting agreed for 2013 (London) with bids being sought for the 2014 meeting.

In the last year we have developed formal links with the Neonatal Nutrition Group and we held a very successful joint sessions with them at the RCPCH annual meeting in Glasgow organised by Sue Protheroe. I hope very much that we will be able to build on this link in 2013 with the Neonatal Nutrition Group now being represented on the Nutrition and Intestinal failure working group and further joint meetings proposed. There is a joint session with the Neurologists planned for the RCPCH meeting this year.

I am grateful to Rajeev Gupta for coordinating our input into the first Digestive Diseases week held in Liverpool in June 2012 with several successful joint sessions. The meeting was a great success and further meetings of this type have been proposed.

I am grateful to David Wilson and Susan Hill for coordinating our input into the BAPEN meeting in December 2012. Susan Hill has continued to represent our interests at the BAPEN council where we are core members and I am delighted to report that the BAPEN executive have agreed that we, as a society, should be affiliated members of the wider BAPEN grouping. BAPEN, as you will all be aware are major stakeholders at the national level in nutritional thinking and commissioning and consider paediatric involvement and engagement at the core of their business.

We held a very successful joint meeting for our Trainees and Associate members in Glasgow in October 2012. I am grateful to Mick Cullen and Richard Hansen for organising this. We held our

second national trainees meeting the afternoon before focussing on endoscopy skills (led by Paraic McGrogan and Patrick McKiernan) and an ST7 training session (led by Sue Protheroe) both of which were very successful and are now set to be annual events.

I am sure you are all aware that the ESPGHAN meeting will be in London this year. Ian Sanderson has put together an excellent programme and I hope very much that there will be a strong BSPGHAN representation at what promises to be a very successful event.

We have continued to work to influence the National agenda with regard to services for children with nutritional problems, gut and liver disease.

This has principally been to influence the commissioning of specialist services at a national level in the new in collaboration with the commissioners and royal college. I am grateful to Sue Protheroe who, on behalf of the society has worked tirelessly to ensure our views are communicated and heard and for the strong engagement of council and the membership during this process. I am very proud of the service scope and specification we submitted which were accepted virtually unchanged. They make clear what a specialist service offers, how it should be delivered and the conditions that should be seen. There is a strong emphasis on the needs of the patient, multidisciplinary care and delivery as part of a network. I am particularly pleased that Nutritional Support has been accepted as a core activity of our speciality, an area of work we have all felt was under recognised and so underfunded. The work stream has also started to address how we measure quality through setting standards and audit and our continued engagement in this process will be crucial to us delivering the best care in the new NHS. I feel as a society we have embraced the network model for delivering care and provided leadership to commissioners on this. This work stream improved our links with the Royal College of Paediatrics and Child Health and we have recently met with the new college president to discuss how we might further develop collaborative working with the royal college.

The next phase of this work stream is to continue with the programme (jointly with the department of health and royal colleges) to produce a consensus document on 'Improving the care of children with Gastroenterology, Hepatology and Nutrition disorders through networks' similar to the one published by the Paediatric Nephrologists previously. The commissioning documents produced this year are the first stage of this process. It will be important to engage all the relevant stakeholders in the process and ensure that the document reflects the best evidence and pathways for delivery of care with quality standards and benchmarking to ensure equality of access and care. We will need to continue to devote time and some of the society's resources to this important work stream.

We are fortunate that the society remains financially robust and I am grateful to Mike Cosgrove's careful stewardship of the society's monies and time and commitment to raising funds and spending those monies wisely. The winter meeting remains a significant income source despite us holding down the cost as a consequence of the continued sponsorship of our partners in industry. The society's expenses do however continue to grow. We have negotiated some longer term sponsorship deals but in addition to this we will need to look at increasing the membership fees if we are going to maintain and further develop the society's profile.

The website remains a priority. Paul Henderson has now been appointed as website lead and will be working with members to ensure we get the right information posted, in the right format, to best serve the needs of the membership. We need to debate whether the site should be essentially a noticeboard to keep members up to date with the society business or a dynamic resource which requires significantly more time to and resource to maintain.

I am delighted that we were able to make 2 further joint BSPGHAN/CORE research awards this year which now makes four in total having awarded 2 previously in 2010. This is now an established collaboration and one which enables the society to directly fund research in line with our mission. I hope very much that we will be able to fund a further joint call in 2013/4.

The research agenda of the society remains active, strengthened considerably by the close link between the research committee led by Julian Thomas and the MCRN led by Nick Croft. The group is working hard on behalf of the membership. It is important that we all engage with the process to

develop an HTA endorsed BSPGHAN research portfolio which they have written to members about and will discuss at the AGM and research meeting in Manchester. This will have considerable lasting benefit to the speciality and the development of the clinical research agenda.

I am pleased that the society has been active in many areas this year. We have continued to work with our surgical colleagues to improve care networks for children with intestinal failure with a strong emphasis on regional services and regional collaboration. This has been in parallel to developments in the adult services. It is clear that data capture will be essential and we have been working closely with colleagues in BAPEN to re-launch the British Intestinal Failure Survey using the e BANS reporting system. Andrew Barclay is leading for BSPGHAN on this as part of a joint initiative with BAPS. We need the members to engage in data entry once the system is live if we are going to improve the care of these infants through collaboration and research. Annual centre specific reports will be available and such data is likely to be used as part of the commissioning process for audit and benchmarking.

Ieuan Davies supported by Ronald Bremner has taken over as chair of the Endoscopy working group and is a member of council. His report reflects the significant progress made over the last 12 months and challenges ahead. We now have agreed training guidelines endorsed by the College Specialist Advisory Committee (where responsibility for accreditation lies) and the Joint Advisory Group for Endoscopy which we are members of. There are many on-going issues including assessment, accreditation and revalidation.

I am grateful to the members for taking part in the 3rd National IBD Audit (2nd for Paediatrics) and hope there will be good engagement with the just launched 4th round. I hope members will continue to enter children who start monoclonals into the biologicals register. It is likely that we will be able to register all cases of IBD into a National register soon. This work stream is all joint with the adults and has been a considerable success in terms of collaboration with BSG members and serving the patients with IBD better during childhood, transition and as adults. Sally Mitton and Richard Russell have worked tirelessly on behalf of the membership to promote the paediatric perspective and help make things happen and I am grateful to them for their time and commitment to this.

We have seen significant changes in the criteria for the diagnosis of Coeliac disease with the new ESPGHAN guidance which we all agree is appropriate and robust although not necessarily easy to implement. Two specific issues include the absence of standard methodology for antibody testing and HLA testing not being easily or universally available. Simon Murch reconvened the Coeliac disease working group and has developed comprehensive guidance now ready for publication. It will be important that with its implementation we audit the diagnostic pathway to ensure the guidance is used properly and the diagnosis of Coeliac disease is made appropriately and definitively.

I am grateful to the other working groups and committees for their considerable enthusiasm and work on behalf of the society, Rajeev Gupta as chair of the Education Working Group, Anil Dhawan as chair of the Liver Steering Group, David Wilson as chair of the Nutrition and Intestinal Failure Working Group, Mick Cullen as chair of the Associates Group, Richard Hansen as chair of the Trainees group, Nikhil Thapar as chair of the Motility Working Group and Robert Heuschkel as chair of the Inflammatory Bowel Disease Working Group. I am grateful to Sue Protheroe who as lead for clinical standards has put considerable time and energy into coordinating our responses to NICE and other consultations.

I would like to thank our PPP partners for their considerable engagement and support of the society: Sarah Sleet who has joined council, Catherine Arkley, Richard Driscoll and Rod Mitchell.

I would also like to acknowledge and thank our partners in industry for their support of the society's activities and meetings.

I would like to thank the retiring council members. David Wilson for his considerable support and commitment as chair of the Nutritional and Intestinal Failure Working group and Rajeev Gupta for his time and commitment as chair of the Education Committee.

I would like to acknowledge the considerable enthusiasm and commitment of Sue Protheroe and Mike Cosgrove and previously Nick Croft and Alastair Baker who have given me so much support as president in their respective roles as convener and treasurer and all the council members I have had the privilege of working with over the last 3 years.

I would like to thank Carla Lloyd the society's administrator for her considerable commitment and enthusiasm for BSPGHAN and for help and support over the last 3 years.

We held a strategy day in November to review the society progress over the last 10 years, our strengths and challenges and how we best utilise our resource to fulfil our mission. The achievements of the society have been considerable. It is clear that infrastructure, time commitment of members, administrative support and website developments are challenges. It is clear that we will have to maintain our strong profile to impact on service delivery and development in the new NHS. It is clear that we need to remain a cohesive society responding to the needs of all of our members' specialists, generalists, trainees and associates. It is clear that our external links with other organisations strengthen our profile and ability to impact. It will be important we reflect on these issues and use them to inform the work plan of council and the specialist and working groups.

It has been a real honour to serve as president of BSPGHAN. My role has been made so much easier by the enthusiasm and commitment of the membership and I would like to wish Alastair Baker every success as he takes over this exciting and fulfilling role.

Convenor's Report
Dr Sue Protheroe

I'd like to give a warm welcome to all 13 of our new members who joined this year. Our membership remains healthy with a total of 411 members (196 consultants, 59 trainees, 22 honorary (retired/ overseas) members, and 147 Associate Members).

Thank you for taking the time recently to vote for the new representative on Council to represent Education. The election result and the Nutrition and Intestinal Failure Working Group representative will be announced at the AGM. Grateful thanks are extended to David Wilson, for his tireless energy chairing the Nutrition & Intestinal Failure working group and for steadfast contributions to consultations from NICE. Many thanks also to Rajeev Gupta for his enthusiasm and commitment to Education and Richard Hansen for organizing a great TiPGHAN meeting this year with Mick Cullen, and for representation for trainee members.

We welcomed Bim Bhadhuri (PEGHAN rep on Council) as a vital link with colleagues with expertise in the specialty and Bruce Jaffray co-opted onto Council from BAPS, who has contributed to relevant topics, including training and JAG, and Sarah Sleet, Chief Executive of Coeliac UK, in the Patient Professional Partnership has provided a valuable advice regarding the patient's voice. We look forward to working with Fiona Cameron as trainee representative. In 2012, Council voted for a change to the Constitution to include an Endoscopy representative on Council and it was a pleasure to welcome Ieuan Davies as Chair. Ieuan has continued a dialogue between BSPGHAN, CSAC, BAPS, The JAG, BSG, educational supervisors and endoscopy leads in developing JAG/JETS, Paediatric GRS, trainee e-portfolio certification, and revalidation. Ron Bremner has provided helpful insights and energy as vice chair to ensure that BSPGHAN input is available when required. We have also welcomed Paul Henderson as webmaster.

Key outputs from the Society in 2012

1. Stakeholder involvement & Contribution to Quality initiatives 2012
NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

- *Scoping workshop coeliac disease clinical guideline, (consultation process begins 14th March).*

- *Eating Disorders (review)*
- *Scoping workshop – GORD in children*
- *Hepatitis B*
- *Intravenous fluid therapy*
- *Obesity (review) & NICE public health guidance: Overweight and obese children and yp*
- *Organ donation*
- Review of HTA Guidance No.140; Infliximab for subacute manifestations of ulcerative colitis
- *Scoping workshop- Cholelthiasis and cholecystitis*
- *Upper gastrointestinal bleeding*
- *HTA -Peginterferon alfa and ribavirin for the treatment of chronic hepatitis C in children*
- *Dyspepsia: Managing Dyspepsia in Adults in Primary Care (CG17)*
- *Update of Diarrhoea and/or Vomiting in children (review)*
- *Quality Standards for Nutritional Support (Adults)*
- *NICE Service delivery guidelines -Seven day working - scoping workshops*
- *Consultation on NICE Clinical guidelines manual 2012 update* ***http://guidance.nice.org.uk/CG/Wave21/1/Consultation/Latest***

Others

- *DH consultation on the UK plan for rare diseases*
- *NPSA rapid response report for consultation: Harm from flushing of Nasogastric tubes*
- *National Screening Committee UK NSC review http://www.screening.nhs.uk/biliaryatresia.*
- *NHS Fetal Anomaly Screening Programme- care pathways for gastroschisis and exomphalos*
- *IBD QIP*
- *Quality Standards Advisory Committee (QSAC)*
- *BAPEN Nutrition and Hydration Action Alliance*

BSPGHAN is a specialist society that is recognized to nominate consultant members for Clinical Excellence Awards Scheme. The ACCEA announced a new national awards round in 2012 (see the consultation process on the Review of CEA Scheme http://mediacentre.dh.gov.uk/2012/12/17/doctors-contracts-fit-for-the-21st-century/).

2. Promotion of education and engagement with colleagues

It was an excellent opportunity to forge closer links with colleagues in the Neonatal Nutrition Network with a joint specialty group programme on Tuesday May 22nd at the RCPCH Annual Conference in Glasgow, 2012. The theme for the Conference was very topical: "The early years..." Professor Neena Modi opened the session with a stimulating guest lecture followed by excellent and lively contributions from Professor Atul Singhal, Dr Peter Willatts and Dr Andrew Barclay. Links were forged between the two specialty groups allowing collaborative working for the new Intestinal Failure Registry that Andy will lead on. A member of the Neonatal Nutrition Network joined the NIFWG.

We are pleased that the BSPGHAN Annual Dinner, kindly sponsored by Mead Johnson, will be on June 6th 2013 to coincide with the 2013 RCPCH Annual Conference which is being held jointly with the 6th Europaediatrics, the biennial conference of the European Paediatric Association, at the SECC in Glasgow. An ESPGHAN Symposium has been arranged on the morning of Friday 7th June and we will follow with our joint Specialty session where BSPGHAN and BAPN, (British Association of Paediatric Neurology), joins forces that afternoon. We are delighted that Dr Hilary Cass will open our session with a guest lecture on the challenges of feeding children with neurodisability and guest lectures will include assessment of migraine syndromes and dysphagia. There will be opportunities for seeing many abstracts and poster presentations and it should be an excellent meeting. I hope you will book your travel to Glasgow in advance and that you will all be there.

Further links with colleagues were made at the BSG, BAPEN, BIFA and DDF meetings in 2012. We have aspired to link up with colleagues in BAPS and are pleased that BSPGHAN has a joint symposium at the BSPGHAN Annual meeting in Manchester.

3. Challenges for the future- and thanks for help with the present

The Health and Social Care Bill was introduced into Parliament in January 2011 with the aim of improving health outcomes for patients in England through modernising the NHS. Specialised Commissioning Groups and their PCT's will be abolished in April 2013. The new NHS Commissioning Board is poised to take control of the day to day running of the health service in England. Much of this will involve CCG's but responsibility for £12 billion worth of Specialised Services will rest with the NHSCB. In preparation for April 2013, when the board will go "live" there has been process of transition, a process of service-specific clinical assurance has been under taken by a Clinical Reference Group for Paediatric Medicine.
This time last year, we were eagerly awaiting the announcement about transition to the new commissioning arrangements and so we prepared ourselves to ensure that the quality agenda was foremost by forming collaboration with RCPCH. We felt that it was important to ensure that nationally consistent service specifications and commissioning policies were developed based on appropriate quality indicators, to ensure that that we could influence the standards to be incorporated into contractual arrangements with providers.

The Head of Transition to new Commissioning then invited BSPGHAN to join the Clinical Reference Group for Paediatric Medicine, to influence the commissioning process for Paediatric Gastroenterology Hepatology and Nutrition. This has allowed constructive working with other specialty groups and we were asked to produce the new Scopes (what should be commissioned by the NHS CB) and Service Specification, allowing our members to make an impact on the way specialized services are commissioned. The consultation work includes assessing patients' needs and ensuring that services are safe, effective, patient-centred and of high quality and provide uniform, better care across the whole of England. BSPGHAN has sought engagement with the four home nationals over these standards and service delivery.

Products of the CRG will include: -

- Quality Standards achieved via Quality Dashboards. *The dashboard is a tool to facilitate discussion between commissioners, the provider organization, and the clinical team to focus on interventions that make a measurable change to care quality. Dashboards should reflect NHS Outcome Framework measures and NICE Quality Standards where these are available.*
- Commissioning for Quality and Innovation (CQUIN) - *Nationally adopted CQUINs will encourage greater consistency of quality and concentrate on the most efficient outcomes from Care Pathways for 2012-2013*
- Quality, Innovation, Productivity and Prevention (QIPP) *brings with it a potential to get new treatments to patients faster as part of a managed evaluation of their value.*
  www.commissioningboard.nhs.uk/files/2012/11/op-model.pdf
  www.commissioningboard.nhs.uk/files/2012/11/comm.int.pdf

There is an opportunity to take part in the Consultation Process for Service Specifications via the link http://www.commissioningboard.nhs.uk/ourwork/d-com/spec-serv/consult/ **and consultation will run from 12 December 2012 until 25 January 2013** and a report of the findings will be published in early 2013. If you are able to respond, please feedback also to secretary@BSPGHAN.org.uk and president@BSPGHAN.org.uk. The commissioning process aims to achieve equity of access to excellence in specialised care, regardless of where patients live. Hence, with equity in mind, we believe that we should plan services around what patients *should* receive, and not around what a centre can currently offer and recommend that we state that: "Care is delivered in a well-defined clinical network with clear mechanisms for communication across the network. The network would have sufficient consultant numbers to provide consultant continuity with cross cover".

Service specifications will be finalized taking into account the feedback from the consultation. The purpose of this exercise is to ensure that they reflect the priorities for the people using those services and to give providers the opportunity to prepare and feedback on proposed changes to services.

And so …Looking to 2013

1] New commissioning- We can celebrate that as a truly multiprofessional organization representing dieticians, nurses, pharmacists and other health care professionals, trainees and patients, we are well

placed to improve and to strengthen the whole patient pathway. Further consultation work will be useful to identify the implications for service delivery of making the developmental standards mandatory and further patient and public involvement will follow all the work. Thanks to Richard Driscoll who has agreed to help the CRG with this work. Grateful thanks go to Richard from BSPGHAN for his many achievements for young people with IBD and we would like to wish Richard well in his retirement.

2] In 2013, BSPGHAN will explore how members can benefit from links with partner Societies. We have been liaising with Hilary Cass at the RCPCH. BSPGHAN will seek to develop a paediatric Intestinal failure registry with BAPS and colleagues in Neonatology, with e-BANS as the tool to ensure consistent audit of the services for Intestinal Failure.

And finally,

Thanks must go to Carla for her invaluable professionalism, much valued knowledge and dedication to the Society and also thanks for help from our partners in industry –we would be unable to run our educational meetings without your support.

It's been a pleasure to work with all Council members, and I know that we will all wish to use this opportunity as Mark moves on, to acknowledge Mark's insights, and skills in steering the Society forward this year.

Many heartfelt thanks must go to Mark- all of the work mentioned here and that detailed elsewhere in the reports, are a product of his dedicated efforts, with his indefatigable enthusiasm and sense of responsibility to get things right. Mark has given his services to BSPGHAN Council for 9 years, and we are indebted to the many hours of personal–time that he has given over nearly a decade for the benefit of members. We are proud of his noticeable achievements including Editor of Archives and I'm sure we will all wish him continued success in that demanding role. I'd like to extend a warm welcome to Alastair; BSPGHAN has a promising future ahead with Alastair at the helm and I know he will be well supported. Last but not least, I would like to thank Council and members too for responding to requests for consultation this year.

Wishing you all a healthy and Happy New Year.

Treasurer's Report
Dr Mike Cosgrove

The last year has continued to be financially challenging for the society. The accounts for the financial year 2011-12 showed a net deficit of £6,000. This was despite a very respectable surplus from the winter meeting in Nottingham of almost £25,000. These figures demonstrate again the importance of maintaining strict control over the financial outgoings of the society, and of continuing to look for means of increasing income.

Sponsorship outside of meetings has continued to be difficult to secure, and was nearly £7,000 less in 2011-12 than in the previous year. However, negotiations with potential sponsors are at a promising stage for future deals.

Membership annual subscriptions have remained unchanged for 7 years, and now account for only 15% of our total income. I will therefore be proposing for ratification at the AGM that membership subscription be increased to £100 annually for full members and to £20 for associate members.

We have investigated the possibility of using the Direct Debit system, which would make collection of subscriptions easier. Unfortunately our relatively small turn-over, and the unacceptability of a potential liability to massive compensation in case of error, mean that we need to continue with the more unwieldy Standing Order system. Having spent a lot of time over the last year reconciling underpaid and overpaid subscriptions resulting from the last change in subscriptions, we would ask the co-

operation of all members in promptly amending their Standing Order instructions if the change in subscriptions is agreed at the AGM.

I would like to thank all council members, and chairs and members of working groups for their help in keeping travel expenses claims to a minimum by taking advantage of discounted fares by booking in advance, and arranging meeting times outside of peak travel times.

We have decided not to restore the BSPGHAN bursary scheme this year, feeling that society funds would be better used supporting educational and training opportunities for all members, especially associates and trainees, rather than just a few.

We have renewed the agreement of engagement and terms of business with our accountants, Hillyates, and I would again like to acknowledge the excellent service we receive from Peter Hill.

Overall the finances of the society remain healthy. However, we recognise the need to continue to explore novel ways of generating income, and with this aim a development committee will be established. Increasing our income will allow us to pursue more of our ambitions as a society.

Committee and Group Reports:

Coeliac Working Group:
Professor Simon Murch

Membership

Ronald Bremner	Paediatric Gastroenterologist	
Assad Butt	Paediatric Gastroenterologist	
Stephanie France	Dietician	
Mark Furman	Paediatric Gastroenterologist	
Peter Gillett	Paediatric Gastroenterologist	
Huw Jenkins	Paediatric Gastroenterologist	
Maureen Lawson	Paediatric Gastroenterologist	
Bruce Mclain	Paediatric Gastroenterologist	
Mary-Anne Morris	Paediatric Gastroenterologist	
Simon Murch	Paediatric Gastroenterologist	Chair
Sarah Sleet	Coeliac UK	
Matthew Thorpe	Paediatric Gastroenterologist	

The Coeliac disease working group reconvened in September 2011 to assess the proposed new ESPGHAN Coeliac disease diagnostic guidelines due to be published in 2012. These guidelines proposed a significant shift in diagnostic approach in symptomatic children found to have high titres of IgA tissue transglutaminase antibodies (x10 x upper limit of normal for assay). In these specific circumstances, diagnostic small bowel biopsy could potentially be omitted for the first time since the 1960's, provided that a second blood sample confirmed that the child was endomyseal antibody positive and possessed the appropriate HLA-DQ type (DQ2 or DQ8).

The working group assessed the ESPGHAN documents and supporting studies at a number of meetings and via correspondence. A group decision was reached that the guidelines, if followed properly, did offer as secure a diagnosis as current biopsy based criteria, as histology may be atypical or difficult to interpret. There was concern however that diagnostic corner-cutting might occur, and that biopsies may be omitted inappropriately if the guidelines were misunderstood. There was also concern that funding for HLA typing might be patchily available, and that health economic analysis might be required before NICE approval.

An outline paper was published for guidance of general paediatricians (Jenkins HR et al. Diagnosing coeliac disease. Arch Dis Child 2012; 97: 393-394). The WG developed updated BSPGHAN protocols for Coeliac disease diagnosis, including both children with symptoms suggesting possible disease and those with associated disorders. These were presented at the 2012 Winter Meeting and the draft submitted to the membership for comments and to Council for approval. The final BSPGHAN guidelines will be launched in collaboration with Coeliac UK.

IBD Working Group:
Dr Rob Heuschkel

IBD WG Annual Report 2012

Membership on 1.11.2012

Nadeem Afzal	Southampton	Gastro
Marcus Auth	Liverpool	Gastro
Ronald Bremner	Birmingham	Gastro
Charlie Charlton	Nottingham	Gastro
Nick Croft	Royal London	Gastro
Mahmoun ElAwad	GOS	Gastro
Vikki Garrick	Glasgow	IBD Nurse
Jochen Kammermeier	Oxford	Trainee
Sally Mitton	St George's	Gastro
Mary-Anne Morris	N & Norwich	Paediatrician
Simon Murch	Warwick	Gastro
Astor Rodrigues	Oxford	Gastro
Richard Russell	Glasgow	Gastro
Rita Shergill-Bonner	GOS	Dietitian
Ian Sugarman	Leeds	Paediatric Surgeon
Adrian Thomas/Tony Akobeng	Manchester	Gastro
Su Bunn	Newcastle	Secretary
Rob Heuschkel	Cambridge	Chair

The group held 3 meetings in 2012 (26.1, 29.5 and 4.10.2012). During the last 12 months, the group has focused on the following priorities:

1. We have continued to support the **Quality Improvement Program** by not only returning data, but by further improving and amending the questions of the dataset that has now been returned twice by many units. This BSG workstream is likely to merge with the IBD Registry in due course, with specific measures of quality being included along with a revised set of IBD Standards. The pilot of the National IBD Registry is planned for 2013. The RCN have agreed to fund expenses for units wishing to arrange peer-review / QI visits to discuss local results and further improve their services. These visits have begun with a team from Glasgow/Aberdeen visiting Leeds in October and Cambridge and Southampton are reviewing each other's services in November 2012. Initial impressions are that these visits are extremely helpful in focusing attention of the local team and management on improving quality of care.
2. The WG spent two meetings discussing and preparing a draft set of **Clinical Outcome Measures.** These measures are increasingly important as commissioners look to fund 'effective' care. The WG has agreed an initial set of key measures which is now for discussion by council and membership. These would then be put forward for inclusion in the longer-term registry data. (Measures attached as appendix)

3. Given the ongoing state of flux for the society website, the WG have been unable to post meeting minutes, pIBD CATs and other working documents produced by the WG during the year. Only one further **pIBD CAT** is being ratified, the lack of enthusiasm at least in part due to lack of ability to have these visible on the website. We look forward to seeing a set of webpages containing all documents next year.
4. The WG (via RR, SM) has remained active in supporting the ongoing biologics audit, to which the majority of units continue to return data. There is an action plan available from the **3rd National IBD Audit**, that is available for local implementation and elements of which have been included in the new Registry dataset.
5. The group worked on a number of documents which will be useful in day-to-day clinical practice. A generic set of medical **Guidelines on Azathioprine** has been produced from a number of local/regional documents available to the group. Following liaison with CCUK (formerly NACC) the IBD WG will have significant input into a new round of documents to be produced by CCUK for children and young people with IBD. This patient information available and utilized by most IBD services nationally will now include input from both the BSPGHAN IBD WG and the BSPGHAN/RCN IBD Nursing Group. A comprehensive **diagnostic dataset** has been ratified and completed by the group and should be available for download once the website is up and running. In the meantime the group will use **Dropbox** as a means of updating and storing completed documents. The same goes for a core **annual review dataset** that the group feels should be captured in an annual review visit/process. The group agrees however, that without adequate IT support a more comprehensive, stand alone, annual review for each patient at present remained beyond the reach of most units. Again such data should be captured in the forthcoming prospective IBD Registry.
6. The WG has continued to provide **comment and representation** on various committees – IBD Standards (RH, VG), IBD Audit (SM,RR), IBD Registry (NC) and Crohn's disease NICE guideline group (AT), BSG Children and Young Adult Forum (SM). During 2012 NICE required feedback prior to the publication of its Crohn's guideline, as well as advance input on both anti-TNF use in ulcerative colitis, and the planned NICE UC guidance due next year.

Endoscopy Working Group
Dr Ieuan Davies

Report of the BSPGHAN Endoscopy Working Group to the Winter Meeting 2013

In early 2010 the Endoscopy Working Group & the PGHAN CSAC was given a mandate by the RCPCH to work with the Joint Advisory Group on GI Endoscopy (JAG) to agree a curriculum for paediatric endoscopy training, to develop suitable assessment systems and to introduce a robust certification process. It follows logically that we should also work with JAG to address the service issues and consider clinical governance under the headings of quality and safety.

In my first year as Chair we have completed work that had been started giving priority to the training side of the equation. Emphasis will now be shifted to utilizing the new structure we have developed to collect data to evidence and support the endoscopic practice of our members.
The group has met formally twice (June 12th & October 16th), I have attended the two JAG meetings this year, I have been co-opted on to the PGHAN CSAC and I have also attended and contributed to every Council meeting.

I highlight the following areas to the society at the AGM:

1. The Group **Terms of Reference** have been redrafted and are available on request.
2. The **Structure** of the group has been changed to avoid duplication and aid communication. The membership is enclosed as an **appendix**. There are now 5 **Regional Endoscopy Leads** and a **Hepatology Lead**. These colleagues will cover both training and service issues across the geographical service network areas and the educational grid regions. It is essential that they develop and maintain a formal network structure to communicate bilaterally between all trainers / endoscopists and the group / JAG.

3. I have worked closely with Adrian Thomas (CSAC Chair) and am grateful for his assistance. The **curriculum** for training in diagnostic upper endoscopy and colonoscopy has been completed, the **certification process** has been agreed and the **JETS system** (although designed for adult practice) is being utilized almost everywhere. The Sheffield endoscopy courses will be assessed by JAG during the spring and we have clarified the aspiration that all trainers should be aiming to complete an endoscopic "Training the Trainers Course" (although this is not yet a necessary requirement to being a trainer).
4. In respect of **Quality & Safety** we are about to pilot a paediatric endoscopy Global Rating Score (GRS) in two units. We will also (through the Regional Endoscopy Leads) be carrying out an anonymised, retrospective audit of rare complications (including colonic perforation). This information is essential to refute the totally unsubstantiated challenge that "paediatric endoscopists are plagued by low numbers and excessive complication rates".
5. **Future direction** will include a prospective audit to identify precisely who is carrying out Endoscopy on Children (through JAG), an extension of the training guidance to cover therapeutic procedures and further changes to our Terms of Reference to ensure continuity.
6. I **thank** those colleagues who laid the foundations for our progress and the current group for taking this forward and **finishing** what has been started. I highlight the previous work of Paraic McGrogan & Mike Thomson , the current efforts of Ronald Bremner (Vice Chair), Mark Feeney (JAG) & David Rawat, the necessary prompting of the Convenor & President, the tactful wisdom of Mark Dalzell & Simon Murch, and the support of Sanjay Rajwal, Mick Cullen, Bruce Jaffray & Ed Giles and (of course) the organizational skill set of Carla Lloyd.
7.

Membership of the BSPGHAN Endoscopy Working Group 2012

Chair – Ieuan Davies (elected, Council Member, representative to JAG)
BSPGHAN **Convenor**
BSPGHAN **President**
BSPGHAN **Associate Members Representative** – Mick Cullen
BSPGHAN **Education Committee Representative** – need nomination
BSPGHAN **DGH Committee** – Bruce Mclain
BSPGHAN **Gastroenterology Committee** – Simon Murch
BSPGHAN **Trainees Committee** – Ed Giles
BAPS Representative – Bruce Jaffray (Paediatric Surgeon)
RCA Representative – a nomination will be requested. (Paediatric Anaesthetist)
JAG Representative – Mark Feeney
PGHAN CSAC Representative – Adrian Thomas
Regional Endoscopy Leads
Scotland – Paraic McGrogan
Yorkshire, East Midlands & North East – Mike Thomson
Liverpool, Manchester & Northwest – Balaji Krishnamurthy (replacing Mark Dalzell)
Birmingham, Wales & South West – Ronald Bremner (Vice Chair)
London, Central & South East – David Rawat
Hepatology – Sanjay Rajwal

Motility Working Group
Dr Nikhil Thapar

The BSPGHAN gut motility disorders working group was set up approximately 1 year ago.

In December 2011 we held the first meeting to discuss the roles of the group as well as specific projects. We reflected on the fact that potential remits of a 'gut motility disorders' working group were very broad and included both common disorders (Gastro-oesophageal reflux, Constipation) through to those that were multidisciplinary (GMD in the context of neurological disorders) and rare and complex (intestinal pseudo-obstruction). The December meeting focused on the development of clinical networks for intestinal pseudo-obstruction given BSPGHAN's involvement in the designation process and commitment to improve available clinical services and UK expertise. It was held in conjunction with a 'study day' to which UK paediatric gastroenterologists, paediatricians, allied professionals and

support groups were invited. Following discussion and agreement these networks are now being developed on a 'reactive' basis dependent on where referrals come from. The process is still being streamlined with gradual improvements in the engagement of secondary and tertiary paediatric/gastro units to be involved in care. A progress update will be provided to BSPGHAN in the new year.

Most recently, by way of a short questionnaire, the group surveyed the BSPGHAN membership to get a sense of the spread of expertise and activity in diagnosing and managing motility disorders across the UK. The response has been fair and the results are currently being collated. Any members that have not submitted the questionnaire are still encouraged to do so.

At a follow-up meeting the GMD WG discussed the following

1. Membership of the group - Unfortunately over recent months the group has somewhat diminished given commitments of some of its original members to other BSPGHAN duties. Although now left with a smaller but active working group it was felt that the group should be expanded. We encourage any interested individuals from across the multidisciplinary team (secondary and tertiary units) to apply. In addition we may come looking for you!

2. Data collection on 'motility activity'- In an effort to expand the important collection of data on expertise and activity and to commence our initial project (see 3.) we may seek to target a number of units in the UK – e.g. from working group units and those that have suggested they have motility activity. We hope that the selected units will partake in this and identify a contact to provide detailed information (on the lines of the questionnaire but more) on their ability and activity. We will be reliant upon, and are grateful for, the initiative of working group members and the units involved.

3. Project 1: Improving and standardising the use of pH/impedance studies. It is hoped that the same group of 'pilot units' from 2. (above) will then be included within an audit of pH/impedance studies determining (i) how many are carried out (ii) protocol used (iii) who runs and interprets the tests (iv) method of analysis (v) treatments initiated (vi) problems/encountered. We chose ph/Impedance because it is clear that a huge number now utilise this investigation and equipment but experience and practice is very varied.

Once this data is analysed we (as a working group) will organise a 'study day' involving the 'pilot units' ± other interested units to start to address this area and hopefully develop (i) shared protocols for indications, procedures and analysis and (ii) possibly build towards a UK consensus. We are looking towards running workshops on analysis and look towards some sort of output. There is potential for the study days and workshops to be run through existing initiatives. More details will be communicated to the membership once a structure and support is decided.

We have opted to focus on some commonly applied motility tests initially to ensure the remit of the group is most relevant to the membership. If the pilot goes well we hope to expand this to more UK units ensuring there is a geographical spread. If this initial initiative is successful we could look towards funding (e.g. NIHR) to support an individual/project on a more nationally inclusive study.

Research
Dr Julian Thomas

<u>BSPGHAN Research Committee Report, Jan 2013</u>

This is a period of significant change for clinical research in the UK, as NIHR undergoes a comprehensive re-structuring process. NIHR support for Paediatric Research from April 2014 onwards will be provided via themes, and delivered through geographically defined units (replacing CLRNs and topics including MCRN). The current consultation document proposes that Child Health will be included in a theme with Maternal and Reproductive Health. That will present us with significant challenges, but also allows considerable opportunities to develop and promote good clinical research in Paediatric Gastroenterology, Hepatology and Nutrition.

Clinical Trials:
The main focus of our efforts over the past year has been to improve our relationships with industry, in line with NIHR core objectives, in order to allow greater access to relevant clinical trials for our patients, but more importantly to allow us to have a significant input into protocol design at an early stage thus producing trial protocols relevant for European Paediatric Populations, which will answer appropriate clinical questions rather than simply producing evidence for drug licensing.

The Research Committee (which is also the MCRN CSG, and is therefore jointly chaired by Drs Thomas and Croft) is taking this forward by developing a European Network for Paediatric Gastroenterology Research. This will initially involve 3 countries (UK, Eire and Netherlands). An application has been made to UEGF in order to support a post for a network manager, who will work under the direction of an Executive Committee (UK representatives Dr Croft, Dr Thomas, Dr Thapar). This application has been made through the BSG Adolescent Committee and approved by the BSG Research Committee.

The main role of the post holder will be to develop and maintain a data base of clinical trial capability and feasibility in Paediatric Gastroenterology Units throughout Europe. The post will also be an important route for developing and maintaining contacts with Industry Research Directors (from whom there has been an enthusiastic response thus far), and to liaise with Clinical Research Facilities.
We anticipate that once established and of proven benefit to industrial partners this will become self-funding.

For pragmatic reasons, the post will be based in London, and the holder will therefore work most closely on a day to day basis with Dr Croft.

We plan to involve additional European Countries as the post develops. To this end ESPGHAN have been approached to provide funding for meetings of the Executive Committee and wider working group within the ESPGHAN annual conferences.

The initial application to UEGF was approved for a full submission which has been made, and a final decision is expected imminently.

A data base of research experience, capabilities, infrastructure and relevant case load will be piloted in the UK. A questionnaire has been developed for this purpose, but we will aim to use REDCAP as a web based tool to undertake this.

We are also aiming to generate a HTA endorsed BSPGHAN research portfolio, by feeding back to HTA our views on the current list of ideas, generated throughout Europe (ERA-NET). We have asked chairs of working groups to put forward key research questions; the Research Committee will take suitable ideas forward for submission to HTA after discussion with Working Groups.

Joint BSPGHAN CORE Research award:

The second set of joint BSPGHAN research grants have been awarded in 2012. Two awards were made, aimed at investigating aspects of paediatric liver disease at King's College Hospital, London. This joint approach with CORE provides a unique opportunity to promote good quality research in Paediatric Gastroenterology, Hepatology and Nutrition, and allow the initiation and development of projects that in the current financial climate may otherwise have found it difficult to obtain research funding. Whilst the initiatives summarised above focus on developing our commercial trials capability, we remain are keen to continue with initiatives such as the successful BSPGHAN Core collaborative funding initiative. In particular we wish to promote translational research.

Other Initiatives:

A separate initiative is being developed along with MCRN to further promote Children's Research panels. An advisory panel of child volunteers who are involved in research is being developed in Newcastle following established processes used for other MCRN associated Children's groups, with a particular remit to address issues in neurodisability and nutrition research projects.

Education
Dr Rajeev Gupta

DDF June 2012- BSPGHAN has actively participated in forming programme of UK digestive disease meeting in summer 2012 at Liverpool. We have been tasked to organise symposium on CF and have organised an excellent programme with very high profile speakers. The discussions were high quality and were commended. There were also symposia on Transitional Care and topics of interest to Trainees.

Collaboration with RCPCH education- We have successful delivery of educational day on Nutrition in collaboration with RCPCH education in March 2012. It was under umbrella of "How to manage" series and it is going to continue on yearly basis. There is potential for developing practical paediatric gastroenterology in the series.

START trainees assessment – RCPCH has started the exit assessment of trainees prior to CCT and would be done at ST7 level to allow time for improvements in areas where weaknesses are found. There were no paediatric gastroenterology trainees in first diet in November 2012 however March 2013 will have potential candidates and the questions have been submitted. Some of the consultant members of BSPGHAN are trained assessors and we would recommend for more BSPGHAN members to become assessors when the next invitation from RCPCH for START assessment training comes.

Telemedicine- There has been successful delivery of many educational topics this year with increased attendance. We have provided technical helpline contact number to increase access. There are however still problems and we are exploring doing educational webinars to increase access and flexibility. Members can access the sessions from their office without need for any software installation on computer and any person with web access from anywhere can attend. It can also be used for virtual meetings and a test trial has been done in the Education group which was exciting for members.

Guidelines- The guidelines that are relevant to BSPGHAN members are being compiled and will be placed on website for easy access.

Case of the month- There has been a suggestion for a web enabled free flow discussion regarding interesting cases among BSPGHAN members. The aim is to get a case every month and invite trainees and senior members to comment on it and that will allow a wider learning how different consultants think about the problem and rationale for decision. It will be adjunct to structured teaching but will need a moderator and would be explored further as website dynamicity develops.

I would like to thank the President and all the BSPGHAN council members for providing me the support and encouragement in past 3 years. I would also like to thank Carla and those education committee members who have worked hard to support the cause. I will be happy to help and support my successor.

Nutrition
Dr David Wilson

1. Meetings 2012 and 2013:

The Nutrition and Intestinal Failure Working Group (NIFWG) has 2 meetings per year, one at the Winter Meeting and the 2nd at a variable location in June. In 2012, these 2 meetings were supplemented by a meeting on 03.12.12 on our IF consensus-based guidelines. A NIFWG Strategy Day is planned for ?Autumn 2013. Meetings (past and future) from 01.2012 onwards are listed below:

(a) Nottingham 26.01.12 (NIFWG) (b) Birmingham 15.06.12 (IF guidelines, NIFWG) (c) Staffordshire 03.12.12 (IF guidelines) (d) Manchester 31.01.13 (NIFWG)

2. Strategy Day:

The proposed strategy day for 2012 was postponed (?to 09/13) due to the work on the new British IF Working Group, the alliance with the Neonatal Nutrition Network, the planned completion of the IF consensus-based guidelines in early 2013, and the appointment of a new chair of NIFWG to commence after 01.13 Manchester BSPGHAN meeting. Mark Beattie first suggested a Nutrition Strategy Day hosted by NIFWG on behalf of BSPGHAN, and we aim to involve other key organisations such as BAPEN, BIFA, BAPS, RCPCH committee on nutrition, Neonatal Nutrition Network, BDA, RCN and SACN. The exact date in 2013 will be determined by the availability of the key other attendees, and chaired by the new NIFWG chair.

3. BSPGHAN & BAPS British IF Working Group (BIFWG) and BIFS:

(i) BIFWG - The 1st report of the BSPGHAN-BAPS IF Register Working Group (current acronym BIFWG) is enclosed separately in this Newsletter by the BSPGHAN lead, Dr Andy Barclay.

(ii) BIFS - (a) BIFS has in reality been subsumed into the British IF Register Working Group. To tidy up (and with now over 600 patients on the BIFS database with full outcome data for most), we expect that a manuscript will be submitted for publication and that BIFS will also prepare a final report to all contributing centres.

(iii) 2010 BSPGHAN HPN period prevalence audit – Most centres have returned data but some large centres are yet to contribute. Plan was to complete an audit with full UK accrual and then produce a manuscript (as was done for BSPGHAN point prevalence audit on HPN, published in Clinical Nutrition).

4. BANS:

The trend for deteriorating rate of registration of paediatric HETF and HPN is expected to reverse with the recent removal of the need for informed consent and the start of electronic data reporting via eBANS. Liaison with eBANS for future paediatric HPN and HETF registration has been led by Dr Sue Protheroe.

5. HPN Transition Questionnaire:

A BAPEN initiative, Dr Sue Beath and Dr Susan Hill are working with Dr Simon Gabe on this questionnaire, which will be used UK-wide. Dr Beath will shortly send the survey document to the 30 centres which contributed to the 2010 HPN point prevalence survey plus the 5 newer UK centres with some paediatric HPN services.

6. Consensus-based guidelines on intestinal failure management:

A systematic review of the evidence on medical and nutritional management of IF in childhood by Andy Barclay and David Wilson was published in Alimentary Pharmacology and Therapeutics in 01.11, facilitating the writing of formal consensus-based guidelines on management of IF in childhood by the NIFWG for BSPGHAN. This draws on the paediatric evidence (few methodologically robust studies for any treatment modality), high quality adult evidence plus the expertise and experience of our multidisciplinary paediatric IF teams in UK. The latest meeting led by Susan Hill and David Wilson occurred on 03.12.12; submitted subgroup work is being reviewed and edited, with clarifications sought, and plan is to finish in early 2013. Our aim is to publish the guidelines in the peer-reviewed literature and have available to all via the BSPGHAN website.

7. Nutrition and Hydration Action Alliance:

Dr Sue Protheroe has continued to represent BSPGHAN, and will continue to do so in this initiative in 2013, but without any further BSPGHAN financial contribution following the 2011 one. No new updates to report.

8. Collaborative Research projects:

(i) Taurolock RCT (lead Jutta Koeglmeier, GOSH). The study proposal has been approved by the Paediatric Gastroenterology Clinical Studies Group and advice from MRCN in Liverpool has been given, but funding has yet to be established.

(ii) RCT of SMOF vs Intralipid to prevent cholestasis in post-GI surgical infants (led by Birmingham Children's Hospital Paediatric Gastroenterology and Surgery) – work still ongoing to major grant application.

9. Closer links with Neonatal Nutrition Network (NNN or N3):
(a) NNN is a new and active grouping within neonatology and NIFWG members have explored closer collaboration with NNN; Council approved the NIFWG proposal that the NNN chair becomes the 16th core member of BSPGHAN NIFWG.

(b) The 2012 BSPGHAN meeting at RCPCH (Glasgow 22.05.12) shared with NNN worked well, was of high interest and quality, and helped cement ties between groups.

(c) BSPGHAN (President, Secretary and NIFWG chair) and NNN representatives (Drs Leaf, Moyes and Menon) met at the Glasgow meeting and formally agreed to work together, including (i) the NNN chair being a core member of NIFWG (with a NNN deputy to cover); (ii) all interested NNN members welcome to be corresponding members of NIFWG; (iii) Full involvement of NNN with the BSPGHAN-BAPS British IF Register Working Group, including a neonatal representative on the Working Group; (iv) BSPGHAN support for NNN to be prominent within BAPEN (via Dr Susan Hill, BSPGHAN representative on BAPEN council); (vi) A commitment to future collaborations and joint meetings.

10. BAPEN:
Dr Susan Hill has a separate report enclosed in this Newsletter.

11. Nutrition CSAC:
Dr Priya Narula is the CSAC Nutrition representative, and led on the planning of the successful RCPCH 'How to manage..' series event on nutrition support, held in London on 05.03.12.

12. RCPCH Committee on Nutrition:
Drs Diana Flynn (as NIFWG rep) and Priya Narula (as CSAC nutrition rep) are both on this group.

13. NIFWG membership changes:
Changes are continuing to be made in the core membership as planned in the updated group ToR of 2011, with replacement of core members in a rolling fashion, plus new corresponding members being encouraged to join the WG. As NIFWG core membership has increased to reflect our roles (BIFWG, CSAC nutrition, and NNN stakeholder reps are the most recent newly appointed core members), a streamlining of the 2011 ToR was needed. The major anomaly was that the BSPGHAN nutrition rep on Council takes up post as Chair of NIFWG 12 months after starting on Council; this has been rectified by making these 2 dates coincide in future. The current chair will therefore serve only 2 years as chair of NIFWG before being replaced by the January 2013 elected Nutrition rep as both Council rep and as NIFWG chair, with the timing being immediately after the BSPGHAN annual meeting 2013 in Manchester.

14. BIFA:
The latest adult-paediatric joint IF meeting was a joint BIFA-Pancreatic Society event at Loch Lomond, Scotland on 14-15th November 2012.

15. RCPCH Committee on Nutrition:
(i) Clearer terms of reference and work plan are currently being delineated.
(ii) Examination questions submitted by BSPGHAN NIFWG representatives.
(iii) With the loss of the Southampton course, a new paediatric nutrition course is being considered.
(iii) A second "How to manage – Nutrition" course is planned for 2013 after the successful first one in 03.12.

16. Other issues:

NICE guidelines and other documents – NIFWG members have provided comments on multiple documents and plans.

17. Future priorities:
The first 6 months of 2013 should see strategy day organised, completion of consensus-based guidelines on intestinal failure, possible multi-centre research project commencement, expansion of BIFWG activities and closure of BIFS, and submission of the HPN point prevalence manuscript. Further priorities (such as HETF and clarification of position on obesity) will be discussed at next Nutrition WG meeting in 01.13 and at the strategy day.

BAPEN
Dr Sue Hill

BAPEN has continued to welcome BSPGHAN involvement as the sole group representing paediatrics. Susan Hill has remained a member of BAPEN Council and has been involved in both the Council meetings and the Programme Committee meetings.

We were delighted to hold a BAPEN paediatric Intestinal Failure Symposium during the DDF (Digestive Disorders Federation Conference) in Liverpool in June 2012 that was well received.

The NIFWG (Nutrition & Intestinal Failure Working Group) is participating in the BAPEN education meeting in December 2012. We are organising a symposium in 'Consensus Guideline for Best Practice in Intestinal Failure in Paediatrics' on December 3rd and 'Nutritional support in Neonates and Neurological Outcomes' on December 4th with the Neonatal Nutrition Group N3.

BSPGHAN is negotiating founder status within BAPEN that could be confirmed early next year.

BIFS
Dr Andy Barclay

It was agreed by Council in 2011 that the BIFS registry continued to under-recruit, although it was recognised that some centres remained excellent in reporting, other centres had fallen off and expansion had not occurred as anticipated. The scope and remit of the BIFS registry also needed to be reappraised to consider its effectiveness in generating data of local use to participating centres.

Andy Barclay was elected to lead a new working group to redesign the BIFS registry at the 2012 AGM. This was to be a joint venture between BSPGHAN and BAPS, co-chaired by nominated leads from each parent organisation. The initial meeting was to be chaired by Prof Kelly to help explore roles and funding. It was also decided to invite neonatal colleagues to a participate

Terms of reference and a work-plan were drawn up and approved and after electoral process working group membership exists as follows.

Core Member Role	**Proposed**	**Date appointed**	**Selection process**	**Stand down re-elect**
BSPGHAN Lead	Andy Barclay	Jan 2012	BSPGHAN Council	Jan 2015
BAPS Lead	Antonino Morabito	Jan 2012	BAPS Council	Jan 2015
Neonatal Data Analysis Unit	Sabitha Utaya	Nov 2012	Invitation	Nov 2015
Neonatal Nutrition Member		June 2012	Neonatal Nutrition Group	June 2015

Paediatric Pharmacist	Deirdre Kriell	June 2012	BSPGHAN associates/BSPGHAN council	June 2015
Nutrition Nurse	Sarah Cunningham	June 2012	BSPGHAN associates/BSPGHAN council	June 2015
Paediatric Dietician	Julie Steel	June 2012	BSPGHAN associates/BSPGHAN council	June 2015
BSPGHAN regional rep	Girish Gupte	June 2012	BSPGHAN NWG and council	June 2015
BSPGHAN regional rep	Sandhia Naik	June 2012	BSPGHAN NWG and council	June 2015
BAPS regional rep	Ingo Jester	June 2012	BAPS council	June 2015
BAPS regional rep	Ian Sugarman	June 2012	BAPS council	June 2015

Two further meetings were held in September and November, both at Birmingham Children's Hospital.

The planned changes from these meeting can be summarised as.

- The committee unanimously decided that a move away from an 'informed consent' registry would be preferable for ascertainment; this will most likely require the closing of the BIFS registry, with an application for ethics for a new data-base

- Patient identification could be greatly improved by collaboration with the neonatal data analysis Unit, imperial College London http://www1.imperial.ac.uk/departmentofmedicine/divisions/infectiousdiseases/paediatrics/neonatalmedicine/ndau/, whom are the Caldicott guardian for care data currently for 167/168 of neonatal units in England and Wales, with plans for expansion into Scotland. Agreement with NDAU was given in principle and Sabitaya Uthayan was invited onto the group.

- A 'point of care' electronic entry data-base would help improve ascertainment, it was unanimously agreed that co-elaborating with the redesigned adult IF registry run by BAPEN (BANS), would be desirable. Due to commissioning changes, funding for this was supported by specialist commission group, England. Despite the lack of designation for Paediatric IF, SCG and BAPEN are greatly supportive of this position, and initial discussion with Trevor Smith (BANS) and Andrew Bibby (SCG) are exploring costs and funding for changes.

- An annual report with individualised centre data needs to be returned to all participating centres

Workplan for 2013

Ethical approval and funding will be sought to launch an extended paediatric version of the BANS IF registry. There will be a natural hiatus from BANS as the new registry go's 'live' with commissioning in April 2013. However this time will be used productively by the group to.

- Approving new data-set gathered by proposed registry
- Clarifying process and recurring costs of obtaining ongoing NDAU patient data
- Completing ethics application to NIGB England, Wales to hold patient identifiable data without informed consent, (this is most likely to be successful if done in conjunction with BAPEN and SCG)

- Apply for additional funding from bodies/charities to finance above changes and to help with local database installation for participating centres.

The aimed projection is to go 'live' with the new electronic paediatric IF registry April 2014, exactly one year after the adult registry.

Website
Dr Paul Henderson

Since taking over the role of website administrator earlier in the year it has become apparent that the current website does not cater for the needs of the society with regard to readability, utility or value for money. In view of this there has been a decision made to completely revamp the website to allow for a more interactive site which will help streamline the business of the society and hopefully encourage members to engage more readily.

As a result there have now been significant advancements in getting the site up and running and the basic structure of the new site is already in place. Although many of the basic pages will remain as before (i.e. research, working groups, conferences/meetings etc.), it is hoped that additional functions will also be added. With the new site now hosted on 1and1.co.uk and Drupal as the content management system, the new site will not only look better and function more easily on all platforms (including tablets, smartphones etc.) but the overall running costs will be substantially lower bringing further benefit to the society.

Due to the ease of introducing 'modules' to the new site it is hoped that certain features can be quickly introduced to allow for a more modern look and feel, for example:

- Member-specific content through simple login on the homepage.
- Biblio: allowing quick uploading of journal articles automatically linked to large indexing sites such as PubMed.
- Cookie Control: to comply with the recently introduced EU/UK cookie law.
- CAPTCHA: to avoid council members and the website administrator being spammed with automated account creations.
- Google Analytics: to track who's using the site on a worldwide basis - allowing detailed analysis of usage to further enhance site.
- Wysiwyg: allowing WYSIWYG editing of site contents replacing the need for updating the site using HTML code.
- Direct Debit Payment: to allow members to join BSPGHAN directly through the website and update their membership details.
- Abstract: for submission of abstracts for meetings such as the Annual meeting and TiPGHAN/Associates meeting.

Other areas which will hopefully be available through the site will be:

1. Annual meeting registration
2. Sub-sites for regional teams
3. Repository for council-specific content allowing the safe and secure transfer of documents.
4. Online voting for council/working group members

It is now hoped that we would be able to bring together a small team of interested BSPGHAN members to help design and configure the site, possibly with several administrators who will be responsible for different sections of the site. The launch of new website is hopefully very imminent and I would encourage anyone interested in helping with the administration of the site to get in touch with me. I would also soon hope to send out a quick online survey to members to understand how members would utilise the site and how they'd like this portal to improve their overall engagement with the society.

Hepatology
Professor Anil Dhawan

Department of health has produced a draft document on service specifications for childhood liver diseases under new commissioning arrangements due for implementation in 2013. The document is on the BSPGHAN website for comments.

Hepatologists and liver surgeons from all the three national units had a first inter-unit audit meeting on 30th of November 2012 in Birmingham. The topic of audit was diagnosis and outcome of surgery for biliary atresia. The participants reflected on the current diagnostic pathways and post-operative management. It was agreed that the outcome is comparable and diagnostic approach is mainly dictated by historical set up of the units and available facilities .It was acknowledged that delays in referral continue and further measures at the primary and secondary care are required for early diagnosis of biliary atresia. Formal report of the audit has been sent to the DoH.

DoH would also like three units to hold a joint stakeholders meeting every year as an educational and information sharing event on the management of childhood liver diseases. The first event will be organized by the Leeds Liver and GI unit, by Dr Sanjay Rajwal in summer of 2013.

Trainees
Dr Richard Hansen

Trainees in Paediatric Gastroenterology, Hepatology and Nutrition (TiPGHAN) Annual Report January 2013

Committee Members

Chair: Richard Hansen, Aberdeen
(Stepping down, succeeded by Dr Fiona Cameron, Glasgow)
CSAC rep: Lisa Whyte, Birmingham
Secretary: Anthi Burtt, London (Stepping down in 2013)

Trainees' Meetings

The recent trainees' meeting in Glasgow on 1st – 2nd October was again extremely well received and successful. Day One repeated the "hands-on" format for trainees, with parallel/crossover sessions on endoscopy and the START exit exam (ST7A) both seeing good attendance and engagement. Pictures of the day follow this report. Day Two was run in collaboration with members from associate professions, featuring a range of interesting and informative talks and presentations on the broad theme of nutrition.

Generous support from the Society meant that trainee members were able to attend the two-day meeting with one night's hotel accommodation, dinner and breakfast for just £75 inclusive. Despite this heavily-reduced price, good engagement from the trainees group and additional sponsorship meant the meeting still made a small profit.
One difficulty with the Glasgow hands-on meeting was the sourcing and transport of dummies for endoscopy training. Endoscopy companies seem happy to provide equipment for performing the procedure, but not the dummies themselves. We secured access to dummies from Glasgow Royal Infirmary in this instance and transported them ourselves to the hotel venue. One possibility for consideration would be the Society buying dummies for ongoing use if this event is to become a regular feature on the annual calendar. Storage between meetings and transport to different sites is however likely to remain an issue.

The 2013 meeting is to be hosted in Birmingham. The broad agreement over the last three years has been of odd years alternating between London and Birmingham with even years rotating between other UK centres. The recent history of the meeting has been:

2009- Birmingham

2010- Manchester
2011- London
2012- Glasgow
2013- Birmingham

New Trainee Chair
We would like to welcome Dr Fiona Cameron as the new Trainee Chair. Fiona is a Grid trainee in Glasgow and is about to start an MD fellowship funded by CICRA at the University of Edinburgh. She takes over leadership of the Trainees Group after this meeting.

Picture 1: Half room layout for mock START exam, complete with sponsors stands

Picture 2: Dr Baker examining one of our trainees in START session

Picture 3: Dr M^{c}Kiernan tutoring trainees on upper gastrointestinal endoscopy

Picture 4: Dr M^{c}Grogan tutoring trainees on colonoscopy

Paediatricians with an interest
Dr Bim Bhaduri

PeGHAN group has been active last year collecting and up-dating the e mails of ID and telephone numbers of all the PEGHAN members.

The PEGHAN rep has been co- opted as CSAC members and had two meetings at the RCPCH. The draft curriculum for the training of the SpR with Gastroenterology interest has been accepted for further discussion. Various SPIN modules are being discussed in RCPCH academic committee.

Service Specification for the Gastroenterology in a DGH has been submitted to BSPGHAN in line with the Specialised Services for Commissioning.

Associate Members
Mr Mick Cullen

2012 has been a year of regeneration for the Associate Group that has had some positive movement forward in engaging the membership at large but has also faltered at times to find a clear direction of travel and a “raison d’etre”. We have welcomed many new members.

Limitations on finance, study leave and generic pressures of workload are having a big impact on the activities and participation of the membership much more than previous incarnations of the group and it is envisaged these are stumbling blocks we will continually encounter

The committee currently five in number will hopefully be strengthened in January. We urgently need new blood to survive. Despite a call for interest we have had just one taker- whilst this is disappointing it is also worrying for the longevity of the group. It has become clearer that the committee needs to be larger more dynamic and more inclusive of specialties beyond nurses and dietitians. We will again call for expressions of interest and encourage colleagues to volunteer in early January before the AGM and hopefully from then we can move forward with the challenges ahead as a cohesive and focused group

A key task for the committee is to help organise the yearly Trainees and Associate study day- the day in October was well received and well rated. The practical approach to the day and the ability to interact and participate was appreciated and welcomed by our members and contributed greatly to the success of this venture. I look forward to working with the new chair of the Trainees to hopefully make the next meeting in Birmingham as successful.

Challenges ahead for the Associate Members :

- Establish a larger committee to facilitate the direction , productivity and longevity of group
- Improve communication within the group -get those involved in various working groups of BSPGHAN to feed back to general membership.
- More collaborative working.
- Better involvement/ interaction with patient groups.

A big thank you to my fellow committee members for their hard work and support over the last year. Thanks also to Carla and BSPGHAN council for encouragement and support.

Patient and Professional Partnership (PPP)
Sarah Sleet

Paediatric Gastroenterology and Hepatology Standards
PPP representatives, Richard Driscoll and Norma McGough, have been participants in the BSPGHAN/ RCPCH Standards development project. Having attended meetings in the early part of the year, the work has been paused awaiting the finalisation of the specialist commissioning approach.

Specialist Commissioning
The patient representatives have contributed to the development of the specialist commissioning document which is now entering its final iteration.

Diagnosis and Management of Coeliac Disease Guidelines
The PPP representative, Sarah Sleet, participated in the Society's working group addressing new guidelines on the diagnosis and management of coeliac disease. Coeliac UK is now working with BSPGHAN to make the documentation publication ready and promote the guidelines to the appropriate audiences.

Other
The patient groups continue to work within their own networks to promote the paediatric care:

- CLDF made a submission to the National Screening Committee on Biliary Atresia and is inputting to the NHSBT Liver Advisory Group work on organ allocation. Whilst this is in relation to adults it is essential that the paediatric needs are considered so the overview is holistic. CLDF continues its work in the Liver Alliance to ensure that any strategy is fully cogniscent of the patient view.

- Coeliac UK has pressed for a NICE review of its guideline on diagnosis and recognition of coeliac disease in the light of the new BSPGHAN guidelines which is now underway. Throughout the year the Charity has fought to maintain access to gluten-free prescriptions, particularly important for children.

- The IBS Network will be launching to the public its Self-Care Plan in early 2013.

- Crohn's and Colitis UK is working with Cicra and the Adolescent Section of the BSG on the Transition in IBD project.

BSG: Adolescent and Young Person Section
Dr Richard Russell

Current Group membership: Sara McCartney (chair), Richard Russell (secretary), James Lindsay, Valda Forbes, Rod Mitchell, Tariq Ahmad, Nick Croft, Richard Cohen, Pat McKiernan.
Over the previous 12 months the group has successfully increased its membership and its overall profile within the British Society of Gastroenterology. As a marker of this the section held two very successful and well attended symposia as part of the 1st Digestive Disease Federation held in Liverpool in June 2012. The section will have 2 further symposia at the BSG being held in Glasgow this year provisionally to be held on 25th and 26th June 2013 (meeting 24-27th June).
A survey of transition views and practice has been completed and published this year (Sebastian S, et al, The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: Differing perceptions from a survey of adult and paediatric gastroenterologists. Journal of Crohn's & Colitis 2012; 6 (8):830-844). The section is now working on developing evidenced based transition guidelines over the next couple of years.
The section is keen in particular to maintain close links with BSPGHAN specifically with BSPGHAN members who serve on BSG committees but who are not part of the section committee. We would

like all relevant members to keep us updated with their activities so we can help co-ordinate the profile of children and young people within the BSG as well as presenting as much as possible consistent, co-ordinated and appropriate representation

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CSAC
Dr Adrian Thomas

National Training Grid
There were 12 applications for the grid this year, 8 were invited for interview and 6 were offered posts, 1 applicant was not able to accept the post offered for geographical reasons so 5 were appointed: 1 to Scotland, 1 to London & Oxford, 1 to West Midlands, 1 to Yorkshire and Humber and 1 to Severn and West Midlands.

In order to increase flexibility and give trainees more opportunities to be appointed to the grid Mark Beattie, Sue Protheroe and I have had a meeting with Mandy Goldstein, Officer for Training at the RCPCH. The bottom line is that trainees cannot apply more than twice for a place on the grid and need to have a minimum of 12 months training on the grid. This means that up to 2 years of pre-grid training can be counted towards a CCT in paediatric gastroenterology provided:

1) the training takes place in a centre approved for training in paediatric gastroenterology by the GMC
2) it is agreed prospectively with CSAC and
3) a written testimonial is provided by the trainer stating that the pregrid training is equivalent to that of a grid trainee

The only other way to enter the specialist register in paediatric gastroenterology is when all or part of the training has taken place outside of the UK, candidates need to apply to the GMC for a Certificate of Eligibility for Specialist Registration (CESR).

Starting this year CSAC will be required to review each trainee's progress via their eportfolios and to submit a report for their ARCP. All grid trainees should have annual speciality specific appraisals which should be sent to the CSAC chair. This assessment should include endoscopy competencies. Many thanks to the trainers that are already sending these to me.

Special Interest (SPIN) Module
The RCPCH has started work on SPIN modules which aim to "provide the general paediatrician with the competencies necessary for practice with particular expertise in the relevant area of clinical practice to the standard appropriate for secondary level paediatric care. Successful completion of the relevant SPIN module will provide employers with evidence of such competencies"

START Assessment
The first START Assessment took place in November and will be repeated in March. As this assessment will include gastroenterology and hepatology it is important that trainees have had exposure to both subjects before their assessment. Trainees should discuss with their grid coordinator and/or educational supervisor if they are concerned about this. Further information is available on the BSPGHAN and RCPCH websites.

Endoscopy
CSAC are working closely with the BSPGHAN Endoscopy Working Group to ensure that trainees are receiving high quality endoscopy training and achieving required competencies.