



British Society of Paediatric Gastroenterology Hepatology and Nutrition

Newsletter

January 2014

Dr Alastair Baker MB ChB MBA FRCP FRCPCH
BSPGHAN President

The year for BSPGHAN began as usual with the Annual Meeting, in 2013 held in Manchester. We must all congratulate Dr Adrian Thomas and his team for fantastic organisation of a wonderful programme in the Great Midland Hotel, building on the success of previous BSPGHAN meetings and yet again exceeding expectations as an educational event, an academic showcase, a social experience and a networking opportunity. We are recognising how much our colleagues in Pharma appreciate and enjoy joining with us to help develop Multidisciplinary Care of patients with gastrointestinal and liver diseases in the UK and Ireland.

I was proud and honoured to become National President of BSPGHAN at that meeting, and during the following year I have been fortunate to benefit from dedication to work already in progress as the Society continues to go from strength to strength. The ambition and effectiveness of the Society is such that I am hard pressed to document every aspect of continued progress but I would like to draw attention to some particular highlights and achievements.

A legacy of the work of my predecessor Dr Mark Beattie and particularly Dr Sue Protheroe has been an important contribution to commissioning of Paediatric Gastroenterology Services between primary, secondary and tertiary care. The work is not yet finished but has made enormous progress, building on a collaborative model of network care with the patient at the centre of receiving services. More recent work led by Dr Mike Cosgrove has focussed on excellence in care at General Hospital or secondary care level in the network where the largest numbers of patients are seen, resulting in a valuable document that sets standards and can be used as a template for other sub-specialities with 'Specialist Paediatricians with an Interest' consultants. In addition, the liver transplant commissioning standards were reviewed emphasising the role of the Society in setting higher standards of care for patients.

Dr Sue Protheroe has worked tirelessly for the Society and amongst her many great achievements has been to provide consistent responses to calls from NICE for contributors to various scoping and development groups. As a result of these responses we are being asked more and more for our opinions on the development of quality in services and excellence in outcome. I hope that all of the membership will continue to support this work and further embellish the Society's reputation nationally.

BSPGHAN continues its active contribution to the specialist training of Consultant Paediatric Gastroenterologists, and with the SPIN 'Specialist Paediatrician with an Interest' training module invited by the College and prepared by Professor Bim Bhaduri, we are very pleased to be leading the way in designing training of doctors to provide excellent quality Paediatric Gastroenterology Services in General Hospitals. In addition Dr Sue Protheroe has done excellent work developing the START examination that has been developed further by Dr Rajeev Gupta, her successor.

Dr Adrian Thomas continues to lead the College CSAC to great effect while promoting links with the Society. This relationship is one more of our strengths so that a professional relationship with BSPGHAN and all its members is integral to training, and the Society with its links can help ensure the training of Paediatric Gastroenterologists and Hepatologists in the UK.

Education has been a longstanding high spot for the Society, but I must say that in his short tenure to date Dr Rafeeq Muhammed has brought its importance to a new level. I am particularly grateful for his continued contribution in adding in education to every BSPGHAN agenda in a very constructive way. May I congratulate him on his sequence of Clinical Challenges, which I know we are all enjoying and learning from him?

The BSPGHAN website has been a thorn in the side of my predecessors for almost 10 years. Finally due to the efforts of the strategy group in clarifying what it was we wanted, but most importantly due to the massive efforts on the part of Dr Paul Henderson we now have a website which is fit for purpose, providing information, education and facilities, such as registration of meeting abstracts and registration for the annual meeting. I cannot over-emphasise what a great achievement this represents.

I must also extend my profound gratitude to Dr Ieuan Davies for his recent and important developments in endoscopy training and standards. Of course we are dependent on the rate of progress of Adult Gastroenterologists through the Joint Advisory Group. Even when they have resolved their own training standards we still have to modify them and develop infrastructure to allow us to quality assure our practice. Ieuan continues to move this agenda on with clarity and precision, recognising how many constraints surround him. I hope he will continue to do so with the help of the endoscopy group because this will be a long term project.

Dr Rob Heuschkel is leaving the IBD Working Group at an important time when he has taken forward pre-existing work in an energetic and fruitful way. We look to his successor to continue this excellent work since IBD is one of the big pathological conditions of the Society. My colleague, Professor Anil Dhawan has also relinquished the Liver Steering Group. Relationships between the three super regional liver units go from strength to strength with collaborative research, QIDIS joint projects and inter-referring of patients. We are most grateful for his contribution. Professor Simon Murch was due to step down as Chairman of the Gastroenterology Committee. However since the Inflammatory Bowel Disease Group is such a large component of gastroenterology we felt it was not appropriate to make two such major leadership changes simultaneously and so asked Professor Murch to stay on for six extra months while the IBD Group reappraises its strategy. He has kindly assented to this. His launch of the new BSPGHAN coeliac guidelines must be warmly congratulated.

The Nutrition Working Group is now chaired by Dr Sue Hill. She brings her links with BAPEN to the group at an important time as the eBANS registry database is being launched under Dr Andy Barclay. This is an exciting development building on the work of BIFS over many years, the excellent work of Dr John Puntis, for which we owe him many thanks. The new project has tremendous potential, and I am very excited about the changes in practice to the benefit of patients that can come out of these new data. Please can all members give their fullest support to Andy in this valuable work?

TiPGHAN goes from strength to strength led by Dr Fiona Cameron, building links with BSG trainees and accessing their training facilities. The autumn TiPGHAN/AM meeting in Birmingham was attended by approximately 50 multidisciplinary colleagues, the most that have ever attended any TiPGHAN/AM meeting. The atmosphere and content were superb, and with this level of activity and enthusiasm I have no fear for the future of the Society. Many thanks to Dr Fiona Cameron and Mick Cullen, as yet again an area of the society gets better and better!

The role of the AMs is a feature that much increases the effectiveness of the Society in almost every sphere of its business. To have a broader view of patient care and represent clinical activities and relationships in the activities of the Society is something that many other similar groups view with envy. I therefore pay special thanks to Mick Cullen whose leadership and input into Council business and the AMs generally that adds so much extra to all WGs and other business.

We welcome Mrs Sarah Sleet from Coeliac UK to council as PPP representative. This role has been performed to great advantage for the Society by each of her predecessors. Sarah has quickly found her feet on council and I am grateful for her commercial, political and management insights to balance the exclusively healthcare experience of the rest of us.

Many of us have worked to establish productive links with adult gastroenterologists through the BSG. Dr Ian Forgacs, my colleague at King's College Hospital is BSG President-elect making informal contact much easier, for me at least. The recent BSG collaborations include Adult and Young Person activities toward Guidelines for Transition and taking part in the BSG symposium in June on Obesity and Functional GI diseases. I very much appreciate the efforts of Dr Richard Russell and Dr Nick Croft to open up this area, as I believe transition and young peoples' medicine will be one of the big topics for the Society in the coming years.

Mr Bruce Jaffray now represents BAPS on BSPGHAN council. I thank him for his support in bringing our two professional societies closer together, marked by what I believe will be a highly successful joint meeting during the Friday of our Annual Meeting.

We were invited to provide feedback as a Society into the consultation for a strategy for the future of the Royal College of Paediatrics and Child Health. I received feedback from many individual members reflecting the multidisciplinary nature of the Society. We also introduced feedback for this consultation as an agenda item in the most recent council meeting. While there was a strong feeling amongst our BSPGHAN membership against any change, there was also a good deal of constructive feedback about the nature of the Royal College of Paediatrics and Child Health, and the role and contribution of specialist Societies within it. I was able to write a formal letter to Dr Hillary Cass, the President of the RCPCH that I think will help her with her laudable intentions to move the College forward to the satisfaction of its membership and the benefit of children in the UK.

Research has become the jewel in the crown of the work of BSPGHAN. We are extremely proud of four BSPGHAN-CORE funded research grants chosen from a very strong field of applicants. These are medium sized projects that would have had difficulty obtaining funding in competition with larger adult led projects and yet are enormously valuable to innovation in the care of children with gastroenterological and liver diseases. We are also very pleased to be in receipt of €70,000 from ESPGHAN, kindly donated by Professor Ian Sanderson because 25% of the London ESPGHAN surplus is given to the local National Paediatric Gastroenterology organisation. I cannot thank Ian enough for this. We propose that a further BSPGHAN-CORE research grant will be organised with a call for applications for funding in 2014 to 2015. The theme is yet to be decided.

The BSPGHAN research committee is almost person for person the Paediatric Gastroenterology and Hepatology CSG with the exception of the former being chaired by Dr Julian Thomas and the latter newly chaired by Professor Steven Allen. We are extremely grateful for the work of Dr Nick Croft previously on the CSG, leading the group in excellent work, establishing research collaborations between the UK, Holland and Ireland as Paediatric European Digestive Diseases Clinical Research Network (PEDDCReN) and also feeding research ideas from the working groups via the PICO format into HTA funding calls.

Any role in the administration of BSPGHAN is respected, but possibly undervalued given the very large amount of work that can appear unheralded and with a short timeline for completion. We are therefore immensely grateful to our Council Members who are relinquishing their three year periods of tenure following moving mountains. Dr Sue Protheroe as Convenor has been an untiring support to me and everyone else on Council with her detailed grasp of Society business, her extensive network of contacts, her understanding of activities of other societies, her admirable ability to hit time and target and her wonderful and thoughtful personal concern. She will be a hard act to follow. I am also immensely grateful to Dr Mike Cosgrove who took over from me as treasurer and raised the control of the Society's finances to new heights. His appreciation of the significance of finance in every activity of the Society and his broad and balanced view of issues has meant that he has been a very major contributor to all decisions and not just limited to counting the pounds and pennies. I am personally grateful to both of them for their support and direction as I found my feet as BSPGHAN President.

The Society, its activities and the annual meeting would not be the success it is without Carla Lloyd. Fortunately, she continues to set her usual high standards in all she does for which we are all very grateful, most of all me. Thank you, Carla for one more high output year.

So, after one year we find ourselves again at the BSPGHAN National Meeting, I hope that this 28th iteration of the highly popular and successful formula will maintain the stratospheric momentum of academic, organisational, social and entertainment standards set by Manchester, and that it will be able to continue to sustain the financial wellbeing of the Society. This time, of course, we will be sharing the academic, educational and social part of the meeting with our friends and allies in BAPS, a model of collaboration that we can carry forward with other professional societies in future years. Thereafter, I look in anticipation toward the continued excellent progression of our multidisciplinary professional Society. I hope this annual meeting can mark the start of another equally successful BSPGHAN year.

Convenor's Report Dr Sue Protheroe

I'd like to wish all our members a happy and healthy 2014 as I highlight some of the changes and achievements of the Society's members in 2013 and propose a few constitutional changes that require the member's consideration and approval at the AGM. It's an opportunity to provide an update on new commissioning plans and explain how influential members can be and make a significant difference to outcomes by recommending how services can be better organized to improve delivery of care in an equitable way. We are truly a multi professional organization representing dieticians, nurses, pharmacists, other health care professionals, trainees and patients. It is our task to broaden our horizons to strengthen the whole patient pathway, including at home and in District centres alongside maintaining good care in the tertiary hospitals.

Membership

Firstly, a warm welcome to all 18 of our new members who joined this year. Our membership remains healthy with a total of 407 members (148 Associate Members and 259 Full members - 196 consultants, 59 trainees, and a few honorary/retired/ overseas members)

Congratulations

It is our enormous delight and pride to report that Professor Bhu Sandhu received an OBE for services to children's medicine in the Queen's New Year's Honours this time last year and Professor Deirdre Kelly was honoured as one of the most Inspirational Women in Healthcare for her achievements advancing care for children with liver disorders. Both awards are richly deserved and the Society is proud of their many achievements. Grateful thanks go to Catherine Arkley, who stood down as CEO of the Children's Liver disease Foundation this year, for her valued input into Council. Catherine must be congratulated on achieving so much for young people and the Society offers her very best with her new consultancy firm. We welcome Alison Taylor as new CLDF CEO and David Barker who has taken over at Crohn's and Colitis CUK.

Council

Thank you for recently voting to elect a new representative on Council as Treasurer. We have had very worthy candidates who have volunteered their services for which we are very grateful. We are delighted to have received a nomination for Hepatology Chair, Dr Suzanne Davison, Consultant Paediatric Hepatologist, Leeds and Convener, Dr Nadeem Afzal, Consultant Paediatric Gastroenterologist, Southampton, and Treasurer Dr Marcus Auth, Consultant Paediatric Gastroenterologist, Liverpool; Dr Girish Gupte, Consultant Paediatric Hepatologist, Birmingham; and Dr Mike Thomson, Consultant Paediatric Gastroenterologist, Sheffield. In accordance with Society Constitution a postal ballot will be held for position of treasurer. Ballot papers to be returned to Carla no later than Monday 27th January 2014. The result of the ballot will be announced at the AGM on Thursday 30th January 2014. A further position on Council will be vacant representing Gastroenterology in 6 months' time. Council has debated the merits of setting up an electronic voting

system and will discuss in January at the AGM that the constitution be changed to allow for the option of electronic voting.

Grateful thanks are extended to Anil Dhawan who has stepped down as Liver representative and also to Rob Heuschshel who has provided an invaluable contribution to the Society, not only in leading the IBD Working Group, but also for his invaluable and sensible oversight of the Service Specification document (at short notice- a personal thanks Rob). Mike Cosgrove steps down as Treasurer. Mike has tirelessly and steadfastly provided sound advice. His wisdom, enthusiasm and attention to detail have made him a highly valued (and always modest) member of the Executive team. Mike has to be congratulated for maintaining the financial viability of the Society but also in making practical progress with the Society's strategy in describing networks. Mike has worked with a productive team (Bim Bhadhuri, Rajeev Gupta, Jim Hart, Vijay Iyer, Mary-Anne Morris and Anna Pigott) to produce the BSPGHAN document called "Commissioning Specifications and Standards for Paediatric Gastroenterology, Hepatology & Nutrition services provided in units outside of lead specialist centres". It provides an intelligent overview on the challenges of providing and commissioning specialist work outside lead centres and sets a precedent for the development of specialty networks.

We have welcomed Susan Hill and Rafeeq Muhammed to Council in 2013. Susan has been an enthusiastic voice and vital link to BAPEN and facilitated BSPGHAN becoming a core member of BAPEN. Rafeeq must be congratulated on his commitment to the Society in with new educational initiatives. Paul Henderson has likewise worked tirelessly to make great strides in updating the website and has our grateful thanks at providing his skilled time so willingly for our benefit. We are grateful that the contents of website are most useful for purposes of education, training, appraisal and revalidation and so on, so please remember to give personal thanks to Paul as the time taken to achieve this change is considerable. Andy Barclay has also to be congratulated for steering BSPGHAN forward to join e-BANS, which will be the tool to ensure consistent audit of the services for Intestinal Failure (IF). National Registration of patients with specific conditions (IBD and IF) will be a necessary part of our daily practice and ensuring that there is a validated, clinically relevant and quick tool is crucial. It makes good sense to join forces with BAPEN and e BANS to achieve this aim and please give Andy your support in engaging with this task and making sure that your unit is represented and in due course your local commissioners will recognize this.

Constitution

Council has voted this year for proposed amendments to the Constitution introducing two new Membership categories, which will be subject to a vote at the AGM. We need to encourage the most bright and committed students to work in our area and their interest in our Society. We also wish to encourage more members to join, but recognize trainees that some might be discouraged by the financial commitment when spending time training outside the specialty for example. Therefore two new membership categories are proposed to be added to the constitution –

RULE 5

Student membership shall be available to undergraduate medical and allied health care students upon payment of an appropriate concessionary fee. Student members may qualify for reduced registration rates for the BSPGHAN Annual meeting to be decided by the local organizer.

Members temporarily working outside the specialty may request to become Suspended Members for up to 2 years and re-join the Society without reapplying. If membership is suspended for more than 2 years, a Full Member shall be required to submit a further nomination for full membership to Council on the Society's proposal form. If a further proposal were not received then the person would be removed from the Society's mailing list.

Students or Suspended members would not be required to pay the annual subscription fee and would not have voting rights at the annual general meeting or at Special meetings. Suspended members would not be entitled to membership benefits such as reduced rates for BSPGHAN or BSPGHAN affiliated meetings.

RULE 6

Conflicts of interest may arise in a range of situations and include financial/ commercial arrangements and other personal interests. A statement will be added to the Constitution stating that Council members should use their professional judgement to identify when conflicts of interest arise and follow established procedures for formally declaring and managing any conflict of interest.

Key outputs 2013

1. Quality initiatives

Congratulations to Simon Murch and colleagues in the coeliac working party including Sarah Sleet, CEO Coeliac UK, for producing the guidelines for the diagnosis of coeliac disease in children, adopting a specific and pragmatic approach to ensure that the diagnosis is watertight but allows some children to achieve a firm diagnosis without a biopsy.

2. Society Consultations and responses 2013

A] NICE QS stakeholder engagement exercises, Technology Assessments, Quality Standards and Clinical Guidelines development have been submitted on relevant topics such as Biologics for UC, Hepatitis B, Crohn's disease, Dyspepsia (review), Obesity (review), Organ donation, Upper Gi bleeding, Nutrition in hospitals, Osteoporosis, IV fluid therapy, and Nutritional Support (Adults).

B] Atlas of variation

Dame Sally Davis has emphasized the need to reduce health inequalities in child health in her recent report. Public Health England has taken on the responsibility for the Atlas of Variation (see <http://www.chimat.org.uk/cm02012>). Relevant to our practice under Domain 2 of the Children's and Young People's Outcome Forum: Enhancing quality of life for people with long-term conditions, is Map 22 A and B which examines admission rates for children for upper and/or lower gastro-intestinal endoscopy per population aged 0-17 years by CCG or PCT (Directly age-standardized covering 2009/10-2011/12).

The map shows a degree of variation, which hasn't been explained, and BSPGHAN has been asked to help with the commentary. Differences are unlikely to be explained by differences in the number of children with symptoms or the incidence of organic GI disease and we can't tell if low rates of GI endoscopy reflect inadequate provision or poor access, however, we agree that the principle of a networked system of delivering paediatric endoscopy is a good thing as will ensure:

- Sustainable levels of activity that relate to local population needs;
- Support for training and quality assurance;
- Equity of access through common thresholds for intervention;
- Rare but life-saving provision of out-of-hours interventional endoscopy in children.

The formalization of paediatric networks, based on existing informal networks for the delivery of specialist children's gastroenterology services, is anticipated under the commissioning work of NHS England discussed below.

Engagement with stakeholders

The Royal College of Paediatrics and Child Health has ambitions to engage more with the specialty groups and have restarted their Specialty Group Forum this year with the aim of improving specialty representation and ensuring relevance of college business for all paediatricians and their associate members. This provides a useful forum for BSPGHAN to engage with and influence the College. BSPGHAN has been cited as an organization where multi-disciplinary membership works well and close working links with the RCPCH will enable College endorsement and ratification of BSPGHAN products.

The joint Specialty session with the British Paediatric Neurology Association at the Annual Meeting of the Royal College of Paediatrics and Child Health in June 2013 in Glasgow was a resounding success. Hilary Cass joined our session with a stimulating discussion on feeding children with neuro-disabilities in the community and there was with standing room only in the venue for the afternoon. The 2014 RCPCH Annual Conference has a theme of "Towards better Outcomes for Children's Health" and our Specialty Session has been arranged with reference to nutritional outcomes and bone

health as we join with the British Paediatric and Adolescent Bone Group and the RCPCH Nutrition Group on Tuesday 8th April 2014, 13.45 to 18.00 at the ICC in Birmingham. I am delighted that Ann Prentice from the MRC will be one of our guest speakers. The BSPGHAN dinner will take place that evening and I hope that you will join us in Birmingham as we have some excellent abstracts submitted for oral and poster presentation at the meeting.

This year, we have welcomed a closer affiliation with BAPEN and the opportunity to work in partnership on common agendas and lobby for recognition of our patients needs including membership of the Nutritional Hydration Action Alliance.

Commissioning - NHS England

We are all challenged 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 together and alongside other stakeholders in order to work out how best to achieve this. Early in 2013, Mark Beattie was appointed to the Paediatric Specialized Medicine Clinical Reference Groups or CRG to represent the RCPCH and I was appointed as W Midlands representative to provide service-specific clinical assurance for the 2014/15 contract service specifications. Development of the consultation work included 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. This includes statements of the primary objectives and descriptors of our service, providing details of what will be provided, for and by whom, and is produced in conjunction with relevant quality requirements. You can find the following service specifications (below) by following this link <http://www.england.nhs.uk/resources/spec-comm-resources/npc-crg/group-e/e03/>

- Paediatric Medicine Gastroenterology, Hepatology and Nutrition
- Liver Transplantation Service (Children)
- Intestinal pseudo-obstructive disorders service – children
- Small Bowel Transplantation Service (All Ages)
- Specialist Liver Disease Service (Children)

Thanks to Alastair and Liver Steering Group for considerable input into the new Liver Transplant specification for children. We recognize that here are real challenges, as these specifications will really stretch our services over time to provide excellence. In late November, NHS England announced a five-year strategy to drive forward the promotion of equity and excellence in commissioning specialized services to feed into plans for 2015/16 to 2019/20

The 5-year strategy is designed to

- Enable the provision of high value specialized services –value being defined from both the patient’s perspective and in terms of value for money;
- Ensure equitable access to specialized services, regardless of geography;
- Enable promotion of NHS England’s specialized services to international partners;
- Ensure directly commissioned services are highly stable and well defined;
- Respond to the UK rare diseases plan to be published by the Department of Health;
- Minimize barriers to access for specialized services that have impact across the whole patient pathway;
- Ensure that services deliver the highest quality, 7-day consultant led care in line with the ethos of “High quality care for all, now and for future generations”;
- Support the development of 24/7 emergency care as close to the patient’s home as is safe and cost effective;
- Ensure sustainable service and workforce planning for services provided by a small number of experts, particularly with regards to highly specialized services;
- Significantly improve partnership working with patient groups, providers and commercial organizations.

Mark and I recognize that input to the CRG has been strengthened considerably by the enthusiasm and commitment of Council and the membership, the insights and informed advice from Sarah Sleet, CEO of Coeliac UK, our representative on Council and the multidisciplinary nature of the society. We will need to continue to respond to the changing health needs of children, the increasing need for health care to be evidence based and quality assured and the challenges of providing sufficient and

appropriately qualified work force which needs planning, training, appraisal and revalidation. At the 2012 AGM, BSPGHAN supported collaboration with RCPCH and DH to produce a joint report. This liaison is relevant now as it was then, as we believe that the next step is to formally describe how a specialty service based in lead and district centres can implement the service specification. This work is best achieved using the RCPCH's involvement in formalizing children's networks and the Department of Health's Clinical Network project. Therefore we propose that BSPGHAN builds upon the document "Commissioning Specifications and Standards for Paediatric Gastroenterology, Hepatology & Nutrition services provided in units outside of lead specialist centres" to explain the accountability of organizations or individuals responsible for governance and funding of shared care pathways with clarity over funding arrangements and responsibilities.

Mark and I are keen to seek and hear your views, have your engagement, your input and of course your wholehearted support. Without BSPGHAN's input, we can't go ahead and secure this work that aims to deliver the best healthcare and achieve the best quality of life possible for patients. A time limited task based Commissioning Working Party within BSPGHAN with representation from Mark and myself, patients and carers and a wide range of contributors including GP's, RCN, commissioners, charitable partners, and other key groups may be the most effective way to complete this work and report back to Council. Mark and I would like to hear your views on this proposal at the AGM.

I will end my last report as Convener. Being Convener has been challenging and interesting and of course enjoyable because of the pleasure to work with all Council members. I would like to especially acknowledging Mark and Alastair's advice. Their skills and leadership, dedicated efforts, enthusiasm and sense of responsibility to get things right have ensured the high quality of all of the work streams mentioned. The Convener particularly has a close insight into the many hours of hard work, knowledge and dedication to the Society that Carla provides and I am personally very grateful for her professionalism, insights, ability to keep on top of deadlines and calmly steering us all in the right direction, even when we were straying way off track. I would like to pass on a huge thank you to you all too for your support, and patience in bearing with the demands to respond to consultations at short notice. I am delighted that we have some brilliant colleagues to take over on Council and BSPGHAN has a promising future ahead. As always, a new year brings challenges for the future. Thanks to all those who I may have inadvertently forgotten to mention for helping with the tasks with which we've all made progress.

Treasurer's Report
Dr Mike Cosgrove

1) Annual accounts April 2012 - March 2013

	2012-13	2011-12
Income	155,791	132,918
Expenditure	*187,771	139,118
Net income	(31,980)	(6,200)

- Includes £35,000 CORE contribution for matched funding for research projects

Total funds carried forward	75,531	107,511
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The deficit of just under £32,000 for the financial year 2012-13 is accounted for by the £35,000 which we put forward in the summer of 2012 to CORE, and received more than matched research funding. The annual meeting in Manchester in January 2013 produced an excellent surplus of £34,447. Annual subscriptions raised £19,607 and sponsorship £12,914. If we wish to continue our ambition of funding a CORE project every other year we need to be able to support this through income. We still have a healthy balance, but need to have reserves to protect against possible losses in the future.

2) Annual subscriptions

The new rates of subscriptions became valid from 1st November 2013. Unfortunately despite repeated reminders to all members to amend their standing orders only around one-third of members did so. This illustrates perfectly the problems with the standing order system – many hours of our administrator's and accountant's time have been spent chasing up arrears and over payments in recent years, and would continue to be so if we stayed with using standing orders. We had previously explored the possibility of using the superior direct debit system, but had been advised that it could potentially leave us liable to significant financial risk. However, our closer relationship with BAPEN led us to a company whom they use for their direct debits. The company, London & Zurich, administer the service and underwrite the financial responsibility, for a set-up payment of £1250 and annual running costs which will not exceed £450 per annum.

We have decided to go ahead with this option with the plan being for the annual subscriptions payment date to move to 1st April, which makes accounting more straight-forward. The first direct debit payment on 1st April 2014 will be for 7/12 of annual subscription to take up to 1st April 2015, then the full annual subscription rate will apply from then on. Payments will be clearly indicated to BSPGHAN on bank statements. The direct debit system will allow arrears and changes to annual subscriptions to be collected without the need for members to request their banks to do so.

We will be sending out direct debit authorisation forms to members before 1st April 2014, and **it is crucially important that these forms are returned promptly. Member's co-operation with this is politely requested.**

We are confident that this change will save many hours of administrator's and accountant's time.

3) Chip and PIN terminal

Along similar lines, and to facilitate ease of payment at the annual meeting (and possibly for other events) for those who have not registered in advance, we have paid £400 to HSBC for a merchant ID and machine rental for one year. There will be a surcharge of 20p for credit cards and 2% for debit cards, payable by the registrant. We expect this will also save a significant amount of administrator's time in chasing up late payments.

4) Sponsorship

We have been successful in obtaining annual sponsorship from 3 companies. This will guarantee a source of income and take some of the pressure off the annual meeting as our main income stream. We continue to pursue similar agreements with other companies.

5) Expenditure

Once again I thank all members of council and working groups for their co-operation in taking advantage of advance off-peak fares when attending meetings on BSPGHAN business, and chairs of these groups for arranging meetings at times to facilitate this. This is an important way of controlling out outgoings.

And finally, as I come to the end of my 3 years as BSPGHAN Treasurer, I would like to express the honour and enjoyment I have had from the post. I would like to thank; Peter Hill of Hillyates for his wise accounting expertise, Carla for her tireless hard work in keeping the society's finances in good order, Mark Beattie and Alastair Baker for their support during their terms as President, and Sue Protheroe who has been a superb Convenor during my time as Treasurer.

Committee and Group Reports:

Coeliac Working Group: 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 McClain	Paediatric Gastroenterologist	
Mary-Anne Morris	Paediatric Gastroenterologist	
Simon Murch	Paediatric Gastroenterologist	Chair
Sarah Sleet	Coeliac UK	
Matthew Thorpe	Paediatric Gastroenterologist	

During 2013, the Coeliac Disease Working Group published the updated coeliac disease diagnostic guidelines, in association with Coeliac UK. These were published via both BSPGHAN and Coeliac UK., in both long and short format. These have been well received.

Additionally, with just minor stylistic changes, the guidelines were also published in the Archives of Disease in Childhood in October 2013 (Vole 98: 806-811) and are available for free download. The Working Group is grateful to Dr Mark Beattie, Editor of the Archives, for allowing this access.

Peter Gillett and Simon Murch, together with other BSPGHAN Members (Rajeev Gupta and Rita Shergill-Bonnar) have joined the NICE Coeliac Disease Guideline Development Group. This has met several times since May 2013, and is due to determine national policy for Coeliac Disease within the next 2 years. So far this is proving a very useful forum, and there is hopefully acceptance of difference in diagnostic stratagems between adults and children, as the BSG approach remains biopsy based.

***IBD Working Group:
Dr Rob Heuschkel***

IBD WG Annual Report 2013

Membership on 1.11.2013

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 just 2 meetings in 2013 (30.1, 1.8). During the last 12 months, the group has focused on the following priorities:

1. **Quality Improvement Program.** In the last 12 months the QIP has essentially been subsumed into the national **IBD Registry**, which was launched at BSG in June. Sally Mitton at St George's is one of three initial sites to be using the platform. Following two initial peer visits between Cambridge & Southampton, there is now a simple template available for other units who are looking to arrange peer visits, with funding still available to facilitate such visits from HQIP. It is expected that the **National IBD Audits** will be carried out via this platform in the future. The group discussed a proforma that might form the basis of a way of accrediting units leading the care of children with IBD (this was developed from specialist services commissioning document, IBD QIP, IBD standards document and BSPGHAN outcome measures). The document and its application require further work.
2. Current **audits** in progress include National Biologics Audit, with 76% of paediatric units entering initial data. An initial report (234 children completed to Feb 2013) was released for paediatric sites in August 2013, documenting clear areas for improvement as the audit continues. Units with >10 patients should receive site-specific feedback. The 4th National IBD Audit also continues to recruit in-patients with UC (until August 2014). Organisational data should be available soon.
3. **Clinical Outcome Measures.** An initial set of clinical outcome measures has been agreed by the group and these were prospectively assessed in pilot survey in Cambridge. Without a functioning IT system to prospectively capture patient data, useful monitoring of outcomes is not realistic for most units.
4. The group worked on a number of **documents** that should be useful in day-to-day clinical practice. The azathioprine information for CYP was finalized in conjunction with CCUK. With the new website these documents should become available to all members.
5. **Research.** This year the group has been active in putting forward a number of potential research initiatives. Following the call from the HTA, a number of ideas were scored and submitted for consideration. Of these, one study on Azathioprine is submitted in greater detail.
6. The WG has continued to provide **representation** on various committees – IBD Standards (RH, VG), IBD Audit (RR), IBD Registry (SM) and Crohn's disease NICE guideline group (AT). The group has also endorsed and will support the ESPGHAN initiative to collate all cases of IBD-related Cancer in the UK. Chris Spray is leading this work in the UK and plans to contact individual groups for regular updates.
7. During 2013 NICE required **feedback** prior to the publication of its UC guideline (CG166; June 2013), and feedback prior to the launch of anti-TNF use in UC (publication expected Feb 2015). Feedback also provided for CE nominations of the use of Humira in children with severe Crohn's disease in Wales. The IBD Standards Group re-launched their 2009 standards on 30th October 2013, for which the CYP section (A12) was updated and amended by the group. The group also fed back on the Society's "Commissioning Specifications and Standards for specialised PGHN services provided in units outside of lead specialist centres".
8. As this IBD WG is now reaching the end of its 3 year term, we reviewed and amended the **Terms of Reference** and proposed a plan to Council for the gradual renewal of the group. Nick Croft, Tony Akobeng, Adrian Thomas, Rob Heuschkel will all leave the group, whilst representatives of paediatric surgery, dieticians, nurses, trainees and general paediatrician with an interest were all asked to obtain new nominations from their groups. The aim is to reduce the size of the group and go out to the membership for a new Chair.

Endoscopy Working Group
Dr Ieuan Davies

Membership of the BSPGHAN Endoscopy Working Group 2013

Chair – Ieuan Davies (elected, BSPGHAN Council member & representative to JAG)
BSPGHAN Convenor
BSPGHAN President
BSPGHAN Associate Members Representative – Mick Cullen
BSPGHAN Education Committee Representative – Rafeeq Mohammed
BSPGHAN DGH Committee – Sonny Chong
BSPGHAN Gastroenterology Committee – Simon Murch
BSPGHAN Trainees Committee – Ed Giles (a new representative is needed)
BAPS Representative – Bruce Jaffray (Paediatric Surgeon)
RCA Representative – a nomination will be requested. (Paediatric Anaesthetist)
JAG Representative – Mark Feeney
BSPGHAN CSAC Representative – Adrian Thomas

Regional Endoscopy Leads

Scotland – Paraic McGrogan
Yorkshire, East Midlands & North East – Mike Thomson
Liverpool, Manchester & Northwest – Balaji Krishnamurthy
Birmingham, Wales & South West – Ronald Bremner (Vice Chair and CSAC representative)
London, Central & South East – David Rawat (a second representative is required)
Hepatology – Sanjay Rajwal

1. Two meetings of the EWG were held in Birmingham on 5th March and 24th September 2013. In addition the Chair represented the EWG on JAG meetings in April and October.
2. The membership of the EWG is described in **appendix a**.
3. The Regional Endoscopy Leads are arranging local meetings that will cover training, service and the network organization of endoscopy before Easter. Utilizing this structure we expect to collect data for a colonic perforation audit.
4. The first few endoscopy trainees are currently in the process of applying for JAG certification as Paediatric Endoscopists. This has highlighted a couple of technical problems with the process that are being addressed and will hopefully lead to a simpler pathway in the future.
5. The following work has been completed in the 2013:
 - a. Diagnostic Paediatric Endoscopy Curriculum (JAG website)
 - b. JAG Paediatric Endoscopy Certification process (JAG website)
 - c. JAG / BSPGHAN visit to the International Academy of Paediatric Endoscopy Training
6. The following work will be completed in 2014:
 - a. The Paediatric Endoscopy GRS
 - b. Retrospective Audit of Colonic Perforation during Paediatric Colonoscopy
 - c. Regional Endoscopy Meetings
 - d. The JAG certification of trainees as Paediatric Endoscopists
 - e. A response and plan to the results of the Atlas of Variation on Paediatric Endoscopy
7. The next meeting will be held in London on **Tuesday 4th March 2014**.

The Chair acknowledges the support of Mrs Carla Lloyd, the President, the Convenor and all the contributing members of the EWG. Over the last year I am also particularly grateful to Mark Feeney, Ed Giles, Ron Bremner and David Rawat for their hard work behind the scenes.

ieuan.davies@wales.nhs.uk

Motility Working Group
Dr Nikhil Thapar

Following our previous survey of the membership the group decided to target a few key areas most commonly dealt with by the membership

1. Improving and standardizing the use of pH/impedance studies.

Following discussion of the core group a study day has provisionally been organized for 30th April 2014 in association with the Academy of Paediatric Gastroenterology. Invites to BSPGHAN members active in such studies will be extended and complimentary places offered. Numbers will be limited to make the study day feasible. The aim of the day will be for training in pH/impedance and to develop a consensus group and shared protocols for indications, procedures and analysis. The ultimate aim is to build towards and possibly publish a UK consensus. Details of the day will be circulated to the membership over the coming weeks.

2. Hypnotherapy for Functional abdominal pain-related GI disorders

Given good evidence of the efficacy of this treatment modality for functional abdominal pain-related disorders the group put forward this area of research as a priority area for the Health Technology Assessment (HTA) Programme. The topic has been shortlisted for discussion in their March 2014 board meeting. In the interim we are developing a protocol for a UK-wide research study. The hope is that this area will ultimately be adopted by the NIHR

3. NICE guidelines for functional constipation

There are plans to look at the implementation of the NICE guidelines and develop research projects associated with this. Again research suggestions looking at the use of laxatives e.g. stimulant have also been submitted to the HTA as possible priority areas. These are awaiting review and response.

Research
Dr Julian Thomas

The overall aim of the Research Committee continues to be to increase the opportunities for and involvement in clinical research for the membership of the society. The joint Chair of the BSPGHAN/MCRN has changed over the past 6 months, with Professor Steve Allen replacing Dr Nick Croft as the MCRN Chair.

A summary of the progress with our key initiatives is given below:

1. The development of suggestions for clinical trials arising from the Working Groups: Suggestions for clinical trials have been produced by Working Groups over the past year, in the proposed PICO format. Three of these have been further developed with support from HTA into potential trials that could lead to a commissioned call. These are now being considered (along with others from other subspecialties) by HTA and the commissioned call for studies from this process is likely to be made in 12 to 18 months' time. The short titles of the projects put forward are; *"The use of iron*

replacement in inflammatory bowel disease”; “e early use of azathioprine in Crohn’s Disease”; “The use of Domperidone in GORD in infancy”.

2. European Initiative for developing a clinical trials network to promote Commercially Funded trials. This project has now run for 6 months with Varsha Tailor as project manager, Monthly telemeetings take place (last one 18/11/2013, brief update to be provided verbally), and a survey is now being circulated to all BSPGHAN members.
3. BSPGHAN/Core grants. The Committee are extremely keen to have a further joint BSPGHAN/Core award this year. In addition, there was a strong desire that applicants should feel that this is a useful process even for unsuccessful applications. CORE has responded enthusiastically to our approach, and will support a joint grant next year. Dr Thomas would like to seek Council’s view on the form these awards should take, and which potential investigators should be targeted.
4. We have begun a process with MCRN examining shared care and governance processes for large studies across multiple Trusts. In concept this draws upon the experience derived from large studies such as UKALL, which by using a unified approach amongst all children in a (rare) disease group in an ongoing National Study has had a substantial impact upon disease outcome. It is likely that a similar approach in specific paediatric gastrointestinal disease could also have a significant impact. There is to be a meeting in the next few weeks between MCRN leads, UKALL leads, Dr Thomas and Prof Allen to explore how we could manage this approach.

The Committee intend that the strands of research development outlined above will increase clinical research in Paediatric Gastroenterology, and are now going on to look at how this can be used to encourage career development in clinical research for members and associate members.

Education

Dr Rafeeq Muhammed

Committee members

Chair: Dr Rafeeq Muhammed, Birmingham

Trainee representative: Fiona Cameron, Glasgow

Associate member representative: Kay Crook, Liverpool

DGH representative: Dr Bim Bhaduri, Maidstone

Website representative: Dr Paul Henderson, Edinburgh

CSAC representative: Dr Adrian Thomas, Manchester

Invited representative from START group in CSAC: Dr Rajeev Gupta, Barnsley

Education committee meeting was held on 31st September 2013. We would be working to promote educational activities among all membership categories. The website has been populated with guidelines in Gastroenterology, Hepatology and nutrition. ‘Recommended read’- a monthly digest of interesting articles for our members have been circulated for the last 6 months. We have introduced ‘case of the month’ and the responses from our members have been very positive for the last three cases. In the next few months, we would aim to provide easy access to CME and revalidation resources via our website. Education committee has helped with the organisation of our annual society meeting and TIPGHAN-AM meeting and we would continue our work in this area.

The success of our activities will be depending on the member’s active participation and WE would encourage you to provide your feedback in the open session of education committee in BSPGHANJ 2014 or via email to education@bspghan.org.uk

Nutrition
Dr Susan Hill

1. The Group

The NIFWG is a multidisciplinary group that is currently composed of approximately 30 attending and corresponding members from about 15 different British specialist centres. There are designated representatives for, dietetics, nursing, surgery, nutrition pharmacy, paediatric gastroenterology trainees, paed e-BANS, BAPEN, BAPS and education and training.

2. Meetings 2013-4

The Nutrition and Intestinal Failure Working Group (NIFWG) met twice in 2013: at the annual BSPGHAN meeting in Manchester and on Monday 18th November in London.

3. Paed e-BANS (Paediatric electronic-British Artificial Nutrition Survey)

Andy Barclay has continued to lead the working group developing Paed e-BANS. He has been liaising with Trevor Smith (adult gastroenterologist, Southampton) who leads on adult e-BANS. Progress will be reported at the BSPGHAN meeting in January 2014 (and in a separate report).

4. BAPEN

BSPGHAN is now one of the six BAPEN Core groups.

The BSPGHAN symposium held within the Annual BAPEN Conference was on 'Feeding the child with neurological disabilities' on Wednesday 27th November in Harrogate. It was well attended and had good feedback.

Susan Hill continues as a member of BAPEN Council. Other representatives from BSPGHAN are needed to establish our BAPEN ties. These include a co-representative for BAPEN and representative(s) on the BAPEN Education & Training Committee. It was agreed by the NIFWG that the E&T post(s) would be suitable for trainees. Trainees have been e-mailed and an interest expressed by three people who we look forward to taking up roles.

A collaborative project on transition of home PN patients completed by members of the NIFWG and adult gastroenterologists (see research below).

5. Neonatal Nutrition Network (NNN or N3)

NIFWG members have continued to collaborate with the NNN. An NNN representative/committee member is a core member of BSPGHAN NIFWG. Full involvement of NNN with Paed-eBANS is expected, facilitated by a neonatal representative on that Group. Future collaborations and joint meetings are planned.

6. Research projects:

a). BSPGHAN/BAPEN survey on transition of Home PN patients to adult care.

There were 32 responses from 180 centres identified from HiFNET (Home intestinal failure network) using a survey monkey questionnaire. Results were presented at the November BAPEN meeting – led by Sue Beath, Simon Gabe, Susan Hill, and Mia Small.

b). Taurolock - Funding has been secured and the study has been adopted by the MRCN. Discussions are continuing with the company – led by Jutta Koeglmeier.

c). Teduglutide – a multi-centre PK study is being carried out. The group would like to facilitate inclusion of all eligible patients from all UK centres in company trials. Julian Thomas suggested that companies need to be advised to approach the NIFWG collectively.

d). IF Consensus based guidelines - still in progress. The aim is to publish the guidelines in peer-reviewed literature and make them available on the BSPGHAN website – David Wilson, Susan Hill

7. Plans for 2014:

- Establish Paed-eBANS
- Complete consensus-based guidelines on intestinal failure
- Arrange symposium on 'Vitamins through the ages' at BAPEN October 14-15th2014
- Consolidate links with BAPEN and NNN
- Establish links with the RCPCH Nutrition Committee

BIFS
Dr Andy Barclay

The planned supplanting of the BIFS registry with the newer electronic Paed eBANS registry is now finalised and phase 1 will launch in 2014 soon after the AGM.

Progress achieved

Ethical approval for a paediatric wing of the eBANS registry with pseudo-anonymised data collection without informed consent has been granted by the Health Research Authority England and Wales (formerly NIGB).

Design of the paed eBANS registry phase 1 has been completed by Paed eBANS WG and Henry Gowen with provider streets heaver, and is now awaiting on-line testing before launch. (Appendix 1)

A project grant (£15,000) for hand held devices for Paed eBANS centres has been submitted to Calea by Andrew Barclay.

The 2012 HPN point prevalence survey has been presented at the UEGW in Berlin in October. (BSPGHAN HPN data suggest a significant rise in paediatric HPN usage short-term. *United Gastroenterology Journal* 2013 Vol 1 Suppl 1 A281). (Appendix 2)

Final draft of this study is awaiting sign off and is ready for submission to *Archives of disease of Childhood*.

Plan for 2014

Phase 1 of Paed eBANS registry to launch as soon after AGM in 2014

Henry Gowen to assist in centre-by-centre registration, and distribution of hand held devices. Access database for local collection can also be installed.

More detailed demographic data to begin on paed eBANS (phase 2) by autumn 2014.

A study of potential use of neonatal national registry information to be coordinated as an examination of existing NDAU data to complete the data collection from BSPGHAN 2012 point prevalence study. This is to be headed up by Akshay Batra and Sandhia Naik, with funding from pledged BSPGHAN and BAPS monies.

BSPGHAN HPN point prevalence repeated Nov 2014 (with multiply points we can create 'epoch' data which can generate far more meaningful statistics on prevalence trends).

First Annual Paed eBANS report with centre-by-centre data prepared by Henry Gowen for 2015 AGM.

Decisions still to be made

Although HRA have given approval for a pseudo-anonymised dataset as per the eBANS registry. This does not give Paed eBANS access to the methodology for the adult HIFNET IF registry. The level of detail is much greater for this and has been approved due to the 'service' nature of such data for commissioning in adults.

A move to this level of information would be seen as beneficial to our societies, although potentially onerous for nutrition support teams. Movement towards such a registry may be easier to make a case for when data collection has been demonstrated for HPN and all type II and III IF being looked after by nutrition support teams, and by clarity on the future of IF commissioning in paediatrics.

Definitions of type II IF and the potential use of neonatal gathered data may be informed by project data gathered this year.

Website

Dr Paul Henderson

So we've finally made some progress. As many of you will know the new BSPGHAN website (www.bspghan.org.uk) went live a few months ago and has since gone from strength to strength. Following the dismantling of the old flash-run site, repopulating the new site is still ongoing but hopefully we now have a more up-to-date and functional site in line with the aims of the Society. From a personal point of view this has been a mammoth task and a steep learning curve but this has been greatly eased by the help (and continued support) of Dr Nick Kennedy (Welcome Trust Research Fellow, Edinburgh) who has dedicated his time above and beyond for the cause of the new site. Council have already approved a token gesture to thank him for his help in getting the site live, and his continued input while we improve the site further.

On a more technical note, the new site has really improved our ability to update the site more quickly and easily. Moving from the old format when all updates were coded in HTML to the new Content Management System (CMS), namely Drupal, has allowed those of us with limited computer knowledge (namely me!) to proceed and produce a working site. The Drupal system allows the easy addition of items to the site and it is hoped that over the coming months this will become easier as the site develops. Additionally, with the site now fully migrated to 1and1.co.uk (including the domain name) we now have full control of the site from one login and we have also made considerable cost savings as a result.

Specific points regarding the site are:

- Members are now able to update their membership details through the site in a more standard fashion.
- We have successfully trialled abstract submission for the BSPGHAN Winter Meeting (over 40 successful submissions) in addition to online registration which will hopefully streamline the entire process.
- Several areas of the site are automatically updated in real time to improve the readability and integrity of the site - this includes a live Twitter feed, IBD in the news, PubMed citations on topics such as gut motility and coeliac disease among others.
- The BSPGHAN video presentations from previous meetings will soon be available to stream directly on the site which will hopefully inspire and encourage members (and non-members) to join us in London in January.

Future Projects:

- Payment of yearly subscriptions and registration fees for meetings may be possible.
- The development of areas of the site to "house" local team news/networks (such as SSPGHAN) will hopefully enhance traffic through the site.

Site statistics (Generated through Google Analytics: Period 01.10.13 - 12.11.13)

- Unique visitors: 1,372
- Page views: 5,986
- Pages per visit: 3.26
- Average visit duration: 2m31sec
- Bounce Rate: 32.12%
- Visits by Country: United States (74.9%); UK (16.1%); Poland (0.65%); Netherlands (0.55%) - this may represent many attempts to "spam" the site
- Visits by City: London (18.7%); Glasgow (9.3%); Sheffield (6.4%); Manchester (3.4%); Edinburgh (3.2%)
- Browser: Internet Explorer (39.6%); Chrome (22.1%); Safari (20.9%); Firefox (11.5%)
- Mobile OS: iOS (78.9%); Android (19.6%)

We now have to ensure that the site is continually updated otherwise we will find ourselves in a similar scenario as has been evident over recent years, with a non-functional site.

I would like to thank everyone who has had any input into the construction/design/population of the new site and hopefully over the coming months and years the site will continue to prove useful to the members of BSPGHAN and further afield.

Hepatology
Professor Anil Dhawan

The LSG continues its progress in developing closer collaboration between the 3 National Paediatric Liver Units

During the year Liver transplant commissioning standards were reviewed and updated led by Professor Dhawan and Dr Baker.

Research collaboration was best illustrated by the IMAGO and IMAGINE studies with rapid establishment and recruitment of the studies by all 3 units.

A National Liver and Small Bowel meeting was held at KCH on 18/12/2013. The meeting was attended by Dr Edmund Jessop, Medical advisor NHS Commissioning who provided an overview of new commissioning arrangements. Paediatric Liver Service is classed as HSS (Highly specialised service).

The topic for review was Hepatoblastoma. All three centers presented data for 2012 with outcomes. There was a debate whether liver biopsy should be part of diagnostic work up. We will be discussing it further with our oncology and liver surgery colleagues and plan to come out with a guideline.

Current status of transition services at the three units was presented and future actions were agreed. New CQUINS for 2014 to be developed with guidance from patients and their representatives.

For a second year running no new paediatric Hepatology trainee could be appointed to the National Training Grid. We will be taking steps on CSAC to ensure suitable candidates are able apply in future. We welcome Dr Suzanne Davison as the new LSG chair and thank Professor Anil Dhawan for leading the group.

Trainees

Dr Fiona Cameron

Dr Fiona Cameron Trainees in Paediatric Gastroenterology, Hepatology and Nutrition (TiPGHAN)
Annual Report January 2014

Committee Members

Chair: Fiona Cameron, Glasgow

CSAC rep: Lisa Whyte, Birmingham

Secretary: Anthi Burt, London (Stepping down in 2013)

Trainees' Meetings

The joint trainees associates meeting was held in Birmingham this year on the 30th September and 1st October at Aston University. Attendance was excellent- we even had to ask for more seats! The theme of this year's meeting was hepatology. We were grateful to all the speakers who presented on a wide range of topics which were all extremely well received. As in previous years, the trainees had a session on the 30th September in which they gained hands on experience with both upper and lower GI endoscopies under the watchful eyes of Dr Pat McKiernan and Dr Ron Bremner. The trainees had the opportunity to practice START sessions with examiners and were given feedback on their performance. The trainees were updated on the new speciality specific assessment that had been announced by CSAC which will be rolled out next year.

A new "hands on" session was introduced on the joint trainees and associates day on the 1st October which asked the delegates to make up a bag of PN for a child and received practical gastrostomy tips. This proved to be hugely popular so will feature in next year's program and will be developed further. This year we have the agreement of council to purchase endoscopy models to ease the issue of having to source them every year which will allow us to further develop this activity as trainees remain hugely enthusiastic about it.

Our next meeting will be in Cardiff in 2014 and continues the trend of moving the venue around the country to increase accessibility; dates have yet to be confirmed. The 2015 meeting will be in London. We remain grateful for the support given by the administrator in organising this event and to Council and our sponsors for their financial support and to the associates whose involvement contributes to its ongoing success. This continues to be a thoroughly enjoyable meeting at low cost to delegates.

Specialty specific assessments

Under the new proposal, in addition to the ARCP (Annual Review of Competence Performance), as speciality or grid trainees, we will be expected to attend a speciality specific review which will be organised by the local CSAC representative. The local CSAC representative will prepare a report which will then be given to the ARCP committee as evidence of the trainee's progression and areas requiring further development.

JETS/JAG/Endoscopy

We are thankful to Iuan Davies and the rest of the endoscopy working group for providing us with an endoscopy curriculum to guide trainees on training and competencies to achieve. Most grid trainees are now using the JETS system to record their endoscopy experiences. However, trainees are not able to complete their sign off competencies using this system as it is adult based and as paediatricians we will not have performed the required number of procedures required under this system, so paper copies should be used at this time. After many years of hard work, Ed Giles who has been our trainee representative on the endoscopy working group has finished his term and we are currently looking for a replacement. On behalf of the trainees, I am very grateful to Ed for all his efforts on behalf on the trainees and ensuring our needs are met and voices heard.

Trainee secretary

After 3 years as the trainee's secretary Anthi Burt is due to step down, we thank Anthi for all her hard work during her time on the committee and wish her continued success in the future. At the moment we have several interested trainees to take on the role; we will be holding a vote at the Annual

Meeting in January 2014 with e mail voting for those who are unable to attend. The new secretary will be appointed in early 2014 and will act as our link to the website.

Website

We thank Paul Henderson for the huge amount of work he has done on the website, in particular, the new trainee web pages. We plan to seek feedback at the Annual Meeting from the rest of the trainees on the website and on other ways to improve its usefulness and resources.

BSG

I have had several meetings with the BSG Trainees Committee about re invigorating our relationship since the dissolution of TiG (Trainees in Gastroenterology) and I now sit on their committee. The BSG trainees organise a yearly education weekend for their trainees and we would like in the future for our trainees to attend this education weekend meeting with a program that appeals to both paediatricians and adult gastroenterologists. We would also aim to improve joint working by encouraging mutual attendance at our respective meetings and by promoting the benefits of being a member of both societies.

Paediatricians with an interest Professor Bim Bhaduri

I am delighted to inform you that the SPIN module in Gastroenterology, herpetology and Nutrition is now finally agreed and should soon be on the College website. Interested trainees should be able to access it and be able to follow through. In recent College Council meeting SPIN CCT has been discussed. Gastro curriculum is competency based and could be assessed at work place which may need to be endorsed by the BSPGHAN.

I am going to send the PDF file of the SPIN module to Paul who will be able to put this document in the BSPGHAN web site.

We have also finalised the Service Specification for the Network centre which also has been submitted.

Now I have about 125 consultant's e mail ID and work place of our PeGHAN membership I will ask trainees rep to supply me with as many trainees' names and e mail ID as possible. But I do not need grid trainees only SpR with Gastro interest. It is very hard to collect information on this.

Unfortunately I am doing compulsory Jury service during the BSPGHAN winter meeting, so I will have to miss it. But Mike Cosgove has kindly agreed to Chair the PeGHAN sub group meeting.

Associate Members Mr Mick Cullen

Committed to you

2013 has been a year of challenges, change and consolidation for the committee and associate group. Roles within the committee have been better defined and we feel as a result communication is better with our membership. We continue to strive to make this better. The current committee stands at four in total -two nurses and two dieticians. Due to pressures of work one new committee member had to step down in early 2013.

We urgently need new blood to survive. It has become clearer that the committee needs to be larger more dynamic and more inclusive of specialties beyond nurses and dieticians. We have called for expressions of interest in the positions in the latter stages of the year and I have received nominations from two ideal candidates- I look forward to liaising with them shortly and we will introduce them at the Annual meeting (Winter Meeting) in January and move forward with the challenges ahead.

Should there be others out there who are thinking tentatively about stepping up to the plate and joining the committee I would encourage you to talk to myself or my fellow members about what is involved.

This is a chance to get involved and help shape the direction and productivity of this group. No previous committee experience is necessary - just a commitment to try make things better and a willingness to share ideas about taking things forward.

Our AGM takes place at 6pm on 29th January 2014 at THE Tower Hotel London - The venue for the Annual BSPGHAN Meeting. Please do your best to attend.

AM Project

Tube weaning guidelines was a collaborative project that never really took hold this year. In the latter stages of the year a new impetus was found and we look forward to developments and a study day in the new year.

It was great to see a user friendly working BSPGHAN web page up and running in 2013. We have a dedicated Web lead on our committee who will help propagate the Associate page and glean from our members what they would like on it.

2013 was a year when limitations on finance, study leave and generic pressures of workload were having a big impact on the activities and participation of the membership- much more than previous incarnations of the group. It is hoped that the economic turn quietly being suggested will filter through to us in 2014.

Despite economic woes Associate members continue to contribute to the various working groups of BSPGHAN and beyond.

In a survey carried out mid 2013 our members felt valued by BSPGHAN and felt it went a long way to meeting their educational and networking needs.

TiPGHAN-AM

This year the annual Trainees, Associate Members Professional Study Day (TRAMPS Day as I like to refer to it as) was in Birmingham at the start of October and proved a great success from an educational, networking and participation point of view. Thanks to all those who presented, chaired sessions and helped organise the day. To those that stood up to the plate at the last minute - I salute you.

Next year the proposed venue is Cardiff which is supported by the associate committee. We look forward to working with the Trainees group and educational committee to devise another great programme.

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. I wish everyone a happy and prosperous New Year.

Patient and Professional Partnership (PPP)

Sarah Sleet

Changing Heads

The year saw substantial changes within patient charities with Richard Driscoll moving on as CEO of Crohn's and Colitis UK at the beginning of the year to be replaced by David Barker who joined from Breakthrough Breast Cancer. Later on in the year Catherine Arkley retired as CEO of the Childhood Liver Disease Foundation after more than 20 years at the helm and was replaced by Alison Taylor, previously Director of Services at the Meningitis Trust. With new faces, the PPP group need to develop new relationships and all have kindly been invited to meet the Society at its meeting later in the month.

Diagnosis and management of coeliac disease

The PPP representative, Sarah Sleet, worked with the Society's working group to develop new guidelines and help ensure their publication on both on BSPGHAN's new website and the Charity's own. Following publication of the new guidelines setting out the circumstances in which a biopsy need not be undertaken to confirm diagnosis, anecdotal reports are being received suggesting GPs are not conforming to the new approach. This is resulting in children being inappropriately managed. As a result a joint letter from the Society and Coeliac UK was sent to the Royal College of General Practitioners seeking joint working to address the problem. We are awaiting their response. During the year development of a new NICE guideline on the diagnosis and management of the coeliac disease got underway. Representatives from the Society and the Charity are fully involved and early concerns that the new diagnostic pathway might be challenged have receded.

Patient input to liver transplant coalition

CLDF is a member of a coalition of liver patient groups and charities concerned with liver transplant and has been liaising with the NHSBT as part of that group, this work will continue throughout 2014.

This year also saw the Charity introduce its latest young person's project -Talk, Tell, Transform, a project that brings together young people living with a liver condition or transplant, and works with them to first share their stories and then go on develop them with confidence into digital video format. Eight very powerful stories from the first project in 2013 are now on CLDF's website and can be found at www.childliverdisease.org/content.aspx?CategoryID=764

2013 also saw the further development of CLDF's Yellow Alert Campaign- which started in 1993 to assist healthcare professionals and new parents in spotting the early signs of prolonged jaundice in new born babies, and to empower early referral for testing. After exposure in the Journal of Health Visiting mid 2013, and a follow up article later in the year, the charity has seen a rise in orders for the free Yellow Alert packs of over 300%.

As well as existing campaigns, last year also saw the launch of CLDF's Say Yes to Consent Campaign. The initiative that has proven very popular and aims to encourage open discussions with family members on an individual's wishes to donation their organs. More information the campaign can be found at <http://www.childliverdisease.org/news/CLDF-asks-you-to-say-yes-to-consent>.

CICRA members survey for children and young people to age 20 years and their families

This questionnaire sought to obtain information about the attitudes of young patients and their families towards research and thoughts on living with IBD, with the questions including:

- Info about you
- Your experience of research
- Your health
- Availability of information

The survey was circulated in the second half of 2013 with access also online via the CICRA website and through Survey Monkey.

CICRA report that a good response was obtained before the closing date of end November 2013 and that currently the results are being analyzed and that they will be publishing the feedback during the first half of 2014.

IBD Standards Update

The updated IBD Standards were launched at the House of Lords at the end October 2013 ahead of the NICE work on Quality Standards and upcoming IBD reviews and it is hoped that the new multi-stakeholder report will be taken into account by NICE and other healthcare agencies, organizations and stakeholders.

Other news

The PPP grouping will be developing content for a PPP page on the Society's new website in the coming weeks.

BSG: Adolescent and Young Person Section Dr Nick Croft

AYP Section

Paediatric European Digestive Diseases Clinical Research Network - PEDDCReN

The Paediatric European Digestive Diseases Clinical Research Network was first established in April 2013 with the key aim of forming a clinical trials network to study (and ultimately provide) effective medicines for paediatric patients in the speciality of Gastroenterology, Hepatology and Nutrition. This has been established with the support of LINKS funding from the UEG (United European Gastroenterology) and is led by the AYP section of the BSG (British Society of Gastroenterology) in collaboration with the ISGE (Irish Society of Gastroenterology), NVK (Nederlandse Vereniging voor Gastroenterologie (Dutch Society of Gastroenterology)), ESPGHAN (European Society of Paediatric Gastroenterology, Hepatology and Nutrition) and ENPR-EMA (The European Network of Paediatric Research at the European Medicines Agency).

The objectives of the project are aimed at supporting both industry and non-industry investigators to run high quality multi-centre clinical trials in the speciality of paediatric gastroenterology, hepatology and nutrition. It is hoped by early and positive engagement with industry the network would be able to play a role in influencing the development of study plans, protocols, including PIPs. With investigators from across Europe it will facilitate identifying suitable sites for studies through knowledge of interest, expertise and resources.

All members of BSPGHAN have been emailed about this initiative and were invited to submit a response on behalf of their unit, this has since been sent to Ireland and the Netherlands and in the New year will be sent throughout Europe via ESPGHAN. A poster on the results so far will be shown at the BSPGHAN Annual meeting.

CSAC
Dr Adrian Thomas

National Training Grid

There were 15 applications for the grid this year, 11 were shortlisted & interviews were held on 2nd December. Only 6 candidates exceeded the threshold for appointability and were offered rotations but unfortunately 2 were unable to accept the offer as they could not be accommodated on their chosen rotation. There were 8 rotations available (6 gastroenterology, 2 hepatology) and appointments were made (all gastroenterology) in: London x2, Mersey/Manchester/Leeds x1 & Southampton/London x1).

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).

From next year CSAC will be required to review each trainees 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 by the end of January. This assessment should include endoscopy competencies.

Special Interest (SPIN) Module

SPIN modules 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”. Many thanks to Bim Bhaduri for his hard work on the SPIN module for trainees which is now awaiting RCPCH approval & publication on the website. The next phase is to adapt this for consultants (i.e. post CCT SPIN).

START Assessment

The College has requested 30 new START scenarios each year. CSAC members have each been asked to write 2 per annum but we need help from BSPGHAN members. Please contact Rajeev Gupta for more information.

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.

