



British Society of Paediatric Gastroenterology Hepatology and Nutrition

BSPGHAN Newsletter

January 2011

President's Report

Dr Mark Beattie

I have really enjoyed my first year as president, particularly the energy, enthusiasm and commitment of the membership to the further development of our specialty. The reports in this newsletter are a testament to this. The society exists to promote education, training and research in paediatric gastroenterology, hepatology and nutrition and we are continuing to achieve in all three areas.

This year has seen the establishment of an education working group under the leadership of Rajeev Gupta and Sue Protheroe. I was pleased to attend the strategy day in November and am confident that the group will contribute significantly in the coming years to our society's development. The re-launch of the website with its increased capacity and flexibility will help considerably with this. I am grateful to Naved Alizai and Carla for the considerable amount of effort they have put in into making this happen.

This year has also seen the formalisation of the research committee and of its links with the MCRN gastroenterology, hepatology and nutrition advisory committee. Both Nikhil Thapar and Nick Croft have worked hard to make this happen and I am sure that through it that the society will be better able to support research across our speciality and foster multi-centre collaborative work and thereby network development. I am delighted that following the joint research call with CORE that two awards were made. This means as a society we are now directly supporting research. We have been working with CORE during the year and I would like us to consider a further joint research call with them which we can discuss at the AGM.

Inflammatory bowel disease is a significant part of most of our workloads. I was pleased to see the society endorsed guidelines published this year and our continued active involvement with the National audit, IBD Standards development of a National biologics register. I am grateful to Sally Mitton and Richard Russell for all their hard work with the National Audit and I am sure we will all work with Rob Heuschkel as the new chair to ensure the continued success of the IBD working group.

I am similarly grateful to Paraic McGrogan and Mike Thomson for their work leading the endoscopy working group and paediatric representation on JAG. Their efforts working with the RCPCH CSAC chaired by Peter Sullivan have resulted in a clear framework for training and potentially accreditation of centres for training and practice which will be invaluable to us in the run up to revalidation.

We are increasingly challenged by children with complex dysmotility syndromes including neurodisability in particular and I have asked Nikhil Thapar, on behalf of council, if he would convene a motility disorders working group. The group will have a broad remit looking at guidelines/audit/education and research covering the full range of motility disorders from pseudo-obstruction (rare) to constipation and reflux (common). The initial task of the group would be to look at the more severe end including the indications for and best techniques for investigation and to put together the UK experience of pseudo obstructive disorders. I hope members will support this initiative. I have asked Nikhil to contact members for expressions of interest in joining the group and helping to work with him to develop the terms of reference further, the group strategy and an action plan.

We have had a series of very successful meetings during the year including the winter meeting in Liverpool with its record attendance and excellent scientific content, the joint Associates/TiPGHAN meeting in October and the joint BPSGHAN/BAPEN meeting in November. We have also contributed with sessions at the RCPCH meeting and BSG. I am grateful to the teams for organising such successful events, particularly the team in Liverpool, Kate Blakely and Richard Hanson for the October meeting and Susan Hill for the November meeting, Nick Croft for the RCPCH meeting and Huw Jenkins for the BSG meeting. I am also grateful to all members for contributing and submitting excellent work for presentation. We have planned for 2011 the Edinburgh meeting, joint sessions at the RCPCH and BSG, the annual associates/TiPGHAN meeting and a further joint postgraduate day with BAPEN. The commonwealth association of paediatric gastroenterology, hepatology and nutrition (CAPGHAN) are holding their 2011 meeting in London in July. This looks to be an exciting event and I hope very much many of you will attend.

We are fortunate to have Richard Hansen as chair of the trainees and Kate Blakely as chair of the associates. Both have put a considerable amount of time into their respective roles over the last 12 months and having such strong and active trainee and associate groups adds considerably to the strength of the society

There are significant challenges ahead for us in the current financial climate which will mean that we will need to work hard not just to expand but to maintain our services. This will need to be achieved by working together through networks and collaboration. This means we need to be clear from a service point of view what we offer as a speciality, how it can be best delivered and how to develop services using the resource available. This ranges from through all tiers of health care and involves the many different conditions we treat. We have established a dialogue with the department of health which I hope will gain us support to work with them to revise our guidelines for purchasers and Nick Croft,

Alastair Baker and myself are due to meet the team there in February. I am aware there are continuing issues regarding the provision of intestinal failure services nationally and John Puntis and Sue Beath are leading on discussions on this with the potential for the society to input into specialist commissioning. This is a significant work stream managed through the nutrition working group which has members representing our surgical colleagues (BAPS), BAPEN and the British Intestinal failure Alliance. All of these issues are complex in the current financial climate.

The society is in an excellent financial state thanks to the careful management of our retiring treasurer Alastair Baker and I am grateful to him for the considerable time and effort he has put into this role. We are also in an excellent administrative state thanks to the considerable efforts and expertise of Carla Lloyd who I am pleased to say has agreed to stay on as administrator for at least the next 3 years.

I would like to thank Patrick McKiernan for his leadership of the liver steering group of over the last 3 years and Paraic McGrogan who as gastroenterology and clinical standards representative who has worked so hard in conjunction with the various working groups to establish terms of reference and work plans.

I would like to pay tribute to Nick Croft as retiring convener who has worked tirelessly over the last three years on behalf of the society and has been a real pleasure to work with.

I feel we should be proud of our achievements as a society and look forward to working with council and the members to build on these over the next few years

Convenor's Report

Nick Croft

This is my final report as convenor after 3 years, I think one of the major achievements in recent years is that BSPGHAN has become increasingly asked for advice in our speciality (Department of Health, NICE, SIGN, JAG, BSG and other organizations) and this remains a major part of council's workload. Now the paediatric part of the speciality of GHN is at least usually considered rather than being forgotten in the wake of the much larger adult GHN services.

This can only happen if BSPGHAN council responds promptly and reliably to questions and consultations, members feed in their thoughts to council when asked and all of us when presented with an issue involving children with conditions we look after highlight the presence and willingness of BSPGHAN to get involved. Other societies use professional lobbying organizations to get their influence noted, I believe we are achieving a lot just with the interest and enthusiasm and goodwill of the members and council.

Our membership remains healthy with a total of 376 members (165 consultants, 65 trainees, 14 honorary (retired) members, 4 overseas, 128 Associates).

Mark Beattie has stepped into the role of president with great energy and I shall look forward to observing progress over the next couple of years. It has been a pleasure working with him.

Changes for council in 2011 include our new Treasurer, Mike Cosgrove and the election for my successor as Convenor between John Fell and Sue Protheroe. We also welcome the new Hepatology Representative, Anil Dhawan from Kings and await the outcome of the elections for the new gastroenterology representative (between Marcus Auth, Simon Murch and Sally Mitton).

Council has agreed some minor changes to the Constitution, which have been sent out for all members to review and will be presented, discussed and then voted on at the AGM. Please consider them, this is your constitution and has to be approved by the members.

The ACCEA process continues to be run in a highly organised manner led by Carla and Professor Deirdre Kelly. Thanks to both of them, and the committee reviewing the applications, for all their hard work.

The up-coming meetings over the next year remain very attractive, in April at the RCPC we have a joint session on the Tuesday afternoon (5th April) with the British Association of Respiratory Paediatricians. In addition to research presentations and posters we will be having sessions on reflux disease and obesity. These joint sessions work very well, both as a way of engaging with other specialities, but also as a way of engaging with general paediatricians. BSPGHAN has really led the way in this.

At the BSG the Adolescent Young Person section (which includes 3 BSPGHAN members) are involved in two sessions; on the Tuesday pm (15th March) it is with the endoscopy section 'Transitional issues for endoscopists'; on Wednesday pm 'Adult paediatrics, clinic problems'.

Being convenor is both interesting and enjoyable but really cannot happen without the support and hard work of a number of people. Mark and previously Huw as presidents were a joy to work with, all council members contribute hugely to everything achieved and of course Carla, as ever the most important of the lot, and I am delighted we have now acknowledged her administrator role formally in the constitution.

Treasurer's Report

Alastair Baker

After making its highly successful first CORE partnership research award the society remains in excellent financial health with adequate reserves and a large surplus. The new financial governance structures are bedding in well and beginning to run smoothly. Budgeting by committees and working parties is maturing nicely and financial

accountability by chairs is being accepted. BSPGHAN Development awards for education, IT, or other society purposes of up to £12000 have been offered with limited uptake.

The major source of society funds is now the Winter meeting. We expect some cost pressures over the medium term due to financial pressures on our non-meeting sponsors from the economic climate. As a result we can only expect to have about £14000 pa free cash for the next 3 years unless extra sponsorship can be found. Nevertheless, using its existing surplus with due prudence the society has funds to pursue its goals including at least one further CORE research collaboration.

An exemplary replacement has stepped forward for the current treasurer whose tenure expires in April.

Research Report

Nikhil Thapar

2010 has seen research established as a key part of the society and a key goal is to develop multicentre collaborative research

1. BSPGHAN/CORE Grant Awards for studies into adolescent transitional care / adolescent health in G,H or N

We were very pleased to see the very successful culmination of the 1st ever joint BSPGHAN/CORE grant awards. Following a very robust response to the grant call with a number of “high quality applications” all comprising multicentre collaborations across large numbers of adult and paediatric units across the UK two projects were funded. The high quality of the submissions was underlined by the fact that CORE decided to increase the overall joint funding budget to permit full funding of the 2 awards. This was excellent news for the applicants and the society

The successful applicants were

(i) Professor Sanderson's team - Royal London Hospital and collaborators
Treatment of Iron deficiency anaemia in adolescents with inflammatory bowel disease: tolerance and effects on haemoglobin, disease activity, mood, quality of life and autonomic nervous system activity

(ii) Professor Kelly's team - Birmingham Children's Hospital and collaborators
An exploration of perceptions and views of key stakeholders about what constitutes successful transition for young people with liver transplants

We wish both teams success with their important studies and look forward to hearing the outcomes presented at our own and other meetings. It is also hoped that work from these studies will progress to obtain further funding e.g. NIHR. The society's membership should be commended for engaging with this process and for their positive response and efforts.

So successful has the venture been with CORE that they have pledged to fund new joint research initiatives with BSPGHAN. We do feel that this is an exciting opportunity and could be used in 2011 to support multicentre research within the society into any aspect of paediatric gastroenterology, hepatology and nutrition. We will discuss these proposals with you at the AGM and hope you continue to support the development of BSPGHAN-led research as a real force in the international arena. In conjunction with this we will also continue to seek other mechanisms to develop funded opportunities for equivalent research.

2. Development of the membership of the BSPGHAN Research Group to establish integrated working with the UK Clinical Research Network

In order to establish a research group not only with clear roles but also one that is best placed to provide support for the society and its members in all aspects of research and academic development we have integrated the BSPGHAN research group with the Clinical Studies Group (CSG) of the UK Medicines for Children Research Network (MCRN) and Non-medicines group of the UKCRN. This new group will be referred to as the UK Paediatric GHN Clinical Studies Group and co-chaired by Nikhil Thapar (representative on council and BSG research committee) and Nick Croft (BSPGHAN convenor and CSG chair).

Remit of the group pertains to all clinical research in children (GHN) in the UK and will include

1. Setting and identifying research priorities and opportunities (eg EU calls, from NICE guidance, national initiatives etc)
2. Encouraging and supporting multi-centre collaborative research and development of clinical research networks
3. Encouraging and supporting applications (peer review etc) for new projects (including maintaining an up-to-date research area on BSPGHAN website).
4. Encouraging and supporting trainees, associates, and members wishing to pursue academic career pathways.
5. Assessment of studies (medicine and non-medicine) and encouragement of adoption for the NIHR portfolio (all studies (med and non-med) should be submitted to the group).
6. Advising PIs on the process and how to benefit from adoption
7. Liaising with and advising industry e.g. PIPs

Membership: The group consists of the established members of the MCRN CSG + 5 new members appointed through BSPGHAN and one representative of the non-medicines network. We are greatly appreciative of the interest from the membership in joining the group and pleased to welcome Wael El-Matary, Nadeem Afzal, Julian Thomas, Tony Wiskin and Emer Fitzpatrick.

All posts will have a 3-year tenure (January 2011 – December 2013) on the research group. The newly established group had its inaugural meeting in December 2010 (face to face and teleconference given the snow!) and will aim to meet face-to-face twice a year and conduct other business by email and phone.

Nick and I would strongly encourage members to contact us, or indeed any member of the new group with any research queries, ideas and proposals

3. Links with BSG / BSG research committee

We continue to represent the paediatric sub-specialities through the work of BSPGHAN and the Adolescent and Young Persons section of the BSG. It is hoped that the coming year will see even closer research collaborations and initiatives across the two societies.

Education report

Rajeev Gupta

A survey of members was done to find evidence base for developing educational activities and expanding these on behalf of BSPGHAN. 68 members replied and the main requirements were web based education, educational meetings, telemedicine, self-assessment tools, means of providing CPD, e-journal etc.

There has been several individual and group discussions and a full meeting of education committee in Birmingham on 23rd November to discuss short, medium and long term goals. Active contribution and enthusiasm of all members was appreciated. The objective of the education committee is to provide all members with mechanisms to expand their learning irrespective of grade or category. Links are being established with other societies and other educational organisations to have better access to learning and revalidation. Deeper links of education committee are set up with trainees and associates through TiPGHAN meeting.

Top 5 articles – This new feature is designed to give access to members about top 5 articles of great interest and link will be published on education page of the BSPGHAN website. The articles would be updated 3monthly initially and perhaps on a monthly basis later. The articles will have free access through web and the first set of Top 5 articles has been placed on 10th December 2010. Members can recommend interesting articles to Rafeeq Muhammed, Girish Gupte or Kate Blakeley for consideration. If members desire, an attempt will be made to set up a system to enable members claiming CPD.

Telemedicine- Further expansion of Telemedicine for professional development and education is being considered and all members are encouraged through reminders to attend. In view of potential limitation to access telemedicine in some hospitals, a survey of telemedicine facilities in the hospitals of BSPGHAN members is being planned to be led by Subra Mahadevan.

Guidelines: Education committee will help organise all the guidelines of interest to BSPGHAN members for purpose of update, education and reference. Jenny Gordon has agreed to pull together all the relevant guidelines and links to NHS evidence which is portal for all NICE and RCPCH guidelines.

Slide casts from Annual BSPGHAN Meeting will become available on the education page of the website. Possibility of **video recordings of key note speakers of annual meeting** is being explored to be made available for those who were unable to attend and also of **podcasts from Telemedicine** to improve cascading the messages and education.

Web based educational modules : links are being explored to have access to relevant educational material of other societies i.e. BSG; BAPS: RCPCH; JAG; BAPEN . The committee would not only draw upon these links but the members of Education Group would also write paediatric gastro educational modules. A meeting with BMJ is in progress to explore mutual benefit.

DDF – BSPGHAN has active involvement in setting up educational programme and symposia of upcoming UK digestive disease foundation meeting in June 2012. It will be a giant meeting of all professionals related to gastroenterology i.e. BSG, BAPEN, AUGIS, BASL, BSPGHAN etc and we will be involved in all relevant symposia.

Supporting Training – Education committee member Priya Narula has done top 10 tips for getting into grid training. Sue Protheroe is actively engaged in ST7 assessment and advice for getting better at these.

Mentorship scheme- There has been expression of need for mentorship, particularly for newly appointed consultants. Carla is writing to previous volunteers who had agreed to act as mentors and also ask for further volunteers. Formal online training can be provided to mentors. Once a group of mentors is identified it will be notified to members.

Exploration is in process to have education material with assessment system to accredit CPD through RCPCH.

The education committee expresses gratitude to Mark Beattie and other council members for support. A special word of appreciation to Carla Lloyd.

Nutrition Report

David Wilson (NWG Rep on Council) and Sue Beath (Chair to 28.01.11)

1. Meetings 2010 and 2011:

The Nutrition WG has 2 meetings per year, one at the Winter Meeting and the 2nd at a variable location in June. In 2011, these 2 meetings will be supplemented by a strategy day. Meetings (past and future) from 01.2010 onwards:

- (a) Liverpool 28.01.10 (b) Birmingham 24.06.10 (c) Edinburgh 27.01.11
- (d) Strategy Day - 06.04.11, Warwick

2. BIFS:

BIFS has been recruiting for over 5 years, increasing in terms of accrual year by year, and has had 384 registered patients by 30.06.10, of which all but 49 had intestinal failure. Recruitment started in 6 centres; more centres have registered year on year but not all are

recruiting. BIFS estimate that by 31.12.10 they are recruiting 35% or so of eligible cases in the UK.

Nutrition WG members and BIFS themselves have concerns about recruitment and thus quality of information arising. BIFS are exploring the possibility of no longer requiring informed consent to facilitate near-complete UK wide accrual, but of anonymised data. WG members have suggested also a later starting point eg 42 or 56 days of PN dependency.

Further publications from BIFS are expected in 2011.

3. Strategy for Intestinal Failure In Children (SIFIC):

There was a meeting of 8 BSPGHAN attendees with National Commissioning Group (NCG) on 09.03.10 to further the England-wide commissioning of IF services (as HIFNET has done for adult IF). It was agreed that John Puntis plus a BAPS representative would meet the regional commissioners in November 2010 to present our case to SCG. After much further discussion, and with the current funding environment not being encouraging, a submission was not entered, with plans to do so after BSPGHAN and BAPS wide-discussions in early 2011.

4. Consensus-based guidelines on intestinal failure management:

Given the disparate writing projects on IF within the group with uncertain timelines and none of which had reached completion, David Wilson suggest the writing of formal consensus-based guidelines on management of IF in childhood by the Nutrition WG for BSPGHAN and to aid IF management within BSPGHAN. A systematic review of the evidence on medical and nutritional management of IF in childhood by Andy Barclay and David Wilson has been published in *Alimentary Pharmacology and Therapeutics* (APT 2011; 33, 175-84) thereby facilitating the writing of consensus-based guidelines. This would draw 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. It will be led by Susan Hill, with David Wilson in charge of the methodological aspects, and has a timeline of completion of all first draft subgroup work by April 2011. The aim is to publish the guidelines in the peer-reviewed literature and to have the full document available to all via BSPGHAN website.

5. Nutrition Strategy Day with other key players:

Dr Mark Beattie's suggestion of a Nutrition Strategy Day (hosted by Nutrition WG on behalf of BSPGHAN, and involving other key organisations such as BAPEN, BIFA, BAPS, RCPCH committee on nutrition and SACN) is moving forward. Sue Beath is convening this meeting, either occurring on 06/04/11 in Warwick or at RCPCH headquarters in March-May 2011. The date will be determined by the availability of the key non-BSPGHAN attendees.

6. Collaborative Research projects:

(i) Taurolock RCT (lead Jutta Koeglmeier). The study proposal has been approved by the Paediatric Gastroenterology Clinical Studies Group and advice from MRCN in Liverpool has been given. A survey of potential collaborating centres to identify subjects

for study and establish level of interest and support is planned. Update to be given at NWG meeting 27 January 2011.

(ii) RCT of SMOF vs Intralipid to prevent cholestasis in post-GI surgical infants (Birmingham Childrens Hospital Paediatric Surgery and Gastroenterology) . Update to be given at NWG meeting 27 January 2011.

7. Published output from Nutrition WG in last 12 months:

Flynn DM, Gowen H. Paediatric parenteral nutrition and lipid usage in the UK – a Pick “N” Mix situation? Clin Nutr 2010;29:275-6.

Beath SV, Gowen H, Puntis JWL Trends in UK paediatric home parenteral nutrition and implications for service development. Submitted to Clin Nutrition 2010.

8. Closer links with paediatric surgery:

These are being actively pursued via BAPS with regards to intestinal failure management.

9. Terms of reference for WG:

Agreement has been reached with Council:

(a) Chair – the incoming Nutrition representative on council will take up the chair 12 months after their joining of council, and would hold the chair for the next 3 years, the last of which was after they had finished their term as Nutrition representative on council.

(b) Core membership – A core membership (eligible for expenses for meeting attendance) of 14 was proposed:

(i) Current chair when new Nutrition representative on council is in first year; stays for next 2 years as past chair (ii) Nutrition rep on council in their first year, then as new chair for 2 years whilst still on council (iii) BIFA rep (iv) BAPEN rep (v) Dietetic rep (vi) Pharmacist rep (vii) Nutrition nurse specialist rep (viii) BAPS representative (ix) Trainee rep (x) BIFS chief investigator (xi) BANS rep (currently also BIFS network manager) (xii) Research representative 1 (xiii) RCPCH Committee on Nutrition chair (xiv) Research representative 2

(c) Corresponding membership – A further group of individuals are both interested and valuable contributing members; they are welcome to meetings but are ineligible for expenses, unless they have been specifically invited to represent a group within BSPGHAN or present some work for consideration by the Nutrition WG. These will hopefully include members from various BSPGHAN subgroups eg psychology, DGH members etc.

Discussion of which positions will start rotating in 2011, with timetable of all rotating over 3 years to 2014, will be drawn up at 27.01.11 meeting.

10. BAPEN meetings 2010:

These have both been successful events from the Nutrition Working Group perspective, and discussions already in place about BSPGHAN contribution to 2011 BAPEN meeting plus joint BSPGHAN-BAPEN meeting. The donation of £2000 from BSPGHAN council to support the November 2010 Paediatric BAPEN meeting is gratefully acknowledged as is the liaison work with BAPEN done by Susan Hill on behalf of BSPGHAN.

11. ESPGHAN work on Nutrition screening:

No updates from Oxford or Glasgow, the involved BSPGHAN centres.

12. BANS:

Henry Gowen has represented the NWG and BSPGHAN on BANS. The deteriorating rate of registration of HETF and HPN is expected to rise with the recent removal of the need for informed consent.

13. Other issues:

(i) 'Malnutrition Matters' – NWG members provided a paediatric appendix to this otherwise adult-orientated BAPEN commissioning document.

14. Future priorities:

The first 6 months of 2011 should see strategy day results, furthering of SIFIC as a commissioning tool, completion of consensus-based guidelines on intestinal failure, multi-centre research project commencement, expansion of BIFS to most if not all 32 centres, publication of HPN point prevalence manuscript, and planning of further BAPEN meetings in 2011. Further priorities (such as HETF and clarification of position on obesity) will be discussed at next Nutrition WG meeting in 01.11 and at the strategy day.

PPP Report

Rod Mitchell

Since 2006 the Patient Public Professional representative has had a seat on Council, which has enabled regular opportunities for dialogue between BSPGHAN and the "Paediatric user/parent/family" community, though primarily via the various Gastro Patient Organisations involved in the link.

During the past year the current PPP representative, Rod Mitchell of CICRA, has participated in all but one of the Council meetings.

A first round table meeting for representatives of the link patient orgs: CLDF (Children's Liver Disease Foundation), Coeliac UK, CICRA (Crohn's in Childhood Research Association), Crohn's and Colitis UK (NACC), PINNT Patients on Intravenous and Nasogastric Nutrition Therapy was held in February and subsequently The Gut Trust (IBS) joined the PPP organisations umbrella group. Outcomes from that round table and from the ongoing and regular communication between the PPP representative and the patient organisations have resulted in a number of topics being submitted to Council; those have included:

- Research agenda/priorities, including possible future opportunities for collaborative programmes/funding including pump priming.

- Issues related to the future Paediatric Gastro Services resulting from political discussions with the NHS Commissioners/GP Consortia, Care standards, etc.
- NICE Guidelines and NICE in general.
- NHS Information provision accreditation scheme pilot - NACC involvement.
- Patient org costs associated with exhibiting at scientific congresses.
- New BSPGHAN website content.

In addition the PPP representative has participated in a number of the British Society of Gastroenterology – BSG Adolescent /Young Peoples Sub Committee meetings in London. BSPGHAN have indicated to PPP rep that the Patient Orgs with links to the BSG A & YP SC might be invited to discuss projects and joint funding initiatives.

Parents/Patient Organisation representatives have again been available to participate in Clinical Study and Work Groups and the October 2010 TIPGHAN day in Manchester. A number of Patient organisations exhibited at the BSPGHAN Annual Conference in Liverpool as well as other similar professional events; on behalf of the PPP Patient umbrella orgs the PPP representative attended the 2010 Annual RCPCH Congress at University of Warwick.

Looking forward:

- the representatives from the PPP link groups will be meeting again for their second round table
- further “User side” information will be submitted for the BSPGHAN website
- we remain ready and willing to continue the very useful dialogue that has been established via the PPP facility. Most importantly further active involvement of the “paediatric patient/parent community” and within the PPP role could be beneficial in the years ahead.

In conclusion we should like to thank BSPGHAN members and Council for facilitating the PPP role and for your support. The present PPP 3 year term ends January 2012.

Hepatology Report

Patrick J. McKiernan

Within hepatology the same structure exists.

Liver Steering Group: This is held twice a year. This constitutes a meeting of physicians and surgeons from three of the national units, representatives of non-NCG centres and from the Children’s Liver Disease Foundation. Interim communication is dealt with by Email etc.

UK Transplant Liver Advisory Group: Much progress has been made in this direction and there is now a national policy that all offered organs which are suitable for splitting are offered for splitting as the first priority so long as there is not a patient with acute liver failure awaiting transplantation.

We have also changed in the listing criterion for children with acute liver failure successfully.

NCG funded services: We are reaching an agreement on standards of transplantation to be agreed between the three centres and our commissioners the National Commissioning Group NCG.

We have been in liaison with the British Association of Paediatric Surgeons and NCG regarding the management of liver tumours. We have had agreement with BAPS that in children proposed for liver resection that the management plan will be discussed at multi-disciplinary team meetings including one of the national Liver Units before surgery is undertaken.

Protocols: We continue to develop these. There is one agreed protocol for the local hospital management of acute liver failure. Current protocols being prepared include the investigation of fatty liver disease.

National research protocols:

Prophylactic variceal band ligation: This is being carried out as a pilot study between the three national centres. Recruitment to the pilot stage has now finished. A total of 65 children were recruited to the study.

The non-invasive markers of fibrosis study will continue as a two centre study.

Future plans include a UK paediatric acute liver failure registry and a prospective study of the pharmacogenetics of immunosuppressants.

Manpower review: This shows that there are no imminently approved consultant vacancies in paediatric hepatology. There are a maximum of two possible job opportunities over the two years but neither of these have been formally confirmed or funded.

Training review: There are currently three national grid trainees in post. As a result of the manpower review among other things, there has been no hepatology appointment to the national grid on the last two occasions. It is however hoped that that this should be re-introduced next year.

There is also an annual specialty review for trainees in hepatology which has proved very successful. Also this year Dr. Rawat organised an abdominal ultrasound course from which the feedback was very positive.

Throughout the year I have also contributed information to support the National Liver Strategy and to a small number of NICE guidelines.

Gastroenterology/Clinical Standards Report

Paraic McGrogan

In the last year there has been a review of the organisational structure, terms of reference and objectives for each of the working group and committees. These are commented in

individual reports. It has been agreed that there will be an additional motility working group set up under the chair of Dr Nikhil Thapar. The council is also giving consideration to a further working group looking at the review and implementation of clinical guidelines that are published relevant to PGHN.

The clinical standards group continues to have significant input to the ongoing development of published guidelines from the Royal College, NICE, SIGN and the NPSA. I am very grateful to individual members of the society who have contributed both by sitting on the various guideline groups and contributing feedback to draft documents that have been circulated. Involvement in the following guidelines in the last year:-

NPSA: Patient safety alert

Reducing the harm caused in misplacement of naso-gastric feeding tubes
early detection of complications after gastrostomy tube placement

NICE:

Food allergy guidelines

Evaluation of pathways for medical technology

Organ donation

Hep B and C testing in children

Alcohol dependency

Sedation in infants, children and young people

Ongoing stakeholder involvement in the following NICE guidelines:

Management of Crohn's disease

Upper GI bleeding

Osteoporosis

Review of nutritional support

Review of eating disorders

Colonoscopy surveillance

Proposed guidelines with already registered stakeholder involvement

Management of ulcerative colitis

Hepatitis B diagnosed management in children, adolescent and adults

We have also provided feedback to the Royal College of Radiology on “clinical radiology services, consultation and draft guidelines”.

It is important that the Society continues to be proactively involved in the development of guidelines. This has given us an opportunity to influence policy and standards of care. The Society has been able to apply appropriate leverage at times to ensure that children and adolescent patients are not excluded from review process. A recent example of this was in the broadening of the remit of NICE on the management of Crohn's disease patients to include children and adolescents.

IBD working group

The group met at BSPGHAN meeting in Liverpool in Jan and Nov 30th in London. Rob Heuschkel has taken over as chair of the IBD working group for the next 3 years

The following is a summary of the year's activity:

1. UK IBD audit – 3rd of UK IBD audit is now active and data entry runs from Sept 1st 2010 – Aug 31st 2011. This is the second time paediatrics is participating and 26 centres have enrolled. Organisational data as of Sept 1st 2010 has already been entered.

2. Biologics audit; this is part of the 3rd round of the UK IBD audit. Different IT will be used for prospective data collection in the biologics audit. This will be trialled by 3 adult centres before the end of this month and Richard Russell and Sally Mitton, for paediatrics in December. The UK IBD audit steering group has agreed paediatrics will be part of the first wave of centres to participate in the biologics audit. The software is well developed although not quite finalised but Richard R and I have contributed to the paediatric dataset. The money received from HQIP for this part of the audit is being spent, in part, on the paediatric component and in recognition of this we should all participate fully. It is expected that data entry for the biologics will continue beyond the 12 month period of the audit and as such become the UK biologics register for adults and children. The software is well developed to enable that. Keith Leiper and Ian Arnott (chair of the UK IBD audit steering group) have expressed clearly their hope that all paediatric centres join in. We are lucky to have this opportunity.

3. NICE released new guidance on tumour necrosis factor in Crohn's (May 2010 TA187). The main changes are that adults can now receive maintenance therapy for one year or until treatment failure (including the need for surgery) which ever is the shorter. Continuation of therapy should be reassessed at 12 months and may continue if there is continuing severe active disease. This also applies to children and adolescents and NICE recognised 'in view of the lower cost and the greater potential for life long consequences from the disease and the side effects of other therapies, that TNF monoclonal antibodies are cost effective for children and adolescents'. Adalimumab may now be used similarly.

4. Grant from Crohn's in Childhood Research Association (CICRA) March 2010 £30,000 pa 'BSPGHAN quality initiative in biological agent usage for paediatric inflammatory bowel disease'; David Wilson, Mark Beattie, Nick Croft, Rob Heuschkel, Sally Mitton, Richard Russell, Adrian Thomas & Ian Arnott

Endoscopy Working Group and JAG

There was an Endoscopy Working Group strategy day in May. This was a very successful meeting and excellent attendance with representation both from CSAC and JAG. This gave an opportunity to review the current state of endoscopy training. The curriculum previously presented at last year's winter meeting was signed off.

Focus was on trying to develop paediatric endoscopy training in line with changes in adult training. It was agreed that all trainees will be required to undertake e-portfolios

through the JETS (JAG Endoscopy Training System). All training centres will need to register with JETS as will all endoscopy training leads. In line with the JAG training certification proposals paediatric endoscopy trainees will have ongoing assessment with DOPS. Summative DOPS assessment will be required before individual trainees can be put forward for certification.

Paediatric endoscopy certification: There will be a generic certification for upper GI endoscopies. There will be a specific paediatric certification for colonoscopy. Currently DOPS for a polypectomy is being validated and the JAG training working group are working on specific DOPS for management of GI bleeding and PEG placements. It is envisaged that trainees can be signed off as competent both in diagnostic procedures and subsequently in individual therapeutic procedures. A consultation paper will be presented later this year to the Society on the paediatric certification process.

Currently there are no JAG visits to paediatric endoscopy training centres (apart from Alder Hey) unless they are attached to adult hospitals. Adult hospitals visits do not to date take in to account paediatric endoscopy. There is a plan to review the adult GRS (Global Rating Score) to have a sub-section for units that undertake paediatric endoscopy. Sub-documentation will review all aspects of endoscopy pertaining to the endoscopy of children. It is envisaged that when this is validated paediatric endoscopy centres will undergo JAG visits.

E-Endoscopy Learning:-This has been currently shelved because of financial restrictions.

Trainees Report

Richard Hansen

Committee Members

Chair: Richard Hansen, Aberdeen

CSAC rep: Ed Giles, London

Secretary: Anthi Burt, London

Trainees' Meetings

The TiPGHAN group currently has a longstanding partnership with the associates group to organise and hold an annual training day. In the past, the programme has been shared between the two groups, but in order to best meet the differing needs of both groups, and also to provide some diversity in the programme, two parallel sessions were piloted at the meeting in Manchester in October this year, one focused on IBD and one mixed session. 41 Doctors and 27 Associate members were registered for the meeting from a total attendance of 74 delegates. A summary of the feedback is as follows:

1. How do you rate the relevance of this meeting to your educational needs?

No part relevant	Fairly relevant	Mostly of relevance	Highly relevant
0	2	17	9

2. How do you rate the overall quality of the education offered by this meeting?

Poor	Satisfactory	Good	Excellent
0	2	14	12

3. How do you rate the effectiveness of the meeting for CPD purposes?

Ineffective <i>Learnt nothing relevant to my practice</i>	Partly effective <i>Learnt little relevant to my practice</i>	Definitely effective <i>Will plan to modify my practice in a minor way or present practice reinforced</i>	Very effective <i>Will plan to modify my practice in a major way or clearer understanding of basic principals achieved</i>
0	2	14	12

4. How do you rate the new format of the meeting?

Poor	Satisfactory	Good	Excellent
0	2	14	12

The next meeting will be in London on 4th October and the provisional plan is for parallel sessions focusing on psychology and hepatology. The 2012 meeting will be in Glasgow.

European Working Time Directive Issues

During 2010 we surveyed all Grid trainees with a questionnaire regarding the impact of the European Working Time Directive (EWTD) on training in PGHAN. The results were supportive of our concerns that trainees were spending significant amounts of time on non-specialty training during working hours and also training in their own time. A similar survey was sent to recently appointed Consultants and statistically significant differences were seen between the two groups in the amount of time spent on subspecialty training (only 4/12 trainees spent the recommended >70% compared to 8/9 Consultants).

The results of this work have been accepted as a letter to Archives of Disease in Childhood with 7 authors, all from different institutions in the UK, including Dr Mark Beattie (BSPGHAN president) and Dr Peter Sullivan (RCPCH CSAC chair for PGHAN). Hopefully this work will stimulate further debate on the issues surrounding paediatric subspecialty training under EWTD.

BSPGHAN Telemedicine

The telemedicine programme was re-launched in late November, with plans to continue regular sessions in 2011. Unfortunately the last date coincided with the recent heavy snowfall and attendance was down as a result. Both the TiPGHAN group and Education groups of BSPGHAN are committed to telemedicine as an invaluable endeavour for delivering consistent and high quality PGHAN teaching to BSPGHAN members across the UK. We are grateful to Dr Andy Barclay for his continued efforts and enthusiasm in driving telemedicine forward.

The Future

ST7A: We are aware that recent pilots of the College exit exam in PGHAN have shown some weaknesses in our trainees compared with general paediatric trainees. Dr Sue Protheroe will address the trainees' group on this during the Annual Meeting. It is thought that targeted training may be required to address weaknesses. Given the findings from our EWTD survey, it is imperative that any such training does not further detract from subspecialty exposure. Specific concerns regarding the examination have already been raised by TiPGHAN with CSAC, namely: assessments in gastroenterology/hepatology can currently be undertaken before a trainee has completed the appropriate rotation, the assessment is examined by general and not subspecialty paediatricians and we are also concerned regarding the financial burden imposed by formal implementation of this exam in addition to currently existing CCT fees. We hope to be closely involved in any future developments.

JETS/Endoscopy e-portfolio: This is being rolled out across the country and all trainees are expected to be using this method of capturing experience by the end of 2011. We are committed to delivering a constant trainee presence on the Endoscopy group of BSPGHAN such that we can promptly and directly report any issues trainees may have with this new system.

Website Report

Naved Alizai

The BSPGHAN website was re-launched in October 2010 and we express our thanks to Mike Ibbotson who spent many hours planning and designing the website based on suggestions from council members.

We plan to use the website as a portal to inform and educate our members, to provide links to other associated Societies i.e. BSG, BAPS, BASL and also provide signposts for families who wish to find out more on their child's illness or disease and to this end we thank our PPP representative, Rod Mitchell, who, in collaboration with CICRA, CACC (NACC), CLDF and PINT, will be putting together some frequently asked questions and answers with signposts to websites that families and children will find useful.

The Society has grown and changed over the last 5 years with changes in Working and Professional Groups and we will be working with them to develop their pages in the website which will provide information to members and the public on the work the Society, through its Groups undertakes.

We plan to store and make available slide presentations from past and future Winter Meetings. There are plans to record and either podcast or videocast key talks from the Annual Meetings.

The website is still under construction and we welcome feedback from our members on how this should be developed and especially what information you feel is essential to keep the membership informed.

Paediatricians with Expertise In Gastroenterology, Hepatology & Nutrition (PEGHAN) Report

Naeem Ayub

At the last meeting a year ago, long term objectives for PEGHAN were identified. These included the following:

1. Greater involvement or representation in the BSPGHAN work groups.

This is happening already with Dr Rajeev Gupta chairing the Education group, Dr Graham Briars previous involvement and my role within the council as a representative of PEGHAN. Future plans to have “open” meetings for all the working groups will undoubtedly enhance this process.

2. Involvement in Guideline formulation and implementation

The recent NICE guidelines in “Constipation” and “Acute Gastroenteritis” have had the full involvement of BSPGHAN with contributions from PEGHAN. Individual PEGHAN members can also get involved in other relevant guidelines through the RCPCH.

3. Involvement in Research

Although the PEGHAN group is very large in terms of numbers and can therefore provide a potential resource for collaborative work, National multi-centre studies require a huge commitment in terms of resources and planning. An initial starting point with National Audits of relevance to the PEGHAN specifically, and the BSPGHAN as a whole is more likely to be successful. Audits indentified for this process are the NICE guidelines on “Constipation” and “Acute Gastroenteritis”. Constipation is a problem of huge magnitude and will be the first one to be audited. . The aims of the audit will be to assess compliance with the guidelines and secondly, effectiveness in treating constipation. Initial contact with the Medicines for Children Network (MRCN) has been favourable. A huge amount of preliminary work needs to be done first but we are hopeful that Trusts that are willing to participate in this audit will be identified as soon as the groundwork has been completed. The BSPGHAN Winter Meeting in January 2011 will provide an opportunity for the PEGHAN to map out a strategy for this project. I am optimistic that the Project can be initiated in 2011.

Associates Report

Kate Blakeley

Membership

We are continuing to get a steady flow of applications for membership from both dietitians and nurses with valuable experience and expertise in gastroenterology, heptaology and nutrition

Associates/Trainee Study Day

Attendance 74 (including speakers and chairs)

Medical Doctors 40 Dietitians 14 Nurse specialists 8 Clinical Psychologists 3

Parallel sessions worked well and were well attended.

Meeting expected to be (almost) cost neutral based on income plus dedicated sponsorship less expenditure

ESPGHAN

A successful associate's programme was run alongside the postgraduate day at ESPGHAN with many speakers from BSPGHAN contributing. Feedback was very positive as to the content and quality of the programme.

Committee

Chris Holden will be finishing her term as secretary at the Winter meeting. A call for interested associate members has gone out.

Strategy Day

Key Themes

1. Working within BSPGHAN.

Administrative Processes

Working Groups

2. Membership

- Encourage more active involvement, particularly from newer members:
- Buddy System
- Develop a Welcome Pack
- Hold a 'new members' meeting

3. Defending services

- Associates should contribute to BSPGHAN's pro-active role in helping members defend those services /posts that may be under threat.

Some of our Achievements

- All Working Groups now have Associate members
- Sit on Guideline Development Groups and have fed into NICE consultation process
- BSPGHAN Associates targeted to lead Associate involvement in ESPGHAN (attended strategy day)
- Supported the establishment of nurse specialists (NAC campaign)

Challenges

- Maintaining current activity whilst day jobs create more pressure (telemedicine?)
- Increasing the number of active members
- What we change and what we want to keep the same
- How we support Associates
- Threat to the nurse specialist role

Appendix 1:

Bursary Reports

Emer Fitzpatrick,

Awarded £450.73 to attend AASLD Boston 2010

Poster presentation: Hepatic lumican expression in paediatric non-alcoholic fatty liver disease.

I was delighted to be able to attend AASLD this year in Boston. This meeting, as ever, brought together those at the cutting edge of hepatology and it was great to be able to attend the various oral sessions, special interest group meetings and early morning workshops.

Of particular interest to me were two sessions on non-alcoholic fatty liver disease. Our adult colleagues are making major advances in the field both in terms of pathogenesis and management.

The much anticipated results of the TONIC trial (NASH US clinical research network) were reported at a plenary session – this trial compared metformin, vitamin E and placebo in paediatric patients with NAFLD and found that vitamin E and not metformin had a significant effect on histological progression.

In addition, there were a number of excellent sessions on hepatic fibrosis. The opportunity to speak to leaders in the field at the poster sessions was unmissable!

The paediatric sessions were also interesting: both the Boston group and the Cleveland group presented data using non-invasive biomarkers of fibrosis in children, a relatively new area, with some interesting results. Continuing with this theme; van der Laans's group from the Netherlands presented their work using microRNA as a potential biomarker of disease outcome in a plenary session. Such was our interest that we have since been able to establish a collaboration with his group. Mike Charlton's group presented some further insights on the role of lumican in liver fibrosis – a particularly relevant topic for me in light of my poster!

Overall the scientific quality of this meeting was undoubtedly excellent and it was an excellent opportunity to meet and network with experts in the field. I am very grateful to BSPGHAN for the support to allow me to attend.

Dr Eleni Volonaki

£300 awarded to attend 4th Paediatric Wireless Capsule Endoscopy Course

Thank you for supporting my participation to the 4th Paediatric Wireless Capsule Endoscopy Course. This unique course was an in-depth view on both theoretical and practical aspects of wireless capsule endoscopy by leaders on the field. Lectures focused on clinical indications, complications and interpretations of results, while all participants were provided with a PC and were given the opportunity to practice on real case scenarios. This valuable introduction to the wireless endoscopy set the foundation for trainees, including myself, to make use of this investigation in our clinical practice to the benefit of our young patients.

**Dr Yasser Ngem awarded £750 to attend 43rd ESPGHAN meeting
Istanbul – Turkey 09-12/06/2010**

I'd like to express my gratitude to the BSPGHAN bursary for facilitating my attendance to a meeting which was really constructive for the progress of my career as a Paediatric Gastroenterologist. My study leave fund was far short of the expenses of travelling to an international conference. I could show my poster for 3 out of the 4 days of the meeting (as I was doing a night shift at Great Ormond Street Hospital on the 4th).

My poster has presented retrospective data of 11 Tufting Enteropathy patients. The title was:

(Tufting enteropathy: The clinical spectrum). Initially, we were told that we'll be able to do a verbal presentation for 3 minutes, but this was later cancelled for all the posters. I believe that the vast number accepted on this occasion was the main reason.

I wasn't allowed to attend the postgraduate day as I haven't paid for it and the organizing committee were rightly very strict about it. So effectively, I've attended 2 days of the meeting: the 10th and the 11th. From my perspective, the most interesting on the 10th was the (State of the Art Lecture: Inflammation, stress and metabolic regulation) by professor Gokhan Hotamisligil. On the 11th, the session of (Biologicals in Paediatric IBD), especially the presentation of (New biologicals in IBD) by Dr Salvatore Cucchiara was the most intriguing.

I could steal some time to enjoy part of the social programme touring Istanbul.

My overall impression of the meeting was positive: Massive, condensed input into my subspecialty both at research and clinical levels, excellent venue and food. The drawbacks were mainly related to lengthy queues for registration and collection of the meeting package on the first day and the absence of representatives of the scientific committee to answer our questions about the arrangements for the posters. On occasions, I felt that the growth of the meeting that big with time limitations wasn't an advantage: More than 1 interesting session at the same time, dozens of posters with no time for even a brief oral presentation or for attendants to see most of them (especially that they were placed in the basement hall and not en route to the sessions halls). If the period of the meeting has to be limited to 3 days, it might be a good idea to merge the exhibition of posters with the time and location of the oral presentations related to the same area of interest. (e.g.: Enteropathy posters to be exhibited only at the time of the enteropathy session and around the room where the session is held. Attendants can discuss them before and after the session during coffee breaks and lunch with 10-15 minutes during the session for oral presentation of the most valuable ones).

Eventually, I have to say that I liked the experience and appreciated the bricks it has cemented in my experience as a Paediatric Gastroenterologist.

Dr Babu Vadamalyan awarded £750 to attend the 2010 UEGW Barcelona

Thank you for your support towards the above meeting in Barcelona, which I found it very useful to update my clinical skills and knowledge in Gastroenterology. I had the opportunity to attend hands on training in endoscopy especially on ERCP and ultrasound examination. On 25th of October, I enjoyed the IBD course particularly “Importance of drug monitoring on IBD patients” and also learned about the techniques and tricks of ERCP and EUS lecture. “Steroid resistant ulcerative colitis in paediatric patients “-symposium was very educational and highlighted the difficulties in managing this group of patients. On the next day, I attended the symposium on controversies and updates in the management of chronic pancreatitis, which was very useful. Evidence based treatment for the management of chronic pancreatitis was interesting and highlighted the need for further research in this field. Over the next 2 days, I participated in various symposiums and particularly enjoyed “The pathogenesis and management of Gastro oesophageal reflux disease”.

Moreover, I also had the opportunity to meet experts in gastroenterology field from all over the world and thank you very much again for your support towards attending UEGW 2010 meeting.

Paul Henderson awarded £750 to attend Digestive Diseases Week 2010

This was my first year attending Digestive Diseases Week, and as a research fellow undertaking work in both clinical and basic science it was an excellent opportunity to discover what was cutting edge in the field of inflammatory bowel disease (IBD). The meeting this year was held in New Orleans, Louisiana which was a great cultural experience and gave me the chance to meet many new people and catch up with my UK colleagues.

The main themes covered this year of interest to my research included the biology of adherent-invasive *E.coli* (AIEC), novel mechanisms of new inflammatory mediators and regulatory T cells in IBD pathogenesis. Several groups presented work on adherent-invasive *E.coli* (AIEC) showing mechanisms of cellular invasion, surface markers involved in internalisation and the effect of anti-TNF therapy on bacterial replication. With the significant increase in the use of anti-TNF agents in IBD treatment, there are currently increasing efforts to identify other cytokine pathways which may be implicated in the inflammatory process to help inform new therapies. Many new cytokines were discussed at this year’s meeting including IL-25 and IL-33. A group from University of Tor Vergata, Italy showed that IL-25 levels were reduced in IBD patients and that levels were increased following infliximab treatment. Additionally, a group from Regensburg, Germany showed that the use of recombinant IL-33 as prophylaxis or treatment significantly reduced colitis in a mouse model with others demonstrating the possible use of IL-33 as a serum biomarker. Although the role of regulatory T cells in the pathogenesis of IBD remains unclear, groups from Canada, USA and France presented work showing that there were in fact large numbers of regulatory T cells in the lamina propria of IBD patients, but that these have an intermediate phenotype, expressing high levels of IL-17 and little IL-10.

he meeting also gave me the chance to present a systematic review I had performed demonstrating the lack of evidence for seasonality in the pathogenesis of IBD. Presenting my poster to such a large audience was an excellent learning experience and has certainly enabled me to discuss my work more confidently. The ability to discuss with others their research was also invaluable as I was able to identify areas of my research which could be improved/enhanced and also set up collaborations with other groups in the UK and further afield.

Due to the excellent opportunity to attend DDW this year with the support of BSPGHAN I was able to present my research, learn about the plethora of work currently being undertaken by groups worldwide and experience the educational value of a large international meeting first hand.

Richard Hansen awarded £687.67 to attend DDW 2010

I am very grateful to BSPGHAN for sponsoring my attendance at Digestive Disease Week this year. I was presenting a “Poster of Distinction” on the epidemiology of inflammatory bowel disease in Scotland between 2003 and 2008. This work went down very well with many interested paediatric and adult gastroenterologists coming to see it during the paediatric IBD poster session. We are currently preparing a paper of the work for submission to a journal and some of the comments and questions I received were very helpful in preparing me for possible reviewers’ comments on the work.

In addition to presenting, I attended many sessions on my main research interests: paediatric IBD and the intestinal microbiota. These included oral abstracts from many groups demonstrating their most up-to-date work and also state-of-the-art lectures by leaders in the field. One particularly excellent talk was an overview of methods for assessing bacterial diversity by Erwin G. Zoetendal in the invited lecture: “Understanding Gut Microbiota: A New Era in Gastroenterology”. Particularly useful oral abstract presentations to my ongoing research included “The Gut Microbiome in Children With Severe Ulcerative Colitis” and “The Fecal Microbiome in Children With Diarrhea-Predominant Irritable Bowel Syndrome” which both revealed changes in the faecal microflora when examining cases against controls by microarray based methods.

I enjoyed the networking opportunities afforded by the world’s largest GI meeting and also managed to sample some of the famous New Orleans nightlife! DDW is a fantastic meeting with plenty of paediatric-related content and an amazing array of high quality basic science content from across the globe. I would highly recommend this meeting to all BSPGHAN members, but particularly those engaged in basic science research.