

British Society of Paediatric Gastroenterology Hepatology and Nutrition

# BSPGHAN Newsletter January 2010

# President's Report

#### **Huw Jenkins**

The Society continues to thrive and advance in many areas, as you will see from the reports in this newsletter.

One of the factors responsible for the Society's progress has been the increase in sophistication regarding the organisation of the finances of the Society and we are very grateful to Dr Baker for the excellent work that he is continuing to do as our Treasurer. Please read his report carefully as it is vital that all members have a say in determining how the monies are best spent in shaping the work of the Society over the next 3 years.

The second important area of advance has been in the field of education and Dr Sue Protheroe has done a superb job in organising the various strands that make the Society stronger. A key part of the education strategy is the development of the new website by Mr Alizai and colleagues and I hope you will all take the chance to comment on this as we need your help to ensure that the website is relevant, useful and user-friendly.

The Nutrition Working Group continues to be a strength of the Society and our thanks go to Sue Beath for all the work she has done in chairing the group over the last few years. It is gratifying that there are now closer links with each of the relevant organisations – a particular example is the developing links with BAPEN.

The Associate Members' Group is thriving, with an increase in membership, and Jenny Gordon must take great credit for this when she leaves as Chair of the Associate Members' Group next year.

We congratulate Dr Ronald Bremner on his new Consultant appointment and thank him for all that he has done for the trainees as their chairman.

Finally, I know the Society will be in excellent hands under the leadership of Dr Beattie as President from 2010 and will continue to go from strength to strength. He is fortunate to have a hard-working and talented Council and our particular thanks go to Nick Croft as Convenor and Carla Lloyd our Administrator, for navigating the Society through all the changes that are occurring on several fronts. It has been a pleasure and privilege to have been President over the last 3 years.

# Convenor's Report

Nick Croft

A year ago my signing off comment was to thank Carla for all her help and support, this year I thought it should come first as I appreciate more and more how much she does for the Society (not to mention the Convenor). So do pass on your appreciation when you see her. A tip is that Carla is particularly fond of some multi-coloured cocktail (sorry Carla, cannot remember which one), please do not ply her with too many of these until after the AGM.

Our membership continues to expand, last year I reported there were over 300 members we are now around 350, a sign I hope that BSPGHAN provide useful support to the members, Council will continue to work hard on this over the next year.

Council continues to evolve. This year we have the final moments of Huw Jenkins as President and I would like to pass on huge thanks on behalf of myself and all the members for his fabulous leadership and skills, including getting into meetings in places such as the Department of Health that I have regarded as the equivalent of Gringotts (go and ask one of your patients if you do not know where that is!). From my point of view has been a joy working with him and I hope our important meetings on various championship golf courses can continue in the future. While a difficult act to follow I know our incoming President, Mark Beattie will certainly live up to that and very much look forward to working with him over the next year.

Other changes include the moving on of the two Sues, Beath and Protheroe who have been absolutely amazing at what they have produced as the Nutrition and Education Rep respectively over the last three years. We certainly cannot afford to lose their interest and enthusiasm and am sure they will contribute to the Society from outside Council. We are delighted to welcome the new Education representative Rajeev Gupta and we look forward to announcing the result of the hotly contested Nutrition rep at the AGM. We also must thank Jenny Gordon for all her work as the Chair of the Associate members who has been a key member of Council, we welcome Kate Blakely as the incoming Chair and look forward to working with her.

After a couple of years with no changes, Council has proposed some 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.

BSPGHAN continues to be increasingly sought after for opinions and input by (amongst others) the RCPCH, Department of Health, NICE, SIGN, JAG and other organisations and this remains a major part of our workload. Over the last year we have managed to get a number of members to join a number of committees making decisions at the highest levels (often previously consisting of mainly our adult GHN colleagues) ensuring our patients and our members will be better represented. While Council deal with much of this it is vital that members respond when we send out calls for help.

The Specialised Services National Definition Set version 3 was finally signed off this year.

The ACCEA process continues to be run in a highly organised manner led by Carla and. now chaired by Prof Deirdre Kelly. I would like to thank Prof Ian Booth for his hard work as chair of the ACCEA committee in previous years.

Having made some changes to the meetings last year we are now settled into having a presence at three meetings, BSPGHAN Annual meeting, a joint session at the RCPCH (this year with British Association of General Paediatrics group on Tuesday 20 April) and the BSG in March where we are involved in joint sessions on Wednesday 21 March (via the oesophageal and adolescent and young adult sections of the BSG): 'Oesophageal disease from cradle to grave' and Thursday 22 March: Adolescent IBD Challenges and Solutions'. Do try to make space for one or more of these meetings, all will be excellent and you will learn plenty at all three.

# Treasurer's Report

Alastair Baker

Following the BSPGHAN Strategy day, I would like the membership to be aware of the following information and opportunities:

1. Summary of BSPGHAN Finances

Reserves saved in NS&I accounts: £35,000

Current Account stands at: £109,000 less CORE research allocation reserved: £35,000

Surplus cash in account as of 1/11/2009: £74,000

Total projected annual surplus for Society 2009-10: £38,500

(Fees plus Sponsorship plus 75% surplus of Winter Meeting - It is anticipated that such a surplus can be maintained for at least 3 years).

Research

The CORE joint research has received a good number of applications of high quality and

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the review process has started. We await the outcome of this prestigious BSPGHAN project. A further call for projects for research grants will be considered in 2011.

#### Increase in Bursaries

The total annual sum for education and training bursaries has been increased from £5000 to £10000. The regulations with respect to awarding them remain the same.

#### **Strategic Priorities**

The major Strategic priorities of BSPGHAN have been identified as A. Education and Training, B. Developing the BSPGHAN Website, C. TeleMedicine and TeleEducation, D. Standards and Audit including Revalidation. E. Research.

#### **Education Committee**

An Education Committee will be set up to direct the Education and Training Strategy with appropriate committee funding.

#### Post-Graduate Education Days

The Strategy Group pledged recurrent support for Annual Post-Graduate Education and Training Days e.g. BAPEN Study Day in November 2010. Also Associate/TiPGHAN training day, Endoscopy post graduate training day, hepatology training day etc.

#### **Innovation Grants**

The Council will invite bids of up to £15000 for 'Innovation Grants' to fund projects that further the BSPGHAN strategic aims. The grants would be for 1 year in the first instance and might include paying by sessions or hourly for skills that are not readily available such as IT or Webmaster, an Educationalist's input, PR or others. It is envisaged that those that are successful and require recurrent funding may be supported thereafter.

# Research Report

Nikhil Thapar

2009 has seen a positive progress on a number of points.

#### **Development of multicentre collaborative research**

# BSPGHAN/CORE Call for studies into adolescent transitional care / adolescent health in G,H or N

Progress – following a successful call for expressions of interest the formal grant call was put out with a closing date of January 11<sup>th</sup> 2009. It was decided to leave the call open to encourage applications and the development of further collaborative efforts. I am pleased to report a successful response to the call with a number of "high quality applications" comprising multicentre collaborations across large numbers of adult and paediatric units across the UK. The grant review and selection process is currently underway and the panel is comprised of both CORE and BSPGHAN representatives (any conflicts of interest declared or clarified). It is hoped that the process will be complete over the

coming 1-2 months allowing the successful project/s to commence. It is also hoped that any successful proposals will go on to obtain further funding e.g. NIHR. I would like to take this opportunity to thank the membership for engaging with this process and for their positive response and efforts. I hope this is the beginning of many such successful ventures. We continue to seek other mechanisms to develop funded opportunities for equivalent research.

2) Development of the membership of the BSPGHAN Research Group and establish integrated working with the GH&N Clinical Studies Group of the MCRN

Progress – Nick Croft has recently taken on the role of chair of the clinical studies group (CSG) of the UK MCRN. We are currently discussing mechanisms to recruit a core membership of individuals that will have remits both for the BSPGHAN research committee and for the CSG. It is hoped that a call for interested parties will be put out to members in the coming months. The CSG will become a key working group of the BSPGHAN research group and be led by the CSG chair. Apart from the UK MCRN we are also liaising with newly formed National Specialty Group for paediatrics (part of the NIHR Comprehensive Clinical Research Network), which deals with non-medicines research in neonates, infants and adolescents. It is envisaged that the remit of the research committee will be broad and not only link with the 2 groups above but also others within BSPGHAN, BSG etc to encourage and facilitate research, training, academic recruitment, research profile, website etc. Members are encouraged to contribute to the website by displaying research/career opportunities.

Establishing links with BSG / BSG research committee

Progress – The BSG research committee, as part of their strategic research review, have created a number of key clinical studies groups representing different sections of the BSG. The newly formed Adolescent and Young Persons section of the BSG is one such section. Given their close alliance with BSPGAN it is not yet clear whether a separate CSG will need to be formed. The A&YP section committee are working with the research group to develop a research strategy across the two societies.

I would encourage members to contact me directly with queries, ideas and proposals

# Education report

S. Protheroe 2010

The Strategy Day in November 2009 presented an opportunity to discuss the Societies aims and priorities for 2010 in terms of Education. It was acknowledged that responsibilities of the Society are expanding and the Council agreed that a priority for 2010 is to provide further strategic support for educational initiatives. We envisage that members can benefit from a more meaningful enhanced role from the Society in terms of education.

A process for change was defined with new terms of reference. Increased involvement from interested members with expertise will be sought to form an Education

Committee with Working Groups for specific projects. These suggestions are to be discussed with members at the AGM at the Winter meeting in Liverpool and reviewed by Council in early 2010.

Alongside strategic changes, the provision of financial support from the Society to assist members achieving educational requirements was considered important in light of the Society's strengthened financial position. A £5000 annual budget has previously been agreed to provide funds for members to attend educational meetings. Eight bursaries totalling £4196 were awarded to trainees in 2009 to attend international meetings. Whilst traditional bursaries can still be applied for, Council has agreed for revision of allocation of funds to be put into an education budget to allow more members to benefit from the Society's expenditure.

The Society intends to provide recurring financial support for education and training days for members including Trainees and Associates. Priorities are to provide sponsorship for a joint BSPGHAN/ BAPEN Study day, the TiPGHAN/ Associates Annual Meeting and Study Day at the Winter Meeting. There is a desire to sponsor BSPGHAN Endoscopy/ Hepatology/ Gastroenterology & Nutrition training days.

Council agreed that capital expenditure should be provided to continue to develop the web site and a telemedicine network in 2010. It was acknowledged that recurrent costs will be incurred to keep these initiatives up to date which the Society would support. It is hoped to produce a Telemedicine curriculum for trainees and identify an overall lead person and a lead in each centre with trainees. Consideration will be given to provision of funding professional assistance to allow the desired development of the Society's activities.

It is expected that funding of both capital expenditure for redevelopment and also recurring costs for future web site development projects (eg podcasting and other packages) will be funded from a website budget separate from the education budget.

The new website will be pivotal for updating education & learning tools for members and offer easy navigable signposting to training resources and assessment strategies. Appropriate information will be available for patients and families working in collaboration with patient support groups. Signposting for patient support sites and charities plus section on frequently asked questions is planned.

The Child Health Specialist Collection, part of NHS Evidence, run by NICE, has requested ongoing advice and commitment from members of BSPGHAN. This work will allow pooling of comprehensive sources of information relevant for our practice such as Evidence Based Medicine, guidelines, patient information, Cochrane Databases of Systematic Reviews, DARE and NHS Economic Evaluation of data. A working party to recommend relevant input and provide Primary care Clinical Knowledge Summaries and Annual Evidence Updates will be formed.

Input into Assessment and Training has continued this year. Quality of grid and other training centres, setting standards for trainees on the National grid and for trainees seeking a CCT with an interest in Gastroenterology in terms of both the curriculum and assessment of competency have been on the agenda at CSAC meetings.

The ST7 Assessment has been piloted by the RCPCH. BSPGHAN was the first speciality group to attend the ST7A Executive at the College to discuss strategies for assessment of speciality trainees in this new process. The ST6 Trainees in Gastroenterology and Hepatology will be the first speciality trainees to undertake a pilot assessment in July 2010. An ST7 question writing group in BSPGHAN has been convened to provide the material for the assessment.

The ST3 e-portfolio assessment documents are to be devised shortly and may require input into this process.

BSPGHAN is responsible for assessment of training and assessment process under the auspices of the Joint Advisory Grouped on Endoscopy Training for the UK (JAG). The Endoscopy training curriculum proposed by the Endoscopy Steering Group has been ratified by BSPGHAN and CSAC this year. Requirements for a CCT in Gastroenterology and Hepatology and for trainees working towards a CCT for a Paediatrician with an interest in Gastroenterology are outlined. Additional higher level skills will be included in the syllabus which are not required for obtaining CCT. Revalidation for consultants and ensuring the endoscopy environment is suitable are set to follow under the auspices of JAG.

2009 saw closer links with colleagues in the BSG with successful Paediatric sections at World Congress of Gastroenterology in London and the Adolescent & Young Persons Section of the BSG Annual Meeting in Glasgow, March 2009. The BSG Annual meeting 2010 in Liverpool includes two joint symposia; the Adolescent and Young Persons / Oesophageal Section symposium on 24<sup>th</sup> March and the Joint Adolescent and Young Person's / IBD symposium on 25<sup>th</sup> March 2010.

It has been a privilege to serve as Council representative for Education over the past few years. It is a pleasure to work with skilled and enthusiastic members of Council and to watch how the Society continues to gathering strength and to move forwards. The enhanced roles, responsibilities and initiatives are well placed to benefit the Society's members. I wish my successor the very best in the coming years in consolidating the exciting changes ahead.

# **Nutrition Working Group Report**

Sue Beath

Since my term of office finishes at the end of January 2010, I would like to preface this report with some words of thanks especially to Mr Henry Gowen who, in addition to being an exceptionally effective administrator of BIFS, has been a huge support to me and much valued colleague within the nutrition working group. I would also like to thank John Puntis and Mark Dalzell who were my predecessors for remaining so committed to the NWG; they, and the other members of the NWG, have made the past 3 years fun as well as highly productive.

#### 1. BIFS

- a) Mr Henry Gowen has continued to work with local investigators. Henry is now the BSPGHAN representative on BANS and will attend their next meeting on 10th February. The BIFS registry now contains 322 patients with 16 contributing centres.
- b) Dr Sue Beath presented an update on the work of the BIFS registry at the UKHPN meeting on 10<sup>th</sup> November. The UKHPN group has been re-named British intestinal Failure Alliance (BIFA) with the explicit intention of making it broader based to include hospital based patients as well children and those needing surgery. Dr Sue Protheroe is the BSPGHAN representative in BIFA.
- c) Audit of prescribing patterns for lipid in parenteral nutrition.

The short report submitted by Diana Flynn was accepted by Clinical Nutrition "Paediatric parenteral nutrition and lipid usage in the UK - A pick N' mix situation? Flynn DM, Gowen H.

Clin Nutr. 2009 Nov 22. [Epub ahead of print]

d) An audit of vascular access teams is under discussion

#### 2. Guidelines:

Currently the reviews are under development: Ms Sarah MacDonald is leading on nutritional rehabilitation after major abdominal surgery in infancy, and Dr Susan Hill is leading on Lipids in parenteral nutrition.

#### 3. Taurolock study.

The Taurolock study has been registered with the Gastroenterology CSG of the MCRN. A pilot study of 42 patients in 3 centres has been proposed with finance being sought from Tauropharm the manufacturers of Taurolock. A meeting with MCRN rep and Prof Herdeis of Tauropharm and Dr J Koglmeier and other investigators has been arranged for February 2010.

#### 4. BAPEN

a) Paediatric BAPEN meeting in Harrogate 1st November 2010 in Harrogate

Dr Susan Hill is the BSPGHAN rep in BAPEN and is working on the programme for this year's meeting in Harrogate. Input from colleagues in A-TiPGHAN has been sought.

#### b) Medical BAPEN

Dr Emma Grieg organises teaching days for medics and is keen to do one which would interest paediatricians in 2010. It has been proposed that there is a joint meeting with BAPEN at Great Ormond Street in September 2010. The programme is under discussion suggestions so far: eating disorders, IBD transition, congenital problems / metabolic disorders, chronic disability, cerebral palsy, cystic fibrosis, PN and differences between adult and paediatric services, PN preventing complications. This programme needs to go via the Education representative as well.

#### c) BAPEN commissioning toolkit

This is currently in draft form and Dr Mike Stroud has asked for some paediatric input. Members of the NWG are reviewing the document now. Advice from members of the RCPCH Standing Committee for Nutrition has also been sought.

#### 5. Contacts with other organisations

## a) National Commissioning Group

A working group consisting of the President of BSPGHAN, BIFS Chief investigator, Nutrition rep, BIFA rep, BAPEN rep, BIFS administrator and BANS rep, and BAPS rep has been convened and will meet Mr Jude Bowler at the DH in Victoria on 9th March to discuss the development of a Strategy for Intestinal Failure Services In Children.

# b) Expert working groups for Chapter F&G (Gastroenterology and Hepatology)

Dr Sue Beath is the BSPGHAN rep on this group which advises the DH on coding matters and comments on tariff setting. Nutrition remains without its own chapter and aspects of nutritional care are scattered through the HRGs - a situation which appears unlikely to change in the short term although it is a problem highlighted by RCPCH Standing Committee of Nutrition, BAPEN and BSPGHAN.

#### c) Best Practice Tariffs

We were asked to make suggestions for care pathways which could be commissioned under best practice tariffs. A recent example is Stroke care where service providers who offer thrombolysis are eligible for an enhanced tariff. We produced a preliminary document on nutritional support services for consideration by the Best Practice commissioners in December 2009.

# PPP Report

Rod Mitchell

At the BSPGHAN January Annual Meeting Rod Mitchell of CICRA succeeded Catherine Arkley of the CDLF at the end of her 3-year term of office on Council. We would like to thank Catherine for her strong commitment to the development of the BSPGHAN professional public/patient partnership.

During the year the present patient group "umbrella": CDLF (Children's Liver Disease Foundation), CICRA (Crohn's and Colitis in Childhood Association), NACC (National Association for Colitis and Crohn's Disease), Coealic UK and PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy) were consulted and various items were submitted for discussion with Council. Among those were:

Proposed new BSPGHAN website - patient /public info
IBD Audit Results/Standards (including Paediatrics) plus the 2010 review
Paediatric Clinical Trials/Managed Clinical Networks
Low numbers of Hepatology trainees
Paediatric transplantation
Input to the Quality Indicators for paediatric GHN services
Nutrition

Following the Paediatric committee changes at the British Society of Gastroenterology (BSG) the newly named BSG/BSPGHAN Adolescent and Young Persons sub committee agreed that with effect from their December 2009 quarterly meeting the BSPGHAN PP representative should participate in that Sub Committee.

For some years to assist in maintaining interactive dialogue with the wider paediatric professionals community patient organisations have been represented at BSPGHAN, RCPCH, BAPEN and other connected professional scientific congresses, workshops and exhibitions and this has continued in 2009.

Looking ahead to 2010 in addition to the continuing patient/public partnership and representation at Council, the participation in a number of the BSPGHAN work groups and in the BSG/BSPGHAN Adolescent and Young Peoples Committee, we are planning for:

- a face-to-face meeting of the representatives from the PPP linked patient groups to undertake a paediatric patient and families "needs" review in Q1.
- the completion of FAQ doc for the new BSPGHAN website
- the scoping of the paediatric/adolescent services provided by the currently associated patient orgs and by those gastro connected patient associations/foundations, who may wish to join in
- a review of current <u>paediatric</u> representative roles and the further opportunities that may exist within government, NHS agency structures and hospitals through public involvement and associated programmes

- continued interactive e-communication with the BSPGHAN patient groups and as appropriate with the public
- the take-up of a recently received request for patient organisation participation in the Taurolock UK study (prevention of catheter related blood stream infections in babies and children with intestinal failure who are receiving intravenous nutrition)

# Hepatology Report

#### Dr. Patrick J. McKiernan

The current structure for communication within hepatology continues. The Liver Steering Group meets twice a year with a single meeting to coincide with a specialty training review. During the year the Chair of the Group responds to any queries and circulates some issues for email discussion between meetings.

**Liver Advisory Group:** Our major work here has been working to maximise the potential use of split liver transplantation, There has been support from the Liver Advisory Group for this and as a result of an aggressive splitting policy waiting times for infants and young children awaiting liver transplantation are at a historical low.

**NCG services:** There has been much clarity regarding this. NCG agreed that the list of referral condition included in the recent document for Children's Specialised Services are appropriate guidelines for referral to any of the three national Liver Units.

**Hepatology Trainees:** A number of concerns have been raised about this. These focused on (a) the structure is inflexible, (b) career opportunities are uncertain and (c) most current trainees are outside of the conventional system.

This has been discussed with CSAC and the suggestion is that all hepatology trainees should spend one year in gastroenterology. Their progress should be assessed carefully after the first year in the national grid. It is also suggested that gastroenterologists should join the hepatology annual training review.

**National plan for liver services:** Paediatric component of this was provided, coordinated by Richard Thompson.

**Research:** The multi centre study of variceal banding continues with recruitment now in all three centres. Other large gastroenterology centres have been offered an opportunity to join but none as yet have taken this up.

**Non-invasive markers of fibrosis:** This is a national study in children with biliary atresia and has been introduced in the three hepatology centres.

**NICE protocols:** Neonatal jaundice has been circulated and commented upon. Protocol for prevention of alcohol misuse in those >10 years was received but too close to the deadline to respond to.

# Gastroenterology/Clinical Standards Report

P McGrogan

#### Clinical Standards Group

At the recent strategy day, the operational systems of the clinical standards group (CSG) was reviewed. The CSG acts to coordinate the various programmes of work undertaken by the subspecialty committees and working groups and ensures implementation of all the operational strategy. It also works closely with the clinical effectiveness department of the RCPCH, NICE and SIGN in providing stakeholder input into relevant topics to our specialty. It has been agreed to review the structure and terms of reference for all committees and working groups in the next year.

#### **Endoscopy**

The endoscopy curriculum is yet to be signed off. In discussions with CSAC the curriculum was altered: level 1 is split into 1a upper GI endoscopy and 1b ileocolonoscopy. Level 2 will remain but level 3 is to be changed to an appendix as these highly specialised skills are currently deemed to be optional.

The Joint Advisory Group for endoscopy (JAG) has currently not been provided with a specific mandate for paediatric endoscopy training. BSPGHAN has asked the RCPCH to give JAG the mandate to take on the delivery and monitoring of paediatric training. The curriculum will not be rubber stamped by CSAC until these has been granted.

There has been initial review and attempted modification of the global rating score (GRS) by the endoscopy committee. This has been taken back to JAG for further discussion. The paediatric GRS remains a priority of the endoscopy committee for 2010.

The endoscopy committee would like to put a call out to BSPGHAN membership for active motivated endoscopists to become involved with the group.

#### JAG

There continues to be paediatric input to JAG both through BSPGHAN and BAPS. Accreditation for adult trainees has now moved to use of the e-portfolios on the JETS website. Logbooks are now kept on the e-portfolio as are both summative and formative DOPS. There has been a change to DOPS required. It is expected that paediatric trainees will adopt a similar process in due course. There is a new website <a href="www.jag.org.uk">www.jag.org.uk</a> that I would recommend visting for further information

The e-endoscopy, a web based training tool is to go live in March 2010. Initially there will be 3 of 9 modules available and there will be paediatric input into these modules. Ultimately it is envisaged that completion of these modules will be built into a paediatric training programme.

#### Guidelines and Protocols

BSPGHAN has been involved in the following guidelines: SIGN; management of diabetes, NICE donor breast milk banks, NICE childhood constipation, NICE neonatal jaundice, recognition and treatment, multiple birth foundation, feeding twins, triplets and high order multiples. We are a registered stakeholder for several other ongoing guideline developments.

In the reconstruction of the website there will be a CSG page. It is hoped in the future that invitations for volunteers to be involved in these guidelines will come through this page.

#### IBD

#### Sally Mitton

- UK Guidelines for management of paediatric IBD and the Evidence Based Review were accepted by JPGN for publication as a supplement. The guidelines have been endorsed by the college
- The UK IBD audit (2<sup>nd</sup> round) data was presented.
- BSPGHAN provided input into the NICE technology appraisal of tumour necrosis
  factor antibodies in Crohn's disease which was repeated in August 2009 after
  reanalysing the cost effectiveness data and a final appraisal determination by the
  committee was held in Oct 2009. The NICE recommendations are essentially
  unchanged for children and adolescents up to 18yrs.
- The IBD standards have been launched across the UK in various venues including the House of Lords in Feb 2009. The third round of the national UK IBD audit will be measured against these standards.
- Research the UK multicentre RCT "Adverse Effects of Glucocorticoid Therapy on Bone in Childhood Crohn's Disease" closed for recruitment in March 2009 as enrollment had been successful with a total of 84 Crohn's patients from the 7 participating centres.
- The paed IBD biologics register has been vigorously discussed at the working gp meetings and a proposal to initiate a pilot study for 1yr of a paediatric biologics register was received from Dr David Wilson in Edinburgh.

#### Aims for 2010 and beyond

- Establish biologics register for paediatric IBD patients if the route via the audit is accepted this will also start in Sept 2010. The key decision is whether we run our own register in collaboration with the adult gastroenterologists or we are part of whatever comes of the adult register proposals.
- Increase participation of paediatric centres in 3<sup>rd</sup> round of IBD audit and ensure that the data collected for the 2<sup>nd</sup> round of paediatric patients better reflects paediatric practice RR & SM to continue this via IBD audit steering gp.
- Establish IBD disease register for paediatric IBD patients if via the audit, should be started in the next 2-3 years

# Trainees Report

Ronald Bremner

Committee members:

Outgoing Chair: Ronald Bremner, Birmingham Incoming Chair: Richard Hansen, Aberdeen

CSAC rep: Ed Giles, London Secretary: Andy Barclay, Glasgow

#### **Trainees' meetings:**

Sheffield Winter Meeting January 2009 Birmingham TiPGHAN/AM Joint Meeting

The Joint meeting in Birmingham was evaluated well by trainees able to attend. There continues to be less than full attendance from Grid Trainees to this meeting, with some reporting the reason being a lack of cover for clinical service commitments.

#### **Training issues:**

There remains concern from several who have reported anxiety about attaining competence in endoscopic skills during training and reduced exposure to specialist clinical experience, especially within a context of reduced working hours with European Working Time regulations.

There has been a perceived increase in the amount of time spent in General Paediatric service, affecting trainees on the Grid rotations and trainees with an interest. To help quantify this, we surveyed Grid Trainees September 2008 to March 2009 experience and are surveying again for March 2009 to September 2009. These results will be shared with CSAC. The DH has requested information on the impact of EWT implementation, and we aim to submit a report.

We support the ongoing implementation of Specialist Training Reviews (StRs) for all trainees Grid rotations, to complement Deanery RITAs, and suggest to trainees that these issues should be raised at these meetings, for solutions to be applied locally. For trainees with an interest, or off the Grid, assessment structures continue to be less well defined.

#### **Telemedicine:**

Co-ordinated by Andy Barclay, we have had two sessions of telemedicine, with video conference equipment. This innovative training tool aims to complement local teaching meetings. We invite all Grid centres to particiapte.

#### **Welcome packs:**

Introduced last year, the Welcome Pack for new Grid Trainees has been updated and distributed again. These are prepared and sent out by Andy Barclay.

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# Website Report

Naved Alizai

Over the last year we have been busy creating a new website for the society. We saw a preview of the site at our strategy day in November 09 and since then have been trying to finalise it. I wrote to the membership in June last year for ideas and updates, but unfortunately, only had couple of replies. Soon after the winter meeting we will send out the website link for the members to have a look following which, hopefully early March, it will replace the current site. I would like to take this opportunity to remind all that we welcome all/any ideas to improve the site and the web designers have agreed to make any changes/updates, free of charge, during the first few months after the launch. Please feel free to contact me directly. I hope you will find the new site user friendly.

# <u>Paediatricians With An Expertise In Gastroenterology, Hepatology</u> & Nutrition (PEGHAN) report Naeem Ayub

The early part of last year saw the completion of the syllabus and training requirements for "Paediatricians with an Interest in Gastroenterology, Hepatology and Nutrition". However, it is important to correlate the training requirements of the future PEGHAN members with the workplace facilities available to them upon completion of their training. The extent and scope of gastroenterology work undertaken by PEGHAN members is also relevant, not only to the Trainees but also the BSPGHAN as a whole. Finally, the views of the very diverse PEGHAN group are critical to determining what role they play in enhancing the objectives of the BSPGHAN as well as their own group. Although there is a database of all BSPGHAN members there is no database specifically for the PEGHAN group.

To achieve these objectives, a questionnaire was circulated to all BSPGHAN members in the latter half of 2009. I would like to thank all the members that completed and returned these questionnaires. The detailed results of this questionnaire will be discussed with the PEGHAN group at the Winter meeting in Liverpool but the preliminary results are:

- 1. The database is almost complete and will be accessible through Carla Lloyd in the near future.
- 2. Although the number of gastroenterology patients seen by individual PEGHAN members varies from 20 100 per month, the average is around 35/month.
- 3. Local facilities for investigations such as PH studies and OGD are available for the majority (75%) although adult facilities are utilised by a third of them for the latter. Colonoscopy, is performed by less than half the members and again, a third use adult facilities.
- 4. Paediatric dieticians were available to the vast majority (95%) but <0.5 WTE were specific to gastroenterology. As many as 40% had Gastroenterology Specialist Nurses.
- 5. **Suggestions for the future**: The majority felt that establishing Networks with guidelines, shared care protocols and educational activities (as part of the network) would be of major benefit. The DGH hospitals could also provide a huge resource for collaborative work on common conditions such as constipation.

Finally, the group would like to have a greater involvement in guideline formulation and implementation. This is already happening to some extent (NICE guidelines on "constipation", "Acute gastroenteritis")

I look forward to working with the Research and Education groups of the BSPGHAN to achieve some of these objectives, once a strategy has been mapped out by the PEGHAN.

# Associates Report ASSOCIATE MEMBERS REPORT 2009

Committee Members

Jenny Gordon (Chair) Chris Holden (Secretary) Sarah McDowell (Treasurer) Angharad Vernon-Roberts Sarah McDonald

2009 has been an excellent year for the Associate Members, our membership goes from strength to strength and we are well represented on BSPGHAN working groups and committees.

We currently have 126 members: 64 nurses, 48 dietitians 14 others including speech and language therapists, psychologists, pharmacists, research assistants. Many thanks to Carla who has worked tirelessly to ensure we have an up to date current database.

The AM e-bulletin has been well received and continues to be circulated 3 times a year, a succinct, easy to read way of keeping up to date with the work of the society, a means of advertising courses, study days, research projects etc. Any items for inclusion should be sent via email to the Chair (Kate Blakeley) or the Secretary (Chris Holden).

Our annual meeting held jointly with the trainees at The Motorcycle Museum in Birmingham went extremely well. The topics covered included Intestinal Pseudo-obstruction, Liver transplantation and Childhood constipation with an expert panel question and answer session. We had some excellent feedback and ideas for our next conference. Thank you to all who attended and made the day a success. We will use the results of the evaluation forms, and the suggestions you made, to shape next years meeting.

On behalf of the Associates I would like to thank SHS / Nutricia Clinical Care/Children's Liver Disease Foundation/Mead Johnson who continue to support us financially enabling members to attend national / international meetings. Future sponsorship will be negotiated in collaboration with BSPGHAN to increase our options for sustainable sponsorship.

Information on applying for funding is available on the BSPGHAN Website (Associate Members page). We are also very grateful for the generous sponsorship towards our Annual Conference and Committee Meetings throughout the year.

Financially our accounts have been amalgamated into the BSPGHAN under an Associates section. This has been done in the best interests of the Associate Members in the light of changing charity commission rules, VAT regulation and for auditing purposes.

Registered as a charity: Registration Number 299294

This has been my final year as Chair and I would like to thank all the Committee for their hard work and support. I have enjoyed every minute of my time in office and your new Chair, Kate Blakeley comes highly recommended and I hope that you will offer her the same support you have given me. We have also completed the balloting of members for a vacancy on the committee as Angharad Vernon-Roberts steps down. We would like to thank Angharad for her unstinting support and valuable contribution to the Associates and hope that she will continue to be an active member! We look forward to welcoming our new committee member, Mick Cullen at our AGM at the Winter Meeting. If you would like to be more actively involved in the work of the AM's please contact any of the committee members.

# Appendix 1:

## **Bursary Reports**

The Bursary Allocation Group was established in 2007 to provide education grants for BSPGHAN members to attend national and international meetings. However due to a slow uptake of these grants the funding was suspended in order to give the Group time to review the Application Rules.

The decision was made to reduce the amount available for 2009/2010 to £5,000; Associate Members would also be allowed to claim. Applications would be considered annually however members who had received an award in the preceding year would only be granted an award if there were sufficient funds at the end of the financial year.

The Bursary Allocation Group is pleased to announce that there was an increased demand for awards in 2009/2010

Applications were received from

Dr Priya Narula (PIBD, France)

Dr Venkatesh Krishnappa (NASPGHAN, US)

Dr Rachel Levi (14<sup>th</sup> International Congress of Mucosal Immunology, US)

Dr Sabari Loganathan (ESPGHAN)

Dr Rafeeq Muhammed (ESPGAN)

Dr Prithvi Rao (UEGW, London; and NASPGHAN, US)

Dr Veena Zamvar (Small Bowel Intestinal Transplant Meeting, Italy)

Dr Intan Yeop (Small Bowel Intestinal Transplant Meeting, Italy)

Dr Priya Narula and Dr Venkatesh Krishnappa had received awards in 2008/09 and therefore a final decision on an award will be made at the end of the financial year. All other applicants were awarded grants from £500 - £750

The Bursary Award will continue and as a result of the increased demand it has been agreed that this will be increased to £10,000 per annum.

Reports from successful applicants:

Dr Rachel Levi Clinical lecturer Paediatric Gastroenterology, Barts & The Royal London Hospital, London. 14<sup>th</sup> International Congress of Mucosal Immunology, US

I am very grateful to BSPGHAN for providing a bursary to enable me to attend the 14<sup>th</sup> International Congress of Mucosal Immunology in Boston. I also attended the one day pre-conference workshop on microbes & mucosal immunity, aimed at younger investigators, which was an excellent introduction to the conference itself. It was an amazing opportunity to hear key note lectures from some of the leaders in the field, as well as interesting more interactive sessions with junior researchers from around the world. I was pleased to present my poster 'Persistent signaling in the intestinal epithelium protects against DSS induced colitis and tumorigenesis in APCmin/+ mice', I got some interesting feedback on my work. I feel I extended my knowledge of mucosal immunology and identified the key areas where research will be focussed over the next few years. I am also grateful for the opportunity to meet other clinicians and scientists working in the field.

# Dr Sabari Loganathan SpR

Thank you very much for supporting my application to attend ESPGHAN 2009 at Budapest.

This is my first attendance to ESPGHAN. It was a great experience.

Firstly my presentation went well and was received well. It was a great learning experience and gave me confidence in presenting in the meetings. It was also an opportunity to observe other presentations and to learn from it. The discussion and questions after my presentation gave me idea towards my paper which I am preparing.

Secondly it was an excellent educational meeting with a mix of topics from basic science to all areas of gastroenterology, hepatology, nutrition and allergy. Lastly it was a nice social gathering as well which gave an opportunity to meet pioneers in the field informally.

Once again thank you for supporting me to attend this excellent conference.

Dr.Rafeeq Muhammed SPR Gastroenterology Birmingham Children's Hospital I am extremely grateful to the BSPGHAN for providing me a bursary to attend the annual ESPGHAN conference in Budapest in June 2009. I had presented two oral posters in the meeting, 1.Paediatric endoscopy provision in the UK and 2. Sudden and marked reduction in PN cholestasis after changing to fish oil based lipid (SMOF) from conventional lipid. I am pleased to say that both papers were very well received. The post graduate day in Budapest was an excellent opportunity to learn about metabolic liver disease, GI immunology and nutrition. I have learned a lot from attending various sessions in the following three days, especially in immuno-gastroenterology, which is my area of special interest. By attending this meeting, I have learned about latest advances in many areas of gastroenterology like congenital diarrhoea, inflammatory bowel disease, eosinophilic oesophagitis etc. From a trainee perspective, I feel that this meeting is worth for the fees paid because of the excellent learning opportunities.

### Dr Prithvi Rao SpR Gastroenterology Leeds

Report from UEGW

Massive congregation of adult and paediatric gastroenterologist, surgeons, nurses and pharmacists.

Organisational wonder – as the delegate numbers were as high as 15-20,000 and with big numbers from eastern and southern half of the world.

Opening plenary session had our own Dr.Mike Thomson's presentation on effectiveness of Monoclonals in Eosinophilic oesophagitis. The Prize abstract was from the group in France looking into factors preceding the onset of Crohns and how it can be prevented.

Day 1- Highlight for me was the to-be-extinction of surgeons with NOTES (Natural orifice Transluminal endoscopic surgery)

Live feeds were arranged from other parts of the world namely:Hongkong and Hyderabad, India. Procedures like diagnostic peritoneoscopy, biliary tree stone removals, cholecystectomy etc were on display and amazed me that there were done as daycases!!

The slant for the future certainly seems to be that the adult gastroenterologist is going down the surgical path.

Day 2 – Mike and I had an oral presentation in the morning on feasibility of Endoscopic Fundoplication (for which I was entitled to the Young investigator award) which was well received with a lot of questions coming particularly from our surgical colleagues.

It was interesting to see most countries including developing nations in Latin America maintaining registries for NOTES/ Monoclonals etc

This apart I spent most day in the hands on sessions using dummy models and practiced Upper GI hemostasis using gold probes, polypectomies etc. They had some wonderful models there. Newer inventions like endo clips to seal perforation endoscopically and combined injection/snare accessoried were on display using animal models.

In addition the OSGE had kept 10 video stations of 20 minutes each which highlighted recent advances in various therapeutic endoscopic techniques.

Day 3 – The main highlight for me were the posters on display which have sparked ideas for future projects and my own poster presentation on Eosinophilic Oesophagitis.

**Reflection**: The world congress gave me an insight to developments in gastroenterology all over the world and gave me a new perspective on the subject. I'm going to consider attending alternate years to see developments in the adult gastroenterology world and how we can keep pace with certain developments that they are able to make.

Dr Prithvi Rao SpR Gastroenterology Leeds

Report from NASPGHAN

NASPGHAN DIARY Harbour, Maryland

NOVEMBER 2009

09 –National

# **Outline / Overview**

NASPGHAN was a massive congregation of paediatric gastroenterologists from largely the western part of the globe. It surprised me that there were nearly 2000 paediatric gastroenterologists in attendance! Every finicky detail was organized to the 'T' with advance email notifications and clearly outlined programmes provided to us in print on registration. The programme kicked off with a very informative postgraduate study day, summarized below .The remainder 2 days were packed with pre-decided scientific themes with lectures from leading experts+ abstract oral /poster presentations + CV's clinical vignettes (posters of case reports to incorporate and encourage junior trainees).

An *interesting* aspect of this meeting apart from an opportunity to network and interact with colleagues from around the world were the forums that allowed this to happen i.e.:-

a) Breakfast with professor's –Which allows one to thrash out a specialist topic with a leading expert in the field in a smaller room and

b) A Hands on Paediatric interventional endoscopy course-where 15 minute slots were given to each registered trainee- to have a go at Upper Gi hemostasis i.e. gold probes/ endo clips etc.

Certain **take home messages** for me from the PG study day:

Obesity	Relevance and importance of doing fasting insulin levels in determining a sub-cohort of patients with metabolic syndrome. Insight on certain motivational interviewing techniques
Mitochondrial diseases	False to assume is muscle biopsy negative –MTC is ruled out as mitochondrial DNA is different in different tissue. Genotyping now
	available to make a diagnosis, OLT successfully used when liver irreversibly damaged
Primary	Made aware that ursodeoxycholic acid at doses greater than
sclerosing	20mg/kg/day carries a risk of death OR liver transplantation by itself
cholangitis	[Ref: Lindor KD et al Hepatology 2009;50:1-7]
Eosinophilic	If high level of suspicion based on macroscopy but eosinophils<15 to
Esophagitis	request histologis to consider using EPX immunostaining which has a
	better pick up rate. Made aware of association which will create
	guidelines-namely "TIGERS" The international gastrointestinal
LI Dulori	Esoinophil researchers.
H.Pylori	Shortly due consensus guidelines on H.Pylori management between ESPGHAN/NASPGHAN.
	Clear criteria on when and how o investigate. Made aware of concept of adding bismuth sulfae OR doing sequential therapy[amox,ppi 5
	days followed by ppi,clarihromycin and tinidazle for next 5] for
	resistant H Pylori and to try and obtain C and S on H pylori samples
	as in the UK resistance >20% [Particularly if using clarithromycin]
IBD	Crp having excellent co-relation with Crohn's and not so with UC.
	Faecal Calprotectin having a role in measuring baseline values when
	IBD patients are well so that any hint of relapse can be picked up by a
	siginificantly elevated calprotecin [At 13 fold rise from 50 Microgram/g]
IBS/ Functional	Hypnotherapy now being made available through internet and efficacy
abdominal	of the same e.g. childpainsolutions.com
pain	Mesalamine shwing early promising results in IBS
Constipation	New therapies being evaluated in feasibility trials namely –
	lubiprostone [A prostaglandin metabolite] with secretory ability and
	Bile acids

Take home messages from an expert panel on : Monoclonals in IBD

- 1. Risk of death [Hepatosplenic Lymphoma] from combined usage of Infliximab and azathioprine should always be portrayed to patients keeping a larger perspective in mind. A road accident incidence in teenagers is 2.3/10000 .Lymphoma from mercaptopurines is 4/10000 and that from infliximab + mercaptopurine is 6/10000.
- 2. Always consider doing trough infliximab levels before considering changeover to alternate as bioavailability varies. If trough level high enough only then to consider that as treatment failure. If levels low should then consider increasing frequency or increasing dose.
- 3. In a situation where active bleeding is taking place and repeated blood transfusions are given for e.g. U.Colitis with active bleeds –Infliximab gets cleared quicker from blood and so doesn't have enough time to induce remission.
- 4. Adalimumab should be tried for atleast 3 months before labeling it as failed as takes longer to kick in. Also to consider weekly dosing instead of fortnightly to induce remission and then can go back to fortnightly after 2 months for maintenance.

#### New medications in IBD around the corner!

- 1.Lactococcus Lactis- Oral bacilli which acts topically (hence no systemic side effects) which induces expression of IL-10 (an anti-inflammatory agent). May also have a role in infantile crohns (which is now proved with genotyping o be secondary to IL-10r deficiency.
- 2. TNF alfa blocker-Golimumab and also Vedolixumab

#### On a personal note

My papers on Eosinophilic Oesophagitis and transoral incisionless fundoplication did generate a lot of interest. It also gave me an opportunity to interact with interventional endoscopists, as to advancements in this field. Areas for future development in training-certainly appear to be fellowship programmes in interventional endoscopy. There will be I gather an ERCP training programme +/-endoscopic ultrasound at Boston Children's hospital. Wireless capsules for Oesophagus and small bowel are already prevalent through most of USA. The oesophageal pillcam is being regularly used to monitor varices in children with Liver problems instead of surveillance ogd. This thus helped me identify potential areas for future sub specialization.

This apart 3 of us from U.K. namely :myself ,Arun urs and Venkatesh each made our respective presentations which were well received. A lot of people have thus expressed an interest in the training programme within the U.K as well.

Did gain insight into organizational aspects of the meeting which will no doubt at a subconscious level help in and personal/professional future engagements.

Thank you for this enriching experience

# Dr Intan Yeop SpR

Some would say that it would be brave or mad to attend a conference to give an oral presentation with a four month old, breast-fed baby. It was probably the latter in my case when I attended the 11th International Small Bowel Symposium in Bologna in September with my baby, Hannah, and a friend to help care for her.

The bi-annual meeting attracts all medical professionals from medical and surgical specialities from small bowel transplantation centres worldwide. It was a relatively small gathering and many delegates knew each other, which made for robust and jovial banter and discussions. As the conference programme covered medical and surgical topics, and having the various members of transplantation teams present, from transplant coordinators to pathologists, there were sessions to interest everyone. There were representatives from Birmingham Liver Unit and King's College. I was there to give an oral presentation on an audit on surveillance endoscopies in patients following transplantation.

There was a lot to learn from the conference, with a fair amount being anecdotal or unpublished. I particularly enjoyed the discussions during the workshops and debates. Patient survival and morbidity following small bowel transplantation are improving with improved surgical techniques, management of immunosuppression, medical care and nutrition.

On the first evening, we were enthusiastically guided through the beautiful city, walking along the covered pavements characteristic of Bologna, ending at the oldest university in Europe. Being in the gastronomy capital of Italy meant delicious lunches and a gelataria around the corner if the dessert on offer did not take your fancy. The conference organizers and people of Bologna were friendly, helpful and accommodating. As I waited for the flight home, the smell of the huge block of my *Parmigiano Reggiano* coming from my hand luggage, I was asked if it was all worth the difficulties of attending the conference with a baby, carting everything including an inflatable bathtub. I thought so.

## Dr Veena Zamvar SpR

The XIth International small bowel transplant symposium was held in a historical old city of Italy, Bologna, and was very well organised by Drs Pinna and Pironi. The venue, food and reception were excellent.

I attended 2 days of the conference. On day -1 there were several workshops at the same time and I chose to attend the pre-transplant management workshop, chaired by Dr Goulet and Dr Pironi. This workshop was relevant to me as I have been working in the regional Intestinal failure unit in Leeds. The topics discussed included time of referral to

the transplant centre, centralisation of the service, indications for the small bowel transplant and surveillance liver biopsy.

The key theme that emerged from this workshop was that early referral to the specialist centre is recommended. Small centres/ unit who are only caring for a few patients should be discouraged and centralisation of the service is superior as they have all the necessary skills and an improved outcome. Indication for the transplantation are life threatening infections, progressive liver disease, loss of venous access due to thrombosis / occlusion of the vein. There was also a debate about on long term stable HPN patient with normal LFTs. Few clinicians were in favour of this whilst the majority felt it was not essential to subject these patients through the painful procedure which also has significant risk. Surveillance liver biopsy isn't essential.

The day was concluded by a guided tour of the city followed by cocktail party.

On day-2, Dr Goulet gave an interesting and educating talk on 'strategy and management of children with Irreversible intestinal failure', which I found useful.

The whole session was generally interesting. I was particularly interested in Dr Diamond's presentation on combination therapy with omegaven and intralipid in children with intestinal failure and advanced parenteral nutrition associated liver disease. There experience has been very similar to that of ours in Leeds where we used omegaven with Clinoleic.

I felt my presentation went well, thanks to Sue Beath / John Puntis and all the other team members for having the confidence in me and also taking time to help me prepare and guide. The whole group from Birmingham were very supportive and looked after me so that I didn't feel isolated, thank you all, it was much appreciated.