BRITISH SOCIETY OF

PAEDIATRIC GASTROENTEROLOGY AND NUTRITION

NEWSLETTER 2004

REPORTS FOR THE AGM JANUARY 2005

PRESIDENT'S REPORT

My first task is to thank the outgoing President, Professor Ian Sanderson and Council Members, Dr Stephen Murphy, Dr Mike Thomson and Dr John Puntis for their great support, commitment and dedication to BSPGHAN.

They have provided an excellent base for me to take over as President.

The highlight of the year to date was the Strategy Away Day held in Birmingham in June 2004, details of which are enclosed with this Report.

It was an important and exciting day attended by members of current and previous Councils. We shared a common view of the current position of the Society and how it can be strengthened in the changing environment of the NHS.

It is important for us to establish a vision and develop a strategy and we will need you, the members, to help us implement it.

We are a strong organisation with over 200 members, associates and trainees. We need to raise our profile and establish ourselves as a professional society.

The strong relationships and friendships developed over the years make our Society a unique group of people to work with.

I look forward to serving you over the next three years.

We are strengthening the Paediatric Section at the BSG with defined members but Chris Spray will be our Education Representative both for the BSPGHAN and the BSG.

Nigel Meadows will attend the Clinical Services Committee for the BSG.

Deirdre Kelly December 2004

SECRETARIES REPORT

This has been a busy year for the BSPGHAN starting with the highly successful winter meeting in Glasgow organised by Lawrence Weaver.

We have a new president and 3 new council members. Council has met three times this year since the last AGM. We have also had a strategy day to look at the aims and objectives and a work plan for the society which involved current and past council members. The outcome of this is on the website as a report and will be presented at the AGM. I felt the meeting was highly productive and I hope members will endorse the action plan that arose out of it.

One specific issue for the society that arose is the need for stable administrative support which will be discussed at the AGM. This will cost the society at least £5,000 per year and can be funded from reserves for 2005 but will after that require an increase in the membership fee which will need to be implemented for 2005. It is clear to me that this will be required if the society is going to grow in size and strength and impact on clinical practice and service provision.

The society has continued to grow in strength with new full and associate members. Council members representing specific areas/groups and subgroups will report at the AGM. I have asked working groups to provide terms of reference, aims, objectives, workplans and timelines for inclusion in their reports. The proposal that came out of the strategy day that we establish a clinical standards subcommittee of the council will be discussed at the AGM.

I am pleased to report that the Guidelines for Purchasers of Paediatric Gastroenterology, Hepatology and Nutrition (shortened version) has been published as a chapter in the Royal College guidance on tertiary service provision which is published and available on the RCPCH website. The full version is available on the BSPGHAN website. This should help us inform purchasers how our speciality service needs should be met.

It is clear that the numbers of Paediatric Gastroenterologist in the UK needs to be expanded considerably in order to provide care in line with National recommendations and establish managed clinic network to deliver care. It is crucial that this expansion is accompanied by expansion of the multidisciplinary team, infrastructure and facilities. Funding expansion remains a real issue for providers and this will become more complex with the implementation of payment by results. There is however within that 'top ups' for speciality work as per the National Specialised Services Definition Set and action on that may improve funding for speciality work.

I am pleased to see the establishment of the DGH paediatrician with an interest group which has representation on council and am grateful to Stuart Nicholls and Graham Briars for this. I am pleased to see the links with the BSG are being strengthened.

We have as a society been able to feed into NICE twice this year with positive feedback from them.

I hope everyone will manage to get to York . Professor Michael Farthing from St George's will be our guest speaker and address the important issue of Traveller's Diarrhoea: from the bench to the bedside. Dinner supported by Mead Johnson will be on the Monday night before the BSPGHAN session on the Tuesday.

This is my last report. I have been on the council for 6 out of the last 7 years the last 3 as secretary. I have enjoyed my time enormously and feel privileged to have been able to serve in this role.

Members asked to keep the new secretary up to date with E Mail and postal addresses and access the web regularly for new information.

Mark Beattie

December 2004

TREASURERS REPORT

Whilst the Society remains financially bouyant, with a balance of approximately £30,000 and Income and Expenditure broadly similar, it is important that we retain a significant reserve, particularly, if we were to incur a large loss from our Winter meeting. Council has been debating whether we should become a more professionally organised Society and this would incur greater administrative cost. To do this would require an increase in subscriptions which have not increased for more than ten years.

I would like to think Bristol Myer Squibbs (Mead Johnson) for continuing to pay the expenditure for Council members attending Council meetings.

Steve Hodges

December 2004

NUTRITION REPORT

As Nutrition member of council, I represent the BSPGHAN in a number of arenas.

The RCPCH Standing Committee on Nutrition.

The committee has sought to consolidate the recognition of specialist training in Clinical Nutrition. The CSAC has a syllabus and training programme www.bspghan.org.uk/training.htm . developed by Professor Lawrence Weaver. The RCPCH Diploma course on Human Nutrition run by Dr Tony Williams, was successful in 2004 and a further course is planned for May 2005. Validation of the course with Southampton University is being sought.

British Association of Parenteral and Enteral Nutrition (BAPEN). www.BAPEN .

The annual meeting was held in Telford in November 2004. The value of establishing a Paediatric advisory group to increase Paediatric representation is under review. There is no doubt that there is common ground between Paediatric and Adult practice and the formation of BAPEN Medical as a founder group at this year's meeting is seen as a forum for the coordination of training and research in all areas of Clinical Nutrition.

British Artificial Nutrition Survey (BANS).

A Standing Committee of BAPEN meets four times per annum to review national trends in data for adult and paediatric enteral and parenteral nutrition submitted by a variety of reporters. The annual report shows increasing trends, but the committee recognise that data variables, consistency of reporting and the current data base contract and funding need review. The data are an important baseline for determining service provision.

www.bapen.org.uk/bans.htm .

The future of intestinal failure services.

A report has been produced by Mark Beattie and John Puntis. A working group continues to review the service needs.

Mark Dalzell

December 2004

ASSOCIATE MEMBERS REPORT 2004

2004 has continued to see the growth of the Associate Members. There are now a total of 135 members, 63 dietitians, 54 nurses and 18 others (including pharmacists, speech therapists and psychologists).

In the New Year we will be mailing all members with a membership renewal form to ascertain a correct membership list.

We started the year with a good turnout at the Winter Meeting in Crieff, where various topics were highlighted for discussion, e.g. transitional care which will be reported back on at this year's Winter Meeting.

There was also a good representation of Associate Members at the world Congress in Paris with members actively involved in organising, chairing and presenting on the Postgraduate Programme. For ESPGHAN 2005 our Swedish colleagues are co-ordinating the Post Graduate Programme, although we still continue to have representation on the Committee, and would encourage all members to consider submitting abstracts for the Poster Session.

October saw our first Annual Conference with the trainees which was held in London . We had approximately 50 delegates from across the country, and evaluation was very positive on all counts. Topics included congenital diarrhoea and the dietary management, IBD, present and future medical therapies and surgical management, autoimmune liver disease and the long term outcome of liver transplant. The day finished with an abstract session with presentations from both associates and trainees. We plan to meet with the trainees at the Winter Meeting to discuss a further joint meeting in 2005. The BSPGHAN committee have also kindly agreed to provide 2 £50 awards for the best associate & trainee presentations.

We continue to be supported by SHS International which enables funding for Associate Members to attend BSPGHAN and ESPGHAN Meetings. Information on applying for this funding is available on the BSPGHAN website (Associate Members page). We are also very grateful to them for their generous sponsorship towards our Annual Conference, and Committee meetings throughout the year.

For the Winter Meeting we still have available £80.00 bursaries (registration costs) for those wishing to attend (application form on the website). Financially the Associate Members account stands at £7987.67 (November 2004).

Next year several positions will become available on the Committee and I would like to encourage those interested to contact myself or another Committee member for further information.

Finally I would like to thank the Committee for all their continued hard work and commitment over the past year.

Jackie Falconer

Chair - Associate Members BSPGHAN

Committee Members:

Jackie Falconer (Chair) **Jackie.falconer@chelwest.nhs.uk**

Jo Grogan (Secretary) **Jo-grogan@rlch-tr.nwest.nhs.uk**

Pam Roger (Treasurer) **pam.roger@luht.scot.nhs.uk**

Liz Mclean **emclea01@bcuc.ac.uk**

Tracey Johnson **tracey.johnson@bhamchildrens.wmids.nhs.uk**

DGH SUBGROUP OF BSPGHAN

Since the last newsletter, the sub-group has met twice. The first meeting was very well attended and held at Crieff, as part of the January meeting. Here, one of the main topics of discussion was the detail surrounding the election of Chair and Secretary to the new sub-group. Subsequently, Dr Graham Briars (Bury St Edmunds) was appointed as Chair, and Dr Stuart Nicholls (Worthing) was appointed as Secretary. Terms of appointment as set in the BSPGHAN Constitution. Dr Nicholls, as acting Chair previously, was appointed at the AGM to represent the sub-group on council.

The summer meeting was held at the RCPCH in October 2004, which was attended by a smaller, but no less enthusiastic group. Issues discussed included the initial results of the survey into the practice of the paediatrician with an interest, including facilities required, confirmation that this group welcomed members from all non-tertiary settings, training requirements and provision for trainees wishing to become a paediatrician with an interest in gastroenterology and implementation of the new consultant contract.

There was unanimity about the opportunities that this group presents for multi-centre research projects and the idea that members should be encouraged to bring their ideas to group meetings. The vacancy on CSAC was discussed and it agreed that Graham Briars would apply.

The next group meeting will be held at Watford and all are welcome and encouraged to attend.

Stuart Nicholls, Secretary

December 2004

ENDOSCOPY STEERING GROUP

The Endoscopy Steering Group has been active over the last year in moving towards the following aims:

1 Assessment of competency vs simple number counting in SpR endoscopy training with an eventual aim for on-line web-based competency assessment as an integral

part of this.

2 The RITA is identified as focus for the competency assessment in the possible award of a CCST specifically for endoscopy to trainees both adult and paediatric alike. The infrastructure for training is to allow this to occur, would involve the following:

2.1 raising the quality of training through specific training lists written into service provision;

2.2 increasing the skill of the trainers with the expectation of attending 'Training the Trainer' courses for endoscopy;

2.3 combining CSAC centre visits with the assessment of standards of endoscopy training to produce a positive critique;

2.4 expectation that all trainees in paediatric endoscopy attend a 'Basic Skill' course with hands-on input and that the Joint Advisory Group (JAG) on Endoscopy Based Basic Skills Paediatric Colonoscopy courses be set up for paediatric practice for the United Kingdom;

2.5 other courses such as Endotherapy hands-on courses and Training the Trainer courses specifically for paediatrics are envisaged and planned.

3 Identification of the imperative to ensure that all trainees fill in their contemporaneous Log Books ratified by the trainers in each centre.

4 Importance of having some way of overseeing the process of ongoing training, i.e. the RITA and CCST, with an external observer.

5 Further work will occur with industry-funded training programmes including Lesion Recognition as a web-based programme with potential for further emphasis on paediatric endoscopic research.

6 A sedation vs general anaesthetic anonymous survey was conducted 2004, the results of which can be presented at the Winter Meeting AGM but essentially 90-95% of all endoscopies in childhood in the UK are now occurring under general anaesthetic, or with an anaesthetist present.

7 Data can also be presented regarding the numbers vs competency endoscopic training issue with regard to the use of virtual training tools.

8 The above encompasses the wide variety of themes that the Endoscopy Steering Group have been involved with this year. It is hoped that the membership and Council will ratify further evolution of the role of this group in particular, and its role in training.

Mike Thomson

December 2004

IBD REGISTER

The Register of Paediatric Inflammatory Bowel Disease was established in 1997 and has been seeking patient/carer consent since 2001. The need to obtain consent has heralded difficult times for all disease registers and we have seen a drop off in the numbers submitted. Nevertheless the decision to be ethically scrupulous is now yielding benefits and the register has now begun to produce significant information. This is especially gratifying as it is generally felt that such data bases need to have been in established for considerably longer before becoming productive.

The consent we seek allows access to patient notes. We therefore involved the top 6 registering centres, as denoted by number of consented patients, in a retrospective notes review by Dr Liz Newby. She has extracted detailed information on the incidence and indications for surgery, growth, multi-agency involvement and changes in diagnosis. Details of this have been admitted in abstract form for both the winter and spring meetings. A detailed paper will be forthcoming.

A further abstract has been submitted detailing Lucy Taylor's work to generate incidence figures obtained from well defined and well represented areas.

This therefore provided an ideal time to reassess the aims and development of the Register. This was done at a seminal meeting on 18 th November at the Royal College of Paediatrics and Child Health. Representatives from the six major centres were invited. The outcome of this was to try and define a specific timeline, succinct aims and to confirm where the register stands in the hierarchy of the society.

It was decided that the Register was best adapted to seek information on specific questions posed by the overseeing committee, which could be achieved by notes review as previously demonstrated by Dr Liz Newby. It was decided that the effort expended on the Register would be best concentrated on several of the top registering centres. In order to decide the centres a three month period of assessment is being undertaken with all the centres being invited to demonstrate their commitment by registering patients. At the end of this process a maximum of 10 top Registering centres will be chosen. A representative from each of these centres will be invited to be on the supervising committee. The centres have also been invited to submit the questions they would like the Register to answer and each will be actively involved in the construction of a proforma to answer these questions.

It is hoped that this approach will also engender a sense of ownership amongst the contributors and will lead to their active involvement in asking questions for the register to answer.

It was felt that five such questions should be identified to be addressed in the space of the forthcoming year and that each centre could identify a suitable candidate to visit the centres and to collect the relevant information.

There had previously been some confusion as to the place the Register occupies in the hierarchy of the Society. It was unanimously decided that the Register should reaffirm its status as a subgroup of the Paediatric Inflammatory Bowel Disease Steering Group.

Thus the register is now emerging as a tool to serve the needs of the society. It is to be streamlined over the next few months and a precise remit established for the next year. Its place as a subgroup of the IBD steering group has been affirmed.

I am extremely grateful for the hard work and commitment shown by the staff of the register, Lucy Taylor and Carla Roberts.

We are indebted to the generous funding and support provided by CICRA. Further financial help has been kindly provided by SHS and Nestle.

Dave Casson

December 2004

INFLAMMATORY BOWEL DISEASE WORKING GROUP

The IBD Working Group continued to meet regularly in 2004. During the year the officers of the working group have changed. Adrian Thomas who had Chaired the Group for some years was replaced by David Wilson (previous Secretary). The Secretary of the Group is now John Fell.

We are still in the process of undertaking a systematic review of the evidence for inflammatory bowel disease treatments. It is anticipated that a draft document will have been collated by Spring 2005. This will then contain systematic review of the paediatric evidence supported by further data from adult studies that have been collated into Cochrane reviews and the BSG Inflammatory Bowel Guidelines. It will come as no surprise to many members of our society that the quality of paediatric evidence is generally poor. Thus most of the recommendations coming out of this review will have the lowest quality grading. When this formal process has been finalised we will be in a position to write a consensus document leading to a consensus conference in 2005 (proposed date 18/04/05 at the York RCPCH annual meeting).

At our meeting in November 2004 which coincided with a meeting of the IBD register the relationship between the Register and the IBD working group were

formalised. The IBD register needs to remain as a sub-group of the IBD working group.

The evidence deficit identified in the systemic review should inform us as to research priorities.
We have been working through the possibilities of undertaking a multi-centre trial of nutrition versus corticosteroids +/- azathioprine for children with Crohn's disease (Stephen Murphy taking the lead). Several funding options have been explored, but unfortunately thus far, no significant funding has been identified.

John Fell

December 2004

CSAC IN PAEDIATRIC GASTROENTEROLOGY, HEPATOLOGY AND NUTRITION.

The current CSAC for Gastroenterology, Hepatology and Nutrition is as follows:-

Professor Deirdre Kelly (Chair) 2004-2007

Training Advisors:

Dr Hew Jenkins (Gastroenterology) (2005-2008)

Dr Anil Dhawan (Liver) (2002-2005)

Dr John Puntis (Nutrition) (2005-2008)

Dr A Evans (General Paediatrician) (2005-2008)

Dr G Briars (General Paediatrician with a special interest

In Gastroenterology) (2005-2008)

Dr J Sanderson (Adult Gastroenterologist) (2002-2005)

Dr R Russell (Trainee Representative)

The Specialist Training Authority (STA) has updated the handbook for training. An error occurred in the accreditation status for Paediatric Gastroenterology, Hepatology and Nutrition.

The recognised sub-specialist designation as originally agreed in 2000 was Paediatric Gastroenterology, Hepatology and Nutrition. The 2003 Paediatric Training Handbook indicates that the recognised sub-specialty is Paediatric Gastroenterology and not Paediatric Gastroenterology, Hepatology and Nutrition. Inadvertently all references to training in Hepatology and Nutrition were removed from the handbook.

Professor Kelly and Dr Mary McGraw (Chairman of the Higher Specialist Training RCPCH) have written to the STA asking for the error to be corrected and an up-to-date curriculum has been submitted.

Accreditation in Paediatric Gastroenterology, Hepatology and Nutrition is as follows :-

The accreditation is entitled CCST in general paediatrics with sub-specialisation in Gastroenterology, Hepatology and Nutrition.

The training programme consists of a core programme consisting of:-

- 6 months of Gastroenterology and 6 months of Hepatology.
- 24 months in either Hepatology or Gastroenterology.
- 12 months research in either specialty may be substituted for 12 months clinical training.

Subsequent accreditation of clinical training during research years is as follows:-

If additional time (ie more than 12 months) is spent in research, trainees may count part of their research time towards their clinical training if they spend at least 20% of their time in clinical activities as indicated below:

1 The clinical time must have a clear educational objective related to the training programme in paediatric gastroenterology, i.e. an endoscopy list or other GI/hepatology/nutrition investigations session, and outpatient clinic or a grand round. On call duties are not counted towards training

2 At least two sessions per week should be spent on supervised daytime clinical duties; any less a period would not allow any realistic clinical training. Evidence of satisfactory formal assessment (RITA) of clinical training will be required

3 No double counting of time spent in a research post will be allowed. If a candidate spends two sessions per week on clinical work with the balance of the time spent on research then the year would count as 20% clinical training and 80% research, similarly if 5 sessions per week were spent on clinical work and the remainder on research the year would count as 50% clinical training and six months would be approved as time counting towards a CCST

4 The arrangement to count clinical training time during a period of research must be approved prospectively by the Postgraduate Dean and the CSAC in paediatric

gastroenterology, hepatology and nutrition for the Royal College of Paediatric Child Health

5 Trainees appointed to research posts are advised that they should obtain written prospective approval from the Regional Advisor of the proportion that will be accreditable for clinical training.

Currently training in Nutrition is recognised as being undertaken with Gastroenterology or Hepatology. A curriculum in Nutrition has been devised, but accreditation of centres has not yet been performed.

Representation of Specialist Gastroenterology and Hepatology at RITA Assessments

Many Trainees and Education Supervisors have commented on the lack of specialist advice at the RITA.

I raised this matter at the Higher Specialist Training Committee Meeting on 8 th September 2004. The HST did not feel it was necessary for a sub-specialist to be present at RITA assessments as this was a Review of Training only, and any concerns should have been raised at an earlier stage by the Educational Supervisor.

In order to address potential issues the CSAC will provide training advice and mentorship for trainees at the National Postgraduate Training Days.

National Grid Interviews

There is only one vacancy for a National Grid position in 2005 which will be a rotation between Scottish Centres and Kings College Hospital . There have been difficulties in communication about the process with the RCPCH and the Deaneries. RCPCH have appointed an Administrator, Robert Heller, who will hopefully resolve the difficulties with administration and communication.

Trainees' Report

Dr Russell has provided an up-to-date grid for the trainees and their CCST dates

Retiring Members

Professor Kelly and the CSAC Committee would like to offer their grateful thanks to Professor Peter Milla, Professor Lawrence Weaver and Dr Bim Bhaduri, who stepped down from the CSAC Committee at the end of 2004.

The Committee are particularly grateful for their enthusiasm, dedication and support over many years.

Deirdre Kelly

Professor of Paediatric Hepatology

CSAC Chair

CLINICAL PAEDIATRIC NUTRITION TRAINING

Nutrition is now recognised within the training programme for paediatricians with a special interest in gastroenterology, hepatology and nutrition as a specialty of equal status as the two former subspecialties (gastroenterology and hepatology). The CSAC in PGHN requires all trainees now to undergo at least six months recognised training in nutrition, within their programme. For all paediatricians who wish to acquire training in nutrition, the intercollegiate course in human nutrition is advised as a basic course, to be attended during the first two core years of SpR training. The Royal College of Paediatrics and Child Health (RCPCH) also encourages trainees to do its Diploma in Paediatric Nutrition thereafter. It is hoped that trainees in other subspecialties (neonatology, community child health, metabolic medicine etc) who wish to obtain training in clinical paediatric nutrition will access the training programme. Centres in which such training can offered as a six month or longer block are in the process of being identified and accredited.

Lawrence Weaver

December 2004

TRAINEES IN PAEDIATRIC GASTROENTEROLOGY HEPATOLOGY & NUTRITION (TiPGHAN)

2004 has been another successful year for the trainees' section of BSPGHAN. The year started with the inaugural BSPGHAN Postgraduate Day held at the Winter Meeting in Crieff. Undoubtedly everyone who was at Crieff will agree that this day was a resounding success and both the invited lectures and abstract sessions were of a very high standard indeed. We are proud to have collaborated with the local organizing committee in achieving this day which Council has acknowledged will be an ongoing feature of the Winter Meeting and will represent one of two annual designated training days for trainees. As if this wasn't enough of a success, the trainees proved overwhelming when it came to the traditional annual consultants versus trainees football match!

In October, TiPGHAN and the Associates group of the BSPGHAN held the first joint annual training day in London and, again, we were delighted with the success of the day. This day has also been recognised by Council as representing the second of the two annual designated training days for trainees. We hope to encourage more trainees and associate members to present abstracts and in future there will be prizes for the best presentations.

We have strengthened our association with the British Society of Gastroenterology and their trainees group, TiG, and are now represented on their committee in order to contribute towards organisation of gastroenterology training in a wider sense. Final year trainees in paediatric gastroenterology, hepatology and nutrition are now able to join excellent sponsored management days organised by TiG.

Our committee met again in May and November when the main agenda topics were the successful introduction of the above training days, planning a rotational syllabus for future study days and the potential introduction of learning contracts and mentoring systems for trainees appointed to the National Grid for Paediatric Gastroenterology and Hepatology.

The second round of National Grid appointments were made this year with a further four SpRs taking up appointments in London , Liverpool and Newcastle in September. All have been formally welcomed into TiPGHAN and we hope will make valuable contributions to our group.

Our goals in 2005 will be to ensure educational agendas are set for future training days and to further establish our links with our adult colleagues training in gastroenterology.

As always, I would ask that if anyone knows of SHOs or core trainees interested in training in paediatric gastroenterology, hepatology or nutrition, please encourage them to contact myself or one of the committee, who will be delighted to welcome them to TiPGHAN and give advice about training.

Finally, 4 of our current 5 committee members come to the end of their term of office in January 2005. We are proud to have represented trainees on the inaugural TiPGHAN Committee and to have been influential in the establishment of the

National Grid, log books for training and setting up of training days. We are extremely grateful to the BSPGHAN Council for support during our foundation years and although we will be sorry to leave our posts, we wish our successors the very best of luck in continuing to represent the needs of trainees.

We look forward to seeing as many of you as possible at Watford in January where we intend to retain our football crown!

Helen Evans - Secretary TiPGHAN

helen.evans@blueyonder.co.uk

Committee members:

Nikhil Thapar (Chairman) thaparn@doctors.org.uk

Richard Russell (CSAC Rep) richardkrussell71@hotmail.com

Helen Evans (Secretary) helen.evans@blueyonder.co.uk

Diana Flynn flynndiana@hotmail.com

Sian Kirkham sian@siark.com

BSPGHAN WINTER MEETING - CRIEFF 2004

The annual winter meeting of BSPGHAN was at the Crieff Hydro in January 2004. Organised by the Scottish Paediatric, Gastroenterology, Hepatology and Nutrition Group (SPGHANG) the meeting combined free papers (oral and posters) with key note presentations from invited speakers, covering a variety of topics within the three cognate subspecialties. In addition there was a workshop on the team approach to complex feeding disorders, and a mini-symposium on prebiotics, with three international external speakers. The meeting was preceded by a postgraduate training day, which attracted almost a hundred trainees and other staff keen to update their skills and knowledge. The main meeting attracted almost two hundred people that included paediatric gastroenterologists, trainees, associates and clinical scientists. The main meeting was generously sponsored by Nutricia Clinical Care, and the postgraduate training day by Mead Johnson Nutritionals.

Lawrence Weaver

December 2004

CHILDHOOD CONSTIPATION WORKING GROUP

The group had 4 meetings this year.

The original remit of the group was to produce national guidelines for the management of childhood constipation.

Work undertaken in 2004

Childhood Constipation was recently proposed as a suggested topic for NICE work programme. There are several stages in the selection of topics. The Working Group together with other 'experts' were asked to review the initial briefing notes, which were then submitted for discussion by the Advisory Committee on Topic Selection (ACTS). Topics are then recommended (or not) for consideration by the Joint Planning Group prior to consideration by government ministers who then finally select topics for inclusion on the NICE Agenda. The topic of 'childhood constipation' is currently being considered by the Joint Planning Group; if they refer it for ministerial consideration it could be added to the NICE agenda by September 2005. However it is unlikely that even if it is successfully included as a topic that any project work will commence immediately, it can take up to 2 years. The Working Group are therefore in contact with NICE and RCPCH to move forward the development of national guidelines in the meantime.

There are major issues that have prevented progress to date:

- There are considerable resource implications (time, financial, expertise etc) required to develop an evidence-based guideline.
- There is a lack of evidence to use as basis for guideline, Literature review in progress. Abstract to be submitted for BSPGHAN Winter Meeting.
- Terminology in childhood constipation is poorly defined and terms are used in different contexts, which makes reviewing the literature problematic.
- Is it appropriate to use guidelines we have e.g. 'Tough Going' and 'IMPACT' and upgrade them to meet national guideline standards (RCPCH, SIGN, NICE)
- Apply for funding to facilitate development. It is likely that funding will need to be accessed from a variety of sources. Preliminary discussions with 'Norgine' regarding an Educational Grant are in progress. RCPCH guidance is that it is acceptable to receive funding from commercial companies as long as they have no input into guideline development.
- Concerns were expressed about expertise in developing guidelines and who to involve - felt it was important to consult widely using Delphi technique - GP's HV's School Nurses, Pharmacists, Parents, Children etc.

Workshop

Last year the Group organised a very successful workshop to ask what health professionals required of a guideline. A follow up day was planned originally to consult on 'constipation framework', which would be prepared by working party prior to workshop as a result of feed back from the last study day. It was felt that a framework would be ineffectual with such variation in practice across the country. Therefore the Nottingham workshop would be best spent collating and reviewing the evidence, which the working party would have sourced prior to the meeting to use under the broad headings:

- The child and family journey - patient centred approaches.
- Prevention- health promotion, Education, support
- Assessment - differential diagnosis
- Investigations - criteria for transit studies etc
- Treatment/Management - psychological, pharmaceutical, nutritional, complementary and alternative approaches, surgery, health beliefs-old wives tales, Concordance
- Specialist Referral
- Evaluation - follow up support, audit cycle
- Education/Training

The date was 18 th October at Queens Education Centre, Nottingham . A wide cross section of interested health professionals working in the area of childhood constipation were invited to attend. The day was postponed due to lack of attendees. It will be rescheduled in 2005.

Childhood Constipation: Standardising Terminology.

One of the key issues in the management of childhood constipation is the need to increase the evidence base for the treatment of constipation by generating well-designed, randomised, controlled trials, which are valid internationally. Currently there is no internationally agreed definition of what defines constipation, in children for example, with differing definitions offered in the Medical Position Statement of the North American Society of Pediatric Gastroenterology and Nutrition, in Rome II criteria and in textbooks. There is an urgent requirement to establish internationally acceptable definitions describing symptoms and how the condition is diagnosed, as this is required entry criteria for clinical studies and the basis for assessing outcome.

Two working group members David Candy and Graham Clayden were part of the *PAris Consensus on Childhood Constipation Terminology* (PACCT) Group - a group of paediatric gastro-enterologists with a special interest in constipation, which met at the World Congress of Paediatric Gastroenterology in Paris in July 2004 to reach a consensus about definitions of terminology used in childhood functional gastrointestinal disorders and constipation, to develop possible working definitions which might help inform potential definitions to be made in Rome III *Diagnostic Criteria for Functional Gastrointestinal Disorders* . Copies of the full report are available from David. Email: david.candy@rws-tr.nhs.uk A summary of the terminology and list of participants are included below.

Summary of the PACCT Group's recommended terminology

Suggested terminology	**PACCT Group definition**
Chronic constipation	The occurrence of **two or more** of the following characteristics, during the last 8 weeks, occurring more than 25% of the time: • Frequency of bowel movements of less than three stools per week • More than one episode of faecal incontinence per week • Large stools in the rectum or felt on abdominal examination • Passing of stools so large that they may clog the toilet • Displaying evidence of retentive posturing (with-holding behaviour) • Painful bowel movements
Faecal incontinence	The passage of stools in an inappropriate social milieu
Organic faecal incontinence	Faecal incontinence resulting from organic disease e.g. as the result of neurological damage or anal sphincter abnormalities
Functional faecal incontinence	Non-organic disease which can be sub-divided into: • Constipation-associated faecal incontinence • Non-retentive (non-constipation-associated) faecal incontinence
Constipation associated faecal incontinence	Functional faecal incontinence associated with the presence of constipation
Non-retentive faecal incontinence	The passage of stools in an inappropriate social milieu, occurring in children aged 4 and older, where there is no evidence of constipation based on history and / or examination
Faecal impaction	Constipation where there is present a large faecal mass in either the rectum or the abdomen, to a degree demonstrable by a physical or rectal examination or other methodology, and which is unlikely to be passed spontaneously.
Pelvic floor dyssynergia	Inability to relax the pelvic floor when attempting to defecate

PACCT Group members

Marc Benninga, MD	Amsterdam	Netherlands
David Candy, MD	Southampton	UK
Tony Catto-Smith, MD	Victoria	Australia
Graham Clayden, MD	London	UK
Carlo Di Lorenzo, MD	Ohio	USA
Vera Loening-Baucke, MD	Iowa	USA
Samuel Nurko, MD	Boston	USA
Annamaria Staiano,MD	Naples	Italy

Working Party Work Plan for 2005

- Write and submit proposal for funding guidelines project.
- Identify key research priorities
- Survey current practice (? Forms in Conference pack)
- Continue to work on currently available guidelines

BSG REPORT

This year has seen the start of us trying to strengthen our links with the BSG and the following action plan is being implemented to help facilitate that process.

BSG to be a standing item on the agenda of council and the AGM

BSPGHAN Council to be the paediatric section of the BSG with minutes of council to be sent on to the BSG.

BSG paediatric section meetings to be held at the same time as the BSPGHAN council meetings

BSPGHAN council to have a council representative with responsibility for BSG liaison.

Nigel Meadows to sit on the BSG Clinical Services and Standards committee.

Chris Spray will sit on the BSG Education Committee

Nikhil Thappar sits on the training committee.

Mike Thomson sits on the endoscopy committee.

Mike Thomson sits on the IT committee

Mike Thomson has arranged the 2005 BSG paediatric symposium,

Chris Spray to be the link for the 2006 BSG paediatric symposium.

Deirdre Kelly to attend the BSG programme committee

All BSPGHAN members (particularly council members) to be encouraged to join the BSG.

RM. Beattie

December 2004

BSPGHAN WEBSITE REPORT

Over the last year the website has continued to function much as before. It continues to provide information about meetings and there has been an increasing use of the vacancy page to distribute information about new posts either for Doctors, Nurses or AHPs. The website is also an easy means of accessing documents published either by the BSPGHAN or their Working Groups.

Once or twice a month an email is sent round to all members with recent changes to the site. Again with each mailing there are normally about 20 or 30 emails which are no longer active and you are again reminded to keep our Secretary informed of any changes in your email address.

The look and feel of the website has not significantly changed for many years and I think it is acknowledged that if the site is to be further developed then professional help will be required. With this in mind I have agreement from the BSPGHAN Council to proceed with the further development of the site and as of November 2004, the Web Design Unit of Aberdeen University are presently producing sample web pages for a redesigned website that will hopefully be enacted upon in the coming months. I would hope also that this service could be used to keep the site up-dated and would allow us to expand the capabilities of the site beyond those of the present web-master who has limited programming and design skills. Hopefully once the new site is up and running I will ask all members for their comments and also for suggestions on

how the site could be further developed. I think we are fortunate in being able to employ Web Designers at cost, rather than commercial rates.

I hope very much to be at the meeting in Watford and look forward to your comments and suggestions. Alternatively I can be contacted at my email address of webmaster@bspghan.org.uk .

W MICHAEL BISSET

BSPGHAN Web-Master

THANKS TO MEMBERS FOR SUBMITTING REPORTS. APOLOGIES FOR ANY ERRORS [or] OMMISSIONS

MARK BEATTIE - JANUARY 2005