
BSPGHAN

British Society of Paediatric Gastroenterology, Hepatology & Nutrition

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AGENDA FOR AGM

1. Minutes of Last Meeting
2. Report of Strategy Day (presentation) - MB
 - Establish Clinical Standards Subcommittee
 - Stable Administrative support
 - Membership fee
3. President's Report - DK
4. Secretary's Report – MB
5. Clinical Excellence Awards - IB
6. Constitution changes - MB
7. Election of secretary, treasurer, liver representative - MB
8. Treasurer's Report - SH
9. Hepatology Report - AB
10. Nutrition Report including intestinal failure survey - MD
11. Associate Members' Report - JF
12. Education Report - CS
13. Trainees' Group Report - NT
14. BSPGHAN Web
15. DGH Paediatrician with an interest sub group of the BSPGHAN - SN
16. Working Groups
 - (a) Endoscopy - MT
 - (b) Inflammatory Bowel Disease - DW
 - (c) IBD Register - DC
 - (d) Constipation - JG
 - (e) Coeliac Disease - ME
 - (f) Intestinal Failure Working Group - JP
17. CSAC Report - DK
18. BSG (paediatric section) report - DK
19. Future Meetings
 - RCPCH Annual Meeting – BSPGHAN Dinner 18/04/05, Meeting 19/04/05

BSPGHAN Newcastle 18-20th January 2006
Proposed Joint Meeting between the Indian and British Paediatric
Societies 26th –28th October 2006, Delhi

BSPGHAN

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AGM Minutes 22nd January 2004 Glasgow

20. Minutes of Last Meeting were accepted as a true record
21. President's Report tabled by Ian Sanderson
22. Secretary's Report tabled by Mark Beattie
23. Constitution changes proposed by Ian Sanderson - Election of president to be by postal ballot other officers and council members to be elected at the AGM (endorsed). Constitution to be amended so that Staff grade practitioners and associate members can be members (endorsed). Proposal for a DGH representative on council as an additional council member (endorsed). Method of election discussed. Alternatives being nomination by DGH sub group and election at the AGM as per other council members (eg representing the liver group) – to be resolved by council. Council to agree the revised constitution as per the above.
24. Treasurer's Report tabled by Steve Hodges
25. Hepatology Report tabled by Alistair Baker
26. Nutrition Report including intestinal failure survey tabled by John Puntis
27. Associate Members' Report tabled by Jackie Falconer
28. Trainees' Group Report tabled by Nikhil Thapar
29. BSPGHAN Web report tabled by Mike Bissett
30. Election of New Officers

Professor Deidre Kelly elected by postal ballot (ballot agreed in item 4 – count occurred post AGM – returning officers Professor I Sanderson, Professor S Tanner and Dr M Beattie.)

New Council members elected by ballot during the AGM (returning officers Dr M Thomson, Dr S Hodges)

Dr Mark Dalzell – Nutrition representative
Dr N Meadows
Dr C Spray

Members to serve on council for 3 years

31. DGH Paediatrician with an interest sub group of the BSPGHAN report tabled by Stuart Nicholls
32. Working Groups
 - (g) Endoscopy report tabled by M Thomson
 - (h) Inflammatory Bowel Disease report tabled by D Wilson
 - (i) Constipation report tabled by J Gordon
 - (j) Coeliac Disease report tabled by M El-Tumi
 - (k) Service Provision Group and workforce survey, Guideline for Purchasers document, tertiary services document report tabled by M Beattie
 - (l) IBD Register tabled
33. CSAC Report report tabled by I Sanderson
34. Intestinal Pseudo-obstruction in adults and children Preliminary Bid for NSCAG Support A Proposal to BSPGHAN – this bid was not successful
35. Questionnaire to assess quality of service and lifestyle in the BSPGHAN – Update to be presented by A Baker in York and society to be informed of outcome of study by AB
36. Intestinal Failure – Society informed that there had been a meeting called by NSCAG to discuss the future provision of Intestinal Failure services in England and Wales and that a consultative document produced by John Puntis/ Mark Beattie would be produced and circulated to the society for feedback prior to the preparation of a response to the issues raised by NSCAG. Discussion re specific issues. Members encouraged to E Mail John Puntis/Mark Beattie with any preliminary thoughts.
37. Future Meetings
 - (a) BSPGHAN meeting at the RCPCH in York – 30th March 2004, Dinner 29th March 2004
 - (b) AGM 2005 – to be held in Watford hoisted by Dr Muftah Eltumi, AGM 2006 to be in Newcastle hosted by Dr S Hodges
38. No other issues raised

Reports were tabled and are available on the BSPGHAN website as BSPGHAN Newsletter and AGM reports December 2003

RM Beattie
January 2004

BSPGHAN NEWSLETTER

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 thank 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 18th 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 RCPC 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 8th 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 18th 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
<i>Chronic constipation</i>	<p>The occurrence of two or more of the following characteristics, during the last 8 weeks, occurring more than 25% of the time:</p> <ul style="list-style-type: none"> • Frequency of bowel movements of less than three stools per week

	<ul style="list-style-type: none"> • 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
<i>Faecal incontinence</i>	The passage of stools in an inappropriate social milieu
<i>Organic faecal incontinence</i>	Faecal incontinence resulting from organic disease e.g. as the result of neurological damage or anal sphincter abnormalities
<i>Functional faecal incontinence</i>	Non-organic disease which can be sub-divided into: <ul style="list-style-type: none"> – Constipation-associated faecal incontinence – Non-retentive (non-constipation-associated) faecal incontinence
<i>Constipation associated faecal incontinence</i>	Functional faecal incontinence associated with the presence of constipation
<i>Non-retentive faecal incontinence</i>	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
<i>Faecal impaction</i>	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.
<i>Pelvic floor dyssynergia</i>	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 OMISSIONS

MARK BEATTIE - JANUARY 2005

BSPGHAN NEWSLETTER

REPORTS FOR THE AGM JANUARY 2004

PRESIDENT'S REPORT

The Society has had a good year. The establishment of working groups continues to develop and this has enabled Council to easily defend decisions taken in relation to our speciality because they have been considered by the appropriate groups of people. Over the last three years, the new groups that were established (the Associate Members Group and the Trainees Group) have continued to flourish. In my last report, I indicated that we would develop a forum for paediatricians with an interest in gastroenterology. I am delighted that this is coming to fruition. An interim Chairman, Stuart Nicholls, has started this process with the establishment of regular meetings. A constitution is being developed; and the possibility of a new Council member representing this group will be discussed at the AGM.

During the course of the year there has been successful scientific meetings both in Dublin (the Winter Meeting) and in York with the RCPCH. The Associate Group has had a successful meeting in Leicester and these meetings will continue into the future.

Finally, I would like to thank every member for their hard work during the course of the year. This is my final report as President. I have taken unity of purpose as the theme that I have tried to adopt. I have been very encouraged by the way our members have worked together harmoniously for the improvement of our speciality in the last three years.

Ian Sanderson
Jan 2004

SECRETARY'S REPORT 2003

This has been a busy year for the BSPGHAN starting with the highly successful winter meeting in Dublin. Council has met 3 times since the last AGM. We now have 205 full members and an increasing and active associate members group. Council members representing specific areas/groups and subgroups will report at the AGM.

I am pleased to report that the Guidelines for Purchasers of tertiary paediatric services updates report is now complete and on the web. I would like to thank Rob Heuschkel, Mike Thomson and Ian Sanderson in particular but also the many members who contributed to the production of this report. I hope that this report will help members with local commissioning. The wider challenge of the response to the National Services Framework has been dealt with by the same group with a shortened version of the report been submitted to the college for inclusion in the college guidance on tertiary service provision which is due to be published soon. I am grateful to members for completing the workforce survey which has helped inform the whole process but also enabled us to show that the numbers of paediatric gastroenterologists 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. Primary Care and district services will be partners in the development of these networks. Stuart Nicholls has led on the establishment of the DGH sub group of the BSPGHAN, which I hope, if the society agrees will have the lead as a member of council. I have been very keen on this as much of our speciality lies within general paediatrics and occurs outside specialist centres and strong district service representation will help us in the decision making about service provision.

Highlights of the year have included the successful joint British Italian Meeting in Lucca in May and thanks to the organisers of that. We need to look for a host centre for the next meeting due here in 2006. There was also the very successful joint meeting with Faculty of History of Medicine at the Apothecaries in November organised by John Walker-Smith and Ian Sanderson with book being planned based upon the meeting.

I hope everyone will manage to get to York. 47 abstracts were submitted. 1 plenary has been accepted and 15 for presentation at our session. Tony Williams from St George's will be our guest speaker and address the important issue of helping infants breast feed. Dinner supported by Mead Johnson will be on the Monday night before the BSPGHAN session on the Tuesday.

I would like to thank Steven Murphy, John Puntis and Mike Thomson for their work on council over the last 3 years.

Finally thanks to Ian Sanderson who soon completes his highly successful term as president.

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

Mark Beattie
Jan 2004

TREASURER'S REPORT

The society's financial situation remains buoyant. Our balance at the end of November 2003 was £27890. Over the last financial year expenditure has been a little more than income. Our biggest is the I.B.D. working group and I, like many of you, look forward to their evidence based guidelines for management, with interest. Over the last year I have been trying very hard to get members and associates to pay their subscriptions. This is not an easy task particularly with the associates as when they were set up founder associates paid 3 years subscription in one go; we then increased their subscriptions and because of the domestic situations of many of them (their direct debits are often in partner's names) deciding who has paid can be difficult.

Expenses are paid in line with the RCPCH regulations i.e. second-class rail fare. I would stress that it is "our" money and the use of budget airline fares and discounted rail fares is appreciated.

I would like to remind trainees and associates, in particular, that the society will pay a grant (up to £500) towards expenses when presenting at overseas meetings if employers/grant awarding bodies will not finance them.

Finally, I would like to thank Mead Johnson Nutritionals for supporting the society by paying council members' expenses when attending council meetings.

Steve Hodges
December 2003

NUTRITION REPORT

Over the past year there have been significant developments in relation to training in nutrition, including the first Nutrition Diploma Course organised through the RCPCH by Tony Williams. This pilot course was judged highly successful by participants, and will be repeated in 2004 for a larger number of registrants. The course itself is likely to be validated by the University of Southampton and could then contribute towards a higher qualification. Lawrence Weaver has also produced a core curriculum for nutrition training of SpRs working in gastroenterology, hepatology and clinical nutrition. The College Diploma would complement this hospital based training for SpRs, but will also have a broader appeal to non-gastroenterology trainees with an interest in clinical nutrition.

The British Intestinal Failure survey was commissioned by the BSPGHAN in 1999 when it was acknowledged that we had very little information on the epidemiology of intestinal failure in infants and children in the UK. A working party was set up under the chairmanship of Ian Booth. Streets Heaver Healthcare Computing, the company who run the British Artificial Nutrition survey, agreed to manage the BIFS survey. It was anticipated that this would involve a monthly invitation to members of both the BSPGHAN and BAPS asking them for details of any patient receiving parenteral

nutrition for more than 27 days. Until recently there have been no funds to take this project further. There have now been two offers of financial support from industry which should allow the survey to run over a two year period, starting this spring.

As an associate organisation of the British Society for Parenteral and Enteral Nutrition (BAPEN), the BSPGHAN has a seat on BAPEN Council. Our representative until recently was Peter Milla, who chaired the Paediatric Advisory Group (PAG) within BAPEN. Currently I sit on BAPEN Council. As a Society we need to decide if this role would best be filled by whoever holds the nutrition brief on BSPGHAN Council (and also sits on the RCPCH Nutrition Committee), and whether the PAG (currently non-functioning) should be reconstituted.

The European Society for Parenteral and Enteral Nutrition (ESPEN) held its 25th congress in Cannes during September 2003. Joint sessions with ESPGHAN ensured that there was a much higher than average paediatric content. A joint ESPGHAN/ESPEN working group is currently developing guidelines for parenteral nutrition across the paediatric age range and a number of BSPGHAN members are actively contributing to this process.

John Puntis
December 2003

ASSOCIATE MEMBERS REPORT

2003 has been another busy year for the Associate Members. There are now a total of 109 members, 52 dietitians, 45 nurses and 12 others (including pharmacists, speech therapists and psychologists). We continue to accept new members on a regular basis. This year has seen a change in committee with myself taking over from Clare Burnett as chair. We congratulate her and her husband on the birth of their new son Henry in June.

New members to the Committee are:

Jo Grogan, Senior Paediatric Dietitian:	Secretary
Liz McLean, Senior Lecturer / Research Nurse:	Education & Training
Liz Chambers, Paediatric Community Nurse:	Treasurer
Tracey Johnson, Senior Paediatric Dietitian:	Deputy Chair

Pam Rogers continues to serve on the Committee. I thank all for their hard work and commitment over the past year.

Our Annual Conference in Leicester was attended by 50 delegates from across the country, evaluation was positive on all counts. Topics included; '*Management of Gastro-oesophageal Reflux*', '*Liver Disease and Cystic Fibrosis*', and '*Obesity Management*'. Four Abstract submissions were accepted and orally presented.

Again this year Associate Members were involved in the Post Graduate Programme for Nurses and Dietitians at ESPGHAN, which was held in Prague. Members participated as Speakers and Chairs. This year saw a dedicated dietitians and nurses poster session alongside the main meeting with good representations from the UK.

The members are actively involved in the programme for the World congress in Paris 2004. The Postgraduate Programme has been expanded to 1½ days with separate nurse and Dietitian Poster Sessions to be held during the main meeting.

We continue to be supported by SHS International which has enabled funding for Associate Members to attend BSPGHAN and ESPGHAN meetings. We are also grateful to them for very generously supporting our own Annual conference, and the Committee Meetings throughout the year. Please contact myself or Liz McLean for information on how to obtain sponsorship.

We are all meeting again at the Winter Meeting in Crieff and I encourage associate members to attend what looks to be a very good meeting.

Thanks to all associate members for their contribution and support over the past four years.

Jackie Falconer
Chair – Associate Members BSPGHAN

TRAINEES IN PAEDIATRIC GASTROENTEROLOGY HEPATOLOGY & NUTRITION (TiPGHAN)

2003 has been another landmark year for the trainees' section of BSPGHAN. We started with a trainees' meeting and AGM at the Winter Meeting in Dublin. Professor Ian Sanderson joined us to speak about the introduction of the National Grid for Specialist Registrar training in Paediatric Gastroenterology, Hepatology and Nutrition. This proved to be a very productive session with much interaction from the trainees'.

Our TiPGHAN committee met again in May and December when the main agenda topics were the successful introduction of the Grid and dedicated log books for training in Gastroenterology and Hepatology and the planning of the first ever Postgraduate Day at the forthcoming 2004 BSPGHAN Winter Meeting at Crieff.

The introduction of the National Grid has been an exciting development for trainees. Seven SpRs were appointed during the first round of applications and took up their positions on rotations in London, Cardiff, Bristol, Manchester, Liverpool and Birmingham in 2003. All have been formally welcomed into TiPGHAN and I'm sure will make valuable contributions to our forum.

Now that the Grid is in place, a priority for trainees and BSPGHAN Council alike will be to ensure consistent high quality teaching and training across the regions. We are delighted to have a Postgraduate Day included in the Winter Meeting for the first time in 2004. This will be open to all BSPGHAN members with priority for trainees. We are hopeful of a good attendance and the meeting promises to be extremely educational and also sociable, with an evening of wining and dining!

Our goals in 2004 will be in further improving communication between trainees, not only for those presently in training but also for those SHOs and Core SpRs wishing to

train in our specialities. To this end, I would ask that if anyone becomes aware of a trainee in this position, 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. Our website planning continues to progress and we hope to have an updated and fully functional section of this website up and running early in 2004. Finally, we are keen to further explore the creation of national training days for trainees. These will be vitally important for both education and for establishing links with people around the country.

Lastly, we look forward to seeing as many of you as possible at Crieff in January but please be warned that we intend to win the traditional annual consultants versus trainees football match this year!!

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

WEBSITE REPORT

The BSPGHAN website has continued to function reasonably well over the last 12 months. The design and feel of the site are essentially unchanged over the last year. We continue to use email as the main source for disseminating information about changes on the website. With each mailing however there are at least 20 returns, meaning that we don't have the correct Email address for all members. I know our secretary is working very hard to try and keep the list updated and ultimately it is your responsibility to inform us of any changes in address.

The vacancy page has been used increasing over the last year to advertise medical, nursing, scientific and dietetic posts. In October 2003 this page on the website had 226 hits. The next most popular page with 223 hits was the page outlining future meetings and third behind that was the training page which gives information about higher training in paediatric gastroenterology and nutrition. Overall the website is having about 600-700 hits per day and so far there have been over 20,000 hits between January and November 2003.

In order to work well the website needs to be continually updated. A simple entry and change to the site takes about 20 minutes to do and a more complex entry can take up to an hour. It is therefore very helpful if entries can be sent to me either as Word or Acrobat files. In addition entries relating to meetings should be laid out in the same format as other entries presently displayed on the meeting page.

Any members keen to help with the development or running of the website should feel free to contact me at michael.bisset@arh.grampian.scot.nhs.uk

Michael Bisset
November 2003

DGH SUBGROUP OF THE BSPGHAN

The inaugural meeting of this new sub-group was held at the RCPCH in London on 27th October 2003, and was attended by paediatricians from most corners of the UK. Attendees were from a varied background including DGH paediatricians with an interest in gastroenterology, to paediatric gastroenterologists from smaller/ newer teaching centres and a spread between the two. It was agreed that membership of the group would not be exclusively limited to those from a strict DGH background, as others felt that their interests could be better represented in a group such as this. A number of issues were discussed including what the function of the group could/should be in the context of the BSPGHAN remit, a survey of practice for non-tertiary gastroenterologists, establishing a reliable database, training opportunities in non-tertiary centres for those wishing to become a DGH paediatrician with an interest, DGH – tertiary links, development of standards of care, and research and audit opportunities. An election for the posts of Chair (who will, subject to Council approval, sit on Council) and Secretary will be held in 2004. We will be meeting again at Crieff where all paediatricians with an interest in gastroenterology or paediatric gastroenterologists who feel that they would benefit from membership of this group will be welcome to join us.

Stuart Nicholls
December 2003

ENDOSCOPY STEERING GROUP

Areas of Interest

With respect to Paediatric Endoscopy issues this last year has focussed on the place or otherwise of sedation versus general anaesthetic for these procedures. Clearly, therapeutic procedures are GA-orientated, but the place of diagnostic procedures under sedation has met with differing viewpoints. This process has not been helped by the SIGN Group who produced a document suggesting GA occur for all procedures of this nature under the age of eight, because the evidence cited was of low grade, and hence the available evidence-base was somewhat unproven. A survey of all the referral units in the UK and Ireland represented by members of the BSPGHAN and a number of the larger DGH Units occurred. This showed all units (31 responses) except one performing all diagnostic procedures under the age of eight under general anaesthetic and some units performing 10-20% diagnostic procedures between the ages of 8 and 16 under general anaesthetic. Further discussions are required to determine the next step on the road to producing a position statement of the

BSPGHAN. It was agreed to invite members of the Society to provide any comments in regard to this issue.

The other major issue which is evolving is the that of training. Points for continuing debate which are likely to be soon resolved include:

Training Unit Assessment associated possibly with CSAC-associated visits; basic endoscopy courses; hands-on courses; trainers going on 'training the trainer' courses; place of log books (and whether they are being used); specific end points for specific trainees with a goal of eventual specific endoscopic CCST, specific for paediatric endoscopy training, but this is some way off; and finally the place of new training initiatives such as virtual model training, practical scope handling learning, net-based training for legion recognition.

Steady progress is being made to proposals for resolution of each of the above issues. Comments are very welcome as always. It should be pointed out that a new Joint Advisory Group on endoscopy training (JAG) document is available at the web page: www.thejag.org.uk. This has had paediatric input all along and has included the consensus statements agreed to by the BSPGHAN Membership over the last eight years.

The other point is that the World Congress in Paris occurring as you will know in the summer will have a postgraduate endoscopy course preceding it.

Mike Thomson
December 2003

IBD WORKING GROUP REPORT

The IBD Working Group was established in September 2000 and includes a broad mix of BSPGHAN members and associate members from across the UK. The group has worked closely with the RCPCH to develop evidence based guidelines for the management of paediatric IBD. A systematic review of the paediatric literature has been completed and has demonstrated a lack of high quality studies in children. In view of the lack of evidence it has been decided to proceed with the development of consensus based guidelines using a Delphi style consensus process. Further details will be circulated in the New Year.

The systematic review has emphasised the need for adequately powered paediatric studies and the group will be happy to consider any proposals from members of the BSPGHAN or elsewhere. A long-term multicentre study of enteral nutrition v steroids which will also address the role of azathioprine is being planned. For further details please contact Stephen Murphy.

A retrospective audit of infliximab has been completed (preliminary results presented at ESPGHAN) and a prospective audit is being planned. For further details please contact Sally Mitton or Tony Akobeng.

Elections for a new chairperson (currently Adrian Thomas) and secretary (currently David Wilson) will take place in the New Year. Members of the group are expected to be actively involved and will be replaced if they don't attend three consecutive meetings. Please contact David Wilson if you are interested in joining the group.

Adrian Thomas
December 2003

CHILDHOOD CONSTIPATION WORKING GROUP

The group met 4 times this year. The original remit of the group was to produce national guidelines for the management of childhood constipation. This has not been possible due to lack of research to support 'best practice'. The group organised a consultative workshop in March to get a clearer remit for the future direction of the group. The feedback from the day can be divided into three key areas and gives the group a clear remit for the coming year:

Research

- To design a Research Map –this would give us an idea of where we are now and where we need to go! It would foster multi team working and collaboration.
- Researchable questions – gaps in research, what do we want /need to know?
- Register of Studies/ research ideas – what has been done, who is doing projects etc.

Members of the group had put in unsuccessful bids for the HTA call for projects. The group felt HTA were not asking right questions and the group need to pursue the issue of what is happening to this funding. The group will write to HTA asking for background of call for bids and what they were actually looking for. Also put committee forward as advisors if money still available and offer to refine question.

Guidelines

- 'Evacuation Framework' Broad framework so that people can tailor guidelines locally to services available. More likely to be adopted if people have ownership of document.
- Development of document along the lines of ERIC 'Childhood Soiling' setting out best practice and minimum standards etc for management of childhood constipation.

Education

- Design a Modular Course for health professionals. This will support best practice. ? advanced level
- Distance Learning Pack/ Web based learning

Need to access funding for research fellow to take forward Framework and this would feed into research map

Three members of the original committee have had to resign due to personal commitments. In order to maintain the group diversity a number of specialist advisors have been invited to comment on work or proposals for work as required. The group would like to approach other people who have an interest in joining the group, which would increase the ability of the group to move projects forward and spread the workload.

The group is planning a committee web page on BSPGHAN Website, which will outline work completed to date and give members opportunity to feed into group. Please send any information or comments to Jenny Gordon.(js.gordon@napier.ac.uk)

A second study day is planned for Nottingham in October 2004. The proposed date is 15th October.

Jenny Gordon
December 2003

COELIAC WORKING GROUP

The following is the outline of the group activity for Jan 2003 to Dec 2003

1. National questionnaire audit for the management of coeliac disease: this study is just completed, the preliminary findings showed discrepancy between units on issues such as screening of siblings and children at risk, patients follow-up, and the need and the timing for gluten challenge. The study highlighted the need for national guidelines which the working group will to address.
2. Established links with diabetologists (Prof Dunger team), this will help us in sharing and disseminating evidence base practice for screen timing etc for children with IDDM and to establish a collaboration for research studies.
3. Coeliac group has been involved in drafting national prescribing guidelines for primary care.
4. The group recently met with the chief executive of Coeliac UK. It was agreed for establishing close collaboration on a number of issues including, raising disease awareness, patients (children) education which is lacking at present, national audit and involvement of some two members the coeliac group on the associate MAC for Coeliac UK

Muftah Eltumi
December 2003

SERVICE PROVISION WORKING GROUP

Mark Beattie
Rob Heuschkel
Ian Sanderson
Mike Thomson

Guidelines for Purchasers

Following many useful comments over the last 12 months, the group met and incorporated many of these into the document that had been posted on the website after last year's annual meeting.

In addition to refining this longer document, our specialty, along with all other sub-specialties, was asked by RCPCH to provide a 2-page document to inform the NSF College Working Group. The document was requested at short notice, and was to highlight the strengths and weaknesses of our current service provision, whilst making recommendations about how best to deal with existing and future pressures.

A shortened document has been produced and circulated amongst council members before being forwarded to the college. It included concerns about the impact of the EWTD and the trend to a more consultant-delivered service.

As the document has not been finally ratified, it is available electronically for those interested by request and will be circulated to the full membership in due course

R Heuschkel
December 2003

THE REGISTER OF PAEDIATRIC INFLAMMATORY BOWEL DISEASES.

The register is continuing to collect consented data on newly diagnosed children with inflammatory bowel disease. To date we have 271 Crohn's, 135 Ulcerative Colitis, 48 Indeterminate Colitis, 1 Orofacial Granulomatosis and 6 Crohn's Disease & Orofacial Granulomatosis thus totalling 461 consenting patients. Many of you will have seen the invited editorial in Archives which pulled together the experience of the register so far (Issues & experience around the paediatric register of inflammatory bowel disease. Arch Dis Child 2003;88:891-893. Taylor,L., Casson,D., Platt,M.J.) The difficult learning curve, which has taken considerable time, has reached its peak. Judging from the way submissions are being received it is apparent that the registering process has become firmly established and widely accepted.

Funding is secure for another year due to astute financial management of the original kind support by CICRA and a further commitment from SHS and from Nestle. In addition SHS have made a substantial contribution to the subsequent 2 years.

There are various planned research projects which will, I trust, demonstrate what potential the register has for providing epidemiological data, qualitative data and cohorts appropriate to any given research trial.

The personnel involved in the register recognise that it is beholden on them to provide the initial research projects. Subsequently it is to be hoped that others will consider applying for use of this resource.

I am grateful for the continued commitment of colleagues to this initiative and would urge all to continue. Despite an apparent lack of output, in the big world of registers we are still ahead of the game and useful outputs will be forthcoming.

We are once again at full staffing levels. Lucy Taylor has returned following maternity leave and will resume her post as research assistant looking at the development of incidence measures. In her absence Carla Roberts was employed and has carried through many changes with great efficiency. We have achieved the funding necessary to continue employing her. Her remit will be to support the various projects as well as ensuring the smooth day-to-day running of the register.

A project assessing relapse rates is presently being piloted at the Royal Liverpool Children's Hospital and will be appropriately taken over by the register once the pilot appraisal is finished.

Please note our contact details below. We are happy to discuss any issues.

Mrs Lucy Taylor – E-mail: lbtaylor@liv.ac.uk

Mrs Carla Roberts – E-mail: robertsc@liv.ac.uk

Tel: 0151 293 3566

Dr David Casson – E-mail: David.Casson@RLCH-TR,NWEST.NHS.UK

Tel: 0151 228 4811 ext 2714

REPORT FROM THE SPECIALIST ADVISORY COMMITTEE ON PAEDIATRIC GASTROENTEROLOGY, HEPATOLOGY & NUTRITION

In last year's report, I mentioned the two objectives for CSAC. One was to develop a modular training programme in gastroenterology, hepatology and nutrition. The other was to develop a national grid for gastroenterology and hepatology. In addition, the Regional Training Advisors, Dr Anil Dhawan and Professor Peter Milla have been active visiting centres.

A modular form of training has been agreed for both hepatology and gastroenterology. Hepatologists and gastroenterologists will do two years in their primary speciality with six months in their minor sub-speciality with six months nutrition spread over the three years.

The main developments in the modular training programme have been to establish nutrition more formally. A six month nutrition syllabus has been approved for those training in hepatology or gastroenterology. Two more developments are envisaged. The first is to develop a two year training programme in nutrition. This will also require six months in gastroenterology or hepatology and six months in another sub-speciality. The second is to develop a six month module in nutrition in nutrition training centres to offer to other CSACs, particularly to neonatology, metabolic disease and endocrinology. Discussions on this module will take place with the Royal College of Paediatrics and Child Health. We have established a third training advisor in nutrition. Centres that have a primary nutrition interest now have the choice of being visited by a gastroenterologist and a nutrition representative.

A National Grid was started in 2003. Interviews took place in March. Seven new paediatric gastroenterologists entered the Grid. They received their log books and were encouraged to join the Society. Their names were also passed to the trainee's representative so that communication was enhanced.

Ian Sanderson Jan 2004

THANKS TO MEMBERS FOR SUBMITTING REPORTS. APOLOGIES FOR ANY ERRORS OMISSIONS

MARK BEATTIE - JANUARY 2004

THE BRITISH SOCIETY OF
PAEDIATRIC GASTROENTEROLOGY HEPATOLOGY AND NUTRITION

Draft Revised Constitution (October 2004)
1997 Constitution which was adopted at
York RCPCH meeting in April 1997, revised in August 1999 and agreed at AGM
January 2000

Rule 1

The title of the Society shall be “The British Society of Paediatric Gastroenterology Hepatology and Nutrition” hereinafter referred to as “the Society”.

Rule 2

The objects of the Society shall be the advancement of research, clinical excellence and training in paediatric gastroenterology, hepatology and nutrition.

In furtherance of the above objects but no further or otherwise the Society shall:

- (i) foster professional relationships with colleagues, both nationally and Internationally.**
- (ii) organise the Annual Meetings which shall remain the fora at which researchers can present their work.**

Rule 3

Alterations to this constitution shall receive the assent of two-thirds of the members present and voting at an Annual General Meeting or a Special General Meeting. A resolution for the alteration of the constitution must be received by the Secretary of the Society at least 21 days before the meeting at which the resolution is to be brought forward. At least 14 days notice of such a meeting must be given by the Secretary to the membership and must include notice of the alteration proposed. Provided that no alteration shall be made to Rule 2, Rule 16 or Rule 3 until the approval in writing of the Charity Commissioners or other authority having charitable jurisdiction shall have been obtained and no alteration shall be made which will have the effect of causing the Society to cease to be a charity in law.

Rule 4

***Membership:* Full membership shall be available, upon payment of the appropriate fee, to Consultants, Associate specialists, Staff grades, Specialist Registrars, Lecturers, Research Fellows and basic scientists in any speciality who are committed to an area of paediatric gastroenterology, hepatology or nutrition. Proposals for membership shall be submitted to the Council by a member on the Society’s Proposal Form and the Council shall recommend those suitable for election to membership to the Annual Meeting of the Society. Honorary Membership**

may be conferred by the Society, at the recommendation of Council, upon distinguished colleagues who have made an outstanding contribution to paediatric gastroenterology, whether they be members of the Society or not. Upon retirement, full members may apply in writing to the Secretary to become Honorary Members. Honorary Members would not be required to pay the annual subscription fee and would not have voting rights at the Annual General Meeting nor at Special Meetings.

Associate membership shall be available, upon payment of an appropriate concessionary fee, to any non-medically qualified health professional who is committed to clinical service and/or research in paediatric gastroenterology, hepatology or nutrition

Rule 5

A member who has been absent from six consecutive meetings of the Society shall be deemed to have allowed their membership to lapse.

Rule 6

Members moving abroad may request to become Corresponding Members and shall pay a Corresponding Membership charge. Membership shall be open to Paediatric Gastroenterologists and Hepatologists from overseas for the duration of their clinical or research attachments in the UK. On their departure they would normally be required to become Corresponding Members if they so desired.

Rule 7

Council: the business of the Society shall be conducted by a Council which shall consist of the President, Secretary, Treasurer and eight other members, one of whom will represent BAPS, one of whom shall be a trainee representative, and one the associate members' representative. Each of the Society's 3 main areas of interest (gastroenterology, hepatology and nutrition) shall be represented on the Council. There will be at least one council member from a district general hospital. A quorum of four must be present at a Council meeting and must include the President or Secretary. The President will be elected by a postal ballot of the membership one year prior to taking up office and sit on council for the twelve months prior to taking up office. The Secretary and Treasurer and five other members shall be elected either by postal ballot or at the AGM and this will be decided by council at their meeting prior to the election. . The trainee's representative will be elected by the trainees group and ratified at the AGM. The associate members representative and the paediatric surgeon (who represents BAPS) will be nominated by their respective groups. The organiser of the winter meeting will be co-opted onto council.

Rule 8

The President, Secretary, Treasurer and other members of Council shall normally serve for a period of 3 years.

Rule 9

The President shall:

- (a) preside at Business Meetings of the Society and chair meetings of Council;**
- (b) be authorised to speak on both academic and administrative issues. The Secretary may attend meetings as their deputy;**
- (c) authorise an appropriate member of the Society, who need not be a member of the Council, to represent the views of the Society to other Associations and Societies and, in particular, shall ensure that the Society is represented at deliberations of the British Association of Paediatric Surgeons (BAPS), the British Association for the Study of the Liver (BASL) and the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN).**

Rule 10

The Secretary shall:

- (a) keep minutes of Business Meetings of the Council;**
- (b) prepare the Agenda and take minutes of the Business Meetings of the Society;**
- (c) maintain a current list of members and their addresses;**
- (d) maintain an archive of documents pertaining to the history and development of the Society**
- (e) deputise for the President;**
- (f) represent the Society at meetings of Convenors of the specialty groups of the Royal College of Paediatrics and Child Health**

Rule 11

The Treasurer shall:

- (a) be responsible for the collection and banking of annual subscription fees**
- (b) be responsible for the payment of bills incurred by the Society out of the Society's Bank Account**
- (c) submit annually to the Society a statement of accounts**

Rule 12

Two meetings shall be held annually:

- (a) The Spring Meeting shall be held in association with the Royal College of Paediatrics and Child Health and shall consist of original scientific contributions. It may include such guest lectures, symposia or joint sessions with other paediatric specialty groups as the Council shall determine.**

Papers submitted to the Society for the Spring Meeting, using abstract forms and submission procedures of the Royal College of Paediatrics and Child Health, shall be chosen by Council. In general, papers will be accepted on the understanding that they have not been published or read at a national or international meeting before the Society's scientific meeting.

Papers shall be spoken not read.

By providing clear guidelines of the acceptable standards for abstract preparation, slide preparation and presentation, the Society shall foster excellence in scientific presentation and discussion.

(b) The Winter Meeting shall be held annually.

Rule 13

***Funding:* A membership fee shall be paid as determined by Council. Registration and accommodation at meetings held in association with the Royal College of Paediatrics and Child Health or with the British Society of Gastroenterology shall be administered by those societies. The organiser of the winter meeting will provide a financial plan and statement of accounts to the society. 75% of profit made will be returned to the society with 25% being kept by the local organisers. Financial arrangements for autonomous meetings shall be made by local organisers.**

Rule 14

The proceedings of meetings of the Society shall be regarded as confidential

Rule 15

Members wishing to relinquish full membership shall have the opportunity of resignation or adoption of Corresponding Membership.

Rule 16

The Society may be dissolved by a Resolution passed by a two-thirds majority of those present and voting at a Special General Meeting convened for the purpose, of which 21 days notice shall have been given to the members. Such resolution may give instructions for the disposal of any assets held by or in the name of the Society, provided that any property shall to be paid to or distributed among the members of the Society but shall be given or transferred to such other charitable institution or institution having objects similar to some or all of the objects of the Society as the Society may determine and if and in so far as effect cannot be given to the provision then to some other charitable purpose.

Objectives

The main objectives of the day were:

- Review and establish the overall future direction for the BSPGHAN
- Explore and agree our main aims, objectives and priority action programme for the next 3-5 years
- Reassess the role of the Society in 2004/05 and agree key developments needed.

Summary

14 members attended representing current and previous BSPGHAN council members including trainee and associate members.

The day consisted of

- A review of the Society's current strengths, weaknesses, opportunities and problems
- Identifying the critical elements of our future direction for the next 3-5 years
 - What do we want to achieve?
 - What unique contribution can the Society make to the development of children's services?
 - Internal – what we what to do
 - External – what do the members and stakeholders expect from us?
- Identifying what is helping and hindering us to achieve this vision and key objectives?
- Identifying and discussing the drivers and hindrances especially political, professional, service development, resources and internal organisation of the Society

Facilitation

Provided by Nick Nicholson, Senior Visiting Fellow at the Universities of York and Leeds and Managing Director of Nicholson Associates

1. Current Strengths and weaknesses of the Society

Strengths

Friendly - coming together
Inclusive
Representative
Surgeons and Associates as members
Trend setting
Professional leadership and development of standards
Receptive to Change
High Standards
The winter meeting
Trainees group

Weaknesses

Not yet very influential
Lack of clarity in relation with Royal College
Poor dialogue with Royal College
Getting too big for current admin structure in Society
(e.g. membership list and management)
Not accessing resources effectively
Confusion over remit - representation and/or standards and advice?
Not clear what relationships are with other societies
Matching training and posts
Don't have relationships we need for maximum influence
Poor influence with purchasers (Trusts and PCT's)
Lack of profile for work

Opportunities

Large clinical need for Society's services and expertise
Increase in need for services from public and professionals
Royal College interaction and increase profile within RCPCH and BSG
Speciality links - everyone needs us!
Training
Modernising Medical Careers
Increased demand for clinical research and evidence
Development of Networks
National Service Framework

2. Threats/Problems to BSPGHAN

Not in a position to offer a professional opinion objectively and quickly
(infrastructure and time)

Lack of resources for society

Manpower engagement

Image - with public and professionals

Public expectations with NSF

Royal College represents a wide variety of disciplines and specialists of which
paediatric gastroenterology, hepatology and nutrition are a small part

Weak links with BSG

Training/MMC

3. Overall Aim of the Society – Mission statement

The Society will provide professional leadership promote standards of care for children with GI, liver and nutritional diseases and support research, training and education for members in order to help facilitate its delivery.

For members of the Society this means developing standards of care for the investigation and treatment of children with GI disorders and giving advice and support to implement child centred strategies to deliver them.

4. Key Relationships Developed/Needed

CSAC

Royal College PCH

BSG

Trusts, PCT's, Regional Specialist Commissioning (Specialist Services Agency)

Department of Health - ? need for group disease specific advisors

Public - web site, PR, Press officer

International links – ESPGHAN, NASPGHAN, UEGF

Industry

Charities

Primary and Secondary Care

Research bodies

5. Priority Ambitions and Objectives for the next 5 years)

1. To become the first point of reference for paediatric gastroenterology, hepatology and nutrition and be the standard setting body in respect of practice, protocols and education
2. Develop seamless training through our collaboration with CSAC with a structured national approach, support and mentorship
3. Increase the educational role of the Society for members
4. Increase the profile and attention for nutrition issues
5. Promote the development of clinical and research networks
6. Improve collaboration with other speciality groups to act cohesively in promoting paediatric subspecialty services
7. Promote multi-centre research and develop relationships with grant awarding bodies
8. Strengthen the financial and administrative organisation of the society

These will be developed through a series of objectives which form the societies Action Plan

ACTION PLAN

Objective 1

To become the first point of reference for paediatric gastroenterology, hepatology and nutrition and be the standard setting body in respect of practice, protocols and education

Improve collaboration with other speciality groups to act cohesively in promoting paediatric subspecialty services

RCPCH – College speciality board, CSAC

Action President/Sec (ongoing)

BSG – Committees – comment on policies and documents

Discussion with Jeremy Sanderson secretary of BSG – Action DK
Action Council member for liaison with BSG – Discussed October Council Meeting – Nigel Meadows nominated
Representation on BSG subcommittees – Discussed October Council Meeting – Nigel Meadows (Clinical Services and Standards), Chris Spray (Education),
Action Revive Paediatric section of BSG – Discussed at October Council Meeting – proposal that the BSPGHAN council = the paediatric section of the BSG – to be discussed at AGM
Action send minutes of council meetings – Discussed October Council Meeting – to be discussed at AGM

Establish Clinical Standards sub committee with representation from gastroenterology, hepatology and nutrition, chaired by council member (? secretary) incorporating within it all the society working groups

Action discussed at October Council Meeting/proposal to members at AGM
Working groups to be asked that 2004 reports include aims, objectives, terms of reference, workplan and timelines – Action MB

Objective 2

Develop seamless training through our collaboration with CSAC with a structured national approach, support and mentorship

Action CSAC chair to report to each council meeting and at the AGM

CSAC to develop system for career guidance and mentorship by end of 2005

Objective 3

Increase the educational role of the Society for members

Establish education sub committee chaired by a nominated council member with emphasis on all aspects of education not just training – include trainee representation and associate members, co-opt organisers of winter meetings/training days. To establish a register of courses and training days to be advertised on the web.

Action discussed at October Council Meeting – C Spray confirmed as education representative /report at AGM

Objective 4

Increase the profile and attention for nutrition issues

Representation on the college standing committee for nutrition
Nutrition representative on council to input into paediatric subcommittees of BAPEN and BANS
Intestinal Failure Working group to be established

Action discussed at October Council Meeting/report at AGM

Objective 5

Promote the development of clinical and research networks

Promote multi-centre research and develop relationships with grant awarding bodies

Highlight areas of good practice
Encourage networks possibly based on regions/training rotations
Consider asking someone to develop a research strategy

Action discussed at October Council Meeting – Agreed standing item on Council Meetings Agenda – NT to consider developing a research strategy
Development of a strategy (next 12-18 months)

Objective 6

Strengthen the financial and administrative organisation of the society

Increase financial income for the society

Increase membership fees – discuss at next council meeting/proposal to the AGM

75% of the profit from winter meetings (and any other organised on behalf of the society) to be returned to the society accounts – agreed by council April 2004

Clarify educational grants from industry

Explore new or additional sources of income

Action to discuss at October Council Meeting/AGM

Issues for the Organisation of the Society

Need for user representation on Council to improve mechanism for dialogue with and input from parents and children

Improve administrative support – Up to date membership list and database which includes members areas of interest, agenda and minutes of meetings, newsletter, constitution, central records for all society matters

Need for a designated office base

Better use of IT for communications within the Society and with others e.g. website Development

Action Website upgrade – MB to liaise with MB/SH

RM Beattie
October 2004

Attendance

Liz Maclean
John Puntis
Mike Thomson
Deirdre Kelly
Mark Beattie
Steve Hodges
Alastair Baker
Mervyn Griffiths
Nigel Meadows
Nikhil Thappar
Helen Evans
Mark Dalzell
Stuart Nicholls
Stephen Murphy

THE FUTURE OF INTESTINAL FAILURE SERVICES
IN ENGLAND AND WALES

RM Beattie, JWL Puntis

on behalf of the BSPGHAN

August, 2004

Executive summary

- following a meeting with the National Service Commissioning Group (NSCAG) in January 2004, the BSPGHAN membership was asked to comment on the desirability and role of supra-regional intestinal failure centres; feedback is summarised below
- there was much positive support for optimising management of intestinal failure, but with the proviso that services remain primarily regional rather than supra-regional (i.e. without the remit of NSCAG)
- there was support for an NSCAG funded intestinal transplant assessment centre, and acknowledgement of the role of such a centre in providing ongoing management advice in patients not listed for transplantation
- there should be further exploration of the possible need for a second intestinal transplantation centre
- there was recognition of the need for integration of gastroenterology and hepatology services within supra-regional liver transplantation units for effective joint management of patients developing liver disease while requiring long term parenteral nutrition

Introduction and Background

In January 2004, representatives from the BSPGHAN and BAPS (British Association of Paediatric Surgeons) were invited to meet with members of the National Service Commissioning Advisory Group (NSCAG) at the Department of Health to discuss the future configuration of services for children in England and Wales with intestinal failure. Although Birmingham has remained the single provider for small bowel transplantation in the UK (a service funded by NSCAG under its specific remit to support national or specialised services for rare diseases) discussions focused on whether Birmingham should be seen as having a wider remit, and included the possibility of further NSCAG funding for one or two additional 'supra-regional intestinal failure units'.

Some background data relating to Birmingham activity were presented. Over the past 13 years, 152 referrals have been assessed by the intestinal transplantation unit. Transplantation was judged not to be indicated in 70 patients, and 28 others were thought unsuitable; 54 were recommended for transplantation. In all, 32 patients have been transplanted, although in recent years, this has been isolated liver transplantation rather than combined liver and small bowel. Developments in management of complex intestinal failure including isolated liver transplantation and non-transplant surgery (bowel tapering or lengthening) therefore raise the question as to whether Birmingham should more appropriately be designated as a supra-regional centre for managing complex intestinal failure rather than specifically as a small bowel transplantation unit. If so, was there a case for having several such supra-regional

intestinal failure units (even if small bowel transplantation was confined to only one site), and what patients would it be appropriate to refer?

The meeting concluded with an agreement to canvass opinion among the membership of both the BSPGHAN and BAPS. A document summarising the issues (Appendix) was circulated electronically to all BSPGHAN members on three different occasions and comment invited. Replies were obtained from 12 specialist centres providing tertiary gastroenterology services; some of these were individual rather than institutional responses. Three paediatricians with an interest in gastroenterology working within district general hospitals also replied. The views expressed by the membership are summarised below. A further discussion meeting has been arranged with NSCAG in September 2004.

Is intestinal failure (when separated from bowel transplantation) a specialised and vulnerable service that is appropriate for NSCAG designation?

There was broad consensus that intestinal failure (and in particular home parenteral nutrition programmes) require additional funding and currently often represent an example of innovative service development without adequate resources. In arguing that regional services need supporting and developing, the role of NSCAG is, de facto, negated. A minority view expressed by five regional centres was that intestinal failure should come under the remit of NSCAG, with between 1 and 3 identified supra-regional units. Logically, these should be sited in currently designated supra-regional liver transplant centres since the main issues at stake were assessment of parenteral nutrition associated liver disease, and the possibility of isolated liver transplantation. Two tertiary referral units felt that consideration should be given to a

second intestinal transplant unit. However, the majority of respondents were not in favour of supra-regional intestinal failure services, other than for assessment of those patients who might require small bowel transplantation. There was acknowledgement of the important role performed by Birmingham in this respect, the accumulated experience in this centre and the combined availability of both gastroenterology and hepatology expertise.

Common problems of long term parenteral nutrition (e.g. catheter related sepsis) and training needs dictate that management needs to be 'local', although based in a centre with multidisciplinary nutritional care team, gastroenterologist, surgeon, etc. working in close liaison with hepatologists. In other words, management should be supervised in tertiary level gastroenterology units rather than district general hospitals. Potential disadvantages of NSCAG designation for intestinal failure include over centralisation, de-skilling of regional units, and an unnecessary burden of travelling for families and patients. Such concerns lead some to conclude that 'complex intestinal failure' comprised only those cases requiring small bowel transplantation. Of course, provision of small bowel transplantation ideally starts with an assessment of high risk patients before major complications have occurred. Not all of these will merit (or be suitable for) transplantation; follow up is required for determining outcomes, and other interventions (isolated liver transplantation, non-transplant surgery) may be appropriate. These aspects of an intestinal transplantation unit deserve recognition by NSCAG.

What kind of patients should be referred (i.e. what constitutes 'complex' intestinal failure)?

The suggested definitions of complex intestinal failure (see 'Appendix') were broadly accepted. With the exception of bowel transplantation and life-threatening difficulty maintaining venous access issues, complex patients could be managed in appropriately staffed and funded regional centres.

How many supra-regional intestinal failure units would be ideal?

Among the minority of respondents supporting the concept of NSCAG funded supra-regional intestinal failure centres, 1-3 units based on current supra-regional hepatology services were proposed.

Information was requested from BSPGHAN members regarding the number of children PN dependent for ≥ 4 weeks and ≥ 12 weeks, in addition to numbers of home PN patients managed during 2003.

Almost no information in response to this request was received. This probably reflects a lack of readily available data, emphasising the problems we have with defining the scope of the problem of intestinal failure, and represents a significant future challenge for the Society.

What facilities/expertise should be available at such a centre?

All intestinal failure should be managed by an expert multi-disciplinary team working in close collaboration with a hepatology unit. Shared care protocols for home parenteral nutrition need to be developed in conjunction with referring district general hospitals. Supra-regional services would principally provide for small bowel

transplantation, and offer advice on non-transplant management of those patients referred for assessment.

Future challenges for the BSPGHAN

Comments received reflect a consensus that the Society should be striving to implement and maintain the highest possible standard of care for children with intestinal failure. Rising numbers of children both with extreme prematurity/necrotising enterocolitis and complex gastroschisis means that numbers of patients are likely to increase. The Society should be working towards national standards for clinical care, shared care protocols, collaborative research, and a supporting network for definitive diagnosis. An intestinal failure registry and home PN register need to be coordinated in conjunction with BAPS, and BAPEN/BANS (British Association for Parenteral and Enteral Nutrition/British Artificial Nutrition Survey) in order to define the level of need. Funding of regional gastroenterology services in a way that reflects work performed is also an area of priority. The Society should consider setting up a permanent intestinal failure committee, which would liaise with the similar ESPGHAN body.

APPENDIX

Introduction

Intestinal failure services for children are currently managed regionally.

Improvements in paediatric intensive care, medical and surgical facilities in the past twenty years has resulted in much greater numbers of children receiving parenteral nutrition for prolonged periods in hospital and at home. Birmingham is currently the single provider for small bowel transplantation in the UK with greater than 50% long-term survival. The service is funded by the National Specialist Commissioning Advisory Group (NSCAG) who fund national services or specialised services for rare diseases. The current service agreement with NSCAG covers the cost of assessment for potential transplant candidates, the transplant episode and follow up.

The current contract does not include the management of those children with complex intestinal failure in whom small bowel transplantation may not be necessary. In recent years such management has included isolated liver transplantation rather than combined small bowel and liver transplantation in children with short bowel syndrome.

This has led to consideration of setting up supra-regional units for the management of children with complex intestinal failure as such patients are small in number and require concentration of expertise.

NSCAG has asked the BSPGHAN to comment on the need for supra-regional centres for the assessment and management of patients with complex intestinal failure. We have not been asked to comment on whether there should be more than one unit performing small bowel transplantation.

Potentially there may be increased funding for children with intestinal failure, and possibly the development of additional supra-regional centres.

The size of the problem

We do not have accurate knowledge of the numbers of patients requiring long-term parenteral nutrition (PN) nationally, and 'complex intestinal failure' is even more difficult to delineate.

If intestinal failure is defined as the need for PN for greater than four weeks there are clearly many patients already being managed in regional centres by gastroenterologists and/or surgeons, often through the agency of multidisciplinary nutritional care teams. If the definition is arbitrarily extended to 6 (or even 12) weeks of PN, the numbers will be less.

For the management of children with intestinal failure complicated by liver disease, regional paediatric units will need either to have hepatology services on site or close links with supra-regional liver units.

Consultation, and report back to NSCAG, September 2004

We are now in the period of a consultative process, involving both members of the BSPGHAN and the British Association of Paediatric Surgeons (BAPS), with feedback to NSCAG scheduled for September 2004. We are therefore requesting your view as a member of the BSPGHAN on this important issue and would be grateful for any comments in relation to how services for intestinal failure should develop.

Specific questions to be addressed include:

1. Is intestinal failure (when separated from bowel transplantation) a specialised and vulnerable service that is appropriate for NSCAG designation?
2. What kind of patients should be referred (i.e. what constitutes 'complex' intestinal failure)?

Possible examples of patients that might be referred include:

- Patients with intestinal failure in whom diagnostic uncertainty persists (e.g. protracted diarrhoea, motility disorders)
- Short gut patients not making reasonable progress with enteral feeding (e.g. tolerating <50% of their nutritional requirement enterally after 6 months of PN)
- Patients with progressive liver dysfunction (rising conjugated bilirubin after three months on PN; not tolerating an increase in enteral feeding)
- Patients in whom venous access is difficult and there is a real possibility that PN cannot be maintained in the near future

- Patients with short gut in whom surgery aimed at bowel lengthening or improving motility (gut tapering) might be considered as a means of establishing full enteral nutrition
 - Patients with recurrent episodes of life threatening catheter related blood stream infection
3. How many supra-regional intestinal failure units would be ideal (1, 2, 3?; it is likely that location would be the subject of a formal bidding process)

Our initial view is that a strong case can be made for more than one intestinal failure centre, but that further development should not be at the cost of weakening current regional services.

The role of the supra-regional intestinal failure unit as part of a managed clinical network could be

- To assess and advise on the management of the small number of complex cases
- Collaborate in the development of management protocols
- Aid in diagnostic difficulty
- Evaluate new treatments
- Support regionally based services
- Facilitate research

The majority of children with intestinal failure would remain within region as now.

In addition, the supra regional unit may also facilitate the standardisation of home parenteral nutrition (HPN) services, although we would not anticipate the need for all HPN patients to be referred to a supra-regional intestinal failure centre. One could therefore envisage most children managed within region with a register of children on home parenteral nutrition. There would be a facility for children from centres with only small numbers of children on HPN to be seen for review in the larger unit if appropriate.

In addition to general views we would also be interested in a number of specific responses including number of children who were PN dependent for 4 weeks or more (and 12 or more) in your centre, and how many home PN patients you managed, during 2003 if these data are available.

What constitutes Complex Intestinal Failure (time frame, clinical condition)?

Whether you feel such patients should be managed in conjunction with a supra-regional centre.

What facilities/expertise should be available at such a centre?

We are grateful for your input so as to ensure that views expressed represent the society's view on this important topic

Mark Beattie; John Puntis

On behalf of the BSPGHAN

Please reply to Dr Mark Beattie by either post or e-mail at the following address

Dr RM Beattie, Consultant Paediatric Gastroenterologist, Paediatric Medical Unit,
Southampton General Hospital, Southampton SO16 6YD