

**Newsletter**

**January 2018**

***President’s report***

***Professor Nick Croft***

Dear Friends and Colleagues.

A Happy New year to all and for those attending the conference in Leeds welcome.

This newsletter is a summary of all we have done over the past year and is sent so you are aware of the work being done even if you are not directly involved in it. All of this work relies on members contributing and so please get in touch if you would like to participate.

First I must thank enormously our outgoing members of council for their fantastic hard work and loyalty to BSPGHAN. Priya Narula (Endoscopy), Steve Allen (Research), Anna Pigott (PEGHAN) and Kelsey Jones (Trainee Chair) have worked tirelessly and contributed enormously over their time on council and have been highly productive with the support of their working groups. As Keith describes below I look forward to our finally approving the new members of council at the AGM. While we did not have to undergo any BSPGHAN elections this year we had excellent candidates and I look forward to them all joining council for my last year as President. Of course this includes a President Elect to be finally approved at the AGM and I look forward to gradually handing over the ship to Sue Protheroe over the coming year whom many of you will know will be a fantastic President. The Trainee Chair is selected by the trainee members and as Kelsey mentions below I look forward to Ros Rabone joining council.

The Annual Meeting 2017 in Glasgow was a huge success (jointly with the Scottish Paediatric Society for Friday), many thanks to all of those that put it together, particularly Richard Hansen and all the team in Glasgow. The programme for the Leeds meeting looks great and we really appreciate all the time and effort put in by the organisers for this, primarily Suzanne Davidson and Carla. We had very successful Associate and Trainees Meeting (Sheffield) and Taster days so thanks to the organisers of these important parts of the BSPGHAN calendar. In 2019 the Annual Meeting will be in Oxford (with a joint meeting with the Paediatric Surgeons) and remember in 2019 we are proud that Glasgow will be hosting the Annual ESPGHAN meeting. I would strongly recommend all to pencil these into your diaries.

I was delighted we managed to get the BSPGHAN RCPCH standards launched after some years of discussion. As I said last year these are very much a first step and so we should all be reading them and working towards ensuring our services fit the standards. We should all also be very pleased with the outcome of the new BSPGHAN Innovation Grants with 3 excellent new projects funded, we look forward to seeing benefits to patient care come from these. Please keep an eye out for a new call in 2018 which may help get your great idea into practice.

We did have very sad news in the untimely passing of Richard Driscoll past CEO of CCUK and still highly active in the area representing patients in the National IBD Registry developments. I had worked with Richard over many years and he was a hugely kind, sympathetic and supportive influence and really helped us all advocate for paediatric IBD patients. This has really helped us in the UK where a lot of the major initiatives in IBD now automatically include children as part of the initiative instead of being artificially separated out by a date of birth. He is and will be greatly missed.

Lastly on behalf of all BSPGHAN members thanks to the council members and the working groups for all their hard work, we continue to be a highly effective and collaborative society and I think this shows to people both inside and outside the UK. In particular thanks to Keith as convenor for efficiently dealing with huge amounts of contacts to the Society (and more) and Astor (treasurer) for helping to keep us afloat so we can use the money wisely. As always thanks to Carla for underpinning all our work and welcome to Sam Gault (Sheffield) who is beginning to take on some of the workload of the Society.

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***Convenor’s Report***

***Dr Keith Lindley***

Dear friends and colleagues

I would like to extend a very warm welcome to all of you to the 32nd BSPGHAN annual Winter Meeting in Leeds and to say a big thank you to Suzanne Davidson for hosting the meeting and arranging an such an excellent and exciting programme. I am really looking forwards to the clinical, scientific and social content of the meeting!

Whilst on the subject of annual meetings I do of course have to extend the Societies thanks to all our colleagues in Scotland lead by Richard Hansen and Richard Russel who did such a fantastic job organising the Annual meeting in 2017. Not only were the scientific and social programs outstanding, but the meeting also made a significant profit (see the Treasurers report)!

I have only been Convenor for 9 months and my most important task in this letter is perhaps to offer my sincere thanks to Nadeem Afzal, our previous Convenor, who did an outstanding job in supporting the Society and keeping Council and the Membership on track. I also have to offer him my personal thanks for setting me off on the right track when I took over. I was absolutely fascinated to see that with my newly acquired email address [convenor@bspghan.org.uk](mailto:convenor@bspghan.org.uk) comes access to a fascinating array of junk mail / spam some of which could only have been meant for Nadeem !

Our current membership now stands at 449 (Associates 136; Full members 280; Overseas 5; Honorary 18. In general the Society is thriving scientifically and socially and I am particularly proud of the Associates and Trainees section for their enthusiasm warmth and determination that the Society should be a cohesive network of close friends and colleagues. Sadly some, who are a little older, continue to nurture the rifts and divisions between factions of the Society that were evident when I was a trainee. It’s time that the old dogs amongst us took a page out of the associates and trainees book and learnt some new trick! Empathic debate is in the best interests of our patients and the Society membership alike.

I would particularly like to welcome all the new BSPGHAN members who have joined in the last year and to encourage then to actively contribute to the various academic and social BSPGHAN activities. Young blood in the working groups and indeed on Council is always appreciated, so please don’t hold back!.

Nadeem has already said a heartfelt thanks to those who left Council last year. It has been my privilege to join Council with some outstanding colleagues including Astor who succeeded Girish as Treasurer and with whom as Treasurer the Societies’ accounts will be safe and Naeem who has succeeded Marcus as Gastroenterology Rep. I have so send my sincere thanks to those who are about to leave us including Priya who has done a fantastic job as endoscopy rep. She has managed to validate the paediatric version of the GRS tool with JAG. As Nadeem noted the paediatric version is specifically tailored for our use and is much easier to use compared to the adult GRS tool but just as important. Steve Allen has also put in a huge amount of work to support the society as Research Chair. What Steve hasn’t done isn’t worth reporting to the Society – he’s been a tower of energy, enthusiasm and above all wisdom. Kelsey is also standing down. I’ve already alluded to the wonderful ATM above and I look forwards to Kelsey joining Council in the future in another role. Lastly I would like to thank Anna Pigott for her commitment to Council in her role as “Paediatrician with an interest”.

Hot off the press is the appointment of new members to the Council (subject of course to a show of hands at the AGM – please note the revised Constitution on which you also have to vote at the AGM).

Sue Protheroe is uncontested at President Elect. I remember the last time we had a (lady) President from Birmingham there was a tornado which altered the Societies trajectory. I would expect no less from Sue who is an experienced pair of hands in political (and of course clinical) circles. Welcome back to the Council Sue.

David Campbell is uncontested as Research Chair. David has a tough act to follow but I know will rise to the occasion with his considerable experience in basic science and clinical GI research.

Babu Vadamalayan is uncontested as Endoscopy Chair. How apt that the chair should move from Sheffield to Kings, the two units running the biggest paediatric endoscopy training courses in the UK. Welcome Babu, you have joined at an interesting and important time for the Society and its membership with regards to endoscopy.

The PEGHAN Council position is currently unfilled although I believe there may be a last minute application which will need to be announced at the AGM.

The working groups have been busy. I would encourage you to read each groups individual report as I cannot mention every nuance of their activities here. There are a few highlights I would like to draw attention to.

I have to thank Jutta for putting so much energy and organisation into chairing the nutrition WG. There is a huge amount Jutta is dealing / has dealt with in a frighteningly organised Germanic female way and I think the two major successes have been facilitating getting eBANS back on track again and that BSPGHAN members can now become BAPEN members for free. I would encourage all members with the vaguest of interests in nutrition to consider this. My own experience of BAPEN has been evolutional. More on eBANS later.

Mohamed has taken over from David as the lead for the motility WG. Whilst I am not unbiased, being a member of the group, I must say that the group is laying down a profile internationally. I was delighted to see that the guidance on esophageal pH impedance measurement, which represents this societies view, was eventually published despite the negative comments of the editorial board of the Archives. I know there are plans afoot to generate and publish other position papers in the next 1-2 years and I am conscious that to facilitate this energetic and knowledgeable individuals are being recruited into the WG some of whom are not as yet members of the Society. I expect these individuals to become members of the Society in the near future

Rafeeq has taken on the role of IBD WG chair with more enthusiasm than a 6 year old in a chocolate factory! I am particularly grateful to him for dealing with the often apparently excessive requests from NICE for expert input into the revision of existing guidance. Naeem has also helped me greatly in this respect.

It is not possible to include all the great work done by the WGs in this report but please read the individual working groups’ reports as the achievements are many and varied.

John Fell and the Standards Group have delivered 10 standards for paediatric GI care in the UK which were unveiled in the Spring RCPCH meeting in Birmingham and which have seemingly already become enshrined in tablets of stone by the RCPCH. John is overseeing a survey of all GI units in the UK to understand where things are at and then it will be down to all our individual Trusts / Commissioners to see that the standards are upheld nationally. This can only be good for all units eventually although initially there might be some pain (I have already personally experienced this at the hands of the RCPCH).

I have to thank Sandhia for organising an incredibly successful “taster” meeting at the Royal London which has followed admirably in Rafeeq’s legacy and which will hopefully continue. I am also particularly indebted to Kelsey for organising such an outstanding ATM in Sheffield this year.

Michael Hughes continues to do a great job with our website with (mostly) smooth running links and removal of any glitches and should be congratulated with the advances in electronic registration for the annual meeting (something I know Carla has been very involved with).

Another highlight of the year has been the awarding of the first three BIG grants by the Society. These include support for an administrator for e-BANS, support for the creation of a Decision Tree in neurologically compromised children who develop GI dysmotility, and support for a Digital Ulcerative Colitis healthcare project. My congratulations to the successful applicants.

Looking forwards, we have a great RCPCH 2018 Spring meeting programme in Glasgow. The Gastroenterology day is on Wednesday 14th March. This year we are jointly hosting with the Paediatric Inherited Metabolic Disease Group. We have interesting invited lectures including “metabolic complications of PN and intestinal failure”, NAFLD, neonatal hepatitis, liver transplantation and eosinophilic GI disease to include a few. Please mark the date in your diaries and do come and support if you can.

Lastly my heartfelt thank you to Carla who continues to be a pillar of support in the running of the Society and who probably has the biggest whip on the planet to keep us all on our toes! Thank you Carla.

See you all in Leeds

BW  
Keith

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***Treasurer’s Report***

***Dr Astor Rodrigues***

1. **Annual accounts – Appendix 1**

**BSPGHAN draft accounts for 2017**

Total income: £235,083

Total expenditure: £232,249

Surplus: £ 2834

**Annual Meeting:** Glasgow Winter Meeting 2017

The meeting generated a surplus of £66,316 out of which £16,579 has been the local organiser’s share

**Membership Fees:**

Direct debits set up for most members. A few members have not responded to calls to change their payment to direct debits despite several reminders and their membership has been revoked, but could be reinstated if the member wishes to join.

**Tax allowance:**

Peter Hill (society’s accountant) is looking at enlisting BSPGHAN onto the HMRC list of approved professional organisations for tax relief purposes.

**Working Group Expenses:**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | ***2012/2013*** | ***2013/2014*** | ***2014/2015*** | ***2015/2016*** | ***2016/2017*** | ***2017/2018*** |
|  |  |  |  |  |  |  | (to date) |
| **Education** | | 0 | 65 | 0 | 120 | 0 | 0 |
| **Liver Steering group** | | 301 | 0 | 0 | 0 | 0 | 0 |
| **IBD** | | 1786 | 1229 | 3600 | 2069 | 3006 | 1402 |
| **Endoscopy** | | 1746 | 838 | 498 | 868 | 1801 | 444 |
| **JAG** | | 895 | 99 | 153 | 0 | 0 | 0 |
| **Motility** | | 0 | 0 | 146 | 246 | 0 | 210 |
| **Quality Standards** | | 0 | 0 | 0 | 482 | 563 | 182 |
| **DGH** | | 0 | 704 | 0 | 0 | 0 | 0 |
| **Nutrition** | | 595 | 1047 | 0 | 112 | 198 | 201 |
| **Research** | | 103 | 0 | 0 | 0 | 256 | 665 |
| **Coeliac** | | 0 | 0 | 0 | 169 | 0 | 0 |
| **Constipation** | | 0 | 0 | 0 | 0 | 164 | 0 |
| **BIFS** | | 722 | 0 | 0 | 0 | 0 | 0 |
| **Total** | |  |  |  |  |  |  |
|  |  | 6148 | 3982 | 4397 | 4066 | 5988 | 3104 |

Request WG chairs to remind members to book their train tickets early at reduced rates through the BSPGHAN Trainline account

Expenses mostly paid promptly via BACS

**BSPGHAN’s contribution towards research spending past 2 years:**

1. 2016 – BSPGHAN & CCUK - 20K; BSPGHAN & CLDF - 10K; BSPGHAN stand alone - 10K: Total £40,000
2. 2017 – BSPGHAN & CORE: Total £40,000

**BSPGHAN Innovation Grants (BIG):**

Agreed £30,000 over 3 years, already awarded £18,500 for 3 projects

1. *Digital Ulcerative Colitis Healthcare Project – DUCH* **(**Jonathan Hind): awarded £5,000.
2. *Paed eBANS administrator; 2 year project* (Akshay Batra): An award of £10,000 will be made over two years - £5,000 that has been paid out
3. *Decision tree for multi professional staff and families caring for patients with neurodisabling conditions who develop severe gut dysmotility* (Sue Protheroe)awarded £3,500

Society’s balance sheet / financial position is satisfactory with a total bank balance of ~ £250,000

**Astor Rodrigues, BSPGHAN Treasurer**

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**Committee and Group Reports:**

***Gastroenterology Chair***

***Dr Naeem Ayub***

**Gastroenterology Report January 2018**

The different Working Groups under the Gastroenterology Umbrella have been extremely productive throughout the year with involvement in multiple areas involving audits, research and publications. Some of the highlights of each group (based on their reports) are illustrated below:

**Coeliac Working Group**

Peter Gillet *– Chair (previous secretary)*

***Members***

Marcus Auth

Mark Furman

Mary-Anne Morris

Maureen Lawson

Assad Butt

Sarah Sleet

Huw Jenkins

(Bruce McLain, Ronald Bremner, Mark Beattie, Matthew Thorpe, Stephanie France)

Although the coeliac working group has been relatively quiet over the last year, they have submitted a response on behalf of BSPGHAN on the Gluten Free (GF) food consultation from NHS England. The outcome is imminent and we will need to think hard as a group and as a society about the response to this - it seems inevitable that there will be a poorer provision for children proposed, although one always hopes it will not happen.

From a research point of view, the group has not convened in order to plan for group research but the meeting at Leeds should hopefully kick start some National work.

This year sees CUK's 50th anniversary with a planned £5 million research fund and plans for priorities from them for important research. The New Year of 2018 will hopefully see some innovative and collaborative work plans produced. Any interest in the group is very much welcomed and Peter Gillet should be contacted regarding this.

**Motility Working Group**

***Chair****: Dr* Mohamed Mutalib (Previously Dr David Rawat until September 2017)

**Members**

Erica Nunn

Joanne Brind

Anna Rybak

Stewart Cleeve

Eleni Athanasakos

Yvonne Slater

Sally Dalton

Nikhil Thapar

Oswaldo Bereli

Keith Lindsay

Marcus Auth

Rachel McGee

Steve Perring

Dr David Rawat stepped down as the Chair because of his Clinical sabbatical & Dr Mutalib took over this role in October 2017.

The working group’s representation on BSPGHAN has been rather limited but the profile of the working group has been enhanced by involving members with experience and expertise in GI motility investigations. A few non-BSPGHAN members have been welcomed by the working group. These include Mr Stewart Cleeve, Paediatric Surgeon with an interest in colorectal GI motility, Dr Eleni Athanasakos, Paediatric Clinical Scientist, Eric Nunn, Constipation Specialist at Kingston Hospital, Sally Dalton, Clinical Nurse Specialist and Anna Rybak, Consultant Paediatric Gastroenterologist with an interest in GI motility.

A large proportion of the GI motility investigations are undertaken by paediatric surgeons and Rachel McGee, GI Physiologist in Manchester has been nominated as the Manchester representative. Dr Kornelia Nikaki who is currently completing her PHD in GI motility and is a member of BSPGHAN will represent the trainees.

**NIHR/research**

David Rawat is stepping down as motility working group representative and Joanne Brind will be taking over this position.

**Research interest for working group**

* Long term follow-up of children with chronic intestinal pseudo obstruction
* Biofeedback for paediatric functional GI motility
* DTSU for achalasia

Massive congratulations to the Working Group on publishing their position statement on PH Impedance monitoring:

***“BSPGHAN Motility Working Group position statement: paediatric multichannel intraluminal pH impedance monitoring—indications, methods and interpretation Frontline Gastroenterology Jul 2017, 8 (3) 156-162; DOI: 10.1136/flgastro-2016-100796)”***

The Group is presently in the process of producing guidelines on ***High resolution anorectal manometry and oesophageal manometry***, as well as ***Clinical guidelines on the management of children with faecal soiling.***

**IBD Working Group**

The IBD WG has worked tirelessly with tremendous results as highlighted below:

**Chair***:* Rafeeq Muhammed

**Members**

Chris Spray Bristol Secretary

Naeeem Ayub Shrewsbury Gastro (GI representative)

Janis Maginnis Stoke IBD Nurse

Sibongile Chadokufa GOS IBD nurse

Jochen Kammermeier Evelina Gastro

Jenny Epstein Chelsea Gastro

Vijay Iyer Stoke Paediatrician with GI interest

Paul Henderson Edinburgh Gastro

David Devadason Nottingham Gastro

Mark Furman Royal Free Gastro

Thankam Paul St George’s Gastro

Anne Wilmott Leicester Gastro

Michael Stanton Southampton BAPS representative

Trainee representative vacant

The group held 4 meetings in 2017. During the last 12 months, the group has focused on the following priorities:

1. The group has published **“G*uidance on monitoring blood tests for IBD patients on thiopurines*.”** This is available on the society website.
2. The document on the initial immunology work-up for patients with ***early onset IBD or IBD like disorders*** is nearly complete and will be available soon.
3. The group is also working on ***“Guidance on the role of vitamin D, folate and vitamin B12 in IBD”.***
4. Other ongoing work includes “Transition in IBD”, “Adrenal suppression in IBD’” and “Fatigue in IBD”. The group has sent out a survey to the IBD medical and surgical leads to assess the current status of paediatric IBD surgery in the UK.
5. New Prospective Incidence study - **PINPOINT study** **(*Prospective Incidence of Paediatric-Onset Inflammatory bowel disease)*** will be led by Paul Henderson and is awaiting funding approval. The Group will be in touch with more details to let everyone know how to take part. Successful completion of this project should benefit all members.
6. The National IBD audit results including biosimilar Infliximab data has been prepared for publication.
7. The working group is supporting the adoption of the IBD registry by paediatric IBD units. The IBD registry will be useful for local data collection and facilitate participation in national audits. The working group aims to enable all IBD units to input data using the IBD registry patient management system or web tool in 2018.
8. The group has continued to support IBD research via its informal clinical research network (UKPIBDnet). This (UKPIBDnet) is integrated into the international networks PIBD-net and has established funding from the EU Horizon 20 20 project. The project comprises a risk stratified ***RCT of methotrexate vs. azathioprine*** for low risk disease and ***methotrexate vs adalimumab*** for high risk disease. This study is led by Richard Russell and is expected to start recruiting in 2018. An inception cohort as part of the same funding initiative has been set up by Nick Croft and has already started recruiting patients.
9. The group continues to participate in several national studies on Inflammatory bowel disease: PRED4, PANTS and PREDICT.
10. The WG has worked closely with Crohn’s Colitis UK and CICRA and represented BSPGHAN in “IBD UK”, a new initiative led by Crohn’s Colitis UK to update IBD standards. It has also participated in the NICE consultation on partial update of Crohn’s disease and Ulcerative Colitis management guidelines.

It is worth noting that two members of the group have completed one term and applications have been invited from interested BSPGHAN members to join this dynamic group. Successful applicants will be decided at the working group in January 2018.

Personally, I am extremely proud to be part of these productive groups and have no doubt that they will continue to build on their successes throughout the year

Dr Naeem Ayub

Gastroenterology Chair

January 2018

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***Endoscopy Working Group***

***Dr Priya Narula***

Membership of the BSPGHAN Endoscopy WG

**Core Members**

Chair – Priya Narula (new chair to be elected at AGM 2018)

Ex Chair Ieuan Davies

Vice Chair and Endoscopy Representative on CSAC – Lucy Howarth (2017-2020)

***Regional Endoscopy Leads***

Scotland – Richard Hansen

Yorkshire, East Midlands & North East – Mike Thomson

Liverpool, Manchester & Northwest – Christos Tzivinikos/ Loveday Jago

Birmingham, Wales & South West – Ronald Bremner

London, Central & South East – David Rawat/ Lucy Howarth

Hepatology – Tassos Grammatikopoulos

BSPGHAN Associate Members Representative – Mick Cullen

BSPGHAN DGH Committee Representative – Anna Piggott

BSPGHAN Research Committee Representative – David Devadason

BSPGHAN Trainees Representative – Rachel Levi/ Kwang Yang Lee

BAPS Representative – Ian Sugarman/ Michael Stanton

**Corresponding Members**

BSPGHAN Convenor

BSPGHAN President

BSPGHAN Education Chair

BSPGHAN Gastroenterology Chair

JAG Representative – Neil Hawkes

PGHAN CSAC Chair

BSPGHAN GRS working group and P-GRS pilot centre leads – Priya Narula, Lucy Howarth, Anna Piggott, Ronald Bremner, Peter Gillett, Paul Henderson, Mick Cullen, Janis Maginnis, Sharon Mckenna, Nadeem Afzal, David Rawat, David Devadason, Sabari Loganathan, Christos Tzivinikos, Mike Stanton. JAG representatives – Debbie Johnston, Raphael Broughton

As I come to the end of my term and reflect on the achievements of our group, I realise what a privilege it has been to have led this group in the last 3 years. During this time, I have made new friends and learnt a lot from this role. I welcome my successor and hope that this role is as interesting and rewarding over the coming years as it has been for me.

Highlights include:

1. Launch of the P-GRS (Paediatric endoscopy Global Rating Scale) in October 2017 as a QI tool following a successful pilot. This was following a lot of hard work by the members of the GRS working group and the leads from the pilot centres with very supportive input from members of the JAG team. Data from the pilot was presented at BSPGHAN, RCPCH and ESPGHAN meetings and there has been considerable interest in this tool. The P-GRS will help develop standards for accreditation of paediatric endoscopy services in time thereby ensuring high quality patient-centred care.
2. Formative DOPS specific to paediatric OGD and Ileocolonoscopy introduced in July 2016 after joint input from members of the BSPGHAN EWG and JAG. Data from the JETS e-portfolio looking at the use of the new paediatric DOPS has been analysed and one oral and three posters have been accepted for presentation at the annual meeting at Leeds.
3. Joint working with the team from JAG enabled the above two but also led to closer links between BSPGHAN and JAG with representatives from JAG attending the BSPGHAN annual meeting. JAG management updates now include separate paediatric data reports.
4. Regular input to endoscopy training for trainees at the BSPGHAN ATM by members of the EWG.
5. Survey from trainees on endoscopy training completed by the trainee representative in 2017. Issues highlighted to be taken forward by the EWG.

Ongoing workstreams:

1. Prospective survey of severe GI bleeding requiring endoscopy – led by Mike Thomson and Nick Croft.
2. GI bleeding pathway for DGH’s - led by Anna Piggott
3. GI bleeding scenario for inclusion in APLS – development led by Richard Hansen and David Devadason
4. Input into group led by Sue Protheroe (Chair NHSE CRG) looking at the Atlas of Variation paediatric endoscopy data
5. Embedding of the P-GRS as a QI tool and development of a paediatric appropriate accreditation pathway working jointly with JAG
6. Analysis of data from the JETS eportfolio to look at paediatric endoscopy learning curves – led by Priya Narula

I would like to thank Sanjay Rajwal for his input as hepatology representative and Rachel Levi for all her hard work and input as Trainee representative. I would like to welcome Tassos Grammatikopoulos as the hepatology representative and Kwang Yang Lee as the incoming trainee representative.

I am very grateful to all my colleagues on the council for their help, support and guidance in the past three years. I would also like to thank close colleagues for their patience and support and wish my successor the very best.

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***Professor Stephen Allen***

***Joint BSPGHAN / NIHR – Children Gastroenterology, Hepatology and Nutrition Research Working Group***

The RWG is a joint group between BSPGHAN Research Group and the NIHR Children GHN Clinical Studies Group

The RWG held 3 meetings in 2017: two face-to-face (one at the Annual meeting in Jan in Glasgow; one at “Liverpool-in-London” in June with NIHR Children providing the venue plus lunch and BSPGHAN covering travel expenses) and one by teleconference in October. NIHR Children took minutes for all meetings.

Activities have been consistent with our overall strategy of promoting and engaging members in research and our workplan for 2017 (Appx 1) as follows:

|  |  |  |
| --- | --- | --- |
| 1. | Joint funding for research start-up projects with pGHN charities in 2017 | BSPGHAN link with CORE to co-fund start-up research grants: see Appx 2. |
| 2. | Joint funding for research start-up projects: plans for 2018 | A joint meeting was held in London on June 12th 2017 with representatives from CORE, CCUK, CICRA, Coeliac UK and CLDF to consider forming a consortium to support research start-up grants.  Although this proposal was generally supported, issues such as benefit beyond existing charity research funding initiatives remain to be clarified. Further discussion are being led by Sarah Sleet, Coeliac UK/RWG charities representative.  It is likely that in 2018 BSPGHAN will again join with individual pGHN charities rather than through a consortium; interest from Coeliac UK and CLDF has already been expressed. |
| 3. | Engaging trainees and associate specialists in research | Surveys of engagement/interest/ barriers to research amongst trainees were led byNicola Ruth (Trainee Rep) and amongst Associate Specialists led by Joan Gavin (Dietician Representative). Findings to be presented at Leeds Annual meeting, Jan 2018 |
| 4. | NIHR Cochrane IBD programme grant; Dr. Gordon Morris: see Appx 3 | BSPGHAN supported this application. Gordon will present a brief overview of the programme and how BSPGHAN members can engage at the annual meeting in Jan 2018. |
| 5. | Website | Content has been regularly updated with links to charities for details of start-up grants awarded. |
| 5 | Continue to respond to requests to review research proposals (inc. commercial studies) for inclusion on the NIHR Clinical Research Network to enhance study effectiveness and efficiency. | The Group has provided feedback on several proposals. |

Other activities in 2017:

Steve Allen continues to represent the group as a member of the RCPCH Research Consultation Committee and also as a member of the BSG IBD Clinical Research Group.

*Succession planning:* SA will end term as Chair in 2018. Job description for replacement has been circulated to members and applications invited.

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***Education***

***Dr Sandhia Naik***

* PGHAN Taster Day June 2017- extremely successful with positive feedback. 40 registered Attendance was good balance of Allied Health Professionals, pharmacists and trainees. A key highlight was patients and parents telling their experiences
  + We plan to hold this annually and sponsors are keen to support, provisionally planned for June 2018 venue to be confirmed
* START – new PGHAN questions utilised this year with good feedback
* Two Trainees have joined the working group Hina Rizvi- Hepatology Grid and Philippa Wood – GI Interest.
* A lot of requests have come in to have a single area on the BSPGHAN Website to look for guidelines, info, key papers. We have had virtual meetings and are now compiling a resources document which will ultimately go on website with hyperlinks

I am sorry but usually Education Chair would be expected to comment on Associates and Trainees Meeting and Annual Meeting but due to illness didn’t go to Glasgow and missed ATM due to leave so report even shorter than usual! ATM for 2018 is provisionally planned for 21st Sept 2018 in London.

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**Nutrition and Intestinal Failure Working Group (NIFWG) of the British society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)**

**Jutta Köglmeier, Chair of the Nutrition and Intestinal Failure Working group (NIFWG) of BPSGHAN**

**November 2017**

**Members: •** Jutta Köglmeier (Chair) • Sue Protheroe/Nkem Onyeador (CSAC) • Theo Wong (BIFA) • Tracey Johnson (Dietitian) • Akshay Batra (e-BANS Chair) • Julian Thomas (e-Bans Secretary and Research) • Tony Wiskin (e-Bans regional deputy lead and research) • Himadri Chakraborty (General Paediatrician) • Pamela Cairns (Neonatology) • Venetia Simchowitz (Pharmacy) • Diana Flynn (RCPCH) • Catherine Richards (Surgery) • Jonathan Hind (Hepatology) • Harween Dogra (Trainee Rep)

**Meetings 2017**

The NIFWG has met on 26th January at the BSPGHAN annual meeting in Glasgow, on 24th May prior to the RCPCH Gastroenterology symposium in Birmingham and on 16th November in London.

The fourth paediatric intestinal failure and rehabilitation meeting was held jointly with BAPEN Medical on 20th November in Birmingham. The day was well received and was dedicated to exciting topics relevant to both paediatric and adult intestinal rehabilitation teams:

* + Management of high output stoma
  + Abnormal liver function test
  + PN composition lipids
  + Line care and CRS
  + Bone disease and acid base balance
  + Transitioning
  + small bowel transplantation

**e-BANS**

Chair: Akshay Batra

Regional deputy lead: Tony Wiskin

Secretary: Julian Thomas

A major focus of the group is to ensure that the paediatric section of e-BANS (Paediatric electronic-British Artificial Nutrition Survey) will continue to be accessed by the intestinal failure units and all relevant patients are captured. The NIFWG has managed to secure a BSPGHAN innovation grant to fund the much required admin support. An administrator has been appointed and will take up the post in December 2017.

Jonathan Hind presented on the epidemiology of intestinal failure in children in the UK, and the evolution of the paediatric e-BANS registry on behalf of the group at the CIRTA meeting in New York on 30th June 2017.

**BAPEN**

The bond with BAPEN is continuing to grow stronger and BPSGHAN members are likely to be entitled to free BAPEN membership next year.

Tony Wiskin has taken up the role as paediatric e-BANS regional deputy lead. His term as BAPEN E&T rep has come to an end.

A call has gone out to all BSGPHAN members to find a replacement and Harween Dogra has expressed an interest in the role. However, the BAPEN E%T committee may change its current format as part of wider restructuring of BAPEN. Jutta Köglmeier is currently awaiting further information from BAPEN.

The joint paediatric/adult intestinal failure rehabilitation symposium on 20th November had a paediatric and adult speaker for each presentation. Topics relevant both to adult and paediatric practice were chosen and sparked interesting discussions.

**Allied Health Groups.**

**Pharmacy**

BPNG (British Pharmacy Nutrition Group):-

Revised National Framework for home PN has been published.

Venetia Simchowitz continues to represent paediatric pharmacists on the Framework.

Blueteq forms have now been in use for some time. Home parenteral nutrition cannot be requested without a completed Blueteq form (NHS England – Initial Funding Application for HPN for children (under 18s) needing parenteral nutrition

Angela Cole continues in her role as the paediatric nursing representative and Susan Hill as the paediatric Gastroenterologist.

The paediatric chief pharmacist group has developed three regimes for standard bags in neonates and children. An industry manufactured commercially available standard bag is being developed.

The new ESPGHAN guidelines on parenteral nutrition in children are still not published. The delay is due to an ongoing debate about the use of parenteral nutrition in the paediatric intensive care setting. Data supports that certain amino acids contribute to the occurrence of infections in children. There is hence controversy about the appropriate timing of the start of PN on PICU.

The guidelines are however expected to become publically available at the end of this year or early 2018.

Members of the NIFWG have taken part in the European wide CVC survey. The outcome of the survey is currently being analysed and will be included in the ESGPHAN PN guidelines.

**Dietitians.**

Blenderised diets continue to attract great attention at present. The BSPGHAN Allied health professionals group dietitians are writing a position paper which will be published on the BSPGHAN website. The associates committee has met with the British Dietetic Group and they are now working together to develop guidelines about decision making.

A further aim of the group is to put together a consensus document on weaning from artificial/tube weaning. The work is ongoing

Julian Thomas is representing the NIFWG as research lead on a HTA application involving six centres.

**Nutrition nurses**

The nutrition nurses continue to work on a number of projects

* standardisation of nursing practices in PN and nurse/patient ratio for home PN children
* equipment and methods used for connecting and disconnecting PN at home. A wide variety of equipment has been requested under the National home PN Framework.

**BIFA**

BSGPHAN representative: Theo Wong

BIFA position statement 2016 on Home Parenteral Nutrition (HPN) has been pusblished and is available on line ([www.bapen.org.uk](http://www.bapen.org.uk)). The BIFA study day planned to take place in Belfast on 18th May 2017 was unfortunately cancelled due to lack of applicants.

**Research, Training and current/future projects**

• Guidelines for the diagnosis and management of intestinal failure in childhood

• The development of a decision making tree for feeding neuro-disabled children with deteriorating intestinal function in conjunction with the Royal College of Paediatrics. A BSGPHAN innovationg grant application has been sent to council. A Delphi process is planned and the NIFWG members will take part. A systematic review (current treatments, therapeutic strategies before consideration of parenteral nutrition) has been carried out by one of the Scottish trainees. The group has successfully secured a second BSPGHAN innovation grant to fund this project.

• to obtain funding for a randomised controlled trial investigating the use of Taurolock prophylaxis for the prevention of central venous catheter associated sepsis

• develop a practical ethical framework for decision making in severe neonatal intestinal failure

• Guidelines for the use of blenderised diets in children

• Recommendations for the best method to wean children from intravenous to enteral nutrition

• National survey on jejunal feeding practices in children across the UK

Following completion the group would like to publish the documents both on the BSGPHAN and BAPEN websites

**Meetings 2018**

1. NIFWG Thursday, 25th January 2018 at 07:45:-09:00 in Leeds (BSGPHAN annual meeting)
2. NIFWG Thursday, 17th May 2018 at 13:30 – 16:30 in London (Barclay House level 4 meeting room)
3. NIFWG Provisionally schedule for Thursday, 15th November 2018 at 13:30 – 16:30 in London (Barclay House level 4 meeting room)

Alternative: Thursday, 6th September, 17:00 – 19:00 (and Friday, 7th September 08:30 – 09:30 if needed) in Edinburgh during national intestinal failure rehabilitation and transplantation network meeting - tbc)

National Failure Rehabilitation and Transplantation Network Meeting, 6th and 7th September 2018 in Edinburgh

**Jutta Köglmeier**

**London, 28th November 2017**

NIFWG Chair and Nutrition Representative on Council

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***Website***

***Technology report***

***Mike Hughes***

[*Webmaster@bspghan.org.uk*](mailto:Webmaster@bspghan.org.uk)

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**Hepatology**

**Dr Indra van Mourik (January 2018)**

This year has seen ongoing collaborative projects between the Liver Specialist Centres, BSPGHAN and many other national and international bodies including NHS England, NICE, BSG, BASL, the RCPCH, ESPGHAN and EASL, as well as family support organisations (Children’s Liver Disease Foundation). The liver steering group continues to provide a valuable forum for these activities to be raised, discussed, debated, co-ordinated and communicated, with a very welcome input from Dr Christine Spray, the Regional centre representative.

Activities over the last year that I wish to highlight are:

Guidelines and audit:

NHS England Commissioners attended the Audit Meeting of the Liver Centres in June 2017, where each centre presented its activity, protocol and management of Non Alcoholic Fatty Liver Disease (NAFLD). It is our aim that this will lead to a national guideline being agreed, which should be finalised later this year and made available on the website.

The group have adapted the neonatal cholestasis guidelines to match the NICE neonatal jaundice guidelines, the guideline for management of oesophageal varices (developed following last year’s joint Audit Meeting) is now available on the website, and the acute liver failure guideline update will be finalised this year.

Transition:

Through BSG representation and presence/presentation at national BASL/BLTG/BSG conferences we continue to work closely with adult services to improve the adolescent transition process. This is much appreciated by adult teams who are generally very open and keen to learn from paediatricians.

Interaction with national bodies:

There is a considerable amount of work ongoing to address the areas highlighted in the Lancet Commission report, particularly transition, with Marianne Samyn, Deirdre Kelly and Paddy McClean being the major forces. Deirdre will give more in depth feedback during the Lancet Symposium session on Friday 26th January.

Representation on British Liver Transplant Group (BLTG), Bowel Advisory Group (BAG) and Liver Advisory Group (LAG) was provided by Girish Gupte (BAG), Jonathan Hind (BAG), Sanjay Rajwal, Tassos Grammatikopoulos, Marianne Samyn, Mona Abdelhady, Sue Beath and myself. As in the previous year there is ongoing concern about the reduced numbers of deceased donor livers that are being split for two recipients, thus reducing the number of possible transplants. We argued that, although paediatric waiting list mortality had not increased during this time, we could not accept trend of reduced number of splits, as it was only because of life saving Living Related Liver Transplant programmes that negativekly impact on waiting lists could be ameliorated. LRLT will not always be available for every paediatric/small adult recipient.

Training:

Although there are currently 4 national grid hepatology trainees in post, there continues to be some concern about a mismatch of trainee numbers and the predicted number of consultant vacancies.

The Taster Day provided an opportunity for Girish Gupte to practise his marketing skills to attract the next generation of hepatologists. We hope to see increasing numbers of trainees considering a career in hepatology.

It is apparent however, that trainees in hepatology, as in other specialist services, are facing ongoing difficulties ensuring sufficient specialty exposure due to working patterns. We continue to interact with the Royal College and our own Trusts as advocates for specialty trainees and to ensure quality of training.

Teaching:

It was Leeds’ turn to organise the Annual Stakeholders Education Day. This was successful and well attended. We are reviewing how to reach a wider audience for these meetings, e.g. general paediatricians and trainees from all backgrounds, even GPs, as the purpose is providing some training and feedback on common paediatric liver related topics.

Finally, on a personal note, my first year as chair of the group has been interesting and has given me clear insight of the dynamics and activities of the Society. I would like to thank my colleagues and members of the liver steering group for their ongoing support.

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***Trainees***

***Dr Kelsey Jones Trainees in Paediatric Gastroenterology, Hepatology and Nutrition (TiPGHAN)***

**BSPGHAN Trainee Chair Report to AGM, January 2018**

**ATM 2017**

The ATM was held in Sheffield in late September. The event was very successful, with a high quality educational programme and 48 attendees. Short talks on topics covering the breadth of PGHAN, a workshop-style session on statistical methods for clinical research, and an outstanding half-day session on endoscopic enterostomy placement with live-link to theatre in Sheffield were all very well received. I am particularly grateful to Priya Narula, Sam Goult and Carla Lloyd for advice, help and support, and to all those who came to present.

The ATM in 2018 will be held in London, hosted by Dr Sandhia Naik and colleagues at the Royal London Hospital – dates to be decided

**Trainee Committee Terms of Reference**

Draft terms of reference for the Trainee Committee have been circulated to members and accepted pending formal ratification by Council. The purpose of these is to ensure there are clear and transparent structures in place for nomination to the various Committee roles and to enshrine a requirement for regular meetings between the Committee group.

**Trainee Committee Composition**

There have been a number of changes to the Trainee Committee in the last few months as members have reached the end of their terms. This includes the Chair, and I’m pleased that Ros Rabone will be taking on that role – as outgoing Chair I wish her luck!

Chair: Ros Rabone

Secretary: Huey Miin Lee

CSAC Rep: Ed Gaynor

Education: Hina Rizvi & Philippa Wood

Endoscopy: Kwang Yang

Hepatology: Lauren Johansen

IBD WG: Elena Cernat

Motility: Kornolia Nikaki

Nutrition: Harween Dogra

Research: Nicola Ruth

BSG Rep: Amar Wahid

I would like to say a personal thanks to all the Council, Trainee, and other members who have helped me in my role, particularly those who have given their time so generously in helping to set up and run the ATM meetings.

Kelsey Jones

Outgoing BSPGHAN Trainee Chair

Jan 2018

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***Paediatricians with an interest***

***Dr Anna Pigott***

**PEGHAN Report for the Annual General Meeting**

**SPIN**

9 new applicants for SPIN training in the last 3 months

24 currently listed as in SPIN training. Mostly trainees, but 3 are post CCT (mixture of consultants and staff grades). 5 have completed the module. 2 trainees started SPIN more than 3 years ago.

I have been in discussion with the RCPCH about the need to update the curriculum, the RCPCH is first updating the general and GRID curriculums, but SPIN will follow and I am keen for the PGHAN module to be one of the first to be updated in the new format.

Feedback suggests trainees would like to be more involved, so I will be inviting all SPIN trainees to the PEGHAN group meeting, to try and improve networking for them (and existing consultant members).

**Endoscopy EWG/GRS**

I have continued to contribute to the endoscopy working group including contributing to the GRS standards and accompanying guidance and producing a draft pathway for GI bleeding for use in DGH’s.

**The description of the role of PEGHAN Chair has been updated**

**Thank you**

I have come to the end of my term as PEGHAN Chair, a post I have really enjoyed, finding it immensely rewarding. It has also been a pleasure to work with all of those on council whose wisdom I have benefitted from. A special thanks to Nick Croft and Sue Protheroe who have been so supportive and helpful.

A big thankyou to all those who contribute to the PEGHAN group, the “Whatsapp” group set up by Himadri Chakraborti has continued to be well used and a great way for us all to keep in contact. A big thanks to all the PEGHAN representatives on the different working groups who are listed below. They all make important contributions and feedback regularly to the wider group.

* Dr Yvonne Slater(Stoke) : Motility WG
* Dr Himadri Chakraborti (Basildon): Nutrition WG
* Dr Vijay Iyer (Stoke): Nutrition WG
* Dr Anna Pigott (Stoke): Endoscopy WG

Thank you

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***Associate Members***

***Mrs Nicky Heather***

2017 has remained a stable year within the Associates committee and Associate Members remain committed to actively support BSPGHAN. There has been an increase in new members in the last 12months. One of the aims this year has been to increase engagement with the Associates who represent us on the working groups so that we get regular updates from their activity. We have also met to discuss how the Associates can be more proactive in establishing task focused groups using the depth of expertise that we have within the membership.

**Education (ATM meeting)**

The ATM 2017 meeting held in September in Sheffield and once again was a very successful event. We were extremely grateful to Priya Narula and her team who made us feel very welcome and the effort that was put in to produce a programme which had a wide variety of topics with excellent speakers. The format of parallel sessions in the morning for Associates and Trainees with joint sessions in the afternoon worked well again. Our focus topic was ‘transition’ this year with local speakers giving us a lively insight on the topic and hopefully good ideas to take back to our teams. Following the success of last years parent speakers this year we had a very eloquent talk from ‘George’ who is Chair of the local Youth Forum for Sheffield Choldren’s Hospital giving us a fabulous insight into his experience of transitioning from paediatric to adult care and his life living with chronic illness. Sheffield appear very fortunate to have such a proactive and lively youth forum who have been very influential in achieving better facilities.

The results ogf our Survey Monkey were presented (see below) and will be discussed further at our AGM.

Before the meeting we had contacted the Representitives of the Working Groups requesting a short report that was presented to the audience by the Committee members attending. We felt this was very informative and should be a regular slot in future meetings establishing the link to the working groups. These reports will also be presented again at the Associates AGM in Leeds.

As always we were very grateful to Carla and Sam in co ordinating the programme and organising the logistics of the 2 days. Numbers of attendees were consistent to last year. The feedback from the meeting was excellent: ‘Really good programme’, ‘Brilliant meeting- great content, highly relevant, thankyou’.

Reflecting on the meeting, it was predominantly new names and faces that attend the ATM. We are therefore considering aiming our future days towards the educational needs and networking of members who are relatively new to PGHAN and local members. Our Survey Monkey results show that BSPGHAN annual meeting remains predominantly the priority for study leave for many of our members so in order to make full use of the ATM we will consider aiming the course content towards the ‘next generation’ welcoming our newer members. We will explore and iscuss this as a group.

We will discuss the content of the 2018 ATM programme at the AGM in Leeds.

Survey Monkey

We conducted a survey to our membership this year to discover preferences for training, barriers to attending meetings and study days; how members would like to be involved in activities within BSPGHAN. (Appendix 2: Results appended). Feedback from this survey should help allow future planning of training, development and how best our members can support the Society whilst recognising the increasing difficulty in obtaining time off and funding for these events and initiatives.

**Associate committee**

We remain as a committee of 4. Emma Jones (Dietitian at Alder Hey) and Jo Brind (CNS at GOSH) and Chris Smith (Dietitian at Brighton) remain on the Committee. Jo is in the role of our secretary with the support of the committee. My thanks go to Chris , Emma and Jo for their support and commitment with the Associates this year. In 2017 we felt more settled with us established in our posts however as for us all the increasing demands in our ‘day jobs’ means we are not always able to give as much as we would

We would welcome any interest in joining our committee and I hope to meet some interested members at the Annual Meeting. We would like to also continue to forge stronger links through our AM representitives from the BSPGHAN working groups who can inform us of the initiatives that are being developed in these groups.

**Membership**

We have had new applications for members during this year with particular interest just before the ATM and winter meetings.

Nicky

Lead Dietitian for Paediatric Gastroenterology

Southampton Childrens Hospital

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***Patient and Professional Partnership (PPP)***

**PPP report 2017**

**Children’s Liver Disease Foundation**

The charity has had one of its busiest years to date. In terms of research the charity held a grant round in the summer with three projects receiving funding, our ongoing grant projects now consist of 10 ongoing projects. We will run another CLDF grant round in 2018, which will be launched in February 2018, we also hope to run a combined round with BSPHGAN in winter 2018.

Support services continue to go from strength to strength with four family residential weekends delivered in 2017 in England, Northern Ireland and Scotland. A further range of one day family events took part in other areas of the country. In addition to our two annual young people’s residential week long projects we also ran our First young persons weekend and conference for 16-25 year olds over 3 days in partnership with Derby University. The projects were all received very well.

During the year we have updated, redeveloped and re published large amounts of our information leaflets with the help and support of a wide range of health care professionals , young people and parents. All of the titles are fully compliant with the Information standard and by the end of 2018 we will have reviewed and redeveloped the entire catalogue of 48 titles.

In December we were delighted to launch our first book specifically for children, Joes Transplant tells the story of a journey from pre assessment to recovery and has input from all three specialist centres. The parents and children who were the first to get access to the book in late December are all very impressed. It will hopefully be a useful tool in preparing children and families for the transplant process.

During 2017 CLDF has continued to contribute to the Lancet commission and has liaised with a variety of statutory consultations include NICE guidelines, obesity, transplant, prescription charging related policy etc. CLDF is currently running a stakeholder consultation on what policy areas the charity should focus on over the coming 3 years.

In 2018 CLDF will launch a new website and host it’s biennial National Conference and Family weekend at Crowne Plaza in Stratford. The charity will also be launching a Research Hub to broker patient involvement in the development of research proposals for external research groups. The CLDF yellow Alert campaign will also be updated and relaunched

**CICRA**

In June 2017, a new CEO, Nick Posford was welcomed to the charity, he may be a familiar face at Family Days or at seminars/meetings. Nick oversaw a survey of children and families and has also been taking feedback from our much valued collaborating health professionals. As a result, CICRA have developed an ambitious new strategy to coincide with its 40th anniversary in 2018. The focus in the first year is twofold – ensuring information and support is readily available to children and their families, and continuing to fund ground-breaking research.

 In 2018, we will be running a fundraising campaign to support these objectives and we will have a new brand and website to support all aspects of our work launching in the spring. We will be refreshing our information as we mentioned last year, with a focus on various overviews in booklet form, some aimed specifically for children, with more detailed and expert information available from our website. We are very keen to work with colleagues who care for children with IBD to both keep our website regularly updated with the latest information and to signpost children and families to it. We are also refreshing our membership approach (still free) and will be grateful for your help in distribution  (we want families to get the benefits of membership as close to diagnosis as possible as that can often be when they most need somewhere reliable for information outside clinic hours.).

We are also piloting a new approach to our popular IBD Family Information Days so we can reach more areas each year. In March and May, we will be holding two afternoon events (1-5pm) in Bristol and Sheffield, with a focussed session of talks from health professionals and a rotating discussion group, as well as activities for children and young people. We are planning a bigger mid-year event as part of our 40th anniversary.

With all of the above, we are indebted to the professionals who so generously give their time and energy whether as a speaker, research panel member, feedback, promoter, supporter or reviewer. We really couldn’t do it without you!

Keep looking at our soon to be upgraded website for the details of our next research round, and of course, we continue to offer all year round bursary grants of up to £400 and one annual endowed international bursary grant of £1000. Further details will be on the CICRA website in due course.

**Coeliac UK**

**Research Fund**

Coeliac UK is developing a £5m Research Fund appeal and has undertaken a number of activities to deliver:

* Established a priorities setting partnership working with the James Lind Alliance which will influence our new research strategy.  BSPGHAN was invited to share the first round of priority question setting with its members and Peter Gillett participated in a subsequent workshop to refine the question list.  We are about to issue the refined list for further consultation to rate for a final top 10 list.  BSPGHAN members will be invited again to complete the survey.
* Created a new Research Strategy Board
* Launched the private phase of the fundraising appeal.

In the coming year we will publish our top ten research priorities and research strategy, and establish the Research Awards Panel. And we will launch the public phase of the research appeal as part of our 50th anniversary celebrations.

**Prescriptions**

The ongoing battle on continuing access to gluten free prescriptions is reaching an end point in England with the issuing of a national consultation on future policy.  The consultation received over 8,000 responses which is by a long way the biggest response the Department of Health have ever had to such a consultation according to officials. Thank you to all BSPGHAN members who have supported at a local and national level in terms of retaining access.  We expect the decision to be announced by the end of between Christmas and the end of January.  We are not optimistic about its outcome. In the event of complete removal of access in primary care we would encourage all BSPGHAN members to keep us in touch with any impact they see in their patients.

**CORE – Guts UK**

This year Core has expanded our staff team from 2 full time members to 5 and half. In April a new office was leased in The Media Centre in Huddersfield, a Yorkshire base for fundraising team. In June Core welcomed its first Head of Research, Fiona Veira-McTiernan.

Core’s Board of Trustee has started a strategic review of the charity’s vision and objectives. The Board commissioned market research in the early part of the year to gather evidence of what people affected by digestive conditions need from and think about the charity. Uniquely placed within the BSG, we are the only charity in the UK leading the fight against all conditions of the gut, liver and pancreas. We are committed to upholding the original mission of funding vital research, providing expert information and promoting awareness around digestive health.

Rebrand: The Digestive Disorders Foundation was established in 1971 with a first donation of £500 from the British Society of Gastroenterology (BSG). Since 2004, the foundation has been known as Core but this year we have changed our name to Guts UK, with a formal launch planned for early 2018. The market research carried out earlier in 2017 identified honest, brave and bold as terms that describe the stakeholders, patients and carers who responded; these values will inform Guts UK vision and strategy going forward. A new, memorable name, increased visibility and improved outreach means Guts UK can champion this cause and grow levels of support for research into the digestive conditions that affect so many.

Grants: In 2017 we have awarded the Core-Derek Butler Fellowship for research on upper GI conditions to Dr Conor McCann (UCL); a Development Grant to Prof Laurence Lovat (UCL) to research the use of epigenetics to stratify risk of oesophageal cancer using saliva samples; two co-funded Development Grants with BSPHAN, for Prof Chris Probert (University of Liverpool) and Prof Sarah Ennis (University Hospital Southampton), both on IBD; a Trainee Research Network Grant to Dr Richard Ingram, at Nottingham University Hospital and two individual Trainee Research Grants to Dr Reenam Khan (University of Birmingham) and Dr Ashwin Dhanda (Plymouth University Peninsula), all co-funded with the BSG. Core and Dr Falk Pharma also awarded a set of [prizes and grants](http://corecharity.org.uk/research/investing-in-future-researchers/) to young doctors, trainees and other health professionals working in gastroenterology to recognise their work and research projects.

Policy and advocacy**:** Core is one of five founding member charities of the Less Survivable Cancers Taskforce [www.lesssurvivablecancers.org.uk](http://www.lesssurvivablecancers.org.uk) . Along with Pancreatic Cancer UK, The British Liver Trust, Action Against Heartburn, and The Brain Tumour Charity the taskforce has come together to improve survival rates for the deadliest cancers of the lungs,  pancreas, liver, brain, oesophagus and stomach. The Taskforce was launched in Scotland and Westminster and secured a follow-up meeting with the Minister for Health Steve Brine on December 13th. This group of charities aims to raise awareness by working together  to challenge decades of neglect and underfunding and level up the less survivable cancers with those where a great deal of progress has been made.

Patient involvement**:** Core also took part in another key joint charity working initiative this year. It attended a workshop on bladder and bowel continence that brought together patients, carers and researchers to encourage more research into this hugely important area. The charities involved included Parkinson’s UK, Alzheimer’s Society, Age UK, Marie Curie, The Urology Foundation, Devices for Dignity and Core, as well as the BSG, NIHR and the James Lind Alliance. All organisations were interested in the reality of living with multiple conditions and the role incontinence plays in these conditions and quality of life. Following on from a James Lind Alliance priority report on incontinence in 2008, the workshop wanted to highlight the need for more research in the area. A new report that acknowledges this need is due out in January 2018.

**Crohn’s and Colitis UK update:**

The charity published a new 5 year strategy, which can be viewed [here](https://www.crohnsandcolitis.org.uk/about-us/strategic-plans-and-annual-accounts/strategic-plan).

Some of our achievements this year include:

* [Launching IBD UK](https://www.crohnsandcolitis.org.uk/news/launch-of-ibd-uk) an exciting new alliance of 17 professional and patient organisations responsible for driving up the standards of care and treatment of people with [Inflammatory Bowel Disease](https://www.crohnsandcolitis.org.uk/about-inflammatory-bowel-disease) (IBD).
* [Research Impact Report](https://www.crohnsandcolitis.org.uk/news/the-power-of-research) published highlighting what we have made possible.
* Working with the [Royal College of General Practitioners](https://www.crohnsandcolitis.org.uk/news/new-spotlight-project-with-family-doctors-brings-inflammatory-bowel-disease) to improve the management and diagnosis of Crohn’s and Colitis.
* Launching the first [All-Party Parliamentary Group](https://www.crohnsandcolitis.org.uk/news/all-party-ibd-group-launched-in-uk-parliament) on Crohn’s and Colitis and [Cross Party group](http://www.parliament.scot/msps/inflammatory-bowel-disease.aspx) in Scotland.
* Delivering a number of successes as part of our [accessible toilets campaign](https://www.crohnsandcolitis.org.uk/news/accessible-toilet-sign-campaign-early-success). The CEO’s of the UKs four biggest supermarkets received over 19,000 emails, leading to new toilet signs in over 2000 stores and counting. 5 major national supermarkets now using ‘Not Every Disability is Visible’ signage.
* 12,000 completions of the annual IBD survey.
* We were successful in increasing the number of [IBD nurses](https://crohnsandcolitis.org.uk/get-involved/campaigning/more-ibd-nurses-better-care-campaign) by 50% in the last 3 years.
* Supported over 500 people through 4 Family Days and increasing young peoples’ confidence through a pilot residential weekend.
* Developed 5 ‘In their own voices’ films with young people to help with transition.
* Over 440 applications for our Personal Grants, £155k given to help people.
* “So you want to be an IBD nurse” study days run in partnership with the Royal College of Nursing.

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***CSAC***

***Sue Protheroe***

***Chair Gastroenterology, Hepatology and Nutrition CSAC***

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| --- | --- |
| Dr Sue Protheroe | CSAC Chair |
| Dr Nkem Onyeador | Assessment Advisor |
| Dr Mona Abdel Hady | Hepatology Training Advisor |
| Dr Anna Pigott | Paediatrician with a Special Interest |
| Dr Lucy Howarth | Gastroenterology Training /Endoscopy Advisor |
| Dr Ed Gaynor | Trainee Representative |
| Dr Akshay Batra | Nutrition Training Advisor |
| Dr Jonathan Hind | Quality Advisor |
| Dr Nick Croft | BSPGHAN President |

I would like to thank the CSAC committee and grid coordinators for their on-going responsibilities. The team works hand in hand with College officials to oversee and improve the quality of Grid and SPIN training and we are currently monitoring the progress of nearly 50 trainees. Welcome to Jonathan Hind, Lucy Howarth and Nkem Onyeador who have joined CSAC. Grateful thanks to Anna Pigott who has worked tirelessly to improve the SPIN assessment process.

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| A] Curriculum The new paediatric training curriculum, RCPCH Progress, has been approved by the GMC.  This is the first of any specialty curriculum to be approved as meeting the needs of the new GMC Excellence By Design standards and to incorporate the GMC’s Generic Professional Capabilities for all doctors in training. Hundreds of trainees, consultants, children and young people, and other key stakeholders have been involved in this work to produce a curriculum, which meets the current, and future needs of the NHS and is easy and instinctive to use for trainees and trainers.  All trainees will switch to this curriculum from August 2018, except those due to CCT before 15th September 2019.  The RCPCH is running an “Early Adopters” pilot scheme throughout the 2017-18 training year. You can find out more about the new curriculum at [www.rcpch.ac.uk/progress](http://www.rcpch.ac.uk/progress) and read the full press release at <https://www.rcpch.ac.uk/news/new-paediatric-speciality-training-curriculum-gets-green-light-gmc>.  B] Annual Reviews of Competence Progression (ARCP) We have worked hand in hand with the College to produce a new trainee led CSAC progression input form, which will be similar to a revalidation form, grouping all the evidence in one place and the relevant learning outcomes. Trainees and their supervisors will populate this prior to a face-to-face annual meeting with CSAC. The form should be completed at least 6 weeks prior to the ARCP but no more than 6 months prior to the ARCP in the summer.  We are piloting the face to face meeting for ST7 and 8 trainees at the BSPGHAN Annual Meeting in 2018, but since this falls more than 6 months prior to ARCP rounds, CSAC have consulted with trainees to see if they might have their annual trainees meeting in May/June each year, merging the Csac meeting with the ATM meeting, Thank you to BSPGHAN Council, who we hope can continue to support an annual meeting for trainees for networking and education as well as offering an opportunity for face-to-face support for development and externality for the assessment process. An alternative is to arrange a separate assessment day for trainee assessment at the RCPCH (but trainees will not be paid their expenses to attend). CSAC agreed that the Hepatology trainees can continue to complete their sub speciality review at their training meeting this November, but they would need completion of the CSAC Progression form with up to date information on the CSAC progression form within 6 months of their ARCP, so the review each November will need to be updated. Nkem, our assessment advisor and the RCPCH Training Services Manager have led on the building and combining the new e portfolio form for PGHAN trainees to use prior to the a face to face meeting, which will replace the current annual speciality specific review paper form. In summary, the process will be started by the trainee and reviewed by the CSAC rep at a face-to-face meeting. The trainee can then work the form on again until May. The Educational supervisor will provide a report and it will be signed off as CSAC progression form at the CSAC meeting June 27th 2018 ready for the ARCP panels in the summer. This would mean four sections:   1. Trainee 2. Educational supervisor 3. CSAC rep face to face meeting 4. Trainee |
|  |
| F] Trainee Engagement One to one contact was made with grid and some SPIN trainees in 2017 at the ATM training day and the BSPGHAN Annual Meeting.  G] Quality Assurance of grid centres by CSAC Following the 2015/6 trainees and centre survey, we are reviewing the annual GMC survey and will analyse and pull together the results for grid centres. As part of the Improving Lives work stream, HEE are exploring deanery study leave budgets and we may be asked to consider what is a “mandatory course” to achieve a CCT (eg an upper GI endoscopy course for grid trainees)  H] Grid Recruitment for 2018 National training Grid posts were advertised and interviews took place 30 November. RCPCH introduced a clearing round in 2017 – any posts that weren’t filled within the first offers for Grid for each specialty were offered to those who were not matched.  I) SPIN CSAC is monitoring the progress of over 20 trainees through the SPIN process for trainees and non-trainees.  E] START Trainees who sat START in October should be working through the RCPCH guidance “ Assessment, Feedback and targeted development. ” We are working on new scenarios for the April 2018 diet.  F] BSPGHAN web page Quality Advisor, Jonathan, will be updating the CSAC page of the web site. |

**Sue Protheroe Chair Gastroenterology Hepatology and Nutrition CSAC December 17**

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***BAPS***

***Mr Michael Stanton***

‘Firstly, a happy new year to everyone from BAPS!

1. Joint annual meeting with BAPS – Oxford, January 2019.

We have now confirmed to hold the Friday of the 2019 BPSGHAN Conference in Oxford as a joint day with BSPGHAN and BAPS. We look forward to putting together an interesting programme and seeing you all there.

1. IBD survey of service provision

A quick thank you to those of you have participated in this survey which is being carried out on behalf of BSPGHAN and BAPS. This has been sent to consultant IBD leads (medical and surgical) at all UK centres. We will share the results with you in due course.

1. Joint acute upper GI bleeding survey

Work is continuing to gain the necessary funding to undertake this UK prospective study of acute upper GI bleeding in children. BAPS have previously agreed to contribute funding to this joint survey.

I look forward to seeing many of you in Leeds, I am honoured to have been asked to co-chair the first session at your conference.’

Regards,

Mike

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**Quality Standards Working Group**

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| **Dr John Fell** | **Project Chair, BSPGHAN** |
| Dr Alastair Baker | Consultant Paediatric Hepatologist |
| Dr Anne Wilmott | Consultant Paediatric Gastroenterologist |
| Dr Carol Ewing | Vice President for Health Policy, RCPCH |
| Dr Fevronia Kiparissi | Consultant Paediatric Gastroenterologist |
| Dr Mark Furman | Consultant Paediatric Gastroenterologist |
| Dr Mike Cosgrove | Consultant Paediatric Gastroenterologist |
| Dr Nick Croft | President, BSPGHAN |
| Dr Rajeev Gupta | Consultant Paediatrician |
| Dr Shveta Chana | Consultant Paediatrician |
| Dr Sue Protheroe | Consultant Paediatric Gastroenterologist |
| Isobel Howe | Head of Health Policy, RCPCH |
| Kay Crook | Gastroenterology Nurse Specialist |
| Melissa Ashe | Project Officer, RCPCH |

Coinciding with its ratification at the BSPGHAN annual general meeting (January 2017) the Quality Standards document was also ratified by the RCPCH.

Subsequently the document was formally launched at the RCPCH annual meeting in May 2017. This is now a working reference document, available on RCPCH and BSPGHAN web-sites.

The next steps are to audit our sites / activities against these standards. This will provide the evidence needed for re-drafting the standards in 3 years.

Many thanks to the committee members and all those who contributed to this project. It is worth emphasising that the help and expertise provided by the RCPCH has been invaluable in producing this document in such a timely fashion.

**RCPCH / BSPGHAN Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition:**

**Summary of the standards**

1. Trusts and health boards that provide paediatric gastroenterology and nutrition services work within a clinical network. Trusts and health boards that provide paediatric hepatology services work within a clinical network.

2. All hospitals have access to specialist gastroenterology, hepatology and nutrition advice by telephone with adequate capacity for transfer to the tertiary centre 24 hours a day 7 days a week to ensure access to services are equitable and designed across geographical, political and NHS/health board boundaries through the network.

3. Transition planning is documented and agreed by the child, the paediatric team and adult services. Transition policies and pathways are published on trust and health board websites.

4. Paediatric endoscopies must be undertaken in a child-friendly environment with appropriate facilities. For children presenting in an emergency, timely access to endoscopy must be available through clear and agreed pathways within the network.

5. Children with suspected inflammatory bowel disease are seen by a specialist service within four weeks in an age appropriate facility by a multi-disciplinary team and reviewed regularly as required within the network.

6. Children who require specialist dietary treatment have a named paediatrician and access to a specialist paediatric dietitian as part of a multi-disciplinary team to ensure their nutritional requirements are met.

7. Children receiving inpatient parenteral nutrition are reviewed at least once a week by a multi-disciplinary nutritional care team to include a paediatrician with experience in parenteral nutrition, paediatric dietitian, parenteral nutrition pharmacist and children’s clinical nurse specialist with knowledge and experience in nutrition support.

8. Children receiving home parenteral nutrition (HPN) are cared for by an intestinal failure or designated HPN unit with a multi-disciplinary nutrition team.

9. The gastroenterology network is linked to a lead specialist centre for hepatology with agreed patient pathways, access to specialist hepatology advice through their on-call rota, outreach clinics and shared care arrangements.