



British Society of Paediatric Gastroenterology Hepatology and Nutrition

**Newsletter**  
**January 2021**

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***President's report 2021***

***Dr Sue Protheroe***

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

Dear members

I hope this newsletter finds you and your families in good health. The newsletter is an opportunity to harness the achievements and the challenges of the previous year. As we moved into 2020, it was impossible to know that we would be facing this unprecedented health crisis. As I write, the pandemic threatens to overwhelm our health and care system. BSPGHAN members have been redeployed to adult units, put themselves forward in alternative roles to support others, to be vaccinators and so on. Thank you. We are proud of you.

The impact on us, patients, families, education, livelihoods and socialisation is profound. Covid 19 continues to create so many other challenges. It was apparent that the pandemic amplified difficulties faced by those with vulnerabilities or are most at risk from anxiety, mental health issues, homelessness or loss of work. The damaging long term consequences of lack of face to face contact among young people and education may have long reaching effects.

There is much to do in 2021 to tackle disadvantage and support the mental well-being of our patients. COVID-19 has sadly shown that colleagues and patients from BAME communities have been disproportionately affected by COVID-19. Acknowledging and actively mitigating health inequalities is rightly high on our agenda. Additionally, the need to tackle discrimination of any kind.

As President, I have valued the contact, collegiality and commitment of BSPGHAN members. Particularly thanks go to Executives, Lucy and Mansoor, and Carla for their support this year.

The Society exists to bring members together. Access to education and research learning is challenging as services and research may be paused. Hence, it was such a hard decision to postpone the Annual Meeting. The virtual forum was designed to give us a unique opportunity to celebrate friendships, talents and achievements of our Society. The heart of BSPGHAN is made up of all our members sharing cohesiveness, a common purpose and being stronger when working together. It became more important to focus on mitigating the effects of the pandemic, ensuring fair access and keeping people rested. We are getting tired, so it was important to reschedule the meeting for when times are better. We will come back together, even if it's not in the usual way. We are delighted to offer new for 2021 dedicated symposia for AHP members, Trainees and PeGHAN members. The main meeting will be a unique opportunity to see the talents of the Working Groups who have all prepared innovative programmes.

It is a credit to our members resilience, resourcefulness and continued passion that the vast majority of Society activities have carried on. This couldn't have happened without the ingenuity and willingness of Kwang Yang Lee and Carla to facilitate new ways of working. Do take the opportunity to put yourself forward to join a Group. I can promise that you will benefit. This year, more than ever, linking up with people and helping out to achieve a common goal will offer that important "feel good factor."

Please see the varied Society activities in this newsletter:-

- We are extremely fortunate to have active Co-Chairing from Jo Brind and Lindsay Hogg, who ably represent Associate members including nurses, dietitians, speech and language therapists and psychologists. For the first time in 2021, Jo, Lindsay and team had planned an exciting Associates Symposium to precede the main BSPGHAN Annual meeting. It will be worth waiting for this opportunity which will be rescheduled later this year.
- Himadri Chakraborty been brilliant at ensuring inclusivity and active participation in the working groups of the society. The group numbers 78 members. I am grateful to Himadri and CSAC for updating the SPIN competency framework curriculum which will come into force soon. Himadri and colleagues had put together a marvellous symposium for PEGHAN members, preceding the Annual Meeting. This is eagerly awaited when the 2021 virtual Annual meeting takes place
- Thank you to Trainee Chair, Neil McConnell for arranging the well-received virtual meeting for trainees In August. It was marvellous that it captured so many trainees' presentations. The trainee's symposium preceding the Annual Meeting will be exciting and interactive.
- Special thanks go to David Campbell for his enthusiasm and innovative ideas chairing the Research Committee & Joint BSPGHAN / NIHR –Research Working Group. BSPGHAN has been awarded a status of National Institute for Health Research (NIHR) non-commercial partner. Appropriate research studies funded through BSPGHAN's eligible funding streams are now automatically eligible for NIHR Clinical Research Network support.

David will be stepping down from council after the AGM. I would like to thank David for his vision to encourage and promote the recognition of new researchers with the BSPGHAN research Prize. A BSPGHAN Systematic Review Fellowship prize is coming soon. Thanks to Marco Gasparetto for stepping forward and we will ask members to ratify Marco as incoming Research Chair at the AGM.

- Akshay Batra continues to ably lead many workstreams on the Nutrition and Intestinal Failure Working Group. Akshay has pulled together some key projects and has ably led on advice on the NHS E HPN Commissioning Framework, making sure that our patients voices are heard, and needs are represented. We look forward to forthcoming consensus based guidance on our website.
- Thanks to Loveday Jago for successfully reinstating the Education committee. Loveday has worked hard to oversee arrangements and governance of the new educational activities of the society as well as guiding the abstract selection committee for our Annual Meetings.
- Special thanks also go to Babu Vadamalayan who steps down as Endoscopy Chair. Babu has steadily steered the group and set the scene well for the next incoming Chair. Liaison with The JAG is increasingly important with a vision to refresh the PGRS to align with paediatric specific quality standards, facilitate pNED, and update scoping recommendations for trainees.
- Chris Spray has ably chaired the wide portfolio of Gastroenterology working groups and has provided helpful input this year. Thanks to Chris, Ed Gaynor and Thankam Paul for representing the Society when the Snomed work is required.
- We took the opportunity to invite WG Chairs to our virtual October Council meeting for the first time. It was enlightening to hear their plans so that we can better support their work. Please remember that the Groups unique talents will be showcased during the 2020 virtual annual meeting. I hope it will encourage you to get involved.
- Special recognition goes to Mohammed Mutalib who stepped down as Motility Chair. Mohammed managed to achieve a considerable portfolio of completed work and notably published position statements on pH impedance and anorectal manometry. Thank you to Mohammed and a warm welcome to Eleni Athanasakos who will bring her expertise as a clinical scientist to the group.

- I am very grateful to our IBD working Group Chair Jochen Kammermeier and his committee for their work driving forward timely Covid advice for IBD patients. Ambitious plans to achieve their vision to improve care with a PIBD network are eagerly awaited and the national PGHAN audit will help with this.
- Thank you to Peter Gillett who has enthusiastically taken on multiple streams to advocate strongly for patients with coeliac disease. Peter steps down as Chair in 2021 and must be thanks for his tireless hard work and achievements.
- We have two new Working Groups. The EoE working group, has an ambitious workstream ably chaired by Marcus Auth with a view to leading on producing national standards of diagnosis and management and research.
- Thanks go to Tassos Grammatikopolous who chairs both the Hepatology Steering group and is leading the new Pancreatitis working group. mapping existing local/regional referral pathways and clinical networks. They will write a step by step investigation protocol. Thanks to Tassos who pulled together national Covid advice for hepatology patients.
- I share many people's sentiments when I acknowledge our Webmaster Kwang Yang Lee's considerable effort, which was truly astonishing during the pandemic. It was clear that trainees were struggling to access education and that we needed to step up and deliver our educational syllabus virtually. Kwang Yang Lee picked up the challenge with the vision of providing the most comprehensive PGHAN education series platform across Europe. I think that this was achieved. By March, the BSPGHAN Education series was live and also available on demand and website hits increased. The on-going series of webinars offers CPD for trainees, associates and all members and overseas friends.
- Thanks to the able group of trainees and consultants who have stepped forward to offer their time and talents to help their peers maintain their learning.
- Kwang Yang Lee has also given his time freely to redevelop the website. Members can now access guidance at any time. Council will ensure that we have a robust strategy to sustain this progress.
- Thank you for Paul Henderson who handed over as Twitter Lead to welcome to Joe Chan who has taken over.
- Welcome to Tony Lander and thank you for stepping forward to represent BAPS. Tony an important link with surgical colleagues to work on joint initiatives and perhaps BAPS will join us again at a forthcoming face to face annual meeting.
- We are delighted that Sarah Sleet has been co-opted to Council as PPP representative. Links with a wider range of partners is rightly growing. The pandemic highlighted the excellent work of our charitable partners in supporting families; filling in gaps with sensible advice where specific guidance didn't exist if the health service hadn't been able to respond. The charities have faced unique funding difficulties and we will continue to reach out to see how best we can support them.
- Heartfelt thanks to all who have produced and rapidly shared information this year for the benefit of members. We need professionals who share relevant and coherent information. Mark Beattie has worked tirelessly this year this year to disseminate evidence rapidly to ensure a clear approach UK wide.
- As CSAC Chair, Mark and his team have kept in touch with trainees to support their progress. Training has been disrupted with a loss of the usual learning opportunities, particularly where endoscopy procedures and clinics have not taken place. As clinical services are restored, the

urgency to deliver on the backlog of elective care may compromise training opportunities. BSPGHAN will work hard to support supervisors to keep our trainees on target as much as possible, particularly where the skillset of a procedure needs to be acquired. Training will catch up. Rulla Al Araji has worked tirelessly as Trainee representative. Thank you Rulla.

The year has been notable for positive things-

**There have uplifting stories of people looking out for each other and pulling together with acts of kindness. Teams continue to be resilient in dealing with patients' needs and concerns.**

1. We know now that very few children and young people are at highest risk of severe illness due to the virus. It was pleasing that many children and young people who were initially advised to shield did not need to continue to do so after August and returned to school as it reopened. It became clear that the benefits of school – in terms of access to education, peer support, therapies for some and developmental support – far outweighed the risk of infection for the majority.
2. The speed of the scientific community in developing Covid19 vaccines
3. Harnessing better ways of working will be important to maintain as we resume work and catch up activity. We need to do some things differently and consider new approaches, taking opportunities to reset the way we work. Thank you for taking the time to respond to the Survey Monkey earlier this year to capture any beneficial clinical changes and share innovation to reset services. This can be repeated to see how services are resetting.

#### **What BSPGHAN has done in 2020?**

I am proud that the challenges presented by COVID-19 have been met with resilience by the talented members of our Society.

- We have rapidly adapting to **virtual communication** and freely sharing information has been an important responsibility. The Society led on providing professional advice as the evidence base emerged. We contributed towards national policies such as the RCPCH Guidance on Shielding to inform chief medical officers and an Update for Children who are Clinically Extremely Vulnerable. It wasn't straightforward to produce the update with the uncertainty of what the releasing of lockdown/ school return would mean.
- I hope that the **BSPGHAN website** can help you find guidance that you need to help you feel as safe as possible, allow remote peer support and provide clarification if existing advice is not clear. Bulletins have aimed to reach out to those who may not have peer support networks. We are watching the impact of our new site; its content, membership activity and engagement. It remains an important objective to develop a continuously improved website and online education.
- The pandemic has meant that **delivering and hosting educational events** is difficult. Advancement of research and clinical practice continues to be a priority. One of the spin offs from the pandemic has been the shared learning opportunities rapidly for the benefit of all. BSPGHAN Trainees have interact and at weekly Zoom teaching sessions to make up for lack of opportunities to meet their requirements in the expected way.
- We have consolidated an affiliation with **Frontline Gastroenterology**. This arrangement offers an exciting opportunity for BSPGHAN members to receive free access to the online journal as a benefit of membership via the secure member area on the BSPGHAN website. Frontline Gastroenterology is especially interested in articles on multidisciplinary research and care, focusing on both retrospective assessments of novel models of care as well as future

directions of best practice. The journal also publishes articles in the domains of clinical quality, patient experience, service provision and medical education.

We can offer the opportunity for publication of poster abstracts from the BSPGHAN Annual meeting in the journal.

Look out for a dedicated session introducing Frontline Gastroenterology at the 2021 virtual BSPGHAN Annual Meeting. .

- Thank you to each centre for completing the **BSPGHAN RCPCH Quality Standards Audit**. It's timely to map our services now as the NHS in England moves towards (following the devolved nations) in developing Operational Delivery Networks in 2021/2. BSPGHAN is ahead of the game in taking stock. This will enable support for our networks in the UK to develop best and equitable delivery of care. John Fell, aided by Ed Gaynor has capably steered the Quality Standards working group audit. This was paused but has been Important for the Society to remain engaged in the professional health care agenda and we decided that the BSPGHAN\RCPCH Quality Standards audit should go ahead last autumn. We have successfully mapped UK specialty networks and looking ahead, we hope that on-going targeted data collection will bring about change management in line with BSPGHAN QS.

**The deadline has been extended for one more week to give the opportunity a few Trusts to complete their return.**

- BSPGHAN has joined the **ESPGHAN Quality of Care (QoC) Initiative**. This was introduced at the National Societies' President's meeting last October. The aim is to create a network of health care professionals across Europe to improve the care of children, identify the existing barriers, causes for country-differences e.g., due to health care structure and funding, availability of staff, training conditions etc., which may give a chance to address and improve existing challenges and the care for European children. The initiative will approach individual centres with BSPGHAN as the link.
- Congratulations to Peter Milla has been nominated for a UEGW Lifetime Achievement award.

I would like to thank you for reading the reports; for your friendship, and for engaging so that we best represent you.

Welcome you to our **AGM on Wednesday 27<sup>th</sup> January 2021**.

Please send questions in advance to [Convenor@BSPGHAN.org.uk](mailto:Convenor@BSPGHAN.org.uk) so we can pay attention to your queries.

We look forward to what 2021 will bring- collectively moving to a time where everyone can feel safe. The pandemic seems unrelenting and it's hard to unwind, but we are resilient. Look after yourselves. Kindness and compassion are key; remain positive despite the difficulties. The pandemic will end. We will come out of this.

Sue Protheroe, President  
January 2021

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**Convenor's Report**

**Dr Lucy Howarth**

[Convenor@bspghan.org.uk](mailto:Convenor@bspghan.org.uk)

This has been an extraordinary year full of challenges and opportunities for learning. I have been so impressed with how our society has pulled together to support each other, lead the way with guidance of how to best support our patients through this COVID 19 crisis and deliver an amazing online education programme to provide much needed CPD and support trainees with their training. Huge thanks go to Kwang Yang Lee for his brilliance at setting up the web site and leading the way with the BSPGHAN zoom education programme, Carla for her tireless administrative genius and all those who have given excellent teaching.

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I am sure that everyone would agree that Sue Protheroe has been a most exemplary leader for us all and I would like to formally thank Sue for all her extraordinary behind the scenes hard work to ensure regular, relevant news letters have been circulated to members and who has continuously been at the forefront of national decision making regarding how best to protect our patients and to ensure that patient needs and safety of staff is at the forefront of all decisions made.

BSPGHAN is a vibrant, growing society that continually changes and rises to the challenges that are presented to us all. We hope and aim for members to feel represented by those on council, on working groups and CSAC and would encourage all of you to put your selves forward for roles as they come up.

I would like to thank all of those who put their time and energy into BSPGHAN council, the working groups and on CSAC and have been greatly impressed with how well everyone has adapted to going onto virtual platforms and risen to the challenges of “keeping calm and carrying on”. While some projects have rightly gone on hold during this dreadful global pandemic much work has continued in all working groups to ensure continued excellence in all areas of PGHAN care is maintained and adapted to the changing needs of our patients during this pandemic. So many condition specific guidelines have been published by our members in response to the COVID pandemic. We are very lucky to be part of such a cohesive, highly motivated, intellectually curious group of like-minded health professionals.

I am delighted to report a healthy growing membership of the society and a hugely increased number of hits on the website. I suspect I speak for us all when I say how much I look forward to meeting all our new members face to face properly. From reading their cv's we have been joined by numerous impressive health care professionals with a shared love of all that is PGHAN. You are all very welcome. It is sad to think that new members will not have the glowing memories of past BSPGHAN winter meeting gala dinners that are usually the highlight of the BSPGHAN calendar and keep us all going. I suspect that once we are all vaccinated and allowed to party it will be a good one!

I am delighted to report that negotiations with BMJ and BSG about the proposal for BSPGHAN to formally affiliate with Frontline journal have come to fruition and members will now have free access to this excellent and relevant journal free of charge on the website as part of their membership of BSPGHAN. This will be an excellent educational resource and will be the go to journal for publication of important BSPGHAN guidelines and academic output from our working groups.

Change is always hard but rightly the time that members can stand on working groups is limited in the terms of reference for each group. This means that exciting new roles have come up and great candidates have put themselves forwards and the results will be announced later. The energy of BSPGHAN comes from its members and new blood coming onto council, onto working groups and as members is crucial to staying fresh and relevant; equally the expertise of senior members is also crucial and highly valued to ensure continuity and prevent any reinvention of wheels.

It was really enjoyable to work with the paediatric nephrologists to co-chair our joint session for the postponed RCPCH spring meeting in Nov 2020. This was one of the first virtual meetings and helped give us the confidence that it is possible to hold high quality academic conferences on line. The attendance of this session was over 300 people and the feedback was very good. The next RCPCH joint session will focus on gastro problems in children with Down's syndrome and will be held jointly with BACD and DSMIG. Please get in touch if this is an area that you have a particular interest in and would like to be involved. There will be a call out for abstracts soon.

I represented BSPGHAN on the RCPCH specialty board meeting in Nov which gave an interesting insight into all the ways in which the RCPCH has responded and changed as a result of the pandemic and the way in which they have ensured children get a voice with, for example, the letter they sent highlighting the adverse effects on so many young people of services closing and ensuring that future school closures would be an absolute last resort. The RCPCH have also effectively supported the ongoing provision of free school meals. There are a number of issues that are under discussion by the speciality board that are highly relevant to BSPGHAN including clarity about chaperoning practice in paediatrics as the GMC guideline is not practicable for paediatrics. Work is also ongoing into advanced BSPGHAN Annual Newsletter 2021

life care planning in paediatrics and there will be a nutritional element to this that we will be asked to input into.

As I am writing this the shifting sands of the COVID crises continues and it has become clear at the 11<sup>th</sup> hour that the 2020 virtual meeting will not be able to go ahead as planned. I know how much work will have gone into this meeting and would like to thank everyone involved for their amazing, think outside the box, can do attitude to jumping all the hurdles in planning this exciting meeting and coping admirably with the great disappointment of postponement.

It looks like 2021 will be all about resilience, flexibility, compassion and resourcefulness. I think we are well equipped to get through it together and emerge fully intact (and vaccinated).

**Dr Lucy Howarth**  
**BSPGHAN Convenor 2020 – 2023**

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**Treasurer's Report**  
**Dr Mansoor Ahmed**  
[treasurer@bspghan.org.uk](mailto:treasurer@bspghan.org.uk)

**Current Bank Balance:** To secure BSPGHAN's funds and to generate additional income to cover some of its running costs, we have opened additional savings accounts in two separate banks. Our intention is to eventually split the savings securely in three separate bank accounts. As of 17<sup>th</sup> January 2021, balances in these accounts totalled £350,834.13 as follows:

£240,646 (Lloyds current account)

£10,000.13 (Lloyds savings account)

£100,188 (Nationwide savings account)

**Statement of accounts for 2019-2020:** Approved by the council on 20 October 2020, these have been filed with the Charity Commission together with its Charity Annual Return. The accounts will be presented to members at the January 2021 virtual AGM and copies can be obtained from the Charity Commission website using the Society's charity number 299294.

Summary of last 3 years account balance is outlined below.

	<b>2017-18</b>	<b>2018-19</b>	<b>2019-20</b>
<b>Income</b>	214141	230744	196011
<b>Expenditure</b>	201691	228281	193079
<b>Net Income</b>	12450	2463	2932
<b>Total Funds</b>	294983	297446	300378

**Frontline Gastroenterology:** Free online access to Frontline Gastroenterology for all the BSPGHAN's members has been a recent triumph. This will incur additional expenditure of £20 per member per annum. It is likely that VAT therein may also be payable and not recoverable. Overall, this will amount to £20 x 455 = £9,100 per annum (excluding VAT) on current numbers, excluding overseas and honorary members.

**BSPGHAN annual membership fee:** This has not increased since 1 April 2013. The Society needs to consider a review of membership fee to cover additional expenses incurred as a result of free online access to Frontline Gastroenterology.

The current annual fee schedule is:

- a. Full members £100
- b. Associate members £20

- c. Overseas members £33
- d. Honorary members £00

New direct debit set up arrangements have been streamlined in conjunction with L&Z which will ease pressure on the BSPGHAN admin team.

Current BSPGHAN membership numbers totalling 461 include:

- i. Full members - 304
- ii. Associate members - 138
- iii. Overseas members - 9
- iv. Honorary members - 10

**Research Spending:** COVID-19 has had an adverse impact on research globally. It has also hit various charities and their income unfavourably. BSPGHAN research spending was suspended in 2020 to pay for QS RCPCH audit at a net cost of £15,587. The majority of the input VAT thereon of £3,117 was recovered by virtue of the Society's partial VAT Registration.

A) BSPGHAN payments made towards research spending during the last 3 years is outlined below.

2018-2019: £54,000 - Guts Charity and CLDF paid  
 2020-2021: £6,000 – Acute GI Bleeding Survey claimed

B) BSPGHAN Innovation Grants:

2019-2020 £13,375 claimed and £10,000 remains to be claimed  
 2020-2021 £10,000 Health Touch and e-BANS paid

In the research arena, BSPGHAN would value your suggestions for 2021 and beyond.

**Brighton annual meeting 2020 (Brighton):** This meeting turned out to be a huge success.

Total profit = £48,810

Host's	share	(25%)	=	£12,202
BSPGHAN's	share (75%)	=	£36,608	

If BSPGHAN decides to hold an annual virtual meeting in 2021 without relying on sponsors, it will sustain a loss in the setting up and delivery using a virtual meeting platform. The costs, however, can partially be offset by savings made as a result of no expenses incurred during virtual meetings held by various working groups and council meetings since March 2020.

**Supporting national educational meetings that are arranged for BSPGHAN members:**

It has been agreed that BSPGHAN pledges £5,000 pa (max of £2,000 per meeting) to support national educational meetings as per approved SOP. No pledges were made in 2020 due to COVID-19.

**One Drive:** BSPGHAN has secured "One Drive" access to safely store all its past, present and future data. The task will be completed in the near future.

**VAT Registration:**

**Thursday 27th**

With support and guidance of Mr Peter Hill (Society's accountant and Independent Examiner), BSPGHAN is now registered for VAT under the partial exemption method. This allows the majority of input VAT incurred by the Society to be recovered although this does mean that the majority of the Society's income, other than membership income, is liable to charge 20% output VAT.

**Expenses claim forms:** New expense guidelines and claim forms have now been ratified and are available on BSPGHAN website. The whole process is almost electronic and BACS payments are made swiftly in the claimant's bank account.

**Uncashed cheques and unclaimed expenses:** BSPGHAN had a historic backlog of uncashed cheques issued several years ago in addition to a few unclaimed expenses. We have managed to track down most of these BSPGHAN members and have paid monies in full. A few members have been inaccessible despite our best attempts to contact them via various platforms, and we propose to donate these monies to charities of BSPGHAN's choice.

Special thanks to Mrs Carla Lloyd for her amazing administrative assistance, to Ms Sam Goult for her scrupulous support as assistant administrator and to Peter Hill for providing sound advice and preparing BSPGHAN Annual Newsletter 2021

the accounts. I would also like to extend my appreciation to BSPGHAN's executive (Sue Protheroe and Lucy Howarth) and its council members for their input and suggestions over the past year.

**Dr Mansoor Ahmed,  
BSPGHAN Treasurer, 2020 – 2023**

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### **Committee and Group Reports:**

**Gastroenterology Chair Report  
Dr Chris Spray**

#### **Chair of gastroenterology Report January 2021**

It has been a busy year with many changes in practice due to COVID – 19 pandemic. However, all WG's have remained active. The development of BSPGHAN website was instrumental in enabling specialist guidance available to members of BSPGHAN and patients and their families. Virtual meetings have become the "norm" but an agreeable way of working for the majority of the time. It has enabled me to join many of the WG meetings.

I would like to thank all the WG for all their hard work, usually their own time, during this difficult time over 2020 in supporting their colleagues and patients/carers with updated current advice throughout, working in partnership with associated patient support groups, BSPGHAN and RCPCH

#### **Gastroenterology Working Group Annual Reports 2020:**

**BSPGHAN Coeliac Working Group  
Peter Gillet (Edinburgh) – Chair**

**Chair: Peter Gillett, Royal Hospital for Sick Children, Edinburgh**

Peter Gillett and BSPGHAN have finalised a TOR for the group. PG remains Chair and Siba Paul (SP) is the secretary.

#### **Activity:**

The WG works actively in partnership with the patient support group CUK and there was a large group of professionals who met face to face in London in 2019 with CUK.

This also was to have paediatric input for the May 2020 campaign material for the awareness week and to discuss the (at that time unpublished) 2020 ESPGHAN guidance.

The group has drafted a response / commentary on the ESPGHAN 2020 guidance

#### **Impact of COVID – 19:**

COVID has done two things - it has reduced the number of children presenting to medical profession as new coeliacs and provided us with real challenges in assessment, with some pragmatic views on no biopsy diagnosis (i.e. Many just put onto GFD and for discussion re rechallenge in the future).

Some group members have been involved in national advice via CUK re COVID and risks of hyposplenism and pneumococcal infection and other immunisations (like Flu A).

Peter Gillett has been involved in the adult guidance pragmatically moving to no biopsy (BSG June 2020). Scottish adult centres are now fully adopting the ESPGHAN no biopsy guidance in symptomatic

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patients due to a follow on project from the Scottish Govt test of change project in CD (published Sept 2020)

Siba Paul (SP) has published on the adult experience in SW England (Frontline Gastroenterology).

PG has encouraged members of BSPGHAN to join the Coeliac SIG of ESPGHAN and it is clear BSPGHAN members filled in the ESPGHAN survey of awareness / practice in CD which is yet to be published, with 80 responses from the UK (4th largest group reporting within ESPGHAN).

The group has not met since BSPGHAN Jan 2020 as a face to face meeting in Brighton Jan 2020. The group will present an hour's session and highlight some controversies / action points for research on 28th Jan 2021 as part of the annual BSPGHAN meeting to be held as a virtual meeting, Birmingham

### **CUK awareness week:**

May 9th to 15th May 2021 will focus on children under age 11. Many WG members provided interviews about CUK questions on kids and will play a part (we hope ) in the week's informatics.

2021 is a potentially exciting year with this, and the ESPGHAN follow up and dietetic guidelines due for submission soon.

BSPGHAN should comment on these in a UK context when the time comes.

There is a resurgence of interest in CD but many unanswered and pragmatic questions - amongst these are the real utility of DQ typing in at risk groups, selective IgA deficiency and CD, follow up bloods, complications of CD, who should see and assess patients (dietitians or medics or both), the use of video and phone and virtual consultations, and preparing young people for independence. The cost and impact of lack of prescription items (England) / financial issues of CD and the psychological impact of the condition.

SSPGHAN has a 2021 online incidence study due to start in the new year to capture new cases of CD and to springboard research as part of this cohort.

I have contacted the PeGHAN group (SP also a part of this) to see if there would be any interest within DGHs (and tertiary centres too if interested) in trying to achieve actual patient numbers and determine practice across the UK. This may be aspirational indeed! The goal would be a national registry to properly research this condition (as in the Spanish registry) but it may just be a dream rather than ever being a reality.

### **Forthcoming plans:**

The CD WG needs to re-focus on key directions for practical research and how we can meet up virtually (as this will be the way forward) in order to delegate workstreams and projects as a UK group.

The promotion of expert dietitians in the management (from diagnosis onwards) is to be promoted. The utility and expertise of dietitians in management should be strengthened and the model of care (in my view) needs to be shifted from medical staff to dietitians with medical knowledge of the condition, with a go-to local / regional lead. This is what we essentially have in Scotland.

Paediatric Gastroenterologists should continue to advocate for patients and to lobby for NICE to change their mind on the updating of NICE NG20 (which they declined to do in late 2019), and to work more closely with adult coeliac-ologists in how we manage young people, as transition does not, in reality happen.

Engagement with the RCGP and CCGs on how best to deliver gluten free items if prescriptions are available. The Scottish system where patients manage their own prescription with their pharmacist. to

me remains an optimal model for such a system (if it exists) and may take away the need for GPs to manage this, which has always seemed odd to me. This is too high a political issue, I think, to ever happen in England but seems pragmatic and patient friendly. The impact of this system on those on low incomes with more than one family member must be financially significant and have adherence implications. I raised this with the RCPCH early in the lockdown when GF bread was popular with non coeliac, and thought it might interest RCPCH but it appeared to fall on deaf ears. I still think this is something that should be pursued.

A new chair will be required in 2021 after PG stands down as chair after BSPGHAN 2021. I would like to get our commentary on ESPGHAN submitted before I do this.

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### **BSPGHAN Motility Working Group**

**Chair: Dr Eleni Athanakos, The Royal London Hospital**

BSPGHAN would like to thank Mohamed Mutalib for his hard work over the last few years as Chair of the WG.

We would like to introduce Eleni Athanaskos as the new Chair. She has extensive experience in motility both clinically and in research. She is director of Children's Anorectal Physiology Service (CAPS), Lead Paediatric Clinical Scientist, The Royal London Hospital; Honorary Senior Research Fellow, the Centre for Genomics and Child Health within the Blizard Institute at the Barts & The London School of medicine & Dentistry

#### **Impact of COVID – 19:**

In 2020, WG was active producing guidance in relation to appropriate investigations in patients during the pandemic. Some of the standard tests for example pH/Impedance studies are considered aerosol generating procedures. Guideline published on BSPGHAN website.

#### **Publication:**

The WG successfully published a consensus for anorectal manometry in children with defaecation disorders in Neurogastroenterology and Motility (Jan 2020). The WG was invited to do a podcast for the journal.

#### **Future plans:**

##### **To produce evidence based guidelines for the common GI motility investigations:**

Colon radiopaque transit markers studies (18 - 24 months)

Oesophageal manometry (12 months) - particularly impedance .

##### **To produce evidence based/consensus based clinical guidance for the management of GI motility disorders:**

Rumination syndrome (12-18 months)

Intractable constipation and faecal soiling (18-24 months) .

To organise teaching/training about GI motility investigation

During annual BSPGHAN meeting (when possible)

Standardise teaching/training in GI physiology

Long term aim: to conduct/participate in research to advance the understanding and clinical utility of GI motility disorders in children

## **BSPGHAN IBD Working Group**

**Chair: Dr Jochen Kammermeir, Evelina Hospital, London**

### **Meetings in Jan 2020 (FTF), April 2020 (virtual), July (brief/virtual) 2020 and October 2020 (virtual)**

During evolution of pandemic and collating evolving evidence of the impact of the virus on children with IBD treated with/without immunosuppression, the IBD WG has been actively involved producing written position statements with BSPGHAN and RCPCH for clinicians and patient/carers during COVID – 19, April 2020 – ongoing keeping fresh updated guidance with the change in situation and government guidelines.

#### **Publications:**

PIBD WG led/involved in 2 publications with colleagues:

guidance re diagnosis of children with IBD, during lockdown without access to standard investigations resulting in publication in **Archives of Disease of Childhood**: Impact of Covid – 19 on diagnosis & management of paediatric inflammatory bowel disease during lockdown: a UK nationwide study, (Ashton JJ. Arch Dis Child 2020,0:1 – 6).

Adaptations to the current ECCO/ESPGHAN guidelines on the management of paediatric acute severe colitis on the context of COVID – 19 pandemic: a RAND appropriateness panel **Gut** (Richard Hansen et al, Gut Sep 2020)

The IBD WG has been actively involved in setting up a survey to review IBD transition services across the UK with manuscript submission pending.

#### **Other research with pIBD WG leadership/involvement:**

UK-wide survey: Transition services for paediatric inflammatory bowel disease; a multicentre study of practice in the United Kingdom (submitted)

Other BSPGHAN work:

SNOMED CT - Representation of pIBD WG (Dr Thankam Paul)

Ongoing work on pIBD training syllabus (Dr Rafeeq Muhammed)

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#### **EoE Working Group:**

**Chair: Marcus Auth, Alder Hey Children's Hospital, Liverpool**

EoE group first met Jan 2020 at BSPGHAN as FTF. It has been a very proactive group too, involving patient support groups within its membership, enabling consistency of guidance for clinicians, patients and their families. Have held 3 further virtual meetings throughout 2020.

Members of the EoE WG took part in EoE awareness week in March 2020 answering questions posed by patients and their parents and produced short video clips on behalf of EOS network

EoE WG have also produced guidance for patients and clinicians in relation to diagnosis and treatment of patients with EoE through the COVID – 19 pandemic.

EoE WG has links with European EoE WG, GAP and national allergy group BSACI.

Review of national EoE service in UK via survey – with a view to leading on producing national standards of diagnosis and management.

## Research Involvement:

Many members of EoE WG are involved in multicentred EoE trials:

trial 24 months on safety on budesonide (multi-country/centre)

study on adrenal gland insufficiency; would be valuable to have UK centre to participant

QoL of EoE patients (use questionnaire in steroid vs elimination diet); interesting to check impact of treatment even on short term treatments; DF will check with R&D team for approval in Scotland and UK

non-invasive testing for EoE biomarkers

## Other activities:

SNOMED CT – representation

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**Endoscopy Working Group**  
**Dr Babu Vadamalyan 2018 – 2021**  
[endoscopy@bspghan.org.uk](mailto:endoscopy@bspghan.org.uk)

### 1. Revised P-GRS:

Current GRS is to be modified to fit for paediatric practice, our target is different than adults. Mostly, paediatric endoscopy procedures are done in theatres. Theatres already have established governance structure in place. All procedures & performances are recorded and audited, and it was felt that no need to duplicate this in P-GRS.

The need for revision is proposed to JAG. Also, JAG is not keen to pilot the accreditation pathway until most units have achieved satisfactory P-GRS standards. Finance related to this exercise also has to be re-discussed with NHSE. We need to work together to identify P-GRS criteria that fit for our current practice, to achieve the established standards.

RCPCH and BSPGHAN have worked together, already published on the expected GI standards (January 2017 edition). Revised P-GRS should take these standards into consideration. Revised P-GRS should be achievable and also to be related to outcome of the patient. I had discussion on this also with Dr J Fell, Quality standard committee Chair and Dr S Protheroe, BSPGHAN President. Revised P-GRS should supplement the PGHAN audit to support that over all GI care is provided in a centre that also meets metrics as per RCPCH & BSPGHAN recommendations.

Below are some of the assessment criteria to be included in revised P-GRS

- a) Paediatric endoscopy is a specialist procedure and this should happen in child friendly environment
- b) Paediatric Endoscopy should happen where MDT facility is available to manage chronic conditions like IBD and nutritional issues
- c) Paediatric Endoscopy should happen where surgery / other specialty like histology / radiology is co-located
- d) Paediatric endoscopy should happen in a place where 24/7 support is available for post procedure management by the endoscopy team
- e) Access / experience in therapeutic procedures like polypectomy, enteral feeding support, stricture dilatation and GI bleeding management
- f) Timely access for urgent endoscopy requests
- g) Agreed pathway for GI bleeding –also -for PHT if non hepatology centre
- h) Annual audit-including indications and waiting times
- i) Completion rates of endoscopy-as per the quality indicators

- j) Review of unplanned admission-post endoscopy (duodenal hematoma, perforation and 30 days mortality)
- k) Patient feed back
- l) Evidence of participation in quality improvement programme
- m) Evidence of participating in endoscopy related CPD activities

## **2. P-NED: Paediatric National Endoscopy Database**

P-NED is essential for ongoing service development, training and governance. Its proposed that as a baseline, all centers providing paediatric endoscopy should have electronic reporting system and then to link ERS (endoscopy reporting software) to develop P-NED database. A short survey was done in 2019 and we identified that 21 units (included all tertiary centres except 2) are using one of the 5 endoscopy reporting software (Endosoft, Unisoft, Endobase, EMS and Medilogic) during paediatric endoscopy.

We proposed that -following indicators are to be included in P-NED.  
Discussion with JAG is still ongoing.

- Age
- Weight
- GA/Sedation list
- Diagnostic/ Surveillance / Therapeutic /Combined
- Operator: Paed Gastroenterologist-Hepatologist/ Paed. Surgeon/ or adult Gastroenterologist-Hepatologist
- Procedure count and completion time
- Type of procedure-OGD:Colon: ERCP: Enteroscopy : Portal Hypertension Surveillance /Others
- Duodenal Intubation
- J manœuvre
- Ileal intubation
- Caecal Intubation
- Bowel preparation quality
- biopsy for diagnosis
- polyp detection rate
- Complication during procedure (both procedure and non-procedure related)

## **3. Scoping under 16s & GI bleeding pathway:**

GI bleeding guideline was approved by BSPGHAN for variceal and Non variceal bleeding, this was already published in BSPGHAN website. Council supported strengthening GI bleeding network pathway with closer link to a specialist centre and networking centre to ensure children get appropriate care at the right place during GI bleeding scenario. Availability of surgical support is also paramount in relation to this. Work is in Progress with BSG regarding this.

## **4. Training: JAG certification & colonoscopy:**

COVID had significant impact during 2020, currently both service and training is on hold except that emergency support. Following was agreed Pre-COVID

1. To have paediatric oriented DOPS in JETS than using adult DOPS, this is delayed due to IT support.
  2. Revised the paediatric pathway for JAG certification- This is to ensure "Trainees are provided quality training in the right place".
  3. During 2019, JAG proposed to increase the number needed for Paediatric colonoscopy certification. This was discussed with EWG and CSAC, and it was agreed that current data is not enough to support a magic number, but further work is needed to improve the competency including offering
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minimum 25 training lists a year and encourage trainer to attend TET course.

4. In Jan 2020 BSPGHAN meeting, we recommended that all new consultant GI endoscopists to have colonoscopy certification prior to starting an independent colonoscopy list. This will encourage employing trust to provide support (post CCT training) for new consultants. This will ensure high standard is maintained from the patient point of view. It was also proposed this information to be updated in BSPGHAN website.

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

**Dr David I Campbell**

[research@bspghan.org.uk](mailto:research@bspghan.org.uk)

The Research activity of the Society has continued to expand and develop. Joint research grants have been awarded again as BSPGHAN standalone grants, or BSPGHAN Innovation Grants (BIG), or jointly with our charity partners. We have joined with GutsUK and The Children's Liver Disease, to support high quality, peer reviewed projects via competitive bid.

Projects currently funded or completed 2019-2020:

1. BIG grant Vap-1 transcription in graft hepatitis. Steffen Hartleif Tubingen and Deidre Kelly Birmingham.
2. CLDF/BSPGHAN Grant, "Genome editing in liver organoids and cell culture for therapy in alpha-1-antitrypsin deficiency." Deborah Gill Oxford.
3. CLDF/BSPGHAN Grant "Single cell sequencing to determine bile duct formation in biliary atresia." Luke Boulter Edinburgh.
4. Guts UK/BSPGHAN Grant, "Pinpoint study: Prospective IBD incidence in UK". Paul Henderson Edinburgh.
5. Guts UK/BSPGHAN, "Intestinal Organoid epigenetic sequencing to stratify therapy responses in childhood IBD". Marcus Zilbauer Cambridge.
6. BIG grant: "Reflux scoring in children with CP". Mark Tighe Poole.

These grants and the publications following them will underpin our society's aims to be research focused, providing new data to guide care of children with nutritional, gastroenterological, liver or pancreatic disease. Further joint funding grants are proceeding with Guts UK, where a focus on paediatric gut and liver projects has been launched for target funding in 2021. We are exploring other ongoing funding opportunities and details will follow.

The BSPGHAN Research Prize

An important aspect of the BSPGHAN funding strategy, is to engage members of all backgrounds in research work. Research funding is expensive and we cannot go on expanding the amount of research work that we fund, neither can we reduce our work to promote research to our growing membership. As such we are releasing a new initiative to Trainees, Allied Health Professionals and new Consultants (within 3 years of appointment). The BSPGHAN Research Prize, will be awarded in the Winter Meeting 2021 to the candidate who can present a portfolio of research undertaken, with a focus on publications, projects funded and a resume of academic work over a two year period. There will be a £500 prize plus the award, bestowed at the next Winter Meeting. This award will mark the high value that the society places upon research activity and will be an important esteem indicator to support competitive research bids that we want to support our members in applying for.

In the next year the society looks to further build our research culture by supporting Associate and Trainees meetings, working with our funding partners. I will be stepping down and handing over to a new chair of the RWG, but hope to continue playing my part in building research as an ordinary member. It has been an honour and a privilege to serve in this way.

David I Campbell

**Education**  
**Dr Loveday Jago**  
[education@bspghan.org.uk](mailto:education@bspghan.org.uk)

Achievements this year:

Established the Education working group and held two working group meetings 9<sup>th</sup> Oct 20 and 8<sup>th</sup> Jan 21

First virtual trainees conference

Zoom trainee's education series

Establishment of the masterclass series

Guidelines in password protected members area on BSPGHAN Website

SOPs developed and approved for endorsement of educational meetings; guidelines produced, published or endorsed by BSPGHAN and zoom teaching including code of conduct for speakers and certificate of attendance.

First virtual annual winter conference with show casing of BSPGHAN working groups, highest scoring oral presentations and virtual poster room

Aims for next year:

Continue zoom series and link to curriculum

Continue master class – next one scheduled April 21

Explore options for further on-line learning modules and moodles

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**Nutrition and Intestinal Failure Working Group (NIFWG) of the British society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)**  
**Dr Akshay Batra 2019 – 2022**  
[nutrition@bspghan.org.uk](mailto:nutrition@bspghan.org.uk)

This has been an unusual year with ever changing challenges and strains on the service. I am very grateful to all the members of the Nutrition and Intestinal failure working group who have devoted time despite the pressures of their clinical practice. A lot of the work around this period was related to change in practice because of Covid but the achievements to highlight are:

1. Managing care for children on HPN

Children on HPN were considered at high risk at the start of pandemic. This was because of their significant dependence on healthcare, both through hospital and community professionals. It was not known what the impact of the pandemic would be on the healthcare delivery and it was felt the care to these patients should be protected. They therefore were in the shielding list at the start of the pandemic, with contingency measures to ring-fence their care. NIFWG represented the needs of these children in discussion with NHS England to ensure continued safe and effective care.

It became very clear as the pandemic progressed that they needed to come out of shielding and back in to education. NIFWG produced advice on unshielding for children on HPN in keeping with the government recommendations. Andy Barclay produced an excellent document detailing the evidence and advice, which was shared through a publication in Frontline gastroenterology.

## 2. eBANS

The paed e-BANS database, hosted on an open site, with home enteral tube feeding has now been closed. This is to allow moving children to the secure N3 network where information is hosted along with adult HPN. The new database would be piloted in a few sites before a national launch. The e-BANS team established a contemporaneous database of patients and improved engagement with 77% patient records updated annually over the last 2 years. We would like to thank all contributors from the IF network and Rachel Russell and Enda Smyth (eBANS administrators) who have worked hard to make this possible. A report describing the data collected through the process has been submitted for consideration for publication to Clinical Nutrition. With the establishment of a network of IF centres further sub projects were undertaken e.g. further investigation of number of children on HPN because of ultrashort bowel syndrome and Feed intolerance secondary to neurodisability.

3. The annual Complex Nutrition and Intestinal Failure 2020 meeting was postponed to September 2021 and would be hosted by Cambridge.
4. There has been increased engagement with PINNT who would be best placed to represent children with complex nutritional needs and their families. NIFWG would perform a survey of patients through 3-4 selected centres to better understand the needs of these patients.
5. There are plans to establish a national intestinal failure forum which would be an educational platform to discuss complicated Intestinal failure difficult cases who would benefit from further medical or surgical interventions including transplant.
6. We are in process of producing a decision tree on investigations and management of gastrointestinal dystonia and Andy Barclay is leading on the RAND process.
7. National Intestinal failure Guidelines have now been completed and going through the process of final formatting and review. We are hoping to submit them to education committee for approval to host on BSPGHAN website.
8. Vacancies There are vacancy for the research representative on NIFWG as Natalie Davies is unable to continue in the post because of personal commitments.
9. **BAPEN:** The 2020 BAPEN paediatric symposium was supposed to focus on the nutrition management of IBD. Unfortunately the symposium did not go ahead as the BAPEN conference was not going to go ahead in the original format in light of the COVID-19 pandemic. The NIFWG is hoping that the 2021 symposium will go ahead.

BAPEN membership for BSPGHAN members is free and several BSPGHAN members have already made use of this opportunity.

Jemma Cleminson has joined the NIFWG as trainee BAPEN representative and will work together with Jutta Köglmeier.

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## Website

Dr Kwang Yang Lee

[webmaster@bspghan.org.uk](mailto:webmaster@bspghan.org.uk)

### 1. BSPGHAN main website

Total views website as of 19 January was 43, 674.

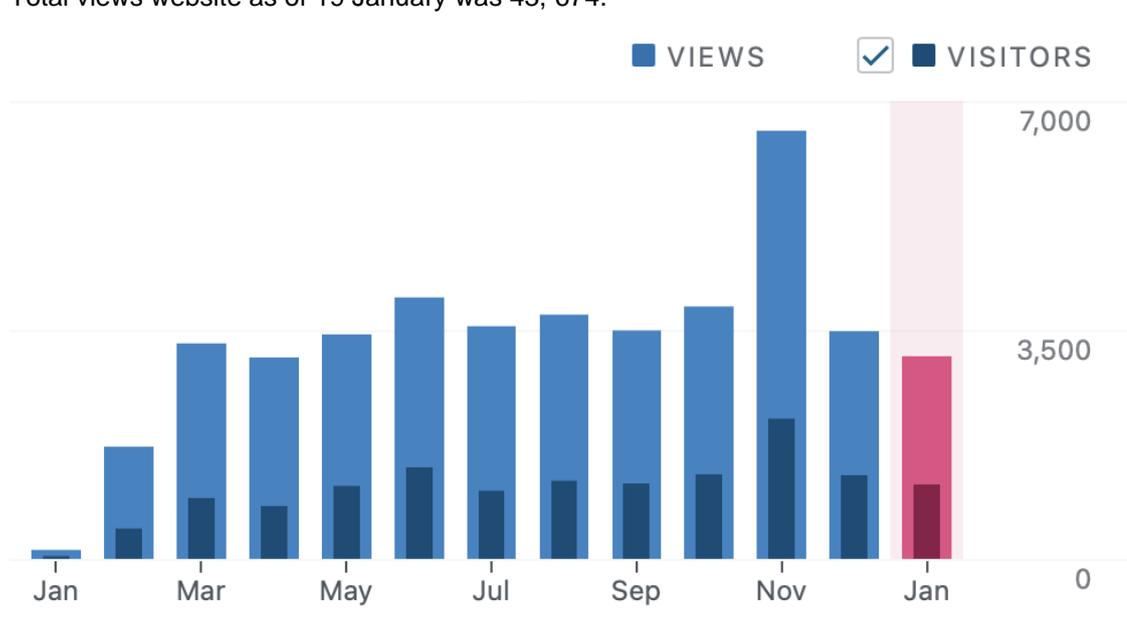


Figure 1: Monthly Website Views in 2020

A secure members area was set up in June 2020 – a total of 461 BSPGHAN members are now registered on the website.

### 2. BSPGHAN Education Series

We have made changes to the format of the Education Series to ensure long-term sustainability. Current set-up is weekly teaching; with the first session each month set aside for liver teaching.

Registration is open to members and non-members; with recordings available to BSPGHAN members only.

The teaching schedule for 2021 can be seen at <https://bspghan.org.uk/education2021>.

#### 2.1 Current Organising Team

We have expanded the number of team members and the current team is as follows:

- Co-ordinators- Kwang Yang Lee, Neil McConnell
- Liver – Chaya Kelgeri (Birmingham), Kavitha Jayaprakash (Leeds), Rob Hegarty (Kings)
- Video Editing- Helen Vanker, David Wands, Laura Kelly, Roxana Mardare
- Session Hosts- Rulla al-Araji, Felicity Beal, Nicola Ruth, Helen Vanker, Kavitha Jayaprakash, Sunitha Vimalesvaran, Harween Dogra, Joe Chan, Hina Rizvi, Kirn Sandhu

From 2021, Neil McConnell will take on the overall direction and management of the Education Series. I will continue to provide support to the series.

#### 2.2 Video Recording

Video recordings of the teaching sessions were started in June 2020 and are uploaded to the BSPGHAN Members Area using Vimeo, a video hosting platform.

Since June 2020, 499 views have been logged for 15 videos. There is currently a backlog of videos awaiting editing.

### 3. BSPGHAN Masterclasses

The first BSPGHAN Masterclass was held in August 2020, with the talk on 'Intestinal Failure- Past, Present and Future' delivered by Dr Sue Protheroe. 92 participants attended the talk, with feedback uniformly positive.

The second BSPGHAN Masterclass was held in October 2020. With the talk on '20 Years of Intestinal Rehabilitation- What do We Know Now' delivered by Professor Christopher Duggan from Boston Children's Hospital. Feedback again was extremely positive with 89 participants attending the talk.

At the Education Group meeting, it was discussed that we would plan for Masterclasses 3 monthly. The next Masterclass will be delivered by Professor Deirdre Kelly on 29 April 2021

### 4. Frontline Gastroenterology

Following the agreement with Frontline Gastroenterology, access to the online version of the journal was set up in the BSPGHAN members area in January 2021.

Kwang Yang Lee

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### ***Hepatology and Pancreatitis***

**Dr Tassos Grammatikopolous 2020 – 2023**

[hepatologychair@bspghan.org.uk](mailto:hepatologychair@bspghan.org.uk)

### **Hepatology**

The Liver Steering Group held their virtual annual CQUIN/Tricentre Audit on 16/09/2020.

Representatives from all 3 paediatric liver centres and NHS Commissioning members participated.

The Audit this year was titled : Clinical practice in treatment of paediatric hepatic haemangioma (1 April 2017- 30 March 2020). As per standard data from 3 centres will be merged and analysed and an investigation and management protocol will be produced.

COVID-19 related issues discussed were:

- reduction in referrals for Biliary Atresia during lockdown
- funding from NHSE home blood testing kits for children with AILD and LT
- impact of 2nd wave of COVID-19 pandemic in paed. Liver services

The COVID-19 Paediatric Liver Management Mitigation Plan is to be revised across the three units by mid-October.

CUSUM outcome reports to be submitted:

- overall survival of patients with BA at 16yrs of age(% alive with or without native liver)
- overall % of patients with AILD in biochemical remission at 16yrs of age

LSG members were updated on Liver Advisory Group (NHSBT) proceedings and discussed:

- revised document on indications for LT in children
- special request process for prioritisation across the 3 paed. Liver centres of children with decompensated liver disease who do not fulfil ALF criteria

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LSG members discussed the proposal to include Non Alcoholic Liver Disease in the UK National Screening Committee. Details will be discussed further amongst the group and BSPGHAN council meeting.

Liver GRID trainees (2) and hepatology clinical fellows (1) participated in the "Trainee's review" session at the end of the LSG business meeting. Vandana Jain (CSAC hepatology training advisor and a representative from each centre participated).

Current online weekly education program was unanimously deemed very constructive from all members. There is also online intradepartmental weekly teaching for all team members.

Hepatology Chair (TG) is in the process of bringing together BSPGHAN members for the new pancreatitis WG-1<sup>st</sup> meeting during BSPGHAN annual meeting

Next meetings

1. Audit /CQUIN+ LSG business meeting TBC (next summer hosted by KCH either virtual or F2F)
2. Next LSG business Meeting (at BSPGHAN)-virtual

### **Pancreatitis**

1. Call for expression of interest has been published and formally closed although as not PeGHAN and Trainee members have not yet come forward. I would like to keep the deadline open and I would welcome BSPGHAN members who fulfil the criteria even at a later stage up until 1 month before the annual meeting.
2. There has been interest from >1 person in some of the positions-selection will be finalised.
3. 1<sup>st</sup> meeting of the group will be during the annual BSPGHAN meeting January 2021.
4. ToR have been finalised and are available for reference.
5. Primary points will be
  - a. -mapping of the existing local/regional referral pathways and clinical networks
  - b. -writing up a step by step investigation protocol
  - c. -contact relevant charities and families aiming to secure engagement and support in this initiative
  - d. -establish a priority list for clinical research topics that will shed light into the management of children with pancreatitis.
6. Further points to be decided after the group's 1<sup>st</sup> meeting in January 2021.

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### **Trainees**

**Dr Neil McConnell, Trainees in Paediatric Gastroenterology, Hepatology and Nutrition (TiPGHAN)**

[trainees@bspghan.org.uk](mailto:trainees@bspghan.org.uk)

Dr Neil McConnell Chair  
Dr Kirn Sandhu, Secretary  
Dr Rulla Al-Araji- CSAC  
Dr Kwang Yang Lee, Endoscopy  
Dr Hina Rizvi and Dr Jeng Cheng, Education  
Dr Elena Volonaki, Motility  
Dr Jemma Cleminson, BAPEN  
Dr James Ashton IBD  
Dr Harween Dogra, Nutrition  
Dr Nicola Ruth, Research  
Dr Kavi Jayaprakash- Hepatology  
Dr Joe Chan- EoE  
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Dr Arati Rao- Coeliac

This year has unfortunately been a year of disruption for us all due to COVID-19. However thanks to the efforts of Dr Kwang Yang Lee and Dr Rulla Al-Araji, the BSPGHAN Zoom Education Series was developed throughout 2020. This initially started with consultants at Birmingham Children's Hospital kindly agreeing to share their local teaching on zoom to a wider group of PGHAN trainees and has now developed into a highly successful twice weekly education series covering the PGHAN curriculum and other topics of interest. This would not have been possible without the efforts of Kwang Yang and Rulla in organising speakers each week and advertising the sessions, and without all the speakers themselves who each have taken time out from their busy units to deliver excellent teaching sessions.

We aim to continue the BSPGHAN education series in 2021 on a weekly basis with registration available via the new BSPGHAN website and recordings of previous talks available in the members section to BSPGHAN members.

We also successfully held our Annual Trainees Meeting over Zoom in September after our usual face to face meeting in May was cancelled due to lockdown. This was well attended and the sessions on the consultant interview and START exam were well received.

The Trainee group also held for the first time a practice GRID interview session for prospective GRID interviewees. This was also well attended and received excellent feedback from the candidates and we hope hold this session annually in the future.

We have a number of posts on the Trainee Committee becoming vacant at this Annual Meeting and are looking for interested Trainees to apply to the roles.

The available positions are:

Trainee Chair  
Endoscopy  
Education x2  
CSAC  
Research  
Nutrition  
BSG  
Motility

I would like to thank Drs Kwang Yang Lee, Rulla Al-Araji, Jeng Cheng, Hina Rizvi, Nicola Ruth, and Harween Dogra for all their hard work and help with the Trainee's committee during their tenures.

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***Paediatricians with an interest  
Dr Himadri Chakraborty 2018 - 2021  
[pegghan@bspghan.org.uk](mailto:pegghan@bspghan.org.uk)***

It's been a very challenging year for all of us and it is compounded now by the fact that our much loved Annual Conference is now indefinitely postponed.

From a PeGHAN point of view , we had a very eventful year . We have managed to rewrite the SPIN curriculum based on the Progress Curriculum. I am happy to inform that we were accepted as the second specialty by College to do so following the proposal we put forward and we finished this in 4 months' time. This is now published on the College website.

I had approved 8 SPIN trainees for their training start and have signed off 5 trainees in the last few months.

I have also managed to complete a database project with one of my Registrars to collate data about all the Secondary care units having a Paediatrician with an interest (PeGHAN) and the networks they work within. This data has now been shared with the Quality Standards audit steering Group.

We have a group of 78 members now and still expanding and we had our own PeGHAN study day this year on Eosinophilic Oesophagitis . We have plans to have similar study days in months to come and aiming for at least 2-3 a year.

This will be my last year as the PeGHAN Chair and I would like to thank all my PeGHAN and BSPGHAN colleagues for all the support that I received in my role.

Dr Himadri Chakraborty  
PeGHAN Chair  
CSAC Lead for SPIN Training

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### **Associate Members**

**Ms Lindsay Hogg and Ms Jo Brind**

[associates@bspghan.org.uk](mailto:associates@bspghan.org.uk)

As we all write our reports to summarise 2020, it would not be surprising to hear across the groups the same language of 'unprecedented', 'disruption', 'overwhelmed', and more positively, 'teamwork'. The Associate Members (AM) committee could certainly apply these words to the year that will historically be remembered throughout the NHS. 2020 was Covid19.

Our main objective for the year was driven by an almost unanimous request from the membership at the AM AGM in Oxford in 2019 – to run the annual training day for AM's as a standalone day still, but as part of the main BSPGHAN winter meeting. The committee had asked the attending AHPs as to why they felt the AM study day (traditionally run in the autumn along with the trainee's) has been poorly subscribed to over that last few years. Long standing issues around getting study leave and/or funding are well known for AHPs, whom which departments often have scant, or no study budget at all. Addressing this, members felt that if the day was 'tagged onto' the main meeting, then the study leave/study costs would be a combined bill, and therefore more appealing to budget holders. This proposal was put the Council, and passed without complaint.

We have welcomed Amy Phipps (pharmacist), and Rachel Wood (dietitian) this year to the committee, to join Sophie Velleman (psychologist), Lindsay Hogg (nurse) and myself Jo Brind (nurse). Together we set about creating a programme for our inaugural day on the main conference. Our aim was to appeal to our delegates by delivering talks at a practical level for treating our most challenging, and yet increasingly frequently seen cases, but also be inspiring by showcasing what AHPs are leading and contributing to the patients and families of children with "GHAN" conditions. Sophie's links to the 'Psychologists with a specialist interest in Gastroenterology' led us to designing an overarching Psychology Theme for the day, and we are very grateful to Sophie for approaching many of the invited speakers.

As the pandemic well and truly crushed any form of normality to 2020, we added C19 talks to our programme, and I personally was proud of the finished programme, and recognise what all the committee contributed. Topics on rumination, addressing body image, creative interviewing with children, and effects on siblings from reduced visiting during Covid must have appealed, as we are informed the day was healthily subscribed to. Proud to run the day we will be, whenever that may be in 2021.

Whilst talking about pride, it should not go unsaid what contributions all the AM committee have given to the pandemic. We scratched together meetings amongst a clinical burden that cannot be understated, and all played our part by taking on additional roles - as varied as vaccination administrators, adult ICU, and redeployment to Nightingale field hospital. Along with the rest of

BSPGHAN colleagues, I'd like to give a big Shout Out to the AM committee for what they have humbly undertaken this year. Well done to you all.

Ms Jo Brind (Co-Chair of the Associates Committee)

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

***PPP report 2020***

***Sarah Sleet, Coeliac UK***

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

**21 January 2021**

2020 was an extraordinary year for everyone, but for anyone working with patients and the NHS it has provided the most profound change to our capacity and approach to supporting patients. All of the charities involved in supporting people with gastrointestinal and liver conditions have faced a major economic shock while at the same time have found their service in more demand than ever before. Many have seen their income drop by a third or more, but have innovated rapidly to meet new information needs and online support in a locked down environment.

We have been humbled by the response from healthcare clinicians in gastro and liver services to the crisis. The switch in mode of delivery of care and the dedication to continuing to provide empathetic care to vulnerable patients has been amazing. And, of course, working with BSPGHAN, to get the right information out, to ensure that the right priorities are reflected in government guidance on shielding and vaccinations has shown how working together, sharing information and perspectives, we really do achieve more for our patients.

And finally thank you to BSPGHAN for the amazing support to our charities especially when it looked like the financial crisis was so profound in the spring of 2020. To provide support to us given the challenges that faced you on the frontline was a light in the dark.

In 2020 we welcomed two new patient support groups to the PPP group – TOFS and EOS Network.

**Reports from individual support groups**

**Cicra**

**Margaret Lee**

Firstly, we would like to offer our thanks to all members of the medical profession for their dedication and commitment. Although maybe not directly involved in COVID care, we know the havoc that is caused by the taking over of wards, theatres, deployment of staff, social distancing and zoom calls. Thank you all.

Our main objective this year, whilst mostly working from home, has been to try and keep things as normal as possible, get information out to parents before they turn to Dr Google, and to be there for those who just want to talk about their fears and worries. Very noticeable has been the amount of parents of newly diagnosed children contacting us from all over the UK. They have been very grateful for the Parent Pack initially, and then the other forms of support we offer such as the very successful EPals scheme for the young people, schools' information and help with their general wellbeing in very difficult times.

At the first lockdown, with the sudden stop on fundraising, there were regular zoom calls amongst the Trustees on the best way forward to protect the longevity of the charity and maintain our Support and Research programmes. I am pleased to say that with careful planning and welcome financial help we have been able to do that. We have also assisted others in the circulation of surveys to help young people with IBD.

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During the year we agreed to fund two new research projects, the Paediatric arm of the UK IBD Bioresource led by Professor Holm Uhlig at Oxford (£100,000) and a project led by Asst. Professor Paloma Ordonez-Mora of Nottingham University 'Targeting a Cxcl10–approach in Ulcerative Colitis' (£50,000) Due to the situation, both have stalled on the start date, but will start as soon as things begin to settle.

Again, due to the situation we have not tried to fill our staff vacancies. Trustees and staff have stepped up and taken on extra tasks to enable us to continue to be there, as and when needed, by the young people, parents and extended family. Also, importantly, to fulfil our remit of funding research into childhood IBD and to offer training for those wishing to specialise in paediatric gastroenterology.

## **Alison Taylor**

### **CLDF**

The charity has managed to stabilise and reconfigure it's offering and ways of working following the hardest year in its history.

Having had to make half of the staff redundant we ended the year 42% down on usual income levels. We are incredibly proud of the staff team who have risen to challenge after challenge.

Services have been reconfigured with peer support and family events happening virtually and one to one support also being offered via phone, digital sessions, email etc.

Over the last 9 months since the beginning of the pandemic we have provided;

- 30 detailed guidance blogs relating to the pandemic specifically for families and young people affected by liver disease, utilised not only by CLDF but all the NHS centres as the basis for patient information. 100's of queries directly relating to the pandemic were also handled.
- Advocacy and liaison work with the 3 specialist units, NICE, NHS commissioning, NHS Scotland, NHSBT, RCPCH and Welsh Liver services to help traverse unintended consequences of the significant reduction in face to face care for paediatrics and community services for neonates.
- 84 zoom group support sessions for young people and families on a wide range of topics ranging including peer support, accessing NHS services, education issues, financial support and young people's concerns – accessed by 364 households.
- 370 telephone and 1858 email, website and social media approaches for support or information from families and young people.
- 91 families received intense case work support from our Children and Families Officer which Included direct intervention to access benefits, grants, special educational needs support, liaison with clinical colleagues, mental health, social work and housing teams.
- Wildcamp and Breakaway, our summer residential projects were converted to virtual projects, not quite the same but they still had positive outcomes
- A virtual conference for Scottish families, to act as a pilot project for UK wide provision in 2021.
- More than 122,000 medical leaflets were accessed digitally over the period with a further, 17,476 printed resources being sent by post.
- The Research Hub was able to provide 15 different external projects with PPI.
- Pilot of virtual clinic attendance at Leeds was undertaken

Unfortunately we had to cancel our Research grant round in 2020 and there won't be a research round in 2021. We will continue to provide beneficiaries with support and guidance around issues related to COVID, the pandemic and vaccination ( in older groups) and provide all our other usual services digitally. We hope to build on the pilot of the virtual clinic session, to see if we can reach more families and the newly diagnosed. We will also aim to provide a virtual National Conference at some point later in the year.

We have found the need to provide advice to under and over 16's very challenging during the year due to the very different approaches taken by the paediatric vs adult hepatology communities.

We feel the financial situation of 2020 will be replicated in 2021. Our resources are incredibly stretched and the staff team are all working flat out to ensure we can still provide CLDF support to all who need it.

## Coeliac UK

### Hilary Croft

#### Awareness Week 2021

Due to the ongoing pandemic the timing of our Awareness Week 2021 is under review. The focus remains the same, achieving an earlier diagnosis for children aged 5 - 11 years. In addition to the animations we shared with you last time for the symptoms of bloating, tiredness and faltering growth, we are adding two more, tummy pain and vomiting. Our [standard diagnosis animation](#) will also be translated into five different languages Polish, Urdu, Punjabi, Bengali and Arabic, thanks to the very kind support of Thermo Fisher.



Our school packs, bespoke for each of the devolved nations, are currently under review but will be relaunched to coincide with the 2021-22 academic year.

#### Pfizer Covid vaccine

We have received some enquires from parents of children with coeliac disease, particularly those with children in their early teens but not yet 16, (the vaccine is currently not licensed for those under 16) asking whether they should, irrespective of their age, be considered for the vaccine, due to Public Health England's information on the risk of hyposplenism in people with coeliac disease. The vaccine priority group 6 includes those aged 16 – 64 years with underlying health conditions, including splenic dysfunction. We have reassured parents that the risk of hyposplenism in children is very low and continue to refer to the [series of Q&As from Paediatric Gastroenterologist, Peter Gillett](#).

In addition, we are receiving enquiries about the suitability of the Pfizer Covid vaccine for the coeliac community per se, after they stumbled across an [NHS website](#). Here it states that although none of the ingredients of the Pfizer vaccine contain gluten, the manufacturer cannot guarantee that minute amounts of substances, such as gluten, are not contained in raw materials from their suppliers. After consulting our Health Advisory Council, we are advising the coeliac community to not be concerned unless they suffer from allergic, anaphylactic reactions, in which case, when invited for vaccination, they should discuss this with their local healthcare team.

#### Local serology audits to aid diagnosis performance

We are hearing about local audits of serology against endoscopy diagnosis. Some areas have found that tTGA ten times the upper limit of normal as the cut off for diagnosing by serology alone (as per the BSPGHAN guidelines) may be a conservative approach and that a value between more than five and ten times the upper limit of normal can still secure a safe diagnosis. This is interesting as we also hear about expanding endoscopy lists and increasing waiting times due to the pandemic. Could further audits

of local serology performance and the development of local bespoke cut off values help to reduce the backlog, a question posed to BSPGHAN?

## **Crohn's & Colitis UK**

### **Sarah Sleet**

Following a very rocky period earlier this year the charity has stabilised and we ended the year in a better than expected position. As a result We're really pleased that we will be able to open a research call in the spring although the funds available will be reduced on previous years.

### **Ongoing support to the community on COVID**

We continue to update information to the community as the situation develops. Particular concerns include which priority group patients belong to as well as how individual treatments affect risk and vaccination response. Clearly the situation for children is different to that for adults.

### **Epidemiology research**

There have been a number of research projects recently suggesting that prevalence of Crohn's and Colitis is greater than previous estimates of around 1 in 300. We have a joint project with Coeliac UK to achieve a more robust UK wide figure using CPRD data. We know that service planning in Wales is based on a prevalence level almost half the reality it could be a powerful tool to improve resources in services. The top level results should be available in June.

### **National Report on UK IBD services**

Auditing against IBD Standards, this is near completion now and thanks to Rafeeq Muhammed for his contribution to the Report and the IBD UK Alliance. It would appear that against many of the Standards paediatric services perform well! We were looking at a launch on 3 March but given the current situation (and now it's likely Budget day) we are looking at possible alternatives. We would welcome the support of BSPGHAN in getting the key messages out about providing a more proactive approach to diagnosis and management plus more holistic (with access to a full range of multidisciplinary services) and personalised care.

## **EOS Network**

### **Amanda Cordell**

EOS Network Eosinophilic Diseases Charity provides community support and a global HCP network. We are delighted to have been invited to join the BSPGHAN PPP groups.

2020 has been a year like no other; the extraordinary circumstances brought about by the pandemic requiring all key workers to become superhero's but also for all charities/support groups to reinvent the wheel and support their communities in ways that have only been dreamed of before. In the midst of this February 2018, we launched our new website [www.eosnetwork.org](http://www.eosnetwork.org) alongside our new global Eosinophilic HCP network, which is now reaching 19 countries.

Like many charities, we focussed on the positive opportunities of this new virtual world of zoom calls: community support, meetings, webinar training, and appetite for collaboration, when planned fundraising and face to face events were impossible.

Our work continued with the newly formed BSPGHAN (EoE) Eosinophilic Oesophagitis working group, online meetings focused on the unmet needs of patients, their families and healthcare professionals. Thanks to the groups' dedication, BSPGHAN EoE COVID-19 advice and FAQ's were developed and disseminated.

Despite the challenges, we have grown considerably this year with increasing community members seeking support in light of the difficulties and fears in accessing or continuing medical care during COVID-19. We hope to alleviate some of their ongoing concerns with a series of "Community Zoom

Wellbeing Wednesdays” throughout the first quarter of 2021 with guest speakers covering the most popular topics raised.

EOS Network also is proud to be the patients voice within the BSG EoE guideline committee and international (EUREOS – CEGIR – IES- RCDRN) working groups, committees and consortia.

With thanks to a small but growing dedicated team of volunteers and trustees, we continue to confront eosinophilic diseases with our goal: to ensure that every person with an Eosinophilic Gastrointestinal Disease receives a prompt, accurate diagnosis, the right treatment for them, and support to live with their condition.

## **Guts UK**

### **Julie Harrington**

Due to new lockdown, we are now back working from home. We are planning to open several new grant calls this year (please go to <https://gutscharity.org.uk/research/grants-and-awards/>, for an update). We are carrying on planning our 50th year celebration and are currently evaluating the impact of our funded research.

## **Updates on joint awards**

### **GUTS UK/BSPGHAN awards given in 2019**

#### **Dr Paul Henderson**

The PINPOINTstudy -The Prospective Incidence of Paediatric-Onset Inflammatory bowel disease in the United Kingdom, University of Edinburgh, £39,936.

The aim of this study involves coordinating 38 centres UK-wide to determine the incidence of paediatric IBD (PIBD) to help inform future epidemiological studies and NHS service design, as well as to create the first traceable UK-wide prospective PIBD cohort and give every paediatric IBD access to IBD registry.

Project update January 2021: The process to get ethical approval was progressing well before the pandemic. Unfortunately, due to Covid-19 this has halted for few months. However, progress has been made. They have received full ethics approval in December 2020 and are working on getting HRA approval.

#### **Dr Matthias Zilbauer**

Stratification of inflammatory bowel disease treatment in children using human intestinal organoid derived epigenetic signatures, University of Cambridge, £40,000

The aim of this study is to analyse mini-guts generated from children diagnosed with IBD and matching controls to find out how patients with IBD differ from children without the disease. These can be used to develop new drugs, test existing drugs, and find out why these cells don't function properly in children with IBD. This project will apply world-leading, novel research technology to a large collection of existing patient samples. The results have a great potential to impact on patient's health by being able to identify novel ways to enable a tailored treatment approach.

Project update January 2020: Professor Matthias Zilbauer has submitted an interim/annual report, that has been evaluated and approved last December by our Research Trustee Professor John McLaughlin for Guts UK and by Dr David Campbell for BSPGHAN.

Main findings: Their findings suggest that cells forming the most inner lining of our intestine may be malfunctioning in children diagnosed with IBD. The degree to which their function is impaired or altered could explain why some children suffer from a mild while others from severe disease. Also, identification of specific functions that are altered may help the researchers to develop novel treatments.

A manuscript reporting these findings is currently under review at Stem Cell Report. The funding from Guts UK and BSPGHAN has been acknowledged.

### **Future Joint BSPGHAN/ Guts UK Grants**

We have been in contact with Dr David Campbell and have agreed to open a research grant call for one grant up to £40K (20K each). We are currently liaising with Dr Campbell to finalise all the term and condition for this award.

### **TOFS**

#### **John Pearce**

It very much remains the case that TOFS would like to work with BSPGHAN toward the UK recognition and adoption of the 2016 ESPGHAN / NASPGHAN guidelines (published in the JPGN) for the treatment and follow up of those born with OA. If the 2021 BSPGHAN annual meeting were to be a traditional Face to Face one (and obviously it can't), TOFS would certainly be there again, trying to raise the subject of these guidelines.

The Covid pandemic continues to limit what we can and can't do. We are just at the point of deciding that our October 2021 conference will have to be substituted with a series of webinars, for instance.

Notwithstanding this, TOFS has now published a recipe book, which was our major aim for 2020. This is called "the soft food recipe book", and is full of recipes for meals which are relatively easy to eat. It is available on Amazon, as is our less recent "The TOF Book", a larger volume written by more than 20 healthcare professionals all about the OA / TOF condition.

We lament the impact of Brexit upon efforts to improve the lot of those suffering from rare diseases. Some leading UK hospitals were making a significant contribution to parts of the EU-sponsored ERNICA activity and have now been excluded from it. Fortunately, TOFS is a founder member of the international federation of OA/TOF support groups (EAT), a German registered body. TOFS continues to make a major contribution to EAT and via EAT, TOFS continues to have good representation at these committees.

TOFS has two new "patient voice" involvements with healthcare initiatives to report. Firstly, TOFS Trustee Graham Slater (who is also Chairman of EAT) has been appointed as a Patient and Public voice partner in NHS England's "Specialized surgery in children" Clinical Reference Group.

TOFS is Patient and Public Interest partner for a major new UK trial, called TOAST. This is to be a major randomized controlled trial, funded by NIHR, which aims to establish whether or not the widespread use of PPI medication is actually helpful to OA/TOF babies. A broad team from Southampton University, The Evelina Hospital, Oxford University's National Perinatal Epidemiology Unit and Liverpool University are leading the work. We expect that the trial's outcomes will eventually bolster one aspect of the 2016 ESPGHAN guidelines referred to above – or lead to a material change in them. Lastly, it is good to report that TOFS's finances remain healthy. Our income had fallen greatly in Spring 2020, and we set up a fundraising working group – something we had never needed before. Our members and the OA/TOF community has responded very positively, taking part in several fundraising initiatives, with the result that TOFS's income in 2020 is set to match that of several recent years. Moreover TOFS is likely to record a modest surplus in 2020, because so many things we planned to do had to be cancelled due to the Covid restrictions. We continue to have four part time staff in post.

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### **CSAC**

**Professor Mark Beattie 2019 - 2022**

**Chair Gastroenterology, Hepatology and Nutrition CSAC**

[csac@bspghan.org.uk](mailto:csac@bspghan.org.uk)

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At the time of writing we are in the third wave of the COVID – 19 pandemic with its massive impact on ourselves, our families, our patients and their families, clinical services, research, education and training. We have all been challenged by the need to do things differently, consider new approaches, develop new strategies and remain positive despite the difficulties faced across all sectors in our local communities, at work, nationally and internationally.

This has had a significant impact on the activities of CSAC with the team, strongly supported by the RCPCH and BSPGHAN, working hard to help support our trainees and in particular support ongoing training in the speciality adapting as required to the continued uncertainty and service need. I would particularly like to thank Dr David Evans, RCPCH vice president and Dr Sue Protheroe, BSPGHAN president for their consistent support of paediatric gastroenterology, hepatology and nutrition trainees despite the many demands on their time during this challenging year.

The committee has had 4 virtual meetings and just completed recruitment for the National Grid posts due to start in September 2021. I am pleased to report we had an excellent field and will hopefully recruit to all of the 10 rotations offered.

We have kept in close contact with the current trainees with regular communications facilitated by Rulla Al-Araji our excellent trainee representative.

We conducted virtual CSAC progression meeting during June/July 2021 with all the current trainees – an amazing feat of organisation and many thanks to Nkem Onyeador for facilitating. I thought this process went very well with good and constructive discussions and all of the committee feeling very positive about the commitment and enthusiasm (and positivity) of the trainees despite most having had interruptions/changes made to their training.

We are very grateful to BSPGHAN for the multiple virtual training initiatives which have been very well received and I think have enhanced significantly education and training with excellent talks and very positive feedback. I hope very much this will continue post pandemic hopefully in parallel to us meeting face to face at least some of the time.

Endoscopy training remains a significant concern as a consequence of the Coronavirus Pandemic and the necessary service restrictions – PPE supply is at least now less of an issue and at the time of writing most units have endoscopy lists up and running. I appreciate this may change in the coming weeks. We have asked trainees to keep in touch and have arranged interim CSAC progression meetings to review trainee progress during January 2021 parallel the virtual annual meeting.

Ongoing issues as per my previous report

- It remains unclear when Shape of Training will be implemented. In summary this reduces the specialist training period to 7 years, although does maintain the full 3 years for higher specialist training (level 3) and does enable out of programme time between level 2 and level 3. The positive for us is that speciality training isn't shortened although the tough thing is that training will be overall shorter and potential recruits to the grid will be less experienced. There is still much discussion of competency based training rather than length of training.
- There are no plans to change the PGHAN Curriculum – please note, like for an adult gastroenterology CCT – JAG certification for Gastroscopy is a key competency but not Colonoscopy with the presumption that to be awarded the CCT reasonable progress to competency in Colonoscopy is being achieved (for Paediatric Gastroenterology trainees) but ongoing experience/training will occur post CCT. We are not able to mandate the ongoing experience/training although agree that is entirely appropriate and in keeping with good medical practice.
- We continue to recommend that GRID trainees have access to at least 25 lists per year and do a reasonable number of procedures on the lists. This is essential to give trainees the enough exposure. I have asked that issues for individual trainees are highlighted early although other than the process of accreditation of training/approval of rotations CSAC have no ability to

mandate this recommendation. I appreciate fully that the COVID Pandemic will have made this more difficult to achieve and we are (as above) keeping in touch with the trainees regarding their progress

- There continues to be much discussion about eligibility for the grid and recognition of previous training. It seems nothing is set in stone however to get a CCT in PGHAN you need to have been appointed to the GRID and in principle you should have at least 2 years of training left although this assumes some of the competencies have been/can be achieved prior to taking up the GRID post – remember this is a 3 year programme – although exceptions can be made and potential applicants should talk the RCPCH/CSAC early and remember that any change in CCT date is a matter for their deanery and the CCT date isn't easily changed
- The new PGHAN curriculum has been approved and is live on the website. Many thanks to Himadri Chakraborty for achieving this. [https://www.rcpch.ac.uk/sites/default/files/2020-06/gastroenterology\\_hepatology\\_and\\_nutrition\\_-\\_v2\\_2020.pdf](https://www.rcpch.ac.uk/sites/default/files/2020-06/gastroenterology_hepatology_and_nutrition_-_v2_2020.pdf)
- We have approved new centres for training – Leicester, St George's (2019) with the intent longer term that training, for at least 12 months, should be available in all regions.
- I am pleased that Great Ormond Street have applied for and been re- accredited as a training centre which is excellent news
- All training rotations need Deanery and CSAC approval and so if you are looking to offer rotations starting in 2022 it is never too early to start planning
- There continues to be a large number of Consultant Posts being advertised at the moment. In the past all consultant post job plans had to have CSAC approval although this is no longer mandatory. I would however encourage this as it is (hopefully) helpful and gives CSAC an overview of what trusts want and an opportunity to input as appropriate

I would like to thank the committee for their hard work and support – Lucy Howarth, Jonathon Hind, Akshay Batra, Nkem Onyeador, Himadri Chakraborty, Vandana Jain and Rulla Al- Araji.

Rulla will soon be stepping down from the committee. Her input as trainee representative on CSAC has been fantastic – we will really miss her – the advert for her replacement is live on the RCPCH website:

[https://www.rcpch.ac.uk/sites/default/files/2020-12/202012\\_council\\_-\\_eao\\_south\\_england\\_0.pdf](https://www.rcpch.ac.uk/sites/default/files/2020-12/202012_council_-_eao_south_england_0.pdf)

Please keep in touch and E Mail me direct with any queries/ comments/ questions or suggestions

Professor RM Beattie  
Consultant Paediatric Gastroenterologist  
Honorary Professor of Paediatric Gastroenterology and Nutrition  
Chair of the Royal College of Paediatric and Child Health (RCPCH) College Specialty Advisory Committee (CSAC) for Paediatric Gastroenterology, Hepatology and Nutrition

7<sup>th</sup> January 2021

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**Tony Lander**  
**Paediatric Surgeon, Birmingham Women's and Children's Hospital**  
**BAPS representative. 2020 – 2023**

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Quality Standards Committee  
J Fell Chair 2019 – 2022  
[Qualitystandards@bspghan.org.uk](mailto:Qualitystandards@bspghan.org.uk)

Following the successful collaboration between BSPGHAN and RCPCH which resulted in the development and publication in the [2017 Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition](#), we commissioned the RCPCH to deliver a National Audit of these Quality Standards.

The PGHAN Audit Objectives are as follows:

This PGHAN Audit aims to improve health outcomes and the quality of life for children receiving care for gastroenterology, liver or intestinal disorders throughout the UK. The PGHAN Audit will seek to identify any variation in care and ensure that equitable services and access are available for all infants, children and young people in the provision of gastroenterology, hepatology and nutrition services across the U.K.

Progress

By March 2020 we had convened a steering comprising of members of BSPGHAN quality standards working group, RCPCH collaborators (Calvin Down and Manna Mostaghim part time project co-ordinator / joint administrator) and other stakeholders.

By April we had started registration of hospital provider sites, and were completing the audit tool. The arrival of the Covid Pandemic necessitated a pause in all work until September 2020.

Current Status.

The audit has been re-activated as of December 2020. The final audit tool was then configured into an online format by an RCPCH collaborator : NetSolving.

The current audit includes:

- The initial audit tool to review adherence to the 2017 Quality Standards document. This process will also help map the current configuration of network provision.
- The audit also includes some questions which aim to look at changes in service provision as a result of the Covid Pandemic.

Results and Presentation:

The intention is for provisional results to be available for presentation at the BSPGHAN Winter Meeting 2021. Full results will be published following council review thereafter.

John Fell

Chair: Quality Standards Working Group

Dec 2020

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### **BSG: Adolescent and Young Person Section (AYP)**

Writing this report made me reflect on the year gone by. Whilst there have been lots of challenges and difficulties, there were interesting opportunities too and importantly a will to change and work in newer ways.

This section although small has continued to raise the profile of delivering developmentally appropriate healthcare including transitional care to adolescents and young people with GI conditions.

Section activities include:

- Adolescent section symposia on BSG campus 22<sup>nd</sup> January 2021
- Section Study day postponed from November 2020 to 2021 (Hosted by Liverpool)
- National survey of adolescent gastroenterology service delivery and training completed in 2020 – findings were to be presented at BSPGHAN meeting

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- Multicentre survey commenced on young person and clinician experience with virtual consultations in gastroenterology clinics
- Outgoing and incoming chairs of this section leading a joint collaboration with James Lind Alliance (which works with Priority Setting Partnerships of patients and clinicians) and NIHR CYP Med Tech Transition theme to explore the role of digital technology in adolescents with IBD. This is in very early stages with funding sources being looked at.

Priya Narula  
Chair BSG AYP section

-----End of Report-----