

Minutes of the BSPGHAN Committee for Nutrition, Institute of Child Health, Birmingham, 1.30pm – 4.30pm 22nd June 2007

Minutes of meeting:

Present:

Dr Sue Beath - Chair and Nutrition representative on BSPGHAN Council
Dr John Puntis – Chief investigator for BIFS
Dr Mark Dalzell – Consultant gastroenterologist at Alderhey Hospital
Ms Christine Holden - Specialist Nutrition Nurse at Birmingham Childrens
Ms Tracey Johnson – Senior Dietician at Birmingham Children’s Hospital
Dr Andrew A O Fagbemi - Consultant Paediatric Gastroenterologist at Booth Hall
Dr Susan Hill - Consultant Paediatric Gastroenterologist at Great Ormond Street
Dr Sue Protheroe - Consultant Paediatric Gastroenterologist at Birmingham Childrens
Mr Henry Gowen – BIFS Administrator, minuting secretary.

1. Welcome and apologies:

Mr Henry Gowen who was appointed as the national data manager for the British intestinal failure survey (BIFS) in children was warmly welcomed to his first meeting of the Nutrition Committee. Dr Andrew Fagbemi, Ms Tracey Johnson and Dr Sue Protheroe were also welcomed to the meeting. Apologies received from Dr Ian Sugarman, Ms Victoria Magnall, Dr Sarah Macdonald, Dr Nigel Meadows were noted.

2. Previous meeting minutes and matters arising:

Some colleagues had not received the minutes of the previous meeting on 8th February so this will be e-mailed to all attendees (HG). The terms of reference of the Nutrition committee were outlined by SB and have been submitted to the Council of the BSPGHAN, although no specific feedback has been received yet. SB confirmed that members of the BSPGHAN had attended the UKHPN group on 2nd May and that Dr Protheroe had given an excellent talk on transferring young people with gastro-intestinal problems onto adult services which was very well received by the audience.

3. BIFS update

HG gave a talk on the state of the BIFS Registry. He identified the two main problems as being under-reporting of patients who had been on PN for >27 days, and poor follow-up.

However, an abstract reporting the progress in collecting pilot data has been submitted to the 10th International Symposium on Small Bowel Transplantation in Santa Monica 6-8th September 2007, where there will be opportunities to learn how registries in other countries operate.

HG is to check if BSPGHAN were still paying Streets Heaver and if so, to cancel the contract as it was felt that the merits of a web-based database didn't justify the costs, as personal contact with the local reported was likely to yield more follow up data.

The issue of improving recruitment and follow up of patients was discussed and the **following actions were recommended:**

- i) JP said he would "sound out" the validity of getting nurses to collect consent with the Patient Information and Advisory Group (PIAG).
- ii) HG will send a copy of the Liverpool data in an ACCESS database to MD to look into the feasibility of registering and updating patient records by sending spreadsheets between centres.
- iii) HG is to contact all surgeons in BCH (following JP talk) and supply them with advisory leaflets and consent / diagnosis forms.
- iv) HG to visit the major neonatal surgical units – JP will liaise with Ian Sugarman to arrange invitation for HG and see if BAPS will include information about BIFS on its website.
- v) AF requested that copy of the multi centre ethical approval is to be sent to Manchester (HG).

4. Collaboration between BSG & BSPGHAN joint meeting – March 2008

It is the stated aim of the BSPGHAN that stronger links be developed and maintained with the BSG. SB reminded committee members that there will be a joint symposium between the BSG and BSPGHAN on March 10-13th 2008 and that the meeting will take place in Birmingham. The theme of this joint conference will include Transition from paediatric services to adult services. Within this theme, committee members felt that the following subjects would be of interest:

- Inflammatory bowel disease
- Short bowel syndrome (excluding those who require homePN)
- Neuro-disabled children requiring nutritional support
- Young people on home parenteral nutrition

It was suggested that

- a) we ask colleagues at the BSG to nominate individuals who could link with a paediatrician to chair sessions jointly and/or prepare lectures eg Jonathan Rhodes, Keith Leiper, Sarah McCarthy.
- b) nurse specialists be approached and asked to describe their personal experience of transition work and the profile their role e.g. John Kenendy at St Marks Hospital.
- c) Patient and parent groups such as CICRA, NAC, CLDF be invited to become involved

Action: SB to write to Jeremy Woodward at the BSG offering our support and suggestions for the meeting.

5. Specialised Services National Definitions Set (SSNDS) – Update and progress in paediatric gastroenterology, hepatology & nutrition

The Specialised Services National Definitions Set (3rd edition) (Draft) document prepared by the convener of the BSPGHAN (Dr MS Murphy) at the request of the DoH was circulated by SB. The document was accepted as a major improvement on the previous edition, but could not be regarded as definitive as so many gaps in definitions and services.

It was noted that a flaw in the document was the focus on “diagnosis and things done” to patients, but the process of health care delivery ie how and why things are done is not considered. For example 2 major areas of concern are:

- firstly almost no mention of the importance of transition and the need to develop new ways of working to accommodate the needs of a young adults,
- secondly the work of nutritional care teams is not captured

The committee considered the issue of “currencies” which we took to mean how costs are calculated and noted that really there seem to be only 2 mechanisms: that of the finished consultant episode (FCE) and the other is bed day occupancy with or without intensive care. In some situations high cost haematology and nutrition drugs could be incorporated into the FCE, and this should extend to nutritional support teams. The committee would be interested in knowing what the costs assigned to various disorders and procedures actually are and would be prepared to participate in any review. Some kind of health technology assessment for nutritional support in children would be useful (eg. Nasogastric tube feeding training of parents in hospital and supervision of home administration). **Action: SB to feed back to Dr Murphy.**

6. Working party guidelines – authors and timescale

We agreed we should identify the priority topics and after some discussion the following were agreed:

Topic	Priority	Named lead	Date for first draft
Central venous catheter sepsis	1	JP	Dec 2007
Intestinal failure associated liver disease	2	SB	Oct 2007
Omega 3 lipids	3	SH	Jan 2008
Re-feeding syndrome	4	AF	Jan 2008
Transition of neurodisabled children with nutritional problems	5	MD	June 2008
Nutritional rehabilitation after surgery to gastrointestinal tract	6	Not assigned	

Other topics which may be considered in the future include: adolescent health in IBD, SBS, food allergy; Managing re-perfusion injury; Re-constructive surgery to gastrointestinal tract; Obesity.

It was agreed that the preliminary draft of the Intestinal failure associated liver disease should be circulated to colleagues on the Liver Steering Group and to take their comments on board before preparing the next draft. **Action SB**

7. Clinical trials and MCRN

JP updated the committee on a proposed study of the efficacy of Taurolock in infection prevention. This study has been put forward to Dr MS Murphy who advises and coordinates applications to MCRN on behalf of the BSPGHAN. A review of evidence published in the literature relating to Taurolock was circulated which laid out a summary of 13 papers according to 5 headings as follows: Author, Type of study and level of evidence, Study population, Substance or drug evaluated, Results. It was agreed that this way of summarising the evidence was very useful and something we should adopt in our own guidelines and reviews.

8. AOB

A nomination by BSPGHAN for a representative to attend an implementation planning meeting on August 1st for NICE guidance on maternal and child nutrition: guidance for mid-wives, health visitors and other primary care services to improve the nutrition of pregnant and breast feeding mothers and children in low income households, has been requested by the RCPCH (Kim Davis clinical.effectiveness@rcpch.ac.uk). The committee recommend Dr Anthony Williams at St Georges Hospital. **Action: SB to inform Dr Murphy and Kim Davis.**

9. Date & time of next meeting

The next meeting should take place in Southampton at the BSPGHAN Annual Meeting on the morning of Thursday 24th January 2008, being held at Botley Park Hotel (www.botleypark.com).

A further meeting has been proposed for Friday 20th June 2008 in London at Great Ormond Street Hospital Birmingham (**to be confirmed by Dr Sue Hill**).

Time	Item	Who
9.00am – 9.05am	1. Welcome and apologies	SVB
9.05am – 9.15am	2. Previous meeting minutes and matters arising	SVB
9.15am – 9.45am	3. BIFS update	HG
9.45am – 10.00am	4. Update on BSG & BSPGHAN joint meeting – March 2008	SVB
10.00am -10.15am	COFFEE BREAK	
10.15am – 10.55am	5. Working party guidelines – update	SVB / JP
10.55am – 11.15 am	6. Clinical trials and MCRN	JP
11.15am - 11.25am	7. AOB	
11.25am -11.30am	8. Date & time of next meeting	