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Ms Melanie J Williamson  
Assistant Coroner  
West Yorkshire (Eastern)  
Coroner's Office  
71 Northgate  
Wakefield  
WF1 3BS

17 APR 2015

Tuesday, 14<sup>th</sup> April 2015



**Inquest touching on the death of LLH reference MJW/JS/1801/13**

Dear Ms Williamson

Thank you for your letter of the 20<sup>th</sup> February and the copy of the regulation 28 report. I sent you an initial opinion in my e-mail of the 3<sup>rd</sup> March and we then discussed the case and some of the issues in a telephone conversation on the afternoon of the 9<sup>th</sup> April. Since then I have had an opportunity to discuss my response with Dr Alastair Baker - President of the British Society of Paediatric Gastroenterology, Hepatology & Nutrition (BSPGHAN) and he is copied in to this formal response.

In your **Regulation 28: Report to prevent future deaths** under "Coroner's Concerns" (item 5) you state:

*The Matters of concern are as follows:*

1. *Birmingham Children's Hospital NHS Foundation trust has a policy in place and/or guidelines dealing with paediatric endoscopy procedures for the banding of an oesophageal varix/oesophageal varices ("the procedure"). Neither Sheffield Children's NHS Foundation Trust nor Leeds Teaching Hospital NHS Trust has such a policy and/or guidelines. Both the latter trusts have undertaken the said procedure for many years.*
2. *There is no standardisation of practises (either locally or nationally) adopted by Consultants when undertaking the said procedure, by reason predominantly of there being no national policy and/or guidelines in relation thereto. Such a national policy and/or guidelines should address the following:*
  - a. *Precise definitions of the grades of oesophageal varices;*
  - b. *Which grades of varices should be subject to banding and which should not;*
  - c. *Those patients who are to be deemed suitable for placing on a banding programme and those who are not;*
  - d. *Once a patient is placed on a banding programme, the assessment process to be adopted prior to the said patient undergoing each procedure;*
  - e. *Post endoscopy care, for example, the administration of sucralfate, frequency of basic observations;*

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*Handwritten initials*

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Dr Huw R Jenkins MA MD FRCP FRCPCH  
Dr Peter J Dale Visiting Consultant Paediatric Gastroenterologist (Royal Gwent Hospital)  
Dr Sarah El-Hadi Visiting Consultant Paediatrician (Princess of Wales Hospital)  
Mrs Claire Sadlier Paediatric Gastroenterology Nurse Specialist  
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Re:



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- f. *The steps to be taken to properly assess for and manage variceal bleeding, for example, the immediate use of antibiotics;*
- g. *The circumstances in which a Consultant is deemed to be competent to undertake the procedure alone or with supervision.*

Given the complexity of the question I shall answer in numbered points:

- (i) I was not called as a witness to the inquest. Had I been present I may have been able to clarify some of the points that we covered in our conversation of the 9<sup>th</sup> April. This could have included the progress that has been made in respect of Diagnostic Endoscopy Training over the last 3 years in collaboration with the Joint Advisory Group on GI Endoscopy (JAG) as well as a clear description of the variety of service models that exist across the UK for the care and management of children with complex liver disease (including portal hypertension).
- (ii) I have handed over the Chair of the BSPGHAN Endoscopy Working Group (EWG) to a Consultant colleague [redacted] who is employed as a Consultant Paediatric Gastroenterologist in the Sheffield Children's NHS Foundation Trust. Clearly this makes her involvement as the new chair impossible given an obvious competing interest in the index case. Neither should I attempt to take your request forward in a personal capacity.
- (iii) I think (irrespective of (ii) above) that a matter of this importance would be better directed to the BSPGHAN President rather than the Chair of the EWG. He is copied in to this response and would be pleased to receive your request and then offer a formal reply on behalf of BSPGHAN. The main reason for this is that your concerns are related to the care of children with complex liver disease and the complication of portal hypertension rather than purely the procedure of the endoscopic banding of varices.
- (iv) [redacted] will almost certainly wish to discuss this with the BSPGHAN Liver Steering Group which has representation from each of the 3 quaternary centres for the UK before responding.
- (v) Alternatively and / or in addition, you may wish to direct your concerns to organizations within the UK that have more power and influence than our relatively small and poorly resourced society. They would almost certainly come to BSPGHAN for advice / direction but may be better placed to take matters forward and compel the change that you seek. Examples would be the Royal College of Paediatrics and Child Health, JAG, the National Institute for Health and Care Excellence (NICE) or the NHS itself.
- (vi) Finally, if such guidance is considered possible and is taken forward by some of the methods I have described. It may be worth considering whether it should be part of a broader Quality Standard (QS) that covers the management of acute severe gastro-intestinal haemorrhage in children. There is only a NICE QS available for patients over the age of 16 years and there are currently no plans to take this forward for children. In part this is down to the relative rarity of the problem, complications of organization and very different service models in existence across the UK.

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In conclusion, I am unable to take your concerns forward myself but hope I have offered several options that may help advance these issues.

Yours Sincerely,

[REDACTED]  
[REDACTED]

**Consultant Paediatric Gastroenterologist & past Chair BSPGHAN EWG**

Copied to:

[REDACTED] (President BSPGHAN)  
Consultant Paediatric Hepatologist  
Paediatric Liver Unit  
King's College Hospital  
Denmark Hill  
LONDON  
SE5 9RS

*de*

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