Mann Pat (RQ3) BCH

From: Mann Pat (RQ3) BCH
Sent: 17 December 2004 10:24
To: 'Noel Gill'; 'Don Jeffries'; 'William Connon'
Subject: URGENT - Haemophilia & vCJD Health Protection Measures

Importance: High

(Dictated by Prof. Hill: 17.12.04.)

Dear Noel, Don & William,

Yesterday I was in the West Country discussing their Haemophilia Service. An agenda item was vCJD - it became apparent that hospitals in the South West were facing difficulties, like many other hospitals, with the implementation of the Health Protection measures, particularly with regard to use of endoscopes. The difficulties at the moment are:

(1) Refusal to endoscope patients with haemophilia.
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(3) Endoscopy services for everyone are affected and units are running out of endoscopes for investigating anyone.
(4) Difficulties in obtaining/making available funds to purchase new instruments.

There does appear in some of the Trusts with Haemophilia Centres to be a reluctance on the part of the Infection Control Teams to engage and take on the responsibilities that are rightly theirs.

There is an urgent need for central discussion, agreed actions and funding, otherwise current Health Protection advice cannot be instituted without causing risk to haemophilia patients and to all other patients requiring endoscopy services.

Yours sincerely,

Frank G.H. Hill
Professor of Paediatric Haematology
& Chairman - UKHCDO

Dept. of Clin. & Lab. Haematology
Birmingham Children's Hospital NHS Trust
Steelhouse Lane
Birmingham B4 6NH.

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→ FQ44

Mann Pat (RQ3) BCH

From: CDSC - Gill, Noel [Noel.Gill@ GRO-C
Sent: 17 December 2004 12:55
To: Don Jeffries (E-mail); Manchester - Painter, Michael
Cc: CDSC - Soldan, Kate; CDSC SW - Gamble, Harvey
Subject: URGENT - Haemophilia & vCJD Health Protection Measures

Importance: High

Dear Don and Mike,

How do you advise we should respond to this?

Clearly, Frank is calling for urgent action following his visit to the West Country.

At the same time I had expected the results from Harvey's survey to be the catalyst for compelling a 'serious' co-ordinated central response to the problem.

In my view there is little specifically the HPA can do, beyond galvanise it's network to help infection control doctors to interpret the relevant endoscope guidelines correctly, but for the present we do not have the evidence to convince ourselves that this is a major problem.

I can pass the email to Ailsa, but this does not appear to be a particularly constructive thing to be doing, unless it is accompanied with a view as to what we think ought to be done next.

Should we be asking the DH to convene a mid-January meeting to consider the problem in depth in the light of the imminent results from Harvey's survey? (Harvey - when do you think sufficient results will be available that will allow such a group to decide what the real problem is?)

Who should be members of such a group - assuming the agenda we are moving towards is identifying what supplementary resources might be needed, for what precisely, and how might these resources be distributed to effectively address the problem?

What do you think?

Regards,

Noel

-----Original Message-----
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→ EGHH + forwarded to you.

Mann Pat (RQ3) BCH

From: Prof D J Jeffries [d.j.jeffries@ GRO-C
Sent: 17 December 2004 12:37
To: 'Noel Gill'; 'William Connon'; Mann Pat (RQ3) BCH
Cc: john.stephenson@ GRO-C peter.bennett@ GRO-C
ailsa.Wight@ GRO-C michael.Painter@ GRO-C
Subject: Re: URGENT - Haemophilia & vCJD Health Protection Measures

Attention Prof. Frank Hill

Dear Frank

Many thanks for relaying this information. As you know, our concerns over the cost and clinical governance issues of the necessary precautions for endoscopy in plasma product recipients, have been strongly emphasised on several occasions to the Dept of Health. There still needs to be a much clearer definition of the need for endoscopy in patients with haemophilia. Not only does the overall use of endoscopes seem to vary in different Centres throughout the UK but also there seem to be very different views about the need to carry out biopsies and other invasive procedures. With this in mind, the HPA are conducting a nationwide, questionnaire-based survey, and I am grateful to you for assisting Harvey Gamble with this.

On 21st October, John Stephenson convened a meeting at Skipton House to bring together scientists working in the DH Decontamination Research programme with a view to commissioning urgent research to measure protein contamination of instrument channels by biopsy forceps and to assess the likelihood of transfer of infected protein to the next patients endoscoped. With the knowledge that this work will proceed swiftly, I have been informing Trusts that endoscopes, quarantined on the basis of possible contact with medium risk material, should be able to be reassessed as soon as this research is completed. I have been advising that this should be in months rather than years.... John told me recently he believes it will be weeks rather than months.

It seems unavoidable to me that Trusts with Haemophilia centres will need to acquire new instruments to compenste for the loss of quarantined scopes. Apart from the general question of whether non-invasive procedures, e.g. imaging, could be used to obtain a diagnosis without prejudicing patient care, I wonder whether other things could be considered. It has been pointed out to me that whereas a modern "all singing, all dancing" gastrointestinal endoscope can cost £25-30K, there are considerably less expensive models (£5-10K has been quoted). Could these be considered without compromising patient care? I have also been informed that after 5 years' use, scopes are pensioned off and indeed these perfectly functional, older scopes may be used in the above-mentioned research project. One microbiologist in a Trust with a Haemophilia Centre has suggested using these time-expired scopes in haemophiliacs identified as "at risk" of vCJD from plasma products. This could well be a way forward, but of course there we run up against the decision to adopt the "umbrella approach" for haemophiliacs.
While the cohort includes people not known to have received a significant amount of potentially contaminated material, the ethics of this approach seem to be prohibitive. If the calculations were applied on an individual basis, it may be justifiable to dedicate scopes to a defined, presumably low risk, "at risk" population in the same way that we have dedicated carefully released gastroscopes for use in patients with CJD who require PEG insertion.

Personally, I shall be happy to engage in further discussions on this, but I thought the
above points might assist you in speaking to your colleagues. As measures are in place
to try to help/solve the problems, it may be wise to wait a little longer to reassess the
impact. Incidentally, I know that colleagues at HPA (Prof. Noel Gill and Dr Kate Solden)
have been receiving comments expressing similar concerns from endoscopists and
haemophilia doctors in several different areas. Kind regards, Don.

Prof. D.J.Jeffries
Acting Chair of CJD Incidents Panel
Chair ACDP TSE Working Group

On 17 Dec 2004 at 10:23, Mann Pat (RQ3) BCH wrote:

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> Dept. of Clin. & Lab. Haematology
> Birmingham Children's Hospital NHS Trust
> Steelhouse Lane
> Birmingham B4 6NH.
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> Email: frank.hill@ GRO-C
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