



"vCJD: Progress update following mtg with PS(PH)"

Document Type:	Formal
File Title:	GHP - CJD - SEAC: General - SEAC Secretariat Neil Ebenezer papers
File Reference:	GHP/008/001/011 Vol 3
Protective Marking:	No Marking
Filed by:	Neil Ebenezer/PH5/DOH/GB on 10/11/2006 at 10:29
Created by:	Rowena Jecock on 13/07/2005 at 10:15

Named Security Prior To Moving To Archive:

Who can edit?	Nobody
Who has edited?	Neil Ebenezer/PH5/DOH/GB
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Modification History Prior To Moving To Archive:

Modified Date and Time	Details
26/02/2010 16:41	Refiled from WRK/029/001
18/04/2012 13:53	Refiled from GHP/008/001/011 to GHP/008/001/011 Vol 3

Rowena Jecock

13/07/2005 10:15

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Subject: vCJD: Progress

update following mtg with PS(PH)

Gerard *et al*,

To update you on the points in Anna Norris' attached note:

- I have agreed with HPA that GPs and local HPA officials will receive information on Monday 18 July (to be sent special delivery on Fri to ensure Monday morning receipt). The one exception to this in my view needs to be a confidential note to the 10 Regional Epidemiologists this week, to forewarn them that they will receive information next week which will need to be cascaded to PCTs & GPs on Wednesday to advise them how enquiries from concerned patients should be dealt with. I plan to agree with HPA what can be said to the REs today/tomorrow. It will be the minimum necessary.
- HPA is discussing with NBS the possibility of offering GPs of the affected donors a conference call to discuss any concerns or answer any queries they may have - but even if not possible, the GPs are being offered the opportunity to speak with NBS or HPA staff in

advance of their patients receiving notification letters.

- The letters to current donors will be sent on Tuesday to arrive Wednesday am.
- **Eileen** is in discussion with NBS re the hours of the NBS helpline for these people. It will not be possible to operate on a 24 hour basis, but we anticipate that it should be possible to operate to the hours in Anna's note.
- You are preparing the WMS. **Eileen** will forward our further comments to you today.
- **Janet** is in charge of co-ordinating the technical briefing material, and is preparing some powerpoint slides for Lindsey to use at the briefing.
- **Sophie** is drafting a press release, and will I'm sure be able to advise on a suitable CMO quote. I believe she will be discussing this with CMO later this week - Sophie could you confirm please?
- I am providing **Neil** and **Zubeda** with the background material to the Doncaster case, to ask them to include lines on a separate 'issues page' in the briefing on why the early DH advice to the NHS was not to tell people of the possible exposure via blood components/products.

Happy to discuss any aspects, and many thanks to everyone involved for their continued hard work on this announcement.

Rowena

----- Forwarded by Rowena Jecock/PH6/DOH/GB on 13/07/2005 09:41 -----

Anna Norris

12/07/2005 19:01

To: Gerard

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cc: Ailsa

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Subject: Re: Secondary

transmission of vCJD 20 June 2005



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Gerard

Thank you for attending the meeting yesterday. The action points were as follows:

- GPs and local HPA officials to receive information no earlier than Monday am
- Team to explore the option of conference call(s) to brief GPs
- Letter to go from NBS to individuals to arrive Wednesday am
- Team to check out the hours of operation of the helpline - this should be at least to 9pm in the 48 hours following the letter
- Written Ministerial Statement 12.30 Wednesday (this needs to come to PS(PH) for clearance by Monday)
- Technical briefing for the technical press on Wednesday afternoon involving DH, NBS and HPA
- Press notice to include CMO quote rather than ministerial quote
- Team to provide lines on the Doncaster case and why those who might have been infected weren't told at that time

Please could you let me have the draft WMS and the lines on the Doncaster case for Monday's box.

Thanks

Anan

Gerard Hetherington

Gerard Hetherington

28/06/2005 17:39

To:

Anna

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cc:

David

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Subject:

Re: Secondary

transmission of vCJD 20 June 2005



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Anna

Your note of 23 June to Rowena Jecock confirmed that PS(PH) agreed the submission of 20 June but sought clarification on a number of questions. Further information on these points is below.

1. ***In relation to the footnote on page one PS(PH) has asked 'Does this affect insurance/mortgage or anything like that?' I assume from paragraph 15 that the answer is yes. Could you just set out what the consequences are please?***

We had brief initial discussions with the Association of British Insurers (ABI) in late 2003. We understand that there are currently no actuarial data upon which to base a decision on whether there might be a case for adjustment of insurance premiums, and the ABI indicated that their response may also depend upon the numbers of people involved, ie if the numbers are small, there may be little point in the industry adjusting its underwriting practices. Nevertheless, this remains an area of concern for the patient support groups, and the decision of individual donors about whether to continue donating might be influenced by uncertainties about the possible future financial implications that knowledge of increased risk status might confer.

2. ***In relation to paragraph 14 (PS)PH has asked for a timeline of when the notification will happen. She also asked 'how much will the media know about numbers, how do we protect identities and how do we prepare people for publicity?'***

We suggest that an announcement be made on **19 July**, announcing the start of the donor notification. Parly is content with this date, and we are awaiting COMMS' advice on the suitability of this date.

We recommend that we be completely open about the number of vCJD patients who received transfusions and the number of donors being contacted. This would be consistent with the approach we have taken previously, where we have disclosed the actual or estimated numbers of individuals affected. We will not disclose confidential patient-identifying information. Nevertheless, should individual donors who are told of their possible increased risk status wish to speak to the media about their own position, they are within their rights to do so. NBS/HPA are best placed to advise on how donors being notified can best be supported, given the inevitable publicity. We will ensure that this is done. Both organisations have dealt with vCJD risk notifications in the past, and the HPA has told us that the contribution of the CJD Support Network (whose co-ordinator is a member of the CJD Incidents Panel) has been very helpful in this regard.

3. ***In relation to the penultimate bullet under paragraph 17 (on the north of England issue) PS(PH) has asked 'how will this be managed to protect confidentiality?'***

There are two aspects to this: contacting the individuals who need to be told of their possible increased risk status. This will be managed by the NBS/HPA, who will handle the patient-confidential aspect of identifying the individuals concerned and ensuring that they are contacted. The second aspect is to ensure that the NHS regionally is aware of what is happening, and knows how enquiries from the press or public should be dealt with. We plan to ask the SHAs in the north of England to co-ordinate dissemination of generic information about the notification to the NHS in each of their patches. We intend that this information set out the basis of what is being done and why, without disclosing patient-confidential information. NHS Direct will be provided with material (currently being prepared by HPA) to enable them to answer queries from the public.

Your email of today suggested a short meeting with Minister to discuss the handling of the announcement. Our view is that this should be held earlier rather than later, if at all possible. I will ask my office to liaise with yourself and Comms to find a suitable date.

Happy to discuss.

Gerard Hetherington
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