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Chief Scientist/Head of Profession/Branch Head Documents - Unformatted Document

## "Fw: vCJD running on Telegraph website"

File Reference:	WRK/002	
File Title:	Working Files - Bovine Spongiform Encephalopathy (BSE)	
Filed by:	Carole Dobson/HPIHSD/DOH/GB on 18/02/2009 at 16:01	
Created by:	Elizabeth Woodeson/CQEG/DOH/GB on 15/02/2009 at 12:55	
Carole Dobson/HPIHSD/DOH/GB, <- By default all readers can see document.		

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Elizabeth Woodeson/CQEG/DOH/GB	Todavid.harper@ <b>GRO-C</b> cc
15/02/2009 12:53	bcc
	SubjectFw: vCJD running on Telegraph website

David See below. All under control. Liz

Message sent from a Blackberry handheld device.

---- Original Message ----From: "David Daley" [David.Daley@ GRO-C]
Sent: 15/02/2009 10:51
To: "Lis Birrane" <lis.birrane@ GRO-C >;"Mike Catchpole"
<Mike.Catchpole@ GRO-C >;Ailsa Wight/PH6/DOH/GB@GRO-C;"Alex Baker"
<Alex.Baker@ GRO-C >;Ailsa Wight/PH6/DOH/GB@GRO-C;"Alex Baker"
<Alex.Baker@ GRO-C >;Steve Chatfield"
<Steve.Chatfield@ GRO-C >;<srolcox@ GRO-C >;"Justin McCracken"
<Justin.McCracken@ GRO-C >;"Helen Janecek"
<Helen.Janecek@ GRO-C >;"Noel Gill" <Noel.Gill@ GRO-C >;"Nicky Connor"
<Nicky.Connor@ GRO-C >
Subject: Re: vCJD running on Telegraph website

To update on media interest, there is a v small news piece in today's Telegraph, with a more detailed piece on its website. The Sunday Mirror followed up on the story and is running a piece, although this too is small.

As things stand we will take no further comms action today and will reexamine tomorrow our timetable for releasing this story to the media. Obviously this is subject to further media interest today. We have reactive messages prepared if we need to respond to individual enquiries about the Tel piece. Thanks everyone for your involvement yesterday - especially Alex for handling the enquiries as they came in last night.

David

----- Original Message -----From: Lis Birrane To: David Daley; Mike Catchpole; 'Ailsa.Wight@ GRO-C <Ailsa.Wight@ GRO-C >; Alex Baker Cc: 'Elizabeth.Woodeson@ GRO-C >; Celizabeth.Woodeson@ GRO-C >; Steve Chatfield; 'GRO-C ' < GRO-C >; Justin McCracken; Helen Janecek; Noel Gill; Nicky Connor Sent: Sat Feb 14 20:35:47 2009 Subject: Re: vCJD running on Telegraph website

David

This is a sound proposal. It is important, if, as is likely, there is followup, that all our key messages are out there asap. Can I suggest that you make the most of any approach from PA to deliver these given that most media follow their lead and then proactively approach BBC Online. I suspect you would probably take this course anyway. I understand DH press office are fully in the loop. If the world does turn pear-shaped we can always get something on the website tomorrow. Do you want me to tee-up Mahesh tonight? Thank you for all your work on this. Regards Lis

----- Original Message -----From: David Daley To: Mike Catchpole; 'Ailsa.Wight@ GRO-C | <Ailsa.Wight@ GRO-C |; Lis Birrane; Alex Baker Cc: Elizabeth.Woodeson@ GRO-C |<Elizabeth.Woodeson@ GRO-C |; Steve Chatfield; ' GRO-C |<GRO-C |; Justin McCracken; Helen Janecek; Noel Gill; Nicky Connor Sent: Sat Feb 14 20:05:20 2009 Subject: vCJD running on Telegraph website

All

This story is already running on the Telegraph website (text below). Contains quotes from Hugh Pennington. His comments that the findings would have 'significant implications' for thouands of people who had been given plasma before the dangers were suspected is not helpful. However, he is also quoted as saying that the risks to those receiving plasma products now would be 'vanishingly low' given the measures that are already in place.

I would suggest that if approached this evening we continue to use the following messages –  $% \left[ \left( {{{\mathbf{x}}_{i}}} \right) \right]$ 

- We are aware of the recent post mortem finding that is referred to by the article

- We have prepared full information for those who might be legitimately concerned, and the doctors who provide their care, and that is are being disseminated on Monday.

- The priority is to ensure that those individuals who might be concerned have the opportunity to discuss the implications of the recent research finding with their doctors.

- The research finding does not does not change our understanding of the risk from vCJD for the general population but it does reinforce the importance of the precautionary measures that have been taken over the years.

I would also like to say - as we say in our draft press release...

- A final view as to how vCJD abnormal prion protein was transmitted to this haemophilia patient has yet to be reached because investigations are continuing to be sure of the source.

- This new finding does not change the public health vCJD 'at risk' status of patients with bleeding disorders. Haemophilia patients have previously been informed by their doctors of their possible increased risk of exposure to vCJD via clotting factors. In 2004 all patients with bleeding disorders who had been treated with UK-sourced pooled plasma products between 1980 and 2001 were told that, owing to potential vCJD infectivity from these products they were to be classified as at-risk of vCJD for public health purposes.

David

Scientists warn of first ever case of human mad cow disease from blood plasma

The first case of a person being infected with the human form of mad cow disease after receiving contaminated blood plasma has been identified by scientists.

By Patrick Hennessy and Laura Donnelly Last Updated: 7:12PM GMT 14 Feb 2009

The man was one of thousands of haemophiliacs who received blood plasma transfusions in the years before strict controls were brought in to eliminate the spread of variant Creutzfeldt-Jakob disease (vCJD).

Until now, scientists had maintained that the 4,000 people who may have received plasma from infected donors were at very low risk of developing the fatal brain disease. Warnings were issued to them as a "highly precautionary measure".

But the Health Protection Agency is expected to announce on Tuesday that an elderly man, who died from other causes, contracted vCJD from plasma.

Although vCJD has been transmitted by blood donations in the past, leading to three deaths, no cases of infection had ever been linked to plasma, which is used to clot blood. Scientists had believed the processing and dilution of the product before it is injected into patients significantly reduced the

risks.

BSE expert Professor Hugh Pennington, Emeritus Professor of Bacteriology at Aberdeen University said the findings would have "significant implications" for thousands of people who had been given plasma before the dangers were suspected.

"This looks like pretty grim news for a group of people who have been through fire and water for so long; they have already had increased exposure to hepatitis B and HIV," he said.

Warnings were sent to 4,000 haemophiliacs, and patients suffering from other rare blood conditions in 2004 to warn them that they had had received transfusions from 200 batches of blood products at risk of contamination with vCJD. The plasma was collected from nine people who went on to develop the brain-wasting disease.

All 4,000 were advised not to give blood or donate organs and to warn doctors and dentists that they had been put at risk by the use of plasma.

To date, 164 people have died from vCJD in Britain, with most cases linked to eating meat infected with bovine spongiform encephalopathy.

Prof Pennington said details of the way the new link had been detected would be crucial in determining further investigations.

"There is a lot more we still need to know. The fact that this person is elderly, when most of the deaths from vCJD have been young people, and that they died from another cause, is another area for research," he said, suggesting that it might mean that the disease progressed more slowly in some people.

He said restrictions over blood donation, which mean anyone who has had a transfusion cannot donate, and that all plasma is now taken from stocks in the United States, meant the risks to those receiving blood or plasma now were "vanishingly low".

The brain-wasting disease vCJD was first detected in the mid 1990s. Most vCJD patients have been infected after eating BSE contaminated meat. The number of deaths peaked in 2000, when there were 28 deaths. That number has dropped to about five cases a year since 2005.

The epidemic of BSE in the 1980s and 1990s was caused by cattle being fed the remains of other cattle in the form of meat and bone meal, causing an infectious agent to spread.

More than 4 million cattle were slaughtered after almost 200,000 were infected with the fatal neurodegenerative disease.

Scientists recently warned that Britain could see a second wave of the vCJD, affecting as many as 300 people, after discovering that genetic differences can affect how long it takes a person to incubate the disease.

From: Mike Catchpole Sent: Sat 2/14/2009 4:28 PM To: 'Ailsa.Wight@ GRO-C ; David Daley; Lis Birrane; Alex Baker Cc: Elizabeth.Woodeson@ GRO-C ; Steve Chatfield; 'srolcox@ GRO-C ; Justin McCracken; Helen Janecek; Noel Gill; Nicky Connor Subject: RE: Haemophilia/vCJD finding

Dear All

Just to summarise where this afternoon's discussions have taken us:

1. It appears that the Sunday Telegraph have had a fairly full "briefing" (source unknown) on the finding at post mortem of abnormal prion protein in the spleen of a haemophilia patient who had had no signs of vCJD. The journalist did not mention haemophilia during their conversation with HPA CfI Comms team, but otherwise seemed to be aware of most of the main points.

2. By the close of play on Friday (13/2) HPA and DH had developed and agreed a full set of letters and briefing materials for haemophilia patients and haemophilia centre doctors, and had agreed that these would be distributed on Monday, and that a public statement (press release) would be made on Thursday.

3. I have discussed with HPA Comms (David and Alex), DH (Ailsa), and HPA Senior Management (Roger and Steve) how we should respond to the approach from the Sunday Telegraph. The current proposed line is as follows:

a) we do not provide the Sunday Telegraph with an interview or any details of the incident, but do reiterate to the journalist that it would not be in the patients' or public health interest to run this story before those who might be legitimately concerned, and the doctors who provide their care, have been fully appraised of the facts. The rationale for this is that this might deter the journalist from running the story, but even if it does not, it is unlikely that any additional information that we might provide (and the newspaper prints) would substantially reduce the anxiety that such a story might cause haemophilia patients, and the fact that we provided information could be seen as compounding a communication that we believe to be wholly inappropriate in terms of public health interest

b) if the Sunday Telegraph does run the story and it generates enquiries on Sunday, then our line should be that we are aware of the recent post mortem finding that is referred to, and that we have prepared full information for those who might be legitimately concerned, and the doctors who provide their care, and that is are being disseminated on Monday. We would also say that we believe that the priority is to ensure that those individuals have the opportunity to discuss the implications of the recent research finding with their doctors, and that we do not propose to discuss the findings publicly until that communication has occurred. We would also emphasise that the research finding does not does not change our understanding of the risk from vCJD for the general population (can we use that phrase?) in any specific way. But it does reinforce the importance of the precautionary measures that have been taken over the years.

4. This is primarily a public health communications issue, but the level of interest may require that the HPA declare it as a level 3 incident. If that is the case, and I will discuss this with Lis after sending this email, then we probably do not need to establish an EOC before Monday

5. It is likely that the process of dissemination of professional and public information, and the issuing of the agreed press briefing, will need to be accelerated; and we may need to consider couriers or electronic mechanisms for getting materials to haemophilia centre doctors on Monday.

Regards

Mike Catchpole

-----Original Message-----From: Ailsa.Wight@ GRO-C [mailto:Ailsa.Wight@ GRO-C ] Sent: 14 February 2009 14:09 To: Mike Catchpole Subject: Fw: Haemophilia/vCJD finding

Holding line as discussed - agreed yesterday pm. Hopefully David D in your comms already has this.

Message sent from a Blackberry handheld device.

From: Rowena Jecock
Sent: 13/02/2009 18:09 GMT
To: Judith Moore
Cc: Elizabeth Woodeson; Ailsa Wight; Mark Noterman
Subject: Haemophilia/vCJD finding

Judith, Many thanks for agreeing the attached as a holding line, and sharing with HPA & NHSBT.

"There are ongoing surveillance and monitoring studies involving patients who have been told they are at increased risk of vCJD. Results from one of these studies will be reported next week."

Grateful if you could inform the w/e duty press officer(s) that if there are media queries about vCJD In a haemophiliac patient that seem to be well-informed rather than fishing expeditions, it is very important that the journalists concerned understand that premature reporting would be irresponsible. Affected patients and their doctors must be informed before this is reported in the press.

Early reporting would be prejudicial to the care of the patients concerned.

To reduce the possibility of a leak in the media we would, as I believe you have discussed with my colleague Mark Noterman, much prefer to go public on Wednesday rather than Thursday. Grateful if you could advise asap on Monday.

Our mobile nos, should they be needed over the weekend, are: Ailsa Wight Mark Noterman Mine

You have given us your mobile, and the newsdesk contact no (in case we need either). They are: (yours)

Thanks, and have a good weekend,

Rowena

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