

Charles Lister  
18/03/2003 11:43

To: Jill Taylor/PH6/DOH/GB@DOH, Zubeda Seedat/PH1/DOH/GB@DOH  
CC:  
Subject: Re: HIV, HEPC, vCJD, Haemophiliacs: Testing for infectious diseases

More on the Carol Grayson issue raised by Briony Enser.

----- Forwarded by Charles Lister/PH6/DOH/GB on 18/03/2003 11:41 -----



"Dr J W Ironside"

<jwi@GRO-C  
uk>

18/03/2003 09:47

To: Rowena Jecock/PH6/DOH/GB@DOH  
cc: Charles Lister/PH6/DOH/GB@DOH  
Subject: Re: HIV, HEPC, vCJD, Haemophiliacs: Testing for infectious diseases

Dear Rowena,

Thanks for your message. I think that the best person to contact concerning the ethics of the current prospective study would be Prof Christine Lee at the Royal Free Hospital. Christine is the Director of the Haemophilia Centre there; her email address is: Christine.Lee@rfh.nthames.nhs.uk.

Christine will be able to inform you about the criteria for entry into the study and the issues of consent. From my own experience, the results of any investigations are sent to local clinicians who (I assume) discuss the findings with the relatives concerned.

Concerning the previous retrospective study, the cases included were collected for research on HIV and the level of consent at that time was deemed to be sufficient for additional research on CJD.

I hope this is helpful,

Best wishes,

James.

> A further query has come up on this I'm afraid, and I thought it best  
> to ask you directly. As we have previously discussed, the  
> requirements around what explicitly needs patients'/relatives' consent  
> are changing. Do your rules currently allow you to undertake  
> examination of brain tissue for possible CJD without the explicit  
> consent of patients or their families?

>  
> From what you have said about the retrospective review of haemophilia  
> cases, it seems unlikely that there was any requirement at that time  
> to go back to families to request their permission for further  
> examination of brain tissue to look for evidence of CJD pathology.  
> Grateful if you could confirm whether this assumption is correct.

>  
> We do not intend to provide a detailed response to Ms Grayson, but it  
> would be useful to better understand the background from your  
> perspective. Given the sensitivity of all of this, we will arrange  
> for you to see a copy of the draft response, in case you feel any  
> amendments are needed.

>  
> Rowena

> Tel: ++44 GRO-C

> Fax: ++44 [GRO-C]  
> Email: rowena.jecock@[GRO-C]  
> ----- Forwarded by Rowena Jecock/PH6/DOH/GB on 17/03/2003 17:02 -----

>  
> Rowena Jecock  
> To: "Dr J W Ironside"  
> <jwi@[GRO-C]  
> 17/03/2003 cc: Ailsa  
> Wight/PH6/DOH/GB@DOH, Mary 14:49  
> Holt/PH6/DOH/GB@DOH  
>  
> Subject: Re: HIV, HEPC, vCJD,  
> Haemophiliacs: Testing for  
> infectious diseases (Document link:  
> Rowena Jecock)

> Dear James,  
> Many thanks for your help with this! I shall ask John Stephenson for  
> further information on the studies you mention.  
>  
> Rowena  
> Tel: ++44 [GRO-C]  
> Fax: ++44  
> Email: rowena.jecock@[GRO-C]

> - - Disclaimer - -  
> This e-mail and any files transmitted with it are confidential. If you  
> are not the intended recipient, any reading, printing, storage,  
> disclosure, copying or any other action taken in respect of this  
> e-mail is prohibited and may be unlawful. If you are not the intended  
> recipient, please notify the sender immediately by using the reply  
> function and then permanently delete what you have received.  
>  
> Incoming and outgoing e-mail messages are routinely monitored for  
> compliance with the Department of Health's policy on the use of  
> electronic communications. For more information on the Department of  
> Health's e-mail policy click here  
> <http://www.doh.gov.uk/emaildisclaimer.htm>  
>  
>

Professor James W Ironside  
Director  
National CJD Surveillance Unit  
University of Edinburgh  
Western General Hospital  
Edinburgh  
EH4 2XU  
Scotland  
UK

Tel: [GRO-C]  
Fax: