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RDD-PROG Documents - Unformatted Document

"Letter from Professor Frank Hill"

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John

Prof Hill is Professor of Paediatric Haematology & Chairman of UKHCDO at the Department of Clinical & Lab. Haematology at Birmingham Children's Hospital NHS Trust. He particularly asked for you to be invited to the meeting, so although you don't know him he seems to know you.

I have attached his recent email to Ailsa.

Lee Robertson
PA to Dr Ailsa Wight
Head of Programme,
General Health Protection,
Standards and Quality Group
640 Skipton House

GRO-C

----- Forwarded by Lee Robertson/PH6/DOH/GB on 13/07/2005 12:34 -----

"Mann Pat (RQ3) BCH"

<PAT.MANN@GRO-C

GRO-C

16/06/2005 14:19

Wight/PH6/DOH/GB@GRO-C

To: Ailsa

cc: William Connon/PD-

PMD/DOH/GB@GRO-C, Julia Stallibrass/POLICY/DOH/GB@GRO-C

'Noel Gill' <noel.gill@GRO-C>, 'Charles Hay'

<CHAY@GRO-C>, 'Don Jeffries'

<d.j.jeffries@GRO-C>, Rowena Jecock/PH6/DOH/GB@GRO-C

bcc:

Subject: Letter from

Professor Frank Hill

(Dictated by Prof. Hill on 16.06.05.)

Dear Ailsa,

The purpose of this email is threefold:-

1. To update you on the progress of using the National Haemophilia Database to record information on vCJD risk to haemophilia patients from UK blood products.
2. Collection of follow-up data and how and with whom this should be shared.
3. To seek your advice on how UKHCDO may secure funding for the National Haemophilia Database to ensure the continuation of the prospective epidemiological study of vCJD risk to haemophilia patients.

Prior to last September's patient notification exercise by DoH & HPA of potential risk of vCJD from blood and blood products, it had been agreed that UKHCDO should collect data on exposure risk to haemophilia and other bleeding disorder patients and record it on the National Haemophilia Database (NHD) together with other treatment associated risk data. This approach had been advocated by the Haemophilia Society, Haemophilia Nurses Association, UKHCDO and endorsed by the vCJD Incident Panel.

The National Haemophilia Database now at Manchester Royal Infirmary was first set up at Oxford in 1968 and annual data collections have been obtained from UK Haemophilia Centres since 1968. The data sets have changed but the resource of the NHD has proved invaluable in planning haemophilia care, documenting adverse events and in research.

How are we dealing with vCJD?

- (1) We have interrogated the existing data sets stored on the NHD and have determined the numbers of patients by diagnostic categories that have been treated with UK sourced plasma products or with non-UK sourced plasma or recombinant products (see attachment).
- (2) These patients have now been broken down into 5 year age bands and this data is to be sent to the HPA to calculate expected incidence of vCJD from dietary exposure and a level at which increased risk from blood product exposure would be suspected (see attachment).
- (3) We have received 3086 notification forms. Patient details are being checked against patients on the NHD and any registration anomalies queried and corrected. We can identify shortfall in notification and will chase outstanding data. A few patients have refused permission to submit their data.
- (4) The extension of database fields to incorporate the vCJD exposure data has been agreed and I will shortly submit an application to John Stevenson for an extension of the existing grant held by Professor Christine Lee and myself on behalf of UKHCDO to allow for this software development and for short term funding for data entry.
- (5) As all patients on the NHD are flagged by the Office of National Statistics (ONS), we receive all death certificate information on haemophilia patients together with information from the patient's Haemophilia Centre. This has allowed an annual evaluation of cause of death in this patient group and has provided valuable information of mortality from previous treatment related illness and mortality with HIV and HCV over the years. We hope to identify which deceased patients have had post-mortems and whether material is available for study.
- (6) Myself and the Deputy Chairman of UKHCDO, Charles Hay, have met with Noel Gill, Anna Molesworth and Kate Soldan to discuss the data we require from the NBA, BPL and the National vCJD Surveillance Unit, to be able to

make risk calculations for patients who have received implicated batches of product.

(7) A UKHCDO Task Force, chaired by myself, is being set up to ensure continuity in handling this issue. We will seek HPA representation on this Task Force.

Subject to obtaining the grant extension funding, this is all achievable and we will have not only identified those at increased risk of vCJD, but also have an appropriate control group for a prospective epidemiological study, provided we can ensure the continued funding for the National Haemophilia Database.

I would value your advice on how we may achieve the necessary funding to maintain and run the National Haemophilia Database, both in the short and long-term. UKHCDO is a registered charity and we organise and finance the database. The latter has been achieved during the last six years, while I have been Chairman, by unrestricted grants from the pharmaceutical industry and from the DoH for projects like the recombinant rollout. UKHCDO also provides information on haemophilia care for the DoH for numerous and regular parliamentary questions, posed by the Haemophilia Society through it's parliamentary lobby, headed by Lord Morris.

The commissioners and DoH have appreciated the value of the NHD as a result of the role of NHD & UKHCDO in managing, informing and auditing the DoH phased recombinant rollout programme. Julia Stallibrass has been involved in UKHCDO and commissioner discussions about building on Haemophilia Centre data systems and the NHD, to facilitate and inform the management of Haemophilia Services in England. Julia would be able to provide you with more detail on these discussions.

I will be in London at Skipton House on Monday 20 June 2005 for a DoH Recombinant Rollout Monitoring Group meeting. William Connon and Julia Stallibrass will be at the meeting. Do you have a window of opportunity at the end of the afternoon so that the four of us could meet? I will try to contact William later today to check his availability.

I realise this is short notice and may not be practicable. I am very willing to come to meet with you at your convenience to discuss how we may take this important Health Protection issue forward and ensure the initiative of setting up this important epidemiological study can continue because of the important information it will provide.

Yours sincerely,

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

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Enc: Attachment(s).

<<vCJD_NHD patient receiving UK products.xls>>

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vCJD_NHD patient receiving UK products.xls