

22rd April 1996



Dr P Hewitt
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Dear Pat

Re: CJD and Blood Transfusion

At the last SACTTI meeting you should have received a copy of the notes that Peter Flanagan made with regard to the "brainstorming" meeting we held in Edinburgh recently. Part of the proposals for obtaining more information with regard to the epidemiology of and transmissibility/infectivity or not of CJD/BSE by blood transfusion was to attempt a limited form of Lookback in collaboration with the CJD Surveillance Group in Edinburgh. A key element to this proposal would be exchange of donor/patient information only between the NBS and the CJD surveillance unit, with no notification of recipients who may have received blood transfusions from donors who later developed CJD. I haven't time now to completely brief you but I know that Peter Flanagan will be contacting you in the near future to fully brief you with regard to this situation.

However, I am formally asking you if, together with Jack Gillon, you could start drafting a proposal for a CJD Lookback study prepared in a format that could be submitted to an ethical committee and also to obtain legal advice from Stephen Janisch with regard to not informing recipients, but only only exchanging data with the CJD Surveillance Unit. I am sorry I haven't time to give you more details - Peter will be able to complete the picture - but it does look as if the MSBT (Jeremy Metters) and the minister are now keen to go down this route. Jeremy has seen Peter Flanagan's notes of the Edinburgh meeting and is anxious for us to follow through with a proposal for a "limited" CJD Lookback, i.e. establish the baseline and be ready to check for any epidemiological changes now 14 cases of this new CJD variant have appeared since 1994, and it was Jeremy's suggestion that any proposal (where the recipients will not be informed) needed to be submitted for Ethical Committee approval and legal advice.

I'm in Strasbourg this week, back for an NBS Board meeting on Thursday. The MSBT meeting is May 2nd when the CJD situation will be discussed - I'll contact you when I get back to see how things are going.

I hope you'll agree to tackle this one! Many thanks and best wishes.

Yours sincerely

GRO-C

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