



Gillian Tutt  
18/01/2001 12:03

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Subject: vCJD and haemophilia

Tracy

You will know from my previous e.mail and the attached that I have taken up this issue with Chris Kenny. The story so far is:

Some time before Christmas, there was limited media coverage of the recall of some batches of blood products because of possible contamination with vCJD (from a previous donor who is showing possible signs of vCJD). There has been a recent national meeting to discuss this and its implications - particularly for haemophiliacs and Factor VIII. Representatives of the National Haemophilia Association were present and discussion took place around whether, when and how possibly affected haemophiliacs should be notified, particularly in the light of the fact that, even if they have received any of the affected batch, they may not be infected, vCJD is extremely difficult to diagnose and there is no known cure. It was decided that at the very least they should be given the opportunity to decide if they wished to know whether or not they may have received products from the infected batches. Sheffield blood bank was one of the centres to receive possibly contaminated batches. In the event, it is thought that the National Haemophilia Association has recently written to all haemophiliacs regarding this issue.

All this is the background to the copy correspondence you received yesterday, which Lindsey sent to you. Chris says they too were unaware of this until yesterday although Sheffield HA have been aware for a while. After speaking to Chris, he offered to find out what was happening nationally on this - particularly on the national lines. He eventually spoke to Mike McGovern who is already well briefed on this - being a national issue. The Department is in the process of revamping some guidance issued three years ago by Graham Winyard. Essentially it is still valid but is being tweaked in the light of the latest developments. Mike is also to obtain a copy of what the National H Association has issued. It is thought the Association is also drafting a letter which can be used by the Trusts to communicate with individual patients.

The bottom line is, therefore, this is being handled nationally and, presumably, national lines to take will shortly be available. Unless and until there is any local media coverage or PO/TO correspondence, I don't think there is much for us to do at present (famous last words). It might be helpful as some stage though to have a quick word with Chris Horner (or Horsfield - whoever that is!) to check he is aware and ready.

Chris Kenny's point about the availability of counselling is a good one, which he is pursuing.

----- Forwarded by Gillian Tutt/TRRO-CORPA/DOH/GB on 18/01/2001 11:32 -----



Christopher Kenny  
18/01/2001 11:29

Sent by: Christopher Kenny/TRRO-PH

To: Chris.bentley@GRO-C  
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Subject: vCJD and haemophilia

Chris - Lindsey passed to me some correspondence yesterday from Mike Makris (Haematologist at the Sheffield Haemophilia Centre) to David Ferguson about the issue of some haemophiliacs being given Factor VIII from pooled blood, which is now known to have come from a patient who has recently developed vCJD. The official line from the DoH is still that which is written in a letter from Graham Winyard to Trust Medical Directors dated 6 February 1998. This is probably going to be updated slightly in the near future, but will essentially be the same.

It is entirely reasonable for the Sheffield Centre to write to all haemophiliacs telling them what has happened and asking whether they would like to know if they have received any of the "contaminated" Factor VIII. It sounds as though a standard letter is being used for this organised by the UK Haemophilia Centre Directors Organisation. The only issue to be resolved locally is the nature of the counselling that will be offered to patients who want to take up the offer of knowing, and whether this is being done properly. It would be helpful if you would liaise with David Ferguson about this, to ensure you are satisfied about what will happen over the next month or so.

Regarding and media involvement, there has been none to date as far as I am aware, but no doubt this will not last long. It would be helpful if our Comms leads liaised over appropriate possible press statements, so that we are ready to respond if necessary.

Please get back to me if you want to discuss this further.

Thanks

Chris