Charles Lister

17/01/2003 18:40

To: Vicki King/PH6/DOH/GB@DOH
cc: Jill Taylor/PH6/DOH/GB@DOH, Zubeda Seedat/PH1/DOH/GB@DOH, Hugh Nicholas/PH6/DOH/GB@DOH, Gerry Robb/PH6/DOH/GB@DOH
bcc:
Subject: TESTING OF HAEMOPHILIA PATIENTS FOR HCV

Vicki

I've been talking to Prof Frank Hill (UKHCDO Chair) about the allegations that patients were tested for hep C without their knowledge and that some found positive were not told until years later. He thinks that this is quite likely to be true.

There are various possibilities:

- some patients were included without their knowledge in blind trails to evaluate the early antibody test;
- when the test became available, there may have been concern that telling a positive patient the bad news would have an adverse effect on them emotionally and served little purpose, eg if they already had HIV. Most haemophilia patients would have been counselled in general terms about the risks from hepatitis, including non A non B virus, including advice on how to avoid the risk of infecting partners;
- there was concern that no one knew exactly what a positive antibody test actually meant in terms of whether a person was going to develop the disease. Patients may therefore not have been told for that reason or again because the evidence was not felt to be strong enough to risk causing the patient emotional damage. It was only with the introduction of PCR testing that it became possible to counsel effectively on the test results and what they meant
- some may have been children, so there parents may have been told but not them.

On the more general question of access to patient records, Frank has reminded centre directors of access rights under the Data Parotection Act. However, patients have often been very unspecific about what they want to see.

Charles