Copy Letter to consultant prior to notification on [illegible] 20-Sept 2004

1ST September 2004

GRO-C

CJD INFORMATION

Dear Dr Talks,

GRO-A and I are sending you a copy of an article from the "Sunday Herald" on v CJD and blood transmission, information which I understand was leaked to the press. I have been informed by NHS Direct that they are not sufficiently briefed to deal with inquiries on this aspect of CJD exposure until 22nd September when an official helpline will be set up.

We hope that we will not be told the same old rubbish about pooled plasma "diluting" the prions. We were initially told that pooled plasma diluted the HIV and hepatitis viruses, therefore there was a low risk of infection. In fact it was the opposite effect, according to the CDC, one contaminated batch could infect the entire plasma pool!

We are disgusted that in the case of Newcastle haemophiliacs exposure to vCJD was entirely preventable. We first wrote requesting recombinant for haemophiliacs in 1995, we were turned down in writing in Spring 1996, and GRO-A's first exposure was in the Autumn of 1996. What is so sad is that no-one listened to us, money was placed before safety, and we are aware that young haemophiliacs who missed infection with HIV and hepatitis C, have now been exposed to, and may be incubating vCJD.

Our understanding from recent legal cases regarding blood contamination is that patients have a right to expect safe blood after 1988 under the Product Liability Act. GRO-A and others have been given defective products, and we would like to ask the PCT what redress we have with regard to this situation.

We have documented a number of incidents related to GRO-A's vCJD exposure which highlight the effects of being exposed to v CJD, in terms of hospital treatment, insurance, discrimination, etc. Will the hospital now be holding meetings with those patients who were exposed to vCJD to discuss the implications of being exposed?

On the matter of the 2nd stage forms for the Skipton Fund. I understand from enquiries made to the Department of Health that they are to be made available very shortly, and assessment will look at non-invasive procedures with biopsies playing no part.

Enclosed is a copy of "Private Eye". We are still trying to gain access to "suspect" numbers batch for hepatitis for our American lawyers, and to add to evidence here. We are aware from old UKHCDO minutes of meetings from the early 1980s that Dr Craske specifically requested that haematologists "continue to collect suspect treatment batch numbers for hepatitis (including non-A, non –B, hepatitis) on the forms provided". As Newcastle staff were recorded as attending these meetings we would presume this was carried out at as requested for the Department of Health funded 3 three year study looking at hepatitis infection rates in haemophiliacs. How can we access this information? There are two questions which remain unanswered, the first question is, were these suspect batches withdrawn from treatment as soon as they were identified, and secondly, were patients who received these suspect batch numbers informed they were likely to have been infected with hepatitis viruses, and any known infections recorded as adverse incidents.

Lord Morris.

please note that this is the current situation unless there are ~~exp~~ further exposures prior to 1995.

We look forward to your reply. Thank-you for your help.

Yours sincerely

GRO-A

Cc Len Fenwick
Mike Laker