7th September 2003

GRO-C

Tel: GRO-C

REQUEST FOR HELP RE SUSPECT BATCH NUMBERS HEPATITIS

Dear Dr Hay,

I have written to you on one previous occasion but unfortunately you were unable to assist me at that time. I have spoken to Lynn Dewhurst so that my husband can access any information on his treatment from the database and we are returning the consent forms. I am writing directly to you however to request your help to access certain other information as detailed below.

I recently acquired UK Haemophilia Centre Director Organisation minutes for 29th April 1982, which was very well attended by haematologists, Government officials, and Haemophilia Society representatives. I note that at this meeting Dr Craske presented his report from the Hepatitis Working Party, (circulated to all Haemophilia Centre Directors), which summarised the findings of the three -year retrospective study on hepatitis B and non-A, non-B hepatitis (hepatitis C) in haemophiliacs. I was particularly interested to read that Dr Craske felt it important to CONTINUE to collect data on the batch numbers of materials received by patients who developed hepatitis. He thought it might be necessary in the future to again ask for details of all patients who had received treatment with a particular "SUSPECT" batch of concentrate.

I would be grateful if you could assist me to access the information collected on "suspect" batch numbers for hepatitis for my husband and other haemophiliacs. Do you know if cases of hepatitis were reported as adverse clinical reactions and if so where would I find this information? Were "suspect" batches for hepatitis withdrawn from treatment to prevent further cases of hepatitis? Is this information on the UKHCDO database or does this information lay with Dr Craske, and if so how can I contact him? Do you have an address?

As I am sure you are aware many haemophiliacs have or are in the process of obtaining their medical and treatment records, including batch numbers of plasma products they received for the American litigation against four major plasma companies. You are no doubt also aware that I set up the contact with U.S. firm Lieff, Cabraser, Heimann and Bernstein for UK haemophiliacs about 18 months ago and the first UK cases were filed in the U.S. courts on June 2nd 2003. It would be very helpful to have the information on suspect batch numbers collected by Dr Craske made available to infected haemophiliacs. Any data identifying suspect batch numbers for hepatitis can be traced back as you know to companies and named brand products which would add to the wealth of evidence already collected.

Haemophiliacs on home treatment of factor concentrates were required to record the following information on cards as a legal requirement, at least that is what they were told by Haemophilia Centre staff. They were also informed that if they did not record the following, they could be removed from home treatment.

Batch number
Name of product
Name of company
Number of units
Site of bleed
Expiry date of treatment
Date treatment was administered etc

We are now finding that hospital staff often failed to follow their own instructions and part of the treatment details if not all in some cases are missing. The omission of batch numbers is very worrying as batch numbers may have been required as part of a look-back exercise in the case of contamination with hepatitis or with regard to any other adverse clinical reaction. This is of concern to patients, as this failure to record appropriately may prevent some patients taking a case forward in the U.S. This has caused great distress to some haemophiliacs and patients have in some cases had no choice but to approach the General Medical Council to report their concerns alongside other matters.

I appreciate that you may not have been working as a haematologist in 1982 but you have access to some of the haematologists who were present at that meeting and unlike the patients would have been fully aware of the concerns around hepatitis viruses. There must be a lot of pressure on haematologists at this time, wouldn't it be better for all concerned if we all finally faced the truth about what happened to the our community and learned lessons from the incidents that led up to the mass contamination and deaths of so many haemophiliacs. What we need is a full and open public inquiry and I fail to understand why haematologists have not supported their patients on this issue.

I understand from a phone call that I received from a fellow campaigner that a former patient of Dr Stevens (Manchester) approached him recently for his medical/treatment records so that he could take a case forward in the States, the patient was told that his records had been destroyed. This patient obviously can't chase up his missing records as sadly I understand Dr Stevens is still missing but haemophiliacs with a life- long condition do need to know why in some cases their records no longer appear to exist.

I note also that cases of non-A, non-B hepatitis were actually being linked to named brand products such as Koate, Hemofil, etc as far back as the 1970s. It appears that haematologists "forget" to mention or discuss the non-A, non-B hepatitis risks with patients, allowing them to make an "informed choice" as to whether or not to risk taking factor concentrates (especially the commercial products) which in some cases were referred to by experts as "EXTAORDINARILY HAZARDOUS", with a "4 TO 20 TIMES HIGHER INCIDENCE OF OVERT NON-A, NON B HEPATITIS ASSOCIATED WITH U.S. COMMERCIAL CONCENTRATE THAN ASSOCIATED WITH NHS".

I note that in 1982 Dr Craske was also stating he would be interested to receive post-mortem specimens of liver from haemophilia patients who came to autopsy, especially where there was evidence of chronic liver disease. Do you know if this happened? Was the permission of relatives sought and were relatives of the deceased informed of any evidence of links to chronic liver disease? Dr Craske also hoped that Directors would "CONTINUE to report cases of chronic hepatitis to the Working Party on the appropriate form". There is obviously a lot of useful information here that many haemophiliacs would wish to access.

I enclose recent press cuttings for your information and call once again for haematologists to support the call to Government in writing for a full and open public inquiry into the infection of haemophiliacs. It is only with a public inquiry that haemophiliacs can move on with their lives and hopefully regain some confidence in those that treat them.

I would be grateful if you could reply to me in writing as soon as possible with answers to the questions above. Thank-you for your help.

Yours sincerely

Carol Grayson (Haemophilia Action UK)