GRO-C

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16. 11. 2000

Dear Jim,

Its seems little has changed regarding information to patients. Here is a copy of a letter I received from a friend. It states patients (haemophiliacs) should not be informed that certain blood products were recalled because a donor was found not to have met the current health requirements for CJD !!!

I have also enclosed a letter from another partner of a haemophiliac in the same situation as ourselves regarding co-infection. I would welcome your comments on both letters.

Thanks

GRO-C

Copy for Sum of-

GRO-A

GRO-A

Tel: GRO-A
Email: GRO-A

17 November 2000

Mr J Sayeed
Member of Parliament
Mid Bedfordshire District Councils Office
Dunstable Street
Ampthill
Bedfordshire

PRIVATE & CONFIDENTIAL

Dear Mr Sayeed,

RE: Infected with HIV and HCV and now possibly nvCJD

Prior to my having an appointment with you on Friday 10th November, I am writing to you with regards to a very serious and important matter. Therefore, you will note that my letter to you is rather lengthy, please accept apologises for this.

My husband GRO-A is a Haemophiliac and is under treatment at a Haemophilia Centre in London. In 1982 he became infected with HIV and HCV (hepatitis C virus), through contaminated factor VIII, and presently he is on combination drugs for the HIV.

In December 1997 he received a letter from the hospital stating that he had already been given Factor VIII, which was recalled due to one of the donors not reaching present health guidelines for CJD. At the time we were very concerned, but trusted what both the Government and the health professionals were saying, "there is no need to worry". When the Phillips Inquiry was made public on the 26th October of this year, again we became very concerned, and on behalf of my husband, I started to investigate the possible risks to him.

To my horror I found out that at present, scientists have not been able to rule out the possible risk of vCJD being transmissible through blood product. They state that if it is happening then the people most at risk would be the haemophilia population (over 10,000 donor's plasma is pooled in one batch and then divided into individual treatments). As you can imagine, we are very deeply concerned at present, as 16 of the victims of vCJD did indeed receive blood transfusions, and trials on sheep and on mice have confirmed that the disease can be passed on within same species, through blood.

On the 31st October 2000 we saw GRO-A's doctor at the hospital. We discussed our concerns with her and as we had also recently become aware that there has been available since ***1995, (two years prior to my husband receiving recalled blood product)*** a safer, non-human alternative factor VIII, this is referred to as "recombinant." This was also discussed with the doctor. We asked if my husband could receive this safer treatment instead of the present human Factor VIII treatment, to which we were told **NO!** We were informed that this was due to DoH policy, i.e. only haemophiliacs under 16 years of age could receive recombinant treatment. She also informed us that most haemophiliacs throughout the rest of the world are now on recombinant. It is also known (within the haemophilia community) that there are other Haemophiliacs who are over 16 and virally free, receiving the recombinant treatment.

We are enraged at all this and can not understand why the Government would have such a policy as there has already been two mayor killer diseases having been introduced into the haemophilia community, i.e. HIV and HCV. This was through contaminated/bad blood, and we feel that this is being done yet again. Unfortunately, my husband has tested positive to two of these diseases and is now at risk of being infected with the other.

I'm sorry, but I feel that the Government would like nothing better for those haemophiliacs already infected with HIV and/or HCV to be also infected with vCJD. And feel that their attitude is, "after all they are already dying, why not expose them yet again to another killer disease, then we will have the controlled group needed, in which to study and find out more about this disease". I may be wrong and I hope I am, but I can find no justifiable explanation as to why the Government would not allow these men to have safer factor VIII treatment. It seems madness, sheer madness to expose them to yet another killer, and who knows what may be uncovered in the future that we presently don't know about. Surely this policy, in light of past infection of HIV/HCV, is entirely unethical and immoral to say the least possibly negligent.

We never did have a public enquiry into the HIV contaminated blood product given to haemophiliacs, and we feel very strongly about this, not only because we never found out the full truth about what happened in the past. Now there is a more urgent need for a public enquiry due to a similar situation now happening again with vCJD. We ask ourselves, "won't this contamination of blood product ever end?" Especially as there is a safer alternative available. My husband's life, together with other haemophiliacs, has been and still is, in the hands of those to whom it is given the very powerful role of making the decisions pertaining to his, and others, health treatments.

When the Government made the "out of court settlement" with the haemophiliacs infected with HIV, all the plaintiffs had to sign a waiver stating that they would not bring the Government or Health Authorities to court over infection of hepatitis. The majority of haemophiliacs that were co-infected i.e. HIV and HCV, did not know that they had HCV, and were not told until after the settlement, my husband being one of them. In fact my husband was only told recently that he is HCV positive and that he had been infected since 1982.

We as a community we get enraged when this present Government will call for an inquiry into why 4 people died at the Hatfield derailment and then throw money at the perpetrators of such a tragedy. What about our tragedy? Over 800 haemophiliacs have died due to HIV/AIDS and many have died due to HCV. We can only guess at the figures for vCJD, if it proves to be yet another killer among the haemophilia community, it may very well completely wipe out the haemophilia population, as vCJD seems to be the most deadly of all, so far. This present government has said categorically that they will not have a public enquiry into the HIV tragedy. I want to know why not?

Mr Sayeed, we are asking you as our Member of Parliament to support and campaign on our behalf. We have a number of objectives, the first being the most urgent, i.e. that the DoH's policy on not allowing **all haemophiliacs** the recombinant Factor VIII, be overturned. The second is for a full and public inquiry into contaminated blood, which infected over 1,200 haemophiliacs with HIV, we also an investigation into the matter of haemophiliacs having been infected with HCV, of which, some were infected with both killer diseases. There is one other MP, I know of, campaigning on behalf of a couple in the same situation as us and he is Labour MP for Newcastle Central Jim Cousins, his number is GRO-C He is very much aware of all the issues pertaining to this situation, and I would ask you to please contact him for further information.

I have enclosed a number of articles for your perusal, and would ask, "Are you going to please help in this very serious situation?"

Yours most gratefully,

Mrs GRO-C

Encs.

cc. Jim Cousins - MP
Patrick Hall - MP

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Facsimile Transmission

To: Angus McGraw

Customer: Royal Free Hospital
Of: Pond Street London

Fax Number: GRO-C
From: Customer Services Department
Total pages: 1
Date: 04/11/97
Subject: Product Recall Incident No. PR97/208/25

Product Recall

In accordance with instructions received from the MCA, based upon advice received from [illegible], Bio Products Laboratory have initiated a recall of the following product some of which your organisation has received. The recall is a precautionary measure only related to post donation information. Subsequent to donation the donor was found not to have met the current health requirements for C-JD. The advice from the Lothian Ethical committee is that the recipients (patients) should not be informed that product that they have received has been recalled for this reason.

Product Names:	batch	dose	expiry
Factor VIII type 8Y	FHB4547	500iu	19/09/99
Factor VIII, Replenate 500	FHE4548	500iu	02/09/98
Human Albumin Solution Zenalb 20	ABD0319	50ml	06/08/98
Human Albumin Solution Zenalb 20	ABD0324	50ml	04/09/98
Human Albumin Solution Zenalb 20	ABD0325	50ml	05/09/98
Human Albumin Solution Zenalb 20	ABD0332A	50ml	05/08/98

Quantity, Batch number(s) and date(s) of dispatch to you:
400 of FHE4548 on 1/11/96

You are kindly requested to return any remaining stock that conforms to the above batch details.
If you have no stock left you should confirm that in writing.
Please recall any of the above material that you have supplied. Action under the recall should be completed within 48 hours.
Please note that before returning any stock to BPL you must contact our sales office on 0181 258 2251 or 0181 258 2267 to arrange return and delivery of replacements. We will, of course, replace such stock free of charge.
Product is to be returned to our Dispatch Department, labelled with Incident Number PR97/208/25 and containing the senders name and organisation.

We apologise for any inconvenience that this recall may cause you.
Yours sincerely,

Pam Hurd
Customer Services Manager