Central Manchester and Manchester Children's University Hospitals
NHS Trust

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Our ref: CRMH/KJ/hep c/carol grayson & peter longstaff

5th November 2003

Mrs C Grayson & Mr P Longstaff

GRO-C

Dear Mrs Grayson and Mr Longstaff

Thank you for your letter of the 7th September. I am sorry I have been slow to respond to it. I enclose a copy of your letter by way of reminder and have the follow comments:-

Your paragraph II; I was not a Centre Director at that time, but can tell you that it would not be usual for the meetings to be attended by government officials or representatives of the Haemophilia Society. Are you sure of the status of the attendees? I would be interested to know where you actually got these minutes. Batch numbers may have been collected locally but were never collected centrally and we have no batch data in the database whatsoever. The idea that there were good batches and bad batches is completely absurd and is refuted by a paper co-authored by Dr Craske in the BMJ of October 31st 1983, in which he showed, probably for the first time, that everyone got hepatitis C from their first exposure to factor VIII concentrate *regardless of the geographical origin of the concentrate.*

Paragraph III; Dr Craske retired many years ago and I have no idea how to contact him or what information he may hold. We certainly have no central records of suspect batches and, from the above you should recognise that hepatitis C was transmitted by all batches at that time.

Paragraph IIII; I note your comments on medical records. These stipulations actually post-dated the period of greatest interest since $^2/_3$ of patients were infected before 1977. The quality of medical records 25 years ago was not what it is now. Furthermore, there is only a legal requirement to retain medical records for 7 years, this period relating to the statute of limitations. Whilst I have every sympathy with the objectives of the legal action, to be honest I really do not understand how the lawyers expect to get around the statute of limitations. Partly because of the statute of limitations, I do not think that any haemophilia centre will have expected to keep detailed records of all the treatment that they offered for a quarter of a century of more. For that reason I think it is a little harsh to criticise haemophilia centres for not having this data now. I also think it is completely misguided of you to stir up complaints to the General Medical Council. I cannot see that this will achieve anything constructive and it can hardly be calculated to encourage support from the medical community for your campaign.

In relation to your last few paragraphs I would make the following comments:-

The assertion that American factor VIII was more hazardous that British, in relation to hepatitis C, is complete nonsense. When hepatitis C testing became available, it became apparent that perhaps 0.5% of donors were carriers of hepatitis C. Since plasma-derived factor VIII is manufactured from batches of tens of thousands of donations, inevitably every batch would have been contaminated with a number of donations from donors with hepatitis C and concentrates from all geographical origins were equally infectious. Of course many patients were already infected from cryoprecipitate, especially if they had severe haemophilia and were regular users.

You discuss informed choice. Although it was before my time, I know that there was discussion across many countries back in the 70s and early 80s about whether to continue to use concentrates and the consensus in every single country was that one should continue to use them. When trying to understand this decision, you have to put it in to its correct historical context. Firstly, until well in to the mid-80s, hepatitis non-A, non-B was generally considered to be benign and non-progressive and, therefore, not to constitute much of a hazard. In the mid 80s several papers appeared which showed that, in a proportion of patients, it was a progressive and serious condition. Secondly, you have to consider the impact that factor VIII concentrate had both on joint disease, quality of life and life expectancy in haemophilia. The life expectancy of severe haemophilia in the pre-treatment era was approximately 10-15 years of age. Concentrates and cryo improved life expectancy enormously. Even when cryoprecipitate was introduced, however, arthropathy was generally severe because the treatment was hospital-based and less effective than concentrate.

I suggest that you address your questions about Dr Craske and 1982 to Professor Hill at Birmingham Children's Hospital, since he is the Chairman of the UKHCDO and was actively involved at that time.

Thank you for the press cuttings from Private Eye and Scotland on Sunday. Any informed observer would recognise that these reports are full of distortions and inaccuracies and bear little relationship to the truth however. As such, I think they will not do your campaign any favours. Unless you report the history of this tragedy in a balanced and straightforward way, DOH is unlikely to take your campaign seriously and you will not enjoy the support of the medical profession.

I am sorry I cannot be of more help.

Yours sincerely

GRO-C

Dr CRM Hay
Director, Manchester Haemophilia Comprehensive Care Centre
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