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DEPARTMENT OF HEALTH
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From the Parliamentary Under Secretary of State
Lord Hunt of Kings Heath

PS(L) 99036

31 July 2000

Jim Cousins Esq, MP
GRO-C

Dear Jim,

Thank you for your letter of 19 June to Alan Milburn enclosing correspondence from your constituent Ms Carol Grayson, GRO-C Newcastle upon Tyne. I am sorry that I have not been able to reply before now.

I also regret that Ms Grayson was unhappy with an earlier response from officials. I recognise her commitment to fighting for justice for her family.

You suggest that the earlier response showed a serious misunderstanding of two linked points, that most of the people with haemophilia who have died from hepatitis C have also been co-infected with HIV and that those who are co-infected do not feel their interests are represented by the Haemophilia Society.

The reply of 18 May to Ms Grayson focussed on hepatitis C because this had been the subject of the 30 March debate in the House of Lords, which Ms Grayson specifically mentioned in her opening paragraph. Recent requests for a public inquiry have also focussed on hepatitis C and blood products, following our decision not to introduce a special payment scheme. I recognise, though, that because of her particular family circumstances Ms Grayson is taking the wider view.

The Haemophilia Society has campaigned for some years on the issue of hepatitis C infection, though on more specific issues such as HIV and hepatitis C co-infection they have links with special interest groups, such as the Birchgrove Group, as well as developing their own initiatives. They remain the major voluntary organisation for all people with bleeding disorders, and receive a grant towards their administration costs as well as specific project grants. They also participate in the Haemophilia Alliance as the earlier letter said. We work with them to ensure that people with haemophilia are increasing well cared for in the NHS and supported in their communities, and this was the point of the earlier letter, that Government is working with others in a positive way.

As Ms Grayson says, we were not self sufficient in blood products in the 1970s and early 1980s. Furthermore, I understand, these newly developing products were in great demand because they were seen as bringing a better quality of life for people with haemophilia, with treatment accessible in people's own homes. I hear from haemophilia doctors and others who worked with haemophiliacs that though it was known that there was an element of risk from undefined viruses, the balance, assessed at that time, was in favour of the blood products and their perceived benefits.

We apply extremely firm safety measures to blood products today, including stringent inspection of the non-UK sources of plasma which the blood service imports for manufacture, but we have to bear in mind that twenty or thirty years ago relatively little was really known, much less safety technology was available and that as a consequence lesser requirements would have been in place. We cannot expect full anticipation, twenty or thirty years ago, of what we know now.

With regard to the development of the Elstree Blood Products Laboratory in the 1970s, I placed official documents in the House of Lords in January, in response to a Parliamentary Question from Lord Lester. Before doing so I sought the permission of the Secretary of State for Social Services at the time. The documents themselves indicated that the work of the Elstree laboratory had developed substantially since its establishment in 1952, that the required manufacturing standards had increased to match those of commercial firms, and that the laboratory did not meet those required standards. The papers discussed short term and longer term action, but clearly set out what was then seen as the excellent safety record of the operation, despite the growing demands of technology.

I understand that deficiencies in other countries' systems for collecting blood in the early days of blood products have been well documented, though I am not familiar with the allegation in relation to blood and cadavers. Neither am I familiar with allegations about product relabelling during shipping. A screening test for hepatitis B was available from the early 1970s, and tests for HIV and hepatitis C from the mid and late1980s respectively.

As Ms Grayson says, some countries have held inquiries and made compensation arrangements. I understand that these too have attracted criticism. That is a matter for each individual country, in the light of their particular circumstances. With regard to offering hepatitis C tests to people with haemophilia from 1991 onwards, we would expect there to have been discussion between individual haemophiliacs and their haemophilia doctors, and testing carried out according to individual circumstances, according to the wishes of the patient, when a test became available. Ms Grayson says that our previous replies have not covered this point because they assumed that even mild haemophiliacs have regular contact with their haemophilia centres. I think we should assume that as part of their professional care for a patient, haemophilia doctors would have reached out to contact those who they might otherwise see infrequently. In some cases, though, patients have moved and can no longer be contacted. In other cases, at a time when no treatment was available for hepatitis C, patients might have chosen not to be tested.

As a final comment on the specific points which Ms Grayson raises, the waiver on future legal action which was signed by those who were to receive lump sum special payments from the Macfarlane Trust was, I understand, part of a specific settlement at the time.

We have expressed regret that people with haemophilia should have suffered infection from treatments which were intended to benefit them and which were though to be a great breakthrough at the time but which, for many, brought a very different outcome.

Finally, you suggest that we might all meet to talk this through. As you will know, the question of haemophilia and hepatitis C has received a great deal of attention since we took office, and issues relating to HIV were predominant before that time. I recognise the energy of Ms Grayson's campaigning, but I am not sure whether any of us will gain from a meeting. Perhaps you would contact me again if you feel strongly that a meeting would be the best approach.

Yours, ever

GRO-C

PHILIP HUNT