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HAEMOPHILIA AND HEPATITIS C

Thank you for your letter of 23 September 1999 about haemophilia and Hepatitis C, which unfortunately crossed with my letter to you of 27 September. I am glad you found our meeting on 14 September useful and I note the two specific responses which you are seeking from the Scottish Executive. I will deal with these in your order, as follows:

1. A full inquiry into how Scots patients with haemophilia came to be infected with HCV and in particular why they were exposed to the risks of HCV for up to a year longer than patients treated with English manufactured product.

You refer to the Scottish Executive having 'agreed to undertake an inquiry.' I stated very clearly at the meeting that I did not consider a formal public inquiry would be the best way forward, and it is important to be clear about the nature of the exercise which I have asked my Department to undertake. With regard to the scope of the exercise, I see two distinct strands which warrant further examination:

a) Allegations about the introduction of heat treatment in Scotland for Factor VIII in the mid-1980s, and whether or not patients in Scotland with haemophilia were exposed to the risks of HCV longer than they should have been, given the state of knowledge at the time.

As I said at our meeting, I want to appraise for myself the circumstances surrounding the introduction of heat treatment for Factor VIII in Scotland in the mid-1980s, with specific reference to the alleged discrepancy between England and Scotland. This exercise will be carried out by officials within my Department, who can access the requisite evidence from the interested parties, including the Scottish National Blood Transfusion Service, the Haemophilia Centre Directors, yourselves, and the Health Department in England.

The key objective is to assess the facts which comprise the chain of events leading to the introduction of an HCV-safe heat treatment for Factor VIII in the 1980s. This information is of course held largely by the blood transfusion services themselves and gathering it together will in the main involve discussions between my Department, the Department of Health in England, and the relevant transfusion services.

However, as you have pointed out, I wish this examination to be carried out in an open and transparent manner. That is why, as I mentioned in my earlier letter, Michael Palmer (the official who is dealing with these matters) would welcome any evidence from your members which might throw extra light on these matters, and would be happy to discuss the Society's concerns in detail. He will be in touch shortly to agree arrangements for submitting comments and to clarify the timeframe for receiving these contributions.

Furthermore he is open to any suggestions you might have for contacting other interested parties who you think could add value in this process, to ensure that they have the opportunity to make a contribution. Otherwise I assume the Society itself will arrange for its members to be made aware of arrangements for submitting comments.

I also welcome the proposed meeting between the Society and the Scottish National Blood Transfusion Service, at which the Department will be present. This will be a good opportunity to pursue a dialogue between yourselves and key individuals within that Service.

Once the facts have been gathered and examined by the Department the findings will be placed in the public domain for all to scrutinise and comment upon, including the Society and the Health Committee of the Parliament. Whether or not the Health Committee wishes to undertake any further enquiries of its own is a matter for the Committee to decide. For its part the Executive will take into account any comments made in response to the findings, and will carefully consider proposals for further examination of specific issues. Again Michael Palmer will be in touch with you to discuss the details and timing of this process.

b) Allegations about whether or not patients with haemophilia in Scotland were given sufficient information about the risks of contracting HCV from blood products in the

1980s to make an informed choice about receiving that treatment, given the state of knowledge at the time.

At our meeting you also raised concerns over the information which had been given to patients with haemophilia about the risks of contracting HCV/NANBH from blood products. You suggested that patients, in particular those with mild haemophilia, might not have been in a position to make an informed choice about their treatment and the associated risks.

The literature accompanying the Scottish National Blood Transfusion Service's Factor VIII products during the mid-1980s clearly stated the risk of hepatitis infection. These particular allegations would therefore appear to concern the relationship between patient and clinician, and of course they would need to be examined on the basis of individual case histories.

Because they are to do with the way in which a clinician may have advised his/her patient they are matters which come clearly within the remit of the NHS complaints procedures, which have been established specifically to address concerns of this nature and are backed up by rights of appeal to the Health Ombudsman. It is not clear how many of your members may have accessed these procedures and I enclose a copy of a leaflet which explains the procedures and how they can be activated.

You will note that the procedures are normally time-limited, although discretion does exist for Complaints Officers in NHS Trusts to waive these limits if it is judged that there are sufficient material grounds to mount an investigation about matters occurring in the more distant past. I shall be advising Complaints Officers to exercise their discretion in these cases.

I presume that some of your members may wish to pursue matters which occurred well over ten years ago, and this may not be judged feasible by the complaints procedures, given the length of time which has elapsed. It is also important to be clear that it is not for the Department to take the place of these procedures – any individual who feels distressed and aggrieved at the way he or she has been treated and who wishes to pursue a complaint should pursue their grievance through the properly constituted channels established for this purpose.

This is not to say that the Department will not, from a wider policy perspective, examine these allegations to see what general policy issues they may raise. Therefore if individuals wished to submit case histories to the Department in order to make a point about general policy (for example, with regard to information given to patients), rather than to pursue complaints on individual cases, then these would be considered as one of the policy matters within the Department's enquiries.

2. A compensation/financial assistance scheme for Scots people who were infected with HCV by contaminated blood products, similar to that already in place for those people with haemophilia infected via the same route with HIV.

As I said at our meeting and in my previous letter to you, it would not be right for me to speculate on the matter of compensation or financial assistance until I have had the opportunity to assess the evidence and consider its implications.

Finally I note your kind offer to meet a number of your members who are HCV infected at an HCV information evening in November. I am afraid my diary is already heavily committed for November, but I have asked the Department to represent me at the meeting and Michael Palmer will be in touch to discuss arrangements for this also.

SUSAN DEACON