



SCOTTISH EXECUTIVE

Minister for Health & Community Care
Susan Deacon MSP

St Andrew's House
Regent Road
Edinburgh EH1 3DG

Karin Pappenheim
Chief Executive
The Haemophilia Society
Chesterfield House
385 Euston Road
LONDON
NW1 3AU

RECEIVED

11 NOV 1999

Telephone: 0131-556 8400
scottish.ministers@scotland.gov.uk

Date: 9 November 1999

Dear Ms Pappenheim,

HAEMOPHILIA AND HEPATITIS C

Thank you for your letter of 23 September 1999 to the Minister for Health and Community Care, Susan Deacon MSP, about haemophilia and Hepatitis C, which unfortunately crossed with her letter to you of 27 September. She is glad you found the meeting on 14 September useful and notes the two specific responses which you are seeking from the Scottish Executive.

First, you have asked for 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.' It is indeed the case that the Minister has asked officials to investigate fully the issues raised and to report to her on their findings. However, as she stated clearly at the meeting, she does not consider a formal public inquiry would be the best way forward. It is important therefore to be clear about the nature of the exercise which she has asked the Department to undertake. With regard to the scope of the exercise, she sees 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 the Minister said at the meeting on 14 September, she is keen to examine for herself 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. Officials within the Department have been asked to examine this matter and they are liaising with the interested parties, including the Scottish National Blood Transfusion Service, the Haemophilia Centre Directors, yourselves, and the Health Department in England, in pursuing these enquiries.

As you have pointed out, the Minister wishes this examination to be carried out in an open and transparent manner and to give your members the opportunity to submit their views to the Department. I understand that you have spoken recently to Michael Palmer, the official who is dealing with these matters, and that it has been agreed that your members will be given until the end of this year to send in their comments. These should be sent to:

Sandra Falconer
Location 2(E) North
St Andrews House
EDINBURGH EH1 3DG
E- mail: sandra.falconer@GRO-C

The Minister also welcomes the meeting between the Haemophilia Society and the Scottish National Blood Transfusion Service which has been arranged for 25 November. This will be a good opportunity to pursue a dialogue between yourselves and key individuals within that Service.

Once the Department have concluded these enquiries their findings will be placed in the public domain and will be passed to the Society and the Health Committee of the Parliament.

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 the meeting of 14 September you also raised concerns over the information given to patients with haemophilia about the risks of HCV/NANBH infection via 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.

You will appreciate that specific concerns arising from the treatment of individual patients relate to the individual patient/clinician relationship and as such are matters which should be pursued through the complaints procedures for the NHS in Scotland rather than the Department.

It is, however, for the Department to consider what wider policy issues may be raised by these case histories, for example with regard to departmental guidance which may or may not have been issued to clinicians in the past. Any comments on these matters should therefore be submitted to Sandra Falconer at the address given above.

The second issue on which you are seeking a response concerns 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 the Minister said at the meeting on 14 September and in her letter to you of 27 September, it would not be right for her to speculate on the matter of compensation or financial assistance until she has had the opportunity to assess the evidence and consider its implications.

Finally the Minister notes your kind offer to meet a number of your members who are HCV infected at an HCV information evening in November. Unfortunately her diary is already heavily committed for November, but she has asked the Department to represent her at the meeting with the SNBTS on the 25 November and to report back to her.

Yours sincerely

GRO-C

RACHEL SUNDERLAND
Private Secretary



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28 SEP 1999

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Date: 27 September 1999

Dear Karin,

At our meeting on 14 September I promised to write to you outlining the way forward agreed between us on the issue of Hepatitis C and the safety of blood products received by haemophiliacs in Scotland.

I hope you will agree that our meeting was a worthwhile and constructive one. I want to reiterate that I come to this issue willing to look afresh at your concerns in the light of the facts which I have asked my Department to gather. As I said at the meeting, that means that until I have had the opportunity to assess the evidence it would not be right for me to begin to speculate on the rights or wrongs of the issue and on whether or not financial compensation might be warranted.

I have made clear that I want to satisfy myself that the Executive properly addresses any matters which may require action. That is why I have asked the Department to look at the events surrounding the introduction of heat treatment for blood products in the mid-1980s, and in particular the concerns you have raised regarding the discrepancy between developments in England and Scotland.

The Department would expect to have examined the necessary evidence on this matter within a month. Having received the Department's advice I would then propose to issue their findings into the public domain. I have also made clear that the Executive would then require a period of time to arrive at a considered position on the matter, taking into account any relevant legal advice.

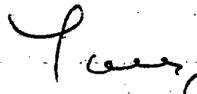
As part of this process the Scottish National Blood Transfusion Service have invited representatives from the Society to an internal meeting during which SNBTS can explain the factual chain of events behind the development of heat-treated blood products in Scotland in the 1980s and take any questions on the subject from the Society. I understand that Michael Palmer from the Department has been in touch to discuss arrangements for this meeting.

During our meeting a number of other matters were raised concerning an alleged lack of information given to patients about the risks of contracting HCV/NANBH from blood products, and about an alleged delay in informing haemophiliacs that they were HCV-positive after they had been tested as such. Concerns were also raised about the need for authoritative data on the numbers of haemophiliacs infected with HCV and to ensure that all of those affected are receiving appropriate counselling and other support.

As I intimated at the meeting, the Department will also consider these points, although I expect a longer timeframe will be required to complete any enquiries around these issues.

We share the same objective of gathering the evidence which will enable us to come to a conclusion based upon the facts of the matter. To this end you should feel free to submit any information which you think would be relevant to the Department's investigation to Michael Palmer.

Finally, I should confirm that I would be content to hold a further meeting with the Society once our enquiries are complete and the Executive's position is clearer.



GRO-C

SUSAN DEACON