

THE HAEMOPHILIA SOCIETY

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Susan Deacon MSP
Minister for Health & Community Care
St Andrew's House
Regent Road
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23 September 1999

Dear Ms Deacon

Haemophilia and Hepatitis C

I write to thank you and your officials for a useful meeting with representatives of the Haemophilia Society last week. It was encouraging to hear your commitment to explore the facts surrounding the infection of people with haemophilia with hepatitis C (HCV). As you appreciate the many complex issues involved in this situation could be touched on only briefly during our meeting, and we hope that the communication between you and the Society will continue over the coming months in order that information and views can be shared fully and openly.

To reinforce the points made during the meeting, the Society is seeking two specific responses from Government in Scotland : 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; 2) a compensation/financial assistance scheme for Scots people who were infected with HCV by contaminated blood products similar to that which is already in place in the UK for those people with haemophilia infected via the same route with HIV. There are currently financial assistance schemes in Ireland, Canada and Italy for people with haemophilia infected with HCV via contaminated blood products, and we would urge you to look closely at these.

It is a very positive first step that you have agreed to undertake an inquiry. Your commitment to conduct the inquiry in an open and transparent fashion is very welcome also. Clearly it was not possible during our relatively short meeting to discuss with you what the terms of reference, consultation and reporting mechanisms for this inquiry would be. However, we would now like to know your detailed thinking on these. Given the sensitivity and importance of the issues involved and the high degree of interest in the outcome of the inquiry, we expect that you will be making a public announcement about the timescale, scope and consultation process, as well as information on who will be conducting it. We are unsure, following our meeting, whether the inquiry is to be delegated to a team of civil servants, or to the Health Committee of the Scottish Parliament or to an independent group of experts. It is important that the remit and names of the inquiry team are made known publicly so that all interested parties can submit evidence and share views. Still more important, in our view, the inquiry team must be seen to be impartial and free from any potential conflict of interest.

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Undoubtedly many of our members who have been infected will wish to submit evidence as they have done recently to the Health Select Committee at Westminster and are anxious to know precisely how the inquiry is to be conducted. After waiting more than ten years for any form of inquiry into how they were infected, many remain angry and distressed at the lack of information provided at the time and subsequently, and the absence of any apology from the NHS or Government for what has happened.

In order that you can hear directly from the individuals concerned, I would also like to offer you the opportunity to meet a number of our Scottish members who are HCV infected at an HCV information evening being organised by the Society in November. This date may be flexible to suit your other diary commitments, as we are very keen for you to attend and to hear at first hand how HCV is affecting the lives of our members.

Our Scottish members are keen to take up the offer to meet representatives of the Scottish National Blood Transfusion Service, and I would be grateful if your office could facilitate this.

Once again thank you for taking a fresh view of this tragedy and I look forward to hearing your response to the points raised in this letter.

Yours sincerely

Karl Pappenheim
Chief Executive

Cc Chris Hodgson, *Chairman, Haemophilia Society*
Philip Dolan, *Vice Chairman, Haemophilia Society; Chairman Haemophilia Society West of Scotland Group*
John McAughey, *Chairman, Haemophilia Society Perth Group*