# NOTE OF THE MEETING HELD ON 14 SEPTEMBER WITH THE HAEMOPHILIA SOCIETY REPRESENTATIVES IN THE MINISTER FOR HEALTH'S OFFICE, SAH TO HEAR THE SOCIETY'S CONCERNS ABOUT THE INFECTION OF HAEMOPHILIACS WITH HEPATITIS C IN THE MID-1980s

**In attendance:**

Ms Deacon, Minister for Health and Community Care
Mrs Lynda Towers, Scottish Executive Solicitor's Office
Dr Aileen Keel, Deputy Chief Medical Officer, Scottish Executive Health Department
Mr Michael Palmer, Health Care Policy Division, Scottish Executive Health Department
Miss Rachel Sunderland, Private Secretary, Minister for Health and Community Care

Mr GRO-A, Chairman, Haemophilia Society
Mr GRO-A Vice Chairman, Haemophilia Society
Mr GRO-A, Chairman, Haemophilia Society Perth Group
Ms Karin Pappenheim, Chief Executive, Haemophilia Society

1. Ms Deacon welcomed everyone to the meeting and explained that as a new Minister in a new Parliament she wanted to appraise herself of the circumstances surrounding the introduction of heat treatment of blood products and to hear at first hand the concerns of the Society. She had already commissioned a departmental examination which would focus on the Society's allegation that patients in Scotland with haemophilia were exposed to the risks of HCV in the mid-1980s longer than they should have been, given the state of knowledge at that time. She made it clear however that it would not be right for her to speculate on the matter of compensation or financial assistance until she had had an opportunity to assess the evidence and consider the implications.

2. Mr GRO-A pointed out that haemophiliacs infected with HIV in the same way were compensated and the effects of HIV were being controlled effectively by drugs but controlling Hepatitis C was much harder.

3. Mr GRO-A recalled his experience:

- the time lapse between being tested and being told of the result;
- the information he was given at that time;
- the effects the infection had had on his life;
- his decision to opt for £200 a month complementary therapy because of the terrible side effects of the treatments currently available through the NHS.

4. Mr GRO-A and Mr GRO-A both confirmed they had similar although different experiences. Mr GRO-A also highlighted the fact that people were dying of HCV, and those who were affected were subject to social stigma associated with the infection and were encountering difficulties in trying to obtain a mortgage/insurance etc.

5. Ms Pappenheim provided a number of case histories, which she considered were representative of the experiences of the estimated 300 haemophiliacs who had been infected and who would all be affected by the stigma and stress associated with HCV. She advised that although the Society had undertaken some research it was felt that it didn't do justice to those affected and she considered others in Scotland who couldn't attend the meeting should be consulted.

6. Mr GRO-A explained that the Society was still receiving calls from members. No figures were available on exactly how many people had been infected. The Society understood that the UKCDO database included information on HIV but did not indicate HCV status and these figures were not published. The Society was anxious that accurate figures should be obtained. The Society representatives also voiced concerns about the lack of information given to patients at the time in terms of the risks of contracting non-A, non-B hepatitis from blood products before 1987. It was further alleged that there were delays in informing patients that they had been infected and that they were given inaccurate assurances about the benign nature of their HCV.

7. Ms Deacon assured the Society that these issues would be investigated and that the Department would now pursue with the Scottish Haemophilia Directors.

8. The Society accepted an offer of a meeting with the SNBTS to explain the factual chain of events behind the development of heat-treated blood products in Scotland in the 1980s.

*(Note: A meeting between the Haemophilia Society and the SNBTS was subsequently held on 25 November.)*

9. Mr GRO-A considered that a full public inquiry was necessary to ensure that there were no further disasters of this nature.

10. Ms Deacon explained that the meeting was a starting point for her and expressed her view that a public enquiry would not be the best way forward. The Minister pointed out that she wished the examination to be carried out in an open and transparent manner. She confirmed that Society members would be given the opportunity to submit their views to the Department and that the findings of the enquiries would be placed in the public domain and passed to the Society and the Health Committee of the Parliament.

*(Note: It was later agreed that Society members would be given until the end of the year to submit their comments to the Department.)*

11. Ms Deacon agreed to hold a further meeting with the Society to discuss the outcome/findings of the Report when completed.