From: Michael Palmer

Health Care Policy Division

Ext GRO-C September 1999

PS/Minister for Health and Community Care

Copy to: PS/First Minister

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HAEMOPHILIACS WITH HEPATITIS C: THE WAY FORWARD FOLLOWING THE MEETING WITH THE HAEMOPHILIA SOCIETY

Purpose

1. To outline a way forward following the meeting with the Haemophilia Society on 14 September, and invite the Minister to send to the Society the draft letter attached at Annex A.

Timing

2. Urgent.

Background

3. The Minister met the Haemophilia Society on 14 September to hear their concerns about the infection of haemophiliacs with Hepatitis C (HCV) as a result of receiving contaminated NHS blood products. She promised to send them a letter confirming in writing the way forward agreed at the meeting.

Consideration

4. The meeting was prompted by the Society's claim that in the mid-1980s Scottish haemophiliacs continued to receive contaminated blood products for over a year longer than English patients. The Minister had already commissioned a departmental

- investigation of this issue to assess whether the NHSiS could be held to be at fault, and whether there was any case for considering financial compensation.
 - 5. It became clear during the meeting that apart from this core issue there were a number of other strands which the Haemophilia Society wanted the Department to investigate (although the Minister made clear her belief that a public enquiry would not be the best way forward). These other strands can be summed up as follows:
 - a) the need to rectify the current lack of an official and authoritative confirmation of the numbers of Scottish haemophiliacs with HCV, and to follow that up with an investigation into the impact that HCV has had on those haemophiliacs, ensuring that they receive appropriate counselling and other support;
 - an investigation into the information provided to patients by clinicians, in terms of:
 - * an alleged lack of information given about the risks of contracting HCV/NANBH from contaminated blood products before 1987;
 - an alleged delay in informing haemophiliacs that they were HCVpositive after being diagnosed as such;
 - * allegedly inaccurate reassurances given to patients well into the 1990s about the benign nature of their HCV.
 - 6. The Minister assured the Society that the issues at 5a) and 5b) would also be investigated, and these are lines of enquiry which we will now need to pursue with the Haemophilia Centre Directors.
 - 7. With regard to the core issue of heat treatment of blood products, the Minister made clear that the Department expected to have marshalled all the evidence within the next month, following which a report could then be issued into the public domain. However she also made clear that:
 - the Executive would then require a period of time to consider what position it
 wished to take on the basis of the report, including the time required to receive
 the necessary advice on any legal implications arising from the report;
 - a longer timeframe would be needed for the investigation of the other strands (5a) and 5b)), although the Department would pursue these. These issues would also be reported upon and the Executive, again, would need a period of time to arrive at a considered position and take any legal advice following receipt of this second report.
 - 8. A handling issue which arises from this is whether we would wish to have two separate 'instalments' of this investigation issuing into the public domain, an approach which would spin out a subject which sends a number of negative signals about the NHSiS. We will therefore look at how we might try to avoid this by reporting our investigations in a more streamlined way.

- 9. In addition, the Society accepted the offer of a meeting with SNBTS, during which SNBTS could explain the factual events behind the development of heat treated blood products in Scotland in the 1980s, and take questions on the subject from the Society. This invitation is confirmed in the attached draft letter.
- 10. Finally, the Minister agreed to hold another meeting with the Society at a later date.

Recommendation

11. That the Minister sends the attached draft letter to the Haemophilia Society as soon as possible.

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