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Haemophilia Society briefing on the Scottish Executive report on

**HEPATITIS C AND HEAT TREATMENT
OF BLOOD PRODUCTS FOR
HAEMOPHILIACS IN THE MID 1980s
(October 2000)**

Among the points the Society would challenge are:

- **Report's scope too limited**

The scope of the report is so narrow, being confined as it was to two central questions, that it cannot be used to make any judgement about issues of negligence or liability. Only a full inquiry into the entire history of the contaminated blood tragedy could achieve this, and this report falls very far short of being that.

- **Patient perspective and views ignored**

Very disturbingly, the report appears to have reached its conclusions about the information given to patients without even talking to patients themselves. Surely it is patients and their families who are best able to provide evidence on what, if any information, was provided about the risks of blood borne viruses in haemophilia treatment products? Whilst the authors of the report evidently had discussions with both SNBTS and haemophilia centre doctors in preparing the report, no discussions were held with patients and the experiences of patients are only referred to in one paragraph. This is particularly serious given that one of the two central areas the report sets out to address was the information given to patients at the time – the report's conclusions on this are based solely on what doctors have said – no attempt has been made by the report's authors to find out from patients themselves what they were told.

The Society is especially disturbed at the claims in the report that all patients were fully informed about the risks of hepatitis. This directly contradicts the evidence put forward by the Society and our members that patients were not clearly informed of the risks and that many were informed of their diagnoses late or by accident. We know from the accounts of our members that patients and their relatives were not routinely advised by doctors of the risks of hepatitis; many individuals did not even know that they had been tested for HCV by their doctors.

- **What steps could have been taken to prevent almost universal hepatitis infection of this patient group? Who is accountable?**

In para 9 the report identifies that *"It is possible nowadays to identify the presence of the virus in pools or in individual donations. Up to around 89-90, it was not possible to do so with any certainty—"*. This ignores the fact that surrogate testing to try to eliminate hepatitis-infected blood had been available for some years. Surrogate testing involves testing blood donations to measure the levels of an enzyme, alanine aminotransferase (ALT). Where ALT levels are high this indicates inflammation of the liver, i.e. hepatitis, and blood donations are discarded thus reducing levels of contamination in the blood supply.

The report totally fails to reveal what consideration was given to surrogate screening. It also fails to consider the international comparisons which the Society asked them to examine which might have helped in forming a view as to whether everything that could have been done was actually done as soon as possible to try to eliminate hepatitis-infected blood from the blood supply. *For example surrogate screening was used in Germany and Italy from the late 60s and early 70s.* Who made the decision not to test each pint of blood and what pressures were brought to bear upon scientists and clinicians by officials and politicians?

Bearing in mind the findings of the newly released CJD inquiry report which closely examined the role of Ministers and senior civil servants, why did this investigation focus only on the SNBTS and the haemophilia doctors and not look at all at the involvement of ministers and officials at the time?

In our submission to the Deacon inquiry the Society stated that it was essential to examine the actions of many different organisations and factors – the Scottish Office, the SNBTS, the haemophilia doctors, UK national policies and politicians and international policies and actions. This has not been done; hence the report offers only a very partial view.

- **Failure to address follow up action**

The Society has continually highlighted the lack of any official follow up strategy to ensure that all people who may have been affected by HCV have been properly traced, tested, counselled and if appropriate offered treatment. In producing the report the Scottish Executive has failed to address this very important issue and in its findings/recommendations has not even taken the basic step of making sure that every person with haemophilia who may have contracted HCV has been traced and offered a test. Because of this lack of follow up, there is still no accurate official figure for the number of people with haemophilia in Scotland who have contracted HCV.

Significantly, in addition to this, there is no commitment to action either in the form of financial recompense or even so much as a promise to ensure that all those infected with hepatitis C receive proper care and support.

- **Inquiry process flawed – not open and transparent**

In our submission to the Scottish Executive in December 1999, the Society stated that the inquiry carried out in Scotland into contaminated blood products must be undertaken by an independent body and not by officials of the Scottish Executive. As there were questions (which still remain) about negligence and liability, we pointed out the possible conflict of interest for a Government body to be investigating the use of contaminated blood products in the NHS. We recommended the establishment of an independent task force to undertake the inquiry including patient representatives, scientists and medical experts.

This was ignored; the conflict of interest issue has never been addressed by the Minister or her department. An internal inquiry has been carried out behind closed doors in a manner which has not been open and transparent, despite assurances given when we first met with ministers and officials in September.

- **Unreasonable rejection of financial assistance**

The issue of financial assistance is not properly considered within the content of the report. A precedent has already been set in 1987 when the Conservative Government of the time accepted a moral responsibility and agreed to provide an ex gratia financial assistance scheme for people with haemophilia infected with HIV through contaminated blood products.

Only this week it has been announced that an ex gratia financial assistance scheme is to be set up by Government for victims of new variant CJD. Again this step has apparently been taken on moral grounds – how then can Ministers justify not taking a similarly compassionate approach for this very small group of people with haemophilia who have suffered hepatitis C infection?

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