

SUBMISSION BY THE HAEMOPHILIA SOCIETY

**RESPONSE TO THE REPORT INTO HEAT TREATMENT OF BLOOD PRODUCTS AND
INFECTION OF
SCOTTISH HAEMOPHILIACS WITH HEPATITIS C**

COMMISSIONED BY SUSAN DEACON – HEALTH MINISTER

Further to your recent invitation to provide a written submission to the Health Committee due to meet on the 14th March 2001 we submit the following. The Haemophilia Society has already responded to the report (copy attached) The Haemophilia Society in Scotland are supplementing this valuable advice which is based on experience drawn from across the UK. Our main concerns are

- 1 At a meeting with the Haemophilia Society in September 1999 Susan Deacon gave a commitment to a full enquiry into the issue of infection of Scottish haemophiliacs with Hepatitis C (HCV). The Report does not deliver on this commitment. Issues and decisions prior to approximate 1984 were not addressed, despite evidence being presented indicating that this is the crucial period. Further, the decisions of government and civil service officials were not scrutinised. This failure is particularly alarming since the Scottish Health Department conducted the investigation itself. Official policy and funding decisions are crucial to the understanding of this tragedy particularly given the potential conflict of interest when government officials who decided on policy operate on the board of the Scottish National Blood Transfusion Service (SNBTS) at the same time.
- 2 Despite a commitment to listen to and giving a voice to the experiences of haemophiliacs infected with HCV and their families, publication of the report was repeatedly delayed yet even then only one paragraph out of 22 pages refers to this. This is unacceptable. Little credence appears to have been given to our evidence when weighed against the submissions of other interested parties. Specifically, many of us were never informed that there was a risk of viral infection from our factor treatment and also many of us were certainly tested for HCV without our knowledge. This is in direct conflict with the report.
- 3 Despite meeting on at least two occasions with both the doctors and SNBTS, patients and patients groups were not invited to meet with the committee of enquiry. There was therefore no mention of the impact that HCV has on the life of the person infected and their family. Also, the number of submissions quoted suggest that this is a small problem but fails to contextualise this. Firstly, by failing to enumerate that the consequences are actually in some cases fatal. (More haemophiliacs in UK have died from HCV than fatalities due to CJD, E-coli0157 or any single rail disaster). Secondly by failing to mention that the stigma associated with this disease is such that many people are not willing to come forward, even in an anonymous capacity.
- 4 The evidence submitted by doctors and medical professionals has not been published within the complete report. This is unacceptable – how can we challenge their conclusions without seeing their evidence – and cast doubts on the transparency of the process.
- 5 Evidence submitted by infected haemophiliacs who gave their permission for it to be published does not appear in the full report. What has happened to this evidence and why was it not published? We are concerned that there was no real commitment to hearing our story.
- 6 There is very little mention of donor screening or screening of donated blood. Specifically, why was the ALT test not used to screen blood in the UK when several other countries thought it appropriate? The decision not to instigate screening when a screening protocol could easily have been developed suggests that the government, or its officials, knowingly exposed patients to potentially dangerous blood and blood products. It appears there has been no consideration of the Blood Bank Minutes submitted to the committee of enquiry and to Susan Deacon. These minutes clearly demonstrate the culture of secrecy and parsimony that exist within the system. It also shows that officials were aware of the potential danger to patients but chose not to adopt the

best practices employed in other countries. (This places them in a similar position to the case of the man currently on trial who knowingly infected his ex-partner with HIV).

- 7 These points demonstrate that the only way to find the truth about this sorry affair is for the Scottish Executive to instigate a full independent Public Enquiry into the infection of haemophiliacs with Hepatitis C. Only in this way will we get the transparent process required to uncover how this tragedy was allowed to happen and learn what we need to prevent similar events in the future.
- 8 The issue of financial compensation for haemophiliacs infected with Hepatitis C was dismissed by the Report without any explanation and we make the following points
 - Why is it an important principle that the NHS does not pay its own users no-fault compensation? Other precedents already exist in agriculture and industry.
 - Why does our government hold its citizens in less regard than the governments of either the Republic of Ireland or Canada to name but two? Other states have accepted that they are responsible for the well-being of their citizens and have fully engaged with victims and put compensation procedures in place – as well as instituting full public enquires. Are we somehow less deserving?
 - If the government is willing to pay compensation to people who develop vCJD on moral grounds, why is it immoral to do the same for those of us infected with Hepatitis C? The argument used by the Health Minister means that if we develop vCJD from eating a burger then we would be eligible for compensation. If, however, we were infected through our NHS treatment, it would be “an important principle” that we were not compensated. Why?
 - We are not seeking compensation from the NHS but from the government. As citizens of the state we entrust ourselves to the state's care through the NHS. Through no fault of ours we have been infected with a deadly disease through treatment supplied by the NHS. The state thus has an obligation to compensate us for the harm that we have suffered as it is obliged to ensure the well-being of its entire people. Given the current emphasis on self-reliance and personal responsibility for pensions etc. it should be noted that those infected with Hepatitis C are unable to secure mortgages or life assurance due to their infection and are thus unable to make any such arrangements. We feel that regardless of any other considerations, the government has a moral obligation to set up an adequate compensation scheme.

We look forward to appearing before the Health Committee to give our evidence in person and clarify any issues arising from our submissions.

Philip Dolan – Chairman
On behalf of the Scottish Haemophilia Society Groups Forum
20th February 2001

APPENDIX A

Haemophilia Society (UK) submission to Health and Social Care Committee

HEPATITIS C AND HEAT TREATMENT OF BLOOD PRODUCTS FOR HAEMOPHILIACS IN THE MID 1980s

The Haemophilia Society is the only UK wide patient group for people with haemophilia and related bleeding disorders and their families. Originally established as a 'self help' group by patients in 1950,

the Society today is a membership organisation in which people with haemophilia and their relatives are involved as volunteers at every level from trustee board to local groups.

The Society has five volunteer led groups in Scotland and approx. 600 individuals in Scotland on our membership database. Their experiences and views have informed this submission. The Society welcomes the Committee's decision to focus on the issues of hepatitis C infection within the haemophilia community in Scotland. We believe the enquiry and report carried out by the Health Department of the Scottish Executive is an inadequate response to the impact of the infection in Scotland, and we set out below our specific concerns and criticisms with regard to the Executive's investigation.

The Haemophilia Society made a submission to the Executive's investigation which is available for Committee members. We remain extremely unhappy that so many of the issues in that submission have not been addressed by the Executive's report.

1) The Executive's investigation and final report are too limited in scope

A full inquiry is needed to properly answer all the questions which remain about accountability and the official decision making process during the era (the 1970s and 80s) when patients with haemophilia were exposed to contaminated blood products. The Society wishes to draw the attention of the Committee to the statement issued recently by Dr Peter Jones, a leading international and UK haemophilia expert, supporting the call for a public inquiry (to be tabled). Dr Jones was involved in treating patients with haemophilia throughout the period, and saw many of his patients die from HIV contracted from contaminated blood products, and is an Executive Member of the World Federation of Haemophilia.

2) 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 1999.

3) Patient perspective and views ignored

The Executive's team appears to have reached its conclusions about the information given to patients without talking to patients themselves. 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 (page 5/6 of the Executive's report). 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 report claims 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.

4) 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?

5) 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.

6) Unreasonable rejection of financial assistance

The issue of financial assistance is not properly considered within the content of the report. In fact, as the question of financial assistance was not within the original remit of the investigation the Society believes that the report and its findings should not be used as the basis to form any conclusions about the case for financial assistance. We are extremely concerned that the Executive's report has been used by Ministers and the Health Department to justify their rejection of the case for financial assistance.

As the report failed to address the impact of hepatitis C fully on the whole haemophilia community — and only refers in one paragraph to the health and social consequences of the infection — it actually provides no substantive evidence to support the arguments either for or against financial assistance.

The fact is that precedents in the UK and abroad already exist for providing Government financial assistance to offset the impact of contaminated blood products on the haemophilia community. In Ireland, Canada and Italy patients with haemophilia who contracted both HIV and hepatitis from contaminated blood products receive financial assistance or compensation.

Within the UK a precedent was 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.

Recently 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?

The Haemophilia Society believes that as a minimum a hardship fund should be established in Scotland to assist those people with haemophilia for whom hepatitis C has caused evident damage to health and consequent hardship. This could be assessed on medical and other evidence of need, as already happens with the hardship fund established for people with haemophilia who contracted HIV from contaminated blood products. Such a fund could be established on a 'no fault' basis — as is the case for the HIV fund.

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A 'no fault' scheme of this kind would stand outside the usual NHS fault-based legal compensation arrangements, a point which has been ignored in comments made by Ministers following publication of the report.

The Society believes this step is justified by the exceptional circumstances. The haemophilia community is a very small one, already facing an incurable and very serious medical condition, to which was added infection by two potentially deadly viruses, HIV and hepatitis C. Nationally, some 95% of the haemophilia patient population were infected with one or both of these viruses through contaminated blood products used in their NHS treatment. Many have lost their lives to these viruses.

The Society maintains that the exceptional situation of the haemophilia community calls for a special response from the Scottish Parliament, and we hope the Health and Community Care Committee will call for a proper and fair examination of the case for financial assistance.

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- Haemophilia Society submission to the Scottish Executive's investigation into hepatitis C infection within the haemophilia community (December 1999)
- Dr Linda Garvican, *National provision of care for patients with HIV and hepatitis by haemophilia centres* (for publication April 2001)