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HEPATITIS C VIRUS: DEVELOPMENTS IN THE SCOTTISH DEBATE

This briefing is intended to inform members on the background to the following motion: **S1M-2565 Margaret Smith on behalf of the Health and Community Care Committee: Report on Hepatitis C** That the Parliament notes, and calls upon the Scottish Executive to act upon, the recommendations contained within the 17th Report 2001 of the Health and Community Care Committee, *Report on Hepatitis C* (SP Paper 398).

What is Hepatitis C?

Hepatitis C is a bloodborne virus previously referred to as non-A, non-B Hepatitis, and first isolated in 1989. It is primarily transmitted when the infected blood or body fluids of an individual come into contact with the blood of an uninfected person. The main routes of transmission include injecting drug use, piercings and tattoos, occupational or therapeutic exposure to infected blood and blood products and, less commonly, sexual transmission and mother to child transmission.

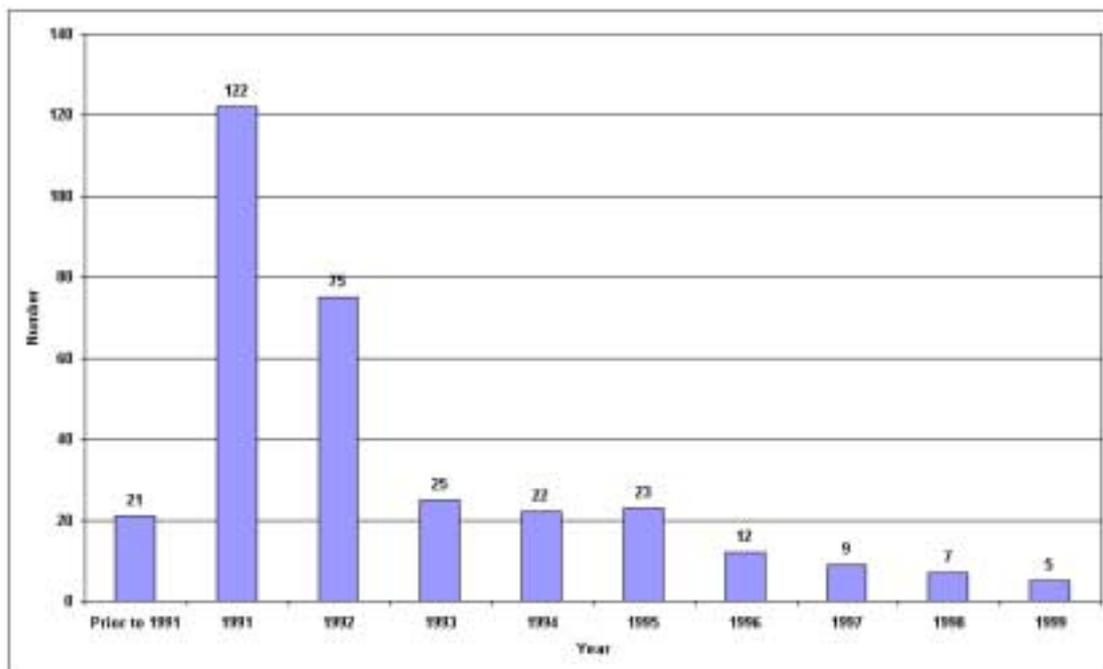
The incubation period of the disease is long and many people may remain symptomless for years. Of those who do become infected, 80-90% will not clear the virus spontaneously and will subsequently develop chronic hepatitis. Of these people, it is estimated that 25% will develop liver cirrhosis after 20 years and 5% will develop liver cancer after 30 years. The remainder will generally suffer from a variety of debilitating conditions such as chronic fatigue and depression.

There is no vaccine available against the virus and treatment options are limited, with only a relatively small proportion of patients benefiting from those that are available.

Number of People Affected

The total number of people in Scotland infected with Hepatitis C (HCV) through contaminated blood and blood products is not known. Figure 1 shows the number of people known to have contracted HCV through contaminated blood factor prior to 1991 and up to 1999. The statistics indicate the date of identification of the infection and not necessarily the date the infection was acquired. Some 321 cases had been identified in Scotland up to the end of 1999.

Figure 1: Hepatitis C Infection (Earliest Positive Specimen) Via Contaminated Blood Factor - Scotland to 1999¹



Chronology of Events in the Debate

Prior to the Hepatitis C virus being isolated in 1989, the virus was known as non-A, non-B Hepatitis and is widely thought to have been in existence since the 1970's when references to it began to emerge in the scientific literature.

The wider issue of patients contracting potentially fatal viruses through blood transfusions and blood products came to light at the dawning of the HIV epidemic. At this time, companies throughout the world started to employ different techniques to eradicate HIV from blood and blood products. No standard technique was used, resulting in a variation in practice between England and Scotland.

¹ Source: Scottish Centre for Infection and Environmental Health: - www.show.scot.nhs.uk/scieh
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The technique used in England eradicated Hepatitis C as well as HIV, however, in Scotland this was not the case, and the technique employed eliminated the HIV virus but not HCV. An equally effective method of heat treatment was not introduced in Scotland until 1987. This led to accusations that the Scottish National Blood Transfusion Service (SNBTS) exposed patients to the virus for longer than was necessary by failing to use a similar process until 2 years later, and by not implementing a screening test for blood and blood products².

The Scottish Executive Inquiry

In response to the accusations, the Scottish Executive launched an internal inquiry into the issue. The [final report](#) concluded that the SNBTS were justified in the delay in implementing the safer blood products, due to the fact that there was no test to identify the virus and that many other processes were being evaluated at the time. The report also pointed out that once a suitable process had been found, the SNBTS were quick to implement it.

In a [press release](#) at the time of the report's publication, then Health Minister Susan Deacon stated:

“Having studied all the facts, I have concluded that there is no evidence that the relevant authorities did anything other than their best for patients. As a result I do not believe that the NHS should pay compensation for non-negligent harm to those haemophiliacs who contracted Hepatitis C during the period covered by the report”

The Haemophilia Society had for some time been calling for an independent inquiry after questioning the objectiveness of the Executive's scrutiny of one of its own agencies, and in 1999, Brian Adam MSP lodged a motion in the Scottish Parliament (S1M 323) calling for such an inquiry³.

The Scottish Parliament's Involvement

In May 2000, the Public Petitions Committee considered two petitions submitted to the Parliament. Petition PE 45, brought by Mr P Ferguson, called for the Scottish Parliament to “hold an independent inquiry into Hepatitis C and other infections of people with Haemophilia”. Similarly, petition PE 185 was made by Thomas McKissock and called for the Scottish Parliament to “take the necessary steps to establish a scheme of compensation to assist people in Scotland who have contracted Hepatitis C infection as a consequence of infected blood transfusions”. The Petitions Committee decided that the Health and Community Care Committee should be asked to consider both petitions. In the process of the committee's

² Scottish Executive Health Department (2000) “Hepatitis C and Heat Treatment of Blood Products for Haemophiliacs in the Mid 1980s” : http://www.scotland.gov.uk/library3/health/hepatitis_c.pdf

³ S1M-323 Brian Adam: Hepatitis C Inquiry—That the Parliament calls for an independent inquiry into hepatitis C and other infections of people with haemophilia contracted from contaminated blood products in Scotland.

investigation the issue was raised in two parliamentary debates ⁴ ⁵ and many written and oral questions have been asked of the Scottish Executive (See Annex A).

The Health and Community Care Committee Report

The Health and Community Care Committee published its [report](#) on Hepatitis C on the 2nd of October 2001. On the same day, the committee issued a [press release](#), outlining some of the findings of its inquiry. The main finding was as follows:

“Financial and practical support should be provided for all NHS patients who contracted Hepatitis C through blood transfusion services, regardless of whether negligence can be proven...Mechanisms to provide such support [should be put in place] within twelve months.”

The demand was justified by reference to the “precedent” created by the MacFarlane Trust, which was set up by the UK government in 1998 to “provide financial assistance to all individuals infected with HIV through medical treatment, regardless of whether there was any medical negligence involved.”

The committee was content to leave undefined the exact nature of this “financial and practical support”, saying it was a matter for the Executive. However, it recommended that the level of financial assistance be determined on the “basis of need” with regard to “physical or psychological loss”.

The committee was also keen to stress that its conclusions should not be seen as an attempt to establish the principle that “all injury caused through NHS treatment should be compensated”. Furthermore, it did not see the need for a further independent inquiry into the question of alleged fault, neither did it discover any evidence of negligence on the part of the Scottish National Blood Transfusion Service.

The table on the following page outlines the main conclusions and recommendations contained in the committee’s report.

⁴ http://www.scottish.parliament.uk/official_report/session-01/or100402.htm

⁵ http://www.scottish.parliament.uk/official_report/session-01/or120202.htm

Conclusions include:

- We are not persuaded of the case for a further, independent inquiry into all the concerns raised by the Haemophilia Society and others, if that were to focus mainly on exploring questions of alleged fault. On the basis of the information we considered, we could find no evidence of negligence on the part of the Scottish National Blood Transfusion Service.
- We have come to the view that financial and other practical assistance, awarded on a no-fault basis, is the clearest solution to the issues raised in these petitions. We believe as a matter of fairness that these individuals who have suffered serious, long-term harm as a result of receiving hepatitis C - contaminated blood or blood products through NHS treatment should receive some practical assistance.
- we also believe that this solution is required for reasons of consistency, in recognition of the fact that HIV sufferers already receive assistance, under clearly analogous circumstances, via the MacFarlane Trust.
- Should the Executive accept the principle of our recommendation, we are content to leave it to the Executive to decide the best mechanism by which to make financial and practical assistance available.

Recommendations include:

- We recommend that the Executive set up a mechanism for providing financial and other appropriate practical support to all hepatitis C sufferers who have contracted the virus as a result of blood transfusions provided by the NHS in Scotland, or which involved blood or blood products produced by the Scottish National Blood Transfusion Service.
- We recommend that this mechanism for providing financial and other support comes into operation within a period of twelve months.
- The level of financial assistance awarded to any claimant should be determined on the basis of need, having regard to the physical or psychological loss individually suffered, and should include redress for practical difficulties such as the inability to obtain an affordable mortgage or life assurance.

The Executive's Response to the Committee Report

On the 11th of December 2001, the Executive produced a [response](#) to the main recommendation in the Health Committee's report that compensation should be provided to those who contracted Hepatitis C. It rejected the proposal on two counts:

1. "Extending the current compensation regime to include all patients infected in this way would be unfair to those who have been affected by other conditions in a similar way."
2. "It would create a 'risk-averse' culture within the NHS."

However, the Executive did propose alternative ways of supporting those affected. These can be summarised as follows:

- Achieving "better dispute resolution", to avoid patients having to endure lengthy and expensive legal disputes.
- "Entering into a dialogue with relevant financial institutions" to see if patients can be given help in obtaining insurance and mortgages.
- "Putting an unprecedented amount of resource and managerial commitment into making sure that patients are protected from any harmful agents that may be present in blood donations."

In broader terms, the Executive also announced that an expert group, with independent and patient representation, is to be set up to examine whether support should be given to people who have been harmed by health service treatment where the NHS is not at fault. The Executive also noted that a reformed NHS complaints system will be introduced in Scotland in 2002.

Subsequently, the Health Committee issued a [second press release](#), on the 19th of December 2001, stating its "disappointment" with the Executive's response. The Committee called for "urgent clarification from the Executive as to when and how hepatitis C sufferers infected through NHS treatment are to receive practical assistance".

The Response of the Haemophilia Society

In advance of the debate in the Scottish Parliament on the 10th January 2002, the Haemophilia Society has released a brief to the members of the Scottish Parliament outlining their disappointment at the executive's rejection of the committee's recommendations, stating:

"The response from Malcolm Chisholm, Minister for Health & Community Care, effectively rejects offering any kind of help to the haemophilia community within the urgent 12 month timescale called for by the Health Committee. This clearly goes against the wishes of both the Committee and the haemophilia community in

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Scotland and calls into question the commitment of the Scottish Executive to respond to the plight of the 300 plus members of this vulnerable patient group”

The society has renewed it’s request of compensation for the individuals affected and a further public inquiry into the matter.

Annex A

Parliamentary Questions

Fergus Ewing (Inverness East, Nairn and Lochaber) (SNP): To ask the Scottish Executive whether it will set up a body, similar to the MacFarlane Trust which exists to provide help to people in the haemophilia community who incur extra costs of living arising from HIV or AIDS as a result of having received contaminated blood products in the UK, to provide such support for those who have contracted Hepatitis C in the same manner. **(S1W-823)**

Fergus Ewing (Inverness East, Nairn and Lochaber) (SNP): To ask the Scottish Executive whether it will make representations to Her Majesty's Government recommending that the remit of the MacFarlane Trust be extended to allow haemophilia sufferers in Scotland inflicted with Hepatitis C as a result of receiving contaminated blood products in the UK to benefit from the work of the Trust. **(S1W-854)**

Susan Deacon (2nd November 1999): The circumstances surrounding those who may have contracted Hepatitis C through treatment with blood products are tragic. I have met the Haemophilia Society to hear their concerns at first hand and officials within my Department are making enquiries into the circumstances surrounding this issue. I will be better placed to consider whether any further action on the part of the Scottish Executive is indicated when these enquiries are completed.

Mr John Swinney (North Tayside) (SNP): To ask the Scottish Executive when heat treatment procedures were introduced in Scotland to eliminate the Hepatitis C virus in blood products. **(S1W-839)**

Mr John Swinney (North Tayside) (SNP): To ask the Scottish Executive what clinical indicators among Scottish haemophilia sufferers led to the introduction of work on heat treatment of blood products with a view to sterilising the Hepatitis C virus. **(S1W-840)**

Mr John Swinney (North Tayside) (SNP): To ask the Scottish Executive whether blood products carrying the risk of Hepatitis C virus transmission were still in use in Scotland in 1987, when the use of such products was discontinued in England and Wales in 1985. **(S1W-841)**

Mr John Swinney (North Tayside) (SNP): To ask the Scottish Executive how many haemophilia sufferers have been infected with the Hepatitis C virus after receiving contaminated blood products: (a) manufactured in Scotland, and (b) imported from abroad. **(S1W-842)**

Susan Deacon (2nd November 1999): The question is among a number of points which I have asked my Department to look at in relation to the safety of blood products from Hepatitis C. I also met with the Haemophilia Society to hear their concerns at first hand. I have noted the question and the points also raised in S1W-840, S1W-841 and S1W-842, and these will be taken into account in the Department's enquiries. I will keep you informed of the outcome of these enquiries as soon as they are completed.

Fergus Ewing (Inverness East, Nairn and Lochaber) (SNP): To ask the Scottish Executive what the rate of Hepatitis was in whole blood recipients at the time haemophilia treatment with blood products factors VIII and IX was introduced. **(S1W-2377)**

Fergus Ewing (Inverness East, Nairn and Lochaber) (SNP): To ask the Scottish Executive whether there were any cases of undiagnosable Hepatitis noticed in haemophiliacs in Scotland before 1987 and, if so, how many. **(S1W-2379)**

Fergus Ewing (Inverness East, Nairn and Lochaber) (SNP): To ask the Scottish Executive what is the current recorded death rate of haemophiliacs from Hepatitis C and up to what date was that number last reviewed. **(S1W-2380)**

Susan Deacon (17th January 2000): This information is not held centrally. I have noted the question however and the points also raised in S1W-2379 and S1W-2380, and these will be taken into account in the Department's enquiries into the circumstances surrounding the safety of blood products from Hepatitis C. I will keep you informed of the outcome of my enquiries as soon as they are completed.

Brian Adam (North-East Scotland) (SNP): To ask the Scottish Executive whether it will review the decision to refuse compensation to patients with haemophilia who contracted hepatitis C through contaminated blood products. **(S10-3236)**

Susan Deacon (5th April 2001) The Scottish Executive has no plans to do so.

John Scott (Ayr) (Con): To ask the Scottish Executive, following the recent court decision in England regarding compensation for those who contracted hepatitis C from blood transfusions, whether it will make payments to those similarly affected in Scotland. **(S1W-14520)**

Susan Deacon (15th May 2001) The Scottish Executive is currently considering the implications of the English judgement.

Mary Scanlon (Highlands and Islands) (Con): To ask the Scottish Executive how many people contracted hepatitis C through a blood transfusion during routine NHS surgery **(S1W-15970)**

Susan Deacon (12th June 2001) The number of cases of infection with hepatitis C where the suspected risk factor of blood transfusion or tissue transfer reported to the Scottish Centre for Infection and Environmental Health (SCIEH) and shown in the figures published at the beginning of May is 206. The figure does not relate purely to those who may have been infected during routine surgery and may also include people who have been infected outwith Scotland.

Mary Scanlon (Highlands and Islands) (Con): To ask the Scottish Executive whether it will request to make a ministerial statement to the Parliament on the implications for people in Scotland of the English court ruling on compensation for people who contracted hepatitis C through blood transfusions on the NHS. **(S1W-15971)**

Susan Deacon (19 June 2001): As indicated by the Deputy Minister for Health & Community Care during the parliamentary debate on 26 April and again during my appearance before the Health and Community Care Committee on 23 May, the Executive is considering constructively the implications of the recent English High Court ruling in the case brought under the Consumer Protection Act 1987. This is a complex issue and is being progressed as urgently as possible. An announcement will be made at the earliest possible date.

Nicola Sturgeon (Glasgow) (SNP): To ask the Scottish Executive how the potential appearance of treatment-acquired disease among haemophiliacs is monitored, given the experience gained from the appearance of hepatitis C as a treatment-acquired disease among haemophiliacs. **S1W-17748**

Susan Deacon I refer the member to the answer given to question S1W-17745

Answer to S1W-17745: Susan Deacon (20 September 2001): This information is not held centrally. I have written to you separately giving contact details to allow you to obtain the information requested in this and your other questions (S1W-17746, S1W-17747 and S1W-17748) through the Scottish Haemophilia Directors

Mr John McAllion (Dundee East) (Lab): To ask the Scottish Executive what action it proposes to take now it has had time to consider the judgement of the English High Court in the case brought under the Consumer Protection Act 1987 involving blood contaminated with the hepatitis C virus. **(S1W-17807)**

Susan Deacon (25th September 2001) The Scottish Executive has instructed NHS Scotland to enter into discussions with the legal representatives of any

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person who has raised an action of the same kind as the decision in the English High Court. These would be actions under the Consumer Protection Act 1987 where people have been infected with hepatitis C as a result of receiving blood from the Scottish National Blood Transfusion Service after 1 March 1988.

These discussions will be with a view to reaching a settlement of those actions which are legally competent and where the relevant facts can be proved.

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