

## AMENDMENTS TEMPLATE

Group [DN]	New Clause After Clause 18
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### OPPOSITION AMENDMENT HB134 – REJECT

**Issue:** Creation of a Committee to advise on Haemophilia, as per the recommendation of Lord Archer's review

**Tabled by:** Lord Morris of Manchester

#### Amendment:

**HB134**

Insert the following new Clause—

**“Committee to advise on treatment of haemophilia**

- (1) The Secretary of State shall by regulations establish a Committee to advise on the treatment of haemophilia in the United Kingdom.
- (2) The Committee shall in particular provide advice on—
  - (a) the selection, procurement and delivery of available therapies for haemophiliac patients;
  - (b) patients accessibility to treatments for haemophilia or any conditions which arise from consequent haemophilia therapy;
  - (c) the financial and other needs of haemophilia patients.
- (3) The membership of the Committee shall include—
  - (a) specialist haemophilia clinicians,
  - (b) representatives from the Haemophilia Society;
  - (c) representatives from the Department of Health;
  - (d) representatives of haemophilia patients, through nomination by the Haemophilia Society and other bodies working to support the haemophilia community.
- (4) The Secretary of State shall consult the Committee before making substantial changes in policy regarding the treatment of haemophilia patients and before introducing legislation which affects them.
- (5) Regulations made by the Secretary of State under this section are—
  - (a) to be made by statutory instrument, and
  - (b) subject to annulment in pursuance of a resolution of either House of Parliament.”

**Purpose:** This amendment is identical to one tabled at Committee. The establishment of a statutory committee to advise Government on the management of Haemophilia is one of the recommendations of Lord Archer's report of his independent inquiry ('NHS Supplied Contaminated Blood and Blood Products'), which was published on 23 February 2009.

Lord Morris asked Lord Archer to conduct his inquiry, following refusals by successive Governments to hold a public inquiry. This amendment would enable one of the report's recommendations to be implemented swiftly.

**Effect:** The effect would be the establishment of a statutory national committee to advise on the management of a specific condition (haemophilia). This is based on a model adopted in the Republic of Ireland.

This would reduce the ability to respond quickly to patient needs and could set a problematic precedent to establish such committees on other specific conditions.

## **Speaking Note – Amendment HB134**

- Amendment HB134, laid by the noble Lord, Lord Morris, is based on a recommendation made by Lord Archer in his report published on February 23<sup>rd</sup>. The report considered the supply of virus-contaminated blood and blood products, and the devastating effect of this on the haemophilia community in particular, from the early 1970s onwards, until tests became available for hepatitis C and HIV.
- We welcome Lord Archer's report, and I most warmly thank him and the noble Lords, Lord Morris and Lord Corbett, for the efforts they are making on behalf of haemophilia patients and their families. We recognise that the lives of many people have been lost or seriously impaired, and appreciate that the noble Lords wish to take every opportunity to remedy this situation as far as they are able. The Government is giving very careful consideration to Lord Archer's recommendations.
- My Lords, there is no doubt this group of patients have suffered tragic consequences as a result of the serious infections inadvertently transmitted via their treatment. I agree that it is very important to ensure

these patients and their families are properly supported, and to act to reduce as far as practically possible any future risk to all patients who need blood and blood products.

- These risks are already reduced following scientific advances and the safeguards put in place by the NHS in the years since these tragic events took place. There are safeguards in place against transmission of hepatitis and HIV in blood donations, and there is an independent committee, with patient representation, to monitor blood safety and make recommendations. The risk to haemophiliacs from transmission of blood borne infection has also been significantly reduced through the introduction of synthetic products that are not derived from donors.
- However, we entirely agree with the argument in the Archer report that it is vital for patients to be represented where decisions about good practice in healthcare provision are being made. That is the centrepiece of our strategy for embedding quality in the NHS. It runs through Lord Darzi of Denham's report "High Quality care for All", where together with

effectiveness and safety, patient experience is a guiding principle for high quality healthcare.

- Under the NHS Act 2006, a strengthened "duty to involve" came into force in the NHS in November 2008. This duty requires organisations to involve users of services in the planning and provision of services. The Government is also taking steps to ensure that patients with long-term conditions are fully involved in decisions about their care.
- However, we are not convinced that a new statutory committee, with powers over the supply of blood as well as treatments for haemophilia, is the best means to involve patients with haemophilia in such decisions.
- We are certainly persuaded that we need to look again to see how patients with haemophilia, as with other groups of vulnerable patients, can be more regularly consulted and directly involved in decisions about treatments. However, we need to consider the merits of other options, such as strengthening current arrangements.

- As noble Lords will appreciate, the advantages of a statutory basis have to be weighed against the inevitable loss of the flexibility that other arrangements may have, for example, in reacting quickly to developments in treatment or to changes in the representation of patient and clinical interests.
- **[DN if MS(PH) agrees:** One option that we are actively considering would build upon the existing UK-wide partnership, the Haemophilia Alliance, between patients, haemophilia doctors and others involved in their care, such as nurses, physiotherapists and social workers. The Alliance is jointly chaired by the Haemophilia Society. We are considering a formal arrangement whereby the Government would seek advice from the Alliance on matters relating to the care of haemophilia patients, and meet with them twice a year. If this were pursued, we would meet the costs of the Alliance in doing so.]
- I can assure the House that the Secretary of State is actively considering other means of strengthening representation and rights of haemophilia patients, in the light of developments in involvement of all

patients, and particularly those with lifetime or other long-term conditions. This consideration also has to include the arrangements in devolved administrations for involving patients with long-term conditions.

- I believe it would therefore be premature to act to implement this specific recommendation, before Government has had time to fully consider all the options for achieving stronger representation for patients with haemophilia. We also need to consider this proposal together with Lord Archer's other recommendations for strengthening support more widely to the haemophilia community.
- The Government will be responding to Lord Archer's recommendations in the near future. I therefore propose that it is not appropriate to adopt this amendment at the present time, and I hope the noble Lord will feel able to withdraw.

## **Supplementary Questions**

### **Q. What is the Government doing about the recommendations in the Archer Report?**

A. We take this issue very seriously. We will respond when we have given Lord Archer's report the consideration it deserves.

#### **Background**

##### **Summary of Lord Archer's recommendations**

- Establishment of a statutory committee to advise government of the management of haemophilia in the UK
- Free prescription drugs and free access to other NHS and support services
- Secured funding by government for the Haemophilia Society (a third sector organisation)
- Review of the current ex-gratia payments system, including bringing payments in line with those in Ireland (very much higher than in the UK), and incorporating them within the DWP benefits system
- Enabling haemophilia patients to have access to insurance
- Establishing a 'look back' exercise to identify any remaining patients who may have been infected, and may not be aware of this.

### **Q. What has the Government done to prevent infection of haemophiliacs via blood products?**

A. To remove any potential for transmission of infection through donor sourced products, since 1998 all children in the UK have had access to recombinant (synthetic) clotting factors. In February 2003 the Government announced additional funding to extend availability to adult haemophiliacs in England.

All haemophilia patients are now eligible for treatment with recombinant products, for which the Government continues to provide funding through the central budget programme directly to strategic health authorities. This expenditure on recombinant clotting factors has risen from £21m in 2004/2005, to £46m in 2008/09.

#### **Background**

##### **Hepatitis C and HIV**

The introduction in the 1970s of clotting factors made from human plasma as a treatment for haemophilia vastly improved the quality of patients' lives. However, during the late 1970s and early 1980s, the majority of regularly treated patients with haemophilia received clotting factors infected with HIV and/or hepatitis C before it became possible to remove these viruses from plasma. In 1985, heat treatment for plasma-derived blood products became available. This removed the risk of HIV and hepatitis infection.



**Q. What are the existing services for 1) haemophiliacs and 2) hepatitis C treatment?**

A) 1) the Government is determined to ensure that people with haemophilia are increasingly well cared for, supported in their communities and fully informed about how best to look after their health. The government is working with the UK Haemophilia Centre Doctors Organisation and the Haemophilia Society to ensure that counselling provision is available and accessible to all haemophiliacs, including those with hepatitis C.

2) the Government recognises the importance of hepatitis C as a public health issue and have set a clear national framework to tackle hepatitis C in the *Hepatitis C action plan for England*.

The action plan sets out three national outcome indicators to track progress rather than setting targets, in line with our policy of reducing the number of national targets affecting the NHS to a small number of issues of highest priority and concern. In recent years there have also been unprecedented increases in NHS funding for services.

Background

Of those with haemophilia and related bleeding disorders in the UK about 450 are currently have HIV, most of those with HIV are co-infected with hepatitis C. Around 3,800 haemophiliacs are thought to be living with hepatitis C.

We recognise the importance of hepatitis C as a public health issue and have set a clear national framework to tackle hepatitis C in the *Hepatitis C action plan for England*. In addition to unprecedented increases in NHS funding for services, we have provided central support for key aspects in implementing the action plan, such as raising awareness among healthcare professionals and the public through publicity and advertising and improved epidemiological surveillance

However, responsibility for implementation at local level lies with primary care trusts and their local partners, as they are best placed to assess what is needed in their areas.

**Q. What arrangements are there for safeguarding the supply of blood and blood products to patients, including haemophiliacs?**

A. Measures are in place to help to prevent similar events happening in the future. The government receives expert advice on safety measures from the independent advisory committee on the safety of blood tissues and organs (SABTO), and NHS Blood and Transplant (NHSBT) is responsible for ensuring a safe and sufficient supply of blood to England and north Wales.

Background

- Since the mid 1980s the position on both safety and supply of blood, components and products has changed significantly. These are now regulated by safety and quality regulations.
- All blood donors are tested for HIV and hepatitis viruses.
- Recombinant (synthetic non-donor derived) product is now available for all haemophiliacs for whom it is suitable.
- Introduction of suitably validated tests for new diseases, such as vCJD, is a priority for the government.

NHS Blood and Transplant (NHSBT – of which the national blood service is a part) needs to ensure a sufficient supply of safe blood to meet the needs of patients in England and north Wales. This includes a clear responsibility to minimise the risk of a blood transfusion transmitting an infection to patients.

The Department of Health's independent advisory committee on the safety of blood, tissue and organs (SABTO) recommend the selection criteria for blood donors and the implementation of blood safety measures for the four UK blood services to the Secretary of State for Health, who makes the final decision.

The committee includes a patient representative and is committed to public engagement. SABTO discusses complex issues of risk and benefit to patients, and is of the view that these should be communicated honestly and openly. Summaries and minutes are released on the website, and there is now an annual public meeting – the first, in October 2008, was on vCJD and blood.

**Q. Why has the Haemophilia Society's funding been reduced?**

A. The Haemophilia Society received core funding under the section 64 general scheme of grants for a number of years. However, section 64 grants are not intended to be permanent sources of funding, and so in 2006 we informed the then chief executive of the Haemophilia Society of our intention to taper the level of core funding over three years to 2010.

I know that officials are in discussion with the Haemophilia Society about funding opportunities in line with the third sector investment programme.

Background

Officials met with the new chair and chief executive of the Haemophilia Society on 18 June 2008, at their request to discuss the society's difficult financial position. We explained the rationale for our decisions at this meeting, and suggested they look for alternative sources of funding. Officials have since met with the Society's chair and chief executive to advise on how they can best tap into third sector funding opportunities.

Ministers are considering options that would provide more secure funding to the society as part of their response to Archer. However, these need to be considered in the light of similar provisions for other third sector organisations.

**Q. Why does the Skipton Fund not give funds to the bereaved or the families of infected individuals?**

A: The Government has great sympathy for the pain and hardship suffered by the widows and dependants of those inadvertently infected with hepatitis C. However, the scheme is designed to alleviate the suffering of those people infected with hepatitis C and it was not designed to compensate for bereavement.

Background

In 2006, ministers agreed to extend the aim of the fund to include dependents of those who had died after the fund was announced, but before it became operational (a period of about a year).

**Q. Anomalies between Skipton Fund and Macfarlane and Eileen trusts are unfair?**

A. The Skipton Fund is not discretionary, unlike the Macfarlane and Eileen Trusts. I know Lord Archer has raised the issue of payments in his report and we will be considering all the recommendations in the report carefully.

**Background**

MFT and ET trustees have recently submitted to officials a set of options for large-scale long-term funding for the trusts, involving sums in excess of £100m. These have yet to be assessed in any detail.

As the number of registrants in these trusts is declining, the argument for increased funding will need to take account of the reduced number of people receiving payment.

In 2006, Caroline Flint (then MS(PH)), reviewed the funding position for the Macfarlane and Eileen Trusts, following a request from the trustees for significantly increased funding (a combined increase of over £4million/year).

The trustees argued that when the trusts were established, registrants were not expected to survive for long. Modern treatments had changed that prognosis, and registrants needs had changed with it.

MS(PH) and SofS were not convinced of the strength of the case made by the trustees, and consequently agreed a partial acceptance of the trustees' claim, via a combined annual increase in funding of £400,000 to be shared between the trusts pro-rata. This represented an increase of around 11% to the trusts' funding, bringing the funding for MFT to over £3.7million, and funding for ET to £177,000.

In contrast, the Skipton Fund is a limited company which administers two lump sum payments; an initial one of £20,000 and a further payment of £25,000 if the individual progresses to severe liver disease as a result of hepatitis C infection. There is no provision for in-year discretionary payments.

**Q. Was UK too slow to implement Lord Owen's commitment to make the UK self-sufficient in clotting factors within 18 months?**

A. The resources promised by Lord Owen were made available and the target number of donations was achieved initially. However, given the effectiveness of these products and the rapid growth in demand, the UK was not able to achieve self-sufficiency. Although self-sufficiency continued to be the aim, and NHS production of concentrate continued to increase, the rising demand for clotting factors meant that commercial products continued to be imported.

Background

The government published in 2006 a report reviewing "Self Sufficiency in Blood Products in England and Wales 1973-91", together with relevant documents. None of the evidence suggests that Parliament was misled or that a public inquiry is warranted.

**Q. Is the government going to co-operate with the public inquiry into these issues that has been set up in Scotland under Lord Penrose?**

A. The permanent secretary has written to his counterpart in Scotland, copied to Lord Penrose, to assure him of the cooperation of the department in his inquiry. The department is currently in correspondence with Lord Penrose's team to establish what help they require.

**Q. Will the department send anyone to give evidence to Lord Penrose's inquiry?**

A. It is for Lord Penrose to decide how he wishes to conduct his inquiry. So far we have received no such request.

Background

The SNP had a manifesto commitment to set up a public inquiry if elected to lead the Scottish Government. A public inquiry was set up under Lord Penrose in January 2009.

Following a judicial review, the inquiry must also investigate the deaths of two Scottish patients following NHS treatment with contaminated blood or blood products. This is necessary to comply with article 2 of the European Convention on Human Rights. This imposes obligations on the UK government, and so DH has given assurances of cooperation.

So far our correspondence with the Penrose team is focused upon the supply of copies of official documents. We have been unable for legal reasons to supply quantities of documents including names of officials and others, as Penrose requested, but have said we can consider similar requests on a case-by-case basis.

## **Lord Morris of Manchester – background**

(source: Hansard web site)

President of the Haemophilia Society

President of the All Party Haemophilia Group 2001-

- MP (Labour/Co-operative) for Manchester Wythenshawe 1964-97;
- PPS: to Minister of Agriculture, Fisheries and Food 1964-1967, and to Leader of the House of Commons 1968-70;
- Opposition spokesperson for social services 1970-74;
- Parliamentary under-secretary of state, Department of Health and Social Security with special responsibility for the disabled 1974-79;
- UK and the world's first minister for disabled people;
- Principal opposition spokesperson for the rights of disabled people 1979-92;

Promoted four Acts of Parliament as private member:

- Chronically sick and disabled persons act 1970,
- Food and Drugs (Milk) Act 1970,
- Police Act 1972;
- Act to transfer to Canberra the original of Constitution of Australia Act 1900.

## **Lord Corbett of Castle Cae – background**

(source: Hansard web site)

Vice chair of the motor Group, 1999 - present

Vice chair of the India Group, 2001 - present

Secretary of the multiple sclerosis group, 2001 - present

Chair of the penal affairs Group, 2002 - present

Treasurer, film industry Group, 2002 - present

Treasurer, renewable and sustainable energy Group,  
2005 - present

- Labour MP for Hemel Hempstead 1974 - 79, and for Birmingham Erdington 1983 - 2001;
- Opposition whip 1984 - 87
- Opposition spokesman for home affairs 1987 - 92, national heritage, broadcasting and press 1992 - 94, disabled people's rights 1994 - 95
- Chair, parliamentary labour peers 2005 - present
- Lords Select Committees: member of European sub-committee f (social affairs, education and home affairs/home affairs) 2003 – 07, and Communications 2007 - present