LORD'S ORAL QUESTIONS BRIEFING PACK

FOR ANSWER ON 5 MARCH 2009

CONTENTS

Elephant traps

Supplementary Questions

Background

Lord Morris of Manchester

5 March 2009

To ask Her Majesty's Government when they expect to respond to the findings and recommendations of the Independent Public Inquiry headed by Lord Archer of Sandwell into the infection and deaths of patients contaminated with HIV and hepatitis C by National Health Service blood and blood products.

Suggested answer

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

Whilst successive Governments acted in good faith, the serious infections inadvertantly contracted by these patients as a result of their treatment have had tragic consequences. I am deeply sorry that this happened.

These events were the subject of long concluded legal proceedings: the Government has established three schemes to provide financial assistance to those affected.

[75 words]

KEY FACTS

Lord Archer of Sandwell published the report of his non-governmental independent inquiry on NHS supplied contaminated blood and blood products on 23 February 2009. He set up his inquiry in response to lobbying from those infected as a result of treatment. A large number of haemophiliacs have HIV or hepatitis C as a result, which has seriously impaired their lives.

- Every sympathy for those who have been affected, and the Government recognises that such inadvertant infection has impaired the lives of many people
- Comprehensive services are in place in the NHS to provide the necessary treatment for HIV and hepatitis C
- We have payment schemes of some years standing in place to support those affected

Blood and blood products, such as factor 8 used in treatment of haemophilia, were contaminated by HIV and hepatitis C (formerly non A non B hepatitis) viruses in the 1970s and early 1980s before these viruses were detectable in blood.

- This problem was not confined to the UK.

Blood products were sourced from donors not only in the UK but from paid donors in the US.

- At the time the success of new factor 8 treatments in haemophiliacs led to significant increases in demand

There were no tests for HIV until 1985.

- The introduction of heat treatment in 1985 removed the risk of both HIV and of hepatitis from blood products.
- Testing of all donations for HIV was introduced in 1985, and for hepatitis C in 1991 when suitable, effective tests became available.

Lord Archer's inquiry investigated the circumstances surrounding the supply of contaminated blood and blood products, the consequences for haemophilia patients and others, and suggested further steps to address the needs of patients and bereaved families.

- This government has gone further than any other administration in making information available.
- Over 5000 documents relating to blood safety during the period 1970-1985 have been released in line with FoI and were available to Lord Archer.
- Only 36 of these have been with-held in full or in part, mainly because they contain personal information, commercial or legal advice. We are nevertheless reviewing these again as our aim is to release as much as possible.

Lord Archer does not find the Government to have been at fault, and does not apportion blame.

The ex-gratia payment schemes established for those affected are not equivalent.

- The MacFarlane (1989) and Eileen (1993) Trusts provide lump sum and discretionary payments to respectively, haemophiliacs and others, who contracted HIV. The Skipton Fund (2004) provides lump sum payments to people infected with hepatitis C.

- Over £45m has been paid out to around 600 MFT and ET beneficiaries.
- £95m has been paid out to nearly 4500 SKF claimants.
- We will be considering carefully Lord Archer's recommendations including those relating to payments for affected individuals and their carers.

Measures are in place to help to prevent similar events happening in the future.

- 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

ELEPHANT TRAPS

Why did the Government not set up an Inquiry into this tragedy sooner?

The time to have held a public inquiry was much closer to the events. Previous Governments decided not to hold an inquiry, and we have also considered the call for a public inquiry very carefully. However the government does not consider a further inquiry is justified as it would not add to current knowledge about how infections happened or the steps taken to deal with the problem.

The point now is to support those affected.

Although the government does not accept that any wrongful practices were employed, as indeed Lord Archer does not allege, successive governments have acknowledged the tragic circumstances surrounding infection in recipients of blood and blood products. That is why ex gratia payment schemes were established.

The Republic of Ireland paid significant compensation to sufferers – why hasn't UK done likewise?

Payments made by the Republic are a matter for them and were in response to circumstances in Ireland relating to the use of blood products. The situation in the UK was different. Action was taken as soon as possible to introduce testing and safety measures for blood and blood products as these became available. The introduction of heat treated product in 1985 was a key factor in protecting our supply.

However, the establishment of the ex gratia schemes in the UK was in recognition of the special and unfortunate position of those who were inadvertently infected.

The department has lost documents – how can we be sure there's been no cover up?

Extensive searches have taken place across the department and we are committed to publishing all relevant documents from the years in question. We have acknowledged that in the early 1990's some documents were unintentionally destroyed and other misplaced. Most of these have now been recovered and published. However, comprehensive published review of extensive existing documentation shows clearly that action in relation to the blood supply was based on the best available advice at the time. This review and the documentation relating to the safety of blood products are available on the website.

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.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.The cut-off point of 29 August 2003 is unfair?

A. The difficult decision not to extend the scheme to people who had died before this date meant that it became an unavoidable cut-off point. We realise that these circumstances are not ideal, but have attempted to provide a pragmatic solution.

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. HAS THE GOVERNMENT RELEASED ALL RELEVANT DOCUMENTATION IN RELATION TO CONTAMINATED BLOOD PRODUCTS?

A. Given the level of public interest in this matter, we voluntarily released over 5000 documents in relation to contaminated blood products between 1970 and 1985, when heat treatment was introduced. We are double checking, and if any more relevant documents are found, these will also be published in line with the Freedom of Information Act.

Background

The Department of Health has assisted Lord Archer as far as it can, and has shared the results of its own review.

35 documents and one further document, from an earlier batch released, were withheld, in whole or part, under exemptions in the FOI Act. This information was provided to Lord Archer in letters accompanying the documents that he received, and has been given in PQs. No request for a review has been received by Lord Archer or another party.

Q. What about the documents you are withholding?

A. Seven of the 36 documents affect commercial interests. In order to remove all doubt, we have already committed to

review these to see if there is some way they can be issued, e.g., by contacting the companies concerned.

Background

To go further, we could volunteer to carry out a review of all the documents and publish the results. However, it is very unlikely that many, if any, would qualify for release.

Officials are satisfied that none of the documents adds anything significant to what is already known from the several thousand documents already released. No documents have been withheld on policy grounds.

IF LORD OWEN ASKS, ALSO – I am pleased that from the 1970s, papers the Noble Lord thought may have been lost have been released to him and published.

Background

The Department has recently found 10 previously unreleased documents on the self-sufficiency initiative dating from the mid-70s, when Lord Owen was Minister of Health. They have been published in keeping with our commitment to put all relevant documents in the public domain.

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.

We continue 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.HASN'T VCJD NOW BEEN TRANSMITTED TO A HAEMOPHILIAC?

A. Very recently (17 February 2009), the finding of vCJD in a haemophiliac who died of other causes, was announced. Investigations are ongoing but it is likely that exposure was due to contaminated blood products in the mid-1990s.

Background

As a precautionary measure against variant CJD, since October 1999 all plasma-derived clotting factors used by the NHS have been made from imported plasma. Although these products have an excellent safety record, people with haemophilia remain concerned that history might repeat itself. These concerns focus on the potential for transmission of vCJD, which has been shown to have been transmitted through whole blood transfused before the introduction of safety measures in 1999. (Details of these are on the DH website).

Synthetic (non-human derived) clotting factors are now used for treatment of haemophilia in all patients for whom they are suitable.

Q. Why haven't you introduced a test to screen for vCJD? What about the Amorfix test? (Discussed on Newsnight two weeks ago)

A. I am aware of the encouraging developments for a vCJD test. A validated test remains a priority for the government.

If pressed:

Officials have met with Amorfix to discuss progress.

Q. HAS THE UK BEEN 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". None of this 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. DH has not replied to the Penrose team yet but will do so shortly.

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.

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.

In July 2008 you answered a PQ from Lord Morris on this subject (see pp 38-40).

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.

PRESS COVERAGE – ALL FROM 24 FEBRUARY (THE DAY AFTER THE REPORT WAS PUBLISHED)

Issue	**Paper**	**Comment / line**
Additional compensation As generous as the Irish scheme	Times; FT; Telegraph; Independent; D Express; D Mirror Times	We will respond when we have given Lord Archer's report the consideration it deserves The financial implications of Lord Archer's recommendations are considerable - potentially £hundreds of millions. We envisage detailed work is likely to be needed in formulating options, and preparing a response. We will need to consult on the recommendations, both internally within DH including legal advisers, and externally, with for example, DWP, and the UK Haemophilia Centre Doctors' Organisation.
An apology	Times; Guardian	Various apologies by Ministers e.g. 20 October 1987 (a PO); 27 October 1987 (a PO); 27 October 2007; 16 November 1987; 13 November 1989; 23 November 1989; 13 December 1995; 7 March 2000; 30 March 2000; 11 December 2003; 20 February 2008 [all Hansard

		unless a PO] We have great sympathy for the patients and families affected by contaminated blood products in the 1970s and 1980s, and will study the findings of Lord Archer's report in detail when we receive it.
Improved testing	Times	We will respond when we have given Lord Archer's report the consideration it deserves.
Setting up an expert haemophilia committee to advise government	Times	We will respond when we have given Lord Archer's report the consideration it deserves.
Free prescription drugs, GP visits and home nursing	Times; FT	We will respond when we have given Lord Archer's report the consideration it deserves
Scheme to ensure that patients can get insurance	Times; FT	We will respond when we have given Lord Archer's report the consideration it deserves
Need to learn lessons e.g. vCJD	Times; Telegraph	At present there are no suitable vCJD blood tests available. We have implemented a number of precautionary measures to reduce the risk of vCJD transmission via blood and blood products,

		and continue to keep the situation under review.
Need for an official enquiry	Telegraph	This Government has gone further than any other administration in making information available, which has included meeting with Lord Archer and cooperating with the inquiry where possible. Thus there would be no practical benefit to be gained from a full public inquiry which would be a time consuming and expensive process, diverting funds away from health services and would depend on the recollection of witnesses about events which took place over 20 years ago. A full public inquiry would not add to current knowledge about how infections happened or the steps needed to deal with this kind of problem now or in the future Contamination with HIV. The causes are well known and are set out in the relevant medical and scientific literature. Measures have been in place since 1985 to prevent further risk. There is no case that, after this time, an inquiry is necessary to establish the facts and

		prevent further cases.
Government and agency procrastination Delay in UK getting "clean" supplies compared with Ireland	Independent Guardian	
Needless deaths	Sun	
The withholding of 35 documents Govt. not helping the inquiry, withholding papers and not giivng evidence	Sun D Mirror; Sun	Only 35 of the batch of 4,500 documents released to the Archer enquiry so far have been withheld in full or in part – less than one per cent. The majority of these were withheld because they contain personal information, legal advice or on health and safety grounds.' An additional 1,000 documents had been released previously, of which 1 had been withheld. The newspaper articles only focused on the 35 documents from the second group. The relevant facts and documents are in the public domain
Government	D Mail; D	

refusal to investigate in order to protect commercial interests.	Mirror; Sun; Metro	
Govt. needs to respond quickly to the report	Guardian	We will respond when we have given Lord Archer's report the consideration it deserves
Patients used AIDS guinea pigs Secret testing of haemophiliacs for hep C	D Mail; Sun	

ADDITIONAL 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.

Initial Reactions to Recommendations *[NOT FOR SHARING]*

Proposal to establish a committee:

- Not minded to do this

Free prescription drugs:

- This will need to be considered in the context of Professor Ian Gilmore's review, looking at long term conditions.

Secured funding for the Haemophilia Society:

- This runs counter to policy on third sector organisations.

Review of payments system:

- We need to consider and carefully cost the options for additional support, and consult DWP.
- However, the financial implications are enormous if we were to operate in line with the Irish system, as Archer recommends. (An initial estimate applying the average Irish payment to our 4-5000 cases would be £3-3.5 billion. We need more work to properly quantify these recommendations.)

Access to insurance:

- We will seek the view of the Association of British Insurers.

Lookback exercise:

- There has already been one lookback exercise, in the 1990s. If it were decided to carry out a further search, we would propose asking the UK Haemophilia Centre Doctors' Organisation to manage it.

Other Key Points from the Report

The report explicitly avoids apportioning blame and recognises that these are historical events. There is a suggestion that a secure supply of safer products could have been provided earlier by a faster drive towards self-sufficiency. However, it is debatable how much contamination could have been avoided, given that domestic products could not have been safeguarded against risk of HIV and hepatitis C any sooner than they were.

Overall, since the 1970s and 1980s, there is a tighter regulatory framework in place and the establishment of NHSBT has brought the safety and supply of blood products under closer control. We will be mapping out the current supply landscape to help provide the context for a Government response.

HAEMOPHILIA - FACTS

There are about 19,600 people with haemophilia and associated disorders in the UK. People with classic haemophilia are mostly male, with the women being carriers. Some female carriers also present mild symptoms of the disease and require treatment especially for surgery and at childbirth. Some rarer forms of haemophilia affect both sexes equally.

The number of people with haemophilia is likely to be increasing slightly. With the development of blood products to treat the disorder in the 1960s/70s, people with haemophilia increasingly had families. While genetic counselling and termination is a possibility, this is often difficult in a family with a history of haemophilia especially where there are good treatments and the family want male children.

In about one third of cases there is no family history of haemophilia, and the condition has arisen because of spontaneous genetic mutation.

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.

BACKGROUND ON THE THREE FUNDING SCHEMES

Macfarlane Trust (MFT)

This was the first mechanism of payment for the relief of haemophiliacs infected with contaminated blood or blood products. The MFT is a DH-funded registered charity, established in March 1988, when the Government committed £10 million. In 1990 the Department of Health made an *ex gratia* payment of £20,000 to each surviving infected person or their bereaved families, and in 1991, payments were made in settlement of potential litigation.

Eligibility to financial aid requires medical evidence of infection and is restricted to:

- haemophilia patients who contracted HIV following treatment with NHS blood products prior to screening programme;
- families of deceased infected patients;
- partners infected by haemophilia patients infected by NHS blood products.

How was funding decided?

We have not been able to ascertain how the original payment of £10m was arrived at. In the 20 years since its inception, DH has given the Macfarlane Trust total funding of £46m.

Eileen Trust

The Eileen Trust, also a DH-funded registered charity, was established by the Government in 1993 to extend the payments already provided for HIV infected haemophiliacs (through the Macfarlane Trust) to non-haemophiliacs who acquired HIV in the course of receiving treatment by blood or tissue transfer or blood products. The scope of the scheme applies to the UK.

The Eileen Trust makes the following lump sum payments:

- Infant - £41,500
- Single adult - £43,500
- Married adult without dependant children -£52,000
- Infected person with dependent children - £80,500

To infected intimates of the above:

- Adult spouse/partner - £23,500
- Child who is married - £23,500
- Other child - £21,500

In addition, regular monthly payments range from £100 - £432 per month are paid by the Eileen Trust, according to circumstances. In addition, single grants are also paid by the Trust.

How was funding decided?

We are unable to ascertain how the level of funding was arrived at in the earlier periods. .Since the Trust's inception, in 1993, the Trust has received a total of approximately £1.2m.

Skipton Fund

The decision to set up the Skipton Fund was made on 29 August 2003, when the Secretary of State for Health and Health Ministers of the Devolved Administrations simultaneously announced that a United Kingdom wide scheme would be set up to make *ex gratia* payments to persons who were treated in the United Kingdom under the NHS by way of the receipt of blood, tissue or a blood product and as a result of that treatment became infected with the hepatitis C virus.

Every person in the UK who was alive on the 29 August 2003 and whose Hepatitis C infection is found to be attributable to NHS treatment with blood or blood products before September 1991 (when screening of blood donations for Hepatitis C was introduced) would be eligible for the payments.

The decision to not to make payments to dependants in respect of those who died before 29 August 2003 was based on the date that Secretary of State made his decision.

People infected with Hepatitis C receive initial lump sum payments of £20,000*. (**Stage 1 payments**)

- those developing more advanced stages of the illness - such as cirrhosis or liver cancer - will get a further £25,000 (**Stage 2 payments**)*; and
- people who contracted Hepatitis C through someone infected with the disease will also qualify for payment

How was funding decided?

The level of the Stage 1 and 2 payments were based on proposals made by the Scottish Executive (e.g. an initial payment of £20k and a further payment of £25k if a person's disease advances to a medically defined trigger point, probably cirrhosis). This structure was decided after comparison with the level of payments made by the MFT and ET and the recommendations made by the Lord Ross expert group in Scotland. Details of funding, based on the number of Stage 1 and 2 payments that are paid each year are given below..

Numbers of Stage 1 & 2 applications paid, and DH funding since inception

Period	Application numbers		Cost of applications paid			DH funding
	Stage 1	Stage 2	Stage 1	Stage 2	Total	
			£000s	£000s	£000s	£000s
Mar 04-Mar 05	3,034	294	£60,680	£7,350	£68,030	£70,147
Apr 05-Mar 06	433	188	£8,660	£4,700	£13,360	£14,000
Apr 06-Mar 07	245	101	£4,900	£2,525	£7,425	£7,000
Apr 07-Mar 08	204	101	£4,080	£2,525	£6,605	£6,400
Total	3,916	684	£78,320	£17,100	£95,420	£97,547

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.

PREVIOUS PQ FROM LORD MORRIS – 9 OCTOBER 2008
HLOPQ49 9 OCTOBER 20008 COL: 331

Health: Haemophila

Lord Morris of Manchester asked Her Majesty's Government: What review was undertaken of the extent and depth of deprivation in the haemophilia community before the decision was taken to cut the Haemophilia Society's core grant by 70 per cent.
[HLOPQ49]

Baroness Thornton: My Lords, the department is very much aware of the importance of the work of the Haemophilia Society. Indeed, we have funded the society for more than 10 years. In 2006, this funding provided 14 per cent of the society's overall budget. However, Section 64 grants are not intended to be permanent sources of core funding for organisations, thus the tapered reduction over three years to 2010.

Lord Morris of Manchester: My Lords, I am grateful to my noble friend. Is she aware that 1,757 haemophilia patients have now died in direct consequence of infection with HIV and hepatitis C through contaminated NHS blood products in what my noble friend Lord Winston described as,

> "the worst treatment disaster in the history of the National Health Service"? .

Lord Morris: Is she further aware that many are terminally ill, unable to work and uninsurable, except at prohibitive cost, while the widows of many of those who have died receive no compensatory help whatever? Finally, is she aware that the Haemophilia Society, which exists to support this stricken community, now faces closure as its core grant reduces from £100,000 to £30,000? I know that she will want to help all that she can.

Baroness Thornton: My Lords, I pay tribute to my noble friend's work and commitment in this field over many years. In 2006-07 and the preceding eight years, the Haemophilia Society received £100,000 annually. This is now reducing over three years to £30,000 in 2010, so, this year, the society will receive £60,000. It is clear that the transition process from core funding is proving a problem for the Haemophilia Society.

The department has provided for this event and will consider capacity-building requests for funding to develop more sustainable funding streams, generate income through trading activities and develop the capacity to work in partnership. We will also fund specific projects such as Young Bloods, which is a good example of how the society has secured funding to focus on the needs of children with bleeding disorders, amounting to £110,000 over three years.

I am, however, happy to make a commitment to my noble friend to ensure that further discussions take place with the Haemophilia Society.

PREVIOUS PQ FROM LORD MORRIS – 14 JULY 2008

HL4657 14 July 2008 : Column WA113

Health: Haemophilia

Lord Morris of Manchester asked Her Majesty's Government:

> Why the Haemophilia Society's Section 64 core grant has been reduced from £100,000 to £30,000; whether the reduction took account of deprivation in the community which the society exists to help; and at what ministerial level the decision was made. [HL4657]

A. The Parliamentary Under-Secretary of State, Department of Health (Lord Darzi of Denham): The Haemophilia Society has received core funding under the Section 64 general scheme of grants for a number of years. In 2006-07, its grant was £100,000. In 2006, a decision was taken, in line with the established criteria for the Section 64 scheme, to taper the Section 64 grant to £30,000 over two years. The Haemophilia Society was informed of its future funding in 2006 in order to allow it to plan for this change.

The following level of funding was agreed. 2007-08—£60,000;2008-09—£30,000; and 2009-10—£30,000.

All decisions on Section 64 funding are taken by the Minister responsible for the relevant area of policy.

ISSUES THAT MAY BE RAISED BY FORMER MINISTERS IN THE LORDS

Lord Owen committed £0.5 million in 1974 to support a drive to UK self-sufficiency in blood products. He has asked why self-sufficiency was not achieved in the time expected.

A. The money was used to increase the output of plasma for the preparation of blood products. The target set for increased output was met in 1977. However, the treatment of haemophilia changed dramatically in the 1970s and demand continued to outstrip UK output. The UK therefore continued to import blood products to enable modern methods of treatment to continue. Self-sufficiency continued to be the ambition for the UK, and the plant for production for England and Wales was extensively rebuilt in the early 1980s at a cost of more than £50 million to support this goal.

Lord Owen has expressed disappointment in the past that DH was unable to give him copies of the papers he dealt with during his term of office (1974-76).

A. There is no separate “archive” of Ministerial papers – relevant papers are sent back to policy divisions for filing with other papers. Unfortunately, many relevant papers were mislaid in DH following settlement of HIV litigation in 1990. We have been quite open about this and published a review of documentation in 2007. We have now rediscovered many documents and believe we have traced most of those previously believed missing. These are available on the DH website. We were able to send Lord Owen some relevant papers late in 2008.

Lord Jenkin has also complained in the past about his contacts with the Department in relation to papers.

A. The same considerations as above apply, although during most of his term of office (1979-81) the Minister for Health, Dr. Vaughan, had the lead on this issue. We have released many papers covering Dr. Vaughan's involvement in these years.

Lord Jenkin is quoted in the Archer report as saying that he was told, at a meeting with the former DH Chief Executive, Nigel Crisp, that relevant papers had been destroyed deliberately to draw a line under this issue.

A. We do not know precisely what was said, but this is a complete and very unfortunate misunderstanding. No papers have been deliberately destroyed in this way, and Lord Archer says that he found no evidence of this. Some committee papers were accidentally destroyed in the 1990s. The internal audit carried out into this in 2000 was released in 2007 with our review of the documentation generally.

Lord Fowler (1981-87) and **Lord Glenarthur** (1983-85) were Secretary of State and Parliamentary Secretary (Lords) respectively in the early 1980s when the threat of HIV/AIDS emerged. Both have been supplied with copies of some relevant papers (as has the Minister for Health at that time, Kenneth Clarke, M.P.). Neither has raised any specific issue although they could be asked for some supportive comment on Government policy at this time.

A. During this time the Department developed its policy for safeguarding blood donations and blood products from HIV/AIDS. A test for HIV in blood donations was introduced in October 1985, the same year in which all blood products were heat-treated to kill HIV (the process had also killed hepatitis C, as was found when hepatitis C was identified in 1989). During the time when the threat of AIDS became better understood, the Government followed a policy of extensive publicity to deter potential blood donors from higher risk groups.

The import of blood products from the USA continued, as around half of all treatments for haemophiliacs were dependent upon it. Guidance suggested restricting these to the most severe haemophiliacs and emergencies. The Haemophilia Society had correspondence with **Lord Glenarthur** urging that the import of these products should continue. The Committee on Safety of Medicines supported this approach. We have published the relevant papers on these developments.

Lord Heyhoe and **Baroness Trumpington** were also Ministers in the Department during the mid 1980s when steps were being introduced to counter the threat from HIV.

DEVOLVED ADMINISTRATION INVOLVEMENT

All of the Devolved Administrations are considering the findings and recommendations of the Archer Report, and will decide how to respond.

The Scottish Executive Office has advised that a number of recommendations relate to issues which the Penrose Public Inquiry, set up by the Scottish Government, is looking at and considering in depth. We have been advised that the Scottish Government will also wish to see the findings and recommendations of Lord Penrose before reaching any final view.