

A

# Briefing Pack

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# B

## Background to the Issue

- Many users (especially haemophiliacs) of blood and blood products were infected with Hepatitis C and HIV in the 1970s and 1980s before effective treatment of blood to remove infection risk or testing of blood for the viruses was available.
- There have been numerous calls for a Government inquiry into these infections.
- With the support of the Haemophilia Society Chairman Lord Morris of Manchester, an independent inquiry chaired by Lord Archer of Sandwell was set up in 2007.
- This took evidence from a number of witnesses (list at **Annex A**) and met with Department of Health officials, and reported in February 2009 (copy of report at **Annex B**). A Government response to the report was published on 20 May 2009 (**Annex C**).
- The response met, in part, a number of key recommendations:
  - Providing a formal mechanism for patients and clinicians to advise UK Health Departments on the management of haemophilia
  - Reviewing financial payment schemes and increasing (doubling average) payments to HIV patients
  - Committing to review Hep C payments in 2014
  - Support for the Haemophilia Society
- Those affected and Lord Archer's supporters in Parliament are dissatisfied that the Government did not agree to all of the Report's recommendations.
  - In particular, there is significant criticism from the hepatitis C community as no current changes is being made to the Skipton Fund on grounds of unaffordability because of the larger number of claimants.
  - To rectify the main anomaly in the Fund - to make payments to dependents of those who died before it was introduced - would cost about £54m, and to introduce annual payments for Fund recipients (even limited to those with the most serious disease) would cost £10m per annum.
- This debate is another route for issues of concern to be raised.

# C

## Reason behind this MP calling the Debate

- Jenny Willott is Joint Secretary All Party Parliamentary Group on Haemophilia. She is started her interest in haemophilia patients after lobbying from one of her constituents Mr **GRO-A** a haemophilia patient infected with both HIV and Hepatitis C, Mr **GRO-A** has also infected his wife with HIV. Mr **GRO-A** has recently received a liver transplant.
- She has asked many PQs (10 PQs this year) on the issues of contaminated blood products and related matters (see **Annex D** for most recent).
- She gave evidence to the Archer Inquiry on 14 June 2007, this is attached at **Annex E**. Her evidence centred on her perception of lack of disclosure from the Department of Health in terms of responses to her Parliamentary Questions and the release of documents.

## D

### Other MPs, and members of the House of Lords, who have an interest or are likely to attend include:

#### MPs

- Adam Holloway - has asked Archer Inquiry related Parliamentary Question.
- Andrew Lansley - has asked Archer Inquiry related Parliamentary Question.
- Andrew Love -Member of All Party Parliamentary Hepatology Group
- **GRO-A** – known to have an affected constituent.
- Andrew Rosindell - has asked Archer Inquiry related Parliamentary Question.
- Anthony Steen -Member of All Party Parliamentary Hepatology Group.
- Betty Williams – member All Party Parliamentary Group on Haemophilia.
- Bob Laxton - co-Chair All Party Parliamentary Hepatology Group.
- Bob Spink -Member of All Party Parliamentary Hepatology Group.
- Brian Iddon – gave evidence to Archer Inquiry. Vice-Chair All Party Parliamentary Hepatology Group.
- Danny Alexander- has asked Archer Inquiry related Parliamentary Question.
- David Amess– gave evidence to Archer Inquiry. Vice-chair Conservative Health/Social Services Policy Committee 2001 & co-Chair All Party Parliamentary Hepatology Group, member All Party Parliamentary Group on Haemophilia.
- David Drew -Member of All Party Parliamentary Hepatology Group.
- Edward O'Hara Vice-Chair All Party Parliamentary Group on Haemophilia.
- Frank Cook – member All Party Parliamentary Group on Haemophilia.
- **GRO-A** whose daughter is a recipient of the Skipton Fund.
- James Brokenshire -Member of All Party Parliamentary Hepatology Group.
- Jenny Willott – gave evidence to Archer Inquiry and Joint Secretary All Party Parliamentary Group on Haemophilia.
- Jim Cousins -Member of All Party Parliamentary Hepatology Group.
- Jim Dobbin – member All Party Parliamentary Group on Haemophilia, and member of All Party Parliamentary Hepatology Group.
- Kelvin Hopkins -Member of All Party Parliamentary Hepatology Group.
- Lindsay Hoyle -Member of All Party Parliamentary Hepatology Group.
- Lynne Featherstone Joint Secretary All Party Parliamentary Group on Haemophilia.
- Martin Caton Treasurer All Party Parliamentary Group on Haemophilia.
- Michael Connarty– member All Party Parliamentary Group on Haemophilia.
- Michael Mates – member All Party Parliamentary Group on Haemophilia.
- Michael Meacher– has asked Archer Inquiry related Parliamentary Question.
- Mike Penning - has asked Archer Inquiry related Parliamentary Question.
- Neil Gerrard – member All Party Parliamentary Group on Haemophilia, and of All Party Parliamentary Hepatology Group.
- Oliver Heald -Member of All Party Parliamentary Hepatology Group.
- Oliver Letwin – member All Party Parliamentary Group on Haemophilia.
- Patrick Cormack – member All Party Parliamentary Group on Haemophilia.
- Paul Goggins – member All Party Parliamentary Group on Haemophilia.
- Peter Bottomley – member All Party Parliamentary Group on Haemophilia.

## E

- Robert Walter – member All Party Parliamentary Group on Haemophilia.
- Roger Berry – member All Party Parliamentary Group on Haemophilia.
- Shona Mclsaac -Member of All Party Parliamentary Hepatology Group.
- Stephen Hammond - has asked Archer Inquiry related Parliamentary Question.
- Stephen Hesford– member All Party Parliamentary Group on Haemophilia.
- Stephen O'Brien – member All Party Parliamentary Group on Haemophilia.
- Stewart Jackson -Member of All Party Parliamentary Hepatology Group.
- Sylvia Heal – member All Party Parliamentary Group on Haemophilia.
- Tim Boswell – member All Party Parliamentary Group on Haemophilia and of the All Party Parliamentary Hepatology Group.
- Vince Cable -Member of All Party Parliamentary Hepatology Group.

### Peers

- |       |
|-------|
| GRO-A |
| GRO-A |

 – was widowed when her first husband, 

GRO-A
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, died aged 34 as a result of receiving contaminated factor VIII blood products. Mr 

GRO-A
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's brother also died as a result of receiving contaminated factor VIII blood products.
- Baroness Masham of Ilton – a vice-president of the Haemophilia Association.
- Lord Addington – member All Party Parliamentary Group on Haemophilia.
- Lord Clement-Jones – member All Party Parliamentary Group on Haemophilia.
- Lord Corbett of Castle Vale – attended Archer Inquiry and has asked Archer Inquiry related Parliamentary Question.
- Lord de Mauley -Member of All Party Parliamentary Hepatology Group.
- Lord Jenkin of Roding – gave evidence to Archer Inquiry. Secretary of State for Health and Social Security May 1979 - September 1981.
- Lord Mancroft -Member of All Party Parliamentary Hepatology Group.
- Lord Morris of Manchester – Parliamentary Undersecretary of State at the DHSS, March 1974 – May 1979, Member of All Party Parliamentary Hepatology Group, President All Party Parliamentary Group on Haemophilia.
- Lord Owen – gave evidence to Archer Inquiry. Parliamentary Undersecretary of State at the DHSS, March 1974 – July 1974, and Minister of State for Health July 1974 - September 1976.
- Lord Roberts of Conwy– has asked Archer Inquiry related Parliamentary Question.

**Note** – a table of DHSS and Department of Health Ministers 1970-1997 is at **Annex F**.

# F

## Recent Events/Reports, including Parliamentary Activity

- Hansard extract from 25 March 2004 – oral question from Lord Morris of Manchester replied to by Lord Warner– **Annex G.**
- The Archer Inquiry report – **Annex B**
- Index and copies of related written PQs (Commons and Lords) since April 2007, including recent oral topical and business questions – **Annex D.**
- Hansard extract from 5 March 2009 – oral question from Lord Morris of Manchester replied to by Baroness Thornton– **Annex H.**
- Hansard extract from 17 March 2009 – debate on amendment to the Health Bill moved by Lord Morris of Manchester replied to by Baroness Thornton– **Annex I.**
- Hansard extract from 23 April 2009 – Lords debate on the Archer Inquiry – moved by Lord Morris of Manchester and answered by Baroness Thornton– **Annex J.**
- Hansard extract from 28 April March 2009 – debate on amendment to the Health Bill moved by Lord Morris of Manchester replied to by Lord Darzi of Denham– **Annex K.**
- Hansard extracts from 20 May 2009 – written Ministerial Statements on the Government’s response to the Archer Inquiry– **Annex L.**
- The Government response to the Archer Inquiry– **Annex M.**

## G

### **Difficult or controversial issues related to the issue [see Key Points and Supplementaries for additional detail]**

#### **Government apology to NHS patients who have been infected following treatment from contaminated blood products**

- There have been many expressions of sympathy and regret from former Ministers. The Government is deeply sorry that patients were infected with HIV and or hepatitis C through contaminated blood products.

#### **Why the Government did not set up their own inquiry into this issue**

- The time to have held a public inquiry was much closer to the events in the 1970s and 1980s.
- The Government does not consider an Inquiry is justified, as it would not add to current knowledge.
- The issue now is to best support those affected.

#### **Lord Archer's report**

- The report does not find the Governments of the day to have been at fault, and does not apportion blame.

#### **Recommendation 1 - Establishing a committee to advise the Government on the management of haemophilia**

- We will invite the Haemophilia Alliance to meet with Government twice yearly. The Department of Health will host, and fund, these meetings.

#### **Recommendation 2 – Testing of haemophilia patients and their partners for any condition recommended by the advisory committee.**

- Any new relevant tests for transfusion transmitted infections would be offered to haemophilia patients.

#### **Recommendation 3 - Every blood donor should be similarly tested**

- The independent advisory committee on the Safety of Blood, Tissues and Organs will continue to advise on tests for blood donors.

#### **Recommendation 4 – Free prescription drugs and free access to other NHS and support services**

## H

- The Department of Health recognises the need for a fairer system of prescription charging and will progressively abolish charges for patients with long-term conditions.

### **Recommendation 5 - Secured funding by Government for the Haemophilia Society**

- The Department will strengthen support for the Society by providing further funding of £100,000 per year for the next five years.

### **Recommendation 6 - 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**

- To help those affected by HIV and Hepatitis C, almost £150 million has already been given out in lump sums and discretionary payments.
- We recognise that further financial assistance is needed which is why we intend to increase annual payments to £12,800 from 20 May 2009 for those infected with HIV [Macfarlane and Eileen Trusts].
- We have committed to review financial assistance to those affected by hepatitis C in 2014, which is 10 years after the establishment of that financial relief scheme [Skipton Fund]
- Payments made by the Republic of Ireland are a matter for them and were introduced following a judicial inquiry, which found failures of responsibility by the Irish Blood Transfusion Service. The situation in the UK was different, and Lord Archer has not apportioned blame.
- The charitable Trusts have developed good relationships with their registrants and we consider this system should continue rather than disrupting this by setting up a new system.

### **Recommendation 7 - Access to insurance should be ensured by providing premiums or setting up a separate scheme**

- The increased payments will help people infected with HIV to meet higher insurance premiums.

### **Recommendation 8 - A look back exercise should be undertaken to identify other individuals who have been unknowingly infected**

- We will fund a look-back exercise for patients with bleeding disorders to identify any others who may be infected.



# I

## **Future treatment of haemophilia patients**

- All patients are eligible for treatment with recombinant products, for which the Government continues to provide central funding. We contributed £46m for the provision of these products in 2008/09.

## **What has the Government done to ensure relevant documents about the subject of Lord Archer's Inquiry have been made available?**

- The Department has released all relevant documents that it holds on the safety of NHS blood and blood products from 1970 to 1985, in line with Freedom of Information procedures. Around 5500 documents have been placed on the web.
- In examining all these documents, neither the Department nor Lord Archer and his team have found any evidence of a "cover up".

# J

## Members of the Public with an interest or likely to attend

- Members of the affected communities are likely to attend the debate. They are likely to include:
  - Representatives from the Haemophilia Society (of which Lord Morris of Manchester is the President); and
  - Representatives from the Manor House Group (a group of Haemophilia Society members – mainly infected with Hepatitis C who campaign for the Society to develop a stronger response to HCV and in particular for those infected to receive recompense along the same lines as the recompense offered to those with HIV).
  
- The Haemophilia Society representatives may include:
  - Chair - Liz Rizzuto
  - Vice Chairs - Matt Gregory and Debra Pollard
  - Other trustees - Philip Dolan, Ann Hithersay, Dawn Prideaux de Lacy, Tim Metzgen, GRO-A, GRO-A
  - Chief Executive - Chris James
  - Policy & Comms. Manager - Dan Farthing
  - Other Officers - Claire Treguer, Rachel Goodkin, Tom Bradley and Georgie Robinson
  
- It is possible that members of the public, especially the haemophilia community may attend the debate and possibly lobby on the day.

# K

## Protests and Direct Action

- In 1998, seven haemophiliacs chained themselves to the railings outside the House of Commons in protest at the government's failure to give compensation. At this or at about the same time blood was thrown by a protestor at a Departmental official.
- These protests were after members of the Haemophilia Society, and its sub-group the Manor House Group, met the then Secretary of State, Frank Dobson, to discuss compensation for those infected with Hepatitis C.
- On Friday 19 June 2009, a group of haemophilia patients, and widows and dependents, protested outside Secretary of State's constituency office. The protestors have said that they will continue regular protests outside Secretary of State's constituency office.
- It is possible that there may be protests at Westminster on 1 July associated with the debate.

L

## **Media Activity**

### **ARCHER RESPONSE – PRESS COVERAGE**

**Tuesday 24 February**

#### **Press coverage**

Coverage in the national newspapers has been critical and fairly widespread. The FT, Times, Telegraph, Sun and Daily Express ran pieces towards the front of the paper whilst the Guardian, Independent, Daily Mail also ran stories on the findings of the report. All reported on the conclusion of the Archer report that the Government should pay compensation and cover future health costs of surviving haemophiliacs.

Evening news broadcasters ran the story including Newsnight, who broadcast a damning and negative package.

#### **Key themes of coverage**

Disappointment/ sense of injustice: There is a sense across the coverage that the Government has not gone far enough and that financial constraints play a big part in this. Most pieces suggest that the families feel appallingly betrayed and want an apology

The Inquiry There is also further comment that the inquiry should have been held earlier, was needlessly delayed and had to be privately funded after the Department of Health declined to give evidence.

### **ARCHER RESPONSE – PRESS COVERAGE**

**THURSDAY 21 MAY**

#### **Press coverage**

Coverage in the national newspapers has been critical but limited. The Guardian and Sun ran pieces towards the front of the paper and the Independent and Daily Mirror. All suggest the Government has not gone far enough.

Evening broadcasters did not run the story, however Newsnight, who have been following the issues closely, ran a highly critical package. As anticipated, they empty chaired the Department.

# M

## Key themes of coverage

**Disappointment/ sense of injustice:** There is a sense across the coverage that the Government has not gone far enough and that financial constraints play a big part in this. Most pieces suggest that the families feeling appallingly betrayed. A widowed spouse indicated those affected plan to take their case to the European Parliament under the Human Rights legislation.

**Hepatitis C.** All the coverage is critical of the decision not to review provisions in place for individuals with hepatitis C for another five years. Most mention the increased funding for HIV but frame it as being insufficient.

**Ireland:** Newsnight focussed on the difference in financial assistance available between the UK and Ireland. They outlined, those affected by HIV receive between £13,000 and the nearly 5 million. The average per person was around £1 million. For those affected by Hepatitis C there is one settlement, which goes as high as £5 million for somebody with hepatitis C, that was the highest payout in Ireland. As Newsnight frames it, "there's a huge gap between 45,000 and 5 million".

**Documents.** Newsnight suggested in their package that we are still withholding documents. They went on to add we had chosen to publish a large number of documents on the day of the Government's response so that those affected would be overwhelmed with the amount of information.