FIRST WRITTEN STATEMENT OF THE RT. HON BARONESS MARGARET JAY
Contents

Witness Name: Margaret Jay
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INFECTED BLOOD INQUIRY

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Contents

Section 0: Preface

I, Baroness Jay of Paddington, will say as follows: -

0.1. I am a former Minister of State for Health. I make this Statement pursuant to a Rule 9 request from the Inquiry dated 13 July 2022, which has asked me questions about my period in office from 1997 – 1998.

The Statement Process

0.2. The Rule 9 request incorrectly identifies my role at the Department of Health ("DH") during this time period as Parliamentary-Under-Secretary. I would like to correct this error and confirm my role at this time was Minister of State for Health. Throughout, when the Inquiry ask me to comment on a query relating to my role, I will be referring to this role rather than the one they have set out.

0.3. It has been 24 years since I was Minister of State at the DH, and my recollection of this time period is very limited, both as a result of the passage of time and the length of time for which I was actually in this role. I have very little independent recollection of the events discussed in the statement request, and in many respects, I am merely commenting on the documentary evidence provided to me. I have also had recent health issues which the Inquiry has been made aware of.

0.4. In the light of this, it has been agreed that my statement will focus on a small number of key issues and key documents. In addition, in order to assist the Inquiry, my legal representatives have created a supplementary Annex which provides further details of relevant events from this time. This has been created from documentation which the Inquiry has provided to me, supplied by the results of further searches by my legal representatives have discovered.

0.5. I have read the Annex, but I have not read or considered the documentation referred to in that document. I understand that the underlying documents will be exhibited so that readers are able to follow any references for themselves.

0.6. I have followed the section headings and question numbering in the Inquiry's request.

Section 1: Introduction

Q1: Personal Details and Professional Qualifications

1.1. My name is Margaret Ann Jay. My address is C/O Baroness Jay of Paddington, House of Lords, London, SW1A 0PW, and my date of birth is GRO-C 1939.

1.2. I have been asked to set out my professional qualifications and to provide a brief overview of my career.

1.3. I was educated at Somerville College, Oxford, and gained a degree in Politics, Philosophy and Economics.

1.4. My career in television production began in 1961, and I worked in a variety of programmes in the BBC tv current affairs department. I later became a broadcast journalist, and presented programmes in the BBC television "Panorama" series, and subsequently for Thames Television's "This Week" programme. During the 1970s and 1980s, except when I was living in the USA, I was also a member of several health authorities in West London, including Queen Charlotte's Hospital for Women, and the Ealing, Hounslow and Hammersmith Area Health Authority. In 1988, I was appointed as the first director of the National Aids Trust ("NAT").

Q2: Career in Government

2.1. I have been asked to provide an overview of the positions I held in government and the dates each position was held.

2.2. I was appointed as a Labour party life peer on 29 July 1992 with the title Baroness Jay of Paddington, and I acted as an opposition whip in the House of Lords and front bench spokesperson from 1992-1993.

2.3. The positions I held in government, after 1997, are as follows:

21 October 1992 (Life peerage)	Member of the House of Lords- Lords Temporal

2 May 1997 – 27 July 1998	Minister of State for Health
2 May 1997 – 27 July 1998	Deputy Leader of the House of Lords
27 July 1998 – 8 June 2001	Leader of the House of Lords
27 July 1998 – 8 June 2001	Lord Keeper of the Privy Seal
27 July 1998 – 8 June 2001	Minister for Women

2.4. The Ministerial Team in the Department of Health from 1997-1998 consisted of (1) the Secretary of State for Health, Mr Frank Dobson; (2) Minister of State for Public Health, Ms Tessa Jowell; (3) Minister of State for Health (Commons), Mr Alan Milburn; (4) myself as Minister of State (Lords); and (5) the Parliamentary Under Secretary of State, Mr Paul Boateng.

2.5. I have been supplied with a document [WITN7410002] which outlines my responsibilities as Minister of State for Health, and those of my colleagues. One of my responsibilities during this time was for blood. It was one of a large number of responsibilities including handling all the Lords DH business. The main priority for myself and Alan Milburn during the early months in our respective DH roles was to address concerns about the services in the NHS. For example, I remember he and I had to deal with the management and function of the NHS throughout a so-called "winter crisis", which was very difficult. CJD was also a major issue.

<u>Q3: Membership or involvement with organisations relevant to the Inquiry</u>

3.1. I have been asked to confirm whether I am a member or was involved with any committees, associations, parties, societies, groups or organisations relevant to the Inquiry's Terms of Reference, including the dates of my membership and the nature of my involvement.

3.2. In February 1988 I was appointed as director of the National Aids Trust, and remained in this role until 1992 when I became a member of the House of Lords.

3.3. I have also had informal advisory positions with other NGOs and charities working in the HIV/AIDs field.

Q4: Relevant business or private interests

4.1 I have been asked to provide details of any business or private interests that are relevant to the Inquiry's Terms of Reference. I do not have any such interests to report. I am married to Professor Michael Adler CBE FRCP, who as the Inquiry will know, was a senior NHS consultant in the field of HIV/AIDs and has written and researched extensively in the field.

Q5: Involvement with other inquiries, investigations, criminal or civil litigation

5.1. I have been asked to confirm whether I have provided evidence to, or have been involved in, any other inquiries, investigations or criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. I have been asked to provide details of my involvement.

5.2. To my recollection, I was not involved in any inquiries, investigations, or criminal or civil litigation in relation to HIV or Hepatitis.

5.3. I can see that the **Annex** provides details of some limited involvement relating to:

a) Approval of draft correspondence regarding litigation claims relating to Hepatitis C infection through blood products.

b) Notice of the establishment of the Public Inquiry into BSE and CJD and of the need to preserve documents.

Section 2: The Macfarlane and Eileen Trust

Q6: Awareness of Macfarlane and Eileen Trusts

6.1. I have been asked about my knowledge of the Eileen and MacFarlane Trusts from my work at the National Aids Trust. I have been referred to a Hansard excerpt dated 15 March 1995, in which I said:

> *"... [I was] peripherally involved in this issue when I was director of the National Aids Trust in the late 1980s and early 1990s. I recall the struggle to get the Macfarlane Trust established, and the concerns which were expressed by many people at that time, were unpleasant and, in a sense, reflected what seemed to be almost a decision on principle by the Government that they were not prepared to act in this field"* [BART0000791].

6.2 I cannot add to this now.

Q7: Briefings in office

7.1. I have been asked to detail what briefing I was given about these Trusts when I first took office.

7.2. I cannot remember what, if any, briefing I received and I am told that no documentation has been found to assist.

Q8: Knowledge of issues relating to the Macfarlane and Eileen Trusts

8.1. Please see the Annex.

Q9: Contact with beneficiaries of the Trusts

9.1. I have been asked to detail what contact I had with the beneficiaries of these Trusts, and what my knowledge and understanding was of the beneficiaries' needs during my time as Minister of State.

9.2. I had no direct contact with the beneficiaries of these Trusts, as far as I can remember. I would have expected that the relevant needs of the beneficiaries would have been outlined in submissions to me, if decisions were to be taken. As a member of the House of Lords, it is also very likely that I would have had some informal contact with other Lords members who spoke for this community, such as Lord Morris of Manchester.

Section 3: Policy regarding a special payment scheme for Hepatitis C sufferers

Q10: Previous support for special payment scheme

10.1. I have been asked to outline why I supported the introduction of a special payment scheme for haemophiliacs suffering from Hepatitis C as a result of NHS treatment, prior to the Labour Party coming into office in May 1997.

10.2. I have been referred to a Hansard excerpt, dated 30 January 1995, in the House of Lords in which I directed a query to the Parliamentary Under-Secretary of State for the Department of Health (who at this time was Baroness Cumberlege):

> *"...is she aware that there was considerable and justifiable anger at the length of time it took the Department of Health to come to an opinion and a decision about the Macfarlane Trust on HIV and AIDs compensation? Will she seek to avoid a similar atmosphere developing and a similar sense of unjust treatment of people with haemophilia who have been infected by Hepatitis C? There really is no difference in the position which the Minister has explained between those infected who have Hepatitis C and those who have HIV and AIDs." [NHBT0009775].*

10.3. Another Hansard excerpt, dated 15 March 1995, debates the expansion of the role and funding of the Macfarlane Trust. The debate discussed the proposal put forward by Lord Ashley of Stoke, supported by me, to the DH for the *"small minority"* of haemophiliacs infected with Hepatitis C who were critically ill or dying, to be given an ex-gratia payment through the Macfarlane Trust [BART0000791]. I said:

> *"As my noble friend Lord Ashley of Stoke said, there really is a moral case here. I think the moral case is made completely and clearly for immediate hardship payments to those who are already ill and to those who are the dependents of those who have already died. I would then like to see an extension of the*

> *Macfarlane Trust to provide some kind of financial adjustment and financial reward – I apologise as 'reward' is an inappropriate word to use – or rather financial funding for those who have the Hepatitis C virus" [BART0000791].*

10.4. As far as I can recall, my political position at the time would have been influenced by my previous experience with the NAT. The NAT was a major non-governmental organisation and lobby group in the area of HIV and AIDS. I believe that I would have carried its concerns and interests into my role in Opposition, and been sympathetic to the argument that Hepatitis C sufferers deserved support akin to that which those with HIV had received. In addition, I was a front bench opposition spokesperson on health, so it would be natural to challenge the Government's position on this matter and to press for more to be done. My perspective was necessarily different in office; however, I have discussed this below.

Q11: Decision not to set up a special payment scheme

11.1. I have been referred to a number of documents relating to the decision made in July 1998 not to set up a special payment scheme for those suffering from Hepatitis C following treatment with blood or blood products. Given my lack of independent recollection surrounding this, I will deal with certain key documents only. There are further relevant documents noted in the Annex.

11.2. It is apparent that the Haemophilia Society, as well as others, were lobbying for a support scheme to be set up: see the Society's letter to me dated 23 May 1997 [WITN7410003].

11.3. The questions that I have been asked arise out of a later document from Mr Charles Lister (a DH official) dated 8 May 2002, discussing how to handle the contemporaneous issues the government were facing with haemophiliacs who were suffering from Hepatitis C. In this, Mr Lister referred back to the *"Dobson review"*. An MP, Michael Connarty, had requested documents from the period when I was in office and Frank Dobson was Secretary of State, seeking to look at our review of the special payment scheme [DHSC0041379_025]. According to Mr Lister:

> *"If the papers are released they would show that Frank Dobson was minded to support a scheme limited to haemophiliacs with hepatitis C but was persuaded from this by officials and Margaret Jay."*

11.4. I have commented on my meeting with Mr Dobson on 13 July 1998 at paragraph 11.12 below. Before that, I note from the Annex that:

a) When I arrived in office in 1997, the established DH "line" was against the establishment of support schemes for those affected by non-negligent NHS treatment, and that this issue was raised by claims from other groups for such help;

b) This included those infected with CJD (or were worried that they might be vulnerable to such infection) via treatment with Human Growth Hormone;

c) The topic of hGH support was handled by Ms Jowell as MS(P) and resulted in a decision to resist payments other than for harm caused by negligence;

d) Parallels were drawn with the situation of haemophiliacs infected with Hepatitis C;

e) Throughout 1997 – early 1998, the issue of a special payments scheme for haemophiliacs infected with Hepatitis C was handled by Mr Dobson;

f) There was a cross-over with issues relating to nvCJD.

11.5. My own direct involvement appears to be limited to events in May – July 1998, just before I left the DH; see below.

11.6. I can see from Mr Lister's chronology [DHSC0042461_030] that by May 1998, the Secretary of State had expressed support for at least a "small hardship fund" for those with haemophilia and Hepatitis C, but officials were said to be concerned for a number of reasons including concerns about no-fault compensation parallels, costs and the impact on patient care funds and

Treasury opposition. Dr Winyard (Director of Health Services, NHS Executive) and Dr Metters (DCMO) were prominent voices. Their concerns about establishing a HCV-haemophiliacs scheme were outlined in [DHSC0041163_008] (and paragraph 11.12 of the Annex).

11.7. I have been referred to a note of a meeting I had on 18 May 1998 with Fiona Anderson (of the Secretary of State's Private Office), Chris Corrigan, and Drs Metters and Winyard, presumably called as a result of their concerns.

11.8. I have no independent recollection of this meeting on 18 May. I am largely reliant on the meeting note [DHSC0004457_040]. I can see that officials outlined their view that payments to hepatitis C sufferers would cause major policy questions about no fault compensation, including potential parallels with decisions on HTLV1 screening and the "looming pressures" of issues such as nvCJD. Although, as I have said, I have now no personal recollection of this meeting, I feel sure that I was most strongly influenced by the arguments about creating a possible NHS-wide no-fault compensation scheme, and by the "*formidable logistical, and medical problems*" referred to in para 11.13 of the Annex to this statement.

11.9. The meeting note from Ms Anderson records that:

> *"... the Secretary of State has been considering writing to No.10 about the scope for an ex-gratia payment scheme for haemophiliacs infected with hep C through NHS treatment. We discussed the principal problems around such a scheme: such as the problems of adding to the precedent already set by the HIV/AIDs scheme; the scope of any system of payments (such as the inevitable pressure - as with HIV - to extend the scheme to blood transfusion patients and deciding the stage in a patient's condition at which such payments should become available); and the dangers of appearing to start a no-fault compensation scheme for the NHS. The last point was the most significant." [DHSC0004457_040].*

11.10. The main outcome was that I asked for a note to be drafted by Chris Corrigan for the Secretary of State, covering the reasons why setting up a scheme would not be advisable; the reasons were further explained in the note.

11.11. I subsequently wrote to Frank Dobson on 1 June 1998, advising him of my view that we should not set a payment scheme up [DHSC0006335_028]. This letter was essentially in the terms of the letter that Chris Corrigan, Dr Metters and Dr Winyard had drafted following our meeting.

11.12. I can see from the documentation that Frank Dobson and I then had a meeting on the 13 July 1998. I do not believe I would have been in this meeting alone; I would think that it is likely that Dr Metters or Dr Winyard may have been in attendance (as well as Mrs Anderson, who minuted out the result of the meeting). However, I cannot recall details of this meeting or confirm this.

11.13. The record of the meeting that I have seen for this Statement is contained in the minute that Fiona Anderson wrote the following day:

> *"Secretary of State and MS(L) discussed the issue of ex-gratia payments early yesterday.*
>
> *They have decided that they do not wish to agree to the Haemophilia Society's call for a special payment scheme for haemophiliacs infected with hep C, on the grounds covered in MS(L)'s note to the Secretary of State of 1 June. They recognise that there will be criticism of the choice not to follow the HIV/AIDS scheme but are prepared to defend the position on the grounds that the HIV decision was taken on the basis of the understanding of the disease progression at that time." [DHSC0041163_003].*

11.14. Mr Lister's Chronology also refers to an undated meeting note that I have not been supplied with. He states that it recorded that: *"MS(L) said that she felt personal discomfort with having to resist the plea but nevertheless felt it should be resisted."* [DHSC0042461_030]. Although I cannot remember the meeting, I am sure that this is right – I, like all of my colleagues, would have much preferred to be able to approve the proposal.

11.15. The decision was conveyed by Mr Dobson to the Haemophilia Society by a letter dated 28 July 1998 [DHSC0016534] and also by a Written Answer from Mr Dobson in Parliament on the same day (see Hansard at [DHSC0006894_097]. This was a day after I had left the Department of Health and I therefore had no further direct involvement in the issue.

Reflections and Comments

11.16. As I have explained, I have no personal recollection of these events, including the meetings with Drs Winyard and Metters, and with the Secretary of State.

11.17. But looking at the papers, it is apparent that DH officials had long-standing concerns about the policy ramifications of agreeing to establish a financial support scheme for haemophiliacs who had contracted Hepatitis C through NHS treatment; and I accepted those concerns after a meeting in which they were discussed. The key issue, as is apparent from note of the meeting on 18 May, was "*the dangers of appearing to start a no-fault compensation scheme for the NHS*" [DHSC0004457_040]. It is clear from the papers that I have been referring to that the NHS/DH was being pressed for financial support for many categories of patients, of whom the haemophiliacs with Hepatitis C were only one group (although a large one). The potential for knock-on policy and financial pressures was significant, and I was persuaded that a consistent approach needed to be taken. The approach that I took had already been accepted by Tessa Jowell as well, in relation to calls for hGH support, and it is quite likely that she and I discussed these issues, although I cannot remember any specific conversations.

11.18. I know that the payment scheme for those suffering from HIV/AIDs was regarded as a comparator (a point I had made in Parliament in 1995). But when this was set up, HIV/AIDS was a near-immediate death sentence. Over time improved drug therapies had increased the life expectancy for those suffering from AIDS; but this meant that the parallel with those with Hepatitis was more complex, and the risks of creating a no-fault compensation scheme by default were more acute.

11.19. I cannot remember how readily or not Frank Dobson came to share this view.

11.20. I think that it is also relevant to mention that, had Frank Dobson agreed to develop a scheme, Treasury consent would have been needed and was unlikely to have been readily given, if at all – this point was made in relation to hGH financial support in the submissions to Ms Jowell on this topic (see the Annex).

11.21. I note that ultimately, under Frank Dobson's successor Alan Milburn, the issue of no-fault compensation and redress mechanisms in the NHS more generally was referred to the CMO to consider, leading to a report "Making Amends" and the NHS Redress Act 2006.

11.22. I appreciate that this decision, and the views I came to have, must have been very disappointing to all affected, including those who had noted my advocacy in support of such as scheme whilst in opposition, in 1995 (Q10 above). I am sure that, as the chronology from Mr Lister suggests, I felt some unhappiness about making the recommendation that I did. But ultimately as a Minister, I had to look at the wider implications of a decision and I could no longer approach it as a single-issue campaign, as in effect I had been doing when in Opposition.

Section 4: Other Issues

Q12: Concerns surrounding vCJD Trust

12.1. I have been asked to outline what my concerns were about the position being taken by the government in setting up the vCJD Trust, i.e. the financial support scheme for those infected with vCJD announced in October 2000, after the BSE Inquiry had reported.

12.2. I have been referred to two documents relating to this [DHSC6287082]; [CABO0000123_013]. The first is a letter dated 23 October 2000 that I sent to the Secretary of State for Health, who by this time was Alan Milburn. I expressed the concern that the proposed creation of an ex-gratia grant scheme for people suffering from vCJD would be an anomaly, as there had not been a similar scheme established for those suffering from Hepatitis C. I also drew his attention to some advertisements I has come across in the Irish news, advertising a Hepatitis C Compensation Tribunal in Ireland, which I thought would create *"unwelcome comparative publicity about our scheme"* [DHSC6287082].

12.3 The second document I have been referred to is the letter in response to my own, from Alan Milburn, in which he distinguished the setting up of a payment scheme for those with vCJD from those suffering from Hepatitis C. He described the plight of individuals and families suffering from vCJD as a *"unique set of circumstances for which society as a whole must bear a moral responsibility".* He also stated that the Irish compensatory scheme was set up following a finding of negligence and that therefore meant there was no precedent for the UK government. [CABO0000123_013].

12.3. Again, I have no memory of this correspondence. But I can see that my concerns about a payment scheme for those infected with vCJD or for their families, were a logical product of the decision that I, together with Mr Dobson, had come to in summer 1998. I felt that a scheme would be inconsistent with our decision not to establish a scheme for those suffering with Hepatitis C. Essentially, I was concerned about the need for consistency. However, Alan Milburn's response was based on the proposition that the vCJD situation was not a comparable one, and certainly vCJD was a "death sentence" in the same way that AIDS had been when the Macfarlane Trust was set up and payments agreed for haemophiliacs with HIV/AIDS.

Q13: Further comments

13.1. I have nothing further I wish to add to this statement.

Statement of Truth

I believe that the facts stated in this witness statement are true.

GRO-C

Signed...[redacted]........

Dated......November 1st 2022.........