Sir Nigel Crisp From: William Connon

Date: 11 April 2005

Copy: Gerard Hetherington

Ailsa Wight
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Linda Wishart
Steve Wells
Frances Smethurst

MEETING WITH LORD JENKIN OF RODING: WEDNESDAY 13 APRIL 2005

Background to Lord Jenkin's request for a meeting

- 1. Lord Jenkin has asked to meet with you to discuss his access to all papers which relate to issues on the treatment of haemophilia patients and blood safety which he would have had access to when he was the Secretary of State for Health and Social Security (DHSS), between 1979-1981.
- 2. He has asked for these papers following a letter he received from GRO-A about haemophilia patients who were infected with HIV and Hepatitis C through blood products. In his letter, Mr GRO-A requests copies of minutes of meetings that Lord Jenkin had when he was the Secretary of State. There are also various other meeting papers that Mr GRO-A has requested. A copy of the letter is attached at Annex I.
- 3. PS(L) has written twice to Lord Jenkin in response to comments made by Mr GRO-A see Annex II. However, Lord Jenkin appears to be under the impression that we are withholding documents from him. He has also commented on the issue of the Department's filing and document management system.

Previous request from Lord Jenkin

4. We understand from colleagues that on a previous occasion, in 1999, Lord Jenkin wrote seeking access to policy papers, including unpublished research studies, that he had brought with him when he arrived at the DHSS in 1979. On that occasion, colleagues were unable to locate the documents. In fact, it is unlikely that they would have been retained, as they would not have been required either to support administrative needs or accountability.

LINE TO TAKE

 Many key papers from the 1970s and 1980s have been destroyed. During the HIV litigation in 1990 many papers from that period were recalled. We understand that papers were not adequately archived and were unfortunately destroyed in the early 1990s.

- We have been in touch with Departmental Records Office to check which files related to the treatment of haemophilia patients and blood safety are still in existence from the period between 1979-1981. We have obtained a list of some files from this period. However, at first glance it is not clear about the extent to which these files will hold papers that Lord Jenkin will have handled. It would require significant staffing resource to go through these files to identify official papers that Lord Jenkin handled at the time.
- We have not sought to deny Lord Jenkin access to any official papers. The reply from PS(L) focused on addressing some very serious comments from Mr GRO-B about blood safety and the transmission of Hepatitis C.
- We are aware of the Civil Service Guidance on access to official papers by former Ministers, produced by the Cabinet Office. If Lord Jenkin is able to be more specific about the subject matter or documentation that he would like to see than we can undertake a search for specific papers.
- Lord Jenkin may be aware that in 2002 Ministers commissioned a review of internal papers to clarify the facts surrounding the drive for UK self sufficiency in blood products in the 1970's and 1980's. We will let Lord Jenkin know when work has completed on this. There has been a long delay in completing the report. A short note is attached at <u>Annex III</u> on this. The report will contain an extensive list of references which may help Lord Jenkin to identify papers he would like to see from his period in office.
- 5. Background briefing is attached on the issue of contaminated blood products and the record management system in DH, including access to official papers by former Ministers.

William Connon General Health Protection Room: 633B Skipton House Ext! **GRO-C**

Infection of HIV and Hepatitis C through blood products

- 1. During the late 1970s and early 1980s, the majority of regularly treated patients with haemophilia were infected with either HIV or hepatitis C, and in some cases both through contaminated blood products supplied by the NHS.
- 2. There are some people in the haemophilia community who allege that the Government knew about the risks of HIV and Hepatitis C and deliberately allowed contaminated blood products to be used, which resulted in many haemophilia patients being infected. They also claim that there was the failure to implement a pledge by the then Health Minister David (now Lord) Owen to make the UK self sufficient in blood products that resulted in patients being infected with plasma imported from the US in the 1970's.
- 3. The facts are that it was not possible before 1985 to make blood products (clotting factors) free from hepatitis C in sufficient quantities to treat all haemophiliacs in the UK. As soon at the technology was available the NHS introduced it. Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time
- 4. In the 1970s and early 1980s clinicians knew about the risks of non A and non B hepatitis (NANBH). However, the prevailing opinion at the time was that NANBH caused a mild and often asymptomatic illness. The more serious consequences of hepatitis C, which may take 20-30 years to develop, only became apparent after full characterisation of the virus in 1989 and the development of tests for its recognition.
- 5. Self sufficiency in blood products would not have prevented haemophiliacs from being infected with hepatitis C. Blood products are made with pooled plasma (around 20,000 donations per pool). Even if the UK had been self sufficient, the prevalence of hepatitis C in the donor population would have been enough to spread the virus throughout the pool. That is why the infection of haemophiliacs with hepatitis C is a world wide problem.

LINE TO TAKE

Public Inquiry

We are aware that some people would like the Government to set up a public inquiry into this issue. Whilst there is great sympathy for those infected with hepatitis C and the Government has considered the call for a public inquiry very carefully, this has been rejected.

In the 1970's non-A and non-B hepatitis infection was generally thought to be a relatively benign condition. Hepatitis C was only identified following major advances in molecular biological techniques. The virus was not fully characterised until 1989.

Self Sufficiency

- 6. With regards to comments about self sufficiency in blood products. Our understanding is that considerable efforts were made to achieve NHS self sufficiency in clotting factors in the 1970s. The fact that self sufficiency was not achieved appears to have been linked to the massive increase in demand for clotting factors at the time not to any failure to implement Ministerial initiatives.
- 7. An informal review to clarify the facts surrounding the drive for UK self sufficiency in blood products in the 1970s and 1980s was commissioned in 2002. Work on this will be completed shortly. This includes a review of the surviving papers between 1973 and 1991 and a chronology of events.

Departmental obligations for record keeping

- 8. The Public Records Act 1958, requires "every person responsible for public records . . . to make arrangements for the selection of those records which ought to be permanently preserved and for their safe-keeping".
- 9. There have been many changes in record keeping practices since Lord Jenkin was Secretary of State:
- The organisation of Departmental record keeping was de-centralised in the early 1980s
- The number of documents and copies of documents being created in the department grew dramatically as the use of photocopiers became widespread,
- The NHS Executive's move to Quarry House in 1992/3 led to a temporary relaxation of the rules for decision-making on the retention of files,
- The Department carried out a substantial training and awareness programme in 1993/1994 to improve the quality of record keeping and the guidance available,
- We have now rolled out a Department-wide electronic records system to help keep track of email and a range of other electronic records.
- 10. But the principles of good record keeping and the advice given to staff have been fairly consistent. In particular, the policies and procedures for the management, review and disposal of files and documents are designed to meet the Department's own administrative needs and the Public Records Act.
- 11. Staff are encouraged to transfer important documents, including email, into registered files at the earliest opportunity, and our electronic records system makes this easy to do. Email messages that form part of the official record are saved for as long as business needs require and stored corporately in accordance with Departmental record management procedures.
- 12. Staff are also encouraged not to retain information any longer than needed to support departmental business. In giving staff this guidance, we are following best practice advice published by the National Archives.
- 13. In particular, the advice has always been that copies of documents held as background to policy thinking, or for reference, are unlikely to be needed long-term either to support Departmental business or to be preserved in the National Archives.

Guidance has been to dispose of such documents when they are no longer required for business use.

14. Guidance on the policy and associated procedures is readily available to staff on the Departmental Intranet, and supported by training and a rolling audit of record-keeping practice, linked with the Department's Knowledge Management Programme.

Access by Former Ministers to Official Papers

15. We have obtained the following guidelines from the Cabinet Office website on access to papers by former Ministers.

Civil Service Guidance 2: Access by Former Ministers to Official Papers

- "1. By convention, former Ministers are allowed reasonable access to the papers of the period when they were in office, although such access is at the Government's discretion. Since 1993 such access has been conditional on potential authors undertaking to comply with the Radcliffe principles governing Ministerial memoirs (see Ministerial memoirs: the "Radcliffe" Rules and their application). Subject to this point, they may have access in the Cabinet Office to copies of Cabinet or Cabinet Committee papers which were issued to them when in office, and access in the department concerned to other official papers which they are known to have handled at the time.
- 2. It is a firm rule that access to official papers must be limited to former Ministers personally. The only exception has been, in the case of former Prime Ministers, to extend access to those formerly on the Prime Minister's staff when in office, who had access to the material at the time. To allow access, for example, to other research assistants would breach the conventions about confidentiality of exchanges between Ministers and of civil servants' advice to Ministers. It would also give them an obvious advantage over other researchers, who have to wait until the papers are released in accordance with the Public Records Acts.
- 3. Departments may provide the former Minister, if s/he wishes, with help in checking references and verifying facts, but their assistance should not extend to "writing up" anything intended for publication. They should, if in any doubt about propriety, consult the office of the Secretary of the Cabinet."

Freedom of Information

16. Since the FOI act came into force in January this year we have had four extensive requests from people in the haemophilia community requesting numerous documents going back to the 1970 and 1980. We have spent substantial resource meeting these requests. We have sought to provide as much information as we can within the framework of the Act.

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Please reply to:

House of Lords, Westminster, London SW1A 0PW.

Tel: 020-7219 6966 Fax: 020-7219 0759

E-mail: jenkinp@ GRO-C

The Lord Warner

14th December 2004

Dan Naman.

Haemophilia

I enclose a letter I have had from a Mr. GRO-A who raises a number of subjects including a so-called secret Westminster-funded report into haemophilia and hepatitis non-A non-B between 1979 and 1982, for most of which time I was the Secretary of State for Health and Social Services. I also enclose a copy of my reply to Mr. GRO-A, which makes it clear that because I was the Minister at the time he is enquiring about, I feel under some duty to try and satisfy his curiosity.

You will also see that I have no present recollection of any secret report into the subject, but it may be that the files could disclose something along those lines.

I would be most grateful if you could consult officials and let me know whether there is any point my taking this matter further. It is clear from Mr. [GRO-A]'s letter that he has been in touch with other Parliamentarians, but as I was the Secretary of State at the time, perhaps I have a special obligation to try to help him.

I would, of course, be very happy to attend a meeting at the Department if this would be one way of taking the matter forward.

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The Rt. Hon. the Lord Jenkid3 of Roding



Please reply to:

House of Lords, Westminster, London SW1A 0PW.

Tel: 020-7219 6966 Fax: 020-7219 0759 E-mail: jenkinp@

GRO-A Esq.,

14th December 2004

Thank you for your letter of the 4th December.

I am afraid, like many former Ministers, I was unable to take away with me any papers that I would have seen during my period as the Secretary of State for Health and Social Services. As you know, this covered the years from 1979-1981 and I have a vague recollection of various papers that will have passed across my desk concerning haemophilia and hepatitis, but I am afraid I have no recollection of the report which you mention. Certainly, I have no way of photocopying any minutes of the meetings that I may have attended.

You will appreciate that all this is nearly 25 years ago and, as I am nearing 80, my memory of events then is becoming very vague.

What I can do, however, is write to the Minister in the House of Lords who speaks on health matters, The Lord Warner, and ask him to get the Department to make enquiries as to whether any of these documents still exist. If they do, the rules would require me to attend the Department in person in order to inspect any files which I may have seen at the time; I am not allowed to make copies nor am I allowed to show them to anyone else.

These matters are covered by strict protocols affecting former Ministers and I know from experience how difficult it is to comply with the rules while informing others of the contents of any such papers.

You speak of a documentary programme with which you are involved and ask whether I might be interested in taking part. The short answer to that question at present must be "no", but if subsequent enquiries suggest that I may have had a part to play in these matters, then obviously this would need to be reconsidered.

I will write to you again as soon as I have had a response from Lord Warner.

GRO-A GRO-A

4/12/04

Dear Lord Jenkin,

I am the GRO-A representative of the Scottish Haemophilia Groups Forum and also the GRO-A of the UK Haemophilia Society.

I am writing to you about a very serious matter to do with the blood products that were given to haemophiliacs in Britain.

Many haemophiliacs have been alarmed by some of the information that is becoming available that shows that the authorities knew there was a problem with the blood products and that they were contaminated with many virus', most notably HIV and Hepatitis but did nothing about it.

Amongst other things, we now know that we were the subject of a secret Westminster funded report into Haemophilia and Hepatitis nonA nonB between 1979 and 1982 where we were tested and samples of livers from deceased taken, all without our consent. We have been assured by consecutive governments that there was nothing more that could have been done regarding safety and that there is nothing to hide. In this case I have asked the Scottish Executive and members of the House of Commons to preside a price of deceased to the provention of the provention of the provention and how

to provide various documents relating to what was known by the government and how decisions were made relating to these blood products.

We have in our possession many of these documents and know that they were numbered etc but would like you to help complete the picture as it where.

We would very much appreciate if you could have someone photocopy minutes of all the relevant meetings that you had in your role as health minister and also of the bodies, including the NBTS, NBA, Haemophilia Center Directors etc from their inceptions, who led to this group of people being given what has effectively been a death sentence. I have informed various senior people in the media of the content of this letter and they are very interested to see the outcome.

Also, I am in the process of making a documentary with ITN about the haemophiliacs' plight and wonder if you would be interested in taking part, in the form of a short interview?

If there was no wrong doing on the part of the Department of Health then providing these documents should be no problem.

I look forward to your response.

Yours Sincerely,

GRO-A

GRO-A

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Annex II

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The Rt Hon the Lord Jenkin of Roding

_Thank you	ı for vour letter of 14 Decembe	r_enclosing correspondence from Mr GRO-A
GRO-A of	GRO-A	about past papers relating to
haemophilia. I apologise for the delay in replying to you.		

I do understand your wish to be helpful to Mr GRO-A As you rightly say, however, it is very difficult to go back some 25 years to recollect details, especially as many of the people involved are, sadly, no longer with us.

My officials have carried out a search of the relevant files, but can find no trace of information relating to the 'secret Westminster-funded report' that Mr GRO-A mentions.

However, I understand that Mr GRO-A also wrote to staff at the Scottish Executive, who have traced a report of the Haemophilia Centre Directors' Hepatitis Working Party for the year 1980/81. A copy of this report has already been sent to Mr GRO-A but I am enclosing a further copy for your records. I apologise for the poor quality of the copy, which is of course over 20 years old.

More generally, I have great sympathy for those who have become ill or who have lost loved ones as a result of contracting illnesses from blood transfusions. The Government takes the issues around haemophilia and blood products very seriously, and has great sympathy for anyone who has suffered harm as a result of NHS treatment. Ministers do understand the hardship and great distress that people with haemophilia and their families have suffered both from HIV and from hepatitis C, and deeply regret that so many people were infected through blood products.

It is important to stress that despite the Department of Health's decision to make ex gratia payments, the position with regards to accepting liability has not changed. The Government does not accept that any wrongful practices were employed and does not consider a public inquiry justified. Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time.

In making decisions about compensation, it was essential for the four UK health departments to strike a balance between a desire to act compassionately and the need to provide a high quality service to all patients. The funds that have been allocated for ex-gratia payments, and the consequent scope of the scheme and the size of the awards, reflect the decision on where that balance should lie. Mr GRO-A will know that the funds are being targeted to help alleviate the suffering of those living with hepatitis C infection.

I am sorry not to be able to provide any more specific information for Mr GRO-A but I hope this explanation helps to clarify the situation.

NORMAN WARNER

Further letter to Lord Jenkin

The Rt. Hon. The Lord Jenkins of Roding

I have been advised that you recently contacted Sir Nigel's office about my letter dated 27 January. I understand that you expressed concern about the Department's filing and record management systems.

I would firstly like to correct the impression I may have given that we hold no records on the treatment of haemophilia patients, blood safety and related issues. The Department of Health has a Departmental Records Office (DRO) that holds closed files on these areas. These files have been subject to a branch review.

Clearly, keeping good records is fundamental to the day to day running of the Department. We recognise that much of the work we do has long term consequences and accurate records are essential if future users are to be able to see why certain decisions were made, or why certain things did or did not happen. This is a message that is regularly communicated and reinforced to staff.

Mr GRO-A refers to what he calls a secret Westminister report. Officials have established that this refers to the document entitled "Haemophilia Centre Directors' Hepatitis Working Party Report for year 1980-81". A copy was attached to the letter I sent you. The paper indicates the existence of non—A and non-B hepatitis (NANBH), and that in the 1970's treatment with blood clotting factor concentrates carried a risk of infection with NANBH (what we now know as hepatitis C).

Unfortunately, in the 1970s and early 1980's, before effective viral inactivation procedures had been developed, many patients with haemophilia were inadvertently infected with hepatitis C from contaminated blood products.

The prevailing opinion among clinicians at the time was that NANBH caused a mild and often asymptomatic illness. The more serious consequences of hepatitis C, which may take 20-30 years to develop, only became apparent after full characterisation of the virus in 1989 and the development of tests for its recognition.

The paper does not show that anyone acted wrongly in the light of the facts and measures that were available to them at the time. I believe that Mr GRO-A has been campaigning for a public inquiry. However, as previously stated, the Government does not accept that any wrongful practices were employed at the time and does not consider that a public inquiry can be justified.

Mr GRO-A has requested copies of minutes from the National Blood Authority (NBA) and Haemophilia Centre Directors Hepatitis Working Party. I would like to suggest that Mr GRO-A contacts the NBA and United Kingdom Haemophilia Centre Directors Organisation directly. They are deemed to be the "holders" of these minutes.

With regards to the reference to minutes of the NBTS. Officials have identified files on the Advisory Committee on the National Blood Transfusion Service which was established in 1980. The first meeting was held on 1 December 1980. It would be

helpful if Mr GRO-A could confirm firstly if it is the papers for this Advisory Committee that he would like to see and secondly if he could be specific about the period and issues that he is interested in, before officials make an assessment on the release of documents. Mr GRO-A should contact William Connon who is based at Skipton House, 80 London Road, London SE1 6LH should he wish to pursue his enquiries.

LORD WARNER

Annex III

Review of internal papers on the issue of self sufficiency in blood products

- 1. Following claims by Lord Owen about unfulfilled commitments in the 1970s to make the UK self-sufficient in clotting factors for haemophiliacs, when she was Health Minister Yvette Cooper agreed to an internal trawl of papers.
- 2. Ministers agreed that someone within the DH should be recruited to undertake a detailed review of the surviving papers between, roughly, 1973-1991 and put together a chronology of events. The job was advertised in July 2002 and the person started at the end of September 2002. This is the date we have given as the date for commissioning the work. Without this it is difficult to answer any detailed accusations levelled against the Department by Lord Owen and others.
- 3. A draft report was submitted to officials in the blood policy team in January 2003, however there were a number of outstanding issues which had to be resolved before the report could be finalised and submitted to Ministers. There were a number unsubstantiated statements in the report which had to be checked for accuracy, we had to draw up a lengthy list of references to the report and include an executive summary. We have also consulted with a couple of haemophilia doctors.
- 4. In 2004, officials commissioned consultants to analyse the papers and finalise the report. The report is now complete and a submission is in preparation for PS(PH) on handling and making the results of the analysis of the papers public.