

Witness Name: Professor Christine Ann Lee

Statement No: WITN0644002

Exhibits: WITN0644001/1; WITN0644002/1-WITN0644002/11

Dated: 6 October 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF PROFESSOR CHRISTINE ANN LEE

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 June 2019 in relation to the witness statement of Courtney Hildyard ("CH").

I, Professor Christine Ann Lee, will say as follows:

#### Section 1: Introduction

1. My name is Christine Ann Lee and my address is GRO-C  
GRO-C My date of birth is GRO-C 1943. I hold the following professional qualifications – MA (Oxon) 1969 BM BCh (1969) MD (London) 1989, DSc (Med) (1996) FRCP (1990) FRCPath (1994) FRCOG (2010). A copy of my CV is exhibited (WITN0644001/1).
2. I have held the following positions as a haematologist for the following organisations and set out below my roles and responsibilities in each of these positions:

Dates	Position	Roles and responsibilities
September 1974 - June 1976	Registrar to Dr J Fielding, Department of Haematology, St Mary's Hospital	Laboratory and clinical; responsible in a district general hospital for the general haematology service. Six-month on call for emergency out of hours haematology including blood transfusion.
November 1976 - December	Senior Registrar to Professor PT Flute, Department of	This appointment was under government scheme HM (69)6, known as The Women Doctors'

1982 (part-time)	Haematology, St George's Hospital Medical School. This included appointments at St James Hospital, Balham, Royal Marsden Hospital Sutton and South London Blood Transfusion Centre.	Retention Scheme, which enabled female doctors with family commitments to work part time. Provision of haematology service and preparation for Membership of Royal College of Pathologists qualifying examination, achieved June 1982. During this time I provided some care for the small number of patients with haemophilia who attended St George's Hospital.
January 1983 -October 1984	Research Senior Registrar to Dr PBA Kernoff and Dr HC Thomas, Royal Free Hospital	Action Research Fellowship to study non-A non-B hepatitis in haemophilic patients. This work contributed to the dissertation for MD University of London awarded in 1989, entitled "The Natural History, Prevention and Treatment of Viral Hepatitis in Haemophilic patients."
November 1984 - November 1987	Senior Lecturer in Haematology, Charing Cross and Westminster Medical School and Honorary Consultant Haematologist, Queen Mary University Hospital, Roehampton, London	Single handed consultant haematologist responsible for the clinical and laboratory haematology service in the busy district general hospital, Queen Mary's University Hospital, Roehampton, part of Charing Cross and Westminster Medical School. I was also Senior Lecturer and provided regular teaching to undergraduate medical students.
September 1985 - November 1987	AIDS counsellor Richmond, Twickenham and Roehampton Health District	Responsibility for provision of HIV testing service using the newly developed test. Responsibility for providing education about HIV/AIDS to every secondary school within the borough of Richmond upon Thames.
April 1986 - November	Honorary Consultant in Haematology	There was no patient contact and these sessions were to prepare

1987	Haemophilia Centre and Haemostasis Unit, Royal Free Hospital, 2 sessions (1 day) per week.	research for publication.
November 1987 - December 2005	Consultant Haematologist Haemophilia Centre and Haemostasis Unit, Royal Free Hospital, London.	Particular care for patients infected with HIV and hepatitis. Together with the director, Dr Peter Kernoff, I provided comprehensive care for people with haemophilia – the largest haemophilia centre in the UK with a patient population equivalent to the whole of Scotland and Northern Ireland. There was also provision of care for patients within the Royal Free Hospital who developed bleeding or thrombotic problems. There was a large anticoagulant clinic.
April 1991 - April 1992	Acting Director Haemophilia Centre and Haemostasis Unit, Royal Free Hospital, London	The Director was not able to work again for health reasons. Overnight I had to take responsibility for the whole Unit as acting Director.
April 1992 - December 2005	Director Haemophilia Centre and Haemostasis Unit, Royal Free Hospital, London	As Director I was responsible for service delivery and management of a staff of 70 including physicians, nurses, physiotherapists, laboratory scientists and counsellors. Although I was an NHS employee, I also conducted research. Relevant to this enquiry, 4 of 18 MD or PhD theses I supervised were about hepatitis: (1) Dr Paul Telfer 1991-4 MD University of Oxford 'HCV infection in haemophilic patients'; (2) Dr Helen Devereux 1992-6 PhD University of London 'The molecular biology of HCV infection in haemophilia';

		(3) Dr Thynn Thynn Yee 1998-2001 MD University of London 'The side effects of therapy for haemophilia'; (4) Dr Esteban Herrero 1998-2001 PhD University of London 'The molecular basis of HIV and HCV interactions'.
January 2006 - present	Emeritus Professor of Haemophilia, University College London	The title Professor of Haemophilia within University of London was an honorary title awarded in 1997 for my work in haemophilia. There was international peer review of my contribution. It was the first professorship in haemophilia in the UK.
April 2007 - April 2010	Honorary Consultant Haematology, Oxford Haemophilia and Thrombosis Centre	Responsibility for women with bleeding disorders.

3. Since May 2010, I have retired from clinical practice.
4. I hold and have held membership of the following committees or groups relevant to the terms of reference:
  - a. April 2001 – December 2005: Member of UK Haemophilia Centre Doctors Organisation
  - b. 1996-2003: Chair of International Haemophilia Training Centres Committee, World Federation Haemophilia
  - c. 1993-2005: Member of Medical Advisory Panel, Haemophilia Society of UK
  - d. 1996-2000: World Federation of Haemophilia Executive with special responsibility for WFH/WHO relationship.
5. I also gave evidence as an independent expert witness at the Tribunal of Inquiry into the Infection with HIV and Hepatitis C of Persons with Haemophilia and Related Matters, which was chaired by Her Honour Judge Alison Lindsay in Ireland. The resulting report was published in 2002 and is available online.

**Section 2: Background information regarding CH**

6. I make this statement on the basis of the medical records which have been disclosed to me by the Inquiry.
7. From the records made available, it is apparent that CH was diagnosed with von Willebrands Disease in 1971 and later mild haemophilia A in September 1977 by Dr Peter Jones, Consultant Paediatrician at Newcastle Haemophilia Centre. CH received his first Factor VIII concentrate treatment in 1981 in Newcastle which is when he was infected with HCV (then known as non-A non-B hepatitis).
8. In 1983, CH became jaundiced whilst in Spain following treatment with cryoprecipitate in Newcastle. Dr Peter Hamilton, Consultant Haematologist, concluded at that time that he had non-A non-B hepatitis.
9. It appears that CH first came under the care of the Royal Free Hospital in November 1993 following a referral by his GP to the liver unit (WITN0644002/1). He was seen by Professor Dusheiko, Consultant Physician, and commenced on interferon treatment for six months which was unfortunately unsuccessful. I do not believe I was involved in his care at this time.
10. On 21 April 1997, CH was referred to the Royal Free Hospital's haemophilia centre by his GP with a request that he be reinvestigated for his bleeding disorder as CH himself had doubts that he was suffering from mild haemophilia (WITN0644002/2).
11. I first saw CH on 11 June 1997. I obtained a detailed clinical history which is summarised in my clinical notes (WITN0644002/3) and letter to his GP, Dr Skalicka, dated 25 June 1997 (WITN0644002/4). Blood samples were taken at this consultation the results of which did not concur with CH's history of mild haemophilia and possible Von Willebrand's disease (WITN0644002/5). In particular, the Factor VIII level was normal at 99 iu/dL [international units per deci-litre] (normal range 50-150) and the VWF activity was also within the normal range at 144 iu/dL (normal range 50-175). In a patient with mild haemophilia one would expect a Factor VIII level of less than 50 iu/dL and with severe haemophilia a Factor VIII level of less than 2 iu/dL. The results at the Royal Free Hospital therefore accorded with previous blood results undertaken in Newcastle when his Factor VIII levels were recorded as 85% on 8 July 1985 (equivalent to 85 iu/dL), 100% on 16 December 1986 (equivalent to 100 iu/dL) and 210% on 5 March 1992 (equivalent to 210iu/dL).

12. On 25 June 1997 I wrote to Dr Peter Jones to explain that CH's blood results and previous treatment did not fit with his diagnosis of mild haemophilia (WITN0644002/6). I requested further information about his past history. I do not believe that this was ever provided by Dr Jones although there is a handwritten note within the disclosed records by Francoise Kendall, our data manager, about information received from Rosemary Spooner who was the data manager for the National Registry kept at Oxford (WITN0644002/7). This states that CH was diagnosed with mild haemophilia A in Newcastle (Factor VIII level 28%) but at a later date Oxford was told that he was 'normal'. In view of his unresolved HCV infection, I also referred CH to the joint liver clinic to see Professor Dusheiko (WITN0644002/8).
13. On 18 February 1998, a full blood work up for CH was done at the Royal Free Hospital (WITN0644002/9). This confirmed that CH's blood results were entirely normal. I wrote to CH and to his GP on 16 March 1998 to confirm that whatever the nature of CH's previous bleeding disorder, this had now resolved (WITN0644002/10).
14. On 29 September 1998, CH was seen again in the joint liver clinic. He was once again advised that his Factor VIII levels were normal. A liver biopsy was recommended in respect of his HCV but this was declined.
15. I note that in section 6, at paragraph 4 of his statement, CH states that he was referred to the haemophilia department at Royal Free Hospital in 2003 when he was seen by me. I assume that this is an error and that CH is in fact referring to 1997.

### Section 3: Criticism by CH

*Response to Question 4 – “Mr H claims that you did not believe his account of his medical history in relation to his diagnosis with a bleeding disorder. He exhibits a letter written by you [WITN2344006] which states definitively that he does not have a bleeding disorder. This is despite subsequent correspondence (attached) that suggests the matter of his diagnosis remains unsettled. Please comment.”*

16. It is not the case that I disbelieved CH in relation to his medical history as I recorded the history he gave me within my letter to his GP dated 25 June 1997. I did, however, question the accuracy of his previous diagnosis as his blood results did not accord with the diagnosis of mild haemophilia in that his Factor VIII levels were normal. I did try to obtain more information from Newcastle about CH's previous medical history and diagnoses. I do not believe that this was ever received from Dr Jones although we did

manage to obtain some information from the National Registry via our data manager. I therefore properly concluded on the information available that his bleeding disorder at that time had resolved.

17. I do not know what the inquiry is referring to when it states in the Rule 9 request letter: *'This is despite subsequent correspondence that suggests the matter of his diagnosis remains unsettled'*. I assume this relates to the subsequent diagnosis of a platelet signalling defect. It was not until 2008 that there were more sophisticated tests available which confirmed that CH had a platelet defect for which he received treatment with DDAVP.

#### Section 4: Other issues

18. In section 6, at paragraph 6 of his statement, CH states that *'Professor Lee has recently tried to justify the use of contaminated blood products as haemophiliacs were not expected to live longer than 20 years without the use of these products'*. I am unclear as to what recent justification CH is referring to.
19. I would, however, point out that in a monograph published by Carroll Birch (*Hemophilia: Clinical and Genetic Aspects* published by the University of Illinois at Urbana, 1937), the death rate in 113 patients showed that 82 died before 15 years of age and only 8 survived beyond 40 years. Many of the causes of death were from trivial injury, separate to the gross deformities which Factor VIII treatment largely averted. I exhibit to this statement a chapter I wrote on the history of haemophilia entitled *'Historical introduction'* which sets out the data from the monograph in Table 1 (WITN0644002/11).

#### Statement of Truth

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

Signed GRO-C: Professor Christine Lee

Dated October 6<sup>th</sup> 2019.

**Table of exhibits:**

<b>Date</b>	<b>Notes/ Description</b>	<b>Exhibit number</b>
18.04.2019	Professor CL's CV	WITN0644001/1
30.11.1993	GP referral to Liver Unit, Royal Free Hospital	WITN0644002/1
21.04.1997	GP referral to Haemophilia Centre, Royal Free Hospital	WITN0644002/2
11.06.1997	Clinical notes of outpatient appointment	WITN0644002/3
25.06.1997	Letter from Professor Lee to GP	WITN0644002/4
11.06.1997	Blood results	WITN0644002/5
25.06.1997	Letter from Professor Lee to Dr P Jones	WITN0644002/6
07.01.1998	Handwritten note by Francois Kendall, Royal Free Hospital data manager	WITN0644002/7
25.06.1997	Referral Professor Lee to Professor Duscheiko	WITN0644002/8
18.02.1998	Blood results	WITN0644002/9
16.03.1998	Letters from Professor Lee to GP and CH	WITN0644002/10
2014	'Historical Introduction' authored by Professor Lee and taken from the third edition of 'Textbook of Hemophilia' edited by Christine A Lee, Erik E Berntorp and W Keith Hoots.	WITN0644002/11