Witness Name: Dr Eleanor Goldman

Statement No.: WITN3067002

Exhibits: WITN3067009-10

Dated: 17 August 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DR ELEANOR GOLDMAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 April 2019.

I, Dr Eleanor Goldman, will say as follows: -

Section 1: Introduction

1. I am Dr Eleanor Goldman, of GRO-C London, GRO-C. My date of birth is GRO-C 1930. I qualified from the University of Witwatersrand in South Africa, obtaining the Degree MB BCh in 1952. I became fully registered with the GMC in September 1953. Between 1970 and 1974 I worked as a Medical Officer at the Far East Rand branch of the South African Institute for Medical Research in the general pathology laboratory. Between 1976 and 1984, I was Clinical Assistant to Dr Katherine Dormandy at the Haemostasis and Thrombosis Centre at the Royal Free Hospital in London. Between 1984 and 1995 I was an Associate Specialist in Haematology, again at the Royal Free Hospital. I retired fully from medical practice in 1995, and relinquished my registration with the General Medical Council on 1 January 2009. I am now 88.

Section 2: Responses to criticism

2. Before responding to the criticisms set out in the Rule 9 request letter dated 15 April 2019, I would like to provide some background information.

3. The Haemostasis and Thrombosis Centre at the Royal Free Hospital was established by the late Dr Katherine Dormandy to provide comprehensive care for patients with bleeding and clotting disorders. This was to include medical treatment and social and psychological support, enabling patients to lead as normal a life as possible. With the development of replacement concentrates, patients were put on home treatment which was administered by parents, and as soon as possible by the patients themselves, with parental supervision as necessary. Patients would be seen on request at any time of day or night. There was also regular general reviews arranged annually or six monthly.

4. Patients were referred to specialist departments as and when necessary – including orthopaedics, gynaecology, hepatology and paediatrics. A special orthopaedic clinic was held monthly with Mr J C Madgwick (orthopaedic consultant), and subsequently Mr N Goddard, to see selected patients with orthopaedic complications of haemophilia, which were not uncommon. Later I arranged for similar clinics with the Head of Paediatrics.

5. My role was to treat patients with acute bleeds as well as seeing them for annual review. At these reviews they were also seen by a full time social worker, Mrs Riva Miller. Mrs Miller was trained as a family therapist at the Institute for Family Therapy. Realising that haemophilia was a family issue, I attended an introductory family therapy course at the Institute for Family Therapy, and a course in systemic family therapy at the Tavistock Clinic.

6. With the agreement of Dr Peter Kernoff, then the Director of the Centre, Mrs Miller and I arranged to see patients together, at the beginning of a review, to explore social or psychological needs. I provided genetic counselling when requested, and later HIV counselling. I was the co-author of a book on Counselling in HIV, with R Miller and R Bor. The counselling method was based on systemic family therapy, which recognized that every individual was part of many systems. The patient's place in these systems and the varied influences upon them shaped their behaviour and reaction to their circumstances. This approach enabled us to offer comprehensive care for the patient and his or her family, with the counselling technique adapted as necessary to individual patients, with varying degrees of success.

7. Counselling sessions were videotaped with the patients' consent, so that we could review the sessions afterwards and plan any future interventions in line with usual practice. The purpose of the tapes was explained to the patients and they signed consent forms which were filed in their clinical records. In the case of children, parents signed the consent form on their behalf.

8. During the 1970s, it became apparent that there was a form of Hepatitis which was neither positive for Hepatitis A nor Hepatitis B antibody tests. This new strain of Hepatitis was initially referred to as "non A non B Hepatitis". Patients being treated with blood products were noticed to have minor abnormal liver function tests whilst remaining negative for Hepatitis A and/or Hepatitis B. In 1990, with the advent of recombinant gene technology, it became possible to identify the virus responsible, which was named Hepatitis C.

   As soon as a test for Hepatitis C became available in 1990, all patients being treated with blood products at the Centre were tested. Many were found to be anti-Hepatitis C virus positive. Dr Christine Lee, Consultant Haematologist and Director of the Centre wrote to all patients affected, to inform them of their results.

9. HIV testing was available from 1984/85 onwards. As soon as the test was available, all patients in receipt of blood products were routinely tested. Existing patients of the Centre were not asked for permission to carry out particular blood tests, including the HIV test, on samples taken regularly. The patients were also not asked for permission to test stored samples, and I do not believe they were aware at that time that samples had been stored as this was not usual practice. The samples were retained after having been used for routine analysis as part of the patients' clinical care and review, so that they could be analysed in future if new tests became available. When the HIV test became available stored samples were sent off for testing in batches, at the request of the then Director Dr Peter Kernoff. Once the test had become available it was therefore possible to go back through any given patient's previous blood samples and retest them in order to establish when (within a maximum window of six months), they had become infected. New patients coming to the Centre after HIV testing had become standard, would be given counselling before they decided whether they wished to undergo testing in line with practice at that time. Further counselling was then given in the event of a positive test result.

10. For existing patients, whose blood was tested as a matter of routine, including HIV testing once available, a different procedure was followed. If routine testing had produced a positive result for HIV, the patient would be counselled at their next attendance at the Centre. Patients visited the Centre frequently on an as necessary basis, or alternatively they would be written to and asked to make a specific appointment. In line with usual medical practice at that time, the counselling would be given before they were asked to decide whether they wished to be informed of the result. The nature of that counselling would be very similar to that given to new patients being offered an HIV test.

11. The patient would be advised that with the advent of HIV testing, a sample of their blood had been submitted for testing. They would then be asked to confirm what they already knew about the HIV infection. We explained that all patients who had received Factor VIII had possibly been exposed to the HIV virus and that before deciding whether they wish to be informed of their test result, they needed to understand the implications of a positive test result. Those implications included (at that time) their continued employment and future employability, their ability to obtain life and/or health insurance, the need to take protective sex precautions, and their duty to inform their sexual partners.

12. In terms of the prognosis we would explain that this was highly uncertain – as was the situation in the 1980s. We would emphasise that the infection reduced natural immunity, and it was the resulting susceptibility to other opportunistic infections which caused problems, rather than the HIV infection itself. We stressed that other infections were dangerous, and that they would need to consult their General Practitioner or doctors at the Centre, in relation to what for other people, would be regarded as everyday illnesses. We would explain that there was no specific treatment for HIV at that time, but that there were effective treatments for opportunistic infections. The counselling session would end with a question to the patient in terms of what they would tell their partner or other relatives, when they got home. This was an effective way of establishing how much of the information they had absorbed. We would then deal with any further questions the patient had.

13. Patients would almost always ask about life expectancy. At that stage we did not know the prognosis, and made this clear. However it was clear that the prognosis at that time was not good. We certainly did not give a life expectancy estimate (because we did not have the evidence to do so or describe the illness as life limiting. I would emphasise however that by 1985 HIV and AIDS were receiving an immense amount of publicity and media attention in which the prognosis was described as very grim indeed, and for all practical purposes the media regarded the infection as terminal.

14. Almost all patients elected to be informed of their test results. Indeed I can recall only one patient who decided that he did not wish to be told. Once the positive result had been communicated to the patient they would then be provided with more definitive advice, coupled with reiteration of the earlier counselling. As such patients were seen very regularly there was ample opportunity for further discussion in the light of new knowledge and developments in diagnosis and treatment. We would emphasise the need to take precautions during sexual contact, and to take extra care if they contracted an infection or sustained an injury. In terms of cuts and bleeding (particularly relevant for haemophilia patients), the need to regard safety of others as paramount was also emphasised.

They would be advised to notify their dentist, and to disclose their condition in advance of any dental or surgical treatment.

15. In the early years following the identification of and testing for the HIV virus there was no treatment. Treatment with anti-retroviral (unfortunately with unpleasant side effects) then developed, but were only offered at the stage when the CD4 (T-cell or white blood cells that fight infection) count fell below a stipulated level. Patients were informed of this and advised that their CD count would be constantly monitored so that anti-retroviral treatment could be commenced if necessary. The first effective treatment for HIV itself – Azidothymidine (Zidovudine) did not become available until 1987 and had limited impact, although with side effects.
    Real progress in treatment of the disease, with a whole range of effective therapies, did not occur until 1995, around the time of my retirement.

16. Patients were always encouraged to bring their partners with them to counselling sessions, and usually did so, not just in relation to HIV and HCV, but for all haemophilia patients, as we needed to discuss the genetic implications of an inherited disorder. When a patient attended with his or her partner following a positive diagnosis for HIV, we would counsel the partner in similar terms as I have described above. We would begin by asking what knowledge they had of HIV, Hepatitis C and/or haemophilia as necessary. We would then tell them what they did not already know. We would ask them whether the information they had been provided had changed anything or surprised them. The partner would be offered testing. Depending upon how much they already knew about HIV, they would be given similar counselling information as described above. If the partner's result was positive they would be referred to an immunologist or genitourinary clinic. If the partner tested negative for HIV they would be warned that they should continue to use barrier contraception. If they tested positive the risks of passing the infection to any children they subsequently had would be explained. They would not be discouraged from having children. Care with cuts and hygiene would be reiterated. Once again we would emphasise the likelihood of progress in terms of research into better and more effective treatments, and the possibility of an eventual cure.

17. Extensive counselling continued at all subsequent reviews, and over the years the advice changed as new knowledge was acquired, and the prognosis began to improve.

18. I have read PE's statement dated 29 November 2018, and reviewed the documentation that accompanies it. I was subsequently provided with copies of his medical notes and clinic correspondence arising from consultations or other contact with PE in the period 1985 to 1995, although some of this material comprised illegible second generation copies which I was unable to read and which also appeared to be incomplete.

Then on 3 September 2019 I was provided with a further set of records obtained by the Inquiry direct from the Royal Free Hospital which are fully legible and appear to be complete. This set of records has been paginated 1-164, and it is to this pagination that I will refer in the course of this statement. I produce these records collectively as **WITN3067009**. I have an (albeit very limited) recollection of PE as a young man with a passion for football. I cannot now recall whether he generally attended the clinic accompanied or unaccompanied. I have noted in particular the comments drawn to my attention in paragraphs 7, 8 and 19 of his statement.

At paragraph 8 of his statement Mr E claims that you did not provide him with advice on how to manage or treatment his HIV. Please respond.

19. The relevant entry appears at pages 22 – 23 of PE's records. Although PE refers to 5 August, I think the correct date is actually 1 August 1985. In the preceding paragraph 7 of his statement, PE refers to being informed that he had contracted HIV in August 1985, more than a year after he was infected. I take his reference to August 1985 as being the date that the diagnosis was disclosed to him. As I have described, patients were given the option of knowing their diagnosis at the first consultation after a positive test result was then received. Almost all patients chose to be informed.

20. PE was seen by me and Riva Miller on 1 August 1985, when he was informed that his blood had been tested for HIV and asked whether he wished to be informed of the result, having been given the pre-result counselling I have described above. His reference to having been infected more than a year earlier probably relates to the retrospective testing I have already described, which was designed to identify as accurately as possible when the patient had become infected. If, as PE describes, Riva Miller was also present during the consultation in question then I believe the consultation would have been video recorded with PE's consent.

21. The disclosure of the result, and the counselling before and after disclosure of that result would have followed the format I have already described. Advice on managing the disease would have been given as described earlier in this statement. In 1985, the evolution of treatments for HIV were in their very earliest stages, and as I have indicated the emphasis at that time would be on the need to treat opportunistic infections rather than the disease itself.

22. At pages 38-40 in PE's records there is a handwritten letter from him following the August 1985 consultation confirming that he had moved jobs and had a new General Practitioner, and further that he would like to nominate his mother and girlfriend to be tested for HIV.

Nothing in this letter or other correspondence from PE suggests that he is displeased with the way in which his HIV test result had been communicated to him or discussed with him and later, his partner. I refer to pages 33, 91 and 98-99 of the records.

At paragraph 8 of his statement Mr E claims that after he was informed of his HIV status, he was left to his own devices to go home and absorb the information he was to die.

23. The actual wording of paragraph 8 reads as follows:

> *"I was left to my own devices to go home and absorb the information; that I would die young. I would suffer and die a horrific painful death. The outlook was bleak and terminal."*

24. It is not clear whether PE is suggesting that this is what was said to him during the counselling session of 1 August 1985, or whether that was his assessment of his situation at that time; his oral evidence to the Inquiry on 30 April 2019 (transcript page 9) suggests the latter. I deeply regret that this was his perception as the counselling sessions were designed to be supportive, and we endeavoured to take as optimistic approach as possible, albeit against the backdrop of a disease about which there was still a great deal to learn, and the prognosis of which was indeed very poor at that time. We emphasised that there would be ongoing counselling available, and that we were available to provide as much support as possible. I am satisfied that the patient would not have been told that he would "die young" or suffer a "horrific painful death", although I appreciate that may have been his perception of what he had been told or that the outlook was bleak and terminal. However there is no doubt at all that this was the message being relayed by the media at that time.

At paragraph 19 of his statement Mr E claims that during one appointment in 1988 you grilled his partner in relation to marrying someone with HIV as you wanted to "put the fear of God into her" and give her the chance to cancel their wedding. Please comment.

25. I have reviewed paragraph 19 of PE's witness statement which I do not think is accurately reflected in the paragraph in bold above. Paragraph 19 reads:

"When Heather first came to one of my appointments in June 1988, Dr (Goldstein) and Riva Miller grilled her about the prospects of marrying someone with HIV. At the time it was rather a stark and brutal appointment due to the content of the discussion and I was unaware that they had intended to address her. I think they wanted to put the fear of God into Heather and give her a chance to call the wedding off."

26. Having now had the opportunity to review PE's hospital records, I can confirm that I did not participate in the consultation in June 1988 to which he refers in paragraph 19. It has recently been confirmed that PE has now reviewed the video consultation of 21 June 1988, in which I do not feature and that he has advised that the comments in paragraph 19 of his statement relate to a different consultation.

27. PE attended a consultation with me on 9 September 1987 when he was accompanied by his girlfriend with whom he had been going out for three months. A copy of my handwritten note appears at pages 150-151 of the records, and states:

*"*Came *in with girlfriend, going out for past 3 months. Informed of haemophilia and HIV status very early in relationship. Well informed girl. Discussed HIV transmission, risks of having children, treatment of haemophilia"*

28. I have now had the opportunity to review the video recording of this consultation. The sound quality is poor in places. The consultation, which lasted over an hour, was attended by PE, his girlfriend and future wife Heather, and me. Riva Miller was not present at any stage.

29. PE and Heather confirm that she has attended the consultation in order to find out more about PE's condition. There was discussion about the retrospective testing of old samples. It is clear that both PE and Heather had a good understanding of HIV/Aids, and I spent some considerable time explaining the nature of the disease. There was then discussion of how haemophilia is passed from one generation to the next. There was specific discussion of how HIV can be transmitted, by semen and blood, but not by saliva. I recommended the use of condoms and that some spermicide was more effective against preventing transmission of the virus than others. We talked about precautions in the event that PE suffered a bleeding injury and the need for rubber gloves and for needle care.

30. There was also discussion of the implications of PE's HIV status for any attempts to start a family. Both PE and Heather explained that it was very early in their relationship to be considering such matters. I mentioned that heterosexual transmission appeared to be less amongst haemophiliac patients in stable relationships. PE appeared to be aware of medical advances and the possibility of "sperm washing" in the future. We discussed how they anticipated their relationship would be affected if it transpired they could not have children of their own, and the possibility of adoption was considered.

    PE remained positive about the possibility that a vaccine would be developed in due course. They were in agreement that whether they remained together would be a matter of Heather's choice.

31. Towards the end of the consultation Heather confirmed that she had found the consultation very helpful and had learned a lot. I expressed my gratitude for their attendance and observed how brave it was for them both to come to the appointment. I observed that they clearly had a great deal to think about, and encouraged them to come and see me again together if they had any further questions.

32. Having reviewed this consultation it is clear that it was cordial and friendly throughout. I asked a mixture of open and closed questions, and gave PE and Heather the opportunity to control the subject matters discussed. It was a thoughtful and informative discussion and the level of understanding and maturity displayed both by PE and by Heather was commendable as was their constructive and positive outlook.

33. No aspect of this consultation could amount to Heather being "grilled" about the prospect of marrying someone with HIV, and at no stage was any attempt made to encourage them to reconsider their relationship. They had only been together for 3 months, and no wedding was imminent at that stage. I commended and encouraged the strength of their relationship and their courage in the light of the uncertainty they faced. Those factors, coupled with the absence of Riva Miller suggests that this not the consultation to which PE refers in paragraph 19 of his statement. I anticipate that if he views the video recording (if he has not already done so) PE will agree with that analysis.

34. I had no other consultation with PE at which Heather was present.

35. My follow up clinic letter of 23 September 1987 appears at page 95 in the records, and notes that PE was about to travel to Morocco, returning in November 1987.

36. PE's next review was on 9 December 1987 when he was seen by Dr Lee. Her notes appear at pages 151-152 and her follow up clinic letter (also dated 9 December 1987) is at pages 92-93. The penultimate substantive paragraph of that letter is of significance:

> *"I had a long talk with Mr Evans and his mother separately, about HIV related problems. Mr Evans now has a girlfriend and he anticipates it might develop into a permanent relationship. He has discussed his haemophilia and HIV positivity with both her and her parents. There is no question of pre-marital sex because of his religion but he is quite aware of the precautions that must be taken and the risk involved.*
> *Both he and* GRO-C *have a strong religious belief which helps them cope with the uncertainties of HIV disease."*

37. PE then wrote to me on 5 January 1988 (page 81 of the records):

> *"I am writing to you to inform you that I have just got engaged to the young girl I brought with me back in September/August last year. It crossed my mind that you might wish to see her alone or with me...*
>
> *If you would like to see us with regards to some counselling that we might need then please get in contact with either of us. I am not sure if I am on your or another doctor's books. Perhaps you could pass this letter on if it's the latter of the two."*

38. I then wrote to PE on 7 January 1988 (page 90 of the records) confirming that as his last appointment had been with Dr Lee, arrangements would be made for PE and his girlfriend to see Dr Lee at their next appointments, which were scheduled for 8th and 9th March 1988.

39. I see from the records (pages 152 to 154) that on 8 March 1988 PE attended a consultation with Mrs Miller and Dr Lee accompanied by his fiancé who he was scheduled to marry that July. The notes are self-explanatory, the first section being in Dr Lee's hand, and the second section written by Mrs Miller. Mrs Miller's note suggests comprehensive counselling regarding PE's HIV status, their future marital relationship and the possibility of having children.

40. I have been unable to locate a clinic letter following this consultation.

41. PE attended a further review appointment with Dr Lee and Mrs Miller on 21 June 1988 on to which detailed notes, again compiled by Dr Lee and Mrs Miller respectively appear at pages 154 to 155 of the records.

42. Dr Lee's clinic letter appears at page 87 of the records, and notes:

> *"This patient was seen with his fiancé and Mrs Miller, our social worker, on 21 June for his six monthly review. He has mild haemophilia with a Factor VIII level of 8% and has been HIV positive since at least February 1985. We had a long discussion about the transmission of HIV in particular about precautions that need to be taken for sexual intercourse. They have been advised to use both a condom and a diaphragm for the patient's future wife. They plan to marry on July 23 1988 and are extremely well informed about HIV infection and its transmission.*
>
> *This patient is very well informed about HIV disease, he has agreed to enter an asymptomatic trial using AZT. He is getting married on July 23rd 1988 and his future wife understands fully about haemophilia and HIV problems."*

43. I have recently been provided with a copy of the video recording of this consultation, which I have reviewed. The sound quality is poor, but it appears to reflect the above extract from Dr Lee's clinic letter. I was not present during this consultation, and therefore I do not propose to comment further upon it.

44. If PE's comments in paragraph 19 of his statement in fact relate to the consultation with me on 9 September 1987, I can say with certainty that that counselling did not extend to considering the viability of their ongoing relationship or the advisability of any contemplated marriage. I can however understand now how our approach in those circumstances may have inadvertently left him with that impression. He may for example have come to that consultation expecting or fearing that his partner might be discouraged by the information provided. Our Socratic method of imparting information through questioning may have appeared to him as stark and brutal or like a "grilling". This was certainly not our intention. The objective was to offer both the patient and his partner constructive advice and support, and the approach was described in detail in a paper by Dr Lee, Mrs Miller and me in the BMJ in March 1992 entitled "Counselling HIV Positive Haemophilic Men Who Wish to have Children" a copy of which I produce as **WITN3067010.**

Section 3: Other Issues

45. Patients like PE had already had to cope with the potentially terminal diagnosis of haemophilia. Factor VIII (and subsequently Factor IX) had liberated haemophilia patients immensely, only for them then to be overtaken with the shattering diagnosis of HIV contracted through infected blood products. I was extremely sorry to read PE's statement, and in particular the comments he makes in

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paragraphs 7, 8 and 19. I particularly regret that our approach during counselling sessions appeared insensitive - this was certainly never our intention. I was moved to tears by his evidence and was pleased to read that their relationship was strong enough to survive the immense hurdles they faced at that time. Our approach at that stage was that by communicating the facts known about HIV (limited though they were at that time), relationships would be strengthened.

Statement of Truth

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

Signed: Dr Eleanor Goldman GRO-C

Dated 17/8/2020

Table of exhibits:

Date	Notes/Description	Exhibit Number:
1985-1995	Medical Records	WITN3067009
22 March 1992	Journal Article 'Counselling HIV positive men who wish to have children', E. Goldman, R. Miller, C. Lee	WITN3067010