

Witness Name: Susan Mary Willder

Statement No. WITN3929001

Exhibits: WITN3929002 - 019

Dated: 10/3/20

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF SUSAN MARY WILLDER

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2 December 2019.

I, Susan Mary Willder, will say as follows: -

#### Section 1. Introduction

1. My name is Susan Mary Willder. My date of birth is GRO-C 1946 and my address is GRO-C. I retired seven years ago but previously worked in clerical administration at Darent Valley Hospital in Dartford. I was married to my late husband George Marcel Willder for 9 years and we had two daughters together. George died just after our ninth wedding anniversary. My daughters have assisted me with this statement.
2. I intend to speak about George's experience living with haemophilia and diabetes and his sudden death in 1978. I will also speak about my family's recent discovery that George was treated with factor products, and that tests had evidenced hepatitis antibodies in his blood prior to

his death. In particular, I will speak about the nature of George's illnesses, how the illnesses affected him, the treatment he received and the impact it had on him, my family and our lives together.

## **Section 2. How Affected**

3. My husband George had severe haemophilia A and was also a type 1 diabetic, dependent on insulin injections. As far as I know his haemophilia was diagnosed when he was about eight years old and his diabetes in his early teens. It would appear that the haemophilia had come from the French side of his family – his maternal grandmother was French.
4. I met George when I was 17 or 18 years old. He went to a boys Grammar and I went to a girls Grammar in Gravesend, Kent. From the time I knew George he took insulin injections twice a day for his diabetes. I cannot recall George being particularly unwell in the early years of our relationship.
5. George and I went out for a little while and then broke up and later got back together. We were married on 12 April 1969 and our daughters GRO-C and GRO-C were born in 1972 and 1977 respectively.
6. George's haemophilia was treated at St Thomas' Hospital in London under the care of Professor Ingram. I know that he had also spent quite a long time in Banstead Hospital in Surrey when he was younger, as I believe he sat his 11-plus exam when he was a patient there. I am not sure why he went to Surrey for treatment when he lived in Kent?
7. It is possible that George may have occasionally seen someone at St Thomas' for his diabetes, but it was for the most part managed by his GP, Dr Ian Crawford of GRO-C. Dr Crawford gave George prescription renewals for his insulin.

8. In spite of missing quite a lot of his education and studies due to his health problems, George went to College and got a degree in English Literature. He eventually became an English teacher at a school in Gravesend, where we were living. Although George was quite stoical about his health, he was in a lot of pain for much of his life.
9. It was eventually decided that George could start treating himself for his haemophilia at home with cryoprecipitate, which was delivered to us in a frozen state by the ambulance service and was then defrosted as and when it was needed. I think it must have been 1973 or 74 when George started self-treating with the cryoprecipitate.
10. George underwent surgery for the fusion of his ankle joint in late March 1976. His medical notes show that he was given Factor VIII at this time (**WITN3929002**). The notes show that he was also tested for his 'HAA status' around this time, which I understand means he was tested for hepatitis associated antigens (**WITN3929003**). This is the first mention we can find of George being given Factor VIII treatment in the medical notes. From later entries however, it appears that Factor VIII became a regular part of his post-operative treatment (**WITN3929004-005**).
11. I noticed that there are earlier references to 'Factor VIII Assays' in the notes around the time that George had his appendix removed in 1972. However, I think this is referring to the doctors checking George's Factor VIII levels, and not Factor VIII treatment.
12. George's medical notes show that he was again tested for hepatitis associated antigens and Hepatitis B on 20 May 1976 (**WITN3929006**). His medical notes also show that on 27 October 1976 an antibody to Hepatitis B antigen was detected (**WITN3929007**).
13. George taught for a few years and then had to reluctantly stop teaching. While his diabetes was well managed, his haemophilia was

necessitating more time off work due mainly to bleeds in his joints. We just assumed that his haemophilia was getting worse.

14. George's medical notes show some letters between Professor Ingram and the Kent Area Health Authority from late 1976 to early 1977 where his ability to continue teaching was discussed (**WITN3929008**). While Professor Ingram thought it would be good for George to stay at work in education, he didn't think that there was any immediate prospect of George returning to regular classes. I think George stayed on with reduced duties for a while, but he then he had to completely give up.
15. In July 1977, George had an eye operation at St Thomas' Hospital. His medical notes show that on this occasion he was also given Factor VIII treatment for "light coagulation" to his eye (**WITN3929009**).
16. George underwent surgery for the formation of a loop fistula in January 1978. His medical notes show that for this operation he was given a new product called Hemofil in addition to Factor VIII (**WITN3929010**). The notes from January 1978 again show that an antibody to Hepatitis B antigen was detected in one of his blood samples (**WITN3929011**).
17. While George was in St Thomas' hospital for the loop fistula surgery, I recall that another haemophiliac had died quite unexpectedly at the hospital. All of the haemophiliacs tended to know each other because they were all in the hospital for treatment. I remember the Sister saying it had come as a shock that someone had died unexpectedly.
18. It was only when we were able to procure George's medical notes in September 2019 that my daughters and I were made aware of the fact that George had been given Factor VIII treatment for his ankle, eye, and loop fistula surgeries and that this had led to the presence of hepatitis antibodies.
19. Upon reading George's medical notes, it also became apparent that from as early as May 1965 George was being treated with something called 'EHF'. There are many notes saying George was given bottles of

EHF, and on one occasion it refers to the EHF being "trial material" (WITN3929012).

20. My daughters and I had no idea what EHF was, however having done some research we believe it is referring to Extended Half Life factor products. It appears that these products are used to treat males with Haemophilia A and B.

21. Neither George nor I were made aware at any time that he was being treated with factor products. We were only aware of cryoprecipitate being used to treat his haemophilia. We were not informed of any potential risks from the use of factor products. We were also never told that George was being tested for hepatitis, nor that the tests had come back positive.

22. After coming home from hospital from his fistula surgery, George was mostly confined to bed as his haemophilia needed more frequent treatment and was proving very painful. He was taking a lot of methadone at this point and we thought that his haemophilia was getting worse. My daughter GRO-C can remember the time vaguely. She recalls George being in bed a lot, but I think she just assumed that fathers spent all their time in bed! GRO-C would still get into bed with George to play.

23. George's diabetes had also been a bit erratic around this time, which was unusual. His GP had called in and, as far as I can remember, put him on an alternative insulin a couple of days before his death.

24. George died very suddenly and unexpectedly on 26 April 1978. I had taken George's lunch up to him and put my younger daughter GRO-C down for an afternoon nap. I went down to get my lunch and then returned upstairs to find George unresponsive. I called his GP and an ambulance, whose crew then pronounced him dead. As his GP had seen him within the previous couple of days, there was no post mortem and the death certificate showed hypoglycaemia as the primary cause

of death (WITN3929013). The death certificate also recorded his diabetes and haemophilia as other contributors.

25. At George's request, his body was donated to St Thomas' Hospital for medical research. I recall speaking to someone who dealt with body donations in order to arrange for his body to be collected from the undertakers. I remember that they made a comment in frustration about his body being cold. I was very shocked by this comment. I can only assume that the donation took place, as I never heard anything further from the hospital.

26. Having now read George's medical notes, it is my family's view that George must have contracted hepatitis from his treatment with factor products. We are unsure how else he could have tested positive for hepatitis antigens. George never used intravenous drugs, nor had tattoos or piercings. The medical notes also demonstrate that George was regularly tested for hepatitis antigens and the test results were negative up until October 1976, just six months after he was first treated with Factor VIII. In view of the question of comorbidities, we are wondering if the hepatitis could have hastened or caused George's early death.

### **Section 3. Other Infections**

27. I am not aware of George contracting any infections other than hepatitis. The detection of antibodies to hepatitis B antigen is the only infection referred to in his medical file.

### **Section 4. Consent**

28. I believe that George was treated with factor products without his knowledge or consent, and without being given any information about the risks involved. George was never asked for his consent to be treated with factor products prior to any of his operations. As I have

already mentioned, George and I were only aware of cryoprecipitate being used for the treatment of his haemophilia.

29. I think it is also possible that George may have been treated with factor products for the purposes of trials or research. I have already referred to his medical notes recording that he was treated with EHF "trial material."

30. The medical notes also show that George was regularly tested for hepatitis antibodies without his knowledge or consent. George was often in hospital and was used to being tested all the time. This was a normal thing for him. However, I was never told that George was being tested for hepatitis, and I am sure that if George knew he was being tested for hepatitis he would have told me.

GRO-C

GRO-C

31. I was never approached by any medical professional to get tested for hepatitis. I was a regular blood donor and I recall a question once came up about haemophilia and I was required to get tested for HIV in order to continue to donate blood. My memory is a bit vague about when this was, but I think it might have been sometime in the 1980's. As far as I am aware, I was never tested for Hepatitis C. I continued donating until about two or three years ago and earned the gold badge.

## Section 5. Impact

32. George's sudden death was a shock for everyone, not only for myself, but for his mother, who was a war widow and had now lost her only child. It also had great impact for our eldest daughter GRO-C who suddenly lost the father to whom she had grown very close. George's

early death also meant that our youngest daughter [GRO-C] who was only one at the time, has no memory of her father.

33. [GRO-C] went to school one day and then by the time she came home her father had gone. [GRO-C] has a daughter who is just over four years old, and she says she often thinks about the fact that the close relationship her daughter has with her husband was what [GRO-C] had with George before he passed away.

34. At the time George died, we had no reason to think anything further of the circumstances of his death. We believed what was written on the death certificate. You didn't really ask questions of doctors at the time, and we never really knew what treatment George was receiving at the hospital. However, we knew that George's haemophilia had always been treated with cryoprecipitate and just assumed that he had never been given Factor VIII.

35. We had tried unsuccessfully to get hold of George's medical notes in around 2013 or 2014. Because my daughter [GRO-C] is a haemophilia carrier, she went through IVF with her husband in order to have her daughter. This involved DNA analysis and the doctors at the Genetics Department of Guys Hospital were interested in the type of haemophilia George had in order to figure out what strand [GRO-C] carried.

36. The Genetics Department tried to get George's medical notes from St Thomas' but were told that there was no record of him being a patient there. My daughter [GRO-C] says this was unusual because we donated his body to St Thomas' for medical research and you would think there would have been a record of samples taken. We wondered whether they may have spelt our surname wrong, but this seemed unlikely because [GRO-C] had written it down for them. I didn't think medical notes were kept that long anyway and we just accepted that there were no notes.



37. It was only when the news of the Inquiry came out that my daughters and I started to become curious. I had told my daughters that George had always been treated with cryoprecipitate, but we thought maybe we should check. We decided to have another go at trying to obtain George's medical records using the form on the Inquiry's website and suddenly the notes appeared. I was quite surprised that the notes were still available. My daughter [GRO-C] suspects that perhaps St Thomas' didn't try particularly hard to pull up the file in 2013 when Guys Genetics Department checked, but when we requested them through the Inquiry they probably paid more attention.
38. George's file was emailed to me and I recall we started looking through it at [GRO-C]'s house. We saw that it said George had been treated with Factor VIII, which I was shocked to find because I had no reason to think he had. I think on a later date [GRO-C] then discovered the notes showing the positive hepatitis results. She says that this felt shocking.
39. I was very annoyed to think we had no knowledge of the test results. It had been quite a few years since George's death by this point, but I was annoyed and believe that we should have been told. There was nothing in the medical notes to say that the results had been communicated to George. [GRO-C] says that the results speak of a time where patients weren't really told about their results. We were really kept in the dark about it.
40. [GRO-C] says that George's death was already something terrible for our family, but now that we have his medical file we have questions where we didn't have questions before. It is not as if the pain and impact of George's death ever went away, but reading his medical file and realising there was more to the story has almost brought it all back up again. It has made us question why George died so young and whether the hepatitis caused or contributed to his death.

41. My daughter [GRO-C] wonders whether George was in a lot more pain at the end because he had hepatitis. The medical notes around the time of George's death, record that he was often complaining about bleeds in his hips and was being prescribed a lot of methadone for the pain. We have wondered whether it was the bleeds causing the pain or whether he was in even more pain than usual because of the hepatitis.
42. We also have questions about the contraindications of hepatitis and diabetes. George's diabetes was always very well controlled until the last week or so before his death, when it suddenly became quite erratic. Two days before George's death, his medical notes state that he was feeling very low and thought his diabetes may be poorly controlled (WITN3929014). Up until this point the notes always said that his diabetes was well controlled. We therefore wonder whether the hepatitis may have made his diabetes worse.
43. We contacted the Haemophilia Society at around the same time we contacted the Inquiry to ask if they could help to explain George's medical file and answer our questions about the contraindications of hepatitis and diabetes. They said that they couldn't really help with the file, but that they were raising questions with the Medical Board and would be publishing a report quite soon.
44. [GRO-C] says she is still glad that we found out that George had hepatitis, but it does open up a lot of questions. It makes us want to ask questions and get answers more than we ever have before. But we have to accept equally that we may never find the answer. Not knowing is the big thing.
45. [GRO-C] says that while George's death has always been horrific for me, it is a different kind of horrible for her and [GRO-C] says that in a way it has made her rethink her whole life. She wonders if she would be a different person if George was still alive. She finds it very difficult to talk about.

46. One thing that has affected both my daughters is the impact George's death had on their respective decisions to have, or not have, children. Because George died so young, [GRO-C] says that to her and [GRO-C] haemophilia meant death. They always thought that they couldn't have a child with haemophilia because the child would also die young and it would be awful. The Haemophilia Society recently told my daughters that just because a child has haemophilia doesn't mean they are going to have a limited life, but my daughters have always seen it as life limiting. For [GRO-C], this informed her decision not to have children, and for [GRO-C] this meant many hugely expensive rounds of IVF.
47. While we appreciate that someone like George with two illnesses would perhaps have a shortened life, we now question whether his life should have been shortened to that extent. Perhaps if he hadn't contracted hepatitis he might have had a little bit longer. This is difficult for my daughters because it makes them think that maybe it would have been fine to have children with haemophilia. It makes them think about what might have been instead.
48. [GRO-C] finds the new information particularly difficult and upsetting. We have shared various parts of the medical file with her, but she has decided not to read the file herself as she finds it too upsetting.
49. [GRO-C] says that in one way we were lucky that because George died so early, we didn't have to see him struggling with an awful illness like Hepatitis C. It also meant that our family didn't experience any of the stigma surrounding the illness. We weren't ostracised like some of the other witnesses to the Inquiry.
50. While we have not directly experienced stigma, George was always conscious of the stigma surrounding his haemophilia. He was very reluctant to tell anyone about it because he said that if people knew he would immediately be at a disadvantage. Sometimes when he was teaching he would have to go into school with crutches, and I recall he told his students that the crutches were for old war wounds. It's not that

George wouldn't talk about his haemophilia, but he didn't advertise it or volunteer any information. He tried to get along with life normally.

51. It is also distressing to see that some of the correspondence between doctors in George's medical file appears to effectively stigmatise George for the frequency of his use of cryoprecipitate and pain relief.
52. There are letters from George's GP Dr Crawford to Professor Ingram expressing his concern that George was treating himself too frequently with cryoprecipitate and questioning whether he was actually bleeding or simply treating himself as an "excuse to take methadone." He refers to George's "drug need" and "obvious addiction" (WITN3929015).
53. In a later letter, Dr Crawford says that George is "...possibly easily addicted to drugs at present" and that he feels he is "aiding and abetting" George to infuse himself frequently (WITN3929016). It is very upsetting to read Dr Crawford implying that George was a drug addict because of the drugs he was taking to ease his pain.
54. We discovered from reading the file that in 1977 George was being prescribed methadone by both Dr Crawford and St Thomas' Hospital and for a period the doctors were unaware of this. When it was discovered, Professor Ingram got the Drug Dependency Unit involved (WITN3929017). It is as if they thought George was selling the methadone or something, when in fact he was taking it because he was in so much pain.
55. Professor Ingram appears to have been more supportive of George's circumstances. There is a letter where he informs Dr Crawford that haemophiliacs should treat bleeds at the earliest stage to achieve the quickest resolution, and that he can't deny the number of treatments a patient thinks he needs. He distinguishes George from a social addict due to the chronic pain he is in, but he says that his drug dependency is "sad" and "suggests a steady erosion of his own emotional resources" (WITN3929017).

56. I think that George was probably getting depressed, but I am sure that in his mind he just thought that he was getting bleeds. If he thought he was having a bleed he would treat himself with cryoprecipitate, and if he was in pain he would take pain relief. It was almost a vicious circle.
57. The doctors' comments are written in a very cold, matter of fact way. I appreciate that this is indicative of the way patients were talked about in the 1970's, but they are very upsetting to read. One comment that we have found particularly difficult is in one of Dr Crawford's letters to Professor Ingram, where he says following a home visit: "George spends most of his day in bed, now we can all see his demise through hepatitis having seen his bed littered with discarded needles, swabs and a bit of polythene tube" (WITN3929015).
58. Dr Crawford's comment annoys me because there is no way I would ever let my children play with George with needles lying around. My daughters and I interpret his comment as implying that George would get hepatitis from all of the drugs and needles he was using. However, it could also be inferred that Dr Crawford knew that George had hepatitis and was almost writing him off. His letter was sent in December 1977 and the first positive test result was in October 1976.
59. Some of Professor Ingram's observations of George have also affected my daughters and I. In a letter to Dr Aronstam at Treloar Haemophilia Centre a couple of months before George's death, Professor Ingram referred to George as "a very pathetic figure who lives at home and seems to think of very little else other than whether or not he is bleeding and how much cryoprecipitate he should give himself" (WITN3929018). In another letter to Dr Crawford he says that George has "obviously built his emotional life tightly around this supposed need for cryoprecipitate" (WITN3929019).
60. I find all of these comments very difficult because they don't paint a true picture. My daughter GRO-C says that it is one view of George's

life that bears absolutely no resemblance to our view. Our memories of George are completely different. We weren't sure about including these comments in my statement originally because we thought they made George look bad. It is horrible, but GRO-C says it feels better to get it all out in the open now that we know other patients were talked about and treated in the same way.

#### **Section 6. Treatment/Care/Support**

61. I appreciated Professor Ingram's treatment and care of George and in fact wrote a letter of thanks to him following George's death. However, having reviewed George's medical file I am not completely satisfied that George was adequately supported with his use of cryoprecipitate and pain relief. I feel that George always received the necessary treatment but perhaps not adequate help in dealing with his pain management.

62. GRO-C considers that the letters between Dr Crawford and Professor Ingram show that Dr Crawford was struggling with George's treatment and needed Professor Ingram's support. Dr Crawford talks a lot of his concerns about George's use of cryoprecipitate and methadone and doesn't seem to know how to manage it. He says in a letter to Professor Ingram that he is "not too happy about the lack of expert supervision" and that he couldn't cope with the situation (WITN3929016).

63. We get the sense from George's medical file that the doctors considered him to be a difficult patient and were perhaps writing him off. Dr Crawford's comment about George's demise through hepatitis certainly suggests that he was writing George off rather than giving him the treatment and support he required.

64. Despite the doctors' concerns about George, counselling or psychological support was never offered to him. I was similarly never

offered any support when George passed away. I wasn't aware that George had been treated with Factor VIII and infected as a result, and so the question of counselling for these specific circumstances never arose.

### **Section 7. Financial Assistance**

65. As I did not become aware that George had hepatitis until September 2019, I have never been offered any financial support by any of the trusts or schemes set up to deal with those affected by infected blood.

66. I think that George had some sort of disability or long-term sickness allowance while he was alive, and when he passed away I had some assistance from his teacher's pension. I eventually ended up meeting someone else and had to give up the pension, but I think the pension contributed until my daughters were through University. We were certainly never flush with money and George's death had a financial impact on our family.

### **Section 8. Other Issues**

67. My daughters and I are pleased that the Inquiry is happening. We became aware of the Inquiry mainly on the news. However, I also saw other programmes on the TV about how there had been a government coverup and that they had been aware of it in 1974. This made me even more angry; disgusted even. I can't understand how they got away with it for so long.

68. Initially we didn't know whether the Inquiry would be interested in George's story because we didn't know anything for certain. We didn't know if anyone would actually care about it. [GRO-C] says we still feel a bit like this. We have this file of medical notes that we don't understand and we don't really know what to do now. As [GRO-C] says, the Inquiry is to answer questions at a macro level, but we are not sure we go for

next steps on a micro level. We have so many questions and would like someone with medical knowledge to look at the file and tell us what happened to George.

69. We have found it reassuring to hear that so many other people have been affected by this. As GRO-C says, we felt very odd reading George's file and were almost embarrassed to show people some of the letters. It is helpful to now know that others were treated the same way as George and that our situation isn't actually that uncommon.

70. GRO-C says that we want it to be on record that this happened to George. While it sounds cliché, it is about finding justice. Although we have lots of questions, at least we have a medical file. As GRO-C says, there will be lots of other families out there that don't even have a file. We would like everything in the file to be put out there and for some use to come from it.

#### **Statement of Truth**

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

Signed GRO-C

Dated 10/3/20

#### **Exhibits**

<b>Exhibit No:</b>	<b>Description</b>	<b>Date</b>
WITN3929002	Medical note regarding Factor VIII treatment	31 March 1976



WITN3929003	Medical note regarding HAA status	29 March 1976
WITN3929004	Medical note regarding Factor VIII treatment	2 April 1976
WITN3929005	Medical note regarding Factor VIII treatment	21 April 1976
WITN3929006	Medical note regarding HAA and Hepatitis B check	20 May 1976
WITN3929007	Virology report showing detection of antibody to Hepatitis B antigen	27 October 1976
WITN3929008	Letters between Kent Area Health Authority and Professor Ingram	23 December 1976 – 4 January 1977
WITN3929009	Medical note regarding Factor VIII treatment	15 June 1977
WITN3929010	Medical notes regarding Factor VIII and Hemofil treatment	24 - 28 January 1978
WITN3929011	Virology report showing detection of antibody to Hepatitis B antigen	16 January 1978
WITN3929012	Medical note regarding EHF trial material	29 January 1975
WITN3929013	Death Certificate	27 April 1978
WITN3929014	Medical note regarding diabetes	24 April 1978
WITN3929015	Letter from Dr Crawford to Professor Ingram	23 December 1977
WITN3929016	Letter from Dr Crawford to Professor Ingram	22 February 1978
WITN3929017	Letters from Professor Ingram to Dr Crawford and Dr T.H. Bewley	28 December 1977
WITN3929018	Letter from Professor Ingram to Dr Aronstam	14 February 1978
WITN3929019	Letter from Professor Ingram to Dr Crawford	27 February 1978