

Witness Name: **Susan Knight**

Statement No.: **WITN0780/001**

Exhibits:

Dated: *28th March 2019*

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SUSAN KNIGHT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 07 February 2019.

I, Susan Knight, will say as follows: -

Section 1. Introduction

1. My name is Susan Knight. My date of birth is GRO-C 1946 and I am a retired former Liberal Democrat councillor. I live in GRO-C West Sussex with my husband Graham.
2. I intend to speak about my husband Graham Knight. He was infected with the Hepatitis C Virus ("HCV") as a result of being given infected blood products.
3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment received, and the impact it had on him and our lives together.

4. My husband and I are members of the Haemophilia Society, but are not participating in their part of the Inquiry, nor in any of their legal actions.
5. I confirm that I am not legally represented and that I am happy for the Inquiry team to take my witness statement.

Section 2. How Affected

6. My previous marriage had broken up in 1987. I had always wanted to go back into education, so I first studied at Hillcroft College, and then completed a degree in Urban Studies at Sussex University, graduating in 1992. I had become a Town and District Councillor in 1981 and continued in these roles whilst at University.
7. I first met Graham in 1988, whilst we were both working in the local party for the local Town and District Council's elections. We have been together since 1993 and we were married over Christmas 1994. We have both been previously married and so together have a large family with 15 grandchildren.
8. Graham and I worked as councillors together for a number of years with the Liberal Democrat party. We have both had a number of roles on councils and have been public figures in our community.
9. Graham was born with von Willebrand's Disease ("VW"). I knew he had VW before we got married, but it didn't really mean anything to me. I just thought 'oh he bleeds'. It would always stop eventually. I didn't see him suffer with it and thought of it as like someone with asthma; it was controlled. It was so mild I didn't think anything of it.
10. In February 1983, Graham had a vasectomy at Guy's Hospital. He received 7 units of Factor VIII during the surgery, and as I understand it, this was not explained to him.

11. Later that year, in around October/November 1983, he suffered from appendicitis and underwent an appendectomy at Guy's Hospital. Again, he was given Factor VIII during the surgery.
12. I did not know Graham at the time, and as such was not present for either of these operations. I therefore do not know what information he may have been provided with before being administered blood products.
13. I believe Graham was infected with HCV during one of these operations, and have subsequently been told his medical notes suggesting the units of Factor VIII blood product administered to him were contaminated with HCV. I was told this verbally at St Thomas' Hospital that Graham's HCV infection was contracted via contaminated Factor VIII during these operations.
14. In around 1997 he began to feel very tired and did not feel well. We went to the doctor's and saw Dr [GRO-D] at Newton Surgery. Graham had liver problems and the doctor assumed this was due to drinking too much. I had only seen Graham drunk twice in my life prior to this so I thought it was wrong.
15. Graham is very good at being able to stop drinking, so he stopped altogether. He would recover, but then be ill again. It was always backwards and forwards. Dr [GRO-D] assumed he had resumed drinking. I lost my temper and told Graham his liver should be recovering. He had stopped drinking and it was not right. Graham had liver problems for around five years before he found out he was infected with HCV.
16. Graham had been having regular blood tests. If they had checked his blood alcohol levels they would have known he was not drinking, but they assumed he was lying.

17. We went back to Dr [GRO-D] yet again, in 2003, and Graham insisted he had stopped drinking. Dr [GRO-D] then said that he would test for HCV. I thought he was a bloody idiot and could not believe he had not tested Graham before. Dr [GRO-D] knew Graham had VW and knew about his previous operations. I am more than cheesed off with him.
18. We were unaware Graham was infected with HCV until 2003. It had lay dormant, like it did for most people.
19. Graham had been really tired for years, and was unable to keep going. He and I owned an engineering firm that we were forced to close because Graham was so unwell. Graham kept trying to work, and was working as a manager at an electrical firm when we were told by Dr [GRO-D] he had HCV. This was in 2003, a few days after he had a blood test checking for HCV.
20. Graham was referred to St Thomas' Hospital. We were informed that HCV was a killer, that at the time there was only one cure, and that it was not always successful. They informed us how HCV could be transmitted, and that is when they told us we should not have unprotected sex. I think that was the only thing they said we should not do.
21. We were told that there wasn't anything to be frightened about with the rest of the family. We were given leaflets. It was similar to what people had been told about HIV, but that it was more difficult to catch. I must have been told it can be transmitted via blood, as I remember telling our family to be careful not to share toothbrushes.
22. I do not think St Thomas' could have communicated this information any differently. They were kind, explained the risks to other people, and did it as nicely as they could.

23. I do not believe this information could have been communicated sooner, as within three days of Graham's HCV test, we were referred to the Haemophilia Centre at St Thomas' and informed about it. Dr [GRO-D] should have done the test earlier, but as soon as it was done we were told immediately.

Section 3. Other Infections

24. I do not believe Graham received any infections other than HCV. They still test him for HIV regularly and he hasn't got it. Every time we go to the clinic they double check and test all his bloods.

Section 4. Consent

25. As far as I am aware, Graham would have given his consent for all operations and procedures; if he did not he would have died. He would have consented to all operations, and would probably have signed any forms they put in front of him.
26. To the best of my knowledge I am not aware of any testing carried out on Graham for the purposes of research.

Section 5. Impact

27. HCV had a number of mental and physical effects on Graham. He would become very tired, but would try to carry on as normal. Previously, he had always been very active and full of energy. He was always doing things, for example he built a pond in our garden. He went from high physical energy levels to always being very tired.
28. Mentally this was awful for him. Because his HCV hadn't been diagnosed at the time, he couldn't understand it. He was cross because he couldn't do the things he used to.

29. Graham had to give up his work. That got him down a lot. It must have been bad, because the firm was his baby. He used to work all hours. He couldn't concentrate very well – This cheesed him off!
30. The HCV infection led to further medical conditions, including cirrhosis of Graham's liver. Between 1998 and 2003 Graham's tests GRO-C GRO-C which indicated his liver was under stress. St Thomas' stated that if they had found out about the HCV earlier he would not have got this.
31. Graham suffers from a number of conditions that cannot be treated due to the damage his liver has sustained.
32. He suffers greatly from Cramp Fasciculation Syndrome. This causes agonising cramps in his legs and sometimes his arms, which wake him in the night. Sometimes he can just walk around the bed for a bit and then can get back in. Other times he goes to the bathroom, shuts the door and cries. He thinks I can't hear him. But I can hear him. If it gets bad he'll shout to me and I'll try and rub his legs. It never does any good. This happens at least once a week.
33. Graham can take, particularly now, endless amounts of pain. He has been to the pain clinic and been taught techniques. It is awful. I just have to sit there and watch this and think 'This ain't alright'. He does his best to get through it, but now he can hardly walk.
34. At the initial diagnosis at the pain clinic the Doctor who examined him diagnosis that he had fibromyalgia. We were told there are around 15 points on the body which signifies the condition. Anything over 9 is classed as having fibromyalgia. Graham had 11-12.

35. He has developed gallstones. Every now and then they move. When he's in pain we need to know if it's just the gallstones or not; if it is he can put up with it. Ordinarily you would have your gall-bladder out, however they cannot do that for Graham because of all the complications from his HCV.
36. He also started having spurs of bone growing out of his spine (Spinal Stenosis), which has caused severe back pain (Neurological Claudication). A surgeon named Dr Smith did an operation on his back.
37. They did it at Guy's Hospital, thinking it would be alright there. Graham was in so much pain Dr Smith thought 'we have to do it'. He'd had so much treatment previously they were worried about anaesthesia. I went away for 2 hours and did shopping and came back and he hadn't woken up from the operation. They said to me that the lifts were broken and to come back in 2 hours. I went off to a beauty salon had a nice chat, and when I got back Graham was in bed awake and fine.
38. Only 2 weeks later Dr Terry Wong, a consultant Gastroenterologist and Hepatologist, said they had called him and said 'they were asking me how to wake him up!'. I would have gone ballistic but thank god they lied to me!
39. Graham's fibromyalgia, which I believe was caused by the HCV treatments. It means he can feel pain when you just touch him. This also causes other debilitating conditions.
40. In 2003 Graham began a 48-week treatment with Ribavirin and Interferon. He would have weekly injections of Pegylated Interferon, and would take daily Ribavirin tablets. Katie, the HCV Nurse at St Thomas', tried to teach me how to administer the injections. They were into his stomach and I just couldn't do it. I do not know why; I just couldn't put the needle inside his skin. I tried it once and then decided not to do it.

41. After he realised, I couldn't do the injections on him; he did them himself. While he was on treatment we drove down to southern Spain, my sister had just had a villa completed in the mountains and we took some small pieces of furniture with us for the house, it helped as respite from the situation, but you never really get away from it. We had bought a small electric car fridge, so we were able to take the Interferon injections with us, and Graham carried on with the treatment while we were away.
42. Graham became bruised everywhere from the needles, and as it went on he became black and blue all over. Graham used to hate when it was time for the next injection; it was awful.
43. At one point they decided to give an Interferon pen to replace the injections. The dosage was all wrong and the pen would leak. We did that for one week and then said no way. I remember confronting the medical rep and telling him that the pen wasn't working. After that Graham went back to the normal injections.
44. Coproxamol would be given to help treat the pain, but the government took it off the prescription list as people overdosed on it. I think they should have kept it for Graham, and people like him, as it actually worked to alleviate his pain. The alternative medication did not work.
45. As far as I know Graham did not receive treatment for his liver; they only monitored it. Dr Terry Wong told me if he needed a new liver he would get one, however he is not on a transplant list currently.
46. I remember the first night of his treatment. We put a bed down in the living room, because we were told he may not be able to walk round. They said it would really be a shock for the body, he would have shivers and he would feel terrible and would have aches and pains like flu and all the rest of it. We went to bed that night.

47. The bed was wet through; he woke up shaking. They said to try and put him in the bath, with warm water in it, to help with all the sweating. They told me what to expect, which was good because otherwise I would have called an ambulance. He was delirious. That first night was awful.
48. I do not believe Graham faced any obstacles in accessing HCV treatments, and I do not believe there were other treatments that should have been made available to him.
49. Graham developed an umbilical hernia as a result of the Interferon injections and the severe shaking. The doctors were reluctant to operate on him, even though it was a minor operation and the pain was excruciating.
50. We eventually went to King's College London to have a hernia repair operation done. Jenna Stanley, Graham's key nurse at St Thomas' had called quite a few times to explain the blood and specific platelets they would require for the operation. She also sent them on several occasions the Care Plan set out by the St Thomas' Haemophilia team, for Graham.
51. When we met the surgeon, he said 'what platelets?'. The man was massive but I was pointing my finger at him and by the time I was done he must have felt two inches tall. They tried to delay the operation, but I told them they bloody well would operate and with the required bloods. They eventually got it right, but I think if I hadn't yelled at that surgeon, he would have had to go home and wait again. As far as I was concerned that was not going to happen.
52. Although I very much appreciate what St Thomas' have done for Graham I no longer just take what NHS staff say as correct and will fight my corner if I feel something is not right or Graham could end up not getting the right treatment.

53. I really worry about not being there for him. If Graham is not okay, then who is going to stand up for him?
54. It really is hard work. If Graham isn't seen by the top consultants who know him, and his condition, it is really tough. It scares the hell out of me because if I'm not there they will operate and they could kill him. I get so uptight with them. It is very stressful.
55. His infected status has impacted on all of his other treatments, including dental care.
56. He has to go to a certain hospital, he can't take certain medications due to his liver, and he still needs the correct blood supplies. I have to explain time and again, particularly when we are abroad, that he can't receive morphine.
57. Graham's HCV infection has had a huge impact on him socially. He cannot play with the grandchildren any more, which is sad. After he started the treatment it hurts him to be touched. One time, his granddaughter Katie ran up and sat on his legs to be bounced, but Graham screamed in pain. The poor girl was upset and beside herself. He used to pick the grandkids up, throw them around and play with them, but he can't do any of that anymore.
58. It has also affected our private life [GRO-C] We don't cuddle much anymore. We used to put arms around each other, but it hurts him now so we don't.
59. It's had a huge impact on us. But we love each other and you just try and do your best. You can show affection in other ways. When that first started that was very difficult for us, the physical side of it.

60. He used to play with the children, and we would go walking as a family, but he can't even walk down the road any more. We used to be bird watchers but can't do that anymore. Walking, running and doing active things is important in our family. Graham and I now drive around in a car. We used to go walking with the rest of the family but he just can't now. We've adapted as much as we can to it.
61. We are close so it impacts us both similarly with family things. We are very protective of each other. Our friends are very protective of us and understand. The only thing I do without him is swimming. He doesn't like swimming. I try to keep fit with aqua-aerobics and things. I feel as if I can do that because he didn't do that anyway.
62. I also can't afford to have a bad back because then I wouldn't be able to look after him so I swim to keep my back in shape. I worry so much about my own health because if anything happens to me then who would care for him? I go to the doctor's and everything I am supposed to do but I still really worry.
63. After the breakdown of my first marriage, before I met Graham, I saw a psychologist twice a week in counselling sessions. I had 2 years of counselling, twice a week.
64. As soon as I told my doctor Graham had HCV, my doctor prescribed me antidepressants (Sertraline 50 mg) to help me manage it. I call them my 'happy pills'. I am on a low dose at the moment.
65. I've not been feeling right for ages, but the doctors can't seem to find anything physically, if there is in fact anything wrong. My new doctor is lovely, she realises I'm a carer and thinks it might just be stress. I therefore take the antidepressant tablets, and she asked if I wanted to up my medicines to help me cope with my stress, but I am at present on the low dose.

66. I like to go in the garden. I find weeding is good therapy. I know I should go walking, but I feel guilty because I know Graham would want to come with me.
67. I wish I'd had a punch bag when he was struggling with his pain and treatments, because I couldn't take it out on him. I couldn't shout at him, could I?
68. My sister Janette and I will sometimes go on holiday together, I am comfortable with that. Graham can't fly for more than three hours – that is what we have been told. We used to go to the Gambia and go bird watching, but we cannot anymore.
69. He once got his cramps on a plane and people thought he was having a heart attack. I was worried that because of his legs locking with cramp he wouldn't be able to sit down and the plane wouldn't be able to land. We were alright in the end. Graham had been tanned a lovely colour, but he went grey with the pain.
70. Graham's condition has impacted me emotionally. I get uptight sometimes. I very rarely cry, but I do cry. I lose my temper with myself. I think 'for god's sake woman you know what to do - just do it!' With Graham I start to go into a shell. He knows something is then wrong and he will try and help me open up. We know each other really well and we try to help each other's pain.
71. I do not believe there has been any stigma associated with Graham's HCV diagnosis.
72. Everybody in our family knows of his condition, and apart from Graham not being able to play with the grandkids I do not think there has been any issues.

73. Graham and I were forced to close our engineering firm, because he was simply too tired to work. We had insurance that would have paid out if we had known Graham was suffering from HCV. But by the time we found out it was too late and we missed out on claiming £40,000. If Doctor [GRO-D] had tested for HCV earlier our financial situation would have been much different.
74. Graham also had to give up his council work because he struggled with concentrating.
75. Back in 2003 I was working as a Chief Executive for Crawley CVS. I was earning £30,000 a year at a company with an annual turnover of over £300,000 a year. I had to come away from that to help care for Graham.
76. I would have kept working until retirement age, if it had not been for Graham's HCV and me needing to care for him. I could manage working 4 days a week, but when Graham was having his treatments I couldn't handle it. I needed to be there with him, and I had to give up work. I wouldn't have given it up until I was 65 or so. I had a lovely job.
77. I gave up full-time work in October/November 2003. In May 2004 I stood for the County Council elections and was elected as a county councillor for the Liberal Democrat party that paid an allowance. I put my name down, everybody knew why; it was part time and allowed me time to be with Graham. It paid £11,000 p.a. After that I went on the Police Authority as a councillor representative, which brought another £7,000 in. So I brought in £18,000 a year, which helped us get by. I never thought I would need to do part-time work to keep things afloat.
78. My councillor job had an irregular work pattern so I could plan my days better. Financially that kept us going. In that job I could worry about other people's situations and not have to think about us and our problems. I have since retired fully to act as Graham's carer.

79. We try to make it as best we can. You have to learn to live with it. I think we are a lot luckier than others; we know this because we've done things to help people not as fortunate as ourselves.

Section 6. Treatment/Care/Support

80. I do not believe Graham has ever faced any difficulties or obstacles in obtaining treatment, care or support in consequence of being infected with HCV. If he needs a treatment he gets it. St Thomas' Hospital in particular have been great.
81. I have been offered psychological support in consequence of Graham's HCV infection. I am more than happy with the support offered. Graham has a counsellor and she offers support to me as well. She invites me in to his sessions sometimes.
82. I don't think they could have done anything more. The only complaint I've got is that they don't give me massages anymore!

Section 7. Financial Assistance

83. I found out about financial assistance from the Skipton Fund the same day as Graham getting the diagnosis. Someone from St Thomas' came and explained Disability Living Allowance and the Skipton Fund scheme.
84. As soon as we were eligible the hospital filled in most of the forms in; Graham just did the front page, signed it, and it happened straightaway. As far as we're concerned with the Trusts, there was no problems.
85. The Skipton Fund paid us £20,000 in Stage 1 and £25,000 in Stage 2. Later on there was another £25,000 allocated to the Stage 2. We received £70,000 in total. They were just lump sums, not regular, annual payments.

86. We also receive regular payments from EIBSS. Graham just has to confirm he is alive each year! They sent us a list of things we can claim for. Our garage roof was done, including the boiler inside. All we have to do is get 2 quotes. We plan on claiming on more things in the future, including repairs to our drain, and car mileage. We have got EIBSS without any problems.
87. The only thing we had problems with was with the Personal Independent Payments ("PIP").
88. As far as we know we got everything we should have got. St Thomas' Hospital helped us with the forms.
89. The hospital told us to apply for Disability Living Allowance, and helped us out with the forms. But Graham decided he wasn't eligible for it after reading the form. Graham felt he was eligible for the PIP however.
90. We got the form, gathered everything we needed to prove and apply for it. They sent us for an interview in Eastbourne. At the interview we were asked questions about what Graham could and couldn't do.
91. However, the lady who interviewed us had no idea what Graham suffered from. It was obvious she didn't know what we were talking about. I have no idea if she had a medical background or not, but she was supposed to have.
92. After Graham finished his treatment, a private doctor saw him and confirmed that he was not fit for work. In the PIP interview nothing was asked about that and they did not physically examine him or anything.
93. One of the mobility questions was 'can you find your way around on unfamiliar routes?'. Graham said he had satnav and he needed it because he can't read and absorb maps anymore. With the satnav he was still getting lost going around roundabouts.

94. Another question was 'can you walk 200m?' Graham had no idea how long that was and apparently it's 20 double-decker buses. And Graham can't. He simply can't.
95. We got rejected. We couldn't fathom what was going on at all. That was the first time I cried since his diagnosis. We got a letter telling us why we'd been rejected. We were both councillors and knew what to do with the forms and were experienced in these matters. Graham cried as well.
96. The letter implied that we were lying. It said that Graham came in looking 'neat and tidy', that he had no gravy down his jacket and this and that and the other. I was sat there as his carer thinking 'would I let him out with stains down his jacket!?' They also claimed that because Graham looked her in the eye he could deal with people fine.
97. I cannot find the original letter; we probably threw it out in disgust.
98. I couldn't believe it. We were both upset and we both got angry. Once you're rejected from PIP you can apply for a mandatory reconsideration; we asked for that and it came back exactly the same. They upheld the assessor's decision.
99. Graham then called the Caxton Fund and spoke to a guy who came from Suffolk. He came down and interviewed us at our home. He said we were entitled to it, no question. He actually told Graham off for giving DWP far too much information in the application! The judgex at the tribunal, and the doctor there were wonderful.
100. The doctor knew all about the condition and answered all the questions. Caxton were brilliant. The tribunal overturned the decision and Graham got put on the Living and Mobility Allowance.

101. Other than the problems with the PIP we have had no real difficulties or obstacles in receiving financial assistance. I am very satisfied on the whole.

102. There were no preconditions made for the applications to get the payments.

Section 8. Other Issues

103. I understand that Professor Savage (deceased), former Head of St Thomas' Haemophilia Centre, wouldn't give factor VIII products to patients at the time. He apparently knew there was a risk of spreading infections. I don't know where he was at that time, as it was before he met Graham. He was pissed off to say the least that people were contaminated from these blood products.

104. The Haemophilia Society know about Professor Savage; he had said to them that he would refuse to give Factor VIII products to patients. If he knew they were dangerous, why were other doctors using infected blood products?

105. Graham is looking to obtain further medical records and notes from a number of places, including St Thomas' Hospital. Requests for this information have all been sent off.

106. Some hospitals, including the Princess Royal wanted it done on their forms, instead of the Infected Blood Inquiry's forms. Two of the options on these hospital forms talk about giving up rights to litigation.

107. Apparently, Graham's Request for Information forms went to St Thomas' and gave all the info they had on the relevant people, but the response from the Haemophilia Centre part of the hospital didn't include the relevant, pink Haemophilia department's forms and notes.

108. I am worried that if St Thomas', a good hospital, can manage to not keep adequate records and return all the requested information, then it could surely happen elsewhere.
109. I have taken part in campaigning. I have been to see our local MP, sir Nicholas Soames. Graham and I have written letters, have asked to see him and to speak in parliament about the infected blood inquiry. We went up to East Grinstead to see him. He was very sympathetic.
110. Within the Liberal Democrat party we always attended conferences about infected bloods. We spoke with Norman Lamb, we spoke to Tim Farron, and also with Baroness Kath Pinnock. They have had meetings about infected blood products and we've attended them.
111. Baroness Kath Pinnock has sent things to the Lords making sure they attend the votes if it was to do with blood products. She has been making sure all of the Liberal Democrats were doing what they were supposed to do with regards to voting and things. We have spoken to MPs through the Liberal Democrat party doing what we can. Ginny, sir Nicholas Soames' PA, has been very supportive.
112. Finally, I am now very anxious about medical insurance, after Brexit. Additional costs for insurance after Brexit are a worry, particularly if healthcare stops being reimbursed when you are in Europe. Could Sir Brian send a letter to the Government regarding this?
113. We have told insurance companies everything, but they haven't got a clue what VW is or liver disease. So the things Graham has wrong with him, the insurance companies don't even have buttons for! So they could turn around later and say 'well you never told us about that'.
114. As far as they're concerned, on paper Graham is perfectly healthy! Whereas myself, I have asthma and my premiums have gone up because I have to take an inhaler every now and then.

Statement of Truth

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

Signed GRO-C

Dated 28th March 2019

