

Witness Name: Kevin Goddard

Statement No.: WITN1885001

Exhibits: 0

Dated: 21 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KEVIN GODDARD

Section 1. Introduction

1. I, Kevin Goddard will say as follows. My address and date of birth are known to the Inquiry.
2. I am married and have a son who is 25 and a daughter who is 22.

Section 2. How Infected

3. I was diagnosed with haemophilia A when I was 8 years old. I had been admitted to hospital to have my tonsils out. They would not carry out the procedure because I bled. We were sent home, I never did have my tonsils out.
4. I am a moderate haemophiliac. I only need products when I injure myself or if I need to have surgery. I have been given Factor VIII several times during my life for various injuries such as slipping on ice or falling off my skateboard when I was a teenager. I had this treatment at different hospitals depending on where

we were living at the time, these included Cambridge Military Hospital, Lord Treloars Hospital, Basingstoke Hospital and Ryde Hospital.

5. I was born on the Isle of Wight. My family moved to GRO-C in 1977 but moved back in 1980. I have lived on the island ever since. I have been under the care of the Haemophilia Centre at Southampton Hospital.

6. I had two teeth removed at St Mary's Hospital on the Isle of Wight, the first in 1989 and the second in September 1990. I was given Factor VIII on both occasions. GRO-C I was aware of the risk of infection and the devastation that it caused. I did not trust them. I knew that there was the possibility of them using old stock. I therefore made a point of asking the doctor whether there was any chance that the blood products were contaminated. He told me that there was no chance that the factor VIII was contaminated, he said that it was 100% safe and that he would even give it to his 7 year old daughter.

7. The night following the tooth extraction I had flu. I was still in hospital and they moved my bed into the supply room. I thought it was weird because I had the flu. From that day on, my health deteriorated. I was discharged after about 4 days but then I had to return to hospital because my stitches split and my gums would not stop bleeding.

8. The flu symptoms lasted for approximately a week. The hospital doctors did not say anything about these symptoms.

9. In the weeks that followed I felt more and more unwell. I was rapidly losing weight. I was going to my GP regularly and was being referred to St Mary's Hospital for various tests. At first they thought that I had a ruptured diaphragm and then they decided that it was my gall bladder. I had my gall bladder removed in around 1993, but the symptoms continued. Everyone was saying that I looked unwell, my skin and the whites of my eyes were yellow.

10. In the meantime I was attending 6 monthly check ups at the haemophilia centre at Southampton Hospital where they would take blood and ask me how I was feeling in general. I was complaining of abdominal pain and they noticed that my eyes were a bit yellow. However the doctors at St Mary's did not talk to the doctors at Southampton Hospital and did not share information between them. I think that if they had spoken to each other about my symptoms and test results then they would have put two and two together.
11. In 1994 I attended a routine check-up with my haematologist at the Southampton Hospital haemophilia centre. At the end of the appointment I got up to leave the room, I had my hand on the door handle and was just going to open the door when my consultant told me that he needed to tell me something. He said that it was his last day in the job before he retired and this was the last time that I would see him. He told me that I had hepatitis C and said that he needed to tell me because he did not want it on his conscience. He advised me to go and enjoy the rest of my life.
12. I sat down again and asked him what he meant. He said again that I had hepatitis C. He told me that it was a blood borne virus that potentially can kill you, he told me to go and enjoy the time I had, and I should go to Disneyland.
13. This appointment had been late in the day on a Friday which meant that I had all weekend to think about it before being able to speak to my doctor. The only thing I could think of was that hep C was exactly the same as HIV. I told my wife to go and find someone else so that she could enjoy her life. We had just had a baby boy; I was looking at him and just could not stop thinking about what was going to happen and about what he would do without me. I felt that I could not touch my child; I could not touch my wife. Every minute felt like a day.

14. I telephoned Tom at the haemophilic society on Monday. He told me that not much was known about the condition but that there was a lot of research going on. He sent me some information.
15. I also went to see my GP and explained what I had been told. I was referred to the Hepatology department at the Royal South Hants Hospital but did not have an appointment for about 6 months. At this appointment I was given only verbal information about the infection, I was then bounced from Royal South Hants to Southampton general, they kept the Isle of Wight Trust out of it.
16. I knew about the risks of others being infected GRO-C
GRO-C I knew if I bled it was a problem for other people and felt that it was pretty much the same as HIV.
17. I do not believe that I was given adequate information to help me manage and understand the infection. My diagnosis was very poorly communicated to me. The most information I got was from the Haemophilia Society in London. There was a guy called Tom Clark who used to answer the phones, he was brilliant. His slant was that everything was going to be fine; it was reassuring because at other times I felt that my life was falling apart.
18. I believe that I should have been given information earlier, I should have been told about the infection as soon as the doctors knew about it. I should have been given full information about the infection from the start.

Section 3. Other Infections

19. I have been tested for HIV, the tests were negative. There might be other infections that I have not been tested for. In 2005 I received a letter which said that I could have been in contact with CJD. But there is nothing I can do about this, I just have to sit and wait. I understand that it is only possible to test for this after death.

Section 4. Consent

20. I did not sign anything to give my consent for a hepatitis C test. I believe that they must have had that positive result on their system for so long. I think that they were frightened to tell everyone and that they thought that ignorance was bliss.

21. I had a road traffic accident in 1990 and brought a civil claim for the injuries that I had suffered. As part of the claim, I had an appointment in 1994 with the consultant haematologist Peter Jones at the Royal Victoria Infirmary so that he could prepare an expert report for the purposes of the claim. He was one of the top haematologists in the country. At the end of the appointment he said "I am going to lunch, there are your notes, it's all tagged". He had marked the medical records that I should read. I had a quick look at my notes but I did not know what I was looking for. I now believe that he was trying to tell me that I had tested positive for hepatitis C a long time before but had just not been told.

22. I do believe that I was monitored and I class myself as a Previously Untreated Patient (PUP). Top haematologist meet all around the country would have PUP – people like me, mild to moderate haemophiliacs without you knowing – didn't tell us, getting info and studied – discussing case notes and how it affected the patient. A lot of people. Consultant knew. Suspect to be true.

23. I have been involved with the campaign groups such as Tainted Blood for several years. A long time ago, I think in around 2007, when the organisation Tainted Blood was first set up I was on the phone to another of the campaigners and I heard a click on the telephone. I believe that someone was listening in to our conversation. We were discussing the Archer report, we said we know what they are doing now, then there were more clicks and then they were gone. I believe they were monitoring us because they wanted to know how widely known

the infection was. This is what they would discuss during their monthly meetings, the directors of haematology.

Section 5. Impact

24. I started to become unwell within hours of the tooth extraction in September 1990. I have never really recovered. Following my diagnosis I continued to lose lots of weight, I went from 15st to 9st in one year. I was very tired all the time, I had no energy whatsoever. I had been the type of person who was always on the go; I would go motorbike racing and car racing. I went from having a really active social life to sofa surfing, watching the tele with the kids.
25. Within a year all of my hair fell out. Stress is a weird thing. I did not realise how stressed I was. I tried to be as I was but I just could not get there. I lost a lot of self-confidence; I went from feeling like a person who could achieve anything to a person who doubted everything.
26. I now have arterial disease in my legs which is caused by the acid build up in my blood that my liver can't clear. I still have bad bouts of aches and pains from my liver and I still take steroids for this and quite a bit of pain medication for my legs.
27. In around 1995 or 1996 I took one dose of Ribavirin at Royal South Hants Hospital. It was a trial of the medication; I had one injection which pickled me. It was awful, bad sickness, really bad intestine pain, it was 10 times worse than the symptoms of hepatitis C.
28. I could not carry on with the treatment. Physically and mentally I am quite a strong person but I just thought enough is enough. I would rather have put up with the effects of the hepatitis C than that treatment.

29. This treatment was not available on the island. I am not aware of any other treatment which should have been made available to me. As far as I knew all of the drugs at that time were new and so they were all trials.
30. At the moment I am non detectable because I am on medication.
31. I have had trouble accessing dental care; because of the hep C I have to go to the dentist at the Hospital. I have not been for a long time; I don't go unless I really have to. I am normally the last patient on the list because they have to make sure that all the equipment is scrubbed down after I have been. This kind of thing has an effect on you after a while.
32. When I go to the liver clinic at South Hants it is next to the GUM clinic which is full of younger people. When travelling from the island to my appointments at South Hants, I always saw the same two other people on the boat from the island, then on the bus to the hospital and then in the waiting room at the clinic. The three of us never spoke to one another but we knew that we were going to the same place. Now there are two of us.
33. I definitely feel as if I am treated differently by hospital staff, they are often cagey and I feel as if they are protecting their own interests. Once I was referred by my consultant for hydrotherapy. When I arrived at the appointment there were a number of others having treatment at the same time. As I was getting into the pool a nurse shouted get out you are infectious! I left the room and burst into tears. I received a phone call that night from the Chief Executive at the Hospital. At first he told me that I was making a big deal out of it but eventually he did apologise.
34. After the diagnosis of hepatitis C my social life disappeared completely. I still have a few friends from before but quite a few who did not understand have disappeared. Some of these were friends that I had gone to school with and had grown up with; I feel that whoever is left standing, these are my mates.

35. Soon after I was diagnosed I went to a friend's house and overheard his girlfriend telling him to wash the cup that I had used with bleach. People will either stick by you or they will disappear from your life, it turns out that some people that you thought were friends are not.
36. I have got a lot of acquaintances but only a small amount of true friends. I told my kids about the hepatitis C as soon as they could understand to make sure that they were not picked on or intimidated in school. Kids can be so cruel to each other, I just thought that if my kids had something simple that they could say to explain hepatitis C then it is harder to use against them. I do not think that they have been impacted by the stigma of hep C; I think they would have told me if they had.
37. My wife is a nurse and has wanted to be a nurse since she was 7 years old. She works at St Mary's Hospital on the island. The NHS is a funny place to work and employees can be effectively black listed very easily. I have always been mindful of this, and have not been as open about my condition as I wanted to be because the island is a small place and the hospital is the main employer. However in 2009 I was asked to give an interview on the BBC, my wife asked her boss who told her to tell me to say what I wanted.
38. My wife used to be on the bone marrow donor register. Several years ago she was contacted by the Anthony Nolan trust because she had been found to be a match for a child in Australia who needed a transplant. However once they found out about my hepatitis C diagnosis they took her off the register. They did not test her; she was kicked off by default because of me. I think this is wrong.
39. I believe that the stigma of having hepatitis C is no different to the stigma of having HIV. Even before I was diagnosed with hepatitis C people would ask me about HIV or say that I had it just because they knew that I was a haemophiliac.

40. People sometimes say things like "drugs, was it?", and then you have to say that you got hep C through a blood transfusion. This is a conversation that I have had a lot.
41. I am aware that some people on mainland had been fired from their jobs because of the diagnosis and have had red crosses painted on the front of their house.
42. In around 1990 when I started to become ill I was helping to run a carpet department store. I went part time because I felt too unwell to work. Soon after that the shop ceased trading because of the financial climate. Around that time I was also working part time as a chef at a local restaurant in the evenings. I enjoyed this job but once I had been diagnosed I had to give this job up; I was constantly worried about cutting or grazing myself in the kitchen, even grating cheese worried me.
43. For a long time I looked after the kids at home. I found it difficult to get work. I applied to be a manager at a local supermarket; I completed the application form which included declaring that I had hepatitis C. I did not get the job. I was told that I had been too truthful and that the reason I did not get the job was because of the hep C, for some reason they were concerned about me dealing with meat and dairy products.
44. Over time I started a furniture and antique business which I could fit in between the school runs. The business really took off, after about four years I had industrial units and was delivering to customers all over the South coast of England.
45. However over time the stress was killing me and physically I just could not do it. During the day I would give it 110% to make sure that everything got done, and then I would get home and crash. I was so dog tired that I would just sit down in

a chair and then wake up four hours later. I had to lift 3 piece suits and heavy chairs. In the last 18 months the pain started getting really bad. I started to get pain in my legs and feet and my toes started to turn blue. I went to see my GP; he told me that he thought I had a fungal nail infection. Over the next few days my feet got worse and began to feel like blocks of ice. I went back to the GP and this time saw a locum. He told me to go to the hospital straight away. I had an angiogram and was told that my blood had stopped being pumped up and down my legs.

46. In 2007 I sold everything. I have not been able to work since, and again have gone from having a bit of money to having absolutely nothing. It is only in the last 8 months that I have started to have money again as a result of the new special category mechanism through EIBSS. It has been a struggle for us financially.
47. My wife is very matter of fact about the hepatitis C. I was upfront with my kids and they accepted it for what it is. Hep c is a virus and it is changing all the time, you never know when it is going to rear its ugly head.

Section 6. Treatment/Care/Support

48. The only obstacle that I have faced in accessing treatment is the discrimination by hospital staff as referred to above.
49. I was referred to a counsellor by my GP in the 1990s after I was diagnosed. I met with him about 6 times. I felt that he looked at me like I had a cold, like what was the big deal. He did not really understand and I felt as if I was wasting his time.

Section 7. Financial Assistance

50. I first found out about the Skipton Fund in 2004 through the haemophilia society. I was never given any information about financial assistance from my treating doctors and nurses. I made the application and received the stage 1 lump sum payment.
51. From July 2016 I received the top up of £3,000 which was paid in monthly instalments, £220 per month. I qualified for the special category mechanism payments and now in receipt of the monthly payments from EIBSS.
52. When the Caxton Foundation was set up I put myself forward to be an ambassador and to sit on the board. I did not get the position; I do not think they liked my straight talking. However at the interview they told me that they had £3.5M given to them by Westminster every year and an extra £5M if they needed it. I believe that when the Caxton Foundation was in place there was more money available to apply for things that you needed. The problem with the Caxton foundation is that they did not tell people what they could apply for.
53. However now that the payments come through EIBSS that is even worse because EIBSS is run by the Department of Health. My heating system was installed in 1985; I do not think that if I applied to EIBSS I would qualify for a new heating system because it would be too expensive. Also the process of applying for money through EIBSS is much more difficult than it was to apply through the Caxton Foundation.
54. In order to apply for money you have to jump through hoops, you have to get three quotes from different suppliers before they will even considering granting the money. For example if your car breaks down you would need to get a quote from three different garages, you would then have to wait for EIBSS to agree to the grant before the work on your car is started. You can't claim for something that you have already paid for; the staff at EIBSS will say that you should have

asked them first. If you made an application to Caxton I would say that there was around an 80% chance that this would be approved.

55. I asked for a bit of money from EIBSS so that I could go away on a respite break, my application was rejected because I had not had treatment in the last 6 months. I had had pain medication but they said that they were not going to pay for it.
56. I believe that the payments to anyone infected through contaminated blood should be equal. Anyone who has the contracted virus in this way should be entitled to the same amount of money. These ex gratia payments make me feel as if we are chipping into the NHS budget. Jeremy Hunt made a comment referring to the money paid out by these schemes as being "frontline money" but it is not.

Section 8. Other Issues

57. This Inquiry must be completely transparent, as much as previous Inquiries have tried to find out what happened the government has pulled rank, certain documents have disappeared and the wrong witnesses have been put forward. Lots of the witnesses who have given evidence at previous Inquiries have had links with big pharmaceutical companies who have covered their own backs. However I believe that Sir Brian can see what has gone on in the past.
58. I hope this Inquiry is able to find out the truth and to find out who is responsible. Because of the time that has passed I think that it is unlikely that anyone is going to be prosecuted, however I believe that there should be prosecutions because what happened is mass murder. The government seems to think that because they are in Westminster they are protected in some kind of castle, and that people are not going to find out what happened. However many of the campaigners know more than the politicians and civil servants do. The

campaigners have handed their research to previous Inquiries and it has been ignored. This Inquiry must not ignore them.

59. Andrew Turner was our MP for several years. I met with him about 9 times. On the final occasion I went to see him to ask him to raise the issue of contaminated blood in the House of Commons. He said that he was a junior minister and did not know anything about it. He said he did not want to get involved as it would be detrimental to his career. He said that he did not think that we should get any support; he said that we did not deserve financial support. That was the last time I met with him.

Statement of Truth

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

Signed

GRO-C

Dated

.....21 February 2019.....