Witness Name: John Boakes
Statement No: WITN2692001
Exhibits: [WITN2692002 -
WITN2692009]
Dated: 26 January 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOHN BOAKES

Section 1. Introduction

1. My name is John Boakes. My date of birth is GRO-C 1970. My address is known to the Inquiry.

2. I live with my wife Alana in our static caravan in Cornwall with our cat. We have a quiet life together, enjoying the same things. We love to cook and watch a good movie. We generally enjoy our own company.

Section 2. How Infected

3. In October 1988 I had a motorbike accident, I was very badly injured and I lost a lot of blood. I went over the handlebars, but my arms stayed fixed to the bars. The nerves in my left arm and shoulder were ripped from my spine and I ripped the main artery in my chest. I also broke my leg, and suffered fractures to my skull, jaw and cheekbones, all on the left side of my body. I was taken to Poole

General Hospital. I had to have several operations and a number of blood transfusions **[WITN2692002]**. I was in an induced coma for quite a while and so was not aware that I had been given blood transfusions. When I came round, I was not informed that I had been given blood. I was not given any advice about the risk of any infection through receiving blood.

4. I was in hospital for about three months. I did not find out that I had had a blood transfusion until much later.

5. In June 1996 I came home from work to find a letter for me from the Blood Transfusion Service **[WITN2692003]**. It said there was a possibility that I had received contaminated blood in 1988. I was shocked. I had never heard of Hep C before. I think I went for a blood test at my GP surgery, but I cannot remember very clearly. I understand that my records indicate that I was told on the phone that some of the results were positive and asked to attend the transfusion centre for a more detailed discussion **[WITN2692004]**. I have no recollection of being told that the test was positive, or of attending the transfusion centre. I thought my GP had given me the news about my diagnosis. I had a very good GP, he was a surgeon and he was really on top of everything. I may have had an appointment with him too.

6. I was referred to Bournemouth Hospital, I don't know how long it took to get an appointment with a specialist. I don't remember a big delay, I think it was quite quick. This time is all a bit of a blur.

7. I think the specialist nurse at Bournemouth Hospital gave me more information about the infection. If I remember correctly it was all skirted over quite lightly, the impression I got was that it was nothing serious, and that they would take care of it. Looking back and comparing the information I was given then to what I know now, I think the doctors at Bournemouth just didn't know much about Hep C at that point.

8. The results and information about the infection were communicated to me in a straightforward manner that I understood. I think we were given as much information to help manage and understand the infection as they had at the time. There is nothing they could have done to fix the problem.

9. I believe I should have been told abut the possibility of infection as soon as they knew themselves.

10. I was told by the specialist nurse that there was a very slight chance that my wife could contract it but as long as we were careful with blood and bits and bobs she would be fine. It was no big deal as long as we were sensible. Normal marital things would not be a problem it was just blood to blood.

Section 3

11. I don't believe that I have received any infection other than Hep C as a result of being given infected blood.

Section 4

12. I did not consent to the blood transfusions in 1988 but I did not have an option.

13. I believe that I was informed of the infection as soon as they knew that they were accountable for it. I have never felt that I should have been told earlier, it never even crossed my mind that someone would be trying to pull the wool over my eyes.

Section 5

14. I count myself very lucky as I have always been healthy, I have only suffered mentally. But physically I have been as fit as an ox. In the years before I was diagnosed, I don't remember having any problematic symptoms, I felt well and my life was normal.

15. The mental impact has been much worse. I continue to suffer with memory loss, tiredness, mood swings, depression, aggressiveness, loss of concentration, forgetfulness, lack of empathy, lack of emotion. These things started with the first treatment and affect me more and more as time goes on.

16. When I was first diagnosed, I was referred to a hospital in Dorchester for a biopsy, it was excruciating, mind blowingly painful. I found out later that muscle from my chest had been removed rather than a liver sample. Because they did not have the sample they needed, I was referred to a different hospital in Weymouth for another attempt at the biopsy. This was less painful and showed that I had mild fibrosis.

17. I have had four rounds of treatment. The first was Interferon and Ribavirin which I started in August 1998. My wife had to do the injections because I hate needles, I have had more injections than most people will ever have but I still hate them. So my wife had to go through it three times per week, on Mondays Wednesdays and Fridays. It was horrible, I would sweat like I had flu, my wife had to cover me in coats and blankets because I was shaking in bed. I also started to get boils which were very painful. Then there were the mood swings which were terrible. It was only after I had been on the treatment for a while that they told me that the drugs can give people suicidal tendencies.

18. I worked throughout the first treatment. I didn't have a choice, I had to work to pay the mortgage. It was really quite brutal, it was like trying to cure something by blood letting back in Victorian times, like hitting it with a hammer. In December 1998, after about three months, I was told that the treatment had been unsuccessful. The PCR levels were not dropping and they didn't want to keep me on it longer than they had to.

19. In June 2000 I was placed on the waiting list for another round of treatment, this time with PEGylated interferon and Ribavirin. I started this treatment in February 2001. I can't remember much about this but I know it was a combination of

injections and tablets again. By the time I started this treatment I was on anti-depressants but even so I felt very low. I became quite aggressive and was referred by my GP for anger management. Eventually I was signed off work for three months with depression.

20. I completed a 48 week course of this treatment. At the end of the treatment my Hep C PCR test was negative but my liver function tests remained abnormal and so I was warned that this may mean the treatment had not been successful. However when I was tested six months after the end of my treatment my PCR test remained negative.

21. I was told they could find no evidence of the virus and fundamentally I was clear. There was not a next step, I wasn't called back in for any blood tests or check ups or anything at all. My clinical nurse specialist wrote to my GP in June 2002 stating that I would be tested again in three months time, however this appointment never took place **[WITN2692005]**.

22. It was great to be told that I had cleared the virus. As far as I was concerned I was free, born again. We continued our daily life and moved to Cornwall in 2009. In August 2010 I had routine blood tests at a GP appointment, he picked up on my liver function tests being abnormal and it all started again from there. He did not understand why my levels were so high. It was a bit of a shock to him. I told him that I had had Hep C but that I was supposedly clear. My GP took more blood to be tested. The results showed that I still had hep C.

23. I was in shock, I thought I was clear. I had not had any physical symptoms since the end of the last treatment. I was still on anti depressants because my aggressive mood swings had continued after finishing the treatment. But physically, as far as I knew, I was fit as a fiddle. I had quite a physical job at that time too, I was working as a salesman and was on my feet a lot.

24. I was angry that they had made this mistake. I had over 8 years of living free, thinking I was clear. It turns out that I should have received follow up

appointments from the Royal Bournemouth Hospital but I got lost in the system somehow. This error and period without treatment has caused quite a bit of damage to my liver. I had a Fibroscan at Derriford Hospital in 2010, which showed that I had significant fibrosis. Following a biopsy in early 2011, I was told that my liver was now cirrhotic. They also told me that I had the most virulent type of Hep C, genotype 1 **[WITN2692006]**.

25. I wanted to start treatment again as soon as possible so that I could try to clear the Hep C. I told my clinicians that I would be willing to be part of a clinical trial if that meant I could have further treatment. In October 2013 I started my third round of treatment, it was PEGylated Interferon and Ribavirin again. I don't recall a great deal about the symptoms of this treatment. However in January 2014 the treatment was stopped because my HCV RNA PCR at week 12 was 157 iu mls, my hepatitis nurse told me that to continue the levels would have had to have been below 100 iu mls **[WITN2692007]**.

26. In January 2014 I was told about the ASTRAL 1 trial. My consultant hepatologist said that he thought I would be eligible however once he had looked into it he told me that there was no space left on the trial **[WITN2692008]**. My wife phoned the research trial nurse and managed to persuade her to find me a space.

27. I started the trial in December 2014. It involved taking just one tablet a day, the drug was Sofosbuvir. After 24 weeks on the treatment I was told that it had worked.

28. I did not have any difficulties or obstacles in obtaining the treatment. It was not easy to get a place on the trial but my wife persisted. I wasn't aware of any other treatments that ought to have been made available to me at the time.

29. I always felt that I was one of the lucky ones because I could have had HIV. But I now know that having hep C, even if you clear it, can mean that you are worse off because of the liver damage and everything else that goes with it. The

treatments themselves have caused me additional symptoms which continue even now.

30. During one of the later treatments I was told that I had diabetes, the medication had interfered with the insulin levels in the body. When I stopped the treatment things went back to normal.

31. I have liver scans every three months and regular endoscopies because liver damage causes high blood pressure which can causes varices in your throat. The scans have shown up some lumps by my gall bladder, they say I have quite a nodular liver like lumpy porridge and nothing can get through it.

32. Now that the tests are showing possible problems, I am more anxious but I am still happy to go for the scans. Because I have been on anti depressants for so long it is difficult for me to feel anything, but I do feel nervous before a scan.

33. I can sleep for 12 hours straight and sometimes longer. I have strange sleeping patterns which have got worse over time, particularly since they started picking up problems on the scans. I can fall asleep in the middle of the day and wake up in the middle of the night.

34. It is the affect on my mental health which has had the biggest impact. I believe it started after the treatment, it's like a cascade reaction. It started with the treatment and the ball rolls and rolls and rolls until it ends up as a mountain at the end. As a result, I have spent long periods on an incredibly strong dose of anti depressants which have helped on one hand but have made me feel separate from normal life on the other. The anti depressants cause a removal of emotions, when you take them they lessen things but where they lessen them they can separate them completely. They helped at the time but once I was cleared of Hep C I was keen to lower the dose.

35. My social life was not really affected by having hep C. I did all my clubbing and social stuff before I was 18. Everything was done and dusted by then. When I

married my wife it was just us, I went out occasionally with some people I used to train with but not very often.

36. However it has put strain on my relationships with my family. Over the past 30 years I have had to go and see the doctor numerous times to try to keep control of myself mentally. There have been times that it got out of hand and I was worried about my marriage. I can be combative, looking for trouble. I'm not a physical person I am verbal. You can do a lot more damage with verbal than you can physical sometimes.

37. Over the last few years my wife and I have read about other people experiencing aggression and anger during and after the treatment. Some of the stories are so similar to my own that you could be reading about me. But I still feel that I cannot get away from the stigma of feeling that it is just me and not the Hep C.

38. When we were on holiday in the United States in 2018, I realised there was a link between the amount I eat and how I feel. We were driving around Virginia and I got a pang and I could feel myself getting edgy, I was starting to change and my mind process was starting to change. That's the first time I realised that if I do not eat properly and I get in a situation that is out of my comfort zone, that's when I get a real troubling perspective and things can get out of control.

39. I don't speak to my mother or my side of the family. This is for reasons unrelated to the hep C. All I have is my wife and her family but as a result of my anger I nearly lost them all. I was very close to her parents, we used to live together and would often go abroad together. In 2018 we went for a night out in Bournemouth and it ended in a huge row. I slept in the car and the next day my wife would not come home with me. She left me for a while but we got back together after a few months. However my relationship with her parents took longer to repair. If I had eaten properly during that day none of it would have happened. But it did happen. I was just not myself.

40. After the argument I came home alone, and two days later had an appointment to have a scan at Derriford Hospital. I was feeling very low about everything that had happened and felt that I needed help. After the scan I went to the main desk and asked to see a psychiatrist. They sent me to A&E. I waited for several hours and eventually got to see a mental health nurse who gave me loads of paperwork and advised me that I needed to get a referral from my GP to see a psychiatrist. I then went back to see my GP who said that I could be referred for an assessment but that it would take a few months.

41. I was feeling very low and felt that I couldn't wait a few months. I knew what type of help I needed because the nurse at Derriford Hospital had explained it to me. I found a counsellor and started treatment. I wanted to finally try to stop these mood swings, to understand things a bit more and to try to quieten my mind down. It came to the point where it had to happen. I paid for this treatment myself but as I needed it as a direct result of the hep C and the treatment, I applied to EIBSS to reimburse me. It took a while but eventually EIBSS paid out for this.

42. The counselling has definitely helped, it sorted things out in my mind and helped to clarify things. I have now reduced my anti depressants from well over 300mg to just 75mg per day.

43. I have hardly told anyone about the diagnosis. Outside of my wife's family I have told two people, my best friend and a former colleague that I was close with. My wife and I did not decide together not to tell anyone, it was just natural. If people don't have to know we are not going to tell them. It is not something you would normally talk about, it doesn't come up in conversations.

44. I have not been on the receiving end of negative attitude from hospital staff because of my Hep C. Nearly every person I have met in hospital has been brilliant because they probably see it more than I do. There were times when I was last in the queue for the dentist but as the years have gone on the professions are not so scared. They seem to be quite ok with it because everyone wears gloves now, they did not so much in those days.

45. Hep C has definitely had an effect on my working life, just the mood swings alone have caused problems. I used to work in sales; having mood swings in sales is a bad thing, very bad. Sometimes I just couldn't work as hard as I wanted to because I wasn't in the mood or I didn't want to go out of my way. I was not working as efficiently as I could have done to earn more money, a big part of my wage was commission and so was based on the amount I sold. The hep C has stopped me progressing. At one point I had an interview for an assistant manager role, I had a hospital appointment the following day and that ruined it, I could not concentrate at all.

46. During the second treatment I was signed off with depression. I found it very difficult to maintain a normal life. Dealing with people's problems all day was incredibly difficult sometimes. Eventually I had to go back because we had a mortgage to pay. This period was very difficult because I was still suffering loss of concentration, anger issues and volitivity. The volitivity got me into trouble at work once or twice.

47. In around 2007 I started working as a carer in Dorset visiting clients in their own homes. Then between 2010 and 2011 I worked at a nursing home in Cornwall, usually on nights. It was brilliant, I thoroughly enjoyed working with the residents. But I did have to be careful and watch out for blood. Even though I had a full disclosure CRB check I was not asked for any details of my medical history. I would be reluctant to tell anyone about the hep C unless there was a need to do so.

48. Once I received the second payment from the Skipton Fund I stopped working. The shifts at the nursing home were 12 hours long. It was hard on me and my wife, she would be out at work all day and then I would see her for 3 hours before I went to work. It was a very short day we had with each other. The second payment from Skipton enabled us to pay off everything we owed. Not being at work has made a lot of difference, it has allowed me to be more relaxed.

49. The Hep C and the treatment has impacted my marriage. My mood swings have caused lots of arguments, but we often don't dwell on them. We have done our best not to make it an issue in our lives. We try to be upbeat not downbeat. Life's too short for that.

50. In the early days of diagnosis because so little was known about hep C the GRO-C In 2015 I was watching a program on Hep C and it mentioned that if I bleed during intercourse my wife could become infected. Psychologically that did some damage GRO-C GRO-C The psychological damage is overwhelming. For some reason that program affected me GRO-C GRO-C GRO-C GRO-C

Section 6

51. I have struggled to get treatment and support for my mental health. When I would go to the doctors and explain how I was feeling, so often the response was to increase my dose of anti depressants. There is an attitude of if its broke, throw tablets at it to fix it. Well as far as I am concerned tablets won't fix it.

52. In July 2017 I was referred for a psychological assessment, they said that I could have a course of CBT but that I would have to wait a few months for it to start. I had my first appointment in January 2018 but I decided not to continue. CBT just wasn't for me, it wasn't the treatment that I needed. When I eventually had counselling it was a different type, everything was talked about and it really helped.

53. It feels as if there is no help out there to support the mental side of being infected with Hep C. At my appointments with the consultants, all they ask about are the physical symptoms. The mental health nurse I saw at Derriford was great but she could not offer long term support. When I have asked for help from my

doctors I felt that they didn't really want to know. It would be helpful if there was a mental health check up for people with Hep C at the same time as the physical health check ups.

Section 7

54. I first heard about the Skipton Fund from my brother in law who heard about it on the radio. I mentioned it to my clinicians at Bournemouth Hospital but they weren't very forthcoming or helpful. I received my first payment in March 2009, we sold the flat and bought a caravan in Cornwall where we now live.

55. In 2011 I received the stage 2 payment when I was diagnosed with cirrhosis. It was hard to get this payment, they said that my results didn't qualify because they weren't bad enough. If they had left it a week or a few months later they would have been. It's the kind of thing that it's not going to get any better. Eventually the specialist nurse got involved and they agreed to pay.

56. At least the Skipton Fund had someone you could speak to and they would listen. The new organisation, EIBSS, are dreadful, absolutely disgusting. They make you feel like you are being a pain, they are very slow to pick up the phone and once they do are uninterested. I phoned them after I came back from the argument with my wife and her parents, I was in tears saying "you have to help me, there must be something you can do to help me get help for my mental health". The lady on the line was sympathetic but said there was nothing they could do.

57. Before EIBSS took over the scheme, you could phone up if you had a problem and you would get help to sort it out. We had a water leak, we phoned up Caxton and explained what had happened and that we didn't have enough money to fix it ourselves. They asked us to get a couple of quotes, we did that and said they would either send us a cheque or pay the company repairing the damage directly.

58. When we applied for help from Caxton, they seemed to do a brief evaluation of your finances and then give you the help that you needed. With EIBSS it feels that they have different criteria and seem suspicious of every application. They seem to be tighter than tight making you jump through all of the hoops. It is like they have a certain amount of funds and they are not going to let you have any of it at all. It definitely wasn't a good idea them going in with the NHS, that was a bad thing to do. When I was applying for money for the counselling, I completed a form which asked whether the counselling is available from the NHS. They should know it is not. I couldn't wait six months or more, I needed help straight away.

59. I am shocked at the varying amounts paid out depending on where you live in the UK. How can they do that, it is wrong. There should be a flat rate across all four nations. We have always said how lucky we are to receive this money and we are very grateful that it has made our lives easier but it is still no compensation for what they have done to me.

60. I don't think it's right that people infected with both HIV and HCV should be entitled to higher payments. It is not HIV that's the killer now, we now know that if you have Hep C it can be worse. I think that it should be the same across the board.

Section 8

61. My records indicate that my details were added to the HCV register and that my clinicians at Bournemouth Hospital and my GP provided updates when requested. The first I heard of this was when I was told by my solicitors who obtained copies of my records on my behalf **[WITN2692009]**.

62. I would like the Inquiry to recommend guidelines for the treatment of people with Hep C, particularly in relation to support with mental health.

63. I hope the Inquiry will get to the truth of what happened. There does not necessarily need to be finger pointing, just the truth and an admission that some people knew what was going on sooner than they told us. I believe that much of what happened has been whitewashed and kept quiet. The fact is at the end of the day that they contaminated us with bad blood, it doesn't matter how they did it, but they did it. They need to admit what they have done and start sorting out proper compensation for the victims.

Statement of Truth

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

Signed GRO-C

Dated 26/01/21