

Witness Name: Alana Boakes

Statement No: WITN2691001

Exhibits: 0

Dated: 26 January 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ALANA BOAKES

Section 1. Introduction

1. My name is Alana Boakes. My date of birth is GRO-C 1973. My address is known to the Inquiry.
2. My husband John Boakes contracted hepatitis C as a result of receiving infected blood. John has provided a full witness statement to the Inquiry. His witness number is W2692.
3. I make this statement as an affected individual in relation to the impact on me of John receiving contaminated blood. John's statement deals with the circumstances of the infection, the details of his illness and his treatment. I will not cover these issues again in detail, I ask the Inquiry to consider my witness statement alongside John's witness statement.

Section 5: Impact

4. I met John in April 1992, we married in GRO-C What attracted me to John was his outgoing personality and confidence. We would go out to places together, visit the cinema and have meals out. We liked the same things. We lived with my parents for 5 years until we purchased our first home together.
5. In June 1996 John received a letter stating that he may have been given contaminated blood during an operation he had in October 1988. I remember feeling shocked! We had no idea what this meant, or even any idea what Hep C was. I remember feeling concerned for John and what this would mean for him. Thankfully we had a fabulous GP at the time who helped us to not let our thoughts get ahead of ourselves, and to wait for the results.
6. John started his first treatment in August 1998. It involved injections three times per week and taking tablets daily. He has a phobia of needles and so I had to learn how to give him the injections, he would not do it himself. The first time I was there with the specialist, I gave John the injection and almost pinned him to the back wall. But it was fine once I got used to it. We just got on with it, we knew it had to be done. There was no point messing around, we just took it in our stride. The effect on John was terrible though, it was a difficult time.
7. It was a blow when that treatment didn't work but we are generally quite positive people and try to take each day as it comes.
8. We faced the second treatment together and were so relieved when John was given the all clear. I was absolutely elated! thrilled! He was going to be ok! I remember telephoning my grandmother from the hospital car park to give her the good news, she burst into tears with relief. She didn't usually show much emotion, so this showed what an impact it had on us all.
9. In the years that followed we just carried on with our lives. It was a real shock when John was told by his new GP that he still had Hep C. I phoned

Bournemouth Hospital to tell them that John was still infected, they said they were really sorry but that he had just slipped through the net. We were angry, you put so much faith in hospitals.

10. So we started having to go to the hospital regularly again. At the time we both had full time jobs and had to try to fit appointments round these, as well as only having one car between us. For me it was a two hour round trip from work to the hospital. It was difficult to manage logistically and was exhausting.
11. We were so disappointed when the treatment didn't work, we put everything into it, ensuring John ate all the right foods and did all the right things. You pin all your hopes on the treatment, we were gutted.
12. When John was told that he might have a place on a clinical trial I was relieved. But then to be told that there was no space was devastating. I phoned up the trial nurse to try to persuade her to take John on. She told me that they were choosing people they thought would be successful. I explained that John had slipped through the net before and I didn't want that happening again. I asked her to make sure that if there was a space that he would get it. And she did, she phoned up later and gave him the space. John will take what he is given a lot of the time, I felt that we needed to push a bit. I felt that if there was a trial going on, I wanted my husband on it.
13. When we finally got the news in 2015 that John was clear we were elated. It was brilliant. After all that we had been through, John taking just one pill per day had cured him.
14. Unfortunately, the effect of all of this on his mental health continued even after the treatment. I did not know John before he had Hep C. Over the time that we have been together his mood swings and aggressive behaviour have got worse and worse. We thought for years that this is just how John is, that it is his nature, because we didn't know any different. I did not know until fairly recently that Hep C itself and the treatment for it can cause people to become aggressive.

15. When I joined some of the support groups on social media and read the stories of other people experiencing the exact same symptoms, I realised the connection between the hep C, the treatment and John's moods. And thinking back this only really became an issue after the treatment started. We lived with my parents for 5 years while we were waiting to get our flat, I don't remember there being any issue apart from the TV being too loud. And then around the time we moved into our flat, John started the treatment and that's when things changed. There were no signs of it when we were living with my parents: you would think with four adults living in a house if there are going to be arguments and anger this would start to show then.
16. John and I are a unit and so socially we are our social life. We always spent a lot of time with my mum and dad who live in Dorset, everything revolved around them as well. So we were all very close and if we did anything we did it together, we often went on holiday together.
17. In 2018 we went out for an evening with my parents and stayed at their house. I think John felt uncomfortable in the whole situation and had not had much to eat. We had a row, and my parents could hear us. It escalated into a huge argument. The following morning John went home by himself and I stayed with my parents for a few weeks. I read up on the connection between mental health and hep C. Eventually I decided to go home to John because I knew mentally he was not well. There is 85% of him that is lovely but there is that 15% which is the dark dog that comes over him. I know that if we had been in our own house that night we would have sorted it out but being in someone else's house you can't resolve things in the same way. I believe the way John behaves is a consequence of the Hep C, if I did not believe it was not connected I would not have come back.
18. I can feel it coming, I can see the darkness coming in his eyes and I can see his whole attitude changing. But we are a unit and we sort things out. After that argument with my parents he went to counselling which really helped. He and my parents are speaking again now. Even though they are back on good terms,

I am full of anxiety every time we visit. I don't want him to say or do anything that will rock the boat. The argument that night has changed my life, things will never be the same again regarding us being all together. When we visit we stay just the one night and not the usual three nights. It's just easier and less stressful.

19. We are such practical people and try to take it all in our stride. But it is horrible to see him go through it. It was horrible to have to inject him and get it right and make sure he had taken his tablets and then wait to see if it had worked and it is all stress, stress, stress. But we are sensible enough to put it in a place where we don't bring it up unless we have to because if not you would be forever under a dark cloud and we don't do that. When I see the mental torture he goes through in his own mind, not necessarily about the disease but just how he struggles mentally it is very sad to watch. The fact that I now know other people experience the same is almost a relief because it means that it is not something caused by you, it is because of the disease and the treatment. You just have to try to make it liveable.
20. No one seems to help with the mental side of it, it is all physical. John has tried his best to get the help he needs but there is not much help out there. Advice from a GP is not adequate, there should be a specialist dealing with these issues.
21. When John was first diagnosed, I didn't tell anyone apart from my parents and my sister. Now that he has cleared the virus, I have told a few more people.
22. When John received the stage 2 payment from the Skipton Fund it replaced his wage and he was able to give up his job. Because I was working so far away and he was working nights we hardly saw each other, so it was better for our relationship when he stopped working. At every place he has worked there has always been someone he hasn't got on with, whether that's because of him or the other person. It is so nice that he does not have to deal with people that he does not want to deal with.

23. In terms of my work, there hasn't been too much of an impact. I remember a couple of teary days but in general I was known as the girl with the smile on her face because that's just the way it was. You go to work and put your smile on and deal with everything when you went home.
24. I've been tested for Hep C and it came back negative, it took me about 10 years to get tested. I hate everything medical and I would rather not know than go through what John went through. I was very lucky.

Section 6

25. I have never been offered any psychological support. I think they should first offer any support to the person infected, but I do think that some support for partners would be helpful. Even just a bit of information about what might happen during treatment would help, for example what symptoms and changes your partner may go through.

Section 8

26. All we want is honesty, the truth for those poor people who have died already and for those who are suffering more than us. I hope the Inquiry can provide some answers from them about what happened
27. We are count ourselves lucky, but only until the next scan. We have been lucky until this point.

Statement of Truth

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

Signed . GRO-C

Dated ...26 January 2021..