Witness Name: Andrea Bernadette Elizabeth Thompson
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANDREA BERNADETTE ELIZABETH THOMPSON

I, Andrea Bernadette Elizabeth Thompson, will say as follows:-

Section 1. Introduction

1. My name is Andrea Bernadette Elizabeth Thompson. I live at GRO-C GRO-C Lancashire, GRO-C I was born on GRO-C 1980. I live with my fiancé John, and our two children, GRO-C and GRO-C, aged 16 and 8. I work at a nursing home as a cleaner and as part of the kitchen staff. I have been working since I was 16 years old.

2. I make this statement in relation to my fiancé, John Shackleton, who was infected with HCV, as a result of contaminated Factor IX concentrate products.

3. **This witness statement has been prepared without the benefit of access to John's full medical records.**

Section 2. How Affected

4. My fiancé John suffers from severe Haemophilia B.

5. In or around 1997, I met John at the nursing home I worked in where he was visiting his grandmother. I then bumped into him in town on a night out. We began to date and two weeks after we first met, he called me to say it was very important he spoke with me. I met up with him and was a bit worried as I had no idea what to expect. The ambience was very sad and emotional; he told me that he had this disease called Hepatitis C. At the time I didn't even know what it meant.

6. John told me that he was a haemophiliac and that he needed to use Factor IX concentrate to treat his blood. I was very blasé about it, thinking it was nothing serious. He said he wanted to give me the time to think about whether I wanted to be with him. John had always been more worried about me, than himself. He was extremely stressed because he knew that his life expectancy was not great. He wanted to warn me of the risks and give me the option to leave him if I wanted to.

7. I know that his mother, Pauline, took him to hospital a lot when he was a baby, due to his suffering from a lot of bruising. On one occasion his mother was even accused of abusing him due to the constant bruises.

8. John's care throughout his childhood would have been at Blackburn Hospital. Eventually his care was moved to Manchester Royal Infirmary, however I do not know very much about his early treatment.

9. I believe that he went to Blackburn Hospital when he was around 14 or 15 years old and that was when he found out he was infected. His mother protected him from a lot of it as a kid. He was, however, told he couldn't share his toothbrush with anyone. The doctor told him in a very blasé way and only asked how he was handling his diagnosis.

10. I know he was in shock. He had seen the adverts on TV, but told me that it was handled by the doctor like it wasn't very serious at all.

11. There was very little information given to him on how to handle his infection. I don't know how much they told him about how he was infected either.

12. John told me that, at the time, he went off the rails a bit; it was a lot to deal with. All the medical professionals kept referring him onto other colleagues. There was just no help.

Section 3. Other Infections

13. In the late 1990s, we received a letter saying that John had been exposed to vCJD. There had been no advice on how to handle this or what the future may look like. All we got was a very factual letter telling us what symptoms to look out for.

14. It felt like just another thing; what else could they throw at us?

Section 4. Consent

15. I do not believe that John or his mother ever gave consent to being tested or treated.

16. I do believe that John was potentially tested for the purposes of research. I think they knew what was going on and they wanted to know how many people they had infected, along with how many people it was going to kill.

Section 5. Impact of the Infection

17. When we first met, we were young and so would tend to go out on Friday nights. When John told me of his infection we reined it all in and both of us stopped drinking.

18. I didn't really used to understand much about what having HCV really meant, but my parents were worried about it. John obviously knew a lot more than I did and researched into it a lot further than I had. We did everything right and

used protection always. He looked after me from the get-go, always making sure I was safe at every step.

19. The impact this infection has had has been horrible. We have had two children and were ecstatic when we found out that we were pregnant. We thought that this would never even be an option for us. I don't know whether this was because of his haemophilia or HCV, but it just never seemed like a future we could see. We now have two beautiful children.

20. John is now constantly ill; he suffers from headaches, has abscesses in his mouth and is sick everyday. Some days are better than others, but he still struggles with his illness every single day. They say that the infection is cleared but I don't believe it. He still gets pain in his liver and is tired all the time, yet he cannot fall asleep.

21. I can't recall when he was told he was cleared of the virus, but I do know that he had two lots of treatment. He underwent the first before I met him, which would have consisted of Interferon. He said this treatment was horrendous, to the point where he physically couldn't get out of bed. It was like he had a constant terrible flu.

22. The second time he was offered treatment, he really didn't want it because of what it had been like the first time. For the sake of our kids however, he went through it all again. He still suffered from the side effects and was particularly grouchy, but it wasn't too bad this time. I believe his second round of treatment was about 10 years ago and undertaken at the Manchester Royal Infirmary.

23. Six months after he cleared the virus, he went for a check up for his blood count, but I don't recall him ever going again for any further check ups. He has been telling his haematologist about his liver pain and other symptoms for the past six years and still nothing has been followed up. He has not been referred on to anyone or even taken seriously.

24. All he takes is co-codamol for pain relief and ulcers, along with antidepressants.

25. It was not difficult to obtain treatment for his infection. He was contacted to have it and never had to chase anybody to obtain it. He has not been told of any long term effects.

26. There is a stigma around it all, but I don't mind talking about it and putting people in their place. John tells me that I am his rock and without me he would have killed himself.

27. We have found the stigma has come more from the medical professionals, rather than anyone else. I went to Blackburn Royal Hospital for my first antenatal appointment, for which they went through all of my medical history. The man there said, 'you do know that you can have an abortion.' It was awful and entirely inappropriate to suggest, that just because John had an infected positive status I would want to abort my child. I was tested for HCV before we decided to have children and throughout my pregnancies anyway.

28. On an earlier occasion, when I first met John, he had a brain cyst and was told it could pop at any minute. Eventually it did on a night out and it was awful. When he was taken into hospital however, the nurse looked at him like he was a drug addict because of his iinfection.

29. Being infected with HCV has had a great impact on John receiving dental care. It's only recently that John has really committed to going to the dentist, because he's hated it so much. We've noticed he is always the last appointment of the day.

30. The hardest bit of it is dealing with the children. When the kids were younger, we had to really watch them to make sure that they were nowhere near John when he was having his injections. Both children are aware of John's status. We had to tell them so they knew that they absolutely cannot use anything of John's.

31. It is hard having to explain to your children not to use 'daddy's razor' or toothbrush. We never leave anything of John's in an accessible place, but kids just find things. We had to make them aware just in case. It's disgusting that he has not received any kind of real support.

32. I worry all the time about what could happen when I am not there. In particular, what happens when I am not around to take care of the kids? What if they fell over and John cleaned it up with a cut on his finger and they got infected too? It terrifies me.

33. I think these thoughts are probably due to what happened with John's mother. When John was eight years old, he fell off a wall and cut his knee. His mum came running out of the house to clear it up. She had a cut on her hand and whilst clearing up his blood, she caught HCV. Pauline died two years ago due to cirrhosis of the liver. John now has this on his conscience too.

34. Pauline was a single parent. I don't know how she coped. At one point they even wanted to section John because of his mood swings, but she managed really well.

35. When Pauline was in hospital and near the end of her life, she had fluid in her brain which made her seem like she had dementia. I remember one of her nurses saying, 'oh everybody has HCV', like it was a normal thing to say. This woman was supposed to be taking care of my mother-in-law!

36. John did used to work as a cleaner with his mum, but it all became too much for him. I used to work full-time but I was needed at home help care for John and the kids, so I cut down my hours from 36 hours a week to 20.

37. We can't get a mortgage or any form of insurance. Although we go on family days out, we have never had a real family holiday because we just cannot afford it.

Section 6. Treatment/care/support

38. The only psychological support that has been offered was from the Skipton Fund. They had a contact number for support on the letters they used to send.

39. Until we started getting support from the online forums, such as Tainted Blood, John never wanted to speak about it. The more people that came out with their stories, the braver John got. He doesn't talk to many people, but he is more than happy for me to talk to my friends and family about it. I have a good support system with my friends and family and of course, John.

Section 7. Financial Assistance

40. I believe the Skipton Fund gave John a £20,000 ex gratia payment but I cannot recall exactly when it would have been; I think it was around 16 years ago. I believe it was a relatively easy process, but I cannot recall the details of it all.

41. I know that whenever he applies for any money he has to fill out a lot of forms, send receipts, proof of address, etc. It became too much of a hassle so we stopped applying for things, despite our need for money when situations occurred, i.e., money for a new fridge or other appliances breaking.

42. John has been receiving monthly payments from the EIBSS of about £2,300. He also receives a monthly child payment of £350. We have to send a lot of paperwork in and have never lied on anything. We will send off any paperwork required that's required of us.

43. We have never had to sign any disclaimers.

Section 8. Other Issues

44. I want to know why this all happened. I have so many questions. Why wasn't John told of his infection early on? If John had been told properly, then his mother would never have been infected. It all comes down to why?

45. They have ruined a hell of a lot of people's lives. People have been left not able to pursue the careers they wanted and now live with no financial security. People just want to be able to support themselves and their families.

46. So many people have been given a life sentence. I have met some amazing people through this Inquiry, but some of the stories you hear are absolutely harrowing.

47. Our MP is a complete waste of time; he has had numerous arguments with John. He is absolutely horrible and has no interest in helping anyone or finding out what is going on. We have sent letters to Parliament, but received no response. We haven't actively campaigned but we do what we can.

48. I am part of the Tainted Blood and Contaminated Blood groups.

Anonymity

49. I do not wish to remain anonymous for the purposes of this Inquiry.

50. I want to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 14|10|19