

Witness Name: Tina Louise Walker

Statement No: WITN2982001

Exhibits: None

Dated: May 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF TINA LOUISE WALKER

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I, Tina Louise Walker, will say as follows:-

#### Section 1. Introduction

1. My name is Tina Louise Walker and I was born on **GRO-C** 1970. I live at **GRO-C** **GRO-C**. I am married to Neil and have been since 1999. I have 3 children and 4 grandchildren. I work part time in a pub.
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 in respect of my husband Neil Anthony Walker. I am aware that Neil is also providing a statement to the Inquiry.
3. This witness statement has been prepared without the benefit of access to my husband's full medical records.

#### Section 2. How Affected

4. My husband Neil has severe Haemophilia A.

5. Neil was infected with HIV and Hepatitis B and C, sometime around 1980 when he was about 14 years old, after being given Factor VIII blood products for treatment of his Haemophilia, at the Derby Royal Infirmary.

6. I wish to rely on the further details enclosed in my husband Neil's statement.

### **Section 3. Other Infections**

7. I am aware that Neil was told he could be infected with vCJD; I opened the letter informing him.

### **Section 4. Consent**

8. I do believe that Neil was tested and treated without his knowledge and therefore without his consent.

9. I do not believe that Neil was ever provided any information on what they were testing him for.

10. I believe Neil was tested for research purposes when he began his HIV treatment called AZT.

### **Section 5. Impact of the Infection**

11. I had always known Neil as my best friend's mum is married to his dad. I therefore knew a little about HIV already because of this but now I obviously understand it all a lot more. Neil's mum used to do everything for him.

12. When I got to know Neil better in around November or December 1997, he was not in a good state and was GRO-C, which made him more ill. He was having some treatment at home. He would stop at my house if he was too weak to go home and he would just sleep downstairs.

13. Within a year of living with me he thought he had something to live for. He thought he would never get married. I didn't want to get married again after my previous relationship, but he is the reason I got married again.
14. HIV has really impacted Neil massively. It stops him doing certain things and makes it difficult for him to even come out with the family at times. The impact is hard to explain on a day to day basis.
15. My grandchildren ask questions like why Neil has to have injections and what is wrong with his leg; trying to explain it is so difficult. I never speak of all this.
16. I went to Neil's hospital appointments with him for the first 10 years but I cannot take it anymore. I do not like hearing everything and so I do not go anymore and Neil protects me from it. Neil is always at the hospital and I cannot keep up. He does not expect me to go with him to these appointments and he tries to look after me in that sense; he shields me from it.
17. I just keep Neil going and keep him positive. I put in a lot of effort into making sure he is not down and I keep him busy, telling him what our plans for the day are. Naturally, all this takes a lot out of him.
18. Neil has had one elbow replacement and is waiting for another elbow replacement. Even that affects everything. Haemophilia is really catching up with him now.
19. Neil's Hepatitis C infection has caused complications. Even when going for a family meal he cannot drink with everyone. Occasionally he will end up having too much to drink and then he does not become a nice person; it is like he is rebelling and taking things out on the people nearest to him.
20. Neil had his first treatment for Hepatitis C at Nottingham Queens Hospital in around 2004 which made him ill. He was often sick and he could not drive anywhere while he was on the treatment. Neil scared me when he was on the treatment and I would go out when he was on it. He would sometimes act out

when we had family over; he just changed completely when he was on that treatment.

21. Neil had his second Interferon treatment in May 2013. It too was horrible. The side effects were crazy and we nearly got divorced. The treatment did not have the effect on Neil that we thought, and we were hoping for, but he continued on it for a few months. I gave Neil an ultimatum and said it was either me or the treatment, as it was making him change. He was not the Neil that I knew.
22. I do not believe there was any problem in accessing the treatment, but he has had issues with some of his treatment. I remember one occasion where Neil went to have an endoscopy but when Neil got to Derby Royal Infirmary, they refused to carry out the procedure. They claimed that Neil was a liar and that the procedure would never have been offered due to his infection due to the cost of the machinery. Neil was told that they would have had to use the machine on Neil only and then no one else could use it. This incident happened in 2018 and then again this year but no one believed me at the hospital when I tried to tell them.
23. Also, when Neil was getting dental work done in 2002, the dentists took away too much of Neil's jaw when they were removing all his teeth and so they could not put his dentures in. They told him he now needs implants but it will cost around £30,000.
24. Not having teeth makes things especially difficult for Neil. It makes him conscious and so it becomes difficult to go out and eat publicly for example. If we do go out, I specifically look for a corner seat in any restaurant because I am paranoid that people will be staring at us with Neil's walking sticks and wheel chair. Some people are so rude and just stare and even then say things; but I always answer back. I am quite fierce and I stand up for anyone.
25. We are open about everything but still very conscious of it all. I had to explain the infection to a couple of people at the pub where I work. They just think

they know everything about HIV and the surrounding issues and so I had to inform them the truth.

26. Neil's current consultant, Dr Angela McKernan is very good and she always informs us of any new treatments available.

27. After the HIV infection, Neil's ex partner would not let him see their child Ashley after they split up. [GRO-C]

[GRO-C]  
[GRO-C] All that changed when I spoke to her and then Ashley, came to stay with us for a bit. [GRO-C]

[GRO-C] I wanted Neil him to see Ashley as often as possible as it gave Neil something more to live and fight for. However, Ashley stopped seeing Neil quite a few years ago. [GRO-C]

28. Neil usually comes with us when we go on family outings when he can but when he is unable to, then even the grandchildren will ask where he is and I have to tell them that Neil is not well. This has got more frequent over the last 2½ years when Neil will tell me that he is in pain. When he tells me this then I know the pain is very bad because he is not one to complain normally. He is on very strong pain killers (Oramorph / liquid morphine) too. When Neil is really ill I don't like to think about it, but things are getting more real over the last 2½ years.

29. Neil used to be a big drinker but now he is more family orientated and he just wants to go home rather than go out. He is not so sociable anymore. He has one main friend but otherwise only really spends time with my family; my mum is like his mum.

30. Financially this had a bad affect on us. He cannot get life insurance and is worried about our mortgage, as if anything happened to him I would lose my

house. If I died, Neil would be okay financially. However, our neighbours are brilliant and would help us if anything happened.

31. Sometimes when I am working in the pub there is a fight with blood and I say we need gloves to clean it up. I am hyper-sensitive to these kind of problems now and just assume others have HIV without knowing, so I take extra precautions in every case.

32. Neil's infections have had a significant impact on my children. My eldest daughter and youngest son in particular are very affected as are their children. We are all very protective over them and so are very careful with any blood spillages and the like. Likewise, all the children are very concerned for Neil; the grandchildren in particular are very close with him.

33. Neil likes to keep busy and so will not wait for me to get home to do things. He then hurts himself sometimes which has knock on effects.

34. I have to work part time and I only do one shift at the pub. I would love to work full time but I cannot do it. I would need a boss that is very understanding when I suddenly need time off. Also, the government will take money off me if I start working full time and really they should be paying Neil.

35. Neil has an injection every other day for Factor VIII equivalent.

36. I still try to think positively. He thought he would die when he was younger. I push Neil to get the best out of his day and fit in as much as he can, although I know his leg hurts him. He has given me a lot in life and we have had some good laughs together. I know there will be a stage where I might be his full time carer and so it is best to enjoy things now, while he can. I comfort him and tell him things will be okay. I think that is why he has got as far as he has. I make sure he tries to live as normally as possible as I do not like things stopping me.

## **Section 6. Treatment/care/support**

37. Neil would have social workers due to his HIV, but he does not have them anymore. Everything we have stopped; all the care support we received was withdrawn.

38. Neil went to see a counsellor, called Simon Thomas, a few times. I went once but I got scared and so I did not go back. I would have liked the counselling but with a different counselor.

## **Section 7. Financial Assistance**

39. At the beginning the Macfarlane Trust would help, but in later years it became harder and harder to claim. I felt sorry for the Macfarlane Trust staff, as we would go out with them for the weekend but they were being told what to say.

40. I believe the Skipton Fund is just a waste of time.

41. I believe EIBSS is bad too. I know that the people on the other end of the phone do not know anything and so it is not their fault, but the amount of paperwork they require is ridiculous. Even on the phone they are just reading from a script and do not understand. We can never get our concerns through to them.

42. We are currently waiting for a letter from the hospital to confirm that Neil needs a motorised wheelchair, as it is killing his arm to use the manual one. EIBSS want this specific letter from the hospital, even though we have letters from the occupational therapists. They will not accept anything until they receive this letter; it is ridiculous and it makes me so angry. They have met Neil and they know of his condition, yet they still insist on receiving this one letter. We have been waiting for 2 months already and we are still waiting.

43. I would like to rely on the further details about financial assistance in my husband, Neil's statement.



**Section 8. Other Issues**

44. I would like to raise the point that when the Macfarlane Trust closed there was £650,000 left, which went to the Terrence Higgins Trust. I believe that should have been for people like Neil. We have not seen a penny of that money and it has been given away to someone else; that is not on.

45. I hope the Inquiry gets to the bottom of this scandal and we get answers. I want something to happen to the people responsible; they were just there for money. They do not care what they have done to people and their families and children. It makes my blood boil because they think it is nothing. If it is not affecting you, you don't know.

46. I hope the people that are involved get compensated so if something happens they would be financially stable.

**Anonymity**

47. I do not wish to remain anonymous.

48. I do want to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed

GRO-C

Dated...

30/5/19.....