Witness Name: Ms Naomi Schillinger
Statement No: WITN 2801001
Exhibits:0
Dated:3th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NAOMI SCHILLINGER

I, Naomi Schillinger will say as follows:-

Section 1. Introduction

1. My name is Naomi Schillinger. I was born on GRO-C 1963 and I live at GRO-C GRO-C London, GRO-C I'm a self employed gardener and gardening writer.

2. I make this statement as the widow of Desmond Kirkpatrick (deceased) (Des) who was infected with Hepatitis C as a result of receiving contaminated blood products and died on the 22nd February 2014.

3. **This witness statement has been prepared without the benefit of access to my late husband's medical records.**

Section 2. How infected

4. Des had severe Haemophilia A and was diagnosed when he was young, maybe around 6 years old. Haemophilia ran in his family. I understand that from his birth in 1962 Des was treated at the Royal Victoria Hospital Belfast

Northern Ireland, by Dr Elizabeth Mayne and then from about 1983 at St Thomas' Hospital London.

5. I understand from Paul Fitzpatrick, Des's brother who has provided a statement to the inquiry dated the xx day of February 2019 WITN 1333001 that neither Des's parents or Des were provided with any information regarding the risks of being exposed to infection from Factor VIII products in fact they were told it was the new "wonder drug".

6. I met Des in 1999 and it was around this time, that he was diagnosed with Hepatitis C (Non A/Non B at the time). He was informed by the doctors that he may 'have some viral thing' in his body but at that time there were no tests to check for this.

7. I believe Des was infected with Hepatitis C in or around 1980 but I am not sure of the date of his first positive test.

8. I believe from information provided by Paul, that Des was infected at the Haemophilia Centre, Royal Victoria Hospital, Belfast. He attended this hospital while he was at Trinity University in Dublin. Later in 1983, at the age of 21 he moved back to London and transferred to St. Thomas' Hospital London. I believe he was treated at St Thomas' at one point as he broke a leg.

9. Des used to go for regular check ups and to have a biopsy, which is a threatening operation for haemophiliacs. Now there are fibro scans but this did not exist back then so Des had no information about the status of his liver then.

10. I believe Des became infected as a result of being given Factor VIII products for general bleeds. It wasn't until the late 1990s that he was told. He mentioned to me that he was told he was to be on a clinical trial for drugs.

11. As far as I can recollect Des and I were not given any information or advice about the risk of being exposed to Hepatitis C. I remember him telling me that the doctors thought that if you're a Haemophiliac, you're going to die anyway and they knew there could be a risk of being infected.

12. I believe Des first found out about his diagnosis of Hepatitis C at St Thomas' Hospital. I am unaware what advice or information was given to him GRO-D GRO-D GRO-D

13. When we first met, Des told me about his Hepatitis C. I went to a sexual health clinic with him as I didn't know what it would mean for me, and having children. We were told by the doctors that there was a low possibility of passing Hepatitis C through sexual intercourse unless it was through blood and so we carried on having unprotected sex. I was tested at the time and thankfully I tested negative.

14. I don't think Des was ever given the above information before we went to the sexual clinic.

Section 3. Other Infections

15. Des died from neuroendocrine cancer which I believe was a result of his Hepatitis C.

16. He also received a leaflet about the possibility that he had been put at risk of vCJD.

Section 4. Consent

17. I believe that Des was treated or tested without his knowledge and consent and or without being given adequate or full information and for the purposes

of research. Des was treated at the same time as his brother, Paul and this is also what Paul believes.

Section 5. Impact of the Infection

18. Des lived with Haemophilia all his life. It's something he had to cope with but when we met, and he told me he had Hepatitis C it felt like it was a death sentence. I knew he would die early.

19. Des told me horror stories about people who had died as a result of being infected with Hepatitis C which really scared me. He was always limping when I met him and he couldn't walk. His joints had deteriorated due to bleeding into the joints as a result of his Haemophilia.

20. The Hepatitis C affected Des enormously but since this was a long term condition on top of the Haemophilia, he didn't know which symptoms related to which. He was depressed at times and had dark angry moods. He didn't take any anti-depressants but he did have some limited counselling.

21. Des and I didn't go out much and he didn't drink alcohol very often. Whenever he did have a drink I was very worried due to his condition. Des had a friend that would persuade him go to a bar every now and then. He did have a little glass of wine once in a while, but was never a big drinker, even though he didn't know at that point how badly affected his liver was.

22. In early February 2014 Des developed a nasty cold and we thought it might be Pneumonia but within 10 days he had died at St Thomas' Hospital. He had many tests and firstly, the doctor said that it might be liver cancer. Then they informed us not to be upset, as they didn't actually know what it was. Then the doctors said it's Lymphoma and that it can be treated so we don't need to worry. Sadly and shockingly, he died the next day. The doctors got it wrong. I was so distraught and angry. It was shocking as his death was so sudden, 10 days before he was fine and I never thought he was going to die like this.

23. Des was on Interferon in 2000 for 48 weeks, during which time he was very down and depressed all the time. The treatment did have physical and mental effects on him. He suffered from depression and had black moods. It was all too much for him to take on. It was very heavy on his body and he found it hard to get through it. I know that he had other side effects, but he didn't let me know about them so as not to upset me. He was later treated with Ribavirin.

24. I don't know if there are any other treatments that ought to have been made available to Des. It was a big decision to decide whether to take the treatment offered due to their side effects.

25. I consider that Des's infected status impacted on the medical care that we received for IVF. Whenever we went for IVF, we were always treated last because of his Hepatitis C. He was treated at St Thomas' Hospital for his dental care and couldn't go to a normal dentist due to his Haemophilia.

26. I remember going to the hospital with Des once and the doctor talked to him in a very condescending way, as if he was talking to a child.

27. The fact that Des had Hepatitis C took me back, when he first told me as In the past, it was associated with drug taking and or excessive alcohol consumption and other risky lifestyles. I knew Des wasn't doing any of these things but it was upsetting for me to know that he wouldn't have a long life and that it was unlikely we would be able to have children. We went through 7 cycles of IVF and for every treatment we had, we were always at the end of the line due to his Hepatitis C. I felt very uncomfortable to be put at the end of the line, which made me feel stigmatised due to due to Des having Hepatitis C. We were made to feel very uncomfortable.

28. I don't think we felt any stigma or were judged by friends. We didn't hide the fact the Des had Hepatitis C from them.

29. Most of Des's family suffer one way or another GRO-C GRO-C I was affected because I wanted to have a family but couldn't. This also hugely impacted on Des as he felt bad that he couldn't give me what I wanted and he also desperately wanted to have children.

30. Luckily, the Hepatitis C did not affect Des's education as he had left school by the time he knew he was infected. However, as he was a hemophiliac, he did take time off school for bleeds and attending hospital so there may well have been some impact.

31. While Des was alive he worked full time so, we were fine financially. However, after he died, there was a huge loss of income and it was difficult for me financially.

32. Everything changed as a result of his infection and death. The lifestyle we planned was ruined. Not having Des here with me makes me very sad and I miss him so much. You don't just get over something like that. His death was very shocking and awful and still is. He was a very funny, lovely man. He never got to say goodbye to anyone. It's not about the money; it's about the fact that he's gone forever through no fault of his own.

Section 6. Treatment/care/support

33. I am not aware of Des facing any difficulties or obstacles in obtaining treatment, and care as a result of his Hepatitis C.

34. I wasn't offered any counselling or psychological support as a result of Des's Hepatitis C or at the time of his death; however I have since then been attending private counselling sessions. These used to be regular weekly sessions but I am now down to monthly sessions. These sessions are paid for by me.

Section 7. Financial Assistance

35. I believe Des received a stage 1 payment of £20,000 from the Skipton Fund. I am not sure how Des found out that financial assistance was available.

36. I don't think Des would've had difficulties in applying for financial assistance as he was an accountant and auditor at the time.I don't know whether there were any preconditions imposed.

37. I'm financially okay but not as a good as I would have been if Des was alive. Luckily Des had some life insurance which paid off our mortgage. If he didn't have that life insurance, I would've been stuck and don't know what I would've done. Des also had a very small pension which I'm receiving. However, it's not about the money alone.

38. I haven't received any money from the Trusts or funds.

Section 8. Other Issues

39. Nothing on Des's death certificate says he died of Hepatitis C. The doctors said he died of Neuroendocrine cancer of the liver. It seems to me highly likely that the Hepatitis C may have caused this, as even if they had cured his Hepatitis C, the damage was still there in his liver which I believe could have lead to the liver cancer. I have always wondered what damage had already been done to Des's liver because they didn't have fibro scans back then. I always knew he wouldn't have a long life, but I never thought he would die at the age of 51.

40. It seems to me as if this was a nasty experiment the doctors carried out on people, including children. It's awful that it's taking so long for the people responsible to admit that they treated people with contaminated blood products knowing there was a huge percentage chance of them catching Hepatitis C from it. They didn't inform anyone about it even though they knew.

41. Des told me that the doctors and nurses were clearly talking to each other about him being infected but told him they didn't know about this infection.

Anonymity

42. I confirm that I do not wish to apply for anonymity and would like 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…… 30th March 2019