Witness Name: Ruth Wilson
Statement No: WITN6421001
Exhibits: WITN6421002
Dated: August 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RUTH WILSON

I, Ruth Wilson, will say as follows:-

Section 1. Introduction

1. My full name is Ruth Elizabeth Wilson. I was born on GRO-C 1936 and I live at GRO-C Cumbria GRO-C.

2. My son, Johnathan Mark Wilson (born on GRO-C 1961), was co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died on GRO-C 1987, aged 25.

3. This witness statement has been prepared without the benefit of access to my son's medical records. My daughter, Fiona, has some of Jonathan's records but there are huge chunks missing and the missing chunks are time relevant to the period in which he would have become co-infected.

Section 2. How Affected

4. Jonathan had severe Haemophilia A, diagnosed when he was two and a half years old. Tests were done at the Cumberland Infirmary in Carlisle after he sustained a puncture wound to his head. I was, at that time, pregnant with Jonathan's younger sister, Fiona.

5. Before the diagnosis, I was unaware that haemophilia ran in my family and I have been unable to trace any known history of it. Jonathan had a blood transfusion at three months old when he needed surgery for a strangulated hernia. It wasn't picked up then. As a toddler, he bruised quite badly, for no particular reason, but that was attributed to him being a typical climbing, tumbling little boy. To learn unexpectedly that your son has haemophilia is very difficult. There were no more children for us after Fiona was born. My husband (Bob) and I stopped at two.

6. Jonathan received haemophilia treatment under the care of the Cumberland Infirmary until he was in his teens. His bleeds were treated there with cryoprecipitate on demand (as and when they occurred). Cryoprecipitate was adequate as a treatment. Jonathan would recover from the bleed after treatment and it was all generally fine.

7. When Jonathan was around 14 or 15 years old, a new treatment was suggested to us that would be better for him, Factor VIII (FVIII) concentrate. In order to access that treatment, we had to take Jonathan to see Dr Peter Jones at the Royal Victoria Infirmary (RVI) in Newcastle. I had read one or two dubious things about FVIII treatment and resisted Jonathan having it at first. When we saw Dr Jones, he painted a glowing picture of the treatment. No advice or pre-warning about the risk of infection was given to us. In fact, we were persuaded by Dr Jones who talked positively and effusively about it. We were told that Jonathan would be able to treat himself at home and that Dr Jones' Head Nurse,

Maureen Fern, would teach him how to self-administer it. It was a much better treatment than cryoprecipitate and he could keep it in the fridge to use it when needed. He would be able to do more and play more contact sport. That was an attractive prospect to Jonathan as he had given up playing football in junior school after twisting his ankle. Peter Jones said that Jonathan would be able to live as close to a normal life as was possible. As a result, we agreed to Jonathan having the FVIII injections under Peter Jones at the RVI, Newcastle and his care transferred there.

8. Jonathan started to feel unwell towards the end of his first year at Manchester University, when he was 19 or 20 years old. He was fatigued and struggled with opportunistic infections, so much so that he wasn't going to lectures and did not want to go back there at the end of that year.

9. Jonathan did not know that he was infected with HIV until sometime in or around the end of 1984/beginning of 1985. By then he had suffered with numerous colds and bouts of flu and he had swollen glands. His strength and energy levels were low and he would sometimes need to sleep in the afternoon. It made it difficult for him to work. He went backwards and forwards to our GP and to Dr Jones. After having to endure a lumbar puncture, Dr Jones eventually told Jonathan that he was infected with HIV.

10. I do not think that Dr Jones provided Jonathan with help, advice or anything useful to him. Jonathan went to the appointment in Newcastle with his girlfriend, Helen. When they got home, Jonathan just said 'it is not good news'. To learn that Jonathan was infected with HIV left us all devastated. It was just terrible.

11. We didn't know or appreciate that Jonathan was also co-infected with hepatitis until after his death when my daughter Fiona obtained his haemophilia data base records and we saw it noted there. Jonathan was very yellow in the latter part of his life and he suffered with very swollen ankles. He used to eat well but

then went off his food. I tried to tempt him with all the most nourishing and appetising foods I could think of, but he struggled to eat and lost weight.

Section 3. Other Infections

12. Jonathan was co-infected with HIV, HBV and HCV. I am not aware of any other infection.

Section 4. Consent

13. Bob and I were sold the FVIII treatment by Dr Jones and without any warning of risk. My initial instinct was for Jonathan not to have the stuff and I feel that we were hoodwinked. We left the appointment with Dr Jones with such a glowing picture of it. We were told that Jonathan's life would be so much better, and that Jonathan would be able to play football. Jonathan was very popular young man. He enjoyed playing table tennis and pool and he loved clay pigeon shooting. He could quite happily have carried on like that. However, Dr Jones was the doctor and we believed that he was recommending the treatment in good faith. The reality is that they were importing blood from high risk donors in the USA. I have latterly read that the Australians were suspicious about the safety of the product and they steered clear of it.

14. Jonathan had lots of FVIII concentrate and I do believe that he was used as a guinea pig. When Jonathan was doing his A levels, Dr Jones advised that Jonathan needed an operation to have an undescended testicle corrected. We did not think it was necessary at that stage, but Dr Jones continued to pester Jonathan about it until he got his own way. Jonathan did not do well in his A levels as a result.

15. The language adopted by Dr Jones and the comments made by him in some of the medical notes we have read speaks volumes. I am referred to as an 'over-protective mother' and in one letter Jonathan was asked why he wasn't coming for his operation as Dr Jones formerly *thought* he '*was dealing with a very intelligent boy*'. That letter was horrible and manipulative. He really overstepped the mark.

16. Jonathan then went on to regular prophylaxis treatment (on what I remember as being every other day). He would self-inject in his bedroom. When he went off to university, he collected the product from the Manchester Royal Infirmary, and kept it in his fridge up there.

17. Jonathan lost all trust and respect for Peter Jones after he was infected. He no longer wanted to go to his appointments and in the last few months of his life he refused to see him.

Section 5. Impact of the Infection

18. Having haemophilia was difficult for Jonathan to deal with in childhood but things were beginning to look better for him in his teens. He was a very good looking, popular boy and he had lots of friends. There were so many activities that he was able to enjoy (including his love of clay pigeon shooting) regardless of having haemophilia, and he should have had his whole life ahead of him, yet, everything including his life was taken from him. The family I loved so much was destroyed in the process.

19. Jonathan was looking to pursue a career in land management before he became unwell as he loved the outdoor life. When he started to become consistently unwell, we did not know why. He had an interest in antiques. He came home from Manchester and we bought a little antique shop for him to run

in GRO-C. Fiona and Jonathan were very close. Fiona gave up her career aspirations to run the adjoining tea shop. It was a joint family venture. Everyone in GRO-C knew us. Jonathan went backwards and forward to the doctors in order to get to the bottom of what was making him ill. I remember one doctor telling Jonathan that whatever he thought was wrong was all in Jonathan's imagination.

20. Jonathan met his girlfriend, Helen, at university and she is a lovely girl. She was at college but she went with him in Jonathan's van to his appointment in Newcastle the day he was told he was infected. Jonathan had started to look as unwell as he felt. To learn that Jonathan was infected with HIV was a living nightmare. It was something we lived with and worried about all the time, and then there was the media. Because of the high profile and negative press coverage people in the town started to make the connection between HIV and haemophilia. They had their suspicions about Jonathan but, we are not a big family, and, we and Helen kept it to ourselves.

21. Jonathan became seriously ill and was given blood transfusions as a treatment from September 1986 onwards. The transfusions initially made him better, and the affect lasted for at least three to four weeks before it wore off. I remember one very beautiful morning with the sun shining, feeling very hopeful that Jonathan might just be able to live longer and have a better quality of life after all, but by February of the following year (Valentines Day) he was really, really poorly. He really did want to live. Even in his last few days he tried very hard to get better.

22. When Jonathan died, Bob and I were so upset and distressed. We couldn't function or stand it. I refer to Exhibit WITN6421002 being a copy of Jonathan's Death Certificate. Bob didn't want HIV or AIDS on the Death Certificate, so lymphoma went down as the main cause of death. I was just so shocked and bewildered for such a very long time. It was dreadful. I didn't want to see anyone, and I couldn't bear to see any of Jonathan's friends, so much so that I

didn't shop in the town for two years. I did my shopping in Windermere instead. My anxiety levels were terrible.

23. The impact on anyone losing a child is enormous, but the way it happened was crueler still. He was infected through no fault of his own and I was left with 'what if?' Despite my anxiety and grief, I had to somehow begin to learn to live a different life. I ultimately went back to working as a supply teacher to keep myself busy and to distract myself from my own thoughts. Nothing gave me any pleasure anymore because Jonathan had gone. The education system was my only saviour, as I kept up my interest in children and I never stopped being a school governor.

24. Psychologically, I do not think that I was even able to lift my head up until Fiona was married and had had her first child, a girl, Flora, born 29 years ago. Future generations were and are big a worry, brought to the forefront of our minds with each expected grandchild. I have three lovely grandchildren. My second grandchild, Wilson, has severe Haemophilia A. Because of the lessons learned through Jonathan and others like him, Wilson has better treatment and is able to lead the 'near to normal life' Jonathan was promised. Wilson can run, he can cycle, and he can play football and all the things Jonathan wasn't easily able to but longed to do. Because of Wilson I do not believe Jonathan has died in vein.

Section 6. Treatment/care/support

25. Jonathan had blood transfusions towards the end of his life. He wasn't given any curative treatment for HIV and we were not aware that he had hepatitis.

Section 7. Financial Assistance

26. Jonathan died before help and support became available through the Trusts and Funds. Bob and I wanted to give him the best possible chance and we financed the antique shop venture and provided financial support to him.

27. We received the sum of £15,000 from the MacFarlane Trust after Jonathan died. This is the only sum of money we received. I wasn't interested in pursuing anything through the Skipton Fund when I heard about it. There is not a day goes by when I do not think of Jonathan. He was my life.

Anonymity

28. I do not seek anonymity and I understand that this Statement will be disclosed for publication to the Inquiry.

Statement of Truth

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

Signed........ GRO-C ....

Dated..........**20th September 2021**.............................