Witness Name: Pauline Alice Wright
Statement No: WITN7278001
Exhibits:0
Dated: October 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAULINE ALICE WRIGHT

I, Pauline Alice Wright, will say as follows: -

Section 1. Introduction

1. My name is Pauline Alice Wright. I was born on GRO-C 1966, and I live at GRO-C.

2. I was made redundant in November 2020 which was a little unexpected following which I had about 8 months away from work. I was able to pay the bills with my redundancy money. I then started temping and one company which I temped for since January 2022 took me on full time in June of the same year. I am employed as a Scanning and Data Specialist. I enjoy this role which involves undertaking projects for the Government. Currently I am working on a confidential data project for Iron Mountain which is as much as I am able to say due to signing the Official Secrets Act.

3. My late husband, Stephen Dick (born on GRO-C 1964) was infected with the Human Immunodeficiency Virus (HIV) and possibly Hepatitis C Virus (HCV) through contaminated blood products. He died aged 29, on 3 January 1994, only 11 days before his 30th birthday.

4. This witness statement has been prepared without the benefit of access to Stephen's medical records. However, I confirm that I have very recently applied for his medical records from The Churchill Hospital, Oxford and Kettering General Hospital, Kettering. I have been advised that his GP records were destroyed 10 years after his death. I have also applied for his UKHCDO records.

Section 2. How Affected

5. I met Stephen in 1986 and I only got talking to him to get rid of someone else who was interested in me. I pretended we were together and then we got together! We married on 12 August 1989. Stephen was one of the nicest and most genuine people you could ever hope to meet. He had a huge number of friends and a great sense of humour. He was extremely patient; I think he learnt this skill through coping firstly with his Haemophilia and then later the HIV together with the resulting health conditions and complications which this caused him. He was always smiling and happy and managed to remain cheerful despite the horrific pain he endured. In fact, he would never shut up! About a year before he passed away, he became extremely poorly and was unable to walk. I gave up work to care for him full time and in the last 2 to 3 months of his life he was bedridden. He died aged 29, on 3 January 1994, only 11 days before his 30th birthday. I was 27 when he died; we were both still kids really just setting out on our lives. He was a fantastic man and I miss him terribly.

6. Stephen had severe Haemophilia A. He had this condition when I met him. He bled frequently and always walked with a limp.

7. Stephen was treated with Factor VIII throughout his life. I do not know the date on which he first started receiving this, but he was on Factor VIII when I met him and continued to be treated with Factor VIII throughout the time we were together.

8. He would receive Factor VIII for bleeds and was also treated on a preventative basis, by way of example if he planned on going out somewhere he would receive Factor VIII.

9. Stephen was treated at The Haemophilia and Thrombosis Centre at The Churchill Hospital in Oxford. I do not know the names of his consultants. I do want to add that the staff at the Churchill Hospital were amazing and very supportive despite what occurred.

10. I don't know what information was given to Stephen regarding whether there were any risks in relation to Factor VIII as he was on this before I met him.

11. Stephen was infected with HIV. I do not know the batch number of the Factor VIII which infected him. I am also unsure of the exact date on which he was infected.

12. However, I do know that Stephen was told he had HIV by staff at The Churchill Hospital in either late 1988 or early 1989. I do not know the date of his first positive HIV test result. Stephen had no idea that he was even being tested for HIV and the first time he heard he had been infected was when he was told at an appointment at the hospital. He attended this appointment with his mother, and I do not know whether it was a routine or specifically booked appointment for the purposes of divulging the shocking news of his infection.

13. Stephen was never told that he was infected with HCV, but he could well have been. As far as both Stephen and I are concerned he was never told that he was being tested for HIV, HCV or any other virus. Therefore, it follows that he must have been tested without his knowledge and consent, at least for HIV, otherwise how would they know that he had the virus?

14. I remember Stephen returning home after the appointment where he was told he had HIV; he was devastated and was worrying about how to break the news of his HIV infection to me. I don't think he was given much information by the staff at Oxford, and I feel that we were basically left to muddle through and learn ourselves. I would say we were left in the dark. Stephen was not given any

information about the risk of passing the infection to me and no one advised me to get a blood test to see if I had contracted HIV. I went ahead, off my own back, to get a test for HIV which was thankfully negative.

15. However, I still feel that the staff at The Churchill Hospital did the best they could but if they had more information about HIV and/or if they had known about his infection earlier then this information should have reached Stephen sooner than it did.

16. Stephen and I ended up finding out information about HIV ourselves. We used to watch the news and we heard people talk about it as AIDS was a big subject in those days. I was employed as a care assistant and worked with Stephen's sister who was close friends with one of the senior residential care workers who seemed to have a lot of information on HIV. Stephen's sister was able to pass this information to us which was helpful. However, the whole period was extremely frightening as we were dealing with the unknown; we did not know what was going to happen or how poorly Stephen was going to get.

Section 3. Other Infections

17. As far as I am aware, apart from HIV and possibly HCV, Stephen did not contract any other infections.

Section 4. Consent

18. I believe that Stephen was treated and tested for HIV without his knowledge and/or consent, without being given adequate information and for the purposes of research. The first time Stephen heard the word HIV in relation to him was when he was told of his infection. Therefore, it follows that he was never told that he was being tested for HIV.

19. I believe that the above could also be possible in relation to HCV.

20. Furthermore, following Stephen's passing I received a letter from a London hospital (I can't recall the name) confirming that they had some of Stephen's blood for the purposes of research. I had no idea about this, and it was very upsetting. GRO-C GRO-C but irrespective of the reason, it was still a real shock to find something out like that. As far as I am aware, neither Stephen nor I had consented to the use of his blood for the purposes of research.

Section 5. Impact of the Infection

21. Stephen was devasted when he found out that he had HIV. He felt dirty and ashamed, and it was truly heart-breaking to witness the resultant changes in him.

22. Stephen used to be a very sociable person and he had a huge friendship group. He loved going out with his friends and all of this changed as the HIV and resulting health conditions took hold. He stopped wanting to see anyone which was doubly hard for Stephen as he had been such a social and outgoing person.

23. Due to the massive stigma attached to HIV and AIDS the reality was that Stephen and I dealt with everything that flowed from his diagnosis alone. I did not tell my parents and it was only when Stephen was in the latter stages of his life that I confided in my mother as I had to give up work to care for him. She was very supportive but of course her first fear was regarding whether I had also been infected.

24. Stephen confided in his parents. They told his sister and his brothers about his HIV infection, but the family were sworn to secrecy such was the bad publicity around HIV and AIDS. Stephen never confided in any of his friends or work colleagues and although his family were initially fairly supportive, I felt that Stephen and I were very much left to deal with matters alone. His mother did attend hospital appointments with him, but she rarely visited our home and

never once offered to sit with him so that I could pop out and get some shopping or medication. Stephen and I supported each other, and I think he tried to remain positive and good fun to help me through. I admire the way he could still joke and laugh about things even though we were in a dire situation. I was, and still am, very proud of the way he handled matters.

25. Stephen suffered with a number of physical health conditions and complications resulting from his HIV, including thrush in his mouth, 3 tumours in his head, epileptic fits, toxoplasma (infection by a parasite), infections, rapid weight loss, pressure sores due to being in bed for so long, bronchopneumonia (inflammation in the alveoli) and cold sores in his nose.

26. Stephen worked at RS Components which was an electrical component company which bought and sold parts. He managed to remain at work until in or around the end of 1992. Prior to this he used to have a lot of sick days and his colleagues lovingly referred to his sick days as him "*having a Stevie dick*" as Stephen's surname was Dick. This showed how popular Stephen had been at work as the norm would have been work colleagues getting frustrated with their peers who took frequent sick days. He had built up such a brilliant rapport with his work colleagues and they had great banter in the office.

27. Stephen was put AZT for his HIV and as far as I can recall he did not suffer side effects from these drugs; his main issues were the conditions which resulted from the HIV. I would say he really struggled with the increasing weakness and the tumours. He struggled to bend down to tie his shoelaces as he could not co-ordinate his arms to do this task. I helped him with all the tasks he struggled with. It became second nature to me.

28. Despite the very real problems that we faced, Stephen and I tried to remain strong and positive. We had some good times in those difficult years. We did avoid shopping in GRO-C which was our local town, as Stephen did not want people to see him in his wheelchair so I would choose towns further away for us to go to. I used to push him in his wheelchair, with the trolley in front, when we did the food shopping. I remember one time in Morrisons we were having a funny argument about some bread, and I walked off and left him in the bread

aisle. He was like "*come back here!*". We had many lovely moments between ourselves, and we supported each other.

29. Stephen's physical health dramatically declined towards the end of 1992, and he spent most of 1993 being unable to walk. I gave up work in or around the start of 1993 to care for Stephen on a full-time basis. We put the bed downstairs and I got a commode as the toilet was upstairs. I had to do everything for Stephen including helping him on the commode as he became so weak. He had to let go of all his pride which was very hard when he had been the man of the house, standing at 6 feet 2 inches in height. He was effectively bedridden for the last 2 to 3 months of his life.

30. I was his sole carer until about 3 weeks before he passed away when a District Nurse used to come in the mornings to attend to his pressure sores. Even when Stephen was in hospital, I would stay by his side as I knew his care routine inside out and I wanted the very best for him. Towards the end of his life, Stephen was on oral morphine and hallucinating. He used to wake screaming in the night as he thought that he had spiders all over him. I had to calm him and sit with him until he fell back to sleep. I had to wake him every two hours at night to give him his medications and I remember being exhausted, drained and acting like a zombie at times. I just wanted to do the very best for my Stephen. I think it was helpful that I had been employed as a carer, but the reality was that nothing could really have prepared me for how it actually was.

31. Following Stephen's death, **GRO-D**

GRO-D

GRO-D all I wanted was what was best for Stephen.

Section 6. Treatment/care/support

32. As far as I am aware, Stephen did not face any difficulties accessing medication for his HIV.

33. Stephen did not suffer any bad treatment or stigma from the staff at The Churchill Hospital in Oxford as a result of his HIV status. They did not change the way or manner in which they treated him after he was diagnosed with HIV. Stephen was well placed to comment in relation to this as he had been attending this hospital since he was a child.

34. Stephen was treated differently due to his HIV by the staff at Kettering General Hospital and this was something that I also witnessed. Prior to his HIV diagnosis, having blood taken seemed to be a normal run of the mill procedure and the staff would chat to us but after his HIV diagnosis, he was put in a room on his own and their attitude and behaviour towards him totally changed. The staff were fully gowned and acted like taking his blood was the worst thing in the world. They barely had time for us. This was very upsetting to witness, even more so as we are talking about health care workers, and I knew it affected Stephen.

35. I believe that Stephen was also treated differently due to his HIV by his GP. On the morning that he passed away Stephen started fitting. The District Nurse had come in to treat him and had also tried to administer Factor VIII. She struggled to get the needle in, so she telephoned Stephen's GP who arrived at the house. He literally forced the needle into Stephen's arm and said words to the effect of "*he has not got long now*" and then he left. He was really abrupt and unprofessional. He showed no kindness, and it was like he did not want to be there. I thought that he possibly had a few weeks to live. It turned out that Stephen died within an hour of the GP's visit. I am very disappointed and upset by the treatment Stephen received by the GP.

36. As far as I am aware Stephen was never offered any counselling or psychological support in consequence of his HIV infection. He was, however, offered a course of holistic therapy. I remember telephoning the organiser on

one occasion to let them know that Stephen was poorly that day and could not attend. I was basically told off for not giving them sufficient notice and I think I actually said something along the lines of *"if you deal with people with HIV you are going to have people who get poorly at short notice".* It beggared belief that on the one hand they offered this type of respite/help and yet on the other hand basically took it away by the way in which it was managed. Following this behaviour, unsurprisingly Stephen decided not to attend any more sessions.

37. I recall that someone at The Churchill Hospital in Oxford suggested some counselling for me. I remember going along to this which took place in a room at The Churchill Hospital. I vividly recall how the counsellor told me that Stephen would be put in a body bag, and I would not be able to say goodbye to him. The counsellor traumatised me and all I could think about for about a year was that this terrible thing was going to happen to Stephen. She was completely wrong as when he died this did not happen. I was able to go the Chapel of Rest and say goodbye to him. I never wanted to go back for any further counselling sessions so my first and only session took place about a year before Stephen died.

38. I also believe that Stephen was treated unfairly when he applied for a Mobility car. I would say this was being treated badly as a result of his Haemophilia as he applied for this assistance prior to being infected with HIV and in fact, it took him years before they agreed to his application. The reason he eventually got this after years of relentlessly fighting the constant rejection was that a specialist consultant in Haematology came to assess Stephen and he immediately fully understood his condition and granted him the Mobility car.

39. I remember asking the local council to erect a ramp outside our house so that I could push the wheelchair in and out the house. This was always a real struggle as the step was too high and I had to lift the wheelchair, with Stephen in it, up down the step by myself. I am not sure exactly when I made this request, but I remember waiting a long time, and in excess of about 10 months, for the council to do this. The council delayed for so long and only installed a ramp about a few weeks before Stephen passed away. I felt like we had both been ignored

and that they did not care for our basic needs. You feel hopeless and sad being treated in this way.

Section 7. Financial Assistance

40. Stephen and I somehow managed to live on my Carer's Allowance of £15 per week and the small amount of disability benefit that Stephen received. We lived in a council house, so our rent and council tax was paid, and we did not really go out much once Stephen's HIV and associated health conditions took hold.

41. I do not think Stephen received financial assistance in the form of regular payments, grants or other help from the MacFarlane Trust (MT) or any other trust. However, we did receive a car chair swing which meant it was easier for me to get Stephen in and out of his Mobility car. I am not sure where the money came from to purchase this.

42. We received no money for any adaptations to the house to help Stephen's failing health due to his HIV. Luckily as I was a care assistant, I could take Stephen to where I worked so he could have a long soak in their specially adapted bath. Without this, he would have had to make do with bed baths for months. Things like this make me very sad as most people would feel that having a bath was almost a basic right but not for my Stephen.

43. Stephen did receive the £20,000.00 compensation payment from the HIV litigation for which he had to sign a waiver.

44. I confirm that I have never received any financial assistance from any of the trusts.

Section 8. Other Issues

45. I want the truth to come out and I want those who are at fault to admit responsibility. I hope the Inquiry achieves these things.

46. I am following the Factor 8 Group and what I am learning is horrifying. I was just a young girl starting out on married life when Stephen was cruelly taken from me. I was 27 and I had to try and rebuild my life. However, my memories and love for Stephen will never leave me and are part of my life today.

Anonymity

47. I do not want to apply for anonymity.

48. I 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....05/10/22.................................