Witness Name: Robert Henry Pye
Statement No.: WITN0212001
Exhibits:
Dated: 19 JULY 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ROBERT HENRY PYE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 01 February 2019.

I, Robert Henry Pye, will say as follows: -

Section 1. Introduction

1. My name is name is Robert Pye. My date of birth is GRO-C 1936 and my address is known to the Inquiry.

2. I retired as a Printer roughly forty years ago and reside with my wife in the Isle of Wight, where we moved in 2006.

3. I intend to speak about my infection with the Hepatitis C Virus ("HCV"), which I contracted as a result of being given contaminated Factor IX Products to treat my haemophilia B.

4. In particular, I intend to discuss the nature of if my illness, how the illness affected me, the treatment received and the impact it had on my life.

5. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry to assist me with my statement.

Section 2. How Infected

6. I remember that when I was younger, I would always get small cuts and bruises and would not be able to stop bleeding. I remember my father would tell me to stop bleeding but I never could. School and growing up were not easy for me.

7. I later joined the Royal Navy and had the same type of problems, including a fractured ankle whilst serving on HMS Bulwark. I had various medical procedures that required hospitalisation to control the bleeding.

8. Eventually I was diagnosed with haemophilia B in 1973 at Orsett Hospital after initially being diagnosed with Christmas disease.

9. Being diagnosed with haemophilia was frustrating for me. I could not play cricket, I loved my cricket and so it was not easy.

10. Having been diagnosed with haemophilia B, I was given Factor IX Products; my factor levels at the time were 6%. I received my first Factor Products during a medical procedure, in 1974 at Barts Hospital.

11. I continued to have factor cover for various medical procedures, until in 1991 I was diagnosed with HCV at the Royal Free Hospital. Two professors working at the Royal Free Haemophilia Centre notified me of my infection. I believe that early on, my blood was being regularly tested, probably as I was a haemophiliac and that this tested blood was the blood used to diagnose me with HCV.

12. I was simply told that I had the infection. I do not recall being given any information on how to manage the condition or on any precautions to take around others.

13. I can't say for sure that I had noticed any symptoms of the HCV, apart from always being fatigued, which I put down to work as my job was quite demanding.

14. I remember there were times where I asked questions about the Factor products I was receiving but nobody would tell me anything. On one occasion whilst visiting a blood bank, I believe at the Royal Free, I went into a sterile storage area. I could see all the blood bags in their shiny environment. They were clearly marked as coming from America. Someone saw me and asked me to leave the room. I informed the hospital that the blood coming from America was likely to be bad but again I was ignored.

Section 3. Other Infections

15. I do not believe that as a result of being given infected blood products I have contracted any infection other than the HCV.

16. However, in October 2004 I was informed that I might be at risk of developing vCJD whilst on a visit at the Royal Free Hospital. I have not been tested for this or heard anything further in relation to it.

Section 4. Consent

17. I have been asked whether I believe that I have been treated or tested without my knowledge or consent and the answer is no. I have always given consent. My doctors would not do anything without consulting me and I was always asked to sign forms. That said, I was not aware that the blood test that uncovered my HCV was for that purpose.

Section 5. Impact

18. In 2000, I received my first treatment for HCV at the Royal Free. I was given Pegylated Interferon and Ribavirin. The course of treatment last for roughly six weeks. It was a combination of injections to the stomach and tablets. It was cut short as I'll explain.

19. The effect on me was horrendous. I felt that I was dying after taking the combination of drugs. I was extremely tired most of the time. I remember one time my knees locked up when I was on the train to see my daughter. I was in great pain and ended up needing assistance; I still suffer with knee problems today. I feel as though some of my joint problems such as carpel tunnel and my knee problems have come about as a result of taking the drugs.

20. The treatment also made me feel suicidal. I felt that my head was almost empty and I could not do anything about it nor could I stir myself into action. It was a terrible feeling of lethargy and a sense of hopelessness. I still have bad memories of it. It felt like all my problems were internal. Unfortunately, the trial was unsuccessful and I did not clear the virus.

21. Other effects of the infection include: having to think constantly about my infection before I do anything. Being worried about my wife and family and the possibility that in the past I may inadvertently infect one of them. This has all taken its toll on me.

22. I have not had any dental problems as most of my major work has been done at hospital, although this in itself can be an inconvenience. I do not feel as though it has had an impact on my social life. I have had little time off work and do not remember anything that could be perceived as stigma. I just got on with life at the time.

23. I have had a number of other surgical procedures and up until 2014 I had to attend the Royal Free hospital for my treatment. This was a drain timewise and financially but it was the Hospital where I had received most of my previous care and I was comfortable there.

Section 6. Treatment/Care/Support

24. In September 2009, I underwent a fibro scan 5.9 for my liver function at the Royal Free. I had a further scan (7.0) at St. Mary's, Southampton in 2018. These are the only liver function tests that I have had.

25. It was not until February 2019 that I started a new treatment for HCV and was placed on Maviret Tablets, which I administer daily. I believe that this is because Royal Free gets a batch of medication and then decides which individuals are ready for treatment and move it to the nearest treatment centre. It must have been my turn and the medication went to St. Mary's.

26. I am due to finish my treatment at the end of May 2019 and have an appointment with my doctors to see what the outcome of the treatment was.

27. I can confirm that I have never been offered psychological support for my infection with HCV.

28. I can also confirm that during my interview with the inquiry, I have been informed about the access to the support mechanism that the British Red Cross provide.

Section 7. Financial Assistance

29. I made an application for payments under the Skipton Fund around three years ago. Somebody came to assist me with the application procedure and to go through my forms.

30. My application was successful and I received a stage one payment of around £20,000. I also currently receive a monthly payment of around £400 - £500. I don't recall any conditions being placed on the payment I received. However, I do feel that the amount I get is minuscule compared to what I have been through with the virus and the way it has influenced a great part of my adult life.

Section 8. Other Issues

31. I have no idea why it took nineteen years for me to get a second course of medication. It may have been because of the effect it had on me first time around or possibly it was decided that the HCV did not affect me as adversely as it did others.

Statement of Truth

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

Signed GRO-C

Dated 19th July 2019