

Witness Name: James Penberthy

Statement No.: WITN0095001

Exhibits: N/A

Dated: 05 February 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JAMES CORBIN PENBERTHY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 03 January 2019.

I, James Corbin Penberthy, will say as follows: -

Section 1. Introduction

1. My name is James Corbin Penberthy. My date of birth is [GRO-C] 1952. I am married with four adult children and five grandchildren. I intend to speak about my haemophilia and infection with hepatitis C. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my family.

Section 2. How Infected

2. I was diagnosed with mild haemophilia in 1956 when [GRO-C] had a serious accident. I was four at the time [GRO-C] When we went to the hospital, [GRO-C] [GRO-C] I was tested for haemophilia [GRO-C] This led to my

diagnosis of mild haemophilia. The disease runs in the family GRO-C

GRO-C

3. In 1978, I had my first hernia operation. I was treated at St George's Hospital in Tooting, where my treatment had been based since 1971. I was given factor VIII as part of the surgery so that my blood would clot properly. I consented to having the factor VIII, but I was not informed of any risks of transmission of hepatitis C through blood products. This was how I became infected with hepatitis C: by receiving factor VIII during my first hernia operation.
4. However, I did not learn of my infection with hepatitis C until many years later. Around the Christmas period in 1992, I received a totally unexpected letter from St George's Hospital asking me to go in and see them. I duly attended an appointment, and in January 1993 the doctors told me that I was severely ill. They informed me that I had hepatitis C and advised me to start a course of interferon treatment immediately.
5. I will never forget that meeting when the doctors informed me that I had hepatitis C. When I heard that information, I felt like I was being closed as in a business deal against my will because I did not have the option of saying yes or no to the treatment, the only treatment that was currently available.
6. I was not given any information about the disease or how to manage it when I was diagnosed. I knew that hepatitis C was a liver disease of some description, but I did not know much about the disease other than that. I was not informed of the risks of infecting others.
7. After my diagnosis, the medical staff at St George's were able to trace my infection with hepatitis C back to 1978, when I had undergone my first hernia operation there. Incidentally, I had a second hernia operation at St George's in 1986. I have subsequently been told that I missed being infected with HIV by about six weeks on that occasion, as the hospital had been using a bad batch of blood products.

Section 3. Other Infections

8. I do not believe that I have received any infection other than hepatitis C as a result of being given infected blood products.

Section 4. Consent

9. To the best of my knowledge, I have not been treated or tested without my knowledge or consent. I have no reason to believe that I have been experimented on for the purposes of research.

Section 5. Impact

Mental and physical effects of infection with hepatitis C, and effect on work

10. Although I was not diagnosed with hepatitis C until 1993, looking back I began to feel the effects of the infection from 1980 onwards. I was only 28 at the time, and I was doing well in my career up until that point. I had taught maths after I graduated and had been promoted to Head of Department and Second Senior Master of a secondary school. Then discovering I enjoyed management more than teaching I decided to move career. Out of 750 applicants, I was the only one to start a super-slipstream entry into retail management in 1980 when I started a new job with M&S. It was around this time when I noticed that I was getting a little more tired than I had previously.
11. My exhaustion continued to get worse until I decided that I needed a step out from my career at M&S in the summer of 1982. I then began a career in The Third Sector, charities, where I was responsible for managing charities and developing commercial arms of charities. However, between 1983 and 1985 I could really feel myself getting exhausted. I thought it was just tiredness at the time, but looking back I know that it was not normal and that it was caused by the then undiagnosed infection.

12. By 1989, I felt that I was very ready to do a Masters of Business Administration (MBA). I was looking into an MBA programme at Heriot-Watt University because it would dovetail very well with my career path. However, I also knew that with my fatigue and subsequent lack of mental focus, I would not be able to complete an MBA. This was the first time that my illness really consciously dented my career and prevented me from doing something I believe that I could otherwise have accomplished.

Mental and physical effects of treatment

13. I was then diagnosed with hepatitis C in January 1993. Prior to that in 1992, St George's Hospital had told me that I was seriously ill, but they were not sure what was causing my illness. Eventually in 1993, Dr Joseph was able to establish that I had hepatitis C.
14. Immediately after my diagnosis, I had to start treatment with interferon. I was put on a research programme but I had to give up the treatment in July or August 1993 without completing the course because the side effects of interferon were so terrible. The doctors had explained to me that I would experience flu-like symptoms, but it was a lot worse than that.
15. The effects of the interferon whilst I was on the treatment were absolutely devastating – it completely knocked me sideways and I felt like I was dying. I experienced severe fatigue, forgetfulness, weight loss and suicidal thoughts. I felt really depressed but it was synthetic in the sense that I knew inside that it wasn't really me and that I wasn't actually depressed; the depression was like a screen coming down, triggered by the interferon.
16. Despite the fact that I did not finish the treatment with interferon I miraculously cleared the virus. The hospital could not explain how I had cleared hepatitis C. I was told that I had somehow "smashed" four research programmes and that I was "the unique of the unique", having got through alive. I believe that it was divine intervention and that I was healed by a miracle. I received the news that I was clear of hepatitis C some time later in 1993.

17. I no longer had hepatitis C but the negative side effects of the treatment did not stop. I had something that is now known as post-viral fatigue syndrome. I was extremely tired, and by 1994 this was beginning to seriously affect my ability to hold down a job. By 1996, I was the chairman of the board of a charity. Unfortunately, I knew that I could not hold down a senior position and had to give up work again.
18. My post-viral fatigue syndrome had escalated again by 1999. At that point, I had managed to re-organise my professional life and had set up a business consultancy focused on advising small and medium-sized enterprises (SMEs). However, I was falling asleep during meetings and even fell asleep at the wheel on one occasion.
19. In 2004, I miraculously obtained a very good contract with a client with a multi-million-pound turnover. I was able to deliver in part and managed to get myself back into proper work. However, the work completely exhausted me. My job involved travelling and I recall being in Paris on business. I had a big conference with the European Union in the evening, and I had to go to bed in the afternoon just so that I would have enough energy for the evening conference.

Financial effects of infection

20. Looking back now, I do not know how I was able to cope. I was securing good deals, but it was incredibly draining and I know that I could have achieved so much more in my professional life had I been completely healthy. The fact that I have had to take breaks between jobs and careers meant that we sometimes experienced cash flow issues, which would not have happened without the hepatitis C. I have not had a proper contract since 2011, which is when I had to let my last Personal Assistant go.
21. Furthermore, since then I have only held board positions at SME level; I have missed out on holding any board positions above that. Nevertheless, when I look back, I sometimes wonder whether I could have attained a

board position at the lower end of the FTSE 100 if I had not had to struggle with hepatitis C or the post-viral fatigue syndrome. It is difficult to be objective, but I believe that hepatitis C has stopped me achieving what I could have achieved after I graduated. I believe that I could have potentially been earning seven-figure sums had I not been infected.

- 22. I now have a small teacher's pension (£150 per month) but mainly live from the monthly payments of £1500 per month from the EIBSS.
- 23. Before my infection, I had my son's name down at a prep school. But after that, all of my four children had to go through state schools. If I had been able to follow my career path properly (I believe I was on an upward trajectory), I am sure that I would have been able to educate all of my children privately. It upsets me enormously that I have not been able to give my children what I could have given them.

Impact of infection on family and private life

- 24. I have been married to my wife since 1974 and we are still married, but we have separate bedrooms. My wife wanted us to get divorced twenty years ago, and although I do not think that the hepatitis C alone is the source of our marital problems, it has certainly added a lot of unnecessary strain to our lives.

- 25. My wife has been struggling GRO-C GRO-C when it first began to seriously affect her. Now, it causes her to live a domestically chaotic life. I believe that my infection with hepatitis C has GRO-C GRO-C she had to deal with seeing me go through the treatment with interferon and I think this was the final straw for her. She was acutely aware of the fact that people have died from hepatitis C, including people who received the same batch of blood products as I did. I think my infection was just too much for her to deal with, GRO-C GRO-C

26. My infection also meant that I was unable to care for my wife [GRO-C] [GRO-C] in the way that I otherwise could have. [GRO-C] [GRO-C] if I had been in good enough health [GRO-C] I could also have given her much greater financial security; she came from a very wealthy background and was used to having a lot of money, so constantly running out of cash did not do her [GRO-C] any good. My infection with hepatitis C badly escalated our situation.
27. I believe that all of this had a profound effect on my children. We have never really spoken about it much, but I know that my older two children at least were deeply affected by my infection. They could see how completely exhausted I was.
28. I remember that on one occasion my son, who was then around 15 years old, very kindly press-ganged a couple of his friends to help me on my much-loved allotment. It was at this time that the exhaustion really hit me. I was sitting in the lounge in an armchair at just after 9pm one evening, when I suddenly realised that if I did not go up to bed at that moment, I would not be able to make it up the stairs.
29. In addition to this, I was not able to live a full social life because of the effects of interferon and the subsequent post-viral fatigue syndrome that I experienced. I just was not able to go out and about, or to really enjoy dinner parties. I remember that we were on holiday in Holland once but I was so exhausted that I simply could not enjoy it.

Impact of stigma

30. I was aware that there was a certain stigma attached to hepatitis C and even to haemophilia, so I mostly kept quiet about my conditions. I only told my close friends about my infection with hepatitis C, and they were compassionate. However, my wife could not cope with coming with me to the appointments at St George's Hospital [GRO-C] [GRO-C]

Impact on medical or dental care for any other conditions

31. I have not had any problems with obtaining medical or dental care for any other conditions. My dental care has always been conducted at St George's Hospital, where they were already aware that I had hepatitis C and it was not an obstacle to receiving treatment.

Further medical conditions resulting from the infection

32. Due to my infection with hepatitis C, I have now also developed cirrhosis of the liver. Exactly when I developed cirrhosis, I either cannot recall or I was not told. I was originally examined and monitored for this condition at St. George's but due to the severity of the cirrhosis, I was then passed to King's College Hospital where I have been for the past ten years. King's has the largest liver unit in Europe. They are currently monitoring my condition.

Section 6. Treatment/Care/Support

33. I have not faced any difficulties in obtaining treatment, care and support in consequence of being infected with hepatitis C.
34. Counselling and psychological support has never been made available to me, but I do not think that I would have used it. I do not think it would have helped.

Section 7. Financial Assistance

35. I am in receipt of financial assistance from the Skipton Fund, having received the initial stage 1 payment of £20,000 and then the stage 2 payment of £25,000, if I remember correctly, once I developed cirrhosis. I also receive the annual winter fuel allowance. I cannot recall whether I received further monthly payments or not from the Skipton Fund, but I now

receive a monthly payment of £1,500 from the NHS Business Services Authority.

36. I have been asked how I found out about the Skipton Fund. I again cannot remember how I found out, but I remember finding the whole process of being paid or compensated emotionally stressful. I know that the payments are trying to make up for what I have lost through my infection, but I find it all a bit of an insult. How did they decide on the round numbers of £20,000 and £25,000? Where did they get these figures from? As I have mentioned above, I cannot say what I could have earned if I had not been infected with hepatitis C, but I believe that I could have achieved a seven-figure income.

Section 8. Other Issues

37. I regret that I will never know what I could have achieved without hepatitis C. I believe that it has certainly reduced my capacity and affected my intellectual grip. Last year I was editing a PhD thesis on behavioural economics and I found it fascinating. I know that I could not have done a PhD with my infection, but without it, I believe that I could have been up there.

Statement of Truth

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

Signed _____  _____

Dated 05 February 2019