Witness Name: P L Hopton
Statement No: WITN3955001
Exhibits: 0
Dated: February 2020

# INFECTED BLOOD INQUIRY

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## FIRST WRITTEN STATEMENT OF PATRICIA LYN HOPTON

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I, Patricia Lyn Hopton, will say as follows:-

## Section 1. Introduction

1. My name is Patricia Lyn Hopton and I am known as *"Lyn".* I was born on GRO-C GRO-C 1949 and I live at GRO-C Cornwall, GRO-C.

2. I was infected with Hepatitis C as a result of receiving contaminated blood via transfusion on 5th April 1978.

3. **This witness statement has been prepared with the benefit of access to my medical records.** I believe that I am in possession of a complete set of medical records which were extremely muddled and not in chronological order.

## Section 2. How Infected

4. I received a number of blood transfusions after giving birth to my daughter and haemorrhaging at the Treliske Royal Cornwall (TRC) Hospital, Truro, Cornwall on GRO-C 1978.

5. My consultant was Constance Fozzard.

6. At no time was I given any advice or information regarding the risk of infection from receiving blood transfusions.

7. When I received the blood transfusions I was extremely poorly. They transfused so much blood into me and in such a short space of time that it caused a Pulmonary Oedema. I was conscious when this happened and I initially thought that I was crying but I soon realised that blood was pumping out of me, including from my eyes. I was conscious for most of the time and then I fell unconscious and ended up on life support in intensive care, where I remained for three days. I then stayed in hospital for two or three weeks afterwards.

8. It was not until some 38 years later that I found out that I had Hepatitis C. The date of my first positive test was 29th February 2016 and I was told that I was infected with Hepatitis C on 2nd March 2016.

9. The reason I eventually found out about my infection was that over the years I had been feeling poorly, lethargic (which I would describe as *"absolute tiredness"*) and had just not been feeling quite right. I therefore attended my GP and the TRC Hospital in connection with my symptoms. I had some blood tests done which showed that my liver was displaying signs of being *"fatty"*.

10. I then developed Porphyria Cutanea Tarda (PCT) which is a type of porphyria/blood disorder that affects the skin. I had huge water blisters all over my hands which left the medical professionals scratching their heads as they had absolutely no idea why I had developed these or why I was experiencing symptoms of lethargy. I was therefore told that I could choose one of four specialist consultants who practiced at four different, relatively local hospitals, in a sort of last ditch attempt to see whether they could make any sense of my symptoms.

11. I chose a young consultant at Duchy Hospital in Cornwall because this was a private hospital and I felt that sometimes you could receive a better service from the private sector. I duly went along and met the young consultant and in the very first meeting he said "*Have you ever been tested for Hepatitis C?*" I replied something like "*I know about Hepatitis A and B but I did not know about a C*".

12. He briefly explained what Hepatitis C was and then took my blood to test me for this virus. A few days later I received a telephone call from my GP surgery asking me to come in. I therefore attended my GP, who was Dr Victoria Hartnell, and she said "*I hate to be the bearer of bad news, but you have Hepatitis C*". On hearing this, I was not really shaken as I did not really appreciate what Hepatitis C was and I certainly had no idea of how serious it was. If she had told me I had Cancer, Leukemia or a Brain Tumour then I would have instantly realised that I was being given some terrible news. I cannot fault Dr Hartnell as she sat me down and talked to me about Hepatitis C. However, I still don't think the severity of the diagnosis sunk in.

13. Dr Hartnell referred me to Dr William Stableforth, who was a Consultant Gastroenterologist and Hepatologist. I saw him at the Hale Hospital in Cornwall. He did not really tell me very much about Hepatitis C but he was helpful in the fact that he advised me about the Skipton Fund (SF).

## Section 3. Other Infections

14. As far as I am aware I have not been put at risk of vCJD.

15. However, very recently I have been feeling quite unwell and rather worryingly I feel almost identical to how I felt when I was unknowingly harbouring Hepatitis C.

16. I am aware that there is only a minute chance that Hepatitis C can return following clearing of the same. However, I have also learned that there is now a Hepatitis G and I am sufficiently concerned about how I am feeling to have

booked in for some blood tests at my GP. I am sincerely hoping that everything comes back clear.

## Section 4. Consent

17. I found out that I had been tested for HIV without my knowledge and therefore without my consent. Whilst I was attending the Hepatology Department at TRC Hospital in 2018, I asked a nurse if I needed to get tested for HIV. She said something like *"I will just check your records"*. She did so and then said "*You are clear*". She then went on to explain that my medical records confirmed that I had been tested for HIV.

## Section 5. Impact

18. I now have kidney disease and ongoing liver problems as a direct result of the Hepatitis C.

19. Only last week I was suffering with another bad bout of back pain and I wasn't sure if this was emanating from my kidneys or my liver. I therefore went to see my GP and he said that I should have had both a kidney and a liver scan last year but that this was overlooked. The scans have now been booked but it is worrying that I was overlooked and that I am the one who is having to be proactive in managing the consequences of a virus that was given to me in the manner in which it was.

20. I also tend to pick up absolutely every cough, cold and bug that is doing the rounds as my immune system is now shot to pieces. An ordinary cold turns into the most debilitating illness.

21. I am constantly lethargic and completely exhausted most of the time.

22. Mentally, I have struggled with my diagnosis and more so once I carried out my own research and realised the severity of Hepatitis C. I had not appreciated that people could die from it until I started reading into it and looking at matters in depth. I started to go downhill and became depressed.

My mood was further lowered due to the terrible physical problems that I had to endure in terms of my liver and kidneys. It was like a double whammy.

23. I then started having panic attacks which came totally out of the blue. It was a bit like depression as both experiences were totally new to me; I was just not that sort of person prior to Hepatitis C.

24. My GP prescribed two lots of Diazepam but this did not help me at all and I think it was because the dose was so low. In the end the panic attacks subsided until very recently when they threatened to make a comeback. I keep telling them to go away and so far I have somehow managed to keep them at bay. It is not the most pleasant way to live life.

25. When I found out about my infection with Hepatitis C and following the research I did, I immediately realised that my husband and children would need to be tested. I therefore went to my GP and asked if they could all be tested and the answer was *"of course, no problem".* However, no one had proactively arranged this; it all came from me. The degree to which patients, and potentially those who could be at risk from infection, are almost forgotten about is frightening.

26. In terms of receiving treatment for my Hepatitis C, I had a course of Zepatier tablets which commenced in the Spring of 2018. The treatment lasted four months and I did not experience any side effects. However, the only problem was swallowing the enormous tablets as they had to be swallowed whole. I was continuously tested throughout the four months and then on 28th August 2018 I received a letter from the TRC Hospital confirming that I had cleared the virus. I was told that I was Hepatitis C PCR negative in terms of virological responses.

27. I am amazed that it is only within the last couple of years that medical professionals have actually being given guidelines and advice in relation to what type of symptomatology to look out for in relation to Hepatitis C.

28. I have always been very open about my diagnosis. I told all of my friends and I have never felt that it was something to be ashamed of. I did not suffer any

stigma as a result of making these disclosures. To be fair, it may have been that my friends were a bit like me, in that they did not really appreciate the significance of what Hepatitis C was. I never made a big thing of it; they may have just thought that it was like toothache or earache and then forgot about our conversation.

## Section 6. Treatment/care/support

29. The standard of care I received from the two specialist nurses who looked after me was utterly brilliant from start to finish. Mary McKenna was with me right from the outset and she explained everything to me. She would tell me what to look up on the internet, advise on treatments (she always knew which was the newest one out) and just gave me unlimited support. She was not attached to a particular hospital; I believe that she rented a room at various hospitals.

30. The other nurse was called Keeley Lane and the only reason I ended up seeing her was when she covered Mary's holiday. She, too, was fantastic.

31. I saw both nurses at TRC Hospital, St. Michael's Hospital, Barncoose Hospital and also at a hospital in Hayle.

32. I confirm that I have never been offered counselling or psychological support in consequence of my infection.

## Section 7. Financial Assistance

33. I contacted the SF towards the middle to latter part of 2016, on the advice of Dr Stableforth. Initially, the staff at the SF were unhelpful in that when I first applied they said I had not proved that I had received infected blood. They made me both fund and obtain my own medical records in order to prove that I had been infected in the manner in which I alleged. The onus was on the infected person to prove their infection but somehow this did not seem very fair, given the mode of infection.

34. However, having listened to the horror stories connected to the Trusts of some of the other infected persons, and in particular from the Haemophiliac community, I believe that I got off relatively lightly.

35. Due to my persistence with the SF, I finally received the Stage 1 Payment of £20,000.

36. I now receive quarterly payments from the EIBSS and I find them easy to deal with.

## Section 8. Other Issues

37. In terms of my suffering, I believe I got off relatively lightly despite the fact that I feel pretty crap a lot of the time.

38. When I hear some of the stories of the suffering experienced by others both infected and affected by this tragedy, and in particular from the Haemophilia community, I am extremely saddened.

39. I believe that the Inquiry should ensure that those infected and affected should receive immediate compensation and the best medical care available.

40. The Inquiry also needs to ensure that those persons responsible for this avoidable tragedy are held to account. I believe that there are still officials working for the UK Government who are aware of exactly what happened and why. I am also aware that other countries, such as France and Japan, have jailed officials for wrongdoing in connection with such matters which occurred in their respective countries.

41. It was both shocking and frightening on hearing confirmation that Scotland had sufficient blood reserves and had offered these to the UK, only to be turned down in favour of the UK purchasing the same from the US.

42. It is also frightening hearing the recent compensation figures being bandied about. The number of those infected (and affected) by this tragedy is

growing each day. The current figures only represent the "*tip of the iceberg*". What about those people who I may have inadvertently infected when I donated blood on two occasions in 1979? I was motivated to do so because I was so grateful to the donor who had "*saved my life*" when my daughter was born (and when I was unknowingly infected) in 1978. There needs to be a comprehensive look back programme.

43. My daughter and I attended the last two days of the Inquiry to hear those infected and affected giving their witness evidence in London. We were both in floods of tears such was the harrowing nature of the testimonies. I could not have coped with listening to such content on a third day. However, despite this, I am so glad we both attended and we found everyone to be very welcoming.

44. For me, the biggest problem to have occurred due to my Hepatitis C was the break up of my 30 year marriage. I couldn't sail, kayak or sunbather anymore due to lethargy and porphyria.

## **Anonymity**

45. I do not want to apply for anonymity and I am happy to give oral evidence to the Inquiry should this assist its aims and objectives

**Statement of Truth**

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

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

Dated.......20th February 2020.......