Witness Name: Mr Mark Harrison
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WITNESS STATEMENT OF MR MARK HARRISON
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is Mark Howard Harrison. My date of birth is GRO-C 1964. My address is known to the Inquiry.

2. I live at home with my wife; who I have been married to for 11 years now and our daughter, who is 9 years old. I work in the telecommunications industry.

Section 2: How Infected

3. In May 1983 at the age of 18 I was involved in a road traffic accident from which I broke my femur, tibia and fibia and I was admitted to Frimley Park Hospital in Surrey. I was an in-patient for over six months during which time I received a number of blood transfusions; I think I received two or three, as my parents told me this. I received the transfusions firstly as a result of blood loss from the road traffic accident and subsequently during my stay as an in-patient for anaemia. At the point at which I requested my medical records from Frimley Park in support of my Skipton application I was sent a blood transfusion record

and a letter from a consultant; only two documents out the entirety of my medical records, despite being under the care of Frimley Park for six months. I am assuming therefore that the blood record is the relevant record and that it is the record that contains the details of the contaminated blood I received. The blood record states that I received two units of blood on 27 August 1983 and that the Blood Pack Numbers were 29564 and 40476 of A Positive blood. This record can be provided to the Inquiry if it would be helpful.

4. I was not infected as a result of a relationship with another person.

5. When I was taken to hospital I was in and out of consciousness. My parents were at the hospital when I arrived, or shortly thereafter. I cannot remember signing any forms myself, but I do not think it would have been discussed at all. My parents have now passed away and they never told me so I think it is correct to say that no information or advice about the possibility of a transfusion or any risk of infection associated with it was discussed beforehand.

6. I was infected with hepatitis C as a result of being given a blood transfusion in 1983.

7. I found out I was infected during 2006.

8. GRO-C I was routinely tested for (amongst other things) hepatitis C. In December 2006 I received a letter from our Consultant Obstetrician & Gynaecologist, GRO-D who wrote to inform me that I was "*reactive to hepatitis C*" and he requested my authorisation to make a referral to a Hepatologist at Royal Surrey Hospital Guilford. This letter can be provided to the Inquiry if it is needed.

9. From receiving the letter in December 2006 to my first appointment with Dr Michelle Gallagher in March 2007 I was given no further information. The wording of the letter I received which said I was "*reactive to hepatitis C*" meant

absolutely nothing to me. I was unsure if I even had hepatitis C; I had never even heard of it before, so "*being reactive to*" meant nothing really. When I saw Dr Gallagher in March 2007 I asked her whether I had hepatitis C and she replied by saying "*yes of course you have*". I remember going numb. Up until that point I was not sure if I had contracted it and then cleared it as some people had. This was obviously what I hoped for. Her approach was very clinical. Once I was under the care of Dr Gallagher she provided me with the relevant information needed to start to process the diagnosis. She gave me some leaflets and explained about the Skipton Fund. There was not a lot of information. GRO-C GRO-C At no point was any emotional support offered at this very stressful time. Dr Gallaher did provide advice on the available treatment and the best time to have the treatment GRO-C

10. I received the infected blood in 1983 and only found out that I was infected with the virus in 2007 and purely by chance. This is 24 years later. So, I do think that I should have been provided with information earlier. I think that there should have been a campaign to inform people who had received transfusions during the relevant period that they may be carrying a virus and to get tested. When I was told I was reactive to hepatitis C, I was in limbo for a number of weeks, unsure if I was gravely ill or if I even had hepatitis C, and unknowing as to how it would affect the quality of my life.

11. The quality of the information in the letter, the fact that a letter was chosen to communicate this serious information to me and the timing of the letter (in between Christmas and New Year) followed by the eight week wait between the letter and an appointment to let me know what was going on was not ideal to say the least. This was unnecessarily stressful. I was left high and dry. This type of information should never be communicated to someone by letter.

12. I was told that cross infection between a heterosexual couple was fairly unlikely

and primary concern at this point was I could pass this on to my wife as we were trying for a family. Some of the information I was given was contradictory as I was asked to contact my ex-wife to advise her of the situation and for her to get tested for hepatitis C. I was told about the risk of infection to others and how I could manage that.

Section 3: Other infections

13. I believe I have been infected with hepatitis C only.

Section 4: Consent

14. I was unconscious at the time that I arrived at Frimley Park, needing the operation and the blood transfusion and so I did not specifically consent to the transfusion or the risk associated with receiving it. I do not know if my parents consented to this treatment either and it was never mentioned. I do not believe that I was tested or treated for the purposes of research.

Section 5: Impact

15. The relentless nature of hepatitis C is challenging and has been both physically and mentally exhausting. I have an awareness of my physical and mental symptoms beginning before my diagnosis, probably from around 1993. My medical records when they arrive should support this and I would like the opportunity to submit a supplementary statement should it be necessary following receipt of those records. I have found that my physical and mental conditions have progressively worsened over the years.

16. Mental effects: The long term increased stress of having hepatitis C can often be overwhelming and depressing. The loss of control and uncertainty of my future has often led to a deep anxiety.

17. Physical effects: I suffer from **chronic fatigue**. The severity of this fatigue does vary. Unfortunately sleep and rest do not always lessen the fatigue and so it is difficult to manage the limited amount of energy I do have. I suffer from **acute**

sharp severe pains in the upper part of my abdomen (left and right upper quadrant), I also suffer from aches and pains in my joints. The worst are my hands and wrists. I also suffer from **Irritable Bowel Syndrome,** this leads to up to 7 bowel movements in a day. My **cognitive thinking** has also been affected; I am aware that my short term memory is not as good as it was and I find it difficult to concentrate for long periods of time, anything over one hour. I would describe myself as having brain fog. Despite having cleared the virus I am still feeling unwell and continue to have all of the symptoms that I have indicated above.

18. I have been diagnosed with Hidradenitis Suppurativa a painful skin complaint which results in large abscesses which reach two or three inches into the body, which have required five operations to resolve over a period of 30 months and have left scars. I believe that the weakening of my immune system due to hepatitis C has caused this condition.

19. First treatment in April 2009. I commenced 48 weeks of Interferon and Ribavirin (tablets & stomach injections). This treatment was unsuccessful. Second treatment in February 2017 I commenced 16 weeks of Zepatier and Ribavirin (both tablets). This treatment was successful.

20. I waited a period of seven years before being offered the second treatment in 2017. This wait was extremely difficult for me to bear. I understand that there were a lot of people waiting for the first treatment and the approach was such that if you were unsuccessful with the first treatment then you have to wait your turn until there are funds available for further treatment. I was told that the hospital trust had to wait some time before being able to prescribe new anti-viral drugs available on the market because of the high cost of them. I understand this is all governed by NICE.

21. I did mention Harvoni to Dr Gallagher at one point because I was aware that the success rate of Interferon and Ribavirin was much less than that of Harvoni

which was 75 – 80 percent. I cannot remember Dr Gallagher's response but ultimately it was not made available to me. In the end I was just grateful for having received some treatment because I had waited so long.

22. The physical effects of the first treatment were extensive; I suffered from extreme exhaustion and fatigue. I had muscle pains, nausea and vomiting, loss of appetite and weight loss; during the treatment I lost two stone. The site of the injection was often swollen, sore and bruised. During the whole of the treatment I had a constant cough (a common side effect of Ribavirin) and this was very debilitating. I was weak and shaky for the first two to three days after each weekly injection. The mental effects of the first treatment were also extensive, I often felt irritable, anxious and aggressive. I was subject to mood changes and feelings of depression. The physical effects of the second treatment; while not as bad as the first treatment, still included, extreme exhaustion and fatigue. I had regular liver pain and the cough from the Ribavirin returned for the entire time of the treatment. The mental effects of the second treatment were just as bad as the first and included irritability, anxiousness, aggressiveness and feelings of depression, however due to the fact this was the second time going through this gruelling treatment there was a high level of stress worrying it would not work again.

23. **GRO-C**

GRO-C

GRO-C I felt like we were discriminated against and labelled throughout this challenging time.

24. I am a strong person and have worked hard to try and counteract any negative impact on my family and private life from my infection with hepatitis C. That said it has undoubtedly affected my family life, especially during the 64 weeks of anti-viral treatment. My wife is a fantastic support to me but I would never have chosen to put her through this. We have worked hard on our relationship to ensure hepatitis C does not come between us. I chose to have the first treatment while my wife was pregnant with our child as we hoped I would be hepatitis C clear so I could be there for my child without the dark shadow of hepatitis C over me. However this did mean that I was very ill with the side effects of the treatment for the second half of her pregnancy and for the first six months of my child's life. I will never get this time back and this has caused me a deep sadness.

25. Personally I found it therapeutic to share my diagnoses with others, and I have encountered only a small element of stigma over the years, but luckily not too much.

26. There have been work and financial related effects of the infection and treatments to me. Since contracting hepatitis C at the age of 18 I honestly believe that my job performance over the years as well as my long term career prospects, have been weakened. I come from a family of high achievers and feel that I have never reached my full potential in my working life. Over the years I have needed time off work for both hospital appointments and due to the side effects of the treatments and while my work has supported me I feel that this has probably affected my career progression.

27. I believe I have answered this question above.

Section 6: Treatment/Care/Support

28. I believe I have received inadequate treatment because of the delay of the seven years before receiving the second treatment and the reluctance to provide me with the treatment I felt I deserved which had better chances of success and fewer side effects than what I received. During the times of the treatment I did have regular appointments with the medical team overseeing my case. For the second treatment I was told at the time that I would have a Multidisciplinary Team (MDT) coordinator who would help me through the process; tell me when blood tests would be, remind me when my appointments would be, check in with me to see how I was getting along. This person was intended to be the go-between, between the consultant and the hepatitis nurse, but I found this support to be wholly lacking. The person only contacted me once and at that point told me I should contact the consultant directly. I have also had many years of being "*monitored annually*" with blood tests and a number of scans but I am no longer being followed up because I am deemed to be clear of the virus. This worries me. I feel I should still be under the care of the gastroenterologist because there is no guarantee that my viral load will not increase, I have been told it can come back and that I can still contract Creutzfeldt-Jakob disease (CJD).

29. Absolutely no psychological support has ever been mentioned or offered and I feel this is an area which has been very lacking. I contacted The Hepatitis C Trust in London and found some element of support from them, but this was not suggested by the medical team it was something I found myself. I felt that I could have done with this support at key stages through this journey, at least. First when I received the letter from the gynaecologist and then when I went through the first and second treatments, but really it should be there on a regular basis because this does not go away it is always there on your mind.

Section 7: Financial Assistance

30. Dr Gallagher (my Hepatologist at the Royal Surrey Hospital in Guilford) gave me details of The Skipton Fund during my first appointment with her in March 2007. As I met the criteria, I applied for the Stage One payment.

31. I received a £20,000 ex-gratia payment from The Skipton Fund in September 2007. From 2012 (unsure of this date) I have received a free annual pre-payment card for my medical prescriptions from The Skipton Fund. From 2016 I have received regular payments (originally £750 per quarter which increased to £1000 per quarter from 2018) from The Skipton Fund (now the EIBBS). I have also received the winter fuel payment since 2016 of about £500 per year.

32. The application process was fairly straightforward and I applied for The Stage One payment in July 2007 and from memory Dr Gallagher was helpful in filling in the forms. The rest of the payments I have received have been sent without me actively applying for them. I believe I received these as I had applied for the Stage One payment in 2007.

33. None, but have I have never actually applied for financial assistance and I am not wholly sure what other options are available to me. I want to avoid the pain associated with applying, the potential rejection and judgement associated with it.

34. No preconditions were imposed.

35. I would give up work tomorrow if I could as I find life very difficult. If I could be ok financially I would do so as I find keeping going and working very challenging. It is all down to my sickness and the hepatitis C.

Section 8: Other Issues

36. I would like accountability for this. I believe that this should never have happened and I want to play a part in helping to stop this happening again. I want people to learn lessons from the past. Hepatitis C is always at the back of my mind and features in every decision I make.

Statement of Truth

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

Signed GRO-C

Date 24th February 2019.