Witness Name: Mr. P M R SANTOS
Statement No: WITN 1505001
Exhibits: WITN1501002/3
Dated: 13 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PEDRO MIGUEL RODRIGUES SANTOS

I, Pedro Miguel Rodrigues Santos will say as follows:-

Section 1. Introduction

1. My name is Pedro Miguel Rodrigues Santos of GRO-C GRO-C, France. I was born on the GRO-C 1975 and live with my wife, our two children and my in laws. I am self employed and run my own swimming pool and property maintenance business.

2. I was infected with Hepatitis A, B and C as a result of being given infected blood products.

3. **This witness statement has been prepared without the benefit of access to my full medical records the majority of which I have been informed by University College London Hospital (UCLH) were lost during an archive move.**

Section 2. How infected

4. I was diagnosed with Haemophilia A classed as severe, with a less than 1% clotting factor when I was about four years old. As a child, I would bruise a lot, particularly on my legs. My parents were concerned and took me to UCLH and it was there I was diagnosed and received Factor VIII treatment initially under the care of Professor Machin, then Dr Ri Liesner from 1979 until 2004 when I moved to France. Since then, I have been receiving treatment at the Centre for Excellence in Toulouse.

5. In or about January 1999 I attended the clinic at UCLH for some "routine blood tests" which had been requested by UCLH to enable them to get their records up to date as the records were in a mess as the original Haematology nurse had had cancer and passed away.

6. I returned on the 2nd February 1999 to UCLH for the results and was told by Dr Ri Liesner that I was HIV negative which was good news but I had been infected with Hepatitis A and B in the past and at some point later on, I had cleared these infections myself. I was also informed that the Hepatitis C tests showed I had also been exposed to HCV in the past and they would need to refer me to a liver specialist for more tests. This meeting was followed by a letter dated the 26 February 1999. I refer to exhibit WITN1505002.

7. I am not sure when I first tested positive for Hepatitis A B and C but Dr Ri Liesner told me at the meeting on the 2 February 1999 that there was a HCV positive test in my medical records dating back to the mid 1980s The meeting was the first time I was informed that I had been infected with Hepatitis A, B, and C.

8. Unfortunately, I wasn't the first of my family to find out about my infections. Both my parents worked at UCLH, and before I found out at the meeting with Dr Liesner, my mother had gone to the haematology department to pick up my Factor VIII treatment and, a member of staff in that department said to her that it must be

disappointing to learn that your son has Hepatitis C. I was an adult at this time and so they owed me a duty of confidentiality. I don't mind that my mother was told, because I would have told her myself, but obviously, this breached ULCHs duty of confidentially to me.

9. As far as I am aware neither my parents nor I were ever advised about any risk of infection from being given Factor VIII products save as mentioned in the next paragraph. As far as I was aware, it was just something I needed.

10. During the 1980s, there was a lot of media attention being given to HIV and it became known that those who received contaminated blood products were at risk. I was approximately 10 years old when Professor Machin told my parents that there was a possibility that I was at risk of HIV so I was tested. Thankfully, I was clear.

11. The only advice or information I received about Hepatitis C from the haematology department was that I had it, and that there was no chronic liver problem.

12. The haematology department was not helpful in giving advice to manage or understand the infection, but when I was referred to Dr Naoumov of the Hepatology department, I received a lot of information. Dr Naoumov was very good to me as were the rest of the staff in that area.

13. I strongly believe that the information about my Hepatitis infections should have been given to me when I first tested positive. I don't understand why I was not told sooner. This caused a great risk to me and others as for at least ten years, I did not know about it.

14. I was angry that I found out in 1999 as opposed to the mid 1980s that there was a positive test. I could have been monitored beforehand. I had been going for blood tests regularly, and had even gone through

major operations before 1999. By way of example, I had a knee operation in the early 1990s and was in hospital for a month constantly receiving Factor VIII treatment. Why was I never told me that I had Hepatitis C?

15. Dr Naoumov gave me advice on the risk of transmitting the infection onto others. I cannot fault her. I was married at the time and so it was necessary for us to know of the possibility of me passing it on to my wife. There was also a risk that it had already been passed on to her, although the doctor had said that the risk of sexually transmitting was very low. Still, to be on the safe side, we decided it was best for my wife tested. Our GP refused to allow the test on the NHS as he didn't want to" waste NHS funds". Since the risk was low, he felt it was unnecessary. As a result of his refusal we had the test done privately.

Section 3. Other Infections

16. To the best of my knowledge, I have no other infections aside from those I have already mentioned in Section 2.

Section 4. Consent

17. I believe I have been treated and tested without my knowledge or consent and or without having been given prior adequate information. As I have clearly been tested for Hepatitis A, B, and C in the mid 1980s and was unware.

18. Before I was put on the clinical trials, mentioned in paragraph 25 I was tested to see if I was infected, but I signed a consent form to do so.

Section 5. Impact of the Infection

19. I consider that I suffered very little side effects from the Hepatitis C. It probably impacted more on my family and friends. Physically, and mentally I experienced very few symptoms. However after, I started the Open label, Expanded Access Program of Peginterferon alfa-2a treatment (The Programme) in 2002 I experienced negative effects, the injection would be administered every Friday evening. The next day I suffered a huge change in my character. I became very impatient, irritable and angry, which was very unlike me. I was usually always calm and composed. My wife called it the 'Saturday Rage' and she would try to stay away from me on that day. At that time my wife was pregnant with our first child. Even today, I am not as patient as I used to be and lose my temper more quickly.

20. Treatment was always available to me when I needed it and the only exception was when I wanted to go on to a clinical trial. I was informed that they had already filled the number of people required for the trial. In the end, they allowed me on the trial because I had an unusual genotype that was only found in those of Mediterranean decent. For this reason, the pharmaceutical companies were keen to have me on the trial as I was the only person with that genotype.

21. Since my condition was not disclosed to me, it didn't impede my ability to obtain dental care. After I found out, I never needed any major treatment so accessing dental care or the GP was never an issue.

22. When we found out about the Hepatitis C I had only been married a year and my wife was completely devastated, mainly due to media coverage, she'd seen about people dying young and getting liver Cancer and there being no cure. Another serious concern was that we may not be able to start a family and have children worried her. She spent time on the phone to the Haemophilia society who gave her a lot of information and helped calm her down. With the

information we had from them and from the Liver specialists at UCLH, we were able to cope.

23. My parents were understandably very upset to find out that I had Haemophilia, particularly my mother. To find out that I had Hepatitis C was an even bigger blow to them. My father felt very responsible for it. For a period of time, I was treated with Factor VIII at home which he would administer. He was traumatised that unknowingly, he may have administered the contaminated blood himself. GRO-C GRO-C

24. The stigma of having a blood borne disease never impacted on me as I didn't allow it to become common knowledge. I only ever told my family and close friends. Nobody ever knew at my workplace about the Hepatitis C nor about the trials I'd entered. As the treatment required me to take days off, I used my annual leave, rather than sick days. I experienced the flu like symptoms, but I never explained to my work colleagues that there was an underlying reason why I was unwell. In that sense I was lucky as out of the 100 people on the trial, about 85 people had to give up work due to serious side effects. I only experienced the mental effects on Saturday.

25. At the end of the Programme it was found that the treatment had been a success and the infection had cleared. I believe that my last Hepatitis C test was conducted approximately 3 to 4 years ago at which point my haematologist in France told me that if the infection has not already returned then I was no longer at risk of it relapsing.

26. Our biggest cost was travelling into London for hospital, appointments and losing out on taking paid sick leave at work and having to pay GRO-C

Section 6. Treatment/care/support

27. No counselling or psychological support was ever made available to me until the inquiry began. I never went for private counselling.

28. After I had cleared my Hepatitis C, hospitals in the UK started using Recombinant Factor VIII blood products. Given what I had been through already, I was very interested in this new product and requested it, instead of old Factor VIII. I was advised that due to my age and the fact that I had been at risk of blood borne viruses, I was not a priority for the recombinant blood and therefore couldn't be put on it. They mentioned it was far too expensive and that many other young people were being taken off the product too. I refer to exhibit WITN1505003 in which this is confirmed. On the other hand, in France, when the contaminated blood scandal broke out, they switched to recombinant for all patients immediately regardless of cost age and previous exposure to risk.

Section 7. Financial Assistance

29. I was a member of the Haemophilia Society and through them I found out about the Skipton Fund. I received an ex gracia payment of £20,000 in 2004. Thereafter I received nothing. In 2017 Teresa May announced she would allow the Inquiry and there was a lot of media attention being given to this case. I scanned through the Skipton Fund website and noticed they had been offering regular payments. I contacted them and they informed me that they had been trying to contact me for a while but couldn't reach me, perhaps because I had relocated. Luckily, they backdated some payments for me. I now receive £333 a month in addition to a winter fuel allowance of £507 which is paid every December.

30. The application process was straightforward but I found the means testing unfair. I am working and run my own business, my wife works and even with that income, because we had children, we were entitled to an increase. Unfortunately, the Skipton Fund refused that

application for payment. I consequently phoned the NHS business Team to discuss their reasoning. Apparently, because my in laws were retired and living with us, their pension was taken into account when calculating our household income. I spoke to the Skipton Fund and they said I could appeal but "that is how it is". I felt there was no point in appealing so I left it but, as far as I am concerned, my in laws pension is their money, not mine therefore it should not be taken into account .

Section 8. Other Issues

31. I would often incur unreasonably high premiums on travel insurance. It was precondition that I would need to disclose my existing medical conditions and so I would tell them I had Haemophilia. This would then lead to a series of further questions and to me having to state that I once had Hepatitis C. Consequently, the premium would become too high. I would opt for the massive premium anyways as I would rather stay on the safe side.

32. I am most upset and disappointed in the fact that the NHS may have known of the potential risks to the Haemophilia community and continued to use infected products.

Anonymity

33. I do not want to be anonymous and want 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 13/3/19.