

Witness Name: Richard Desmond Oates

Statement No: WITN3246001

Exhibits: WITN3246002

Dated: July 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF RICHARD DESMOND OATES

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I, Richard Desmond Oates will say as follows:-

#### Section 1. Introduction

1. My name is Richard Desmond Oates. I was born on the GRO-C 1972 and I live at GRO-C
2. I am married to my wife, Carolyne. We have 2 children together and GRO-C GRO-C a third child GRO-C. We live in a 3-bedroom house in GRO-C GRO-C
3. I run my own IT consulting business and my wife runs an occupational therapy practice.
4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited treatment records, the relevant entries are set out in the medical chronology at the end of this statement.

#### Section 2. How Infected

5. I was diagnosed with severe Haemophilia A at birth. In my early life, I was treated with Cryoprecipitate (copies of the batch numbers are exhibited at

**'WITN3246002'** and then in or about the early 1980s, I was treated with FVIII Plasma Concentrate (FVIII). For the last few years, I have had recombinant FVIII.

6. I was born in South Africa and in 1975, when I was 3 years old, we moved as a family to the United Kingdom (UK) and lived in Birmingham for a year. In that year, I was treated with Cryoprecipitate at the Birmingham Children's Hospital (BCH). We later went back to South Africa and lived there until 2001 when I moved back to the UK. I have lived here ever since.
7. As a result of receiving FVIII blood products in the UK, I was infected with Hepatitis C (Hep C).
8. After I returned to South Africa in 1976, I was treated at the Red Cross Children's Hospital in Cape Town (RCCH) by Dr Cyril Karabus who I believe is now a professor. He was a lovely, caring man and was treating me with FVIII concentrate from the Western Province Blood Transfusion Service (WPBTS).
9. At a routine appointment, my mother was told by Dr Karabus that there was a blood product shortage in South Africa and the Government was importing blood products from America. She was also told that we had to cut down on the FVIII treatment I was receiving. My mother asked why they couldn't use the blood imported from America, and he responded by saying he would prefer I didn't use those products as they had been obtained from prisoners in jails across America and as such, were from high-risk donors (e.g. intravenous drug users etc) and could be contaminated with all sorts of infections. She was told that as the FVIII blood product was made from about 10,000 people's blood, there was thus a good chance that the FVIII could be infected. He therefore told my mother that he was not going to treat me with the FVIII products from America. My mother was worried and asked what would happen if I was to bleed and Dr Karabus told her that they would use ice, wet towels and bed rest and that I would only be treated with local FVIII from South Africa if I had a severe bleed.

10. In 1987 when I was 15 and living in South Africa, I was told that I had Non A Non B Hepatitis, now known as Hep C. I was told that the Hep C would not really affect me at the time but may do later in life. It was only later that I realised that Hep C was malignant and life threatening and not something that you just live with. The gravity of the infection became clearer to me as I got older.
11. I am glad that Dr Karabus refused to treat me with the FVIII imported from America as many haemophiliacs who used those products ended up being infected with HIV and have since died.
12. In the early days, my mother was self administering FVIII to me and during the blood shortages mentioned previously, Dr Karabus refused to give her any FVIII products from America. She took his advice at the time but was surprised at what he said. She did push really hard for me to be treated as she was secretary of the Haemophilia Society back then and she knew other Haemophiliacs received the product, but Dr Karabus refused to treat me with the FVIII from America.
13. Doing your own research was difficult back then as there was no internet and information was not readily available. Dr Karabus had some knowledge that the products were unsafe and relayed that information to us. I believe he had connections with other international doctors and so he knew what he was talking about.
14. I think Dr Karabus probably knew I had been treated in the UK for a year as he would have had my medical history. He had a good relationship with my mother and so my mother would probably have received more information than other patients carers did. I believe I was treated as his special patient as we had a close bond and I held a special status in his mind as a "model patient". I believe he would have found it hard to reconcile his conscience if he gave me blood products that he knew were unsafe. He's an incredibly principled man and would refuse to do such a thing. I think it is highly unlikely that he would have authorised these products to any of his other patients. I

believe he would have denied other haemophiliacs the American blood products as well.

15. The RCCH only treated people until the age of 13, and then they would be transferred to Groote Schuur Hospital (GSH) which is the state hospital in Cape Town. I know that other Haemophiliacs that were older than me did get the American blood products there. Once we were transferred to GSH Dr Karabus no longer had jurisdiction over these patients.

16. Dr Karabus is a well-known South African haematologist with a worldwide profile. He was certainly well-respected internationally and he is well documented on the internet. He's a very straight-talking doctor and could be approached to talk about what he knew at the time if it is deemed relevant to the Inquiry.

17. I do not know what information or advice was provided to my mother in the UK (if any) about the risk of being exposed to infections from contaminated FVIII. As stated above, my mother was given a lot of information in South Africa.

18. I believe I was given enough information at the time of my diagnosis so that I would not worry. It was not until I got back to the UK in 2001 and treated at the Oxford Haemophilia Centre (OHC) for a year or two after, that I was told that Hep C was actually a really bad infection and could destroy my liver. At that time I was told that there was treatment for it and that I should consider it. It was at that point that I believe I received appropriate information about the infection.

19. It would have been nice to have received adequate information earlier although it would not have changed much as there was nothing they could do at the time and the treatment options were limited, had bad side-effects and were not particularly effective. However, I believe that it could have changed some life decisions I made.

### **Section 3. Other Infections**

20. I do not believe that I contracted any other infections. However, I received a letter from the NHS stating that there was a possible risk that I had come in contact with vCJD. I was told that I had to declare it on all my insurance applications and inform doctors at every appointment. I received this letter when I returned to the UK probably about 10 years ago. It was totally out of the blue.

21. I certainly don't think my Hematologist even knew I got the letter. I seem to get the impression that it came from the NHS authorities, sending out a letter for blanket immunity in case they received claims from patients. What they pretty much told me was that I had to declare that I was vCJD at risk even though I may not actually have it and no testing for it was offered.

### **Section 4. Consent**

22. I do not believe that I was treated or tested without my knowledge or consent or without being given adequate or full information.

23. I believe however, that blood was taken from me for the purposes of research in the UK. I believe that the doctors were doing DNA/genetic testing on Haemophiliacs to see where the Haemophilia came from. I do not believe that the blood products were given to me for the purposes of research, however but in response to bleeding episodes.

### **Section 5. Impact of the Infection**

24. The Hep C did not have any physical effect on me but it did cause mental effects. Hep C is a silent killer so I did not generally feel unwell. The only indication was that the liver functions aren't as great as they should be when it was tested. I was concerned when I was told I had Hep C. I knew at some point there was a possibility that I would get cirrhosis and that I would then need a liver transplant. I knew that there was a possibility that my body might even reject the liver transplant and that I will be on anti-resistant drugs for the rest of my life. I was not happy with that at all and I was concerned about it. I

had married by that point and had children and I was worried that it may impact on my family and that my children may grow up without a father. It therefore played on my mind a lot.

25. I do not think I suffered further medical complications as a result of the Hep C. However, there might be some scarring of my liver as a result.

26. I was offered 3 lots of treatment for the Hep C. The first treatment was Interferon and it was offered to me when I first came back to the UK. I didn't take this course of treatment because I was told by the doctors that the success rate was really low and the side-effects were horrible. I was told that only 30% of the people who received this treatment cleared the Hep C. A couple of years later, I was offered Interferon again along with another drug at Basingstoke Hospital which was close to where I lived at the time. I cannot remember the name of the second treatment. My liver function was tested and I was fine at the time and therefore refused the treatment again because of the low success rate and the associated side-effects.

27. I was offered a third course of treatment a year later in 2012 which consisted of Peg-Interferon, Ribavirin and Telaprevir. I did not accept this course of treatment straight away as I knew the treatment would have an impact on my life. At that time we had just had a baby and I was contracting for work. If I was contracting in an unstable environment, I would get no income if I got ill. I later re-considered the treatment and accepted it in 2012. The course was for 24 weeks.

28. I do not believe I faced any difficulties or obstacles in accessing the treatment. The doctors were upfront with the treatments that were available.

29. I don't know whether there were treatments which ought to have been made available to me at the time. I took the doctors advice in relation to the treatments that were offered to me.

30. I suffered mental and physical effects from the treatment. I was quite depressed as a result. I felt so low that I was given anti-depressants to lift my mood. I got a rash in a number of different places on my body which was

constantly itching. I had to use a cream given to me by the doctors daily to ease the itching. It felt like Eczema. The treatment also affected my diet considerably - I had to have a special diet rich in fat which I found odd at the time. I had to keep the amount of fat that I was consuming high so that the treatment would have the best effect. My hair also went grey prematurely. It became snow white with a much softer consistency like cotton wool. It is only in the last year or two that my hair has returned to a brownish-grey colour and become more wiry. I felt very uncomfortable on the treatment. I felt very fluey, a bit nauseous and tired a lot of the time as well.

31. Hep C impacted on my private, family and social life. I became depressed and as a result I wasn't nice to live with. I wasn't a very happy person and I really didn't feel like doing a lot on the weekend. I didn't have much resources for anything else other than getting through the treatment and working. I believe my children missed out on me being available for them and being able to communicate freely with me as I was not always in a good mood.

32. I did not suffer much of a stigma. I did receive a lot of sympathy from people. I made it very clear to my employers that I was on a treatment regime and what that would mean in relation to my work. They were very helpful and supportive. Most of my colleagues were very nice and worked around me and accommodated all the appointments, blood tests etc.

33. I believe the treatment that I had made me a very grumpy person which was difficult for my wife. I wasn't the friendliest person although she was very caring and supportive towards me. I am so happy that she was never infected as result of me.

#### **Section 6. Treatment/care/support**

34. I wasn't offered counselling and psychological support but the sister at the hospital who looked after me during my treatment did provide me with the support that I needed. She told me concluding the treatment was really important and they would do everything they could to help me manage the side-effects e.g. she told me that if I felt depressed, they would give me anti-

depressants, if I was ill, she would give other medication and so on to assist me through the treatment.

35. I am still on anti-depressants because of the infection. The dose has been reduced since the treatment. I feel that I am dependent on them because if I come off them, I feel grumpy and my mood changes. Coming from South Africa, I do feel down during the winter period when the mornings and evenings are dark and the anti-depressants help me with this.

## **Section 7. Financial Assistance**

36. I received a payment of £20,000 from the Skipton Fund in or about 2010. I have only received a Stage 1 payment as there was no evidence of liver damage.

37. I received a monthly payment from the Skipton Fund as well. I don't remember when it started. I continued to receive payments after the Skipton Fund was formed into the EIBSS. I believe I receive £300 a month although this has recently increased to about £1,500 for which I am very grateful. The only requirement was that I had to prove that I had received blood products in the UK which I was able to do through the treatment records attached.

38. I do not feel like patients who were infected with Hep C are treated the same as those infected with HIV. People who had HIV were granted more financial assistance than those who had Hep C but the fact that Hep C is just as life-threatening as HIV was underplayed. I think all those who were infected by any infection should have been given the same level of support and financial assistance. I feel the financial assistance regime is unequal.

## **Section 8. Other Issues**

39. When I had the Hep C, I could not get chronic illness cover on my life insurance policy. I gave up applying for it and never applied after being cleared due to the long-winded application process.



40. I also find it very hard to get insurance cover. Haemophilia is one thing but when you add Hep C to it, it makes it a lot more difficult to get insurance cover.

41. An apology in Parliament is fine, but that does not get to the root of the problem. Some people are no longer with us due to a mistake or course of action that someone took. That is sad and needs to be dealt with. If it was knowingly done, there should be accountability for that.

42. I'm quite amazed that my treatment records were still available at QEH from 1975. I believe that if I hadn't asked for them back then, they would soon have been destroyed. I think others should ask for their treatment records before they are destroyed too.

**Anonymity, disclosure and redaction**

43. I do not wish to remain anonymous.

44. I do not mind giving oral evidence at the Inquiry.

**Statement of Truth**

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

Signed. GRO-C .....

Dated 25 July 2019

## MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

### Virology Results

02.02.2007      HCV RNA = 1,486,720 IU/ML