

Witness Name: David Russell Chandler

Statement No.: WITN0824001

Exhibits: Nil

Dated: 22 July 2019

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF DAVID RUSSELL CHANDLER**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 February 2019.

I, David Russell Chandler, will say as follows: -

#### **Section 1. Introduction**

1. My name is David Russell Chandler. My date of birth is GRO-C 1941 and my address is known to the Inquiry. I intend to speak about how my son, Simon Chandler, was infected with HIV, Hepatitis B and Hepatitis C through contaminated blood products he received to manage his haemophilia.
2. I live in GRO-C with my wife, Joy Chandler. We have been married for fifty-four years and have three adult sons, including Simon. I retired in 2000 after having worked in the electricity industry for 43 years. Both Simon (WITN0816) and Joy (WITN0825) are also providing statements to the Inquiry.
3. Simon's HIV has had a devastating impact on our family. Not only has it impacted Simon's health, but it has also had an impact on his career,

social life and family life. Joy and I have tried to support Simon as much as we can but it has been extremely difficult for us all, particularly given the stigma surrounding HIV and the poor standard of care Simon has received from many of his doctors.

## **Section 2. How Affected**

4. Simon has moderate to severe Haemophilia A, with a Factor VIII level of 2.4%. He was diagnosed at thirteen months old. There is a history of haemophilia in Joy's family and she is a carrier. GRO-C

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5. Until the last six years of my career, I was working long and unsociable hours. Consequently, I was often tied up with work when Simon went for appointments regarding his haemophilia and for Factor VIII injections. Generally, it was Joy who attended these appointments with Simon.
6. When Simon was a child, he was initially treated with cryoprecipitate at Ladywood Hospital. He then started receiving Factor VIII in the 1970s at Coventry and Warwickshire Hospital and Walsgrave Hospital, now known as University Hospital Coventry and Warwickshire. Simon was under the care of two haematologists: Professor Neville Shinton, who was the senior haematologist, and Dr Morris Strevens, a junior haematologist.
7. Although Simon had Factor VIII regularly when he was growing up, the doctors never informed us about the risk that it could be contaminated. We had heard about hepatitis and so we had concerns about the safety of Factor VIII, particularly in relation to the American product as we had heard on the news that people were paid to give blood there. Joy therefore did her best to try to ensure Simon only had British product, but this was not always possible. The doctors tended to prefer the American Factor VIII because it mixed better.

8. In 1985, Simon went to Kingston Polytechnic, now Kingston University, to study a Higher National Diploma in Chemistry. While he was there, he had a spontaneous bleed and had to go to Kingston Hospital. Joy had given Simon vials of British Factor VIII and he had one vial left; however, the doctors told him that this wouldn't be enough and that they would need to give him American Factor VIII. The doctors told Simon that it was heat treated and perfectly safe, even though this hadn't been proven at the time. This was the last time Simon had Factor VIII before his HIV diagnosis.
9. In Christmas 1986, Simon was called into hospital by Professor Shinton and was told he had tested positive for HIV. Professor Shinton told Simon that they had been testing him for some time and that all his previous tests had returned a negative result. Simon was unaware that this testing had been taking place.
10. Simon was retested in January 1987 and it was confirmed that he had HIV. He was away studying at the time and he did not tell Joy and I about his diagnosis until he came home around Easter 1987.
11. We all feel that Simon and our family were not given adequate information to understand and manage Simon's HIV infection. We did not receive any helpful information from the doctors at Walsgrave.
12. Simon continued to receive Factor VIII after his HIV diagnosis and he was later diagnosed with both Hepatitis B and C. He suffered from jaundice as a result of the Hepatitis B. However, he was able to clear both of these infections without treatment.

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

13. As far as we are aware, Simon has not contracted any infections other than HIV, Hepatitis B and Hepatitis C. However, in July 2009, Simon

received a letter from University Hospitals Coventry and Warwickshire NHS Trust which said that there was a risk he may have also contracted variant Creutzfeldt-Jakob disease ("vCJD").

#### **Section 4. Consent**

14. Given Simon had haemophilia, Factor VIII was a fairly routine part of his life. However, Joy and Simon were explicit with the doctors about Simon's preference for British Factor VIII. The doctor at GRO-D Hospital insisted that the heat-treated American Factor VIII was perfectly safe, which was then administered. When Simon questioned this decision, indicating that his Mother wished that only British sourced products be used, the doctor asked whether Simon's Mother was a qualified doctor.

15. We also feel that we were not given enough information about the tests they were doing on Simon. He was tested on a regular basis due to his haemophilia but none of us were ever told that he was being tested for HIV or hepatitis. We only found this out when he was diagnosed.

#### **Section 5. Impact**

16. In the early stages of the infection, Simon physically did not look or act any differently. However, this gradually began to change as his CD4 count decreased. By 1993, he had started losing weight and was suffering from flaky skin and terrible fevers.

17. Simon started taking antivirals in 1992. However, his health continued to deteriorate. In 1995, we had to rush Simon to Walsgrave Hospital as he had a particularly bad fever. The doctors didn't seem to know what to do. They informed us that the virus seemed to be making its way through Simon's body and that he was probably dying.

18. Dr Strevens seemed to have washed his hands of Simon. He said that Simon wouldn't benefit from the antivirals because he was "too ill". This is when I realised how difficult it was going to be to get proper care for Simon. I understand that it was the early stages of HIV and that the doctors were still learning about the virus themselves. However, Simon should have been immediately referred on to someone who was an expert in this area and could have helped him.
19. It wasn't until around Christmas 1996 that Simon was finally referred to an HIV specialist, Dr David White, who worked in the Tropical Diseases department at Heartlands Hospital. Simon was very unwell at this stage. He was in a wheelchair and his weight had dropped to 45kg. When we wheeled Simon in, Dr White told us that Simon should have been referred twelve months ago. It was distressing and frustrating to hear this given we had been trying to get Simon referred to a specialist for so long.
20. After Simon was referred, things initially continued to go downhill. Given Simon's immune system was so weak, he suffered from a number of infections, including blood poisoning at one point. He was put on antibiotics but these had side effects, including terrible vertigo.
21. By 1997, Simon was taken off AZT and was put on a mix of different antiviral drugs. However, none of the treatments seemed to be working. They also had various side effects on Simon, including loose bowels. One of the antivirals also made him lose a lot of the fat deposits on his face.
22. Dr White was very good with Simon. He was determined to find the problem and fix it. Simon was eventually put on a high dose steroid for about a month in August 1997. Fortunately, his health improved; however, he soon developed osteoporosis, which we believe was partly due to the steroids. Around 1998, because of Simon's

osteoporosis, he crushed two of his vertebrae. He still has ongoing issues in relation to this now.

23. Simon's CD4 count started to rise for several years after taking the steroids; however, by 2004 it had started to fall again. It took the doctors a while to discover the cause of this. It was only last year that they concluded that Simon has a rare condition called Protein Losing Enteropathy ("PLE"). The result of this condition is a lowered CD4 count, lymphocytes and low albumin levels.

24. As previously stated, I was working long hours for most of my career. The main difficulty while I was working was trying to fit everything in. I would often have to take time off at lunch to take Simon to hospital. This could take around three hours and I would then have to drive back to work afterwards. Fortunately, my employer was understanding and sympathetic about me needing to take time off. However, I didn't share the details of Simon's HIV and only told them that Simon was seriously ill.

25. Joy and I were initially able to look after Simon while we were both working, as we would take turns coming home to check on him. However, when Simon became really ill, it was impossible to manage. In 1995, Joy had to tell her employer that she would not be coming back for the foreseeable future. She initially took six months paid leave but when Simon was still very ill after this, Joy decided to take early retirement.

26. I appreciate that I did less than Joy in regards to caring for Simon; however, I did as much as I could. Someone had to work and be the breadwinner, particularly after Joy had retired.

27. Since my retirement in 2000, I have had more time to support Simon. The last six years of my career involved more of an office job so I could

bring work home or slip out of the office to see how Simon was doing and give Joy a break.

28. Life was very stressful and difficult for us as a family when Simon became particularly unwell. Joy was very upset and I was constantly worried about what the future would bring. You have to deal with it the best way you can but this became more difficult as time went on and Simon had to spend more and more time in hospital.

29. The worst period was when Simon was ill, my mother-in-law was living with us because she was ill, and my other son and daughter-in-law were living with us because they were homeless. This was not a good time and I know it really affected Joy.

30. It has been extremely difficult for Joy and I to see how all of this has impacted Simon. Initially, there were periods of ups and downs, with Simon being okay at one stage, to him suddenly being unwell. However, when the HIV started to manifest itself and Simon became extremely ill, he wasn't able to do anything. He would spend all day in bed or in the lounge asleep. It felt as though he was slowly wasting away but there was nothing we could do about it. We felt helpless. Although Simon's health has improved to an extent, the PLE is now the latest thing we have to live with.

31. Simon's illness, and Joy's consequent early retirement has impacted us financially. I was on a fairly good salary so we managed. However, our joint income went down significantly after Joy retired and so, had it not been for Simon's HIV infection, we would be in a better position financially. I am also conscious of the fact that if I die before Joy, she will only have her small pension and half of my company pension, as the other half of my company pension and all of my state pension will go with me. Joy's pension is not very big given she did not work for as long as she could have done had Simon not been ill. This is something I am very aware of and concerned about.

32. Our social life has also been impacted by Simon's HIV, particularly in relation to holidays. We weren't able to go abroad as Simon would often become ill before a planned holiday or would fall ill while we were away. We had to give up our timeshare in Madeira and had to limit ourselves to holidays in the United Kingdom. We managed through it, but it has been difficult.
33. When Simon was ill, we weren't able to go out as often as we do now. I am a member of the Lions, where there is as much socialising as there is raising money for charity. However, when Simon was unwell, we couldn't get involved with the social side, including trips and events, as much as we do now. We often had to care for Simon so it was difficult to leave the house.
34. We have been very cautious and selective about who we have told about Simon's illness. A few of our friends who are in the Lions were aware that Simon has haemophilia and they have figured out that he also has HIV. However, a lot of people there still do not know. You have to be cautious about who you tell due to the stigma that HIV can provoke. Back then, there was so much prejudice surrounding HIV and AIDs. I could not discuss Simon's illness with anyone at work. When the AIDs epidemic broke out, the conversations in the office were full of ignorance and I found it difficult to be around that.
35. The early government adverts only made this worse. They were designed to provoke fear in an attempt to stop people from being promiscuous or using intravenous drugs. I understand that they wanted to make people aware of the risks and the consequences. However, it also had the added effect of prejudicing everyone. These adverts were the worst thing they could have done as they ignored people like Simon who had been infected through blood products. It tarred them with the same brush as drug addicts and did nothing to separate them.



36. Fortunately, the prejudice surrounding HIV has got better in recent years. It was only in recent years that the government changed their method from this blame game and at least now people are aware of the link between haemophilia and HIV. Princess Diana's attitude also made a difference and helped to combat the stigma, particularly when she kissed the child with HIV. However, even today, I am cautious about who I talk to about Simon's illness.

37. Sadly, the stigma surrounding Simon's HIV has drawn a wedge between Simon and his brother. Simon's sister-in-law doesn't want people to know about Simon's illness and they have not told their son, Simon's nephew, which upsets Simon. Simon's sister-in-law also doesn't want people to know about Simon's HIV as she is worried that friends will desert her if they find out.

#### **Section 6. Treatment/Care/Support**

38. At times, I felt the doctors were very unprofessional. They gave us very little information about Simon's condition and we had no proper communication with any of them, except for Dr White at Heartlands Hospital. On one occasion, we were in a meeting about Simon's condition and the two doctors just spoke to each other about Simon right in front of us. It was as though we were invisible and I had to say something before we were acknowledged. I can't recall for certain which doctors these were but I believe one of them may have been Dr Strevens.

39. Of all the medical professionals, Dr Strevens was the worst. As stated previously, we felt he had washed his hands of Simon and it was very difficult getting Simon referred to Heartlands. A further issue is that the hospitals weren't well connected and they didn't seem to communicate with one another. As a consequence, it was a fragmented process. We had to go to various hospitals for Simon's care and they didn't seem to know what was going on at the other hospitals. Simon's notes had to

be sent from one hospital to another by paper so it was a very disjointed process.

40. We feel that there should have been more support available to Simon and our family. We have never been offered counselling or psychological support through the NHS. Joy and I attended a counselling support session through the Haemophilia Society; however, the counsellor there was terrible. The only helpful part of the session was that we were able to meet other people in our area who had also been affected. However, we chose not to continue attending these sessions. We were concerned that getting to know others who had been infected would mean more funerals to attend and constant reminders of what the illness can do to people.

## **Section 7. Financial Assistance**

41. Simon has received money from the Macfarlane Trust and from Armour Pharmaceuticals. He found out about this financial support through solicitors he had instructed, not the doctors. He received £20,000 from the Macfarlane Trust in around 1989 and a further £20,000 around 1990 as a settlement for a class action he was involved in. Around 1991, he received a further £40,000 from Armour Pharmaceuticals.

42. Simon also receives monthly top-up payments, which were initially around £300 a month and are now around £2,000 a month. This payment is now administered by through the England Infected Blood Support Scheme. These monthly payments have been helpful for Simon. However, it has been a stressful process at times, as he has had to submit so many applications for these payments and constantly has to justify the money he receives to the Department of Work and Pensions.

43. I believe that the level of support Simon has been given is, quite frankly, inadequate. It is also frustrating that people infected in other

countries were paid a lot more than those infected in England. Even in Scotland people were given more financial support.

#### **Section 8. Other Issues**

44. Simon, Joy and I have never been involved in any previous inquiries or campaigns. I hope that this Inquiry will be able to get to the bottom of why this has happened. It is frustrating knowing that the conservative government under Margaret Thatcher kept on supplying potentially contaminated blood products, despite knowing the risks. All of this has possibly been covered up to this day and so I hope the Inquiry will finally be able to expose what has really happened.

#### **Statement of Truth**

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

Signed GRO-C

Dated 22/7/2019