

Witness Name: Joy Edith Chandler

Statement No.: WITN0825001

Exhibits: None

Dated: 1 July 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOY EDITH CHANDLER

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

I, Joy Edith Chandler, will say as follows: -

Section 1. Introduction

1. My name is Joy Edith Chandler. My date of birth is GRO-C 1942 and my address is known to the Inquiry. I intend to speak about how my son, Simon Chandler ("Simon"), was infected with HIV, Hepatitis B and Hepatitis C through contaminated blood products he received to manage his haemophilia.
2. I am a retired school teacher and I currently live in Coventry with my husband, David Chandler ("Dave"). We have been married for fifty-four years and have three adult sons, including Simon. Both Simon and David are also providing statements to the Inquiry.
3. Although Simon was able to clear the Hepatitis B and C, his HIV has had a significant impact on his health over the years. In many ways, it is like a death sentence. It wears us all down and has impacted our lives in so

many ways. On top of the effects on Simon's physical and mental health, we have all been impacted financially, socially and emotionally.

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 my family up to my great grandmother, who was a carrier. I am also a carrier and I passed it on to Simon. GRO-C
- GRO-C The transmission of haemophilia through a family is as follows: usually it passes from father to daughter who becomes a carrier and she passes it onto her son. In my case, it passed from my grandfather to my mother GRO-C
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5. When Simon was a child, he was initially treated with cryoprecipitate at Ladywood Hospital. He then started receiving Factor VIII in the 1970s at Walsgrave Hospital and Coventry and Warwickshire Hospital, now known as University Hospitals Coventry and Warwickshire. Simon was under the care of two haematologists: Dr Morris Strevens at Walsgrave Hospital and Professor Neville Shinton at Coventry and Warwickshire Hospital.
6. Simon had Factor VIII regularly when he was growing up, usually at the hospital. Eventually as he became older, we went to home treatment. The doctors would give me a bottle of Factor VIII and I had to mix it with sterilised water before injecting Simon.
7. The doctors never informed us about the risks associated with Factor VIII. However, we were aware that Factor VIII was a blood product and so we did have concerns about it being contaminated. I was particularly concerned about the Factor VIII from America as I had heard on the news that people were paid to give blood there. I felt that blood given for

altruistic reasons, as in the UK, would likely be safer than blood given by people off the street who were paid and potentially feeding a habit.

8. The doctors preferred the American Factor VIII because it mixed better. However, I didn't want Simon to have it so I asked the head technician at the laboratory, Mr Lavington, if Simon could continue using British Factor VIII. He said that he would try to keep Simon on British product and for the most part, he did. However, during times Simon was in hospital, they couldn't guarantee that they would give him British product. I discussed this with a number of Simon's doctors and even offered to go and get the British product from the laboratory myself whenever Simon needed treatment. However, I was told that this was not possible and that Simon would just have to use what was in stock.
9. In 1985, Simon went to Kingston Polytechnic, now Kingston University, to study a Higher National Diploma in Chemistry; he returned later to obtain a Bachelor of Science. While he was there, he had a spontaneous bleed and had to go to Kingston Hospital. He had one vial of British Factor VIII with him but was told by the doctors that this wouldn't be enough and that they would need to give him American Factor VIII. The doctors said 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.
10. 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.
11. Simon was retested in January 1987 and it was confirmed that he had HIV. However, he did not tell Dave and I about his diagnosis until around Easter 1987. I think he needed a while to get his head around the diagnosis before telling anyone.

12. When we first spoke to Professor Shinton about the diagnosis, he asked me if I had any other children, with the inference I felt, that Simon was expendable. This was deeply upsetting as I thought that it didn't matter how many children I had; none of them were expendable.

13. We all feel that Simon and our family were not given adequate information to understand and manage Simon's HIV infection. Despite being his main carer, I was not given any information about how to support Simon. I think the doctors assumed he would not be around for very long. Initially, I wasn't given any advice about precautions to take. At some point, I asked the doctor about this myself but I was only told to avoid spillages and to be as hygienic as possible.

14. 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

15. 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

16. Whilst receiving treatment at GRO-D Hospital, Simon informed the doctor of my preference for the English Factor VIII. The doctor asked my son what medical degree his mother had and informed him that the Factor VIII he was being given was heat-treated and was therefore safe. This clearly was not the case.

17. 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

18. Because Simon had such terrible fevers, his bed would be soaked with sweat every morning. I had to strip his bed and ensure he had clean pyjamas every day.

19. One day, I came home at lunch and Simon was shaking, even though he was still in his pyjamas and wrapped in a blanket against the radiator. I took him to Walsgrave Hospital but the doctors didn't really know what to do. We were informed that the virus seemed to be making its way through Simon's body and that he was probably dying. In all honesty, from the look of him we really did not think that he could survive. I informed my school and was initially given six months leave. I retired after this time as it was becoming obvious that I would need to be Simon's full-time carer.

20. Simon's physical health has suffered greatly over the years due to his HIV infection. At first, his health deteriorated fairly gradually but his symptoms became worse as his CD4 count continued to drop. He suffered from red, flaky skin and started losing weight rapidly. He also experienced terrible fevers.

21. Simon started taking AZT in 1992. However, his CD4 count continued to fall and by 1995, he was very unwell. It was difficult for him to eat during this period. I would cook his favourite meals in an attempt to get him to eat but he could only manage a couple of mouthfuls and nothing more. It was upsetting because you could see all of the weight dropping off him. We were sometimes at loggerheads because I could see him not eating or drinking enough. He had to start taking Fortisip, a meal replacement,

but Simon hated it so it was quite distressing. Simon was diagnosed with septicaemia during this time. His temperature was so high he was delirious.

22. Despite how serious Simon's condition was, Dr Strevens at Walsgrave Hospital seemed to have given up on Simon. He kept saying he wasn't an expert in HIV, which we understood. However, I told him that he should have referred Simon to the appropriate specialists straight away. It took us twelve months to get Simon to Heartlands Hospital in Birmingham for the most appropriate treatment. Doctor Strevens told us that Coventry NHS would now have to pay Heartlands Hospital for Simon's ongoing treatment.

23. 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. Shortly before Simon was referred, GRO-D the head nurse at Walsgrave, came to our house to give Simon his injections and saw a card from an MP addressed to Simon. We suspect that this was why they finally decided to make the referral.

24. Simon was very unwell when he was first referred to Heartlands. He was in a wheelchair and his weight had dropped to 45kg. Doctor White's first reaction was "I should have had this man a year ago". Imagine my reaction to this comment after trying so hard to get him there. 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. Other side effects included haemorrhaging from the nose, not good for a haemophiliac!.

25. By 1997, Simon was on a mix of different anti-viral drugs. These 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. He used to have

quite a round face, but this changed after he started taking the medication. Once he got to Heartlands Hospital, they made a very important discovery regarding Simon's health.

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GRO-C Doctor White was now able to treat the infection specifically.

26. They tried Simon on so many different antivirals but none of them were working. At one stage, we were going into hospital about once a month trying to figure out what to do next. The doctors would rack their brains and then would try him on a new treatment.

27. Simon was eventually put on a high dose steroid for a month in August 1997 to kick-start his body's response to the new antivirals he was taking. Fortunately, his health improved; however, he soon developed osteoporosis. I imagine this was due to a combination of the steroids, Simon's constant high temperature effectively stewing his bones, and his inability to eat anything.

28. One evening around 1998, Simon started shouting out in pain shortly after he had been out driving. We later found out he had crushed two of his vertebrae. He had just been out in the car and hadn't even done anything physical. I rang the hospital who sent out an ambulance; he was in such pain the ambulance crew gave him morphine just to get him down the stairs. It just happened due to his osteoporosis. These fractures have caused long-term damage to Simon; he is two inches shorter than he was previously and has only tingling feeling in his feet.

29. Although Simon's CD4 count started to rise for several years after taking the steroids, it started to tail off again in 2004. 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.

30. Due to Simon's haemophilia, he has never been particularly outgoing. However, socialising became even more difficult for Simon after he was diagnosed with HIV. Around 1992, when he became unwell, he came back home to live with us. His routine would generally be to have breakfast, get dressed then go downstairs and watch television. I was working at the time but I would come home during my lunch break to check on him.
31. Even now, Simon's HIV continues to impact his social life. Money is tight so he can't spend much on socialising and overseas holidays. He also has had to be selective about who he tells about his illness. He is a very active member of the church and his friends there are aware and very accepting. However, he has not told many people outside of the church, including those he has met at his local gym where he goes swimming a few times a week. In the early stages Simon became very despondent. He said he felt that he should walk around with a bell calling out "unclean unclean".
32. It has been difficult for Simon not having a family of his own. I remember him asking me shortly after his diagnosis whether I thought anyone would marry him. Dave and I are very close with Simon; he comes to our house every Sunday to walk the dog and he comes on holiday with us. He is also very close with his niece and nephew but it isn't the same as having his own family.
33. Simon is very intelligent; however, his HIV has meant that he has not been able to pursue a career in science, as he would have like to. He did work for a couple of years shortly after his diagnosis; first in agrochemical research and then in a role where he was running a Nuclear Magnetic Resonance ("NMR") Spectrometer. However, when his health started to deteriorate, he was essentially pushed out of his job. He became too ill to work and was barely able to leave the house.

34. Given Simon has not been able to work for many years, he is reliant on the financial support he has received and it is only due to him investing this and his frugality that he was able to buy his own house. However, the financial support has been much less than what he would have earned had he been able to work all these years, particularly given he has a Masters Degree.
35. The Department for Work and Pensions constantly review Simon's case and insist that he actively look for employment, despite his consultant saying he is unfit for work. He has been refused the out of work sickness benefit on two occasions. Although he successfully appealed both of these decisions, while he was appealing he had no money to get by and had to go onto the Job Seekers Allowance. This causes Simon distress and anxiety, further impacting his mental health.
36. Simon's HIV has had a devastating impact on our family. When I first found out that Simon had HIV, my dad had a bad heart and my mum told me not to tell him about Simon because it would upset him. I found this very difficult because my dad and I had been very close since I was a young girl and I would normally talk to him about everything.
37. At one point, my mother was ill at the same time as Simon and I was caring for them both. My mum had dementia and she lived with us for about nine months. One of my other sons and his wife were also living with us for some of this period, as he was between jobs and they were house hunting. It was a very stressful time. My mum was often up most of the night with urinary incontinence and I was concerned that Simon would catch any infections Mum had. A young doctor came to the house one day and said to me, "you've got a big house to clean, these two to look after – what would happen to them if you collapsed?" Although I wanted Mum to stay with us, I was very worried that something might happen to Simon and so, after nine months, my mother went into a home. She became very unwell after this and hardly spoke. She passed away within a year.

38. It was difficult for me to leave the house when Simon was unwell and so this had a big impact on my social life. Things like holidays also became extremely difficult. Before Simon was ill, we bought a timeshare in Madeira and we would stay there for two weeks every year. However, when Simon became unwell, we weren't able to use it. We couldn't go abroad because it was impossible to get travel insurance for Simon and we were terrified that something would go wrong whilst we were away. We were concerned about Simon falling ill and needing treatment, language barriers and so forth. Even within the UK, this could be an issue because a lot of hospitals aren't geared up for Simon's condition.
39. For a while, we let friends and family use the timeshare but we eventually swapped it for one in Cornwall where we were able to take Simon and the whole family. I remember one holiday in Cornwall that Simon was very keen to go on. When we got there Simon was very ill and had to rest most of the time. Dave and I felt as though we couldn't go anywhere because whenever we left the house, we wanted to get back to check on Simon.
40. On another holiday, we decided to hire a canal boat so that Simon could sit in the boat and see everything going on around him. We did our best to get around things and make it as enjoyable as we could for Simon but it was very difficult at times.
41. Because of the stigma associated with HIV, Dave and I have been very selective about who we tell about Simon's illness. I knew I could cope with the stigma but I didn't know whether Simon could. You don't know how people will react and we therefore had to be very cautious about who we told. I worked as a Teacher in a Primary School so I felt that I had to keep Simon's condition to myself. My colleagues would have accepted the situation but I was concerned on how the parents would react.
42. Although we haven't told many people that Simon has HIV, others can see that Simon is unwell and so it is difficult when they ask questions. We

have had neighbours ask what is wrong and I have just had to say that it is too complicated to explain. I did not want to say anything for fear of Simon and our family being ostracised.

43. We did have to tell our family dentist about Simon's HIV. He has known the family for years and has been my dentist since I was a teenager. He was very understanding and knew it was difficult to transmit. However, Simon has to be attended to at the end of the working day as the surgical instruments have to be sterilised. If he required anything other than a routine inspection he would have to be hospitalised, especially for an extraction which has always been the case due to his haemophilia.

44. My working life was greatly impacted by Simon's illness. In the beginning, I could just manage looking after Simon alongside work. Dave would often come home early to check up on Simon, which made things easier. However, I still checked on Simon everyday during my lunch break so there was a lot of going backwards and forwards, which takes a toll after a period of time.

45. Then in 1995, after 16 years of teaching, I had to leave work to take care of Simon. He had become very ill and I had to rush him to hospital after coming home from work one day at lunch time. I realised it was no longer possible to manage working while also looking after Simon so I told the school that I would not be coming back for the foreseeable future. I felt as though I was not being a good teacher or a good mother and Simon needed me.

46. I initially took six months of paid leave in the hopes that I could go back once Simon got better. However, after six months, Simon was still very ill and I realised I could not go back. I was just over fifty at the time and I received early retirement.

47. The National Teachers' Union were very good to me. They guided me through the procedure and liaised with the Education Authority who gave me an extra four years of pension.
48. Later I was offered a part-time teaching post, but I decided that I could not accept the offer as Simon was still being hospitalised on a regular basis. Working would have been impossible in these circumstances.
49. Between 1998 and 2002, when Simon was feeling a bit better, I went back to work as a supply teacher. This was a better set-up because if Simon was ill, I could turn the work down.
50. Our family has also been financially impacted given I had to take early retirement. At the time, the loss of money wasn't a priority as it was outweighed by our concern for Simon. Dave continued to work and I had my pension so we were able to get by financially. However, I missed out on many years of wages and my pension is not as much as it would have been had I been able to continue working. We will therefore feel the impact of this later on in our retirement.
51. The psychological impact of leaving work affected me more than the financial loss. I missed the children most of all, and I missed being at work. I also found it difficult seeing the children I used to teach out and about as they would always ask me why I was no longer there.
52. Simon's HIV has been a bit divisive, even within the family. It has had an effect on all of us. Simon's brothers have moved on with their own families and it has put a bit of wedge between them. One of my sons lived in London when Simon was very ill and the other in Nottingham; however, I could not visit them because I had to look after Simon. I only saw them when they came to visit us.
53. As stated previously, I feel as though Simon's illness is like a death sentence. You try to ignore it for a while but then something else comes along, such as Simon's PLE, and it brings your mind back to it all. It is not

the life I envisaged Simon having. He is very bright and I could see him having a very different life had this not happened to him.

Section 6. Treatment/Care/Support

54. I didn't find any of the initial doctors, including Professor Shinton and Dr Strevens, very helpful. We were left dangling, not knowing whether Simon was going to die or whether he would be able to pull through. We had no idea what was going to happen. We got some information through the Haemophilia Society and online but there was very little information from the doctors to help us understand Simon's situation. I don't think they really knew themselves to be honest.

55. As stated previously, we felt Dr Strevens had washed his hands of Simon when Simon became ill. It didn't come easy getting Simon referred to Heartlands. On one occasion, I really shouted at Dr Strevens and Dave had to restrain me. I'm surprised security didn't take me out. It is not right that we had to fight so hard to get proper treatment for Simon.

56. Counselling or psychological support has never been offered to Simon or our family through the NHS. Dave and I attended a one off counselling support session through the Haemophilia Society; however, the counsellor there was not constructive. The only helpful part of the session was that we were able to meet others in a similar position. We realised that our reactions to Simon's infection was similar to others in a similar situation.

57. I believe that there should have been more support offered to Simon and our family. It was only when we attended the counselling session that we realised what we were missing out on and how useful proper support could have been.

Section 7. Financial Assistance

58. 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.

59. Simon also receives monthly top-up payments, which were initially around £300 per month and are now around £2,000 per month. This payment is now administered by the England Infected Blood Support Scheme. These top-ups 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 is constantly having to justify the money he receives. The biggest issue is Simon constantly having the Department of Work and Pensions ("DWP") on his back. It is upsetting for him having to keep on going backwards and forwards to get reports from doctors that the DWP doesn't even look at before making their decision. This situation affects us also when we see how distressed he is.

60. I do not feel that the amount of financial support Simon has been given is enough, particularly when you compare it to what Simon could have earned had he been well enough to work. People infected in other countries were paid a lot more than those infected in England. It is not right.

61. I have not received any financial support for giving up my job to care for Simon and I never received a carer's allowance from the Government. I did not want to take money from the NHS when we could cope without it.

Section 8. Other Issues

62. Simon, Dave and I have never been involved in previous inquiries or campaigns. I have written to MPs a couple of times regarding the issue, such as Jeffery Robinson and Jim Cunningham. They both acknowledged my letter but nothing ever came of it. I am grateful that all those who were treated with HIV infected blood are being remembered in a woodland memorial.

63. I hope that after this Inquiry, the Government will apologise and acknowledge the mess they made of so many people's lives. It has ruined all of our lives; mostly Simon's but, in many ways, it has made things difficult for all of us. I hope that nothing like this ever happens again. Simon didn't get the life he could have had and I don't want anyone else to have to go through what we have been through.

Statement of Truth

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

Signed

GRO-C

Dated

1.7.19