Witness Name: Christine Agutter
Statement No: WITN5602001
Exhibits: WITN5602002
Dated: 7.3.22.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHRISTINE AGUTTER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 September 2021.

I, Christine Agutter, will say as follows: -

Section 1. Introduction

1. My name is Christine Agutter. My date of birth is GRO-C 1967 and my address is known to the Inquiry. I live with my partner of 29 years and I have 5 children, the eldest from a previous relationship. I have lived in GRO-C for around 21 years. I work for the Marie Curie charity as a senior coordinator.

2. I intend to speak about my brother Shaun David Hole and his infections with HIV and Hepatitis C (HCV). In particular, the nature of his illnesses, how the illnesses affected him, the treatment he received and the impact it had on him and the lives of his loved ones.

3. I can confirm that I am not legally represented and that having had the anonymity process explained to me, I am happy for my story to be in the public domain. I am making the statement without any reference to medical records and dates should be taken as approximations. Where possible I will relate events to significant dates in my life.

Section 2. How Affected

4. Shaun was born on GRO-C 1964 in GRO-C Devon. He was diagnosed with Haemophilia A when he was around 3 years old, after falling down some stairs and bleeding profusely. He was the only one in the family with haemophilia; my mum was 1 of 14 children, and none of them were haemophiliacs.

5. From around the age of 7 or 8, Shaun was treated for his haemophilia at the Churchill Haemophilia Centre in Oxford. This was the closest treatment centre to GRO-C where we were living at the time. The journey back and forth to the Centre was so difficult that my parents decided to move the family to GRO-C. This was a huge upheaval and they left behind all their extended family and their support system behind to move for Shaun's care.

6. Shaun was treated by 2 particular doctors at Churchill Haemophilia Centre, Dr Rizza and Dr Matthews. He was a regular bleeder and had 3 or 4 injections of Factor VIII a week. He would go to the Centre in order to have these injections. I remember that he would always wear long sleeves due to the marks on his arms from all the injections. He didn't want others to see them.

7. When Shaun was about 8 or 9 years old, his doctors spoke about a new product from the USA which would mean that Shaun could inject less regularly. They were really

singing and dancing about this new product, and it seemed like an exciting new development in haemophilia care. However, Shaun had one dose of this new product and had a very bad reaction to it.

8. After having just one injection of this new product, the name of which I can't recall, Shaun was very sick and he vomited a lot. He ended up being in hospital for a few days as he was so unwell from the reaction. I remember this incident clearly as I was taken out of school so that the family could be with him as it was deemed quite serious. Mum was angry at what had happened and made it clear to his doctors that he should never be given this American product again.

9. Sometime after this incident, Mum had an operation and we went to stay with her sister in GRO-C for Mum to recuperate. Shaun had to visit Torquay Hospital for his injections, and they had tried to give him the new product there too, but Mum refused this on his behalf and insisted that he had the old product. When Shaun was around 13 years old, he was taught to inject himself and kept his Factor VIII injections in the fridge at home. Sometimes when he wasn't able, mum or dad would help out with the injections. They never wore gloves or took precautions. I don't know if anyone did back then.

10. When Shaun was about 15 or 16 years old, so around 1980, he was told that he had contracted HIV through infected blood products. It was implied that it was the American product he had reacted badly to that had caused his HIV infection. This was a complete shock to my parents as he had only had one dose of this product. He had never had any bad reactions to the normal injections he had been receiving. At no stage had Shaun or my parents ever been informed that there may be a risk attached to his use of Factor VIII or any other product used in his treatment.

11. GRO-D

12. GRO-D

13. As far as I am aware neither mum or dad were tested for HIV and I don't recall any mention of it being suggested by the medical profession. I was not tested at that time either although I suspect my blood would have been tested during pregnancy.

14. It was also devastating news for my mum as mentioned but also for my dad. I don't think they fully understood what it meant and were just left to get on with it themselves. They had to conduct their own research to have some idea of what the future held.

15. Lots of other haemophiliac boys that Shaun grew up with also received similar news that they had HIV. I think there were about 20 boys in total who were all under the care of Dr Matthews and Dr Rizza at the time. At one point. one of Shaun's friends, David, kicked up a lot of fuss in relation to what had happened to them and went to the press. My parents did not want Shaun's name mentioned due to the associated stigma.

16. Shaun was only notified that he was infected with HCV when was in hospital towards the end of his life, weeks before he died. I doubt whether he had any particular feelings about this or even time to consider it due to his prognosis with the HIV at the time.

Section 3. Other Infections

17. 13. I am not aware if Shaun was infected with any other infections apart from HIV and HCV. I don't recall any letters warning of a risk about vJCD.

Section 4. Consent

18. As Shaun was told that they had known about his HIV years for years before they had informed him of his diagnosis, he would not have been asked to consent to an HIV test. It is not something that my mother or father ever mentioned providing consent for either. As far as I am aware, Shaun was also not asked to consent to the HCV test he had and was just told that he had tested positive.

Section 5. Impact

19. After receiving his HIV diagnosis, Shaun very much withdrew into himself. He stopped seeing his friends and never went on to form an intimate relationship. It was a very difficult time and the whole family was very worried about his diagnosis as well as about what other people would think. What were the consequences going to be for Shaun? At the time, HIV was very much in the headlines and there were rumours being spread that you could catch HIV by sitting on the same chair as a person with HIV or drinking out of the same cup.

20. My parents were upset that the doctors had waited such a long time before telling them about his HIV, as he had been around 8 or 9 when he had the injection that caused his HIV. Where was their duty of care towards Shaun and the rest of the family? I would like to know how long they knew before telling us.

21. Mum cried a lot after Shaun's diagnosis and became quite depressed. She stopped working as a cleaner for some time. Shaun pretty much became her sole focus. Mum had always felt guilty that Shaun had been born with haemophilia which had caused him so many difficulties in life. I know that Mum had been so upset that Shaun had haemophilia that she had considered having an abortion when she found out she was pregnant with me, but she was too far along to do this. As my dad worked as a lorry driver, Mum had been the one to take Shaun to the hospital to have his injections, and knowing these injections led to his infection with HIV was difficult for her to cope with and just added to her feelings of guilt.

22. My dad became quite angry after Shaun's diagnosis with HIV and he would sometimes direct this towards myself or Shaun. He found it difficult to accept the information the hospital was giving them about Shaun. I was gutted when I found out about Shaun's diagnosis but as my parent's attention completely shifted onto him, I did become a bit resentful at the time, although I now understand why my parents acted that way. I just felt a bit put out as my parents were so much more protective of Shaun. I used to think he got everything and was so spoilt, but I think that was just me being a teenager.

23. I ended up leaving home early at just 17 years old as I was fed up with the situation and all the arguments I was having with my family. If the situation had been different I probably would not have left home so early and I might have made better life choice decisions. I do have some guilt about how I acted during this time as I probably said some horrible things, especially in heat of the moment situations but after I left home my relationship with Shaun did improve and he would come over to see me regularly.

24. Shaun did his O-Levels and finished school. He went to work for Oxford Instruments as a wiring technician where he made parts for satellites, which involved fine detailing by hand. He loved electronics and although he was not qualified in this field, he had natural ability and really enjoyed his work. He continued to live with my parents and had a few friends he would still see from time to time. He loved cars and motorsports and would like to go and watch this with friends.

25. When Shaun was around 26 or 27 years old, I started to notice that he was losing a

lot of weight. He started to get lots of thrush in and around his mouth, he developed welts on his skin and face and his hair started to thin. He stopped wanting to go out and spent a lot of time on the sofa as he was so fatigued. Eventually, he was forced to stop working which was awful for him as he had always really enjoyed his work.

26. In the last few years of his life Shaun became very depressed. Some of his friends found out about his HIV status and they were no longer part of his life. He would sometimes go on his own to watch motorsports but eventually he stopped doing this. My dad would get angry at Shaun because he stopped even trying to go out and do things. Dad felt he was giving in but eventually Shaun just became too ill to do anything.

27. As Shaun's health deteriorated, my parents had to look after him 24/7 and eventually help him with personal care. This was embarrassing for Shaun. You think you will eventually have to look after your parents but you never expect it to be the other way around at such a young age. He was still given no medication or treatment and he was just continuing to have his factor VIII injections as he had before.

28. Shaun had worked for quite a while and had earned a good wage until he was forced to give up work. He had been quite shrewd with his money and as he did not go out a lot he had managed to save quite a bit. He also received a £25,000 payment in around 1993/1994 due to becoming infected with HIV through contaminated blood products and he bought me a cheap little car. However, Mum and Dad were eventually supporting him financially too as he was unable to work for the last few years before he died. Thankfully, my Dad's boss was very supportive and understanding if Dad needed to go to the hospital with Shaun at short notice, and it did impact his career. I recall Dad's boss even coming to visit us at home.

29. Shaun's health seemed to become significantly worse very quickly, especially in the last few weeks of his life. I remember that I was going into hospital to have my second daughter, Kelly, and my parents were meant to look after my eldest daughter, Debbie. In the morning I saw that my parents had put a note through my door saying that Shaun had been rushed to hospital and they could not look after Debby, so we had to ask someone else to do it. I discharged myself from the hospital 5 days after having Kelly and took her to see Shaun who was in the Churchill Haemophilia Centre. I am grateful that I have a photo of them together.

30. When I saw Shaun in hospital, my heart sank, he was just skin and bones. He could not get up or do anything for himself by this point. His HIV had clearly developed into AIDS although I don't recall this ever being explained to us. While he was in hospital we were also told that he had tested positive for HCV, but there was no mention about what further impact this was having on his health. He was still not receiving any treatment.

31. In Shaun's last 24 hours alive, his health continued to deteriorate and he suffered a brain haemorrhage. He died on 04 June 1997. His death certificate listed an intracranial bleed, haemophilia and AIDS as his causes of death. **See Exhibit WITN5602002** We were told by the hospital staff that his funeral had to be a cremation due to his HIV infection, even though Shaun had wanted to be buried. We had no choice in the matter.

32. After Shaun died, my parents changed. They used to look after my daughter Debbie all the time before Shaun died, but when my sons came along they really didn't want anything to do with them. I think my sons reminded mum of the son she had lost, but this was very sad for my children who lost out on a relationship with their grandmother.

33. Mum took Shaun's death the hardest and she became very depressed. She was on antidepressants and she also had to start taking blood pressure medication. She had never really been the same again after Shaun's HIV diagnosis and after his death, she struggled even more. She was a broken woman and it hurt so much to see her suffer.

34. Mum had always been very outgoing and sociable before Shaun's diagnosis and used to often have friends and neighbours over to our house. However, due to the

stigma surrounding Shaun's HIV diagnosis, she lost a lot of her social circle. Two of my mother's sisters would still visit regularly, but some of the other family members we used to spend a lot of time with, we just completely stopped seeing. We had previously been a close family and had a lot of big gatherings, but that all ended due to the stigma surrounding Shaun's HIV. Mum and dad lost that support and so did Shaun.

35. Mum was just in her 60s when she died. She suffered from normal pressure hydrocephalus for which she had to have a shunt fitted, but unfortunately this became blocked. I do think the stress and depression associated with Shaun's care and early death contributed to her poor health and early death. My dad died in 2014 of lung cancer; he had been a heavy smoker. Prior to his death he had moved in with me, as he could not cope at home on his own.

36. I would like to mention that due to Shaun having to be cremated, my mum and dad had to change their funeral arrangements. They had always wanted to be buried. It is the tradition in our family. Shaun as I've said wanted that as well. As he had to be cremated they were too, in order that their final resting place could be with him. They had purchased a small plot for his ashes and wanted to be laid to rest alongside him.

37. Sadly, I feel like I have been robbed of my family. I have no parents no brother and my children will never have cousins from my side of the family. I feel like it is just me left. Although we have my husband's side of the family, they aren't my family and I feel like I have lost out on those relationships.

38. I believe that most of the haemophiliac boys that Shaun grew up with and who were treated alongside Shaun at Churchill Haemophilia Centre have now died as a result of HIV or HCV.

Section 6. Treatment/Care/Support

39. Shaun received no treatment for HIV and as mentioned, was only diagnosed with HCV shortly before his death, so he was never offered any treatment for his HCV. He would only visit the Churchill Haemophilia Centre and did not have any contact with his GP. All of his health problems were linked to his haemophilia so this is why he would only really visit the Churchill Centre.

40. I recall that his doctors encouraged him to have Yakult for the good bacteria, and our fridge was always full of this. It seems ridiculous that this was the only advice he was given with regards to managing his HIV.

41. Shaun was not offered any counselling or psychological support at the time of his diagnosis or later despite becoming more depressed and withdrawn over the years. After his death, the family was not offered any counselling or psychological support. My Mum suffered from depression from the time of Shaun's diagnosis with HIV and after his death, she was taking antidepressants until she passed away.

42. Shaun did not visit the dentist after his HIV diagnosis. He used to visit a dentist in Cowley, Oxford prior to his diagnosis and would have Factor VIII injections before he had any dental work done.

Section 7. Financial Assistance

43. As I mentioned above, Shaun received a payment of £25,000 in 1994. I'm not sure if he applied to a fund for this payment; I thought he had been contacted in relation to this and it was some type of Government scheme.

44. I have been informed that my Dad had applied to the Skipton Fund in 2011 and received a payment from them but I don't recall any details relating to this. My Dad grew up in an orphanage so he always struggled with his reading and writing, so I would usually help him to fill out forms and do any applications.

45. I have been made aware that I sent a letter to the Skipton Fund with bank details to facilitate the payment but again it is not something I recall.

Statement of Truth

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

Signed GRO-C

Dated 7/3/22