Witness Name: Sharon Pace

Statement No: WITN1448001

Exhibits: WITN1448002

Dated: November 2019

INFECTED BLOOD INQUIRY

FIRST	WRITTEN	STATEMEN	T OF SHAR	ON PACE

I, Sharon Pace will say as follows:-

Section 1. Introduction

- My Name is Sharon Pace of GRO-C

 GRO-C My date of birth is the GRO-C 1971 and I am 48 years old, single with 1 daughter. I am currently employed as a manager for William Hill and have been with the firm for 5 years.
- 2. I make this witness statement in relation to my late father, Christopher Pace who was born on the GRO-C 1942 and sadly passed away on the 27 May 1999, aged 57. He passed away from an HIV related infection after a very drawn out and painful time since being diagnosed in the early 1980s. I exhibit at 'WITN1448002', my father's death certificate which confirms his cause of death.
- 3. This witness statement has been prepared without the benefit of access to my late father's full medical records as I am currently in the process of accessing them.

Section 2. How Affected

- 4. My father had severe haemophilia with clotting factor 0%. I do not know when he was diagnosed with haemophilia. He was treated in the hospital as a child until home treatment became available in 1971, and I believe this treatment was called cryoprecipitate which allowed less hospital visits. I remember as a small child seeing bags hanging up on the cupboard as my father had his 'medicine'. I later recall that my father also received Factor VIII (FVIII) and continued to be treated with FVIII until he passed away.
- I believe that my father was under the care of The Katherine Dormandy Haemophilia and Thrombosis Centre at the Royal Free Hospital, London (RFH).
- 6. My father also had many operations at the RFH to repair damaged joints as a result of bleeds which included both knees being removed, his shoulder being fused and his hip being replaced. We believe it was during this time he was infected with HIV as he did not move to the Oxford Haemophilia Centre until after he was diagnosed with HIV, which was in or about 1984.
- I do not know if my father was given any information or advice beforehand about the risk of being exposed to infection from using contaminated blood products.
- 8. As a result of receiving contaminated blood products, my father was infected with HIV and Hepatitis C (Hep C).
- 9. My father was obviously unable to work as a result of his joint damage but he kept himself involved with the local haemophilia group and was, I believe, a treasurer. My mother was a secretary within the group. Through connections within this community they heard the first set of rumours surrounding haemophiliacs and HIV. It was during this time that my parents marriage broke down (not connected to the infection as it was unknown then, but it obviously distracted my father from the ongoing rumours). He carried on with life, raising my brother and myself. As the rumours about HIV got louder and the campaign on the TV got bigger he got himself tested and although I am

- unsure of the exact date, I believe it to be around 1983 at which he was diagnosed with HIV.
- 10.1 do not know what advice or information he was given as my brother and I were only 12 and 13 respectively so it was kept from us for a period of time. Given the time and the fear that was associated with HIV, I think my father was trying to protect us. I only found out later that he felt like he was tested and left without any help or information and that he had to research the infection himself. I therefore do not believe that he was provided with adequate information to help him understand or manage the infection.
- 11. My father was advised to make contact with his now ex-wife and inform her to be tested

 GRO-C

 I believe it was around this time he sat my brother and myself down and told us that he tested positive for HIV. I believe this would have been in or about 1984. The only information about the infection that we got was provided was by my father. I do not remember any offer of support being offered to us at all at that time.
- 12. As stated above, my father was also infected with Hep C as a result of receiving contaminated blood products. I believe he was diagnosed with Hep C in the early 1990s. Unfortunately I do not have any information or medical records at present as to whether this was known by the hospital at an earlier date. However, as stated above, I am in the process of obtaining my father's medical records which may provide further information in relation to his Hep C infection.

Section 3. Other Infections

- 13.I recall that after my father was diagnosed with Hep C, he received a latter warning him about vCJD. I cannot recall what the letter said exactly.
- 14.1 do not know if my father received any other infections other than HIV and Hep C.

Section 4. Consent

- 15. As stated above, when the HIV rumours got louder my father got himself tested. I therefore believe that my father was tested with his knowledge and consent, although I do not have his medical records to confirm whether or not he was tested prior to his knowledge.
- 16.I do not know if my father was treated or tested for the purposes of research.

Section 5. Impact of the Infection

- 17. Despite my father's physical disabilities he was an active man and a father who had full custody of both his children after my mother left the family home. However, when he was told that he tested positive for HIV the change in him was massive. As stated above, he kept it from us for a period of time but I remember him changing and becoming a different man in himself. He became hugely introverted. Once we found out ourselves it became clear why he had changed and we understood the fear he felt as we had the same fear ourselves. Unfortunately, we had to bumble on without help or support until my father began AZT treatment in 1987. He later moved onto combination therapies. I do not remember him complaining about any treatment he had received from any of the medical professionals although he did say when he was in hospital he was always put in the "leper" room as he was always in a side room no matter what he was having done. This was obviously done because of his status.
- 18. My father's illness took the course of a steady downhill decline. He was 6ft tall and although never big he became thin and weak. My father had many infections and hospital visits and every time we would always wonder if this was 'it'. He had to deal with side-effects of the medication which included nausea, dizziness, fatigue and pain and this was all on top of trying to keep on top of his severe haemophilia and his joint problems at bay; it was never ending.
- 19.1 do not believe that my father had any trouble regarding his treatment. He was under the John Warin Ward at the Churchill Hospital, Oxford and he

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- always said they treated him really well there. I lived next door to the haemophilia centre which made visits easier for him. I never heard him complain about any treatment from either centre.
- 20. As stated earlier, my father changed hugely when he was told that he had HIV. It was a horrendous time to be HIV positive in the early 1980s with the adverts on the TV and the so called 'gay' disease; it was awful. He became introverted and hugely depressed, there were even suicide attempts as he tried to cope with the stigma attached to not only him but his children as well. He felt in his own words 'dirty' and knew that being open about it was not an option. We even moved away from Essex to the Midlands and cut all ties with the family as he felt this was the best thing to do, although all it did was isolate him more. It was just the 3 of us and we had to make do with that. My father's positive status did get out eventually though my brother and myself probably taking to friends etc and he did suffer with some ignorance like the time the police came to see him about me (I was a bit unruly for a while). The police refused to come in the house and would only speak to him through a window; this and some name calling made him feel even lower and lead to another suicide attempt. This became a very hard time all round for everyone. He became almost reclusive. He stayed in bed for most of the day and would only really go out for hospital visits etc. He always said that he felt he had a big red arrow over his head pointing him out and felt that everybody knew about the infection.
- 21. My father never had another relationship and spent the rest of his life a very lonely man even when things did improve slightly with his depression. He was frightened of being judged. I even remember him saying he was scared to fall in love with his grandchildren (my brother had three children at the time) as he knew he wouldn't be around to see them grow up. He had two brothers and a sister and apart from the brief contact and maybe one visit in many years, he never fixed his relationship with them. The relationship he had with my brother and myself also became different as I became a carer and my brother would just go off for months on end. Three little letters ruined him and it didn't stop.

- 22. My father was further diagnosed with Hep C and, as stated above, he received a letter warning him of vCJD. It was never ending and it was all caused by treatment that he needed for his haemophilia. Haemophilia was difficult in itself and being infected on top of it, I don't know how he lasted as long as he did.
- 23. Contaminated blood took away the man I knew and the father I remembered. My overwhelming memory of my father was that of a very sad man who had enough so much to the point that the night before he died he tried to cut his wrists in the hospital and when we saw him, he had big plasters on the wounds. This cruelty took away the man I idolised and adored.
- 24. My father was my dad and he did as much as he possibly could with his physical limitations and stepped up when my mother walked out and left her children behind. He was a funny guy who loved his children with all his heart. He always said he was made to be a family man, it was all he ever wanted and he excelled in his role as a father. When I became aware that something was wrong my father became withdrawn and mentioned that we needed to find my mother. I suppose in my innocence I thought it was just an adult thing that I didn't need to know about, but it turned into what began the nightmare that blighted all our lives. It may sound strange but I don't remember actually being told it just became a part of daily stress and worry, as my father was falling apart and doing what he needed to do. I became a housewife, cooking, cleaning, ironing, shopping anything that needed doing, sometimes to the detriment of schooling, especially after his first suicide attempt as I felt it was my place to keep him alive. My brother was away at boarding school a lot of the time so he didn't see as much I did, so I took on the responsibility of keeping us going as "normal" as possible.
- 25. Unfortunately, as a young girl myself, eventually it took its toll and I became a handful, acting out and getting into trouble. Having a father with major issues (understandable) was kind of a licence to do what I wanted to. I hung out with the wrong crowd and found an escape with drink GRO-C. It was an escape from the horrendous things going on in our lives. Unfortunately this became a

habit for a long time	GRO-C	and I ended up in a cycle
of wanting to escape but	feeling bad for letting	ng my father down. In my
defence I was a young girl	who had a father who	was dying slowly in front of
my eyes and found the who	ole thing very overwh	elming. My father didn't live
to see me sort myself out,	GRO-C	and he never got to
meet my daughter which is	s unjust and unfair.	The overwhelming feeling I
have had since the start	of all of this is lone	eliness. The infection was
something we couldn't sp	eak about, somethir	ng we had to defend and
something we had to try or	ur best to fight. Unfo	ortunately it wasn't a battle I
think any of us won.		

Section 6. Treatment/care/support

- 26.I do not recall my father ever having any trouble getting treatment. As stated above he was under the care of the Churchill Hospital in Oxford which was his haemophilia centre and next door to that was the John Warin ward which was the infectious diseases ward. Both from what I remember were very supportive and I do not recall my father ever complaining about them.
- 27. In relation to counselling my father found solace in a support group that he used to attend in Coventry. I cannot remember the name of it but he would be there a couple of times a week and became involved with the running of the group which seemed to give him the support he needed.
- 28. My brother and I were never offered any support. I don't know if it was because of the stigma that was attached to it or because it was so raw, but we were never factored into any support.

Section 7. Financial Assistance

29.I believe my father received an ex gratia payment in the 1990s and following that he had a monthly payment, which he received from the Macfarlane Trust. Unfortunately, I do not recall the amount that he received. My father was never well off and the lump sum payment that he did receive he spent mainly on us. He died without receiving any financial assistance towards his funeral.

30. My brother and I received a Stage 1 lump sum payment of £20,000 from the Skipton Fund in August 2017, which we shared between ourselves. We have received no other financial assistance.

Anonymity, disclosure and redaction

- 31.I do not wish to remain anonymous.
- 32. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

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Signed.	1
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