Witness Name: Collette Jean Pigden
Statement No: WITN0365001
Exhibits: WITN0365002-009
Dated: 2nd September 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF COLLETTE PIGDEN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 January 2019.

I, Collette Jean Pigden, will say as follows: -

Section 1. Introduction

1. My name is Collette Jean Pigden. My date of birth is GRO-C 1962 and my full address is GRO-C. I am a Franchise Engagement Lead in Haemophilia and rare diseases for a pharmaceutical company, an ex-haemophilia research nurse and an ex-Trustee of the Haemophilia Society. I intend to speak about my father, a Haemophiliac who contracted HIV and HCV and subsequently died on 9 December 1988, my cousin, a Haemophiliac who contracted HIV and subsequently died and my son, also a Haemophiliac who may have been exposed to vCJD. In particular, the nature of their illnesses, how the illness affected them, the treatment received and the impact it had on them, my family and our lives together.

2. I am a married mother of three. My husband Charles and I were married on 2 March 1985 and we have three children, Samantha (32), Matthew (30) and Christopher (27).

Section 2. How Affected

3. My father Henry George Minter, known as Harry, was born on GRO-C 1931 and died on 9 December 1988. He was 57.

4. He had severe Haemophilia A and was co-infected with HIV and HCV. My father was diagnosed with severe Haemophilia A as a child and spent much of his childhood in the National Children's Home at Chipping Norton, Oxfordshire.

5. My earliest memories as a child were that the only treatment for Haemophilia was a blood transfusion, so Dad spent a lot of time in hospital. He was a good dad but he always struggled with mobility, I don't remember a time when he didn't have bad knees or hips.

6. He was registered at St Bartholomew's Hospital when we lived in GRO-C then we moved to GRO-C in 1972 and he transferred his care to Lewisham which was the local Haemophilia Centre. He learnt to drive when we moved to GRO-C so he could drive himself to the centre. He was offered Fresh Frozen Plasma or Cryoprecipitate; home treatment wasn't available then. I have provided his medical records showing the blood product batches he was given from 1974 to 1986 (**WITN0365009**).

7. When I was a teenager, I left school at the age of seventeen and went to work for the police for a year and then decided to train as a nurse. When home treatment became available, my father was not able to self-treat and my mother was not able to treat my father so he had to attend the hospital every time he had a bleed. As I got older, I would often accompany him to the treatment centre and showed an interest in his treatment.

8. When I was nineteen years old, I had started nurse training, so it made sense for me to train to do Dad's treatment at home. This was in 1982. Learning to treat my father was life changing for him but I will never know if he had been infected prior to this point or if it was me that injected him with the product which caused his infection. Unknown to any of us at this time, I was also putting myself and my family at risk.

9. In order to train, I was given a white coat and spent some time in the phlebotomy department at the hospital, taking blood from members of the public. No gloves were worn at this time. I do not know if any of these patients were infected. From then on, I treated my father at home when he had a bleed. He was never given prophylaxis.

10. After Charles and I got married we moved down to Kent and Mum and Dad moved down there to be close to us and often came on holiday with us. Dad was quite frail by this point but continued to work in GRO-C until he retired on health grounds in the summer of 1988. His venous access was poor so the hospital attempted to construct two AV Fistulas, but both were unsuccessful. They did them quite close together, in May and July of 1988 and he never really recovered. I have provided letters from my father's medical notes regarding these attempts (**WITN0365007**).

11. Dad was admitted to Maidstone hospital as an emergency in October 1988 and he was there for some weeks before he was transferred to St Thomas' on 3 December 1988. They were investigating the issues and he was meant to go for surgery for a thoracotomy and drainage of chest locules but he never had it as his condition had deteriorated. He died six days later on 9 December 1988.

12. His death certificate and post mortem stated pneumonia, HIV/AIDS and cirrhosis as the cause of death and I have provided a copy of the post mortem report (**WITN0365002**). The Inquest concluded it was an accidental death and Maidstone hospital settled out of court. I don't remember the HIV being a big part of the Inquest, but I do remember it being mentioned that

they had two attempts at doing the fistula close together. I have also provided a copy of the Inquest report (**WITN0365003**) and a form notifying the UKHCDO of his death (**WITN0365008**).

13. During his inpatient stay at Maidstone Hospital a locum doctor had inserted a chest drain without giving any additional Factor VIII and my father suffered a cardiac arrest. We had never been told about it by the hospital and we only found out from reading the medical notes in the solicitor's office before the Inquest. I have provided a copy of the medical notes from St Thomas' Hospital (**WITN00365004)**. I just remember reading those notes and being shell-shocked that they never told us because to me, as a nurse, that is just unforgivable. We have been informed that the medical records from Maidstone are no longer available.

14. My father must have been diagnosed with HIV sometime between 1981 and 1985, the Coroner's Report following the Inquest into his death states that he was HIV positive for more than five years, so it must have been 1983 or earlier that he contracted it, based on that, but I don't remember when it was. Part of me thinks it wasn't in 1985 because that's when we got married and that would have put a bit of a dampener on the proceedings so I think we must have known about it before that.

15. I don't remember Dad being told, Mum wouldn't have been with him, she never went to the hospital with him, so I guess he came home and told us. I don't know if it was a routine appointment or if he was called in. It would have been at Lewisham Hospital, Haemophiliacs don't tend to use their GPs much they tend to just go straight to the hospital. It would be really helpful to have the notes from Lewisham; however, although requested, we have been informed that they would have been destroyed by now.

16. I am not aware whether he was given any special advice. Certainly, I was never advised to treat him differently. In those days nurses didn't wear gloves and there was no advice to change practice and I don't remember any medication. The fact that I wasn't even given gloves and I was still

treating him as normal implies that the information we were given wasn't adequate.

17. After my father died, I had to have the awkward conversation with Mum and she assured me that her and Dad had not been intimate since my brother was born in 1965. That was just their form of contraception I think, but it would have unknowingly reduced the risk of Mum becoming infected.

18. Dad was never told about the HCV, that only came to light for us when we saw his death certificate and cirrhosis was one of the causes of death.

19. A few years after my father died, we also lost my cousin at the age of 22. He too, had severe Haemophilia A and was infected with HIV. He was Godfather to my youngest son. I don't know a huge amount about it but he had a horrendous death as a result of his infection. I am not aware if he was co-infected, but his immediate family have reported separately to the inquiry.

20. My sister and I are both obligate carriers. In 1986 I became pregnant with my first child; a girl, Samantha GRO-C In 1988, I became pregnant with my second child, a son, Matthew, who was born on 8 November 1988 by Caesarean section. He was diagnosed at three weeks with severe Haemophilia A.

21. When Matthew was born, he was born in the local hospital and we had to fight to get him tested for Haemophilia because they couldn't understand why we wanted it done. The Haematologist knew Dad so they agreed to do it, he was three weeks old when we got the diagnosis but I think we already knew anyway.

22. Obviously, we registered Matt at Lewisham because we knew the staff at the Haemophilia Centre there and they knew us. We managed to hold off treating him until he was 14 months old. We were faced with having to inject our son with a similar treatment to the one that had potentially killed my father. I still think we were quite lucky, because of my training we were able

to treat Matt from quite a young age, others weren't so fortunate and were reliant on the hospital to administer the infusions.

23. The doctors at Lewisham offered us the trial of a pasteurised Factor VIII replacement product, which was considered to be safer. The regulations around clinical trials was very different back then. Although it still involved an increased amount of documentation, for us there was no choice, it was absolutely the right thing to do for our child.

24. The trial was very successful for about a year until he developed an inhibitor. In August 1991, he had bitten his tongue and continued to bleed for a few days so we took him into hospital. His Hb count dropped to 4g/dL and he had to have an emergency blood transfusion. My husband asked to donate his own blood for this, but there was no time. Again, we were faced with having to put our child's life at risk and again, we were faced with having to inject our son with a different treatment; one that was plasma derived. For us as parents this was an extremely stressful time.

Section 3. Other Infections

25. I don't think my dad or my cousin were infected with anything else but my son, Matthew, has received a letter from the hospital to say he had possibly been exposed to vCJD.

Section 4. Consent

26. I don't believe that Dad was ever treated without his knowledge. I'm sure that he wasn't offered any drug trials and I don't remember any medication for the HIV. The medical records suggest that he was never medicated for this.

Section 5. Impact

27. I would say there was probably a decline in my dad's physical capabilities. He was a planning engineer and used to travel internationally for his work. He went to Brazil and Yugoslavia in spite of his Haemophilia, he was a very brave man. Then he retired in 1988 due to ill health.

28. Dad was always a very jovial man, certainly on the outside he appeared to just take it all in his stride. He wasn't upset or angry. I'm very aware there are people out there who are very angry. But, as far as I am concerned, our lives carried on as normal.

29. The day my dad died, my brother took my mum to see him at the hospital, I never saw him because once they did the post mortem it was no longer possible to view the body due to the HIV. As far as I'm concerned, St Thomas' handled everything very well and our son's care was transferred to there when he developed the inhibitor in 1991 and we had no qualms about him going there. They treated my mother very well too.

30. Medical notes say that my mum wasn't happy with the treatment but that seems unlikely. Mum wouldn't have questioned the authority of the doctors. She would have just accepted what she was told.

31. My mother is very non-confrontational and she definitely looked to my dad for direction. Up until my dad's death she had never ever lived on her own. GRO-C she went straight from there to being a House Mother at a National Children's Home when she was sixteen. It was a home for disabled children. It was here that she met my father when he returned as an 'old boy'. Then from there she got married and only lived on her own once dad died. Her sister moved in with her following my father's death, but she's been on her own now for twelve years since her sister died and she often talks about loneliness.

32. Mum has become more independent now but because she's had to be. Now I don't imagine her being that young when my dad passed, but she was actually the same age that I am now. She did join the Women's

Institute and became more independent. She had learnt to drive before Dad died, but she never actually drove the car afterwards because the car went back to Motability and she didn't have the confidence to buy another.

33. Mum's always been financially secure, she got dad's pension, which was quite good and she got the top up payments from Macfarlane. Dad was fifty-seven years old when he retired in the summer of 1988 due to ill health. He was in and out of hospital and died in December so there wasn't really time for it to have an impact on him financially. Mum never suffered any financial impact, I'm not aware that they had a mortgage or anything but she was fine financially.

34. I don't remember Dad suffering any stigma due to the HIV. When we had the Inquest, the tabloids were there and I think that was part of the AIDS thing at the time. The press hadn't got in touch with us, it was a surprise that they were there, I think they were just hoping for a story. The Inquest was reported on in the Daily Star under the headline, "AIDS Victim's Tragic Death". A copy of this article has been provided to the Inquiry. (**WITN0365005**). Dad's mother was still alive at the time and it must have been very difficult for her to see. I don't remember it affecting us in anyway, I know some people were stigmatised by their HIV status but I don't remember it being a big issue at all.

35. The impact of stigma is more relevant to my son and us bringing him up. There wasn't really stigma specifically around the AIDS thing but other mums were always nervous about inviting him to their houses to play but only due to worrying what to do about his haemophilia as far as I know.

36. When we were looking for primary schools we had some difficulty where the headteacher at our local primary school wanted Matthew to sit indoors for breaks and for us to pick him up from school and take him home for lunch, so of course he didn't go there. This also impacted our other children as they obviously all needed to attend the same school. Aside from that the schools have been very good with us and him. As Matthew had the inhibitor they did have to be extra cautious but they included him in all the school

trips and everything. They never asked us or him about the risk of infections. His friends always protected him. They used to make sure he got the care he needed and didn't get left out. The school trained him to be a line judge when he couldn't play rugby so he could still participate.

37. I remember when Matthew was quite young he won a Haemophilia Society sport award and they held a dinner at the Rainforest Café and some people there were saying they were keeping it secret, but it never occurred to us to do that. I suppose we were just lucky we had a good circle of friends but no one was really bothered by it.

38. In 1987 when I was pregnant with Samantha, Maidstone Hospital suggested that I should have HIV screening due to Dad's status. It was negative but we elected never to tell anyone. In those days if you'd had a test for HIV you were meant to declare to insurance companies and I didn't want to.

39. GRO-C

Section 6. Treatment/Care/Support

40. I don't think Dad ever had any trouble accessing treatment but the Inquest decision says that he had a lack of care, no feeding or medication while he was at Maidstone. It's hard to say whether he did have trouble getting treatment because most of his care in Maidstone was while I was having a

baby by c-section, so I don't know. As a nurse, I feel that it is unacceptable that a patient can become malnourished and have a chest drain inserted without adequate cover and I have considered whether things may have turned out differently had I been in a different position at the time and more able to see what was going on.

41. The Inquest questioned why he hadn't been given Azidothymidine (AZT) and found that it was very expensive, the doctors had no experience of it and the side effects were terrible so it could have made him much worse. They also found that the treatment was considered not suitable for HIV patients before they developed AIDS. All of that points to denial of treatment.

42. I'm not aware whether Mum and Dad were offered any psychological support but it might just be that they were offered it, decided not to take it and didn't say anything about it.

43. I'm not aware of any stigma at the hospital, I don't know if things were different for Dad because they would have been aware that I was a nurse. I never experienced any stigma myself.

44. I don't think there was any stigma issue with the funeral directors. It was just a case of you couldn't go and see him after the post mortem and because of the HIV status they sealed the bodies in plastic.

45. I don't remember Dad going to a dentist. If he used one at all he probably used the hospital one but I don't think that changed due to his HIV status.

Section 7. Financial Assistance

46. My mother has received both stage one and stage two payments from the Skipton Fund. I know I did the application in 2011 but I can't remember how I found out about it. When we received the first payment they just sent the form for the other payment because of the cirrhosis cited on the death

certificate. That was the only evidence we had. Mum got the £20,000 then the £50,000 on 4 October 2012.

47. Mum previously received a payment in May 1991 from the MacFarlane Trust in connection with my father's HIV infection. However, she had to sign a legal waiver to confirm that she would not take any future legal action against the government or the health service with regards to receiving contaminated blood. I have provided this document to the Inquiry (**WITN0365006**).

48. I found the application process reasonably straightforward. There was a form that had to be filled in and witnessed but my friend witnessed it because she has known my parents for years.

49. We were sent a letter about a £10,000 payment for the bereaved from the Department for Health England Infected Blood Support Scheme and we have since received this payment.

50. She has received two lump sums from the MacFarlane Trust for the bathroom and kitchen. I think the application process was ok but my mum would never have managed it on her own. She doesn't even have a computer so she couldn't and wouldn't have done it.

51. Until this year, she was also in receipt of the means tested income support from the Macfarlane Trust. But, she is no longer eligible for the means tested top-up payment due to increases in the state pension and the static threshold for payments to be made.

Section 8. Other Issues

52. From my side, after a career break from nursing to care for my son, I returned to nursing some years ago and eventually became a research nurse in Haemophilia. I was also elected as a trustee for the Haemophilia Society in 2015. In October last year, I was offered and accepted a position

with a pharmaceutical company as a Clinical Educator, working in Haemophilia and other rare diseases. The company is new to the Haemophilia arena and have no connection to events or treatments of the past.

53. I enjoy my job and try to ensure that everything is done with the best interests of the patient in mind and have received awards for my work of bringing the voice of both the patient and the healthcare professional into the service that we provide. After a while, some Haemophilia Society board members took exception to the fact that I work in the pharmaceutical industry and ultimately, I felt that I had no choice, but to resign from the board as some members thought this would land badly with some of the membership. Sadly, this attitude is not uncommon in this patient group, even after all this time, the actions of the past are still influencing people's opinions and consequently, people's lives and careers.

54. Working as a nurse in a Haemophilia Centre in London in 2015, I applied to be a Trustee of the Haemophilia Society. I was successfully elected by the membership and it was all going well. Then I applied for my job with the pharmaceutical company and I went to speak with the CEO of the charity to ask if it would be a problem to stay on the board. Accepting the job was not an easy decision to make. We checked with the Charities commission who said it was fine so long as if there were any conflicts of interest, I would just step out of the room during the discussion.

55. Then the Inquiry was announced and the Society employed someone to lead on the inquiry work who had previously worked in the pharmaceutical industry. Some members were very anti that decision; however, the decision was defended by the Society and the board. The Chairman of the Board emailed the trustees to say they were calling an anonymous vote to decide whether I could remain as a trustee. This felt very unfair and I felt that I had no other choice than to resign. Some of the trustees were quite shocked with how I was treated. I had been a trustee for two years and had

always worked in the best interests of the charity; representing my views as a mother, a daughter, a carrier, and a nurse.

56. I am still a member of the Society; I was putting magazines together for them when I was 7 years old and my dad helped to run a local group. I wouldn't want to leave completely. As a family we've been members forever. At the most recent AGM and member's conference the Chairman changed and named thanks were given to all the board members, past and present, but I was not mentioned, even though I was in attendance. I understand that this was raised with the board at the next meeting and I received a card, but it was a little odd and meaningless by that point.

57. I think being on the board has been a real eye-opener. As a family I think we've always been quite actively involved and Matthew and Samantha used to go to all the away days and activity weekends. I feel very let down by the community that I have tried to do my best for.

58. The Inquiry might be having a negative effect. I think one of the issues is they've focussed so much on the Inquiry that the day-to-day objectives are being neglected. I think there are some people within the team that are trying to maintain the day-to-day running of the Society but the Inquiry appears to be a dominant feature. They seem to have lost sight that they exist to serve the whole community and some people are not affected by the Inquiry at all.

59. I quite like the way the Inquiry is going. It seems to me quite thorough and quite open. Although I understand the need for the Inquiry, it's going to cost a huge amount of money and I would prefer all the money to go into patient care and supporting those who have been affected. For me lessons have been learnt, it could no longer happen in the same way again. It's appalling there appears to have been this huge cover up and that it has taken so long for it to be properly investigated, but I don't see what can change that hasn't already. My daughter disagrees, she told me that she does want answers.

60. My opinion is that you can't affect change without being a part of that change. I hope, I think, I know, that because of my experience I have had a huge impact on the way my company approaches haemophilia care and engages with doctors, nurses and patients, not only in the UK, but across Europe and the World.

Statement of Truth

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

Signed GRO-C

Dated 2nd September. 2019.

EXHIBITS - WITN0365002 – 09

Exhibit Number	Document	Date
WITN0365002	Post Mortem for Henry Minter	2 March 1989
WITN0365003	The Inquest of Henry George Minter	Undated
WITN0365004	Medical Notes from St Thomas' Hospital Haemophilia Centre for Mr Henry Minter	1988
WITN0365005	News article from the Star entitled, "AIDS Victim's Tragic Death"	Undated
WITN0365006	Macfarlane Trust Litigation documents regarding settlement payment to non-litigants	5 June 1991
WITN0365007	Letters regarding AV Fistula	25 May 1988 – 10 October 1988
WITN0365008	Notification to the UKHCDO regarding the date and cause of death of Mr Minter	12 December 1988
WITN0365009	Medical records with blood product batch numbers listed	1974 - 1986