Witness Name: Jana Godfrey
Statement No: WITN2965001
Exhibits:0
Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JANA GODFREY

I, Jana Godfrey, will say as follows:-

Section 1. Introduction

1. My name is Jana Godfrey, born GRO-C 1955, and I live at GRO-C GRO-C

2. My husband, Philip Peter Godfrey, born GRO-C 1957, died on 9 August 1991 at the age of 34 after being infected with HIV through contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my late husband's medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. Phil suffered from severe Haemophilia A which was diagnosed when he was two years old after a tooth fell out and caused a heavy bleed. There was no known history of haemophilia in his family. He had 0% Factor VIII clotting factor in his blood.

5. He was treated at the Royal Free Hospital, London between 1968 and 1970 and Lewisham Hospital between 1970 and September 1973. At that time he was treated with Cryoprecipitate.

6. He was involved in a car accident in 1968 and required a hip operation following this which meant he also required 15 whole blood transfusions.

7. He moved on to Factor VIII in October 1975 when it became available and was treated at the Queen Elizabeth Hospital (QEH) in Birmingham. In January 1976 he moved onto home treatment. This was very exciting as it gave him the freedom to travel. Phil would be given 10 bottles of home treatment which generally lasted about 3 months.

8. In January 1982 he had his wisdom teeth removed.

9. The majority the Factor VIII administered to him was American products such as Armour and Travenol until 1988 when he was moved on to home sourced products (8Y).

10. In March 1982 he moved to Richmond, Virginia, USA on a 2 year scientific exchange programme following the receipt of his doctorate from the University of Birmingham. This was where we met. We met at church and soon our friendship blossomed. We got married in March 1984 and moved back to GRO-C together the following month.

11. Phil told me about his haemophilia when our relationship was developing as he was receiving treatment in the US; he had signed up with a local haemophilia centre in Virginia. He was under Dr Lymen Fisher at the Department of Haematology at the Medical College of Virginia, Richmond.

12. Phil first became aware of the risk of HIV associated with Factor VIII in or about 1983. He was a scientist, a Biochemist, and kept abreast of the latest literature. This is how he first became aware of the issue. He raised it with his doctor but was told that there wasn't enough information available for an informed response to be given to him.

13. We married on 24 March 1984 and returned to the UK a month later and settled in GRO-C. On our return to the UK I believe that Phil was advised by the Oxford Haemophilia Centre (where he was treated under Dr Rizza) of the danger of HIV associated with Factor VIII before there was in fact a test available for the virus.

14. Phil was tested for HIV in autumn 1985 at the Oxford Haemophilia Centre and was told that he had tested positive shortly after. Phil already knew quite a bit about the virus and the associated implications. We were told to wear condoms and take precautions. I do not recall much specific advice other than this.

15. I remember Phil coming home and telling me about his infection. It came as a complete shock but I didn't want to know too much information about the virus because I just wanted our lives to be as normal as possible. We wanted to get on with life and not think about it. I may have distanced myself from Phil a little bit initially but this was short lived.

16. When we returned to the USA on holiday in December 1988 Phil met with Dr Fisher and Dr Fisher mentioned that he had retrospectively tested a lot of his old blood samples for HIV and that Phil's blood sample taking in mid March 1982 (just after he arrived in the USA) had been tested and tested positive for HIV.

17. I do not have any knowledge as to a potential Hepatitis C infection and I do not recall it ever being discussed.

Section 3. Other Infections

18. I do not have any knowledge as to any other infections that Phil may have been exposed to.

Section 4. Consent.

19. I am not sure of what testing Phil consented to but I believe he was aware that he was tested in 1985 and of the implications of the test.

20. I do not recall being told explicitly that I was being tested for HIV, although I was monitored throughout my pregnancy. After Phil died I had to wait a certain amount of time before being tested to ensure that I was definitely clear.

21. Despite this I did not give blood for years due to lingering doubt that my blood did not contain the virus.

Section 5. Impact

22. After Phil's diagnosis we wanted our lives to remain as normal as possible so we concentrated on doing things that made us feel "normal".

23. There was a period immediately after his diagnosis that I found it very difficult to be intimate with him. I felt a sense of revulsion and that I didn't want to be near him; it wasn't really him that was the issue; it was the virus and the feeling soon passed.

24. I wanted to have children and Phil told me that it was totally my decision. We discussed it with the doctors at the Oxford Haemophilia Centre who explained the risks to us. I fell pregnant shortly after.

25. I was monitored throughout my pregnancy and our daughter was born at the John Radcliffe Hospital on GRO-C 1987. I believe that our daughter was tested for HIV at birth. I was not put in an isolation ward but I was kept in a room on my own, which I believed was done as a HIV precaution. However, I ultimately do not feel like the nurses treated me any differently.

26. Shortly after our daughter was born Phil had PCP. When Phil asked the doctors about his prognosis we were told he had 3 – 3 ½ years to live. I remember thinking that it was incredibly brave of him to ask the question.

27. We did try for a second child on several occasions but nothing came of it, and we gave up as Phil's health started to deteriorate.

28. Phil was working for the research unit at the Radcliffe Infirmary in Oxford when he applied for a job in Switzerland with Glaxo.

29. He was successful and we moved to Geneva in January 1990. However by this stage Phil's health had deteriorated. He had meningitis in May 1988 and after ever illness he wasn't able to bounce back.

30. He was suffering from neuropathy which affected his mobility so he required a wheelchair. As a result, he was delayed in starting his new job.

31. When Phil was able to start working, he told his boss about his infection. He had not told them at interview because he was afraid it would prevent him getting the job. His employer was extremely supportive and they provided Phil with a computer to work from home which gave him some much needed flexibility.

32. Prior to the birth of our daughter I had worked in retail. I was unable to work in Switzerland because of the rules about foreign workers.

33. Phil had numerous infections which started occurring from May 1987. These continued for the last few years of his life and Phil lost a lot of weight. This, combined with the neuropathy meant that I would have to carry Phil's wheelchair down the stairs and then carry him in my arms down the stairs to the car. At that time we were in a first floor flat.

34. Phil wasn't a complainer. He was a good dad and instilled much life in our daughter. He had a lot of interests and kept himself busy; Phil's illness wasn't the main focus of his life. We had friends and family who came out to visit us in Switzerland and helped where they could. In 1991 my sister-in-law came over and took our daughter to England for a week to allow me and Phil to go to a sanatorium for a week. Whilst we were away he felt slightly better, however Phil became increasingly unwell after this.

35. We went away to France with Phil's family in July 1991 and this was where he started to struggle to swallow and found it hard to eat. Phil wanted to put weight on so he chose to drink sports drinks and shakes.

36. Phil died on 09 August 1991 in Geneva. He was cremated and I do not remember having any problems when making funeral arrangements. He had wanted to give his body to science but I wasn't in the right mind to arrange that. I have always regretted not doing so but I was just operating on autopilot. We had a funeral in Switzerland to which a number of people from England flew out for, and then a thanksgiving service for him in **GRO-C** in August.

37. I was unable to look into the future after Phil's death; everything became short term. When you get married you expect to have your 50 years together, so it was very difficult to have that taken away from me. But even though we were only married for seven years, he gave me so much.

38. I retrained as a Speech and Language Therapist after Phil's death and I worked in this role until September 2018 when I retired. After Phil died I found it helpful to throw myself into work.

39. We didn't really suffer from the stigma of HIV, although there would be general comments made by people who didn't know about Phil's illness that could be very hurtful. We had someone from our church group make a comment that 'all people with AIDS should die' and I overheard someone joking about AIDS at the child benefit agency. In a way I can understand the fear, as this was the time of the AIDS media campaign which caused a lot of panic.

40. One of the things that helped me a lot after Phil died was my faith in God. I think I am quite a resilient person and I was raised to be very independent. I was also fortunate to have the support of Phil's family who were extremely loving and generous.

41. I occasionally think what our life would have been like had Phil never been infected. Would we have had more children? Phil was an extremely intelligent scientist and had started speaking at conferences, but he was never given the opportunity to fulfil his potential.

42. I miss him. I haven't spent much time looking for other relationships and I never remarried.

43. His premature death also ruined the opportunity for our daughter to have a relationship with someone whom she would have really got on with. It was really tough for Phil knowing that he would never get to see his daughter grow up.

44. My in-laws knew someone who had been through a traumatic experience and wrote a book, and they thought that it could be beneficial for me and Phil to do the same thing. They arranged for us to meet the publishers and Phil was happy to go ahead with it, although unfortunately he passed away before the book truly got underway. The publishers arranged a co-author to help me write the book who was very helpful and easy to work with, and the book was released in the Spring of 1992. Although it is quite hard to go back and read it, I am glad it's there. My book is called "The Last Mountain: Living with Aids".

45. I have seen how some haemophiliacs have been affected and sometimes I feel quite fortunate. My husband had asked his mother to always support me and we are still very close. My mother-in-law calls me every weekend and I have recently moved to be closer to

my in-laws so I can care for them. Even though our life is different, we have survived. We have got on with things and tried not to be bitter.

Section 6. Treatment/Care/Support

46. Phil was initially treated with Zidovudine. He was later tried on different drug cocktails and his treatment continued in Switzerland.

47. Neither Phil nor I accessed formal counselling although the Oxford Haemophilia Centre let us know they were available, but most of my support came through my friends at the church.

Section 7. Financial Assistance

48. Phil was a party to the 1991 Litigation and was awarded an ex-gratia payment of £20,000. I know that Phil signed papers to say that he would not pursue further compensation but I do not recall signing these documents.

49. I received winter heating payments and monthly payments from the MacFarlane Trust for a short while, although I have not heard from the Trust since 2014. I do not recall having any real difficulties with the MacFarlane Trust.

50. Phil was unable to obtain life insurance as a result of his infection. His employer in Switzerland did give me and my daughter some extra money after Phil's death and I was also given a pension from the Swiss Government as he had died in Switzerland. He also had a pension from Oxford University.

51. I also now get a pension having retired in September 2018.

Anonymity, disclosure and redaction

52. I do not want to apply for anonymity.

53. I would be happy to speak at the Inquiry if they thought my evidence would be helpful.

Statement of Truth

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

Signed GRO-C

Dated 13.03.2019