

Witness Name: Joanna Victoria Gower

Statement No: WITN1658001

Exhibits: 0

Dated: March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JOANNA VICTORIA GOWER

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I, Joanna Victoria Gower will say as follows:-

#### Section 1. Introduction

1. My name is Joanna Victoria Gower. I was born on GRO-C 1982 and I live at GRO-C London GRO-C I am single and I am my father's carer.
2. I make this statement on behalf of my father, Michael John Gower, who was infected with Hepatitis B (Hep B), Hepatitis C (Hep C) and HIV as a result of contaminated Factor VIII (FVIII) blood products. My father and my mother, Heather Gower have also produced a witness statement (**WITN1748001 & WITN1659001**)
3. This witness statement has been prepared without the benefit of access to my father's full 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. My father suffers from severe Haemophilia A. He was diagnosed with Haemophilia in 1946 when he was 1 year old following a mouth bleed after biting his lip.
5. I believe my father started having FVIII from the mid/late 1970s.
6. My father only had FVIII as and when he had a bleed. I have seen my mother administer FVIII to my father. I am a Haemophilia carrier so they knew I would have to get used to seeing injections at some point.
7. I believe my father was infected with Hep B, Hep C and HIV at the Royal London Hospital where he was treated by Dr Brian Colvin. He is now under the care of a Professor Pasi as Dr Colvin has retired.
8. I have had dealings with Dr Colvin as I used to be present with my father when he attended his hospital appointments, as a child and teenager. I also had a meeting with Dr Colvin as I am a Haemophilia carrier.
9. I believe my father was infected with Hep B and he was told following a knee surgery in 1977. He came home after the surgery and a few weeks later, he was jaundiced. He was told at this point that he had Hep B but that it was nothing to really worry about.
10. In 1985, my father found out that he was infected with HIV when he was admitted for an elbow operation and the nurses refused to enter his room without barrier protection. In the 1990s, he saw a liver specialist who told him he had tested positive for Hep C.
11. When I was 4 years old, I worked out that my father had HIV after watching an AIDS advertisement. I asked my mother whether it was AIDS that my father had and she did not deny it.
12. When I was about 15 years old, my father had a blister which I popped stupidly, after which I had to be tested for Hep C and HIV. There were more

concerns about Hep C as it was easier to pass on than HIV. When I was tested, I was a bit concerned. I tested negative for both tests.

13. I do not believe my father was not provided with much information about Hep C. My parents were all more concerned about HIV as everyone knew what it was back then.
14. I do not believe my parents were not provided with any information or advice beforehand about the risk of being exposed to the infections. I believe they should have been told earlier as there was a possible risk that my father could have transmitted the infections to me and my mother. I believe my father was infected even before I was born, so it was just pure luck that my mother and I did not get it.
15. At the time, HIV was in the media and advertisements warned people not to share things like knives, forks and toilet seats. However, my parents did not get information from the doctors and hospitals. My parents later joined a local support group and this is where my parents received most of the information.
16. Dr Colvin was quite a close family doctor and he was even at my parents' wedding. I believe he knew what was going on but did not say anything. I believe my father was one of the oldest severe haemophiliacs who survived. Dr Colvin always brought in medical students to see my father as my father was like the wonder for him as not many severe haemophiliacs survived. He was just one of the few.
17. For more detailed information about how my father found out about the infections, please see his witness statement (**WITN1748001**).

### **Section 3. Other Infections**

18. My father's witness statement (**WITN1748001**) details this section further

#### **Section 4. Consent**

19. I believe my father was treated and tested without his knowledge and consent. My father just agreed to whatever Dr Colvin told him. I do not think my father would have been aware of what was being told to him.
20. I believe my father was not given adequate or full information. When Dr Colvin told my father that he had HTLV-III, my father would not have even known that it was HIV. My father put his trust in Dr Colvin and so did not ask questions and agreed to everything he said.
21. I believe that it was quite likely that my father was used for the purposes of research. Dr Colvin used my father as a teaching tool at the time and whenever he came to visit my father, he was always followed by a trail of medical students. My father just wanted to help so he agreed for the medical students to be there. Dr Colvin used my father as if he was a miracle as there was not a lot of Haemophiliacs of my father's age with so many joint problems and severe haemophilia who were alive. Dr Colvin was proud that he had treated such a person.

#### **Section 5. Impact of the Infection**

22. My father suffered mental affects as a result of his HIV. When he found out that he had HIV, he was very scared as he thought he was going to die. He now has horrible survivor's guilt as so many of the friends he made over the years have now passed away.
23. My father also suffered physical affects as a result of his HIV. He attended the hospital following a bleed in his elbow and knee joints. The nurses would not treat him for it. As a result, he had to have operations which affected his elbow and knee permanently. My father had jaundice at least twice. He used to fall asleep in his chair a lot. My father has also suffered from malnutrition. I took him to the hospital numerous times about his loss of appetite and the fact that his stomach was so swollen but no real tests were done and eventually it was so bad that I took him to A&E and it was then noticed that he had

diverticulitis that was completely blocking his bowel so he needed emergency surgery as he would have died if it had not been rectified. This has left him with a permanent stoma bag which has further impacted his quality of life. Even this life saving operation was pushed to the end of the day due to contamination risks.

24. My father resisted having combination treatment for HIV for a long time, which is the reason I believe he is still alive today.
25. I believe that my father had a course of treatment for Hep C, which was a trial drug, but it did not work. He was then offered a further course of treatment in 2015, which I believe cleared the Hep C.
26. My father's infected status had impacted upon his medical treatment. All through the years and even now, my father is always at the bottom of the list for any operations or procedure. Sometimes, his treatment is pushed to the next day and he is always the last to be treated. I think they did this because they have to sterilise the whole place.
27. My father's infections had a huge impact on my private, family and social life. It was a nightmare knowing that my father was infected with HIV and that I had no one to talk to. Things are slightly better now and I am starting to open up about what happened. All our life, we were told by the doctors not to tell anyone what had happened to my father. At that time, people's houses were being vandalised because of the stigma attached to HIV and AIDS.
28. I remember when I was at junior school, aged about 8 years, a supply teacher was talking about HIV and said that a parent had died as a result of it. I burst out crying and was sent to head teacher's office, who was the only person in the school that knew my father had HIV.
29. Secondary school was really hard for me too. One teacher who was the head of the social and health department knew that my father had HIV as she used to go to the same health groups as my mother. I could never explain why I was so upset at school and so everyone assumed that I was just a depressed

child which meant I was often bullied and had problems making friends. I could never bring friends to my house in case they saw medication or letters from the hospital. I had a PSHE teacher who always used to put pressure on me during the lessons and would ask me questions about HIV like I knew the answers. I was isolated and depressed at school and I messed up my exams as I just could not concentrate. I went back to college at the age of 19 and did more GCSEs, which was much later than everyone else.

30. I also remember in a PSHE lesson, the teacher asked everyone to tell her one law we would change if we could. One girl said she would make a law to leave all gay men isolated on an island as she believed HIV was a 'Gay Disease' and also because of the way the media portrayed it. When she said this, my blood was boiling. Back then people would have assumed my father was gay or that he was taking drugs.

31. The mentality was that if you shared a toilet seat, knife or fork with someone who had HIV, you would catch it. I blame the media for portraying it in such a bad way.

32. GRO-C When I was 5 years old, I went to her house and she would not open the door to me as she found out my father had HIV. As a child, it was devastating for me.

33. I was close to one of my GRO-C until the age of 4 years old, but after that, he completely cut me and my family off. We only speak to 1 of my father's sisters GRO-C

34. At that time, we lived our lives thinking my father was going to die any time. My mother wanted me and my father to make memories and make the most of the time that he had left which meant she withdrew from me to let him spend as much time with me as possible so I almost lost my mum too for awhile. This put a huge strain on our relationship and it is only now as an adult that I really understand why she did it. I was terrified. I used to go to school everyday and come back home thinking "is today the day that I receive

bad news". I grieved for him even though he was alive which was absolutely heart breaking for me.

35. The ambulance would come in the middle of the night when my father had a bleed and I would not be allowed into the room. In or about 1988 when I was about 5 or 6 years old, my father had a bleed from his stomach and went to hospital. The next day, my grandmother and I went to the hospital to see him but they would not let us in. I was in flood of tears in the car as I was convinced that my father was dead. They did not give me any information. I was always brought up as a mature child but they always treated me as a young child who should be kept away.
36. From the age of 10, I attended about 3 funerals each year as we were part of a support group. This was really hard for me as I kept thinking that soon I would attend my father's funeral.
37. Once, I remember speaking to a few medical students and saying I wanted children and one of the students told me that I should not have children as I could pass on my haemophilia to them. I was only a teenager and I started crying when I was told this. This still plays havoc in my head.
38. As a result of my father's infections, I have suffered financially as well as work-related affects. I have always wanted to be a nursery teacher but have never been able to pursue the career. At the age of 20, I started working in a pharmaceutical company in central London. I worked there until the age of 31. Unfortunately, I had to give up that job in order to care for my father. I went from earning £21,000 a year to £60 a week, as I now receive a carer's allowance.

#### **Section 6. Treatment/care/support**

39. I believe my father did not have any difficulties in obtaining treatment, care and support.
40. I do not believe my father received any counselling or psychological support as a result of the infections.

41. I believe my mother received some counselling for her depression.

42. When I was 12 years old, I had counselling on a regular basis for about 3 months. The counselling was offered through the support group that we were a part of.

43. When I was 15 years old, I was not old enough to be classed as an adult but mentally I was not classed as a child and so they did not know where to place me. I was incredibly depressed at this time and would not involve myself in anything. The male counsellor from the hospital had no idea what to do with me and he would just keep asking questions such as how I felt and that was it. If I was offered proper counselling, it would have helped me.

44. My mother and I are now on anti-depressants. I suffer with extreme anxiety which I have had explained to me as so much of my life has been out of my control that I panic about things that are, such as locking the car. I have severe insomnia which I think in part is because I am always worried that the phone will ring in the middle of the night and I will have to rush my dad to hospital.

## **Section 7. Financial Assistance**

45. For a long time as a child, we struggled financially as a family.

46. I am unaware of the financial assistance that my father received but I know that he did receive some payments.

47. When I was 19 years old, I received about £500 from the Macfarlane Trust in order to pay for my tuition fees for college. The form was quite straight forward to fill in.

48. I have helped my father make applications to receive some financial assistance to get a reclining chair and a mobility scooter but the process became more and more complicated over the years. It was a minefield trying



to get some financial help to get a reclining chair, but my father got in the end. I believe my father also received a mobility scooter.

#### Section 8. Other Issues

49. If my father had not been given contaminated FVIII blood products, he would not have been infected and our lives would have been different. I could have gone to university and made a career for myself.

50. My whole life, I feel like I have never fitted in. Even at the Inquiry, most of the Haemophiliacs have died so even with them I do not feel like I fit in with them as my father is still alive.

51. My father has real survivor's guilt that he is still alive and a lot of his other younger haemophiliacs have died. My father was in floods of tears during the Inquiry opening. He is a very happy person usually but that broke him that day.

#### Anonymity, disclosure and redaction

52. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

53. I do not mind giving oral evidence to the Inquiry.

#### **Statement of Truth**

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

Signed,

GRO-C

Dated 28/03/19