Witness Name: GRO-B
Statement No.: WITN0772001
Exhibits: NIL
Dated: 04.07.19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30th January 2019.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1984 and my address is known to the Inquiry. I am a GRO-B and full-time doctoral student.

2. I intend to speak about my experience relating to my father, GRO-B: F GRO-B: F being infected with HIV and Hepatitis C ('HCV') and the impact this has had on my life. In particular, the nature of his illness, how the illness affected myself and him, the treatment received and the impact it had on our lives.

3. I am aware that my mother, GRO-B, has written a statement with the Inquiry, and she will be able to provide more exact details regarding the details of initial infection and the treatment involved. I request that my statement be read in conjunction with my mother's.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Affected

5. My father had mild Haemophilia A, and was treated with Factor 8, which was how he became infected with HIV and HCV. In 1982 he suffered a bleed in his femoral artery caused by a sports injury, this was treated with Kogenate (Factor 8). I am not aware of the details of this event because it took place two years before I was born.

6. I knew my father had haemophilia from when I was 16 years old. Around the same time, I found a letter on his desk about the possible risk of CJD from infected blood products and I spoke to him about this. I became aware of the HIV and HCV infections in 2009, when I was around 24/25 years old. Everything I know about the original infections, I was told by my parents as an adult.

7. I am not aware of further details as to how my father became infected because my parents protected me from having to know. I am not aware of which hospital my father was given infected blood products. As I have previously stated, I would ask that this statement be read in conjunction with my mother's.

8. I have not been infected. I was tested when I was 2 or 3 years old. I feared for both my parents' health due to the risk of infection. I was concerned that my mother would also become infected, this could have easily happened as I was conceived when my father was HIV positive. I can confirm, from what I imagine to be sheer luck, that my mother was not and is not infected.

Section 3. Other Infections

9. My father was informed, through a letter from the NHS, about the risk of Creutzfeldt-Jakob disease (CJD). This was when I was around 15 years old. My father declined to be tested for CJD, I believe this is due to the slow progression of the disease and his belief that he would not live long enough for it to have an impact.

Section 4. Consent

10. I am not aware whether my father gave consent to treatment or testing. For details on this subject, my mother's statement should be read.

Section 5. Impact

11. My father believed he was protecting me by not informing me of his illness during my childhood. I only became aware that he was extremely ill during his treatment for HCV in 2009. He became visibly unwell, appearing thin and frail and experiencing side effects such as sensitivity to light and skin burn. It was very distressing for me to witness. At this point he informed me of his HIV and HCV diagnosis, which was incredibly upsetting.

12. In October 2009, my father was taken into hospital. I had landed at GRO-B airport, returning from a holiday in GRO-B, when I received a phone call from my mother asking me to get the next flight to Newcastle. She informed me that my father had reacted badly to the Pegylated Interferon treatment, this caused encephalitis and his liver could not tolerate the treatment either. My mother told me it was likely he would die, and I got the next flight home to be with him.

13. I vividly remember seeing my father weak, in pain and confused. He did not know why he was there, nor was he able to recognise people, including myself. Although he recovered enough to return home, from this point on he experienced dizziness, slurred speech, mild cognitive impairment, such as slow recall in terms of his memory, and he

remained very thin and underweight. My father was perpetually tired and lost his quality of life because he was unable to do most of the activities he had previously enjoyed.

14. It was as a result of these side effects that my father experienced a number of falls. Some of these falls required treatment for the bleeds, which led to further pain and discomfort for him. This was difficult to witness. Due to his weakness and poor health, his life became very difficult. He limited the time he spent around others, and he became socially withdrawn.

15. In terms of the support the medical staff provided, I believe there was generally minimal assistance, due to my mother being a nurse and therefore being able to monitor him and give him the Factor 8. I do remember a nurse from the haemophilia clinic coming to the house to treat my father with Factor 8 in 2009, and she was very pleasant and professional. But it is my opinion that the reason my father lived so long was due to my mother's care. She was fully depended on, beyond the scope of a carer, and there should have been more support available to her.

16. When he was hospitalised in 2009, the staff from the tropical disease unit at Newcastle General Hospital did not know how to deal with his haemophilia in conjunction with his HIV and HCV infection. They did not know how to administer Factor 8 and he waited for at least a day in significant pain for someone to treat him. I believe the staff refused due to fear of doing something wrong when administering the blood product. When Dr Talks arrived, the doctor who treated my father, she was incredibly unhappy with the staff's conduct and immediately gave him Factor 8.

17. The staff did not support my mother or myself. I believe this was due to their assumption as to how my father got both infections, although I cannot prove this. The stigma associated with such infections affected

how my father was treated by the hospital staff. After his stay there, he was moved to the Newcastle Freeman Hospital.

18. I moved back to Newcastle in 2009, after completing my undergraduate and Masters degree in GRO-B. I chose to move back home to be closer to my family and this meant delaying my career progression for a year. I took a part-time job in another field because there was very little related to GRO-B and GRO-B in Newcastle at this time.

19. After my father returned from hospital in 2009, he became more stable generally and I made a career move to take up a GRO-B traineeship in Oxford. I then trained and worked in various GRO-B GRO-B with the National Health Service (NHS), alongside a Masters degree in GRO-B at GRO-B. This academic work coincided with my practical learning.

20. To me, my father's death in 2014 was unexpected. I was called away from work by my mother on GRO-B August. I was working as a trainee GRO-B with GRO-B in Surrey. I was fortunate enough to make it home on GRO-B August to see my father awake and aware one last time in the Newcastle Freeman Hospital, before he died on GRO-B August. His death was drawn out and horrible to witness. My mother and I arrived at the hospital at 7am and I saw my father gasping and choking in his bed. My mother ran to get a nurse who gave him morphine to settle him - he did not regain consciousness after this. I believe his oeseophageal varices burst because his liver was failing. My mother and I spent the day using the suction machine to remove blood from his mouth and nose, before he stopped breathing at around 6pm.

21. The staff on the unit where he passed away did not know how to competently deal with his haemophilia. To the extent that they gave him an anti-coagulant injection to prevent blood clots, due to him being bed-ridden. My mother and I had to explain to them twice that he did not need this, and that it could increase his risk of a bleed. Throughout the

period the staff did not appear to realise we were well informed on and familiar with his medical condition, despite the fact that we were the ones to point out issues with his medical treatment. The second time my mother explained to the nurse that she should not give my father anti-coagulants, she was told that because it was on the chart they had to follow instructions. My mother had to ask them to get a doctor remove it from his chart. Although the doctors and nurses were professional, neither myself nor my mother received appropriate support, nor any general assistance.

22. My employers at the time would only allow me two weeks off due to my caseload of clients, and I had to return to GRO-B a week after the funeral. At this time I was also a month from completing a postgraduate diploma in GRO-B. Due to the timing of being at home and his illness, I could not submit my final paperwork for the course, and this delayed my qualification and the associated wage increase by a year. The university requested a death certificate to grant me the extension, which felt deeply personal. I had no choice because my studies and job were so closely linked.

23. Prior to my father's death, I had accepted a place on a Doctorate in GRO-B at the University of GRO-B. I had planned to start this immediately after my GRO-B post-graduate diploma was completed. My father had been very proud that I had been accepted onto the programme and had offered to help pay my university fees as he believed this was the best career move for me. He had always been incredibly supportive of me. I did not want to place my mother under increasing pressure so I remained working part-time as a GRO-B during the full-time doctoral course. The combined stress of the course and my employment meant that three months after beginning the course, I opted to take a year out from university and later return to full time doctoral. I was very anxious and stressed, and grieving. This created friction with my employer who had been

sponsoring my university placement. I had to end this placement and find another a year later, whilst continuing to work for them.

24. GRO-B GRO-B. GRO-B GRO-B GRO-B. GRO-B GRO-B GRO-B Attending personal therapy so soon after my father's death, highlighted the trauma associated with the incident. I experienced insomnia, panic attacks, high anxiety, a low mood and poor memory recall. While I made the choice to suspend my studies for one year, I continued with the personal therapy as it became clear I needed support.

25. I find it hard to recall the specifics of the first 3 to 6 months following my father's death. My relationship with my partner ended the following February after my father's death; I did not believe I was in the right place emotionally to continue. While I was able to work reduced hours, I do not believe that I was functioning very well. This continued into the next year, where even after my return to university, my General Practitioner (GP) had prescribed antidepressants. I eventually made the decision to leave university altogether, because I still felt low and I felt that I could not study to the level I had been able to before my father had died.

26. I had previously enjoyed exercise and healthy eating, but after my father died I gained four-stone within two years due to increased stress and comfort eating. This affected my confidence and in turn affected my mood.

27. My general ability to cope changed within the first three years following his death. Attending personal therapy meant I had to process and come to terms with the impact of his HIV and HCV diagnosis on myself and my father. Looking back, I realise that my entire childhood has been

impacted to some extent. I had believed that it was normal for my father to be unwell so often during my life. I can recall his embarrassment when his hair fell out due to alopecia, or when he had Bells palsy and half of his facial nerves were paralysed, or the pain he was in with shingles. I can remember other times when he was unwell with coughs and colds, and because I did not know any different as a child, this was normal to me.

28. I recall family holidays after 2011, where my father was embarrassed and ashamed with his low weight. He was upset that he had to be near other holiday makers. The psychological impact of seeing him suffer, and the thought of his death as painful, has had a lasting impact on my mental health.

29. When I found out about my father's illness, I told some friends about the diagnosis and their reaction was often difficult to deal with. It stemmed from an attitude of fear and stigma, which I believe were related to their recollection of the advertisement campaigns and general attitude cultivated in the 1980s and 1990s.

30. My father kept his emotional distance from our extended family and his siblings. I believe this was either because he did not want them to worry, or because he was concerned about their reaction. This meant that the three of us as a family were isolated. We could not spend time with them, especially if he was unwell.

Section 6. Treatment/Care/Support

31. In terms of treatment for his haemophilia, my mother was able to inject him with Factor 8. I believe he only sought treatment for his haemophilia in extreme cases or for severe injuries. I do remember a bad bleed he had in early 2014, where he had a stent placed in his femoral artery, which was at Newcastle Freeman Hospital.

32. I believe my father should have been encouraged to seek more psychological support. I am not aware if he was offered counselling.

33. I have never been offered counselling or psychological support. I was never made aware as to whether this was available to me. Whilst I had to attend therapy as part of my studies, and for the reasons explained under Section 5, as the child of someone treated with tainted blood, I have never been contacted or offered any mental health support specific to this.

Section 7. Financial Assistance

34. I have no knowledge of financial assistance offered to my father or family. For more information, my mother's witness statement should be looked at.

Section 8. Other Issues

35. The impact and scope of what happened goes far beyond the initial events of infection. I have watched my mother suffer with extreme anxiety and insomnia for years, unable to seek support due to the fear of stigma and judgement. To a certain extent, I believe we will carry this with us for the rest of our lives.

36. The way in which he died, and others who suffer from HIV or HCV died, is terrible and traumatic to witness.

Statement of Truth

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

Signed GRO-B

Dated 4/7/19