Witness Name: GRO-B
Statement No: WITN1597001
Exhibits:
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1: Introduction

My name is GRO-B. My date of birth is GRO-B and I live at GRO-B GRO-B. I live with my wife, GRO-B, who is in effect my full-time carer. I am a retired artist/illustrator. I am medically retired.

This witness statement has been prepared without the benefit of access to my 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 infected

Method of infection

1. I suffer with severe Haemophilia A with spontaneous bleeds. I was diagnosed as a Haemophiliac at around 1 year old. I had cut myself on a metal toy and the bleeding did not stop. My condition is believed to be genetic.

2. In order to treat my Haemophilia, I was initially given Cryoprecipitate blood clotting product. I later received Factor VIII blood clotting product. I was not given a choice of treatment, nor were the reasons for changing to Factor VIII communicated to me. Further to this, I was not informed of the risks of infection.

3. I was mainly treated with clotting factor at the hospital, although from the mid to late 1980s I started to self administer the treatments from home as and when needed on demand.

4. Since 1974/75, I have regularly attended the Oxford Haemophilia Centre. I was originally treated by Dr Charles Rizza and Dr James Matthews. Dr David Keeling and Dr Paul Giangrande took over in the early 1990. Prior to 1974/75, I was treated at the Queen Elizabeth Hospital, Birmingham.

5. As a result of receiving contaminated blood products, I was infected with HIV and Hepatitis C. I cleared Hepatitis C in 2002.

6. The Haemophilia Centre doctors told me that they were unsure how and when I had been infected. Although I am unsure which batch of clotting products infected me, there are several occasions which I suspect may have been the possible moment of infection. In particular, I underwent an operation at age 24, for which I received a significant amount of clotting factor to prepare for any possible complications in surgery.

Discovery of Infection

7. I received my HIV diagnosis in August 1985. I was called to attend the Haemophilia Centre and one of the consultants informed me that I was HIV positive. It may have been Dr Matthew or Dr Rizza I am unsure. I remember I was told to sit down to hear the news. I remember thinking 'Oh my God. I don't like this'. I had heard about HIV but it was not at the forefront of my mind. I was told that due to my infection my life expectancy would not exceed two years. I was advised not to have children as I would pass my infection on.

No further information was provided to me when I was first informed. The medical professionals did not provide any further information, regarding cause of the infection, or how to manage and understand HIV.

8. I had to go away and think about who to tell. I had been out with girlfriends. I had just moved to GRO-B and had started seeing GRO-B. I later told GRO-B in a pub where I had arranged to meet up with her for a drink. I told her there was no future for us. I had 2 years to live and could never have children. We just sat there staring into space.

9. Some time between 1989 and 1992, I was asked to attend the Oxford Haemophilia Centre again. They informed me that I was Hepatitis C positive. I was told briefly by the doctors that they were unsure about the cause of my infection. They did not discuss this with me in any detail. Much like when I was informed I had contracted HIV, no information was provided to enable me to understand or manage my infection.

Section 3: Other Infections

10. I received a letter, stating that I am at risk for vCJD.

Section 4: Consent

11. I believe that I have been tested for HIV and HCV without my knowledge or consent. Prior to being informed of my diagnoses I had no knowledge that I had been tested for HIV and HCV. I attended the Clinic for appointments every four months, where vials of my blood were taken for testing. I was not informed what these tests were for, so I believed they were routine tests to observe my clotting factor.

Section 5: Impact

Impact of the infections

12. I do not typically allow things to do with my physical health to affect my mental health, and I try to move on and remain strong. I do not tend to dwell on things as a coping mechanism. As a result of this and because of memory loss from a stroke, I have forgotten a lot of historic detail. Being infected with HIV and HCV and the cascade of health issues I have endured has of course impacted upon me mentally.

13. Upon first being informed of HIV, I was very frightened and did not know what would happen to me. I was told that I had only two years to live and should not have children. As such, I really did not think I had a future for myself, nor did I think a long term relationship to be a realistic prospect. Fortunately, GRO-B was very understanding and wished for us to remain together anyway. She then later also had to shoulder the news of my Hep C diagnosis.

14. Although we remained a couple, GRO-B and I did not have children as were advised not to do so. I regret not having children and know that my wife does as well. However, I try not to dwell on this as thinking about what could have been is not healthy.

15. For many years I did not share my status with anyone, other than medical professionals and my wife. I did not ever feel that I could tell my parents such devastating news. They had seen stories on the news linking Haemophilia to HIV, so they may have had their suspicions but it was not something we discussed. GRO-B and I have very close friends whom we have only told very recently.

16. I was concerned about people finding out about my infections because I did not want them to treat me differently. There was a great deal of stigma associated with HIV and people were saying that you could not even share a toilet seat with someone who was infected. Even at the surgery the staff would sometimes wear full gowns to treat HIV patients. There was one

incident in the late 1980s when I was attending the local GP surgery to have a dressing changed on a leg ulcer. When the practice nurse found out I had HIV she froze and left the room. I was told that she had actually left the building and gone home.

17. I feel a lot more comfortable talking to very close friends about my infected status now. It has taken me many years to confide in them, but I would rather tell them myself than them find out another way. Despite having confided in them, I do not discuss it with them regularly and it still only a very select few people that I have trusted with this information.

18. As mentioned above, I did not inform my parents of my HIV and HCV positive status. They have now passed away, and my wife's family has become my family. I do not discuss my medical issues with them, but I know that GRO-B has discussed this with her sisters as talking about it helps her to deal with it. Without GRO-B I would have led a lonely and isolated life.

19. Although we have been very fortunate with friends and family, we have still missed out on a lot and HIV and my treatment for Hep C has had such physical effects on me that it has undoubtedly impacted our lives.

Impact of the treatment

20. In 2001 my health took a downturn. I was hospitalised for 4 days with severe internal bleeding/haemorrhaged varicies caused by liver disease. I began treatment with Pegylated Interferon in 2002 to clear my Hepatitis. I was required to self-inject Pegylated Interferon into my stomach. I was informed that I may feel quite bad sometimes, but will feel okay on other days. It was actually a gruelling treatment resulting in long term health problems.

21. On Christmas Eve in 2002 I was laid up in bed, poorly and shivering from the effects of my treatment. Two days later, on Boxing Day, I was admitted to hospital where I contracted sepsis which was almost fatal. I stayed in hospital for 5 weeks. When I left the hospital I had an issue with swelling to my right knee and problems with my left wrist. I left on crutches and could not return to

work for over a year as I am left handed. I was however declared as clear of the Hep C virus.

22. In November 2006 I collapsed and was admitted to hospital with severe bleeding in the groin/upper right leg and was hospitalised for 2 weeks. As a result of that I had to re-learn how to walk. I was in agony and on crutches for several months. I repeatedly told doctors that my right leg was shorter than my left leg. Nothing was done about this and the doctors told me that the engorgement of blood from the bleed in my femur has caused the muscle to shrink; I was advised to leave it to go back to normal. In August 2007, I was finally sent for an X-ray and the results revealed that I had split my femur in half in 2006 which had healed itself. When the bone calcified, it trapped nerves and muscle which still causes me a great deal of pain.

23. I then suffered from a brain hemorrhage on my birthday, GRO-B 2007. The stroke paralysed my right side and consequently I was hospitalised for 6 months.

24. I suffer from hypertension, osteoporosis. I have been given HAART medication to treat my HIV. I believe my HIV and Hep C treatments to have been the cause of a variety of health issues that have resulted. I can no longer walk and I can no longer use my right hand. I use an electronic wheelchair for mobilising.

25. Prior to contracting HIV and my HCV clearing treatment, I lived a fairly active life and had lived my life normally. When I was young I enjoyed playing sport. Although I had issues with bleeds, I was able to manage them and cope with day-to-day life. Unfortunately, HIV and HCV were forced on me and the side effects from the treatment have completely changed my lifestyle.

26. I discovered that I had a talent for art at school and studied Art at University. It is something I have always loved doing. My career as an artist/ illustrator has been curtailed. Aside from some freelance work and some part-time teaching work, I worked for a firm of illustrators since university and I loved my job. My employers had been very accommodating of my health issues, but I

was unable to work at all between 2002 and 2003. I received full pay for at least nine months and was then made redundant in 2004 or 2005. I did some work on a part time/free lance basis, but I have been unable to work at all since 2007.

27. I had to stop driving when I had my stroke. I really enjoyed driving and had a fairly new car at that time. I had to give this car up and have not driven since. I now struggle to get in and out of a car as a passenger.

28. As a result of my deteriorating health, my wife has had to stop working to care for me. Although GRO-B tried to continue working, her employers were not satisfied with the hours she could work whilst caring for me, so she was in effect constructively dismissed.

29. After being made redundant we still had to pay all our household outgoings and struggled financially for a while. I tried to continue working as a freelance illustrator up until 2007, but was unable to continue doing this for very long and had to completely cease working after my brain haemorrhage in 2007. Following this, I relied on benefits and charitable payments. When my mother and GRO-B's uncle passed away, we inherited some money which helped a lot.

30. I am very aware of the impact HIV and Hep C has had on my wife, GRO-B Every time I have been admitted to hospital in the past she has had the worry and stress of wondering whether I will survive, particularly when I contracted sepsis and when I suffered from my brain haemorrhage. We are both fed up of hospitals and have watched friends and friends' children pass away from the Haemophilia Centre. My consultant, Dr Keeling, recently commented that I was one of very few original patients left alive.

Section 6: Treatment/Care/Support

31. In the early period, counselling was offered to me. However, I did not take them up on this offer and have never participated in counselling or psychological support.

Section 7: Financial Assistance

32. I received financial payments from McFarlane Trust. We also received small monthly payments from Skipton. I now receive payments from EIBSS.

33. I have never applied for any extra assistance and tend to be quite strict on ourselves regarding financial assistance, we would rather let other people have it because we feel fortunate enough with what we have.

34. With regards to the assistance we do receive, the process of applying is not straightforward. It feels as though we are required to beg for the money by filling in the questionnaire every year, having to declare our state pensions, and to provide copies of all relevant documents. I once received a rude letter from the MacFarlane as I had forgot to provide council tax information as an oversight.

35. I was asked to reapply for the EIBSS payments by 11th July 2018 and threatened that otherwise my payments will be stopped. The forms were not sent to us and my wife had to call the EIBSS office to request them.

Section 8: Other Issues

36. In addition to this issues described above, we have faced many obstacles regarding insurance. I am unable to obtain house insurance or sickness cover, due to my infections. Likewise, my health impacts my ability to get travel insurance if I wished to go on holiday.

I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry. I do not wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed. GRO-B ....

Dated 10 November 2018