Witness Name: GRO-B
Statement No: WITN1450001
Exhibits: 0
Dated: FEBRUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I GRO-B, will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I was born on GRO-B 1949 and I live at GRO-B

2. My husband, GRO-B: H (born on GRO-B 1946) was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated blood products. He died from heart failure on GRO-B GRO-B 1994, aged 47.

3. My daughter, GRO-B has given her own Witness Statement to the Inquiry (Witness Number GRO-B

4. This Witness Statement has been prepared without the benefit of access to my husband's medical records.

Section 2. How Affected

5. H had severe haemophilia A. He was treated at the Nottingham Haemophilia Centre initially at the Children's Hospital and then at the Queens Medical Centre, Nottingham under the care of Dr French. He then transferred to the Sheffield Haemophilia Centre at Royal Hallamshire Hospital, Sheffield.

6. H rarely needed treatment. In fact he was lost to the system for a period of time in his teens and early twenties. His medical records were lost or disappeared. H only had Factor VIII (FVIII) treatment when he reached his late twenties. He did not know anything about FVIII until he joined the Notts & Derby Haemophilia Group. H never took FVIII on a 'just in case' prophylaxis basis.

7. No information or advice was provided to H about the risk of being exposed to infection from FVIII before treatment. Apart from some issues with a couple of his joints, H was a well preserved man. H would not have touched the stuff had he any clue that it was dangerous. He was told by members of his haemophilia group that FVIII had made an enormous difference to their lives. I thought that H s suffering was at an end and that he would never again have to endure the pain of joint bleeds. H always treated the FVIII with great respect, using it only when needed and not abusing it in any way. H would not have agreed to treatment had he thought that there was anything sinister about it.

8. The day H and I first knew about the existence of HIV and AIDS is one I will never ever forget. We were watching a programme on television - probably Horizon or Man Alive – when, quite calmly and in a matter of fact way, they were talking about American haemophiliacs being infected with the virus through the use of blood products. We just stared as each other in disbelief.

9. Until that moment we were totally unaware that the life saving FVIII H was using could actually kill him. Shortly afterwards, I remember reading the

headlines in a national newspaper, it said: the Government can assure the public that NO British haemophiliac has been infected with the AIDS virus.

10. We felt relieved, but it was still a terrible time for us, we had two young girls aged 6 and 4 and every day in the newspapers more stories emerged of haemophiliacs and their families being ostracised, snubbed and even attacked.

11. Dr French and his team tried to assure us that their FVIII was safe to use but in May 1985 they bowed to pressure and H was finally offered a blood test. Up until then they maintained that there was no conclusive test available to offer him.

12. After H took the test we went away on a nice holiday. We felt hopeful about the result. We had been told that only 1 in 5 haemophiliacs had been tested positive for HIV at that time. The result awaiting us on our return from holiday was what we had feared all along – H was HIV positive. There was a letter on the mat asking H to attend at the hospital to 'discuss the result'. There was no 'we are pleased to inform you'.

13. H and I attended the appointment together. H was angry and quite rightly so. How dare he be put at risk like this? It was a devastating blow and our lives were never to be the same again. H had not only lost his life but his quality of life with the knowledge of the diagnosis hanging over him. We had no idea what was coming when we saw that (Horizon or Man Alive) television programme.

14. No adequate information or advice was given to H to help him understand and manage the infection by Dr French and/or his team. We were told nothing more apart from to use condoms and not to share toothbrushes. We had no other help than that. H was refused British FVIII. He was told by the Centre that as he was already infected with HIV, to continue with the

American stuff wouldn't make much difference. We were basically told to go home and deal with it, there was nothing they could do.

15. Fortunately he was then able to transfer to the Royal Hallamshire Hospital. They had a totally different attitude and I cannot fault them for the care and kindness they showed both of us.

16. H was told that he had been infected some time over the course of the preceding four years (1981 to 1985). Some months later, I got tested and the result was negative.

17. Some time in the late 1980s HCV raised it's ugly head with reports in the media about it. H was told he had HCV. I do not remember what H was told about HCV. He was physically well but kept a lot from me. He became increasingly withdrawn and did not want to talk about anything relating to his health. H joined a support group at the hospital and I understand that some of the group were suffering terribly with their symptoms. I believe the members of the group had made a conscious and collective decision to keep what they talked about to themselves.

Section 3. Other Infections

18. I do not believe tha H received any other infection than HIV and HCV.

Section 4. Consent

19. I do not believe H to have been tested or treated without his consent.

Section 5. Impact of the Infection

20. H was an Accountant by occupation. He left school at sixteen with no qualifications but he worked hard, never took time off and became a well-liked and respected member of the community. He endured crippling joint pain and

remained focused and positive. After he was diagnosed with HIV, H became depressed, bitter and withdrawn. He dealt with it by not talking about it. It had a terrible impact on his mental wellbeing. It was horrendous.

21. On 2nd December 1993 H was admitted to hospital suffering with an AIDS related infection. He spent his last birthday there. He had lost weight and he looked and felt awful. They were unsure at the hospital as to the precise nature of the infection and did not know what to treat the infection with. He was close to death and they made the decision to give him some form of treatment rather than none at all, not knowing whether or not it was the right drug to target the infection. He was very frightened.

22. Although poorly, H was allowed home for Christmas and I collected him on Christmas Eve. While I was waiting for him to get ready I went for a walk and bumped into one of his doctors. We talked for a while, H was responding to treatment, he said, and then I asked, "what is the bottom line doctor?" He told me H was terminally ill and only had a short time to live, probably a few months at the most. What a Christmas present.

23. H died of a heart attack on the GRO-B 1994, aged just 47. Everyone agrees that it was a great tragedy that Prince William and Prince Harry lost their mother at a critical age in their lives, well my daughters were just fourteen and fifteen when they lost their dad.

24. In terms of work related/financial impact, H had a promising career in computers. He was doing well at the company he worked for and was head of department. The future was bright and he was on course to progress further. Once H's HIV status was known, things began to change (the company did know he was a haemophiliac) and, although there was no obvious change in attitude, progression within the company stagnated. He left the company around 1990 after 16 years loyal service. He then joined the NAAFI. They were aware of his status at the time he joined them and they were extremely supportive, especially when he was poorly. He was there for

less than 4 years before he died. Again, he had a very promising career. H did not live to enjoy the fruits of his labours. It has also had a significant impact on my life. Apart from five years leave to raise a family I have always worked since leaving school until 2010. Notwithstanding, I do not have the quality of life I would have had, had H lived. My financial security is continually being eroded through the efforts of the NHSBSA - EIBSS by limiting my annual income to £19,000.00. This benchmark was set in April 2012 and has not moved since. This means that, for every penny I get from the government through tax relief and increased state pension, I end up giving back to them via reduced payments from the EIBSS!

25. In the year 2000, I moved house, not because I wanted to but because I couldn't afford to live there anymore. At the time I was getting no help from the MacFarlane Trust. It broke my heart. I had a lovely home, full of memories - my youngest daughter was born there - H and I bought the house in 1974 when it was little more than a wreck. Through our own hard work and determination, we turned it into a place to be proud of. This is just another example of the devastating effect this whole sorry business has had on innocent lives.

Section 6. Treatment/care/support

26. H had AZT treatment in the late 1980s. His cell count was down but he felt quite well in himself. The AZT treatment made him very unwell. The side effects were unbearable. He felt ill, he was nauseous and could not sleep. He had a terrible rash that he could not stop scratching. He decided to end the treatment and the hospital supported his decision.

27. H joined a support group at the hospital and there was also a support group for partners. The support group was helpful to H, and, whilst well meaning, it was not helpful to me.

Section 7. Financial Assistance

28. I received a Stage 1 Skipton Fund payment of £20,000 in 2003. I was encouraged to make a Stage 2 claim which was refused because of lack of evidence of liver disease.

29. I receive a monthly payment (now through EIBSS) which is means tested and has never increased. It should increase every year with inflation, but it does not. It remains stagnant notwithstanding my only other form of income is H s occupational pension and my state pension.

30. I am unhappy about the way in which The MacFarlane Trust (MFT) has been administered. In the 1980s/early 1990s there were two payments, the first being an ex gratia payment of £20,000 and then a compensation payment of £60,000. In order to receive the compensation payment we were compelled to sign a disclaimer. We were pressured into doing that having been told that unless we did so, no-one would receive a penny. We were concerned that some of the younger victims were not going to get as much as they needed. You could not network at the time and easily ascertain the views of others. We were told that everyone else was signing the disclaimer. We were just lied to.

31. During the Lord Archer Inquiry it was noted that other countries had settled compensation payments at something like ten times our £60,000 compensation pay out. What a difference £600,000 would have made to H. He could have retired and be relieved of any financial burden.

32. The MFT was set up to provide financial assistance to sufferers and their bereaved dependents. Over the years, the goal posts have been moved and the purpose of the MFT has been eroded. I received a £10,000 Bereavement Payment in May 2017 but I was refused the further payment for an AIDS related loss. I did not want to complete the forms and sent a heart rendering letter with my application but it made no difference.

33. H's death is attributed to a heart attack on his death certificate, in 1994, a time when it was taboo for anything AIDs related to be cited. This has then been used by the State to avoid the payments due to us. H suffered for 9 years and I have been on my own for 25 years. I believe the widows of the bereaved to have been abandoned. In setting up the MFT I believe they thought the majority of the victims would be dead in 5 years and their widows re-married within 7 years and they would be able to close the door on the rest of us.

Section 8. Other Issues

34. I believe the government of the time and the NHS deliberately kept information from us and willfully told us lies. My husband was a wonderful man, cut down needlessly in the prime of life. For that I will never forgive them for as long as I live. No amount of money could ever make up for the loss my daughters and I have suffered, but as the government measures everything by how much it costs, they should be made to pay and pay dearly. It is about time they started treating people of this country like human beings.

35. I believe my husband's suffering and early death could have been totally avoided if only the Government and Department of Health acted more promptly and responsibly. It is quite clear that, had they acted more quickly, the infection of HIV in all haemophiliacs could have been prevented, lives would have been saved and suffering would have been avoided. Yet, in spite of this, successive Government and departments of Health have perpetually and deceitfully denied responsibility.

36. I have carried a heavy burden for many, many years – my darling man gone from my life. I have never received an apology, never had closure, never been able to completely move on and never been properly compensated for my loss.

Anonymity, disclosure and redaction

37. I do not want to give oral evidence and 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.

Statement of Truth

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

Signed. GRO-B

Dated 21st February 2019.