Witness Name: GRO-B
Statement No.: WITN7100001
Exhibits: WITN7100002 – WITN7100019
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I, GRO-B, will say as follows:

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B and my address is GRO-B. I am making this witness statement about GRO-B: H, who was my husband. I met H in 1992 and we married in 1993. H had severe haemophilia A and died as a result of being infected with HIV and Hepatitis C ("HCV") through being treated with contaminated blood products. H was born on GRO-B and died on H, aged 38.

2. H and I were together for five years; we were married for just over three of those years. They were the most joyful years, apart from the final months when we had to face the inescapable fact that he was not going to live long.

3. I remarried in 2005 but I did not go on to have children. It was my dearest wish to have children with H but due to his diagnosis with HIV and his declining health, this was not advisable/possible **[WITN7100002]**.

Section 2: How Infected

4. As I met H in our adult years, I did not have a comprehensive knowledge of H diagnosis as a haemophiliac or the treatment he received before we met. However, my sister-in-law, GRO-B, has also provided a witness statement to the Inquiry GRO-B in which she details her understanding. The knowledge that he was HIV and HCV positive was all I needed to know; we were determined to stay focused on his

remaining as healthy as possible and staying optimistic was easier for me if I was not struggling with anger and fear created by the knowledge of how he had been failed so badly in his health care. Subsequently I have applied for and received H medical records and have some knowledge of his medical history from those.

5. I am aware that H was treated with Factor VIII and that he was not warned about the associated risks of infection.

6. I do not know the specific details about how, where and when H was told that he was infected with HIV and HCV but there is data in his medical notes which indicates he was HIV positive on 30th July 1984 and HCV positive on 29th January 1990 **[WITN7100003][WITN7100004]** and that he had tested positive before care for his haemophilia condition was transferred to the North Hampshire Haemophilia Centre **[WITN7100005]**. I understand H health care for his haemophilia condition was the responsibility of Oxford prior to this.

7. I am aware that in the early days following H diagnosis with HIV, very little was known about it and not a great deal was made of it. As the knowledge increased, H was informed that he had to be very careful with bodily fluids. H was told and was aware that HIV could be transmitted by sexual contact but he was also told not to share toothbrushes and the like and to be aware of the risk that dental procedures could pose. I cannot recall H mentioning anything more specific than that and these cautions were given prior to our meeting.

8. After I met H, I attended most of his appointments with him. I was very concerned about him and wanted to provide him with support, saving him any unnecessary strain or pressure, particularly given the discomfort that a lot of driving could cause. His appointments were at the Lord Mayor Treloar Hospital (also known as The North Hampshire Haemophilia Centre) in Alton, Hampshire and Basingstoke Hospital (also known as The North Hampshire Hospital). Due to the number of bleeding episodes into his joints and the pain that this caused, I would drive H to his appointments. The mileage was tremendous, nearly 30 or 40 miles away - a cost that we had to cover ourselves. H had regular review meetings and weekly physio at the Lord Mayor Treloar Hospital and, in the later stages as his illness progressed, increasingly frequent visits to Basingstoke Hospital. The trips were numerous – costly both financially and in terms of physical discomfort for H who was either suffering the pain of a bleed or ill-health through HIV and HCV.

9. In terms of provision of information of the risk H infection posed to me, as already stated, H and I had been very keen to have a family and sought advice on this [WITN7100002]. I was tested at Basingstoke District Hospital for HIV and HCV in November 1994 (the results were negative), as requested by staff at the Lord Mayor Treloar Hospital. I do not recall specific advice or information but all concerned would have been aware we were careful to engage in protected sex and I found the staff at Lord Mayor

Treloar Hospital, particularly, helpful and approachable. Although relatively young (I was 25 years of age), I was sensible and not afraid to ask questions.

10. In terms of H being informed that he had contracted HIV, the period between his last negative test (8th November 1984) and first positive test (9th May 1985) was relatively short and I do not feel that he could have been told sooner. However, in terms of his HCV diagnosis (which was then known as non-A non-B hepatitis), my understanding was that there was a test for it in the early 1990s. I am aware that H was told that his liver function tests were unusual prior to that and as far as I am aware, he was not told that he was being tested for HCV.

11. I do know that during that period in the late 1980s/early 1990s, the impact of having HCV was downplayed, that it was not going to be much of a problem to H. Whether that was because it followed in the shadow of HIV, which was then known to be disastrous, I do not know but I do not recall there being any great fuss made about it.

12. In hindsight, I believe that as the risks that HCV posed became apparent, H knew more about the severity of his liver condition through being infected with HCV than he let on; reading through paperwork – both his letter to his local MP **[WITN7100006]** and various medical notes, it is clear that he was aware of how dangerous it was to the chances of his maintaining long-term health.

Section 3: Other Infections

13. As far as I am aware, H did not contract any other infections apart from HIV and HCV from contaminated blood products.

Section 4: Consent

14. H may have consented to the various blood tests which he had but I do not believe that he was told that he was being tested for HIV or HCV.

Section 5: Impact

Stigma

15. When I met H, I was drawn to his incredibly positive, sunny and upbeat nature. He loved life and was engaged with it and he himself was very engaging. He downplayed his conditions (not that he diminished the gravity of the situation) and was resolutely cheery and optimistic. There was a 10 year age gap between us and I was very young when news of the outbreak of AIDS first appeared. I recall it was stark and frightening, with public health posters and flyers depicting caution with pictures of coffins and similar themes. It was very much seen as a disease involving and affecting homosexual men, prostitutes and drug users.

16. In spite of H optimism, I know that his diagnosis with HIV and HCV was very isolating for him, quite understandably. Only a few of his and my very close friends knew about his infections. Certainly, there were not more than a handful of his work colleagues who knew and that would have been on a need-to-know basis. It was a private matter for us and the people who did know respected that.

17. Before I met H, he had a long-term girlfriend to whom he was engaged but I understand that their relationship broke down because she could not take on his uncertain health status. I do not know if she was afraid of not just losing him, but also of being infected herself.

18. I was very close to my grandfather who was understandably extremely concerned about H health status when he and I first met – and what the implications might be for me and my health. However, he was a sensible, pragmatic man and he could see that it was a serious relationship developing between us. Once he got to know H, he made it his business to learn as much as he could about HIV and HCV in order to support us as best he could but it cannot have been easy for him, knowing there was no cure for these infectious diseases. I came from a small family and it would have been a source of tremendous concern for him. He and I were each other's closest family member.

Family and social life

19. As I have referred to at paragraph 3 above, H and I were denied the chance of having a family of our own – some part of H that I could have kept back for myself and our families. I will never forget the indescribable pain on seeing him sitting up in bed shortly before he died, holding the new-born infant of one of our closest friends, knowing that he would never hold our child. I had to leave the house for that visit.

20. From a practical, familial aspect, H represented the last of the GRO-B name in his family and I know this has been a source of some great sadness and disappointment too.

21. H illness did not initially stop us from having a social life. I recall that we went to a Pink Floyd concert but I was not keen for us to go because it was at a huge venue and there would have been a lot of people, a lot of shouting, singing and general exhalations. I was worried about H health, that he might catch a virus or the like but he continued his life, he would not be smothered by me and whilst he was well we got on with it. He was, however, throughout this mindful of his own responsibilities to other people.

22. We were all utterly devastated when it became clear that despite our best efforts and H courage and resilience, he was going to die. I remember walking into our bedroom and hearing his mother, in tears, asking him if he regretted her having had children (more specifically, a boy – him) since she was the carrier of haemophilia and he had had the tremendous misfortune of inheriting the condition. It was a moment of raw

anguish and not a question I feel any mother should have to ask her son. Clearly H suffered a great deal with his haemophilia but the HIV and HCV infections ensured that he did not stand a chance.

Work, financial impact

23. H was a GRO-B with his GRO-B and that is how we met, through work. He was always upbeat and enthusiastic and GRO-B with his easy conversational manner, his sense of fun GRO-B. He also had his own sound and lighting business, which he eventually withdrew from in the early 1990s due to increasing tiredness and a need to conserve energy. H diagnosis did not impact on his ability to do his GRO-B job whilst he was well; he needed the focus of work to keep him positive and motivated, as well as the plans we had for our future, as far as we dare dream. As far as I am aware, only his work colleagues who became our mutual friends and managers on a need-to-know basis knew about his health status.

24. I cannot recall exactly when H became unable to continue with his job but I believe it was around March 1996. His medical notes indicate he was deemed to have developed AIDS in October 1995 and his social worker, GRO-B, wrote to the Macfarlane Trust on 16th November 1995 to inform them that H health was seriously deteriorating and that he had been advised to give up work **[WITN7100006]**. Looking back, I am amazed at H resilience and determination to keep going but, as stated at paragraph 23 above, an ability to maintain some level of normality at a time when all else seemed to be falling apart around him provided him with focus and motivation **[WITN7100007]**. That was how we dealt with the horror of what he (we) may face – to take it one day at a time and just keep going.

25. As H needed to reduce and subsequently give up his work, there was a huge financial impact on us. H was the main earner in our household and as GRO-B, he was paid for those shifts he worked. I had already put my developing career as a GRO-B GRO-B on hold to care for H – which I did willingly but it is difficult to care and to earn at the same time. I had taken part-time work as an administration assistant within the NHS in order to bring in some income whilst at the same time fitting work around H medical needs. Thankfully we had a very good benefits advisor through the Macfarlane Trust who told us that we could claim Invalid Care Allowance as soon as I gave up work to care for H - which I did and I claimed that allowance in September 1996. H also received Incapacity Benefit and I eventually also claimed Income Support. We therefore went from being a working couple to having to rely on benefits.

Physical Impact of H illness and the treatment he received

26. Whilst H was gregarious and on the face of it appeared to be his usual self, I do know that the time he spent alone with his thoughts was very lonely and frightening. He had to be constantly aware of his physical health, which obviously impacted on his mental health and caused a great deal of stress and anxiety. The amount of energy it took for him to put a brave face on his condition would have been enormous. He is the bravest and most resilient soul I have ever met. Reading through his medical notes has been heart-breaking, particularly as the course the disease was taking is quite clear to see. His consultant haematologist on various occasions noted: "...for the first time seemed quite down and tearful" **[WITN7100008]**, 'H is feeling well, although he is looking as yellow as ever..." **[WITN7100009]**, 'H was reviewed on DAU and whilst he says he feels not too bad he looked absolutely ghastly with clearly marked loss of muscle bulk, but massive oedema..." **[WITN7100010]**. H died a month after this last observation and it is testimony to his resolute optimism and determination to keep going in spite of the odds against him.

27. From a social aspect, H had to be very careful about consumption of alcohol – he was not a big drinker in any event but due to the issues he had with his liver and his medication regime, he had to be even more careful. He very much enjoyed sharing a meal and a bottle of wine but had to be vigilant as to what he could tolerate - which although a seemingly trivial consideration, was another curtailment of his enjoyment of life.

28. H was on a cocktail of medications for HIV including AZT (Zidovudine), 3TC nebulised Pentamidine and Fluconazole. Whilst he worked hard at maintaining a healthy lifestyle, managing to stay well for around 10 years whilst his body battled HIV and HCV, he developed AIDS a year before he died (October 1995). It is difficult to separate the effects of H treatments from the effects caused by his HIV and HCV infections or the infections which he subsequently developed over the course of his illness. There were so many effects, it's difficult to remember them all. He had hairy leukoplakia, chronic and distressing night-sweats, dreaded weight loss/muscle wasting, headaches, nausea, fatigue, peripheral neuropathy, pain from his diseased liver, uncomfortable itchy skin (pruritis), jaundice, ascites, oedema, gastro-intestinal bleeding, haematuria and diarrhoea; all frightening symptoms over which he had no control at all.

29. H contracted tuberculosis (diagnosed in November 1995), for which he received treatment including Clarithromycin, Rifabutin and Ethambutol; I do not know how he contracted it. I remember that he had to have a very painful biopsy from his spine to see if it was in his bone marrow.

30. H developed CMV retinitis and by the time he died, he was completely blind in his right eye; he had a Hickman line (central line) inserted, through which Ganciclovir was administered **[WITN7100011]**. I managed the application of this and care of the line at home myself, which I was keen to do.

31. In the last year of H life he was very jaundiced and clinicians would often mention his bilirubin levels. There are many references to H liver function readings in his medical notes, the palpability of his liver, the discomfort he was experiencing and eventually the shocking ascites he endured as his liver gave up **[WITN7100012 – example]**. His entire system appeared to be breaking down and it became impossible to know what was cause and effect beyond the ravaging effects of HIV and HCV. I believe the HCV damaged his liver to the extent that he could not tolerate the medication needed to enhance or prolong his life **[WITN7100013 - example]**.

32. I do not remember H encountering any administrative obstacles in relation to receiving treatment for HIV, but shortly before he died, the Ganciclovir delivery did not appear. It was always sent by courier in a refrigerated polystyrene box. I spoke to the hospital about it and I was told that it had been stopped because H was at the end of his life, which was deeply upsetting.

H *passing*

33. H last year was horrific to experience and devastating to observe. I would not want anyone involved in the Inquiry to be in doubt as to the nature of deterioration and the horror of final death that a HIV/AIDS patient goes through. I feel very strongly about this.

34. H was last admitted to Basingstoke Hospital for two weeks in October 1996. I was told that there was nothing else that could be done for H and so I cared for him at home, as was our wish. As I have previously mentioned, H had a Hickman Line (central line) inserted and this was also used to administer morphine for pain. He had a pressure mattress, a stair lift, anything to try and make his last days as comfortable as possible.

35. H death was unspeakable; it was anything but peaceful and I find it almost impossible to talk about now, 26 years later. To watch the person you love most in the world die incoherent with confusion from HIV induced dementia and the effects of morphine and loss of hope is beyond description and deeply upsetting – I would go so far as to say traumatising. I used to think that if I could hold him and sit very still, then nothing could take him away; I could keep him safe. In the end, as the disease hastened and it became quite clear that he would die, I left his side briefly and prayed for him to go. I have never felt so desperate – so sad, so helpless and so distressed.

36. We do not have family photographs of H looking unwell for obvious reasons. However, a year before he died, he had to have a photograph taken for his Orange-Badge for car parking; H had a naturally round, open face. He went from vibrant **[WITN7100014]** to being heavily jaundiced and emaciated in the period of a year, the last year of his life. I want the Inquiry to see and acknowledge what contaminated blood did to H **[WITN7100015]**.

37. H died a painful and protracted death with tuberculosis, CMV, pneumocystis carinii pneumonitis and a diseased liver.

Section 6: Care and Support

38. H was never offered counselling in relation to his diagnosis and I had to pursue counselling privately whilst H was alive. H never pursued or expressed any desire to receive counselling.

Section 7: Financial Assistance

39. As set out at paragraph 25 above, H and I relied on a number of state benefits when his illness took hold. H was a proud man, he worked hard and we were both careful with money and keen to be as an independent as possible. We lived simply and did not have expensive holidays. Whilst his DS1500 form was fast-tracked by the Department for Work and Pensions, there were times when it felt like we were begging and that was humiliating. The thought that we may not be able to afford to live was frightening and a stressful pressure that we – H in particular – could have well done without.

40. H did receive financial support from the Macfarlane Trust. I believe that it started at around £55 per month and increased to around £200 per month.

41. H also received a one-off payment of around £25,000 from the Macfarlane Trust in around 1990, which was before I met him, so I cannot provide any details in relation to this.

42. I do recall that H had to make an application for a one-off payment for his medication and I remember thinking 'he shouldn't have to apply for this'.

Section 8: Other

43. In April 1995 H backed The Haemophilia Society's campaign on behalf of haemophiliacs infected with HCV by writing to his local MP, David Howell **[WITN7100016]**. H said that by then around half of the haemophiliacs infected with HIV had died (which was approximately 600) and that he and his fellow surviving haemophiliacs, in addition to the ever present fear of HIV developing into AIDS, now had the prospect of facing liver cancer or liver failure and at that point, he did not feel that his prognosis was good with an already enlarged liver. H asked his MP to back The Haemophilia Society's campaign for financial and other support from the Government to make infected haemophiliacs' remaining years more comfortable. David Howell wrote back to H on 18th April 1995 **[WITN7100017]**; he was sympathetic and said he would pass the matter onto Virginia Bottomley who was then Secretary of State for Health. David Howell said that he would do everything that he could and recognised that whatever he did, there would be no compensation for the misfortune that H was so bravely confronting. David Howell sent a further letter to H on 18th May 1995 **[WITN7100018]** enclosing a response from Virginia Bottomley which had been written on 16th May

[WITN7100019]. Virginia Bottomley stated that most haemophiliac patients had been infected with HCV before blood products were treated to destroy viruses and that these patients had received the best treatment available in light of medical knowledge at that time. The Government did not accept that there had been any negligence and there were no plans to make any payments to patients. Virginia Bottomley went on to say that on the more general issue of compensation, the Government had never accepted the case for a no fault compensation scheme for medical accidents.

44. I understand from various articles that I have read, many of them in The Haemophilia Society's publication 'The Bulletin', that heat treated products were introduced as early as 1978 which would have subsequently eliminated the threat of HCV, possibly HIV too. I have also read articles regarding the failure of the United Kingdom to achieve self-sufficiency in blood stocks. I therefore cannot accept Virginia Bottomley's somewhat dismissive and perfunctory response that "patients received the best treatment available in light of the medical knowledge at the time" – my overriding feeling is that something could have been done sooner to avoid this tragedy.

Section 9: Conclusion

45. I have been dreading the findings of the Inquiry as this is such a raw and emotive subject for me, [redacted] family and many others affected by contaminated blood products. It absolutely had to be done and I give credit to The Haemophilia Society for its perseverance in pursuing an Inquiry into how the haemophiliac community could have been let down so badly. There needs to be some accountability, an acknowledgment and an apology from the Government and that is what I am hoping for. Whatever the outcome, it is too late for [redacted] but I feel that an honest and human response to this tragedy would go some small way towards acknowledging the immense suffering which cannot be overestimated.

46. As previously stated, [redacted] died 26 years ago, aged 38. It has taken tremendous energy to revisit the misery and anger at what he went through and my and his family's indescribable loss. I have been signed off work with 'acute stress and low mood' in re-visiting this, such has been the impact of seeing the wasted potential of a vibrant and much-loved young man's life. To think of the measures we took to preserve and enhance his life – the revolting and costly aloe vera and lecithin granules and the Andrews liver salts to name but a few vain attempts – makes me sad and angry. The dread of his weight loss and what that meant as an indicator of his health, the attempts at weight gain when we had to be careful of not too much fat for his liver to process, not too much sugar so that we would not increase disease progress – the list of evasive or preventative action was constant and pressing. We might have had the courage of David facing Goliath but the reality of the situation was that he simply never stood a chance. I cannot finds the words to tell the Inquiry how difficult it is to reconcile this.

47. I would like to know when it became apparent that there were risks associated with the blood products being used, why the UK had not managed self-sufficiency in blood stocks and why blood products were not being heat treated sooner? It has been known for over a century that viruses can be blood borne yet we have accepted blood from high risk donors such as drug users, prostitutes and promiscuous homosexual men etc without taking what would seem obvious and responsible action to try to achieve the greatest degree of safety possible.

48. Our haemophiliac community, by the very nature of their condition, has represented one of the most vulnerable groups in our society. It feels to me that they have been betrayed and cast aside as an inconvenient and costly burden for the government to bear and at a time when HIV, HCV, vCJD etc emerged as vital threats to life and livelihood. The haemophiliac community were stalled with misrepresented facts at best and abandoned at worst in their hour of need. It would be worth knowing that no-one is so elevated in position as to not be able to offer a human response to the suffering and loss that has been inflicted by the mis-management of blood products.

49. I would like my evidence to be anonymous but I am happy to give oral evidence to the Inquiry if selected to do so.

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

Signed: GRO-B

GRO-B

Dated: 12th October 2022