

Witness Name: GRO-B

Statement No: WITN2762001

Exhibits: WITN2762002-8

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I have been married to my husband, GRO-B: H, since 1992. He has also provided a witness statement to the Inquiry. I am retired and I am GRO-B: H full time carer.
2. I am an affected person in relation to H who has been infected with HIV, Hepatitis B and Hepatitis C as a result of being given contaminated blood products.
3. This witness statement has been prepared without the benefit of access to H full medical records.

Section 2. How Affected

4. H has severe Haemophilia A and received multiple blood products. **Exhibit WITN2762002** is the National Haemophilia Database record confirming which products and over which time periods he received blood products.

ANONYMOUS

5. When [H] lived in [GRO-B] he was under the care of [GRO-B] at The All Saints' Hospital in Chatham. As a child, he was under the care of [GRO-B] [GRO-B]. He was also treated at St Thomas's Hospital where he alternated between two consultants [GRO-B] and [GRO-B]. Currently, he is still monitored and treated at St. Thomas's Hospital.
6. He was not provided with any information or advice regarding the risks associated with blood products. His mother also advised him that she was not provided with any advice pertaining to the risks of receiving blood products. Factor VIII was considered to be a "wonder drug" because it allowed the Haemophiliacs to go out and play and "be boys again".
7. [H] was infected with HIV, Hepatitis B and Hepatitis C as a result of being given blood products. **Exhibit WITN2762003** is a letter dated 10th March 2013 to [GRO-B] from [GRO-B] which states "During his treatment for his haemophilia, he has contracted HIV".
8. **Exhibit WITN2762004** is a letter dated 25th November 1982 from [GRO-B] to [GRO-B] which states "we have a degree of low grade liver damage, possibly resulting from non-A and non-B hepatitis acquired from Factor VIII medication".
9. **Exhibit WITN2762005** is a letter from [GRO-B] to [GRO-B] dated 26th February 1987, stating that he had a "a short discussion about the significance of the latter ... and that I shall be ready to answer further questions he may ask me about it." This is not correct. [H] saw [GRO-B] for a general appointment and at the end he just mentioned, in a very matter of fact way, that he was HIV positive and that he had approximately two or three years to live.
10. **Exhibit WITN2762006** is a letter dated 13th June 1989 from [GRO-B] to [GRO-B] which stated "He has been Hepatitis antibody positive since 1979". To this day no-one in the medical profession has ever advised [H] that he is Hepatitis B positive.

11. [H] should have been told sooner about his infections. He was also never told about the risks of infecting others.

Section 3. Other Infections.

12. There was a risk that [H] had received blood products from a donor who had been exposed to or had vCJD. However, he received a letter to confirm that, as far as the medical professionals were aware, he had not actually received blood products from a donor who had been exposed to or had vCJD.

Section 4. Consent.

13. **Exhibit WITN2762007** is a letter dated 21st March 1985 from [GRO-B] to [GRO-B] [GRO-B] which states *"I am now doing HTLV III screening on all haemophilacs and have arranged for [H] to take 10mls of clotted blood next time he has to give himself an injection of Factor VIII"*. [H] had no knowledge of this and was therefore unable to consent.

14. [H] has been tested without his knowledge and therefore without his consent on multiple occasions.

Section 5. Impact

15. In 1997, our lives changed for the worst when [H] depression became very difficult for him to manage and deal with. He was unable to function properly. I recall that I received a telephone call from him at work; he was at his desk, distraught and in tears. He was in a terrible way. At the end of the call he said he was going to the bathroom. I was extremely worried about him and as I used to work at the same company as [H] and because I knew people there I was able to contact them and get someone to come to his aid. From this point, he never really went back to work.
16. In hindsight, his depressive state had been boiling up within him for a long time and everything had suddenly reached a crescendo. He just completely

collapsed and he did not know how to deal with his infections or his mental state.

17. Eventually, he managed to see [GRO-B] who was a Consultant Clinical Psychologist. **Exhibit WITN2762008** is a letter dated 10th May 2001 which confirmed [H] treatment with [GRO-B] in which [H] is described as "*an extraordinarily courageous and stoical person*" who was clinically depressed.

18. The psychological help which [H] received was beneficial. However, this help was later distorted by the antiviral medication called Efavirenz. Unbeknown to us at the time, this medication was known to cause depression. [H] suffered extremely badly as a result of taking this medication. At this time, I was still working so [H] was attending appointments on his own. The doctors were always mindful of his poor mental health and frequently asked him how he was doing. However, [H] would respond that he was totally fine so the medication continued to be prescribed.

19. [H] had a very frightening experience in 2004/2005. He had an episode of seeing red lights coming towards him whilst he was driving the car. This totally distorted his view of the road and how [H] survived that journey I will never know; it was a miracle.

20. As a result of this episode, I spoke with [H] doctor who had prescribed this antiviral medication and he told me that the medication was known to cause depression, panic attacks and anxiety. He immediately took [H] off the medication and things improved substantially; I would describe it as a light being switched on. Prior to this, our marriage had been hanging by a thread due to the severity of [H] depression.

21. This was without doubt the most difficult time of our lives. Since [H] has been on different medication and antidepressants, things have been so much better. [H] still gets depressed, even with the antidepressants, but these episodes are nowhere near as bad.

22. Moving into our current home in **GRO-B** was such a positive step for both of us. The nature of where we live is both spacious and beautiful. The positivity of our surrounding is a really good thing for **H**. He has started his hobby of stained glass work again and feels motivated to do more. Previously his lack of motivation was a massive problem.

23. **H** suffered ongoing fatigue even after clearing Hepatitis C. The ongoing level of fatigue is serious because frequently after breakfast **H** retires to the sofa to sleep.

24. Physically, the biggest change for **H** was when he underwent the Interferon treatment. Before this treatment, **H** could finish off a whole packet of chocolate biscuits and never put weight on. During the treatment **H** lost a substantial amount of weight. However, following the treatment **H** put on a fair amount of weight and now struggles to maintain his weight and easily puts it on. Physically **H** looks completely different now because he used to be so lean.

25. Unfortunately, he cannot join a gym or go for a run because of his bad joints; therefore trying to get any extra weight off him is a real problem. Equally, the extra weight he carries has a negative impact on his joints anyway; so it is a "catch 22 situation".

26. In the winter months **H** suffers especially as simple illnesses such as the common cold can have a really bad effect on him.

27. The impact on me extends back to our wedding day. When we got married, we had no idea how long we were going to have together. At that time, **H** was living with a death sentence. This is not something most people think about on their wedding day.

28. I feel eternally grateful that **H** is still here with me and that we have been able to have the life we have. Equally, I was very lucky with the job that I had throughout the years. Admittedly, it was not the best job but it paid well and

we managed to save, which enabled us to be able to purchase our current home.

29 [H] will hopefully live into his 80s. I once read that thyme boosts the immune system; so I always pop some into a casserole when cooking for [H]. We always laugh about that, and even to this day [H] says "*Don't forget the thyme*".

30 [H] would have loved to have had children. We have spoken about it. There were alternative methods of conception, such as sperm washing. For me, if it happened naturally I would have embraced it, but I would not have wanted to go through the rigmarole of such traumatic intervention. The choice of having children naturally was taken away from us and it was a difficult situation to come to terms with.

31. I was never the person who had to have children at any cost and recently, I was talking about my great-nephews to a sales assistant in a shop. She misunderstood and asked how many grandchildren I had. When I told her that I had no children her face glazed over with a look of horror. People's reactions, when I say I have no children, can be hurtful.

32. I never told my employers that [H] was infected. When [H] had to give up work and friends or colleagues used to ask why, we told them that it was due to his severe arthritis. I dealt with my feelings alone and by talking to [H] because I did not want to speak to other people about our private lives.

33. Most people who we know and whom we have now told about [H] infections are fine because most of their lives they've known us as people as opposed to "*people with this*". Nearly everyone has been extremely supportive. But I do wonder if we had disclosed it earlier, or at a time when the Inquiry had not started, whether I would have got the jobs that I did and enjoyed the same acceptance from people.

34. We are still new to the village where we live, and we have therefore not told any of the locals about [H] infections.

Section 6. Treatment/Care/Support

35. [H] did not have any difficulties or obstacles in relation to accessing medical or dental care. [GRO-B] put [H] in touch with a local dentist who was happy to treat patients with HIV. When we moved to [GRO-B], [H] new dentist did not bat an eyelid about his HIV status and treated him like a normal person.

Section 7. Financial Assistance

36. In approximately 1991, [H] received £10,000 from the MacFarlane Trust. Considering that [H] and I were living together and were engaged to be married, we pursued and successfully obtained the uplift payment of £32,000.

37. [H] also received about £200 per month from the MacFarlane Trust until about 2010. This increased to £10,500 per annum and gradually increased beyond this figure. He now receives approximately £18,000 per annum from the Macfarlane Trust.

38. [H] received the Stage 1 payment from the Skipton Fund which was a total of £20,000. However, due to lack of cirrhosis of the liver, [H] application for the Stage 2 payment was turned down.

39. [H] receives the SCM payments. The application process for these payments was particularly difficult.

40. We applied for grants for washing machines and bedding.

41. The amounts of grants and payments took into account my income. [H] monthly payments were reduced as a result of my success at work. I believe that this was unfair and I believe that we were penalised by the Trusts which were, ultimately, not fit for purpose.

Section 8. Other Issues/Conclusion

ANONYMOUS

42. I want to find out what happened and why. This tragedy affected so many lives in such a horrific way.

Anonymity, disclosure and redaction

43. I confirm that I want to apply for anonymity and I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..... **GRO-B**

Dated..... *11 FEBRUARY 2019*