

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3234001

Exhibits: WITN3234002

Dated: June 2019

INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF GRO-B

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I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B 1961 and I live at GRO-B GRO-B with my husband.
2. My husband GRO-B: H (born on GRO-B 1966) is co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated Factor VIII (FVIII) concentrate. H has provided his own Witness Statement to the Inquiry (Witness Number GRO-B).
3. This witness statement has been prepared without the benefit of access to H's full medical records. Some of the the documents in H's possession are exhibited to his Statement.

**Section 2. How affected**

4. [H] has severe haemophilia A, diagnosed at 9 months old.
5. [H] first received treatment as a baby at St Mary's Hospital, Portsmouth. He was then under the care of the Department of Haematology at the Worthing and Southlands Hospitals as a child. [H] has been treated at the Guy's and St Thomas' Haemophilia Centre for as long as I have known him.
6. [H] was told that he had HIV in or around 1985, four years before we met. The information as to how [H] was infected with HIV is covered in [H]'s Statement.
7. [H] and I met in a nightclub in January 1989 and we started going out together soon after. Our relationship developed at a steady pace. [H] would pick me up, take me somewhere nice and drop me home. [H] presented to me as wanting to move things along slowly. At times, it felt like he was holding back in making a commitment to me. [H] told me he was HIV positive in April of the same year. By then it was too late in my mind to change my mind about wanting to be in a long term relationship with him. I had fallen for him before he told me. I said to [H] that we would get through it together.
8. I believe [H] to have been in a form of denial about his HIV status at first. I would accompany [H] to his routine haemophilia appointments in London. We travelled up by train together and as we approached London the mood between us would become sombre and our conversation would dry up. On our return journey the same thing happened in reverse. As the distance between us and London became greater, our mood would lighten and we became what I would describe as [GRO-B] and [H] again.
9. I refer to **Exhibit WITN3234002** being letters documenting [H]'s psychological state and his three attempts at suicide not long after he was first informed that he

had HIV. I cried when I read them. I recently found these documents amongst [H]'s medical records and brought them to [H]'s attention. He had no recollection of these events and has blocked out the trauma of it. The doctors at the time appear to have dismissed [H]'s distress as little more than a girlfriend issue.

10. When [H] and I married in 1992, it was planned by us in just 6 weeks. Everyone thought I must be pregnant. [H] and I had no idea how long he would have to live/we would have together. It should have been the happiest day of my life but I spent the morning of our wedding silently praying that we would have two years together and the rest of the day putting on a brave and happy [GRO-B] and [H] face for our guests. Everyone kept telling us how lucky we were to find happiness in each other and I kept thinking 'if only you knew'. No-one from my side of the family knew that [H] was infected with HIV, not even my mother. We kept our secret for the next 20 years or so. [H] and I have dealt with the knowledge of [H]'s HIV status alone, on our own.

11. Our very first (and only) home together was purchased in 1991 in my name because of [H]'s HIV status and limited life expectancy. [H] would have been rejected upon application for a mortgage and associated insurances.

12. It wasn't until 1997 that [H] was informed that he also had HCV. He had by then started to take anti-viral drugs to treat his HIV and his CD4 count had improved. A doctor of Australian origin (his name has escaped us) at Guy's and St Thomas' told [H] (and me) in a matter of fact way "Now that we have your HIV under control, we need to look after your Hepatitis C". He told us as if we should have known and it came as a shock to us. He said this virus would be more dangerous to [H] than the HIV now under control. This was more likely to kill him.

13. Some years later (in 2007) when [H] was being pressed into Interferon clearing treatment by his medical team at the hospital, Professor Geoff Savidge told [H] that he had been infected with HCV in 1974 when [H] was just 8 years old. [H] and I were taken into a side room and [H] asked when he was likely to have been infected. Professor Savidge responded with '1974' without using his computer for notes on [H]. [H] also asked Professor Savidge if he thought the treatment would work and was told NO. [H] and I thought that the team wanted [H] to agree to the treatment so that they could strike it off the list as tried but failed.

### **Section 3. Other Infections**

14. [H] received a letter in 2004 informing him that he may have been exposed to vCJD.

### **Section 4. Consent.**

15. I have seen [H]'s medical records and he appears to have been tested for hepatitis throughout the 1970s. The tests were undertaken without [H]'s knowledge or consent.

### **Section 5. Impact**

16. I have lived under a cloud of uncertainty as to when I am going to lose [H] for 30 years. Simple rituals that are common place to other people hold significance to me. With every Christmas that I have got the tree out to decorate I have always been reluctant to pack it away, wondering whether in doing so I am saying goodbye to my last Christmas with [H]. I have only enjoyed the last two Christmases without the same level of worry.



- 17 [H] and I had a meeting with [GRO-D] Haemophilia Nurse, before we married to discuss our plans. She asked us about children and we responded by saying that we had assumed that we would not be able to have any. At this, [GRO-D] commented "Good" as if satisfied. She was not interested in any other response. Inside myself, my world fell apart. No-one helped us to understand or offered any counselling or support. We later found out that there were advancements in treatment options to enable us to become parents eg IUI sperm washing. It is our one big regret not to have had children. [H] and I would have loved to have been parents and, later, grandparents. We led a double life, telling people that we just didn't want them. They probably thought that we couldn't but not in the way they might think. I would break down behind closed doors.
18. All the decisions we have made over the years have been made with [H]'s infections at the forefront of our minds to include affordability issues, remaining in our flat and the inability to plan for our retirement like other couples.
19. [H] was very reluctant to start treatment as he became mistrustful of the medical profession. He also didn't want our friends finding out because of the fear of stigma. When [H] started HCV clearing treatment with Interferon in 2009, the side effects were horrendous. I would only really see him and spend time with him at 20 minute intervals as he spent so much time in bed. He became extremely emotional. One evening I asked him if he wanted mash or chips for dinner and he burst into tears. He suffers with panic attacks and severe anxiety and depression to this day. He also suffers with chronic fatigue.
20. [H]'s Interferon clearing treatment attempt in 2009 was a particularly hard time for us both with him going through it and me watching. We then had the devastation of learning that the treatment hadn't worked. I can just remember bursting into tears with the haemophilia nurse. At this point our Hepatologist Consultant, Mr Terry Wong, just explained that there was no other treatment

available and it would be a few more years before anything. He just said "we need to keep you alive now [H]". My world fell apart again.

21. No further treatment was made available to [H] until 2015. We were repeatedly told how very expensive the new Harvoni treatment was. I would say "I don't care. You gave him this (HCV)". When [H] cleared HCV in 2016 with Harvoni Mr Terry Wong added "it's gone [H] but I can't promise you that you won't in the future have liver cancer. The damage has been done to your liver." The relief I felt when I learned that [H] had cleared the HCV was immense. I thought 'My God. Its gone' but then your next thought it 'But is it just in remission?'. We still have to go up to London for six monthly Fibroscans and Ultrasounds. We still go quiet to this day as we approach London on the train. I worry on a daily/hourly basis about [H] and the worry never goes away. He is my last thought when I go to sleep at night and my first thought when I wake.

22. Stigma and the lack of understanding and support in others has been difficult and upsetting for me and [H] even in this day and age. After my mother died in 2011 I confided in my sister about [H]'s infections and what we had been through when she asked me over the phone "what's going on (with me)?" She hung up on me after dismissing what I had to say with "Well that could happen to anyone who sleeps around". We haven't had any contact since that day. [H] and I have experienced the same negative reaction when we have recently told very good friends of ours and have been given a wide berth by them. If [H] had been diagnosed with cancer we would be swamped with support and care but because he has an 'infectious' disease we feel like we have been shunned.

23. There is still so much stigma in peoples minds. I had to call paramedics to the house for [H] a couple of years ago and made them write on [H]'s forms that he has HIV and HCV *through contaminated blood* via the NHS.

24. [H] has been unable to work since 1991 and we have struggled financially with just one salary coming in. We have had to remortgage several times and have only very recently been able to pay off the mortgage. My working life has been extremely tiring with a long commute resulting in me being out of the house from 7 am until 6 pm each day. I have worked for 34 years without any breaks and was offered redundancy in 2011. At this time (2011) and mindful of Mr Wong telling us that no other treatment was on offer and [H] had to stay alive, I grabbed redundancy with both hands thinking I would lose [H] very soon.

#### **Section 6. Treatment/Care/Support**

25. The only time [H] and I were offered counselling was when he started the Interferon treatment.

#### **Section 7. Financial Assistance**

26. [H] was a party to the 1991 litigation and had to sign a waiver to receive the payment. I remember it was like sign it or no one would receive anything. It was the year before we married and we had no idea that he had HCV or vCJD exposure.

27. [H] receives monthly payments from EIBSS. I think that the schemes need to consider outgoings as well as income in relation to means-tested payments. It is also wrong that the income of children in the household has been taken into consideration for some families. Of course these payments have recently changed, so no need for means-tested payments, but in my mind this is too little too late. We struggled in the 1990s onwards.

28. On one occasion (2008/2009 or earlier) they reduced [H]'s monthly payments because I was making a £200 monthly payment from my net salary towards my

work pension. The MacFarlane Trust (as it was then) told [H] when he contacted them by phone that they considered my £200 pension contribution to be an "unnecessary payment" and would not have it any other way.

29. The financial assistance available when [H] dies of a widows payment of £10,000 and monthly allowance is only paid out in the event that [H]'s death is associated with HIV or HCV and not in the event of an accidental death eg if he is killed by a bus. I would like to point out that I am unable to take out a life policy for [H] regardless. I cannot get one full stop.

30. There is no stability or certainty surrounding the payments [H] receives. They have gone up this year, but what happens if they are reduced in the future? It makes it impossible to plan for the future. In any event, the very fact that we are made to feel that we have to go and beg for support is wrong.

#### **Section 8. Other Issues**

31. I would like to finish with a little bit more about my amazing husband who throughout all of this has been the kindest, supportive, loving man I have ever met. He deals with everything thrown at him and is still the man I fell in love with in 1989. I sometimes feel powerless to support him but back in 1989 we said we would fight this to the end and I certainly will.

32. I would like the people or departments in Government to be found responsible for what they did to [H] as a child, just 8 years old. For all the pain we have suffered, for us not to have a family, grand children and a future ... dreams fulfilled. We have lost so much. Sorry is a word that is just not enough anymore.

#### **Anonymity, disclosure and redaction**

33. I would like to apply for anonymity.



34. I would not like 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

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Dated.....12.7.19.....