

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3629001

Exhibits: 0

Dated: December 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 live at GRO-B
GRO-B My date of birth is GRO-B I currently live with
GRO-B who is my lifelong companion. I am his full time carer
and make this statement, as GRO-B was infected with Hepatitis C, as a result
of receiving contaminated blood products.

2. GRO-B has provided his own statement to the Inquiry at GRO-B.

3. This witness statement has been prepared without the benefit of access
to GRO-B full medical records.

Section 2. How infected

4. I would like to refer to GRO-B statement in regards to how he was infected
and the information he was provided upon diagnosis.

Section 3. Other Infections

5. I would like to refer to **GRO-B** statement in regards to other infections.

Section 4. Consent

6. I would like to refer to **GRO-B** statement in regards to consent to treatment and testing.

Section 5. Impact of the Infection

7. **GRO-B** and I met in 1974 through shared interests of music and climbing and became partners soon after. In 1995, we split up because we preferred to be friends and **GRO-B** moved to Germany. He returned to the UK in the same year and since then we have remained extremely close friends. **GRO-B** did however agree to bring up my son who was four years old at the time we met and gave **GRO-B** two parents. We have never been in a sexual relationship and see ourselves as a partnership.
8. When I first met **GRO-B** I considered him to be an active and energetic man, who enjoyed climbing and cycling. He never allowed his suffering with haemophilia to get in his way and together we lived a very high quality of life. After receiving contaminated blood, his health declined very rapidly.
9. Within two weeks of his transfusion in 1985, he became very ill with jaundice and suffered from rapid weight loss, reducing from 15 stones to 8.5 stones. His urine was the colour of beer. It took him a whole year to recover.
10. From 1992 onwards, **GRO-B** continued to suffer from poor health and had to give up his job. He would go for six weeks feeling absolutely dreadful, but get up one morning and be as good as new. He would randomly fall asleep at any given time and struggled to cope with severe fatigue, joint pains and brain fog. He would often get lost in his own thoughts sometimes for hours on end. In addition to that, **GRO-B** gets extremely cold during winters, but during a heatwave, he struggles to breathe.

11. **GRO-B** also suffers from terrible headaches. Very little could be done to treat him due to ill health and a weakened immune system. To follow on from this, **GRO-B** also has to seek dental treatment as a result of getting constant gum infections.
12. From 2002 until 2016, **GRO-B** fell into chronic low level depression and would not get out of bed. The curtains were permanently drawn and even the dogs would not come inside. If I tried helping him, he would become frustrated and ask me to leave. As I was worried about him, I contacted the doctors who informed me that **GRO-B** was depressed and should seek medical attention. No matter what I tried, **GRO-B** simply refused to go to a hospital.
13. **GRO-B** now suffers from acute chronic emphysema. In the past, he used his inhaler twice a day, however more recently he has to use it almost every 15 minutes.
14. In regards to treatment, **GRO-B** decided not take the Interferon treatment that was also being tried out on people with serious addiction issues, because he did not trust the health authorities.
15. Instead of having the Interferon treatment, **GRO-B** used self-help homeopathic remedies (with my help,) such as acupuncture and milk thistle, which have been scientifically proven to help the liver. I also paid a lot of attention to his diet. We changed our lifestyles and only ate organic food produced locally. He also pursued meditation and yoga, which helped his mental state.
16. When **GRO-B** first started acupuncture treatment, it cost us around £40 per hour. The NHS partially funded it, however they eventually stopped contributing. This was ridiculous as **GRO-B** had saved the government so much money, by not pursuing Interferon and only minimally had he used the NHS services throughout his lifetime. In total, the homeopathic remedies cost around £200 to £300, which we self funded using our meagre income.

ANONYMOUS

17. To get **GRO-B** weight back up, he received advice from doctors to eat a lot of food, to include junk food. He spent his life eating a good diet, involving only organic food. He cannot simply start eating fish and chips everyday, as that would impact his health in other ways.
18. In 1995, **GRO-B** and I decided to part ways. At the time we were both raising **GRO-B** who was 25 years old at the time. We were both getting extremely short tempered. **GRO-B** was no longer able to do simple things like pick up bread from the bakers or help around the house. This impacted on our relationship and since I did not know what the cause of his behaviour was; I was not empathetic. I had to think of myself and my son's well being.
19. Thereafter, **GRO-B** left for Germany. Unfortunately, he returned immediately after I received a letter in the post disclosing his diagnosis of Hepatitis C. I did not open the letter before getting **GRO-B** permission so I phoned him. We were both shocked. On **GRO-B** return, I had a long discussion with my family regarding the situation we were in and I decided that from that moment on, we would care for **GRO-B** I just had to take care of him. In my family, once we made a commitment like that we do not go back on our word. We adopted **GRO-B** as though he was our own. The family decided to include him as our own family member (his own mother died when he was 15 years old.) My parents, my siblings and my extended family loved him from day one.
20. In terms of our social life, it has been difficult to host gatherings with friends and family. As a host, I have to ensure that none of our guests have colds or flus, as **GRO-B** would catch it from them so easily. This is very upsetting for both of us as when we entertain, we entertain big. It is like living in a care home and as a precaution, we have stored flu jabs in the house.
21. Even with our granddaughter, we have to be cautious. At times, **GRO-B** and his family have had to stay in a Bed and Breakfast nearby, when they wanted to visit. **GRO-B** would then remain standing by the door and wave as our granddaughter stood by the gate. He cannot even hug them. Sometimes, he

ANONYMOUS

had to make do with talking on the phone. This was disheartening as he adores children.

22. As **GRO-B** was a climber who had long hair, people would often ask if he contracted Hepatitis C through drug abuse and if he was using heroin. This was a common misconception.

23. When **GRO-B** was well, he was the general manager of a furniture shop, called **GRO-B**. He would make furniture from scratch and create special designs unique to each customer. Unfortunately, he struggled to cope due to the brain fog and physical exhaustion. He gave this up in 1992.

24. In 1992, **GRO-B** earned £35,000. Considering inflation and the fact that everything was handmade, that value would have been at least £60,000 now. The financial loss in this alone is incalculable.

25. On **GRO-B**'s return to the UK, he was initially offered a council home, but it was appalling. The council remit was to move drug addicts across the whole estate and that was really affecting **GRO-B**'s mental state of mind. I decided that **GRO-B** should move into my home and that we would live as flatmates.

26. In 1997, we chose to move from that property to a better location that was quieter (our current address in **GRO-B**). It was a much needed change; however on the sale of the property, we did not receive much. Our current property is rented and we pay £800 per month. Luckily, we were granted a long term lease of 28 years as **GRO-B** had previously undertaken furniture work for the landlord.

27. The property was derelict at first and required a lot of work. Financially, it was difficult to raise the money, as **GRO-B** was retired and I did not qualify for Carer's Allowance until 2018. At the time, **GRO-B** received Personal Independence Payments (PIP).

28. In 1997, [GRO-B] was awarded Disability Living Allowance (DLA) for life. For the application we liaised with a representative from the DWP, who was training to be an occupational therapist. He was only 22, but was extremely rude and ignorant. By way of example, he asked [GRO-B] when he had caught haemophilia. Furthermore, he refused to accept that I was [GRO-B] spokesperson and kept asking me to leave the room. I kept trying to explain to him that [GRO-B] was distressed and unable to comprehend what he was saying. From [GRO-B] previous PIP application, they should have known that I was his spokesperson and it should not have been disputed like it was.

29. Recently, instead of giving me Carers Allowance, the DWP gave me Pension Credit. This means that instead of getting £64 weekly, I now receive £32 monthly due to me being over the age of 60.

30. Aside from the proprietary aspect of finances, as I mentioned, instead of relying on the NHS for treatment, thus saving government funds, [GRO-B] chose to use homeopathic remedies and incurred a considerable cost. As we never thought we needed them, we never kept any receipts or proof of such treatments.

Section 6. Treatment/care/support

31. No counselling or psychological support was made available to me, as a result of [GRO-B] being infected.

32. All psychological support was self-funded and undertaken privately.

Section 7. Financial Assistance

33. I would like to refer to [GRO-B] statement in regards to the topic of financial assistance.

34. I want to add that as [GRO-B] representative and spokesperson, I have faced difficulties in convincing people that I speak on [GRO-B] behalf, as he is

ANONYMOUS

unable to handle these things himself. They simply do not believe me as I am not, (strictly speaking,) a family member.

Section 8. Other Issues

35. Little did any of us know, that during the ten years after we met and through various treatments and being the recipient of blood products, that we would be looking at **GRO-B** chronically ill for the rest of his life.

36. I would like to highlight that the blood products which he received, we later found the batch numbers were not filed and subsequently destroyed.

37. No one in the medical profession admitted anything until he was finally diagnosed in 1995 and then was told he was in the new CJD watch list!

Anonymity

38. I wish to remain anonymous.

39. 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

GRO-B

11/11/2019