Witness Name: GRO-B
Statement No: WITN1701001
Exhibits: 0
Dated: October 2022

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 1945, and I live a GRO-B GRO-B

2. My daughter, GRO-B: D (born GRO-B 1970), was infected with the Hepatitis C Virus (HCV) through contaminated blood products.

3. This Witness Statement has been prepared without the benefit of access to my daughter's full medical records.

4. D has provided her own Witness Statement (Witness Number GRO-B). This Witness Statement should be read in conjunction with her Statement.

Section 2. How Affected

5. D's father GRO-B has Haemophilia A. When D was 7 years old, we were told that she is a haemophilia carrier with low factor levels. D and her father were both treated (with Cryoprecipitate) at the Haemophilia Centre at the Royal Free Hospital (RFH).

6. I was very familiar with the doctors at the RFH to include Dr Dormandy, Dr Kernoff, Dr Toddenham and Dr Eleanor Goldman as I met GRO-B in 1963, and went with him to his appointments.

7. D was infected with HCV through a contaminated batch of Factor VIII (FVIII) concentrate administered to her when she had a tonsillectomy in 1980. She was at that time under the care of Dr Goldman at the Haemophilia Centre, and was cared for by John Win, Registrar, for the tonsillectomy. It was the first time that D was treated with FVIII concentrate. Her treatment was changed without our knowledge and consent.

8. D only found out that she had been infected with HCV in 1995, after 15 years of very poor health. I saw (and videoed) a Panorama programme linking HCV to blood products and transfusions. All the reported symptoms of HCV matched D's symptoms. I immediately rang D and said 'I know what is wrong with you'. As a result, D asked a nurse at her appointment at the RFH if she could be tested for HCV. The nurse initially laughed at D and told her that she wouldn't have it before checking her notes and telling her that she had actually tested positive for the virus in 1991.

9. D subsequently saw Dr Goldman who was quite blasé about the matter. She told D little was known about the virus, and it may not affect her for 20 years. Moreover, she told D that she was 'lucky' she didn't have AIDS.

10. No advice was given to us about the risk of infection through blood products and we had no idea that her treatment had changed. We were never informed. D found out many years later (in or around 2002 when she obtained some of her medical notes) that she had been given FVIII concentrate (on several occasions). No-one ever discussed it with D or us. Despite Dr Goldman's apparent lack of concern, D also found out that Dr Kernoff had directed D's GP to perform liver function tests on a two-week basis. These tests were never carried out. We knew nothing at all about it. D knew nothing about it (until she saw her own notes relatively recently). Dr Goldman, Dr Kernoff and the GP didn't make sure that D had any liver function tests at all, not least every two weeks. That appals me. To me that is the worst of it.

Section 3. Other Infections

11. Whilst at the RFH, D saw (and took a photograph) of a note in her record that she had tested positive for the Hepatitis G Virus. This has never been discussed with her and was not in her notes when she applied for her medical records.

12. D received a letter in 2004 stating that told her she was at risk of vCJD.

Section 4. Consent

13. D was most certainly used for the purposes of research. We, D's parents, should have been told that D had been given FVII treatment (not just once but on several occasions). They D's clinicians, knew that she had been placed at risk. The previously untested patients (PUPs) were cheaper than chimpanzees for testing.

14. I was never informed that D was being tested for HIV when she was 13 years old (or at all). It was only D, Dr Goldman and a social worker named Reeva Miller who were present at the time of testing. I was absent.

15. None of us were told or consented tc D being tested for HCV in 1991.

16. I spent 15 years trying to find out what was wrong with my daughter. D was a normal, active and healthy girl until she had the contaminated treatment. After the treatment, her character changed. She was tired and sickly and would take herself off to bed. Her legs ached, she had weight issues and her face looked bloated.

17. In 1981 (the year afte D was treated with the contaminated FVIII batch), D spent 6 weeks in hospital, having been placed on a 500 calorie (daily) restricted diet. I remember that GRO-B was suffering with a painful knee bleed and needed treatment. A junior doctor, Dr Blundle (I think her name was), examined GRO-B (on D's hospital bed) and said 'I don't want to give it to you'. I intervened and explained to her that haemophiliacs suffer with joint damage from unseen, internal bleeds, and that my husband (a haemophiliac from birth) was in agony and that if he said he had a bleed, he had one! I will never forget her words in response 'It is not always good to have treatment, no matter how bad it is!' I believe to this day there was a hidden message there that she way trying to convey to us.

18. I was so certain that D had a problem with her health, that I became fixated with it. I had no way of connecting the problem witl D's treatment. I was told that D's aching legs, were growing pains and that her weight issues were somehow our doing. Dr Howard, D's Paediatrician, accused us of sabotaging D's weight loss/hospital admission by bringing food into her. I was pretty much dismissed by the RFH doctors as being some sort of nutcase. They would run off when I asked to talk to them. Dr Goldman was downright

rude, and I never really met Dr Lee as she wouldn't come out of her office. I took D to Dr GRO-D at the Oxford Haemophilia Centre for a second opinion. He was worse than useless, telling me that there was nothing wrong. I developed an under active thyroid and paid privately for tests to try to ascertain whether or not D had the same problem. She was a different child and I knew it.

Section 5. Impact of the Infection

19. D's work suffered as she could no longer concentrate. Her school contacted Hertfordshire County Council School Psychology Service as they were so concerned. She would come home from school absolutely exhausted and she started to struggle academically. When D left school at aged 16, she had only obtained four GCSEs.

20. D went on to work as a nursing assistant dealing with mental health patients. She was permanently tired and drained and would frequently suffer from aches, pains, rashes and bloating.

21. Our whole family was affected. D's father walked out when she was just 12 years old. As a result and in retrospect I asked too much of my son for support to include asking him to look after D and take her under his wing. I think that took it's toll on him. I very much regret that.

Section 6. Treatment/care/support

22. D has never been offered counselling. At one stage she made enquiries about receiving counselling, but this was never followed up.

Section 7. Financial Assistance

23. D was denied any payment from the Skipton Fund as she was deemed to have self-cleared the virus within six months. She had to fight that decision. She had to fight to obtain her medical records.

Anonymity

24. I wish to remain anonymous and I understand that this redacted Statement will be published by the Inquiry.

Statement of Truth

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

Signed. GRO-B

Dated......24th October 2022.