Witness Name: GRO-B
Statement No: WITN5653001
Exhibits: 0
Dated: MAY 2021

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 1969 and I live at GRO-B Ireland.

2. My ex-husband, GRO-B:H (born on GRO-B 1959), is co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products.

3. This witness statement has been prepared without the benefit of access to a full set of H's medical records. I have a limited number of his medical records only.

Section 2. How Affected

4. H has mild Haemophilia A. He was under the care of Professor Christine Lee and her team at the Royal Free Hospital (RFH) in Hammersmith for his appointments. However, he very rarely needed treatment and it was only ever provided to him in a hospital setting.

5. H was given contaminated Factor VIII (FVIII) concentrate manufactured by the Armor Pharmaceutical Company, Batch Number W92508, administered to him at the GRO-B on 30th November 1982. H had an accident and sustained an injury wherein most of his finger was severed. He was 23 years old. He hadn't needed treatment for many years beforehand.

6. H was told that he had been infected with HIV on 17th June 1985. He was identified as being infected with HIV from a blood sample taken in February 1985.

7. H wasn't informed that he had also been infected with HCV until some time in 1994, when I was pregnant with our first child. I was tested for HIV and H found out that he had HCV when I was given the result. I was told that I was HIV negative and I was told that I was also negative for 'Hepatitis C'. I said 'Hepatits C? What is that?' I didn't even know that I had been tested for HCV and had not provided consent. Professor Lee then told H that he was infected with HCV, hence her concern. It was presented to H casually, as an incidental infection as though it was something H should have been aware of previously. He wasn't.

8. No information and/or advice was given to us to help manage the infections. I had to ask all the questions over time. I literally had to pull the information out of them. You just don't know what you don't know.

9. H was not prewarned of any risk before he had FVIII concentrate. He should have been told that he had become infected with HIV and HCV much sooner.

Section 3. Other Infections

10. Some time in the very late 1990s/early 2000s, I applied on H's behalf for his medical records and we found out that H had been placed at risk of a possible infection of variant Creutzfeldt-Jakob Disease (vCJD) through blood products from a FVIIII donor who had died from vCJD.

11. When the records arrived, the FVIIII batch recall letter sent to the RFH was left there at the top of H's file (by Professor Lee I believe). The letter also specified that the RFH should not tell their patients the reason (the vCJD risk) for the recall.

12. H and I remembered the recalled FVIII because, as stated, H very rarely needed treatment. H and I went together to the RFH when he had an accident at home in the late 1990s. I remember that it was a Saturday and the nurse went to get some FVIII concentrate because H was bruising badly. She came back into the room after 10 minutes and said she had not been able to find it in the fridge but had eventually found it in reception. After seeing the file and the recall letter, we realised that the batch known to be at risk (and administered to H) had been left in reception after the recall and was waiting there for collection and return.

13. I started campaigning for an Infected Blood Public Inquiry alongside the campaigner GRO-B and I gave a story (anonymously) to my local GRO-B newspaper. It was then picked up by the BBC for a 6 pm news report. My motive and emphasis for the story was to highlight the pattern adopted by the health authority in failing to tell patients about HIV and HCV. They had now 'done it again' with vCJD. Professor Lee was interviewed, and

she expressed her own dissatisfaction during that interview at being directed not to tell patients that they had been placed at risk (and 'fair play' to her).

14. After that, I remember asking Professor Lee to put H on recombinant treatment. She refused, citing the Government guidelines of the time to refuse recombinant treatment to those infected with HCV. I remember saying 'So, it's a matter of H being told to piss off and die then, is it?' She did not respond. We later learned that H's HCV infection had cleared itself and had been at undetectable levels from around the late 1990s onwards. He was not informed that he was clear of HCV until quite some time later.

Section 4. Consent

15. H was tested for HIV and HCV without his knowledge and consent. I was tested for HCV without my knowledge and consent.

Section 5. Impact of the Infection

16. I met H when I moved into his flat in GRO-B as a lodger, a year after moving from Ireland to England in 1989. The (three bedroomed) flat was owned by H's grandmother but she allowed him to take it over and he rented the other two rooms. I had one room and the other was occupied by a nurse. I did not know that H was infected with HIV. H and I started dating but I was unclear where I stood with him and whether the relationship was going anywhere. We were both very involved in the local Church. H had some friends there that knew he had HIV, but he wouldn't tell them that we were together. He was afraid that, if he told them, they would then tell me that he had HIV.

17. After a while, I told H that I needed some commitment from him, and he said that he needed to tell me something first. He eventually told me that he was infected with HIV and how it happened, and I told him that it didn't matter to me. H took a real leap of faith in telling me. HIV/AIDS was known to

be a death sentence and people were dying all around us. Everyone was afraid. H confided in the nurse we lived with and her (bad) reaction was very upsetting to H. She told him that everything he came into contact with needed deep cleaning and that even the door handles should be washed down each time he touched them. I recall an MP at that time saying that everyone infected with HIV/AIDS should be isolated on an Island and left there.

18. I don't know much about the circumstances in which H was first told about his HIV diagnosis, at aged 25, although he told me that he 'hit the bottle'. Ironically, at the exact same time that H was told that he had HIV, I was learning all about it, at aged 15, from a forward-thinking teacher at school in Ireland.

19. After H told me that he was infected, I went with him to all his haemophilia appointments. I pushed for a lot of information to include information about H's treatment and care. H was very compliant and went along with whatever they suggested. H is also dyslexic which doesn't help. He has had a rough journey although he always says that other haemophiliacs had it worse.

20. H and I married in GRO-B at our Evangelical Church in 1991 and we had our reception at the GRO-B. I came from a large family and they were opposed to the marriage. It was very difficult. My father refused to come to the wedding and would not give me away. My sister said that it didn't feel like she was going to a wedding, it felt like she was going to a wake. I had no support from my family whatsoever and there were friends we were never able to tell at all.

21. When we told Professor Lee of our intention to start a family, she was horrified. She said 'Why would you want to have a child with a man who is HIV positive? You need to use a donor's sperm'. I burst into tears and said 'I don't want another man's baby'. I looked at H and said 'Do you want me

to have another man's baby?' to which he said 'No'. Professor Lee said 'Sorry, we are still learning'. It was a very scary time.

22. When I was pregnant with our first child, one of two sons, in 1995 my mother's exact words to me were 'Well, I'm sorry to hear that. I give you my condolences'. I will never forget her words.

23. Riva Miller, the Social Worker at the RFH, was very good and supportive during my pregnancy and they were relieved there when I tested HIV negative at three months gestation. They wanted me to have my baby at the RFH, but I had him at Edgware Hospital where I worked, on GRO-B 1995. I knew the nurses there and the midwives were brilliant.

24. H maintained a low viral load count for quite some time. He was involved in one of the first AZT (initially used for cancer treatment) trials although we later found out that he had been given a placebo. When he was asked to join a second trial, I was against it as we were told that on this trial there would be no placebo and that an AZT combination would most definitely be used. We had previously been told H would be denied a treatment if they later found a cure for HIV with the use of AZT and H had already been part of that trial - as this drug could only be administered on one exposure. I reminded the lady doctor (under Professor Lee) of this as our reason to refuse it. Her response was to say, in front of H, 'He won't live long enough to get the cure'. We were shocked and stunned at her lack of compassion and sensitivity. I couldn't believe that she said that about H in front of him. It was just horrible to hear.

25. H had all his dental appointments at the RFH. I went there with him once and they came out in full PPE from top to toe to include a face screen. I was taken aback. I just thought 'Oh God. This is horrible.'

26. H worked for a marble table and counter wholesaler and later for a whole food company. We used the first payout from the MacFarlane Trust (MFT) as a deposit for our first house. We weren't able to tell the mortgage company

that H was infected, and we have never had life insurance. When H talked about things like life insurance I would always cry, not because we didn't have it but because he was going to die. H did very well to keep working. He suffered with his health and sleeps very, very badly. He was constantly tired and would fall asleep all the time, even in company. I lived in a constant state of anxiety. I worried if H had a cold or at any sign of illness. It was a terrible cloud to live under, never knowing whether each day could be the last for him.

27. H suffers with chronic depression and has suicidal thoughts and ideation. He has high blood pressure, high cholesterol as well as suffering with insomnia/sleepless nights. The depression and suicidal ideation placed a huge strain on our family and it was a terrible strain for me to be without the support of my family. I returned to Ireland in 2002 when it all became too much for me. H later followed me there and we reconciled. It has been a long and very hard journey for us. We were twice married and twice divorced. Our second son was born in 2012 in GRO-B During the pregnancy the midwife registering me for anti-natal care informed Social Services that H was HIV positive without telling us (and without gaining our consent). We found out about it after the fact.

28. We are very protective of our two sons. We live in a rural Irish community and our youngest is only 8 years old. If people in our community got hold of this information, we would be ostricised. H and I are still close. We are very good friends and are very supportive of each other. H is a good father. I see him every weekend when he comes to collect his son and we have dinner together. We have been through a lot together and would otherwise still be together. All of his issues have arisen through being co-infected with HIV and then HCV.

Section 6. Treatment/care/support

29. H's memory is affected through taking the HIV medication.

30. H has self-cleared HCV spontaneously as his HCV levels have been undetectable from 2000 onwards.

31. Our stress and anxiety levels have been very difficult to manage at times. It is stressful being married to someone with HIV, the stigma, the hiding of it and not being able to discuss it. I've had difficult and awkward conversations with people, the worst being my family. In recent years I have had more contact with my family. They were terrified that I was going to die and couldn't understand why I would want to risk having H's children. My close friends became my family when I was lacking in the support I desperately needed. I had some counselling with Riva Miller. I trained as a bereavement counsellor and worked for Cruse organisation whilst in England. I am now training to be a psychotherapist and am in my final month and year.

Section 7. Financial Assistance

32. I refer to H's Statement.

Anonymity, disclosure and redaction

33. I do seek anonymity and understand that my 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......30.07.2021...