

Witness Name: GRO-B

Statement No: WITN3579001

Exhibit: WITN3579002-8

Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS 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 1963 and I live at GRO-B
GRO-B
2. My partner GRO-B: P (born on GRO-B 1967), was co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV), genotype 1b, from contaminated blood products. He died from treatment of a High Grade (Non-Hodgkins) Lymphoma on GRO-B 2019, aged 51.
3. The witness statement has been prepared without the benefit of access to P's full medical records. I have exhibited the relevant documents I have in my possession to this Statement. The notes in my possession were read by P before he died and he marked/flagged up segments he believed to be relevant.

Section 2. How Affected

4. [P] had severe Haemophilia A with inhibitors.
5. [P] was treated at the Haematology Department at St George's Hospital, Blackshaw Road in London under the care of Professor Flute, Dr Parker-Williams, Dr Lee, Dr Hill and Dr Bevan. [P] transferred to Guy's and St Thomas' Hospital under the care of Dr Rangarajan in 1999 and was latterly treated (from 2009) at the Bristol Haemophilia Centre under the care of Dr Mumford.
6. I refer to **Exhibit WITN3579002** being [P]'s National Haemophilia Database record. According to that record, [P] was treated with Cryoprecipitate initially and then FEIBA, Factor IX (FIX) and Factor VIII (FVIII) concentrate from 1978 onwards. According to the same record, [P] tested HIV positive on 30th January 1985 and was identified as being jaundiced on 12th June 1984.

HBV

7. I refer to **Exhibit WITN3579003** being documents from [P]'s hospital notes confirming that [P] was found to have HBV on the 21st June 1984. It is noted that [P] 'almost certainly' acquired the HBV infection from either Factorate made by the Armour Pharmaceutical Company or FEIBA. The product batch numbers are provided in the documents contained in both Exhibits.

HIV

8. I refer to **Exhibit WITN3579004** being documents from [P]'s hospital notes pertaining to his HIV diagnosis in 1985. It was noted on 11th September 1989 that [P] was infected from a batch of product 'supposedly given in 1981/2'. It is also noted '? No written documentation in notes' and 'HIV though no

documentary evidence in this folder'. There are gaps with missing documents in [P]'s medical notes and records. Some of the lost information in relation to HIV seems to be missing from before September 1989.

HCV

9. I refer to **Exhibit WITN3579005** being documents from [P]'s hospital notes confirming his HCV diagnosis. [P] appears to have been identified as being HCV positive from 19th February 1992 and the last document of the Exhibit states that he acquired HCV 'from concentrates pre 1985'.

[P]

10. [P] told me that he was just 18 years old when he was informed that he had HIV in the latter part of 1985. [P] was with his mother at a routine haemophilia appointment when he was told. He was informed of the diagnosis in an offhand, matter of fact manner. It was just dropped into the conversation by way of chit chat. He was not mature enough to fully understand the gravity of what he was told and could not take it in. He then left to digest the information.

11. At a subsequent appointment [P] was told that he had a maximum of 10 years to live. He was told that there was no treatment available and that he would die of AIDS.

12. [P] said he found out that he had HCV much later. He only found out that he had HCV by accident, having seen it reported in a letter from the hospital. Contrary to what is stated in his notes, no one sat him down and told him he had HCV and he wasn't offered any counselling or anything like that.

- 13 [P] and his parents were never warned of the risk of infection before being given blood products even when they questioned the risk. Referring once again to **Exhibits WITN3579003 and WITN3579004**, the known risk of hepatitis in January 1979 was 'played down' and [P] and his mother were told within days of the HIV positive result in 1985 'that the new FVIII conc. is AIDS free'.

Section 3. Other Infections

14. I refer again to **Exhibit WITN3579002**. [P] was confirmed to have been at risk of variant Creutzfeldt–Jakob Disease (vCJD) in 2004. [P] was never informed. We knew nothing about it. I refer to **Exhibit WITN3579006**. [P] was infected with Cytomegalovirus (CMV) in 1983 having also been tested for Epstein-Barr Virus (EBV).

Section 4. Consent

- 15 [P] was tested for infections without his or his parents' knowledge and consent. Referring again to **Exhibit WITN3579003**, [P] was tested for HBV due to the known hepatitis risk from 26th July 1978 onwards (if not before). In 1983 he was also tested for CMV, EBV and the Hepatitis A Virus (HAV).
- 16 [P] also believed that he was treated with blood products for research purposes. He believed that he and other young haemophiliacs were used as guinea pigs for testing purposes for the financial benefit of the pharmaceutical companies being able to charge large amounts of money for their products. [P] had bouts of depression and challenged his worthiness in society as a result. In being treated as a guinea pig his value as a human being was lost and it made him feel awful.
- 17 [P] and I also both took part in a two year research study conducted by the Southmead Centre in Bristol into the behaviours of those infected with HIV and

their non-infected partners. During the study I was tested for HIV every three months.

Section 5. Impact

18. Having severe haemophilia, inhibitors and spontaneous heavy bleeds for no reason were massive problems for P. To find out that he had HIV on top of that put extra strain on him psychologically. P became very depressed. P was extremely bright and could have done anything with his life but he left school without qualifications. He watched as his friends went off to university. If things had been different I have no doubt that P would have gone into journalism or politics. He was so sharp and articulate. P's relationship with his father deteriorated. His father accused him of being lazy and they had huge arguments. Apart from being depressed, P was always tired. When he found out that he also had HCV at that time, the fatigue made sense to him.

19. HIV was a huge family secret because of the stigma. P and his parents were distraught watching the adverts on the TV, knowing that P would probably die a painful death. He, his younger sister and his parents kept it to themselves for fear of being ostracised. As soon as the gravity of the HIV diagnosis and his 10 year life expectancy hit P, he wanted to get the most out of his time left as he could. He pretty much went off the rails, drinking and partying.

20. P had a few girlfriends but he used condoms. He was worried about passing the virus on. He was blasé about his life believing that he had very little time left but he was very careful and responsible towards other people.

21. When P received around £20,000 from the 1991 HIV litigation, he was 24 years old. He was compelled to sign the waiver before he was given it. He formed a friendship with someone similarly infected and they each blew the money they received drinking and partying.

22. P then met his future wife and their son was born in 1995. They married around GRO-B years later. Their son was the ring bearer. P worked for a while as a GRO-B but he was retired on medical grounds not long after the wedding. P said that the marriage was under a great strain and that it was actually doomed from the start. In or around 2001 they moved to Somerset in the hope that a fresh start would save their marriage.

23. P then started his own business in Somerset, working as a GRO-B. He managed that for 10 years as he could cancel the lessons when he felt particularly unwell.

24. P's marriage broke down shortly after they moved to Somerset. Because of P's short life expectancy he gave his wife the proceeds of sale from their jointly owned property in order to meet her housing needs and those of their son. P ended up in a small flat in a GRO-B. I refer to **Exhibit WITN3579007** being a comment written by P before he died with the intention of providing evidence to the Inquiry.

25. P and I met in GRO-B in 2005. He was the love of my life. We were soulmates. P was a very private person. He was secretive about his health issues even about his haemophilia but not long after we met and had got to know me a little better, he told me everything. It all came out in just one, but long, evening. He was shocked by his own candour. He said that I was the first person he had been able to really open up to. He had been stuck in a bubble of silence with so many problems but with nobody he felt that he could trust and/or feel comfortable to talk to.

26. He was then still under the care of Guy's and St Thomas' Hospital and was journeying to and from London. He would be out all day for a mere 10 minute

appointment. When he transferred to Bristol in 2009 I was able to accompany him to all his hospital appointments right up until he passed away.

27. Aside from the problems P had with his joints and mobility, P suffered with fatigue, insomnia, digestive problems, glaucoma, high blood pressure, asthma, respiratory infections, kidney and liver damage, heart problems, depression and confusion/foggy memory.

28. P had had six months of HCV Pegylated Interferon and Ribavarin clearing treatment before we met in 2002. He said it was awful. At the end of the six months and because of his genotype he still had HCV. Many of the side effects of the treatment stayed with him and worsened to include the depression, chronic fatigue and foggy memory mentioned at paragraph 27. P's GP put him on antidepressants to boost his mood as he was completely sapped of energy. He eventually came out of it. He always found something that brought him round. He was angry about what had happened to him but he was incredibly positive and did not want his illness to define him. He had previously felt powerless and unable to talk to and/or confront anyone but in the late 2000s he started campaigning about the contaminated blood scandal.

29. P commenced HIV anti viral therapy in September 2010 and was on a variety of powerful drugs with various side effects to include headaches, nightmares, insomnia, night sweats and tremors, malaise, nausea, abdominal pain and gastro issues and painful and regular diarrhoea.

30. P had a second attempt at clearing HCV in 2016. It was tough on him. I recall that he used to complain that he felt foggy and confused, his concentration levels were low and it took even longer for him to process stuff but it was successful.

31. P's health took a serious downturn last year. At the end of July 2018 he noticed he had a lump behind his ear. We did not think it serious but then P complained of ear ache and the lump grew bigger until the size of a thumb nail. Moreover it was moveable. It took two weeks before P finally had an appointment at his GP and was immediately sent for an emergency ENT appointment at Musgrove Park Hospital. This resulted in a PET scan, a needle biopsy and was fast-tracked to an oncologist all in the space of 10 days. On 1st or 2nd September 2018, P was diagnosed with stage 4 Non-Hodgkins Lymphoma.

32. We were devastated but the doctors told us it was treatable with 6 months chemotherapy. The medical consultations were a three way affair with the involvement of P's oncologist, the haematologist and his HIV consultant. It was essential that the chemotherapy was going to be compatible with P's haemophilia and his HIV treatment drugs.

33. P had three weekly visits to the Oncology Department. He first had an all day treatment session followed by subsequent half day ones. Two of his inpatient chemotherapy sessions lasted the entire week to target the cancer and (hopefully) prevent it from spreading to his brain and spine. As Christmas approached P had a bad infection in his toe and was put on a massive dose of antibiotics. He looked like hell. He had no hair and had lost a ton of weight but he still maintained his sense of humour and was fighting it.

34. On 31st December 2018, P had his very last chemotherapy session having by then been given the all clear. P was due to start an Open University degree course in History and Politics in GRO-B 2019. He was very courageous to apply given his health and cognitive issues. We were determined that GRO-B 2019 was going to be our new start but due to lack of immunity, P caught a cold GRO-B and was completely wiped out. The doctors

advised us that as long as P had no temperature and felt reasonably well he could stay at home and so I returned to work the week commencing GRO-B

GRO-B

35 P was upset that he had not been well enough to buy me a GRO-B present and we promised it would be the last time we celebrated without exchanging presents. With that on his mind and unbeknown to me, P went out to town the day before my birthday to buy me a present. GRO-B I woke up to lovely birthday presents. I was very upset with him for going to the shops when he was so unwell. GRO-B I left him in bed. He was sleeping well for once. He did not sleep well throughout the duration of our relationship. He came downstairs at around 9.30 am and he looked awful. He had an elevated temperature and I got on the phone to the cancer centre. They took him in and treated him for sepsis (unconfirmed) and (after a chest x-ray) said that he might also have flu.

36 P was quarantined in a side room with a bio-hazard sticker on the door and very little nursing care. I spent as much time at the hospital with P as I could only returning home to see to our two dogs. We were then able to Face Time each other. He had an oxygen mask which left him with a dry mouth. I brought him grapes and fruit juice and fetched his urine bottles (which stacked up because they were rarely cleared). There was very little staff monitoring of him except for looking in on him through the window. On the day he died he was looking and feeling much better. His oxygen mask was changed to one fitted through his nose and he no longer suffered with a dry mouth. He was his usual self again. I left the hospital at 4 pm and we arranged to have a Face Time conversation at 8.05 pm. My daughter was training to be a psychologist. He was joking with us and taking the micky out of her during our Face Time conversation calling her "Dr Porkface" (she is a vegetarian). I asked P to Face Time me again when he was feeling sleepy to say goodnight and to tell each other our usual "I love you" but that didn't happen. It was the last time I spoke to him.

37. I received a telephone call from the hospital at 9:40 pm to tell me P was in a poor way and that I needed to get there. He was heavily sedated and on life support having bitten through his tongue, he could not swallow. P had had a seizure. He had either pulled the oxygen away resulting in the seizure or he had a seizure and then pulled out the oxygen tubes. P had organ failure and was put on dialysis. He had four heart attacks. His brain activity was gone. If he survived and he would not be the P that I had known. A joint decision was made by me, the Consultant, P's mother and P's son to take him off life support. We were told that his death would be quick over no more than half an hour but several hours later he was still fighting. One of the staff members said that P must be waiting for something. I got on to the bed for a last cuddle. They put his arms around my waist and he died within minutes of me being in his arms. .

38. P's Consultants from the Oncology Department, the Haemophilia Centre and the HIV department arrived. They had been on a training course at the hospital. None of them could believe what had happened to P. He had been doing so well. They all gave me a hug and later they came with flowers to the funeral.

39. P's Lymphoma type (high grade) was directly linked to infected blood. P never knew that. There was an Inquest as P was clear of Lymphoma when he died and his death was unexpected. I was informed of the wrong date for the Inquest. I refer to **Exhibit WITN3579008** being a copy of P's Death Certificate. 'Misadventure' is the Inquest's conclusion.

40. P was a very brave and positive man. He always accepted whatever was thrown at him, no matter how grave. Whenever he spoke about infected blood to the medical staff then denied having any prior knowledge of it. There was a constant passing of the blame. He just lived his life. He never allowed any of this to define him but it caught up with him in the end. P was an amazing

human being. He was full of life and full of love. He was so special and oozed with generosity and compassion.

41. When [P] passed away my whole world caved in. [P] and I had just bought a house together. I had to pay the mortgage on my own. I returned to return to work five weeks after [P]'s death because although told to take my time, I was only paid for four days compassionate leave. I realised that I was not able to afford the monthly mortgage repayments so I cannot afford to stay there. We were only able to buy our house because when I reached 55 [GRO-B 2018) as I was then able to withdraw on my pension. I received £34,500 to put down as a deposit. We thought we would grow old there together as a couple. The £34,500 I paid was not ring fenced in the form of a Trust Deed or anything legally binding and [P]'s son as next of kin is claiming a full half share of the house.

42. I have been under so much stress and distress that I have been unable to grieve. The house feels too big, empty and lonely without [P]. I do not want to stay there but now have to look for [P]'s son's authority and input in selling it. This I find very upsetting as [P]'s entire family knew of our relationship and [P] would be mortified to know what was happening to me. I earn too little to be able to get a new mortgage and I have no energy to fight the sale of the house. I currently stand to lose half the pension capital lump sum I drew for the deposit on our house.

Section 6. Treatment/Care/Support

43. We were never offered any counselling in relation to [P]'s infections.

Section 7. Financial Assistance

44. After [P] passed away a close friend of his got in touch. He is also an infected haemophiliac. He informed me that I could claim help as [P]'s partner. He then

got in touch with England Infected Blood Support Scheme (EIBSS) on my behalf to let them know that I would be in contact.

45. They then sent me the paperwork that I needed to fill in to apply for grants, bereaved partner payment and a top up payment. The funeral grant was not a problem. All I needed was to provide them with the receipts. I also received a bereaved partner payment of £10,000.

46. I had problems with the paperwork for the monthly income top up. I had to provide them with my salary for January, February and March. My monthly salary was inaccurate as my employer had messed up my salary after I passed away because of time I had taken from work. I then had to provide my P60. I had to send it all off again when I heard nothing further and found out the originals had gone missing. I then had to send it all a third time after finding out that the documents had gone to their old address, only collected by them bi-monthly. They had twice provided me with the old forms with the previous address. They finally got back to me and acknowledged receipt of all three applications. I was under huge financial strain.

47. I am in receipt of monthly payments I believe to be incorrect. I believe I am being overpaid. I am worried because I think I am going to be asked to return the difference. To avoid that I keep the difference separately from all my other money and I do not use it.

Section 8. Other Issues

48. My partner and the love of my life lost his life due to a scandal the government and NHS are responsible for. He was an innocent man. His life was affected tragically and dramatically. He wanted justice which he never got. I would like to do this for him with whatever it takes. For all his life I had to make a case for himself in order to access charitable funds and contend with the stigma of having

ANONYMOUS

HIV. Those infected were and are more courageous and of a higher moral standing than any of those with knowledge that the blood and blood products were infected and still went ahead with the 'treatments'. Shame on them.

Anonymity, disclosure and redaction

49. I am applying for anonymity and would like this Statement redacted. I understand this Statement will be published and disclosed as part of the Inquiry.

50. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed.....

GRO-B

GRO-B

Dated 2nd Sept 2019