Witness Name:		GRO-B
Statement	No: \	WITN7240001
Exhibit	ts: WI	TN7240002-5
Γ	Dated:	October 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN	STATEMENT	OF	GRO-B

GRO-В , will say as follows:-

Section 1. Introduction

- 1. My full name is
 GRO-B
 I was born on
 GRO-B
 1968, and I live

 at
 GRO-B
 , West Midlands
 GRO-B
 1968, and I live
- 2 My partner/fiance, GRO-B: F (born GRO-B 1965), was infected with the Human Immunodeficiency Virus (HIV) through contaminated Factor VIII (FVIII) concentrate. He died on GRO-B 1994, aged 29.
- 3. This witness statement has been prepared without the benefit of access to F is full medical records, just his GP records. I have requested his full medical records from the Queen Elizabeth Hospital, but I understand that they have a large backlog due to demand for records. At no time was F ever informed that there were any

risks attached to being treated with Factor VIII. He had trust in the treatment from the NHS and put his faith in the doctors and nurses treating him.

Section 2. How Affected

- F had severe Haemophilia A. He was treated at the Birmingham Haemophilia Centre initially at the Children's Hospital and at the Queen Elizabeth Hospital (QEH) in adulthood under the care of Dr Frank Hill (and very latterly by Dr J Wilde).
 F was treated with Cryoprecipitate initially. He then moved onto FVIII concentrate as treatment. He received many treatments due to the severity of his Haemophilia as his records show he had 0% clotting factor.
- I refer to Exhibit WITN7240002 being a copy of F s UKHCDO record. F is noted to have first tested HIV positive on 28th January 1985 F was treated with the FVIII product brands 'Factorate' and 'BPL' between 1977 and 1985.
- 6. I believe it likely that F became infected with HIV some time in or around 1984. He was never informed of any risks arising from the treatment of his haemophilia using Factor VIII. The Haemophilia Society had never alerted him that there was any risk. I refer to Exhibit WITN7240003 being a letter from Dr Hill to F s GP dated 19th May 1989. F is said therein to have been seropositive for *at least* 4 years prior to that date.
- 7. F had no idea that he had been infected with HIV until sometime in the very late 1980s. F had a bad bleed and called for an ambulance to take him to A&E at QEH. When he arrived the ambulance paramedics told F that he wouldn't have been accepted at any other hospital because of he had AIDS.

- 8. F and I had been good friends. We became a couple in 1989 when I was 21 years old. F was trying to come to terms with his HIV status at that time. He had not long found out that he was HIV positive (through the ambulance service).
- 9. I refer to again to Exhibit WITN7240002. It appears to be possible tha F was also co-infected with HCV. We knew nothing about it.

Section 3. Other Infections

10.1 refer again to Exhibit WITN7240002. F seems to have also been exposed to the risk of vCJD infection.

Section 4. Consent

- 11 F s parents were not prewarned of risk of infection before F s treatment was changed to FVIII concentrate.
- 121 refer to Exhibit WITN7240004 being a letter from the Children's Hospital to F s
 GP dated 8th August 1980. F s blood was then being used to test for Hepatitis.
 F didn't know that he was being tested for Hepatitis and later for HIV.
- 13. The hospital clinicians must have been aware of risk, but this was never discussed with F or his family. F is sister recalls taking an anonymous call from someone at the Hospital after a hospital appointment telling her to warn F not to use FVIII. The caller declined to give their name.

- 14. F was kept in the dark. He felt completely excluded from vital information that he was entitled to about his own health. He was not told that his blood was being tested for HIV, Hepatitis, vCJD, nor was he told that he had tested positive for any of these.
- 15. The failure of the hospital clinicians to inform F that he had tested positive for HIV meant that F was unable to make informed decisions around his health, to take relevant precautions to prevent infection of others. This was something that F found incredibly difficult to come to terms with he was a caring person and would have found the possibility of putting anyone else at risk absolutely abhorrent.

Section 5. Impact of the Infection

F <u>s Health</u>

- F is health deteriorated from 1990 and he started to suffer with a raft of complex health issues. He had Enterococcal Faecalis Meningitis, Pneumoystitis Carinii Infection and Thrush in September 1990. He had Acute Sinusitis in December 1992.
 F suffered with a Bronchoaveolar Lavage/Haemophilius Influenza Infection in January 1993. He had Oral Hairy Leukoplakia the following month, and Neutropenia, Sinusitis (again) and Otitis Media in June 1993.
- F had Acute Secretory Otitis Media and an upper respiratory tract infection in July
 1993. F had an acute viral illness in October 1993, a rash and urinary tract infection again in May 1994. He suffered with severe shortness of breath and dysuria in July 1994, a severe cough, Pityrosporon Folliculitis, and Excoriated Red Papules in September 1994.

- Before F died, he developed Cerebral Atrophy and pyrexial illness, he had very low CD4 counts, Periventricular Inflammation, HIV related Encephalopathy, Bronchopneumonia and generalised debility.
- 19. Due to the stigma and prejudice around HIV/AIDS at the time, **F** was very reluctant for his HIV status to be shared and requested that this was not listed as a cause of death on his Death Certificate, exhibited here as Exhibit WITN7240005. It was his wish to protect me from stigma arising from being him being HIV positive.
- 20. F and I were engaged, and it was my wish to marry him. Due to his concerns around the stigma of AIDS at the time, he did not want me to become an "AIDS" widow and we did not marry because of this. It is important to remember that at this time, there were public campaigns running about HIV/AIDS and there was a huge stigma and fear within society around the risks of infection. This should not be underestimated as it impacted greatly on F and his concerns and worries around me.

Emotional and Psychological Impact

Provide a straight forwards".
21 F was a wonderful person. He was very witty and terribly handsome. When he walked into a room everyone turned to look at him. He was smooth, and he was confident. Despite being so very young F 's hair was silver grey, and he looked very distinguished. He was stately and he had a bit of a swagger. At a party people would radiate to him. He would end up with everyone sitting around him. They found him very funny - just a hoot. He wasn't loud or bombastic though. He had a quiet charm that meant everyone loved to spend time with him. Time and again, his medical notes refer to him being a "delightful young man", "pleasant", "extremely honest and straight forwards".

- 22. **F** was also very clever. He was into cars, boats and computers. He could code and programme computers. **h** 1989, that was impressive. He was asymptomatic, able to work, and he was eminently employable.
- 23. We bought a flat in Kent because I was covering the London area in my job and lived there for about a year. I was an Executive working for a shipping company. We came back to Birmingham when F s health began to decline for family support and to be in closer proximity to the QEH. I then took a job as a Rep for a company based in Leicester. I was on the road doing a lot of travelling and commuting. I worked for as long as I could. I then stopped working to look after F for what became the last six to 12 months of his life.
- 24. F had the most horrendous accident several months before his death. He fell and crashed through a glass door, splitting the side of his face and leaving it hanging open, spurting blood. I pushed the wound together and applied pressure whilst we waited for the ambulance. He was bleeding profusely and in shock. There were about 10 people (including me holding the suction machine) working on him at A&E. once he was stabilized he was taken to the ward and I took a taxi home, alone and anxious. F was then left with a huge scar that he was very conscious of.
- 25. Because of the fear and stigma of HIV/AIDS, we told no-one outside our respective families that F was infected with HIV. F was adamant about it. h addition to having the unsightly scar on his face F lost weight and he felt, and he looked very unwell. We had a night out at a Comedy Club after the accident and F was ridiculed as we walked through by someone shouting at me 'what are you doing, why are you with the AIDS victim?'. At the time, there were campaigns regularly run in the media around AIDS, and there was a lot of ignorance around people thought that you could catch AIDS from a drink, off cutlery, from shaking hands. It was a truly wounding nerve to hit. That is how cruel HIV is and how cruel

people can be. I would buy F what we called 'little things of loveliness' to tempt him to eat and try to combat the weight loss, but he just wasn't able to eat towards the end.

- 26 F started to forget things and was diagnosed with Encephalopathy in October 1994. I spent so much time with F on the hospital ward (always 3A) and nursing him at home when his body started to shut down. He didn't want people visiting towards the end. The visits wore him out and he was embarrassed. He looked exceptionally gaunt. He was always meticulous with his appearance, but at one stage I was barely able to get him to let me wash him.
- 27. His deterioration was quite rapid in the end. He was back in hospital for three days at the beginning of December. He was belligerent and rude. It was completely out of character for him to be like that, but this was down to the encephalopathy arising from the HIV infection. I was told that the outlook was bleak, that he had HIV related Dementia and he was put on medication to slow his brain. This seemed to help him and he was back to the F I knew and adored. After his discharge, he was barely able to move as the disease took over. I would just lie there next to him. I put his favourite Terminator films on at home and he would lie there with his eyes open looking between me and the television.
- 28. Large chunks of my memory of that time are lost to me. I don't have any memory of F s funeral except for a couple of snapshot moments. What happened has coloured everything in my life. I haven't been the same since. I am godmother to F s nieces. F 's brother met my sister at F s funeral and they have been married now for 20 years. F s family are still a huge part of my life. Whilst a blessing, they are also a constant reminder of what I lost.
- 29. The years immediately after F s death were particularly tumultuous to me. I drank far too much in order to try to blank it all out and, in 1997, ended up in The

Priory for three months. I have been diagnosed as having a major depressive disorder and Complex and Continuing Post Traumatic Stress Disorder (CPTSD). I have very bad anxiety. I haven't been able to work since **F** is death (albeit I did some voluntary work for the Terence Higgins Trust for a very short while). I had a good career working for a very successful company previously. I have developed lots of health issues (skin, bowel, high blood pressure) and they are all stress related.

- 30. When I met F, he was a vibrant, beautiful, funny, carefree person and we had so much fun together. We were completely happy in each other's company, and we could have had a wonderful future together. HIV/AIDs took that away from us, and I spent the last few years of our relationship looking after a fragile, sick person whose body and mind had failed him. We went through this together, with me supporting him and fighting one illness after another as the disease progressed. We were bewildered and frightened, and isolated by a disease that everyone was frightened of.
- 31. Even though F died over 27 years ago, the pain of the loss is still raw and painful today. I tried to get on with my life, but the scars from the devastating loss and cruel illness meant that I have never managed to let him go, and the mental scars remain with me still. I did marry and F s family were at the wedding, with his nieces as my bridesmaid. F 's morn spoke to me at the wedding to tell me to let F go and concentrate on my future. However, I have never been able to forget him and our lost future, and since his death I have kept pictures of him in my home, and he is always in my thoughts.
- 32. The pain and scars from the horror of watching F suffer live with me today, and the pain of reliving this as part of my evidence has been horrific. I have done so because I feel that it is vitally important that F s voice is heard as part of the

Inquiry. He is not able to tell you how it impacted on him, how his future was taken away from him, so it is important that I speak for him.

- 33. It was unbearable watching the person I loved decline with such a cruel disease he fought so bravely and was so positive about everything. The Doctors and nurses at the hospital battled alongside us to try and keep F alive, but I feel that it was only those dealing with this on the ground who cared. The institution failed him terribly in letting the infection happen to him and others in the first place, in not telling him that he was at risk of infection, not informing him that he was infected, what that meant for him as a person and how he would be robbed of his and our future.
- 34. It is not over for me. It will never be over for me or for any one of F s family members, the friends that knew and loved him and those that came after. Just to speak openly about F has opened a huge sceptic wound. It is horrific.

Section 6. Treatment/care/support

35 F had AZT treatment and was offered some counselling by the hospital Social Worker which he declined.

Section 7. Financial Assistance

F received an initial payment from the Government in 1992/1993.

Anonymity, disclosure and redaction

37. 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	
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