

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2998001

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** 1962, and I live at **GRO-B**
GRO-B
2. I was co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) through contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

4. I have severe Haemophilia A, having been diagnosed at birth. I suffered badly with bleeds to my joints, and I needed a lot of treatment. I was treated with Factor VIII (FVIII) concentrate of many different commercial brands over the years. I was treated at the Oxford Haemophilia Centre (OHC) at the **GRO-B** **GRO-B** under the care of Dr Charles Rizza and Dr James Matthews.
5. I am the youngest of three brothers. My (middle) brother **GRO-B : B** was five years older than me. He too suffered with severe Haemophilia A. We were given the same treatment products at corresponding times. We were summoned to come to the OHC for our HIV test results some time in 1984 and we were told by Dr Matthews that we were HIV positive together.
6. Dr Matthews provided as much information and advice to help us to understand and manage the infection as I believe was available to him at that time. Very little was known about the infection and Dr Matthews did what he could to answer our questions in a positive way. **B** and I were in shock. As we drove home, we promised one another that we wouldn't tell anyone at all about the diagnosis because of the culture of fear and hostility about HIV/AIDS. We kept it a secret from our family because we dreaded the effect the news would have on them. It came out/got around the family in different stages, starting with my mother. **B** broke down and told her a few months later. Our father found out about a year later and I only told my elder brother in 1991, five years after **B**'s. I deeply regret not being honest with my family for so long.
7. There was no sign of **B** advancing to AIDS, but his mental state was very badly affected. When he died suddenly in 1986, they refused to do an autopsy because he had HIV. They said it was too risky for them. There was never a cause of death. Instead, the Coroner returned an open verdict. It was terrible for

ANONYMOUS

our parents. It was terrible for my older brother and me. It was beyond devastating for all of us and the pain of losing him remains very present. I believe it hastened my parents' deaths.

8. I was told that I was infected with HCV in the early 1990s. I didn't attach much importance to it at the time. I believe it likely that **B** would have also been co-infected with HCV we had the same FVIII concentrate. I began to better understand the significance of being infected with HCV through Dr **GRO-B** Consultant Hepatologist, at **GRO-B**. She monitored the abnormal enzyme levels in my liver. The fact that I might go on to develop liver cancer was a very frightening prospect.

Section 3. Other Infections

9. At some point, I was informed that I had also been exposed to the Hepatitis B Virus (HBV) as I have HBV antibodies. I was also later notified that there was a risk that I had been exposed to vCJD, through a batch of FVIII concentrate found present in an infected donor.

Section 4. Consent

10. I do not accept that I was treated and tested without consent and/or unwittingly used for the purposes of research. Consent was given in broad terms and assumed going forward. We were very well supported by the doctors at the OHC and by Nurse Mary Fletcher. The alarm and concern they felt when their patients became infected weighed heavily on them.

11. I opted to take part in trials, studies and experimental treatment at Oxford and my T cells were monitored monthly. I became close to the researchers there. They told me how very good triple therapy was and urged me to transfer to the Chelsea and Westminster Hospital for treatment there when my T cells (already on the slide) were found to have dropped down to almost nothing. I did so immediately. I do not think that I would have survived otherwise. I don't know how much longer it was before triple therapy became available to Oxford HIV patients. It was certainly not available at that time because I remember Dr. **GRO-B** **GRO-B** at **GRO-B** telling me that he could not prescribe it.

Section 5. Impact of the Infection

12. I developed several quite bad skin problems due to my compromised immune system, including vitiligo and psoriasis which developed into Psoriatic Arthritis. My brother died as did many friends and acquaintances I met through the OHC. I feel that grief and a sense of survivor's guilt.

13. I suffer with depression and chronic fatigue. I have been helped so much by family, friends and health professionals and have deep gratitude to them all.

14. I feel a huge amount of anger towards the American drug companies. I believe them to have been outrageously and criminally negligent. I do not blame any of the clinicians (or the NHS) for what happened to those of us infected. I believe the clinicians to also be victims of this. It was traumatic for them, but they stuck in their jobs and helped us to get through. The NHS had an incredibly difficult situation to deal with. If they had had the clean blood supply originally budgeted for it would have been fine. David Owen's evidence to the Inquiry that the monies meant for product safety and self-sufficiency were redirected by the Department of Health is just nothing short of terrible.

Section 6. Treatment/care/support

15. I took part in a psychological research study at GRO-B and then withdrew from it. It became a bit of an emotional strain.

16. I had excellent care at the Department of Immunology at the Chelsea and Westminster Hospital under the overall care of Professor Brian Gazzard. I had extraordinarily good care and support from Dr Chloe Orkin and other professionals there. I feel privileged to have become a good friend of the eminent infectious disease researcher Professor Frances Gotch (now retired) and her team at Imperial College London. I owe my life to all these dedicated people who I admire very much.

17. I cleared HCV after a second course of Interferon and Ribavirin in the late 1990s. It was a tough treatment regime.

18. I was referred for psychologist support under Chelsea and Westminster which was helpful, and I now engage in Talking Therapy locally.

Section 7. Financial Assistance

19. I wasn't a big fan of the MacFarlane Trust and the Skipton Fund. They seemed to me to be very inward focused organisations. However, I didn't have any particular issues with them and they helped me with a number of grants.

Anonymity, disclosure and redaction

ANONYMOUS

20. 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
GRO-B

Dated 28/10/22