

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3260001

Exhibits: 0

Dated: JUNE 2019

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 and I live at GRO-B.
2. My son, GRO-B: S (born on GRO-B), is co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) from contaminated blood products. He has provided a witness statement to the Inquiry (Witness Number GRO-B).
3. This witness statement has been prepared without the benefit of access to my son's full medical records.

Section 2. How Affected

4. S has severe Haemophilia A, diagnosed at 13 months old. He has a less than 1% clotting ability. There was no prior history of haemophilia

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in my family and my husband and I did not expect that diagnosis. We had two children. Our daughter, [GRO-B], is younger than [S]

5. [S] was treated at the Leeds Haemophilia Centre at St James University Hospital under the care of Dr Swinburne except for his time (two to three years) away at a special school [GRO-B] in [GRO-B] when he was treated at the Pathology Department at York District Hospital under the care of Dr Wiley.
6. [S] had regular Factor (FVIII) treatment which was 2 and even 3 times weekly. [S] had a lot of bleeds during his school years particularly in his left ankle and left elbow. As a result, he received a lot of FVIII. He was unable to retain the correct levels and required regular treatment and he was being given an inadequate dose for his weight and age. [S] condition was misunderstood by Dr Wylie who believed that he was being abused as he returned to hospital for further treatment regularly.
7. We were never informed of the risks associated with him being treated with blood products and FVIII was supposed to be a more successful, advanced and quicker treatment to administer (than cryoprecipitate). At one time we were informed that [S] had not been given enough FVIII to prevent his bleeds during his time in York. Because of that we transferred [S] back to Leeds for treatment.
8. [S] started home treatment at around the age of 11. He had started being trained to self-administer his FVIII at the York Hospital and that continued when he was transferred back to Leeds. [S] was told that he had HBV by Dr Wiley during his time in York. I was not present and was informed by [S] afterwards. I did not know [S] had been tested for HBV, when, in what circumstances or why.
9. In the early to mid-1980s the news of Acquired Immunodeficiency Syndrome (AIDS) started to raise it's head in in the media. I recall that we were invited to attend a conference/reception with food and drinks in a hotel hosted by the

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Armour Pharmaceutical Company attended by many other haemophiliac families. There we were told that the Armour FVIII was completely safe and that we had nothing to worry about in choosing their product, apparently the best and safest product on the market. We were advised to ignore any bad press about their product. [S] is one of a very few haemophiliacs from that gathering to have survived.

10. In or around 1985, I took [S] to one of his routine haemophilia check-ups. There Dr Swinburne mentioned to us in a very matter of fact manner that [S] had the 'AIDS virus' (later known as HIV). I stopped her in her tracks and said "What?" and she replied "Oh yes, they all are Mrs [GRO-B] I am losing them all. All my boys have it". I was reeling with shock and I knew that [S] was too. We knew that AIDS was a death sentence.

11. Very little advice was provided about managing the infection. [S] was given some basic advice about intimate contact with the opposite sex and to be very careful. He had only just started to become interested in the opposite sex. It was a terrible thing for a boy of his age. There was no treatment on offer. It was awful.

12. [S] learned that he was also infected with HCV much later in or around 1992. He was told at the Leeds Haemophilia Centre.

Section 3. Other Infections

13. [S] had no other infection than the HIV, HBV and HCV infections outlined above.

Section 4. Consent

14. [S] was tested for viruses without our consent. Bloods were taken at routine haemophilia appointments. We were given to understand that [S] blood

was being tested for clotting levels. I believe that [S] had tested HIV positive at the age of 14 (in 1984) and before we were told by Dr Swinburne in 1985.

Section 5. Impact of the Infection

15. The stigma associated with HIV/AIDS was huge. There was such a lot of bad press and dreadful adverts. [S] was shaken to the core at finding out that he was HIV positive. He avoided his friends through fear of passing it on to them and became an outcast.
16. We lived in a village in a close knit community. Everyone knew that [S] was a haemophiliac and they assumed that he was infected with HIV/AIDS as a result in any event. [S] bled a lot, particularly so when having dental treatment. People were terrified of [S]. In ignorance they thought they could become infected through simply sharing the same lavatory seat. It affected our friendships and we were shunned.
17. The news of the HIV diagnosis had a devastating psychological effect on [S]. He was convinced he would suffer an early death. We moved home and transferred [S] and [GRO-B] to new schools. We were broken as a family. [GRO-B] had to leave her friends and her former life behind her. It affected [S] behaviour. His school attendance was poor and he stopped bothering. He developed a school related phobia. He passed 7 O levels which was in fact testimony to how bright he is but he did not pursue A levels for long before he dropped out. He developed mental health issues and depression.
18. [S] weight plummeted over a very short period of time. He had horrendous nose bleeds. Since HIV his immune system was compromised, he suffered from gastrointestinal problems to include severe diarrhoea and stomach ulcers as well as thrush in the throat, mouth and stomach.
19. [S] has suffered with a whole raft of health issues to include pneumonia. There was a period of time when [S] CD4 cells dropped below 200 and we were told that [S] had gone on to develop full blown AIDS. [GRO-B] was given

compassionate leave from work as we all thought we were about to lose [S]. Miraculously his CD4 cells started to rise again but it was still hanging over our heads that they might drop again too. He is reliant on a cocktail of drugs to endeavour to treat his associated health issues and keep his HIV under control.

20. As a family, HIV has been like having a very dark cloud hanging over us. We became secretive and very careful about confiding in anyone. [S] behaviour became more and more reckless as he went off the rails. He really suffered and had a nervous breakdown. He later turned to religion and, in his twenties, met a lovely girl through the Church. Sadly the girl's father intervened and threatened [S] to stay away from his daughter, accusing [S] of trying to kill her. He forbade her to carry on seeing [S] and, after that, I was really worried that [S] might do something drastic. He thought he was going to die anyway. [S] was heartbroken and has never let himself become involved in a close relationship again. He lives alone. His life has been blighted by contaminated blood.

21. Some time after the HCV diagnosis, [S] went on Interferon as a trial in clearing the virus. He was at that time living away from home as a mature undergraduate having been away travelling. His care was transferred to the Sheffield Haemophilia Centre at the Royal Hallamshire Hospital. [S] became so poorly through the treatment that he was hospitalised and the trial ended. He eventually had to drop out of university as he had missed too many lectures through poor health. The second attempt at clearing the treatment with Interferon and Ribavirin worked but he has sustained liver damage.

Section 6. Treatment/care/support

22. [S] had no counselling when he was told he had HIV. We were not offered any. [S] has paid for psychiatric help on a private basis from the trust money he received through the schemes.

Section 7. Financial Assistance

23. [S] received a modest capital lump sum of what I believe to be something in the region of £42,000 from the trusts set up by the MacFarlane Fund and Skipton Fund. I believe that he had to sign a waiver before he was given the initial amount. He was blackmailed into taking it with threats that nobody would get anything unless everyone accepted what was offered. _

24. What [S] received was in my view derisory in comparison to what he should have had. [S] had a mental breakdown and his GP put him on antipsychotic medication. He used some of the trust money to pay for psychiatric treatment privately and spent time in a retreat in [GRO-B] for a year. After a year he decided to buy a camper van and spent time travelling to include volunteering in distributing supplies at Chernobyl.

Section 8. Other Issues

25. There are no other issues.

Anonymity, disclosure and redaction

26. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

27. 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]

Dated 26.06.19 2019