

Witness Name: Valeria Edna Sanders

Statement No: WITN1504002

Exhibits: WITN1504003-4

Dated: February 2021

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF VALERIA EDNA SANDERS

I, Valeria Edna Sanders will say as follows:-

Introduction

1. My name is Valeria Edna Sanders. I was born on GRO-C 1942 and I live at GRO-C Staffordshire GRO-C.
2. My son Ian Robert Mather nee Share (born on GRO-C 1968) was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII) treatment. He died on 22nd February 1994, aged 25.
3. This is my Second Statement. It should be read in conjunction with my First Statement to the Inquiry (Witness Number WITN1504001) dated 24th January 2019.

How Affected

4. Ian had severe Haemophilia A (with a 5% clotting factor). He was under the care of the Haemophilia Centre at Birmingham Children's Hospital (BCH) until adulthood when he transferred to the Queen Elizabeth Hospital (QEH), Birmingham.
5. Ian and I were told that Ian was infected with HIV by Dr [GRO-D] at a routine appointment at BCH in early 1983. Ian was 14 years old. We were told that Ian had been infected with HIV through the FVIII treatment he was given when he was just 9 years old.
6. We were similarly informed by Dr [GRO-D] that Ian was infected with what was then referred to as Non-A, Non-B Hepatitis sometime in the mid-1980s, as suspected by the BCH team as far back as in 1979 when Ian was 11 years old. Ian was having pains in his stomach and awful nose bleeds but there was no treatment they could offer. No adequate information and/or advice was given to us. We did not know it was a life-threatening form of hepatitis. It was not until November 1993 that we were told that Ian was infected with HCV.
7. Since making my First Statement I have obtained some of my son's medical records, to include his UKHCDO record. I refer to Exhibit WITN1504003 being a copy of the UKHCDO record. The Factorate product made by the Armour Pharmaceutical Company (with batch numbers listed) appear to be named as being the source of the hepatitis contamination. It is also apparent that Ian was identified as being at risk of exposure to vCJD. I knew nothing about this.

Other Infections

8. Referring again to Exhibit WITN1504003, I am now aware that Ian was identified as being at risk of exposure to vCJD.

9. It would also appear that Ian was exposed to the Hepatitis B Virus given the positive HBsAg test in February 1985.

Consent

10. Ian was tested for infection without our knowledge and consent.
11. Ian was treated with FVIII concentrate without my consent and without full and adequate information. I wasn't asked whether Ian could have the treatment. I was told he was having it. I was just told that the treatment was better at clotting the blood than Cryoprecipitate. I have a photograph, taken for inclusion in the hospital newsletter, of Ian being given FVIII concentrate for the first time when he was 9. My four (haemophiliac) brothers were given the choice between Cryoprecipitate and the new FVIII concentrate. They opted to stay on Cryoprecipitate and are alive to this day.

Impact of the Infection

12. I refer to my First Statement.
13. The hospital records I have acquired since making my First Statement have been the source of further distress to me. Many of the hospital records are missing and the rest very heavily redacted, so much so that apart from notes about the bleed Ian had in his groin and his nosebleeds, nothing of essence remains. The limited information there about Ian's infections are pretty much as documented in the UKHCDO record.
14. I refer to Exhibit WITN1504004 being a small sample of some of the heavily redacted pages of Ian's hospital records I have been sent. I do not have Ian's GP records. I was informed years ago that they were destroyed. I do not understand why. I worked for the NHS for 30 years. I knew medical records were kept for at least 20 years (and longer if the matter was serious).

15. It came as a shock to me to read in the UKHCDO record that AIDS was the cause of Ian's death. I refer to paragraph 17 of my First Statement. I was told that liver cirrhosis/liver failure had caused Ian's death. I was not told that the HIV infection had progressed to fully blown AIDS.

16. It feels to me that everything has been hidden from me and I am very upset by it all. Ian was a lovely boy, my only child and the son I had waited many years (7 years of marriage) before becoming a parent (that took courage for me, knowing I was a haemophilia carrier).

Treatment/care/support

17. I refer to my First Statement.

Financial Assistance

18. I refer to my First Statement.

Other Issues

19. I refer to my First Statement.

Anonymity, disclosure and redaction

20. I confirm that I do not wish to apply for anonymity. I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed.....

GRO-C

Dated.....

10/03/2021