

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1325001

Exhibits: 0

Dated: APRIL 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

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
GRO-B
2. My son GRO-B: S (born on GRO-B) was co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) through contaminated blood products. He developed Non Hodgkins Lymphoma and died on GRO-B aged 15.
3. This witness statement has been prepared without the benefit of access to S full medical records.

Section 2. How Affected

4. S had severe Haemophilia A with a clotting factor of less than 1%. He was diagnosed with haemophilia at 13 months old. There was then no known history of it in the family and the diagnosis came as quite a shock.

ANONYMOUS

5. **S** was a much younger brother to two older sisters. Our fourth child, **GRO-B: S2** was born two years after **S** and the two boys were closer to each other in age than their two sisters. One of my daughters is a haemophilia carrier and my grandson (one of six grandchildren) is a haemophiliac.
6. **S** was treated at the haemophilia centre at the Royal Victoria Infirmary (RVI) in Newcastle under the care of Dr Peter Jones.
7. **S** was treated with cryoprecipitate before moving on to FVIII (FVIII) concentrate. He had home treatment from the age of 8.
8. My husband and I were part of a small local community of parents of children with haemophilia. We met at clinics and get together outside of the clinics to provide each other with advice and support. In the early to mid 1980s there was talk between us about concerning issues surrounding the FVIII concentrate and a new virus and then HIV/AIDS began to hit the headlines.
9. The children were called in for testing at the RVI in the summer of 1985. We then had to return at a later appointment for the results. I remember seeing another mother at **S** sports day, the day before his appointment. I asked her how her appointment went; her reply was short and to the point 'not good'.
10. At the appointment the next day, Dr Jones came out and told us (me, my husband and **S** **GRO-D** that **S** was HIV positive.
11. We were told to continue with the FVIII concentrate treatment and to continue to bring **S** for his routine appointments. Apart from that we were expected to get on with our lives and we didn't know then how bad it was going to get.
12. **S** was just a child. He didn't want to know the 'ins' and 'outs'. He just said 'that's it then'. We had been told that **S** was Australia antigen (HBV) positive a couple of years before and I think that **S** thought HIV

ANONYMOUS

was something like that; just something to do with his haemophilia. My husband had then contracted HBV through [S] and had lost a lot of weight.

13. I recall it being noted at [S] check ups that he was not gaining in height which I believe is relatively common among children with HIV.

14. Some time later, in or around 1988, we were told that [S] had tested Non-A Non-B Hepatitis (later named HCV) positive. [S] was 13 years old and his health had started to take a down turn. He was in quite a bit of discomfort and was vomiting. I was out with my daughter when I received a call to go straight to the RVI where [S] had been admitted on to the ward. After an investigatory blood test, Nurse Maureen Burns told us that [S] had Non-A Non-B Hepatitis and said that they, at the RVI, didn't know much about it yet.

15. Through the discussions I have had with the affected parents I am still very friendly with, I share their collective belief that the product 'Factorate' was culpable in infecting our children.

Section 3. Other Infections

16. I do not think [S] was infected with anything else through contaminated blood products.

Section 4. Consent

17. I do not think that [S] was ever treated or tested without our consent. I do not think that [S] was treated or tested for the purposes of research. The RVI seemed to be upfront in relation to what they were doing.

Section 5. Impact of the Infection

ANONYMOUS

18. We kept the HIV infection a secret because of the fear and stigma of the time.

Our daughters were older and we told them but that was it. **S** began to ask a lot more questions about having HIV as a result of seeing so much on TV about it. **S** didn't want anyone to know (and I find it hard to talk about it now as a result). No-one at **S** secondary school ever found out even after he became seriously ill. **S2** followed **S** on to the same secondary school and we didn't want **S2** to be stigmatised either.

19. **S** missed a lot of schooling through poor health from around the age of 13. He developed a problem with his lungs which led to pneumonia.

20. We went away on holiday to Malta in the summer of 1989 and it was a good holiday. **S** was then admitted to hospital with pancreatitis that October (I remember that he missed Halloween but was out for the fireworks on November 5th). **S** was quite stoic but he could not do pain and he had lost his immune defence by then. He suffered with migraines and his hands would go numb.

21. **S** suffered with another bout of pneumonia between Christmas 1989 and the 1990 New Year. I knew that things were going to end badly but I couldn't face the thought and I was in a state of denial. **S** was prescribed steroids to give him a boost and we spent the weekend in London celebrating **S** 15th birthday and, coincidentally **GRO-B**. I remember **S** happy amusement at the Chinese tourists in the Wimpy bar at Leicester Square whilst all the other tourists were in Soho enjoying the celebrations there.

22. Non Hodgkins Lymphoma and haemophilia are stated under cause of death on **S** Death Certificate. He had sepsis and was in critical care and on a ventilator before he died. To see the reports on TV about Covid19 at this time bring terrible memories of **S** death and the death of my husband flooding back to me.

23. I have a very supportive family. Two of my daughters are nurses (and one is about to come back out of retirement to help with the Covid19 on the NHS

front line). My 28 year old granddaughter has taken a real interest in the contaminated blood scandal and wants to know everything that happened to S My son-in-law (working in mental health with those addicted to drugs and alcoholic) is also very supportive about me making this Statement. It is very important to me, because it was so important to S that S anonymity is protected.

Section 6. Treatment/care/support

24. We were never offered any psychological therapy and I am unsure as to whether we would have accepted any. We didn't tell anyone outside the family what had happened, not even our close friends. We were left devastated as a family. We didn't want to talk about it to other people. We could scarcely believe it had happened. My son, S2 was just 13 years old when S died. He needed me and I had to keep going for him otherwise I would have gone under.

25. I would just add that the social workers at the haemophilia centre were a support. They were brilliant.

Section 7. Financial Assistance

26. We had no adverse issues with the trusts and funds. They helped us with a grant for our holiday and for a gas boiler. Lump sum funds were paid out for S in stages. After that we decided that we didn't want any more money.

Anonymity

27. I would like to remain anonymous and I do not want to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-B

Dated..13-04-2020.....