

Witness Name: Donna Saunders

Statement No: WITN4021001

Exhibits: 0

Dated: March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DONNA SAUNDERS

I, Donna Saunders, will say as follows:-

Section 1. Introduction

1. My full name is Donna Louise Saunders. I was born on [GRO-C] 1972 and I live at [GRO-C] Worcestershire [GRO-C]. I am a Qualified Teacher, currently Preschool Manager and Forest School Leader. I live with my partner, John and two children [GRO-C] (aged 13) and [GRO-C] (aged 9).
2. My brother, Stuart Gregg (born on [GRO-C] 1975), was co-infected with the Hepatitis B Virus (HBV), the Hepatitis C Virus (HCV) and the Human Immunodeficiency Virus (HIV) through contaminated Factor VIII (FVIII) blood products. Stuart has provided his own Witness Statement to the Inquiry (Witness Statement Number WITN1252001).
3. I make this Statement without the benefit of access to my brother's full medical records.

Section 2. How Affected

4. Stuart (Stu), the person infected, is my brother and two years younger than me. We have always had a close relationship, all through our childhood, we were very close in our twenties, going on holiday with our partners and the like.
5. Growing up I knew Stu had haemophilia. I spent a lot of time at Birmingham Children's Hospital (BCH) or with grandparents while my parents took Stu to hospital. As a child I knew that the life expectancy of haemophiliacs (at that time in the 1970s) was shorter than that of those without haemophilia. I remember my paternal grandfather being quite upset that he could/would outlive his grandson. I believe this is where my fear of losing Stu came from, a fear of being without him. This was when my fear of losing Stu started and was then heightened when I found out he had HIV.
6. I didn't know Stu was infected in the 1980s. I was about 10/11 years old at the time and wasn't told. I was kept out of what was happening to him. I wasn't told until I was 19, although I knew something had happened prior to being told but didn't know what.
7. Stu has moderate to severe Haemophilia A. He was treated at the Birmingham Children's Hospital (BCH) under the care of Dr Frank Hill and Nurse Sister Marion. Stuart was infected with HIV in or around 1984. I was not told what had happened to Stu until in 1990s. I was then told that he had been given FVIII treatment from infected blood from America. This all took place at BCH. Stu told me in the car on our return journey from somewhere. I was at University studying for my BEd Degree. I knew that there was something wrong but I didn't expect that and it was a lot to take in.
8. I do not know what information or advice was given to Stu and/or our parents about managing the infection. My mum had been told not to tell anyone and it is the secrecy and lies that have affected me the most. If I have learned anything from this it is to talk.

9. Since giving birth to my own son with Haemophilia A, I have been very cautious about what products are given to him. I always ask for confirmation that any products are synthetic and not derived from any blood products.

Section 3. Other Infections

10. I refer to Stuart's Statement.

Section 4. Consent

11. Stuart was treated and tested without his knowledge and consent and without the knowledge and consent of our parents. Stuart was treated and tested without being given adequate and/or full information. I also believe that Stuart was treated for the purposes of research and as a financial incentive through the drug companies.

Section 5. Impact of the Infection

12. The infection has had a massive physical and mental impact on Stuart. He thought he was going to die. He was aware that any illness to include a cold or flu could lead to complications and ultimately death.
13. Stu has had to take a cocktail of drugs over the years. He thought he'd never have children. Haemophilia alone impacts on every day life; being different to others and having to be careful not to have a bleed; having to have intravenous injections and missing out on things that friends might be doing because of visits to the hospital or due to bed rest. Multiply all of that to an even greater impact of the effects of co-infection and then add the massive stigma attached to having HIV and the fear of the reaction of others if they found out; the fear of contamination; fear of death; the fear and worry of those close to him that he might just give up; being unable to have children naturally and the fear of infecting your partner, children and others. All this is just a flavour of what Stu has dealt with.

14. As stated, I didn't know that Stu was infected with HIV. I was kept in the dark. Moreover Stu spent a lot of time in hospital during the 1980s. I was separated from Stu. We were very close and I was profoundly affected. I was sent away to spend protracted periods of time with my maternal grandmother and that went on all through my teenage years. I didn't even holiday with my own family. I remember spending holidays with my grandmother on Shearing coach holidays in the company of pensioners. It was not a 'normal' life for a teenager. There were no mobile phones then to enable me to keep in contact with friends. I had to go to a pay phone to speak to my mother. Looking back, there were big issues at home and I do not think that my father coped well.
15. Even after being told by Stu that he had been infected, we still didn't talk about it. I instinctively knew that the subject was taboo. I only ever told my ex husband, my current partner and one very close friend. I am a protective older sister and I did not want anyone unfairly judging Stu. In order to protect Stu from the reaction of others and the associated stigma of having HIV, my mother always impressed upon us the importance of keeping details of our home life to ourselves. I was brought up with 'you don't say anything'.
16. My mother has recently shared with me a horrible experience of her own. A parent whilst Stu was at middle school threatened to go to the papers after getting a hint about his condition and my mother had to fight hard for the school to stop that happening. My mother is still as economical with the truth as ever she was. Her mind set has rubbed off on me. Not telling the whole truth is not a healthy habit to form. It is not always rational. I could never understand why we had to lie to everyone. I took my driving test at the age of 17 and was told by mum not to tell anyone. When I passed first time my friends were confused and disappointed in me that I hadn't told them I was taking it. What should have been happy news to tell friends was awkward for me and left them bewildered.

17. I have had concerns (particularly in the early stages of my teaching career) that my brother's infection might impact on my own position at work (in the event that my employer or the parents of a pupil learned of it).
18. I worry a lot that Stu will die. I adore my brother and my fear of losing him grew throughout my twenties. Other people are able to share their fears if their loved one has cancer. Your fears are made worse if you are unable to tell anyone. I have come to realise that life is fragile. I can never leave anyone on an argument and/or with any bad feeling or without a hug.
19. My fear of losing Stu and keeping close to each other has affected me in terms of the choices made by me. I was sent to a different school, away from the friends I had made at the age of 9. This was because it was a school on route to the hospital so would be better for Stu in two years when he moved schools. Then as a teenager I chose universities that were not too far from home. Stu came to the same university as me. We both moved back home after Uni and now live very close to each other. I want my daughter to spread her wings a bit more and experience life outside of Worcestershire as I wish I had but I know I can't be without Stu.
20. My parents always had 'a thing' about cleanliness, heightened because of Stu. We didn't want Stu to become ill because of low immune system or for anyone else to become infected. I have developed cleanliness OCD now and that behaviour has rubbed off on my own children. My partner is very aware of this.
21. I have developed a mistrust of doctors.
22. My son, GRO-C is a haemophiliac and I fought for him not to be given treatment on a prophylaxis basis. He had never had a joint bleed. Fortunately I had gained the confidence to argue the issue with the doctors on the point. The doctors do not like to be contradicted and I now have a bit of an insight as to what my own mother went through with Stuart. After the

dispute I actually viewed a letter from my consultant reporting that my husband, 'dad' was 'under the thumb' and would have gone along with whatever I 'mum' would have said. There was definitely pressure designed to make me feel guilty in making a stand for what I thought was right despite misleading (scaremongering) information.

Section 6. Treatment/care/support

23. The worst treatment for Stuart was the HCV clearing treatment. It affected him to the point that he was no longer the brother I knew and loved. He became depressed and was hard work to be around at that time.

24. We were never offered counselling and/or support.

Section 7. Financial Assistance

25. I refer to Stuart's Statement.

Section 8. Other Issues

26. There are no other issues.

Anonymity

27. I do not wish to remain anonymous.

28. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.

GRO-C

Dated.....28/04/2020