

Witness Name: Justin Christopher Stewart

Statement No: WITN2401001

Dated: 7th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JUSTIN CHRISTOPHER STEWART

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Justin Christopher Stewart will say as follows:-

1. Introduction

1. My name is Justin Christopher Stewart. My date of birth is GRO-C
GRO-C 1977. My address is GRO-C
GRO-C

2. I live at this address with my wife Kelly Joanne Stewart and our son

GRO-C

3. I intend to speak about my infection of hepatitis C, which I contracted from a blood transfusion in the 1980's. In particular, the nature of my illness and how this affected me, the treatment I received and the impact it has had on me.

2. How Infected

1. As far back as I can remember my childhood was spent back and forth to the hospital every time I had a bump on the joints of my body. I was diagnosed with Haemophilia A, which meant I needed to be injected with Factor VIII to mainly stop internal bleeding when I bumped my elbows or knees. I would bleed internally and spent a lot of time in Bristol Children's Hospital.
2. I believe I was infected with hepatitis C between the time I was born up until I was 13 or 14 years old.
3. When I was about 8 or 9 years old, my parents were taught how to inject me with Factor VIII. The product was stored at home, so in the eventuality of me bumping myself, it was on hand to administer it to me. This was a regular occurrence.
4. When I was very young I had Cryoprecipitate administered to me. I can't remember up until when but I remember the name of the product.
5. I was 16 or 17 years old when I was told I had contracted the hepatitis C infection. It was either Dr GRO-D or Dr GRO-D who told me at the Haemophilia Unit in Cardiff. I believe they had been testing me for three years without my knowledge.

6. No other family member has Haemophilia A. It is also unclear as to what status my haemophilia is, as there are conflicting diagnosis from the hospitals I have had treatment from, with regard to it being moderate or severe, I seem to be borderline.

3. Other Infections

1. There is a possibility I have contracted CJD. I think it was in the year 2000 I was in University in Newcastle where I was studying Marine Technology, I received a letter from the Royal Victoria Infirmary, Newcastle informing me that I received Factor VIII from an infected pool of blood products. To date, I have not been offered testing for this.

4. Consent

1. I believe I was tested for hepatitis C without my knowledge or consent for three years before I was told.
2. During the time I was being tested I was not given any information.
3. I think I may have been tested for the purpose of research as I had regular consultations with Professor **GRO-D** and his team leading up to being told of my condition.

5. Impact

1. When I was told I had contracted hepatitis C through infected blood products I was in deep shock. I couldn't believe it had taken them

three years to tell me, by which time I'd had several sleeping partners. I remember being very worried about these women, as I hadn't any information to go on with regard to me potentially infecting them. I can recall wondering if I had contracted HIV, would they have told me any sooner?

2. I don't tell anyone about being infected with the hepatitis C virus because it has a strong connection to drug abusers. There is still a stigma attached to this infection. I also believe it's a private matter.
3. Even though I had a lot of time off from school, I managed to get through my A levels and I also achieved a degree in Marine Technology at University.
4. In 1996, when I was 19, I was diagnosed with Hodgkin's Lymphoma. I remember having several 3-4 units of blood transfused at Withybush Hospital in Pembrokeshire several times. I got over this illness however; it came back. I was treated again using intensive chemotherapy and autologous bone marrow transplant. It hasn't come back.
5. When I had Hodgkin's Lymphoma I wanted to have my sperm stored in order for me to have children in the future. Not one hospital in Wales, private or NHS would store my sperm because of the hepatitis C. It made me feel like nobody wanted to touch me, including health professionals. Eventually, Dr Saleem from Withybush Hospital found Middlesex Hospital in London who agreed to store my sperm for me.
6. Eight years ago, my wife and I decided to start IVF. We were made to have treatment at the Chelsea and Westminster Hospital, London as they were the only hospital that would deal with frozen sperm from someone infected with Hepatitis C.

7. We had to have treatment privately as the NHS refused to fund this as my wife has a daughter from a previous relationship.
8. We were both prepared, all had gone well and my wife had her eggs taken out to be fertilised this was when the bombshell was dropped. My sperm wasn't viable. We were told at the time that the Doctor, who had frozen the sperm, hadn't done it properly. We were both gutted and words can't describe the way I was feeling at the time. I was very angry with the Doctor who didn't freeze my sperm properly, angry with myself and angry at the fact I had hepatitis C. It was at this point where the impact of this infection hit me. I felt my life had been ruined.
9. We later went on to have donor IVF and on the fourth attempt my wife Kelly was pregnant. We now have a son called GRO-C
10. The IVF treatment cost around £34,000. This had a financial impact upon us. However it was worth every penny now we have a son who is now six years old.
11. Since I have learned of contracting hepatitis C, I bottle up my worries about it. I have been cleared of it through Alpha Interferon, but no one will say I have been cured and there is always that worry it may come back.
12. I always felt embarrassed when I have to have my blood tested as it is put in bags with Bio- Hazard written on in large writing for all to see. Just from a local perspective I would feel really awkward if someone who knows me saw this.
13. Life insurance is too expensive, so I don't take any out. Holiday insurance is expensive and I don't like my condition written on the policy for anyone to see.

6. Treatment/Care/Support

1. As soon as I was informed of my diagnosis I was prescribed the Alpha Interferon treatment. Other than chronic fatigue I didn't suffer any side effects. In fact I was one of the lucky ones out of the 20% who are cleared of this infection. I didn't tell any of my friends and only immediate family I was having this treatment.
2. I was not offered any information or support when I was informed I had contracted hepatitis C. The only advice offered was that I needed to inform my dentist. The same applied when I had a letter from the Royal Victoria Infirmary, Newcastle regarding the vCJD.
3. As far as I am aware no information about any risks of the potential of infected blood was offered to my parents when I was a young child or to me when I was older.
4. I have arthritis in my joints and in 2017 I was prescribed Naproxen, which caused an ulcer in my stomach. This subsequently, created a bleed in my stomach, which resulted in me having five units of blood transfused in me. This was carried out at Worthybush Hospital, Pembrokeshire.

7. Financial Assistance

1. Fifteen years ago I was awarded £20,000 from the Skipton Fund through the Velindre Trust. Dr Dasani from the Haemophilia Clinic in Cardiff filled in the forms on my behalf. I also get £385 monthly payments.

2. The Haemophilia Clinic in Cardiff applied for the second stage but this was refused due to it not being proven that Hodgkin's Lymphoma is caused by hepatitis C.

8. Other Issues

1. I have put my name down for the Group Litigation for Haemophiliacs.
2. I feel that the awarded compensation from the Skipton Fund etc is not sufficient for the suffering and loss of life this 'cover up' has caused.
3. To put this into perspective, I have received £20,000 from the Skipton Fund for contracting something that could have been fatal, and will affect me for the rest of my life.
4. I broke my hip in 1997 by falling on a wet floor and it was decided that compensation should be £92,000. I therefore think that £20,000 Stage 1 and £50,000 Stage 2 is not representative of the suffering endured and lives ruined.
5. I think there has been a massive cover up and they should be paying out more. There have been a lot of people who have died as a direct result of being infected with hepatitis C and HIV.
6. Why has taken so long to get to this Inquiry?

Statement of Truth

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

Signed

GRO-C

Dated

07/02/19