Witness Name: WE Johnson
Statement No: WITN1311001
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Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF WAYNE EDWARD JOHNSON

I, Wayne Edward Johnson, will say as follows:-

Section 1. Introduction

1. My name is Wayne Edward Johnson of GRO-C GRO-C GRO-C. My date of birth is GRO-C 1970. I am currently in full time employment in insurance and I am married with one child.

2. **This statement has been prepared without the benefit of access to my full medical records.**

Section 2. How Infected

3. I suffer with a rare Factor VII deficiency severe form of Haemophilia.

4. I received both whole blood transfusions and Factor VII concentrate. When I was a child and I suffered with bleeds, initially the hospital could only provide whole blood transfusions. Factor VII concentrate became available when I was a teenager and I commenced home treatment of the concentrate at age 16.

5. I do not know whether I was infected through a whole blood transfusion or Factor VII concentrate. I received Factor VII intermittently as and when required.

6. I attended Huddersfield Royal Infirmary Hospital, and the consultant I recollect was Dr GRO-D.

7. I was infected with Hepatitis C as a result of the above treatment.

8. I believe that I was infected in the late 1980s.

9. I distinctly remember the day I was told about having been infected with Hepatitis C and this moment is etched in my memory because of its significance. In October 1990, following a routine appointment and blood test, Dr GRO-D told me in a matter of fact and most definitely flippant manner that I had been infected with Hepatitis C. This news was casually dropped in at the very end of my routine appointment.

10. At this time, I was given no adequate information to allow me to manage or even understand my infection. This was also due to the fact that the medical profession knew little about this virus; therefore, no advice or support was offered.

11. I seem to recall when the first Factor concentrate was made available to haemophiliacs it was promoted as a brilliant and life changing product which was 96% safe. As a figures oriented person, I felt positive about those odds and I was persuaded by them. It was all very much good news that Factor VII was available and there was no absolutely no advice given about the risks of this treatment.

Section 3. Other Infections

12. I believe that I was advised that I could have been exposed to the risk of vCJD but it turned out that I had escaped this.

Section 4. Consent

13. I was never told that I was being specifically tested for Hepatitis C, Hepatitis B or HIV. I used to go to the hospital for monthly check ups and I underwent routine blood tests but I was never informed of the reasons or purpose for which my blood had been taken. Due to the paternalistic nature of doctor patient relationship, the haemophiliac community never asked questions in this regard. Therefore, to the best of my knowledge, I was tested for viruses without my knowledge and therefore impliedly without my consent.

14. I recall that after I was told I had been infected with Hepatitis C, it was subsequently mentioned that I was also being tested for Hepatitis B. Nonetheless, there is a fairly large chance that I had been tested for Hepatitis B prior to this, without my knowledge and therefore without my consent.

15. I believe that in the main, the bodies which were looking after me were doing their best to find a solution; but I am also aware that they did not do as much as they should have done. I always think, at the back of my mind, that I have been used as a guinea pig and for research in relation to the new Factor VII concentrate.

Section 5. Impact

16. I was infected with Hepatitis C in the 1980s, but I did not find out about my diagnosis until October 1990.

17. My life expectancy has always been short due to my Factor VII deficiency. Nobody expected me to live past my 20th birthday. This was naturally a difficult thought for my parents to live with.

18. My Factor VII deficiency dictated that I was not a particularly well child. The illness manifested into joint, nose and internal bleeds. I knew when I had bleeds because they were painful. What I do remember is that I ran for the last time when I was aged 15 in 1985 because my ankles self fused after this.

19. Nevertheless, I always managed to go to school and I remained a "*top of the class*" student. I managed to achieve good grades at this juncture and I am proud of this fact.

20. In the latter years of my teenage life, things went in a completely different direction. In hindsight, I do think that my Hepatitis C symptoms were operating behind the scenes. I took my mathematics O Level ahead of everyone else and as a result I was expected to fly through the rest of my exams in the last year of school. I was expected to get ten more O Levels but I only managed to achieve one more. There was definitely something wrong with me; I was very ill during my last year of school. I then attended and completed a year at college and went onto work in insurance.

21. Physically and mentally, the last year of my school life was most definitely the hardest for me and I strongly believe it was a result of my Hepatitis C. I was bed ridden, lethargic, suffered with a lack of concentration and a lack of motivation. Basically all of the things that I have never been suddenly "*became me*". In hindsight, it would have not been the biggest shock in the world if it was confirmed that I had been infected with Hepatitis C aged 15 or 16.

22. My mother has since commented on my behaviour during this time and said it was a very difficult time for me.

23. Once I was told about having been infected with Hepatitis C, the doctors began to monitor my liver function. These tests always worried me because I never knew exactly when my liver might give up on me. I carried out a plethora of research which was massively worrying.

24. Eventually, after numerous tests, I underwent a liver biopsy in my mid to late 20s. In itself, the procedure was a significant risk due to my Haemophilia and I remember it as the most painful procedure I had ever experienced in the entirety of my life. I did not suffer with cirrhosis, but my liver was damaged by Hepatitis C.

25. I recall after having come round from the biopsy and when I was back on the ward that I was rigged up to a blood pressure machine because the biggest threat to me was internal bleeding following the biopsy. This machine took my blood pressure every 30 minutes. I was specifically told by the doctors that if the readings went up to a certain level then it would signify, in all likelihood, that I was having an internal bleed, which with my Haemophilia would have been a significant concern. I was incredibly scared and anxious throughout this time worrying as the figures flashed up and panicking that they would rise above a certain level. I was own my own for most of the time that I was rigged up to this machine.

26. Dr Sobala was the consultant who conducted my check ups which occurred every 6 months. He offered me Interferon treatment in the early 2000s. As a figure oriented man, I did not like the odds given that I was told that Interferon was a new drug on the market with a mere 20% chance of success. Dr Sobala explained I would have to inject the drug into my stomach every day for a duration of 6 months and that I would be highly likely to have to endure terrible side effects. On those facts and figures, the treatment did not appeal to me and I declined the offer.

27. Over the years, the chance of success of various Hepatitis C treatments increased as both medicine and science progressed.

28. Subsequently, I was transferred to St James' Hospital, Leeds because they boasted the most specialist doctors. I continued to be tested and monitored and eventually in approximately August 2016 I was offered an 8 week treatment programme of Harvoni which cleared the virus.

29. I can confirm that I was told that the Harvoni treatment was 98% likely to clear the virus and the that the treatment comprised taking one tablet daily for 8 weeks with minimal side effects. I very much liked the sound of that and that is why I consented to the treatment.

30. Following the completion of the Harvoni treatment, I underwent comprehensive check ups at the 3, 6 and 12 month stages and was then signed off as having cleared the Hepatitis C virus.

31. I recall that the side effects of Harvoni were manageable. I stopped drinking any alcohol and watched my diet in order to aid and complement the treatment programme.

32. The impact on my private, family and social life were difficult. I was quite insular about Hepatitis C due to the stigma. I was not told about risks in relation to transmission from a sexual point of view. The only advice I was given was that Hepatitis C could be transferred via blood contact. This advice was received later in my life and not when I was initially told about having contracted the virus.

33. I brushed my virus under the carpet. My mother and close friends knew that I was infected. However, out of the fear of stigma I did not disclose it to my employer or any of my peripheral contacts. I was embarrassed about it. I remember a comment by somebody who I used to work with who referred to the virus as a "*kissing disease*". I remember my face turning red as I knew I had what they were referring to and they did not know or understand what it really meant or how it could be contracted. These were just views of other people and it was upsetting and showed their lack of understanding in relation to how I came to be infected.

34. I recently found some letters which I wrote to my friends at that time. I drank alcohol to an extreme, I went off the rails and there was a real change in my mentality. Looking back on those letters, I understand that at the time I did not believe the virus had an effect on me, but it massively changed my outlook on life in the most negative way possible.

35. I had plans for my life. I knew I wanted to do well in my O Levels so that I could go on to study Sports Journalism at Darlington University. Unfortunately, due to my infection with Hepatitis C, I failed almost all of my exams which meant that I ended up taking a different path. I could not play sports professionally due to my Factor VII deficiency, but desperately wanted to be involved within sport in some form. It is therefore somewhat ironic that Hepatitis C may well have precluded me from even pursuing this desire.

36. I managed to go to work but I had more days off than I would have done due to a combination of Haemophilia and Hepatitis C.

37. When I was still a teenager, my father had put together a basic life insurance plan for me to the sum of £50,000 because of the fact that it did not require a medical check at this young age. This enabled me to get my first mortgage which I was thankful for. Had my father not researched this, I would not have been able to obtain a mortgage due to my infection. This is still the case today and I struggle to obtain any type of insurance despite the fact that I have now cleared the virus.

Section 6. Treatment/Care/Support

38. During routine blood tests, I had the yellow and black hazard warning marker which read "*Increased risk of infection*" stamped all over my sample pots and the plastic bags in which they were submitted. These were in full view of the entire waiting room.

39. Counselling or psychological support was certainly not offered to me.

40. I have recently read the EIBSS paperwork which states that there is an option for counselling, but this is the first time it has been on the table.

41. I have a great relationship with my physiotherapist and we talk about my various ailments and my physical as well as my mental wellbeing. We also often discuss the Inquiry.

Section 7. Financial Assistance

42. My brothers' girlfriend worked for the local council and informed me there was some financial assistance which I should look into and she introduced me to the Skipton Fund. I applied and received the Stage 1 Payment of £20,000. I do not recollect the application process.

43. I have also received free prescriptions for a while now.

44. Approximately 12 months ago I have started receiving the EIBSS, Special Category Mechanism Payments (SCM) which gives me a financial boost of £1,500 per month.

45. I also receive winter fuel payments of £500 which has been ongoing for some time now.

46. I recently found out that grants were available to apply for financial assistance. I have regular physiotherapy appointments and my physiotherapist advised me that I should purchase a new Tempur mattress. I therefore applied to the EIBSS for this product. I provided letters from my physiotherapist, Haematology nurse and doctors as evidence. After a very convoluted process which involved jumping through massive hoops, I was eventually granted the requisite financial assistance.

47. The process from start to finish made me feel that I was begging for this help. I believe that a majority of the population would struggle to be able to comprehend an application process as such and would therefore be unable to apply.

Section 8. Other Issues

48. I lobbied my MP about 5 years ago in relation to the issues of contaminated blood and blood products and I am enclosing a letter I composed which best explains my thoughts and emotions. **Exhibit WITN1311002** refers.

49. I regularly visit the Tainted Blood website to obtain updates and current information.

50. I am not bothered about an apology nor am I bothered about a witch hunt. I would like to be comprehensively compensated. My mentality is that I should have been given the resources to live my life to the very fullest for whatever time I was expected to be here for.

51. I am in a better position now than I was two years ago due to clearing Hepatitis C but no one can guarantee to me that it has gone for ever and the liver scarring remains.

52. I have a five year old child and I don't know how much time I have got left with him. Therefore, I would like comprehensive compensation to maximise our enjoyment of whatever time I have left. Compensation needs to be substantial and warranted as the physical and mental impact the virus has had on the last 27 years of my life needs to be recognised.

53. What happened is a tragedy; and so many people have passed away as a result.

Anonymity, disclosure and redaction

54. I do not want to be anonymous and 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........27/3/19...............................