

Witness Name: WAYNE ROBERT STEWART

Statement No: WINT1546001

Exhibits:WITN1546002-3

Dated: MARCH 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF WAYNE ROBERT STEWART

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I, Wayne Robert Stewart, will say as follows:-

#### Section 1. Introduction

1. My name is Wayne Robert Stewart. My date of birth is GRO-C 1975, I am 43 years old. I live at GRO-C  
GRO-C
2. I was diagnosed with moderate to severe Haemophilia and treated with contaminated Factor VIII (FVIII) concentrate. I tested positive for the Hepatitis C Virus, genotype 1a (HCV) in 1995. I cleared HCV in 2017.
3. This witness statement has been prepared with the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement. I believe that the records I have been provided with are incomplete as they do not contain records for the relevant period of my treatment in the 1970s/1980s.

## **Section 2. How infected**

4. At nine months old, I was diagnosed with moderate to severe Haemophilia A.
5. Throughout my younger years I was in and out of hospital with minor bumps and bruises. During my teenage years, these became increasingly worse. I was treated with cryoprecipitate as child.
6. As a child I was treated mainly at the Royal Victoria Hospital, Belfast. As I got older my care was moved to Belfast City Hospital under Dr Benson.
7. Full details of my treatment are set out in my UKHDO Haemophilia Database records which are exhibited at **WITN1546002**.
8. Until I received my Haemophilia Database records I believed that I was not treated with FVIII concentrate until I was a teenager. However, according to these records, I was first treated with Factor VIII in 1979.
9. I was a very active person throughout my teenage years – my mother wanted to wrap me up in cotton wool. She was very concerned for my health as I was growing up.
10. I was fortunate enough to have my grandmother pay for a preparatory school and a private primary school. However, due to unfortunate circumstances, she was unable to continue paying for my school and I moved to a state school when I was 7 or 8 years old.
11. Throughout my schooling, a teacher had communicated to my class that I was a haemophiliac. News quickly spread to the entire school and I was then subjected to an immense amount of bullying because of the stigma around haemophiliacs at the time which was caused by the media campaign linking it with AIDS.
12. I had to miss a great deal of my education as a result of treatment for my haemophilia. I then did not want to even return to school because of the bullying I had to endure.

13. I was never able to escape the bullying. As a result I left school at 15 in order to get away from it all. I could not then even sit my GCSEs because I did not feel that I was academic enough.
14. I then left school and started work in a bakery on computers ordering ingredients from different suppliers. I couldn't do manual work because of my haemophilia but I didn't have any exams behind me. In the end I obtained a City and Guild's qualification. I was a hard worker with a great work ethic that had been instilled in me because of my grandparents who had always worked on the markets. I was brought up with the ethic: if you do not work, you will not get paid. Leaving school was supposed to be a fresh start.
15. During my later teenage years, I was treated with FVIII concentrate. At the time, my parents and I were given minimal information about the risks of FVIII. I was only told that FVIII is a much safer method of treating wounds as a result of haemophilia.
16. Around this time I saw a number of stories on in the news about Haemophiliacs being infected with HIV. I was deeply concerned at the time, as were my parents. My doctors at the time seemed sure that I was not infected with HIV although I do not believe that I was informed that I was tested for the same.
17. In or about 1993/4 I met Belinda and started a long term relationship. We dated for 18 months and then planned to go on holiday. However, my Dad convinced us that it would be more sensible to use the money as a deposit on a house to get on the property ladder. He happened to know someone who was selling a flat at the time so we decided to go for it and enquire about a mortgage.
18. One of the terms of the mortgage was to have a full medical for life insurance because of my haemophilia. My blood was tested by an independent practitioner.

19. I was then informed that I had contracted HCV. This was not communicated to me by my own doctors. I found out via the insurance company's independent practitioner. The mortgage had fortunately been granted because of my wife-to-be at the time, Belinda.
20. There is now shown to me marked **WITN1546003** a copy of the letter sent to my GP by Dr Maine, the Medical Officer who carried out the tests. This makes it clear that I was unaware of my condition and that he hoped my GP would discuss it with me before I was informed of the decision to decline my cover. This did not happen. I got a similar letter before my GP arranged an appointment with my Consultant, Dr Benson at Belfast City Hospital.
21. Dr Maine tried to explain what had happened but I didn't understand the severity. I thought there had been a mistake as I didn't believe I had any symptoms. He gave me a few leaflets but no real information was given to me.
22. Dr Maine referred me to a haematologist. When I saw the HCV consultant I was very angry. They discussed my diagnosis with me. They had no clue when, where or how I had contracted HCV. They told me that they would have to do blood tests to see what level the virus was at and liver tests to check for damage. They did not discuss any treatment options with me. I felt my life falling apart in front of me as I was told that I could not have children and start a family. I completely broke down during this meeting, I was distraught.
23. I had to drive 40 miles home from Belfast on my own. I was not advised to prepare myself for the kind of information I was about to be given, or else I would have brought somebody with me for comfort. Additionally, I was never tested for HIV. I was never told about the risks to haemophiliacs regarding HIV.
24. As a result of contracting HCV, I could not then get life insurance. The way these results were communicated to me was a disgrace. I had to find out through the mortgage broker rather than my doctor.

### **Section 3. Other Infections**

25. I also received a letter communicating that there was a risk that I could have been infected with vCJD. I felt that this was an extremely impersonal and harsh way of being told about this risk.

26. Fortunately, I was subsequently tested and my test was negative.

### **Section 4. Consent**

27. My UKHCDO records confirm that I was tested for HIV on 1 January 1985 and 8 June 1986. Both tests were negative. I do not recall the tests or results being discussed with me and I do not believe that my parents were asked to consent to the same.

28. I consented to the tests carried out in my medical examination in order to get my mortgage in 1995. However, I was not specifically aware that I was being tested for HCV.

29. I believe that I should have been tested earlier given the state of knowledge about the link between FVIII treatment and HCV in the early 1990s.

### **Section 5. Impact of the Infection**

30. Due to my secondary school being fully aware of my haemophilia and the stigma that surrounded the illness, I was bullied extensively at school. I was called "AIDS victim" and "gay" and lots of other names along a similar theme. This meant that I could not even finish school and I am positive that if I had been able to finish I would have been able to get a better job later on down the line.

31. When I had my full medical examination to try and get my mortgage, it was like a punch in the teeth as I was again reminded about all the bullying at school. It was horrendous.

32. The initial psychological impact of being informed that I had contract HCV was absolutely horrendous. In the meeting with the haematologist, I completely broke down. I felt that my life was falling apart.
33. Having been told about the risks of HCV to my partner and the risks of having children, my relationship with Belinda eventually completely broke down. We did marry in 2002/3 but our marriage broke down 2 years later. For the next ten years of my life, I had to use protection. I felt a massive amount of guilt that I was not able to provide a family to her. I felt that my life was not worth living anymore. Family meant everything to me.
34. When we split up, I went through a whirlwind of emotions. The guilt I felt was unbearable. Fortunately we are still good friends, but I understood why we split up. She wanted a 'normal' life, with kids and a family. I could not give her that or deny her the opportunity to find it with someone else.
35. I am lucky enough to have had a healthy 11 year old daughter from a subsequent partner and I am now trying to foster another child. My daughter was conceived in between treatments, when I managed to get the all clear. If I was not able to have kids I honestly do not know what I would do. **GRO-C**
- GRO-C**
36. There was a horrible stigma attached having haemophilia. Over the years, I have lost friends. A very close friend of mine came over to my house and asked me if a drinking glass had been washed. This then led to a massive argument. Along with that, a lot of people have not said directly to my face their opinions and prejudice about haemophilia, but I have lost contact with a number of people because of this.
37. Being infected with HCV had a huge impact emotionally and psychologically on both my mother and father. They blamed themselves for giving me the haemophilia and then taking me to that hospital to have treatment with the infected blood products. It made my mother very emotional as she had always been very protective over me.

## **Section 6. Treatment/care/support**

38. It is difficult to recall if there were any obstacles in obtaining treatment. I do not remember specifically being told about any treatments, although my GP may have mentioned them.
39. In or about 1999/2000 I was treated with Interferon. This involved injecting myself 2/3 times a week. The side effects were terrible. There were things happening in my head that I couldn't understand. The mental impact was huge. However, I kept on the treatment because my main aim at the time was to get rid of HCV. I was told that I might experience some side effects from the treatment but the reality was I had most of them. I suffered from depression and anxiety (which continue to this day) and flu-like symptoms. I looked gaunt and yellow. I couldn't think straight. I had to be off work because I couldn't concentrate. At that time I was working as a machine operator.
40. Eventually I was taken off the treatment after 6 months because it was destroying me. After a break I went back on the treatment and completed the course. Unfortunately the treatment was not successful in clearing the HCV.
41. My second round of treatment was in October 2005. I was treated with Pegylated Interferon and Ribavirin. This involved taking tablets as well as doing injections. It was a 48 week course. The side effects were not as bad and I was more prepared for them but it was still very unpleasant. My mindset at that time was that I was not going to let it get me down and I tried to be as active as possible even though I still felt lethargic and depressed. One of the most difficult things about the treatments was that I was taking the treatment to get rid of HCV but then I would have to take other tablets to combat the side effects of the treatment. In the end I felt like I was in a pharmaceutical bubble with boxes and boxes of tablets.
42. At the end of my second treatment I was told I had cleared HCV. At my six month review I was told it had returned which was a devastating blow.

43. Following this treatment I was advised it would be best for me to wait until new drugs were available before further attempting to clear the virus because although a long term course of combination therapy could be used, the chance of this being successful would be lower than the 30-40% figure I was originally given.
44. My third and final treatment was in 2013 with triple therapy (Pegylated Interferon, Ribavirin and Telaprevir). This was a 2 year course which finally cleared my HCV. I had a fibroscan in December 2015 which was essentially normal and I have therefore been discharged from the liver clinic without the need for further monitoring.
45. I not offered any counselling or psychological support as a result of being infected. When I requested the counselling myself, I remember it taking nearly a year and a half to actually receive the treatment – I felt that this was unacceptable. I am of the firm opinion that the hospital and Haemophilia Centre could have done a lot more for me.
46. Face to face meetings with doctors were extremely rare. On the occasions I actually got in front of a doctor, I felt resentful and distrusting. There was little to no sympathy provided to me. This is made even worse by the fact that, to this day, I still need to visit doctors on a regular basis because I am a haemophiliac. I never know when doctors are telling the truth because of this horrendous displacement of trust.

## **Section 7. Financial Assistance**

47. I received a stage one payout of £20,000 from the Skipton Fund. I have never received a stage two payment.
48. I receive monthly payments from EIBSS; however this organization is extremely difficult to deal with. The staff are not sympathetic and very impassionate. It is almost like talking to a brick wall. If you ask for help, you'll be waiting three months for a response.



## **Section 8. Other Issues**

49. I believe that there should be a recommendation made by the Inquiry to grant some form of compensation to the victims of this scandal. There are a lot of families struggling and I count myself as one of the lucky ones because I have not contracted HIV.

50. I also believe that treatment should be looked at as I am still worried my HCV may return and that this will not be picked up because I have been discharged from the liver clinic.

## **Anonymity**

51. I do not wish to apply for anonymity and I understand this statement will be published and disclosed as part of the Inquiry. I do not wish to give oral evidence.

**Not Relevant**

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### **Statement of Truth**

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

GRO-C

Signed.....

Dated 1 - April - 19.