

Witness Name: Trevor Paul Allen

Statement No: WITN1073001

Exhibits: WITN1073002-4

Dated: February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF TREVOR PAUL ALLEN

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I, Trevor Paul Allen, will say as follows:-

#### **Section 1. Introduction**

1. My name is Trevor Paul Allen. I am 51 years of age. I am married with two teenage children.
2. I am not currently working due to Haemarthrosis, Hepatitis C (genotype 1a) and possible variant CJD (vCJD).
3. I was infected with Hepatitis C from contaminated blood products.
4. This witness statement has been prepared without 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.

#### **Section 2. How infected**

5. I suffer from severe Haemophilia B.

6. As a child I was placed in care and foster homes up to the age of 17. These were in a number of different locations and counties which were under different health care authorities. There is now shown to me marked **WITN1073002** a copy of my treatment record from the UK National Haemophilia Database which lists my Factor IX treatments and the centres where I was treated.
7. Unfortunately I do not know which batch was contaminated from those I was treated with and therefore I cannot say which treatment centres or doctors were involved. After I received a copy of my treatment data from the National Haemophilia Database I tried to find out more information but no one could or would answer my questions.
8. I believe that I was informed I was infected with Hepatitis C in or about the mid 1990s when I was being treated at Addenbrookes. When I was told I think I just switched off because of the shock but, as far as I can recall, limited information was given to me about the virus at that time. I do recall being told that I needed to tell people I had Hepatitis C if I had a bleed and needed assistance. Unfortunately, due to the passage of time, I cannot recall the name of the person that told me I was Hepatitis C positive.
9. I note from my medical records that my Hepatitis C test in 1990 was negative. On 13 February 1995 Dr Baglin wrote to my GP stating that the possibility of Hepatitis C had been discussed with me. This letter is now exhibited at **WITN1073003**. I first tested Hepatitis C antibody positive on 13 February 1995. There is a clinic note in 1996 which states that Hepatitis C was discussed and my positive Hepatitis C test result was confirmed again in 1997 and 1998. Dr Baglin was my Consultant at the time.
10. I was tested for HIV in October 1985, August 1986 and again in February and June 1995. As a haemophiliac I had regular check up and blood tests but I was not told what the blood tests were for unless I specifically asked. I do not recall being told I was being tested for HIV.

11. I also believe that I was exposed to Hepatitis B as Hep Bc Ab were found when I was tested on 16 November 1990 which I understands indicates past exposure to Hepatitis B. This is confirmed in the letter from Dr Baglin exhibited at **WITN1073004**.

12. I was never given any information about the potential risk of infection from contaminated blood products. I believe that information should have been provided to patients as soon as it was known that certain blood products contained lethal and/or life threatening viruses. It saddens and upsets me that little or no information was given or provided. This could have saved lives.

13. I was only really made aware of the risk of infecting others with Hepatitis C when my wife and I were planning a family. We were both told that there was a risk of passing on the infection to my wife and possibly children.

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

14. I have been advised that I am at risk of vCJD. This only came to light after another haemophiliac died suddenly and it was found he had vCJD.

### **Section 4. Consent**

15. I believe I was tested without my consent. I was not aware that I was being tested for Hepatitis C.

16. I believe that the health care professionals were quite possibly kept in the dark until it became increasingly evident that there was an issue because of the number of people who were ill and/or dying. Very little information was provided to patients and for a number of years no support was offered.

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

17. My Hepatitis C infection had a significant impact on my mental state and continues to do so to this day. The most difficult thing was thinking about what would happen if I took a turn for the worse and left my wife without a husband and my children without a father. This was mentally graining to the point where I felt I didn't want to put my family through my illness anymore. I found that my personality changed and I became very short tempered. I did not speak to my GP or any other medical professional about my anxiety and depression. I relied on my wife to support me.
18. The main physical effect of my infection is severe fatigue which impacts me every day in all my activities. I feel drained and exhausted all the time.
19. To date I have declined any treatment for my Hepatitis C infection. I am aware of the severe side effects of the treatments which have been offered to other people and I have no desire to have my already short temper and severe fatigue doubled by the side effects of that medication.
20. In 2015 I was diagnosed with moderate fibrosis based on a Fibroscan result of 9.0.
21. I have lost friends and work as a result of my Hepatitis C infection. I have been refused countless jobs partly because of my haemophilia but also partly because of my Hepatitis C. When I have to explain to prospective employers that I have both conditions and the impact of that of my health I never get the job. I believe I have been discriminated against because of my Hepatitis C infection but of course no employer accepts this.
22. There is a stigma attached to having Hepatitis C and at times I felt I was treated as a leper, shunned and stigmatized. Whenever I declared my infection at work and/or during interviews I found that the attitudes, mannerisms and style of questioning would change in a matter of moments.
23. My family has taken the brunt of my mood swings and this has impacted on my relationship with both my wife and children.

24. For years we have had to get by financially. I was doing agency work as a welder fabricator which involved working in different locations at different companies. When I had to finally give up work it was increasingly difficult to get any financial help until new schemes became available. It was only really when the new scheme (EIBSS) came along that I received the lower payment. Once the government decided to open up the higher rate for those of us who are left I applied for that and was finally granted it. I know that other assistance was available from the Skipton fund but I never felt I really fell into the right category for financial help.

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

25. I have not undergone any treatment for my Hepatitis C infection for the reasons set out above.

26. I have not been offered any counselling/psychological support.

#### **Section 7. Financial Assistance**

27. When it became evidence that the Government/NHS had played Russian roulette with thousands of lives by infecting haemophiliacs (and others) with deadly or life threatening viruses they tried to palm us off with a one off payment from the Skipton Fund.

28. I received the Stage One payment from the Skipton Fund.

29. I believe that the Skipton Fund scheme was discriminatory because the amount paid depended upon how severe your infection was despite the fact that we had all been infected with Hepatitis C.

#### **Section 8. Other Issues**

30. It has been emotionally, physically and mentally frustrating to be treated as a third rate citizen for decades whilst people who made the choice to play God with thousands of lives carry on as though it is no longer their problem or concern.

**Anonymity**

31. I do not wish to apply for anonymity.

32. I do not wish to give oral evidence at the Inquiry.

**Statement of Truth**

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

Signed GRO-C .....

Dated 14/02/19