

Witness Name: Stephen Dolby

Statement No.: WITN0782001

Exhibits: None

Dated: 25 March 2019

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF STEPHEN DOLBY**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 February 2018.

I, Stephen Dolby, say as follows: -

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

1. My name is Stephen Dolby. I am sixty-one years of age having been born GRO-C 1956. My address is known to the Inquiry. I am a self-employed joiner and fitter and I have been married to my wife, Julie Dolby, for over 40 years. I have two children, aged 33 and 37, three grandchildren and one step-grandchild.
2. I intend to speak about my experience of contracting hepatitis C ("HCV") as a result of receiving contaminated blood products for treatment of my haemophilia A. In particular, I will discuss how being infected with and treated for HCV has impacted my family and me.

#### **Section 2. How Infected**

3. When I was 24 years old I suffered a knock to my leg playing football that resulted in severe bruising to my leg and swelling to the joints. As a result, I was taken to the Royal Hallamshire Hospital Sheffield ("the Sheffield Hospital") for treatment. While at the Hospital, I was under the care of Professor Preston and Professor Greaves who informed me that I suffered from mild haemophilia A

("haemophilia"). I was told my blood's clotting factor was in the range of 17. This was the first I learned I had haemophilia. I was the first person in my family to be diagnosed with haemophilia. My brother, two nephews, grandson and my cousin's children have since been diagnosed with haemophilia.

4. I found Professor Preston and Professor Greave's care of me to be brilliant. Both doctors spoke to me in plain English and avoided using medical jargon, which helped me to understand my diagnosis. The doctors were shocked to learn I was a joiner and fitter, drove motorbikes and enjoyed diving off the diving board at Grimsby swimming pool. The doctors told me I shouldn't do those things anymore and had to be more careful.
5. While at the Sheffield Hospital, Dr Greaves advised me about a blood-clotting agent used to treat haemophilia. I can't be sure of the name of the agent but I think it was Factor VIII. Dr Greaves said to me words to the effect "If you will be a guinea pig, I will go along with you". Dr Greaves and I both sat together while he treated me with the bleeding clotting agent. I think he treated himself with the agent as well, as he sat on the end of the bed and described the effects of the medication.
6. The football injury was the first time I received bleeding clotting factors. Since then, I have received Factor VIII blood products on a number of occasions including during a liver biopsy, a vasectomy, two operations to remove teeth and after various injuries, including a thumb injury, bruised legs and a cut to my hand. All procedures occurred at the Sheffield Hospital. I remember on one occasion I was taken to the Sheffield Hospital for a bleed. During the night, I was woken up at 2:00am by a young nurse who advised me she was giving me Factor VIII. The nurse was unable to find a vein and soon there was blood all over the sheets and me.
7. I was never informed of the risks associated with Factor VIII blood products and I am unsure on which occasion I received contaminated blood products. I trusted the doctors to take care of me and thought the treatment I was receiving was necessary and what I needed for the sake of my health. I put my trust in the NHS.

9. On another occasion at the Sheffield Hospital, a nurse came into my room during the night to give me Factor VIII. I was under the care of Professor [GRO-D] at the time. The nurse asked me how I was coping with my "hep C". I had never heard of "hep C" and asked, what it was. The nurse responded by telling me I have it. I told her no one had ever told me and she said words to the effect of "well you have it". Up until that point, I had never heard of hepatitis being abbreviated to "hep". I did not even understand what she was referring to. To this day I find it disgusting how the nurse told me about my HCV status.
10. After the nurse told me I had "HCV", no one, not even Professor [GRO-D] came to explain the disease to me. I wasn't even provided with a brochure or information booklet. I wasn't told how it is transmitted, whether I could pass it on or what the disease does to me.
11. While in hospital, Professor [GRO-D] told me that I had suffered 15% liver damage but that my liver would mend itself in time. He also mentioned that there were potential treatments for HCV in the pipeline but they weren't yet available in the UK at the time. At the time, I didn't let it bother me and thought to myself that 15% liver damage isn't too bad.
12. As I was never provided with adequate information about HCV, I am still not entirely aware of the risk of infecting others, including my wife, children and grandchildren, which has had a significant impact on my private life.

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

13. To my knowledge, I have never been infected with any diseases other than HCV.
14. At some stage after my HCV diagnosis, I badly injured my thumb requiring me to attend the Sheffield Hospital for four days. While at the hospital, I was placed on the Hospice Ward under the care of Sister Joy Farnsworth. One day, Sister Farnsworth told I that I was required by law to undertake an AIDS test, which deeply shocked me. I remember thinking how could I have AIDS? I'm not a drug user, I don't take drugs and I'm in a committed relationship with my wife?

15. The AIDS test results were negative, thankfully. I have had a second AIDS test since, which was also negative. I was told by Sheffield Hospital that I don't have AIDS but the virus passed through my body. I think they meant the blood products I was treated with had the virus but I don't know. I just remember feeling shocked.

#### **Section 4. Consent**

16. I do not believe I have ever been treated or tested without my knowledge or consent. I always put my faith in the NHS and the care of my doctors. However, I was never provided with adequate information as to the risks of blood products or my HCV diagnosis.
17. I had never thought that I was treated for the purposes of research however I now wonder if I have been, given Professor Greaves asked me if I would be willing to be a guinea pig as mentioned above in paragraph 5.
18. I am unaware of any other occasion, other than outlined above where my treatment of haemophilia or HCV was used for the purposes of research.

#### **Section 5. Impact**

19. I have suffered various mental and physical effects as a result of my HCV infection. When I was first diagnosed, I was moody and stopped eating properly. I still find that I am often tired and lethargic and suffer from a loss of appetite. My wife tells me that I always sleep. I've had to change my lifestyle in that I can no longer do any strenuous physical exercise. For example, at work I sometimes require the assistance of others to pick up heavy objects. I am a self-employed joiner and fitter but I also used to accept all kinds of work. These days, I find myself knocking back work because I'm too lethargic.
20. Knowing I have HCV gets me down. I don't like to talk about it. I sometimes suffer from anxiety and lie awake at night thinking about my diagnosis. The entire ordeal has been daunting and weighs on my mind. My sleep hasn't been

the same since my diagnosis, I regularly I wake up in the middle of the night and think about the fact that I could be dead right now.

21. My experience has made me constantly doubt my health. I wonder If I can trust what my doctors are saying. That being said, I am also grateful that I am alive and consider myself lucky, as I have heard stories of other people in similar situations sadly passing away.
22. As previously stated, I suffered 15% liver damage as a result of being infected with HCV, and I was told that my liver would eventually regenerate itself over time.
23. Not long after I was diagnosed, I received two rounds of treatment for my HCV infection at Grimsby Hospital. I can't remember the names of the medication prescribed but it involved injections and tablets. The medication may have been called Interferon. I suffered extreme side effects to the medication. I remember having lunch with my wife and some friends when I suddenly became so weak and started violently shaking. My wife and friends had to wrap me up in a quilt and told me to stop me from shaking.
24. After this reaction, my wife rang the nurse at Grimsby Hospital to tell her about my reaction and to say that I would be stopping the treatment. The nurse told my wife that I can't stop and that the treatment had worked on a heroin addict who also GRO-C I was upset for being put in the same category as a drug user, as I'd never taken drugs. I stopped the treatment and went about my life. The nurse told me she was disappointed.
25. In 2018 I underwent a twelve-week course of treatment for my HCV at the Grimsby Hospital. The treatment involved taking two rounds of tablets a week for 12 weeks. Thankfully, I did not suffer any side effects from the treatment. The medical care I received by both Grimsby and Sheffield Hospitals was excellent.
26. In late 2018, I was told by Grimsby Hospital that my HCV had been cured. However, the doctors at Sheffield Hospital have told me that my HCV is not cured but dormant, as it is still present in my blood. Either way I have been told

my HCV is being managed and I am in good health. I continue to have regular check ups every few months.

27. In terms of other treatments that weren't available to me, at one point Professor GRO-D informed me of a less invasive treatment for HCV that was in the pipeline but not yet available in the UK due to a lack of funding. In 2018, I started this treatment when funding became available.
28. I can't say whether my infected status has impacted upon my medical treatment or dental care. I have always had poor teeth, which I had removed prior to my diagnosis. I was advised to have ten removed at once due to the risks of bleeding associated with my haemophilia. These days, I only tend to seek medical care when I'm very unwell or have a serious bleed. These days, whenever I go to the doctor they make me give a blood sample.
29. Being infected with HCV has had a deep impact on my private, family and social life. When I was first diagnosed with HCV I was told that it could be passed to other people, but I was not told how it was passed. It weighs on my mind to think I could have infected my family and friends.
30. The only person I have told about my HCV infection is my wife, Julie. I have never told my other family or friends about my infection due to the stigma attached to the infection. Hepatitis is commonly associated with drug users, promiscuity and needles. I don't use drugs or sleep with people other than my wife yet I feel my HCV is associated with those things. Even when I provide a blood sample at the hospital I am given a container and plastic bag labelled "beware of contamination" in which to put my sample, which makes me feel ashamed.
31. I feel both upset and agitated that I am unable to discuss my HCV infection. Recently a work mate told me about compensation he received for a car accident. I found myself wanting to tell him about payments I received for my infection but I was unable to.

32. Being infected with HCV has also changed the way I behave around family and friends. I constantly take precautionary measures to make sure that I do not pass the infection on. I make sure not to use other people's cups and I am very careful about letting my grandchildren kiss me for fearing of passing on my HCV.
33. I also felt the effects of the stigma when I was told that I needed to be tested for AIDS at Sheffield Hospital, as HIV/AIDS is another infection associated with drug use, homosexuality and promiscuity.
34. My HCV has impacted my ability to work. Due to my haemophilia, I am unable to work if I get a bleed, which means I lose money, as I'm self-employed. I have also found that due to a combination of my haemophilia and HCV, and I can no longer undertake work that is physically strenuous, and I have had to turn down jobs that are too physically demanding.

#### **Section 6. Treatment/Care/Support**

35. I don't believe I have faced obstacles in obtaining treatment for HCV. I can't remember being referred to specialists for my HCV but I did start treatment, which I later stopped, shortly after being diagnosed with HCV. I still feel I have never been provided with appropriate support regarding my HCV, as it has never been properly explained to me.
36. At no stage did my treating medical professionals refer me to counselling or psychological support. I was made aware of counselling services when I received a letter from the Skipton Fund however I have not accessed these services. I feel as if it is too late and that it is best for me to deal with my situation in my own way.

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

37. In 2004 I received a phone call from the Sister in charge at Sheffield Hospital who advised me that I was going to receive a £20,000 payment as a result of being infected with HCV from infected blood products. I understand the medical professionals at Sheffield Hospital made my application on my behalf.

38. Being offered £20,000 immediately made me suspicious. I had a meeting with Professor [GRO-D] and the Sister regarding the money. I told them that I felt the £20,000 payment was "shut up money". The sister told me that I was the only person she had heard describe the payment that way.
39. Professor [GRO-D] and the Sister told me that people receive a £45,000 payment if their infection was more severe. I remember meeting one man at the hospital who had received £45,000 payment and later died. I was thankful I wasn't dying.
40. I received the payment of £20,000 from the Skipton Fund on 10 September 2004.
41. In approximately 2015-2016, I applied for further financial assistance through the Caxton Foundation and the Skipton Funds. The applications involved filling out three or four sheets of paper about my personal and medical background.
42. The Skipton Fund accepted my application for financial compensation. They did not challenge it and I didn't receive any push back. For the past two years or so, I have received monthly payments of £1742.
43. I would rather receive a lump sum payment than monthly payments. If I were to receive one lump sum, I would be able to retire from work and enjoy the money. I feel as if the payments are made monthly in order for the government to save money.

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

44. Despite not being previously involved in any campaigning, other inquiries or litigation, I decided to make a statement to the Infected Blood Inquiry after I was provided with the inquiry's details by one of the sisters at Sheffield Hospital. My infection weighs heavily on my mind and I want to put my story forward.
45. I would like to see someone take responsibility for the infected blood scandal and apologise for what has happened to others and myself. If I make a mistake at work I own up to and take responsibility for my actions. I fix the mistake. I want



whoever is responsible for the infected blood scandal to do the same. I feel that to date, no one from the government has done this.

**Statement of Truth**

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

Signer

GRO-C

Dated 28<sup>th</sup> MARCH 2019

