

# ANONYMOUS

Witness Name:

Statement No.: WITN0066001

Exhibits: WITN0066002- WITN0066014

Dated:

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 October 2018.

I,  will say as follows: -

### Section 1: Introduction

1. My name is  My date of birth is  1972 and my address is known to the Inquiry. I am 46 years old, married with two children and living in England.
2. I intend to speak about myself, in particular, the nature of my illness, how the illness has affected me, the treatment I have received and the impact it has had on me and my family.

### Section 2: How Infected

3. I do not have access to my medical notes so cannot provide exact details in relation to times and dates of treatment, particularly in relation to my

## ANONYMOUS

childhood. Some of the dates provided are therefore an estimate. My father is no longer resident in the UK and has not provided me with additional information. I have, however, spoken with my mother and she has been able to verify some of the details. She does not have any additional papers. I do have letters sent to me from 2004 with regards to the payment scheme and in relation vCJD, which are detailed below.

4. I am a mild haemophiliac (c.15%) with Haemophilia A. My parents did not discover I was a haemophiliac until I was about 9 or 10 years old. They suspected that I had an issue with bruising and bleeding but were unable to get a clear diagnosis until I was older.
5. Whilst growing up in [GRO-B] between 1976 and 1992 my GP was Dr [GRO-B] of the [GRO-B] Medical Practice.
6. I was registered at the Haematology Centre at Copthorne Hospital in Shrewsbury from 1980 until 1992 under the care of two consultant's haematologists Dr M. J. O'Shea and Dr E. G. Rees.
7. I had an annually appointment for a check-up but only received Factor 8 treatment occasionally or when necessary. I remember seeing Dr O'Shea regularly during that time.
8. The first time a significant bleeding issue arose was during a medical intervention to remove my adenoids at the Ear, Nose and Throat Hospital in Shrewsbury Hospital (c. 1977). In spite of this being a routine operation there was significant issues with bleeding and healing. Haemophilia was not diagnosed at this time.
9. At approximately aged 9-10 years old (c.1980) I had a dental operation at the Copthorne Hospital in Shrewsbury to remove some teeth. I had significant bleeding issues and complications during that operation, and spent up to a

## ANONYMOUS

- week in hospital. I understand from my mother that I needed an emergency blood transfusion during this operation.
10. Following this issue I was referred to Dr O'Shea at the Haematology Department at Copthorne Hospital, who established the diagnosis of Haemophilia A and diagnosed the level and severity of the condition.
  11. I subsequently discovered my grandfather Mr [GRO-B] (now deceased) was also a mild haemophiliac and my condition was inherited in the common way down the female line. My mother: [GRO-B] (nee [GRO-B]) is a carrier.
  12. I was registered in Shrewsbury until 1995. I was at University in Manchester between 1992 and 1995; I transferred myself to the Haematology Department at the Manchester Royal Infirmary towards the end of my studies in 1995.
  13. In 1995, I was seen there by Dr Charles Hay then Senior Consultant Haematologist. Dr Hay carried out a blood test at my request and diagnosed that I had the Hepatitis C Virus (HCV), he also initiated my first HCV treatment programme, a two year course of Intereron Alpha and Ribavirin.
  14. I have subsequently been registered at the Bradford Royal Infirmary (1996), Hull Royal Infirmary (1997 to 2002), The Royal Devon and Exeter Hospital (2003) and the Haemophilia Centre at Addenbrooke's Hospital in Cambridge (2004), where I am currently registered.
  15. I do not and never have received regular prescribed treatment. I have tried to manage my haemophilia condition myself seeking treatment only on demand or when necessary. The treatment I sought was for injuries I received playing sport, accidents and for very occasional medical intervention, such as a liver biopsy that I had in [GRO-B] (c. 2000).

## ANONYMOUS

16. I do not need treatment on a regular basis but when I was younger the frequency of treatment would be up to once or twice in a year. This pattern continued whilst I was at school and until I was about 16, when I was able to manage my condition better and was able to avoid and manage risks, and incidents.
17. The frequency of treatment since 1992 has declined to once every two or three years.
18. With the exception of a blood transfusion received during the dental work (c. 1980) I have only ever been treated with Factor 8; this was always administered at hospital intravenously.
19. I received Factor 8 treatment only at the Copthorne Hospital in Shrewsbury from c. 1980 until about 1992.
20. I can confirm that I have never used prophylaxis or treated myself at home and do not or never had had a portacath. Additionally, I do not have a tattoo nor have I ever been an intravenous drug user. I have never been treated abroad with any blood products for or received dental treatment outside of the UK. I have never knowingly had a sexual relationship with any person infected with Hepatitis C and I have only had heterosexual relationships.
21. I believe that I contracted HCV in the period from c.1977 to 1992. I believe that either my blood transfusion following dental work or the Factor 8 treatment I received whilst under the care of the Haematology Centre at Copthorne Hospital in Shrewsbury, contained infected blood.
22. I was not treated at any other hospital or with any other blood product during this time. I do not believe I have ever been at risk from HCV from any other transmission routes.

## ANONYMOUS

23. Neither I nor my parents were ever given any information about the risk posed by infected blood or in relation to the product known as Factor 8 at any time during my childhood.
24. I first became aware of contaminated blood issues from the news articles and the campaigns run by the Haemophilia Society in early 1990's. I had never heard of Hepatitis C until I read about in the Haemophilia Society publications.
25. I was invited by my GP Dr GRO-D for a blood test when I was approximately 16 years old. I was informed by letter a few weeks later that it was a test for HIV and it had been negative. I was not told what the objective of the blood test was at the time, nor was I given any information about contaminated blood at that time. Neither I nor were my parents given any details at the time of why the test was carried out, why it was necessary or what the implications were. HIV had never been mentioned before this time and at no point was HCV ever mentioned or discussed.
26. I went to university in 1992 and during my time in Manchester I became aware of the issue of infected blood and the issues relating to Hepatitis C. In 1995 during my final year I become involved with a new partner and she suggested that given the issues faced by other haemophiliacs in relation to HCV, it would be a good idea to get a test.
27. I then registered with the Manchester Royal Infirmary and soon after registration in 1995 I was tested for HCV; the test was positive. Dr Hay carried out the tests at Manchester and confirmed the HCV diagnosis. He provided some details at the time about the issue.
28. Dr Hay told me that HCV could be an aggressive disease and that my life expectancy was compromised as a result of the infection, that it was a degenerative condition, and the outcome was potentially advanced sclerosis or liver cancer. I was later given information about the genotype of the virus,

## ANONYMOUS

that it was not the most aggressive strain and that it had originated in South East Asia. I have never been able to verify this detail, nor do I fully understand the relevance of that statement, or if true how it came to be in British blood products.

29. The information I received at that time from Dr Hay was perfunctory at best. I was unable to comprehend the issue at first and do not consider the information was adequate enough for to understand the condition or the issues that I was experiencing.
30. I found out much more from information from the Haemophilia Society and from external sources than from the hospital. After the initial appointment to discuss the diagnosis I was however immediately offered treatment for HCV by Dr Hay. Again, the information provided about the treatment was limited. I was told it was a recently developed treatment, the only treatment available and that there were likely to be potential side effects.
31. Although I was given information at the time of the diagnosis and was on treatment there was little follow up from the hospital and had to gain additional information from other sources.

### **Section 3: Other Infections**

32. I confirm that I have not contracted any other infections as a result of being given infected blood; I was tested for HIV when I was about 16 and that test was negative.
33. I was contacted by Addenbrooke's Hospital by letter in 2004 in relation to vCJD (**Exhibit WITN0066002**). The letter stated that plasma products had been used between 1980 and 2001 that led rise to the possible risk vCJD. It noted that not all patients were affected, however, I was in an at risk category.

## ANONYMOUS

34. I was copied into a letter to my GP in 2010 by Addenbrooke's Hospital (**Exhibit WITN0066003**) who stated that they had been contacted by the Haemophilia Centre in GRO-B who'd undertaken a 'look back' exercise. The letter went on to say that this exercise had revealed that I had been given plasma derived from outside of the UK and therefore I was no longer at risk. This was a great relief to me; however 6 years was a long time to carry that weight.
35. To the best of my knowledge, I have not had any other infections as a result of having received infected blood and blood products.

### **Section 4: Consent**

36. Although I consented to it, the HIV test when I was 16 was not explained to me by my GP. I was not told what I was being tested for and there was no information given about any problems with HCV at that time.
37. I do not have any awareness of any tests having taken place without my knowledge.
38. I have consented to taking part in research in Manchester and Cambridge. I do believe research is an important part of the process of developing solutions to issues and I am happy to have been involved in this.
39. I was also registered on the National Database of Haemophiliacs held by the United Kingdom Haemophilia Doctors' Organisation in 2004 (**Exhibit WITN0066004**).

### **Section 5: Impact**

## ANONYMOUS

40. The physical impact of being infected with HCV in terms of outward symptoms is negligible. I was not aware of the infection and I never felt any outward symptoms.
41. I am aware from medical tests that there has been an impact upon my liver, but I understand from letters I received in 2011 that there was at that time minimal scarring on my liver as a result of the infection.
42. I believe that because the diseases were diagnosed and treated in Manchester in 1995, the treatment at that time, although not removing the virus altogether, did have the result of slowing down the deterioration in my liver.
43. The impact of the hepatitis treatment between 1995 and 1997 was considerable. I lost over 3 stone in weight and suffered from extreme tiredness, depression, erectile dysfunction and I had a number of skin rashes and lesions. I was unable to maintain normal activities and struggled with maintaining and holding my job. My relationship also broke down at this time. My long-term partner at the time cited the issues raised by HCV, the treatment, and my depression from the treatment in the breakdown of our relationship. There were also longer-term impacts following the conclusion of the treatment, including rapid weight gain.
44. I was treated again in 2010 and suffered with similar side effects. I had delayed treatment until the birth of my second child, and although this decision was taken to reduce the risk of birth complications I was unable to function fully in a family environment for that year. Again I suffered a weight loss of over three stone; I struggled with extreme tiredness and suffered from depression with rapid mood swings. I struggled to maintain my job and my family life suffered considerably. I also had another unexplained skin rash that required specialist medical diagnosis at a sexual health clinic. I also gained weight again rapidly on concluding the treatment.



## ANONYMOUS

45. Since discovering I was a Haemophiliac I have been very wary of having any medical intervention. All treatments have been carefully planned. I am lucky in that I have had only had a few minor accidents since I was a boy, and very few that have resulted in medical intervention. I have never to date had to have major surgery, and the only medical event that has resulted in a hospital stay was a liver biopsy (GRO-B c. 2007), which was for the investigation and management of the HCV condition.
46. I confirm that dental treatment has however been very difficult. I am very aware of the issue that I had when I was a small boy with extraction and have never had another tooth extracted. I have for example two protruding canines which are in the wrong place, which affects the outward appearance of my mouth and face. All of my dentists so far have declined to extract these once they became aware of my medical history and the complications of having Haemophilia A.
47. The risk of infection from HCV has also been a significant issue in gaining access to dentists. I was also told by a dentist in Hull that he would treat me, but only on a very limited basis. I was told only to book the last appointment of the day so as to enable them to fully disinfect the treatment room and any equipment following my visit. Whilst this may have been sensible it has always felt discriminatory.
48. On a personal level the impact of finding out I had HCV was devastating. In 1995 I had just completed my university degree and was looking forward to building a career in academia. I had been offered the chance to study for a PhD at Manchester which I eventually had to decline due to the significant personal issues I was having with the side effects of the treatment for HCV.
49. In 1995 I was given detailed information about the transmission risk and was able to establish more detail about this from the Haemophilia Society. I felt

## ANONYMOUS

- that the responsible thing to do was to contact previous sexual partners (prior to 1995) and let them know of the potential risk. This was an extremely difficult time for me and there I felt considerable embarrassment and consternation in having to contact previous partners and then having to tell them of the risk. I understand that all of these people were tested and the results were negative for HCV. This was and is a great personal relief. I have taken precautions by using condoms ever since.
50. Additionally, I was in a stable relationship at that time, and this subsequently failed with the impact of the HCV virus and the treatment being cited by my then partner as a contributory factor in the breakdown of this relationship. After this I found it very hard to form relationships, primarily because of the issue of coinfection and the need to discuss my medical history with a person before entering into that relationship.
51. I was eventually very fortunate to find a partner who was willing to consider taking on the risks involved in having a relationship with somebody who had HCV. I do feel very lucky to have been able to go on and get married and have children. There have however been significant issues to overcome with cohabitation and in having a family. In particular, the combined problem of haemophilia and the infected blood required very careful management to ensure there was no coinfection, particularly as I am very prone to bleeding. Meticulous cleaning of all blood spills for example, and isolating my personal items such as toothbrushes and razors.
52. The risk of coinfection has been an issue that I have had to discuss with all subsequent partners including my wife. My wife has been tested for infection on a regular basis and we weighed and balanced the risk associated with the infection very carefully in the decision to start a family. This was also discussed with the Haemophilia Centre in Cambridge. In the event we decided to try, and were able to, conceive children naturally. This meant putting my wife at risk of coinfection.

## ANONYMOUS

53. Having children was also a significant issue, although we were given very good advice by the Haemophilia Centre at Addenbrooke's Hospital, in seeking to conceive naturally my wife had to take a decision to put herself at risk of coinfection. My wife has always felt stigmatised by having to have blood tests to ensure she had not been co-infected. The issue of second round of treatment was particularly wearing on my family and even though we were prepared for the side effects, the impact of the depression left a lasting impression on my wife and children and our friends.
54. At the time I also found it very difficult to maintain full time employment whilst I was taking treatment for HCV. I was often exhausted and had to manage a number of illness related absences. During the winter of 1996-1997 I was only able to manage to get to work and did not have the physical capacity to do anything else. I consider that my career has suffered as a result of my ability to undertake work during this period.
55. I also believe there have been considerable financial penalties caused by the HCV infection. I have for example experienced difficulty in getting a mortgage and discovered there were only a limited number of lenders who were available to me. I have never been able to get, and still do not have life insurance, and travel insurance has always been significantly more costly for me than for other people. This is due to the need to declare both the Haemophilia and the HCV.
56. I also feel incredibly guilty to still be alive. I do not know why I have survived my infection with HCV when so many haemophiliacs have died. I have found this situation very hard to manage over the years and the death of so many people like me has had a significant impact upon my thoughts and feelings.

## ANONYMOUS

57. My parents have expressed to me their significant feelings of guilt in relation to early treatment. In that by trusting in the medical advice they had contributed in some way to my infection and illness

### Section 6: Treatment/Care/Support

58. I am not currently on any medication, or receiving treatment for complication relating to infection with HCV or any on-going related condition, but do receive regular checks in relation to the virus and liver function.

59. Between 1995 and 1997 I spent nearly 2 years being treated for the HCV virus with a combination of Interferon (non-pegolated); this required a three times a week subcutaneous injection into my stomach and Ribavirin in tablet form. This was inconclusive and the virus was still present in my system.

60. I had a liver biopsy whilst living in GRO-B (c. 2000) which confirmed the HCV virus was still present. This was undertaken with Factor 8 given prior to the operation but was after the time in which blood products were unscreened.

61. I was offered a second course of treatment in 2009-10 from Dr Aloysius Aravinthan, who was then Consultant Haematologist at Addenbrooke's Hospital (now Professor at the School of Medicine at Nottingham University). Dr Aravinthan proposed a 12-month course of treatment.

62. This course of treatment was with pegolated Interferon A which I started in January 2010. It was again a self-medicated treatment with a weekly injection. This was successful and at the end of the course I was declared free of the HCV virus. Subsequent tests have all been negative.

63. I confirm have not faced any difficulties or obstacles in accessing treatment. I am not aware of any treatments that have not been made available to me.

## ANONYMOUS

64. The treatment was extremely challenging but I was offered it very quickly following diagnosis by Dr Hay in Manchester. I confirm that I did not have any issues in accessing medication, or seeing the specialists.
65. The second round of treatment was also very well handled at Cambridge and a range of support was offered particularly by the Consultant.
66. My wife and I sought and were given very good advice on having children and managing the HCV treatment by the Haemophilia Centre in Cambridge.
67. I confirm have never been offered to my knowledge any counselling or psychological support.

### Section 7: Financial Assistance

68. I have retained some papers from late 2003 to the present with regards to the financial assistance scheme.
69. I can confirm that I found out about the financial assistance proposal from the Department of Health in August 2003. I registered an interest with them towards the end of 2003. I was subsequently contacted by them by letter later in January 2004 which announced the launch of the scheme (**Exhibit WITN0066005**). This was followed by a press announcement with the same information in it, which was also dated January 2004 (**Exhibit WITN0066006**).
70. The scheme was supposed to be up and running by April 2004 but I was informed by the Department of Health (**Exhibit WITN0066007**) that it had been delayed but that I could now register for the scheme.
71. I was advised by the Department of Health to register with one of a number of organisations that would manage the fund on their behalf. I subsequently registered with the Skipton Fund and have been registered with them since. I

## ANONYMOUS

- received a payment of £20,000 pounds in October 2004 (**Exhibit WITN0066008**). I have retained the receipt. I was deemed ineligible for a further stage payment of £25,000 due to my condition not having deteriorated.
72. The payment scheme was reviewed in 2011 and I was contacted at that time by the Haemophilia Society and who was announced the changes to all members (**Exhibit WITN0066009**). I was also contacted by the Hospital where I was registered with the same information (**Exhibit WITN0066010**). I contacted the Skipton Fund but following their advice I considered that I was not eligible for further payments (**Exhibit WITN0066011**). This is because I had not gone on to develop additional complications from the HCV virus that I was not eligible for further assistance.
73. The assistance scheme was again reviewed in 2016 and I was informed of changes by the Department of Health which included a copy of a ministerial statement (**Exhibit WITN0066012**).
74. The Skipton Fund wrote to me informing me of my eligibility (**Exhibit WITN0066013**) and again, to say I would receive regular payments and a winter fuel allowance (**Exhibit WITN0066014**). These payments were again reviewed and then stopped in 2017. I do however receive a winter fuel payment annually in December.
75. I am not aware of any difficulties in applying for the funds although as stated above I have been deemed in eligible for some payments due to the HCV virus no longer being present.
76. The delays were a concern and I am also aware that by agreeing to the payments in 2004 I may have been prejudiced in making any future claims.
77. At that time I was just about to get married and was trying to buy a house. The money was very welcome on a personal front because I had had great

## ANONYMOUS

difficulty in getting a mortgage and the choices of lenders were restricted because of the HCV. I was also unable and still cannot get life insurance or have significantly restricted options in that area.

78. The Skipton Fund has in my view always been very helpful and I have never felt excluded by them. The payment scheme was however only agreed after considerable campaigning and was very delayed in the first instance. That this was too late in coming for many people who had already died.
79. I have been concerned about the number of reviews of the eligibility criteria. In particular, I am very concerned about the way that less ill people were excluded from further payments. Whilst it is right that people who are at end of life or have severe conditions relating to infected blood should receive additional help, I don't think this takes into consideration the stress involved in managing HCV of any severity in daily life. In particular, the mental shock of the diagnosis and coming to terms with the infection and secondly managing that condition on a daily basis.

### 8. Other Issues

80. Although I have supported the Haemophilia Society's work and chaired the Regional Group in [GRO-B] I have never been involved in any previous campaign or litigation in relation to contaminated blood.
81. I don't have any documents from my childhood and do not have access to medical records from that time.
82. I present the following exhibits to accompany my statement:

<u>Exhibit Number</u>	<u>Description</u>
WITN0096002	Letter from Addenbrooke's Hospital to Mr [GRO-B] [GRO-B] regarding vCJD

ANONYMOUS

	20 September 2004
<b>WITN0096003</b>	Letter from Addenbrooke's Hospital to Dr <b>GRO-B</b> <b>GRO-B</b> copied to <b>GRO-B</b> regarding a 'look back' exercise 17 September 2010
<b>WITN0096004</b>	Letter from Addenbrooke's Hospital to Mr <b>GRO-B</b> <b>GRO-B</b> regarding the United Kingdom Haemophilia Doctors' Organisation's national database of haemophiliacs 24 June 2004
<b>WITN0096005</b>	Letter from the Department of Health to Mr <b>GRO-B</b> regarding announcement of Hepatitis C payment scheme 26 January 2004
<b>WITN0096006</b>	Press release from the Department of Health to Mr <b>GRO-B</b> regarding announcement of Hepatitis C payment scheme 23 January 2004
<b>WITN0096007</b>	Letter from the Department of Health to Mr <b>GRO-B</b> regarding the launch date of hepatitis C ex gratia payment scheme announced 18 June 2004
<b>WITN0096008</b>	Letter from the Skipton Fund to Mr <b>GRO-B</b> <b>GRO-B</b> regarding ex gratia payment scheme, attached Remittance Advice 13 October 2004
<b>WITN0096009</b>	Letter from The Haemophilia Society to Mr <b>GRO-B</b> regarding a new payment scheme 20 January 2011



