

Witness Name: Mr. R J Waring

Statement No:WITN1721001

Exhibits:WITN1721002/5

Dated: June 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF RICHARD JOSEPH WARING

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I, Richard Joseph Waring will say as follows:-

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

1. My name is Richard Joseph Waring. I was born on the [GRO-C] 1959 and live at [GRO-C] Cornwall [GRO-C] with my wife. I am self employed and work part time in the electronic business. I have a adult daughter and a grandson [GRO-C]
2. I was infected with Hepatitis C (HCV) and B (HBV) as a result of being given infected blood products.
3. **This witness statement has been prepared without the benefit of access to my full medical records.**

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

4. I suffer from Haemophilia A classified as severe, with a clotting factor of less than 1%. I was diagnosed at Middlesbrough Hospital, North Yorkshire, when I was about 5 or 6 months old. (There was no previous

history of Haemophilia in my family prior to me). They were preparing me for a Lumbar puncture and I started bruising and I was diagnosed.

5. I was initially treated at Middlesbrough Hospital where there was precious little treatment available for me. If I had a very serious bleed this was treated with large amounts of blood plasma by transfusion .This had only limited success as only a small amount of Factor VIII could be assimilated in this way. I believe this is when most of my joint damage occurred
6. In or about 1963 my family moved to Wolverhampton and I was treated at the Birmingham Children's hospital .At the time this treatment consisted of a stay in hospital for periods of time varying between 1 to 6 weeks depending on the severity of the bleeds. I was given blood plasma in large doses by intravenous transfusion and Cryoprecipitate.
7. In or about 1969 we moved to Torquay and my treatment took place at Torbay Hospital, Torquay where I was treated with Cryoprecipitate and early Factor VIII of intermediate purity, Kryobulin, BPL FVIII,( various versions) and occasionally Oxford FVIII, when I had a bleed I was also treated briefly at the Royal Devon & Exeter Hospital in Exeter, Devon where I received Cryoprecipitate
8. In or about 1977 when I was on holiday visiting friends I attended the Birmingham hospital for them to administer some Factor VIII. Whilst I had my own supply of Kryobulin (issued by Torbay Hospital) they insisted on administering their own supply of BPL Factor VIII.
9. In or about 1983 whilst I was working in Bristol for about a year I received some treatment at Bristol Royal infirmary.
10. In or about 1984 I moved to Plymouth, and my care was transferred to Freedom Fields Hospital Plymouth and later to Derriford Hospital, Plymouth where my bleeds were treated with Factor VIII products made

by Amour ,Cutter and Alpha but to name a few. Although I moved to Cornwall in 2010 I am still being treated at Derriford Hospital.

11. In or about 1996 I was treated at Oxford Haemophilia Centre and the Nuffield Orthopaedic Hospital with BPL Replenate Factor VIII whilst I had a full elbow replacement.
12. I also spent a year being treated when required at my GP's. if any additional treatment was necessary I would go to Exeter Hospital however there are no details of either these visits/treatments on the National Haemopliac Database (NHD) Records which are exhibited at WITN1721002.
13. In or about the summer of 1985 I was contacted by my previous consultant at Torbay Hospital as the issue of HIV infection had come to light. He suggested I should have a HIV test, which I agreed to. I waited 3 agonising weeks for the results, which came back negative. I had further tests in 1986 and 1990 which also came back negative. However, antibodies for Hepatitis B were found in my body, although I had never to my knowledge had the virus. I went on living my life the best way I could within the confines of my Haemophilia feeling safe in the belief I was infection clear.
14. In or about January 1992 my wife and I requested a further HIV test because we wanted to start a family. Unbeknown to us a HCV test was also ordered. I refer to the letter dated 29 January 1992 from Doctor GRO-D to our GP, DR R Woods at Exhibit WITN1721003 confirming this.
15. In January 1993 my wife and I were advised by the Haemophilia Society to have a HCV test due to the discoveries being made of HCV in blood products and we were planning to start a family. However no results were ever given to us . When we made enquires we were lead to believe they

had been lost when the Haematology Department moved from the Freedom Fields Hospital to the new Derriford Hospital.

16. In 1994 we received a letter from Derriford Hospital advising us to be tested for HCV. I was not worried at the time as I didn't know much about HCV. My wife and I went to our GP and had new tests done.
17. I was first told of my HCV infection in 1994. This was when my wife was 8 months pregnant.
18. My wife found out I was HCV positive when she was casually informed by the receptionist, at our GP, (with complete disregard for confidentiality and the consequences,). She was told in front of the busy waiting room that my test results for HCV were positive. The shock of hearing this news in such way nearly sent my wife into premature labour. My wife was left to inform me as I walked in the door from work. We both sat on the sofa in tears and I said 'What do we do now?' However after receiving and reviewing my medical records, I see that I first tested positive for HCV in or about January 1992 and this was not communicated to me or my wife by the consultant Haematologist Dr [GRO-D]. I refer to a letter from him to my GP dated 26 June 1992 at Exhibit WITN 1721004 which confirms I was HCV positive in 1992 and that this result had not been discussed with me.
19. Following the GP receptionist letting the cat out of the bag the GP phoned my wife as a follow up, and referred us to Derriford hospital to see the consultant Dr [GRO-D] who tried to smooth things over. Several months later we were referred to a Dr [GRO-D] a Hepatologist who said very plainly "have you got your affairs in order"; with a patronising tap on the arm to my wife. She kicked me under the table and we left. There was no bedside manner or sense that he cared.
20. Neither my parents or I were warned beforehand that there was any risk of being exposed to infection from blood products

21. Neither my wife or I were advised of any risk we and our unborn child faced as a result of me being HCV positive despite the doctors knowing full well we were planning to start a family I believe full and adequate information should have been given as soon as they knew about my infection.

22. As a result of receiving the news I was HCV positive both my wife and later my baby daughter had also to be tested .Fortunately they were both negative..

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

23. I believe I have been exposed to the risk of being infected with vCJD. I first became aware of the possibility in or about January 2001 when I received a letter from the Haemophilia Society informing me a blood donor in 1996/1997 had later developed vCJD. I also received letters from the NHS in 2004 and again in 2009 saying the same thing. After receiving the second letter my wife and I were on edge and nervous. I remember we thought it was like having the sword of Damocles hanging over your head you never knew when it would fall. My wife went to see Dr. GRO-D at Derriford Hospital and pressured him in to giving us the batch numbers of the blood products which were known to be infected. When I reviewed my own records (which I still have) several of the batch numbers matched. However I will not know if I am infected until symptoms manifest themselves as no test is available to confirm. Much of this definitely played on my mind and I am convinced, looking back on this time, the stress led me to having a "black out" and seizure in 2009 where I fell and sustained a head injury and fracture to my left which resulted in an admission to hospital for three days and Factor treatment for bleeds, an ECG, EEG and MRI scans to be done, but no physical cause was ever established.

24. I became very fearful after this with unpredictable panic attacks and was very worried about being on my own for quite some time, and unable to

drive. Most of this I attribute to the revelation that vCJD could be the new "death sentence "placed on my life.

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

25. I believe that I have been tested without my knowledge or consent. A clear example is the HCV testing conducted by Dr [GRO-D]. These tests were carried out without my knowledge or consent or adequate and full information on why and what they were testing for. We were not made aware of the results until 2 years had passed. I also firmly believe I was tested for the purpose of research because whilst I had regular liver function and factor levels tests, in addition to having no inhibitors they were still taking blood from me very frequently.
26. Between 1974 and 1975 my parents took me back to the hospital after a treatment of Cryoprecipitate, I was cold and shivering; this is when I believe I was infected. They kept me in and said they had probably given me the wrong blood group. (Which would have been medical negligence). My body was achy and sore for days, after a few days of being kept in and being repeatedly tested they sent me home. This is when I believe I was exposed to HBV in particular. The laboratory test records I have obtained for the period 1972-1976 seem to back this up. The later tests confirm the presence of HBV antibodies which were not there in the earlier tests, so my body likely cleared the virus during this time.

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

27. It's hard to put into words how much the infection has had an impact on my life; the mental and physical effects have been huge. From the late 1980's I suffered unexplained flu like symptoms however I never came down with anything. I felt extremely fatigued and on occasions faint. These symptoms became worse as the years went on. There was one time, when I was at work where my boss had to take me home as I was too fatigued to go on my own. After finding out I had HCV it was like my world

was turned upside down, I became really anxious, depressed and worried. Waiting for results of further tests created huge anxiety and uncertainty, as I wondered whether there could be more bad news..

28. I started treatment for the HCV in 2001 for six months which consisted of 3 injections of Interferon a week and taking Ribavirin tablets daily. It felt like my mood was bouncing up and down from dose to dose as I would start to recover and start feeling better then I would need another injection and I would feel bad again. I experienced changes in my personality; it felt like I was living in a fog, unable to concentrate.

29. I developed Vitiligo on my legs and arms, which worsened during the treatment for HCV. I would also suffer from rashes sporadically appearing across my body. I also developed shingles

30. I suffered from severe headaches and the feeling of being exhausted all the time. I would wake up, after burning up during the night and feel like I had drunk 6 pints of alcohol although I had drunk nothing. During this time I lost my appetite and constantly felt like I needed to be sick. I experienced a drastic weight loss of over a stone and half, my hair became very thin and started falling out,

31. I suffered from severe mood swings coupled with anger issues. I was Indecisive in everyday tasks which would lead to frustration and more anger. I experienced an earth shattering loss of confidence, which was so bad, I would only drive locally and often I would still need someone to accompany me to help reduce the anxiety.

32. Soon after I commenced the treatment I developed shingles due to my immune system being so low. The treatment however eventually did yield a good result as I was later confirmed clear of the HCV virus; although, it took a year of gradual recuperation to partly recover from the side effects of the treatment.

33. Some of the side effects of the infection and treatment have never completely faded. Although reduced I still suffer from anxiety and panic attacks which are often triggered when I am under pressure such as new situations, busy events or large crowds of people.
34. Being infected with HCV completely destroyed the sexual intimacy and the relationship I should have had with my wife due to the fear of infection. It also stopped us from having more children which we both wanted. The impact of the infection stretched to our basic social interaction and community involvement as we had to keep it quiet and a secret.
35. The stigma associated with the being HCV positive was a living nightmare as people associated Haemophilia straight away with HIV and HCV due to the scaremongering public campaign started by the government and facilitated by the media. Even though I was lucky enough to avoid HIV. I know a previous girlfriend finished with me when the smear campaign came out as her parents urged her to finish the relationship.
36. Our daughter was targeted at school by other year 6 children who said "her dad was a spaz" and had AIDS, taunting her. My wife had to go into the school to meet with the headmaster to put the record straight and give him the facts. The Teaching assistants who dealt with minor medical incidents were out of their depth so always avoided any treatment of our daughter to do with haemophilia regardless of the issue of HCV and my wife would have to go pick her up if she was ill.
37. When the Archer inquiry started we decided to stick our heads above the parapet and we were then subjected to a massive backlash from the local community. People we considered friends suddenly became 'busy' or just didn't return calls or texts. My wife would often have to stand by herself when waiting in the school playground I understand my wife also overheard "gossip2 amongst people we thought were friends, discussing not to come to our house to visit for fear they would "catch it". It has had a serious effect on mine and my family's: social, mental, emotional and



physical life. I still struggle to answer the phone for my business due to anxiety.

38. I kept a detailed note of my treatment and the side effects which runs to 27 pages and which are exhibited at WITN1721005
39. Whilst my HCV infection didn't have any effect on my education as it was contracted after I had finished. It has had an immeasurable effect on my work life. Pre treatment I had only suffered a couple bouts of illness. However during and post treatment I have had many and long bouts of illness.
40. I have spent years trying to recover from the effects of the infection and treatment. As a college lecturer I was fortunate to be supported on full pay and then on sick pay for about 6 months. I was also allowed to tag on holiday which I had missed so I would continue to be paid. On my return to work my employers accommodated me on a phased timetable which meant I could come in the mornings initially, gradually building to full days and a normal timetable after the New Year. I had the chance to be a level 2 lecturer however I felt that I didn't have the stamina to take on the additional responsibilities and after the end of that academic year my poor health forced me to take early retirement on medical grounds.
41. We had to survive with the small pension from my previous employment and the benefits which we secured (Disability Living allowance, Carer's allowance and a small incapacity benefit) ,which was only about £25 due to my pension. We still had to pay our mortgage and to bring up our daughter. I have been unable to work full time which has had a damaging financial effect on our lives and stability.
42. The financial repercussions from the infection and treatment have been profound. My early retirement in late 2002 meant that our income dropped by over 50% from about £26,000 to £11,000. As a result we had to cut back on everything; we had no holidays for 10 years. We had to

obtain free school uniforms and lunches. The school had to subsidise our daughter's school trips. We had to shop in charity shops. I had to put a lot of my pension into the mortgage to stop our house being repossessed. It came as a welcome surprise when the government finally decided to set up the Skipton Trust to provide financial assistance to people who were HCV positive. When we received the Stage 1 payment of £20, 000, it helped stabilise our situation however we soon realised this small payment would do nothing to help us in the long term.

43. We made a decision to use a lump sum from my pension to pay off part of our mortgage as it became apparent we would not be able to sustain our mortgage payments, as we were on the brink of losing our home before the payment. This gave us a little 'breathing space' for a time. We continued to survive through my daughter's secondary school years however during 2008/2009 we were forced to reluctantly sell up and downsize as costs were increasing but our income was not keeping pace. We spent a year in rented accommodation sharing with friends whilst we looked for somewhere we could afford. Most of the stage 1 Skipton payment also went into reducing our mortgage to a manageable level to keep our home secure. Our "backs were very much to the wall" at this point in time.

44. In 2010 we moved to Cornwall, and bought a run down property we could afford without a mortgage, but unfortunately this needed a lot of work to bring it up to acceptable living standard. I was not eligible for the increased payments recommended by the Archer Inquiry. Instead we applied to the Caxton Fund for grants towards essential repairs to the house which we could not afford. We were refused, but were lucky enough to be given a kitchen by a charity. After we had the kitchen work done, the Caxton Fund came back and granted our original application for a grant which then allowed us to finish the kitchen and have a new, more accessible, toilet and shower room.

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

45. In 1999 I experienced great difficulties in obtaining treatment. Initially no treatment was offered, however after being proactive and carrying out research we spoke to Dr. GRO-D He talked about to us about Interferon treatment only at first, explaining the success rate as being only 10-20% so he said it wasn't considered worthwhile. We took it on ourselves to obtain a second opinion,( which was not received well at our local clinic). We went to the Royal Free in London and saw Professor Christine Lee and she gave us useful advice on the Interferon and Ribavirin combination trials, which she said had much better odds of success at about 40%-50%. However at this time there was no health authority approval for this this treatment as most health authorities were awaiting a decision from NICE.
46. About 2 years later in September 2001 a new consultant Haematologist Dr. T Nokes was appointed Consultant Haematologist to Derriford Hospital who we were referred too. He obtained funding for me to start on the combination treatment trial for 6 months. However this meant that my treatment was delayed for nearly 2 years. When Dr Cramp preformed CT scans on me he identified a slightly inflamed liver, which could have potentially been avoided if I could have obtained the treatment sooner and more easily. These treatments should have been made available straight away without having to 'make a case' or be proactive, this just added to the stress and anxiety to an already horrific situation.
47. Over the years I had difficulties in obtaining other types of healthcare such as dental care due to my infected status.
48. In 1996 I needed an elbow replacement and was shunted around the country before it was finally agreed it could be done in Oxford by Surgeon Andrew Carr. I personally think what tipped the balance for this was that they were trialling a new continuous infusion method for Factor VIII products, which were provided free, as long you switched to Replenate.

49. In addition in the early days I had to walk around with Bio hazard stickers and warnings over anything when going to the dentist or hospitals.

50. We were never offered any counselling or psychological support as a consequence of me being infected. The possibility was briefly mentioned however it never bore any fruit. We went to the Eddystone Clinic however we were lumped together with sex workers drug addicts and homosexuals. The Clinic tried their best, but they just didn't understand our predicament and thus the support wasn't effective.

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

51. As stated in paragraph 38 above I received from the Skipton Fund the stage 1 pay-out of £20,000. We received this in 2004. We had a second blow as they said people who had cleared the virus were not eligible for the pay-out however with media pressure they backtracked quickly.

52. I also received £5,000 as a result of the American litigation I was involved in but had to sign a waiver agreeing not to sue.

53. In 2011-2012 multiple areas of the house needed immediate attention; and we applied to the Caxton Fund for a grant to cover double glazing and a new boiler. The approximate cost was £2,000-3,000. We had to pay £300 additionally out of our pocket for the glazing.

54. Our next application to the Caxton Fund was for cost of installing a kitchen and bathroom. As stated in paragraph 40 the applications were initially refused and we had to appeal. In 2013 after the majority of the kitchen work had been carried out they finally granted both applications. We asked if we could use it all for the bathroom and they agreed. We sent all the invoices for the work to the Fund whom paid them. We had some of the budget left over, which it was agreed we could use to finish the kitchen.

55. I also receive a winter fuel allowance of about £500 per annum which helped a lot.

56. In 2017 we started receiving monthly payments from the EIBSS of £3,000 a year. These payments rose to £4,000 in 2017-2018. I was recently awarded the Special Category Mechanism payment which is now £18,000 a year.

57. The process for applying to the Trusts and Funds were and are terrible. We had all our finances securitised and questions asked. The process was extremely obstructive and intrusive it felt like you were on your knees begging which we shouldn't have to do. An example of the obstructive process is we have to obtain 3 separate estimates for any work required. It also is completely wrong to have the grants means tested. They even checked our child's finances.

58. In my eyes there wasn't enough money put aside or provided soon enough. It felt like charity, it was not compensation. We deserved compensation like anyone else who has been injured through no fault of own.

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

59. I feel the government continues to force the Hemophiliac community to go 'cap in hand' to beg for financial help just to keep going, which is both demeaning and exhausting, for a disaster that in no way can they can be to blame. The latest moves to re-assess all long term recipients of the disability Living Allowance on the new more stringent criteria for PIP, increases my families stress further, as I could even have my existing benefits cut. I could now potentially be plunged into yet another crisis where my Motability car is taken away. As I live in rural Cornwall, I would then be left completely stranded, unable to drive as we don't have the finances to afford to buy a new suitable reliable automatic car that I could

actually drive (given my limited joint mobility). Meanwhile my health will, at best, certainly not improve and will probably deteriorate in years to come.

**Anonymity, disclosure and redaction**

60. I do not wish to apply for anonymity and I am prepared to give oral evidence to the Inquiry if required.

**Statement of Truth**

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

Signed... GRO-C .....

Dated... *2<sup>nd</sup> JULY 2019* .....