

Witness Name: Paul Thomas Bullen

Statement No.: WITN3114001

Exhibits: WITN3114002– WITN3114003

Dated: 11<sup>th</sup> September 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF PAUL THOMAS BULLEN

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I, **Paul Thomas Bullen**, will say as follows:-

#### Section 1: Introduction

1. My name is Paul Thomas Bullen. My date of birth is **GRO-C** 1958 and my address is **GRO-C** I live at home with my wife and I have two children who are 35 and 29 years old. I officially stopped working on 31 January 1985 as I was unable to work due to my medical condition. I am passionate about music and listen to all genres.

#### Section 2: How infected

##### *My experience of treatment with blood products*

2. I have moderate-severe haemophilia A (i.e. around 4% of normal factor activity in my blood) and was infected with Hepatitis C through contaminated blood products.
3. I recall being diagnosed with haemophilia when I was 2 or 3 years old, when I had my first admission to hospital. This was memorable because I lost my favourite teddy bear during the hospital stay. I consider that living with

haemophilia today to be more of an inconvenience compared to it being a potentially life threatening condition when I was growing up. As a child, I remember having to spend weeks at a time in hospital following a bleed.

4. At school I always tried to cover up my condition as I just wanted to play and do everything the other children did. Both my primary and secondary schools were aware of my haemophilia and they informed my class of my condition when I was absent from school for a period of time in hospital. I also remember not being able to play rugby with my friends.
5. Although I was diagnosed with haemophilia at Royal Manchester Children's Hospital in around 1961, this was the only time I attended this hospital. I believe I was registered at the Manchester Royal Infirmary Hospital ("MRI") (part of the Manchester University NHS Foundation Trust) in 1963, and I was under the care of several consultants at the MRI. I think that I was under the care of Dr. I.W. Delamore when I was first treated with Factor VIII, although Dr. R. Wensley mainly looked after the haemophilia patients. Dr Charles Hay (Haematologist and Haemophilia Centre Director) became my consultant in early 1995 and continued in that role until 2004. However, after 2004 Dr Hay continued to be involved in my care, although I was under the care of a different consultant. In September 2008, I moved my care to the Royal Liverpool University Hospital ("RLU") (part of the Royal Liverpool and Broadgreen University NHS Trust, as discussed below).
6. In my childhood, my treatment after a bump or bruise mainly consisted of ice packs and/or bed rest. Occasionally I would be given plasma, but that was not very effective from what I recall. I do not recall my parents or I being given any warnings about the risks of receiving plasma.
7. I recall it was in 1973 when I first started receiving Cryoprecipitate for the treatment of haemophilia, although this was not at the MRI and I do not have the medical records from this admission. I have a record showing the data collected by haemophilia centres, which indicates I was treated with Cryoprecipitate in

1971; I have absolutely no recollection of this. Then, following a very bad knee bleed on 11 February 1976, I started receiving Factor VIII treatment.

8. I do not recall being given any warnings about the risks of being treated with Cryoprecipitate and/or Factor VIII.

*Testing for HIV and Non-A Non-B Hepatitis*

9. From what I remember, the risk of HIV infection from blood products made headlines in the early 1980s. Following this scandal, I recall being told that there was a risk of passing on HIV if I had contracted it from blood products I had received and that both my wife and I had to be tested every six months for around a two year period. Fortunately, we were both told that we had not contracted HIV.
10. I do not remember there being a test available for Hepatitis C at this time, or at least not that I am aware of. I also do not believe it was even considered by the NHS or the government to be a serious infection at the time and it appeared to have been overlooked.
11. All the focus at the time appeared to be on HIV and the risk of transmitting that virus. There seemed to be less interest in Hepatitis C (or as it was then known, "Non-A Non-B Hepatitis").
12. In October 1980 I started to feel my body function changing. For example, in August 1980 I was fit enough to go on a canoeing trip with my wife. This resulted in a bleed and following intensive Factor VIII treatment I recall feeling tired from just walking up the stairs and had to visit my GP, Dr Jones, about it. I remember there being some confusion about what could be making me feel tired. In the early 1980s my liver function tests began showing signs of abnormality. I recall feeling this change after having had nine days as an inpatient on Factor VIII twice daily in 1980. I have never recovered.

13. My health and energy levels started declining rapidly from the early 1980s onwards.
14. In around 1982, after Factor VIII had been found to be contaminated with HIV, I do remember on one occasion going to the MRI for some treatment following a bleed and Dr Galarti told me that there was "*still a risk of infection*". I assumed by this she meant a risk of contracting HIV from using Factor VIII. She then advised me to try to manage without taking any Factor VIII, but to come back if I did not heal. I rested and was extremely cautious not to aggravate it and did not need to go back for treatment. This was the only occasion I can ever recall being refused treatment.

### **Section 3 – Other Infections**

15. I have had complications as a result of the Hepatitis C infection, such as varices due to portal hypertension and now, liver cancer. However, I did not contract any other infections as a result of the infected blood products, as far as I am aware.

### **Section 4 – Consent**

16. I recall that in October 1980, Dr Jones came to my house in the middle of the night after I had complained of abdominal pains. Dr Jones said that it might be due to Hepatitis. I was then admitted to the MRI and told that I had contracted what is now known as Hepatitis C. This corresponds with a letter in my medical records dated 21 April 1982 from Dr Stevens to Dr O'Shea (Exhibit WITN3114002) suggesting that I was showing signs of Non-A Hepatitis Non-B Hepatitis from at least that date. If I had been tested for Hepatitis C before this date, then this would not have been with my consent and I certainly was not aware of it.

## Section 5 – Impact

### *Impact on my health*

17. As mentioned above at paragraph 12, before I was diagnosed with Hepatitis C my body started changing and there was a steady reduction in my strength and fitness, which corresponded with my abnormal liver functions tests throughout the early 1980s.
  
18. I developed gallstones in my gallbladder, which I feel is almost certainly as a result of my liver not working as it should have been. As a result, I was admitted to MRI on 1 November 1995 to have my gall bladder removed. At the time of the operation, I was asked if I would consent to a liver biopsy but I refused. The gallbladder operation was performed laparoscopically and, after a lot of pain and discomfort in the ward following the operation, it was later discovered that the surgeon had accidentally severed an artery during the operation and I was haemorrhaging. As a result, the on-call haemophilia doctor gave me another 3,500 units of Factor VIII even though I was already at 100%. The result of the additional Factor VIII was that it took my count up to 314% and I developed clots on my lungs, heart, liver and kidneys and went into a coma.
  
19. The MRI did not think I would make it through the night and they rang my wife in the middle of the night, so that she could come and visit me one last time. Fortunately, I survived and came out of the coma reasonably well. The additional 3,500 units of Factor VIII may not have been under Dr Hay's direct instructions, but he was responsible for my care and I consider it may have been the result of inadequate planning.
  
20. Three weeks prior to this operation in 1995, I recall having attended a clinic for a routine review and was told that, *"I don't think you have Cirrhosis"*. Three weeks later during my operation the surgeon performed a liver biopsy which showed severe fibrosis. In 1997, I was told that I had developed Cirrhosis. From about

1999 until January 2009 I was admitted to hospital many times with gastric bleeding and oesophageal varices due to portal hypertension.

#### *Treatment for Hepatitis C*

21. I was put on a treatment course from May 2002 to April 2003 to clear the Hepatitis C virus, which consisted of a combination of Pegylated Interferon and Ribavirin medication. The immediate side effects of the treatment made me miserable and I felt like a zombie. My wife says it was the only time she ever considered leaving me and my son used to call the medication '*daddy's grumpy juice*'.
22. I was still under the care of Dr Hay and the liver department at the MRI at the time. It was the liver department that prescribed the treatment course. However, almost immediately I was unable to take a full dose of the medication, as it became extremely difficult for me to take due to the side effects. As a result, the liver department decided to prescribe half doses but over an extended period of time for the remainder of my treatment course. The course of treatment is normally for six months but as I was only able to take a half dose I was treated for 11 months. The doctor then wanted me to continue with the treatment for a further two months, but I could not bring myself to take it any longer.
23. Dr Hay did not agree with the prescription of half doses over an extended period and wrote to the liver department on 22 November 2002 (Exhibit WITN3114003) saying that the treatment should be stopped because it would not work. He used to paint the picture as black as possible. Thankfully the liver department ignored Dr Hay's letter and prescribed half doses of the medication. I cleared the virus in 2003.

#### *Further complications*

24. Although I had cleared the virus, I suffered later complications including requiring a Hickman line and later a PICC line. As referred to above at paragraph 20, from about 1999 to January 2009 I was admitted to hospital on numerous occasions

with gastric bleeding and oesophageal varices due to portal hypertension. During one instance in January 2009 the bleeding would not stop and I had an emergency TIPPS procedure, my first procedure at the RLU, which is a shunt inserted to connect the two veins in the liver.

25. This operation was a success but the major side effect has been encephalopathy, which affected me badly for four years and I was unable to hold a coherent conversation again until around 2013. Whilst the effects have since reduced, I still use medication to control the encephalopathy.
26. In around 2009 I was added to the liver transplant waiting list as a result of the Cirrhosis. My liver had decompensated 3 times by then. However, by 2014 my condition remained stable and the transplant team suspended me from the waiting list because, in their opinion, the risk of the operation became greater than the potential benefits.
27. I continued to have regular six monthly hospital appointments and ultrasound scans. In October 2018 I started feeling stomach pains and, at one point, I lost a lot of weight. The doctors did not seem to know what it was causing the weight loss and asked if I had suffered from jaundice previously. I asked my GP for an ultrasound, but I was told that my local hospital was unable to do a Doppler scan so I waited for my regular six monthly scan at the RLU. I had the scan on 24 January 2019 and a growth was found on my liver which was determined to be cancerous. The growth quickly increased in size and as a result, I did not meet the criteria for a liver transplant and I was taken off the waiting list.
28. I now require radiotherapy to reduce the tumour. If the radiotherapy is successful in shrinking the tumour enough, then I understand that I might be put back onto the liver transplant list. However, given that a recent MRI scan had showed the tumour had doubled in size in around an eight week period, I do not feel that I will ever get a liver transplant. I began radiotherapy treatment on 24 June 2019.

*Impact on my family and employment*

29. Contracting Hepatitis C through contaminated blood products has had a devastating impact on my family and work life.
30. Firstly, there was the stigma of not providing for my family because I was unable to work due to my health condition. I had previously been employed as a retail buyer. My employers were aware that I had haemophilia but I did not tell them about being infected with Hepatitis C at the same time, as this was before I had been diagnosed. Whilst I believe my employers were partly to blame for my redundancy – they promoted me shortly before making me redundant and increased my work tasks and put obstacles in my way to prevent me doing the job properly, making it impossible to complete – I was also unable to do my job because I was so exhausted from Hepatitis C. I was ultimately made redundant in May 1981.
31. I did a few different part time jobs after this, including working on my father's dairy farm when I could. However, I gave up work completely in 1985 due to my deteriorating health. Despite this, I continued to volunteer with The Haemophilia Society and the Manor House Group when physically able to do so (which I explore further in my second witness statement WITN3114004).
32. My wife also had to give up work to look after me and the children. The stigma was so bad that I even used to pretend to work on the farm so nobody would look negatively at us.
33. As a result of not being able to work and before I received any financial assistance (which I elaborate upon in section 7), my wife and I really had to adapt and change our spending habits. I had grown up on a dairy farm where money was no problem. However, after being unable to work regularly as a result of my condition from 1981, and altogether after 1985, we had very little money in the 1980s and we struggled to make ends meet. We struggled to pay our bills and to make sure our money went that bit further, we mainly bought second hand items.



34. Our financial situation was so bad in around 1986 that we were unable to afford to buy our daughter a Christmas present. It was an awful feeling. We compensated by buying her as many small presents as we could afford to.
35. My wife has had to live with me being close to death's door on numerous occasions and she says it is the constant not knowing whether I am coming or going that is the worst thing to deal with. I am just grateful she has stuck with me. I know of a few couples in similar circumstances who have separated because the burden has become too much to bear.
36. My family have been there to support me throughout my hospital trips and illnesses. If my wife has not been available to take me to hospital (or has been up all night with me at hospital), my daughter, who now lives next door, helps out.
37. Our daughter was born in 1983 and so she was able to have a "normal" dad for the first six years of her life. I was able to do normal things - albeit limited - with her and enjoyed taking her to my father's dairy farm to milk cows or go walking.
38. My son was born in 1990 and he has never seen me well. I suppose he has not known any different and has just dealt with it. I do recall my son asking me for help with his garden one time. I tried to help as best I could but I was exhausted after a short period of time and could not really do anything. It was at this point that my son turned to me and said *"you really are unwell aren't you, dad"*.

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

### *Obstacles to treatment*

39. Dr Hay became the Haemophilia Centre Director at MRI in early 1995. I consider he wrongly diagnosed me on several occasions. Throughout my time at the MRI and during my treatment to clear the Hepatitis C virus, I felt that Dr Hay made the wrong choices. My confidence in Dr Hay became so bad that it became a major

factor in my decision to leave the care of the MRI and moved to the RLU. However, there were more problems during my time as a patient at MRI. Collectively these were the reasons I moved my care to the RLU.

40. During a stay as an inpatient at the MRI in 2007, I spent 4 weeks in an isolation ward and during my time the room was not cleaned at all; as soon as I recovered I began to make arrangements to transfer my care to RLU. I began by writing to the CEO to complain about how dirty the MRI wards were. I was actually surprised to receive a response from the CEO admitting there were hygiene issues on some wards. As a goodwill gesture I requested my complete hospital notes free of charge, which he agreed to.
41. I think it was only because of this complaint about the cleanliness that I was able to obtain my complete medical records from the MRI. I recall another patient I knew told me that he had asked Dr Hay for his medical records and Dr Hay refused on the basis that they had been destroyed. It was only after that patient threatened to take the matter further that Dr Hay suddenly changed his position and provided the medical records; they were in the drawer of his desk. Unfortunately, I have lost contact with this patient so I am unable to guarantee the accuracy of my comment, but this is what he told me at the time.
42. The main difficulty I faced during the treatment to clear the Hepatitis C virus appeared to come from Dr Hay (see paragraph 23). Thankfully the liver department ignored Dr Hay's correspondence and continued with the treatment so that I am now clear of the Hepatitis C virus.

#### *Psychological Support*

43. I do not remember being offered any psychological support or counselling as a consequence of being infected with Hepatitis C. It really was a horrendous period of time and I believe 90% of the recovery battle is the emotional support. I believe psychological support should have been available, similar to how the MacMillan

Cancer Support are providing support for my battle with cancer. I am just glad my family and I fought through, unlike some friends I know in similar circumstances who ended up with severe depression.

### **Section 7 - Financial assistance**

44. We did not receive any financial assistance until 2004 when the Skipton Fund allocated £45,000 for stage 2 payments to me. There were also discretionary funds we could apply for. Whilst we are obviously grateful for the financial assistance, it always felt like you were begging in order to receive any money from the Skipton Fund, and this meant we did not apply for the funding when we could have.
45. I am glad that my financial assistance has now transferred to the England Infected Blood Support Scheme (EIBSS). I find EIBSS to be a lot easier and more efficient than the Skipton Fund was.

### **Section 8 - Additional information**

46. I separately pursued a class action in the United States of America (the "US"), which was brought against the manufacturers/exporters of the contaminated blood products.
47. From what I remember, a firm called Anderson Eden wrote to the members of The Haemophilia Society in the early 2000s to discuss bringing a law suit in the US. The class action soon outgrew this firm of solicitors and Irwin Mitchell solicitors took over. As part of the process I had to pay a £65 fee for my medical records from the MRI. Later, I received additional copies following my complaint just before I left the MRI (see paragraphs 40 and 41). When I compared the medical notes which I paid for with those I asked for as a result of my complaint, I realised that the first batch of medical records were not complete.

48. An out of court settlement was eventually agreed and I received around £5,000-£6,000 from this law suit in around 2009/2010.
49. I have never pursued a claim in the UK simply because Legal Aid was not made available and I did not have the financial means to bring a claim myself.

**Statement of Truth**

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

Signed .. GRO-C .....

Dated..... 11<sup>th</sup> September 2019.....