



FINAL

Witness Name: Robin Brown

Statement No.: WITN0004001

Exhibits: WITN0004002

WITN0004003

Dated: 4th September 2018

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF Robin John Brown

I, Robin Brown, will say as follows: -

1. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 August 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference
- 1.1 My name is Robin Brown (I like to be referred to as Rob or Robbie). I live at an address known to the Inquiry. My date of birth is GRO-C 1963. I have been married since 2007. We have an 11 year old daughter. I also have a 23 year old son from a previous marriage. I work as a freelance Project Manager.
- 1.2 My infection happened when was about 10 or 11 years old, so some of the details of that time have been told to me by my mother. She is available to give a statement if further details of that time are required. I have also used some of my medical letters which I have.
2. In early summer of 1974, I was a petite 10 year old at that time, I fell ill with Appendicitis, and went into Farnham Hospital, Surrey to have my appendix removed. The operation appeared to go well, I was in hospital for about 1 week. I do recall this as the Doctor asked if I liked football, because I would have the whole summer to watch the World Cup.

Infected Blood Inquiry

Fleetbank House, 1st Floor, 2-6 Salisbury Square, London EC4Y 8AE

contact@infectedbloodinquiry.org.uk

Freephone 08081691377

- 2.1 On the 22 July 1974, I complained to my parents that I had severe stomach pains. They phoned for an ambulance but were advised to drive me to Farnham Hospital as it was quicker than waiting for the ambulance. I coughed up blood in the A & E area and I underwent an emergency operation. I was found to have numerous abscesses in my stomach and the surgeon found dressings which had been left inside me from the Appendix operation.
- 2.2 Between July and October 1974, I had 19 blood transfusions during numerous operations (most of these were at Farnham Hospital but the last few were performed at Frimley Park Hospital) to repair the damage that had been caused by the abscesses leading to gangrene, peritonitis and septicemia. Apparently one of the operations lasted more than 7 hours.
- 2.2.1 I remained in hospital throughout this period. On the 5 September 1974; I was transferred to Frimley Park Hospital, which was newly opened and closer to home.
- 2.2.2 On 23 August 1974 I was also diagnosed with jaundice, due to this all the other patients and staff had to be injected with Gamma Globulin, to protect them.
- 2.3 I had great difficulty with my digestive system at this stage but my father worked for British Aerospace and was able to source sachets of Vivonex which was developed by NASA for astronauts, it had no waste products when eaten.
- 2.4 I have a letter headed with my name, dated 25 September 1974, which states (in the 5th paragraph, 2nd sentence) *'On 23rd August he was noted to be mildly jaundiced – LFT were normal and as he had had a recent blood transfusion it was suspected that the transfusion was to blame.'* A copy of this letter (2 pages) has been handed to the investigators and is produced as **WITN0004002**.
- 2.5 I was discharged from Frimley Park Hospital on 11 December 2014 (for Christmas) but I then had to have hospital check-ups every 2 days as an outpatient.
3. I have been asked if I received the infection as a result of a relationship with another person, this scenario is not applicable to me.
4. I have discussed this with my mother and at no point did anyone mention anything about the risks associated with receiving a blood transfusion. My mother gave her permission for me to be operated on initially, which was a life-saving situation.

5. Following my multiple transfusions in 1974, I was much later diagnosed with hepatitis C. Other than this period of operations when I was a child, I have not had other transfusions, I have also never had any tattoos or body piercings or taken any drugs intravenously.
- 6.1. In August 2006, I went to my GP to get inoculations for a holiday in Cuba. As some of these inoculations were for hepatitis B, I told the nurse that I had previously had jaundice. She then tested me for hepatitis A, B & C. A week later (the day before my holiday) my doctor himself, called me and said he needed to see me urgently. In the surgery he explained that I had tested positive for hepatitis C.
- 6.2 My GP at the time, did not offer to explain the issues of being infected with hepatitis C to me, other than being told not to drink alcohol and they would be back in touch. I do not think that this information was sufficient.
- 6.2.1 In September 2006 I was referred to Royal United Hospital (RUH), Bath. The literature provided by the NHS was far too complicated.
- 6.2.2 Later I was referred to a specialist hepatitis nurse at RUH, who gave me much better advice about life style and how to cope with hepatitis C.
- 6.3 The good advice I eventually received, should definitely have been given earlier probably at the GP's surgery.
- 6.4 I was informed about the infection at a very bad time for me, as I was just about to go on holiday. This was a worrying time.
- 6.5 My wife and I feel we should both have been provided with some information individually about the risks of infection.
- 7.1 I had numerous blood tests as a child but I was never told what they were for.
- 7.2 Having had so many blood tests, I cannot be sure that I or my parents gave 'informed' consent to each of them.
- 7.3 Very rarely was sufficient information given to me about procedures that were to be done to me.
- 7.4 I wasn't ever informed, that any of these tests were for research purposes.
- 8.1 I was always an extremely fit and active person but I would always be very tired in the evening, falling asleep and usually in bed by 9pm. At the time I put this down to my active lifestyle but with hindsight I now put this down to the undiagnosed hepatitis C.

- 8.1.1 As an adult I have always suffered with: persistent lack of sleep, short temper, impatience and generally not easy going. I find it difficult to walk long distances. These I believe are as a result of the infection.
- 8.2 I also had a period of 3 or 4 years when I had to use a wheelchair due to fatigue. This was from the age of 11 with the wheel chair being returned to the Frimley Park Hospital when I was 13 years old. Being in a wheelchair, became a stigma, not with school friends but more with adults and typically the adult would talk to whoever was pushing me and rarely to me. "How is he?" "Is he getting any better" as though I couldn't talk. My late father had to adapt the wheelchair so in the early days a drip stand could be connected meaning I was no longer confined to my hospital bed.
- 8.2.1 I was told by the RUH in 2006, that if my wife and I wanted to have children we should do so before I started the 'cocktail' of drugs Ribavirin and Interferon (for hepatitis C) otherwise there was a high possibility that the child would be deformed at birth. We therefore deferred the treatment until my wife became pregnant.
- 8.2.2 I have developed a persistent cough and my lungs fill with mucus, which hospital staff say could be a side effect of the 'cocktail' of drugs to treat the Hepatitis C. For this condition I am treated with Montelukast which is a 10mg tablet, which should be taken once every day but I only take it when I really need to, as it gives me insomnia.
- 8.3 In January 2007, I started a 6 month course of treatment for hepatitis C at the RUH, this was referred as a 'cocktail' because it was made up of 2 separate drugs called Ribavirin (believed dosage 200mg) and Interferon (dosage unknown). This is apparently no longer used as there are drugs available with far less side-effects.
- 8.3.1 I am currently tested every 2 years and I am classed as being clear of hepatitis C, as my blood 'count' is 12 or less, they cannot accurately measure lower than this.
- 8.3.2 A few months ago I had to go into hospital as I had burst a blood vessel in my head. The doctors asked me all about the 'cocktail' of drugs treatment I had received. I believe they thought they were linked.
- 8.3.3 I have had so many blood tests over the years, it is now very difficult for medical staff to manage to take a blood sample from me.
- 8.4 I have been happy with the treatment I have received, post diagnosis.

- 8.5 I am not aware of any other treatments that I could or should have been offered.
- 8.6 Some of my side effects of the 'cocktail' drugs treatment I was given have been: tiredness, light sensitivity, massive swings in body temperature, severe anxiety, sleeplessness and irritability.
- 8.6.1 Additionally on many occasions I had to have someone with me, to act as my care assistant if I went out, in case I collapsed, which I had done in the past.
- 8.7 My infection has only affected me interacting with medical personnel, e.g. ambulance crews, nurses and dentists, who I always inform that I have hepatitis C. Although I am official 'clear' of hepatitis C as I have a very low 'count' of 12 or under, I still tell people I have it, as it is potentially an on-going issue.
9. The continuing issue with my infection is irritability, whereby I am short tempered and if my wife has to impart bad news to me, she has learnt to 'drip feed' it to me. I still suffer from a lack of energy in the evenings and often fall asleep in the chair.
- 9.1 Although I have never been big alcohol drinker, I was told to stop completely. I haven't done that and have an occasional glass of wine at social functions.
- 9.2
- GRO-C**
10. There is a stigma and lack of understanding by people about hepatitis, therefore my wife and I do not tell anyone outside the family. The children are partially aware but they just think that I have a liver problem.
- 11.1 I didn't do well at school, having missed a lot of time whilst being in hospital. Later in life (in my 30's) I went on to get a degree in Business Management at night school. I have been offered a study course as a project manager through Royal Institute of Surveyors.
- 11.2 Before my diagnoses in 2006, I was able to work and work, then when I started the hepatitis treatment I had to have an injection every week, which would always debilitate me for days. I was lucky I had a good employer at that time. They allowed me to have my injection every Wednesday evening, then work from home on the Thursday and Friday for the entire 6 months of treatment.
- 11.3 I cannot think of any specific side effects financially. At the time of my treatment for hepatitis C, I was salaried so the time taken off would be sick leave.

12. I am not aware that I have been infected with any other infections.
13. My mother has been greatly affected by my illness, including the initial flawed operation on my appendix and the numerous operations to try and clear up the effects of that. Also in relation to my infection, which she wrongly believes may have been because of some fault of herself and my father
- 13.1 There is an almost daily effect on my wife due to numerous issues I have listed above, which she has to deal with.
- 14.1 In December 2006, I applied for compensation from the Skipton Fund and received a payment of £20,000. This was referred to as a 'Stage 1 Hepatitis C payment'
- 14.1.1 3 or 4 years after that, I received the winter fuel allowance of £500. I got that for 2 years.
- 14.1.2 In 2016 I started to get an allowance each month, to help with bills. I think this was just below £250 per month. I received this amount for about 18 months, then it stopped.
- 14.1.3 When this allowance stopped I was sent a long form to complete with the assistance of my doctor. I returned this and about 2 months ago NHS England wrote to me saying I would now get £1,500 per month but all other payments (including free prescriptions) would stop.
- 14.1.4 In relation to my numerous operations when I was a child, my parents or I never applied for or was given any compensation, in relation to this specifically. It was twenty three years after my illness was I told dressings left inside me were the cause. I was told this by a member of medical staff at Frimley Park while I was visiting my terminally ill father at that time in 1997.
- 14.2 My original Skipton Fund application was arranged by the RUH, which made it very easy for me at a very difficult time, having just been diagnosed.
- 14.3 My view on the applications I have made are that they are far too complicated. I am a professional man, who can understand forms but still found them difficult to understand and complete.
- 14.4 There have not been any pre-conditions attached to the sums I have received.
- 14.5 The impression I have about the various trusts and funds is positive.

15. I have had no issues with my treatment or care but I have in relation to life insurance; specifically to cover my mortgage for my family, should I die. In 2008/9 I told companies that I had hepatitis C and they all refused me cover. I wrote to the Insurance Ombudsman and then a small firm quoted me £942.47 per month, to cover £150,000 of my £165,000 mortgage at that time.
- 15.1 Later I contacted the Skipton Fund to see if they could assist me to find a company to provide life cover. The only quote I got was from Zurich who offered just £50,000 cover for £750 per month. I explained that my Hepatitis C count was now taken as 12 or below (effectively clear) but this made no difference.
16. I have not received or requested any specific psychological counselling.
- 16.1 I have sought and obtained support and advice on my infection from the Skipton and Caxton Funds and anytime I need to, I can phone or see the specialist nurse at RUH in bath,
- 17 I have given another copy of a letter (1 page) dated 15 November 1974 to the investigators, this details many of the medical issues I had at this time. Exhibited as **WITN0004003**
- 17.1 I understand from medical staff treating me; that there are 6 sub-groups of hepatitis C (referred to as 'genotypes'). I have been told that I have been diagnosed with genotype 4 – which is has Central and Sub Saharan Africa as its origin.
- 17.2 The 2 letters (exhibits) referred to above were given to me in July 1997 by my GP at the time (Doctor Harris) of Frimley Road, Camberley. He said he thought I should have them as the NHS didn't want them. I am not sure why these had been retained in my medical records.
- 17.3 I was told by my mother that in about 1990/91, she was working in the Medical Records Department at Frimley Park Hospital. She was told to shred numerous medical records including mine, which she did.

- 17.4 I do not understand why medical records are ever destroyed before the expiration date.
I understand from my research & working within NHS Trusts, in particularly medical records that the following NHS England retention rules apply:
Cancer patients – 25years
Children in full time education – 25 years
Autopsy/ Crime related – 25 years
Everything else – 7 years
- My understanding of these criteria is that my medical records were destroyed 7 – 8 years before they should have been, as I was in fulltime education for many years after my operations.
- 18.1 I have not previously been involved in any litigation, relating to infected blood.
- 18.2 Additionally I have never been involved in any previous investigations or campaigns.
- 18.3 I have not had any children taken into care as a result of my infection.
- 18.4 As stated above I had to delay my treatment for hepatitis C, to enable my wife to become pregnant. Following the successful birth of our daughter, we decided not to have further children. My wife and I, had hoped to have two children, so unfortunately the treatment has effectively 'robbed' us of another child.

Statement of Truth

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

Signed

GRO-C

Dated

4/9/18