



Witness Name: Suzanne Brandt

Statement No.: WITN0312001

Exhibits:

Dated: 18th January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUZANNE BRANDT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 October 2018.

I, Suzanne Brandt, will say as follows: -

Introduction

1.1. My name is ~~name is~~ Suzanne Brandt. My date of birth and address are known to the Inquiry. I am retired having worked in retail for my whole working life. I intend to speak about the fact that I contracted Hepatitis C from a blood transfusion. In particular I will cover, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my wider life.

Infected Blood Inquiry

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

contact@infectedbloodinquiry.org.uk

Freephone 08081691377

How Infected

- 2.1. In October 1988 I went for a routine smear test which revealed that I had borderline cell changes. As a result, I was referred to the Colposcopy Clinic and on the 4th of July 1989, my Colposcopy revealed CIN3 cells in my cervix. CIN3 cells are usually pre-cancerous cell changes. I was told not to worry as the CIN3 cells were easily removed using a procedure called a cone biopsy.
- 2.2. I was referred to Bristol General Hospital for pre-op checks the same day as my smear test. That evening I was informed by the hospital that my blood tests showed I was very anaemic and the surgeon, Mr Anderson, would not operate until my iron levels increased. I asked if I would be given iron tablets but the nurse on the phone told me that I would need a blood transfusion the following morning. This surprised me as during my pregnancies with my two children I was given iron injections which I had responded well to. With hindsight I believe that I was told I needed a blood transfusion because it would have an instant impact on my iron levels meaning that my biopsy would not have to be rescheduled.
- 2.3. I arrived to have my blood transfusion on the morning of the 5th of July 1989. Mr Anderson explained that I would receive 4 units of blood. My husband, Michael, was concerned about me receiving blood because there was a lot of publicity about the AIDS virus at the time. Michael asked Mr Anderson if the blood was tested and we were told that it had been thoroughly tested and not to be concerned. I was not given any information about any of the risks of having a blood transfusion.
- 2.4. The transfusion started at 16:00 on the 5th of July and finished at 04:30 on the 6th of July. I remember when I finished having the transfusion the nurse who was flushing through my drip with saline said to me that I was going to have "so much energy". I didn't have any energy. I felt

very tired but put this down to having been monitored every half an hour through the night and the fact that it's hard to sleep in hospital.

- 2.5. I went into hospital on the 26th of July 1989 to have the Cone Biopsy. The procedure went well and I was discharged on the 30th of July with instructions to take iron tablets and have a yearly smear test for 10 years. On the 13th of February 1990 I was told that my smear test was entirely clear.
- 2.6. Almost immediately after the blood transfusion I realised that something was wrong. I was very tired and nauseous; I felt like I had flu all the time. I also had very severe headaches which I hadn't had before. In the months following the transfusion my health declined and some days I was unable to get out of bed. I tried a variety of alternative treatments but nothing had a long-term effect on my health.
- 2.7. In January 1993, the Doctor found a possible ovarian mass during my routine smear test and, after a scan, I was found to have an ovarian cyst. Mr Anderson was my surgeon again, but this time I was admitted to the Gynaecology Unit at St Michael's Hospital. I was admitted on the 17th of March 1993 and given 2 unit of blood as, once again, I had low iron levels. I got the impression that the anaesthetist was uncomfortable giving me anaesthetic while I had low iron levels. During my pre-surgery checks it was found that I had abnormal liver function with high alkaline phosphatase levels. At the time this was put down to a possible reaction to the fluid from the cyst.
- 2.8. Dr Anderson informed me that he wanted to perform a full hysterectomy but I expressly told him that I didn't want that unless it was absolutely necessary as it would trigger early menopause. During the operation I was found not to have a right ovary and a large part of the left ovary was taken in order to remove the cyst. Although a small portion of the left ovary remained I still went into the menopause shortly afterwards.

- 2.9. I had two follow up appointments in May and July 1993 and I still had raised liver function. The doctors no longer believed this was a side effect of the cyst so a letter was sent to my GP to follow up on my abnormal liver function.
- 2.10. My GP referred me to Dr Barry's clinic at the Bristol Royal Infirmary where I saw Dr Gore on the 16th of September 1993. Dr Gore suggested that I go for a variety of tests including an endoscopy. My first endoscopy was on the 2nd of November 1993 and on the 13th of December I was diagnosed as having Coeliac Disease. I remember being so relieved because I finally thought that I could do something about how I was feeling. I immediately changed my diet and I felt a little bit better but I was still extremely tired and achy.
- 2.11. I had an appointment at Dr Berry's clinic on the 10th of February 1994. I was losing faith in the doctors and the NHS so I told them that I was ok and I knew it would take a while for me to feel 'normal' on my new diet. I still had flu like symptoms, nausea and tiredness but I had suffered with these for so long I just accepted them.
- 2.12. I started to suffer from bloating, loose bowels and flatulence in the summer of 1994. The doctors believed that this was because I wasn't sticking to my coeliac diet even though I repeatedly assured them that I was. I had a second endoscopy on the 24th of January 1995 which showed that I was sticking to my diet.
- 2.13. On the 21st of February 1995 I was reading a newspaper and I saw an article with the headline 'Helping hand for victims of mysterious blood disease.' The article was about a woman who had a blood transfusion after spinal surgery and had later been diagnosed with Hepatitis C. Her symptoms were the same as mine and so, at my next appointment on the 24th of April 1995, I asked Dr [GRO-D] for a Hepatitis C test. He laughed at me for asking and asked if I had a history of drug taking. I told him that I had had a blood transfusion but I still had to stick to my guns to get the test.

- 2.14. For my 46th birthday my mother treated us to a holiday in Devon and I forgot about the hospital appointment in which I was due to receive my test results. When I returned home I had a letter which said that I had missed my appointment on the 10th of August 1995 and that I had a new appointment for the 19th of December 1995. As a result I thought that the appointment couldn't be anything urgent.
- 2.15. On the 19th of December 1995 I went to the hospital on my own as Michael was busy in the shop that we owned and we had been given no indication that I might need support. I saw Dr **GRO-D** and I remember that I had only just sat down when he told me that I had Hepatitis C. He pushed a leaflet on Hepatitis C across the desk. He told me that the transfusion was the likely source of the infection. I don't remember much of the conversation as I was in shock. What I do remember is that he asked if I had suffered with jaundice and I responded by shaking my head and he also told me that I would need a liver biopsy. I was told they would see me again in four months.
- 2.16. When I got back to the shop I burst into tears and put the booklet onto the counter. Michael asked about the advice that the doctor had given me and I told him that I wasn't given any advice other than the booklet. The booklet did contain information about taking precautionary measures but it wasn't explained to me in the appointment. Michael rang the Liver Trust who faxed us some information and articles on Hepatitis C.
- 2.17.

GRO-C
GRO-C
- 2.18. In January 1996 I received a letter from the hospital which said that the results of my test in December showed that the Hepatitis C virus could not be detected in my blood. I was over the moon, I thought that I was clear and so did my family. We went out for a meal to celebrate.

- 2.19. At my next hospital appointment I was told not to celebrate too quickly because they needed to do additional tests before they would know whether I had naturally cleared the virus. I agreed to the liver biopsy but I left feeling very confused as to why I had been told that I didn't have Hepatitis C. When I left the hospital I felt like I was back at square one. I felt let down and couldn't stop crying. I had to ask my GP to chase up the appointment for the biopsy and the GP said that I needed to be tested for Hepatitis C again before I received the biopsy.
- 2.20. When I returned for an appointment in 1997 the Hepatitis test had come back positive for Hepatitis C. The doctor said that it could lead to cancer or cirrhosis and there were no treatments available. The appointment left me with very little positivity or hope and I was simply told that I would be monitored and given a liver biopsy. I did not have a biopsy while I was being treated at Bristol. The first biopsy that I had was at Southampton after I transferred my care there in 2001. I received the results on 11th of July 2002 which showed that my liver was inflamed but I didn't have cirrhosis. In 2003 I phoned Bristol and asked to be discharged as I was being seen by another hospital.

Other Infections

3. I do not believe that I have received any other infection.

Consent

4. As I requested the Hepatitis C test I do not believe that I have been tested without my knowledge or consent.

Impact

5. As stated above, there was an immediate impact on my health following the blood transfusion. The fatigue, nausea and headaches continued through the period that I had Hepatitis C. While my symptoms did improve slightly when I was diagnosed with coeliac disease I still found the fatigue debilitating.
- 5.1. In 1988 I opened a Health Food shop in Bristol which was the culmination of working in retail for my whole working life. The shop was very successful in its first year and even turned a profit owing to the very innovative product line and bespoke sandwich service. Before I contracted Hepatitis C I ran the business full-time with the help of one full-time member of staff and one part-time member. It was our goal for Michael to help run the business for the first 12 months and then focus on acupuncture and the administration of supplements.
- 5.2. After I was diagnosed with Hepatitis C I found I could work less and less. I would make myself go into the shop but would end up sleeping on the floor in the office. The fact that I was working less and less had a financial impact on the shop because we had to take on a disproportionate number of full-time staff to cover the work that I had been doing. As the years passed I began to feel useless and guilty at not being able to contribute to the running of the business. So the full responsibility of the business now fell on Michael.
- 5.3. The shop suffered financially both from my absence and the recession. We decided that we would have to sell the shop and it was sold in January 1996. The leases had been valued at over £100,000 the previous year but when we came to sell we were only offered £17,000 plus the value of the stock.
- 5.4. We were left in a very difficult financial position with negative equity in our house. Just before we sold the shop we were being visited by bailiffs and they even turned up at our house the week before

Christmas. My mother and Michael's mother would give us money to try and support us. Between them they kept food on the table. In 1998 I applied for Disability Living Allowance which not only involved filling in yet more forms but also being seen by a DSS doctor. The examination was soul destroying. It was carried out in a dingy room with a doctor who had no interest in me. After all of this I was told I would receive £13.47 a week and every year I would have to fill out the forms and see the doctor. The process was so degrading and upsetting that I stopped at the end of 2002.

- 5.5. In order to receive benefits, while Michael went back to teaching to support our family, I had to fill in forms and list all of our day to day expenses to receive £79.66 a week. This had to cover our mortgage and living costs. We were informed that if we could not afford our living costs then we should move into cheaper accommodation. We weren't able to do this because of the negative equity. We also had to stop paying into our private pensions after I got ill and so our vision of retiring to Italy to be with Michael's family has, unfortunately, never become a reality.
- 5.6. The Hep C also impacted my ability to do things like drive as I constantly felt extremely tired and unwell.
- 5.7. To this day I still feel guilty about the fact that I spent so much time feeling down. As part of the group litigation my lawyer sent me for psychological evaluation to a clinic in London which showed that I was depressed. On one occasion Michael caught me sending my clothes to the Oxfam shop so that he wouldn't have to do it when I died.
- 5.8. I know that this attitude was projected on to the kids. I tried to put on what I called my "happy hat" so that they wouldn't know how I was feeling. Some days however, I couldn't hide how I felt and I know that it affected them. When my son told us that he didn't want to go to university he admitted that he was worried about the financial implications for us. He also didn't see the point, I feel that this is a

reflection of my attitude while I was struggling with the Hepatitis C and I felt guilty for that.

- 5.9. The kids also helped out at the shop during busy period which would not have been necessary, had I not been really unwell. I felt guilty about not being able to look after them and about the extra support that they had to give Michael.
- 5.10. I also felt guilty when I was involved in the class action because the action was against the National Blood Transfusion Authority. They do amazing things and save people's lives.
- 5.11. We were worried about the stigma of Hepatitis C. The NHS were telling people that only haemophiliacs were affected by infected blood products and that if you had Hepatitis C it was a drug related illness. I didn't tell anyone outside of our immediate family. Recently, I mentioned to Michael's cousin that I was preparing my witness statement and when they asked what the statement was for I explained about my Hepatitis C to them for the first time.
- 5.12. In 2015 I developed strange itchy patches on my leg and shoulder. My daughter said that I should get it checked out because she was worried that it was skin cancer even though I had never really been out in the sun. I went to the GP and they said that they would send me to dermatology. It took about 4 months for an appointment and they took some scrapings and biopsies. When the results came back I was told that I had discoid eczema and was given steroid cream to apply sparingly. I then felt that I had been dismissed.
- 5.13. When I got the diagnosis I googled the condition and it said that one of the causes of it was people who had been treated for Hepatitis C with Interferon and Ribavirin. I was told by my GP that it couldn't possibly be a cause but I had never had infantile eczema or any other form of eczema. It just appeared.

- 5.14. Then in November 2017 I got up and didn't feel brilliant. I had been going for walks every morning and I only got to the end of my road before I had to turn around and come home. I rushed upstairs and was violently sick and had to lay down. I was feeling hot and cold and in a clammy sweat the whole time. Michael came home and rang 111. I was told that as the surgery was open I had to go and see my GP, I had to get in the car with a bucket and go to the surgery. I was trembling and shaking. She examined my leg because it was all red and swollen. I was told I had cellulitis from where I had been scratching my eczema. I was given antibiotics which didn't agree with me and I was so ill that Michael called the GP surgery again. They reluctantly sent a doctor to the house who told me to continue with the treatment. My condition severely worsened so Michael and my son took me to A&E at around 18:00 the same day. I was so dehydrated they put me on a drip and told me I had a reaction to the antibiotics because they were unsuitable and far too strong.
- 5.15. After that incident the eczema started to creep down to my hands and my knuckles. I went back to the dermatologist who took a biopsy. I am still waiting for the results but they think that it is coeliac dermatitis. I find this assumption frustrating because I have always kept very strictly to my diet.
- 5.16. I have to have B12 injections which could be a result of my treatment, anaemia or my coeliac disease. In addition, a few years ago I developed balance problems with my ears but we don't know what caused that.
- 5.17. I had to have treatment on my teeth because when I was on the Hepatitis C treatment it suppressed my immune system so much that I had to have repeated deep cleaning, old fillings removed and some teeth replaced. The doctors have never put that down to the treatment but I definitely think that it was.

Treatment/Care/Support

6. In April 1998 Michael heard about a friend of a friend who had paid for Interferon treatment. When I attended my appointment, at Bristol Hospital, the doctor informed me that NICE had not approved funding for the treatment on the NHS. Due to our financial situation we were unable to fund the treatment ourselves.
- 6.1. On the 14th September 1999 I was told at Bristol that NICE had decided to fund the treatment but the success rate was between 20 and 30%. Michael and I decided that the success rate was too low considering the potential side effects.
- 6.2. By the 8th of December 2005 I had been under the care of Dr Rosenberg's clinic in Southampton for a couple of years and I was advised to have another liver biopsy. On the 9th of March 2006 I was told that my liver had deteriorated and small holes were forming. The next stage would be cirrhosis. I was advised to have treatment and was informed that the success rate had increased considerably as the treatment now involved a combination of Interferon and Ribavirin. I was advised to transfer back to Bristol as I would need regular monitoring over the coming twelve months of treatment owing to the fact that I had genotype 1.
- 6.3. I started treatment on the 7th of September 2006; being treated for Hepatitis C is the hardest thing I have ever done.
- 6.4. My treatment involved taking two Interferon tablets in the morning and two in the evening. Then once a week I had to inject myself with Ribavirin. After the first week I could hardly walk up the stairs due to total exhaustion. It felt as if someone had put a weighted suit on me and I was 95 years old. I could barely lift a cup tea and doing even

simple tasks was so difficult. I felt constantly nauseous and had a constant neck and headache.

- 6.5. On one occasion I remember Michael suggesting we went out for a drive, but I fell asleep almost immediately and woke up at Porlock Weir around two hours later. I then fell asleep again on the journey home.
- 6.6. When I went for the next appointment at Bristol Hospital I was told my white cell count was really low. As a result, I was told to only take one Interferon tablet. This seemed sensible to me as a fairly petite woman - I thought it was silly that I took the same dosage of tablets as prescribed for a 6ft male. Throughout the year of my treatment I was advised to vary my doses depending on the results of my blood test.
- 6.7. At the time of my treatment the only place to park the car at the hospital meant that one had to walk up a hill to get to the entrance. But half way through the treatment Michael would have to assist me as I simply did not have the strength or energy to do this on my own.
- 6.8. In addition to the physical exhaustion, the medication had other side effects. I became aggressive which was not at all like me; I would snap at the kids for no reason and I constantly felt very down and had black moods which were really horrible.
- 6.9. At the end of November I phoned the hospital and was told that they could not detect the virus. That was enough to spur me on until Christmas but after that I remember begging not to have to take the tablets or receive the injections. Michael motivated me to keep going for the sake of the children.
- 6.10. I kept a book throughout the treatment and on the last day I wrote "I did it." My sister threw a party for me with my immediate family in attendance so as to celebrate my results.
- 6.11. At the final appointment of my treatment I was told that I had cleared the virus but would have to return for tests and a liver scan in three

years. In 2010 I went back to see the Hepatitis nurse with my daughter and had a test and a liver scan. I was told to ring for my results in a week.

- 6.12. My test results showed that my blood and liver were near normal and my white blood cells were low but not to worry. As a result I was discharged from the hospital.
- 6.13. During the whole period of my illness I was never once offered any psychological support. I was advised to seek psychological support when we received our settlement but I was told that it would have to come out of the money that I received. The closest thing I had to psychological support was when my GP managed to secure me an appointment at the Homeopathic Hospital in Bristol. My first appointment was in July 1998 with Dr Spence and I have later realised that, for me, these sessions were like therapy sessions. I stopped visiting in 2004 when the funding for the hospital was withdrawn.

Financial Assistance

7. I found out about the Skipton Fund from a national newspaper article and went to my GP and asked if he knew about it. He said he had only vaguely heard about the fund but that he would fill out his section of the form and if I came in and completed the rest he would send it off. I was awarded £20,000 by the Skipton Fund in August 2004.
- 7.1. At the beginning of 2017 I was automatically transferred over to EIBSS because I had been on the list for the Skipton fund. I started receiving monthly payments which total £3,000 a year and fuel payments. For a while I thought that I wouldn't receive this support because I had cleared the virus but then they changed their minds.
- 7.2. I also received a settlement as a result of legal action I was involved in between 1996 and 2002. I received £37,000. I never signed anything

which waived my right to make an additional claim and could have done so if my Hepatitis C had got worse.

Other Issues

8. My experience at Bristol Hospital was very negative. I would never see the same doctor more than once and each time I would have to explain the whole story again. In one of my appointments at Bristol the doctor stopped me talking mid-sentence in order to take a personal call. He turned his back on me and had a conversation as if I wasn't there. The doctors did not really have any bedside manner.
- 8.1. I frequently found that appointments at Bristol were not made until I had followed up numerous times or asked my GP to do so. It's hard to imagine what happened to people who weren't proactive in pursuing the things that they needed for their health as at times, I felt I had to follow up my situation of my own accord. When I needed to have my first liver biopsy I phoned up on the day and was told that I couldn't have a bed. I was given a new day to phone up and check whether there was availability. I called to cancel because I was so fed up with everything. There were no repercussions from cancelling the appointment and Bristol Hospital did not contact me. When I transferred back to Bristol from Southampton I didn't hear anything from Bristol about an appointment so I contacted the Hepatitis C nurse at Southampton. It wasn't until after I had contacted Southampton that Bristol sent me through a letter to go to Dr Gordon in Hepatology.
9. I would like to note that when I returned to Bristol for my treatment I had two very good Hepatitis C nurses. I also received excellent treatment from Dr Rosenberg in Southampton. I was shown care and understanding. When I first told him my story he told me that every time I went there I would see him and not have to explain myself all over again. Which was exactly as it was.

Statement of Truth

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

Signed _____ GRO-C _____

Dated 19th JANUARY 2019.

