

Witness Name: Hazel Busby

Statement No: WITN0072001

Exhibits: WITN0072002-6

Dated: 20 June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF HAZEL BUSBY

Section 1. Introduction

1. My name is Hazel Busby. My date of birth is GRO-C 1951. My address is known to the Inquiry. I am divorced and live alone with my cat Boo-Boo. I am unable to work due to long term disability.
2. My witness statement has been prepared with as much medical evidence as possible and has been given access to limited records; the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

3. I married when I was aged 16 GRO-C
GRO-C and miscarried my first three babies.

4. I gave birth to my son on GRO-C 1971 at North Hertfordshire Hospital. The hospital does not exist anymore. I understand that all of my records from there have been destroyed.

5. I had been taken into hospital early to prevent further miscarriage and I gave birth to my son on the bed on the normal maternity ward. The girl in the bed next to me had to go and find someone to help me as I felt the baby coming. The nurse came to me and told me to stop being silly and the baby was not due to till the next day. She lifted the bed cover and saw my baby with the cord around his neck twice. The nurse and sister did not want to phone for a doctor because they had failed to transfer me to the labour room prior to his birth.

6. Whilst my baby son was passed to one of the junior nurses the senior nurse (sister) got her wrist around the cord. It felt like she punched me in the stomach while tugging to remove the afterbirth. I was still on the maternity ward. I also haemorrhaged on the same bed, there was blood everywhere. The Sister rang the emergency bell and within a few minutes a young female doctor came in and examined me.

7. I was taken immediately to theatre for the extraction of the placenta and also for a repair. I was given a blood transfusion of two units. I believe that this is the only blood transfusion and blood product that I have ever received. I understand that it is through this transfusion that I contracted hepatitis C (HCV). I attach a copy of my maternity card which shows the transfusion given **WITN0072002**.

Section 3. Other Infections

8. I am not aware of any other infection other than HCV.

Section 4. Consent.

- 9. I consented to blood tests, but I was unaware that my blood was being tested for HCV. By this very fact I was provided with inadequate information.
- 10. To this day I have no knowledge of how and if the results of my tests were used in terms of research.

Section 5. Impact

- 11. I have been ill virtually all my life since the birth of my son Stephen in [GRO-C] 1971 which is since I received the blood transfusion. I was suffering real fatigue and painful joints, but I didn't know why at the time. I suffered spasms too and the medical profession did not know what was wrong with me. In those days you were not treated well, and I was made to feel like an outcast.
- 12. As a young mum [GRO-C] I was given advice by a very good solicitor and began to proceed with the divorce. However, I discovered that I was pregnant with Ian.
- 13. In 1973 the divorce laws changed, and it was easier for women to get a divorce. [GRO-C]
[GRO-C]
- 14. In August 1974 I remarried. Our daughter Justine Hazel was born on the [GRO-C] [GRO-C] 1976. Throughout the pregnancy, I had consistent blood tests I asked them why; their response was it is good for the baby. I never felt as unwell in a pregnancy before. She was a full-term baby but only lived for 20 minutes. No one ever explained to me why she was so ill or why she died. I was never

given the opportunity to see her or hold her in my arms. However, I was asked to ask to sign many forms which were not explained to me.

15. I now know that when I was pregnant with Justine the hospital was aware that she had Spina Bifida, but they did not tell me. When I went into hospital to have her, they took me to an operating theatre instead of the ward.
16. They told me that I could not have pain relief and that I should grin and bear the pain. After approximately 36 hours of labour Justine Hazel was born and she was immediately taken away from me. A senior registrar came to talk to me and said, "I am sorry Mrs Reynolds, but we've had to let her go and that she had died at 20 minutes old". A Sister came in to see me while I was still in the theatre and told me that my baby, Justine Hazel had been christened as Baby Reynolds. I asked to see my baby, but I was denied. I asked for a lock of her hair but was informed that she had already been transferred to the Lister Hospital in Stevenage for a Post-mortem
17. I was then taken to a side room which was opposite the nursery where all of the new-born babies were kept. I could not cope and discharged myself due to the lack of support, compassion and the trauma of listening to the new-born babies where I knew my baby Justine Hazel should have been.
18. I was back home c GRO-C and was knocked out for three or four days with drugs prescribed by my GP for headaches. My husband told me not to worry. We never talked about Justine again. That was not my choice and I was never involved in her funeral. It was only later in my life around 1997 that I found where she had been buried.
19. We went on to have a further daughter Lucy on GRO-C 1977. GRO-C
GRO-C
GRO-C. I was told that I needed to stay in hospital as my baby needed breast milk. GRO-C
GRO-C

20. During this time, I was allocated a room that had not been used for years. It had previously been used for nursing staff. As far as I can remember, I was the only patient down there and there were many rooms.
21. Following this I suffered with heavy bleeding and when I was 26 and Lucy was 8 months I had to have a hysterectomy. I was not told what was wrong with me although there was a suggestion at the time that I may have ovarian cancer.
22. There were so many things happening to my body for years; I have suffered so many illnesses. At the time I did not know why I was so ill, but I do now. I suffered from severe fatigue and extremely painful joints. I would pass out and not know why. I had body spasms and not know why. I kept seeing medical professionals, but they did not know what was wrong with me.
23. I had been in and out of hospital for all sorts of tests. I was having terrible trouble with my legs, my spine and with spasms. My legs and feet used to go into spasm, and I was told this was coming from my back. I was only mobile in a wheelchair.
24. I did not know what was wrong with me and I suffered from anxiety and depression. Inside I was a happy person, but I felt that I was constantly put down. I felt very strange, but I had to get on with my life because I had three children to support and bring up.
25. Between 1978 and 1980 I was attending the Royal Orthopaedic Hospital Great Portland Street, London. I needed surgery for my knee. I was told that my liver markers were high, and I was told at the time that if I did not stop drinking that I would get severe cirrhosis of the liver. I told them that I did not drink; that I was a mum with young kids. They told me that I must have been drinking and I was treated like an alcoholic.

26. I did not take this information any further; in fact, I forgot all about it. I thought that it could not have been that bad because they were not doing anything about it. I think there has been something happening to my body for years because I have suffered so many illnesses. It is only now that I know why.
27. In 1981 and 1982 I had two separate incidents of deep vein thrombosis. This seemingly came from nowhere. I was taken into hospital and on one occasion the blood clot in my leg burst and sent several little blood clots around my body. I was put on warfarin for a year.
28. I had remarried in 1974 but I divorced in 1984 due to my ill health. I had married a businessman who wanted to party. He wanted a wife who could have dinner parties and to be a wife. [GRO-D]
 [GRO-D] I blame my illness on the breakdown. I loved him ever so much
 [GRO-D]
 [GRO-D]
 [GRO-D]
29. In 1989/1990 I moved to [GRO-C] from [GRO-C] and in 1993 I married Sean. We lived on the [GRO-C] at [GRO-C] and whilst my life was idyllic I was still ill, and I was in a wheelchair more often than not. I had severe back problems causing physical disability through the 1990's.
30. Sean looked after me, but he could not cope with my ill health. I thought we were alright, but one day he just left me and never came back.
31. I was left alone; I could not get out of bed. My doctor had to break through the window to get to me. I have heard since that Sean could not cope with my health problems. He had thought I would get better, but I didn't. In 1999 I also developed Cohn's disease. Sean divorced me in 2000.

32. Also, in 1999 I had an operation to my leg which had swelled with poison. I understand that they cut MRSA out of my leg. My son's friend had taken me to hospital and carried me in as I was very ill. The doctor went to examine me and touched my leg and the whole thing burst. I was in my own room in hospital for a long time. I was told that my immune system was not working properly but no one could tell me why. I now feel that the HCV poison has been running around my body doing what it wants to do.
33. After Sean had left me, I was moved into a little cottage. Suddenly everything was gone; I could not go out of the house. I could not go upstairs. I was unable to even get into the garden; I could not walk. It was a dreadful time. Even my children no longer lived near to me and whilst I had carers, they only came to get me out of bed and would then just leave me.
34. On 27 October 2000 I took an overdose; I felt there was nothing left. I was in misery and pain and felt that I was going to be disabled for the rest of my life and I could not take it. I did not succeed but I tried my hardest to do it; I took a massive overdose. I feel desperately ashamed because I know it upset my children and I feel now that I was lucky to survive it although it does not change the pain I live in; I have had a life of pain.
35. In 2005 my GP surgery telephoned me and told me that the doctor wanted to see me on an important matter. I made an appointment and went to see Dr GRO-D. He said that he was really sorry but that I had hepatitis C (HCV). I asked him what on earth it was, and he told me that it was a disease carried in the blood and was very dangerous. I did not know that my blood was being tested for HCV, but I do know that I must have the most tested blood in the world.

36. He asked me if I had any idea from where it had come from and asked me if I had had any blood transfusions or whether I had injected drugs. At the time [GRO-C] was messing around taking speed and I went to see one of those unsavoury people to protect [GRO-C]. Someone ran at me with a needle, but he did not inject me. I told him that I had had a blood transfusion in 1971. Dr [GRO-D] said that it must have been when I was given the blood transfusion. I asked him what I could do, and he said that he did not think I could do anything.

37. I was given no advice when I was told I had HCV. It was just like he was telling me that I had a cold. I do remember reading about Anita Roddick, The Body Shop founder who was also infected with HCV and died in 2017.

38. At the time I was being treated by Dr Pugh who was a gastroenterologist treating my Crohn's disease. The next time I saw him I told him about my HCV. He offered me an opportunity to take a new drug which had just come out called Interferon and Ribavirin and was I interested in being part of the trial. I said that if it would help then I would.

39. However, that opportunity was missed as at the time my sister was helping me move and helping me sell my house. At the time I was having a nervous breakdown; I seemed to be losing everything. There was too much going on in my life. [GRO-D]

[GRO-D]

40. [GRO-D]

41.

GRO-D

42. I was put into sheltered housing and I am still living here.
43. I went back to Dr Pugh and I started the treatment in or around 2007. Before I started this, I had prepared my body for it by going on a diet and trying to get my body as healthy as it could. I started the treatment of Interferon and Ribavirin which I was on for four months. I have seen a letter from Dr Pugh that indicates I was on the treatment for one month, but this is incorrect.
44. I was so sick whilst on this medication and it screwed my body up. It brought back all my anxiety; it was dreadful, I could not cope with it. I felt all spinny and faint and very unwell, so I came off it.
45. However, I did not want to die from HCV. I had been so lucky in the past and I did not want this to get me. I started the treatment again in 2009/2010. Dr Pugh had made me wait because I was not well enough. I was on interferon and ribavirin the second time for a few months. I had the same dreadful side effects, but I thought I had to bite the bullet and endure them. After a few tests they said that I was clear of the virus. I felt like I was booted out with no care. Dr Pugh appeared pleased with himself because he could tick a box that I was cured but I was in bits. My hair had fallen out and my mouth was so full of ulcers my tongue would not operate properly.
46. As a result of the treatment given specifically for the HCV I have suffered from lichenoid keratosis to my lips with ulcers to my mouth and a benign tumour on my tongue. I am told that on the balance of probabilities these are all side effects of the interferon and ribavirin treatment. The lichenoid keratosis are black blobs which grow on my lips. They reach a stage where they just burst

and blood spurts everywhere. I attach copies of photographs of my mouth and the ulcers and growth on my tongue as **WITN0072003**.

47. I also suffer from peripheral neuropathy which I understand is also a consequence of the hepatitis treatment. My feet constantly burn; it feels like your feet are set on fire with needles and I cannot feel them when I walk.
48. I have also had to have surgery on my back for stenosis of the spine due to osteoporosis. I understand that this is another side effect of the interferon and ribavirin treatment. This surgery caused damage to my bladder and as a consequence I now have to self-catheterise for the rest of my life. I constantly have infections as a result.
49. I do not have liver function tests; I do not know how my liver is. No one tells you anything and I sometimes think that I ought to find out and have it tested.
50. All I have ever wanted is to be a good mum, but I have been unable to give my children what I had wanted to. I am now living in sheltered housing. I cannot drive and I am presently on antidepressants.

Section 6. Treatment/Care/Support

51. I have carers and I need a support worker with me to go anywhere. I can no longer drive.
52. I have not been treated well. I can remember when I was on the interferon/ribavirin treatment and I required regular blood tests. One time the nurse found it difficult to access my vein and she said that she had tried once but that she was not going to try again on a drug addict. I said, "I beg your pardon" and she said, "it's right here, you have HCV".

53. When I have been in hospital in the past, I have overhead doctors asking if I was a “druggy”. I feel that I have been treated differently because of my HCV status. It has left me feeling that I’m a dirty, filthy person but I am not.

54.

GRO-D
GRO-D

 I do not have anyone and cannot live a normal life. I normally have carers, but I feel I need them for longer, but I cannot get the funding. I wear a Fentanyl skin patch all the time which needs changing every 72 hours. This is an opioid used as pain medication which is usually given at end of life. I also take oxycodone for pain relief. Nobody ever warned me about the side effects of the drugs I took to clear hepatitis C.

55. I have peripheral neuropathy in my feet which I understand is also a side effect of the treatment. Whilst I have developed late onset diabetes type 2 which can make this condition worse the diabetes was not the cause of it. When the patch is beginning to wear out, I have to wrap my feet in blocks of ice to numb the pain. I cannot feel my feet touching the floor when I walk and once, I had a drawing pain stuck in my foot for three days because I could not feel it.

Section 7. Financial Assistance

56. Dr Pugh wrote to the Skipton Fund for me. He told me about the financial assistance, but I did not know it existed until then. I got the stage 1 payment which I think was £23,000.

57. I receive monthly payments of £1,750 from the EIBSS but because I receive benefits, £250 of my benefits are deducted, because, I think, of the payment from EIBSS. I do not think it is fair that my payments from EIBSS are affected by my benefit payments. I live in fear that this money will be taken away from

me and I will not be able to have the care I require, and I will become a prisoner in my own home.

58. The Skipton Fund has provided me with an electric bed and a scooter, but I had to go through a lot to get it. I feel like a “dirty nothingness” to beg and borrow. I have not been able to work because I have been so ill. It’s not about the money it’s about how you’re made to feel. I feel sad and broken. I feel there are other people worse than me, but I am in dreadful, dreadful pain and I am very unhappy.
59. I receive £900 per annum from the EIBSS for counselling. My doctor supported me with this application, and I enclose a copy letter from Dr Meguer dated 11 February 2019 **WITN0072004**.

Section 8. Other Issues

60. Whilst I am shy and never wanted to talk out, I would overcome my shyness to speak at the Inquiry. I had a cousin called Martin who was a haemophiliac. My GRO-C was the carrier of the haemophilia gene. Martin was 19 years old when he died. There is no one left to speak for him, but he died from AIDS having been infected through contaminated blood products. He rotted to his death. He was an only child and his parents have died. The nurses treated him like he was a drug addict or a homosexual.
61. I would like to clear up an issue within the very few medical notes that I have. I attach a copy letter from Dr Pugh to the Skipton Fund dated 29 September 2011 as **WITN0072005**. In this letter Dr Pugh refers to a needlestick injury. Whilst I was approached by an unsavoury character with a needle I can categorically state that the needle did not pierce my skin. I attach a copy letter from my GP to the Skipton Fund dated 15 July 2011 which refers to the only

transfusion I had following the birth of my son in 1971 **WITN0072006**. I would also like to add that I never been a drug user or an alcoholic.

Anonymity, disclosure and redaction

62. I do not wish to retain anonymity. I understand that my statement will be disclosed and published as part of the inquiry. I would very much like to give evidence at the Inquiry.

Statement of Truth

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

Signed

GRO-C

HAZEL BUSBY

Dated.....20 June 2019