

Witness Name: Ellen Martin

Statement No: WITN1928001 Exhibits:
[WITN1928002 – WITN1928005]

Dated: 15 December 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ELLEN MARTIN

Section 1. Introduction

1. My name is Ellen Martin. My date of birth is GRO-C 1973. My address is known to the Inquiry.
2. I make this statement in relation to my mother Evelyn May Martin, who contracted hepatitis C as a result of receiving infected blood. My mother passed away on 1 March 2013. I make this statement as an affected individual.
3. My daughter Maria Martin has also submitted a witness statement to the Inquiry. Her witness number is W1927. I request that my statement is read in conjunction with Maria's statement.

Section 2. How Affected

4. My mum was born in 1945. She was known as Babs by everyone. Apparently she was first called this by a Scottish Nurse when she was born because she was so small "the wee babs". It stuck and she preferred it to being called Evelyn. She was never overly maternal but I then neither am I with Maria. I always knew that I was loved. Mum had a cracking sense of humour and was very crude at times. She did not take any rubbish from anyone. Often she was seen as nosey but was a great friend to those who knew her best.
5. Some of the best times I can remember with my mum were when we moved to Ramsgate, leaving Dad in Croydon. At the time I did not know they had separated. It was just mum and me and my nan round the corner having a laugh and making friends. That was when we were at our closest. After that my dad moved back in and we were more or less allies for each other until she could stand no more. We fell out for a while and weren't really close again until I lost a baby in 1993 and then fell pregnant with Maria in 1995.
6. Mum had her gall bladder removed in 1973 and had a hysterectomy in 1976. These operations either took place at Kings College Hospital or Mayday Hospital in Croydon. Through my solicitors I have requested my Mum's notes from both of these hospitals; however I have not been able to obtain the records for these operations. However her GP records confirm that she had blood transfusions at the time of both operations.
7. As far as I am aware my mum was not given any advice or warning about the risk of being exposed to an infection as a result of having a blood transfusion.
8. My mum was diagnosed with Von Willebrand's Disease in 1976 [WITN1928002]. In 1984 we moved from Croydon to Ramsgate, Mum was referred to the Kent & Canterbury Haemophilia Centre. She had not seen a haemophilia doctor until we moved to Ramsgate. As far as I was aware she was first given Factor VIII In around 1988 when she was 37 or 38, and had it many times after that. However I understand that her medical records indicate that she was given Factor VIII before we moved to Ramsgate [WITN1928003].

9. As far as I am aware my mum was not given any advice or warning about the risk of being exposed to an infection by being given factor VIII.
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10. I was diagnosed with Von Willebrand's when I was about 11 or 12 years old., Maria was diagnosed when she was a baby. However, in 2011 we were all told that we had haemophilia A and not Von Willebrand's. the medical cards that we have to carry with us were changed. I have mild haemophilia and Maria has moderate, I think it tends to get a bit better as we get older. I have not ever needed a blood transfusion or Factor VIII; however I have been given tranexamic acid several times to help clot my blood. They are very cautious about performing medical procedures on us, we would not be given an operation unless it was an emergency.
11. I remember mum always being tired and confused. I don't think we really thought about that much before she was diagnosed. She had lots of problems with her stomach, she suffered from diverticular disease, she had diabetes and she often had aches and pains that did not seem to be attached to anything.
12. My mum was diagnosed with Hepatitis C in 1995 when she was 50 years old [WITN1928004]. Her records indicate that the doctors at the haemophilia centre believed this was as a result of Factor VIII that she had been given before 1984 [WITN1928002].
13. I wasn't at the appointment when the GP gave her the diagnosis. She told me that she had been taken aback. She was referred to what was then Thanet District General Hospital, now Queen Elizabeth the Queen Mother Hospital in Margate. She was told by the doctor there that she had four years to live, that really took her aback. I went with her to her to almost all of her appointments after that.
14. I don't think she was given much information about hepatitis C when she was first diagnosed. The staff at the Kent & Canterbury Haemophilia Centre were the most supportive, they were like family in the early years. If we had any questions it was

them we rang or went to, but they could not always tell us the answers. I think often they just did not know.

15. We were given information about how the Hep C could be passed. I asked whether I could catch it from mum, they said not unless I drank a pint of her saliva. They said that sharing cups or bottles was not going to make any difference. Mum was worried that Dad could have got it but he was tested and he did not have it

Section 3. Other Infections

16. My mum received a letter which said that she may have been exposed to VCJD. I remember it being a bit of a joke, mum said that she had mad cow disease and used to show people the letter. It did not freak her out, she just did not see the point of them sending her a letter like that. She couldn't do anything about it, the doctors couldn't do anything about it. It was the Hep C and cirrhosis that killed her off, even when she died they did not run any tests for vCJD. I don't understand the point of the letter; it was a waste of paper.

Section 4. Consent

17. Mum was given infected blood and/or blood products without being informed of the risks of infection. She did not have the opportunity to give her informed consent for these treatments.
18. After she was diagnosed I do not believe that mum was treated without her knowledge, without her consent, without being given adequate of full information or for the purposes of research.
19. Once she knew about the Hep C, mum had knowledge of everything that was going on, I would go with her to appointments and we would talk it out. Even when she signed her DNAR she knew exactly what she was doing.

Section 5. Impact

20. My Mum and Dad had quite a difficult relationship. After she left my dad in August 1991, she seemed well, like she was on a roll. She was working as a telephonist, I was working and we were living our own lives.

21. Then in 1996 she was diagnosed with hep C. From that point onwards everything started to go downhill. Her body started to break, everything happened quite suddenly. She was told that same year that she had cirrhosis. She started to suffer from hypokalemia, low potassium levels, which caused major pains in her legs. She had lots of urinary infections. She suffered mini strokes or TIAs; we would be talking to her one minute and the next her face would droop on one side or she would be flat out on the floor. At the beginning they said that they did not know what was causing this.
22. It got to the stage where she had a long list of medical conditions that were related to her hep C. She had an enlarged spleen, erosive oesophagitis, grade 1 varices, osteoarthritis, chronic abdominal pain, and anaemia. Mum had several blood transfusions for her anaemia. After a transfusion Mum was on top form, she could go for days. Once she had one before we went on a trip to New York City and she walked the whole of Fifth Avenue. I don't think having blood transfusions bothered her as she knew the blood was being screened properly by that time and it made her feel well again for a few weeks.
23. As soon as she was told by her GP that she had Hep C Mum just thought that she was going to die. We were later told that the consultant at the first appointment should not have said that she only had four years to live. In fact she lived for 17 years after being diagnosed. On the four year anniversary we celebrated her best before date and then every year we would mark her being one more year past her sell by date.

24. Mum started to get her head round the idea of dying and made her will out. She had a lot of life goals that she wanted to achieve. Holidays were a massive thing, when she received the money from the Skipton Fund she paid off the little bits that she owed and blew the rest. We went to Memphis, to Egypt, to Malta and she took Maria to Rome. We would stay in 5* hotels, she didn't do things by halves. We stayed in the Hilton in Malta, the Sheraton in Egypt, the Hilton in Washington DC, New York and Boston. We made a lot of memories. Mum tried to live to see Maria's 18th birthday but she did not quite make it. She made it to my 40th birthday, but she was in hospital by then.
25. Despite all of her health problems we got out when we could and made the most of our time, often just to take her mind of things. We would go out with Maria in the morning and could be out all day. Sometimes Mum would say that she wanted to go out for a drive, I would drive and we would get lost, end up in the middle of the countryside. Sometimes I said if we are out we may as well stay here, so we would stay in hotels or in a BnB, just anything to keep her happy.
26. We bought a tent once and the three of us ended up putting it up laughing in the pouring rain. That was just another impromptu thing we did. After that first time we went camping a few times but never without electricity. It was kind of like early glamping. We would have electric duvets, takeaways delivered to the tent and once we took the lean mean grilling machine.
27. Mum was as active as she could be but over time it became more and more difficult for her. She could not walk far, she had pains in her legs, she dropped things a lot. She got carpal tunnel syndrome and could not hold anything heavy, she could not even hold her kindle. She continued to have pins and needles even after the carpal tunnel surgery. She was always cold and everything about her hurt. Towards the end she could not walk, she could not sit, she would have pain in places they said she should not have pain. Her stomach became so swollen, just the weight of that was exhausting for her to carry around and if you touched her she would flinch.

28. She developed cryoglobulinaemia which caused rashes all over her legs which were hot to touch. Her legs would swell and the skin would split, even having cream on was agony for her. I would put as much cream on my hands as I could and try to rub it all over her legs in one go because she could not handle being touched. This was one of the conditions that upset her the most because she loved her legs. She had always worn stilettos but when her legs started to swell she had to start wearing flat shoes. She bought her first pair of trainers, it was a shock because it just wasn't her, she started to wear trousers and jeans instead of dresses and skirts. But she was still very glam. Mum was always very proud of her appearance, she would go every week to the hairdresser. Even when she had trouble walking she would go on her mobility scooter to get her hair and nails done. She loved getting her hair done.
29. From the start mum was adamant that she did not want to have treatment for her Hep C. I understand that there is reference in mum's records to her not being offered Ribavirin and Interferon in 2000 because of financial pressures [WITN1928005]. However I do not believe this would have made any difference in mum's case because I doubt she would have taken them up on the offer.
30. In July 2010 mum was referred by her doctors in Kent to Kings College Hospital for advice on treatment for her Hep C. I went with her to a few appointments there, the doctors discussed with her having a course of treatment and possibly a liver transplant. She was told that if she was going to have a transplant she would have to have Ribavirin first. The doctor said the chance of the treatment succeeding was 25% to 35%, and explained to Mum about the side effects. Mum was worried about having the treatment, the doctor said carrying out the transplant operation would be difficult because of her other complications. This put her into such a depressive state. Mum decided not to have the treatment or to have a liver transplant.
31. I think it was right that she did not have the treatment. We had long conversations about it, it was her body and she knew her own mind. She knew what she wanted and I wasn't willing to let her go through the pain. Obviously I wanted her for as long

as possible, but I knew she was going to die and I did my best to keep her well by checking her foods and medicine.

32. Mum was angry sometimes and you can understand why, she was missing out on a lot of things. She said that she had been told once that we all write our own book for our lives, she said "why on earth would I write this? Why would I make myself so ill?" Being ill was always in her mind, she definitely blamed whoever it was for using infected blood products and passing Hep C to her.
33. In the last few years of her life the doctors were helping her the best they could but they did not know the answer to many of her questions. They told her that she was the oldest person in Kent with Hep C, they told her that she was setting the precedent.
34. Towards the end she had these episodes where she just fell asleep, sometimes in the middle of conversations. If you pointed it out she would get very angry, her attitude changed and she would say things to people that was totally out of character. Mum started to forget things, she put this down to old age. When she started to have accidents it would embarrass her no end. Eventually she was incontinent and when she wanted to wee she would cry, we would still try and take her out and about, we would always be prepared for her having an accident.
35. There were a couple of occasions that mum took too much morphine, she said that she had forgotten that she had taken the first dose and so had another one.
36. In the first few months of 2013 Mum was admitted to hospital several times, she had a couple of falls and was becoming more and more confused. By that time her whole body was swollen with water, when they took blood in the hospital water came out. Her eyes were bulbous, she looked like the Michelin Man. If you put your finger on her skin it left an indentation.

37. The last time she was admitted I knew she was not right. You knew when she was well because she knew everyone else's business on the ward. But when I got there she had been moved towards the nurses' desk, you don't get moved closer to the nurses' desk without a reason.
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38. The day before she died, one of the nurses told me that the consultant needed to talk to me. As soon as they said that I knew what was coming. When I met the consultant I said that I knew she was not coming out of this one. She was put on palliative care, on the Liverpool Care Pathway on 28 February 2013. Mum knew what was coming, she had got all of her things in order. She was ready to go, she would not have wanted me to prolong it.
39. Mum died on 1 March 2013. Her cause of death was:
I(a) End stage decompensated liver disease, cirrhosis of the liver
II Hepatitis C, Type II Diabetes Mellitus, Chronic Kidney Disease, Von Willebrand Disease
40. Mum did not like telling people she had hep C. When nurses started to take blood with no gloves on, mum would have to tell them about the Hep C. There would be some doctors who just did not know about hep C and would ask her questions like *How long have you been an alcoholic?* They just did not know anything about it. This question came up again and again. Mum did not drink that much, she had a couple of drinks a week with her friends, on a Friday or Saturday night but that was it.
41. Even now lots of doctors do not understand about my haemophilia because in my medical records it states that I have Von Willebrand's, I have to argue with them to convince them that what I am saying about my own health is correct. It was the same with Mum. Some doctors would say *What do you mean you have hep C? Have you ever taken drugs?*
42. At work Mum was treated like a leper, people said stupid things and they would not let her touch their mugs. She was told by her dentist that she could not been seen

until the end of the day, I was a dental nurse at the time and I knew this was not right, you can't catch Hep C like that. So we changed to a different practice where she could be seen for routine check ups at any time of the day.

43. Any stigma she faced she knew was just ignorance, it upset her but she would not let it stop her from doing anything. She was adamant that she would not become a victim of Hep C, she would not let that happen. She did not want to be anyone's victim.
44. Mum gave up work in 1997, not long after she had been diagnosed. She could not cope with how people treated her when they found out that she had Hep C. Because of all of her health conditions she was eligible for disability benefits, and she was finding work increasingly difficult as she could only think about one thing at a time. She had been told that she only had four years to live, what did it matter whether she was working or not? Her leaving work did not have a big impact on her finances, when she was working she had most of her bills covered because she had been on a low income. We lived as well as we could, as long as Maria was fed and Mum had enough food to cover her diabetes we were fine.
45. Mum's Hep C had a huge effect on my life and on Maria's life. I was angry about her being given infected blood and sometimes I was angry with her that she was ill, sometimes I would say "why can't you be well?" In 1996 Maria and I moved in with Mum just while she was getting her head round the diagnosis and leaving work. Then she started having the TIAs and I would often find her on the floor. We stayed for a while longer because she wanted to spend as much time with Maria as possible. After a while she started to come to terms with everything and seemed to be coping so in 2000 we moved out and she lived in a flat by herself.
46. In 2004/2005 we had to move back in with her because she started to drop things and she was having lots of urinary infections. When she had them she did not know what planet she was on, I always knew when it was happening because she would always give her address as our old address in Croydon.

47. I went back to work in 2004 when I got my bus driver's licence. Around that time my dad got ill as well and I was trying to look after the both of them. I had to give up work in 2007 and became a carer for mum again, I claimed the carers allowance because this was the only way I could survive.
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48. Maria and I moved out again in 2011. I decided that we should move for selfish reasons really. Even after we moved out I would be with her most days. I would drive from Ashford to Sandwich to drop Maria at school and then on to mums. In 2012 I went a bit less frequently because Maria started 6th form college closer to where we lived. I thought Mum was coping ok but I suppose I also didn't want to see that she wasn't coping because I wanted my own life. Selfish I know but unless you have lived it you wouldn't understand.
49. In many ways living with mum was a nightmare for me, when you live with a parent however old you are you are treated like a child and are questioned about everything. It became mentally and emotionally draining and was very frustrating at times. Mum could be very spiteful at times, but looking back I realise that the majority of this was her illness. I understand now that she was being poisoned from inside out.
50. For Maria it was tough, it was like having two mothers, she became like a young carer when I was out at work. She spent the majority of her childhood in and out of hospital wards and with adults.
51. At one point we were very close to our extended family, but when mum outlived the four years she was given in 1996 some of the family were annoyed with her and accused her of lying to them about dying. We don't talk to them anymore. No one was really there to help us or her in the end, it's amazing how many people don't turn up. They only wanted the phone call to say that she was dying.

52. When mum was feeling up to it she would go out to see her friends, she did not let her health affect her social life. But most of her friends just did not do sickness and so really it was just left to me and Maria.

Section 6. Treatment/Care/Support

53. Mum found that there was a lack of understanding about hep C. Everyone knew about Hep B and HIV, but some members of staff at the hospital would read the first page of her notes and act as if they could catch Hep C just by touching her. When she was rushed into hospital the odd registrar would make a comment but most of the doctors that she saw regularly were fine, and her GP was helpful.
54. Mum received counselling at the Haemophilia Centre when she was first diagnosed. One of the nurses there was a counsellor. Mum would go there for hours, they told her that she could call whenever she wanted. I think she worked through a lot of anger about being given it, anger about it being passed on and anger about the way people treated her. She was very angry that she had been given it. The counselling worked a bit but towards the end when she became very ill, she was angry again.
55. When we first started attending appointments at the haemophilia centre it was very family orientated, everyone knew us by name. But at some point the staff changed and they did not know who mum was. They cut back the services at the centre and after that we could only go two days per week rather than it being open to us every day. That had an impact on Mum.
56. I have been offered counselling but I do not want it. I do not think that it is right for me.

Section 7. Financial Assistance

57. Mum found out about the Skipton Fund in 2004 from the staff at the haemophilia Centre. She received the stage 1 payment straight away and the second stage payment a couple of years later.
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58. I don't think Mum had any trouble applying for the money. The haemophilia centre helped her to apply for stage 1, and then when it came to stage 2 we just had to tell Skipton about her cirrhosis and then a cheque arrived. Mum did not have any hassle whatsoever.
59. I did not have enough money to pay for Mum's funeral and Skipton helped with that.
60. I don't think that the money given out by Skipton is enough but you can't put a price on a life.
61. I found out later that people who got HIV from infected blood were given more money than those who were infected with hep C. People infected with HIV and people infected with hep C will both suffer and both groups will die. There should not be a difference in the amounts paid to those with hep C.

Additional questions for witnesses

62. I would like the Inquiry to find out when people in power knew about the risks of infection and when they decided it should be kept quiet. An apology isn't always good enough but accountability can be. Sometimes you don't need to apologise but just acknowledge that you screwed up
63. If there had been more knowledge and information out there about infected blood and about Hep C, Mum and others would have been treated better. Because people were being infected with Hep C in around the same time as HIV was in the news so much, I think that Hep C was pushed to the side a bit. The doctors did not seem to

know what would happen to people because everyone was getting different symptoms.

64. We are meant to trust our doctors and our government but they messed up royally without giving anyone a choice in the matter. Who was it that was making these decisions about giving risky blood and keeping quiet about it? Was it even someone in the health service or was it an MP who was voted out a couple of years down the line? Their decisions have had such an impact on people's lives, they probably don't realise the damage done. In the future these decisions should be left up to medical people rather than MPs. Some of these MPs have not got a clue, they forget that their actions and decisions affect people.

Statement of Truth

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

Signed

GRO-C

Dated 15 December 2020.....