

Witness Name: Pauline Bowles

Statement No: WITN0958001

Exhibits: WITN095002 – 003

Dated: 15 October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAULINE BOWLES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 June 2019.

I, Pauline Bowles, will say as follows: -

Section 1. Introduction

1. My name is Pauline Bowles. My date of birth is [GRO-C] 1952 and my address is [GRO-C] Hemel Hempstead, [GRO-C] I am retired and live with my husband David. We married in 1972 and had three children James, Simon and Kate born in 1976, 1978 and 1980. We have lived at this address for 36 years.
2. I intend to speak about my late son Simon Bowles, who was born on [GRO-C] [GRO-C] 1978 and sadly passed away on 28 June 2011. Simon had been infected with the Hepatitis C virus ("HCV"), as a result of being given infected blood required for a bone marrow transplant. He passed away in 2011 following a second liver transplant as a result of liver failure.

3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.
5. My husband David Bowles assists me with my statement.

Section 2. How Infected

6. Simon was born on the GRO-C 1978 and it was on his first birthday we found out he was ill. At 10 months old the health visitor noticed he had a slightly enlarged stomach and was concerned. She told us to come back in a month's time if it was still enlarged. A month elapsed and we went back to the health visitor, who directed us straight to our GP.
7. Following an appointment with our doctor, he referred Simon to Hemel Hempstead General Hospital (now incorporated as part of West Hertfordshire Hospital), and he was seen the next day.
8. After the initial hospital examination the paediatrician was concerned something was seriously wrong, so we were sent straight to Great Ormond Street Hospital (GOSH) via ambulance. This would have been in October 1979.
9. At GOSH Simon was diagnosed with Monosomy 7 – he only had one chromosome 7 and this would eventually progress to myeloid leukaemia. We were told nothing could be done at this point, but they would continue to monitor him.
10. My husband and I were informed that a bone marrow transplant had not been done for this particular illness before, but they would see if it was a

possibility. They tested the bone marrow of our eldest son James, but it did not match that of Simon's.

11. Not long after the diagnosis I became pregnant with our daughter Kate. As a couple we wondered how we would cope with another child along with Simon's illness, but as the pregnancy progressed I calmed down. GRO-C

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12. Simon kept relatively well up until the age of 5, and in that time we moved into the house we currently reside in. It needed a lot of renovation, so we lived at my in laws whilst Dave carried out the work. We ended up moving into the house earlier than expected (in June 1983), as we were told that the bone marrow transplant would be imminent.
13. By October 1983 GOSH said that Simon's health was deteriorating, and he had to be radiated at St Bartholomew's Hospital in preparation for the bone marrow transplant. It was very traumatic.

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15. The Anthony Nolan Charity paid for us to have a nanny for Kate whilst Simon was in hospital.
16. Simon was discharged from hospital a couple of months after the transplant. He could not walk and was very weak, but he gradually got better. The bone marrow continued to grow and everything seemed to be well – at each hospital check up they were pleased with his progress.

17. The transplant was completely successful and Simon was cured of leukaemia. We had the best team under the supervision of Professor Chessells. It was one of the first bone marrow transplants for myeloid leukaemia, and the hospital were very pleased with the outcome.
18. Simon missed his first year of education, but the school was very understanding and sent a teacher round to the house. A few years later an educational psychologist tested him at school and she commented that he had such a computer logical brain. Computers were only in their infancy at this point, but Simon scored 98/100 and they had never seen such a high score.
19. Some years after the bone marrow transplant Simon had his tonsils taken out and he had some nodules on his leg removed, but he did not receive any blood for the procedures.
20. In May 1995 we received a letter from Professor Chessells notifying us that Simon received a unit of blood during the transplant, from a donor who in retrospect had HCV and that Simon may have been affected as a result (**EXHIBIT WITN095002**). It was completely out of the blue, and was the first indication we had that Simon had been infected. At the time we thought some unfortunate person had given blood, and that it was a complete accident. GOSH never explained how it had happened and used the phrase 'look back programme'. It is only when you start to hear things on the outside, and put the jigsaw pieces together that you realise this should have never happened. It was not until we became involved with the Skipton Fund that we discovered blood came from America.
21. The letter came as a shock because Simon was so well at the time, and we did not realise the full implications of the virus. He was only 17 at the time. None of us knew how serious HCV was – if they had said there was a chance Simon could have been infected with HIV, we would have been much more worried. We thought that we would get to GOSH, and

they would confirm Simon did not have the virus because he was so well. There were no visible signs of what HCV was doing to his body.

22. An appointment for a test was arranged, and the results were positive. Simon was diagnosed with genotype F – a very rare type of HCV. Dr Vas Novelli told us the news as a family face to face. All of the staff at GOSH was sympathetic and compassionate.
23. We saw Dr Vas Novelli at GOSH and he stressed not to worry too much about the diagnosis, because other people could be walking about not knowing they were infected. He went on to say that Simon would probably not have any symptoms until the age of thirty.
24. It was decided that nothing would be done straightaway but Simon's condition would be monitored.
25. They did not discuss any implications of the virus with Simon and that is typical of children's hospitals – they continue to treat teenagers as children and everything is dealt with via the parents.
26. Simon was such a happy-go-lucky person, so the diagnosis was not something he would dwell on. Initially it did not bother him and he never knew life without hospitals

Section 3. Other Infections

27. Simon did not contract any other infections as a result of being given a blood transfusion.
28. The risk of vCJD was never mentioned.
29. David had a discussion with Dr Kingsley about VCJD, after it had been found in the brain tissue of a haemophiliac. Dr Kingsley assured David

that it had not been found in our area, but I recall he came home and said 'I might have mad cow disease as well'. We came to the decision that there was no point in worrying about it, because there was no way of finding out for certain.

Section 4. Consent

30. Simon may have been tested for HIV as he had his blood taken every time he went into hospital for an appointment – but I presume consent would have been given.
31. As a family we built up a trust with GOSH because we were there so often in Simon's early years, and you would hope the hospital had no ulterior motive.
32. At one stage Simon was put on the same medication used to treat AIDS patients, as the hospital were trialling its use on rare strains of HCV. Again as far as I am aware Simon would have consented to this – they were desperately trying every combination of drugs they could find in hope of attacking the virus.

Section 5. Impact

33. Simon received a combination of Interferon and Ribavirin to clear the HCV. He was initially placed on a three-month trial of the treatment and was self injecting the interferon, but the side effects were so bad. Two or three course of medication was taken in the end, but they were unable to attack the virus – as it was such a rare strain.
34. Simon's liver was already vulnerable as it had fought the leukaemia, and his spleen was removed prior to the bone marrow transplant.
35. At the age of 19 Simon met Keli over the Internet – this was very much before the start of Internet dating. Within 6 months she moved over from

California with her daughter Jasmine, and they married in the October. They initially lived with us but were fortunate in receiving a council flat, which they later bought. Simon later adopted Jasmine.

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37. During this time Simon was regularly going back to GOSH for check ups and was receiving the same drugs treatment for AIDS patients. He suffered with very bad side effects. He felt worse on the treatment than he did with the illness, and it made his life unbearable on a daily basis. Our first thoughts were how he was coping. Simon had such a rare genotype of HCV, so none of the treatment helped. After 10 years married to Keli, Simon got very ill and the hospital did not know exactly what was wrong. It had been over looked that he had also had an overactive thyroid, which meant that he lost so much weight. He was given radiation treatment for his thyroid.
38. There was a period when Simon went yellow and suffered with jaundice.
39. At one point Simon mixed up his tablets by accident and would be tired all of the time – he had in fact got one of the drugs mixed up with a sleeping tablet and it was some time before the doctors realised. Although Dave and I were closely involved with Simon, we were not living with him at the time and could not supervise the drugs.
40. In his mid twenties, Simon moved on to University College Hospital (UCH). If he had not contracted HCV he would have probably continued to be under the care of the follow up clinic at GOSH, but the transfer was necessary, as he could no longer be treated there.
41. Dave and I ended up looking after Jasmine regularly so that Simon and Keli could have some time together. She was almost like our fourth child.

We supported Simon and his family more than you would for a family that did not face health problems.

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43. At this point, Keli said that she could not cope with Simon's illness any longer and the marriage broke down. They were together 10 years but Simon became very ill and no one really knew what was wrong. Everyone was devastated, but we have remained very close with Keli and Jasmine. Keli still lives in the cottage they bought after their flat, and she is best friends with our daughter Kate.
44. After the divorce was finalised, Simon lived life to the full – he did lots of travelling and did very well at his work. Although he did not leave school with good grades, a friend offered him a job working with computers and this led him into other opportunities. He never had an issue finding any work.
45. Simon kept changing up his diet for his wellbeing – he became vegetarian, and then followed another plan. When he came to live back with us after the divorce I would juice things for him everyday. He would try anything for chance that it would help.
46. Despite keeping himself busy, Simon did not want to be on his own and wanted to move on. Shortly after he met Marie over the Internet, and they became close very quickly. She is French but worked and lived in England.
47. Soon after David and I realised Simon and Marie would need somewhere to live, so we extended our mortgage to help them out. They lived close by for a year.

48. Eventually the HCV started to cause Simon problems and he lost a bit of faith in University College Hospital.
49. Simon started to deteriorate in his late twenties and it was a cloud hanging over him and Marie – they did not know what the future would bring and how long they would have together. One day he would be in a bad way and the next day he would be fine. Simon did start to worry about his health and wonder if he would get better.
50. While on holiday to visit Marie's parents in France, Simon took ill. He ended up being very impressed with the care at Montpellier Hospital and as a couple they made the decision to relocate to France. As Simon was an entrepreneur in web design and support, and Marie was a translator and interpreter, they could both work remotely and keep their clients. In 2010 they moved to Pezenas and had the support of Marie's parents.
51. As Simon worked and paid tax in France, he came under the French healthcare and continued to be treated at Montpellier Hospital. He was placed on the French liver transplant list.
52. Simon did have a liver biopsy because I recall it being very painful for him and he struggled for a while afterwards. He probably ended up having a couple of biopsies before the transplant.
53. On the 18 December 2010 we had a family get together to celebrate my parents diamond-wedding anniversary. We received a call from Simon at the party, to say that a liver had become available and they wanted him in straight away.
54. There was really bad snow at the time, and my husband and I could not get any flight over to France. We decided to go by car via the Eurotunnel, but as it was just before Christmas the port was flooded with people. We

did get priority to get over to France, but it was awful travelling down to the South. Our daughter Kate came with us.

55. Simon had the liver transplant by the time we arrived, and the hospital was pleased with the procedure. We took some French macaroons in for him, and he seemed fine. After spending some time in France, we thought Simon was on the up so I returned home.
56. Soon after everything went pear shaped, and the virus started to attack his new liver. Dave stayed with Simon as he was retired, but I worked for the local government at the time so had to fly over to France every 10 days. My work was very understanding during this time.
57. Simon was kept in hospital for 7 months and could not communicate well with the staff as his French was not very good – Marie did not have the patience to teach him because she was so particular. A tracheotomy was done at one point, so he could not even speak with us.
58. Marie's parents were amazing – they lived a 45-minute drive from the hospital but went down every day with Dave to visit Simon.
59. Eventually Simon ended up with drug-induced diabetes and he went downhill. He was put on the top of the list for a second liver transplant, and the procedure was carried out on Good Friday 2011. Dave was still over in France, so I flew over with Kate prior to the operation.
60. After the second transplant, the HCV attacked the liver even worse and his organs started to shut down. There was nothing the hospital could do. On 28 June 2011, surrounded by all of the family (even his brother James flew out) Simon passed away. I exhibit a copy of his death certificate **(EXHIBIT WITN095003)**.
61. The hospital in France was so lovely towards us and they were so upset over what had happened to Simon.

62. Kate was quite insistent that she wanted to bring Simon home, and as a family we wanted to bury him in England. My parents were still alive at the time, and insisted that whatever it cost to bring Simon home they would cover it – so this took away some of the financial worry. The repatriation process was a total palaver because of the HCV – they would only bring him back in a zinc-lined coffin and on a special flight because of contamination. It was so expensive.
63. The funeral directors back at home were not helpful at all – they had no compassion and kept everything formal and business like. I find it very hard to think back at how they treated us. They were very hot on formalities and did not try and cushion anything despite it being a hard time – it was not nice at all. I thought to myself I would never use them again, and we went to different directors when my father died.
64. The plan had been for Simon and Marie to get married. She even bought her wedding dress, and they contemplated getting married in the hospital but there was no time. Simon thought the liver transplant would be a new lease of time for him and his life would start all over, but unfortunately the HCV took hold.
65. Marie wanted children but Simon was unable to have children because of all of the radiation he received to treat the leukaemia. They were thinking of other ways of having a family before he died.
66. Simon would probably say that the best years of his life were those with Marie, but she never knew him in good health. As a couple they did make the most of it.
67. The last 10 years of his life became a rollercoaster and he could not plan ahead, but Simon never let that rule what he did in life and remained positive. He only felt down after hospital appointments.

68. Simon had a real lasting legacy on the people that were in his life. When he was with Keli, he completely financed her university degree and she now has a wonderful job. This would have never happened without his support. I still often have a coffee with Keli as she still lives in the cottage they purchased together, and she will always remind me of something humorous Simon did. He was so funny, and we always end up laughing, albeit with a few tears. I really appreciate the fact that we still have a friendship.
69. There is some good news out of all of this. Simon's best friend Mikey kept his business going whilst he was in hospital. He would fly out to France regularly to visit and would do anything for Simon. Mikey and Marie are now married and they ended up having two sons – one of which is named after Simon. The children know us very well and we see them from time to time. With Mikey being Simon's best friend, Marie can talk about Simon freely and on the anniversary of his death this year she sent us a lovely text message.
70. Just before Simon went self-employed he was offered the ultimate role working in Canary Wharf for a bank, on an incredible salary. He went in for the first few days but then developed some anxiety – this was so unlike him. He ended up having a panic attack at the train station and then decided to hand in his notice. The bank understood, but he had no option but to leave. This is the only time we have known him to suffer with anxiety, but it would have been whilst he was having treatment.
71. Simon made the decision to work for himself and he was very dedicated to the business – he was not the type to leave things if he did not feel very well. He consistently had the desire and drive to provide for his family, despite what was going on in his life. Simon loved what he did for work.
72. He ended up providing IT support to a company in Sweden, who paid him £4000 a month. Mikey continued to work for them whilst Simon was in hospital, but they wanted Simon specifically because of his experience

and expertise. The number of clients on the books therefore dropped. If Simon had survived and did not have the HCV he would have earned very well. The loss of earnings had a ripple effect on Marie and Jasmine.

73. People do not realise how the contaminated blood scandal continues to affect families – it has a real psychological impact and a ripple effect. As a couple we have found a faith through all of this, and now feel very cared for. Our **GRO-C** family have been so supportive and amazing.

74. **GRO-C** we do still ask why this has happened, as we would still have Simon with us if it were not for the HCV – he had been fully cured from leukaemia. All the issues stem from the HCV and you cannot help but think *what if*. My husband and I always find it difficult when people ask how many children we have.

75. I donated blood up until Simon was diagnosed with HCV, but stopped afterwards.

76. What happened to Simon has had a real psychological affect on Kate, and her marriage broke up soon after he died. As she saved him from the leukaemia in the first place, she felt as though it was her responsibility to keep Simon alive. Kate even offered part of her liver to the doctor for Simon. Kate gave him 25 years of extra life, and it is a total tragedy that he was completely cured from leukaemia but then died through this. Kate's issues are rooted in what happened to her brother, and it has had a devastating affect on her life.

77. She totally distanced her self at one point, and I would think to myself – we've already lost one child, and now we're losing another. She needed space at the time, and we respected that but it was hard.

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79. If you are to speak with Kate she puts on a front – she is beautiful and so uplifting to everyone, but behind closed doors you do not know what is going on in her mind. She remains very close to Simon's ex-wife Keli and I think it is because of what has gone on. In hindsight we should have been more aware of how all of this would affect Kate.
80. We are all very close as a family, but this has affected our son James differently and his priority is his own family now. James is the life and sole of wherever is he and he always brightens up the room whenever he comes in. We are very blessed to have him as a son, and he is very caring.
81. Simon's adoptive daughter Jasmine is like Simon in so many ways. She was only 3 when she moved over from America, but even Keli comments that Jasmine is more like Simon than her. They even love the same music. She was only 17 when he died. Jasmine is very comfortable in her own skin and she is a very confident young woman, and there is no real negative impact on her. She is now studying in California, but Simon would have contributed towards her university fees and later her wedding. It is now all down to Keli to support Jasmine, and Simon would have certainly chipped in financially.
82. I do not think people really understood what HCV was at the time Simon was diagnosed and I cannot recall any stigma. We are not the type of family to keep secrets from people. Simon would have been at college at the time, but I do not think they were aware – it was not until years later that we realised the extent of the virus.
83. There was certainly a fear and stigma surrounding AIDS and it was worrying that this was another disease that could be transmitted via blood.

84. Simon and Keli ended up purchasing a cottage in Hemel after their flat, but he had real difficulty getting a mortgage. Due to his illnesses Simon could not borrow from any of the high street lenders. In the divorce proceedings Simon handed the house over to Keli, so she is well provisioned.
85. The only person who has not gained financially is Jasmine, but she is Keli's only child and she continues to provide for her.
86. Simon could not take out a life insurance policy, which had a knock on affect when he died.
87. Simon was informed at the start to be careful with dentists and disclose the HCV infection. He was never refused dental treatment and to my knowledge never received any stigma from dentists.

Section 6. Treatment/Care/Support

88. To my knowledge, I do not think Simon was ever offered any counselling or psychological support.

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90. As parents we were never offered any counselling or psychological support.
91. My husband and I have no complaint with the care received at GOSH. In regard to the leukaemia they saved his life, and he was one of the first to trial a bone marrow transplant for myeloid leukaemia. We even raised

money for the hospital because we were so grateful of what they had done.

92. Simon was only let down by the blood transfusion, and it astounds me that contaminated blood could be used in a children's hospital. If only they had asked us at the time whether we could give Simon some blood we would have done – the whole family would have. There should have been a call out that they required blood for children. I do not understand why they had resort to using blood purchased from America – it just seems so unnecessary.
93. There would be more of a complaint towards the NHS – Simon ended up receiving care in France and went on the French Transplant List. He felt lost in the system once he moved to University College Hospital – he became a number in a cattle market. It was demoralising and such a contrast to GOSH where you build a relationship with the doctors.
94. You put your total trust in hospitals to make the right decisions, but I have often wondered how they calculate priority on the liver transplant list. We are very grateful for the NHS, but it has its frustrations whilst Simon was waiting for a liver.

Section 7. Financial Assistance

95. Simon did receive £25,000 from the Skipton Fund when he was still alive.
96. The increase in EIBSS payments has not taken into consideration those that have died. People who die in other tragedies receive a financial settlement that takes their loss of earnings into account. As parents we do not need any financial compensation, but we would like to see Simon's adopted daughter Jasmine comfortable.

97. We recently got in touch with the EIBSS because we wanted the documents of evidence Simon submitted. So far they are refusing to release them because Simon did not have a will and we have no grant of probate. The government should force the scheme to release information to families, for the common good of humanity.
98. There was a barrier between the Skipton Fund and the EIBSS. These bodies should be contacting us, instead of the onus being on the individual.

Section 8. Other Issues

99. About 2 years ago our friends informed us that Theresa May was setting up an Inquiry on the contaminated blood scandal, and alerted us to news coverage. We have a good friend who is a lawyer in London – he often sends us updates on the Inquiry and he is very interested from a legal point of view.
100. If I had not heard about the Inquiry and registered myself, none of this witness statement process would have happened. No information is passed on from other bodies – it is as if they do not want people to contact.
101. If there has been a cover up by the government, I want every person affected to be counted and named as they all have their own individual stories. It is important to have a true figure of those infected, to realise the extent of the problem caused. You could never have a service to commemorate all of the people infected, because there is not a fully known number. I want Simon's name to be recorded in a list of names.
102. The Inquiry should take into account the ripple effect and the on going loss for families that the contaminated blood scandal has created. When you just look at the facts, you miss the emotions and trauma that goes in

between. This has been a complete emotional roller coaster for us as a family.

103. I want to know why blood was bought from other countries – it is ridiculous and the public are not aware of what goes on behind the scenes. Through the Inquiry all of the floodgates should open and information should flow.

104. We finally need some closure on the contaminated blood scandal. Every couple of years it is brought back up by a third party but fails to provide any justice. The scandal needs to be brought to an end and a final apology issued.

Statement of Truth

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

Signed

GRO-C

Dated

15th October 2019

Exhibits:

Exhibit Number:	Description	Date:
WITN095002	Letter from Professor Chessells to Mr and Mrs Bowles stating that Simon received a unit of blood from a donor who in retrospect has HCV and that Simon may have been affected as a result.	24/05/1995
WITN095003	Copy of Simon's Death Certificate	28/06/2011

