

Witness Name: JEAN HILL
Statement No: WITN1285001
Exhibits: 0
Dated: FEBRUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JEAN HILL

I, Jean Hill, will say as follows:-

Section 1. Introduction

1. My name is Jean Hill. I was born on [GRO-C] 1954 and I live at [GRO-C] [GRO-C] Devon [GRO-C]
2. My husband, Ronald Hill (born on [GRO-C] 1956), was infected with the Hepatitis C Virus (HCV) from contaminated blood products. He died from Hepatic failure (Liver failure) & Sepsis, Hepatic Artery Thrombosis, Liver Re-graft for Hepatitis C Recurrent, on 1st September 2004 aged 48.
3. My daughters, Hayley and Stacey, have given their own Statements to the Inquiry (Witness Numbers WITN1715001 and WITN2923001 respectively)
4. This witness statement has been prepared without the benefit of access to Ron's medical records.

Section 2. How Affected

5. Ron had mild haemophilia A. He was diagnosed when he was 4 or 5 years old. He fell over and cut his head and mouth and had a profuse bleed. Ron had three sisters and one brother. Ron's brother, Jimmy, 10 years younger than Ron, was diagnosed with haemophilia from birth.
6. Ron was under the care of the Birmingham Haemophilia Centre, at Birmingham Children's Hospital initially and then at the Queen Elizabeth Hospital. Ron rarely needed Factor VIII (FVIII) treatment and never at home. Ron was only really treated with FVIII at dental appointments, to include dental check ups. From 1993 when we moved as a family to Devon, Ron was under the care of the Torquay/Torbay Haemophilia Centre.
7. I do not believe that any information or advice was provided to Ron beforehand about the risk of being exposed to infection from blood products. I do not believe that Ron's parents were given advice about the risk to Ron and Jimmy of being exposed to infection from blood products.
8. I believe Ron was tested HCV positive in 1990. He was not informed at that time and he knew nothing of the diagnosis until September 1995. Ron received a letter from the Torbay Hospital around that time inviting him in to meet Dr Boothe, the new Head of Haematology. We usually went to Ron's hospital appointments together. I remember that I offered to go with Ron and Ron told me that there was no need as it would be just to say 'Hi'. I would have had to arrange for my parents to collect the children from school if I had gone, so I left him to go alone.
9. When Ron came home I knew immediately that something was very wrong and asked him 'What's the matter?'. He was grey and drawn and looked tortured. He said 'I have Hep C and they are transferring me back to Birmingham'. Ron

had met Dr Boothe and Dr Boothe had said 'How are you coping with your Hep C?' Ron was horrified he didn't know he had it. Dr Boothe told him he had been diagnosed with HCV in 1990. Ron recoiled when I approached him. He said 'Don't come near me and don't let the children near me'. I did not know what HCV was. Ron described it as 'HIV, just slower'. Jimmy had died in 1991, aged 25, of full blown AIDS. Ron had been left devastated.

10. Ron and I were not offered any help or support. We did not know how to live with the infection or how I should protect myself and/or the children. I remember that we approached our local Citizens Advice Bureau for advice and they could not help except to talk to us about welfare benefits. We had to wait for Ron's appointment with Dr David Mutimer (liver consultant at the Queen Elizabeth Hospital) which was scheduled to take place in December 1995 just after Christmas.

Section 3. Other Infections.

11. I believe it highly likely that Ron was infected with other viruses. I remember one of the doctors commenting to Ron that he probably had every letter of the hepatitis alphabet categorised ie A, B, C, D, E and G.

Section 4. Consent.

12. Ron was undoubtedly tested by the QEH, Birmingham without his knowledge and consent. The QEH identified Ron as HCV positive in 1990. I recall a doctor in Birmingham telling Ron that it would 'not have benefitted' him to know about his HCV status (in 1990). The statement is incredible to me as there were so many things we would have changed if we had known. We had a bigger support network in Birmingham in Ron's family and our friends. We would not have moved to Devon had we known, Ron could have had treatment and been

properly monitored for signs of liver disease. I would have been aware of the risk of cross infection.

Section 5. Impact

13. I met Ron in 1981 and we married the following year in 1982. Before Ron became ill, we were a happy family unit. Ron was a wonderful father to my son Ryan and our daughters Hayley (born in 1983) and Stacey (born in 1988). Ron was a lorry driver when I met him but found his vocation in Sales and Management. He had a high profile/lucrative job running a big construction depot for a company with a £2m annual turnover and he had a lot of staff under him to manage. He had a company car and we would travel to Europe.
14. Ron was left devastated when his younger brother, Jimmy, contracted HIV/AIDS in his early twenties. Ron refused to believe Jimmy had HIV and thought Jimmy had somehow been misled into thinking he had it through the influence of the television AIDS campaign. Ron said he would not believe it until he heard it himself and went with Jimmy to the hospital. He returned from the appointment in shock, having been present when the diagnosis was confirmed to Jimmy and also learning that Jimmy probably only had two years to live. Ron later went to his own GP, Dr Skingle, and asked for an HIV test for himself and was told he did not have the virus. I have the letter from Dr Skingle confirming Ron's blood sample is clear of the virus. He was told to stop worrying. It bears the date of 21st August 1987.
15. When Jimmy was dying he was just skin and bone. Ron took time off, carried him to his car like a baby (he was too weak to walk) and drove him around Birmingham just to get him out of the hospice. It broke Ron's heart that Jimmy, his baby brother, had such an awful disease, but he did not. Jimmy died in a hospice on 18th September 1991. No-one was allowed to see his dead body, not even his mother and father. He was zipped up in a body bag and taken away.

16. After that, Ron changed. He felt vulnerable and had mood swings. He was angry and depressed and could not concentrate. Ron came home from work one day towards the end of the following year (1992) and said 'I cannot do this anymore', he could not cope with living in the same way and devoting all his time to work. He wanted to go somewhere we could be a family and the children would grow up safe. We moved in January 1993 and rented a house in Torquay. We used the money from the sale of our home to start up a shop in Fleetwalk printing and selling T shirts and mugs. My parents retired and moved to Devon to be near us.

17. We did well at first and then Ron began complaining he was tired and nauseous and started to spend less time with me at the shop. He was always falling asleep and was backwards and forwards to the doctor about pains in his side and stomach. He had cameras up and down him at Torbay Hospital and was treated with FVIII ahead of the procedures (for the first time since moving to Devon). I took a shop in Plainmoor selling children's clothes as I could not print T shirts without help from Ron. Money was tight and Ron signed on to receive benefits for a while.

18. When Ron was referred to Dr Mutimer at the QEH (having been told he was HCV positive) we learned that Ron had liver failure and needed a liver transplant to survive. Ron was placed on the transplant list and we were then sent home to wait. It was a very stressful time for us with what turned out to be months of waiting to see whether Ron would get a new liver. Ron spent nights crying. He did not want to die. He wanted to see his children grow up.

19. I remember with absolute clarity the Saturday afternoon in June 1996 when Ron took the call from the hospital that they had a live for him. It was the day before Fathers' Day. Ron was told to leave for Birmingham straight away. He couldn't believe it. He collapsed on to the garden patio and he and my mother cried. I

ran up and down the road in bare feet looking for the girls. We lived out in the countryside. Stacey was two doors up from us at a friend's house and Hayley was out horse riding. Our neighbours helped me look for her.

20. Ron was placed in an induced coma after his transplant. The doctors said he could not see or feel anything but he might be able to hear. I held his hand tightly in mine and could feel each of his fingers move in turn over and over again. He also moved his eyebrows every time I spoke and I told the nurse that Ron was not asleep. The nurse only believed me when he moved his eyebrows for her too.

21. Months later, I mentioned the moving of each of his fingers to Ron and he remembered it. He said he was in heaven and the meaning of life was simple but he could not later recall what it was. He was with Jimmy and Jimmy wanted him to stay. He wanted to come back to us and was using his fingers to focus on keeping us all together. Each finger represented each one of us 'Ron, Jean, Ryan, Hayley, Stacey' repeated like a mantra until Jimmy told him to come back to us.

22. Ron was in a coma for over a week and in intensive care for around a month. The girls were back with my parents in Devon. I spent as much time as I could by Ron's side. I bathed him, shaved him, massaged his feet, and wet his lips with water. I did everything. One of the doctors told me to go home and get some rest. A nurse went to hug me but I stopped her because I would have broken down, I needed to stay strong for Ron and was just about holding myself together.

23. When I got Ron home we had to go back to clinic every other day for the first week. I took Ron by train to Birmingham New Street with the assistance of a wheelchair and family support at each end to transport us to and from the station. I had to do it in one day to get back for the children. I relied on my parents for so

much support at that time and then the frequency of the appointments began to lessen.

24. For two years Ron was better than he had been (although still a little yellowish in colour). He embraced life and saw it as a second chance. He had a new lease of life and wanted to help people less well than himself. If you asked him how he was, he would respond with a cheerful "Never better". He would look at me first thing in the morning in a dressing gown, with ruffled hair and tell me I was 'looking beautiful'. We took the children to the beach and made the most of each day. Ron was on a lot of medication including anti-rejection drugs and steroids. He suffered with ascites (he looked heavily pregnant) and swelling in his legs. He went to Torbay Hospital two or three times to drain his abdomen. Nineteen pints of fluid were removed on one occasion.

25. Ron still had HCV. He had no immunity because of the anti-rejection drugs. He had a biopsy a year after his first liver transplant, which showed signs of cirrhosis and all the previous symptoms returned. Torbay struggled to provide Ron with the right care, given his haemophilia and post transplant status. Ron was blue lighted up to Birmingham Hospital again. Dr Edwards (a consultant at Torbay Hospital) said she did not think he would make it through the weekend on that occasion but he did. It was just ongoing all the time. Ron was so ill and went back on the transplant list. I was glad Ron was on the list again because I thought he would get a new liver and he would be okay. We would be ok.

26. At the start of 2002, the doctors told Ron to make the most of the coming year as he was so ill. Ryan was at University but we took the girls with us to New York State to visit friends. We had had a secure life before HCV but had not had a family holiday in years. Ron had stopped work completely before his transplant in 1996. He tried to make the most of the trip and never complained but it was all too much for him. On the aeroplane, Ron's legs swelled to the size of tree trunks.

27. Dr Simon Bramhall (who became notorious for branding livers of patients with his initials) performed Ron's second liver transplant in November 2003. Ron was wheeled to the theatre and he hugged and kissed us goodbye. We all said 'I love you'. I held his hand until he went to sleep in the pre-op room. To walk away and leave him there, not knowing if I would ever see him again, was so traumatic, heart-breaking. The doctors brought him into intensive care but I could not see him until much later in the day when I did I was pre-warned that I might be shocked. When I went in to him, Ron was all wired up to machines and in an induced coma with machines breathing for him.
28. In surgery they thought they would lose him. He had thirty units of blood during the transplant. Dr Bramhall told me that Ron 'had made him work for his money'. He said it had been like a blood bath with so much scar tissue to cut through that Ron was swimming in blood.
29. Ron was extremely agitated when he started coming round. People were using the antiseptic sanitiser and rubbing it into their hands when entering the ward. Ron thought they were praying over him. He was clearly having some very disturbing and frightening hallucinations. He thought the girls were in danger (of being raped) and was signalling at them to flee. Ron's sisters visited him and he would hold on to them lovingly whereas he thought I was the enemy and would flinch and turn away from me. He was having great difficulty breathing and had to be put back on a ventilator. Then it was decided to give him a Tracheostomy, which would not stop bleeding. His whole pillow was soaked in blood. He was in a terrible state.
30. The doctors allowed Ron to come home that Christmas and discharged him on Christmas Eve. I kept thinking why would they sending him home when he is so ill. He was skin and bone. In hindsight I believe they did so knowing it would be his last Christmas with his family. We had not done any Christmas shopping but

we did not care. They wheeled him down in a chair and put him in the car. He could not sit up straight, due to the wound from his operation, it was too painful. It was called a Mercedes cut and went from his chest down, then across his abdomen. So we had to lay the seat back almost flat. We had to drive 180 odd miles home. When we got home I could not get him out of the car. All the neighbours came out and helped carry him in. They did banners and balloons for him. I will never forget it.

31. Ron was home for 3 or 4 days. One of our neighbour's was a doctor and he came over and gave Ron morphine but said that apart from that there was nothing more that he would be able to do over the Christmas period. The nurse that came to change Ron's tracheostomy dressing and was horrified by the poor state of the wound. After 3 or 4 days Ron was blue lighted back to Birmingham. As I set out to follow the ambulance in my car, I took a phone call from a PC Williams to inform me that the Police were going to prosecute the girls who had been bullying Stacey at school. Up until then, I had no idea that Stacey was being bullied and that she had to endure such an ordeal whilst her father was so ill. If Ron had known, it would have broken him that that was happening to Stacey and he was not in a position to protect her. Hayley had tried to protect me and Ron from what was happening to Stacey by taking on a parental role, liaising with the school and trying to deal with the problem herself. It broke my heart and made me feel terrible and a useless mother not being there to protect my children.

32. Once re-admitted to the QEH, Ron had problem after problem. Every other week or so there was something for the medical team to try to deal with. He kept getting blood clots on his liver. They tried to insert a stent and had a camera down into Ron's stomach. He was extremely poorly and I felt torn and conflicted. I was unable to prioritise and/or successfully deal with any of the childrens' issues.

33. If it was not for my parents I do not know how I could have managed, as they were all I had by way of support for the children. My parents had booked a two week cruise for their 50th wedding anniversary in March 2004. I had to return home to look after the children. I assured Ron that his father and sisters would be in to watch over him. I was home for six days when I received a phone call from Ron saying 'If you do not come back, I am going to die' and I got in the car and just drove back. I was under so much stress.

34. Ron had no white cells and it was thought he might need a bone marrow transplant. The doctors did not think that he would live. Ron was a fighter and he did not want to die. The doctors thought it was a miracle that he hung on and lived as long as he did. In April Ron was allowed home again, but after a few days he quickly began to deteriorate, so much so that I had to call for an ambulance. At hospital he was placed on a trolley in the corridor. He was so thin, just skin and bone. The trolley he was lying on had a thin black mattress, which offered no comfort, and Ron was in a lot of pain with the pressure of his bones poking through his skin. The hospital had nowhere to put him, so he was blue lighted back to Birmingham again. Ron broke down and cried. He said he knew he would never be coming home again. I cannot put in to words the distress of that journey. Ron was in hospital for a full 10 months (except for the 4 days at home at Christmas and a few days in April). Ron had another operation on his liver and within 12 hours they operated again because he was bleeding. They doctors were apparently scooping the blood clots out with their hands and dropping them into buckets, they was so much.

35. The doctor in Intensive Care put Ron on a ventilator and said to me 'Mrs Hill we are putting him on a ventilator and it is very unlikely he will come off'. Ron had sepsis, septicaemia and his organs were shutting down. Ron had made me promise that he would not die in Intensive Care. I begged the male nurse with me not to let Ron die there. I was distraught. The Sister came in and took me outside and said she would phone the family for me. She phoned the children

and Ron's father and sisters. It was in the early hours of the morning. Ryan was in Cornwall. Hayley drove through the night from Devon with Stacey.

36. The next day after a final scan, Dr Hayden took me into a room and said "I am really sorry there is nothing more we can do". I begged him not to give up on Ron and asked for another liver. Before Ron was sedated, he said he loved me and I said I love you too. As he did so he stretched his arms out to me. Those were the last words he ever said to me. We were all there and there was nothing we could do but watch him die when they took him off the ventilator. Even then I could tell that Ron was fighting to breathe on his own and struggling to live. It seemed like forever watching him slowly die. It was heart breaking and I could not bear the children seeing Ron struggle. I leaned over and kissed his forehead and eyelids to shield his face from them.

37. Ron's death broke me. He told me so many times 'I don't want to die'. He wanted to walk the girls down the aisle on their wedding day and see his grandchildren. After his death I was gripped by anxiety and depression (and I continue to suffer with anxiety). I could not function and did not want to leave the house, for something like four years. I suffered with panic attacks and had them whilst out shopping. I would have to put my shopping basket down, mid-shop and leave. Even now, I struggle to leave the house without one of my children with me. I sought counselling at one time but my counsellor attributed my feelings to grief. It is more than that. I feel traumatised like I have a continuing stress disorder. The constant state of worry and distress I lived with whilst Ron was ill has never left me.

38. My life would have been completely different if Ron had not been infected with HCV. I am not half the person I used to be. I used to be able to drive on the motorway, following the blue light of an ambulance from Devon to Birmingham. I now barely use my car. I am not really up to having the grandchildren all at once and/or for extended periods of time. Ron would have made a wonderful

grandfather and I would have been able to spend more time with them if Ron was still with me.

39. Stacey did not have her parents support at a crucial time for her at school. Instead, she was bullied and failed her GCSE exams. Hayley had to grow up fast in trying to take responsibility for her sister at that time. After Ron's death, Hayley was the only person in the household bringing in an income and she tried to shoulder the responsibility of meeting the household outgoings at a young age. It was a responsibility she should not have felt belonged to her.

40. I waited until Ron had died before asking to be tested for HCV. I would not have wanted Ron to be burdened with the guilt of knowing that he had been the source of infection had I been tested positive. I have a Nephew who has HCV. He has also been exposed to vCJD. My heart breaks for his family because I know what they are going through.

41. Ron and I had to manage without any money coming in for so long whilst he was ill. We were unable to provide the girls with anything except the bare essentials.

42. After Ron's death, I had to sell the house because I could not afford the mortgage repayments. It was awful to lose Ron and then for us to be displaced from our family home in a neighbourhood we loved. The girls were upset because they lost the family home, a place to talk to their father and feel his presence. Stacey and I survived on the Skipton Fund lump sum for five years after Ron's death. I then battled with my anxiety to find a job. I got a job at the local holiday camp and then I started working at the Co-Op just down the road until my father became ill and I had to care for my parents. I have no pension and am left with next to nothing.

Section 6. Treatment/Care/Support

43. Ron was not offered any counselling or support.

Section 7. Financial Assistance

44. In the months before Ron died, he made a Stage 1 payment claim to the Skipton Fund. I remember Ron panicking about a specific deadline date for making the claim. He wanted to be sure that he had signed the form and that I sent it off in time. He was worried about his family whilst so very ill. We had loans to repay and bill payments to make to the hospital for my accommodation there and other expenses during the ten months Ron was in hospital. I kept the details and the extent of the monies I owed to the hospital from Ron. I did not want him to worry. He was anxious about signing the form before the deadline so that I was 'looked after' by him. It felt like a kick in the teeth when the payment of £20,000 arrived six weeks after Ron had died. I used £4,000 for the funeral and the rest of the £20,000 paid our debts.

45. I then received a Stage 2 payment of £25,000 from the Skipton Fund. I lived off that money and used it to support Stacey for something like four to five years after Ron died. It was my main source of income and I had to make it last because I could not function in the outside world.

46. From 2011 I received a monthly payment from the Skipton Fund of just £30 per week. There was very little equity in the property and I was unable to keep up with the monthly mortgage repayments. I had no alternative but to sell our family home. It was traumatic to have to leave the home I had shared with Ron. I tried to tell myself it was just bricks and mortar but the children were deeply affected too. We all were. It had been my dream home for years.

47. We moved in 2010 to a house with the help of my parents. Without the help of my parents we would not have had a roof over our heads. In 2011, I received a grant of £25,000 from the Skipton Fund which I used to help with household bills and work on the house. My application for a new boiler was turned down and my roof needs fixing. In applying to the Skipton Fund you have to provide evidence that you were living together as a couple at the time of death. That is not easy to do after a move. Fortunately for me, Dr Mutimer was on the Skipton panel so I referred them back to him and they appeared to be satisfied. The Skipton Trust asked me to send them Ron's death certificate five times.

48. In September 2018, I received a significant increase from the former discretionary payment paid by the Skipton Fund. The payments are now inline with what the MacFarlane widows had received over many years. I had to apply, I feel like I have struggled for so long, fighting, swimming up river for something I should have received from the beginning. If I had had the payments 15 years ago, I would have been able to keep my home and I would still have the jewellery that Ron had bought me, which I had to sell. I now worry that the payments will be reduced and/or withdrawn. There is no certainty for me. I just want some security in my life.

Section 8. Other Issues

49. There are no other issues.

Anonymity, disclosure and redaction

50. I confirm that I do not wish to apply for anonymity and that I understand this Statement will be published and disclosed as part of the Inquiry. I am willing to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..... GRO-C

Dated..... 21/2/2019