

Witness Name: Penelope Rae

Statement No.: WITN1962001

Exhibits: WITN1962002-

WITN1962020

Dated: 19 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PENELOPE RAE

Section 1. Introduction

1. My name is Penelope Rae. My date of birth and address are known to the Inquiry.
2. I work for Hampshire Behaviour Support Service as an advisory teacher. I have worked there for about 20 years.
3. I have one daughter, Bronwyn (Bronnie) Rae-Le Bourn. She is an adult and no longer lives with me. She is also providing a written statement for the Inquiry.

Section 2. How Affected

4. I am writing this statement in memory of my late husband, Paul David Le Bourn. My husband was infected with Hepatitis C (HCV) by a blood transfusion in 1982 after a motorcycle accident. He died in June 2013.

5. Paul had a motorcycle accident on 31 August 1981. **(WITN1962002)**. During the accident he sustained a severe compound fracture in his right leg. He was taken to Southampton General Hospital (SGH) and remained there in a coma for a period of weeks, and then attended as an outpatient for about 18 months while the doctors tried to repair his leg. On 22 January 1982 he received a transfusion of six units of blood. **(WITN1962003)**. Ultimately his leg was too damaged and it was amputated on 25 January 1983. **(WITN1962004)**.
6. Paul had no memory of ever being told of the risks of being infected with HCV during his stay in hospital. I understand that the doctors were focused on his leg and the rehabilitation process after the amputation.
7. I met Paul in 1985. At the time he was not aware of being infected. He was fit, healthy and handsome. He did lots of swimming, walking, camping and worked full time.
8. Paul smoked for many years, and eventually developed lung problems including emphysema and chronic obstructive pulmonary disease (COPD). In October 1997 he was scheduled to have an initial and follow-up assessment at Papworth Hospital (Papworth) to see if he should have a lung transplant. I understand that during the initial assessment it was discovered that he had HCV. However, we were not told of this and did not hear from the hospital for a while regarding scheduling the follow-up assessment.
9. I chased the hospital by phone in early 1999 to see about the follow-up assessment. When I spoke to them, they asked if Paul had had "the treatment". I did not know what treatment he was referring to. I asked what he meant and he confirmed that he had Hepatitis C (HCV) and they had sent a letter to his GP in 1997 following the assessment informing him of this and asking him to let Paul know. They did not provide any information about how Paul had contracted HCV.

10. There is a letter in Paul's records from Papworth from 17 May 1999 noting that they are sorry to hear Paul was unaware of his HCV status and enclosing a copy of the letter they had sent to his GP confirming this on 4 November 1997. That letter to his GP reads "I would be grateful if you could bring this positive result to Paul's attention along with the necessary counselling". **(WITN1962005)**.

11. There is also a letter from Paul's GP to Royal South Hampshire Hospital (RSHH) on 2 November 1998 - one year after Papworth had notified Paul's GP of his HCV status, but before Paul found out himself. Paul's GP said as follows:

*A year ago I had a letter from Papworth that was copied to you saying Paul's virology screen had been positive for Hepatitis C antibody. They asked that I bring this to Paul's attention along with the necessary counselling. The reality has been that Paul has not returned to my surgery until now. He had a good deal to tell me and I was pleased to find him in a fairly positive frame of mind. I therefore did not have the heart to add to his worries when I had not seen him for so long. I am also uncertain as to what the current wisdom is for counselling patients about Hepatitis C. Can I therefore pass the buck? Paul is due to see you in early January. We clearly have to inform him of this finding and I will tackle it next time, if you feel unable to raise the matter in January. I am sorry to pass this on. I normally see him several times a year in which circumstances it would have been easier to raise. **(WITN1962006)**.*

12. There is then a letter from 9 November 1998 from the consultant at RSHH to the Virology department at SGH stating:

*I wonder if you can advise me about counselling and Hepatitis C. This patient has very severe emphysema and may be going for lung transplantation in the foreseeable future. We have been asked to counsel him about Hepatitis C, but he is an extremely anxious man and I do not want to raise yet more fears in his mind. **(WITN1962007)**.*

13. The same day, the RSHH consultant responded to the GP saying:

"I did not know that we had to counsel people about Hepatitis C and I am going to try and find out about this from the Microbiologists. I shall try to have some definite information about it by the time I see Mr Le Bourn in January. (WITN1962008).

14. On 7 December 1998, the Virology department at SGH responded to the RSHH hepatologist, noting that Paul had likely contracted HCV from his blood transfusion, suggesting that Paul be referred for more tests to confirm his HCV status and get an opinion on his suitability for treatment. Paul had still not been informed of his status at this time. **(WITN1962009).**
15. As soon as we found out about Paul's diagnosis from Papworth in 1999, we phoned the GP and enquired about it. He told us that he had received the letter from Papworth in 1997 but had not told Paul about his diagnosis because he didn't think Paul was emotionally ready to hear about it. He did not provide us with any further information at this time about what HCV was, how Paul had contracted it, or Paul's options for treatment. I felt that he knew he had screwed up and didn't want to discuss it.
16. Professor William Rosenberg, a Consultant Hepatologist at RSHH, was very helpful, straightforward and communicative. He discussed the possible causes of HCV and once he realised that Paul had had a blood transfusion in 1981, he told us that this was likely how he became infected with HCV.
17. On 5 February 1999 Paul's respiratory consultant confirmed that Paul had low grade HCV and referred him to a Hepatologist at SGH. His referral letter also states:

"I have not told Mr Le Bourn that his tests have also shown evidence of previous Hepatitis B. I did not want to question him closely on his sexual and possible IV drug habits, although I think you may have to do this. As far as I know he has never had a blood transfusion, but again I have not asked directly. (WITN1962010).

18. According to the records the Hepatologist then met with Paul, determined his only risk factor for HCV was the 1982 transfusion, and contacted the Wessex Blood Transfusion Service to obtain records for this transfusion. The letter did receive a response, but these records were never obtained. **(WITN1962011)**.
19. I understand that there was then some discussion among medical professionals at SGH and RSHH about the possibility of Paul having interferon and ribavirin treatment for his HCV. Paul had a liver biopsy and the benefits of the treatment were explained to him (40% chance of success), along with the risks of having treatment (deterioration in his lung disease). **(WITN1962012)**.
20. It was eventually decided that he would not have HCV treatment because Ribavirin would pose a risk to his lungs and Interferon would not be helpful alone. Instead he was to have another biopsy in 2 to 3 years. They did not tell us about any side effects of the treatment at this point, or any other information about Paul's prognosis or about HCV in general.
21. Neither the professionals at SGH or RSHH, nor Paul's GP informed us of the risks of Paul infecting others. When I asked if I was at risk of contracting HCV from him, they said it was unlikely that I would become infected but that there was a risk if Paul and I had sex during my period.
22. I know there were many other ways Paul could have infected me, Bronnie or others. His amputated leg would sometimes bleed, and he often did woodwork which sometimes caused injuries. Because of his low oxygen levels, Paul's skin was very itchy and he would scratch it, at night making himself bleed onto the bed linen.
23. Paul's GP was also our family GP for myself and Bronnie, so I think he should have thought of the risks of us contracting HCV and advised us

accordingly. For example, he knew that Paul and I were trying to have another baby at the time, and that perhaps I or the baby could be at risk of infection, but didn't mention this.

24. After doing my own research I learned not to share towels, cups, nail brushes or nail scissors with Paul if he was bleeding. I learned to be extra careful not to put myself at risk. This was onerous as Paul loved to be outside, always had cuts and scratches. I had to use rubber gloves and put whatever touched his blood into a bag.
25. I think that Paul should have been informed of his diagnosis as soon as the medical professionals found out about it. It was shocking to me that his GP was told about it in 1997 and did not tell him about it until 1999, even writing to the hospital to say he didn't tell Paul so as not to worry him.
26. We found out about Paul's diagnosis entirely by accident because Paul was being tested to see if he could have a lung transplant. If he had not needed the transplant we may never have found out about his infection as the GP did not tell us until we raised it to him. I find this unbelievable.
27. I also think that once it was known that some people were at risk of contracting HCV through blood transfusions these people should all have been contacted and tested.

Section 3: Other infections

28. As far as I know, Paul did not contract any other infections aside from HCV from the blood transfusion.
29. It is noted in Paul's medical records that he initially showed some signs of previously having Hepatitis B, but it was determined later that he did not have it and was in fact immune to it. **(WITN1962013)**.

Section 4: Consent

30. From 1999 to 2005, I do not believe that Paul was given enough information about the risks and benefits of HCV treatment in order for him to make an informed decision about whether he wanted to undergo treatment. He was simply told he should not have treatment because the HCV was not active yet and it would be harsh on his lungs. However, he was given treatment later when his lungs were in worse condition. I don't feel Paul understood all the factors in this decision and felt able to participate in the decision making.
31. In 2006, I do not believe that Paul was provided with adequate information about the potential side effects and consequences of the HCV treatment he received, which were debilitating and had a severe effect on his ability to understand daily life. He was therefore unable to give informed consent about whether to undergo the treatment.

Section 5: Impact

32. As a result of the HCV his general health deteriorated and he became very weak. Every small illness became a hospital stay. He could not fight anything – chest infections, flu, stomach upsets. It was explained that this was because the liver is the organ in the body that fights toxins, and his liver was compromised.
33. In terms of mental effects, his personality changed and he became illogical, with fuzzy thought patterns. He was always an interesting and intelligent man, and a bit feisty. But as he got more ill this feistiness turned to anger and volatility. A normal discussion would become an angry rant, and he became an exaggeration of himself.
34. He also noticed the change in his way of thinking. He would say that he could not think straight, or could not follow a thought through to the end.

He could not understand why he was getting so angry and was frustrated that he could not do anything about it.

35. The most serious complication resulting from the HCV was that he was unable to receive the lung transplant he needed.
36. When Paul was first assessed for a lung transplant in 1997 it was noted that his emphysema was not advanced enough to warrant one, although too advanced to allow Ribavirin treatment. However, by 2006 his respiratory symptoms had progressed to the extent that he had developed secondary polycythaemia and type II respiratory failure. **(WITN1962014).**
37. He was again referred for pre-transplant assessments but told he could not have a transplant until he had cleared the HCV. However, in the end he was never able to have the lung transplant because the HCV treatment was not successful and he was not able to clear the virus.
38. If he had been able to have the transplant he would have had a very different quality of life. Instead, his lung conditions continued to progress, requiring long term oxygen therapy during the day and a ventilator at night. He would get up every morning and if he did not have oxygen within two hours of waking, he would start to turn blue and get confused. We had to test his oxygen levels regularly with a finger tip device, and if his levels were too low we would put him on his ventilator (usually used at night) during the day. If he got tired of pulling his oxygen machine with him and tried to walk from one room to another without it, he would sometimes collapse or become so confused that he couldn't make his way back to the oxygen. At night, if his oxygen got too low, he would start to panic and require us to help him. He really required almost 24 hour care.

39. He was also unable to walk due to shortness of breath, requiring us to buy a mobility scooter in late 2000. **(WITN1962015)**. This bothered him as he had been very independent before, using a one-stirrup bicycle to cycle to the high street and often going out to walk the dog.
40. He had difficulty flying on planes as many airlines do not allow passengers to bring oxygen on board. British Airways made him pay to bring oxygen, and made us feel unwelcome when we asked about this. He would always make the metal detector go off and be viewed suspiciously. This stopped us from going on quick trips to France or Italy, which we used to love doing.
41. Prior to the possibility of having a lung transplant, Paul had to have all of his teeth removed. Unfortunately, he could not have a general anaesthetic because of his lung conditions, so had to endure being awake for the whole procedure.
42. The HCV treatment consisted of two courses of a combination therapy, interferon and ribavirin. Each treatment lasted 6 months and then we had to wait 6 months to know whether the HCV had cleared. He was undergoing treatment from around 2006 to 2008 and was initially thought to be clear of HCV following this but was found to be HCV positive again in January 2009. **(WITN1962016)**.
43. The side effects of the interferon and ribavirin treatment were largely psychological and emotional; he became increasingly angry and depressed, confused, had odd thought patterns, short term memory problems and fatigue.
44. We were never told about the extent of the side effects he would experience from the treatment except that he would be tired and need looking after. Because of this, he thought he was going mad and struggled very much with the side effects.

45. The mental side effects were so dominant that we did not have a chance to consider what the physical side effects were. However, when he went for liver tests it was confirmed that he was jaundiced and his liver was swollen.
46. When it was determined that both treatments had not been successful this was even more difficult for him. He was infuriated that he had had to withstand the treatments for so long and now could still not move forward with having his lungs sorted because the HCV was not cleared. After this point, he became more hopeless and angry that there was no more treatment that could help, and also more and more confused and difficult due to the worsening symptoms of his HCV and lung disease.
47. There was a new treatment, Harvoni, which we found out had been available in the last year of Paul's life. We found out about this from friends after Paul's death. From our research into this treatment it seemed that it had been still effective in patients with advanced liver disease; however, this was not offered to us. It was available online to buy directly, but we didn't know about this at the time. If we had known, we would have purchased it ourselves.
48. In 2010, he had a liver biopsy and was diagnosed with grade 1 fibrosis of the liver. **(WITN1962017)**.
49. In January 2013, Paul was diagnosed with cirrhosis of the liver. This seemed late to us, as he was already very seriously ill by then and passed away 6 months later. He was having regular scans of his liver before then and the doctors always said he had scarring but they would not call it cirrhosis. I believe that he may have met the criteria for a diagnosis earlier than this but was not given one.

50. On 25 April 2013 Paul went to the hospital for ascites drainage. I remember that his stomach was so large that he looked pregnant. He was told he would probably have to have this treatment once or twice a year. There was no indication from them that he was deteriorating further; he seemed to be stable at this point.
51. On 12 May 2013 he went back to hospital as he was vomiting blood. **(WITN1962018)**. We were arranging for him to be transferred to a hospice called Oakhaven, where he used to do voluntary work, for a two week rehabilitation programme, as we thought he was fairly stable.
52. One day I went in to hospital to see him and I knew something was wrong. He almost didn't recognise me. I asked the doctor working on the wing (not his usual doctor) what was happening and he said "we'll put him on the pathway now" and walked off. I didn't know what this meant. I found this an unbelievable way to be told my husband was not stabilising but dying.
53. The doctor said they would put him on morphine and he would die that day. I called my daughter at university three hours away and had to tell her to come immediately. We stayed with him all night; he woke up in the middle of the night saying he was in pain, but there was no doctor to give sign off on giving him more morphine. I ran around the hospital, found a doctor to sign off on the morphine and he survived the night.
54. The following morning, with the help of the palliative care team, I took him to Oakhaven to stay for a few days. Paul died there on 5 June 2013, aged 63. **(WITN1962019)**.
55. The effect on Paul's private and family life was extreme. He went from being an active husband and father to requiring constant care, and becoming alienated from his friends and family due to his personality changes and the stigma of having HCV. His relationship with me also

became strained. We eventually stopped being intimate and I started sleeping in another room.

56. During this time I was very tired and stressed. I was emotionally very wobbly but did not show this in front of Paul. I ate little and exercised too much as I needed to be in control of something, and lost 2 stone. When we stopped sleeping in the same room, I felt alienated from our family as they made unpleasant comments about it. When his friends stopped supporting him and he lost his job, I felt we had lost everything; our family, our friends, our livelihood. After he died I had to take sleeping pills for weeks to be able to sleep. I felt I had nothing left.
57. I was also concerned about how to protect our daughter Bronnie, both from becoming infected and from the negative effects on Paul's character. I didn't know how to protect our daughter Bronnie from him when he was upset or angry while also supporting their relationship. The only thing I could tell her was that he was acting strange because he was ill.
58. Trying to explain it to his family was really hard for him due to the stigma around HCV. Paul was different to the rest of the family. They were less educated and informed about life in general, and one of his brothers had brain damage, so they found it difficult to understand. When he told his mum, she told him to get out. He was shocked and scared and confused, and the one person in his life who should love him no matter what was the first person to throw him out the door, which was horrendously shocking for him.
59. His family all thought that by being in the room with him they were all going to get AIDS, and told him not to tell anyone else because they wouldn't talk to him if they knew. He ended up not speaking with his mum for a while as he was trying to come to terms with things himself.

His relationship with them did ease a bit over time but was never the same.

60. Paul did have support from my side of the family. They understood his diagnosis, got on well with him and were able to support him when his family did not.
61. Paul did not tell many friends about his diagnosis either because he was worried about the stigma. I would tell people that he was not well but he did not want anyone to know why. He did not mind my family and a couple of friends knowing but that was it.
62. As time went on, his friends disappeared because he became very difficult to socialise with. Our social life went to pot; our friends rejected us because of both the stigma around Paul's HCV diagnosis and also because they were scared of how much his behaviour had changed due to the mental effects of the HCV and the treatment.
63. My daughter Bronnie was very badly affected by it all. She faced a lot of bullying and abuse from friends, and there were so many misconceptions. Someone at her school found about Paul's diagnosis and asked the teacher how you get HCV, and the teacher said by taking drugs. After that, she was known at school as the child whose father had taken drugs. Her mental health deteriorated; she ran away once at 15 and she overdosed on paracetamol during this time.
64. In the early 2000s Paul started to find it difficult to go to work because of his confusion and foggy thinking. He fought to stay as long as he could. He was a social services manager who conducted assessments of patients eligible for disability benefit. His managers put him on garden leave which he found insulting. His managers would come to our house and have meetings about what was happening. He had to retire due to ill

health around 2003 as his confusion was getting worse and worse and his short term memory was becoming an issue. He was in his early 50s.

65. Losing his job was a major blow to him emotionally and financially. He had started it later in life and fell in love with what he was doing. Having to stop working so early completely mucked up his sense of self, his feeling of self worth, and his need to provide for his family. The emotional effect of this was huge.
66. I know that they were right in stopping him from working as he could not think clearly anymore, but I felt for him because everything was going wrong in his life and work was one of the only good things left. He had wanted to continue working for a few more' years. He did have his pension and disability payments to support him after leaving work, but that was all.
67. Paul's illness mucked up our daughter's education. Bronnie had to leave her local 6th form college and go to a boarding school where there was more stability and safety than at home. Neither any of her schools nor her university seemed to have any understanding of HCV, and her university, Exeter, did not take into account her father's illness or death for her degree award. Earlier, the school she sat her GCSEs did not even let her back after her overdose to study or to sit all her exams. Only the boarding school, Downside, seemed sensible and supportive and she blossomed there. Then Paul died during her university exams, which was completely horrendous for her. Of course this affected her educational outcome.
68. My work was also negatively affected. I needed my job to be flexible so I could support Paul, especially with his hospital appointments and administering his medication, so I was not able to be on a contract for some years and had to work hourly instead. This affected my pension and ability to be considered for promotion and salary increases. Even

when I went back on contract, it was not full time as I needed some time off to support Paul and Bronnie. I would not have had it any other way because Paul needed someone with him, but it has meant that my career became a job. It's now too late for me to rebuild my career. I have no career prospects or chance of a better income.

Section 6. Treatment/Care/Support

69. Paul was assessed as being a good candidate for HCV treatment as early as 1999, but not given the treatment due to his lung disease. Eventually he was offered treatment in 2006, when his lung disease worsened to the stage that he did require a transplant, and it was decided that he could not the transplant without undergoing the treatment.
70. If he was able to withstand the treatment with more advanced lung disease in 2006 I do not understand why he was not provided with the treatment at an earlier stage when his conditions were less serious. I am not a doctor, but I would have liked to be provided with adequate information by his care team to participate in the decision about what treatment he should receive and when.
71. Paul was not offered the new Harvoni treatment when it became available even though it was proven to be effective in advanced cases.
72. Paul had to go to a specialist dental surgery because his usual dentist would not treat him due to the risk of becoming infected.
73. There is an exchange in Paul's hospital records in 1998 (before he was told about the HCV) between his GP, his consultant at SGH and the Microbiology department concerning whether Paul should be offered counselling in relation to his HCV. The consultant noted that he had

been asked to provide counselling but he didn't want to raise more fears in Paul's mind, and that he didn't know the hospital needed to counsel people about HCV but would try to find out more information about it. **(WITN1962007- WITN1962008).**

74. We never knew about this exchange and Paul was never offered any counselling.
75. In terms of support, he was not offered any information about what was going to happen each time he was tested at hospital or received treatment. He was simply told after each test, "those are your levels, see you in six months" and had no understanding of what was going to happen. If I asked about next steps, the doctors would say we will see.
76. Information about the disease and options for support would have been really helpful. I don't know if they do a support group. At least he could have had someone to phone and say "I feel really crap, I don't understand what is happening to me and my relationships are deteriorating." Instead, he had only us to rely on.
77. I was never offered any counselling or support. I phoned the Inquiry number to ask about this and have never heard back from them. I would be interested in counselling if this were offered to me.

Section 7. Financial Assistance

78. Professor Rosenberg advised Paul's GP that he would not likely be eligible for compensation for the infection in a letter on 30 October 2003. **(WITN1962020).**
79. We found out from the Hepatitis C Trust that financial support was available from the Skipton Fund and the Caxton Fund around 2004. We applied for a Stage 1 payment using their paper application form and Paul got the lump sum of £20,000.

80. With that money we had to pay for the downstairs loo for him and shower and bought a stronger mobility scooter.
81. I remember Paul not wanting to apply for financial assistance, as it felt like admitting that he was suffering. He became frustrated with the application process, as it seemed to involve a lot of paperwork. The staff were always very polite on the phone, however. It was just clear that they funded the things they funded and said no to things they didn't.
82. In 2013, Paul applied for a Stage 2 payment of I think £50,000 from the Skipton Fund. This application was contingent on the doctor signing off that Paul had cirrhosis, so we were not able to apply until he was diagnosed.
83. I do wonder if Paul had actually had cirrhosis longer than this, as he was tested regularly and had lots of scarring on his liver, but the doctors kept saying he technically did not have cirrhosis until January 2013. I would hope that this delay in diagnosis was not malicious, but I do wonder what pressure the doctors were under not to be registered for Stage 2, as this provided patients with a monthly income. We were approved for Stage 2 but this was only one month before Paul's death.
84. After Paul died, I received £3,500 from the Caxton Foundation towards funeral costs.
85. I also received a £10,000 bereavement payment from the Skipton Fund in March 2017.
86. The Caxton fund did provide Paul with assistance towards part of Bronnie's rent for a year while she was at university. I do not remember how much this was.
87. I receive annual winter fuel allowance of £500 from EIBSS.

88. I would have liked to be compensated for more than we were. I think that if we are going to be compensated for having HCV, we should be compensated in a way that makes sense, such as providing a living wage for him.
89. I also wish compensation had been provided in a way that didn't feel like we had to ask for it. In my mind, they screwed his life up, and compensation for this should be provided automatically rather than us having to submit documents to prove how he has been affected and apply for every little thing. This would have made things a lot easier.

Section 8. Other Issues

90. My solicitors have a copy of Paul's medical records.
91. I have not been involved in any litigation or campaigning work on this issue.
92. I would expect that the Inquiry will be conducted succinctly and thoroughly, with clarity and fairness. I know they have always said that they are going to do that to the best of their abilities. I expect them to be respectful of the people who have died and those supporting them, and those who are still infected.
93. I would want the Inquiry to ask for information from a range of infected and affected people, and then if people feel that they are able to provide this information, great, and if not then that should be respected too.
94. I would want them to make sure that everyone is involved, from MPs and other government officials to medical professionals. If someone has done something wrong and had an impact in the scandal then they should not be able to hide behind a speckled mask. It is important for

those in authority not to be able to rely on legal professional privilege. They must stand up and be prepared to understand the consequences of the decisions they have made.

95. I want Paul's voice to be heard. I want justice, clarity and understanding for him, for his suffering and by default for my daughter's suffering. I want some sense of finality and justice to help the people who are infected to be able to try and live the rest of their lives in the most uplifted and happy way possible and be supported to do so. People who only have a few years left should be given everything so that they and their families can spend that time in the way that they want to, not begging for help to heat their homes at winter and help the people who have been left behind.
96. I would like the Inquiry to make the public more aware of the scandal and do more work on a national scale to encourage anyone who received a blood transfusion during the 'at risk' years to go and get tested. I think they should try to get a celebrity following to encourage this. Most people don't know what HCV is. It sounds like there are people still out there who don't know they are infected; let us at least find these poor people who don't know.
97. I think there should be more efforts to spread awareness of it. There should be an HCV day with posters on the tube, at bus stations, and initiatives to get people tested and try to prevent it. Now treatment is widely known about and available, with less detrimental side effects, hopefully people who find out in the early stages can be sorted out. No one should have to go through what Paul went through – what we went through.
98. I definitely think the Inquiry should provide psychological and emotional support for whoever needs it. I definitely need that support; now I can hold my hand up and say that.

99. The process by which we found out about Paul's diagnosis left me less than confident in our GP. He lied to Paul by omission, he failed in his duty of care and Hippocratic Oath to do no harm both to Paul and myself and Bronnie.
100. I believe Papworth Hospital were honest with us. I believe they may have discovered the HCV at Paul's initial assessment and then written a letter to the GP asking if he had had treatment for it, before informing us at the follow-up testing appointment.
101. From the time of Paul's diagnosis until his death, I feel I was misled or not provided with the whole truth by SGH regarding where Paul was in terms of the stages of HCV. The doctors would say that he had some scarring or that his levels were a little raised but nothing drastic, but waited years to diagnose him with cirrhosis.
102. There were huge issues with poor care and mistakes being made during Paul's final stay at Southampton General Hospital. I was extremely upset by the doctor on call informing me that Paul was being 'put on a pathway' instead of telling me that Paul was dying. I was standing at the end of Paul's bed in the middle of a ward. The doctor walked away. No explanation, understanding, time.
103. In addition, I felt the doctors and nurses were careless in the way they treated him. They often forgot to take his prosthetic leg off in bed, to remove his dentures and put them back in, to feed him, or improperly administered his oxygen. They handled his blood often without using gloves, despite knowing he had HCV. I did not feel I could leave him alone with them and as a result I stayed in hospital from 7am to 9pm each day during his final stay there. When he was being transferred to Oakhaven hospice, the ambulance used had a flat tyre and I had to convince them to go ahead with the transfer, knowing he had only days left to live. They were fine, but they made stupid mistakes that had a

serious effect on him, and they weren't knowledgeable or helpful to either of us.

104. I personally did not have a very positive experience at Southampton General Hospital. I was hardly spoken to at all even though I was there for 90% of everything. At many times they could not talk to him because he was too ill, so I was there trying to advocate for him and find out what was going on, but was ignored by staff.

105. When I phoned the DWP the person I spoke to there was very helpful.

Statement of Truth

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

Signed

GRO-C

Dated 19 February 2019.....