

Witness Name: Catherine Johnston

Statement No.: WITN0158001

Exhibits: **WITN0158002**

Dated: 13/12/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CATHERINE JOHNSTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25th March 2019.

I, Catherine Johnston, will say as follows: -

Section 1. Introduction

1. My name is Catherine Johnston. My date of birth is GRO-C 1963 and my address is known to the Inquiry. I was a civil servant but I retired after my husband passed away. I intend to speak about my husband, Paul Johnston, who was suffering from leukaemia when he was given a contaminated blood transfusion. In particular, the nature of his illness with hepatitis C, how the illness affected him the treatment received and the impact it had on him and our lives together. I am here because I felt Paul's story needed to be told.
2. I do not require legal representation and I am not seeking anonymity at this time.

Section 2. How Affected

3. My husband, Paul, was a talented footballer. He played for our local football team. When I met him he was a happy, big, tall man who had a great zest for life and did not let anything get him down.
4. Then when he was 24, in 1986 he started having to walk off the pitch with bad nose bleeds and would complain of being tired all the time. Eventually, this led to him being admitted on to a ward in the Royal Victoria Hospital in Belfast for tests under the care of Professor Bridges, who has since retired.
5. At the time, he was not told the nature of his illness. Paul found out about his illness from a fellow patient in the bed next to him, who informed him that they were both getting the same treatment. The other patient then revealed he had cancer of the blood. Paul was receiving chemotherapy treatment but neither the doctors nor his parents had told him. He was the eldest child in his family and his parents couldn't bring themselves to tell him he had leukaemia; he was the blue-eyed boy of the family and they were devastated.
6. Paul was on and off that ward for two and half years and by the end of it, he was the only remaining patient who survived. After he went into remission we would attend hospital appointments every so often to be monitored.
7. We were told that because of the amount of chemotherapy that Paul received it was unlikely that we would be able to have a family. This was difficult news for us to hear, but we accepted it, moved on and got married. The following year Rebecca was born in 1992. The doctors in the Royal, were delighted to see me

pregnant. Everything was good and we were living a normal life; we were both working in the civil service and Paul was back playing football again for his local team. Life was great, we had our own home and then we had our second daughter, Hannah. At this time, our lives were going so well and the future was looking bright.

8. This all changed in 1997 when we went to the Royal, to one of Paul's annual haematology appointments. On this occasion, the doctor brought us onto the ward, showed us to a bed and pulled a curtain round us. He then said to us 'we always thought there was something different about your blood but we weren't sure what it was but now we have discovered it. You have hepatitis C and we are not liable.' The doctor then gave us some leaflets but nothing else and that was it; no advice on precautions to take or how to manage the infection and no explanation as to how or why it had occurred.
9. I remember asking the doctor; 'If Paul has it can I have it? Could the kids have it?' The doctor said that it can only be passed from the mother to the child. I then asked him; 'Do I not then need to be tested because my kids are 3 and 5?' I remember him replying that if I wanted to, I could to which I replied that; 'I think I need to be tested.' He then took my blood and we went off down the road. We were in total shock, just numb. We could not really take much in at that very short meeting.
10. In the car journey home, I remember that Paul was annoyed because the doctor said that the hospital was not liable. Paul was very upset at the use of this word and it really got to him.
11. After that we started to look into it more at home and learn more about Hepatitis C. When we were first told, we did not appreciate completely the seriousness of the infection and what it would

mean for us. It was new to us and the casual delivery of the diagnosis by the doctor did not convey any sense of a life-changing illness.

12. We were then called back three months later, where the diagnosis was confirmed. The blood tests had to be sent to Scotland to find out which type of hepatitis it was. I was also told at this meeting that I had not contracted the infection. Why did that take so long? I then asked the doctor why we were still seeing a haematologist as from my research Hepatitis C was a liver condition and Paul had been in remission from leukaemia for ten years. We were no longer worried about cancer but instead about Paul's liver and the effects of Hepatitis C. Then, but only at my insistence, the doctor referred us to a hepatologist.

13. When Paul was sick in 1986-87, he received over 90 units of blood during his chemotherapy treatment. At least one of these units of blood must have been contaminated. The first consultant that told us about his HCV infection noted that he contracted it during this period in the Royal.

14. Paul did not have any tattoos or piercings, nor was he an intravenous drug user and we were happily married so he could not have contracted the infection other than from a contaminated blood transfusion. As far as I am aware he had no blood transfusions or major surgery prior to these during his cancer treatment.

15. I do not recall that my husband was given any warnings or advice regarding the risk of being exposed to infections from blood transfusions before he received them in 1986-87.

16. I think that when we were told about Paul's infection, the doctor should have brought us into an office or somewhere private

instead of telling us on a ward. Paul sat on the bed and I sat in the chair, this was not the best setting to tell us. Particularly, as our conversation could have been overheard by other patients lying in the beds next to us.

17. I also think that they should have told us as soon as they found out about the infection. They obviously tested him for it before they told us which meant they didn't share their suspicions immediately with us. I am not sure how long they knew about it before they told us. I decided not to obtain Paul's medical records because on his death certificate it notes he died of Hepatitis C from a blood transfusion. **(See Exhibit WITN0158002)**

18. I am also not satisfied with the level of information that we were given in those leaflets. I found that searching on the internet was a more informative process. Nobody ever told us about taking sexual precautions, we found that out ourselves. This meeting was a very short appointment with the doctor considering the diagnosis of such a serious condition and the likely questions that the patient would have.

19. I think had I not insisted on being tested for Hepatitis C or asked for Paul to see a hepatologist, we would not have been advised by the doctors to take these steps which I find very unsatisfactory.

Section 3. Other Infections

20. To the best of my knowledge I do not believe that Paul was infected with any other diseases from contaminated blood but I cannot be certain. The thing is if they are testing for a particular infection in blood they will find it. You cannot be certain that they will uncover anything else that is there with that test. That is why

I am sure he was tested without his consent as they must've been looking for this virus.

Section 4. Consent

21. Paul was obviously tested for Hepatitis C without his consent or knowledge. Apart from this time, I do not know if this happened on any other occasions but as far as I am concerned as they have been screening blood for HCV since 1991 and what the doctors said; 'We always knew there was something funny with your blood', demonstrates that they had been testing his blood without his consent.

22. I do not think that Paul was treated without our knowledge but as I have not seen his medical records I cannot be sure. Although, I suspect that because of the special treatment for Hepatitis C that he received, in 2000, supposedly a different type of Ribavirin from Scotland, he may have been used as a guinea pig on that occasion.

Section 5. Impact

23. Initially, apart from seeing Dr Callander, the hepatologist, every three to six months who took liver biopsies and monitored the scarring on Paul's liver, the future disruption the infection would cause was not apparent. Up until this point, Paul did not suffer from the classic symptoms of hepatitis. He was as healthy as a trout and was still playing football with the local team.

24. Then in 1999, Dr Callander offered us the "miracle treatment" as he put it. He warned us not to have any more kids during the treatment and for six months after if finished as it may harm the foetus. We had intended to have a big family. I feel when you have a big family you have lots of support and we both came from

big families but in the end, the impact of the Hepatitis C treatment was so horrendous that this no longer became a priority or even an option.

25. In December 1999, he received his first treatment of Interferon and Ribavirin, where he had an allergic reaction to the first injection. A rash of hives spread all over his body. This treatment was supposed to last for 6 months but because of his allergic reaction they soon sent him home. I remember the doctors saying this treatment obviously does not agree with you.

26. We were then offered another treatment in December 2000. We were told that this treatment was from Scotland and was a different and very expensive form of Ribavirin and Interferon. I have no idea as to why there was a year of delay between treatments.

27. Once Paul started this medication all hell broke loose and his life was turned upside down. He initially started the treatment in hospital. For a few days before they had him on antihistamines in order to allow his immune system to accept the treatment and to prevent him breaking out in a rash again. During this hospital stay they also showed him how to inject himself before he could return home; he was in hospital for a week.

28. During this course of treatment, Paul had to inject himself three times a week and had to take tablets daily. He finished this medication in after 6 months in June 2001.

29. Paul suffered terribly throughout this treatment. The mental and physical side-effects were horrendous. He would have permanent flu symptoms, terrible headaches, depression, diarrhoea. He was exhausted all of time and would have aches

and pains all over his body. This made him very irritable and hard to live with.

30. In the first month, he worked part-time. He would only go to work on the day he had the injections as the following day he would suffer from the side-effects which were unbearable. Eventually though, he had to stay off work during the rest of his treatment due to the severity of these side effects.

31. He underwent a total change of personality. He became very aggressive during the treatment, where he would have fought with a glass. The depth of depression and psychological side effects were also unbelievable to the extent he would tell me to lock him in the house because he wouldn't know what he would do or where he would go. He could lose total control.

32. One day I went to work and locked him in house at his behest. When I returned he was not there I contacted family and we searched frantically for hours. Eventually, he turned up 7 miles away in a local village. He had absolutely no recollection of how he got there. I felt an amount of guilt at leaving him on his own but I had no choice as we had a family to look after and at times mine was the only income we had.

33. I remember ringing his GP, Dr **GRO-D** to tell him that Paul was in an awful state. I asked him can you please come out and see him as Paul couldn't get out of the bed. After a while, he finally gave in and said he would come out and visit. He came to the house and prescribed anti-depressants, Lustral. However, he never followed up to check on Paul if he was any better or needed further help. This would have been around the same time that Paul started to drink, before he would have been a social drinker but now he became a heavy drinker. I often think with a bit more help and support that he may not have taken that path.

34. When we went up to Belfast during the treatment I would tell the doctors that we were both struggling. Living as far away from Belfast as we do, was a very isolating experience. We were scared to tell anybody because you don't know how people are going to react. I kept telling them Paul is not coping. The issue was that we always saw different doctors and we had to keep telling them the same thing each time, but none of them seemed to take it seriously.
35. For me the depression was the worst thing, I was scared he was going to do something harmful to himself. Whenever I came home from work, I would first check the house to make sure that he wasn't hanging so that the girls wouldn't see it. I felt it was that bad and I know how down Paul felt. Once I knew it was safe, then I would collect them from the childminder's and bring them home. He discussed suicide quite a lot and we were both very scared. I raised this with the doctors. They just kept telling us, just hang on for one more month and then that will be it the treatment will work and everything will go back to normal.
36. The main issue was that when the treatment was over nothing changed, Paul stayed the same. He went from this happy go lucky man who never let anyone beat him to a person who felt that they had a ticking time bomb in them and was not going to see his children grow up. Even his work colleagues noticed the change in him, he was just a completely different person. There was a world of difference between the big 6ft 1 happy, healthy fella that I married to the shrunken, 5ft 9, skinny, shadow of a man that Paul was when he died.
37. In June 2001, when his treatment had finished he had his blood tested which showed that the Hepatitis was dormant. When we heard this news, we were delighted especially after all we had

gone through. We had survived the duration of this horrendous treatment. But then, the doctor said that 25% of people relapse once they stop the treatment. That brought us back to earth with a bump! We were so elated before, they didn't need to tell us that straight away. This was similar to a kick in the face for Paul.

38. In August 2001, at a follow up appointment Paul then had further blood tests which demonstrated that it was back again. At this appointment, Paul turned around to me and said; 'I can't do that treatment again' and I replied that I couldn't do it either. It was as if it just never left him and his mood changed. I think he just felt defeated and thought; I am never going to see my children grow up and get married; that I am never going to beat this. It knocked him for six.

39. After this meeting, he went back to work and he was on anti-depressants and had bouts of sickness. Paul just had a repeat prescription and Dr [GRO-D] never followed up on his depression. I would take him to every alternative therapy I could find to try and get some relief. He was always just so tired. I travelled all over the country to see if anything would work.

40. Nobody offered us any counselling when we saw the doctors in Belfast, I told them how much Paul was struggling; we were 70 miles from Belfast and as I've said we felt very isolated. They never even gave us a phone number we could call just to talk to someone when things were bad. These alternative treatments cost us a fortune and we didn't have that much money to go around. Paul's depression got deeper and he was drinking more and more and just kept slipping slowly into a much worse place.

41. At some point, in 2002, whilst still working work, we noticed he started to retain fluid in his legs and ankles. Dr [GRO-D] prescribed

Paul some tablets, furosemide. I am not sure if there is a link between a build-up of excess fluid in the body and Hepatitis C.

42. Paul's GP Dr [GRO-D] was a waste of time. At least my GPs would ask after Paul when I went into to see them. Dr [GRO-D] did not seem to take any interest in my husband. He didn't even know what treatment he was on for the infection.

43. Paul was on those fluid tablets for the rest of his life. He died in 2015. The last five years of life were really difficult.

44. From 2002-2006 we still went up and down to Belfast for Hospital appointments in the Royal. At this stage the only option left to improve Paul's health would be to obtain a liver transplant because further treatment through the available drugs was like hell on earth for Paul. But he was refused this option as he continued to drink. I remember Paul would say to the doctors: 'You gave me the blood that caused my liver to have problems and then you gave me the treatment to cure the problem which made me a depressive alcoholic and now you are denying me a liver transplant because I can't stop drinking!'

45. After he was denied the new liver, Paul decided to not go back for anymore hospital appointments and at this stage he gave up on the doctors. They would just conduct more blood tests and stick a big illuminous sticker on it, which made Paul feel bad. They were never very discreet with this. There was no point going back to Belfast, the Royal Victoria Hospital were offering us nothing.

46. Meanwhile, Dr [GRO-D] just kept upping his fluid tablet dose as his swelling got worse. On one occasion Paul was in work and it got so bad that he couldn't climb the stairs, he was so out of breath. I picked him up and took him straight over to his GP surgery,

where he saw a different GP, who referred him straight to Erne Hospital. He was in kidney failure and all because Dr [GRO-D] kept upping his dose of fluid tablets without physically monitoring him for any detrimental effects.

47. I am not sure if it was Paul's Hepatitis that caused Dr [GRO-D] to treat him so poorly or if he was like that with all his patients. Fortunately, the doctors in the Erne said that we caught it in time and his kidneys started to work again after the right medication was prescribed.

48. Then over the next few years another problem arose, Paul started to retain fluid in his chest. He had to have 33 chest tubes put in to drain the fluid. On the first occasion that they inserted a tube, they slowly drained 12 litres in one session so that his body wouldn't go into shock. They did try and do different things but nothing worked. Every 6-8 weeks we would go over to Enniskillen to get the chest tubes put in. Each time it was a very painful and difficult treatment for Paul to endure.

49. In the last year of his life, Paul really suffered from a swollen chest. Most people would hold excess fluid in their abdomen but he held it in his chest which pressed on his heart.

50. At that stage we knew he was going to die, he also knew he was going to die and would say; 'I am prepared to die. I would rather die without more treatment (for hepatitis).' He had no quality of life, he was fading away and he couldn't do anything despite his best efforts.

51. Paul officially retired in 2013, but he had been off sick the year before that. He worked as much as he could until he requested early retirement on health grounds. He then became house bound until he passed away.

52. Paul had to go to Enniskillen to get a chest tube inserted before Christmas 2014. Normally, for his birthday which is just after Christmas, we would go out for dinner but we just got a take away on this occasion. He simply wasn't fit enough to leave the house.
53. At this stage, we had nurses visiting us to monitor Paul. One nurse spotted that he had developed fluid in his stomach and that it needed to be drained. He then went straight into hospital, where they discovered that he had an infection in the fluid and after that he just deteriorated.
54. We made the decision the following Monday that he should be moved to a palliative care unit. Hannah was at college in Belfast and she had January exams and she had to sit an exam on the Tuesday so she couldn't be there. In order to comfort her, we sent her a photo of her daddy eating a chip butty, at the time we all thought it was a great photo.
55. On the Tuesday he drifted in and out of sleep and on the Wednesday, we knew the end was coming. He died on Thursday evening. He just had enough, he said he was tired. His body took such a battering, nobody else could have survived that long. We could have fought on but at that point we felt enough was enough. At that stage Paul wasn't really with us anymore.
56. I remember the doctors saying at the time that it was all linked; his liver couldn't process and filter the toxins. He used to take these turns when we were with him, where he would just phase out of a conversation. It was as if he was in a trance. The doctors said that it was because the toxins were going up to his brain and that it was very serious. They wanted Paul to go into the hospital but he refused to go. These turns occurred during the last few years of Paul's life and meant that we could not leave him alone.

Once he was awake you had to be very careful. He could fall over and bruise very badly, in fact just touching his hands would bruise them.

57. Paul was never denied dental treatment but he stopped going after a few times because he was always seen at the end of the day and everything would be covered and they would wear masks because of his Hepatitis C. These practices, while understandable, unsettled Paul and made him feel very uncomfortable.

58. He also had to have knee surgery and again he was always scheduled for the end of the day. I believe this was also to do with his Hepatitis C infection and added to the sense of stigma Paul felt.

59. Every time we went into hospital, we always felt we had to explain ourselves to the doctors and nurses because otherwise people would look at you and draw conclusions about your way of life. We saw so many doctors, we rarely saw the same one so we were always having to explain what happened to Paul. We both noticed the extent to which people would treat you differently when we didn't explain what had happened. There was always a stigma with the doctors and staff and you always had to make sure that they knew what happened in order to avoid their judgement.

60. I had a book that I brought with me to every appointment. I noted down what they gave him and recorded how it affected him. I would know if a particular medication did not agree with him; he sometimes would have funny turns. He would hallucinate a lot with certain medications. After a while the doctors started to listen me and took my observations seriously.

61. The impact of being infected with Hepatitis C on Paul's private, family and social life was hugely detrimental, so much so that it is difficult to convey. Paul completely changed during his treatment for HCV which obviously affected his private family life and social life. He became an aggressive, depressive alcoholic with suicidal tendencies, which affected his relationship with me, and his two daughters. Receiving contaminated blood irrevocably changed his life and had tremendous repercussions for all of us, including to this day. He could have lived a completely different, normal life had he not been infected and subsequently treated.

62. My family were very supportive of the situation but Paul always felt that we had to be careful around ours and other people's children. He was overly protective in the beginning but then we settled down a bit. Paul would never have nursed the children but he was still there for our daughters and engaged with them. He always kept his toiletries in the bedroom so nobody accidentally used them.

63. He just would have always been very cautious, we would have bleached everything after use. I was also extra careful too, it just rubbed off. I couldn't trust the doctor's advice so in the later years, when the fluid would ooze out of his legs I would have worn rubber gloves and made sure everything was washed and disinfected.

64. Consequently, Paul's infection had a significant impact on me. The last holiday that we went on abroad was in 1999, which was just before Paul received his first treatment for Hepatitis. After that, if we went on a holiday it would be to our caravan in GRO-C Paul loved going there. This was what life was for us, we just worked our lives around Paul. Our two girls didn't have a childhood, it was just revolved around their dad. They would

choose to not go away on holidays because they would be scared in case anything would happen to their daddy.

65. It was particularly difficult when I contracted breast cancer in 2011. My eldest daughter Rebecca, was frightened she would lose me too. I think that Paul's infection has significantly affected Rebecca, perhaps more so than our youngest daughter Hannah, as she was old enough to witness it all.

66. I remember when Rebecca was 14, she was struggling in school. She didn't want to leave daddy's side during the day because she was scared of what may happen in her absence. She wouldn't go anywhere, she just stayed at home. In contrast, Hannah our youngest, went off to college.

67. It really had an adverse effect on Rebecca. GRO-C

GRO-C

GRO-C	Paul's illness affected both our girls. Rebecca would not attend to provide a statement as it is still too raw. Hannah has engaged with the Inquiry. (See WITN3504001).
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68. When Paul was alive we couldn't do normal things in the last few years of his life because we could not leave him alone. The three of us girls couldn't all go out together say on a trip or shopping or for dinner as a family. One of us always had to stay behind to mind their daddy so it was very strange for all of us to go out for dinner after he passed away.

69. After Paul passed away I realised that I had spent so much time looking after him that now I needed some time for myself. I was just physically and mentally exhausted, so in the end I applied for voluntary retirement. The day that it was granted was the same day as the anniversary of Paul's death and I interpreted this as a positive sign for me.

70. It also impacted our life as a couple I was used to always having someone there to bounce thing off. Although when he died, I probably thought to myself, his suffering is over now but I didn't really want to be single. Most of our marriage wasn't easy when it should have been. That's what makes me angry, at the time when it was all done, had Paul not had that bad blood we wouldn't be here today.
71. At the end of the day when he went into hospital he should have been safe and been given safe blood, not something that has been brought in from goodness knows where. I have missed out, I was a widow at 50. Paul and I were supposed to retire and travel the world together We didn't get to do any of the things we had planned to do together.
72. For the last ten years of our marriage we didn't really have one, we just stayed together for the girl's sake. Paul did leave the family home for a year 2008-9 to live with his brother because his drinking and aggressiveness became so bad. We were trying to shock him but deep down I knew it wasn't his fault. The girls didn't know what daddy they were going to get from one day to the next. Sometimes Paul would just pick a fight and argue about stupid things. Often it ended in tears.
73. Obviously, it affected Paul's ability to progress in the civil service to earn a higher income because he had to take so much time of work but he did his best.
74. The civil service was good but I took a five year career break for the children and then Paul had his treatment and got a one-off payment of £500 from welfare support. At that time our joint income was reduced to £300 per month. This was a very difficult time for us, we were living hand to mouth. I had to borrow from

Peter to pay Paul, from half pay and pension pay to credit cards and overdrafts just to maintain a normal way of life. Our budget was so tight that my family gave us some money to help pay the mortgage.

75. We also struggled to get insurance because of Paul's Hepatitis C. I had a sole endowment policy on our mortgage because it was too expensive to add Paul. We were also told we would never get life insurance so never applied.

Section 6. Treatment/Care/Support

76. Paul did not receive a liver transplant because he refused to give up drinking. However, his cirrhotic liver was a direct result of being infected with Hepatitis C. The clinical protocol of covering every surface and wearing masks made medical and dental appointments very difficult. In some respects, this practice prevented him from accessing further treatments because of how it made him feel, whether this was intended or not.

77. To date we have never been offered any counselling. Dr. GRO-D despite knowing how depressed my husband was, did not offer him any form of counselling service. The doctors would just tell Paul stay off the "top shelf" and you will be fine which was not very helpful. The last thing he needed was any sort of encouragement to drink alcohol. At this time, I was struggling to cope. I found it very difficult on my own and I would call Care Call in the evening to try and hide it from the girls. This service was fortunately provided by my employer.

78. I have never asked my GP for counselling and she didn't offer. Even after Paul's death we were not offered any counselling or bereavement services.

Section 7. Financial Assistance

79. In 2010-11 we received financial assistance from the Skipton Fund. After I discovered it online, I rang and contacted them. Nobody had ever mentioned it to us during the course of treatment. It was a very easy process; they sent me a form and I got Paul to fill it in.

80. At that point he had stage 2 liver scarring so he qualified for two payments; the first was for £20,000 and the second was for £25,000. I don't remember there being any preconditions attached to these lump sum payments. In addition to this we then started to receive between £1200-£1300 per month once the application was agreed. None of the doctors we saw ever told us about this fund.

81. This money was unbelievable, Paul was able to buy himself a car which we wouldn't have been able to afford before and the girls were learning to drive so it really helped them and improved his quality of life at the time in that it improved his mobility.

82. I still receive financial support from the Blood Health Trust. I am no longer working full time so I have a pension of £550 and I get £300 from a part-time job so I am just about getting by.

Section 8. Other Issues

83. I have never been involved in any litigation or campaigning.

84. I don't think it is fair that in England they receive higher payments than we do in Northern Ireland. Although, I am thankful that I receive something.

85. Finally, I would like to say that this should never have happened and I would hope that it will never happen again. If I ever need blood I am not sure I would have a blood transfusion, not unless it was life or death because of what has happened to my husband. The whole experience has shaken my faith in the National Health Service in general and I now know never to take what I am told at face value.

Statement of Truth

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

Signed

GRO-C

Dated

13/12/2019.