

Witness Name: Christine Demers

Statement No: WITN53730001

Exhibits: Nil

Dated: 13 May 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHRISTINE DEMERS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 November 2021.

I, Christine Demers, will say as follows: -

Section 1. Introduction

1. My name is Christine Demers. My date of birth is GRO-C 1945 and my address is GRO-C.
I am widowed and I live alone. I have 3 children, Karen, Alison and Mark. My eldest daughter Karen is married with 2 grown up sons: 22 and 20 years; Alison has 2 twin boys aged 14. Mark has 2 girls who are 6 and 11 years old.
2. I intend to speak about my late husband, Paul Demers. In particular, how he died and how we found out that he had contracted Hepatitis C (HCV).
3. My eldest daughter, Karen Hague has assisted me in providing this statement. I would like to acknowledge that due to the passage of time

memories can fade and some dates may be near to, rather than exact, as I have been unable to obtain Paul's medical notes as they have been destroyed. After all these years I am very grateful of having the opportunity to tell my story.

4. I confirm that I am not legally represented and that I am happy for the Inquiry team to assist me with my statement. I also confirm that the Inquiry Investigator has explained the Inquiry's "statement of approach" and that if I am critical of an individual that they will have the right to respond to that criticism. I have also had the option of anonymity explained to me but I wish for my story to be heard in full.

Section 2. How Affected

5. Paul was born on [GRO-C] 1942 and died on 24 April 1994 at the age of 51. His family moved to [GRO-C] after the war. I met my Paul when I was 17 years old, he was a few years older than me. Paul was a haemophiliac. His haemophilia had previously been diagnosed as a child because when he was 5 years old, he fell under a milk float, which back then milk was delivered by horse and cart, and hurt his leg. However, I am not sure if that was when they found out about his haemophilia or if they knew before that particular incident. Paul was diagnosed as being haemophilia A with 5 percent factor VIII - therefore moderate.
6. Paul used to play in a band as a drummer and he used to regularly play gigs at weekends. His job was in finance and he worked for [GRO-C] Council in the finance office, where he remained throughout his working life.
7. Paul's leg was damaged in the milk float incident, so he had to put bandages on every day and to support his leg. He had a skin graft on the leg so it remained weak and would often bleed.

8. Paul didn't medically treat himself at home with any blood products for his haemophilia and I didn't treat him either. In those days you didn't see a doctor unless you were practically dying. He did not bleed frequently or attend hospital but when he did bleed it was straight to Guildford Hospital which was not as it is now but was just a small cottage hospital then.
9. He managed life quite well. He didn't have Factor VIII in the fridge at home and took no pre-emptive measures. He only required treatment when he had a bleed.
10. Paul went into the Royal Surrey Hospital, Guildford in about 1977 to have his wisdom teeth out, my son was about 6 months old at the time.
11. He went in to Royal Surrey Hospital again sometime between 1983-1984 because he had a badly injured leg, the left one, from his former milk float accident. His leg was so bad that he had virtually no skin on it, so anything like just knocking it on a chair would open it up. A lot of the time he had to bandage it round and round to protect it and support it.
12. He had a limp but his energy levels were fine. There were no outward signs that he had a virus effecting his health. He was a normal sized man, he had a bit of a tummy but not much of one. There was nothing out of the ordinary with his health that I was aware of which would indicate that he had a virus.
13. On Saturday 23 April 1994, Paul was on stage playing the drums when he suffered a brain haemorrhage, he was pronounced dead on Sunday 24 April 1994. I was told that someone said that the drummer had fallen asleep but he had collapsed whilst playing. He was taken to Frimley Park Hospital by ambulance but they were unable to treat him and from there he was whisked to Atkinson Morley hospital Intensive care unit.
14. Paul was playing the drums, locally in a room on a Saturday night at a gig. He used to play 60 and 70s music in a band. When he left home to

attend the gig, little did I know that was the last time I would see him alive.

15. I was told by one of his band mates that Paul had complained of having a headache that evening whilst he was playing. He didn't feel well and someone rang me to tell me that he wasn't feeling well. He carried on playing and then I got a call ten minutes later to tell me that they had called an ambulance. By the time the ambulance got to Frimley Park Hospital so had I, as one of the band members had driven me there.

16. Frimley Hospital said that they couldn't treat him there and they got him straight to the Atkinson Morley's Hospital, I followed in a car as one of the band members took me to the hospital. When I got to Atkinson Morley's I was told to just go home because he had 'gone' and the Doctor told me that they couldn't help him.

17. Paul died on 24 April 1994, GRO-C before my daughter Karen's birthday.

18. I asked the doctor if they could keep him wired up as I did not want my son to see him just laid out. His father had dropped him off for a sleep - over with a friend before his gig and this was the last time he saw him alive. I had to pick him up from his friend's house and he asked me where his Dad was as he was expecting to be picked up by him. I took him to the hospital to see his father one last time and as we left, I turned back and nodded that they could turn his life support machine off.

19.

GRO-C

20. At that time Karen was living away from home and was into her first year of teaching professionally. She came home and was allowed to see her

father's body at Atkinson Morley Hospital. Karen wanted confirmation in her own mind that it was her dad who had died. She needed closure.

21. A medical record from Atkinson Morley Hospital states that I was phoned due to Paul's poor condition and that the doctor would will speak to me on arrival. I went to the hospital with my daughter and her fiancé where they explained what had happened and that stem tests would be carried out later that day. The document records that I was spoken to about his stem cell death and that we wanted to go for organ retrieval and donation.
22. We wanted to donate Paul's organs and this is when we found out that Paul had HCV and that his organs were not suitable for donation, this left us feeling devastated as we wanted his organs to go to other people. In a document from St Georges' Hospital it states that, "The family offered his organs for transplantation but virology confirmed that he was hepatitis C positive and that this was not indicated."
23. When I found out about Paul's HCV, I said, "what is this?" I didn't know anything about it, I said, "He had what?" They told me when we made the organ donation request that he had HCV. I didn't know anything about it. No one explained what HCV was or what the implications for us as a family could be, I was shocked.
24. Paul died at the Atkinson Morley Hospital at the age of 51. A medical document from the Atkinson Morley's Hospital, Department of Neurosurgery, states that, 'This 51-year-old haemophiliac collapsed at 23:00 hrs on the 23.04.94. He was admitted to Frimley Park Hospital where his GCS were documented as being 6 and at 0015 hrs he dilated his right pupil and was intubated and ventilated. A CT scan demonstrated an extensive right occipital intracerebral haematoma and he was referred to Atkinson Morley Hospital for urgent neurosurgical assessment. At this time his left pupil had started to dilate'

In another document from the hospital there is an entry which reads, 'This man was admitted and the paralysing agents reversed to assess him neurologically. Both pupils were fixed and dilated and he had no brain stem reflexes present. Ventilation was continued until brain stem death could be confirmed. He was certified dead at 18:00 hrs on 24 April 1994' RIP'

25. On 25 April 1994 the same document states that the transplant co-ordinator spoke to me at 9pm and made me aware that Paul was unable to donate his organs due to being found to be Hepatitis C positive. This was not discovered until after he passed away.
26. I had no idea and I don't think that anyone had said anything to Paul about his HCV. Paul just thought that the childhood cart accident was the problem.
27. Paul's cause of death was recorded as intracerebral haemorrhage and haemophilia. Karen's opinion is that because her dad's blood could not clot very well the bleed just continued and caused the damage to his brain and his subsequent death.
28. We don't know whether his brain haemorrhage was attributable to HCV, we will never know.
29. In an attempt to obtain Pauls records, Karen contacted Frimley Park Hospital to ascertain information regarding her father's Haemophilia status. Karen had previously been tested and identified as being a carrier and we thought they would have all the family records.
30. Karen's factor levels are 50 percent under. She is under the care of Kathryn Marshall, University Hospitals Coventry and Warwickshire NHS Trust. If she has a bleed, she goes straight to Coventry Hospital rather than going to Warwick, to have products just in case. She has products at home in the event of a bleed, but she doesn't need to take them. Karen

was referred to University Hospital to have a tooth out as her blood clotting is low and she had to have medication before the extraction.

31. When Karen wanted to start a family, Karen contacted Janet Shirley on 25 August 1998. Janet informed her that she no longer worked there but put her in contact with a Consultant at Frimley Hospital, Peter Alton. Karen made this enquiry with regards to her father's haemophilia on 10 November 1998 as she wanted to know what her chances of passing on haemophilia and at what level.

Section 3. Other Infections

32. I am not aware of any other infections Paul may have had as a result of receiving contaminated blood.

Section 4. Consent

33. I am unable to comment on whether Paul gave consent to any treatment he received for his haemophilia. As far as I am aware Paul is likely to have consented when he was older but I don't recall anyone saying anything about it. The only time I remember him being in hospital was when he had his teeth out in 1977 and 1983-4 as previously described.

34. Neither am I able to comment on whether he gave consent to any testing or if he was tested without his knowledge.

35. I may have been tested for HCV but to be honest I cannot really remember. After speaking with you I think we will all ask to be tested to give us peace of mind.

Section 5. Impact

36. Karen lost her dad when she was quite young as he died in 1994. At the time she had qualified with a history degree from York University. She was also in the first year of her PGCE qualified status and was teaching. She had been living away from home for 4-5 years.

37. GRO-C She had gone shopping with her fiancé, who was then her future husband and was due to be getting married in 3 months. She called me but I was not there, so she called her grandmother (my mother) and she remembers her grandmother saying, "It should have been me, it should have been me." So that is how she found out that her father was dead. The following day she came back home and I arranged the funeral.

38. Her brother gave Karen away at the wedding. Paul knew about the wedding and had his wedding suit ready. Karen's wedding was a bitter, sweet day as her father was not there to give her away. Instead my son had to perform this special role.

39. It affected my son and put a lot of pressure on him as he was in the first year of his A levels. He went a bit haywire and it affected him more as he was younger than Karen by 6 years. He was only 17 years old when his dad died and he was very close to his Dad and he was still living at home.

40. GRO-C

41. We had no lead up to my husband's death, Paul took his son to a friend's house for a sleep-over and that was the last we saw him alive, and then we got a phone call with the news.

42. In terms of stigma, we didn't experience any problems or issues with the funeral directors or undertakers with regards to the HCV revelation. Paul's funeral was full and lots of his work colleagues attended.
43. We as a family are left with unanswered questions. At the time of my husband's death, we had no idea of his HCV positive status or the implication it could have on our family. No explanation was given to us re any preventative measures. We were offered no support or counselling. Karen's forthcoming marriage actually helped us with the fact Paul had gone.
44. I am surprised that he wasn't diagnosed with HCV before he passed away during his visits to hospital for treatment/check-ups for his haemophilia. This has left the family with unanswered questions not only as to why but as to our own health and as I have said previously, we intend to arrange for the family to be tested for HCV.

Section 6. Treatment/Care/Support

45. Paul managed life quite well. He didn't have Factor VIII in the fridge at home and took no pre-emptive measures in connection with his haemophilia. He only required treatment when he had a bleed.
46. They didn't really have any treatment for him with regards to his haemophilia. As mentioned earlier in my statement he just used to bind his leg up which would bleed easily, if he knocked it on a chair for example.

Section 7. Financial Assistance

47. Paul died intestate, without leaving a will and I had to go to the law courts to sort out the estate and finances.
48. He used to work for **GRO-C** Council in a finance role so I receive a very small pension from them. He had no life insurance. I received £20,000 from the Skipton Fund.
49. I was 3 years younger than Paul, so I was 48 when he died. I remained single throughout and did not have any other partners. I have been on own for over 28 years.
50. After Pauls death, I raised my children on my own and saw them through university, they are all good kids and I have even better grandchildren!
51. My daughter Karen found out about the Skipton Fund when one of the haemophilia nurses, Kathryn Marshall at the University Hospitals, Coventry and Warwickshire, NHS Trust, asked her if she was aware of the fund when she had her tooth taken out at Coventry University hospital.
52. We applied for his medical records for the Skipton Fund application in 2015. However, we were informed by Frimley Health NHS Foundation Trust, from the Medical Governance Department in a letter dated 13 May 2015, that medical records of deceased patients were only kept for a period of 8 years after death and that his records had been destroyed.
53. I submitted my Skipton application on 9 July 2015 with the help of Karen. I received a letter dated 27 July 2015 from Nicholas Fish the scheme administrator, referring to a Skipton Fund ex gratia payment which was approved and ready to be paid. There were no problems with making the Skipton application as such.

54. I received a letter from the Skipton Fund dated 27 July 2015 stating that the Skipton Fund first stage ex gratia payment application in relation to my late husband had been approved and was ready to be paid. I just needed to provide a letter stating that the late application was due to the fact that I had not heard of the Skipton fund.
55. I received a payment of £20,000 from the Skipton Fund as a Stage one payment on 5 August 2015. This was a one-off payment and there were no other payments.
56. My understanding is that Skipton had a data base of Haemophiliac patients who had received contaminated product and they accepted that my husband had been treated with infected blood products due to haemophilia, hence their granting the Stage one payment.

Recent requests for medical records

57. More recently we attempted to request Paul's medical records again in connection with the Infected Blood Inquiry. I thought that Paul went into the Royal Surrey Hospital, Guildford for treatment twice so I contacted them on 8 January 2022 and they wrote back with information. The undated letter stated that they had looked on the system for any records but that they had been destroyed in 2005 in line with national guidelines and apologised for any difficulty this may cause. This reply was received on an un-headed and undated letter from the Access to Healthcare Records Officer.
58. I contacted Frimley Park Hospital in January 2022 to again request Paul's medical records. This was to no avail there were no other records available.
59. Yesterday, Karen contacted Pauls GP at GRO-C
This is the second time of asking. We are still waiting for the result from the first time we applied on 08 January 2022.

Section 8. Other Issues

60. My daughter Karen, saw the Infected Blood Inquiry on the national news and contacted me about it. She sent me the link to the Inquires website. Before I had the chance to contact the Inquiry myself the Inquiry approached me.

61. If a lot of the blood came from America that should not have been allowed or to have happened.

62. Karen and our family want recognition that the blood was not monitored, we do not want to play the blame game, but someone should have been responsible and accountable for the blood affecting peoples' lives. We just want accountability really and the fact it has happened so far back and has not yet been resolved.

63. The biggest question is why Paul was not tested for HCV or if he had been why he wasn't told.

Statement of Truth

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

Signed GRO-C

Dated 13th May 2022